

Small Group Sessions: Diagnosis/Screening

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Although the American Academy of Pediatrics has issued guidelines about screening for ASD, their uptake has been limited. In Canada there are no formal guidelines (and no professional group has recommended universal screening). As well, Canadian physicians are generally apprehensive about the use of standardized tools to screen for ASD, preferring more of a surveillance approach. They believe that their clinical skills are good enough to detect children at risk and they are also concerned about the effects of a false positive result. It is apparent that there is an ongoing need for further dialogue and consensus-building regarding best practice for ASD screening in Canada, given the potential implications for age of diagnosis, timing of intervention and other services, family experiences, and long-term developmental course.

Researchers are making progress in the development of screening tools, and clinicians are gaining experience in the use of tests for 18 to 24 month children. However, it may be that a multistep screening process needs to be put in place to ensure that appropriate and early referrals are made for diagnosis. Canadian studies have identified 2 patterns of trajectory. One group of children is less communicative and withdrawn between 6 and 18 months. A second group has clear symptoms in the first year but less rapid change between 1-2 yrs of age. Some of these children may later have a profile of children with Asperger disorder, who are usually diagnosed later than children with other ASDs.

Clearly, there are many factors that contribute to the age at which children with ASD are diagnosed and receive services, and there is a need for further research on many fronts. We're interested in hearing more about the various perspectives on research priorities in this area.

Participants' Perspectives

Parents live with their concerns about their child's development long before a diagnosis is made. Parents are quite accurate in what they describe as being symptoms of ASD, but getting the diagnosis is the critical point for opportunities to intervene. Early diagnosis is also viewed as leading to improved quality of life, access to school supports, and also helping persons with ASD understand their own behaviours (e.g. perseverative interests) so they "don't have to feel guilty about it" and because "it has helped me navigate through society"

Group members stated that they believe that early intervention works and that high-risk children should be diagnosed early and intervention commenced in a timely fashion. However, there were concerns expressed about the variability in physician practice around diagnosis and treatment recommendations. They believe that a national population level screening program should be

carried out. They also identified the need for tools to definitively diagnose autism because it is unacceptable for parents to wait for long periods for a definitive diagnosis after the child has been identified as 'possibly having a pervasive developmental disorder'. Delays in diagnostic process lead to undue stress and anxiety for families. However, physicians should be clear about their decision to refer a child -- A physician should never give a 'possible ASD' diagnosis. The terms around the autism should be specific and not ambiguous. Other comments included:

- Recognizing that there are many older youth and adults with ASD who have not been able to access an appropriate diagnosis, assessment research supporting improved diagnosis should involve participants across the life span. This should include assessment of screening in childhood, adolescence and adulthood.
- The practicality of screening: who, what, where and when. Can a single measure be used to identify a child at risk, or is a more sequential approach needed?
- Due to the lengthy delays that commonly occur between first concerns and definitive diagnosis, research should focus on the identification of early signs and the development of economical interventions (e.g., effective but potentially less intensive) for very young children with early signs, regardless of diagnosis.
- There must be safeguards to misdiagnosis and initiating interventions inappropriate to a child's needs.
- Access to intervention (and eligibility for treatment research) should not be based solely on diagnosis. We should evaluate different therapies and see which is best suited for specific constellations of symptoms. Policy/ mandates must be more flexible to ensure that children and adults can access interventions based on functional needs e.g. starting social skills groups.
- Who is the authority on diagnosis? Parents vs. professionals? Some participants commented that parents know their children best, and thus are the authority when it comes to identifying atypicalities in development but expert clinical judgement is needed to evaluate how these atypicalities relate a specific diagnosis such as ASD. More collaboration is needed.
- Is being termed "high functioning" a burden on the child? Is this label inappropriate? Does it lead to inadvertent inappropriate expectation laid down for parents?
- Are there different critical phases for different individuals with ASD? Are there different critical junctures depending on trajectory?
- Challenge of moving these children into services. Is the system ready to take on early screening when there is a considerable wait time for diagnosis and then an additional wait for service? Thus we need capacity building in the system- but how do we do this?
- Need for diagnostic staff to have understanding of what supports are available in the community that they are working in, better understanding of what you are sending families out into. Diagnosis and service provision are especially important in adult system.
- Ethical obligations: if you screen for ASD, what other diagnoses are you going to screen for? Approximately 30% of Canadian children enter the school system with developmental vulnerabilities. Perhaps a general screen with an autism algorithm could

be used. Regardless, researchers (and the health system as a whole) must be prepared to address the needs of the broader range of children with developmental differences who are flagged by screening programs.

- How do families understand the information that is given to them? What kind of translational process needs to occur here? Can we communicate more effectively and how?
- What happens when the diagnosis changes over time? Need to have children (and variation in developmental trajectories) better described in the research literature so we know exactly who is responding and not responding to interventions or how to interpret when trajectories shift/diverge?
- How well do current screening and diagnostic tools scale down to very young age groups (i.e., does sensitivity and specificity vary by age and developmental level)?
- Will this lead to over or under diagnosis until we have a better understanding of ASD in infants?
- Is it really early intervention that brings about the change or is it natural trajectory?
- We should begin to listen to adults who are living with autism and talk about concerns about research. Need to change policies around research.

PROPOSED RESEARCH QUESTIONS

- How do we go about understanding and determining what is important for a family and child who is diagnosed with autism. How can we empower families to articulate their needs?
- How can we utilize parent reports and known characteristics of ASD to promote early/timely diagnosis of autism? This should be approached at three levels: dissemination of tools for parents, professional education and greater focus on the need for screening tools across the lifespan (including adults).
- What will work in a rural setting where there is lack of resources? Should we be utilizing public health nurses as initial contact persons who will initiate screening if there are a concerns about a child's development? How might different systems of care (as opposed to different screening tools) perform in various settings?
- Is there a role for prenatal education about red flags for ASD in early child development?
- How can we identify children who are higher functioning earlier, especially girls, whose profile is often atypical or more subtle compared to boys? This influences opportunities for early intervention and may possibly change outcome.