

**Making an Impact for People with Disabilities and their Families:
 Prioritizing Stakeholder Needs from the 2016 Environmental Scan**
 A Knowledge Exchange Forum on Neurodevelopmental Conditions in Canada
 Hyatt 655 Burrard Street, Vancouver, BC
 Wednesday January 18, 2017

Detail on top 10 priorities from breakout sessions and report back

Priority #1

Theme: Treatment

Focus area: 8

Need access to a menu of evidence-based treatment options with information about what each of them does, and need fluidity of the system(s) that delivers these treatments so that access to families/individuals is available when needed for as long as it is needed. Need information on what evidence-based treatment is, and what is gold standard. Parents need help figuring out what's important to prioritize, can't do everything. (39 votes, Afternoon Table 5)

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

<p>1. How can we begin to address this priority in an effective manner?</p> <p>a) What should we be trying to accomplish?</p> <ul style="list-style-type: none"> • We need to have a list of a range of therapies both evidence based and not • Need to have education for parents regarding quality of evidence • Parents spend time and money • Parents don't necessarily know how to evaluate research • National standards report on autism should be more widely read – it is accessible. 93 page report it's what we do here in the absence of Canadian guideline – National Autism Center.org • ASA Association for Autism Treatment • Assumption parents should do this work why isn't government informing the public about evidence based practice. • Educate the parents • How many GPs and pediatricians know what a parent should do, where a parent should go to look, where they'd find information? GPs should have those resources at hand and be able to point to a menu of what are the resources that are available that are evidence based. • Determine where this menu should live, what should be in there • RASP (Registered Autism Service Provider List) list which is a list of service providers who have been vetted in some way by the government to provide services (as an example) • Access the funding that comes with an ASD diagnosis in BC

- ACT Autism Community Training
- Break silos down, everyone can come to one place for information
- Accredited site with best standard information (e.g. national standards report)

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

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

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

a) Barriers

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

b) Enablers

- Transparency
- ASAT (the *Association for Science in Autism Treatment*) and the ASN (*Autism Support Network BC*) are organizations that should be considered as potential "enablers"
- Child Youth Services Network used to have people who could encourage – point to something that "fits" the individual. An equivalent kind of person would be helpful in reviewing the evidence, and information about the child and making recommendations¹

¹ There used to be a government funded position within the ministry of children and family development, and this person really played an interface role within the families so if a family had a diagnosis of autism, they'd meet with this person and that

<ul style="list-style-type: none"> • Having a person facilitate this decreases the gap between information and effective action • Standards of practice promote research (increases capacity)
<p>3. Who should be consulted/involved in the process?</p>
<ul style="list-style-type: none"> • Researchers, parents need to be consulted, clinician/provider expertise within a field is essential. • CASEL (Collaborative for Academic, Social and Emotional Learning) – database of evidence based and lesser evidence levels interventions for social emotional learning – they have an evolved and articulated assessment process, as does the CP Alliance in Australia, for CP-specific therapies. • Technical expertise is needed for maintaining the resource and developing a user-friendly interface • Community based organizations² with expertise supporting learning on science based treatment for neurodevelopmental conditions • Expert system navigators have important insights to offer. People with life/lived experience who can provide insights to parents or agencies outside people coming in, what it's like to have to navigate these systems.
<p>4. As we go through this process, how can we engage these stakeholders (that you have identified above in #3)?</p>
<ul style="list-style-type: none"> • Have all the groups come together to identify what they're doing and the gaps that exist unclear under whose auspices this would occur.

person would not only share with them the services that are out there, but also would explain to them what the services were about, and how good of a fit they might be for their present situation. That position no longer exists (due to funding).

² (i) Any community organization that can assist with expertise from lived experience, to make this expertise accessible. (ii) parent network support system, someone to talk to (iii) Autism support network does monthly education presentations, (iv) it's also an important resource for clinicians, in rural and remote areas you don't see a lot of children with a variety of different conditions so they need to have a place to go and access what's best practice for each condition where somebody else has done the legwork in looking up the best evidence, clinicians would be important in the creation of this because they would be ultimately the one using it.

Priority #2

Theme: Education

Focus area: 19

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

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

1. How can we begin to address this priority in an effective manner?
<p>a) <u>What should we be trying to accomplish?</u></p> <ul style="list-style-type: none"> • Inclusive education environment that addresses individual needs by trained, qualified professionals • Specific training for the specific needs • One-stop service spot – transitions are difficult for our kids • Broader understanding of needs / common language • Opening the doors to those qualified people who can provide the service – territorial issues get in the way • Where appropriate, specialized programs that specifically address needs – at different levels / age groups – e.g. Alternated Life Skills / Work Skills program at the secondary level <p>b) <u>If we do that, what would be the desired outcomes?</u></p> <ul style="list-style-type: none"> • More success for people with disabilities in the educational environment • Specific IEP goals based on the specific needs of the child • Matched professionals to specific needs
2. What would be some barriers and enablers of the approach above?
<p>a) <u>Barriers</u></p> <ul style="list-style-type: none"> • too many children in classrooms / too many varied needs • ‘specialists’ in schools with the specific training that’s needed (currently schools say “no” to allowing in trained professionals who are external to the school system) • Territorial issues with schools / unions • Intimidated by system bureaucracies – unions, bumping • Funding structures – inside / outside professionals • Two-tiered system for those who can pay • Limited resources • Lack of creative ways to solve ‘problems’ / being restricted by our ‘boxes’ • Filling capacity

b) Enablers

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

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

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

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

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

Priority #3

Theme: Broader System & Society

Focus area: 44

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

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

1. How can we begin to address this priority in an effective manner?
<p>a) <u>What should we be trying to accomplish?</u> Equity in Funding for different neurodevelopmental conditions:</p> <ul style="list-style-type: none"> • Access to treatment and services as needed regardless of the diagnosis • Clear definition of what functioning means in order to determine funding levels • We are comparing apples to oranges. There is the illusion that ASD families have a lot • ASD families do not get access to some services because they have ASD funding such as mental health, SLP • Basing funding on what someone else is getting is not equitable • Equal access for all cultural backgrounds <p>b) <u>If we do that, what would be the desired outcomes?</u></p> <ul style="list-style-type: none"> • Definition of functioning including the whole child. Different kinds of supports need to be addressed. Including emotional as well as medical aspects • Examination of using Int'l Classification of Functioning, Disability and Health as a measure to define functionality • Increased funding for CP • Evaluate criteria for accessing At Home Program funding • Not competing for funding based on what someone else gets

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

a) Barriers

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

b) Enablers

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

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

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

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

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

Priority #4

Theme: Diagnosis

Focus area: 4

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

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

1. How can we begin to address this priority in an effective manner?
<p>a) <u>What should we be trying to accomplish?</u> Timely diagnosis and early identification:</p> <ul style="list-style-type: none"> • American paediatric society using mandatory screening to catch these conditions early. Can we do this in Canada with GP's and NP's in more rural areas. Maybe include nurses and/or paraprofessionals as screeners. Access for parents to use on line surveys and broadening capacity of tele-health • GP perceived as barriers - how can we overcome this by using other professional (e.g. PHNs at opportunities like vaccinations to do the screenings etc.). Currently this is gated by specialist centers only accepting GP referral for in-depth assessments leading to diagnosis • Needs a system of triaging the waitlist so that services can be implemented as needed prior to getting a diagnosis • Specialist centres for diagnosis like FASD and ASD are centralised and limited and those travelling are not compensated for travel expenses to getting this diagnosis. Look at broadening tele-health to all remote areas in BC (and elsewhere) • Very vigorous process for assessment to get diagnosis. Streamline the assessment process to what is needed! <p>b) <u>If we do that, what would be the desired outcomes?</u></p> <ul style="list-style-type: none"> • More kids getting services and assessment • Moving towards early diagnosis assessment of need

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

a) Barriers

- Requires policy change to expand scope of practitioners to be able to access - NP's nurses, LPNs. Requires a real hard look at how things are financed. This is one of the main reasons for waitlists!
- Stigmatization - how to address this globally in Canada. Start with education and promotion and normalizing disabilities.
- Lack of cross ministry framework on how we will be addressing the health and wellbeing of all children. There are three different ministries who are informing us on what we need to be doing: the ministry for children and family development, the ministry of health, the ministry of education and possibly other ministries
- Stigmatization of the diagnosis itself for families
- Cultural competencies of practitioners that are dealing with the families

b) Enablers

- Build on cross ministry collaboration for health and wellbeing of all. Only have one ministry instead of 3, broaden tele-health, and build on using technology as a whole.
- Build on current climate of wanting to improve and come up with equity and mobilization of change.
- Increased awareness in general of these issues and desire to want to address these by so many different agencies

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

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

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

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

Priority #5

Theme: Education

Focus area: 15

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

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

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

a) What should we be trying to accomplish?

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

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

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

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

a) Barriers

- paucity in research evidence in some sectors
- gap in policy
- union- teachers have autonomy about their own professional development
- tensions between educators and para professionals and/or consultants

b) Enablers

- Parent Advisory Committee
- support agencies such as POPFASD, BC Centre for Ability
- certification for additional education and training taken
- professional recognition for additional training- make this important at a higher level of government
- a whole school approach- get buy in from entire agencies and schools

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

- Government funded Resources such as provincial outreach programs such as POPARD and POPFASD
- Representation from the Health Authority
- Representation from Cultural group such as First Nation and Immigrants
- parents
- peers in education and employment
- the self-advocate, other self-advocate groups that could teach and train
- advocates for individuals who have complex and a myriad of needs
- parent support groups within the school system –meeting at the schools- apart from the current role of PAC- look for administrative buy in
- engage with PAC groups to be welcoming and including the individuals with additional needs
- investment and involvement at a school district level that comes down from Ministry of Education
- Developing some demonstrations projects with education models

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

- Community Presentations
- sending out preliminary research work and passing on ideas
- find networks to disseminate information about current research and evolving research and encourage cross sector contributions
- develop mentoring networks

Priority #6

Theme: *Diagnosis*

Focus area: 3

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

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

1. How can we begin to address this priority in an effective manner?
<p>a) <u>What should we be trying to accomplish? (additional detail from large group report back is provided in italics)</u></p> <ul style="list-style-type: none"> • Early screening programs for children under two. Consistently informing various professionals about the research. Physicians need to be informed about importance of diagnosis, option to connect with other families. Families to be able to inform themselves about the condition and how best support child • Professionals with experience in working with young children. Expertise, training • Didn't find people with expertise working with 18 months to two years • Need expertise in children under two years of age. Denver model, targeting very young kids • Categorical and non-categorical – people need a diagnosis so that they can get treatment. Funding and diagnosis don't need to go together, but they do • Specialists need to be able to identify children across a wide range of specialities. Funding needs to be available on the basis of children's needs. If only funding for specific diagnosis, or diagnosed at all • Diagnosis as early as possible to inform families, expedite services based on the child's functional needs • Titrating: start early, should not require diagnosis to start intervention program. Should still be based on child's needs. What are the suspected concerns <p>b) <u>If we do that, what would be the desired outcomes?</u></p> <ul style="list-style-type: none"> • Earlier access to the most appropriate, evidence based service. All the evidence in the research says that children can get the best impact from the funding available if intervention starts early. This also ameliorates family stress • If an answer earlier, ameliorate family stress by providing clear information and related social supports • Outcome of the individual – better long term functioning maximizing and potential – neurological and physical development. Acknowledge neurological and social emotional needs. Individuals with NDD would have better functioning across these issues. Enables hardwiring of prosocial behaviour, more intellectual and physical capacity • Recognition if child not yet diagnosed, that it remains a priority as lifelong disability. Diagnosis follows the person. If suspected of diagnosis but don't have one still receive services • If no early diagnosis, at age when can diagnose, better sense of strengths, child's abilities

- Funding not just for those who meet rigid diagnostic categories

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

a) Barriers

- If don't meet criteria, don't get services. Funding restricted to diagnosis
- Not about every child is special, that's just a label. It shouldn't be a barrier to treatment.
- Diagnostic guidelines, functional assessment domains meet requirements for FASD. Can't assess all until 7 or 8 years of age. Confirmed exposure. If a child has full on FAS, facial features, severe delay, that's the time when would have early diagnosis. Complexity.
- Developmental milestones mask a condition
- The child diagnosed at 18 months or 2 , no functional assessment able to be done. Need to be able to provide the child
- Important to understand really research signs are difficult to spot for a lot of pediatricians, eye gaze, joint attention
- Invisible disabilities picking up things
- Challenging behaviour is an enabler, a sign, as is lack of speech development
- First indicators were not those behaviours when I change him doesn't play peekaboo. Joint attention piece
- Clinician training – pediatricians what to listen for. Barrier kids are coming to unnatural environment
- Diagnosis is expensive for families, expensive for families. We do get diagnosis in BC
- Barriers in way families way children are treated
- Barrier from physician perspective for CP because clinical diagnosis, chromosomal condition search for causation that may never come. Don't use clinical diagnosis
- Fee for service for a medical condition don't have that for any other issue. You access your diagnosis. Not always the case for FASD or autism
- Have to diagnosis with multidisciplinary team
- Delay in diagnosis, means parents are paying for treatment prior to diagnosis
- Don't get a diagnosis of CP – physicians reluctant to give that diagnosis. Global delay, it doesn't affect your funding - as a clinician deciding which interventions I might recommend
- Physiotherapists in community knows it's CP, can't say to the parent cant diagnose
- Early diagnosis for FASD not as early as autism. Not able to diagnosis til 5 years old, 8 – thing is we're 90 percent sure this child – kids still go into the system still have the support
- Generic level of functioning is not enough, assessment of needs of individual needs and individualized response

b) Enablers

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

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

- Parents should be consulted in this process
- There is a lack of professionals currently who families can take their children to for assessment. There is a huge training issue
- Federal ministry of health to set national standards for diagnosis and treatment³
- Pediatricians, family doctors. We have to have a referral. College of physicians and surgeons
- In BC, involvement from a speech pathologist
- Colleges of Occupational Therapy, Physical Therapy, psychology, multidisciplinary team
- BC MSP and equivalent provincial systems

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

- Require federal legislation to mandate professionals across the board requiring scope of practice training
- Reality is the provinces get money and professionals at appropriate level of government or regulatory body.
- Government to provide funding – feds provide, provinces don't have required
- Make all services "medical" even if mental health or social

³ KBHN is a national organization, would like this to be addressed by the Federal Ministry of Health to set national standards for diagnosis and treatment, we can't rely on individual provinces. Working with the members of various professional colleges to set standards for their professional development so they can't opt out because they're too busy.

Priority #7

Theme: Life Course Perspective

Focus area: 36

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

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

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

a) What should we be trying to accomplish?

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

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

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

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

a) Barriers

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

b) Enablers

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

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

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

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

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

Priority #8

Theme: Life Course Perspective

Focus area: 37

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

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

1. How can we begin to address this priority in an effective manner?
<p>a) <u>What should we be trying to accomplish?</u></p> <ul style="list-style-type: none"> • We need to engage stakeholders to be able to provide a range of supported living options for youth and adults with a variety of disabilities • In order to do this we need to identify <i>and engage</i> the various stakeholders (Federal, provincial /territorial departments social services, justice, health) and engage them in planning • We need to identify the barriers to appropriate housing from the perspective of communities, landlords, etc. and provide education and support programs to encourage their engagement. For example, substance abuse, mental health issues, poor financial management, lack of ability to access a living wage either through employment or Services for Persons with Disabilities • Continue to provide opportunities for Registered disability plans (RDSP, Disability tax credit) • Full range of safe and secure, low barrier, housing, individual, group, home share, room and board, shared accommodation, communal living, and in some cases specialized residential care • Premature aging is a significant issue for some disabilities like FASD such as early dementia, auto-immune disorders, so the need for supportive housing increases at an early age • More support to municipalities for supported housing initiatives • Life skills programs to assist individuals to develop the skills necessary to maintain their residence and residential support services on site (e.g., free washer and dryers on site, a building manager trained in disabilities, mental health <i>staff</i> support on call) <p>b) <u>If we do that, what would be the desired outcomes?</u></p> <ul style="list-style-type: none"> • Reduction in homelessness • Safe secure housing • Low barrier housing options • Access to other services because of stable housing • Reduction in secondary health issues and resulting cost savings (across the board)
2. What would be some barriers and enablers of the approach above?
<p>a) <u>Barriers</u></p> <ul style="list-style-type: none"> • IQ criteria for service access • 3 SD (standard deviations) below the mean for adaptive skills is a barrier • Lack of diagnostic access for adults • People with disabilities often have difficulty managing their resources

- Financial burden for caregivers who buy houses for their kids
- Lack of appropriate training and service to assist individuals with disabilities to manage their own living space
- Financial barriers (lack of availability, lack of funding for first and last month rent)

b) Enablers

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

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

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

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

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

Priority #9

Theme: Treatment

Focus area: 9

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

Priority #10

Theme: Mental Health/Quality of Life

Focus area: 27

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

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

<p>1. How can we begin to address this priority in an effective manner?</p> <p>a) <u>What should we be trying to accomplish?</u>⁴</p> <ul style="list-style-type: none">• To give our kids the [teaching] tools they need to be more successful in life• More hands-on, practical, authentic learning opportunities in different environments to ensure skills can be generalized• Schools could be trained in implementing these skills• More specific teaching is needed for some people – a coordinated approach between school and home will be more successful• Consistency across all environments that kids encounter is important• We all have a role to work together. Collaborative is essential – school/home/community• Identifying individual needs, across environments is critical in creating powerful interventions• Early identification and intervention is so very important• More opportunity for community/after school programs focused on self-regulation [the school building could provide this space]• Improved quality of life for everyone• Created framework where post-secondary students could utilize their program volunteer requirements (and knowledge) to these learning opportunities <p>b) <u>If we do that, what would be the desired outcomes?</u></p> <ul style="list-style-type: none">• To allow people (with needs) to feel safer in all kinds of environments• Will be more able to learn if anxiety is alleviated – greater access• Allow inclusive practices to move forward, greater acceptance in all social settings
--

⁴ This is a conversation that was happening in the background during the breakout session that was recorded: [Discussion of parent role being paramount/case managers/consultants....Each situation might be different. Advocacy is crucial – consensus that needing a key person]

2. What would be some barriers and enablers of the approach above?
<p><u>a) Barriers</u></p> <ul style="list-style-type: none"> • people who are not on board • lack of knowledge around mental health and coexistence • possibly not believing that children can have mental health difficulties • not knowing how to proceed • lack of funding <p><u>b) Enablers</u></p> <ul style="list-style-type: none"> • the redesigned curriculum – the Core Competencies • focus on social-emotional learning/self-regulation in the school system • growing conversations around mental health in different systems • grants/other sources of funding deliberately addressing social skills/self-regulation strategies • recognition of the value/practicality of this approach • school/community space to operate these programs
3. Who should be consulted/involved in the process?
<ul style="list-style-type: none"> • Students • Families • Professionals – for their expertise and feedback • School educators/Community teams/after-school programs – to facilitate learning
4. As we go through this process, how can we engage these stakeholders (that you have identified above in #3)?
<ul style="list-style-type: none"> • More public (community) education – mass media • Presentations/public workshops for everyone working with these children • Actual opportunities for university students and workers working with these children and youth, to have opportunities to take part in this learning (need the programs, the providers and the funding)

Theme	Focus Area #	Focus Area	# votes	Priority Rank
2. Treatment	8	Need access to a menu of evidence-based treatment options with information about what each of them does, and need fluidity of the system(s) that delivers these treatments so that access to families/individuals is available when needed for as long as it is needed. Need information on what evidence-based treatment is, and what is gold standard. Parents need help figuring out what's important to prioritize, can't do everything.	39	1
4. Education	19	Need for (more) professionals working within the school system (e.g. nurses, educational assistants, those delivering interventions such as physical therapy, ABA, etc.) with appropriate training to work with children with neurodevelopmental conditions.	22	2
9. Broader system and society	44	Need for more equity in funding for different neurodevelopmental conditions. In some cases, CP supports/services seem to be well-funded, ASD is also well-funded but FASD remains under-served/under-funded in comparison.	17	3
1. Diagnosis	4	Need reduction or removal of barriers to obtaining diagnosis such as: limited training for frontline health care (GPs); access to skilled diagnostic professionals, waiting lists, financial (out of pocket costs) for private diagnostic assessment, geography including rural/remote locations.	16	4
4. Education	15	Need specialized and in-depth, mandatory training for teachers, EAs, resource teachers, principal, anyone who interacts with children in schools in terms of approaches for children who have a neurodevelopmental condition. Includes need for knowledge, attitudinal and cultural training for all service providers (e.g. how to work with children/youth/adults with neurodevelopmental conditions, as well as how to work with different cultures, ethnicities and other groups of populations including indigenous communities).	15	5
1. Diagnosis	3	Need (early) diagnosis so that targeted and specific supports can be obtained for what is needed (in schools, getting services/supports, etc.). Non-categorical treatment does not allow matching of treatment to diagnosis for best outcome for the child.	13	6
7. Life Course Perspective	36	Need continuity in services at key times/transition points during the life course, and need assistance filling out required forms for access to resources (including funding programs for adults with disabilities) during transition periods. Find ways to provide continuity in services for those with ongoing medical needs (this is often lost during transition from child to adult doctors).	13	7
7. Life Course Perspective	37	Need (good) supportive housing for youth/adults to be able to live as independently as possible (some need more supports than others to maximize independence).	13	8
2. Treatment	9	Need more resources allocated to alleviate financial/resource constraints of the system as well as parents, plus more efficient use of existing resources within programs and larger system to maximize benefit to the child/family.	12	9
6. Mental Health/Quality of Life	27	Need social skills/behavioural training, and strategies for self-regulation of emotions/anxiety for the child with the neurodevelopmental condition.	11	10

Theme	Focus Area #	Focus Area	# votes	Priority Rank
1. Diagnosis	1	Need specialized training for healthcare professionals so that observations of parents will be recognized, and will ensure early diagnosis and treatment.	4	
	2	Need non-categorical treatment for the child as soon as possible, without the barrier of a lack of diagnosis getting in the way of being able to address functional deficits.	9	
	3	Need (early) diagnosis so that targeted and specific supports can be obtained for what is needed (in schools, getting services/supports, etc.). Non-categorical treatment does not allow matching of treatment to diagnosis for best outcome for the child.	13	6
	4	Need reduction or removal of barriers to obtaining diagnosis such as: limited training for frontline health care (GPs); access to skilled diagnostic professionals, waiting lists, financial (out of pocket costs) for private diagnostic assessment, geography including rural/remote locations.	16	4
2. Treatment	5	Need context-specific, timely and convenient access to treatment, centralized services with experts. Wait times, criteria for treatment eligibility (e.g. age, IQ) exclude those in need.	5	
	6	Need clear, consistent, effective communication among service professionals, to relieve this burden from parents. Need for coordination of communication among organizations; services.	2	
	7	Need non-judgmental approach by frontline workers toward parents. There is heterogeneity among parents to (accept diagnosis and) receive interventions. Feeling judged as either not motivated enough or too motivated because they want to do everything, causes undue stress to parents.	2	
	8	Need access to a menu of evidence-based treatment options with information about what each of them does, and need fluidity of the system(s) that delivers these treatments so that access to families/individuals is available when needed for as long as it is needed. Need information on what evidence-based treatment is, and what is gold standard. Parents need help figuring out what's important to prioritize, can't do everything.	39	1
	9	Need more resources allocated to alleviate financial/resource constraints of the system as well as parents, plus more efficient use of existing resources within programs and larger system to maximize benefit to the child/family.	12	9

3. Services	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.	8	
	11	Need for consistent service, especially in situations where there is high staff turnover. Can mitigate high turnover rates with full-time well paid positions with good benefits.	3	
	12	Need to allow family members to be employed/subsidized as support worker for the child, as an option.	6	
	13	Need coordinated and integrated 'wrap around care' for the child.	4	
4. Education	14	Need to identify, acknowledge, and create workaround for aspects of the physical and social environment that can help or hinder the child's success in school.	8	
	15	Need specialized and in-depth, mandatory training for teachers, EAs, resource teachers, principal, anyone who interacts with children in schools in terms of approaches for children who have a neurodevelopmental condition. Includes need for knowledge, attitudinal and cultural training for all service providers (e.g. how to work with children/youth/adults with neurodevelopmental conditions, as well as how to work with different cultures, ethnicities and other groups of populations including indigenous communities).	15	5
	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. Getting what they need (or not) affects the child's mental health and potential for success.	7	
	17	Child needs to be able to fit in with their peers at school.	9	
	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.	8	
	19	Need for (more) professionals working within the school system (e.g. nurses, educational assistants, those delivering interventions such as physical therapy, ABA, etc.) with appropriate training to work with children with neurodevelopmental conditions.	22	2

5. Health Care	20	Need additional specialized in-depth training in neurodevelopmental conditions for GPs, nurses, ER doctors, administrative staff, dentists, etc. Includes need for knowledge, attitudinal and cultural safety training for all health professionals and service providers (e.g. how to work with children/youth/adults with neurodevelopmental conditions, as well as how to work with different cultures, ethnicities and other groups of populations including indigenous communities).	9	
	21	Need smoother management of complex cases, easier access to specialty equipment, services.	3	
	22	Need timely access to psychiatrist for child/youth with neurodevelopmental conditions in order to reduce the potential for self-medicating with alcohol and/or illegal drugs and involvement with justice/police systems.	9	
	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.)	8	
6. Mental Health/Quality of Life	24	Need support(s) for parent mental health such as: self-care, support workers, respite, socializing with others who understand their situation, parent support groups which can also help address issues of isolation and stress on the marriage.	7	
	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.	9	
	26	Need to treat siblings as equally and fairly as possible, paying attention to the mental and emotional health and quality of life for neurotypical siblings.	5	
	27	Need social skills/behavioural training, and strategies for self-regulation of emotions/anxiety for the child with the neurodevelopmental condition.	11	10
	28	Need more financial control for families & a system coordinator to help access services.	5	
	29	Need equity in terms of financial cost and access/availability of inclusive recreational programs for children. Place(s) to go to find purpose, enjoyment, physical fitness and socialization.	5	
	30	Child needs purpose/meaning (in school, later in life in their employment) and needs day programs or other activities for adults who do not fit into work environment.	5	
	31	Need to acknowledge safety issues in terms of: child's difficulty managing emotions (can lead to physical aggression, self-medicating with drugs/alcohol); parents' lack of sleep which can result in medication errors, automobile and other accidents, etc.	5	
	32	Need to identify and address sleep issues in children with neurodevelopmental conditions which affect daytime behaviours of the child and parental sleep/stress.	9	

	33	Interventions and services need to be tailored to children (not based on adult mental health service model) with neurodevelopmental conditions (treatments for neurotypical children might not work).	7	
7. Life Course Perspective	34	Need supports for being successful in education at all levels, and to maximize the chances for individuals with neurodevelopmental conditions to obtain meaningful employment.	10	
	35	Adults need services to maximize their potential throughout the life course, especially if they missed the window of services during childhood. There are very few options for adults to obtain diagnosis and/or treatment or services of any kind. There is nothing for seniors.	7	
	36	Need continuity in services at key times/transition points during the life course, and need assistance filling out required forms for access to resources (including funding programs for adults with disabilities) during transition periods. Find ways to provide continuity in services for those with ongoing medical needs (this is often lost during transition from child to adult doctors).	13	7
	37	Need (good) supportive housing for youth/adults to be able to live as independently as possible (some need more supports than others to maximize independence).	13	8
	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.	10	
	8. Culture and Context	39	Need culturally specific services developed by and for a particular cultural group, offered in native language and appropriate adaptations to interventions to suit a particular culture.	4
40		Need innovative means for delivering and monitoring services and intervention delivery in remote/rural regions (e.g. tele-health).	5	
41		Need to identify and understand regional differences among provinces/territories (policies/services offered), rural vs urban, remote/northern regions including what works and doesn't work in each.	2	
9. Broader system and society	42	Need timely access to new research knowledge for informing policies, best practices, and services.	6	
	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).	2	
	44	Need for more equity in funding for different neurodevelopmental conditions. In some cases, CP supports/services seem to be well-funded, ASD is also well-funded but FASD remains under-served/under-funded in comparison.	17	3

3.0 Methodology

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

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

Analysis was conducted using the constant comparative method, using two types of coding: open and axial (Glaser, 1978; Strauss and Corbin, 1998). Situational analysis (Clarke, 2005), an extension of grounded theory method, was utilized for the purpose of illuminating variability in stakeholder positions, and interactions within the situation under study. In order to support the validity of the substantive grounded theory which was generated through this inquiry, member-validation, a method for ensuring the rigour of research findings, was employed (see Sandelowski, 1993). This involved contacting research participants, and providing a portion of the theory for comment, in order to verify its ability to truly represent the phenomena from their perspective; in other words, a grounded theory must be 'grounded' in the data (Glaser, 1978). Interview data were triangulated (see Moran-Ellis et al., 2006) with document data as well as information obtained through planning, attending and synthesizing data from a full-day in-person stakeholder event held in Vancouver where stakeholders were asked to prioritize the focus areas (and detail the needs for the top 10) obtained from the qualitative analysis. Within the subject area of this study, the basic social problem (a 'core category'¹) and the basic social process (the solution to the 'basic social problem') emerged from the data through analysis. The *basic social problem* and the *basic social process* are detailed in the results section.

3.1 Data - Online survey to KBHN researchers and trainees

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

¹ A core category is one that reoccurs frequently in the data, and is related to as many other categories (within the data) as possible (Glaser, 1978)

3.2 Data – Survey and Interviews

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

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

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

We reached ‘saturation’ after conducting thirty two (32) one-on-one in-depth semi-structured telephone interviews. Saturation is the gold standard for ensuring that adequate and quality data are collected to support the study. Saturation means that the collection of more data will not add any more information; nothing new can be learned from conducting additional interviews (Patton, 2002). These interviews were conducted between June 30, 2016 and August 29, 2016 with a mixture of different types of stakeholders from across Canada: clinician researchers within KBHN, clinicians/frontline workers not affiliated with KBHN, provincial and program level policymakers, and parents. Best efforts were made to equally represent all three neurodevelopmental conditions that are the focus of the Network: FASD, ASD, and CP and each province and territory. Interviews ranged in length from 45 minutes to three hours. Many interviews were at least 2 hours.

Table 3.1. Distribution of Interviewees by Role and area of Expertise. Interviewee/transcript number is indicated for identification of multiple areas of expertise within each role (but not multiple roles within each area of expertise).

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

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

Geographic Distribution of Interviewees

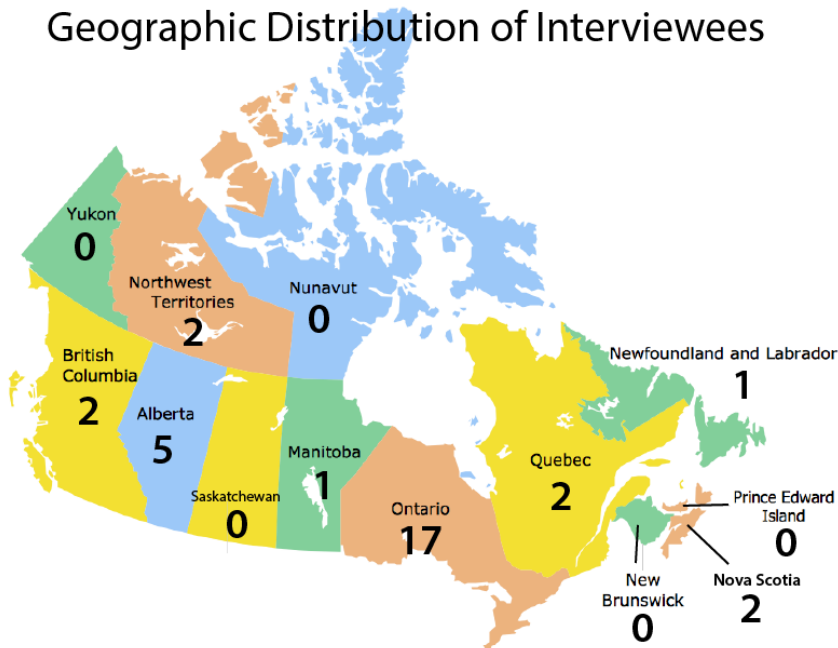


Figure 1. Geographic distribution of the number of individuals who participated in a telephone interview as part of the stakeholder engagement project, according to their current location.

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

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

3.3 Data - Triangulation Documents

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

Geographic Distribution of Government Reports Reflecting Stakeholder Needs

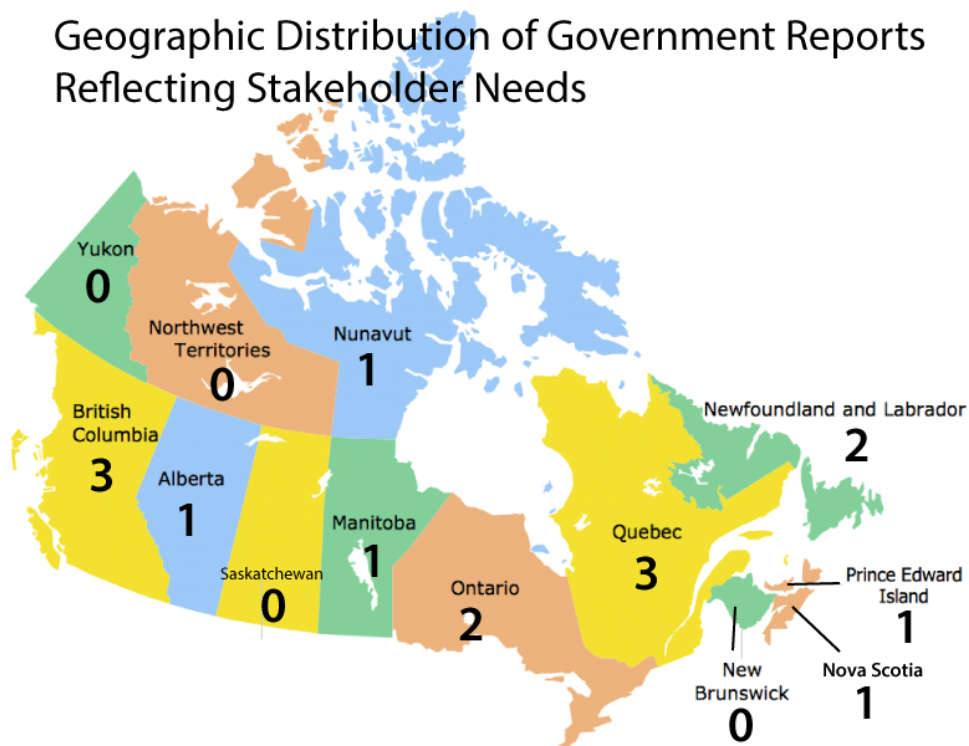


Figure 2. Geographic distribution of reports based on stakeholder consultations conducted by government or community organizations funded in part by government.²

3.4 Analysis

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

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

² *there were 2 national level reports that were included in the analysis and scan but are not included in the map because as national reports they are not associated with any individual province or territory.

Qualitative analysis was conducted using the constant comparative method (Glaser, 1978). N-Vivo 11 software was used for open and axial coding (see Appendix I) with memoing. Initially, 9 themes and 43 focus areas were identified and sent to participants for feedback in November 2016 and revised accordingly (see 3.6 Trustworthiness) resulting in 9 themes and 44 focus areas.

3.5 Trustworthiness through validation with participants

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

Member-checking or member-validation is a method for ensuring the rigour of research findings, by contacting research participants and providing a portion of the findings for comment, in order to verify its ability to truly represent the phenomena from their perspective (Glaser, 1978). The key dimension of trustworthiness is ‘fit’, in other words, do the findings ‘fit’ with what the situation actually is? In order to determine ‘fit’, participants were provided with initial results which identified 9 themes with 46 focus areas and asked to provide feedback within a 2 week period ending November 23, 2016 (see Appendix G; Birt et al., 2016). After November 23, feedback from 13 out of the 32 respondents was compiled and used to revise and refine into 9 themes and 44 focus areas. Another layer of establishing trustworthiness involved triangulating interview data (see Moran-Ellis et al., 2006; Lincoln and Guba, 1985; Sandelowski, 1986, 1993) with the document data. The 17 reports that had been identified and included in the analysis were purposely not reviewed prior to coding of interview data, in order to minimize coding bias. After initial coding and member-validation, the 17 reports were reviewed, and portions that supported the findings of this study were extracted. This information was inserted in the results section where appropriate to support or clarify what had been articulated as a result of our analysis of our interview data. In order to allow us to make recommendations to the Network for strategic planning and resource allocation, we enlisted the help of a similar (but different) set of stakeholders in Vancouver, BC to help us prioritize the 44 focus areas into a ‘top ten’ list, as well as to provide additional detail about how to approach each priority (see Appendix L).

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

3.6 In-person Stakeholder Consultation Priority-Setting Event

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

This event provided additional information (about which focus areas should be prioritized, and details on how we can address them) beyond what our previous analysis and results could provide. The rationale was, we needed the wisdom of our stakeholders to help 1) prioritize the 44 items in terms of what is most important to address first (acknowledging that they are all important but recognizing the reality that all 44 cannot be addressed at once), and 2) provide us with additional details for how KBHN can begin to address these priorities. The structure of this event utilized the well-established facilitation framework ‘ORID’ (Objective, Reflective, Interpretive, Decisional) (Hogan, 2005) which, due to its format, allows individuals to move through the necessary stages of thinking to provide the information that was being sought (see Mungia et al., 2015). The day began with one presentation to anchor the day, containing information about the Network, stakeholder engagement and research study purpose, process and results (the “objective” stage, to ‘get everyone on the same page’). After presenting the results (the 44 focus areas) to the 25 stakeholders (a different set of parents, clinicians/frontline workers, policymakers) in attendance, they were provided with an opportunity to vote (the “reflective” stage, whereby participants are provided with an opportunity to have an emotional reaction to what they have just heard. Without this, participants would be unable to enter the interpretive phase during which critical thinking

can take place). Stakeholders were asked to vote using a process called ‘dotmocracy’ to help identify the top 10 priorities that the Network could focus on. Each of the 44 priorities had been printed and laminated on separate cards and placed around the room, and participants were provided with a ‘map’ to help them locate the card(s) they wished to vote on and 14 stickers to use for voting. Participants were instructed to place dots on the focus areas that they believed were a top priority; one sticker could be placed on 14 individual items or all 14 on one item if they felt strongly about it (and any combination in between). The results of the voting are provided in a table (Table 4.2, Section 4.0). The top 10 priorities were then discussed by participants in breakout groups (the “interpretive” and “decisional” stages), 5 priorities discussed in the morning and another 5 in the afternoon, one per table (5 tables) using a template with focused discussion questions (see Appendix L). Each group was asked to elect a note-taker to fill out the electronic template provided on a laptop at each table during the breakout discussions. Afterwards, the templates were collected from each group on a USB key and opened on a laptop that was connected to a projector, so that during the large-group report back everyone could see and comment on the answers provided by the one group to help clarify or add to any of the information provided. The additional information and comments gathered through the large group report back exercise was audio recorded and utilized to refine and clarify the input provided by stakeholders for each of the prioritized needs that were discussed in breakout groups. The resultant document is provided in Appendix L.

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

3.7 Limitations

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

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

Appendix A: Methodology – additional detail and rationale

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

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

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

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

with situational analysis, provides a way to describe and organize the findings about human interaction at the interpersonal, institutional, community and global levels (Strauss and Corbin, 1998).

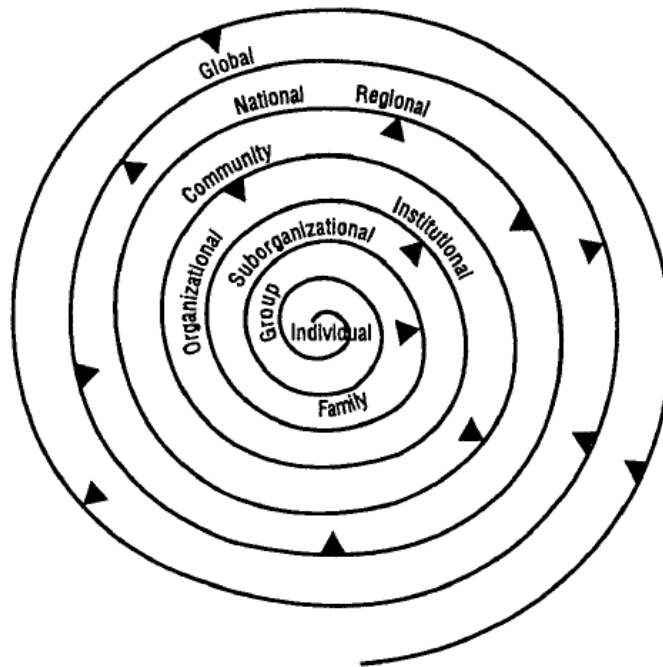


Figure 3.1. Strauss and Corbin's (1998) Conditional Matrix.

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

Summary of methodology and timeline

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

Date(s)	Activity
May, 2016	Online survey ³ administered within the Network. Survey data utilized for identification of previous stakeholder consultation activities with formal documentation of stakeholder needs as well as potential clinicians to interview
June, 2016	Emails sent to survey participants requesting documentation related to stakeholder engagement activities reported in online survey, that have taken place within the Network throughout its existence
June, 2016	Online search for policymakers, emails sent to individuals identified
June 21, 2016	Ethics approval received for conducting one-on-one interviews
June-September 2016	One-on-one telephone interviews conducted. Transcription, open/axial coding (constant comparison and memoing) completed in parallel
July-August 2016	Document data collection, online search for reports on government-funded stakeholder consultations that identified and reported on stakeholder needs with respect to ASD, FASD, CP
July 27, 2016	Ethics approval for amendment #1 received (to interview clinicians outside of the Network)
November, 2016	Identified themes and focus areas sent to interviewees for feedback as part of member-validation
December, 2016	Themes and focus areas updated according to feedback received from interviewees
January 11, 2017	Ethics approval for amendment #2 received (to record stakeholder event and write paper)
January 18, 2017	One day in-person stakeholder consultation event in Vancouver, BC with similar categories of stakeholders but different set of individuals than those who were interviewed, to prioritize the 44 focus areas that emerged from the analysis of interview data, and help detail next steps for the top 10 priorities

³ Using REDCap (Research Electronic Data Capture), access and support provided through KBHN’s Neuroinformatics Core

Appendix B – Letter of Informed Consent

Date: June 7, 2016

Study Name: KBHN Stakeholder engagement project of Stakeholder Needs

Researchers:

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

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

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

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

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

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

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

Withdrawal from the Study: You can stop participating in the study at any time, for any reason, if you so decide. Your decision to stop participating, or to refuse to answer particular questions, will not affect your relationship with the researchers, York University, or any other group associated with this project. In the event you withdraw from the study, all associated data collected will be immediately destroyed wherever possible. Should you wish to withdraw after the study, you will have the option to also withdraw your data at any time.

Confidentiality: The interviews will be digitally recorded in order to facilitate transcription and qualitative analysis. Your identifying information will be associated with the transcripts only for the purpose of being able to return to you at a later time to obtain clarification of your response(s) if needed. All information you supply during the research will be held in confidence and unless you specifically indicate your consent, your name will not appear in any report or publication of the research. Your data will be safely stored in a locked facility at York University in Kaneff Tower. Only research staff will have access to this information. The data will be stored for 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 (dhipps@yorku.ca). This research has received ethics review and approval by the Human Participants Review Sub-Committee, York University's Ethics Review Board and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines. If you have any questions about this process, or about your rights as a participant in the study, please contact the Sr. Manager & Policy Advisor for the Office of Research Ethics, 5th Floor, Kaneff Tower, York University (telephone 416-736-5914 or e-mail ore@yorku.ca).

Legal Rights and Signatures:

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

Signature _____

Participant

Date _____

Signature _____

Principal Investigator

Date _____

Appendix C – Semi-Structured Interview Questions - Clinicians

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

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

Section A: Getting to know respondent

A. Where are you located? (city/province)	
B. What project(s) are you working on that are funded by KBHN? ⁴	

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

<p>1. In the survey you recently filled out, you had indicated that you are aware of stakeholder needs because of the interaction you have with families/children/youth with neurodevelopmental disabilities.</p>	<p>a. which neurodevelopmental disability do you mainly focus on in your work (e.g. CP, FASD, ASD, all)?</p> <p>b. what are the main challenges parents/children/youth affected by (CP, FASD, ASD) tell you they experience?</p> <ul style="list-style-type: none"> • Challenges encountered with health care services and/or programs? (e.g. getting a diagnosis, access to treatment programs and services, access to assistive technologies, services for families) • Biggest challenge in terms of “life with a neurodevelopmental disability” (e.g. quality of life for individual who has the disability, quality of life for the parents/whole family, isolation, recreation, school etc) • How do you know what are the needs of families/parents (what are the sources of information that you access, to understand the needs/challenges of families? e.g. personal interaction/discussions with families, academic literature, other?) <p>c. what are your challenges as a clinician/service provider?</p> <ul style="list-style-type: none"> • Being able to provide early diagnosis/treatment to your patients/clients • Being able to help improve the quality of life (in general) for your patients/clients • Anything else
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⁴ Note: This question was skipped in the case of interviewing a non-network affiliated clinician

	<p>d. what do you think is/are the solution(s)?</p> <p>e. what do you think KBHN can do to facilitate working towards making these solution(s) a reality?</p>
<p>2. If you had unlimited resources, time and power to change anything you wanted, in order to make life better for your (clients/patients and/or their families) what would it be?</p>	<p>a. Why?</p> <p>b. How would you accomplish it?</p>
<p>3. Do you have any formal synthesized documentation of the needs/challenges of parents/families/children affected by NDD that you could share, to become part of this stakeholder engagement project?</p>	<p>a. stakeholder consultation meeting report(s)</p> <p>b. in the absence of formal meeting report(s), any raw data such as breakout activity forms, or any forms filled out by stakeholders where they gave feedback/input?</p> <p>c. meeting evaluation forms? (not the most important documents, but would be nice to see)</p>
<p>4. The main purpose of these interviews, and collection of information about stakeholder needs/challenges is to inform the future work of KBHN including future research programs. Is there anything else you would like to add, that maybe I didn't ask about that you think is important to mention?</p>	

Appendix D – Semi-Structured Interview Questions - Policymakers

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

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

Section A: Getting to know respondent

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

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

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

Appendix E – Semi-Structured Interview Questions - Parents

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

[KBHN](#) is a federally funded [Network of Centres of Excellence \(NCE\)](#) focused on the early diagnosis and treatment of neurodevelopmental disabilities such as Fetal Alcohol Spectrum Disorder, Autism Spectrum Disorder and Cerebral Palsy. As a pan-Canadian Network, we collectively strive toward achieving real change in policies and practices in Canada in order to maximize the quality of life for children, youth and parents/families affected by neurodevelopmental disabilities. The way we do this is by finding out (and responding to, by forming our research projects on) what are the main challenges/needs of policymakers and practitioners, as well as parents/families/children/youth. We are interviewing you as a parent to find out about the challenges and needs you and your child experience, and what could be done about those experiences that would improve your/your child's/your family's quality of life⁵. This information will be used to inform KBHN's future research programs, training of the next generation of researchers, and for effective knowledge translation of research findings toward positive changes in policy and practice in Canada.

Section A: Getting to know respondent

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

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

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

⁵ Definition of Quality of Life: the standard of health, comfort, and happiness experienced by an individual or group.

Appendix F – Email Sent to Interviewees for Member Checking

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

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

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

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

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

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

Thank you in advance for your time in reviewing this.

Kindest regards,
Anneliese Poetz

Appendix G – List of Documents Triangulated with Interview Data

1. Accessibility 2024: Making B.C. the most progressive province in Canada for people with disabilities by 2024. British Columbia. 1-17. Accessed November 15, 2016 from: http://www2.gov.bc.ca/assets/gov/government/about-the-bc-government/accessible-bc/accessibility-2024/docs/accessibility2024_update_web.pdf
2. Borisoff, J., J. Ho, S. Jamal, et al. (2012). Minister's council on employment and accessibility: action plan framework for the Minister of Social Development and Social Innovation. British Columbia. September: 1-6. Accessed November 15, 2016 from: <http://www2.gov.bc.ca/assets/gov/government/about-the-bc-government/accessible-bc/accessibility-2024/docs/action-plan-framework.pdf>
3. Aitken, J. et al. (2016). Connecting family needs to ASD research in BC: full report 2015/2016. British Columbia. 1-50. Accessed November 15, 2016 from: http://informeveryautism.com/wp-content/uploads/2016/05/Autism_Full_Report_April25_screen.pdf
4. FASD 10-year Strategic Plan (2008). Alberta. 1-36. Accessed November 15, 2016 from: <http://fasd.alberta.ca/documents/FASD-10-year-plan.pdf>
5. Together we are stronger: continuing the success of Manitoba's FASD strategy. Manitoba. 1-5. Accessed November 15, 2016 from: http://www.gov.mb.ca/healthychild/fasd/fasdstrategy_en.pdf
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