



Community Priorities for Research on Neurodevelopmental Disorders

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April 2018



Acknowledgements

The Neurodevelopmental Disorders Priority Setting Partnership would not have been possible without the input from over 300 individuals, families, carers, and professionals across Ontario, Canada who participated in the surveys and final workshop. Thank you for lending your voices.

The Ontario Brain Institute (OBI) would like to thank the members of the Steering Group and the James Lind Alliance adviser, Katherine Cowan, for overseeing and guiding this process. We would not have succeeded without their leadership, expertise, and dedication.

Thank you to the organizations and patient advocacy groups who disseminated the surveys and helped us reach the broader community.

Finally, a special thanks to the final workshop participants and facilitators for helping us prioritize the Top 10 questions.



Acknowledgements

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Forewords



Tom Mikkelsen

I am pleased to introduce the outcome of this Priority Setting Partnership process and to present the Top 10 unanswered questions on neurodevelopmental disorders from the community.

The Ontario Brain Institute takes a team science approach to research, maximizing the value of the neuroscience community by bringing together researchers, clinicians, companies, patient advocates, and patient advocacy groups to form collaborative research networks. By bringing together these diverse stakeholders, we enable high quality research that can be translated into the community and create meaningful impact for those that this research is meant to help – people living with brain disorders and their families.

An essential part of creating meaningful impact for the community is incorporating the patient voice. It is important to understand the needs and concerns of individuals with brain disorders as well as those in their support system. By engaging this group of stakeholders in various stages of the research process, we help to ensure that research remains relevant and addresses the unmet needs of the community.

Partnering with POND, OBI's research program in neurodevelopmental disorders, and the James Lind Alliance on this initiative allowed us to reach out to the greater neurodevelopmental disorder community and gain a better understanding of their daily challenges and concerns. We were impressed by the enthusiastic response we received and found that many of the concerns and questions were shared across this community, regardless of diagnosis.

The results of this process, the Top 10 unanswered questions, will have an important impact on the field. We hope that you will join us in prioritizing research in the Top 10 areas.

A handwritten signature in black ink, appearing to read 'Tom Mikkelsen', written in a cursive style.

Tom Mikkelsen, MD, FRCPC
President and Scientific Director
Ontario Brain Institute

Forewords



Evdokia Anagnostou

Neurodevelopmental disorders are prevalent and persistent, impacting opportunities for participation and inclusion in society and affecting quality of life. I am thrilled to see the results of the Neurodevelopmental Disorders Priority Setting Partnership. As a clinician scientist and the principal investigator for the Province of Ontario Neurodevelopmental Disorders (POND) Network, it has been a privilege to work with so many individuals, families, clinicians and community organizations, all of whom recognize the need for more patient-driven research in neurodevelopmental disorders. Our gratitude goes to all who took part in the surveys, participated in the workshop or helped in any other way to make the priority setting a success, and for their commitment and openness to consider the multiple perspectives involved. The results of this partnership will be critical for researchers and funding agencies to prioritize research in interventions, according to the wishes of those experiencing neurodevelopmental differences, their families and those who support them.

We look forward to harnessing the tremendous enthusiasm generated through this process to drive research that will make a real difference to patients with neurodevelopmental disorders, their families and carers.

A handwritten signature in black ink, appearing to read 'E. Anagnostou'.

Dr. Evdokia Anagnostou

*Senior Clinician Scientist,
Holland Bloorview Kids Rehabilitation Hospital
Chair of the Steering Group*

Introduction

Research is vital to finding better ways to improve the health and wellbeing of people with neurodevelopmental disorders. Traditionally, research topics are chosen by researchers. However, researchers may not be fully aware of the issues and uncertainties that matter most to families and individuals. 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. This is why we worked with people living with neurodevelopmental disorders, their families, people who regularly look after people with neurodevelopmental disorders (carers), and health/education professionals to identify questions and priorities that have not yet been addressed by the research community.

A Priority Setting Partnership for neurodevelopmental disorders was started in February 2016, to ensure future research is more aligned with needs of the community and guided by their perspectives.



“Asking the right questions is an integral part of research, hence setting priorities in partnership with the patient community is central to ensuring our work has direct impact.”

Dr. Evdokia Anagnostou

*Senior Clinician Scientist, Holland Bloorview Kids Rehabilitation Hospital
Chair of the Steering Group*

Background

The World Health Organization estimates that 15% of the world's population lives with a disability, and neurodevelopmental disorders contribute to this high amount of disability worldwide. Neurodevelopmental disorders are a group of conditions that start early in development, and are characterized by developmental differences that often produce impairments of personal, social, academic, or occupational functioning. The range of developmental challenges varies from very specific difficulties of learning to global impairments of social skills or cognition. Examples of neurodevelopmental disorders include Attention Deficit Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Obsessive Compulsive Disorder (OCD), Intellectual Disability (ID), Rett Syndrome, Tourette Syndrome, Fragile X Syndrome, and Down Syndrome.

In 2011, with the support of the Ontario Brain Institute (OBI), the Province of Ontario Neurodevelopmental Disorders (POND) Network was created to bring together a multidisciplinary team of scientists, clinicians, engineers, and community stakeholders who share the goal of improving the long-term outcomes for children and youth with neurodevelopmental disorders. By researching multiple disorders together, the POND Network hopes to better understand the unique and overlapping biology, risk factors, and clinical outcomes across neurodevelopmental disorders.



For collaborative research across teams and disorders to be successful, contributions from many stakeholders are needed. In health research and beyond, there is growing support and recognition for the importance of engaging patients and others with lived experience at various stages of the research process. By engaging people with lived experience, researchers hope to improve the quality and outcomes of research, making research more relevant and impactful to those for whom it concerns.

Background

One way to engage people with lived experience and other stakeholders in research is to identify unanswered questions which are most pressing to the community and have them shape the research agenda. To prioritize the community voice in setting research priorities, OBI and the POND Network partnered with the James Lind Alliance.

The James Lind Alliance is a United Kingdom-based organization created to address the imbalance in the decision making of what gets researched, bringing together patients, carers, clinicians and other professionals through Priority Setting Partnerships. Through standardized methodology established by the James Lind Alliance, Priority Setting Partnerships allow the community to work together to identify and prioritize the Top 10 uncertainties, or unanswered questions, that research should address. Involving stakeholders through Priority Setting Partnerships allows for new and different perspectives in research, and ensures research is conducted on topics that matter most to the community. To learn more about the James Lind Alliance, visit <http://www.jla.nihr.ac.uk/>.



The James Lind Alliance approach aligns with the priorities of OBI and POND to focus on research that is meaningful to the patient, to integrate across Ontario and across disciplines, and to have a translational thrust to research. In February 2016, a collaboration was started between OBI, POND and the James Lind Alliance to identify priorities from the neurodevelopmental disorder community which have not yet been answered by research. The resulting Top 10 will help shape the future of neurodevelopmental disorders research to address the needs and priorities of the community.

How We Got To The Top 10



How We Got To The Top 10

Step 1

Establishing the Priority Setting Partnership

A Steering Group of clinicians and patient advocates was formed. It was responsible for overseeing and guiding the priority setting process. The Steering Group for this Neurodevelopmental Disorders Priority Setting Partnership played an active role in setting the scope of the project, making decisions on how questions were categorized and grouped, and ensuring that the perspectives brought forward from the community were accurately represented in the final summary questions. The project scope was limited to treatments/interventions (e.g. biological, psychosocial, educational, system navigation) for neurodevelopmental disorders, in order to not put people in a position of having to choose between diagnosis, causes/biology, or treatment/interventions.



Step 2

Gathering Questions

A survey was open for three months to gather questions or uncertainties from the community about treatment/interventions for neurodevelopmental disorders. We mainly targeted the Ontario community through our dissemination partners. However, we collected responses from the broader community as well. A total of 258 individuals responded to the survey, with a total of 1264 questions. These individuals were people with a neurodevelopmental disorder, family members, carers, or professionals who work with people who have a neurodevelopmental disorder (e.g. clinician, service provider). For more information about the distribution of experience, neurodevelopmental disorder diagnosis, and geographical representation from the 258 individuals who responded, see Figures 1–3 on page 11–13.

How We Got To The Top 10

Step 3

Analyzing the Data

Of the 1264 questions, 366 questions were deemed out of scope (not related to treatment/interventions). The remaining 898 questions were grouped into summary questions, based on their similarity. For example, questions about biological and psychological treatments in anxiety were grouped together into a single treatment question about anxiety. Similarly, anxiety treatments in ADHD were grouped together with questions about anxiety treatments in ASD into a summary question about all anxiety treatments in neurodevelopmental disorders. The 898 questions were collapsed into 64 summary questions. The 64 summary questions were checked against published research to see if they had already been answered. One question with enough evidence from systematic reviews could be answered and was removed (see Appendix B). 63 summary questions remained.

Step 4

Interim Ranking Survey

To further narrow down the list of uncertainties, we sent out a second survey asking the neurodevelopmental disorder community to choose and rank the 10 questions most important to them from the list of 63. A total of 177 people responded and ranked their priorities. Once the survey closed, rankings from each submission were scored. A question ranked first was scored as 10 points; a question ranked second was scored as 9 points and so on, with questions ranked tenth receiving a score of 1 point. For each question, scores from all the surveys were totaled, and then the 63 questions were ranked overall from the highest to the lowest score. The top 20 ranked questions were brought to the final prioritization workshop. (See Appendix B on page 29 for questions 21–63.)

Rankings and scores were also considered for each of the two groups, those with lived experience (individuals with neurodevelopmental disorders, parents, carers) and those with professional experience (health and education professionals, organization representatives). The 10 highest ranked questions from each group were almost all found within the top 20 ranked questions overall, showing consistent overlap between the needs of the two groups.

Step 5

Final Prioritization Workshop

The final prioritization workshop took place on September 28, 2017 in Toronto (Canada). It brought together a diverse group of 31 stakeholders from the neurodevelopmental disorder community to help prioritize the Top 10 questions from the shortlist of 20 questions. The Steering Group ensured a balance and variety of perspectives was present at the workshop. This involved the participation of 17 participants 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).

In the workshop, each question was discussed and the ranking placement of each question was debated. Participants reached consensus on the ranking order, producing a final Top 10 list of research priorities.

Respondent Demographics

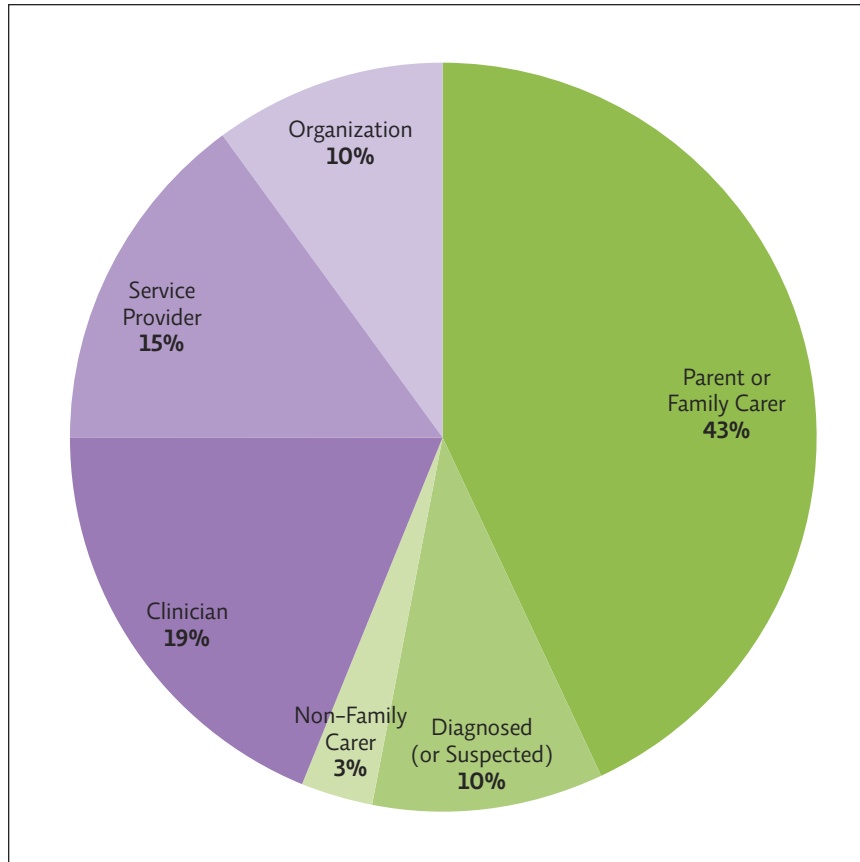


Figure 1

Respondent Experience

The distribution of survey respondents with lived experience (green) or professional experience (purple).

There were 258 people who submitted questions in our first survey. There was a good balance between respondents who identified as having lived experience with neurodevelopmental disorders or who completed the survey on behalf of someone with lived experience (184 respondents), and respondents identified as having professional experience with neurodevelopmental disorders (139 respondents) [see Figure 1]. We heard from the vast neurodevelopmental disorders community, with respondents

having experience in over 35 neurodevelopmental disorders. Individuals with lived experience with ASD and ADHD were the most common [see Figure 2]. We also heard from people across Ontario, with highest response from central, southwestern, and metropolitan Toronto [see Figure 3], which is consistent with where the majority of Ontarians live.

Respondent Demographics

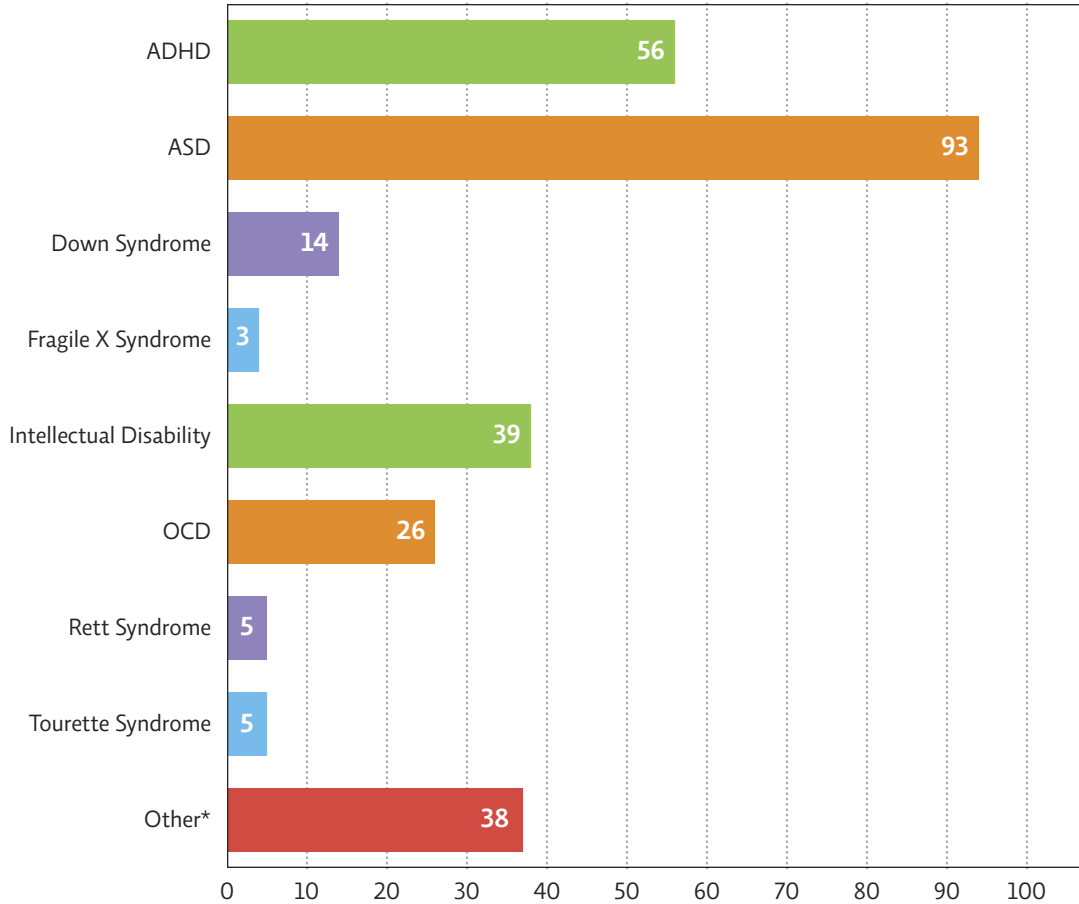


Figure 2

Neurodevelopmental Disorder Diagnosis

The occurrence of different neurodevelopmental disorder diagnoses for survey respondents with lived experience.

* This group includes other genetic syndromes related to intellectual disability or comorbidities identified by respondents.

“Autism touches people from all walks of life. Our families, experiences and passions shape our priorities. When it comes to the future of autism research, our hopes reflect what we see as success and quality of life for our families. Opening up this project to the public gave every one of us a chance to have our voices be a part of the future of research in neurodevelopmental disorders.”

Susan Cosgrove
Parent Advocate
Priority Setting Partner

Respondent Demographics

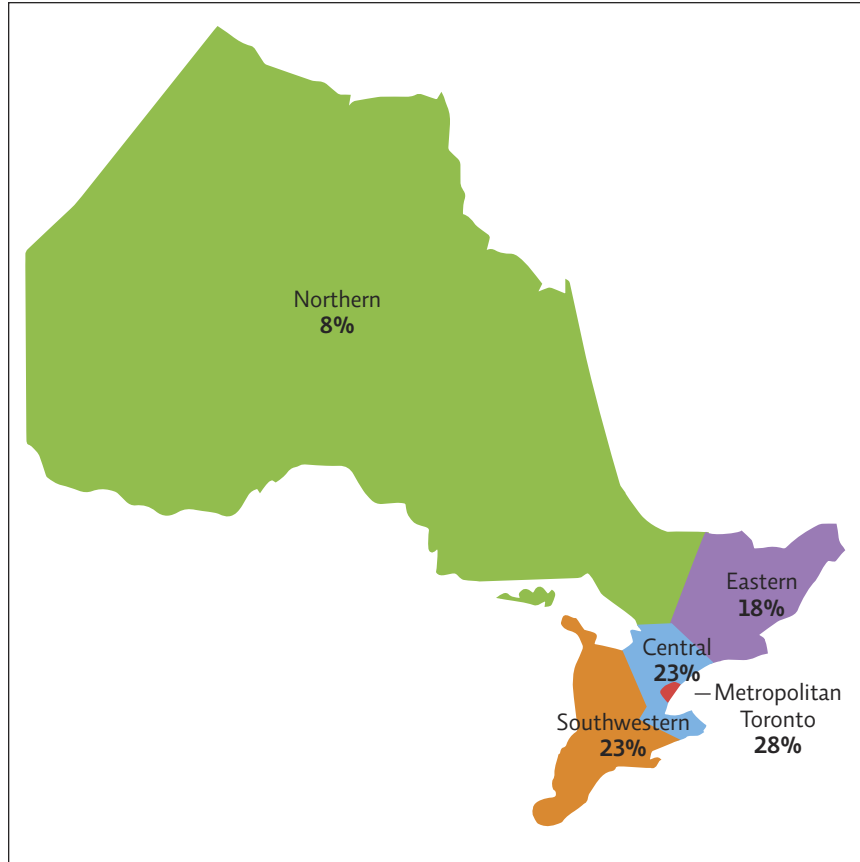


Figure 3

Geography

The geographical distribution of survey respondents in Ontario.

“People who are autistic (like myself) have a hard time communicating. But this project made it easy for me and people like me to tell researchers about what we want them to study.”

Liam Cosgrove
Youth Self-Advocate
Priority Setting Partner

The Top 10

The Top 10 research priorities from the neurodevelopmental disorder community are:

- 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?

See Appendix A on page 28 for questions 11-20 ranked at the workshop.

Priority 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?



Example of original questions submitted*

- *Person with lived experience*
What non-drug interventions can be proven to work, both short term and long-term?
- *Professional*
What are the best ages or developmental stages for treatment to begin?

** The examples of original questions in this section are unedited and were taken verbatim from survey submissions we received.*



Explanatory note

This question is aimed at understanding the short-term vs. long-term outcomes of treatments. It also asks about the timing of treatments (i.e. how long and how often), as well as intensity/dose of treatments (i.e. how much).



Why we need more research

More research is needed to determine effective treatment plans that include when to start or stop a given treatment(s), considering what will be the most impactful in the short term as well as the long term, as well as different intensities/doses. This question is a challenging one that has yet to be answered mainly because of its complexity. Most studies examine the effect of a treatment on a specific behaviour or skill rather than overall benefit. There are very few head-to-head studies of different treatments, so we don't necessarily know what treatment is best for what person. Further, there are very few studies comparing combinations of treatments (such as medication plus behavioural intervention).

Priority 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?



Example of original questions submitted

- *Person with lived experience*
How can we design a system of care that transitions from preschool to school and meets the child and family's needs across the lifespan (incorporating health education and social supports)?
- *Professional*
When are children identified and what resources are given to them? As it currently appears, a lot of parents are at a loss for where to go.



Why we need more research

There is very little information or research done on effective ways to organize and coordinate services for people with neurodevelopmental disorders. There is no research into coordination across service sectors (i.e. health and rehabilitation, education, housing, and vocational training) across the lifespan.



Explanatory note

This question speaks to how to improve the current supports and services so that 1) they are coordinated (across different service providers), 2) each person is able to navigate them, and 3) there is a consistent level of support to meet the needs of individuals with neurodevelopmental disorders throughout their life. Traditionally, there are more services and supports available in early years, fewer available in adulthood, and difficulties navigating these systems at all transitions points. These gaps in the system make it challenging for individuals and families to get the resources and services they need.

Priority 3



Which biological treatments (including medications, gene therapy, stem cell therapy, etc.) are effective for neurodevelopmental disorders and associated symptoms?



Example of original questions submitted

- *Person with lived experience*
What is the role of stem research for Down Syndrome?
- *Professional*
What are pharmacological and non-pharmacological interventions that can harness gene over-expression responsible for cognitive delay and other disease processes?



Explanatory note

This question encompasses whether treatments such as medication as well as novel treatments (e.g. gene therapy, stem cell therapy, fecal transplant, or hormonal supplements) are effective for individuals, and at reducing symptoms.



Why we need more research

Although there is fairly good evidence to support the use of some medications in the treatment of certain symptoms in neurodevelopmental disorders (e.g. ADHD symptoms, irritability/aggression), many of these medications are only effective for a proportion of persons. As such, we need novel treatments that address a variety of different impairments causing distress and dysfunction in the majority of individuals. In addition, there are few if any studies comparing different medications or different biological therapies to each other. Consequently, it is difficult to say what treatment is best for what person or what treatment is best for what pattern of symptoms. Finally, a lot of popular interventions have little evidence to support both their usefulness as well as their safety. Patients and families need a reliable source of evidence that demonstrates the effectiveness and safety of biological treatments.

Priority 4

4

Which child and family-centered interventions or approaches promote optimal individual and family functioning?



Example of original questions submitted

- *Person with lived experience*
How the school system can provide better access to intervention that is more family-focused?
- *Professional*
How can we work with individuals with ND in a way that makes them and their caregivers feel encouraged, supported, and empowered?



Explanatory note

This question refers to interventions that build positive family functioning or family health, in order to improve outcomes for everybody in the family.



Why we need more research

Empowered families have a positive impact on children's health, wellbeing, productivity, and social outcomes¹, and there is early evidence to support that empowering the whole family improves outcomes for all involved. However, there is little evidence available for how to promote optimal individual and family functioning, especially for families parenting a child with a neurodevelopmental disorder. More research and understanding about interventions and approaches to promote healthy individuals and families will have a huge impact on children, siblings, parents, and others.

¹ Pezzullo, L., Taylor, P., Mitchell, S., Pejoski, L., Le, K., & Bilgrami, A. (2010) *Positive Family Functioning*. Retrieved from Australian Government Department of Social Services: https://www.dss.gov.au/sites/default/files/documents/positive_family_functioning.pdf

Priority 5

5

Which interventions best help individuals with neurodevelopmental disorders develop emotional and behavioural regulation (including increasing impulse control and reducing compulsive behaviour)?



Example of original questions submitted

- *Person with lived experience*
What therapies can be developed for children who struggle with self-regulation and haven't responded well to existing strategies (e.g., mindfulness, CBT, DBT)?
- *Professional*
How can we best help people with ND become better able to self-regulate their behavior, thinking, and emotions?



Why we need more research

Emotional and behavioural regulation skills are important for success in school, work, and life. For individuals with neurodevelopmental disorders, these skills can be underdeveloped and presents a challenge for everyday tasks. Research is needed to best understand which interventions are most effective to develop these skills in individuals with neurodevelopmental disorders. Effective interventions may improve functioning, reduce their barriers to participation and social inclusion, improve their independence, and decrease burden on caregivers.



Explanatory note

This question identifies a need to know which interventions are most likely to be effective to regulate emotion. This includes psychological, social, and biological treatments. Interventions needed could include approaches for recognizing "warning signs", and regulating emotions and behaviour in different settings such as home, school, or work.

Priority 6



Which resources are needed to more effectively address the health, social and emotional needs of families or caregivers of individuals with neurodevelopmental disorders?



Example of original questions submitted

- *Person with lived experience*
How is the physical health of the family altered when one or more children have a diagnosed neurodevelopmental disorder?
- *Professional*
Are there communities or formalized support for these families of individuals with complex and rare neurodevelopmental disorders?



Why we need more research

Caring for individuals with neurodevelopmental disorders can take a toll on the physical and psychological health and wellbeing of families and caregivers². More research is required in order to identify how to better support and address their health, social and emotional needs. Ensuring the health and wellness of those who support individuals with neurodevelopmental disorders may improve the quality of life of the family or care unit as a whole.



Explanatory note

The importance of supports for those who care for individuals with neurodevelopmental disorders, such as parents, siblings, other relatives, or caregivers is raised through this priority. The question aims to identify or develop resources that ensure families and caregivers of individuals with neurodevelopmental disorders are sufficiently supported in terms of their physical and emotional wellness. The supports may be community-based or formalized support (e.g. intensive training). Accessibility and financial burden are important factors in answering this question.

²Lach, L.M., Kohen, D.E., Garner, R.E., Brehaut, J.C., Miller, A.R., Klassen, A.F., & Rosenbaum, P.L. (2009). The health and psychosocial functioning of caregivers of children with neurodevelopmental disorders. *Disabil Rehabil.*, 31(9), 741-752.

Priority 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)?



Example of original questions submitted

- *Person with lived experience*
For people with autism – is there some way we can group people based on their strengths and weaknesses to determine an individualized therapy plan that is best suited for the individual person?
- *Professional*
Are we able to more precisely determine which approach might work for which person?



Why we need more research

Due to the heterogeneity of neurodevelopmental disorders like ASD, precision medicine is an approach that is gaining favour in the healthcare community. However, little is known yet on how to tailor intervention to specific individuals' needs. Further research is needed to understand what characteristics or biomarkers are most useful in helping to predict the best treatment pathway for each individual, in order to best meet their needs.



Explanatory note

Each person with a neurodevelopmental disorder may have a unique set of symptoms, needs and abilities. This question raises the importance of how to tailor treatment decisions to the individual – based on diagnosis, age, or functional need. This question also encompasses whether subgroups of individuals are more likely to respond to a certain treatment.

Priority 8



Which are the most effective pharmacological and non-pharmacological treatments for aggressive and self-injurious behaviour in individuals with neurodevelopmental disorders?



Example of original questions submitted

- *Person with lived experience*
Are therapies that use a cognitive approach to treat aggression in ADHD effective in reducing social stigmatization and developing social connection with peers?
- *Professional*
Are there ways to prevent aggression from developing in individuals with neurodevelopmental disorders (specifically that of the autism population)?



Why we need more research

Aggressive and self-injurious behaviour can be a danger to individuals with neurodevelopmental disorders and those around them. It also leads to social exclusion and prevents individuals from accessing community services. Although there are some approved medications in this area, the evidence is limited and the side effects are significant^{3,4}. We need more research into effective approaches of reducing aggressive and self-injurious behaviour to improve both individual and family outcomes.



Explanatory note

This question is aimed at identifying which treatments (medication as well as non-medication options) are best to improve aggressive or self-injurious behaviour.

³Ali, A., Hall, I., Blickwedel, J., & Hassiotis, A. (2015). Behavioural and cognitive-behavioural interventions for outwardly-directed aggressive behaviour in people with intellectual disabilities. *Cochrane Database of Systematic Reviews 2015*, Issue 4.

⁴Levine, S.Z., Kodesh, A., Goldberg, Y., Reichenberg, A., Furukawa, T.A., Klevzon, & A., Leucht, S. (2016). Initial severity and efficacy of risperidone in autism: Results from the RUPP trial. *European Psychiatry*, 32, 16–20.

Priority 9



Which are the most effective pharmacological and non-pharmacological intervention(s) to reduce anxiety in individuals with neurodevelopmental disorders?



Example of original questions submitted

- *Person with lived experience*
What are the effective interventions for learning how to control anxiety for those who do not have access to professionals (those who live rurally/remote communities)? (e.g., innovative on line/virtual)?
- *Professional*
Specific treatment approaches (including pharmacological) for anxiety in teens/young adults with neurodevelopmental disorders.



Why we need more research

There is significant comorbidity between neurodevelopmental disorders and anxiety^{5,6}. Evidence on medications for anxiety, although present for children with anxiety disorders with no neurodevelopmental concerns, is lacking in children with neurodevelopmental disorders. A variety of options to manage and reduce anxiety are needed in order to improve the quality of life for people with neurodevelopmental disorders. More research is also needed in order to determine which interventions to reduce anxiety are effective, acceptable and safe for persons with neurodevelopmental disorders.



Explanatory note

This question is aimed at identifying which treatments are best to reduce anxiety, including medication-based treatments and non-medication options (e.g. cognitive behavioural therapy).

⁵van Steensel, F.J.A., Bögels, S.M., & Perrin, S. (2011) Anxiety Disorders in Children and Adolescents with Autistic Spectrum Disorders: A Meta-Analysis. *Clinical Child and Family Psychology Review*, 14, 302–317.

⁶Schatz, D.B. & Rostain, A.L. (2006). ADHD with comorbid anxiety: a review of the current literature. *Journal of attention disorders*, 10(2), 141–149.

Priority 10

10

Which interventions are most effective to help individuals with neurodevelopmental disorders improve their social skills and develop and maintain social relationships?



Example of original questions submitted

- *Person with lived experience*
Is a school (i.e. social) environment really beneficial for a child with ASD to 'work on' or develop the skills lacking in those areas, or might there be a better, less stimulating and more helpful/sensitive way of building these skills that will be less stressful for the child?
- *Professional*
How can we have adults with neurodevelopmental disorders make friends in a more natural kind of way?



Why we need more research

Difficulties with social skills can put people at risk of peer rejection, academic failure, mental health difficulties, trouble with the law, or losing a job or relationship. Social skills are learned differently by individuals with neurodevelopmental disorders. Although there are some approaches currently in use, they may not be effective in all situations and may not be applicable to everyone. More research is needed to develop novel interventions for individuals at different stages of life to effectively facilitate a meaningful social life according to the individual's wishes.



Explanatory note

This question aims to identify which interventions are best for improving social skills, improving interpersonal relationships, and helping individuals with neurodevelopmental disorders have a meaningful social life across the lifespan (childhood, adolescence, adulthood).

Next Steps

The Top 10 priorities for neurodevelopmental disorders research was released on October 18th, 2017 through press release, website, and social media. Determining the Top 10 unanswered questions is not the end of priority setting, but instead the beginning of another important part of the process – finding answers to these priorities.

OBI and the Steering Group will continue to promote the Top 10 research priorities. We will also support our partners to promote them to help ensure that the Top 10 priorities are reaching the right audiences. This includes submitting a scientific publication, presenting at conferences to researchers, clinicians, and practitioners, and sharing with other community stakeholders and government. Beyond dissemination, we plan to work with researchers, funders, and other partners to see these research questions addressed.

By including the voice of the community in setting priorities for research, we gain a better understanding of the priorities of the neurodevelopmental disorder community and where research can create the most impact. These Top 10 priorities will serve as a powerful and valuable tool to spur patient-oriented research into neurodevelopmental disorders.



“Thank you again! All of you – every family, every doctor, every therapist and every scientist – who heard us after over a decade of asking for inclusion and answering with such dedication.”

Annette Tophen
Parent Advocate
Priority Setting Partner

How You Can Help

Funders

In order to find answers to these questions, there needs to be funding allocated to these community priorities that will help incentivize and enable research to be done in these key areas of importance. We encourage funders and grant organizations to use these priorities to help inform funding decisions in the field of neurodevelopmental disorders. We hope you can provide the leadership to guide the field towards research aligned with the needs of the community. If you are already funding one or more of these priorities, we would love to hear about how you are addressing the priority (email us at prioritysetting@braininstitute.ca).

Researchers

We need researchers working to find answers to these questions; therefore we encourage you to consider these priorities to help inform the direction of your work. Working towards one of these priorities allows for meaningful research to have a huge impact on the lives of individuals with neurodevelopmental disorders. These questions came from the community, and your findings will be relevant and needed. If you are planning to research one of these priorities or if your research already aligns with one of them, reach out to us and tell us about your work (prioritysetting@braininstitute.ca). We are trying to keep track of efforts made to address these questions in order to capture the influence and impact of this Priority Setting Partnership.



In addition, researchers can help us increase awareness of these priorities. Spread the word to your colleagues in the field. Make mention of the Top 10 when presenting your research. We have resources on our website to help present the Top 10 and to communicate the importance of them to others.

“Having experienced this process, I can attest to the interest, care and diligence in the Steering Committee’s consideration of every idea, every comment and every experience reflected in the survey responses.”

Sue Lynch

*Regional Executive Director, Community Living Toronto
Steering Group Member*

How You Can Help

Health, Education or Other Professionals

If you have professional experience working with individuals with neurodevelopmental disorders and their families, we need your help sharing and advocating for the priorities of those you work with. We hope this initiative can serve as a powerful tool to demonstrate the needs of the neurodevelopmental disorder community.

If you know someone who could support any of these priorities and would like us to connect with them, please reach out to us. We welcome the opportunity to speak with any researchers, funders, organizations, or other stakeholders who can help address these priorities (prioritysetting@braininstitute.ca).

Persons with Lived Experience

If you are an individual with a neurodevelopmental disorder, a family member, or a carer, we also need your help increasing awareness of and advocating for these priorities. The more people know about these priorities, the more likely we are to see these priorities addressed. Share them with your networks and use the Top 10 as an advocacy tool for more attention, funding, and research into neurodevelopmental disorders.

To get in touch, please email us at: prioritysetting@braininstitute.ca, or visit: www.braininstitute.ca

“The benefits from this research are going to spill out at every level, from down to every single person who has any of these disorders all the way up to ministries.”

Rick Green
Patient Advocate, TotallyADD.com
Priority Setting Partner



Interested in the Data?

The data from this initiative will be made publically available on OBI's neuroinformatics platform BrainCODE. The open-access data will include the original questions submitted, with associated summary questions and some de-identified demographics data. We hope to encourage interest in these priorities and stem further patient-oriented research on them. Please visit www.braincode.ca for more details.

Appendix A

Questions 11–20

Questions 11 to 20 discussed at the workshop, ranked in their priority order.

- 11 How can educators and multi-disciplinary teams be better trained to provide individualized education for and accommodate children with neurodevelopmental disorders to ensure optimal outcomes?
- 12 Which supports are most effective to protect individuals with neurodevelopmental disorders from abuse (e.g. physical, sexual, bullying) and other threats to their wellbeing?
- 13 Which intervention(s) are the most effective for improving executive functioning (e.g. rigid thinking, planning, organizing, sustaining attention, working memory, etc.) in individuals with neurodevelopmental disorders?
- 14 How can barriers be reduced to ensure timely access of services, treatments and supports for neurodevelopmental disorders?
- 15 How can access to coordinated care (including diagnosis and treatment) for individuals with multiple neurodevelopmental disorders be improved?
- 16 How can families and caregivers be more involved and supported to make informed decisions that address their needs, preferences and priorities?
- 17 Which are the most effective interventions to improve cognition and address learning deficits in individuals with neurodevelopmental disorders?
- 18 How do co-occurring disorders impact treatment decisions for individuals with a neurodevelopmental disorder?
- 19 Which teaching strategies, classroom approaches and supports/services work best to meet the academic needs of students with neurodevelopmental disorders?
- 20 What are the beneficial effects of cannabis products and/or medicinal marijuana for individuals with neurodevelopmental disorders?

Appendix B

43 Unanswered Questions

The remaining 43 unanswered summary questions identified by the community but not shortlisted for the final workshop. The questions are grouped by theme but are not in any order of priority.

Access/System navigation

- How can we improve the health care of underserved populations and refugees with neurodevelopmental disorders?
- What end-of-life planning interventions can be implemented to improve outcomes and ensure the necessary care of individuals with neurodevelopmental disorders following the loss of a caregiver?

Benefits of non-traditional interventions

- Which vitamin, mineral and supplement treatments best promote symptom relief in individuals with neurodevelopmental disorders?
- What are the beneficial effects of mindfulness or meditation for individuals with neurodevelopmental disorders?
- What are the benefits associated with arts-related therapies (e.g., art therapy, music therapy) for individuals with neurodevelopmental disorders?

Effectiveness of traditional interventions

- Which interventions are most effective for treating sensory issues in individuals with neurodevelopmental disorders?
- Which pharmacological and non-pharmacological treatments are effective for improving attention in individuals with neurodevelopmental disorders?
- What are the comparative benefits and weaknesses of different treatments for individuals with neurodevelopmental disorders?
- What are the most effective ABA-based (applied behavioural analysis-based) interventions for individuals with neurodevelopmental disorders at various age ranges?
- What are the benefits of technology-enhanced treatments for individuals with neurodevelopmental disorders?

Independence & transitions

- How can the adaptive skills (e.g. independence, self-efficacy and self-determination) of individuals with neurodevelopmental disorders be enhanced?
- How do we construct our social system to optimally support adolescents/adults with neurodevelopmental disorders?
- What is needed to best support youth with neurodevelopmental disorders and their families through the transition between pediatric and adult care?
- Which supports and housing options best meet the needs for individuals with neurodevelopmental disorders?
- What are the best practices and employment-related services and supports for individuals with neurodevelopmental disorders? (e.g., skills training, aptitude testing, placement programs, etc.)

Appendix B

Interventions for co-occurring conditions

- What is the frequency and types of supports needed to most effectively address the mental health needs of individuals with neurodevelopmental disorders?
- Which interventions are the most effective to improve sleep issues in individuals with neurodevelopmental disorders?
- How can the onset of early dementia and Alzheimer's disease be prevented and/or treated in those with Down syndrome?
- Which dietary regimens are most effective for providing therapeutic value for health and symptom relief in individuals with neurodevelopmental disorders?
- Which interventions are effective for preventing obesity in individuals with neurodevelopmental disorders?
- Which are the most effective interventions to improve muscle tone in individuals with neurodevelopmental disorders?
- Which interventions are most effective to reduce eating and/or feeding issues in individuals with neurodevelopmental disorders?

Interventions for core symptoms

- Which are the most effective interventions to help individuals with neurodevelopmental disorders, including those who are non-verbal, with their speech, language and communication?
- Which pharmacological and non-pharmacological interventions help to optimize brain/nervous system biological functioning in individuals with neurodevelopmental disorders?
- How can empathy in individuals with neurodevelopmental disorders be promoted?

Interventions for families and caregivers

- Which education approaches improve families' and caregivers' knowledge of neurodevelopmental disorders to lead to better health outcomes?

Appendix B

Personalized medicine/care planning

- How can combining interventions (e.g. pairing ABA (applied behavioural analysis) with physiotherapy) be optimized for individuals with neurodevelopmental disorders?
- How can biomarkers help to influence treatment options/plans for individuals with neurodevelopmental disorders?
- How can the outcome or outlook for an individual with a neurodevelopmental disorder be predicted and monitored throughout the lifespan?
- Can interventions that work with one neurodevelopmental disorder generalize to others and how can this be implemented?

Quality of life and integration in society

- How can the quality of life of individuals with neurodevelopmental disorders be measured and enhanced?
- What are the most effective strategies to improve understanding of neurodevelopmental disorders and reduce stigma?
- What are the benefits associated with participation in sports, recreational and leisure activities for individuals with neurodevelopmental disorders?
- How can the impact of social support be promoted and assessed among individuals with neurodevelopmental disorders?

Training and strategies for professionals

- What are effective ways of training law enforcement and the justice system to properly handle individuals with neurodevelopmental disorders who may be at increased risk of exhibiting behaviours that get them involved with the justice system?
- How can family doctors and other healthcare professionals be better trained to treat children with neurodevelopmental disorders to ensure optimal outcomes?
- How can inter-professional collaboration and the use of multi-disciplinary teams be promoted in the care of individuals with neurodevelopmental disorders?

Appendix B

Other topics of interest

- Which interventions have the most impact on development (including prenatal interventions, interventions before diagnosis, early interventions relative to the timing of diagnosis) in individuals with neurodevelopmental disorders?
- Which supports are needed to improve enrollment and success in post-secondary education for individuals with neurodevelopmental disorders?
- Which education and/or treatment decision-making tools increase individuals with neurodevelopmental disorders' understanding of and involvement in their own care?
- How is the safety of medical and non-medical interventions assessed and optimized?
- Which quantitative outcome measures are optimal to evaluate interventions for neurodevelopmental disorders?
- How are interventions for neurodevelopmental disorders evaluated for cost effectiveness and resource allocation?

One Answered Question

One summary question with enough existing evidence answered.

- Summary Question: What are measures to reverse the effect caused by compounds in vaccines?
- Answer: There is no research that suggests that vaccinations are associated with the development of neurodevelopmental disorders. There is also no research evidence that components of vaccinations such as mercury are associated with neurodevelopmental disorders.

Evidence from systematic reviews

- Demicheli V, Rivetti A, Debalini MG, Di Pietrantonj C. Vaccines for measles, mumps and rubella in children. *Cochrane Database of Systematic Reviews* 2012, Issue 2. Art. No.: CD004407. DOI: 10.1002/14651858.CD004407.pub3.
- Modabbernia, A., Velthorst, E., & Reichenberg, A. (2017). Environmental risk factors for autism: An evidence-based review of systematic reviews and meta-analyses. *Molecular Autism*, 8, 13–28.
- Ng M, G. de Montigny J, Ofner M, T. Docé M. Environmental factors associated with autism spectrum disorder: a scoping review for the years 2003–2013. *Health Promotion and Chronic Disease Prevention in Canada : Research, Policy and Practice*. 2017;37(1):1-23.
- Taylor LE, Swerdfeger AL, Eslick GD. Vaccines are not associated with autism: an evidence-based meta-analysis of case-control and cohort studies. *Vaccine* 2014;32(29):3623–9.



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