

Identifying and Prioritizing Stakeholder Needs in Neurodevelopmental Conditions in Canada



Stakeholder Engagement Activity Report
Spring 2017 Toronto, Ontario

“The aim of (this) work is to provide robust information that strengthens your understanding of your organization’s long-term context, to enable you to make wise strategic decisions today”

Acknowledgements

To the stakeholders who generously gave their time and shared their knowledge by participating in various aspects of this project whether it was one-on-one interviews or the one-day in-person consultation event held in Vancouver on January 18, 2017. This project would not have been possible without you. The insights gained from the interviews allowed us to generate a list of themes and focus areas that were then prioritized and detailed further at the in-person consultation by the parents, policymakers and frontline workers.

To Bethany Becker, KBHN Communications Manager, journalist and parent, for reviewing and providing thoughtful feedback on research questions, participating in our in-person stakeholder engagement event, providing content and feedback on drafts of this report, and making valuable connections within the small community of Cerebral Palsy, Fetal Alcohol Spectrum Disorders and Autism Spectrum Disorders.

The authors would like to acknowledge the generous funding of Kids Brain Health Network and the Government of Canada Networks of Centres of Excellence, which is an initiative of CIHR, NSERC and SSHRC.



Government
of Canada

Gouvernement
du Canada

A Note of Appreciation

“Hi Anneliese,

Good to hear from you and thank you for sharing the draft copy of your study with your participants before you publish. It completes the circle for myself as someone who invested time and inspires me to participate in other research when I have this type of experience with researchers like you. I have looked over the quotations you captured from our interview and they reflect what I remember saying (so long ago!) and are contextually appropriate in the larger whole.

I am just finishing a program evaluation training course where I learned about qualitative data and analysis. As a (now) semi-informed reader of your research, I found it impressive in its scope and detail, given what I’m sure was a mountain of material you had to code, memo and analyze. Bravo! I know it’s “what you do”, but your report is all the more impressive to me now that I know all the steps you have to go through to pull it together and the rigour that you have obviously applied to make the study a good one.

As a parent, I am happy that the study is being done and hope that that it makes its way into the hands of those who can make positive changes for the future of our ASD community—professionals, clinicians, legislators among them.

I read the final comment (Appendix M) about the practices that go unfunded and untried as they do not have the seal of evidence-based approval. As someone who has developed an arts-based program of teaching social understanding, I echo that person’s concern and hope that the collective minds in the field might be open to more inquiry about practices that generate more qualitative data than quantitative. I know the balance is important but where Social Literacy is concerned, there is so much more to it than simply counting smiles or numbers of playdates (I’m being reductionist here but I hope you get my meaning.)

It’s been a pleasure being involved in your project. Thanks for including me from beginning to final draft. All the best as you prepare to publish.

Looking forward to the next time our paths cross.”

– Alana Shields Barker, Parent

(shared with permission)

Table of Contents

Executive Summary	6
Detailed Summary	8
1.0 Introduction	12
1.1 Who we are	12
1.2 Why we are doing this stakeholder engagement activity	14
1.3 Objectives and Research Questions	14
2.0 Methodology	16
2.1 Data - Online survey to KBHN researchers and trainees	17
2.2 Data – Survey and Interviews	17
2.3 Data - Triangulation Documents.	20
2.4 Analysis	21
2.5 Trustworthiness through validation with participants	21
2.6 In-person Stakeholder Consultation Priority-Setting Event.	22
2.7 Limitations	23
3.0 Results and Discussion – Themes and Focus Areas	24
3.1 Diagnosis	36
3.2 Treatment	39
3.3 Services	41
3.4 Education.	43
3.5 Health Care.	44
3.6 Mental Health/Quality of Life.	46
3.7 Life Course Perspective	49
3.8 Culture and Context	51
3.9 Broader System and Society	53
4.0 Conclusions	55

Table of Contents *continued*

5.0 Recommendations	56
5.1 Recommendations for Kids Brain Health Network	56
5.2 For Organizations and Governments	58
5.3 For Ongoing Research	58
5.4 Dissemination and Engagement Strategy for this Report	59
References	60
Appendix A – Survey questions and selected data	62
Data from selected survey questions.	66
Appendix B – Methodology – additional detail and rationale	71
Summary of methodology and timeline.	73
Appendix C – Letter of Informed Consent	74
Appendix D – Semi-Structured Interview Questions - Clinicians	75
Appendix E – Semi-Structured Interview Questions - Policymakers	77
Appendix F – Semi-Structured Interview Questions - Parents	79
Appendix G – Email Sent to Interviewees for Member Checking	81
Appendix H – List of Documents Triangulated with Interview Data	82
Appendix I – List of N-Vivo Nodes	84
Appendix J – Categorical (Disease Perspective) versus Non-Categorical (Disability Perspective) Approaches	90
Appendix K – Agenda for Stakeholder Priority Setting Event	91
Appendix L – Top 10 Priorities with Detail from Stakeholder Consultation, January 18, 2017	93
Appendix M – Letter received from frontline worker post-stakeholder event	114
Appendix N – Post-Project Comment from a Parent	115
Appendix O – List of Acronyms	116

Executive Summary

Executive Summary

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.

Executive Summary

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.

Detailed Summary

Detailed Summary

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 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 CP, FASD and/or 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).

The objectives of this stakeholder engagement approach are:

1. To explore individual and family experiences of life with CP, FASD and/or ASD;
2. To investigate the manner in which needs and challenges are addressed (or not) within the broader system, and potential solution(s);
3. To explore the relationships between professionals, parents and children affected by CP, FASD and/or ASD;
4. To generate a list of themes and focus areas, and prioritize them to help inform Network decision-making.

Detailed Summary

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 clinicians and other frontline workers, policymakers and parents 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.

The methodology for this stakeholder engagement project employed a multi-staged approach using grounded theory research methodology. The three neurodevelopmental conditions under investigation were CP, FASD, and ASD. Key stages in the project included:

Date(s)	Activity
May, 2016	Online survey ¹ administered within the Network. Survey data utilized for identification of previous stakeholder consultation activities with formal documentation of stakeholder needs, as well as potential clinicians to interview
June, 2016	Emails sent to survey participants requesting documentation related to stakeholder engagement activities reported in online survey, that have taken place within the Network throughout its existence
June, 2016	Online search for policymakers, emails sent to individuals identified
June 21, 2016	Ethics approval received for conducting one-on-one interviews
June-September 2016	One-on-one telephone interviews conducted. Transcription, open/axial coding (constant comparison and memoing) completed in parallel
July-August 2016	Document data collection, online search for reports on government-funded stakeholder consultations that identified and reported on stakeholder needs with respect to ASD, FASD, CP. (Triangulation with existing reports reinforces the validity of the data derived from stakeholder interviews).
July 27, 2016	Ethics approval for amendment #1 received (to interview clinicians outside of the Network)
November, 2016	Identified themes and focus areas sent to interviewees for feedback as part of member-validation
December, 2016	Themes and focus areas updated according to feedback received from interviewees
January 11, 2017	Ethics approval for amendment #2 received (to record stakeholder event and write paper)
January 18, 2017	One-day in-person stakeholder consultation event in Vancouver, BC, with similar categories of stakeholders but different set of individuals than those who were interviewed, to prioritize the 44 focus areas that emerged from the analysis of interview data, and help detail next steps for the top 10 priorities
March 28-April 6, 2017	Quotes used in the report were sent back to interviewees along with surrounding text and full report, to verify the context and use within the report. In total, 20 interviewees were contacted and 17 responses were received.

¹ using REDCap (Research Electronic Data Capture), access and support provided through KBHN's Neuroinformatics Core.

Detailed Summary**OUTCOME**

The top 10 priorities are (in order according to the stakeholders present January 18, 2017):

# votes	Priority	Needs expressed by stakeholders during one-on-one interviews
39	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.
22	2	Need for (more) professionals working within the school system with appropriate training.
17	3	Need for more equity in funding for different neurodevelopmental conditions.
16	4	Need reduction or removal of barriers to obtaining diagnosis such as: limited training for frontline health care (GPs); access to skilled diagnostic professionals, waiting lists, financial (out-of-pocket costs) for private diagnostic assessment and geography, including rural/remote locations.
15	5	Need specialized and in-depth mandatory training for teachers, EAs, resource teachers, principals, anyone who interacts with children in schools.
13	6	Need (early) diagnosis so that targeted and specific supports can be obtained for what is needed (in schools, getting services/supports, etc.).
13	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 pediatricians to doctors who serve adults).
13	8	Need (good) supportive housing for youth/adults to be able to live as independently as possible.
12	9	Need more resources allocated to alleviate financial/resource constraints of the system as well as parents, plus more-efficient use of existing resources.
11	10	Need social skills/behavioural training, and strategies for self-regulation of emotions/anxiety for the child.

We noticed that there were four 'groupings' of needs according to the number of votes. The first and second priorities, with 39 and 22 votes, respectively, were distinct in the number of votes they each received. Another grouping can be seen in priorities #3, 4 and 5 (17, 16 and 15 votes, respectively) and finally a third grouping can be seen in the remaining priorities #6-10 (mainly 13 and 12 votes each). While it is acknowledged that all of the 44 needs identified are important, the gap between the first and second grouping, once stakeholders were asked to vote on priorities to address first, suggests the top two priorities are of special significance to that group of stakeholders.

Appendix L contains additional details from stakeholders about what we should be trying to accomplish, what would be the desired outcomes, what would be some barriers and enablers of the approach(es) suggested, who we should involve and/or consult in the process, and how can we engage them.

Detailed Summary

RECOMMENDATIONS for KBHN:

Recommendation 1: Apply the insights from stakeholders contained within this report to KBHN investments including funding allocations for new and existing projects 2018-2020.

Recommendation 2: Apply the insights from stakeholders contained within this report to KBHN strategic planning for 2020-2025.

Recommendation 3: Consider the diversity of viewpoints presented in the positional diagram in Appendix J with respect to a categorical versus non-categorical approach.

Recommendation 4: Continue (and expand if necessary) ongoing stakeholder engagement with the stakeholders who participated in this project, stakeholders in regions not captured in this project, and specific types of stakeholders for input on individual projects as necessary.

Recommendation 5: Promote the report in-person with provincial and federal governments, as well as community organizations across Canada to facilitate uptake and make this the definitive report for Canada.

Recommendation 6: Invest in methods for assessing the impact of KBHN-funded projects against identified and prioritized needs.

RECOMMENDATIONS for Organizations and Governments:

Recommendation 1: Organizations outside of the Network that serve individuals, families and children with neurodevelopmental conditions and governments that provide funding and policy guidance for them may find the needs and priorities identified in this report to be helpful for informing their policies, services and/or research.

Recommendation 2: Emphasize and operationalize collaboration among units and sub-units of government (e.g. across different ministries, provinces/territories), within and across teams in service organizations, within and across teams of professionals providing care to individuals and families.

RECOMMENDATIONS for Ongoing Research:

Recommendation 1: Replicate this investigation using disability groups other than CP, FASD and ASD to discover whether there are similarities in needs across conditions that could comprise a formal theory for application more broadly across disability groups in Canada.

Recommendation 2: Ask physicians, educators and allied health professionals to prioritize the 44 focus areas.

1.0 Introduction

1.0 Introduction

1.1 Who we are

As a Canadian Network of Centres of Excellence (NCE), **Kids Brain Health Network² (KBHN)** and its investigators work across traditional disciplinary boundaries with partners and stakeholders in academia, the community and not-for-profit sector, industry and government. Together, we ensure our findings are translated into tangible social, economic and health benefits to society as a whole.

We do this through transformative research—engaging in high-impact projects that challenge and advance current understanding. We provide innovative training opportunities to seed a new generation of Canadian researchers dedicated to the same objectives, and empower communities with tools and information to promote earlier diagnosis, better treatment, and optimal outcomes for children today, and in the future.

KBHN's current research projects focus on autism spectrum disorder, cerebral palsy, fetal alcohol spectrum disorder, sleep, the social determinants of health and health economics, supported by collaboration with Core services in neuroethics, neuroinformatics and knowledge translation.³

KBHN involves individuals and organizations passionate about helping children with neurodevelopmental conditions: parents, community groups, researchers, health care professionals, businesses and governments. The Network's governance includes the Board of Directors, Research Management Committee (RMC), Research and Training Committee (RTC), Scientific Advisory Board (SAB), Commercialization Committee, staff and researchers (members) at academic institutions across Canada.

KBHN considers impact to have been achieved when children:

- 1) are diagnosed sooner
- 2) receive validated interventions
- 3) are provided with family services to maximize their potential

² Kids Brain Health Network is the new name of NeuroDevNet, the first trans-Canada initiative to focus on improving diagnosis, treatment and support for families raising children with brain-based disabilities. Since 2009, our researchers have been working to understand the causes of conditions including autism spectrum disorders, fetal alcohol spectrum disorders and cerebral palsy, training the next generation of leaders in developmental neurosciences, and mobilizing our findings into practice and policy (source, <http://www.neurodevnet.ca/about>, (credit: Bethany Becker)).

³ source: <http://www.neurodevnet.ca/about> (credit: Bethany Becker).

1.0 Introduction 1.1 Who we are

As KBHN matures from a research network into an NCE focused on making real change for children and families we need to engage the perspectives of our stakeholders⁴ to inform design of the call for proposals for Years 9-10 funding as well as our Cycle III renewal application for Years 10-15 funding.

Vision:

KBHN will do the right thing for people with disabilities and their families through research that will: help meet their needs; make an impact on diagnosis, interventions and services for families; and, increase their quality of life.

Mission:

For Years 9-10 and Cycle III, KBHN will work towards solutions of significant challenges and needs experienced by kids with disabilities. Evidence of the input of families in defining the research problem will be a necessary prerequisite in all requests for funding from KBHN.

Gap:

What are the needs that will guide our program of research, training, services, and Knowledge and Technology Exchange and Exploitation (KTEE)?

Solution:

KBHN needs stakeholder input, in particular from families, policy makers and clinicians/frontline workers.

In the spring of 2016, KBHN's RMC directed the Knowledge Translation Core to conduct a comprehensive stakeholder engagement activity. The purpose of this stakeholder engagement project was to collect and analyze information on the "big problems" experienced by children with disabilities, and provide information and recommendations for informing the development of the call for research proposals for funding during Years 9-10, and subsequent RMC and board approval of these proposals.

The input of families, policy makers and clinicians, and other frontline workers (stakeholders),^{5,6} was sought in order to guide decisions regarding our program of research, training, services and KTEE based on their identified needs. As a result, KBHN will be well positioned to help meet the needs of stakeholders; make an impact on diagnosis, interventions and services for families; and, increase their quality of life.

⁴ stakeholders include any individual or organization interested in the broad field of childhood neurodevelopmental disorders and children's brain health. This may include children and families, advocacy/patient organizations, policy makers, service providers, educators, social workers, clinicians and allied health professionals, as well as industry.

⁵ definition of Stakeholder: One who is involved in or affected by a course of action (Merriam-Webster).

⁶ definition of Stakeholder: A group or person who has interests that may be affected by an initiative or influence over it (International Institute of Business Analysis).

1.0 Introduction 1.2 Why we are doing this stakeholder engagement activity**1.2 Why we are doing this stakeholder engagement activity**

This is a focused scan, for the purpose of identifying themes of needs identified by stakeholders. The intended output of this stakeholder engagement activity is a focused report to i) inform priorities for the strategic planning cycle for KBHN as a primary goal, ii) to potentially 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 CP, FASD and/or ASD.

The purpose of this stakeholder engagement activity is to determine the current needs of individuals and families affected by CP, FASD and/or ASD. These needs 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), and policymakers (based on what they've heard from stakeholders through consultation exercises, and/or personal interaction with families).

1.3 Objectives and Research Questions

The purpose of this project was to explore the perceptions of 32 stakeholders and learn more about their experiences as a person with intimate knowledge about neurodevelopmental conditions, including: being the parent of a child with a neurodevelopmental condition such as Cerebral Palsy, Fetal Alcohol Spectrum Disorders and/or Autism Spectrum Disorders and/or being employed in a position that serves parents and children/youth, and/or as a policymaker; all within the current 'system' in Canada. While it is acknowledged that there is a lot of good work being done in terms of services, education, and health care for children and families, the primary purpose of this study was to identify currently existing needs so that these may serve as a focal point for KBHN's research and knowledge translation activities for Years 9-10 and our Cycle III renewal application. It is anticipated that through a better understanding of individual needs and challenges encountered as a result of current policies and services, a grounded theory can be generated in order to explain the situation under study (using subjects' lived experiences), and provide recommendations for future research and knowledge translation. Therefore, this stakeholder engagement activity explores the experiences of participants receiving or providing services, interactions with professionals in a variety of related roles, creating policies or being in a position to benefit from them.

1.0 Introduction 1.3 Objectives and Research Questions

The objectives of this stakeholder engagement approach are:

1. To explore individual and family experiences of life with CP, FASD and/or ASD;
2. To investigate the manner in which needs and challenges are addressed (or not) within the broader system, and potential solution(s);
3. To explore the relationships between professionals, parents and children affected by CP, FASD and/or ASD,
4. To generate a list of themes and focus areas, and prioritize them to help inform Network decision-making.

This stakeholder engagement project is informed by a social-constructivist perspective for interaction and exchange of information. Knowledge of the social world is seen by the constructivist as embedded within the mechanisms of human experiences such as actions and using language to create meaning (Denzin and Lincoln, 2000). Given this, there are three specific research questions to be addressed through this project:

- i. What did participants perceive was the role of information and/or knowledge in contributing towards their experiences with services and/or policies?
- ii. What did participants perceive as predominant needs and challenges for individuals and families affected by CP, FASD and/or ASD? What are potential solutions?
- iii. How can these needs and challenges inform future research and knowledge translation activities of Kids Brain Health Network (formerly NeuroDevNet)?

2.0 Methodology

2.0 Methodology

With the approval of the York University Research Ethics Board, the experiences and perceptions of 32 stakeholders affected by or knowledgeable about Cerebral Palsy, Fetal Alcohol Spectrum Disorders and/or Autism Spectrum Disorders were studied. These stakeholders had valuable life and work experiences as parents, practitioners (clinicians and/or frontline workers) and/or policymakers. This investigation used the qualitative research approach known as grounded theory method (Glaser, 1978; Strauss and Corbin, 1990, 1994, 1998; Charmaz, 2000, 2006).

Purposeful and theoretical sampling was employed for the purpose of conducting in-depth interviews, which were the principal method of data collection. The interview questions (see Appendices D, E and F) were used as a guide during the interviews, but in cases where participants were both a parent and a policymaker, or a parent and a practitioner/clinician, the participant was provided with both sets of questions and all questions the participant felt they could answer from their experiences were addressed. The information obtained through conducting 32 interviews with key stakeholders formed the basis for the findings of this study; triangulated with government-commissioned reports. Interviews were recorded and transcribed, and in order to maintain confidentiality of participants, interviewees were identified only by the category of participant (parent, policymaker, clinician/frontline worker) they felt most represented their contribution to the study at the time of their participation in the interview.

Analysis was conducted using the constant comparative method, using two types of coding: open and axial (Glaser, 1978; Strauss and Corbin, 1998). Situational analysis (Clarke, 2005), an extension of grounded theory method, was utilized for the purpose of illuminating variability in stakeholder positions, and interactions within the situation under study. In order to support the validity of the substantive grounded theory which was generated through this inquiry, member-validation, a method for ensuring the rigour of research findings, was employed (see Sandelowski, 1993). This involved contacting research participants, and providing a portion of the theory for comment, in order to verify its ability to truly represent the phenomena from their perspective; in other words, a grounded theory must be 'grounded' in the data (Glaser, 1978). Interview data were triangulated (see Moran-Ellis et al., 2006) with document data as well as information obtained through planning, attending and synthesizing data from a full-day in-person stakeholder event held in Vancouver where stakeholders were asked to prioritize the focus areas (and detail the needs for the top 10) obtained from the qualitative analysis. Within the subject area of this study, the basic social problem (a 'core category'⁷) and the basic social process (the solution for addressing the 'basic social problem') emerged from the data through analysis using open and axial coding, followed by a higher level of abstraction. The *basic social problem* and the *basic social process* are detailed in the results section (Section 3.0, page 24).

⁷ a core category is one that re-occurs frequently in the data, and is related to as many other categories (within the data) as possible (Glaser, 1978)

2.0 Methodology 2.1 Data – Online survey to KBHN researchers and trainees

2.1 Data – Online survey to KBHN researchers and trainees

Following a network-wide announcement requesting participation in an online survey (See Appendix A for questions and aggregated quantitative data) to discover the types of stakeholder engagement activities that had already taken place within the Network, individual reminder emails were sent to 248 Network investigators and trainees between May 20, 2016 and May 25, 2016. By June 10, 2016, the total number of responses was 52, a response rate of approximately 21 per cent. Customized emails were sent to individual respondents in order to request any existing documentation of the stakeholder engagement activities they had indicated in the survey had been done so that we could incorporate ‘already known’ stakeholder needs into this project. Of the responses received, several provided documents but they did not contain information about stakeholder needs. One respondent provided a link to a YouTube recording of a stakeholder meeting organized by the project team which consisted of a panel of the research projects’ investigators and discussion with parents, which was useful. This recording was transcribed and included in the analysis. The survey was also useful for identifying clinicians who regularly interact with children and families with neurodevelopmental conditions, for the purpose of inviting them to participate in an interview.

2.2 Data – Survey and Interviews

While the focus of the scan was to understand the needs and challenges of individuals and families affected by neurodevelopmental conditions such as CP, FASD and/or ASD, we sought the perspectives of parents (to learn about their needs directly), clinicians and other frontline workers (to learn about individual and family’s needs based on their experiences providing services), and policymakers (to learn: what do they know of individuals’ and families’ needs; what do they need to inform policies).

Ethics approval was received from the York University Research Ethics Board on June 21, 2016. An amendment to allow inclusion of non-Network clinicians as interviewees was approved on July 27, 2016. A second amendment was received on January 11, 2017, in order to allow (with consent) audio recording of the event mainly for the purpose of capturing all the details.

In order to identify policymakers, a list of Federal and Provincial/Territorial policymakers as part of the Public Health Network (PHN) was sought. Individual emails were sent to each province and territory contact with information about the project requesting participation. These emails were forwarded in some cases many times before a response was received from the person who would be most appropriate to participate. Some of these individuals were policymakers, some were clinicians/frontline workers. While we had ethics approval to interview clinicians within the Network, we did not have ethics approval to interview clinicians outside of the Network so an amendment was sought and granted (amendment #1) to allow for their participation.

2.0 Methodology 2.2 Data – Survey and Interviews

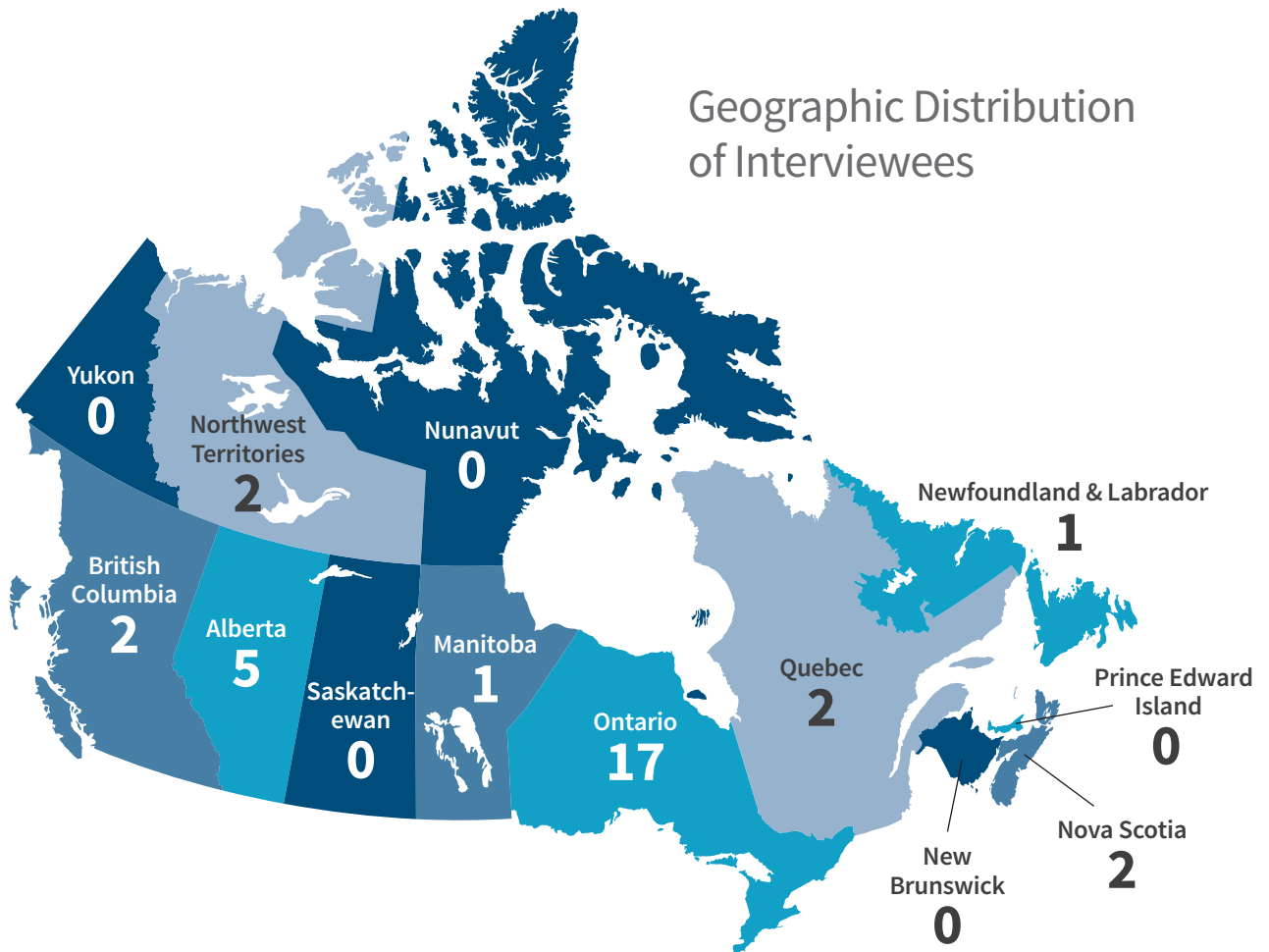
We reached ‘saturation’ after conducting 32 one-on-one, in-depth semi-structured telephone interviews. Saturation is the gold standard for ensuring that adequate and quality data are collected to support the study. Saturation means that the collection of more data will not add any more information; nothing new can be learned from conducting additional interviews (Patton, 2002). These interviews were conducted between June 30, 2016, and August 29, 2016, with a mixture of different types of stakeholders from across Canada: clinician researchers within KBHN, clinicians/frontline workers not affiliated with KBHN, provincial and program level policymakers, and parents. Best efforts were made to equally represent all three neurodevelopmental conditions that are the focus of the Network: FASD, ASD, and CP in each province and territory. Interviews ranged in length from 45 minutes to three hours. Many interviews were at least two hours.

Table 2.1

Distribution of Interviewees by Role and Area of Expertise. Interviewee/transcript number is indicated for identification of multiple areas of expertise within each role (but not multiple roles within each area of expertise).

	Policy	Clinician/Practitioner	Parent
FASD	1, 15, 18, 20, 25, 26	3, 7, 11(2)*, 21, 23, 31	6, 8, 9, 16, 19
ASD	1, 18, 20, 26, 29	2, 3, 7, 11(2)*, 13, 17, 21, 23, 24, 29, 31	4, 5, 10, 12, 29, 30
CP	18, 20, 26	11(2)*, 14, 23, 27, 31	22, 28, 30, 32
Total interviews: 32			
Length of interviews (range): 45min – 2h:52min			
Average length of interviews: 88 minutes			

*The table should be interpreted in the following manner. Interviewee #1 is a policymaker working within the areas of both FASD and ASD. Interviewee #11 has a (2) beside the number because two clinicians/practitioners were interviewed together (at their request), and this table shows that they work within the domains of FASD, ASD and CP. Although the table separates interviewees into three categories: policy, clinician/practitioner and parent, it was often the case that a policymaker or frontline practitioner was also a parent. However, this detail is not reported for the purpose of preserving the confidentiality of participants in line with our ethics protocol.

2.0 Methodology 2.2 Data – Survey and Interviews**Figure 2.1**

Geographic distribution of the number of individuals who participated in a telephone interview as part of the stakeholder engagement project, according to their current location.

The letter of informed consent can be found in Appendix C, while guiding interview questions can be found in Appendix D (Clinicians), Appendix E (Policymakers), Appendix F (Parents). The questions were tailored to each type of stakeholder through slight modifications on a list of base questions. By customizing the questions to each type of stakeholder, it allowed parents to comment from the perspective of personal experiences, and clinicians/frontline workers and policymakers on what they have observed are the challenges facing families based on their interactions with them. Policymakers were also asked about their challenges with respect to policy such as barriers to making necessary changes, while clinicians/frontline workers were specifically asked about the challenges they face in effectively serving their clients toward improving their quality of life.

Interviews were recorded and transcribed. N-Vivo 11 software was used for open and axial coding of transcripts, with the use of constant comparison and memoing during the coding process toward identifying emergent themes.

2.0 Methodology 2.3 Data – Triangulation Documents

2.3 Data – Triangulation Documents

Verification of knowledge (also referred to as trustworthiness, credibility or faithfulness), which is created through qualitative narrative analyses, is assessed by triangulation of data sources (Lincoln and Guba, 1985) in addition to checking for the theory's representation of the data by consulting with research participants themselves (Sandelowski, 1986; 1993). Reports that were funded or commissioned by government and that included information on stakeholder needs were included in the analysis. These documents were sought in several ways: 1) requested via emails to each province and territory, 2) by asking participants for any recommendations at the end of the one-on-one interviews, 3) by conducting an online search for reports from each province and territory, as well as national reports. This online search was conducted in August 2016 to find and retrieve government-funded reports that reflected stakeholder needs for either FASD, ASD or CP in Canada. Of the full list of 29 reports, 17 were chosen for inclusion in this stakeholder engagement project. Reports that were government funded and written as a result of an in-person stakeholder consultation event were selected for inclusion for the purpose of triangulation with interview data (see Appendix H).

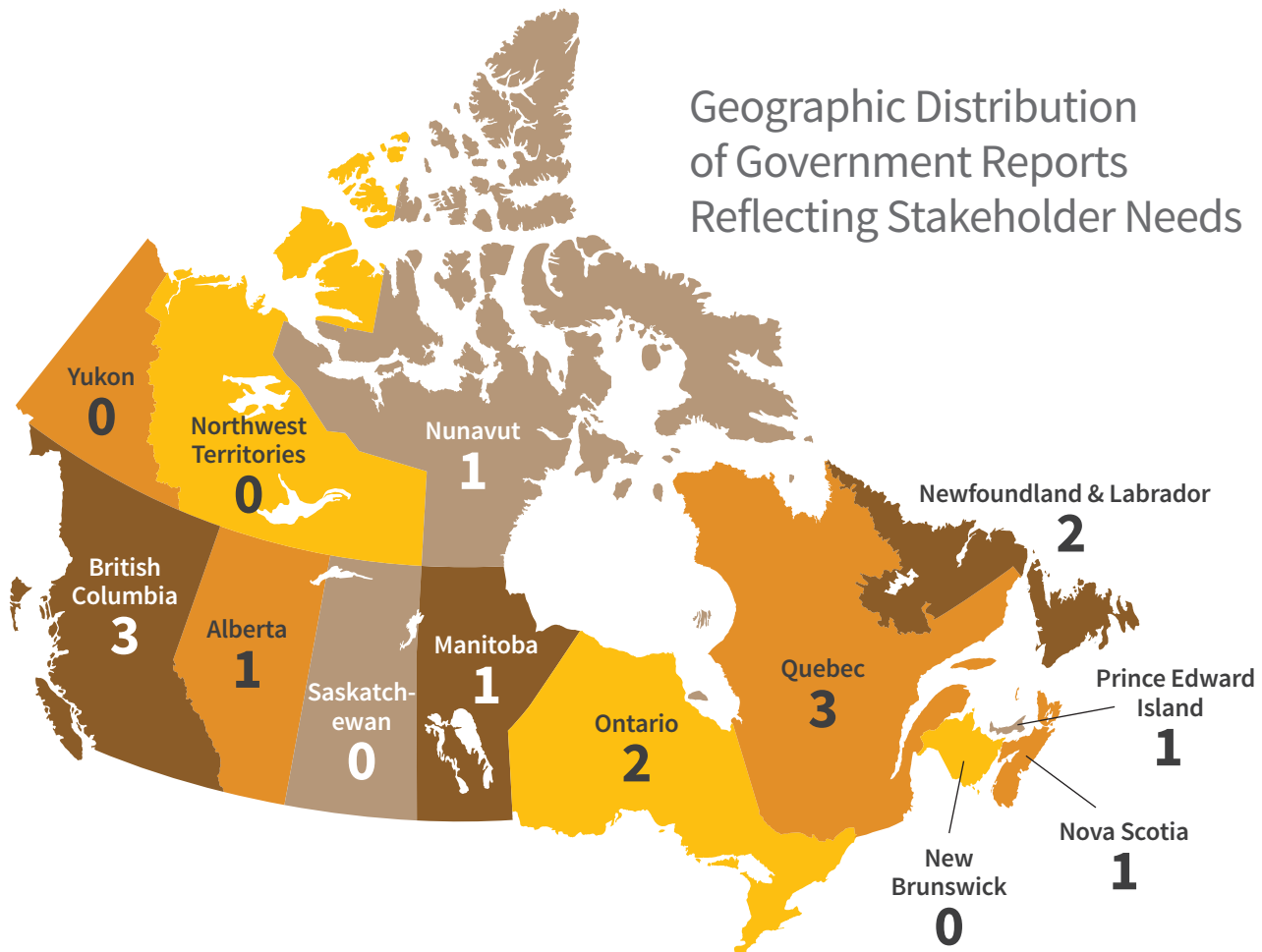


Figure 2.2

Geographic distribution of reports based on stakeholder consultations conducted by government or community organizations funded in part by government.⁸

⁸ there were two national level reports that were included in the analysis and scan but are not included in the map because as national reports they are not associated with any individual province or territory.

2.0 Methodology 2.4 Analysis

2.4 Analysis

The theoretical perspective adopted for this study was social constructivism. The social constructivist perspective assumes the position that ‘reality’ based on perceptions, facts, values and knowledge are all socially constructed (Berger and Luckmann, 1966). Using a constructivist approach, the research is centred upon the notion that people can derive meaning from objects in the environment as well as from social interactions (McMahon, 1997; Crotty, 1998).

The coding and subsequent analysis of transcripts was completed independently by the researcher, using the qualitative analysis software program N-Vivo 11. During the coding process for this research, memoing occurred throughout, by keeping hand-written notes of conceptual ideas as they occurred. Memoing is an important process, in which insights are recorded and later used by the researcher in developing the emergent theory. Memos are written records of the researcher’s thoughts, feelings, progress, and analytical and conceptual interpretations (Schrieber and Stern, 2001). The purpose is to keep the research grounded in the data as well as to maintain awareness of the researcher throughout the research process and to move beyond description to conceptualizing and depicting relationships among concepts (Glaser, 1978; Strauss and Corbin, 1998). It is important to note that the N-Vivo software is merely a tool for analysis; it is the mind of the researcher that creates and refines that conceptual framework which illuminates the problems and processes in the situation (Stern and Covan, 2001). Open coding is the first step in coding according to grounded theory method, although axial coding does not occur as an entirely separate process (Glaser, 1978; Strauss and Corbin, 1998). Categories and their relationship to one another begin to emerge during open coding and are captured in the form of memos; axial coding continues when these fractured data become re-assembled into abstracted categories (Glaser, 1978; Strauss and Corbin, 1998). These interpretations were validated by constant comparison throughout the coding and analysis processes (Glaser, 1978).

Qualitative analysis was conducted using the constant comparative method (Glaser, 1978). N-Vivo 11 software was used for open and axial coding (see Appendix I) with memoing. Initially, nine themes and 43 focus areas were identified and sent to participants for feedback in November 2016 and revised accordingly (see 3.6 Trustworthiness) resulting in nine themes and 44 focus areas.

2.5 Trustworthiness through validation with participants

“Validity is not so much a property of interpretations as it is the collective agreement of intended audience(s) that the interpretations are convincing.” (Glaser, 1978: 73)

Member-checking or member-validation is a method for ensuring the rigour of research findings, by contacting research participants and providing a portion of the findings for comment, in order to verify its ability to truly represent the phenomena from their perspective (Glaser, 1978). The key dimension of trustworthiness is ‘fit’: in other words, do the findings ‘fit’ or accurately represent the reality of the situation? In order to determine ‘fit’, participants were provided with initial results which identified 9 themes with 46 focus areas and asked to provide feedback within a two-week period ending November 23, 2016 (see Appendix G; Birt et al., 2016). After November 23, feedback from 13 out of the 32 respondents was compiled and used to revise and refine into nine themes and 44 focus areas. Another layer of establishing trustworthiness involved triangulating interview data (see Moran-Ellis et al., 2006; Lincoln and Guba, 1985; Sandelowski, 1986, 1993) with the document data. The 17 reports that had been identified and included in the analysis were purposely **not** reviewed prior to coding of interview data in order to minimize coding bias.

(continued on next page)

2.0 Methodology 2.5 Trustworthiness through validation with participants

After initial coding and member-validation, the 17 reports were reviewed, and portions that supported the findings of this study were extracted. This information was inserted in the results section where appropriate to support or clarify what had been articulated as a result of our analysis of our interview data. In order to allow us to make recommendations to the Network for strategic planning and resource allocation, we enlisted the help of a similar (but different) set of stakeholders in Vancouver, BC, to help us prioritize the 44 focus areas into a ‘top ten’ list, as well as to provide additional detail about how to approach each priority (see Appendix L).

It should be noted that the conclusions of this work are theoretical, not confirmatory. As such they are a suggestion for viewing the situation.

2.6 In-person Stakeholder Consultation Priority-Setting Event

A full-day in-person stakeholder consultation event was held in Vancouver, British Columbia on January 18, 2017, with 25 frontline workers, policymakers and parents. As was the case with the one-on-one interviews, these categories overlapped; some parents were also policymakers or frontline workers. Stakeholders were sought using a variety of means: 1) online searches, 2) searches using LinkedIn’s advanced search option, as well as searching within the 500-plus connections to the KBHN LinkedIn profile that had previously been established by the KT Core, 3) asking Network Principal Investigators for contacts with parents and/or frontline workers in BC.

This event provided additional information (about which focus areas should be prioritized, and details on how we can address them) beyond what our previous analysis and results could provide. The rationale was that we needed the wisdom of our stakeholders to help 1) prioritize the 44 items in terms of what is most important to address first (acknowledging that they are all important but recognizing the reality that all 44 cannot be addressed at once), and 2) provide us with additional details for how KBHN can begin to address these priorities. The structure of this event utilized the well-established facilitation framework ‘ORID’ (Objective, Reflective, Interpretive, Decisional) (Hogan, 2005) which, due to its format, allows individuals to move through the necessary stages of thinking to provide the information that was being sought (see Mungia et al., 2015). The day began with one presentation to anchor the proceedings, containing information about the Network, stakeholder engagement and the research study purpose, process and results (the “objective” stage, to ‘get everyone on the same page’). After presenting the results (the 44 focus areas) to the 25 stakeholders (a different set of parents, clinicians/frontline workers, policymakers) in attendance, they were provided with an opportunity to vote (the “reflective” stage, whereby participants are provided with an opportunity to have an emotional reaction to what they have just heard. Without this, participants would be unable to enter the interpretive phase during which critical thinking can take place). Stakeholders were asked to vote using a process called ‘dotmocracy’ to help identify the top 10 priorities on which the Network could focus. Each of the 44 priorities had been printed and laminated on separate cards and placed around the room, and participants were provided with a ‘map’ to help them locate the card(s) they wished to vote on and 14 stickers to use for voting. Participants were instructed to place dots on the focus areas that they believed were a top priority; one sticker could be placed on 14 individual items or all 14 on one item if they felt strongly about it (and any combination in between). The results of the voting are provided in a table (Table 3.2, Section 3.0). The top 10 priorities were then discussed by participants in breakout groups (the “interpretive” and “decisional” stages), five priorities discussed in the morning and another five in the afternoon, one per table (5 tables) using a template with focused discussion questions (see Appendix L). Each group was asked to elect a note-taker to fill out the

2.0 Methodology 2.6 In-person Stakeholder Consultation Priority-Setting Event

electronic template provided on a laptop at each table during the breakout discussions. Afterwards, the templates were collected from each group on a USB key and opened on a laptop that was connected to a projector, so that during the large-group report back everyone could see and comment on the answers provided by the one group to help clarify or add to any of the information provided. The additional information and comments gathered through the large-group report-back exercise were audio recorded, and utilized to refine and clarify the input provided by stakeholders for each of the prioritized needs that were discussed in breakout groups. The resultant document is provided in Appendix L.

The agenda for the day is provided in Appendix K. Participants were encouraged to self-organize around the table with the focus area they wanted to discuss. Interestingly, although priority #9 was in the top 10 in terms of votes, there were no participants at that table, yielding no detailed information about that priority.

2.7 Limitations

Limitations stem from qualitative research methodology in general, as well as issues which are more specific to the context within which the study was conducted. With respect to the methodology, since qualitative analysis ultimately rests with the experiences, thinking and choices of the researcher, the issue of subjectivity introduces concerns of bias. Member validation with interviewees is intended to mitigate this bias, by asking participants to review the findings and comment about how well the results of the analysis reflect their experiences. Triangulation of reports about stakeholder needs also provides support for the outcomes of this analysis. Other limitations included:

- Limited participation in the initial survey by Network members (52 out of 248)
- Some respondents to the survey indicated certain stakeholder engagement activities had occurred, but had no documentation of stakeholder needs
- Inability to obtain representation (both interviews and reports for CP, ASD, FASD) for all provinces and territories
- Majority of interviewees in Ontario
- Short time frame for completion of the project
- Interviews conducted, and reports included, were in English only
- While reports specific to ASD and FASD were available in some provinces and territories, there were no reports that were specific to CP only (CP was usually captured within more general “persons with disabilities” reports/departments)
- ‘Dotmocracy’ allowed participants at our in-person stakeholder consultation on January 18, 2017, to use as many stickers as they wanted (of the total 14 stickers each attendee was given to vote with) on the items they deemed to be a priority. Priority #9 may have received a high number of votes from one participant. The self-organization of individuals around tables with focus areas they wished to discuss likely served as a secondary ‘check’ on whether the priorities actually represented the needs of stakeholders.

3.0 Results and Discussion – Themes and Focus Areas

3.0 Results and Discussion – Themes and Focus Areas

The basic social problem: Quality of life

At the outset of this project, Kids Brain Health Network sought a better understanding about how to achieve impact for its stakeholders. KBHN considers impact to have been achieved when children 1) are diagnosed sooner, 2) receive validated interventions, 3) are provided with family services to maximize their potential. A core category or ‘basic social problem’ arising from the data was *quality of life*. This project was approached with an openness to all emergent categories that arose from the data. This basic social problem that emerged also fits with (one of the components of) the Network’s vision, that is, to help individuals and families achieve the greatest quality of life possible. By seeking to understand this ‘basic social problem’ more fully, it can inform future activities and projects undertaken by KBHN, governments and community organizations in order to help meet stakeholders’ needs for being able to maximize their quality of life.

The basic social process: Managing (life with a) neurodevelopmental condition through empowerment

The analysis led to the identification of another type of core category called a ‘basic social process’ (BSP) that addresses the basic social problem. The basic social process identified was empowerment. Individuals living with a neurodevelopmental condition desire meaningful engagement: in school, employment and in relationships. Parents are motivated to do the best for their child. They need to be empowered, which can be accomplished in part by removing existing barriers which only serve to delay, minimize or prevent parents of children (and the children/individuals themselves) with neurodevelopmental condition(s) from achieving the highest quality of life possible, now and in the future. Frontline workers including clinicians also need to be empowered to be able to provide the best services and interventions to their clients, when needed and for as long as they are needed.

3.0 Results and Discussion – Themes and Focus Areas

Barriers to empowerment include: policies, service availability and quality, waiting lists for obtaining a diagnosis and access to interventions, lack of information about rights and services, financial constraints, environmental conditions including aspects of the physical environment⁹ and the social environment¹⁰, and individuals in positions of power to help (such as physicians) but who do not fully understand the condition of the child/individual and/or who are unwilling to listen to parents. By removing barriers, parents and frontline workers become more empowered to help children/individuals with a neurodevelopmental condition, and self-advocates become better equipped to obtain what they need to maximize their potential now and in the future. To this end, facilitating empowerment of children/individuals, parents and frontline staff emerged as an overarching need that relates to all nine themes and 44 focus areas. Thus, the basic social problem of *quality of life* is addressed by the basic social process *managing (life with a) neurodevelopmental condition through empowerment*.

The interviews identified nine themes common to stakeholders:

1. Diagnosis
2. Treatment
3. Services
4. Education
5. Health Care
6. Mental Health/Quality of Life
7. Life course perspective
8. Culture and context
9. Broader system and society

The findings are organized first in terms of the emergent themes and focus areas, which are situated within the broader category of empowerment for individuals and families. The themes and focus areas below are based on the experiences of parents, clinicians/frontline workers and policymakers as they navigate the interrelated systems and sub-systems for improving quality of life for the individual affected by a neurodevelopmental condition that they care for. The data comprise proxy information about the experiences of the person with a neurodevelopmental condition according to observations of parents, clinicians and policymakers since we did not interview the children directly. However, some interviewees disclosed that they also were personally affected by a neurodevelopmental condition. Therefore, although we did not seek self-advocates as part of the interview sample, we also were able to benefit from this perspective by chance.

(continued on next page)

⁹ such as terrain for wheelchair use; lights, sounds, smells, etc. that affect those with sensory issues.

¹⁰ isolation, parent support groups, societal perceptions, etc.

3.0 Results and Discussion – Themes and Focus Areas

In some cases, needs were identified from proposed solutions by interviewees. While the themes and focus areas are presented in the table below as ‘separate’, they are in fact, all interrelated. Their interrelatedness will be detailed in the sections below the table, including illustrative quotes from interviewees. As an example, the explanation for the diagnosis category contains quotes about the importance of diagnosis of sleep issues. Sleep issues are mentioned later in the table under mental health, from the perspective of sleep issues on child behaviour and parent mental health. However, under diagnosis, the importance of establishing a diagnosis for sleep is mentioned because of the identified need for early diagnosis and treatment, which encompasses not only CP, FASD and ASD but associated issues such as sleep. Where relevant, information and quotes from reports have been triangulated to support and strengthen our findings. All themes and focus areas are related either directly or indirectly to knowledge translation including considerations for policy and practice. The items appearing within the following table have **not** yet been prioritized.

Table 3.1 below, presents the nine themes and 44 focus areas by category. Table 3.2 which follows, represents the same themes and focus areas, re-organized according to the number of votes received for each item (from highest to lowest) as a result of the ‘dotmocracy’¹¹ exercise during the January 18, 2017, stakeholder engagement event in Vancouver, BC.

Table 3.1:
9 themes and 44 focus areas emerging from the interview data

Themes	Needs identified by all stakeholders (parents, clinicians, policymakers)	
1. Diagnosis	1	Need specialized training for health care professionals so that observations of parents will be recognized and will ensure early diagnosis and treatment.
	2	Need non-categorical treatment for the child as soon as possible without the barrier of a lack of diagnosis getting in the way of being able to address functional deficits.
	3	Need (early) diagnosis so that targeted and specific supports can be obtained for what is necessary (in schools, getting services/supports, etc.). Non-categorical treatment does not allow matching of treatment to diagnosis for best outcome for the child.
	4	Need reduction or removal of barriers to obtaining diagnosis such as: limited training for frontline health care (GPs); access to skilled diagnostic professionals, waiting lists, financial (out of pocket costs) for private diagnostic assessment, geography including rural/remote locations.

(table continued on next page)

¹¹ dot-voting (also known as dotmocracy or voting with dots) is an established facilitation method used to describe voting with dot stickers or marks with a marker pen. In dot-voting, participants vote on their chosen options using a limited number of stickers or marks with pens — dot stickers being the most common. Source: <https://en.wikipedia.org/wiki/Dot-voting>

3.0 Results and Discussion – Themes and Focus Areas

Table 3.1: *(continued)*

9 themes and 44 focus areas emerging from the interview data

Themes	Needs identified by all stakeholders (parents, clinicians, policymakers)	
2. Treatment	5	Need context-specific, timely and convenient access to treatment, centralized services with experts. Wait times, criteria for treatment eligibility (e.g. age, IQ) exclude those in need.
	6	Need clear, consistent, effective communication among service professionals, to relieve this burden from parents. Need for co-ordination of communication among organizations, services.
	7	Need non-judgmental approach by frontline workers to parents. There is heterogeneity among parents to (accept diagnosis and) receive interventions, and judging them as either not motivated enough or too motivated because they want to do everything, causes undue stress to parents.
	8	Need access to a menu of evidence-based treatment options with information about what each of them does, and fluidity of the system(s) of treatment delivery to allow access to families/individuals when needed for as long as it is needed. Need information on what evidence-based treatment is, and what is the gold standard. Parents need help figuring out what's important to prioritize; can't do everything.
	9	Need more resources allocated (financial/resource constraints of the system as well as parents) plus more efficient use of existing resources within programs, and larger system to maximize benefit to the child/family.
3. Services	10	Need case managers who can co-ordinate communication among professionals and who can advocate for what the child needs, so parents don't have to do it all (case management involves a high volume of work). Acknowledge additional challenges in managing complex care, which further emphasizes the need for a case manager to help the family. Ideally this person also needs to understand the specific neurodevelopmental condition of the child/individual.
	11	Need for consistent service, especially in situations where there is high staff turnover. Can mitigate high turnover rates with full-time, well-paid positions with good benefits.
	12	Need to allow family members to be employed/subsidized as support workers for the child, as an option.
	13	Need co-ordinated and integrated 'wrap-around care' for the child.

(table continued on next page)

3.0 Results and Discussion – Themes and Focus Areas

Table 3.1: (continued)

9 themes and 44 focus areas emerging from the interview data

Themes	Needs identified by all stakeholders (parents, clinicians, policymakers)	
4. Education	14	Need to identify, acknowledge, and create workaround for aspects of the physical and social environment that can help or hinder the child’s success in school.
	15	Need specialized and in-depth mandatory training for teachers, EAs, resource teachers, principals or anyone who interacts with children in schools in terms of approaches for children who have a neurodevelopmental condition. Includes the need for knowledge, attitudinal and cultural training for all service providers (e.g. how to work with children/youth/adults with neurodevelopmental conditions, as well as how to work with different cultures, ethnicities and other groups of populations including indigenous communities).
	16	Individualized Education Programs (IEPs) are created but not used. A child must be allowed to self-advocate, if they are able, for what they need in school to be successful (don’t assume a teacher will remember everything in IEP). At the same time, the child cannot assume all responsibility. All participants affect a child’s mental health and potential for success.
	17	Child needs to be able to fit in with their peers at school.
	18	There is a need for parental concerns to be heard and acted upon appropriately by teachers, EAs, principals, without barriers imposed by unions, when it comes to implementing parental advice/strategies for helping the child to be at their best. Parents need help from school to explore alternate solutions such as scaling-back classes in high school with a scheduled work period, or an extra year in high school with co-op placements that suit the child’s strengths.
	19	Need for (more) professionals working within the school system (e.g. nurses, educational assistants, those delivering interventions such as physical therapy, ABA, etc.) with appropriate training to work with children with neurodevelopmental conditions.
5. Health Care	20	Need additional specialized in-depth training in neurodevelopmental conditions for GPs, emergency room (ER) doctors, nurses, administrative staff, dentists, etc. Includes need for knowledge, attitudinal and cultural safety training for all health professionals and service providers (e.g. how to work with children/youth/adults with neurodevelopmental conditions, as well as how to work with different cultures, ethnicities and other groups of populations including indigenous communities).
	21	Need smoother management of complex cases, easier access to specialty equipment, services.
	22	Need timely access to psychiatrist for child/youth with neurodevelopmental conditions, in order to prevent self-medication with alcohol and/or illegal drugs, and involvement with justice/police systems.
	23	Need co-ordinated supports and protocols for neurodevelopmental condition(s) as a medical condition, similar to what is available for other medical conditions (e.g. diabetes, heart disease, cancer, etc.).

(table continued on next page)

3.0 Results and Discussion – Themes and Focus Areas**Table 3.1:** *(continued)***9 themes and 44 focus areas emerging from the interview data**

Themes	Needs identified by all stakeholders (parents, clinicians, policymakers)	
6. Mental Health/ Quality of Life	24	Need support(s) for parent mental health such as: self-care, support workers, respite, socializing with others who understand their situation, parent support groups, which can also help address issues of isolation and stress on a marriage/relationship co-habitation.
	25	Need for broader societal awareness of neurodevelopmental conditions and acceptance of neurodiversity toward reducing stigma. Encourage inclusion by determining the child's strengths and giving them opportunities to contribute using their interests and natural abilities.
	26	Need to treat siblings as equally and fairly as possible, paying attention to the mental and emotional health, and quality of life for neurotypical siblings.
	27	Need social skills/behavioural training, and strategies for self-regulation of emotions anxiety for the child with the neurodevelopmental condition.
	28	Need more financial control for families and a system coordinator to help access services.
	29	Need equity in terms of financial cost and access/availability of inclusive recreational programs for children. Place(s) to go to find purpose, enjoyment, physical fitness and socialization.
	30	Child needs purpose/meaning (in school, later in life in their employment) and needs day programs or other activities for adults who do not fit into work environment.
	31	Need to acknowledge safety issues in terms of: child's difficulty managing emotions (can lead to physical aggression, self-medicating with drugs/alcohol); parents' lack of sleep, which can result in medication errors, automobile and other accidents, etc.
	32	Need to identify and address sleep issues in children with neurodevelopmental conditions which affect daytime behaviours of the child and parental sleep/stress.
	33	Interventions and services need to be tailored to children (not based on adult mental health service model) with neurodevelopmental conditions (treatments for neurotypical children might not work).

(table continued on next page)

3.0 Results and Discussion – Themes and Focus Areas

Table 3.1: (continued)

9 themes and 44 focus areas emerging from the interview data

Themes	Needs identified by all stakeholders (parents, clinicians, policymakers)	
7. Life Course Perspective	34	Need supports for being successful in education at all levels, and to maximize the chances for individuals with neurodevelopmental conditions to obtain meaningful employment.
	35	Adults need services to maximize their potential throughout the life course, especially if they missed the window of services during childhood. There are very few options for adults to obtain diagnosis and/or treatment or services of any kind. There is nothing for seniors.
	36	Need continuity in services at key times/transition points during the life course, and need assistance filling-out forms required to access resources (including funding programs for adults with disabilities) during transition periods. Find ways to provide continuity in services for those with ongoing medical needs (this is often lost during transition from child to doctors who serve adults).
	37	Need (good) supportive housing for youth/adults to be able to live as independently as possible (some need more supports than others to maximize independence).
	38	Need societal and system acknowledgement that this is a life-long condition by providing access to supports that last a lifetime/don't disappear at a certain age. This includes associated child mental health care and mental health condition(s) that could evolve over time.
8. Culture and Context	39	Need culturally specific services developed by and for a particular cultural group, offered in native language and appropriate adaptations to interventions to suit a particular culture.
	40	Need innovative means for delivering and monitoring services and intervention delivery in remote/rural regions (e.g. tele-health).
	41	Need to identify and understand regional differences among provinces/territories (policies/services offered), rural vs urban, remote/northern regions, including what works and doesn't work in each.
9. Broader system and society	42	Need timely access to new research knowledge for informing policies, best practices and services.
	43	Need more flexibility in policies guiding programs, so that changes based on experiential knowledge can also be implemented to better serve clients (e.g. even small changes such as allowing text message reminders from practitioners to clients about upcoming appointments).
	44	Need for more equity in funding for different neurodevelopmental conditions. In some cases, CP supports/services seem to be well-funded, ASD appears to also be well-funded but FASD remains under-serviced/under-funded by comparison.

3.0 Results and Discussion – Themes and Focus Areas

In Table 3.2 (below) the first and second priorities, with 39 and 22 votes can be grouped together, another grouping can be seen in priorities #3, 4 and 5 (17, 16 and 15 votes, respectively) and finally a third grouping can be seen in the remaining priorities #6-10 (mainly 13 and 12 votes each).

Table 3.2:

The nine themes and 44 focus areas that emerged from analysis of the interview data, re-organized in order from highest to lowest number of votes (first priority to last priorities) received for each item during the January 18, 2017 stakeholder engagement event in Vancouver, BC.

Theme	Focus Area	Needs as expressed by stakeholders interviewed	# votes 2017 Jan 18
2. Treatment	8	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. Need information on what evidence-based treatment is, and what is the gold standard. Parents need help figuring out what's important to prioritize, can't do everything.	39
4. Education	19	Need for (more) professionals working within the school system (e.g. nurses, educational assistants, those delivering interventions such as physical therapy, ABA, etc.) with appropriate training to work with children with neurodevelopmental conditions.	22
9. Broader system and society	44	Need for more equity in funding for different neurodevelopmental conditions. In some cases, CP supports/services seem to be well-funded, ASD is also well-funded but FASD remains under-served/under-funded in comparison.	17
1. Diagnosis	4	Need reduction or removal of barriers to obtaining diagnosis such as: limited training for frontline healthcare (GPs); access to skilled diagnostic professionals, waiting lists, financial (out-of-pocket costs) for private diagnostic assessment, geography including rural/remote locations.	16
4. Education	15	Need specialized and in-depth mandatory training for teachers, EAs, resource teachers, principals or anyone who interacts with children in schools in terms of approaches for children who have a neurodevelopmental condition. Includes need for knowledge, attitudinal and cultural training for all service providers (e.g. how to work with children/youth/adults with neurodevelopmental conditions, as well as how to work with different cultures, ethnicities and other groups of populations, including indigenous communities).	15
1. Diagnosis	3	Need (early) diagnosis so that targeted and specific supports can be obtained for what is needed (in schools, getting services/supports, etc.). Non-categorical treatment does not allow matching of treatment to diagnosis for best outcome for the child.	13

(table continued on next page)

3.0 Results and Discussion – Themes and Focus Areas

Table 3.2: *(continued)*

The nine themes and 44 focus areas that emerged from analysis of the interview data, re-organized in order from highest to lowest number of votes (first priority to last priorities) received for each item during the January 18, 2017 stakeholder engagement event in Vancouver, BC.

Theme	Focus Area	Needs as expressed by stakeholders interviewed	# votes 2017 Jan 18
7. Life Course Perspective	36	Need continuity in services at key times/transition points during the life course, and need assistance filling-out required forms for access to resources (including funding programs for adults with disabilities) during transition periods. Find ways to provide continuity in services for those with ongoing medical needs (this is often lost during transition from child to doctors who serve adults).	13
7. Life Course Perspective	37	Need (good) supportive housing for youth/adults to be able to live as independently as possible (some need more supports than others to maximize independence).	13
2. Treatment	9	Need more resources allocated to alleviate financial/resource constraints of the system as well as parents, plus more efficient use of existing resources within programs and larger system to maximize benefit to the child/family.	12
6. Mental Health/Quality of Life	27	Need social skills/behavioural training and strategies for self-regulation of emotions/anxiety for the child with the neurodevelopmental condition.	11
7. Life Course Perspective	34	Need supports for being successful in education at all levels and to maximize the chances for individuals with neurodevelopmental conditions to obtain meaningful employment.	10
7. Life Course Perspective	38	Need societal and system acknowledgement that this is a life-long condition by providing access to supports that last a lifetime/ don't disappear at a certain age. This includes associated child mental health care and mental health condition(s) that could evolve over time.	10
1. Diagnosis	2	Need non-categorical treatment for the child as soon as possible, without the barrier of a lack of diagnosis getting in the way of being able to address functional deficits.	9
4. Education	17	Child needs to be able to fit in with their peers at school.	9
5. Health Care	20	Need additional specialized in-depth training in neurodevelopmental conditions for GPs, nurses, ER doctors, administrative staff, dentists, etc. Includes need for knowledge, attitudinal and cultural safety training for all health professionals and service providers (e.g. how to work with children/youth/adults with neurodevelopmental conditions, as well as how to work with different cultures, ethnicities and other groups of populations, including indigenous communities).	9

(table continued on next page)

3.0 Results and Discussion – Themes and Focus Areas

Table 3.2: *(continued)*

The nine themes and 44 focus areas that emerged from analysis of the interview data, re-organized in order from highest to lowest number of votes (first priority to last priorities) received for each item during the January 18, 2017 stakeholder engagement event in Vancouver, BC.

Theme	Focus Area	Needs as expressed by stakeholders interviewed	# votes 2017 Jan 18
5. Health Care	22	Need timely access to psychiatrist for child/youth with neuro-developmental conditions in order to reduce the potential for self-medicating with alcohol and/or illegal drugs, and involvement with justice/police systems.	9
6. Mental Health/Quality of Life	25	Need for broader societal awareness of neurodevelopmental conditions, acceptance of neurodiversity, toward reducing stigma. Encourage inclusion by determining a child's strengths and giving them opportunities to contribute using their interests and natural abilities.	9
6. Mental Health/Quality of Life	32	Need to identify and address sleep issues in children with neurodevelopmental conditions, which affect daytime behaviours of the child and parental sleep/stress.	9
3. Services	10	Need case managers who can co-ordinate communication among professionals and who can advocate for what the child needs, so parents don't have to do it all (case management involves a high volume of work). Acknowledge additional challenges in managing complex care, which further emphasizes the need for a case manager to help the family. Ideally this person also needs to understand the specific neurodevelopmental condition of the child/individual.	8
4. Education	14	Need to identify, acknowledge and create workaround for aspects of the physical and social environment that can help or hinder the child's success in school.	8
4. Education	18	There is a need for parental concerns to be heard and acted upon appropriately by teachers, EAs, principals, without barriers imposed by unions, when it comes to implementing parental advice/strategies for helping the child to be at their best. Parents need help from school to explore alternate solutions such as scaling back classes in high school with a scheduled work period, or an extra year in high school with co-op placements that suit the child's strengths.	8
5. Health Care	23	Need co-ordinated supports and protocols for neurodevelopmental condition(s) as a medical condition, similar to what is available for other medical conditions (e.g. diabetes, heart disease, cancer, etc.)	8

(table continued on next page)

3.0 Results and Discussion – Themes and Focus Areas

Table 3.2: *(continued)*

The nine themes and 44 focus areas that emerged from analysis of the interview data, re-organized in order from highest to lowest number of votes (first priority to last priorities) received for each item during the January 18, 2017 stakeholder engagement event in Vancouver, BC.

Theme	Focus Area	Needs as expressed by stakeholders interviewed	# votes 2017 Jan 18
4. Education	16	Individualized Education Programs (IEPs) are created but not used. A child must be allowed to self-advocate, if they are able, for what they need in school to be successful (don't assume the teacher will remember everything in IEP). At the same time, a child can't assume all responsibility. Getting what they need (or not) affects the child's mental health and potential for success.	7
6. Mental Health/Quality of Life	24	Need support(s) for parent mental health such as: self-care, support workers, respite, socializing with others who understand their situation and parent support groups, which can also help address issues of isolation and stress on the marriage.	7
6. Mental Health/Quality of Life	33	Interventions and services need to be tailored to children (not based on adult mental health service model) with neurodevelopmental conditions (treatments for neurotypical children might not work).	7
7. Life Course Perspective	35	Adults need services to maximize their potential throughout the life course, especially if they missed the window of services during childhood. There are very few options for adults to obtain diagnosis and/or treatment or services of any kind. There is nothing for seniors.	7
3. Services	12	Need to allow family members to be employed/subsidized as support worker for the child, as an option.	6
9. Broader system and society	42	Need timely access to new research knowledge for informing policies, best practices and services.	6
2. Treatment	5	Need context-specific, timely and convenient access to treatment and centralized services with experts. Wait times, criteria for treatment eligibility (e.g. age, IQ) exclude those in need.	5
6. Mental Health/Quality of Life	26	Need to treat siblings as equally and fairly as possible, paying attention to the mental and emotional health and quality of life for neurotypical siblings.	5
6. Mental Health/Quality of Life	28	Need more financial control for families and a system co-ordinator to help access services.	5
6. Mental Health/Quality of Life	29	Need equity in terms of financial cost and access/availability of inclusive recreational programs for children. Place(s) to go to find purpose, enjoyment, physical fitness and socialization.	5

(table continued on next page)

3.0 Results and Discussion – Themes and Focus Areas

Table 3.2: *(continued)*

The nine themes and 44 focus areas that emerged from analysis of the interview data, re-organized in order from highest to lowest number of votes (first priority to last priorities) received for each item during the January 18, 2017 stakeholder engagement event in Vancouver, BC.

Theme	Focus Area	Needs as expressed by stakeholders interviewed	# votes 2017 Jan 18
6. Mental Health/Quality of Life	30	Child needs purpose/meaning (in school, later in life in their employment) and needs day programs or other activities for adults who do not fit into work environment.	5
6. Mental Health/Quality of Life	31	Need to acknowledge safety issues in terms of: child's difficulty managing emotions (can lead to physical aggression, self-medicating with drugs/alcohol); parents' lack of sleep, which can result in medication errors, automobile and other accidents, etc.	5
8. Culture and Context	40	Need innovative means for delivering and monitoring services and intervention delivery in remote/rural regions (e.g. tele-health).	5
1. Diagnosis	1	Need specialized training for healthcare professionals so that observations of parents will be recognized, and will ensure early diagnosis and treatment.	4
3. Services	13	Need co-ordinated and integrated 'wrap-around care' for the child.	4
8. Culture and Context	39	Need culturally specific services developed by and for a particular cultural group, offered in native language and appropriate adaptations to interventions to suit a particular culture.	4
3. Services	11	Need for consistent service, especially in situations where there is high staff turnover. Can mitigate high turnover rates with full-time, well-paid positions with good benefits.	3
5. Health Care	21	Need smoother management of complex cases, easier access to specialty equipment, services.	3
2. Treatment	6	Need clear, consistent, effective communication among service professionals, to relieve this burden from parents. Need for co-ordination of communication among organizations; services.	2
2. Treatment	7	Need non-judgmental approach by frontline workers toward parents. There is heterogeneity among parents to (accept diagnosis and) receive interventions. Feeling judged as either not motivated enough, or too motivated because they want to do everything, causes undue stress to parents.	2
8. Culture and Context	41	Need to identify and understand regional differences among provinces/territories (policies/services offered), rural vs urban, remote/northern regions including what works and doesn't work in each.	2
9. Broader system and society	43	Need more flexibility in policies guiding programs, so that changes based on experiential knowledge can also be implemented to better serve clients (e.g. even small changes such as allowing text message reminders from practitioners to clients regarding upcoming appointments).	2

3.0 Results and Discussion – Themes and Focus Areas 3.1 Diagnosis

3.1 Diagnosis

A diversity of positions on the appropriate role of diagnosis were expressed, and were tightly linked to the second theme of “Treatment” (section 3.2 below). Opinions ranged between those who believe certain treatments should be accessible without a diagnosis (the disability or functional perspective, which aligns with a non-categorical approach) and the opinion that supports the notion of targeted interventions based on specific diagnosis. The positional diagram in Appendix J features axes which contrast access to treatment with the potential effect on the child (of taking a “disease perspective” versus a “disability perspective” when attempting to achieve improvement in the child’s functioning)¹². The issue of adopting a “disease perspective” versus taking a “disability perspective” remains an active debate among stakeholders. It should be noted that diagnosis is believed to be important within both the disease perspective as well as the disability perspective. Diagnosis informs overall care, management and policy for children with neurodevelopmental conditions. A diagnosis not only provides much-needed confirmation to parent(s) but also facilitates communication and may guide aspects of treatment. However, having an accurate medical diagnosis is less critical for treatment planning in an era in which there are few therapeutic technologies specific for particular brain dysfunctions. An important range of interventions for children with disabilities (or neurodisability, or a neurodevelopmental condition) are (re)habilitative and supportive, and lend themselves to a non-categorical (disability or functional perspective) approach in which commonalities of function and need, at the level of child, family and community, **across** conditions are sought. In line with this, some have argued that diagnosis **must** be properly combined with full functional formulation, and that it is knowledge of functional status that should be most important in shaping these interventions and the eligibility criteria that surround them (see Appendix J for range of opinions expressed by interviewees).

“...in part (a better balance of non-categorical disability or functional perspective thinking with approaches based on having a discrete diagnosis) would be more equitable and fair because right now children are being kind of excluded from access to services that they need because they don’t have the ‘magic diagnosis’ that unlocks resources. This is especially the case with ASD where children have a similar range of behavioural challenges but no diagnosis of ASD and they can’t access help. Does it really matter if they have cerebral palsy or autism or fetal alcohol spectrum disorder to get things like the behavioural, emotional and family interventions they need? If they’re in a wheelchair they’ve all got the same functional issue of mobility impairment. If they’re non-verbal they’ve all got the same functional issue of language or communication impairment. If they’ve got behavioural issues, it doesn’t really matter about their diagnosis. It’s how do we work with them after identifying the particulars of their functional status and needs to find the best solution.” – Clinician

¹² For further information on categorical versus non-categorical approaches, please see the KBHN-supported two-page clear language summary (which links back to the original research paper): <http://www.neurodevnet.ca/sites/default/files/Miller-Separating-disability-from-disease-a-constructive-approach-for-health-services-and-policy%20.pdf>

3.0 Results and Discussion – Themes and Focus Areas 3.1 Diagnosis

“...some of the higher needs kids that were identified early, that seems to be, you know, fairly smooth for the most part. I think the challenge is the kids that come into our service and not necessarily with one of these diagnoses but just are having difficulties, they’re not really fitting into any category...are identified....later on to get a school program set up for them and then a...recreational program set up, that is really challenging ‘cause they’re not in a category, they’re just different. That’s tough.” – Clinician

Parents need to have a diagnosis so that they can educate themselves and prepare, and a broad diagnosis of ‘developmental delay’ is not very helpful especially for getting accommodations in school. Schools often adopt a ‘wait and see’ attitude.

“You know, I think it’s one thing to see that your child is having challenges, to be receiving supports, but it’s always a question in your head is this really what it is.” – Policymaker

“Parents want their child’s needs to be assessed earlier so that they are diagnosed and treated earlier. Families said they really need to get a diagnosis when their child is young. One family’s experience was that their school had a ‘wait and see approach’—whereby they consider kindergarten to be a ‘observation years only’ which further delays assessment and the child receiving services.”

– Services for Children and Youth with Special Needs in Ontario, p. 17

We heard from stakeholders in our January 18, 2017 stakeholder consultation meeting that the services and interventions should be based on the child’s needs (see Appendix L), and this was also reflected in the *Services for Children and Youth with Special Needs in Ontario* report.

For issues with physical functioning, children seem to be able to access treatment (e.g. Occupational Therapy, Physical Therapy) without having received a diagnosis of either ASD, FASD or CP. However, the perception was that interventions aimed at social or behavioural issues such as Applied Behavioural Analysis (ABA)/Intensive Behavioural Intervention (IBI) (and others) were mostly inaccessible without a diagnosis. Many also acknowledged that while diagnosis is important, the absence of a diagnosis should not prevent a child from receiving treatment for functional challenges whether physical or social/emotional. The need for early diagnosis so that targeted and specific supports can be obtained in schools was ranked as priority #6 in our stakeholder consultation on January 18, 2017 (see Appendix L).

“A diagnosis can provide greater understanding and acceptance. It can also result in more realistic expectations and contribute to positive outcomes.”

– FASD Provincial Roundtable Report (Ontario), p. 13

3.0 Results and Discussion – Themes and Focus Areas 3.1 Diagnosis

In terms of FASD, there is the additional diagnostic barrier in terms of the requirement for confirmation of maternal alcohol consumption during pregnancy. While the findings reflect common themes of needs across all neurodevelopmental conditions (CP, ASD, FASD), FASD presents a special situation because the diagnosis currently carries with it a fair amount of stigma and risk of judgment of the mother, which can present a significant barrier.

For all conditions, diagnosis is complex and often multi-staged. There are long waiting lists for access to diagnostic assessment. If the family can afford it, sometimes they may seek private diagnostic assessment but due to these out-of-pocket costs, this option is not accessible to all families. Early diagnosis is made more challenging when parents' observations about their child go unrecognized by frontline workers who may not have the specialized training to be able to recognize these observations as potential symptoms of a neurodevelopmental condition. Early diagnosis was desired, especially before the child enters school; this was not only reflected in the interviews but also in the *Ontario Fetal Alcohol Spectrum Disorder Provincial Roundtable Report*.

The need for early diagnosis appeared in the BC report *Connecting Family Needs to ASD Research in BC* and the *Ontario Fetal Alcohol Spectrum Disorder Provincial Roundtable Report* where challenges identified included: wait times for diagnosis; lack of trained professionals; an expectation that their GP should be the first one to suggest the diagnosis; lack of emotional support and education, post-diagnosis; and the complex fragmented system that parents are left to navigate on their own. Reduction of wait times and assistance for families to navigate the system were recommended in the Newfoundland needs assessment survey in the autism community report, and the Nunavut FASD stakeholder engagement activity of services, and gaps in Inuit communities identified a need for diagnostic services. One interviewee emphasized the need for full diagnostic services that are provided using best practices, and “not just through a 15minute survey”.

Co-morbid conditions such as anxiety, ADHD, and learning disabilities were also reported as often co-existing with CP, FASD and ASD. Sleep problems are an issue reported across conditions, yet are often missed. The importance of diagnosis of sleep problems was emphasized, since this can reduce unnecessary medications and improve daytime behaviours, while also reducing stress on the parents.

“...sleep problems have been missed and (parents) received lots of diagnoses and sometimes also lots of medications. And we have to try to sort out which medications caused which effect. So it's a discussion about missed, neglected sleep problems.” – Clinician

The issue of adult diagnosis was mentioned mostly for FASD and ASD. For adults with FASD, services for obtaining a diagnosis are unavailable or difficult to obtain and there are few if any interventions and services available for adults, including seniors.

Geographical challenges due to rural or remote locations were also cited in terms of being a barrier for obtaining a diagnosis. This was mainly an issue characteristic of Northern (remote) communities, however, it was also noted to be an issue in rural communities located in southern regions of Canada.

3.0 Results and Discussion – Themes and Focus Areas 3.2 Treatment

3.2 Treatment

The themes of ‘treatment’ and ‘services’ overlap in the sense that services are required to deliver certain interventions (treatments). Access to treatment and services does not occur automatically once a diagnosis is received. Often parents are left on their own to navigate the system. This is further discussed in the section below on ‘services’ where the need for a ‘case co-ordinator’ is articulated. It is related to the need for a menu of evidence-based treatments and the power to choose what would be best for the child with advice from a clinician on what might work best based on the child’s diagnosis or functional difficulties. This includes enriching and developmentally appropriate activities that can be incorporated into regular routines. Without a treatment plan, the effect on parents is significant:

“So once diagnosed, there was no services or supports offered to us...and that was devastating to me as a parent, because then you think, what am I going to do? I don’t know anything about the disorder.” – Parent

“There was no roadmap, there was no menu of all the possibilities...the challenges your child will end up facing and here’s what you can possibly do about it, there was none of that. I didn’t know where to start and I didn’t know where to stop....I also didn’t know what could be done at home.” – Parent

“I think a lot of parents – I think they would like to know everything that’s available and be able to choose instead of just being prescribed something.” – Parent

In terms of access to evidence-based treatment, many noted that when a child has moved up on the list to receive treatment, the parents often do not know whether the treatments being offered are evidence-based, and what their options are. Timely treatment, by experts familiar and experienced with the particular neurodevelopmental condition, was suggested as a solution, with a central ‘hub’ of all services in one spot to make it the most convenient it could be for families to access. Indeed, these needs were articulated in several reports:

“More intervention isn’t always better; it’s the timing and the focus that matters.”
– Services for Children and Youth with Special Needs in Ontario report, p. 13

“Parents said they wanted to be given a system overview: a basic description of provider agencies, including what age range they serve and what services they provide.”
– Services for Children and Youth with Special Needs in Ontario report, p. 13

“...review of evidence-based practices and programs, what is available, suitable and transferable throughout a life.”
– Quebec report: Policy Forum, Autism across the Lifespan, p. 9

3.0 Results and Discussion – Themes and Focus Areas 3.2 Treatment

The KT Core planned and held an in-person stakeholder consultation on January 18, 2017, as part of this project. The results of the consultation showed that ‘a menu of evidence-based options’ ranked as the #1 priority. During the breakout sessions participants provided more detail, including a need for a central repository of information on treatments “both evidence-based and not” that is accessible to everyone (see Appendix L). The *Connecting Family Needs to ASD Research in BC* report identified the need for clear language summaries of research about best practices for treatment, while also citing a lack of research into alternative treatments to ABA, which can be appropriate and useful for only some individuals. Alberta’s 10-year FASD Strategic Plan includes treatment approaches for children with FASD while Ontario’s FASD Provincial Roundtable Report includes a focus on the life course by identifying the need for support for individuals with FASD to transition to adult services, which in many cases are sparse or not available at all to adults and seniors.

Included in the issue of eligibility for access to treatment is the notion that criteria are often arbitrary and inappropriate given the fact that many children with neurodevelopmental conditions may have a higher IQ, or be the legal age of an adult (18 years old) yet remain socially and emotionally under-developed and still in need of services.

Most respondents indicated they would like an increase in volume of services. Some families resort to non-evidence based alternative treatments (e.g. stem cell treatments for CP), that must be paid for out of pocket.

“...the importance of increasing the degree of evidence base that we have and rigorous scientific study around the interventions that we want to provide. There are many things that are provided that have some evidence, some sense of effectiveness...but often those kinds of interventions have yet to be studied in the most rigorous of ways and I think that’s really needed across the board...the more we can have that the better off all clinicians and patients are going to be with the care options that exist.” – Clinician

Wait times were a common issue that was raised, both for diagnosis and for access to services and treatment. Once a diagnosis is received, the child is placed on another waiting list for access to interventions and services. At the same time, the child is getting older, and it becomes more difficult to optimize the outcomes of interventions. Several reports also identified wait lists as a barrier (see Appendix H, references: 7, 11, 14). As noted by one clinician interviewed:

“...that wait is tremendously detrimental to the child and to the family.” – Clinician

The Report *Quebec Ombudsman, Service access, Continuity and Complementarity* further identifies ‘fair positioning of users on any waiting list’, which would place children/individuals on a waiting list in a triaged order. This notion was also articulated at our January 18, 2017, stakeholder consultation (see Appendix L). However, having no wait times doesn’t completely solve the problem. In Newfoundland, there are no wait times for ABA but according to the *ASD Provincial Needs Assessment in Newfoundland* (see Appendix H, #12) parents are experiencing difficulty finding a home therapist to deliver ABA, and when they do find someone often they are not qualified. The solution, according to this report, is to have accountability and co-ordination by the regional health authority.

3.0 Results and Discussion – Themes and Focus Areas 3.2 Treatment

There is heterogeneity among parents in terms of acceptance, ability and desire to participate in different services and interventions available. A non-judgmental approach and motivational interviewing were suggested by some clinicians for the purpose of being able to determine parent-readiness and to inform any workarounds that could be created in order to help maximize outcomes for the child and minimize stress on the parent.

Many interviewees mentioned a need for more funding to enable more volume of services to be provided, and where quality was an issue, to increase the quality of services. However, some noted that in light of resource constraints, more could be done with existing resources if used more efficiently. The ability to maximize efficiencies was believed to be related to policies that affect service delivery, and effective communication among service providers.

3.3 Services

After receiving the diagnosis, parents are often left to figure out how to navigate the ‘system’ of services, interventions and supports for their child on their own. Parents not only have to locate supports, but are also responsible for figuring out how to acquire them, make decisions about which interventions to focus on, and are often the central communicator and repository of information about their child’s condition among individuals and organizations. Essentially, parents currently have to be case co-ordinator on top of all the responsibilities of caring for a child with special needs. Being on a waiting list for diagnosis translates into waiting again for services and access to treatment (which may or may not be evidence-based).

“It’s hard for some families to know how to navigate the system. I think as services get more scarce it feels like there’s bigger hoops to jump through...it’s hard to get an appointment in a clinic even if you’re trying to get a diagnosis for your child...it’s hard to find a community physician to make the referral in the first place...often the services don’t seem to be well coordinated and so after the diagnosis the parents are left on their own to figure out what’s available and how you access it and how you fund it.” – Clinician

“...there’s a need for that, someone to help organize the frontline people who are busy, run off their feet servicing everybody. There needs to be someone external to that but knowledgeable about resources and who to pull together to try to make this happen for that child.” – Clinician

“Parents showed a need for support in navigating the sometimes confusing networks of resources, support and services for people living with ASD. They felt completely unprepared after diagnosis, and quickly had to become experts in finding and accessing support.”
– Connecting Family Needs to ASD Research in BC, p.35

Several other reports similarly identified the need for a system co-ordinator or navigator (Appendix H, #4, #7, #8, #10, #12, #14).

3.0 Results and Discussion – Themes and Focus Areas 3.3 Services

The need for, and quality and consistency of communication were identified together as a key issue. At an individual level, the person with the neurodevelopmental condition should be able to communicate their needs to their caregiver(s) and may require assistive technology to do so. On the other hand, as mentioned above, parents are usually the central coordinator of information flow among service providers, organizations and individuals such as health professionals and the education system. Interviewees expressed a range of opinions from the need for professionals to take the initiative to communicate with each other by traditional means such as telephone, to using assistive technology such as an online resource (e.g. tyze.com), where all professionals can input and access service information provided for an individual. A strong theme that emerged was the need for case managers to assist parents not only with co-ordinating communication among individuals and organizations (e.g. schools, health professionals, etc.), but also to help find and obtain resources within the community that they would not otherwise become aware of, thereby helping them to navigate the ‘fragmented system’. This can significantly reduce parental stress.

Continuity of services at key transition points was also noted by interviewees as well as attendees at our in-person stakeholder event, where it was voted to be the #7 priority (see Appendix L). There is a need for consistent service. In some cases, high staff turnover creates a situation where the child and family need to adjust to a new service provider. However, sometimes consistent service can be achieved when low staff turnover is facilitated by positions that are well-paid with good benefits. In some contexts, policies that allow funding for the family to obtain a service provider for their child prevents family members from being eligible to be the child’s service provider, despite the reality that it may be better for the child. Because of the familiarity of the person with the child and familial bond, there is a greater chance the person will stay in that position, and the child and family will be able to avoid the stress of having to adjust to a new service provider. Finally, the term ‘wrap around care’ was used to describe the need for multiple community-based supports that are available when needed and for the length of time they are needed.

“...they need somebody to be able to come in to their home, with their invitation and to work with that person on a daily basis in order to help modify and help build those skills that that person needs...It’s the stark opposite of a consultation or a time limited service. What they really need is a responsive service that can come in quickly into the home, meet with the family and the adolescent, work with them, directly after these kinds of things are happening and stay involved until the problem is no longer a problem...service termination needs to be dictated by success in terms of addressing the target, rather than by a predetermined set of time or financial resources.” – Clinician

Service issues are also related to the theme of context (location) and culture (Section 3.8):

“...right from access to services, to responsivity of systems, to personal capacity in the family to follow up with appointments, to disruptions in school attendance, to removal due to Child Welfare issues, to accessing specialist care in remote settings, to accessing assistive technologies, to having access to any kind of evidence-based care at all...there’s all sorts of challenges.” – Clinician

3.0 Results and Discussion – Themes and Focus Areas 3.4 Education

3.4 Education

Creating workarounds for facilitating the child's success in school can either be for social or physical aspects of the environment. Social aspects can include peer relationships, acceptance and inclusion, as well as the child's relationship with their teacher and other staff.

"...he was one of those people who still kind of thought it was more a character thing... he was the kind of educator that said 'if we do that for your son, we'll have to do that for everybody.' So I would say, 'well, I need glasses. So if I go into the classroom with my glasses on, does that mean everybody has to have glasses? Or does that mean you take my glasses away?'...and he...just looked at me as....if he could have, he would have given me a detention." – Parent

"So grade one...[the teacher] met us outside. She went to [my son] and she said '...I have your sensory box all ready and it's on the corner of my desk, and I want you to know that, whenever you need it, you must go and get something right away.'...the whole class was invited to use the things in the sensory box. For her, it was good...she knew if people are able to calm...themselves it helped her. So it became a part of the classroom....and I have to say she was one of the few educators I met, at that level, who really got that part...she understood immediately what these kids needed to learn and that they were all different. She wasn't asking them to be little machines. She wanted to meet these kids as they were." – Parent

Part of facilitating the child's success in school is to encourage self-advocacy by the child but also to create an environment where parents can be listened to, work with the school to explore alternatives in order to help the child have what they need to be successful. While all responsibility can't or shouldn't be placed on the child, teaching children to advocate for themselves as they grow older can be another avenue for getting needs met:

"(our kids) don't like to challenge authority, and that's what they think they're doing when they're self-advocating. And sometimes they meet teachers that...aren't receiving. They don't have their catcher's mitt on. They're not saying, oh thank you for telling me that, we'll do it this way. They're saying no, this is the way it is, adapt to it. And our kids can't do that. So they stop self-advocating because they meet people that aren't meeting them. So that's hard too. So if we want them to be self-advocates we have to be ready to listen to what they're saying." – Parent

The consequences of ignoring the social and physical environments is only detrimental to the child's success in school and their mental health and well-being, even after the school day is over.

"The hardest thing is negotiating the school system. Because your child is there for seven hours a day and you can make your home a beautiful oasis, but if the school isn't working they come home completely and utterly stressed, and you know they've been there at school, misunderstood and stressed. And that's very stressful for a parent." – Parent

3.0 Results and Discussion – Themes and Focus Areas 3.4 Education

The *Newfoundland ASD Provincial Needs Assessment* identified “lack of services and supports in (the) school system” (p.50). Training is needed for personnel who interact with children in the school setting. This finding is also supported by several stakeholder reports (see Appendix H, #3, #11), but there are several political and practical barriers to be overcome in order to accomplish this.

“Sometimes because the community is very small to find someone to work with the child, get training for that individual....how can a support person train within the school? It’s quite challenging to find the individual and then give that para-professional or para-education person the amount of mentoring that they might require. That’s pretty tough.” – Clinician

“...the therapists only come in I think once or twice in the whole school year and what they do is they basically train the classroom aides, ‘this is the exercise you should do with this kid,’ or, ‘try this or try that’ and that’s it. These classroom aides are just typical individuals that obviously love what they do but they’re not therapists and so if they don’t catch on right away they could be doing it wrong for six months out of the year....the therapies that are offered through the school system are limited.” – Parent

Our January 18, 2017, stakeholder consultation identified the need for more professionals working in the school system with the appropriate training to work with children with neurodevelopmental conditions as the second highest priority, emphasizing a need for an inclusive education environment characterized by qualified professionals who have specific training to address children’s specific needs (see Appendix L). The *Special Ombudsman Report, Services for Young People and Adults with a Pervasive Developmental Disorder report* (see Appendix H, #9) called for improvement of specialized interventions at school. Priority #5 reflected a need for specialized and in-depth mandatory training on different conditions, as well as attitudinal and cultural aspects of working with individuals with a neurodevelopmental condition for teachers, EAs, resource teachers, principals and anyone who interacts with the child in the school setting (see Appendix L).

3.5 Health Care

The data revealed a strong need for specialized in-depth training in neurodevelopmental conditions and in cultural safety for all frontline workers in health care, including administrative staff. The need for training of frontline staff and other health professionals was also noted in the FASD Provincial Roundtable Report (Appendix H, #6). Ideally, training should take place in post-secondary school, as well as within ongoing professional development, and provide much more detail than a general overview of neurodevelopmental conditions. The end result, for example, could enable GPs to recognize the signs of a possible neurodevelopmental condition in a child or adult that would prompt them to refer to a specialist (relates to theme 3.1 Diagnosis). For children who visit the ER often, and who associate it with painful procedures, this may also require special consideration by frontline workers. Nurses, dentists and all emergency room staff were also mentioned as important personnel to have training in how to serve an individual with a neurodevelopmental condition, since emergency rooms are often characterized by waiting in an environment that presents challenges for an individual with sensory issues.

3.0 Results and Discussion – Themes and Focus Areas 3.5 Health Care

“...(our son) flops on the ground and he ain’t getting up and he’s not going anywhere near getting on the table...the technician, thanks to (the doctor’s) instruction says let’s see how far this (x-ray) thing will reach...they drape us in the lead apron, six tries, they get four pictures, it works....because (our son) ain’t moving off the tile and they kneel...on the floor, get (our son) casted and then we get out of there. So that’s a good visit to the ER.” – Parent

“...so they had (my son) restrained on a gurney and the incompetent nurse says no, no, we’ll just undo him here so the doctor can have a look at him...so he just got off the gurney and they couldn’t restrain him and he walked out...they wanted to you know, get the dart gun or call security is what the nurse was doing...the situation was resolved by an experienced paramedic...he got everybody else to shut up and the one voice thing is an important thing... like imagine if you’re stressed and nine people are giving you instructions at the same time... and we got (my son) back on the gurney, got him restrained and got him back inside.”

– Parent

While complex cases may exist in small numbers, there is a need for smoother management and support both within the hospital and at home for families caring for a child that has multiple and complex health care needs. This is illustrated by the following quote:

“(my son) has awake bedside nursing now because of seizures combined with respiratory issues. We did not have the levels of support whatsoever at home to support his very high needs, so my husband and I...(were) responsible for keeping him alive basically on a 24-hour basis, and of course that led to a crisis in our family. So I think it’s access to appropriate levels of support at home, and also coordinating complex care both in the hospital and in the community.” – Parent

Another dimension of health care is waiting lists for access to psychological support. Where access to such support is unavailable in a timely manner, youth will tend to self-medicate with alcohol and illegal drugs, especially during a mental health crisis. Waiting lists to see a psychiatrist could be as long as a year and a half. Self-medicating behaviour was believed to be connected with a greater potential for experiencing issues with the police and broader justice system, which could be avoided with more immediate access to mental health care. Finally, there is a need for the health care system to treat and provide services for persons with neurodevelopmental conditions in a similar manner as those currently provided for heart disease, diabetes and other chronic conditions. For these conditions, once diagnosed, the individual will be supported by a team of service providers assigned to work with the individual to manage their condition.

3.0 Results and Discussion – Themes and Focus Areas 3.6 Mental Health/Quality of Life

3.6 Mental Health/Quality of Life

The ‘relentless’ nature of having to care for a child with special needs was a huge factor in parents’ mental health. While mental health care for the child with the neurodevelopmental condition was identified as an issue, the need to preserve and support the mental health of parents was even more prominent. It was acknowledged that parents need to be encouraged to take time for self-care and socialize with others who understand their situation such as parent support groups. Support workers and access to (the right kind of) respite were also mentioned as necessary supports.

“The word respite is thrown out there all the time but for my son and his needs, sending him off to a respite centre is not giving anybody respite, because when he comes back the behaviours are going to be through the roof. So developing models of respite that actually meet and suit the needs of that family and that child’s needs as opposed to assuming everybody with a developmental need is going to fit inside a box and all services are going to meet that.” – Parent

In contrast, the presence of support workers in the home could also cause additional stress to parents:

“For ages and ages, we had therapists coming into my house, so they were there evenings, weekends. So I really never had any downtime, because any downtime when I wasn’t at work, I had therapists in my house...my grocery bill is ridiculous because my therapists are... there so many hours, they reach into the fridge and they grab dinner, and sometimes there isn’t dinner for me when I get home. They sound like dumb things, right, but done over and over again they’re unbelievably stressful.” – Parent

Stress on parents puts strain on the marital relationship, further emphasizing the need to support parents’ mental health. Families need access to system co-ordinators to help access services rather than having to research and pursue everything on their own. It was suggested that mental health is affected by availability (or lack of) access to support workers to help navigate the system of services, as noted in the *Canadian Autism Spectrum Disorder Association (CASDA)* report:

“Families are often so busy coping that they can’t research what is available. It would be great if they could have a case manager that guides them through the maze and gets them on waiting lists early.” – CASDA report

In terms of child mental health, interventions that are tailored specifically for children, and even further for children with a particular neurodevelopmental condition, are needed since existing interventions for adults or for neurotypical children will not necessarily be effective. Supporting the mental health of the individual with a neurodevelopmental condition (throughout the life course) also includes circumstances not related to an intervention per se. For example, providing opportunities for purpose and meaning in their school work, employment, or day programs if the individual is unable to participate in employment. This is the case regardless of level of functioning:

3.0 Results and Discussion – Themes and Focus Areas 3.6 Mental Health/Quality of Life

“I think (with my son) it’s demands being put on him when he doesn’t understand the reason why...like at school for example...yeah you’ve got me doing matching exercises or...put the purple triangles together for the 14th...year in a row...and now I’m flipping the table. And that happens, and it’s like well, yeah little wonder, you’re boring the crap out of him and there’s no purpose to this. There, I did that now can I have lunch, right? Now, when can I get on the bus and get the hell out of here?” – Parent

The need for social skills/behavioural training and strategies for self-regulation of emotions, and anxiety for the individual with a neurodevelopmental condition was voted within the top 10 priorities for KBHN to address (see priority #10, Appendix L). This was similarly reflected in several reports (see Appendix H, #3, #6). What’s needed, but isn’t available, are appropriate (and affordable) recreational program(s), social skills group(s), day programs and other places where persons with neurodevelopmental conditions of all ages can find meaning and socialization.

“I think we’ve underrepresented the power of recreation and leisure for people with neurodevelopmental conditions. In terms of the potential impact...I think it’s such an important part of a person’s life that we often take for granted...imagine what we’d all be like if we were stuck in that much more closed in environment that was not to our choosing and what that would feel like, that kind of isolation...if they’re stuck at home in their one or two rooms of their apartment with nowhere to go for weeks on end...and the only interactions that they have are maybe over the phone with a paid worker of some sort...beyond the fact that it would be nice to have, this actually can improve their sense of self and help them develop.” – Clinician

Mental health for neuro-typical siblings of special needs children is also an important consideration. Some mentioned the positive aspects on siblings, such as the opportunity to develop more empathy for people with challenges. However, siblings may worry about having the responsibility of caring for their sibling with special needs once their parents have passed away, or may become resentful when their sibling receives more attention. Efforts made by parents to treat both neuro-typical and special needs siblings as equitable as possible despite the increased needs of the child with the neurodevelopmental condition were noted as important for the mental health of the neuro-typical sibling. However, frustration among siblings occurs in both directions:

“I would say one of the things for (my son) is his frustration...when his younger brother is able to do something, anything from being able to ride his bike across the street to the schoolyard on his own, to when he sees his brother able to read a book and he can’t, that’s when we really see the frustration and he yells and has meltdowns saying I can’t do it, it’s not fair.” – Parent

3.0 Results and Discussion – Themes and Focus Areas 3.6 Mental Health/Quality of Life

Safety was another issue and was represented across a number of dimensions. As the child grows larger and also has difficulty managing their emotions, interactions with all family members, including younger siblings, can be a concern. Safety issues are also present when parents who are sleep-deprived risk making mistakes with medications or becoming involved in a car accident. Teens responsible for taking medications may not remember what prescriptions they are taking, what dosage or which medications they are allergic to.

“I think once hormones start to kick in...he became much more angry and volatile, physically big...and I think just needed...to learn how to control his emotions as much as he could learn how to.” – Parent

“...somebody comes in my clinic and is at the end of her ropes, a mother. I’m afraid of sending her back because she might have an accident. The question would be for me can I improve her situation of sleep deprivation with offering a kind of respite, or this kind of help and that kind. And then I’m lost, I’m alone. I need a social worker, I need this, I need that... so simple things which impact survival I would say...there is no real immediate support if you are afraid.” – Clinician

The report entitled *Services for Children and Youth with Special Needs in Ontario* states “providers noted that early access to information about services, such as respite, will help prevent crises” (p.14) which relates to the need for information on available interventions and services as stated in section 3.2 Treatment above. Respite was noted in several reports to be important yet the reality is there are not enough respite workers and there is a high turnover rate (see Appendix H, #6, #9, #12, #13).

Sleep issues in the child with a neurodevelopmental condition can not only make daytime behaviours of the child worse, but is detrimental to the parent’s ability to sleep and also function well during the day. Having a child who has trouble sleeping can also impact parents’ mental health because it diminishes the quiet time they have in the evenings as ‘down time’:

“Upwards of 90% of children with neurodevelopmental disorders have trouble initiating sleep and staying asleep...when parents with typically developing children put their child to bed at eight o’clock they get a few hours to themselves to do what they have to get done, but parents with kids with neurodevelopmental disorders often don’t get that break in the evenings...their children put up a lot of resistance to going to bed, once they’re in bed they don’t fall asleep, they’re up through the night...and then that results in of course tired parents and...when people are tired they have less well developed decision making skills and...they are more reactive...so it kind of builds this big negative cycle. So you have tired kids and tired parents and then it’s harder to...cope with those day-to-day stressors.”
– Clinician

3.0 Results and Discussion – Themes and Focus Areas 3.6 Mental Health/Quality of Life

Finally, it was believed that broader societal awareness of neurodevelopmental conditions and acceptance of neurodiversity toward reducing stigma would go a long way towards helping improve mental health for children, siblings and parents. Some found it stressful to go on family vacations or complete ordinary tasks such as grocery shopping, because people in the community didn't understand their child's behaviour and were very judgmental. This also contributed to more feelings of isolation.

"...advocacy...needs to be done in various settings. You know, whether it's in the parking lot at a grocery store, where (my son) had a mini meltdown the other week because we accidentally locked the dog in the car, people go to call the police, and it was just awful."

– Parent

"...because really, nothing's going to change unless you're open and educate people, right? I mean that's the first step in change, is awareness and education." – Parent

3.7 Life Course Perspective

There are several transition points in the child's life: from pre-diagnosis and working with a particular health care team, to post-diagnosis when the child and family transition to a more specialized health care team; from in-home services before the child enters school to in-school services; from elementary school to high school (which comes with more freedom, presenting more challenges for some individuals who need structure); from the pediatric health care system to the adult health care system and new service providers; from high school to post-secondary and/or employment; from living at home to living as independently as possible. These key transition points are interrelated with themes 3.4 (Education), and 3.5 (Health Care) and 3.6 (Mental Health/Quality of Life). Transitions are difficult and supports are needed for the individual with the neurodevelopmental condition, including assistance filling-out forms required to access resources, continuity in services for those with ongoing medical needs and supportive housing to be able to live as independently as possible:

"...the transition from high school to college is hard. The transition from college to work is hard. (My son) wants to be independent...he wants to be like other people in that they're able to run their lives." – Parent

"...there's transition to adult services. That's a whole big area. It's...across the country. How to help kids transition from pediatric services to adult services either through the medical side, post-secondary side, just getting the rehab support they might need. Trying to help them navigate that whole transition is a big challenge." – Clinician

"...housing is a big issue for adults in terms of having affordable housing that doesn't put vulnerable people in at-risk placements and we need different kinds of housing that can accommodate for their needs. I mean, some need some support – supported housing. Others need a little bit less support. So there's all sorts of issues around having a menu of housing options that can work for whatever the needs of that specific individual are."

– Policymaker

3.0 Results and Discussion – Themes and Focus Areas 3.7 Life Course Perspective

Services for transition support have also been identified as a need in the national CASDA study “comprehensive planning for adulthood, including transition support services... a plan to address the housing needs of adults with ASD” (Appendix H, #16). Good supportive housing was voted to be the #8 priority at our in-person stakeholder event (see Appendix P). Adults need services that are currently scarce or non-existent, especially for diagnosis and/or treatment services if they missed the opportunity during childhood. Overall, there is a need for society and the ‘system’ to recognize that neurodevelopmental conditions are life-long, and services need to be available throughout the life course.

“...neurodevelopmental conditions are really lifelong conditions, yet the kind of services that are provided are not considered a right or entitlement that a person must receive but instead are resource dependent...so I think that is a real issue because these problems don’t go away and so we need to have a kind of policy in place where the services don’t go away either.”

– Clinician

“Once your child turns 18 and is no longer in the children’s services anymore and switches over to adult services, you might as well just roll up into a ball and die because no one sees you...nothing exists after 18.” – Parent

“...and then they turn 18 and you think, okay my job is done now, the government’s going to help you, and that’s exactly when they abandon you. Because there’s no money in adult services, you know, that’s why they call it falling off the cliff.” – Parent

This “life course perspective” theme relates to parental mental health in the sense that parents worry about the future for their child’s well-being and ability to live as independently as possible. The report entitled Services for Children and Youth with Special Needs in Ontario supports the notion that “many parents want information and support in order to have a plan in place for their child’s care in the event that their child outlives them.” (p. 21). This was also reflected in our findings:

“The challenge is, what they’re going to do for the future, like will they have a job? What are they going to do when I die, because parents like to think about that earlier than regular parents, than parents of typically developing kids, you know?” – Clinician

“...(our son) has terrible fear of something happening to my husband and me, especially me. He avoids that constantly. Fear knowing that he needs somebody to help him organize his life. I think fear of not getting married and having children because that’s something he really wants. Fear of wanting to live independently but not feeling he can do it.” – Parent

3.0 Results and Discussion – Themes and Focus Areas 3.7 Life Course Perspective

Also related to the life course perspective is child mental health (Theme 3.6) that could carry throughout their lifetime and may change over time either from social isolation, unmet mental health care needs and/or worry about the future:

“Just being left not having friends or...not being involved in activities outside of school, being left out of things as they get older...not having good options after high school, in terms of continuing education or opportunities in the job place. So, many are cut off socially, both in terms of personal relationship level and also at a societal level.” – Clinician

There is also a need for supports for individuals with neurodevelopmental conditions to be successful at education at all levels and later on, for employment. Post-secondary education, job opportunities and continuity of services are more difficult to obtain in smaller, rural and remote communities because there are fewer opportunities than in urban centres (Theme 3.8). The challenges in terms of supporting individuals and families throughout the life course can be summarized by the following quote:

“How do we create a kind of fabric of supports and interventions that makes sense over a life course and that we understand if we kind of pursue them what is going to lead to success... meaning adults or young people with disabilities that they get to participate in the work environment...they have personal networks of friendships and of support and have people in their lives...they have daily routines that are meaningful and rewarding for them. And I think we don’t connect all those dots to get to a point where we can say, this is likely, this can happen, this should happen; and what needs to be in place in order for that to kind of follow along to that end.” – Policymaker

3.8 Culture and Context

The notion of culture applies to several possible dimensions such as: adaptations to interventions to suit the Canadian context; differences among provinces and territories within Canada with respect to legislation, policies and funding allocations for different programs and services; ethnicity; and language. There is a need for policies, interventions and services to be developed in partnership and sometimes driven by the populations that are served by them. This is especially true for First Nations populations. Contextual issues also relate to differences in service availability in rural and remote communities. This theme also relates to the need for specific training of frontline workers.

“...we have to make sure that the research is relevant and our approach is relevant to First Nations populations...thinking rural and remote, again what is the best way to deliver services to this population when you’re in a small community and we have a very generalist type of worker, whether it’s in health or education or whomever...how can we expect them to have very specific knowledge to assist a child with FASD and/or ASD or CP or whatever the challenge may be...” – Policymaker

3.0 Results and Discussion – Themes and Focus Areas 3.8 Culture and Context

“...lack of available supports and services that...understand indigenous contexts is a huge challenge...it really is...an interesting kind of practice in that you’re doing a lot of problem solving, you’re doing a lot of trying to match evidence with what’s available...every time you see something that’s new and exciting you have to really give some thought to is it applicable to the families and communities that we’re managing...social workers, teachers, professionals may think that certain things are great ideas but just can’t be implemented as easily as they’d hoped.” – Clinician

Services are usually less frequently available in rural/remote regions of the country and these challenges are not just restricted to Northern communities, and require a greater amount of travel for the families to attend appointments and/or creative workarounds such as tele-health for follow-up appointments and certain types of service delivery. First Nations communities often have limited access to clean water, food, housing, education opportunity and income; social determinants that are not usually considered in the mainstream system. Other cultural considerations include the ability of French-speaking Canadians to access services and other types of supports in their native language. The (Ontario) *FASD Provincial Roundtable Report* supports the identified need for more services provided in French, and culturally appropriate services for Aboriginal populations both on and off the reserve, as well as recognizing and reflecting regional diversity of communities (see Appendix H, #6). A report from PEI states, “the social, linguistic, cultural diversity and values of families and educators must be recognized and considered in the provision of services” and is also reflected in a report from Nunavut (See Appendix H, #14, 15). This theme also relates to focus area #24 in the mental health theme, because of issues of isolation, especially in rural and remote communities where the family may be the only one in the community that has a child with a neurodevelopmental condition.

“I think isolation of families is a challenge. Again, there may only be one family in a community that’s been through this process...sometimes families feel like they’re pretty isolated in terms of supports in their community.” – Clinician

Because of the diversity of policies, services and programs offered in each province and territory there is a need for sharing of best practices and policies, ‘what works’ among these different regions. There was also the contrasting notion that the experiences and needs of individuals and families living with a neurodevelopmental condition transcends geography.

“...hearing the personal stories from families...and from individuals...and the peer reviewed literature, the articles that I read that highlight these kinds of difficulties both locally as well as all the way to an international perspective...what researchers are documenting...you start to notice these patterns that are not bound by particular borders.” – Clinician

The national CASDA report also identified “targeted outreach to address the unique issues of Canada’s northern communities...to linguistically and culturally diverse communities...facilitating understanding of their service needs and improving their access to service” as needs of individuals and families affected by ASD (Appendix H, #16).

3.0 Results and Discussion – Themes and Focus Areas 3.9 Broader System and Society

3.9 Broader System and Society

Some interventions offered can be considered effective, despite not having an evidence base to support their application. However, having an evidence base to understand and support the use of an intervention is best. Conversely, there are evidence-based interventions that are not being implemented for various reasons, either because practitioners or policymakers don't know about them, or because they are used to providing a particular intervention and prefer what's familiar.

“...most jurisdictions from my understanding have really embraced ABA as their method of early intervention. But there's a lot of emerging types of interventions that are different from ABA and having a good understanding of how those emerging practices and different methodologies compare or what's left, because from a system perspective people end up doing what they know rather than what's most evidence-based sometimes.” – Policymaker

There is a need for all stakeholders to have timely access to information about new research knowledge to inform them of evidence-based interventions and other information as it becomes available, in order to help inform best practices, policies and/or services, and facilitate timely implementation:

“...the main problem with published research is timeline. By the time you get it published and complete a peer review, two things may happen. One, I needed it two years ago, so it's too late, and the other is, by the time I have that problem your research is out of date, according to you. So, it's really hard to line policy up with published research because of timing. Research takes a long time and policy issues have a much shorter cycle, so that's why you have to stay in touch over the long-term. You might have a lot of information that hasn't been published and you might be very reluctant to talk about it because it's not peer reviewed yet, but it helps me understand what the research is looking at and what else might be needed to help me with my problem.” – Policymaker

Sometimes what is in the best interest of the individuals and families requires a policy revision to enable a change in service provision. However, the process for changing policies can be rigid, even for small changes. There is a need to be able to modify policies in a more efficient manner if it something that makes sense and enables better service.

“...(clients with FASD) have all sorts of issues with time management... in order to get them to appointments with their probation officers, or to keep regular appointments or whatever, you know, whether it's a therapy appointment or a whatever appointment, text reminders are really important. And when we've been able to get through the agency's policy to be able to allow that, people are attending their appointments and actually making it, attendance has gone up tremendously.” – Policymaker

3.0 Results and Discussion – Themes and Focus Areas 3.9 Broader System and Society

Each province and territory offers different types and levels of support for the different neurodevelopmental conditions Cerebral Palsy, Autism Spectrum Disorders and Fetal Alcohol Spectrum Disorders. More equity in terms of funding and services available for different neurodevelopmental conditions were suggested. These not only arose during the one-on-one interviews, but were discussed in depth during our in-person stakeholder event (see Appendix L, priority #3). Stakeholders strongly suggested that it was an ‘illusion’ that one group of families (affected by either CP, FASD or ASD) ‘has a lot’ when compared to another group of families, and that the focus of funding decisions should be level of functioning and specific needs of the child, not based on what others receive.

Many stakeholders emphasized the need to change the existing system. The *Ontario FASD Provincial Roundtable Report* states that “...silos exist between sectors such as health, justice, education and social service, as well as between organizations and ministries”, which also reflects the findings of this investigation. The themes and focus areas described in the sections above exist within the context of different levels of systems which affected the basic social problem under study, namely ‘quality of life’.

“...quality of life is not founded by one person’s interaction with a client but instead by how that client develops within systems of care and ecologies.” – Clinician

The *Special Ombudsman Report, Services for Young People and Adults with a Pervasive Developmental Disorder* report suggests that we should “think of a child as ‘of the system’ rather than ‘of a particular agency’ or ‘of a ministry’” (p. 12).

“...coordinate Canadian research, policy and service efforts, develop closer partnerships with national and provincial advocacy groups, realize the need for services across the spectrum and throughout life, foster Canadian research on lifelong...needs in a range of areas and ensure effective knowledge exchange of best practices.” (p. 2)

The above report’s recommendation supports our findings that a system-level approach is needed, including cross-communication among provinces and territories. There is also a need for cross-ministerial communication and collaboration, another finding from this investigation, which is supported by another report:

“...governance structure needs to be driven from the executive level of government (Minister), requires interdepartmental cooperation, coordination and collaboration, having access to an expert panel’s advice on questions of leading-edge science, and strengthens communication and engagement with community input”

– Recommendations toward a PEI Autism Action Plan: Another Piece of the Puzzle (p. iv)

A collaborative approach is also recommended at an individual level:

“Team approach to working with these children best benefits everyone”

– ASD Provincial Needs Assessment Final Report of Needs Assessment (p.60)

The need for collaboration among government ministries, provinces, organizations and professionals was reflected both in the one-on-one interviews and our in-person stakeholder event (see Appendix L).

4.0 Conclusions

4.0 Conclusions

According to grounded theory methodology, the basic social process *managing (life with a) neurodevelopmental condition through empowerment* is intended to address the basic social problem *quality of life*. To this end, 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? Individuals and families need to be empowered in different aspects of life in order to maximize their quality of life.

The purpose of this study was to explore the perceptions of 32 stakeholders and learn more about their experiences as a person whose life experiences include being the parent of a child with a neurodevelopmental condition such as Cerebral Palsy, Fetal Alcohol Spectrum Disorders and/or Autism Spectrum disorders and/or being employed in a position that serves parents and children/youth, and/or as a policymaker; all within the current 'system' in Canada. We discovered nine themes, 44 focus areas of needs and two core categories (a basic social problem and a basic social process). These 44 focus areas were reviewed with a different set of stakeholders in the context of an in-person consultation. We asked these parents, practitioners and policymakers to help us prioritize the 44 items as well as provide us with more detail from their perspective, about how these priorities may be addressed in terms of: what we should be trying to accomplish, what would be the desired outcomes, what would be some barriers and enablers of the approach(es) suggested, who we should involve and/or consult in the process and how can we engage them.

The following section provides recommendations for Kids Brain Health Network and other like-minded organizations including governments, as well as for ongoing research.

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?

5.0 Recommendations

5.0 Recommendations

The following recommendations are offered, based on the findings, analysis and conclusions of this investigation. The recommendations that follow are for a) Kids Brain Health Network NCE, b) further research, knowledge translation and commercialization in the area of neurodevelopmental conditions, c) policymakers and practitioners engaged in decision-making processes either through policy creation and revision, or day-to-day decision-making as a frontline practitioner.

5.1 Recommendations for Kids Brain Health Network

This section is directed towards the Board, Research Management Committee, KBHN Headquarters, researchers and trainees who are part of KBHN. These recommendations are made with the goal of maximizing the impact of research in Years 9 and 10, and strategic planning in preparation for KBHN's Cycle III application.

Recommendation 1: seek to apply the insights from stakeholders contained within this report toward informing KBHN investments, including funding allocations for new and existing projects from 2018 to 2020.

Rationale: by working towards solutions for stakeholder needs, this will lead to meaningful and impactful changes in policies and practice toward improving the quality of life of individuals and families affected by neurodevelopmental conditions.

Recommendation 2: apply the insights from stakeholders contained within this report to KBHN strategic planning for 2020 to 2025.

Rationale: this report began with a quote about environmental scanning that states "The aim of (this) work is to provide robust information that strengthens your understanding of your organization's long-term context, to enable you to make wise strategic decisions today". Informing KBHN's long-term strategy with stakeholder insights will maximize the potential for KBHN to achieve impact for similar stakeholders across Canada, creating a sustainable future for its investments.

5.0 Recommendations

Recommendation 3: consider the diversity of viewpoints presented in the positional diagram in Appendix J with respect to a categorical versus non-categorical approach.

Rationale: deciding between a categorical and a non-categorical approach without consideration of multiple viewpoints about access to treatment (with or without a diagnosis needed) and the potential effect on the child's well-being and what may not be in the child's best interest.

Recommendation 4: continue (and expand if necessary) ongoing stakeholder engagement with the stakeholders who participated in this project, stakeholders in regions not captured in this project and specific types of stakeholders for input on individual projects as necessary.

Rationale: this project represents stakeholder needs captured during a specific time period and for a specific purpose, and prioritized with only a single stakeholder group. Ongoing stakeholder engagement is necessary since systems and sub-systems, politics and funding, incidence and prevalence of neurodevelopmental conditions are constantly evolving. For specific projects that are crafted in order to address the needs in this report, more targeted stakeholder engagement is necessary for fine-tuning the research questions and goals of the project throughout all stages from research to impact.

Recommendation 5: promote the report in-person with provincial and federal governments, as well as community organizations across Canada to facilitate uptake and make this the definitive report for Canada.

Rationale: placing the report online is not enough; in order to facilitate uptake and implementation, in-person workshops are necessary. This will not only facilitate uptake of the report, potentially leading to changes in policy, programs and service provision, but will also serve to create awareness for the Network by building relationships with policymakers in neurodevelopmental conditions across Canada.

Recommendation 6: invest in methods for assessing the impact of KBHN funded projects against identified and prioritized needs.

Rationale: having a mechanism for measuring the effectiveness of KBHN projects in terms of addressing stakeholder needs not only holds Principal Investigators (PIs) accountable but will provide a convincing basis for KBHN's Cycle III application, since it will provide evidence that we aim to maximize the usefulness of our work to Canadian society.

(continued on next page)

5.0 Recommendations

5.2 For Organizations and Governments

Recommendation 1: organizations outside of the Network that serve individuals, families and children with neurodevelopmental conditions, and governments that provide funding and policy guidance for them, may find the needs and priorities identified in this report to be helpful for informing their policies, services and/or research.

Rationale: most of the needs identified are within the mandate of KBHN to address. However, each of the items could be addressed with large scale projects that each have a different strategy and focus. Even though KBHN may work towards addressing the top 10 or any of the remaining 34 focus areas, there is still room for other organizations to tackle these issues in a different way. One of the top 10 items is outside of KBHN's mandate to address: priority #8, "Need (good) supportive housing for youth/adults to be able to live as independently as possible", may be addressed by other organizations including governments and/or Canadian Mortgage and Housing Corporation.

Recommendation 2: emphasize and operationalize collaboration among units and sub-units of government (e.g. across different ministries, provinces/territories), within and across teams in service organizations, within and across teams of professionals providing care to individuals and families.

Rationale: a team approach facilitates shared knowledge and resources that can create efficiencies in the system, policies that are effective, and overall improve care for the individual with a neurodevelopmental condition.

5.3 For Ongoing Research

Recommendation 1: replicate this investigation using disability groups other than CP, FASD and ASD to discover whether there are similarities in needs across conditions that could comprise a formal theory for application more broadly across disability groups in Canada.

Rationale: since the needs identified as a result of this investigation were cross-cutting through CP, FASD and ASD, it seems reasonable that additional disability groups may also share similar needs and challenges that could inform a more comprehensive approach to serving individuals and families affected by a wide range of disability in Canada.

Recommendation 2: ask physicians, educators and allied health professionals to prioritize the list of nine themes and 44 focus areas.

Rationale: to determine the degree of coherence between the needs prioritized by frontline workers, parents and policymakers, and those who clinicians believe are priorities.

(continued on next page)

5.0 Recommendations

5.4 Dissemination and Engagement Strategy for this Report

The goal of the dissemination plan for this report is to make it publicly available, and to target several audiences. These include: audiences internal to KBHN such as the Board, Research Management Committee and headquarters staff, as well as researchers, trainees and clinicians. External to the Network, this report will be provided to organizations and individuals who may find it useful, such as policymakers at the Federal, Provincial and program levels, practitioners including frontline workers, and of course, individuals, parents and families affected by neurodevelopmental conditions.

There are several avenues we will use for dissemination including:

- direct emails to participants in the project, and to KBHN headquarters (for distribution to the Board and RMC)
- the report and associated power point presentations will be placed on the KBHN slideshare site, and linked to the KBHN website
- the report will be distributed via email to those who declined to be interviewed but expressed an interest in receiving the report, distributed to all CMOH/MOH in Canada, and to all C4BD members.
- this report will be promoted using social media, such as Twitter and Facebook, and by posting on the KBHN blog to allow for dialogue and feedback
- we may publish details of the process and outcomes of this stakeholder engagement activity in targeted peer-reviewed journals for improving dissemination and uptake
- we will conduct a webinar on the report for the Board, RMC and the Network PIs and trainees, especially those who wish to submit proposals for nine to 10 and Cycle III. We will record this and place it on the KBHN YouTube channel.

Avenues for ongoing stakeholder engagement will include:

- ongoing updates and input sought from stakeholders who participated in this project
- in-person workshops for policymakers in provinces and territories in Canada to facilitate uptake and implementation of the report findings (priority to regions currently undergoing policy changes)
- prioritization with groups of physicians, educators and allied health professionals
- a potential in-person cross-Canada policymaker-focused event in response to policymakers' identified need to share and learn best practices and lessons learned from other provinces and territories to maximize impact.

References

References

Berger, P. & Luckmann, T. (1966). *The social construction of reality*. New York: Doubleday and Company Inc.

Bertalanffy, L. (1950). An outline of general system theory. *The British Journal for the Philosophy of Science*, 1(2), 134-165.

Bertalanffy, L. (1968). *General System Theory*. New York: George Braziller.

Birt, L. S. Scott, D. Cavers, et al. (2016). Member Checking: A Tool to Enhance Trustworthiness or Merely a Nod to Validation? *Qualitative Health Research*, 26(13), 1802-1811.

Charmaz, K. (2000). Grounded theory: objectivist and constructivist methods. In N. Denzin & Y.S. Lincoln (Eds.), *Handbook of Qualitative Research* (2nd ed., pp. 509-535). Thousand Oaks, CA: Sage Publications Ltd.

Charmaz, K. (2006). *Constructing Grounded Theory: A practical Guide Through Qualitative Analysis*. Thousand Oaks, California: Sage Publications Ltd.

Clarke, A. E. (2005). *Situational Analysis: Grounded Theory After the Postmodern Turn*. Thousand Oaks: Sage Publications Inc.

Clarke, A. E. (2009). From grounded theory to situational analysis. In J.M.Morse, P. N. Stern, J. Corbin, B. Bowers, K. Charmaz, & A. E. Clarke (Eds.), *Developing grounded theory: the second generation* (pp. 194-235). Walnut Creek, California: Left Coast Press.

Colomy, P. (1992). *The Dynamics of Social Systems*. Oxford: Sage Publications Ltd.

Crotty, M. (1998). *The foundations of social research: meaning and perspective in the research process*. London: Sage Publications Ltd.

Denzin, N. K. & Lincoln, Y. S. (2000). *Handbook of qualitative research*. (2nd ed.) Thousand Oaks, CA: Sage Publications Ltd.

Glaser, B. (1978). *Theoretical Sensitivity*. Mill Valley, CA: Sociology Press.

Glaser, B. G. & Strauss, A. L. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. New Brunswick: Aldine Transaction Publishers.

References

- Hogan, C. (2005). *Practical Facilitation: a Toolkit of Techniques*. Sterling, VA: Kogan Page Publishers.
- Lincoln, Y.S. & Guba, E.G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage Publications Ltd.
- McMahon, M. (1997). Social constructivism and the world wide web - a paradigm for learning. In Perth, Australia: ASCILITE conference.
- Moran-Ellis, J., Alexander, V. D., Cronin, A., Dickinson, M., & Fielding, J. (2006). Triangulation and integration: processes, claims and implications. *Qualitative Research*, 6, 45-59.
- Mungia, R. H. Hayes, S. Reyes, et al. (2015) Generating National Dental PBRN Research Ideas through the ToP Consensus Method Workshop. *Proq Community Health Partnersh*. Autumn: 9(3): 447-456. Accessed February 24, 2017 online from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4643395/>
- Patton, M. Q. (2002). *Qualitative Research & Evaluation Methods*. (3rd ed.) London: Sage Publications Ltd.
- Sandelowski, M. (1986). The problem of rigour in qualitative research. *Advances in Nursing Science*, 8, 27-37.
- Sandelowski, M. (1993). Rigor or rigor mortis: the problem of rigor in qualitative research revisited. *Advances in Nursing Science*, 16, 1-8.
- Schreiber, R. S. (2001). The “How To” of Grounded Theory: Avoiding the Pitfalls. In R.S. Schreiber & P. N. Stern (Eds.), *Using grounded theory in nursing* (pp. 55-84). New York: Springer Publishing Company.
- Strauss, A. & Corbin, J. (1998). *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. (2nd ed.) London: Sage Publications Ltd.
- Strauss, A. L. & Corbin, J. (1990). *The basics of qualitative analysis: grounded theory procedures and techniques*. (1st ed.) Newbury Park, CA: Sage Publications Ltd.
- Strauss, A. L. & Corbin, J. (1994). Grounded theory methodology: an overview. In N. Denzin & Y. S. Lincoln (Eds.), *Handbook of Qualitative Research* (pp. 273-285). Thousand Oaks, CA: Sage Publications Ltd.
- Wilson, B. (1990). *Systems: concepts, methodologies and applications*. 2nd ed. New York: John Wiley & Sons.

Appendix A – Survey questions and selected data

Appendix A – Survey questions and selected data

Needs Assessment and Evaluation - Stakeholder Engagement NeuroDevNet

NeuroDevNet's focus in Cycle II is on engagement of stakeholders, toward informing more relevant research questions, methodologies, and KT products. This will maximize the chances NeuroDevNet can achieve impact during Cycle II, to position ourselves well during Cycle III renewal.

This survey represents PART ONE of an environmental scan being conducted by the KT Core, as directed by NeuroDevNet's RMC. NeuroDevNet researchers and trainees have already done (and continue to do) a substantial amount of stakeholder engagement. The purpose of this environmental scan is to: 1) find out what types of stakeholder engagement have already taken place in the Network, and 2) what stakeholder needs/challenges were identified as a result. These data will be synthesized into one report that will inform the formation of the proto-teams in Years 9-10.

The KT Core (or a representative of the KT Core) may contact you for more details regarding your responses. These one-on-one interviews will comprise PART TWO of the data collection for this environmental scan.

We may also publish the results in a scientific journal, toward advancing the field of KT. The study may also provide insights and benefits for advancing other NCEs. If we do so, any identifying information will be removed from your responses.

1) Please enter your first and last name:

2) Please enter your email address:

3) Please enter the name of your
project/program/core:

(What program/core do you report through? What is the name of your small project?)

Appendix A – Survey questions and selected data**Methods of FORMAL Stakeholder Engagement**

	Email lists/listserv	Bulletin Board/post messages to website no discussion	Web-forum - real time chat/filessharing (webinar)	Web-based discussion/post and respond to messages, discussion threading	
4) Which ONLINE METHODS FOR SE have you used to inform your NeuroDevNet funded work?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
5) Notes/additional detail re: ONLINE METHODS FOR SE checked above:					
	Advisory group/steering committee/task force	Focus group	(Key person) interviews	Workshop	
6) Which TELECONFERENCE or SMALL GROUP meeting based methods for SE have you used to inform your NeuroDevNet funded work?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
7) Notes/additional detail re: TELECONFERENCE or SMALL GROUP methods checked above:					
	Retreat (informal meeting emphasizes social interaction as well as discussion of issues)	Town Hall meeting (less formal public hearing, all stakeholders can speak and vote on issue)	Public hearing (formal single meeting, stakeholders present official statements or positions which are recorded into formal record for delivery to the agency)	Large/small group meeting (opening presentation, group broken into smaller groups to discuss issue or complete task)	Stakeholder consultation meeting (multi-day intense effort to inform work with stakeholder input - also called a Charette)
8) Which LARGE GROUP METHODS FOR SE have you used for informing your NeuroDevNet funded work?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9) Notes/additional detail re: LARGE GROUP methods for SE checked above:					
	Comment forms/workbooks (publication with contextual info invites stakeholders to suggest solutions to problems or challenges)	Delphi process (group with different points of view, comment and discuss issues until consensus or stable disagreement)	Deliberative polling and dialogues (participants are surveyed, review docs, assess changes from initial perceptions)		
10) What other methods of SE have you used to inform your NeuroDevNet funded work?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
11) Notes/additional detail re: OTHER methods of SE checked above:					

Appendix A – Survey questions and selected data

Methods of FORMAL Stakeholder Engagement *continued*

	Referendum (direct vote on proposal or course of action)	Poll or survey (in-person, telephone, or online)	Booth at event	Conference or info session			
12) Which OTHER methods of SE have you engaged in for your NeuroDevNet funded work?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
13) Notes/additional detail re: OTHER methods of SE checked above:							
	Weekend events (e.g. exergame demo at science centre)	Travelling roadshow (e.g. exergame promo tour)	Hotline (answer caller questions and collect input)	Radio & TV shows	Open House	Field Trip	Letters
14) What methods of OUTREACH have you used for informing and/or raising awareness of your NeuroDevNet funded work?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15) Notes/additional detail re: OTHER methods of SE checked above:							
16) What kind of INFORMAL stakeholder engagement have you been doing? For example (please check all that apply) to complete the sentence "I know what are the needs of families because..."	<input type="checkbox"/> I am a clinician/clinician researcher and hear from parents/patients during appointments <input type="checkbox"/> I am a service provider (administer interventions) and listen to my clients' needs during appointments/therapy <input type="checkbox"/> I am a service provider (coordinate/help families obtain services) and I know what are the most common challenges they ask me to help them with <input type="checkbox"/> I am both a service provider/clinician/researcher and a parent so I know from personal experience <input type="checkbox"/> I am a researcher and I know what the research says <input type="checkbox"/> I am a researcher and I talk regularly (either in person, email, or social media) with my stakeholders <input type="checkbox"/> I am a policymaker and I talk to families regularly <input type="checkbox"/> I am a policymaker and a parent so I know from personal experience <input type="checkbox"/> I am on a committee/board with parents that has helped me understand more about the needs of families <input type="checkbox"/> I have presented at conferences/workshops and other events and I know what the needs are based on the questions asked afterwards <input type="checkbox"/> Other						

Appendix A – Survey questions and selected data**Methods of FORMAL Stakeholder Engagement *continued***

17) Is there anything else you would have done to engage your stakeholders in your NeuroDevNet-funded work that we have not asked about above?

18) What other stakeholder engagement activities have you done that are NOT NeuroDevNet funded, but that have potentially informed NeuroDevNet's work?
(e.g. any stakeholder engagement activities that were for other research projects, but with the same relevant stakeholders)

19) Who are the stakeholders and/or end-users you have engaged with?

- Policymaker(s) - Federal
 - Policymaker(s) - Provincial
 - Policymaker(s) - Municipal
 - Policymaker(s) - Organization (e.g. Hospital)
 - Policymaker(s) - Program level (e.g. Program Manager)
 - Practitioner - clinician
 - Practitioner - service provider
 - Parent(s) of child with disability
 - Child(ren) with disability
 - Self-advocates (youth and/or adult) with disability
 - Professional association(s)
-

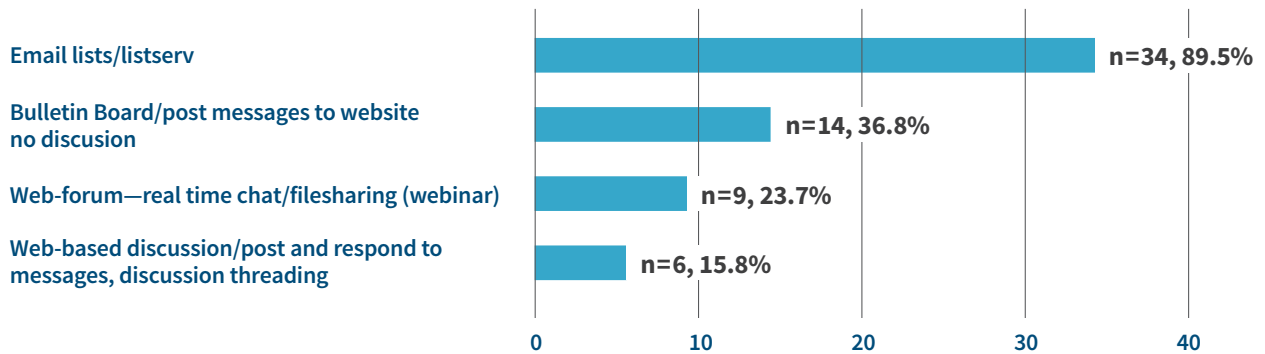
20) Who are the stakeholders and/or end-users you have engaged with (that are not listed above)?

Appendix A – Survey questions and selected data

Data from selected survey questions¹³

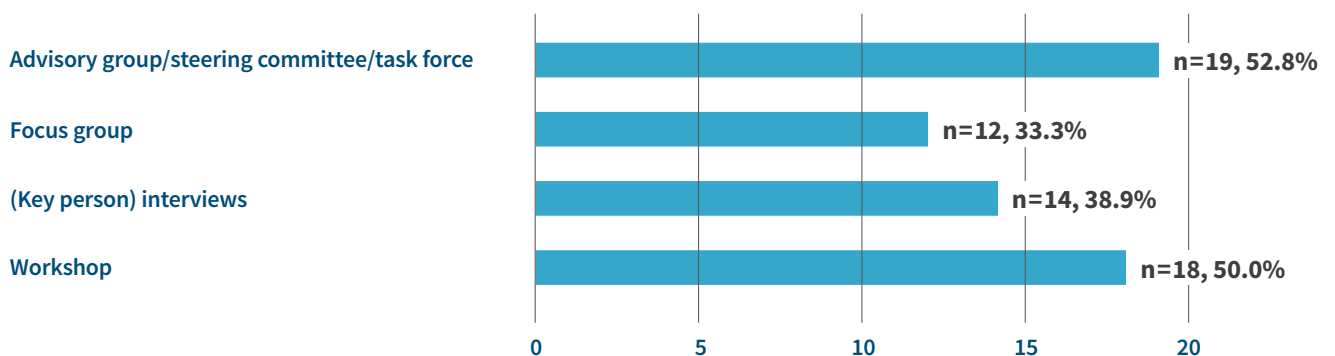
Question: Which online methods for SE have you used to inform your NeuroDevNet funded work?

Total Count (N)	Missing	Unique
38	14 (26.9%)	4



Question: Which teleconference or small group meeting based methods for SE have you used to inform your NeuroDevNet funded work?

Total Count (N)	Missing	Unique
36	16 (30.8%)	4



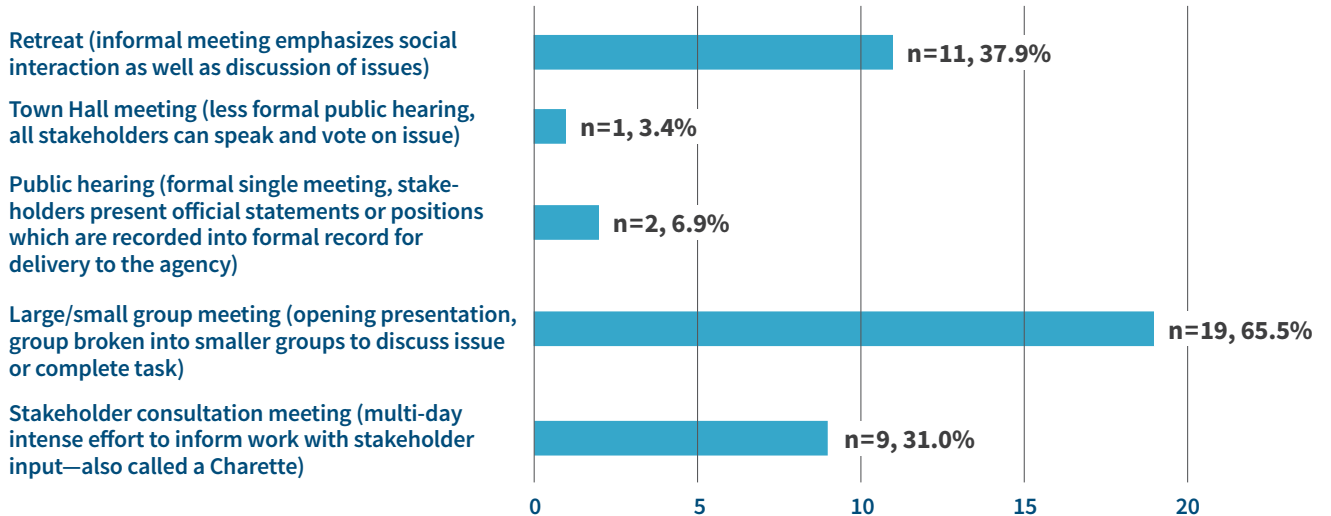
¹³ For most questions, users were permitted to select multiple answers. REDCap, the software used for this survey, calculates the percentage for each option as the number of times the option was checked divided by the number of responses to the question, so the percentages reported for each question do not necessarily add up to 100%.

Appendix A – Survey questions and selected data

Data from selected survey questions *continued*

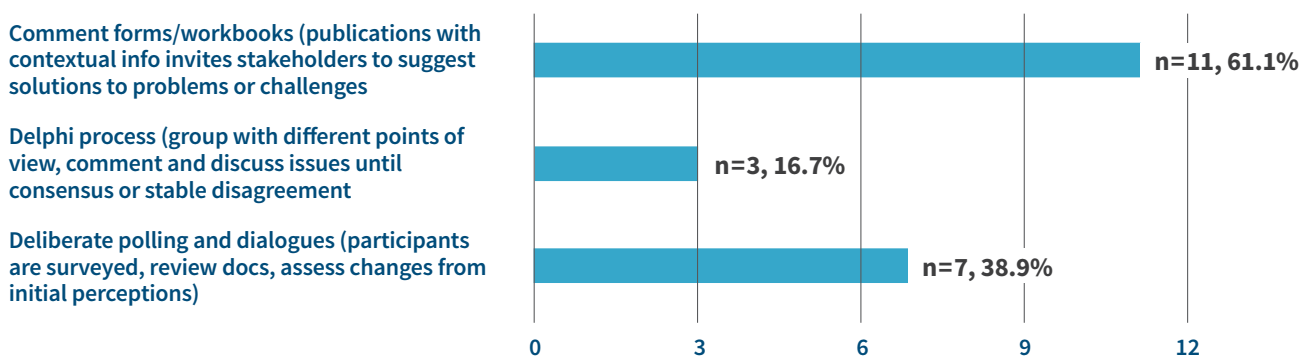
Question: Which large group methods for SE have you used for informing your NeuroDevNet funded work?

Total Count (N)	Missing	Unique
29	23 (44.2%)	5



Question: What other methods of SE have you used to inform your NeuroDevNet funded work?

Total Count (N)	Missing	Unique
18	34 (65.4%)	3

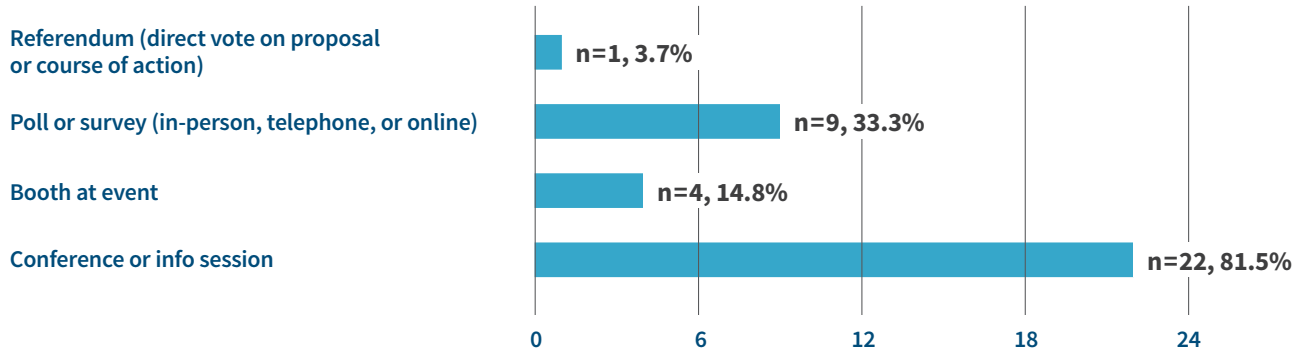


Appendix A – Survey questions and selected data

Data from selected survey questions *continued*

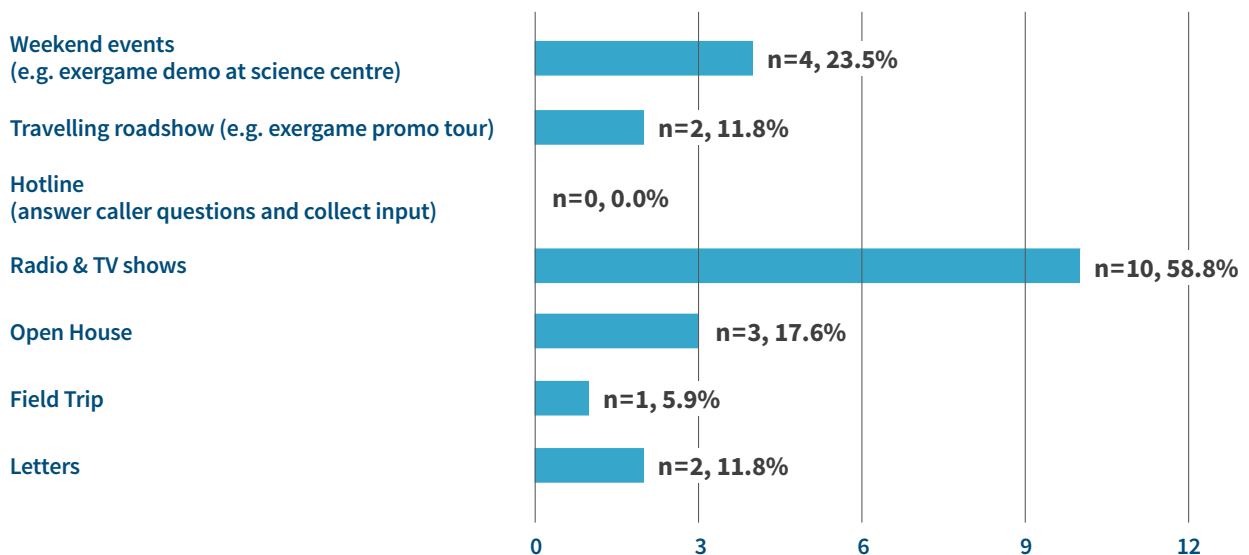
Question: What other methods of SE have you used to inform your NeuroDevNet funded work?

Total Count (N)	Missing	Unique
27	25 (48.1%)	4



Question: What methods of outreach have you used for informing and/or raising awareness of your NeuroDevNet funded work?

Total Count (N)	Missing	Unique
17	35 (67.3%)	6

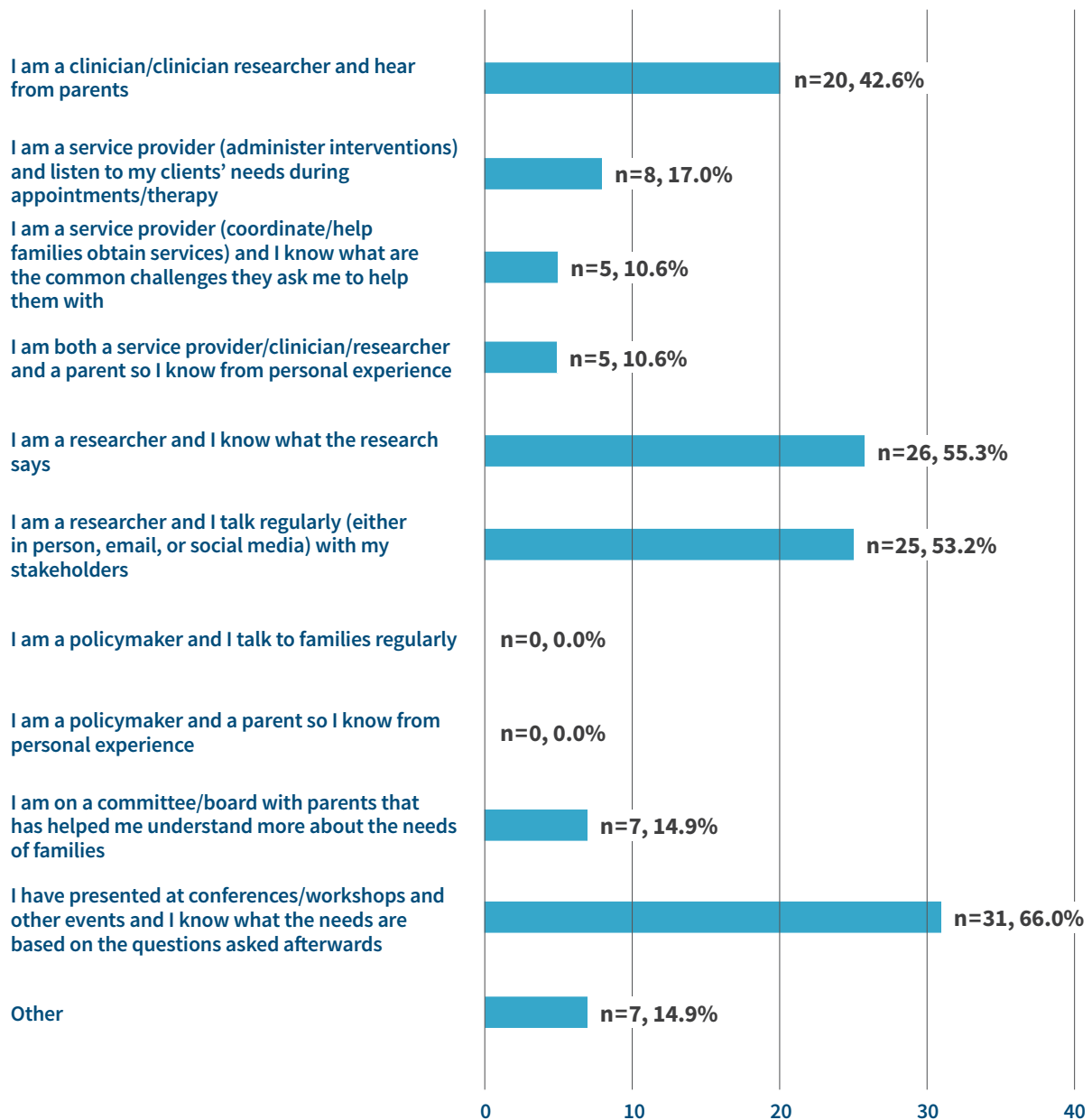


Appendix A – Survey questions and selected data

Data from selected survey questions *continued*

Question: What kind of informal stakeholder engagement have you been doing?
For example (please check all that apply) to complete the sentence
“I know what are the needs of families because...”

Total Count (N)	Missing	Unique
47	5 (9.6%)	9

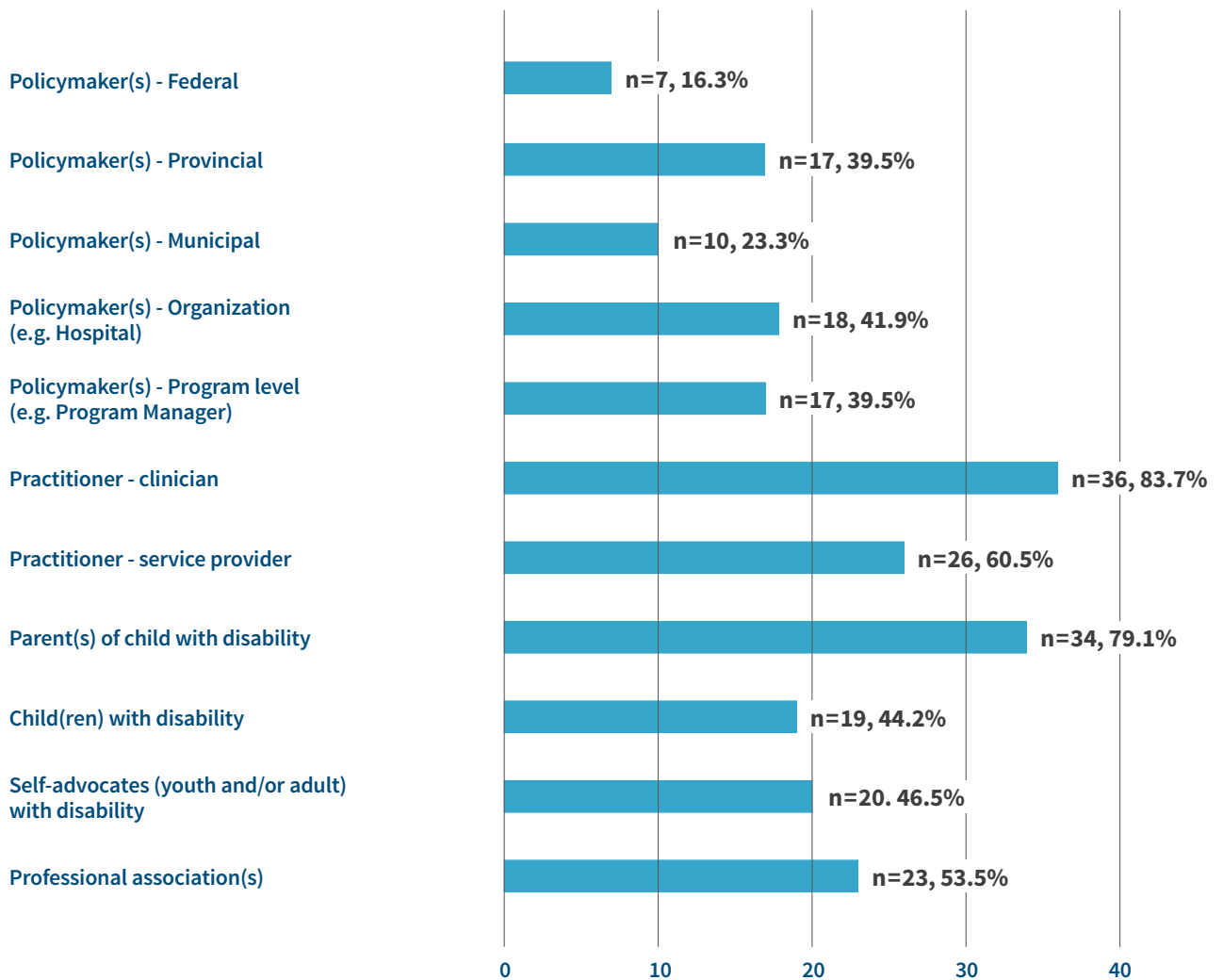


Appendix A – Survey questions and selected data

Data from selected survey questions *continued*

Question: Who are the stakeholders and/or end-users you have engaged with?

Total Count (N)	Missing	Unique
43	9 (17.3%)	11



Appendix B: Methodology – Additional detail and rationale

Appendix B – Methodology – Additional detail and rationale

A system is a “structured set of objects and/or attributes together with the relationships between them... at the same time [a system is] a subsystem of some wider system and is itself a wider system to its subsystems” (Wilson, 1990: p. 24 & 30). The original research on systems theory presented by Bertalanffy, the father of systems theory, approached the subject from a quantitative perspective, proving the interrelationships among individual parts with elaborate sets of equations (Bertalanffy, 1950). One of the earliest examples given of an ‘open’ system is an organism. It maintains a steady state by engaging in biological processes which manage (direct and indirect) environmental inputs and outputs to its system. More recently, within the social sciences, Morgan (1986) states that organizations must remain ‘open’ to contingencies in their environment, and attain a meaningful relationship with that environment in order to be successful. Thus, despite its origins in the pure sciences, a systems approach considers dynamic interaction as the central problem in any field of scientific inquiry (Bertalanffy, 1950, 1968). Systems theory has become important for understanding complex social systems within fields such as organizational behaviour, psychology of human behaviour, and other social sciences (Patton, 2002).

Systems theory therefore provides a useful perspective for understanding the complex processes inherent in managing life with a neurodevelopmental condition, which include social environmental factors that impact the individual’s and family’s quality of life as system(s) within the larger system. These factors include: relationships within and outside of the family, individual (in)ability to regulate emotions and anxiety, behaviours, (quality and availability of) service provision, and others. Systems theory is especially relevant to this research because it reflects the foundation of social constructivism with its focus on the effects of the “behaviour of the parts of a system [as] interdependent” and the belief that “the performance of a system is not the sum of the independent effects of its parts; it is the product of their interactions” (Patton, 2002: p. 121). In other words, systems theory considers the nature of many interconnections, such as the relationship between organizations and individuals (Colomy, 1992; Patton, 2002). Relationships can be transformed with the provision of a setting in which personal experiences and narratives can be expressed and acknowledged by others (Rich et al., 1995). Thus, a systems theory in practice can provide a useful framework for engaging as partners with all stakeholders involved in a situation (the immediate setting in which behaviour occurs), and positively change the conditions of the relationship (Colomy, 1992; Tew, 2002). The reason for the usefulness of this framework is simple: when opposing claims are encouraged to be expressed, “...such social systems are able to readjust their structures by eliminating the sources of dissatisfaction... and to re-establish unity” (Coser, 1967: p. 307). Patton states “...systems thinking has profound implications for program evaluation and policy analysis where the parts are often evaluated in terms of strengths, weaknesses, and impacts with little regard for how the parts are embedded in and interdependent with the whole program or policy.” (2002: p. 121).

Appendix B: Methodology – Additional detail and rationale

According to Glaser (1978), the purpose of Grounded Theory method is to explain the behavioural processes (not individuals themselves) that evolve over time and impact the social problem under study. Constructivist grounded theorizing seeks to illuminate heterogeneous positions, contradictions, and multiple voices, perspectives, and intensities as they appear in the data. Grounded in the constructivist perspective, Adele Clarke's (2005) situational analysis was used as a tool in conjunction with the conditional matrix in order to facilitate the production of system maps to help understand the influences and interactions among individuals, groups and organizations within the Canadian context.

The conditional data matrix (Figure 3.1) is an analytic tool for researchers to be able to organize the chain of events in the 'story' told by the data. The purpose of a conditional matrix is to stimulate the thinking of the researcher in terms of the scope of the project (micro versus macro), to extend the consideration of conditions beyond the individual (micro) level, to trace the connections between actions and interactions, to make choices concerning which factors to consider in theory development, to assist in the organization of data for a more persuasive argument using the data, and to provide direction for theoretical sampling by helping to identify which analytic threads are important and how events might interrelate with each other (Strauss and Corbin, 1998). Using a conditional matrix to frame the analysis allows for the consideration of macro (e.g. federal and provincial policies) and micro (family and individual) level factors that intersect and interact within the situational context (Strauss and Corbin, 1990; 1994). This framework, in conjunction with situational analysis, provides a way to describe and organize the findings about human interaction at the interpersonal, institutional, community and global levels (Strauss and Corbin, 1998).

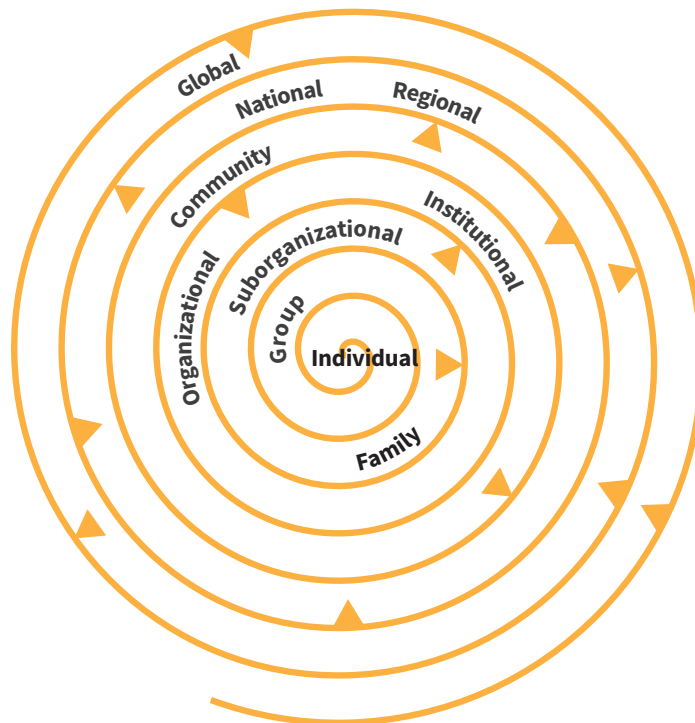


Figure 3.1. Strauss and Corbin's (1998) Conditional Matrix

Appendix B: Methodology – Additional detail and rationale

Adele Clarke's (2005) situational analysis was used in conjunction with the conditional matrix since it builds upon interactions among stakeholders, and how these influence the social problem and basic social process being studied. This was accomplished through the use of a situational map that provided an overview of the actors, discourses and other elements which comprise 'the situation' under study. Illustrations, called social worlds or arenas maps, identify the interactions among stakeholders from different knowledge and experiential backgrounds, and positional maps identify the variability in positions on major contested issues. By providing this visualization, situational analysis extends the conditional matrix to include articulation of variability in the data (e.g. polarized views) and most importantly, causes 'silences' in the data to be 'spoken'.

Summary of methodology and timeline

The methodology for this stakeholder engagement project employed a multi-staged approach that used grounded theory research methodology. The three 'cases' under investigation were CP, FASD and ASD. Key stages in the project included:

Date(s)	Activity
May, 2016	Online survey ¹⁴ administered within the Network. Survey data utilized for identification of previous stakeholder consultation activities with formal documentation of stakeholder needs, as well as potential clinicians to interview
June, 2016	Emails sent to survey participants requesting documentation related to stakeholder engagement activities reported in online survey, that have taken place within the Network throughout its existence
June, 2016	Online search for policymakers, emails sent to individuals identified
June 21, 2016	Ethics approval received for conducting one-on-one interviews
June-September 2016	One-on-one telephone interviews conducted. Transcription, open/axial coding (constant comparison and memoing) completed in parallel
July-August 2016	Document data collection, online search for reports on government-funded stakeholder consultations that identified and reported on stakeholder needs with respect to ASD, FASD, CP.
July 27, 2016	Ethics approval for amendment #1 received (to interview clinicians outside of the Network)
November, 2016	Identified themes and focus areas sent to interviewees for feedback as part of member-validation
December, 2016	Themes and focus areas updated according to feedback received from interviewees
January 11, 2017	Ethics approval for amendment #2 received (to record stakeholder event and write paper)
January 18, 2017	One-day in-person stakeholder consultation event in Vancouver, BC, with similar categories of stakeholders but different set of individuals than those who were interviewed, to prioritize the 44 focus areas that emerged from the analysis of interview data, and help detail next steps for the top 10 priorities

¹⁴ using REDCap (Research Electronic Data Capture), access and support provided through KBHN's Neuroinformatics Core.

Appendix C – Letter of Informed Consent

Appendix C – Letter of Informed Consent

Date: June 7, 2016

Study Name: KBHN Stakeholder engagement project of Stakeholder Needs

Researchers:

*Dr. Anneliese Poetz, 201 Kaneff Tower, 416.736.2100 x44310,
apoetz@yorku.ca*

*Dr. David Phipps, Kaneff Tower 5th floor, 416.736.5813,
dhipps@yorku.ca*

Purpose of the Research: KBHN wishes to conduct a stakeholder engagement project with diverse stakeholders in order to inform future research directions, based on the needs and challenges experienced by parents of children with Cerebral Palsy, Fetal Alcohol Spectrum Disorders and Autism Spectrum Disorders. This information will be collected from parents directly, as well as service providers/clinicians and policymakers who are aware of the needs of families based on regular interactions through their work.

What You Will Be Asked to Do in the Research: We would like to ask you to participate in a 60-minute telephone interview, and we will provide the questions in advance to give you time to think about your responses.

Risks and Discomforts: We do not foresee any risks or discomfort from your participation in the research.

Benefits of the Research and Benefits to You: KBHN is well-positioned to make real changes for parents and children affected by neurodevelopmental disorders, with its Federal, Provincial and local contacts and networks. By participating in this stakeholder engagement project and sharing your insights based on your experience and knowledge, you will help us to maximize the potential usefulness (and impact) of the research being conducted by KBHN, to help improve the quality of life for children, parents and families affected by Cerebral Palsy, Fetal Alcohol Spectrum Disorders and Autism Spectrum Disorders.

Voluntary Participation: Your participation in the study is completely voluntary and you may choose to stop participating at any time. Your decision not to volunteer will not influence the nature of the ongoing relationship you may have with the researchers or study staff nature of your relationship with York University and/or KBHN NCE either now or in the future.

Withdrawal from the Study: You can stop participating in the study at any time, for any reason, if you so decide. Your decision to stop participating, or to refuse to answer particular questions, will not affect your relationship with the researchers, York University or any other group associated with this project. In the event you withdraw

from the study, all associated data collected will be immediately destroyed wherever possible. Should you wish to withdraw after the study, you will have the option to also withdraw your data at any time.

Confidentiality: The interviews will be digitally recorded in order to facilitate transcription and qualitative analysis. Your identifying information will be associated with the transcripts only for the purpose of being able to return to you at a later time to obtain clarification of your response(s) if needed. All information you supply during the research will be held in confidence, and unless you specifically indicate your consent, your name will not appear in any report or publication of the research. Your data will be safely stored in a locked facility at York University in Kaneff Tower. Only research staff will have access to this information. The data will be stored for four years and will be destroyed after April 1, 2021. Confidentiality will be provided to the fullest extent possible by law.

Questions about the Research? If you have questions about the research in general or about your role in the study, please feel free to contact Dr. Anneliese Poetz either by telephone at (416) 736-2100, extension 44310 or by e-mail (apoetz@yorku.ca) or Dr. David Phipps by telephone (416) 736.5813 or by e-mail (dhipps@yorku.ca). This research has received ethics review and approval by the Human Participants Review Sub-Committee, York University's Ethics Review Board, and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines. If you have any questions about this process, or about your rights as a participant in the study, please contact the Sr. Manager & Policy Advisor for the Office of Research Ethics, 5th Floor, Kaneff Tower, York University (telephone 416-736-5914 or e-mail ore@yorku.ca).

Legal Rights and Signatures:

I (*fill in your name here*), consent to participate in *KBHN Stakeholder engagement project of Stakeholder Needs* conducted by *Anneliese Poetz and David Phipps*. I have understood the nature of this project and wish to participate. I am not waiving any of my legal rights by signing this form. My signature below indicates my consent.

Signature

Participant

Date

Signature

Principal Investigator

Date

Appendix D – Semi-Structured Interview Questions - Clinicians

Appendix D – Semi-Structured Interview Questions – Clinicians

Background about KBHN and this stakeholder engagement project (to read to respondent):

KBHN is a Federally funded **Network of Centres of Excellence (NCE)**, focused on the early diagnosis and treatment of neurodevelopmental disorders such as Fetal Alcohol Spectrum Disorders, Autism Spectrum Disorders and Cerebral Palsy. As a pan-Canadian Network, we collectively strive toward achieving real change in policies and practices in Canada in order to maximize the quality of life for children, youth and parents/families affected by these neurodevelopmental disorders. The way we do this is by finding out (and responding to, by forming our research projects on) what are the main challenges/needs of policymakers and practitioners, as well as parents/families/children/youth. We are interviewing you as a practitioner to find out i) what you know from the parents/families/children/youth you interact with on a regular basis in your practice, about their challenges and needs with respect to improving their quality of life, and ii) what are your challenges and needs as a service provider, for being able to help your clients/patients. This information will be used to inform KBHN's future research programs, training of the next generation of researchers, and for effective knowledge translation of research findings toward positive changes in policy and practice in Canada.

Section A: Getting to know respondent

A. Where are you located? (city/province)	
B. What project(s) are you working on that are funded by KBHN? ¹⁵	

(continued on next page)

¹⁵ Note: This question was skipped in the case of interviewing a non-network affiliated clinician

Appendix D – Semi-Structured Interview Questions - Clinicians

Section B: Respondent’s activities, related to engaging with stakeholders (e.g. parents, youth, families affected by neurodevelopmental disorders (NDD) such as Cerebral Palsy, Fetal Alcohol Spectrum Disorder, Autism Spectrum Disorder) and what they have learned about stakeholder needs

<p>1. In the survey you recently filled out, you had indicated that you are aware of stakeholder needs because of the interaction you have with families/children/youth with neurodevelopmental disabilities.</p>	<p>a. Which neurodevelopmental disability do you mainly focus on in your work (e.g. CP, FASD, ASD, all)?</p> <p>b. What are the main challenges parents/children/youth affected by (CP, FASD, ASD) tell you they experience? Challenges encountered with health care services and/or programs (e.g. obtaining a diagnosis, access to treatment programs and services, access to assistive technologies, services for families)? Biggest challenge in terms of “life with a neurodevelopmental disability” (e.g. quality of life for individual who has the disability, quality of life for the parents/whole family, isolation, recreation, school, etc.)? How do you know what are the needs of families/parents (what are the sources of information that you access, to understand the needs/challenges of families (e.g. personal interaction discussions with families, academic literature, other))?</p> <p>c. What are your challenges as a clinician/service provider? Being able to provide early diagnosis/treatment to your patients/clients? Being able to help improve the quality of life (in general) for your patients/clients? Anything else?</p> <p>d. What do you think is/are the solution(s)?</p> <p>e. What do you think KBHN can do to facilitate working towards making these solution(s) a reality?</p>
<p>2. If you had unlimited resources, time and power to change anything you wanted, in order to make life better for your clients/patients and/or their families what would it be?</p>	<p>a. Why?</p> <p>b. How would you accomplish it?</p>
<p>3. Do you have any formal synthesized documentation of the needs/challenges of parents/families/children affected by NDD that you could share, to become part of this stakeholder engagement project?</p>	<p>a. Stakeholder consultation meeting report(s)?</p> <p>b. In the absence of formal meeting report(s), any raw data such as breakout activity forms, or any forms filled out by stakeholders where they gave feedback/input?</p> <p>c. Meeting evaluation forms (not the most important documents, but would be nice to see)?</p>
<p>4. The main purpose of these interviews, and collection of information about stakeholder needs/challenges is to inform the future work of KBHN including future research programs. Is there anything else you would like to add, that maybe I didn’t ask about that you believe is important to mention?</p>	

Appendix E – Semi-Structured Interview Questions - Policymakers

Appendix E – Semi-Structured Interview Questions – Policymakers

Background about KBHN and this stakeholder engagement project (to read to respondent):

KBHN is a Federally funded **Network of Centres of Excellence (NCE)**, focused on the early diagnosis and treatment of neurodevelopmental disorders such as Fetal Alcohol Spectrum Disorders, Autism Spectrum Disorders and Cerebral Palsy. As a pan-Canadian Network, we collectively strive toward achieving real change in policies and practices in Canada in order to maximize the quality of life for children, youth and parents/families affected by these neurodevelopmental disorders. The way we do this is by finding out (and responding to, by forming our research projects on) what are the main challenges/needs of policymakers and practitioners, as well as parents/families/children/youth. We are interviewing you as a policymaker to find out i) what you know from the parents/families/children/youth you interact with on a regular basis in your work, about their challenges and needs with respect to improving their quality of life, and ii) what are your challenges and needs as a policymaker, for being able to help Canadian families affected by neurodevelopmental disorders. This information will be used to inform KBHN's future research programs, training of the next generation of researchers, and for effective knowledge translation of research findings toward positive changes in policy and practice in Canada.

Section A: Getting to know respondent

A. Where are you located? (city/province/territory)	
B. In what way have you been engaged with KBHN (if at all)?	e.g. collaborator, partner, consulted informally on policy needs, have not been engaged with KBHN before, etc.

(continued on next page)

Appendix E – Semi-Structured Interview Questions - Policymakers

Section B: Respondent’s activities, related to engaging with stakeholders (e.g. parents, youth, families affected by neurodevelopmental disorders (NDD) such as Cerebral Palsy, Fetal Alcohol Spectrum Disorder, Autism Spectrum Disorder) and what they have learned about stakeholder needs

<p>1. I would like to ask you about how you stay current in terms of your awareness of the needs and challenges of parents/families and children/youth affected by neurodevelopmental disorders (such as CP, ASD, FASD)?</p>	<p>a. Which neurodevelopmental disability do you mainly focus on in your work (e.g. CP, FASD, ASD, all)?</p> <p>b. What are the main challenges parents/youth affected by (CP, FASD, ASD) tell you they experience?</p> <ul style="list-style-type: none"> • Challenges encountered with health care services and/or programs (e.g. getting a diagnosis, access to treatment programs and services, access to assistive technologies)? • What are you hearing is the biggest challenge in terms of “life with a neurodevelopmental disability” (e.g. quality of life for individual who has the disability, quality of life for the parents whole family, access to health care, recreation or education, etc.)? • The above questions were about the needs/challenges of families based on your experiences and interactions with them, but are there any other sources of information that you access, to understand the needs/challenges of families? <p>c. What do you think is/are the solution(s)?</p> <p>d. What do you think KBHN can do to facilitate working towards making these solution(s) a reality?</p> <p>e. What are the biggest challenges you face, in terms of policy related to families/children affected by neurodevelopmental disabilities such as CP, FASD, ASD?</p> <ul style="list-style-type: none"> • Published research doesn’t give you the information you need? Explain... • Face barriers (e.g. political, financial, human resource, time, etc.) to making policy changes that are needed? • Do not have enough awareness/access to information about: current research and innovative technologies, current problems with service provision, quality of life issues experienced by persons with NDD and their families? • Conflicting messages from stakeholders (i.e. parents say one thing while clinicians say another)? • How can KBHN help you overcome these challenges, to help facilitate necessary changes in policy to improve the lives of families/children affected by NDD?
<p>2. If you had unlimited resources, time and power to change anything you wanted, in order to make life better for children/youth affected by NDD and/or their families, what would it be?</p>	<p>a. Why?</p> <p>b. How would you accomplish it?</p>
<p>3. The main purpose of these interviews, and collection of information about stakeholder needs/challenges is to inform the future work of KBHN including future research programs. Is there anything else you would like to add, that maybe I didn’t ask about that you believe is important to mention?</p>	

Appendix F – Semi-Structured Interview Questions - Parents

Appendix F – Semi-Structured Interview Questions – Parents

Background about KBHN and this stakeholder engagement project (to read to respondent):

KBHN is a Federally funded **Network of Centres of Excellence (NCE)**, focused on the early diagnosis and treatment of neurodevelopmental disabilities such as Fetal Alcohol Spectrum Disorder, Autism Spectrum Disorder and Cerebral Palsy. As a pan-Canadian Network, we collectively strive toward achieving real change in policies and practices in Canada in order to maximize the quality of life for children, youth and parents/families affected by neurodevelopmental disabilities. The way we do this is by finding out (and responding to, by forming our research projects on) what are the main challenges/needs of policymakers and practitioners, as well as parents/families/children/youth. We are interviewing you as a parent to find out about the challenges and needs you and your child experience, and what could be done about those experiences that would improve your/your child's/your family's quality of life¹⁶. This information will be used to inform KBHN's future research programs, training of the next generation of researchers, and for effective knowledge translation of research findings toward positive changes in policy and practice in Canada.

Section A: Getting to know respondent

A. Where are you located? (city/province/territory)	
B. Which KBHN affiliated researchers/ personnel have you interacted with previously?	If they can't remember the names, please ask them to describe (or name if they can) the project

(continued on next page)

¹⁶ Definition of Quality of Life: the standard of health, comfort and happiness experienced by an individual or group.

Appendix F – Semi-Structured Interview Questions - Parents

Section B: Respondent’s experiences related to diagnosis/treatment (services, policies that govern them) for neurodevelopmental disabilities (NDD), such as Cerebral Palsy, Fetal Alcohol Spectrum Disorder, Autism Spectrum Disorder and what are their biggest challenges/needs (to inform improving services and policies)

<p>1. The following questions relate to family life with a child that has a neurodevelopmental disability.</p>	<p>a. What’s your child’s diagnosis (e.g. CP, FASD, ASD, all)?</p> <p>b. What are the main challenges that you as a parent with a child affected by (CP, FASD, ASD) experience (or have experienced)?</p> <ul style="list-style-type: none"> • Challenges encountered with health care services and/or programs (e.g. obtaining a diagnosis, access to treatment programs and services, access to assistive technologies, services for families)? • Biggest challenge in terms of “life with a neurodevelopmental disability”? <p>c. What are your challenges as a (whole) family unit?</p> <ul style="list-style-type: none"> • Relationships, communication, maintaining friendships, finances, etc.? • Anything else? <p>d. What are the challenges you have observed/know that your child encounters (from their perspective—what would they say if they were interviewed)?</p> <ul style="list-style-type: none"> • Any aspect of their life that makes them happy/unhappy? • Social interactions? • Interactions with health care/services? <p>e. What do you think is/are the solution(s)?</p> <p>f. What do you think KBHN can do to work towards making these solution(s) a reality?</p>
<p>2. If you had unlimited resources, time and power to change anything you wanted, in order to make life better for your family and other families in Canada like yours, what would it be?</p>	<p>a. Why?</p> <p>b. How would you accomplish it?</p>
<p>3. The main purpose of these interviews and collection of information about needs/challenges is to inform the future work of KBHN including future research programs. Is there anything else you would like to add, that maybe I didn’t ask about that you think is important to mention?</p>	

Appendix G – Email Sent to Interviewees for Member Checking

Appendix G – Email Sent to Interviewees for Member Checking

Body of email text sent to each interviewee along with the initial Themes and Focus Areas identified:

You may remember participating in a telephone interview with me, regarding the needs and challenges of parents, clinicians and policymakers, and at that time I'd asked you if it would be okay to share the copy of the report for feedback. I am pleased to provide you with this short summary of the major themes that have arisen from the stakeholder engagement project you participated in as an interviewee, for your review. These themes represent what I have identified as needs and challenges that are common amongst all three conditions focused on by NeuroDevNet (e.g. Cerebral Palsy, Fetal Alcohol Spectrum Disorders and Autism Spectrum Disorders). I would be grateful if you could **provide any feedback you may have** on these themes within two weeks (**by Wednesday November 23, 2016**), if possible.

Any feedback would be appreciated, including specific ideas related to:

- 1) have all the needs/challenges been captured in these themes? If not, what is missing?
Please provide as much detail as possible.
- 2) would you modify any of the themes? If so, please use tracked changes in Word (or email me your changes in the body of an email)
- 3) anything else at all?

I am truly grateful to you for your time and attention to this. Your feedback is very important!

A longer report will be written after receiving feedback on these major themes that have arisen from the analysis. If I use a quote from my interview with you, I will contact you to make sure I have used it appropriately and not taken the meaning of your words out of context.

Thank you in advance for your time in reviewing this.

Kindest regards,
Anneliese Poetz

Appendix H – List of Documents Triangulated with Interview Data

Appendix H – List of Documents Triangulated with Interview Data

1. Accessibility 2024: Making B.C. the most progressive province in Canada for people with disabilities by 2024. British Columbia. 1-17. Accessed November 15, 2016 from: http://www2.gov.bc.ca/assets/gov/government/about-the-bc-government/accessible-bc/accessibility-2024/docs/accessibility2024_update_web.pdf
2. Borisoff, J., J. Ho, S. Jamal, et al. (2012). Minister’s council on employment and accessibility: action plan framework for the Minister of Social Development and Social Innovation. British Columbia. September: 1-6. Accessed November 15, 2016 from: <http://www2.gov.bc.ca/assets/gov/government/about-the-bc-government/accessible-bc/accessibility-2024/docs/action-plan-framework.pdf>
3. Aitken, J. et al. (2016). Connecting family needs to ASD research in BC: full report 2015/2016. British Columbia. 1-50. Accessed November 15, 2016 from: http://informeveryautism.com/wp-content/uploads/2016/05/Autism_Full_Report_April25_screen.pdf
4. FASD 10-year Strategic Plan (2008). Alberta. 1-36. Accessed November 15, 2016 from: <http://fasd.alberta.ca/documents/FASD-10-year-plan.pdf>
5. Together we are stronger: continuing the success of Manitoba’s FASD strategy. Manitoba. 1-5. Accessed November 15, 2016 from: http://www.gov.mb.ca/healthychild/fasd/fasdstrategy_en.pdf
6. (2015). Fetal Alcohol Spectrum Disorder Provincial Roundtable Report: a report from parliamentary assistant Granville Anderson to the Minister of Children and Youth Services. Ontario. September: 1-31. Accessed November 15, 2016 from: http://www.ottawainuitchildrens.com/wp-content/uploads/2015/09/FASD_Roundtable_Report.pdf
7. MacCharles, T. (2013). Services for children and youth with special needs in Ontario, and their families: opportunities for improving their experiences and outcomes. Ontario. March: 1-37. Accessed November 15, 2016 from: <http://www.children.gov.on.ca/htdocs/English/documents/specialneeds/PAreport.pdf>
8. Report by the Quebec Ombudsman (2015). Service access, continuity and complementarity for young people (0-18 years old) with an intellectual disability or an autism spectrum disorder. Quebec. March: 1-3). Accessed November 15, 2016: https://protecteurducitoyen.qc.ca/sites/default/files/pdf/communiqués/2015-03-24_summary_intellectual-disability-autism.pdf

Appendix H – List of Documents Triangulated with Interview Data

9. (2012). Special Ombusman’s Report: services for young people and adults with a pervasive developmental disorder: from government commitment to cold hard facts. Quebec. May 23, 2012: 1-138. Accessed November 15, 2016 from: https://protecteurducitoyen.qc.ca/sites/default/files/pdf/rapports_speciaux/2012-05-23_rapport_ted_2_EN.pdf
10. (2009). Policy forum: autism across a lifespan. Quebec. February 5 & 6, 2009: 1-17. Accessed November 15, 2016 from: http://www.excellence-jeunesenfants.ca/documents/Forum_Autism_2009-Report_ANG.pdf
11. Audas, R., D. Ryan, K. Harris Walsh, et al. (2015). Needs assessment survey: autism community, Newfoundland Labrador. October: 1-82. Accessed November 15, 2016 from: https://www.autism.nf.net/wp-content/uploads/2016/03/ASNL-Needs_Assessment_FINAL_SC.pdf
12. (2012). Autism spectrum disorder (ASD) provincial needs assessment 2012: final report of needs assessment findings. Newfoundland & Labrador. September: 1-116. Accessed November 15, 2016 from: https://www.autism.nf.net/wp-content/uploads/2013/06/Autism-2012_Final-Report-of-Needs-Assessment-Findings-v4.pdf
13. Bryson, S.E. (2010). Autism management advisory team report on lifespan needs for persons with autism spectrum disorder. Nova Scotia. 1-142. Accessed November 15, 2016 from: <https://www.ednet.ns.ca/docs/autismmanagementadvisoryteamreport.pdf>
14. (2009). Recommendations toward a Prince Edward Island autism action plan: another piece of the puzzle. Prince Edward Island. September: 1-86. Accessed November 15, 2016 from: http://www.gov.pe.ca/photos/original/edu_autismplan1.pdf
15. Buell, M., C. Carry, M. Korhonen. (2006). Fetal Alcohol Spectrum Disorder: an stakeholder engagement project of services and gaps in Inuit communities. Nunavut. 1-38. Accessed November 15, 2016 from: http://www.naho.ca/documents/it/2006_Inuit_FASD_scan.pdf
16. Carroll, C. M. Lyons, M. Whelan (2014). CASDA National Needs Assessment Survey: for families, individuals with autism spectrum disorder & professionals. August: 1-51. Accessed November 15, 2016 from: http://www.casda.ca/wp-content/uploads/2015/12/NationalNeedsAssessmentSurvey_July-30.pdf
17. (2016). FASD Research: Learning Together. Canada FASD Research Network (CanFASD). 1-28. Accessed February 17, 2017 from: <http://canfasd.ca/wp-content/uploads/sites/35/2016/10/FASD-Learning-Together-Final.pdf>

Appendix I – List of N-Vivo Nodes

Appendix I –

List of N-Vivo Nodes

Name	Description	# times coded in across all transcripts
ABA or IBI	Specific mention of ABA or IBI as an intervention	30
Advocacy Awareness	Need for advocacy and awareness, examples of advocacy, anything related to advocacy	65
Analogy	When the respondent provides a good analogy, so you can understand the point they are trying to make. Maybe a new way for us all to think about/be able to understand better (use for KT purposes?)	22
Anxiety	Anxiety experienced by child, anxiety experienced by parents, any other family members	41
Appreciate Env Scan Being Done	Interviewee expresses that they are glad we are listening by performing this stakeholder engagement activity	10
Broader Disability Community	Any mention of neurodevelopmental condition beyond KBHN's three: CP, ASD, FASD	10
Child - happy	What makes the child with neurodevelopmental condition happy	24
Child - mental health	Anxiety, stress, low self-esteem, other mental health challenges of the child or youth with a neurodevelopmental condition	110
Child - unhappy	What makes the child with neurodevelopmental condition unhappy	15
Child - worry about future	Any mention of the child being worried or afraid about things that might or will happen in the future	1
Child's Diagnosis	From parent interviews, sometimes the child had multiple diagnoses beyond CP, FASD, or ASD, so this node captures all the diagnoses mentioned by the parent.	16
Clinician - Stress	What causes stress, to the clinician working to help families affected by neurodevelopmental conditions	13
Communication - within family	Having to communicate differently because of the effects of the NDD on the child's ability to communicate, or any other communication challenges within the family	21
Communication (need for)	The need for, or issues related to, communication among professionals, between professionals and parents, within families, etc.	100
Comprehensive Clinic	Doctors, dentistry, interventionists, social workers, etc. all under one roof, with expertise/understanding in FASD, ASD, CP various special needs	5
Culture	Importance of culture. For example, in the design and delivery of interventions as being culturally appropriate. Includes language(s)	19
Dentistry	Need for dentistry services for persons with special needs	9

Appendix I – List of N-Vivo Nodes

Name	Description	# times coded in across all transcripts
Diagnosis - importance	The importance of getting a diagnosis for the child. Includes beliefs that support the need for getting a diagnosis for various reasons, as well as opinions about how a diagnosis should not be considered important before treatment	106
Diagnosis - post	The experiences of the first few years after diagnosis	22
Diagnosis - treatment drop off	When the parents receive a diagnosis and then are left on their own to “figure it out”, no co-ordination, no information, no assistance provided for helping parents navigate the system or services	23
Diagnosis experience	What was parents’ experience leading up to and including obtaining the child’s diagnosis	78
Education - Post Secondary	Experiences or importance of college, university education	23
Education School - challenges	Challenges encountered in school, either with other people, with the material being taught, policies, or any aspect of the educational environment	146
Education School - solutions	Proposed solutions that could help make the school experience more enjoyable and more effective for students	89
eHealth	Health care provided at a distance, through the use of technology to those in rural/remote regions where geographical distance and travelling to appointments is a challenge	10
Emotions	Importance to parents of having feelings acknowledged, of being ‘heard’ by those supposed to serve the family (e.g. education, health care, etc.)	55
Employment	Employment experiences, prospects, worries, challenges experienced by the child with NDD as they transition to adulthood, or worry about future by either child and/or parent	49
Environment - physical	Aspects of the physical environment that are mentioned that have an effect on the child and/or family’s well-being	64
Environment - social	Aspects of the social environment (interactions with others in various settings) that are mentioned, that have an effect on the child and/or family’s well-being	123
ER	Experiences of the ER, visiting with a child that has a neurodevelopmental condition	9
Evaluation	Evaluation of services, policies, anything related to NDD	10
Executive Functioning and Maturity	Any mention of executive functioning, what it is, how it affects the child/ family’s life, etc. and any mention of the child not being mature according to what age they are (often have the maturity of someone much younger)	48
Extended family	Issues with extended family, either health issues of grandparents, or issues getting along with aunts, uncles, cousins, grandparents due to lack of understanding or other	27
Family needs - complex and changing	Family’s needs are complex, and change over time (are not static)	50
Family Quality of Life (QoL)	Things that impact on the family’s quality of life, either the parent’s QoL, the child’s QoL, the siblings’ QoL and/or the family as a whole	160

Appendix I – List of N-Vivo Nodes

Name	Description	# times coded in across all transcripts
Financial - Efficiency	Financial struggles encountered by parents, or by program managers, policymakers, clinicians, etc. Need for efficient use of resources to maximize benefit	143
Fluidity	Fluidity of services, approaches, etc. needs to change as needs change.	34
Frustration – child’s perspective	Frustration experienced by the child with NDD	25
Geography	Any mention of distance or location (usually as an issue or challenge, but sometimes just mentioning differences in various locations)	55
Going out - Errands and Vacation	What it’s like to engage in normal family tasks such as grocery shopping, eating at a restaurant, or going on vacation	19
Government - asking family input	Government (any level) conducting consultations or other activities to get feedback and/or input from families to inform policy/decisions	19
Grandparent	The interviewee is a grandparent of a child with NDD	3
Health Care - challenges	Challenges encountered with the healthcare system, could be during diagnosis, treatment, or anything else	118
Health Care - solutions	Solutions suggested, that could address the needs the respondent identified	54
Home-based	Interventions or other services that are delivered in the home environment	14
Housing	Being able to obtain/sustain housing for child with neurodevelopmental condition, now (if they are a teen) or in future when the child becomes an adult	24
Hub - Centre for families	to go for everything all in one place, diagnosis, treatment, research, everything	10
Humour	Use of humour as a coping mechanism	8
Inclusiveness Equity	Making sure all kids have access to appropriate school experience and other appropriate services	26
Info Sharing	Among professionals who are providing different services to a child/family (e.g. could be database, could be picking up the phone and calling, etc.)	3
Interventions	For teaching social skills, or anything to improve functioning	114
Isolation - clinician	Any mention of clinicians experiencing professional isolation	4
Isolation - social	Any mention of parents, children/youth, families experiencing social isolation/lack of friends as a result of living with the neurodevelopmental condition	80
Knowledge Translation - challenges	Challenges with respect to effective KT	90
Knowledge Translation - solutions	Ideas and insights into solutions for KT challenges identified, including dissemination and suggested ways to achieve impact	49
Labels	Challenging perceptions and labels that cause a certain perception (either negative or positive)	3
Lack of Info for Parents	Either nothing was known about the child’s condition, or the parents were not provided with the information they needed	34

Appendix I – List of N-Vivo Nodes

Name	Description	# times coded in across all transcripts
Leadership Advocacy	Any mention of someone taking a leadership role in terms of advocacy	12
Legislation	Any mention of legislation with respect to neurodevelopmental conditions	2
Marriage - Stress and Strategies	Of having a child with a neurodevelopmental condition	26
Menu of Treatment Options	Any mention of a desire to have a range of options for interventions and an understanding of what each option does or doesn't do for the person with the neurodevelopmental condition	34
Mindfulness	Any mention of mindfulness meditation	4
Minimization	When a person doubts the diagnosis (the child, despite diagnosis, 'looks okay on the outside', so people believe they are lazy and/or should just 'try harder')	36
Need for purpose	Child with neurodevelopmental condition's need for purpose and meaning in life	17
NeuroDevNet Projects	Ideas that respondents expressed, that fit with currently existing KBHN/NeuroDevNet projects and/or specific mention of KBHN/NeuroDevNet projects	55
Northern Communities	Any mention of needs or experiences of individuals, families, communities in the Northern regions of Canada. This could include the three Territories, and/or northern regions of southern provinces.	32
Parent - health issues	Any issues with parental health, concurrent with having to help child with NDD (e.g. cancer or other serious health problems)	4
Parent - resources	Mention that resources should be, or are, provided to parents to improve their knowledge and/or wellness for the benefit of their child	6
Parent - stress - mental health	Any mention of stress, coping or lack of coping in terms of parenting a child with a neurodevelopmental condition	167
Parent - worry about future	Parents worrying about the future for their child - what will happen when they die	46
Parent Advocacy	Parents have to dig for information on their own, have to advocate for a teacher's assistant (TA) in school, have to advocate for pretty much everything for their child	144
Parent support networks	Parent groups as a source of support and knowledge exchange, coping	25
Parent with NDD	When respondent talks about one of the parents of the child with a neurodevelopmental condition, also having a neurodevelopmental condition (usually similar to what the child has been diagnosed with). Parents report that in many cases one of the parents also has the same neurodevelopmental condition (FASD, ASD mainly) that the child does, and that this complicates the family dynamics	15
Parents - don't know where to go	Parents don't know what to do or where to go, too busy or no information	39
Parents overwhelmed - family impact	Impact on families, stress levels, having too much to do	28
Physical challenges	Such as co-ordination, motor skills, etc.	13

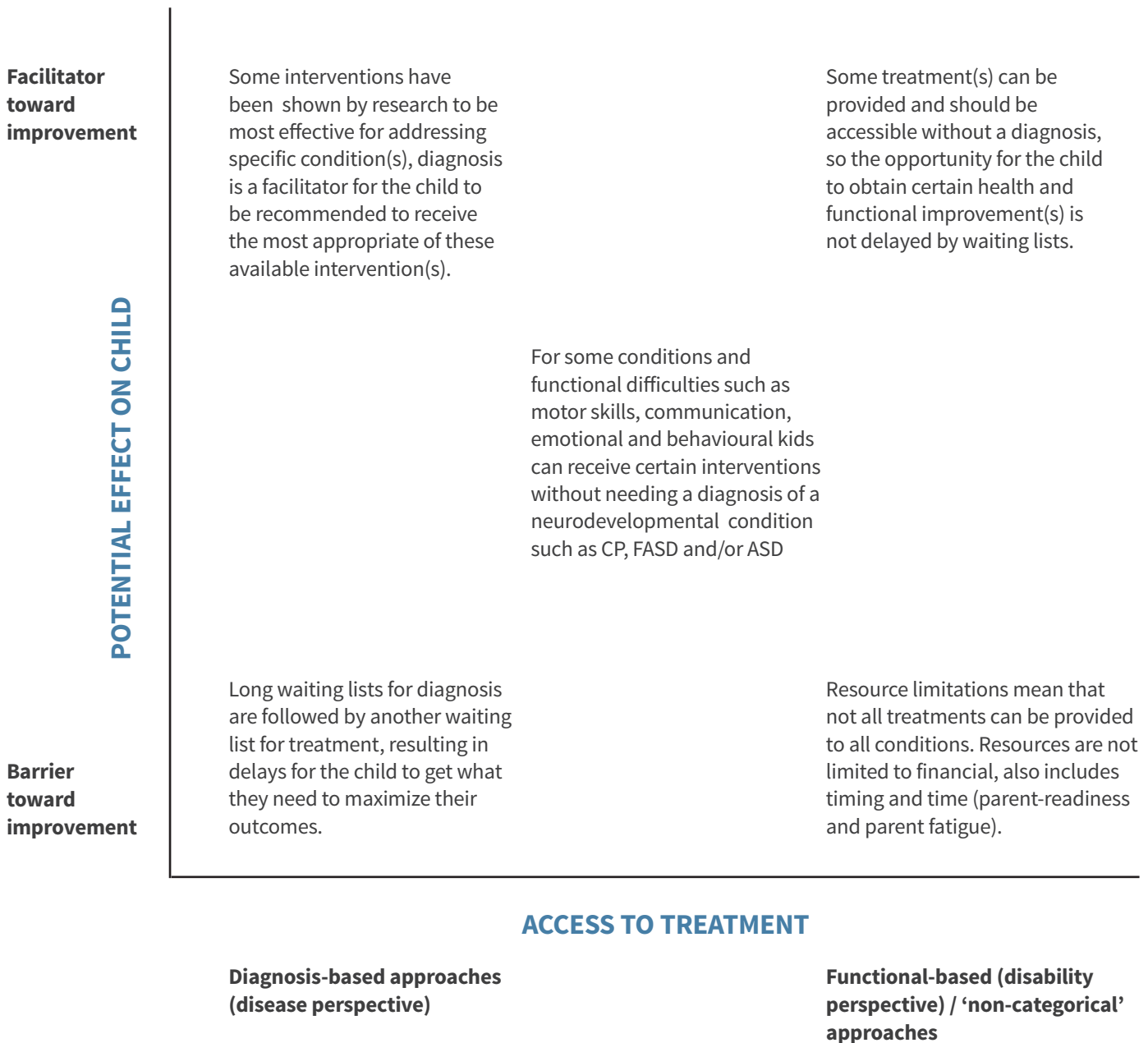
Appendix I – List of N-Vivo Nodes

Name	Description	# times coded in across all transcripts
Physical health	Of parent, child/youth or the whole family	14
Police	Any mention of police interactions that happened, or could happen, or any related issues relevant to policing	24
Policy - Challenges	Challenges for policymakers, challenges in achieving what needs to be achieved by policies	107
Policy changes	Barriers or other difficulties in achieving the necessary changes to policies, and/or mentions of changes that were successfully made to policies, or forthcoming changes to policies	28
Politics	Any mention of politics with respect to neurodevelopmental conditions	7
Positive qualities	Positive qualities possessed by the person with the neurodevelopmental condition	21
Prevention	Any mention of the need for prevention or awareness toward prevention	10
Quotes	Illustrative quotes, to use in the write up	209
Quotes2	Illustrative quotes to use in the write up - coded after the first draft of the themes/write up	70
Recreation	Need for recreation programs, accessible, affordable	42
Relationships - challenges	Need for, and challenges in terms of establishing relationships between researchers, policymakers, etc.	98
Relationships - solutions	Ideas for solutions to the challenges identified, in terms of relationships (typically between researchers and policymakers but could go beyond)	30
Reports - online	Relevant reports, websites or studies mentioned by respondent	6
Research - participated in	Experience participating in a research project	3
Research Gap	Identification of an existing research gap or a proposed research question or idea	69
Research Collaborations	Any mention of collaborations for research	1
Respite and Support Workers	Need for respite for parents, absence of respite, type of respite needed. Any mentions of support workers	55
Rural challenges	Any challenges faced, or exacerbated, because the family was located in a rural or remote area	32
Safety	Accommodations for the child for safety reasons	31
Sensory Issues	Child needs/seeks either more or less sensory stimulation.	17
Services - challenges	Understanding of challenges with respect to families accessing services for their child with a neurodevelopmental condition	248
Services - need for coordination	Need for co-ordination of services, related to the experience of the families accessing the services	156
Services - quality	Any mention with respect to the quality of services received or available	72
Services - solutions	Proposed/ideas for solutions for the challenges identified with respect to services	139

Appendix I – List of N-Vivo Nodes

Name	Description	# times coded in across all transcripts
Siblings	Effects on siblings, of having a sister or brother with a neurodevelopmental condition	26
Siblings - equity	Issues with needing to give more attention to the sibling that has a neurodevelopmental condition, at the expense of attention given to the higher functioning and/or neurotypical sibling(s). Double or triple standards or sets of rules for different children in the same family	13
Sleep	Effect on child's, parents' or anyone in the family's sleep quality, duration, timing, etc.	34
Social Skills	Any mention of the social skills of the child/person affected by the neurodevelopmental condition	18
Staff turnover	Education, health care, any staff/service provider who leaves their position, causing any level of distress to the family	14
Stakeholder input - listening	When stakeholders are listened to for input, usually by government or other organizations	38
Staying Current - how	How do you stay current on research and what are the needs and challenges of families/children, etc.	3
Success Stories	Examples given by respondent, when something good happened because people did the right thing in the right way	26
System - challenges	Challenges to the overall Canada-wide 'system', usually refers to the health care system specifically but it is usually implied that the system also includes other moving parts associated with the health care system	138
Teachable Moments	Recognize and maximize teachable moments with child with NDD	9
Technology Use	Use of technology such as assistive devices for communication, wheelchairs, apps, etc.	20
Transitions and Life course	Need for care throughout the lifespan	72
Trust	Trust among individuals, organizations, etc.	5
Understanding	The important role of understanding, whoever it is who 'gets it' (e.g. parent, teacher, service provider, health care worker, etc.). Includes mentions of the need for training. Also role of lack of understanding (contributing to stigma, etc.)	341
Waiting List	Any mention of waiting lists, either how long they were on one, the fact that there should not be a wait time, or whether there is a waiting list or not, etc.	56
Wrap around support	Comprehensive multi-faceted support for the individual and family affected by the neurodevelopmental condition	15
Youth Advocacy Individ or Group	Any mention of youth advocacy by individuals or groups of youth	4

Appendix J – Categorical (Disease Perspective) versus Non-Categorical (Disability Perspective) Approaches¹⁷



¹⁷ For further information on categorical versus non-categorical approaches, please see the KBHN-supported two-page clear language summary at the following link: <http://www.neurodevnet.ca/sites/default/files/Miller-Separating-disability-from-disease-a-constructive-approach-for-health-services-and-policy%20.pdf>

Appendix K – Agenda for Stakeholder Priority Setting Event

Appendix K – Agenda for Stakeholder Priority Setting Event

Making an Impact for People with Disabilities and their Families: Prioritizing Stakeholder Needs from the 2016 Environmental Scan

A Knowledge Exchange Forum on Neurodevelopmental Conditions in Canada

Hyatt Regency Vancouver, 655 Burrard Street, Vancouver, BC
604.683.1234
Wednesday, January 18, 2017

Agenda

Purpose

To provide a forum for information exchange and open discussion between Kids Brain Health Network (KBHN, formerly NeuroDevNet), clinicians, policymakers and parents of children with Cerebral Palsy, Autism Spectrum Disorders and Fetal Alcohol Spectrum Disorders about their challenges and needs to help inform the research and knowledge translation priorities of KBHN.

Objectives

- Provide participants with an overview of the outcomes of KBHN's Environmental Scan
 - Prioritize the themes and focus areas identified in the Environmental Scan
 - Detail ways to address the focus areas that are prioritized during this meeting
 - Provide participants with opportunities to exchange information and ideas related to services, policies and strategies for neurodevelopmental conditions in Canada
 - Inform the potential role for KBHN to facilitate the improvement of services for diagnosis and intervention(s) for people with neurodevelopmental conditions and their families in Canada
-

Meeting Agenda

(continued on next page)

** The meeting will be conducted in English.*

***To accommodate those with chemical sensitivities, we ask that you kindly refrain from wearing perfume/cologne or other scented products*

Appendix K – Agenda for Stakeholder Priority Setting Event**Making an Impact for People with Disabilities and their Families:
Prioritizing Stakeholder Needs from the 2016 Environmental Scan****A Knowledge Exchange Forum on Neurodevelopmental Conditions in Canada****Meeting Agenda****Wednesday January 18, 2016**

Location: Grouse Room, Top Floor

8:00 – 8:30	Registration and breakfast	
8:30 – 8:50	<ul style="list-style-type: none"> Housekeeping Welcome remarks, meeting objectives, quick round of introductions around the room Introduction of Tom Philpott 	Facilitator: David Phipps
8:50 – 8:55	Explain structure of the day	Anneliese Poetz
8:55 – 9:00	Overview of KBHN, where we are, where we're going	Tom Philpott
9:00 – 9:30	Presentation: KBHN 2016 Environmental Scan i) Process – David Phipps (10 minutes) ii) Results – Anneliese Poetz (10 minutes) iii) Q & A (10 minutes)	David Phipps & Anneliese Poetz
9:30 – 10:00	Dotmocracy – individual participants place dots on themes/focus areas on laminated place cards on the tables around the room (a room map will be provided as a handout to let participants know which focus areas are at which table)	All (Anneliese Poetz & Stacie Ross will add up the totals as people finish, and during break)
10:00 – 10:20	Break	
10:20 – 10:30	David report to group what the top priorities are and assign one priority topic per table for priorities 1-5. Stacie and Anneliese will create signs for each focus area, to place on each table, depending on what will be prioritized... maybe 5 runaway topics for 5 tables, maybe 6, etc. Let group self-organize around topic they want to discuss.	David Phipps
10:30 – 11:30	Breakout group activity #1: Use templates provided to discuss and detail how exactly to address the need/challenge (that their table is discussing)	David introduce activity
11:30 – 12:30	Large group report back and discussion, clarification of points proposed	All (have audio recorded), Anneliese type on screen, David help clarify points
12:30 – 1:25	Lunch [during lunch, Anneliese and Stacie place new signs for priorities to discuss during next session]	
1:25 – 1:30	David: same as Breakout group activity #1 but for priorities 5-10	David Phipps
1:30 – 2:30	Breakout group activity #2: Use templates provided to discuss and detail how exactly to address the need/challenge (that their table is discussing)	David introduce activity
2:30 – 3:30	Large group report back and discussion, clarification of points proposed	All (have audio recorded) Anneliese type on screen, David help clarify points
3:30 – 3:50	Break	
4:00 – 4:25	Evaluations (ask to fill out) & wrap-up/summary of day	David Phipps
4:25 – 4:30	Thank you and closing remarks	Bethany Becker

Appendix L – Top 10 Priorities with Detail from Stakeholder Consultation, January 18, 2017

Making an Impact for People with Disabilities and their Families: Prioritizing Stakeholder Needs from the 2016 Environmental Scan

A Knowledge Exchange Forum on Neurodevelopmental Conditions in Canada

Hyatt Regency Vancouver, 655 Burrard Street, Vancouver, BC
604.683.1234
Wednesday, January 18, 2017

Detail on top 10 priorities from breakout sessions and report back

Priority #1

Theme: Treatment

Focus area: 8

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. Need information on what evidence-based treatment is, and what is gold standard. Parents need help figuring out what's important to prioritize, can't do everything. (39 votes, Afternoon Table 5)

(continued on next page)

Appendix L – Top 10 Priorities with Detail from Stakeholder Consultation, January 18, 2017

With respect to the priority being discussed at your table, what are the important elements that should be included?

1. How can we begin to address this priority in an effective manner?

a) What should we be trying to accomplish?

- We need to have a list of a range of therapies both evidence based and not
- Need to have education for parents regarding quality of evidence
- Parents spend time and money
- Parents don't necessarily know how to evaluate research
- National standards report on autism should be more widely read—it is accessible. 93-page report—it's what we do here in the absence of Canadian guideline – National Autism Center.org
- ASA Association for Autism Treatment
- Assumption parents should do this work—why isn't government informing the public about evidence based interventions that are available
- Educate the parents
- How many GPs and pediatricians know what a parent should do, where a parent should go to look, where they'd find information? GPs should have those resources at hand and be able to point to a menu of the resources that are available, that are evidence based
- Determine where this menu should live, what should be in there
- RASP (Registered Autism Service Provider) list, which is a list of service providers who have been vetted in some way by the government to provide services (as an example)
- Access the funding that comes with an ASD diagnosis in BC
- ACT (Autism Community Training)
- Break down silos, everyone can come to one place for information
- Accredited site with best standard information (e.g. national standards report)

b) If we do that, what would be the desired outcomes?

- Clear, concise information that's reliable
- Core of specialists mandated to maintain hub of information with content geared to provider/practitioner/clinician as well as parent level – people
- Improved information sharing among practitioners
- A place that's accessible
- Information is available geared towards a variety of levels of knowledge and cultures
- A standard approach to assessment and treatment across the country and across specialties would be facilitated
- Funding to support provision of this information
- Ongoing review of the information; things that are no longer valid will not be covered or facilitated, decisions informed by new research evidence, panel of experts, persons with lived experience etc., because nothing is static, need a way to evaluate research that is upcoming/constantly being produced
- Families don't experience the same degree of delay and stress in identifying treatment options
- People treated more quickly and effectively may not require treatment for as long—less burden financially, emotional and psychologically on the individual, the family, the system and taxpayers; may not require that treatment as intensely or for as long of a period, so in the long run will save money, emotion and trauma

(continued on next page)

Appendix L – Top 10 Priorities with Detail from Stakeholder Consultation, January 18, 2017**2. What would be some barriers and enablers of the approach above?****a) Barriers**

- Right now it's no one's mandate to do this
- Lack of security of portal—data confidentiality
- Lack of funding—at federal and provincial levels lack of information about evidence base
- There is a risk one more place to go, one more person you have to talk to and tell your story to
- Keeping up to date—curation—as well as the person and organization that's the interface
- Sifting through the masses of information is daunting and time consuming
- There is no one answer to a person's disability, so a wide range of evidence-based information is necessary even for one individual. This exemplifies the complexity of doing this well for many populations.

b) Enablers

- Transparency
- ASAT (the *Association for Science in Autism Treatment*) and the ASN (*Autism Support Network BC*) are organizations that should be considered as potential “enablers”
- Child Youth Services Network used to have people who could encourage – point to something that “fits” the individual. An equivalent kind of person would be helpful in reviewing the evidence and information about the child, and making recommendations¹⁸
- Having a person facilitate this decreases the gap between information and effective action
- Standards of practice promote research (increases capacity)

3. Who should be consulted/involved in the process?

- Researchers, parents need to be consulted, clinician/provider expertise within a field is essential.
- CASEL (Collaborative for Academic, Social and Emotional Learning)—database of evidence based and lesser evidence levels, interventions for social/emotional learning—they have an evolved and articulated assessment process, as does the CP Alliance in Australia, for CP-specific therapies
- Technical expertise is needed for maintaining the resource and developing a user-friendly interface
- Community-based organizations¹⁹ with expertise supporting learning on science based treatment for neurodevelopmental conditions
- Expert system navigators have important insights to offer. People with life/lived experience who can provide insights to parents or agency's outside people coming in, what it's like to have to navigate these systems

4. As we go through this process, how can we engage these stakeholders (that you have identified above in #3)?

- Have all the groups come together to identify what they're doing and the gaps that exist unclear under whose auspices this would occur

¹⁸ there used to be a government-funded position within the Ministry of Children and Family Development, and this person really played an interface role within the families. If a family had a diagnosis of autism, they'd meet with this person and that person would not only share with them the services that are available, but also would explain to them what the services were about, and how good of a fit they might be for their present situation. That position no longer exists (due to funding).

¹⁹ (i) any community organization that can assist with expertise from lived experience, to make this expertise accessible. (ii) parent network support system, someone to talk to (iii) Autism support network does monthly education presentations, (iv) it's also an important resource for clinicians; in rural and remote areas, you don't see a lot of children with a variety of different conditions, so they need to have a place to go and access what's best practice for each condition where somebody else has done the legwork in looking up the best evidence. Clinicians would be important in the creation of this because they would be ultimately the one using it.

Appendix L – Top 10 Priorities with Detail from Stakeholder Consultation, January 18, 2017

Priority #2

Theme: Education

Focus area: 19

Need for (more) professionals working within the school system (e.g. nurses, educational assistants, those delivering interventions such as physical therapy, ABA, etc.) with appropriate training to work with children with neurodevelopmental conditions. (22 votes, Morning Table 4)

With respect to the priority being discussed at your table, what are the important elements that should be included?

1. How can we begin to address this priority in an effective manner?

a) What should we be trying to accomplish?

- Inclusive education environment that addresses individual needs by trained, qualified professionals
- Specific training for the specific needs
- One-stop service spot—transitions are difficult for our children
- Broader understanding of needs / common language
- Opening the doors to those qualified people who can provide the service—territorial issues get in the way
- Where appropriate, specialized programs that specifically address needs—at different levels / age groups—e.g. Alternated Life Skills / Work Skills program at the secondary level

b) If we do that, what would be the desired outcomes?

- More success for people with disabilities in the educational environment
- Specific IEP goals based on the specific needs of the child
- Matched professionals to specific needs

(continued on next page)

Appendix L – Top 10 Priorities with Detail from Stakeholder Consultation, January 18, 2017**2. What would be some barriers and enablers of the approach above?****a) Barriers**

- Too many children in classrooms / too many varied needs
- ‘Specialists’ in schools with the specific training that’s needed (currently schools say “no” to allowing in trained professionals who are external to the school system)
- Territorial issues with schools / unions
- Intimidated by system bureaucracies—unions, bumping
- Funding structures—inside / outside professionals
- Two-tiered system for those who can pay
- Limited resources
- Lack of creative ways to solve ‘problems’ / being restricted by our ‘boxes’
- Filling capacity

b) Enablers

- Keeping qualified people with our children throughout their school years
- Openness to working together
- EA qualifications that match the needs
- Valuing EAs as member of the team—not trained, not recognized for their input, not remunerated
- Capacity-building
- Centres of Excellence

3. Who should be consulted/involved in the process?

- Parents
- Students where they can
- Professionals
- Health professionals beyond the school system
- Ministry of Education / School Boards / Unions

4. As we go through this process, how can we engage these stakeholders (that you have identified above in #3)?

- Goal-focussed discussion / planning instead of just system discussion

Priority #3

Theme: Broader System & Society

Focus area: 44

Need for more equity in funding for different neurodevelopmental conditions. In some cases, CP supports/services seem to be well-funded, ASD is also well-funded but FASD remains under-serviced/under-funded in comparison. (17 votes, Afternoon Table 1)

With respect to the priority being discussed at your table, what are the important elements that should be included?

1. How can we begin to address this priority in an effective manner?

a) What should we be trying to accomplish?

Equity in Funding for different neurodevelopmental conditions:

- Access to treatment and services as needed, regardless of the diagnosis
- Clear definition of what functioning means in order to determine funding levels
- We are comparing apples to oranges. There is the illusion that ASD families have a lot
- ASD families do not get access to some services because they have ASD funding such as mental health, Speech Language Pathologist (SLP)
- Basing funding on what someone else is getting is not equitable
- Equal access for all cultural backgrounds

b) If we do that, what would be the desired outcomes?

- Definition of functioning including the whole child. Different kinds of supports need to be addressed. Including emotional as well as medical aspects
- Examination of using Int'l Classification of Functioning, Disability and Health as a measure to define functionality
- Increased funding for CP
- Evaluate criteria for accessing At Home Program funding
- Not competing for funding based on what someone else gets

(continued on next page)

Appendix L – Top 10 Priorities with Detail from Stakeholder Consultation, January 18, 2017**2. What would be some barriers and enablers of the approach above?****a) Barriers**

- Policy. What's in place right now is not working for any diagnosis
- Lack of flexibility within policies
- Parents also dealing with their own diagnosis of FASD
- Service discrepancy between children in foster care and children in their homes. Barriers to being adopted
- General exhaustion of parents
- Producing research takes a very long time
- Intervention research is very underfunded for FASD
- Huge gap in evidence based intervention research for FASD
- Federal funding funneled into bureaucracy instead of transferred to the provinces for health care (for example, new structure proposed by MP Mike Lake for \$19 million)
- Fear of Ministry of Children and Family Development (MCFD) in BC

b) Enablers

- Parent support groups
- Coalitions that represent various disability groups
- Existing funding is an enabler—we want to build on it
- Kids Brain Health Network (can fight for more funding)
- Ongoing research for evidence-based practice for FASD. There is some longitudinal research with recommendations. More intervention research needed

3. Who should be consulted/involved in the process?

- Parents, families. Especially in policy meetings. Have parents at the table with policy makers when decisions are being made
- Researchers
- Kids Brain Health Network to focus on community-based interventions
- Aboriginal communities involved in policy making
- CanFASD
- Inclusion BC (for example)

4. As we go through this process, how can we engage these stakeholders (that you have identified above in #3)?

- Parents, engage with your MP, MPP and/or MLA
- Go to the opposition critic
- Media—there is more awareness and interest, in general
- CanFASD has established a family advisory. Ask research networks to construct an entity within their organization to consult with families
- Researchers have ethics guidelines. Policymakers do not have the same guidelines. Friends of Medicare is a group that demands to be at the table around health policy
- Mandatory engagement of families before policy gets rubber stamped

Priority #4

Theme: Diagnosis

Focus area: 4

Need reduction or removal of barriers to obtaining diagnosis such as: limited training for frontline health care (GPs); access to skilled diagnostic professionals, waiting lists, financial (out-of-pocket costs) for private diagnostic assessment, geography including rural/remote locations. (16 votes, Morning Table 3)

With respect to the priority being discussed at your table, what are the important elements that should be included?

1. How can we begin to address this priority in an effective manner?

a) What should we be trying to accomplish?

Timely diagnosis and early identification:

- American Pediatric Society using mandatory screening to catch these conditions early. Can we do this in Canada with GPs and nurse practitioners (NPs) in more rural areas. Maybe include nurses and/or paraprofessionals as screeners. Access for parents to use online surveys and broadening capacity of tele-health
- GP perceived as barriers—how can we overcome this by using other professionals (e.g. Public Health Nurses at opportunities like vaccinations to do the screenings etc.)? Currently this is gated by specialist centers only accepting GP referral for in-depth assessments leading to diagnosis
- Needs a system of triaging the waitlist so that services can be implemented as needed prior to obtaining a diagnosis
- Specialist centres for diagnosis like FASD and ASD are centralised and limited, and those travelling are not compensated for travel expenses to getting this diagnosis. Look at broadening tele-health to all remote areas in BC (and elsewhere)
- Very vigorous process for assessment to get diagnosis. Streamline the assessment process to what is needed!

b) If we do that, what would be the desired outcomes?

- More children getting services and assessment
- Moving towards early diagnosis assessment of need

(continued on next page)

Appendix L – Top 10 Priorities with Detail from Stakeholder Consultation, January 18, 2017**2. What would be some barriers and enablers of the approach above?****a) Barriers**

- Requires policy change to expand scope of practitioners to be able to access—NPs, nurses and licensed practical nurses (LPNs). Requires a hard look at how things are financed. This is one of the main reasons for wait lists!
- Stigmatization—how to address this globally in Canada. Start with education and promotion, and normalizing disabilities
- Lack of cross-ministry framework on how we will be addressing the health and well-being of all children. There are three different ministries that are informing us on what we need to be doing: the Ministry of Children and Family Development, the Ministry of Health, the Ministry of Education, and possibly other ministries
- Stigmatization of the diagnosis itself for families
- Cultural competencies of practitioners who are dealing with the families

b) Enablers

- Build on cross-ministry collaboration for health and well-being of all. Only have one ministry instead of three, broaden tele-health, and build on using technology as a whole
- Build on current climate of wanting to improve and come up with equity and mobilization of change.
- Increased awareness in general of these issues and desire to want to address these by so many different agencies

3. Who should be consulted/involved in the process?

- Post-secondary institutions
- Government at all levels
- Expert groups with specialists
- Parent groups and people affected by these conditions
- Cultural groups representing Canada's melting pot (everybody)

4. As we go through this process, how can we engage these stakeholders (that you have identified above in #3)?

- Opportunities for families and people affected to engage in services that would best meet their needs. Give them opportunities to talk to government agencies, etc. at every level
- Provincial and Federal Government needs to be aligned and recognise this as a priority
- Outcomes and accountability sharing of results and follow up to all stakeholders needs to be legislated

Appendix L – Top 10 Priorities with Detail from Stakeholder Consultation, January 18, 2017

Priority #5

Theme: Education

Focus area: 15

Need specialized and in-depth mandatory training for teachers, EAs, resource teachers, principal, anyone who interacts with children in schools in terms of approaches for children who have a neurodevelopmental condition. Includes need for knowledge, attitudinal and cultural training for all service providers (e.g. how to work with children/youth/adults with neurodevelopmental conditions, as well as how to work with different cultures, ethnicities and other groups of populations including indigenous communities). (15 votes, Morning Table 2)

With respect to the priority being discussed at your table, what are the important elements that should be included?

1. How can we begin to address this priority in an effective manner?

a) What should we be trying to accomplish?

- Aim high so that there is cross-training across the team- aim for continuity with all team members in knowledge and skills in key areas. Para professionals and professionals in systems, global consistent training at all levels across the school setting including post-secondary.
- All approaches are evidenced based with role clarity (establish and disseminate information on evidence-based practice when it exists)
- Build a culture of safety and inclusion
- Development of school policy
- Evidence based is affirmed with children with ASD
- Need to work with approaches that are based on diagnosis—e.g. a brain-based approach, e.g. FASD-informed
- Helping an individual feel included and emotionally and physically safe—how to train the team to cultivate this
- A deep awareness of the community (school community) of the benefits of inclusion and how it enriches a community

b) If we do that, what would be the desired outcomes?

- People in school system are aware of evidence based practice and this information is disseminated as far and wide and deep in the system as possible- from the janitor to the EA to teachers, etc. wherever and however possible
- Building a community of inclusion—a culture of inclusion—identifying the individual's go-to person
- Thriving school communities
- Less bullying
- When learners are thriving then families are thriving

(continued on next page)

Appendix L – Top 10 Priorities with Detail from Stakeholder Consultation, January 18, 2017**2. What would be some barriers and enablers of the approach above?****a) Barriers**

- Paucity in research evidence in some sectors
- Gap in policy
- Union- teachers have autonomy about their own professional development
- Tensions between educators and para professionals and/or consultants

b) Enablers

- Parent Advisory Committee
- Support agencies such as Provincial Outreach Program for Fetal Alcohol Spectrum Disorder (POPFASD), BC Centre for Ability
- Certification for additional education and training taken
- Professional recognition for additional training—make this important at a higher level of government
- A whole school approach—get buy-in from entire agencies and schools

3. Who should be consulted/involved in the process?

- Government-funded resources such as Provincial Outreach Program for Autism and Related Disorders (POPARD) and POPFASD
- Representation from the Health Authority
- Representation from Cultural group such as First Nation and Immigrants
- Parents
- Peers in education and employment
- The self-advocate, other self-advocate groups that could teach and train
- Advocates for individuals who have complex and myriad needs
- Parent support groups within the school system –meeting at the schools- apart from the current role of PAC- look for administrative buy in
- Engage with PAC groups to be welcoming and including the individuals with additional needs
- Investment and involvement at a school district level that comes down from Ministry of Education
- Developing some demonstration projects with education models

4. As we go through this process, how can we engage these stakeholders (that you have identified above in #3)?

- Community Presentations
- Sending out preliminary research work and passing on ideas
- Find networks to disseminate information about current research and evolving research, and encourage cross-sector contributions
- Develop mentoring networks

Appendix L – Top 10 Priorities with Detail from Stakeholder Consultation, January 18, 2017

Priority #6

Theme: Diagnosis

Focus area: 3

Need (early) diagnosis so that targeted and specific supports can be obtained for what is needed (in schools, getting services/supports, etc.). Non-categorical treatment does not allow matching of treatment to diagnosis for best outcome for the child. (13 votes, Morning Table 1)

With respect to the priority being discussed at your table, what are the important elements that should be included?

1. How can we begin to address this priority in an effective manner?

a) What should we be trying to accomplish?

(additional detail from large group report back is provided in italics)

- Early screening programs for children under two years of age. Consistently informing various professionals about the research. Physicians need to be informed about importance of diagnosis, option to connect with other families. Families to be able to inform themselves about the condition and how best to support their child
- Professionals with experience in working with young children. Expertise, training
- Didn't find people with expertise working with 18 months to two years
- Need expertise in children less than two years of age. Denver model, targeting very young children
- Categorical and non-categorical—people need a diagnosis so that they can get treatment. Funding and diagnosis don't need to go together, but they do
- Specialists need to be able to identify children across a wide range of specialities. Funding needs to be available on the basis of children's needs. If only funding for specific diagnosis, or diagnosed at all
- Diagnosis as early as possible to inform families, **expedite** services based on the child's functional needs
- Titrating: start early, should not require diagnosis to start intervention program. Should still be based on child's needs. What are the suspected concerns

b) If we do that, what would be the desired outcomes?

- Earlier access to the most appropriate, evidence-based service. All the evidence in the research says that children can get the best impact from the funding available if intervention starts early. This also ameliorates family stress
- If a diagnosis is obtained at an early age and clear information and related supports are outlined to the parents at that time, it ameliorates family stress
- Outcome of the individual—better long-term functioning, maximizing and potential—neurological and physical development. Acknowledge neurological and social emotional needs. Individuals with NDD would have better functioning across these issues. Enables hardwiring of prosocial behaviour, more intellectual and physical capacity
- Recognition if child not yet diagnosed, that it remains a priority as lifelong disability. Diagnosis follows the person. If suspected of diagnosis but don't have one still receive services
- If no early diagnosis, then at an age when they can be diagnosed, establish better sense of strengths, child's abilities
- Funding not just for those who meet rigid diagnostic categories

(continued on next page)

Appendix L – Top 10 Priorities with Detail from Stakeholder Consultation, January 18, 2017**2. What would be some barriers and enablers of the approach above?****a) Barriers**

- If child doesn't meet criteria, don't get services. Funding restricted to diagnosis
- Not about 'every child is special'; that's just a label. It shouldn't be a barrier to treatment
- Diagnostic guidelines, functional assessment domains meet requirements for FASD. Can't assess all until seven or eight years of age. Confirmed exposure. If a child has prominent FASD, facial features, severe delay, that's the time when would have early diagnosis. Complexity.
- Developmental milestones mask a condition
- The child diagnosed at 18 months or two years, no functional assessment able to be done. Need to be able to provide for the child
- Important to understand really research signs are difficult to spot for a lot of pediatricians, eye gaze, joint attention
- Invisible disabilities picking up things
- Challenging behaviour is an enabler, a sign, as is lack of speech development
- First indicators were not those behaviours, e.g. when I change him doesn't play peekaboo. Joint attention piece
- Clinician training—pediatricians what to listen for. Barrier children are coming to unnatural environment
- Diagnosis is expensive for families, expensive for families. We do get diagnosis in BC
- Barriers in the way families or in the way children are treated
- Barrier from physician perspective for CP because clinical diagnosis, chromosomal condition search for causation that may never come. Don't use clinical diagnosis
- Fee for service for a medical condition. Don't have that for any other issue. You access your diagnosis. Not always the case for FASD or autism
- Have to have diagnosis with multidisciplinary team
- Delay in diagnosis, means parents are paying for treatment prior to diagnosis
- Don't get a diagnosis of CP—physicians reluctant to give that diagnosis. Global delay, it doesn't affect your funding—as a clinician deciding which interventions I might recommend
- Physiotherapists in community knows it's CP, can't say to the parent cant diagnose
- FASD is diagnosed between age 5 and 8 whereas Autism is diagnosed at a much younger age. Generally we know with 90% certainty that the child has FASD but we cannot give them any support until they are officially diagnosed which limits our ability to give a child early intervention when they have FASD
- Generic level of functioning is not enough, assessment of needs of individual needs and individualized response

b) Enablers

- Commitment to being willing to give a provisional diagnosis as early as possible allow for treatment
- Increased resources to enable training of more diagnosticians across the lifespan

(continued on next page)

Appendix L – Top 10 Priorities with Detail from Stakeholder Consultation, January 18, 2017

3. Who should be consulted/involved in the process?

- Parents should be consulted in this process
- There is a lack of professionals currently to whom families can take their children for assessment. There is a huge training issue
- Federal Ministry of Health to set national standards for diagnosis and treatment²⁰
- Pediatricians, family doctors. We have to have a referral. College of physicians and surgeons
- In BC, involvement from a speech pathologist
- Colleges of Occupational Therapy, Physical Therapy, psychology, multidisciplinary team
- BC Medical Services Plan (MSP) and equivalent provincial systems

4. As we go through this process, how can we engage these stakeholders (that you have identified above in #3)?

- Require federal legislation to mandate professionals across the board requiring scope of practice training
- Reality is the provinces get money and professionals at appropriate level of government or regulatory body.
- Funding should be governed by the Federal government and not the Provincial governments. This would provide a) consistency across provinces, b) equitable funding across provinces since some provinces don't have enough funds available to support the services that are needed
- Make all services "medical" even if mental health or social

²⁰ KBHN is a national organization, would like this to be addressed by the Federal Ministry of Health to set national standards for diagnosis and treatment, we can't rely on individual provinces. Working with the members of various professional colleges to set standards for their professional development so they can't opt out because they're 'too busy'.

Appendix L – Top 10 Priorities with Detail from Stakeholder Consultation, January 18, 2017

Priority #7

Theme: Life Course Perspective

Focus area: 36

Need continuity in services at key times/transition points during the life course, and need assistance filling out required forms for access to resources (including funding programs for adults with disabilities) during transition periods. Find ways to provide continuity in services for those with ongoing medical needs (this is often lost during transition from child to doctors who serve adults). (13 votes, Morning Table 5)

With respect to the priority being discussed at your table, what are the important elements that should be included?

1. How can we begin to address this priority in an effective manner?

a) What should we be trying to accomplish?

- Lobbying government for funding. Make sure existing programs are properly funded and accessible throughout the life course
- Medical coverage for treatment as needed, e.g. psychologist for FASD and behavioural treatment/ABA for autism. This would also encourage professional students to pursue some specialties which are currently not funded (like FASD)
- Be able to show the cost-benefit (“pay now or pay later”) of receiving treatment/services. This issue is financial and quality of life. Cost benefit of early intervention vs the ongoing costs and impact of crisis intervention related to not addressing needs in the first place
- Support provided for parents. Financial and access to services (under Medicare)
- Accessibility to information about what is available
- Look to other countries for successful models, better access to treatment and support (if it exists)
- Continuing access to services through transition times, e.g. “aging out” of programs
- Reduce paperwork and bureaucracy
- Looking at models for housing and building communities around the needs of individuals. Provide assistance with forms and process

b) If we do that, what would be the desired outcomes?

- Access to treatment/services. Continuity of care throughout the lifespan

(continued on next page)

Appendix L – Top 10 Priorities with Detail from Stakeholder Consultation, January 18, 2017

2. What would be some barriers and enablers of the approach above?

a) Barriers

- Families are unable to afford services
- Accessibility of services – you need to be in the know and able to advocate
- Availability of services. Not enough specialists
- Bureaucracy. Paperwork and process around transition times
- Parent burnout. Being overwhelmed
- Public/private partnerships

b) Enablers

- Parental advocacy. Organizations that will help advocate
- Finding good service providers that stay (home therapists/support workers)

3. Who should be consulted/involved in the process?

- Government – federal and provincial
- Special interest groups who have expertise in the field
- Professionals (psychologists, psychiatrists, etc.)
- Educators/teachers/education assistants (EAs), everyone involved in the education process especially in transition stages
- Front line crisis workers (hospitals, police)
- Lawyers/legal help
- Philanthropic/foundations

4. As we go through this process, how can we engage these stakeholders (that you have identified above in #3)?

- Presenting cost/benefit analysis
- Meeting with MP, MLA and/or MPP
- Increasing awareness. Building community to advocate together to make systemic change
- Develop messaging to make health care a priority for neurodevelopmental conditions that require early diagnosis, early intervention and ongoing care
- Psychosocial aspects of health are currently ignored. Develop messaging and advocacy to address this

Appendix L – Top 10 Priorities with Detail from Stakeholder Consultation, January 18, 2017

Priority #8

Theme: Life Course Perspective

Focus area: 37

***Need (good) supportive housing for youth/adults to be able to live as independently as possible (some need more supports than others to maximize independence).
(13 votes, Afternoon Table 2)***

With respect to the priority being discussed at your table, what are the important elements that should be included?

1. How can we begin to address this priority in an effective manner?

a) What should we be trying to accomplish?

- We need to engage stakeholders to be able to provide a range of supported living options for youth and adults with a variety of disabilities
- In order to do this, we need to identify and engage the various stakeholders (Federal, provincial /territorial departments, social services, justice, health) and engage them in planning
- We need to identify the barriers to appropriate housing from the perspective of communities, landlords, etc. and provide education and support programs to encourage their engagement. For example, substance abuse, mental health issues, poor financial management, lack of ability to access a living wage either through employment or Services for Persons with Disabilities
- Continue to provide opportunities for Registered disability plans (RDSP, Disability tax credit)
- Full range of safe and secure, low-barrier housing, individual, group, home share, room and board, shared accommodation, communal living, and in some cases, specialized residential care
- Premature aging is a significant issue for some disabilities like FASD, such as early dementia, auto-immune disorders, so the need for supportive housing increases at an early age
- More support to municipalities for supported housing initiatives
- Life skills programs to assist individuals to develop the skills necessary to maintain their residence and residential support services on site (e.g., free washer and dryers on site, a building manager trained in disabilities, mental health staff support on call)

b) If we do that, what would be the desired outcomes?

- Reduction in homelessness
- Safe secure housing
- Low-barrier housing options
- Access to other services because of stable housing
- Reduction in secondary health issues and resulting cost savings (across the board)

(continued on next page)

Appendix L – Top 10 Priorities with Detail from Stakeholder Consultation, January 18, 2017**2. What would be some barriers and enablers of the approach above?****a) Barriers**

- IQ criteria for service access
- 3 SD (standard deviations) below the mean for adaptive skills is a barrier
- Lack of diagnostic access for adults
- People with disabilities often have difficulty managing their resources
- Financial burden for caregivers who buy houses for their kids
- Lack of appropriate training and service to assist individuals with disabilities to manage their own living space
- Financial barriers (lack of availability, lack of funding for first and last month's rent)

b) Enablers

- Tax incentives for landlords renting to individuals with disabilities and to parents providing rent to their children (regardless of their age)
- Tax credits for parents supporting (financially, providing rent) adult children (with no residential requirement, e.g. not living with them). Currently, you can get a tax credit if your disabled child is living with you but if they're not, you don't get any tax credits for it
- An advocate (ideally for the family, but definitely for the individual) to assist in managing resources
- A legal resource that is disability informed (like a disability rentalsman) who can assist individuals with disabilities to deal with less reputable landlords who capitalize on their vulnerability
- Protection in the Landlord Tenants Act
- An understanding of the need for interdependence for individuals with disabilities that is clearly understood by all stakeholders

3. Who should be consulted/involved in the process?

- Parents and caregivers
- Individuals with disabilities
- Social development, housing, legal community
- Supporting agencies
- Core neighbourhood programs and services
- Food banks
- Landlords and potential landlords
- Community associations
- CLBC (Community Living BC)
- Police
- Health services
- Federal and provincial departments including Health, Housing, Corrections, Social Development, Employment)
- Entrepreneurs (how to best work with persons with neurodevelopmental conditions, having them at the table)

(continued on next page)

Appendix L – Top 10 Priorities with Detail from Stakeholder Consultation, January 18, 2017**4. As we go through this process, how can we engage these stakeholders (that you have identified above in #3)?**

- Invitation to be part of the discussion (many have never been invited)
- Peer-driven /peer-provided training on disabilities for the stakeholders (as they understand more about the disabilities they are more likely to be interested in being engaged)
- Access to and KT of effective models of supportive housing (show them it can work). There are a number of models of supportive housing throughout Canada that we know are very effective, and that save money. Need some research on those and share that information
- Federal Disability Act which requires action on homelessness would help
- Cost benefit analysis on homelessness versus cost of providing supported housing
- Figure out what is in it for them (e.g. landlord tax credit, reduction in crime, less homelessness, options for housing upon release from Criminal Justice Systems)
- Cross sectorial conversations which include the voices of those with the disability (to reduce stigma) and families

Priority #9

Theme: Treatment

Focus area: 9

Need more resources allocated to alleviate financial/resource constraints of the system as well as parents, plus more efficient use of existing resources within programs and larger system to maximize benefit to the child/family. (12 votes, Afternoon Table 3: no participants at this table for discussion).

Priority #10

Theme: Mental Health/Quality of Life

Focus area: 27

Need social skills/behavioural training and strategies for self-regulation of emotions/anxiety for the child with the neurodevelopmental condition. (11 votes, Afternoon Table 4)

With respect to the priority being discussed at your table, what are the important elements that should be included?

1. How can we begin to address this priority in an effective manner?

a) What should we be trying to accomplish?²¹

- To give our children the [teaching] tools they need to be more successful in life
- More hands-on, practical, authentic learning opportunities in different environments to ensure skills can be generalized
- Schools could be trained in implementing these skills
- More specific teaching is needed for some people—a co-ordinated approach between school and home will be more successful
- Consistency across all environments that children encounter is important
- We all have a role to work together. Collaboration is essential—school/home/community
- Identifying individual needs, across environments is critical in creating powerful interventions
- Early identification and intervention is so very important
- More opportunity for community/after-school programs focused on self-regulation [the school building could provide this space]
- Improved quality of life for everyone
- Created framework where post-secondary students could utilize their program volunteer requirements (and knowledge) to these learning opportunities

b) If we do that, what would be the desired outcomes?

- To allow people (with needs) to feel safer in all kinds of environments
- Will be better able to learn if anxiety is alleviated—greater access
- Allow inclusive practices to move forward, greater acceptance in all social settings

(continued on next page)

²¹ This is a conversation that was happening in the background during the breakout session that was recorded: [Discussion of parent role being paramount/case managers/consultants....Each situation might be different. Advocacy is crucial – consensus that needing a key person]

Appendix L – Top 10 Priorities with Detail from Stakeholder Consultation, January 18, 2017**2. What would be some barriers and enablers of the approach above?****a) Barriers**

- People who are not on board
- Lack of knowledge around mental health and co-existence
- Possibly not believing that children can have mental health difficulties
- Not knowing how to proceed
- Lack of funding

b) Enablers

- The redesigned curriculum—the Core Competencies
- Focus on social-emotional learning/self-regulation in the school system
- Growing conversations around mental health in different systems
- Grants/other sources of funding deliberately addressing social skills/self-regulation strategies
- Recognition of the value/practicality of this approach
- School/community space to operate these programs

3. Who should be consulted/involved in the process?

- Students
- Families
- Professionals—for their expertise and feedback
- School educators/Community teams/after-school programs—to facilitate learning

4. As we go through this process, how can we engage these stakeholders (that you have identified above in #3)?

- More public (community) education—mass media
- Presentations/public workshops for everyone working with these children
- Actual opportunities for university students and workers engaging with these children and youth, to have opportunities to take part in this learning (need the programs, the providers and the funding)

Appendix M – Letter received from frontline worker post-stakeholder event

Appendix M – Letter received from frontline worker post-stakeholder event

Hi Anneliese,

Thanks for the opportunity to be part of KBHN. I enjoyed the day.

Final thoughts...

With respect to Evidence-Based practices and the need for solid research to guide parents in their search for interventions, I think it is important to keep in mind that there are many new developments in the health sciences. Unfortunately, as you are well aware, funding is a primary requirement of research and many new/novel interventions are not able to get funded research to support them. Given this, many new approaches may never be recognized and families may never learn of their existence if they are only guided by evidence-based research.

There needs to be a means for parents to learn of interventions which show promise and are on the horizon. It is rarely one intervention which resolves all the issues for a child, but a mix of interventions which creates a combined positive effect.

There were several parents at the meeting who were unable to see the value in anything but evidence based research. If it's something that is effective for individuals, by their own account, but lacks research, does it have value for others who maybe in a similar place?

All the best to you and the team,

[name withheld]

Appendix N – Post-Project Comment from a Parent

Appendix N – Post-Project Comment from a Parent

During the finalization of this report, we had the opportunity to speak with a parent who was not part of this project in any way. She offered the following thoughts with respect to future research needed to inform clinical practice, particularly with respect to diagnosis (relates to Theme 1 – Diagnosis, Focus areas 1, 2, 3 and 4).

“There are a lot of six to 10 year-olds diagnosed in London (Ontario). Doctors in London are reluctant to diagnose autism; they just say, “the child is quirky”, and then the school system says they have to have a diagnosis, and parents don’t know what to do about their child’s behaviours.

Girls on the spectrum between eight and 12 are very hard to diagnose. Doctors think it is just “tweens acting up”. Sometimes when parents already have a child on the spectrum, their sibling presents differently, so doctors think it is anger issues and they don’t think it is autism. There is a huge difference between boys and girls. For girls, doctors usually get a second opinion from a psychologist. Part of it is that girls are complex because they’re better at socially masking the problem, so doctors are hesitant to make the diagnosis without a second opinion.

I think this could be a good area for future research, the difference between girls and boys in terms of how autism presents itself, and how they get diagnosed.”

– Kelly Wilson (parent)

Appendix O – List of Acronyms

Appendix O – List of Acronyms

ABA – Applied Behavioural Analysis
ACT – Autism Community Training
ASA – Association for Autism Treatment
ASAT – the Association for Science in Autism Treatment
ASD – Autism Spectrum Disorders
ASN – Autism Support Network (British Columbia)
CASDA – Canadian Autism Spectrum Disorder Alliance
CASEL – Collaborative for Academic, Social and Emotional Learning
CLBC – Community Living British Columbia
CP – Cerebral Palsy
CYSN - Child Youth Services Network (Canada)
ER – Emergency Room
FASD – Fetal Alcohol Spectrum Disorders
GP – General Practitioner (family physician)
IEP – Individualized Education Program
IBI – Intensive Behavioural Intervention
KBHN – Kids Brain Health Network
LPN – Licensed Practical Nurse
MCFD – Ministry of Children and Family Development (British Columbia)
MLA – Members of the Legislative Assembly
MP – Member of Parliament
MPP – Member of Provincial Parliament
MSP – Medical Services Plan (British Columbia)
NAC – National Autism Center (United States)
NDD – Neurodevelopmental Disabilities
NP – Nurse Practitioner
PI – Principal Investigator
POPARD – Provincial Outreach Program for Autism and Related Disorders
POPFASD – Provincial Outreach Program for Fetal Alcohol Spectrum Disorder
RASP – Registered Autism Service Provider
SLP – Speech Language Pathologist



Kids Brain Health Network (formerly NeuroDevNet) NCE **Knowledge Translation Core**

Identifying and Prioritizing Stakeholder Needs in Neurodevelopmental Conditions in Canada

Stakeholder Engagement Activity Report
Spring 2017 Toronto, Ontario

Prepared by: Anneliese Poetz, David Phipps, Stacie Ross

Dr. Anneliese Poetz

Manager, Knowledge Translation (KT) Core
Kids Brain Health Network (formerly NeuroDevNet)
4700 Keele Street, 201 Kaneff Tower
York University
Toronto, ON M3J 1P3
apoetz@yorku.ca
T: 416.736.2100 (x 44310)

Copyright 2017

This document is shared under a Creative Commons non-commercial, non-derivative license (see: [Attribution-NonCommercial-NoDerivatives 4.0 International](https://creativecommons.org/licenses/by-nc-nd/4.0/)):

Suggested citation:

Poetz, A., D.J. Phipps, S. Ross (2017). *Identifying and Prioritizing Stakeholder Needs in Neurodevelopmental Conditions in Canada: Stakeholder Engagement Activity Report*. Retrieved from Kids Brain Health Network slideshare site: <https://www.slideshare.net/NeuroDevNet/identifying-and-prioritizing-stakeholder-needs-in-neurodevelopmental-conditions-in-canada>