

**Executive Summary**

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**PURPOSE**

This report presents the results of a detailed scan, for the purpose of identifying the needs of stakeholders in neurodevelopmental disorders. Potential uses of this stakeholder engagement activity include

- i) to inform research priorities of Kids Brain Health Network (KBHN) 2018-2020;
- ii) to inform priorities for the strategic planning cycle for KBHN 2020-2025; and,
- iii) to inform decision-making regarding policies, programs and services offered, service delivery methods and approaches, and other activities of organizations external to KBHN that similarly have a focus on improving quality of life for individuals and families affected by neurodevelopmental conditions such as cerebral palsy (CP), fetal alcohol spectrum disorders (FASD) and/or autism spectrum disorders (ASD).

In other words, how can KBHN and other like-minded organizations and governments work towards maximizing quality of life through their activities toward facilitating more empowering policies, programs and services across Canada?

These needs of neurodevelopmental stakeholders were obtained from the perspectives of parents directly (based on their personal experiences), clinicians and other frontline workers who serve families (based on what they've heard and observed are the needs of families), as well as policymakers (based on what they've heard from stakeholders through consultation exercises, and/or personal interaction with families).

**PROCESS**

We surveyed the researchers and trainees in Kids Brain Health Network seeking information and documentation from any previous stakeholder consultations conducted. We followed this by conducting 32 one-on-one telephone interviews with stakeholders across Canada. Qualitative analysis was conducted in parallel with data collection, and led to the discovery of nine themes and 44 focus areas representing all the 'needs' of individuals and families affected by a neurodevelopmental condition. After revising these needs using feedback from interview participants, we sought stakeholder input during a one-day in-person event held in Vancouver, BC, on January 18, 2017. These stakeholders helped prioritize the 44 focus areas and provided us with additional details on how to approach addressing the top 10.

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### OUTCOME

The 44 focus areas were grouped into nine themes: Diagnosis, Treatment, Services, Education, Health Care, Mental Health/Quality of Life, Life Course Perspective, Culture and Context, Broader System and Society. Of these 44, the top 10 priorities identified by the January 18, 2017 prioritization event are (in order):

1. Need access to a menu of evidence-based treatment options with information about what each of them does, and need fluidity of the system(s) that delivers these treatments so that access to families/individuals is available when needed for as long as it is needed. Parents need help determining what's important to prioritize.
2. Need for (more) professionals working within the school system with appropriate training.
3. Need for more equity in funding for different neurodevelopmental conditions.
4. Need reduction or removal of barriers to obtaining diagnosis such as: limited training for frontline health care (general practitioners (GPs)); access to skilled diagnostic/professionals, waiting lists, financial (out-of-pocket costs) for private diagnostic assessment and geography, including rural/remote locations.
5. Need specialized and in-depth mandatory training for teachers, education assistants (EAs), resource teachers, principals and anyone who interacts with children in schools.
6. Need (early) diagnosis so that targeted and specific supports can be obtained for what is needed (in schools, getting services/supports, etc.).
7. Need continuity in services at key times/transition points during the life course. Find ways to provide continuity in services for those with ongoing medical needs (this is often lost during transition from paediatricians to doctors who serve adults).
8. Need (good) supportive housing for youth/adults to be able to live as independently as possible.
9. Need more resources allocated to alleviate financial/resource constraints of the system as well as parents, plus more-efficient use of existing resources.
10. Need social skills/behavioural training, and strategies for self-regulation of emotions anxiety for the child.

**UPDATE: Due to the small sample size (25) of stakeholders that took part in the prioritization exercise appearing in Appendix L of the full report, a Canada-wide stakeholder prioritization survey is currently underway, with results expected to be available after November 2017 in a supplementary report.**