Kids Brain Health Network (formerly NeuroDevNet) NCE **Knowledge Translation Core**
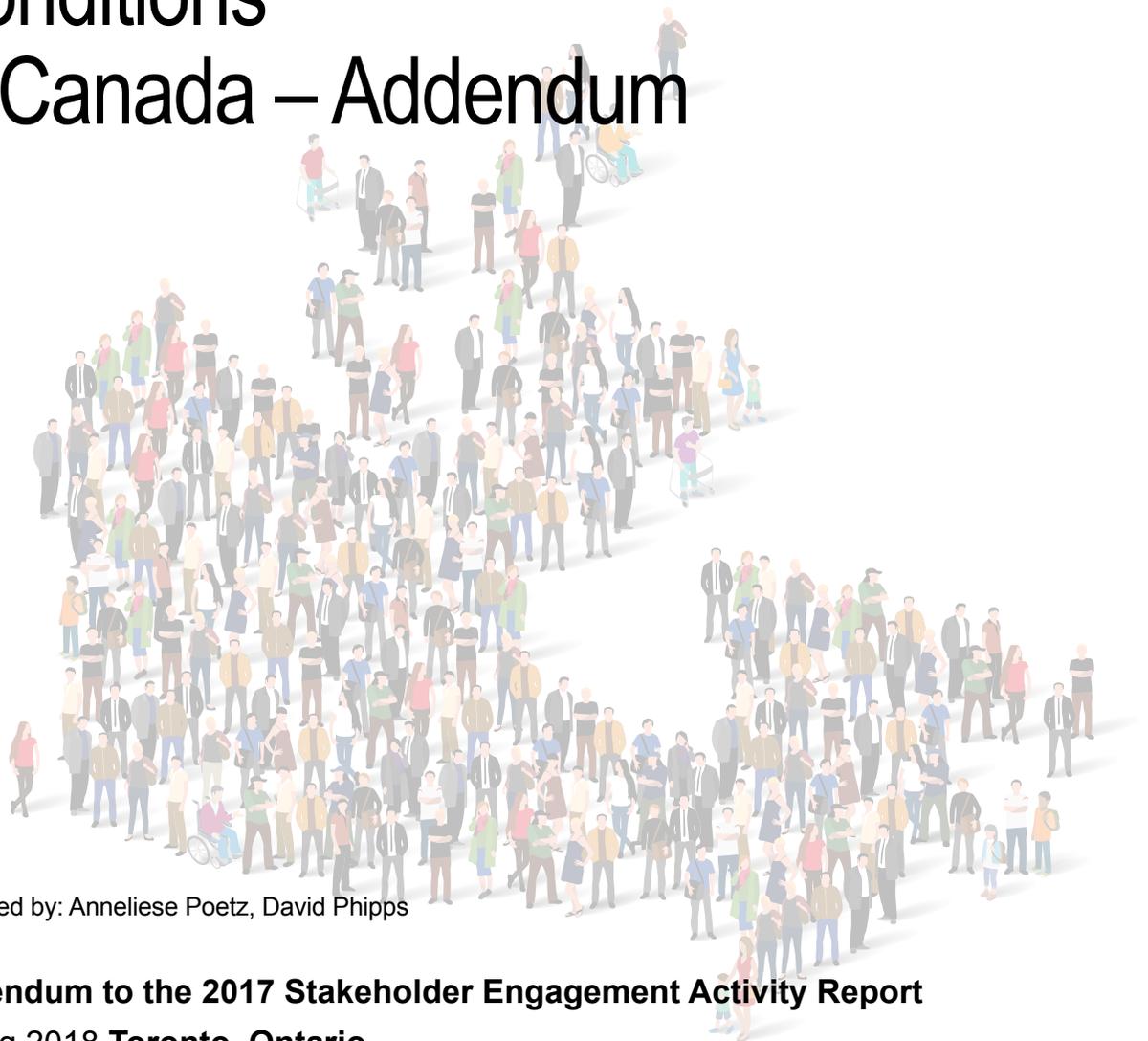
Identifying and Prioritizing Stakeholder Needs in Neurodevelopmental Conditions in Canada – Addendum

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Addendum to the 2017 Stakeholder Engagement Activity Report

Spring 2018 **Toronto, Ontario**

1.1 Reason for this Addendum

The environmental scan report "Identifying and Prioritizing Stakeholder Needs in Neurodevelopmental Conditions in Canada" was published in the Spring of 2017, and included a list of 44 stakeholder-identified needs based on a qualitative study conducted during 2016/17. The 44 needs identified by the qualitative interviews with stakeholders (policymakers, practitioners and parents), were voted on by 25 stakeholders during an in-person meeting held in Vancouver on January 18, 2017. While the regional consultation in Vancouver provided detailed information on how to begin to address the top 10 of these 44 needs[1], the voting exercise with this small local sample did not provide the pan-Canadian perspective necessary to inform KBHN decision-making and strategic planning. Therefore, using a similar format to the in-person consultation voting process[2], we provided diverse stakeholders[3] with the opportunity to vote for their top priorities using an online survey-based adaptation. This addendum provides an update to the previously published Spring 2017 stakeholder needs report by documenting the findings from our national online stakeholder prioritization survey (see the List of Appendices for summary data tables, surveys, and full data tables).

1.2 Data Collection & Analysis

The 44 stakeholder-identified needs were placed into an online survey format (see Appendices B, C, D) using REDCap software because it is the software available through KBHN. Ethics approval was obtained on April 28, 2017 through York University and participants were recruited to fill out the anonymous online survey through KBHN's website and social media channels, as well as targeted email outreach to organizations across Canada until the survey was closed on October 31, 2017. Initially, two versions of the survey were distributed: the originally worded English list of 44 needs and the French translation of it. We worked with a community organization to produce a plain language version of the survey, at the request of a few organizations.

The final survey data were downloaded from REDCap into an excel file on November 2, 2017. The total number of responses received was n=688 (545 original English survey, 9 French survey, 134 plain language English survey). After cleaning the data there were 656 analyzable responses (see Table 1). Table 1 illustrates how the data regarding stakeholder type, as identified by survey respondents, were categorized before analysis.

1.3 Results & Conclusion

The results of the online prioritization survey are described in summary tables[4] in Appendix A. These tables provide self-explanatory highlights of the findings in multiple ways. Table 1.3.1 contains an overall summary of results and top 10 priorities among all survey respondents, Table 1.3.2 represents high and low priorities that are similar across all stakeholder types, Table 1.3.3 shows the top 10 and bottom 10 priorities for each of ASD, FASD, CP and 1.3.4 the top 10 and bottom 10 priorities by stakeholder type. Dividing the data by stakeholder type enables comparison within and across priorities, providing insight such as differences between researcher's priorities and those of parents and/or practitioners.

Kids Brain Health Network is unique in terms of its combined focus on all three neurodevelopmental conditions: CP, FASD and ASD. While the primary reason for conducting this pan-Canadian survey was to obtain information to inform KBHN decision-making, other Canadian organizations and governments may also find the findings useful in their own contexts. Acknowledging that certain external organizations may focus their mandate(s) on only one, perhaps two neurodevelopmental conditions, we also separated the data into priorities for those affected by CP, FASD and/or ASD. Finally, due to regional differences in Canada among provinces and territories in terms of policies, resource allocation, programs, and service delivery, the data are separated by geography. It was not feasible to create a summary table for geography, however, because of small numbers (less than 10 responses) in some regions.

The full set of results provided in Appendices: E (results organized by stakeholder group), F (results organized by geographic region), and G (results organized by perspectives of stakeholders affected by either FASD, CP or ASD). These tables provide additional information beyond the summary tables in Appendix A, including the number of total votes for all 44 needs alongside the data split by stakeholder group, geographic region, and

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1 Poetz, Phipps, Ross (2017). Identifying and Prioritizing Stakeholder Needs in Neurodevelopmental Conditions in Canada. Report. 1-118.

2 Each attendee received 14 dot stickers, and were instructed to place either one sticker (vote) on 14 different needs, or all 14 stickers (votes) on one need if they felt strongly about it, or any combination in between.

3 Anyone directly or indirectly affected by the neurodevelopmental conditions: Cerebral Palsy, Fetal Alcohol Spectrum Disorders, Autism Spectrum Disorders.

4 Please consult the full Spring 2017 Environmental Scan report (see: https://www.slideshare.net/NeuroDevNet/identifying-and-prioritizing-stakeholder-needs-in-neurodevelopmental-conditions-in-canada) for full articulation and explanation of the needs, as the summary tables presented in this addendum provide a truncated representation of each need/focus area.

neurodevelopmental condition. The top 10 (shaded blue) and bottom 10 (shaded red) voted needs colour coded for easy side-by-side comparison. For example, it will be easy to see where there is agreement among needs considered to be 'top ten' among different stakeholders, regions, and neurodevelopmental conditions. Similarly, it will be visually easy to see where there is disagreement or, divergence in priorities. The sample size n=656, was not large enough to allow further splitting of the data, such as reporting votes by stakeholder type *and* neurodevelopmental condition, geographic region *and* neurodevelopmental condition, or geographic region *and* stakeholder type.

1.3.1 Summary of online survey findings[5]

The first summary table (Table 2) contains the overall voted top 10 needs (n=656). The six shaded rows represent those needs which are within the mandate of Kids Brain Health Network to address. The #1 priority has over 500 votes, priorities #2 and #3 can be grouped together since they have between 400-500 votes, and priorities #4, #5, #6 have between 300-400 votes each. These top 6 needs include:

1) specialized in-depth training for educators (533 votes)

2) reduction/removal of barriers to diagnosis (446 votes)

3) more professionals working in the school system such as occupational therapists, physical therapists, speech language therapists, etc. (410 votes)

4) non-categorical treatment for functional deficits (368 votes)

5) early diagnosis for targeted supports (364 votes)

6) more (efficient use of) resources (348 votes)

Areas of convergence, or, where stakeholder priorities appeared aligned (either voted within the top 10 or within the bottom 10) across neurodevelopmental conditions and stakeholder types were identified, as well as areas of divergence where the votes were most dissimilar. For any given need or challenge, it is important to be able to identify the stakeholders who feel this is most important to address, even if their priorities do not necessarily align with other stakeholders. This is because it helps KBHN and/or others who wish to address these needs through further in-depth stakeholder engagement toward creating solutions, to be able to identify the different target audiences to include. Areas of divergence can illuminate differences in priorities between neurodevelopmental conditions, and stakeholders. For example, the priorities of researchers may be different than the priorities of parents. A good strategy toward achieving impact can include first, the identification of the top needs overall, which of these are within the mandate of the specific organization to address, choosing one (or more) of those needs, and developing a plan. Planning necessarily includes the identification of broad and specific target audiences (also referred to as stakeholders, customers, end users, clients, patients, etc.) for co-creation and collaboration throughout solution-development and broader dissemination after the solution is ready to deploy. Potential partner organizations can be identified after the articulation of target audiences, since partners will likely have pre-existing relationships with end users as either customers (if it is an industry partner) or end-users/clients/patients (such as governments and other organizations responsible for policies and decision-making regarding the availability and quality of products and services; hospitals, schools and other service providers).

An example of how these tables can be used in this way is the following. Choosing the number one overall priority which is within KBHN to address (see Appendix E, need #15), the need for specialized and in-depth training for educators about neurodevelopmental conditions, the relevant stakeholder groups include: parents/self-advocates, professionals within education, allied health care practitioners (psychologists, OT, PT, SLP, etc.), researchers and policymakers. The only stakeholder group for which this does not apply, identified by the absence of blue shading in the table, is health care practitioners (e.g. family physicians, psychiatrists, emergency physicians, etc.). These stakeholder groups should necessarily be included in any projects intended to create solutions for this need. Partners should necessarily be organizations (not individuals), and could include those that employ education professionals (such as schools, school boards, colleges that train new educators), professional associations for occupational therapy, physical therapy, speech-language pathology, and government organizations such as Ministries of Education in each province and territory in Canada. The remaining needs and tables can be used in the same manner for target audience identification (for both integrated knowledge translation and stakeholder engagement, as well as dissemination).

1.3.2 A note on "Prevention"

This 'note on prevention' is added to the addendum to address informal feedback received from a few stakeholders asking about the representation of "prevention" in the Spring 2017 report. These comments advocated for more emphasis on prevention. We heard from one researcher after the report had been published that there needs to be more focus on prevention of CP. Following is an explanation for the way issues relating to prevention are represented (or not) in the report, based on correct procedures for conducting a study using grounded theory methodology.

Grounded theory methodology requires that the findings from the study are *grounded in the data*; in other words, if a finding cannot be supported by the data, it cannot be included. Correct methodology involves interviewing stakeholders being careful not to ask leading questions. Furthermore, the 44 needs articulated in the Spring 2017 report are supported by data which indicated similar need(s) across **all 3** neurodevelopmental conditions (FASD, CP, ASD). The way that Theme 6, Focus Area 25 is characterized (e.g. "Need for broader societal awareness of neurodevelopmental conditions…") in the Spring 2017 report was meant to capture prevention within it, without prevention being the focus. This is the correct characterization because the need for broader awareness was expressed in relation to CP, FASD and ASD with a mention of prevention in relation to FASD only. This doesn't mean that prevention isn't important for CP or ASD, but the data doesn't support it. The questions were written to elicit needs and challenges of stakeholders affected by CP, FASD and/or ASD; if the interview questions had included a specific exploration of prevention there would have been more data to inform the representation of prevention in the findings. However, that was not the purpose of the study. The purpose was to explore the needs and challenges of those currently affected by CP, FASD and/or ASD in relation to quality of life for children/self-advocates and families.

1.4 Recommendations

1.4.1 For Kids Brain Health Network

1. Use the information in this report for internal decision-making including resource allocation.

> **Rationale:** By creating evidence-informed solutions based on the needs identified by policymakers, practitioners and parents, it maximizes the potential for being able to create value for stakeholders which is the path towards achieving impact on policy, practice and quality of life for individuals and families. Impact on policy and practice with the ultimate goal of improving the lives of Canadians living with neurodevelopmental conditions is what Kids Brain Health Network is aiming to achieve. The voting exercise reported in this addendum helps to inform decision-making based on what are the most pressing needs of the 44 identified in the Spring 2017 report.

1.4.2 For Kids Brain Health Network and potential partners

2. Use the information on stakeholder-identified priorities as the basis for initiating and/or maintaining strategic partnerships for co-creation of evidence-informed solutions in a shorter timeline than what would be possible alone.

> **Rationale:** Organizations that have an interest and resources for addressing one or more of the 6 needs that are within the top 10 and within the mandate of Kids Brain Health Network can help KBHN achieve its strategic organizational objectives.

3. Focus on addressing the most highly voted needs first.

> **Rationale:** while it is acknowledged that all 44 needs are important to address, the purpose of this prioritization exercise was to help identify the greatest and most urgent. By working toward addressing the top 6 needs (the shaded needs in Table 4) KBHN can maximize the potential for achieving impact(s) and their magnitude.

1.4.3 For policymakers and other decision-makers

4. Use the information in this report to make decisions on policy revision(s) and resource allocation for improvement of programs and services.

> **Rationale:** the Spring 2017 report represents an evidence-based document that identifies 44 stakeholder needs, while this addendum provides insight into the relative importance of each by stakeholder type, geographic region, and neurodevelopmental condition. These various representations of the prioritization data including the overall results can provide policymakers with insight into where allocation of resources can achieve the greatest value for investment.

5. Consider the system and interrelated sub-system(s) implications that could result from policy, program and practice changes during decision-making.

> **Rationale:** many of the needs (including and beyond those captured within Theme 9 'Broader System & Society') require federal and provincial level changes that will involve creation of new, or revision of existing, policies, programs and/or services. Changes made at Federal, provincial, organizational and program levels constitute various levels of systems and sub-systems that could be involved and/or affected by responsive solutions. By considering the systems and sub-systems that could be affected by decision-making (ideally, by drawing a systems map) this can help Ministries, provinces, organizations, and individuals ensure seamless implementation of solutions that are effective and avoid introducing new challenges throughout interrelated systems and sub-systems.

1.5 Next Steps for Use of This Report

1.5.1 How KBHN has already used the information contained within this report

1.   On Thursday October 5, 2017, Kids Brain Health Network's KT Core presented and handed out printed copies of the Spring 2017 report during an afternoon drop-in event for three Ministries in British Columbia: Ministry of Child and Family Development (MCFD), Ministry of Health, and Ministry of Education. Policymakers commented on the usefulness of the report because i) it contained information on stakeholder-identified needs, and ii) all information (especially the list of government-funded stakeholder-needs reports from across Canada) was consolidated conveniently in one document.

2.   On Saturday October 11, 2017, in Montreal, Quebec, Kids Brain Health Network met with Canadian Network for Child and Youth Rehabilitation (CN-CYR) which is a network of partners and members within the Canadian Association of Paediatric Health Centres (CAPHC) interested in the delivery of child development and rehabilitation services. The purpose of this initial meeting was to review the stakeholder-identified needs in this report (preliminary results since the survey closed on October 31, 2017) and discuss which priorities the two organizations could work together to address.

3.   Kids Brain Health Network is currently in the process of searching for new, and matching current and/or previous partner organizations, that could partner with us toward creating evidence-informed solutions for the top (6) identified and prioritized needs that are within the mandate of Kids Brain Health Network (see needs that have been shaded in Table 4).

1.5.2 Future uses of this addendum include:

1.   Informing decisions regarding funding for KBHN year 9-10 applications for funding in response to the 2017 Request for Applications (RFA).

2.   For strategic planning for KBHN toward maximizing potential impact that can be achieved, and in the most effective and efficient manner.

List of Appendices

Appendix A – Summary Data Tables

Table 1.
Grouping of 'stakeholder type' for data analysis

"Stakeholder Type" reported in findings	Stakeholder type option(s) within the survey	Additional detail (informed by data entered into "other" text box option in survey)
Parent / Self-advocate	Parent of a child with either CP, FASD, ASD; Self-advocate (adult); self-advocate (teenager)	Includes some grandparents, caregivers, sibling, and spouse of person(s) with neurodevelopmental condition(s)
Education	Elementary school teacher; High school teacher; Educational Assistant; Educator (pre-school)	School Principal(s) and superintendent were classified as policymakers as well
Health Practitioner	Family Physician; ER Physician; Psychiatrist; Nurse	Also includes specialization of physicians such as developmental pediatrician, medical student, pediatrician
Allied Health	Psychologist; Occupational Therapist; Physical Therapist; Speech Language Therapist; Social Worker	Includes counselor/therapist, student psychologist, neuropathologist, law enforcement, school (+other) interventionists
Researcher	University-based researcher	
Policymaker	Policymaker	In cases where "policymaker" was unchecked (because this option was added later on in the data collection), responses that included text entered in "other" that suggested hat they were a policymaker such as: managers, supervisors, directors, CEO, department head, government organization; were recoded as "policymaker"
Other	There were 13 responses collected before the addition of the question about whether the person had experience/knowledge of CP, FASD or ASD (an amendment was sought for this change to the survey, through the ethics protocol approved by York University's REB)	While these data were not included in the breakdown of CP, ASD, FASD, they were included in the overall total priorities.

Table 2.
The top 10 overall needs across Canada, as voted on, are the following (in order highest to lowest) with rationale based on KBHN's mandate

Rank	Theme	Need / Focus Area	# total votes	Within KBHN mandate to address (yes / no)	Rationale (KBHN seeks to have impact on policy and practice toward improved QoL for children/families, through partnerships where possible)
1	4. Education	15. Specialized in-depth training for educators	533	**Yes**	Practice improvement for better QoL for child
2	1. Diagnosis	4. Reduction / removal of barriers to diagnosis	446	**Yes**	Policy / practice changes to enable early diagnosis
3	4. Education	19. More professionals working in the school system (OT, PT, etc.)	410	**Yes**	Practice improvement for better QoL for child
4	9. Broader System & Society	44. More equity in funding for NDD	409	No	We can influence policy on this if there is an opportunity but doesn't align with 3 KBHN strategic priorities
5	7. Life Course Perspective	38. Access to lifetime supports for lifelong condition	374	No	This will improve QoL for children/ families over time, we can support policy changes if and when opportunity arises or work with partners for whom it is their mandate to address this
6/7	1. Diagnosis	2. Non-categorical treatment for functional deficits	368	**Yes**	Practice improvement for better QoL for child
6/7	7. Life Course Perspective	37. Good supportive housing for independent living	368	No	Our focus is on children, this need is for adults. We could partner with or inform organizations with a mandate to address this need.
8	1. Diagnosis	3. Early diagnosis for targeted supports	364	**Yes**	Policy / practice changes to enable early diagnosis and targeted treatment(s)
9	2. Treatment	9. More (efficient use of) resources	348	**Yes**	Changes needed to practice/service delivery, enabled by policy changes so existing resources are used most efficiently
10	7. Life Course Perspective	35. Adults need services, nothing for seniors	326	No	KBHN is focused on children, but can partner with other organizations (such as AgeWell NCE) with a mandate to address this need

Table 3.
Areas of Convergence (top 10 'high' priorities)

Theme	Need / Focus Area	ASD (n=502)	FASD (n=330)	CP (n=266)	OTHER (n= 53)
4. Education	15. Mandatory training for teachers, staff	▲	▲	▲	▲
1. Diagnosis	4. Remove barriers to diagnosis	▲	▲	▲	▲
4. Education	19. More professionals in schools	▲	▲	▲	▲
7. Life Course Perspective	37. Supportive housing	▲	▲	▲	▲
1. Diagnosis	3. Early diagnosis to inform treatment	▲	▲	▲	▲

KEY

▲ Top 10
△ Above average
▽ Below average
▼ Bottom 10

Table 4.
Areas of Convergence (bottom 10 'low' priorities)

Theme	Need / Focus Area	ASD (n=502)	FASD (n=330)	CP (n=266)	OTHER (n= 53)
6. Mental Health / Quality of Life	28. Financial control, coordination of services	▼	▼	▼	▽
9. Broader System & Society	43. Respond to experiential knowledge	▼	▼	▼	▼
6. Mental Health / Quality of Life	31. Acknowledge safety issues	▼	▼	▼	▼
8. Culture and Context	41. Respect for regional differences	▼	▼	▼	▼
8. Broader System & Society	39. Culturally specific services	▼	▼	▼	▼

Table 5.
Areas of Divergence (stakeholder needs are the most different among stakeholders affected by different neurodevelopmental conditions)

Theme	Need / Focus Area	ASD (n=502)	FASD (n=330)	CP (n=266)	OTHER (n= 53)
7. Life Course Perspective	35. Services for newly diagnosed adults	▲	△	▽	▽
3. Services	12. Support families as partners in care	△	▽	△	▲
6. Mental Health / Quality of Life	27. Self-regulation strategies	△	▲	△	▽

Autism Spectrum Disorders

Table 6a.
Top 10 needs as identified by stakeholders affected by Autism Spectrum Disorders (ASD)
n=502

Theme	Need / Focus Area	# votes
4. Education	15. Mandatory training for teachers, staff	393
1. Diagnosis	4. Remove barriers to diagnosis	358
4. Education	19. More professionals in schools	334
1. Diagnosis	2. Non-categorical early treatment	315
1. Diagnosis	3. Early diagnosis to inform treatment	281
7. Life Course Perspective	38. Access to care throughout life course	275
9. Broader System & Society	44. Equitable funding for all ND conditions	273
7. Life Course Perspective	37. Supportive housing	273
7. Life Course Perspective	35. Services for newly diagnosed adults	271
2. Treatment	9. Adequate, responsibly used resources	259

Table 6b.
Bottom 10 needs as identified by stakeholders affected by Autism Spectrum Disorders
(ASD) n=502

Theme	Need / Focus Area	# votes
6. Mental Health / Quality of Life	29. Equitable access to recreational prog's	71
4. Education	14. Workarounds to physical, social barriers	66
8. Culture and Context	4. Innovative service delivery options	65
2. Treatment	7. Non-judgmental treatment	58
5. Health Care	21. Support, equipment for complex cases	56
6. Mental Health / Quality of Life	28. Financial control, coordination of services	52
9. Broader System & Society	43. Respond to experiential knowledge	51
8. Culture and Context	41. Respect for regional differences	48
6. Mental Health / Quality of Life	31. Acknowledge safety issues	47
8. Culture and Context	39. Culturally specific services	36

Fetal Alcohol Spectrum Disorders

Table 7a.
Top 10 needs as identified by stakeholders affected by Fetal Alcohol Spectrum Disorders (FASD) n=330

Theme	Need / Focus Area	# votes
9. Broader System & Society	44. Equitable funding for all ND conditions	345
4. Education	15. Mandatory training for teachers, staff	265
1. Diagnosis	4. Remove barriers to diagnosis	229
1. Diagnosis	2. Non-categorical early treatment	222
4. Education	19. More professionals in schools	189
7. Life Course Perspective	37. Supportive housing	180
1. Diagnosis	3. Early diagnosis to inform treatment	170
7. Life Course Perspective	38. Access to care throughout life course	170
2. Treatment	9. Adequate, responsibly used resources	156
6. Mental Health / Quality of Life	27. Self-regulation strategies	156

Table 7b.
Bottom 10 needs as identified by stakeholders affected by Fetal Alcohol Spectrum Disorders (FASD) n=330

Theme	Need / Focus Area	# votes
4. Education	17. Fit in with peers	43
6. Mental Health/ Quality of Life	33. Tailored treatments	43
9. Broader System & Society	43. Respond to experiential knowledge	43
2. Treatment	7. Non-judgmental treatment	41
6. Mental Health / Quality of Life	29. Equitable access to recreational programs	40
4. Education	14. Workarounds to physical, social barriers	40
6. Mental Health / Quality of Life	26. Fair treatment of neurotypical siblings	38
6. Mental Health / Quality of Life	31. Acknowledge safety issues	37
8. Culture and Context	39. Culturally specific services	30
8. Culture and Context	41. Respect for regional differences	26

Cerebral Palsy

Table 8a.
Top 10 needs as identified by stakeholders affected by Cerebral Palsy (CP) n=266

Theme	Need / Focus Area	# votes
1. Diagnosis	2. Non-categorical early treatment	209
4. Education	15. Mandatory training for teachers, staff	182
1. Diagnosis	4. Remove barriers to diagnosis	170
9. Broader System & Society	44. Equitable funding for all ND conditions	167
4. Education	19. More professionals in schools	167
2. Treatment	8. Evidence-based treatments	165
3. Services	1. Case managers to support parents	149
2. Treatment	6. Clear communication	136
1. Diagnosis	3. Early diagnosis to inform treatment	134
7. Life Course Perspective	37. Supportive housing	126

Table 8b.
Bottom 10 needs as identified by stakeholders affected by Cerebral Palsy (CP) n=266

Theme	Need / Focus Area	# votes
9. Broader System & Society	43. Respond to experiential knowledge	41
2. Treatment	7. Non-judgmental treatment	41
5. Health Care	23. Coordinated health care support	36
6. Mental Health / Quality of Life	33. Tailored treatments	34
6. Mental Health / Quality of Life	26. Fair treatment of neurotypical siblings	34
4. Education	16. Implement IEPs, children as self-advocates	32
8. Culture and Context	41. Respect for regional differences	31
6. Mental Health / Quality of Life	31. Acknowledge safety issues	23
6. Mental Health / Quality of Life	28. Financial control, coordination of services	20
8. Culture and Context	39. Culturally specific services	19

Other disabilities

Table 9a.
Top 10 needs identified by stakeholders affected by disabilities but not identifying within the categories of either CP, FASD, ASD n=53

Theme	Need / Focus Area	# votes
4. Education	15. Mandatory training for teachers, staff	49
2. Treatment	9. Adequate, responsibly used resources	38
4. Education	19. More professionals in schools	35
1. Diagnosis	4. Remove barriers to diagnosis	34
2. Treatment	8. Evidence-based treatments	33
7. Life Course Perspective	38. Access to care throughout life course	33
1. Diagnosis	3. Early diagnosis to inform treatment	32
3. Services	12. Support families as partners in care	31
6. Mental Health / Quality of Life	24. Support for parents' mental health	27
7. Life Course Perspective	37. Supportive housing	25

Table 9b.
Bottom 10 needs identified by stakeholders affected by disabilities but not identifying within the categories of either CP, FASD, ASD n=53

Theme	Need / Focus Area	# votes
9. Broader System & Society	42. Timely access to new knowledge	6
8. Culture and Context	4. Innovative service delivery options	6
4. Education	14. Workarounds to physical, social barriers	6
6. Mental Health / Quality of Life	33. Tailored treatments	6
8. Culture and Context	41. Respect for regional differences	6
6. Mental Health / Quality of Life	32. Address sleep issues	5
4. Education	17. Fit in with peers	5
9. Broader System & Society	43. Respond to experiential knowledge	5
8. Culture and Context	39. Culturally specific services	4
5. Health Care	21. Support, equipment for complex cases	3
6. Mental Health / Quality of Life	31. Acknowledge safety issues	3

Parents and self-advocates

Table 10a.
Top 10 needs as identified by parents and self-advocates affected by any neurodevelopmental condition(s) n=320

Theme	Need / Focus Area	# votes
4. Education	15. Mandatory training for teachers, staff	308
3. Services	12. Support families as partners in care	240
7. Life Course Perspective	38. Access to care throughout life course	231
1. Diagnosis	4. Remove barriers to diagnosis	205
7. Life Course Perspective	35. Services for newly diagnosed adults	203
7. Life Course Perspective	37. Supportive housing	193
2. Treatment	9. Adequate, responsibly used resources	181
9. Broader System & Society	44. Equitable funding for all ND conditions	175
4. Education	19. More professionals in schools	169
1. Diagnosis	3. Early diagnosis to inform treatment	162

Table 10b.
Bottom 10 needs as identified by parents and self-advocates affected by any neurodevelopmental condition(s) n=320

Theme	Need / Focus Area	# votes
2. Treatment	7. Non-judgmental treatment	44
6. Mental Health / Quality of Life	28. Financial control, coordination of services	42
9. Broader System & Society	43. Respond to experiential knowledge	35
6. Mental Health / Quality of Life	31. Acknowledge safety issues	34
9. Broader System & society	42. Timely access to new knowledge	32
6. Mental Health / Quality of Life	33. Tailored treatments	32
5. Health Care	21. Support, equipment for complex cases	23
8. Culture and Context	41. Respect for regional differences	21
8. Culture and Context	4. Innovative service delivery options	20
8. Culture and Context	39. Culturally specific services	13

Education

Table 11a.
Top 10 needs as identified by stakeholders in education affected by any neurodevelopmental condition(s) n=48

Theme	Need / Focus Area	# votes
4. Education	15. Mandatory training for teachers, staff	53
4. Education	19. More professionals in schools	35
6. Mental Health / Quality of Life	27. Self-regulation strategies	35
1. Diagnosis	4. Remove barriers to diagnosis	31
1. Diagnosis	3. Early diagnosis to inform treatment	31
2. Treatment	9. Adequate, responsibly used resources	27
3. Services	11. Consistency in face of high staff turnover	27
9. Broader System & Society	44. Equitable funding for all ND conditions	23
2. Treatment	8. Evidence-based treatments	22
7. Life Course Perspective	37. Supportive housing	21
6. Mental Health / Quality of Life	24. Support for parents' mental health	21

Table 11b.
Bottom 10 needs as identified by stakeholders in education affected by any neurodevelopmental condition(s) n=48

Theme	Need / Focus Area	# votes
5. Health Care	2. Specialized training for frontline clinicians	5
6. Mental Health / Quality of Life	32. Address sleep issues	5
6. Mental Health / Quality of Life	29. Equitable access to recreational programs	5
6. Mental Health / Quality of Life	28. Financial control, coordination of services	5
6. Mental Health / Quality of Life	31. Acknowledge safety issues	5
4. Education	14. Workarounds to physical, social barriers	4
8. Culture and Context	41. Respect for regional differences	4
9. Broader System & Society	43. Respond to experiential knowledge	3
5. Health Care	21. Support, equipment for complex cases	1
8. Culture and Context	4. Innovative service delivery options	1
8. Culture and Context	39. Culturally specific services	1
6. Mental Health / Quality of Life	33. Tailored treatments	0

Health care practitioners

Table 12a.
Top 10 needs as identified by health care practitioners affected by any neurodevelopmental condition(s) n=44

Theme	Need / Focus Area	# votes
1. Diagnosis	4. Remove barriers to diagnosis	41
7. Life Course Perspective	37. Supportive housing	39
1. Diagnosis	2. Non-categorical early treatment	38
1. Diagnosis	3. Early diagnosis to inform treatment	37
1. Diagnosis	1. Specialized training for health care professionals	34
4. Education	19. More professionals in schools	29
7. Life Course Perspective	35. Services for newly diagnosed adults	27
5. Health Care	2. Specialized training for frontline clinicians	25
2. Treatment	5. Timely access to treatment	22
2. Treatment	9. Adequate, responsibly used resources	19

Table 12b.
Bottom 10 needs as identified by health care practitioners affected by any neurodevelopmental condition(s) n=44

Theme	Need / Focus Area	# votes
4. Education	16. Implement IEPs, children as self-advocates	6
9. Broader System & Society	42. Timely access to new knowledge	6
6. Mental Health / Quality of Life	32. Address sleep issues	6
4. Education	14. Workarounds to physical, social barriers	6
6. Mental Health / Quality of Life	31. Acknowledge safety issues	5
3. Services	11. Consistency in face of high staff turnover	4
4. Education	17. Fit in with peers	4
6. Mental Health / Quality of Life	26. Fair treatment of neurotypical siblings	4
6. Mental Health / Quality of Life	29. Equitable access to recreational prog's	4
8. Culture and Context	39. Culturally specific services	4
6. Mental Health / Quality of Life	33. Tailored treatments	4
6. Mental Health / Quality of Life	28. Financial control, coordination of services	3
8. Culture and Context	41. Respect for regional differences	2

Allied health care practitioners

Table 13a.
Top 10 needs as identified by allied health care practitioners affected by any neurodevelopmental condition(s) n=210

Theme	Need / Focus Area	# votes
9. Broader System & Society	44. Equitable funding for all ND conditions	186
1. Diagnosis	4. Remove barriers to diagnosis	151
4. Education	19. More professionals in schools	148
4. Education	15. Mandatory training for teachers, staff	135
1. Diagnosis	2. Non-categorical early treatment	132
2. Treatment	8. Evidence-based treatments	129
7. Life Course Perspective	38. Access to care throughout life course	120
2. Treatment	6. Clear communication	109
1. Diagnosis	3. Early diagnosis to inform treatment	107
3. Services	1. Case managers to support parents	106

Table 13b.
Bottom 10 needs as identified by allied health care practitioners affected by any neurodevelopmental condition(s) n=210

Theme	Need / Focus Area	# votes
4. Education	17. Fit in with peers	28
3. Services	12. Support families as partners in care	27
4. Education	14. Workarounds to physical, social barriers	27
6. Mental Health / Quality of Life	26. Fair treatment of neurotypical siblings	27
5. Health Care	23. Coordinated health care support	26
9. Broader System & Society	43. Respond to experiential knowledge	26
6. Mental Health / Quality of Life	28. Financial control, coordination of services	24
8. Culture and Context	39. Culturally specific services	17
6. Mental Health / Quality of Life	31. Acknowledge safety issues	14
8. Culture and Context	41. Respect for regional differences	13

Researchers

Table 14a.
Top 10 needs as identified by researchers affected by any neurodevelopmental condition(s) n=25

Theme	Need / Focus Area	# votes
1. Diagnosis	2. Non-categorical early treatment	28
1. Diagnosis	4. Remove barriers to diagnosis	17
2. Treatment	8. Evidence-based treatments	16
6. Mental Health / Quality of Life	24. Support for parents' mental health	16
4. Education	15. Mandatory training for teachers, staff	15
7. Life Course Perspective	37. Supportive housing	15
3. Services	10. Case managers to support parents	14
5. Health Care	22. Timely access to mental health supports	13
9. Broader System & Society	44. Equitable funding for all ND conditions	12
2. Treatment	6. Clear communication	12
1. Diagnosis	3. Early diagnosis to inform treatment	12
5. Health Care	2. Specialized training for frontline clinicians	12

Table 14b.
Bottom 10 needs as identified by researchers affected by any neurodevelopmental condition(s) n=25

Theme	Need / Focus Area	# votes
9. Broader System & Society	42. Timely access to new knowledge	2
7. Life Course Perspective	34. Meaningful employment	2
4. Education	16. Implement IEPs, children as self-advocates	2
6. Mental Health / Quality of Life	26. Fair treatment of neurotypical siblings	2
9. Broader System & Society	43. Respond to experiential knowledge	2
8. Culture and Context	41. Respect for regional differences	2
6. Mental Health / Quality of Life	33. Tailored treatments	1
8. Culture and Context	4. Innovative service delivery options	1
4. Education	17. Fit in with peers	1
6. Mental Health / Quality of Life	28. Financial control, coordination of services	1
6. Mental Health / Quality of Life	31. Acknowledge safety issues	1

Policymakers

Table 15a.
Top 10 needs as identified by policymakers affected by any neurodevelopmental condition(s) n=29

Theme	Need / Focus Area	# votes
1. Diagnosis	3. Early diagnosis to inform treatment	21
6. Mental Health / Quality of Life	27. Self-regulation strategies	20
1. Diagnosis	4. Remove barriers to diagnosis	19
2. Treatment	9. Adequate, responsibly used resources	19
4. Education	15. Mandatory training for teachers, staff	18
7. Life Course Perspective	37. Supportive housing	18
2. Treatment	8. Evidence-based treatments	17
7. Life Course Perspective	35. Services for newly diagnosed adults	17
5. Health Care	22. Timely access to mental health supports	16
2. Treatment	6. Clear communication	16

Table 15b.
Bottom10 needs as identified by policymakers affected by any neurodevelopmental condition(s) n=29

Theme	Need / Focus Area	# votes
4. Education	18. Respect parents' concerns	4
9. Broader System & Society	42. Timely access to new knowledge	4
4. Education	17. Fit in with peers	4
6. Mental Health / Quality of Life	28. Financial control, coordination of services	4
6. Mental Health / Quality of Life	32. Address sleep issues	3
5. Health Care	21. Support, equipment for complex cases	3
4. Education	16. Implement IEPs, children as self-advocates	3
8. Culture and Context	41. Respect for regional differences	3
4. Education	14. Workarounds to physical, social barriers	2
6. Mental Health / Quality of Life	26. Fair treatment of neurotypical siblings	2
6. Mental Health / Quality of Life	29. Equitable access to recreational programs	1
5. Health Care	23. Coordinated health care support	1

Appendix B – The online survey (English original)

Prioritizing Needs for CP, FASD, ASD in Canada

Informed consent form

Date:

April 26, 2017

Study name:

Kids Brain Health Network (KBHN, formerly NeuroDevNet) Environmental Scan 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, dphipps@yorku.ca

Purpose of the Research:

Kids Brain Health Network (formerly NeuroDevNet) wishes to conduct an environmental scan 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, 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 an online survey to help us prioritize the 44 stakeholder needs that we identified in the first phase of this project (qualitative interviews).

Risks and Discomforts:

We do not foresee any additional risks or discomfort from your participation in the research as your responses will be anonymous. There are two questions asking you to identify 1) your province or territory of residence, and 2) your category of occupation. This information is necessary to help us make sure we have a representative sample regionally as well as occupationally.

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 survey you will be helping KBHN to make resource allocation decisions for future research and knowledge translation activities, based on your insights, experience and knowledge. This will in turn help KBHN to maximize the potential usefulness (and impact) of the projects 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 at any time, for any reason, if you so decide, by not completing the survey. 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. Since the data are anonymous, it will not be possible to withdraw your data after submitting your answers.

Confidentiality:

The researcher(s) acknowledge that the host of the online survey (e.g., REDCap) may automatically collect

participant data without their knowledge (i.e., IP addresses.) Although this information may be provided or made accessible to the researchers, it will not be used or saved without participant's consent on the researchers system. Further, "Because this project employs e-based collection techniques, data may be subject to access by third parties as a result of various security legislation now in place in many countries and thus the confidentiality and privacy of data cannot be guaranteed during web-based transmission. The data will be housed in Canada. Only research staff and KBHN Headquarters personnel will have access to this information. The data will be stored for 4 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 (dphipps@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 consent to participate in Kids Brain Health Network Environmental Scan 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 participating in this survey. By filling in and submitting the survey I am indicating my consent to participate.

SURVEY BEGINS:

1) Please let us know which region you are located in (so that we can do our best to ensure equal representation across Canada):

- ☐ Alberta
- ☐ British Columbia
- ☐ Manitoba
- ☐ New Brunswick
- ☐ Newfoundland and Labrador
- ☐ Northwest Territories
- ☐ Nova Scotia
- ☐ Nunavut
- ☐ Ontario
- ☐ Prince Edward Island
- ☐ Quebec
- ☐ Saskatchewan
- ☐ Yukon

Please let us know which stakeholder group you represent (check all that apply):

- ☐ Parent of a child with either CP, FASD, ASD
- ☐ Self-advocate (adult)
- ☐ Self-advocate (teenager)
- ☐ Elementary school teacher
- ☐ High school teacher
- ☐ Educational Assistant
- ☐ Early Childhood Educator (pre-school)
- ☐ Family Physician
- ☐ ER Physician
- ☐ Psychiatrist
- ☐ Nurse
- ☐ Psychologist

- ☐ Occupational Therapist
- ☐ Physical Therapist
- ☐ Speech Language Therapist
- ☐ University-based researcher
- ☐ Social worker
- ☐ Frontline worker delivering interventions to children/youth with CP, ASD, FASD
    - ☐ Other (please specify in box below)

  [   ]

- ☐ Policymaker
- ☐ Other (please specify):

  [   ]

3) I work with and/or have experience with (check all that apply):

- ☐ Cerebral Palsy
- ☐ Fetal Alcohol Spectrum Disorders
- ☐ Autism Spectrum Disorders

The following 44 items are "focus areas" representing the needs of persons whose lives have been directly or indirectly affected by Cerebral Palsy, Autism Spectrum Disorders and/or Fetal Alcohol Spectrum Disorders. While all of these needs are important to address, we can't work on all of them so need your help to prioritize what should be worked on first.

Pretend you have been given 14 "stickers" to vote with. You can vote with 1 sticker on 14 different items, or put all 14 on one item if you feel very strongly about it, or any combination in between.

Please enter the number corresponding to the # of VIRTUAL STICKERS you would like to vote with, beside each item you think should be priorities for KBHN to work on.

PLEASE BE CAREFUL NOT TO EXCEED 14 VOTES.

If you do, we will unfortunately have to exclude your response from the analysis, for data quality purposes. Here is an example for how to use your 14 "votes": if you feel strongly about "need specialized training for healthcare professionals" you may place a "5" beside that item, indicating you are using 5 "stickers" for that item. In this case, you would have 9 stickers left to vote with. You may choose to use up "1" sticker for 9 more priorities, so then you would enter a "1" beside each of those 9 (for a total of 14 "stickers" or "votes"). Please verify the number of votes you have used totals 14, before clicking submit.

When you are finished, click the "submit" button at the bottom of the page.

- ☐ 1) Need specialized training for healthcare professionals so that observations of parents will be recognized, and will ensure early diagnosis and treatment.

- ☐ 2) Need non-categorical treatment for the child needed 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 they need (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.

- ☐ 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 coordination 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 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.

- ☐ 10) Need case managers who can coordinate 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 worker for the child, as an option.

☐ 13) Need coordinated and integrated 'wrap around care' for the child.

☐ 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, 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).

☐ 16) Individualized Education Programs (IEPs) are created but not used. Child needs to 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, can't put all responsibility on the child. All affects child 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 and without barriers imposed by unions, when it comes to being able to implement 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.

☐ 20) Need additional specialized in-depth training in neurodevelopmental conditions for GPs, nurses, 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 coordinated 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.)

☐ 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 the marriage.

☐ 25) Need for broader societal awareness of neurodevelopmental conditions, acceptance of neurodiversity, toward reducing stigma. Encourage inclusion by finding what the child is good at and giving them opportunities to contribute using their interests, strengths 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 & 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)

☐ 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 needed to be able 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 adult doctors).

☐ 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 lifelong 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.

☐ 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.

☐ 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 in comparison.

Appendix C – The online survey (French)

Priorisation des besoins liés à la PC, aux TSAF et aux TSA au Canada

Formulaire de consentement éclairé

Date :

Le 26 avril 2017

Titre de l'étude : Analyse des tendances concernant les besoins des intervenants, par le réseau Kids Brain Health (KBH, anciennement NeuroDevNet)

Équipe de recherche

Dr. Anneliese Poetz, bureau 201, Kaneff Tower, 416-736-2100, poste 44310, apoetz@yorku.ca; Dr. David Phipps, Kaneff Tower, 5e étage, 416-736-5813, dphipps@yorku.ca

Objectif du projet de recherche.

Le réseau Kids Brain Health (anciennement NeuroDevNet) souhaite mener une analyse des tendances auprès de différents intervenants, dans le but d'orienter les recherches futures pour qu'elles répondent aux besoins et aux difficultés des parents d'enfants atteints de paralysie cérébrale (PC), d'un trouble du spectre de l'alcoolisation foetale (TSAF) ou d'un trouble du spectre de l'autisme (TSA). L'information sera obtenue directement auprès des parents, ainsi que des fournisseurs de services ou médecins et des décideurs politiques qui, à cause de leur interaction régulière avec les familles à titre professionnel, connaissent leurs besoins. Ce qu'on attend de vous. Nous aimerions que vous répondiez à un questionnaire en ligne. Ce questionnaire doit nous aider à prioriser les 44 besoins des intervenants déterminés dans la première phase du projet (par des entrevues qualitatives).

Risques et désagréments.

Nous ne prévoyons aucun risque ou désagrément liés au fait de participer à la recherche, puisque vos réponses demeureront anonymes. Deux questions vous demandent d'indiquer 1) votre province ou territoire de résidence, et 2) votre catégorie professionnelle. Ces renseignements sont nécessaires pour assurer la représentativité de l'échantillon, tant sur le plan géographique que sur le plan professionnel.

Avantages de ce projet pour la recherche et pour vous.

Le réseau KBH est bien placé pour améliorer réellement la situation des parents et de leurs enfants atteints de troubles neurologiques du développement, grâce à ses contacts avec les gouvernements et les réseaux fédéraux, provinciaux et régionaux. En répondant à ce questionnaire, vous nous transmettez vos idées, votre expérience et vos connaissances, et vous aidez le réseau KBH à prendre des décisions éclairées concernant l'allocation des ressources destinées à la recherche et aux activités d'application des connaissances. En retour, cela aidera le réseau à maximiser l'utilité (et l'impact) des travaux qu'il dirige, toujours dans le but d'améliorer la qualité de vie des enfants, des parents et des familles qui sont aux prises avec la PC, les TSAF ou les TSA.

Participation volontaire :

votre participation est entièrement volontaire et vous pouvez décider d'y mettre fin à tout moment. Le fait de ne pas participer n'influencera en rien la nature de votre relation avec les chercheurs, le personnel de l'étude ou de l'Université York, le réseau KBH ou le réseau de Centres d'excellence – ni maintenant ni plus tard.

Retrait de l'étude.

Vous pouvez décider de mettre fin à votre participation à l'étude, à tout moment et pour toute raison, en ne remplissant pas le questionnaire. Votre décision de mettre fin à votre participation ou de refuser de répondre à certaines questions n'affectera pas votre relation avec les chercheurs, avec l'Université York ou avec n'importe quel autre groupe associé à ce projet. Veuillez prendre note que, puisque les données sont anonymisées, il ne sera pas possible de récupérer les vôtres une fois que vous les aurez envoyées.

Confidentialité.

Les chercheurs sont conscients que l'hôte du sondage en ligne (c'est-à-dire REDCap) pourrait obtenir

automatiquement certaines données des participants à leur insu (p. ex., les adresses IP). Bien qu'il devienne alors possible que cette information soit fournie aux chercheurs ou que ceux-ci puissent y avoir accès, elle ne sera pas utilisée ni sauvegardée sur les appareils des chercheurs sans le consentement des participants. De plus, « [sc1] parce que ce projet emploie des techniques de collecte électroniques, les données pourraient devenir accessibles à des tiers conséquemment à diverses lois sur la sécurité en vigueur dans de nombreux pays ; pour cette raison, la confidentialité des données ne peut être garantie pendant la transmission sur le web. Les données seront stockées au Canada. Seuls le personnel de recherche et celui du siège du réseau KBH auront accès à ces informations. Les données seront stockées pendant 4 ans, et détruites après le 1er avril 2021. La confidentialité maximale est préservée dans les limites permises par la loi.

Avez-vous des questions sur cette analyse ?

Si vous avez des questions sur ce projet en général ou sur le rôle qu'on vous demande d'y jouer, n'hésitez pas à contacter Anneliese Poetz, par téléphone au 416-736-2100, poste 44310, ou par courriel (apoetz@yorku.ca), ou David Phipps, par téléphone au 416-736-5813, ou par courriel (dphipps@yorku.ca). Ce projet de recherche a été examiné et approuvé par le sous-comité de révision des études avec des participants humains (Human Participants Review Sub-Committee) du Conseil d'examen de l'éthique (Ethics Review Board) de l'Université York. Il répond aux exigences indiquées dans les directives de l'Énoncé de politique des trois Conseils sur l'éthique de la recherche. Si vous avez des questions sur le processus d'approbation ou sur vos droits en tant que participant, veuillez contacter le conseiller principal en gestion et politiques du Bureau de l'éthique en recherche, 5e étage, Kaneff Tower, Université York (par téléphone, 416-736-5914, ou par courriel, ore@yorku.ca).

Garanties juridiques et signatures :

J'accepte de participer à l'Analyse des tendances auprès des intervenants menée par Anneliese Poetz et David Phipps pour le réseau Kids Brain Health. Je comprends la nature de ce projet et souhaite y participer. Je ne renonce à aucun de mes droits garantis par la loi en participant à cette étude. Le fait de remplir ce formulaire et d'en transmettre les données confirme mon consentement à y participer.

1) Veuillez indiquer votre région (afin d'assurer, autant que possible, une représentation égale de tout le Canada) :

- ☐ Alberta
- ☐ Colombie-Britannique
- ☐ Manitoba
- ☐ Nouveau-Brunswick
- ☐ Terre-Neuve-et-Labrador
- ☐ Territoires du Nord-Ouest
- ☐ Nouvelle-Écosse
- ☐ Nunavut
- ☐ Ontario
- ☐ Ile-du-Prince-Édouard
- ☐ Québec
- ☐ Saskatchewan
- ☐ Yukon

2) Veuillez indiquer à quel groupe d'intervenants vous appartenez (cochez tout ce qui s'applique) :

☐ Parents d'un enfant atteint de PC, d'un TSAF ou d'un TSA

☐ Adultes qui s'autoreprésentent

☐ Adolescents qui s'autoreprésentent

☐ Enseignants du primaire

☐ Enseignants du secondaire

☐ Assistants en éducation

☐ Éducateurs à la petite enfance (préscolaire)

☐ Médecins de famille

☐ Urgentologues

☐ Psychiatres

☐ Personnel infirmier

☐ Psychologues

☐ Ergothérapeutes

☐ Physiothérapeutes

☐ Orthophoniste

☐ Chercheurs à l'université

☐ Travailleurs sociaux

☐ Travailleurs de première ligne intervenant

☐ auprès d'enfants ou de jeunes atteints de PC,

☐ d'un TSA ou d'un TSAF

  ☐ Autre groupe (veuillez préciser lequel dans la boite ci-dessous)

  [   ]

☐ Décideur politique

☐ Autre (veuillez préciser) :

  [   ]

3) Je travaille ou j'ai de l'expérience dans le domaine suivant (cochez tout ce qui s'applique) :

☐ Paralysie cérébrale

☐ Troubles du spectre de l'alcoolisation foetale

☐ Troubles du spectre de l'autisme

Les 44 éléments présentés ci-dessous sont des « zones d'intervention » : ce sont des besoins énoncés par des personnes dont les vies ont été directement ou indirectement touchées par la paralysie cérébrale, un trouble du spectre de l'alcoolisation foetale ou un trouble du spectre de l'autisme. Bien qu'on doive tâcher de répondre à chacun de ces besoins, on ne peut pas intervenir partout en même temps ; c'est pourquoi nous avons besoin de votre aide pour les prioriser.

Imaginez qu'on vous remet 14 pastilles autocollantes qui vous servent à voter. Vous pouvez mettre une pastille sur 14 éléments différents, ou 14 pastilles sur un seul élément si votre besoin est énorme dans ce domaine particulier - toutes les autres combinaisons entre les deux sont possibles.

Entrez le nombre de PASTILLES VIRTUELLES que vous souhaitez apposer à côté de chacun des besoins qui, selon vous, doivent être traités en priorité par le réseau KBH. Prenons un exemple. Vous pensez qu'une « formation spécialisée pour les professionnels de la santé » est une grande priorité ; vous inscrivez donc « 5 » à côté de cet élément, comme si vous colliez 5 pastilles. Il vous reste alors 9 pastilles à répartir entre les différents besoins.

Vous décidez que 9 autres besoins doivent retenir à part égale l'attention du réseau KBH ; vous inscrivez donc « 1 » devant chacun. Vous pourriez aussi accorder 4 pastilles à un besoin que vous jugez presque aussi prioritaire que le premier, 3 à un autre et 1 chacun à deux autres (toujours pour un total de 14 pastilles).

Quand vous avez terminé, cliquez sur le bouton "Submit" dans le bas de la page.

☐ 1) Formation spécialisée pour les professionnels de la santé, afin que les observations des parents soient prises en compte et que le diagnostic et le traitement soient offerts précocement.

☐ 2) Traitement non spécifique de l'enfant le plus tôt possible, sans que l'absence de diagnostic empêche de traiter les déficits fonctionnels.

☐ 3) Diagnostic précoce, afin d'obtenir un soutien ciblé et spécifique en fonction des besoins (à l'école, auprès des organismes de services ou de soutien, etc.). Le traitement non spécifique n'est pas nécessairement celui que le diagnostic associe à l'issue la plus favorable à l'enfant.

☐ 4) Atténuation ou élimination des obstacles à l'obtention d'un diagnostic. Exemples d'obstacles : la formation limitée des fournisseurs de soins de première ligne (omnipraticiens) ; l'accès difficile aux spécialistes qui posent le diagnostic ; les listes d'attentes ; les couts (à débourser soi-même) de l'évaluation diagnostique au privé ; les facteurs géographiques, notamment le fait d'habiter en région rurale ou éloignée.

☐ 5) Accès rapide, pratique et sur mesure aux traitements et à des services centralisés offerts par des spécialistes. Le temps d'attente, les critères d'admissibilité aux soins (p. ex. l'âge, le QI) excluent des personnes qui ont besoin de soins ou de services.

☐ 6) Communications claires, suivies et efficaces entre les différents professionnels, afin de soulager les parents de ce fardeau. Coordination des communications entre les organismes et les services.

☐ 7) Attitude ouverte et sans préjugés du personnel de première ligne envers les parents. Tous les parents n'accueillent pas le diagnostic et les interventions de la même façon. Quand on juge leur degré de motivation (pas assez motivés, ou trop motivés parce qu'ils veulent tout faire), on leur cause un stress inutile.

☐ 8) Accès à la liste des options de traitements reconnus scientifiquement, avec de l'information sur les effets de chacun, et fluidité dans le système de prestation des traitements, afin que les familles ou les individus aient accès aux traitements en temps opportun et aussi longtemps que nécessaire. Information sur la définition d'un traitement «reconnu scientifiquement », et d'un traitement « de référence ». Les parents ont besoin d'aide pour comprendre ce qui est prioritaire, puisqu'il n'est pas possible de tout faire.

☐ 9) Augmentation des ressources (le système de santé et les parents ont des contraintes financières et manquent de ressources), et utilisation plus efficace (par les programmes et dans l'ensemble du système) des ressources existantes, afin de maximiser les bienfaits des ressources pour l'enfant et sa famille.

☐ 10) Désignation d'un gestionnaire de dossier, capable de coordonner les communications entre professionnels et de faire valoir les besoins de l'enfant, afin que les parents n'aient pas à faire ce travail eux-mêmes (la gestion d'un dossier s'accompagne d'une lourde charge de travail). Reconnaissance des difficultés supplémentaires soulevées par un cas complexe, ce qui augmente encore le besoin de désigner un gestionnaire de dossier pour aider la famille. Idéalement, cette personne doit comprendre les particularités de l'état neurodéveloppemental de la personne atteinte.

☐ 11) Services suivis et cohérents, en particulier dans les situations où le taux de roulement du personnel est élevé. On peut diminuer le taux de roulement en offrant des postes à temps plein bien rémunérés assortis d'avantages sociaux intéressants.

☐ 12) Reconnaissance des membres de la famille à titre de travailleurs de soutien (employés ou subventionnés) optionnels auprès de l'enfant.

☐ 13) Coordination et intégration des soins de l'enfant dans une formule de prise en charge « de A à Z ».

☐ 14) Évaluation du milieu physique et social, afin de renforcer les éléments pouvant aider à la réussite scolaire de l'enfant et d'atténuer les éléments pouvant lui nuire.

☐ 15) Formation spécialisée avancée des enseignants, assistants en éducation, consultants en enseignement (enseignants ressources), directions d'école et de toute personne qui interagit avec les enfants dans les écoles en ce qui concerne les approches à adopter avec les enfants atteints d'un trouble neurodéveloppemental. Une telle formation doit porter sur les connaissances, les attitudes et la culture, et rejoindre tous les fournisseurs de services : comment travailler avec des enfants, des jeunes ou des adultes atteints d'un trouble du neurodéveloppement ; comment travailler avec des

personnes issues de cultures ou d'ethnies différentes ou de divers segments de la population, en particulier les communautés autochtones).

☐ 16) Les programmes d'éducation personnalisés existent, mais ils ne sont pas utilisés. L'enfant doit pouvoir exprimer lui-même, s'il le peut, ce dont il a besoin pour réussir à l'école (ne pas tenir pour acquis que l'enseignante ou l'enseignant se souviendra de tout dans un programme personnalisé). En même temps, la responsabilité ne doit pas revenir entièrement à l'enfant. Tout [est susceptible] d'influencer la santé mentale et le potentiel de réussite de l'enfant.

☐ 17) L'enfant doit pouvoir trouver sa place parmi ses pairs à l'école.

☐ 18) Les préoccupations des parents doivent être entendues par tout le personnel enseignant et la direction, qui doivent réagir adéquatement, sans que s'élèvent des obstacles syndicaux à la mise en oeuvre des conseils ou des stratégies des parents qui cherchent à donner les meilleurs outils possibles à leur enfant. Les parents ont besoin de l'aide de l'école pour explorer les solutions de rechange, par exemple : la formation de classes plus petites au secondaire et l'intégration à l'horaire de périodes réservées au travail scolaire ; le prolongement des études secondaires par une année comprenant un stage adapté aux forces de l'enfant.

☐ 19) Dans le système scolaire, augmentation du nombre de professionnels (p. ex., personnel infirmier, assistants en éducation, intervenants en physiothérapie, en analyse appliquée du comportement, etc.) disposant d'une formation appropriée pour travailler avec des enfants atteints d'un trouble neurodéveloppemental.

☐ 20) Davantage de formation spécialisée avancée en troubles du neurodéveloppement pour les médecins généralistes, le personnel infirmier, les urgentologues, le personnel administratif, les dentistes, etc. Une telle formation devrait porter sur les connaissances, les attitudes et la culture, et rejoint tous les professionnels de la santé et tous les fournisseurs de services : comment travailler avec des enfants, des jeunes ou des adultes atteints d'un trouble du neurodéveloppement ; comment travailler avec des personnes issues de cultures ou d'ethnies différentes ou de divers segments de la population, en particulier les communautés autochtones.

☐ 21) Fluidité dans la gestion des cas complexes, accès simplifié aux services et à l'équipement spécialisés.

☐ 22) Accès en temps opportun aux soins psychiatriques pour les enfants ou les adultes atteints d'un trouble du neurodéveloppement, afin d'éviter qu'ils se « soignent » eux-mêmes en prenant de l'alcool ou des drogues ou qu'ils se trouvent aux prises avec le système judiciaire ou la police.

☐ 23) Coordination du soutien et des protocoles concernant les troubles neurodéveloppementaux considérés comme un état pathologique, comme c'est le cas pour d'autres problèmes de santé (p. ex. le diabète, les maladies cardiaques, le cancer, etc.).

☐ 24) Soutien en santé mentale pour les parents : renforcement de l'autonomie, accès à des travailleurs de soutien, répit, socialisation avec des personnes qui comprennent leur situation, groupes de soutien capables d'aborder les problèmes d'isolement et de tension dans le couple.

☐ 25) Conscientisation de la population aux troubles du neurodéveloppement et acceptation de la neurodiversité, en vue de diminuer la stigmatisation. Inclusion de l'enfant par la découverte de ses forces et sa participation aux activités, en mettant à profit ses champs d'intérêt, ses forces et ses habiletés naturelles.

☐ 26) Traitement égal et équitable des membres de la fratrie, en tenant compte de la santé mentale et émotionnelle et de la qualité de vie des frères et soeurs neuronormaux.

☐ 27) Formation sociale et comportementale de l'enfant atteint d'un trouble du neurodéveloppement, afin qu'il acquière des stratégies d'autorégulation de ses émotions ou de son anxiété.

☐ 28) Augmentation de l'autonomie financière des familles et ajout d'un poste de coordination au sein du système afin de faciliter l'accès aux services.

☐ 29) Répartition équitable des couts et de la disponibilité de programmes récréatifs inclusifs pour les enfants. Endroits où s'occuper, s'amuser, faire de l'exercice et socialiser.

☐ 30) L'enfant a besoin de se sentir utile et de trouver du sens à sa vie (à l'école, et plus tard dans son emploi), et l'adulte qui ne peut pas fonctionner dans un milieu de travail a besoin de programmes ou d'activités lui permettant de sortir de la maison.

☐ 31) Reconnaissance des enjeux liés à la sécurité : la difficulté de l'enfant à gérer ses émotions peut mener à des agressions physiques ou à la consommation de drogue ou d'alcool pour soulager sa souffrance ; le manque de sommeil des parents peut causer des erreurs de dosage des médicaments ou des accidents (de voiture ou autres), etc.

☐ 32) Reconnaissance des problèmes de sommeil, qui influencent le comportement de l'enfant pendant la journée et le sommeil ou le niveau de stress de ses parents, et moyens d'y remédier.

☐ 33) Interventions et services conçus expressément pour les enfants (plutôt qu'adaptés du modèle de services en santé mentale destiné aux adultes) trouble du neurodéveloppement (les traitements conçus pour des enfants neuronormaux ne fonctionnent pas nécessairement).

☐ 34) Soutien à la réussite scolaire à tous les niveaux, afin de maximiser les chances des personnes atteintes d'un trouble du neurodéveloppement d'occuper un emploi épanouissant.

☐ 35) Services destinés aux adultes afin de maximiser leur potentiel tout au long de la vie, et spécialement s'ils n'ont pas pu bénéficier de services pendant l'enfance. Il existe très peu de possibilités pour les adultes d'obtenir un diagnostic, des traitements ou des services de quelque nature que ce soit. Il n'existe rien pour les ainés.

☐ 36) Continuité des services dans les moments clés ou les périodes de transition tout au long de la vie, y compris de l'aide pour remplir les formulaires donnant accès aux ressources (en particulier aux programmes de financement destinés aux adultes souffrant d'un handicap) pendant les périodes de transition. Mise en place de moyens assurant la continuité des services pour les personnes qui ont des besoins médicaux chroniques (elle est souvent rompue au moment de la transition entre les soins pédiatriques et les soins des adultes).

☐ 37) Logements offrant un soutien adéquat aux jeunes ou aux adultes, afin qu'ils puissent vivre de façon aussi autonome que possible (certains ont besoin de plus de soutien que d'autres pour maximiser leur indépendance).

☐ 38) La société et le gouvernement doivent reconnaitre qu'il s'agit d'un état pathologique permanent, en fournissant un soutien permanent - qui ne cesse pas d'être offert à partir d'un certain âge. Cela comprend les soins pédiatriques en santé mentale et les maladies mentales connexes susceptibles d'évoluer dans le temps.

☐ 39) Services distincts selon la culture, mis au point pour des groupes culturels particuliers, offerts en langue maternelle ; adaptation des interventions aux cultures particulières.

☐ 40) Moyens novateurs de fournir des services et de réaliser des interventions et d'en assurer le suivi dans les régions rurales ou éloignées (p. ex., télésanté).

☐ 41) Reconnaissance et compréhension des différences régionales entre les provinces ou territoires (politiques, services offerts), les régions rurales et les régions urbaines, les régions éloignées et les régions nordiques ; dans chaque cas, savoir ce qui fonctionne et ce qui ne fonctionne pas.

☐ 42) Accès en temps opportun aux nouvelles connaissances issues de la recherche afin d'adapter les politiques, les pratiques exemplaires et les services.

☐ 43) Assouplissement des politiques qui orientent les programmes, de manière à ce que les changements fondés sur le savoir expérientiel puissent être implantés pour le bien des utilisateurs (p. ex., de tout petits changements comme le fait de permettre aux praticiens d'envoyer des rappels par message texte aux patients concernant les prochains rendez-vous).

☐ 44) Financement équitable des soins pour les différentes formes de problèmes neurodéveloppementaux. À certains égards, le soutien et les services semblent bien financés pour la paralysie cérébrale, de même que pour les TSA, mais en comparaison, les TSAF reçoivent moins de financement et offrent moins de services.

Appendix D – The online survey (plain language)

Prioritizing Needs for CP, FASD, ASD in Canada_Plain

Informed Consent Form

Date:

April 26, 2017

Study Name:

Kids Brain Health Network (KBHN, formerly NeuroDevNet) Environmental Scan 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, dphipps@yorku.ca

Purpose of the Research:

Kids Brain Health Network (formerly NeuroDevNet) wishes to conduct an environmental scan with diverse stakeholders (A stakeholder is someone who has an interest or a concern about this) 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, Autism Spectrum Disorders (these will be called Neurodevelopmental conditions in the survey). 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 an online survey to help us prioritize the 44 stakeholder needs that we identified in the first phase of this project talking to people using the same interview questions, and listening for what are the things that are similar among all of the people we talked to. What we found out was that there were 44 things that everyone thought were "needs" based on their life experiences).

Risks and Discomforts:

We do not foresee any additional risks or discomfort from your participation in the research as your responses will be anonymous (no one will know what you answered). There are two questions asking you to identify 1) your province or territory of residence, and 2) your category of occupation (what you do for your job). This information is necessary to help us make sure we have a representative sample regionally as well as occupationally.

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 survey you will be helping KBHN to make resource allocation decisions for future research and knowledge translation activities (taking this research and passing it on to the people/organizations who can put it to use), based on your insights, experience and knowledge. This will in turn help KBHN to maximize the potential usefulness (and impact) of the projects 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 at any time, for any reason, if you so decide, by not completing the survey. 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. Since the data are anonymous, it will not be possible to withdraw your data after submitting your answers.

Confidentiality:

The researcher(s) acknowledge that the host of the online survey (e.g., REDCap) may automatically collect participant data without their knowledge (i.e., IP addresses.) Although this information may be provided or made accessible to the researchers, it will not be used or saved without participant's consent on the researcher's system. Sometimes when people fill in online surveys, the information that you enter may be seen by others, because when you enter information into an online survey it has to be sent from your computer to the internet. The ability of others to see the data you enter, or your IP address (for example) depends on things like the way the survey software works, the security of your internet connection, the laws in your region, etc. and these things are beyond our control. The data will be housed in Canada. Only research staff and KBHN Headquarters personnel will have access to this information. The data will be stored for 4 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 (dphipps@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 consent to participate in Kids Brain Health Network Environmental Scan 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 participating in this survey. By filling in and submitting the survey I am indicating my consent to participate.

1) Please let us know which region you are located in (so that we can do our best to ensure equal representation across Canada):

- ☐ Alberta
- ☐ British Columbia
- ☐ Manitoba
- ☐ New Brunswick
- ☐ Newfoundland and Labrador
- ☐ Northwest Territories
- ☐ Nova Scotia
- ☐ Nunavut
- ☐ Ontario
- ☐ Prince Edward Island
- ☐ Quebec
- ☐ Saskatchewan
- ☐ Yukon

2) Please let us know which stakeholder group you represent (check all that apply) (A stakeholder is someone who is directly or indirectly affected, and/or has an interest or a concern about this):

☐ Parent of a child with either CP, FASD, ASD

☐ Self-advocate (adult)

☐ Self-advocate (teenager)

☐ Elementary school teacher

☐ High school teacher

☐ Educational Assistant

☐ Early Childhood Educator (pre-school)

☐ Family Physician

☐ ER Physician

☐ Psychiatrist

☐ Nurse

☐ Psychologist

☐ Occupational Therapist

☐ Physical Therapist

☐ Speech Language Therapist

☐ University-based researcher

☐ Social worker

☐ Frontline worker delivering interventions to children/youth with CP, ASD, FASD

   ☐ Other (please specify in box below)

   [ ]

☐ Policymaker

☐ Other (please specify):

[ ]

3) I work with and/or have experience with (check all that apply):

☐ Cerebral Palsy

☐ Fetal Alcohol Spectrum Disorders

☐ Autism Spectrum Disorders

There are 44 ideas that are "focus areas" about the needs of persons whose lives have been affected by Cerebral Palsy, Autism Spectrum Disorders and/or Fetal Alcohol Spectrum Disorders; (referred to as "neurodevelopmental conditions") including family , friends and professionals. All of these "focus areas" are important to look in to, but we can't work on all of them so we need your help figuring out what is most important to work on first.

Pretend you have been given 14 "stickers" to vote with. You can vote with 1 sticker on 14 different items, or (for example) 5 stickers on 2 and 4 stickers on another, or any other combination you like which equals 14 stickers. You can't go over 14 stickers/votes. You can even put all 14 on one item if you feel very strongly about it. Please enter the number STICKERS/votes you would like to vote beside each idea/focus item you think should be what Kids Brain Health Network should work on first.

PLEASE BE CAREFUL NOT TO EXCEED 14 VOTES. If you do, unfortunately your survey will not be counted.

Please count the number of votes you have used before clicking submit. Make sure it equals 14. When you are finished, click the "submit" button at the bottom of the page.

☐ 1) Healthcare professionals need focused training to recognize how and what parents are seeing (like symptoms, movements and behaviors) to help with early diagnosis and treatment.

☐ 2) We need treatment for the children that do not fit into a specific category or diagnosis. Just because a child does not have a diagnosis this should not prevent starting the process of getting the supports they need to help them be able to do the things they need and want to do.

☐ 3) We need early diagnosis so that children can receive the specific help they need in school/receiving services/support etc. There are some treatments that work best with a specific diagnosis, so when treatment isn't diagnosis specific children don't get the best outcome.

☐ 4) We need to reduce or remove what gets in the way of children obtaining a diagnosis, such as: Doctor/GP who have not had appropriate training, access to the professionals who are skilled in giving a diagnosis, wait lists, having to pay for a private assessment out of your own pocket, living somewhere far away where services are not easily available and/or you have to travel to get service.

☐ 5) We need access to treatments that are specific to our needs, with all the experts that can help us in one location. Wait times, and the way that they decide who gets treatment (such as age or IQ) exclude those in need.

☐ 6) We need clear, consistent and effective communication among all the different service professionals so that parents don't have to always be the ones to do this. We need organizations and service providers to better communicate together about our care.

☐ 7) We need front line workers not to judge parents. Parents react in variety of different ways in accepting their child's diagnosis and the help that their child might need. Frontline workers often judge parents as not motivated enough or too motivated because they want to do everything and this is causing extra stress to parents.

☐ 8) We need easy access to a full list of treatment options that includes information about what each of them does. We need to have these treatment options available for as long as we need them. We need information on what evidence-based treatment is and what is considered the best possible options. Parents need help figuring out what is the most important to do first, can't do everything.

☐ 9) We need more resources given to the system (for programs and service delivery) as well as funding directly to parents. We need the resources that are already there to be used better so that children and families get the most out of them.

☐ 10) We need case managers/workers who can coordinate communication among professionals and can advocate for what the child needs so parents don't have to do it all. Case management is a lot of work, so it is hard for parents to have to do it all themselves. It needs to be known that complex care is more challenging to manage so it is even more important to have a case manager helping the family, and one that understands the exact condition of the child/individual.

☐ 11) We need consistent service, especially in situations where there is high staff turnover. Staff should be paid well, with good benefits and a full time position so that they will stay in the job long term.

☐ 12) Family members should be allowed to be employed/subsidized as a support worker for the child, as an option for the family.

☐ 13) Supports and care need to work together and be coordinated to best support the child.

☐ 14) We need to know all the things in the physical environment (buildings, classrooms, playgrounds, smells, sounds etc) and social environment (relationships with staff, teachers, other children etc) that help or don't help a child's success in school. We need to create solutions for the things that don't help the child's success at school.

☐ 15) We need it to be mandatory that anyone who works with children in schools (like teachers, Education Assistants, resource teachers, principals etc) has special and in-depth training on how best to work with children who have a neurodevelopmental condition. This training should also include how to best work with different cultures and other groups of people including First Nations communities.

☐ 16) Individualized Education Programs (IEPs) are created but not used, and teachers often don't remember everything in them. The child needs to be allowed to self-advocate, as they are able, for what they need in school to be successful, but without taking on the full responsibility. All of this affects the child's mental health and potential for success.

☐ 17) Child needs to be able to fit in with other kids in their school.

☐ 18) Parent's concerns, including advice/strategies for helping the child to be at their best, need to be heard and acted on appropriately by teachers, Education Assistants, principals and other staff without union rules getting in the way. Parents need help from the school to explore different things that could help their child (such as taking less classes in high school in a certain amount of time, a job that lasts as long as one school term and counts as a course credit, or an extra year in high school with classes that better suit that child's strengths)

☐ 19) We need more professionals (nurses, educational assistants, physical therapists, ABA-Applied Behavioural Analysts, etc.) who have appropriate training to be able to work with children who have a neurodevelopmental condition to be working in the schools.

☐ 20) We need special, in-depth training about neurodevelopmental conditions to be given to all those who provide health services including: Doctors/GP's, nurses, ER Doctors, administrative staff, dentists etc. This training should include not only how to best work with children who have these conditions but how to best work with different cultures and other groups of people including First Nations communities. Training should also be about how their attitude can affect the person they are serving.

☐ 21) We need smoother management of complicated cases with easier access to specialty equipment and services.

☐ 22) We need faster access to psychiatrists for children/youth who have neurodevelopmental conditions so that they can get the help they need so they don't have to use alcohol and/or illegal drugs to help them feel better, because doing that can also get them in trouble with the police.

☐ 23) We need coordinated supports and protocols (ways of doing things) for neurodevelopmental conditions as a medical condition, similar to what is available for other medical conditions like diabetes, heart disease, cancer etc.

☐ 24) We need support(s) for parent's mental health such as self-care, support workers, rest, time with other people who understand their situation and parent support groups so that parents don't feel alone or have stress between partners/marriage.

☐ 25) We need society and our communities to be aware of and accept all the different neurodevelopmental conditions. Inclusion should be encouraged by finding out what a child is good at and give them opportunities to contribute using their interests, strengths and natural abilities.

☐ 26) We need to treat brothers or sisters in a family as equal and fair as possible, while paying attention to the emotional health and quality of life for the child who does not have a neurodevelopmental condition.

☐ 27) We need training in social skills/behavioural training/strategies etc for children who have a neurodevelopmental condition to learn how to self-manage their own emotions or anxiety.

☐ 28) Need more financial control for families & a system coordinator to help access services.

☐ 29) We need equal access and availability to inclusive recreational programs for children. This means recreational programs that are inclusive should cost the same as for other kids and there should be enough spots that all kids with neurodevelopmental conditions can participate if they want to. Place(s) to go to find purpose, enjoyment, physical fitness and socialization.

☐ 30) Children need purpose/meaning (in school, and later in life in their employment). Adults who do not fit into work environment need day programs or other activities.

☐ 31) We need to recognize there are safety issues like a child's difficulty managing emotions (can lead to physical aggression, using drugs/alcohol); parent's lack of sleep (which can result in medication errors, accidents in the car etc).

☐ 32) We need to figure out and find solutions to sleep issues in children who have neurodevelopmental conditions which affect daytime behaviors of the child, as well as the parent's sleep/stress.

☐ 33) Interventions and services need to be tailored to children with neurodevelopmental conditions, and not be based on services adults or children who do not have a diagnosis get, as these treatments might not work.

☐ 34) We need supports for being successful in education at all levels, and give the biggest chance for individuals with neurodevelopmental conditions to find meaningful employment.

☐ 35) Adults need services to make the most of their potential throughout the course of their life, especially if they missed out on services during childhood. There are very few options for adults to obtain a diagnosis and/or treatment or services of any kind. There is nothing for seniors.

☐ 36) We need a smooth flow (continuity) of services at key times/transition points during our lifetime, and need assistance filling out the forms which are needed to be able to access resources (including funding programs for adults with disabilities) during these transition times. Find ways to make sure the type and quality of services stays the same for those with ongoing medical needs (this is often lost during the change from doctors who only work with children to regular family doctors).

☐ 37) We need good supportive housing for youth/adults to be able to live as independently as possible. Some people will need more support than others to make the most of their independence.

☐ 38) We need a common understanding that this is a lifelong condition and access to supports should be provided for a lifetime without disappearing at a certain age. This includes child mental health care and mental health condition(s) that could change over time.

☐ 39) We need culturally specific services that are made by and for that particular cultural group, given in their native language and we need interventions (treatments) that are adapted in the best way to suit that particular culture.

☐ 40) We need new and creative ways to deliver and monitor services and interventions in places that are far away/remote/rural. (e.g. telehealth)

☐ 41) We need to find and understand regional differences among provinces/territories like services offered, the policies that each province/territory has, city vs country, remote/northern regions including what works and doesn't work in each.

☐ 42) We need fast access to new research knowledge to help create policies, best practices and services.

☐ 43) We need more leeway in policies guiding programs, so that changes based on experience can be made to better serve clients. (e.g. even small changes such as allowing text message reminders from professionals to clients about upcoming appointments)

☐ 44) We need funding for different neurodevelopmental conditions to be more equal. In some cases CP supports/services seem to be well-funded, ASD appears to also be well-funded but some say that FASD remains under-serviced/under-funded in comparison.

Appendix E – Overall Survey Results (by stakeholder group) Full Data Table

Themes	Needs identified by all stakeholders interviewed in qualitative study (parents, clinicians, policymakers)	Total compiled # votes (n=656 CP, FASD, ASD)	Parent/Self Advocate (n=320)	Education (n=48)	HealthPract (n=44)	AlliedHealthPr (n=210)	Researcher (n=25)	Policymaker (n=29)
1. Diagnosis	1. Specialized training for health care prof'ls	284	152	19	34	84	4	8
	2. Non-categorical early treatment	368	112	20	38	132	28	14
	3. Early diagnosis to inform treatment	364	162	31	37	107	12	21
	4. Remove barriers to diagnosis	446	205	31	41	151	17	19
2. Treatment	5. Timely access to treatment	259	110	16	22	93	11	13
	6. Clear communication	278	121	18	13	109	12	16
	7. Non-judgmental treatment	90	44	12	7	30	8	5
	8. Evidence-based treatments	306	125	22	16	129	16	17
	9. Adequate, responsibly used resources	348	181	27	19	105	11	19
3. Services	10. Case managers to support parents	301	125	16	12	106	14	12

(top 10 in green, bottom 10 in red)

Themes	Needs identified by all stakeholders interviewed in qualitative study (parents, clinicians, policymakers)	Total compiled # votes (n=656 CP, FASD, ASD)	Parent/Self Advocate (n=320)	Education (n=48)	HealthPract (n=44)	AlliedHealthPr (n=210)	Researcher (n=25)	Policymaker (n=29)
3. Services, cont'd	11. Consistency in face of high staff turnover	164	54	27	4	61	6	7
	12. Support families as partners in care	276	240	19	16	27	3	6
	13. "Wrap-around" care	127	48	13	7	39	10	9
4. Education	14. Workarounds to physical, social barriers	94	51	4	6	27	11	2
	15. Mandatory training for teachers, staff	533	308	53	16	135	15	18
	16. Implement IEPs, children as self-advocates	102	54	10	6	30	2	3
	17. Fit in with peers	102	66	18	4	28	1	4
	18. Respect parents' concerns	166	105	14	11	43	7	4
	19. More professionals in schools	410	169	35	29	148	11	13

Themes	Needs identified by all stakeholders interviewed in qualitative study (parents, clinicians, policymakers)	Total compiled # votes (n=656 CP, FASD, ASD)	Parent/Self Advocate (n=320)	Education (n=48)	HealthPract (n=44)	AlliedHealthPr (n=210)	Researcher (n=25)	Policymaker (n=29)
5. Health Care	20. Specialized training for frontline clinicians	187	67	5	25	56	12	10
	21. Support, equipment for complex cases	75	23	1	13	31	4	3
	22. Timely access to mental health supports	218	95	12	15	70	13	16
	23. Coordinated health care support	106	65	17	9	26	6	1
6. Mental Health / Quality of Life	24. Support for parents' mental health	276	131	21	14	94	16	8
	25. Reduce stigma	167	92	18	8	53	4	10
	26. Fair treatment of neurotypical siblings	97	61	12	4	27	2	2
	27. Self-regulation strategies	257	128	35	12	57	8	20
	28. Financial control, coordination of services	74	42	5	3	24	1	4
	29. Equitable access to recreational prog's	104	53	5	4	38	6	1

Themes	Needs identified by all stakeholders interviewed in qualitative study (parents, clinicians, policymakers)	Total compiled # votes (n=656 CP, FASD, ASD)	Parent/Self Advocate (n=320)	Education (n=48)	HealthPract (n=44)	AlliedHealthPr (n=210)	Researcher (n=25)	Policymaker (n=29)
6. Mental Health / Quality of Life, cont'd	30. Activities with a purpose	197	75	15	12	60	10	8
	31. Acknowledge safety issues	64	34	5	5	14	1	5
	32. Address sleep issues	114	60	5	6	40	7	3
	33. Tailored treatments	96	32	0	4	47	1	8
7. Life Course Perspective	34. Meaningful employment	170	105	13	9	42	2	6
	35. Services for newly diagnosed adults	326	203	13	27	76	11	17
	36. Service continuity during transitions	196	82	10	13	70	5	10
	37. Supportive housing	368	193	21	39	100	15	18
	38. Access to care throughout life course	374	231	17	18	120	8	8
8. Culture and Context	39. Culturally specific services	44	13	1	4	17	7	8
	40. Innovative service delivery options	74	20	1	8	35	1	6

Themes	Needs identified by all stakeholders interviewed in qualitative study (parents, clinicians, policymakers)	Total compiled # votes (n=656 CP, FASD, ASD)	Parent/Self Advocate (n=320)	Education (n=48)	HealthPract (n=44)	AlliedHealthPr (n=210)	Researcher (n=25)	Policymaker (n=29)
8. Culture and Context, cont'd	41. Respect for regional differences	55	21	4	2	13	2	3
9. Broader system and society	42. Timely access to new knowledge	97	32	6	6	54	2	4
	43. Respond to experiential knowledge	69	35	3	7	26	2	5
	44. Equitable funding for all ND cond's	409	175	23	14	186	12	14

Appendix F – Overall Survey Results (by geographic region) Full Data Table

Themes	Needs identified by all stakeholders interviewed in qualitative study (parents, clinicians, policymakers)	Total compiled # votes (n=656 CP, FASD, ASD)	Alberta (n=81)	British Columbia (n=178)	Manitoba (n=56)	New Brunswick (n=15)	Newfoundland (n=14)	Northwest Territories (n=7)	NSova Scotia (n=18)	Nunavut (n=2)	Ontario (n=220)	Prince Edward Island (n=7)	Quebec (n=30)	Saskatchewan (n=23)	Yukon (n=5)
1. Diagnosis	1. Specialized training for health care prof'ls	284	42	69	22	2	7	1	8	2	83	1	28	9	10
	2. Non-categorical early treatment	368	43	120	24	6	9	2	9	1	126	3	15	10	0
	3. Early diagnosis to inform treatment	364	31	85	28	5	7	2	10	2	126	12	27	24	5
	4. Remove barriers to diagnosis	446	64	124	28	7	5	4	6	1	145	6	36	17	3
2. Treatment	5. Timely access to treatment	259	30	59	39	1	4	0	8	1	80	9	12	16	0
	6. Clear communication	278	41	54	32	4	6	4	12	2	87	1	24	6	5
	7. Non-judgmental treatment	90	14	21	6	3	2	0	1	1	30	1	10	1	0
	8. Evidence-based treatments	306	41	77	30	13	2	1	12	1	102	1	9	14	3
	9. Adequate, responsibly used resources	348	31	124	17	10	4	3	9	1	117	3	13	12	4
3. Services	10. Case managers to support parents	301	46	69	26	4	9	6	5	3	90	4	20	12	7

(top 10 in green, bottom 10 in red)

Themes	Needs identified by all stakeholders interviewed in qualitative study (parents, clinicians, policymakers)	Total compiled # votes (n=656 CP, FASD, ASD)	Alberta (n=81)	British Columbia (n=178)	Manitoba (n=56)	New Brunswick (n=15)	Newfoundland (n=14)	Northwest Territories (n=7)	NSova Scotia (n=18)	Nunavut (n=2)	Ontario (n=220)	Prince Edward Island (n=7)	Quebec (n=30)	Saskatchewan (n=23)	Yukon (n=5)
3. Services, cont'd	11. Consistency in face of high staff turnover	164	23	41	20	6	2	5	4	1	41	8	6	5	2
	12. Support families as partners in care	276	39	70	6	16	3	16	3	0	111	3	6	1	2
	13. "Wrap-around" care	127	24	27	7	7	3	2	5	1	31	1	12	3	4
4. Education	14. Workarounds to physical, social barriers	94	22	13	1	4	1	1	1	0	41	2	7	1	0
	15. Mandatory training for teachers, staff	533	62	139	38	24	14	3	7	2	194	14	15	14	7
	16. Implement IEPs, children as self-advocates	102	16	26	7	2	5	6	0	0	34	0	4	2	0
	17. Fit in with peers	102	5	24	8	6	1	3	1	0	44	1	4	5	0
	18. Respect parents' concerns	166	15	50	11	15	3	0	4	0	50	1	10	7	0
	19. More professionals in schools	410	38	124	36	8	9	5	25	1	125	4	14	21	0
5. Health Care	20. Specialized training for frontline clinicians	187	25	55	11	2	7	0	3	0	66	0	8	5	5

Themes	Needs identified by all stakeholders interviewed in qualitative study (parents, clinicians, policymakers)	Total compiled # votes (n=656 CP, FASD, ASD)	Alberta (n=81)	British Columbia (n=178)	Manitoba (n=56)	New Brunswick (n=15)	Newfoundland (n=14)	Northwest Territories (n=7)	NSova Scotia (n=18)	Nunavut (n=2)	Ontario (n=220)	Prince Edward Island (n=7)	Quebec (n=30)	Saskatchewan (n=23)	Yukon (n=5)
5. Health Care, cont'd	21. Support, equipment for complex cases	75	16	28	4	4	0	0	2	0	14	0	4	3	0
	22. Timely access to mental health supports	218	25	64	17	1	10	6	3	0	78	4	5	5	0
	23. Coordinated health care support	106	16	19	16	1	2	2	0	0	42	0	4	2	2
6. Mental Health / Quality of Life	24. Support for parents' mental health	276	30	70	26	10	8	4	6	2	95	3	8	14	0
	25. Reduce stigma	167	32	40	14	9	2	0	3	1	51	1	12	2	0
	26. Fair treatment of neurotypical siblings	97	18	26	3	2	1	1	3	1	31	0	4	7	0
	27. Self-regulation strategies	257	38	82	19	3	5	1	8	0	90	1	1	5	4
	28. Financial control, coordination of services	74	7	22	4	0	1	1	0	0	33	1	1	2	2
	29. Equitable access to recreational prog's	104	14	32	13	0	1	0	2	0	35	2	4	1	0
	30. Activities with a purpose	197	36	52	15	2	5	2	5	0	65	2	8	5	0

Themes	Needs identified by all stakeholders interviewed in qualitative study (parents, clinicians, policymakers)	Total compiled # votes (n=656 CP, FASD, ASD)	Alberta (n=81)	British Columbia (n=178)	Manitoba (n=56)	New Brunswick (n=15)	Newfoundland (n=14)	Northwest Territories (n=7)	NSova Scotia (n=18)	Nunavut (n=2)	Ontario (n=220)	Prince Edward Island (n=7)	Quebec (n=30)	Saskatchewan (n=23)	Yukon (n=5)
6. Mental Health / Quality of Life, cont'd	31. Acknowledge safety issues	64	5	15	4	0	1	2	3	0	25	0	5	4	0
	32. Address sleep issues	114	17	31	22	1	2	1	2	1	26	1	4	6	0
	33. Tailored treatments	96	11	23	8	2	2	1	1	0	29	0	4	15	0
7. Life Course Perspective	34. Meaningful employment	170	22	48	16	0	6	1	8	0	52	2	11	4	0
	35. Services for newly diagnosed adults	326	41	57	14	3	9	2	15	0	165	1	11	8	0
	36. Service continuity during transitions	196	21	39	32	7	7	2	5	0	66	1	13	3	0
	37. Supportive housing	368	56	76	37	4	3	4	10	1	147	2	16	9	3
	38. Access to care throughout life course	374	37	109	54	6	17	2	16	0	104	2	17	10	0
8. Culture and Context	39. Culturally specific services	44	1	13	3	1	2	0	1	1	16	0	1	5	0

Themes	Needs identified by all stakeholders interviewed in qualitative study (parents, clinicians, policymakers)	Total compiled # votes (n=656 CP, FASD, ASD)	Alberta (n=81)	British Columbia (n=178)	Manitoba (n=56)	New Brunswick (n=15)	Newfoundland (n=14)	Northwest Territories (n=7)	NSova Scotia (n=18)	Nunavut (n=2)	Ontario (n=220)	Prince Edward Island (n=7)	Quebec (n=30)	Saskatchewan (n=23)	Yukon (n=5)
8. Culture and Context, cont'd	40. Innovative service delivery options	74	4	26	18	2	1	0	2	0	17	0	2	2	0
	41. Respect for regional differences	55	7	11	10	1	2	0	0	1	21	0	0	2	0
9. Broader system and society	42. Timely access to new knowledge	97	7	34	14	2	2	1	5	0	27	0	3	2	0
	43. Respond to experiential knowledge	69	14	15	8	4	0	0	1	0	21	0	2	4	0
	44. Equitable funding for all ND cond's	409	20	208	14	0	4	1	19	1	120	0	2	17	3

Appendix G – Overall Survey Results (by neurodevelopmental condition) Full Data Table

Themes	Needs identified by all stakeholders interviewed in qualitative study (parents, clinicians, policymakers)	Total compiled # votes (n=656 CP, FASD, ASD)	CP n=266	FASD n=330	ASD n=502	Other (none of the above) n=53
1. Diagnosis	1. Specialized training for health care prof'ls	284	117	130	211	23
	2. Non-categorical early treatment	368	209	222	315	21
	3. Early diagnosis to inform treatment	364	134	170	281	32
	4. Remove barriers to diagnosis	446	170	229	358	34
2. Treatment	5. Timely access to treatment	259	118	125	206	22
	6. Clear communication	278	136	132	222	23
	7. Non-judgmental treatment	90	41	41	58	16
	8. Evidence-based treatments	306	165	147	238	33
	9. Adequate, responsibly used resources	348	123	156	259	38
3. Services	10. Case managers to support parents	301	149	149	229	20
	11. Consistency in face of high staff turnover	164	73	89	146	7
	12. Support families as partners in care	276	90	91	182	31

(top 10 in green, bottom 10 in red)

Themes	Needs identified by all stakeholders interviewed in qualitative study (parents, clinicians, policymakers)	Total compiled # votes (n=656 CP, FASD, ASD)	CP n=266	FASD n=330	ASD n=502	Other (none of the above) n=53
3. Services, cont'd	13. "Wrap-around" care	127	56	71	98	12
4. Education	14. Workarounds to physical, social barriers	94	43	40	66	6
	15. Mandatory training for teachers, staff	533	182	265	393	49
	16. Implement IEPs, children as self-advocates	102	32	53	80	9
	17. Fit in with peers	102	45	43	82	5
	18. Respect parents' concerns	166	65	79	124	20
	19. More professionals in schools	410	167	189	334	35
5. Health Care	20. Specialized training for frontline clinicians	187	79	116	146	10
	21. Support, equipment for complex cases	75	53	49	56	3

Themes	Needs identified by all stakeholders interviewed in qualitative study (parents, clinicians, policymakers)	Total compiled # votes (n=656 CP, FASD, ASD)	CP n=266	FASD n=330	ASD n=502	Other (none of the above) n=53
5. Health Care, cont'd	22. Timely access to mental health supports	218	88	133	166	20
	23. Coordinated health care support	106	36	53	80	9
6. Mental Health / Quality of Life	24. Support for parents' mental health	276	117	155	197	27
	25. Reduce stigma	167	63	73	133	9
	26. Fair treatment of neurotypical siblings	97	34	38	74	7
	27. Self-regulation strategies	257	110	156	184	17
	28. Financial control, coordination of services	74	20	17	52	11
	29. Equitable access to recreational prog's	104	46	40	71	12
	30. Activities with a purpose	197	74	96	158	12
	31. Acknowledge safety issues	64	23	37	47	3
	32. Address sleep issues	114	57	67	86	5

Themes	Needs identified by all stakeholders interviewed in qualitative study (parents, clinicians, policymakers)	Total compiled # votes (n=656 CP, FASD, ASD)	CP n=266	FASD n=330	ASD n=502	Other (none of the above) n=53
6. Mental Health / Quality of Life, cont'd	33. Tailored treatments	96	34	43	79	6
7. Life Course Perspective	34. Meaningful employment	170	42	58	119	23
	35. Services for newly diagnosed adults	326	77	115	271	13
	36. Service continuity during transitions	196	89	93	152	21
	37. Supportive housing	368	126	180	273	25
	38. Access to care throughout life course	374	108	170	275	33
8. Culture and Context	39. Culturally specific services	44	19	30	36	4
	40. Innovative service delivery options	74	45	45	65	6
	41. Respect for regional differences	55	31	26	48	6
9. Broader system and society	42. Timely access to new knowledge	97	53	53	82	6

Themes	Needs identified by all stakeholders interviewed in qualitative study (parents, clinicians, policymakers)	Total compiled # votes (n=656 CP, FASD, ASD)	CP n=266	FASD n=330	ASD n=502	Other (none of the above) n=53
9. Broader system and society, cont'd	43. Respond to experiential knowledge	69	41	43	51	5
	44. Equitable funding for all ND cond's	409	167	345	273	20

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

Identifying and Prioritizing Stakeholder Needs in Neurodevelopmental Conditions in Canada – Addendum

Addendum to the 2017 Stakeholder Engagement Activity Report
Spring 2018 **Toronto, Ontario**

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