Screening, Assessment and Diagnosis of Autism Spectrum Disorders in Young Children

CANADIAN BEST PRACTICE GUIDELINES

MIRIAM FOUNDATION 2008
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Introduction, Background & Methodology

Recent media attention has brought to light a public perception that the prevalence of Autism Spectrum Disorders (ASD) is increasing. The American Center for Disease Control and Prevention reported the prevalence of Autism Spectrum Disorders (ASDs), including autistic disorder, Asperger's disorder, and pervasive developmental disorder – not otherwise specified (PDD-NOS), ranged from 4.5 to 9.9 per 1,000 8-year-old children in 2000. Research by scientists in Canada show results comparable to the CDC findings with estimates ranging from 3.8 to 4.1 per 1,000 5 to 9 year olds in Manitoba and Prince Edward Island in 2002 to a high of 6.7 in 8-year-old children in one Montreal school board in 2003. The prevalence of autistic disorder is estimated at 13 / 10 000, 20.8 / 10 000 for PDD-NOS and 2.6 / 10 000 for Asperger’s disorder. These rates represent an increase in diagnosed individuals since the mid 1980s, consistent with the public perception that ASDs are on the rise. An important question is whether or not this increase reflects a real increase in the incidence of ASDs. Fombonne, Shattuck, Taylor, and most recently Ouellette-Kuntz et al and Coo et al. provide evidence that suggests this upward trend may actually reflect evolving diagnostic criteria, diagnostic substitution, changes in special education policies, and the increasing availability of services, rather than a secular increase. Regardless of the underlying cause, the increasing prevalence of ASDs, along with the increasing demands of stakeholders for adequate care and treatment of individuals with ASDs, has been an impetus for changes in policies and practice.

In the 2007 document, Pay Now or Pay Later: The Final Report on the Enquiry on the Funding for the Treatment of Autism, The Standing Senate Committee on Social Affairs, Science and Technology responded to the growing sense of urgency regarding the needs of Canadian individuals with autism and their families. In particular, the report focused on the funding of early treatment for young children with ASDs and emphasized the importance of early investments to offset future costs. The report highlighted the significant wait times endured by families seeking a diagnostic assessment of ASD for their child, and identified the shortage of well-trained professionals in the area of ASDs as a contributing factor for this problem. The report also cited Motion M-172, adopted by parliament on December 5, 2006, which called for the development of a national autism strategy, including the development of evidence-based standards for the diagnosis and treatment of autism, innovative funding methods for the care of those with autism, the provision of additional federal funding for autism research and the implementation of a national surveillance program for autism. It is clear that the early identification and treatment of ASDs is recognized widely as a critical issue in need of attention.

In their position statement regarding early intervention for children with ASDs, The Canadian Paediatric Society suggested that intensive behavioural interventions, provided early in life, lead to positive outcomes for children with autistic disorder. Although more research is needed to provide a stronger empirical basis for these treatments, it is clear that it is beneficial to provide behavioural interventions to children with delays or atypicalities such as ASDs as early as possible. Crucial to the success of early behavioural intervention is early identification.

Research has shown that children can be identified with signs of an ASD by the time that they are 18 – 36 months of age, and prospective research programs offer promise in the possibility of determining the earliest possible indicators of ASDs in infancy. Examinations of early family videos (e.g., first birthday parties) of children
with diagnoses of ASDs have revealed signs and symptoms by the first year of life. Not only is it necessary to identify children in the toddler years, it is also possible to do so, given the use of appropriate tools and techniques. As research in this area grows and diversifies, and community awareness of ASDs increases, it has become necessary to create a Canadian national strategy for the early identification of ASDs in young children.

The purpose of this document is to delineate Canadian best practice guidelines for early screening, assessment and diagnosis of ASDs in very young children (ages 0-5 years). The best practices described in this document were derived from scientific literature and agreed upon by expert consensus of Canadian researchers in ASDs, with input from active clinicians and parents. The following document is intended to provide a useful set of guidelines for professionals and policy makers involved in the screening, assessment and diagnosis of ASDs to assist in their timely and accurate detection. Further, we have included recommendations for future research and policy to promote continued development within the field toward an ideal standard of practice, beyond what is currently possible given existing research and policy.

The following guidelines are not mandatory and may or may not be consistent with current provincial legislation or organizational policy. They are intended as aims or ideals for clinical practice, research and policy, given the current scientific evidence and expert consensus. The guidelines are intended for use by individuals, organizations, and governing bodies to promote practices and policies that will result in earlier detection of ASDs in young children, through effective practices of surveillance, screening, and diagnosis. It is recommended that these best practice guidelines be reviewed regularly, in order to remain up-to-date with the most recent scientific evidence. It is further recommended that services in this area review their current standards and practices in ASD diagnoses with reference to these evidence-based guidelines.

**Autism Spectrum Disorders**

The standard criteria for the diagnosing ASDs are found in the Diagnostic and Statistical Manual – 4th Edition, Test Revision (DSM-IV-TR). The DSM-IV-TR refers to a set of conditions called the Pervasive Developmental Disorders, which includes the sub-types of Autistic Disorder, Asperger's Disorder, Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS), Rett Syndrome, and Childhood Disintegrative Disorder. This category of disorders is connected by a symptom set including impairments in reciprocal social interaction, in verbal and nonverbal communication skills, and by the presence of restricted, repetitive and stereotyped patterns of behaviour. The first three disorders (autistic disorder, Asperger’s disorder, and PDD-NOS) are known as the Autism Spectrum Disorders. Although Rett syndrome and childhood disintegrative disorder are included in the DSM-IV categorization, they are not included in this document, as they are characterized by a unique symptom profile reflecting a later onset and degenerative course.

The International Classification of Disease (ICD-10) published by the World Health Organization also identifies the Pervasive Developmental Disorders as a group of disorders characterized by qualitative abnormalities in reciprocal social interactions and in patterns of communication, and by a restricted, stereotyped, repetitive repertoire of interests and activities. The Pervasive Developmental Disorders category in the ICD-10 comprises more types of disorders than the DSM categorization; however, the groupings are comparable. Similar to the DSM-IV-TR, the ICD-10 includes the sub-types Childhood Autism and Asperger’s Syndrome. The DSM-IV-TR category of PDD-
NOS is represented in the ICD-10 by both Other Pervasive Developmental Disorders and Atypical Autism. In addition, the sub-types Rett’s Syndrome, Other Childhood Disintegrative Disorder Unspecified, and Overactive Disorder Associated with Mental Retardation and Stereotyped Movements are included. The DSM-IV-TR and ICD-10 criteria are presented in Appendix A.

The two diagnostic systems correspond in their conceptualization of the three basic symptom categories of ASDs, including impairments in social interaction and in verbal and non-verbal communication, and restricted, and repetitive and stereotyped patterns of behaviour, interests and activities. The following summarizes a description of each category by the American Academy of Pediatrics. The first symptom category, impairments in social interaction, encompasses problems with relating socially to others and share corresponding feeling states. Children with ASDs tend to withdraw from others, have difficulty in engaging with other children or adults, and may not seek attention from others. These children demonstrate difficulties with joint attention, or, sharing interest. Children with deficits in joint attention may not follow a gaze or a point to see what someone is looking at, point to show interest (although, they may point at something they want), or indicate by gaze, point or vocalizations for another individual to attend to something that they find interesting. They have a diminished ability to orient to social stimuli (not turning to respond to hearing their name) and lack a Theory-of-Mind (the understanding that others have thoughts, desires, and beliefs which differ from one’s own, as required in being able to consider something from the perspective of another). These deficits make it difficult for children with ASDs to form social relationships that are truly reciprocal in nature. The second set of symptoms involves impairments in communication, ranging from a complete absence of spoken language to odd or idiosyncratic language. These oddities may include language that seems scripted from television, repetitive or echolalic language (parrotting), and “pop-up” and/or “giant” words (such as “whatisthis”). Finally, children with ASDs demonstrate restricted repetitive and stereotyped patterns of behaviour, interests, and activities. These symptoms may tend to emerge later than the others due to early limitations in physical development and may include highly specific and focused interests (e.g., obsessions with maps or sea creatures, to the exclusion of other interests), inflexibility with regard to routines (e.g., perseveration on using a particular route), and stereotyped mannerisms (e.g., hand-flapping, self-injurious behaviours).

Although the ASDs are characterized by this triad of symptoms, there is wide variation in the presentation of these symptoms among children with ASDs, and the severity of the different symptom sets vary by diagnostic sub-type and developmental level. Children with autistic disorder, the most severe manifestation of the ASDs, display all three symptom subsets to varying degrees. Children with Asperger's disorder tend to have speech difficulties relating more to their pragmatic use of language rather than in regard to speech production or comprehension, in addition to stereotyped interests and social difficulties. Although many children with autistic disorder have concurrent cognitive limitations, the presence of an intellectual disability excludes a diagnosis of Asperger's disorder. Finally, a diagnosis of PDD-NOS is typically applied to children with some combination of the three symptom areas, but who do not meet the criteria for either autistic disorder or Asperger's disorder.

Although the exact etiology of ASDs is unknown, they are generally considered to involve abnormalities of brain structure or function. The cause of ASDs remains a topic of continued investigation; however, it is clear that ASDs appear to have a genetic contribution, involving more than one gene. Twin studies suggest a high concordance rate among monozygotic twins compared with dizygotic twins. There is strong
evidence for familial aggregation\textsuperscript{34,35}, that is, when one member of the family has an ASD, other members of the family are more likely than the general population to have an ASD or sub-threshold autistic traits\textsuperscript{36}. More than 15 different genes have been implicated in the development of ASDs and it is likely that multiple gene interactions are implicated\textsuperscript{37}. Environmental triggers have also been implicated; however, research has supported this to a lesser degree. Vaccines have widely been suggested as a possible trigger for the onset of ASDs; however, well-designed investigations have not supported this hypothesis\textsuperscript{3,5,38,39,40}. Other environmental factors, including viruses, extreme prenatal stress and the presence of environmental toxins, may warrant further investigation.

Definitions and Core Concepts

**Best Practices**

There are many measures, methods, and techniques available for the diagnosis of ASDs. Only some of these have been scientifically evaluated and even fewer have been demonstrated as effective and efficient. In this document, best practices refer to the measures, techniques and methods that have been demonstrated to be valid and reliable through scientific research and/or have been agreed upon by a committee of scientific experts and experienced clinicians, with input from active clinicians and parents. The documentation of a set of evidence-based best practices offers a summary of the most up-to-date research and practice standards to professionals in the field. Further, access to best practice guidelines may enable parents to avoid the negative outcomes of a misdiagnosis or lack of diagnosis, and could lead to better uses of precious resources such as time, energy, and money.

**Developmental Surveillance**

According to Dworkin\textsuperscript{42} developmental surveillance is a “flexible, longitudinal, continuous process in which knowledgeable professionals perform skilled observations during child health encounters” (p. 829) with the goal of detecting developmental problems in young children. Surveillance requires knowledge of typical and atypical development as well as clinical experience and specific training in early childhood development.

**Screening**

Screening utilizes standardized measures on an identified population in order to assess for possible or probable cases by comparing achieved scores to normative standards. Screening tests do not result in diagnoses but suggest the need for further investigation.

**First Level Screening:** First level screening, also referred to as universal screening, involves applying a standardized screening tool to a large population with the goal of identifying individuals with a high likelihood of having a specific disease or disorder, leading to a referral for a more in-depth assessment or treatment. In regard to ASDs, first level screening would involve assessing all children of a given age for symptoms of ASDs, regardless of whether or not there were any indications of developmental challenges. This could occur during a regular “well-baby” check-up, regardless of whether or not parents have raised concerns.

**Second Level Screening:** Second level screening also employs standardized measures, but is employed with a subgroup of individuals considered to be at an elevated risk for a disease or disorder. A positive score on a screening test should lead to a referral for a more in-depth assessment. In regard to ASDs, second level screening would be employed with children who had demonstrated signs of the disorder (such as missed developmental milestones, delays in communication and social development) or who are
at elevated genetic risk (children with a sibling or parent with an ASD, or other related disorder).

**Sensitivity:** Sensitivity is the likelihood that the screening tool will indicate the presence of an ASD when an ASD is actually present.

**Specificity:** Specificity is the likelihood that the screening tool will indicate the absence of ASDs when the child does not have an ASD.

**Positive Predictive Value:** Positive predictive value is the likelihood that a positive screening test result will be obtained for a child with an ASD.

**Negative Predictive Value:** Negative predictive value is the likelihood that a negative screening test result will be obtained for a child who does not have an ASD.

**Assessment**
Assessment typically involves the administration of a combination of standardized tests and behavioural observations in an order to achieve a specific, pre-determined goal. Four reasons for conducting an assessment for a person with (or suspected of having) an ASD include: (1) To help understand the person, (2) To obtain or clarify an initial diagnosis, (3) To document diagnostic status necessary for access to services or funding, and (4) To obtain information for program evaluation or research purposes. An assessment can also provide information useful for treatment planning.

**Interdisciplinary Team:** An interdisciplinary approach to assessment and diagnosis involves the integration and synthesis of information gathered by professionals of different disciplines, through an interactive group process. In the interdisciplinary team, team members are located in close proximity and communicate frequently in order to inform each other and ensure that there is no duplication of effort. Findings of one member of the team are considered in light of findings from other members. This approach is more coordinated and holistically-oriented than the multidisciplinary team approach.

**Multidisciplinary Team:** Like the interdisciplinary team, the multidisciplinary team involves multiple types of professionals, but lacks the integration and coordination of the interdisciplinary approach. In the multidisciplinary team, each professional acts separately from the others and draws conclusions without input from the other team members.

**Reliability:** Reliability is the degree to which the assessment, if repeated, would result in consistent results. That is, if a child is assessed as having an ASD on one occasion, an assessment on a different occasion by the same or different assessors should result in similar findings.

**Validity:** Validity refers to the degree to which an ASD assessment actually measures the symptoms of ASDs.

**Diagnosis**
Despite evidence suggesting that ASDs have a biological basis and genetic origin, there is currently no known biological marker for ASDs. That is, ASDs cannot be diagnosed using medical procedures, such as blood tests or brain scans, although these evaluations may be useful corollary investigations in children with medical or neurological indications. A diagnosis of an ASD is made by an expert.
diagnostician or interdisciplinary team, based on the child's developmental history and direct behavioural observation. A process of differential diagnosis must be undertaken to rule out other disorders with overlapping symptoms, and corollary investigations may be needed to determine the presence of commonly co-occurring disorders and / or to identify strengths and weaknesses for intervention purposes. This type of assessment requires a high level of training and experience on the part of the assessors. The diagnosis of an ASD is typically made by physicians (child psychiatrists and pediatricians, in particular) and / or psychologists.

**Methodology**

The methodology for this set of guidelines was broadly based on the rationale and methodology of the New York State Department of Health's Early Intervention Program employed in the development of their clinical practice guidelines, and included the following components: review and synthesis of best practice guidelines from other provinces, provinces, and organizations, literature review, development and review of evidence tables, meetings of parent and clinician committees, expert consensus, and document reviews, both by committee members as well as two expert reviewers who were not part of the original committee.

**Best Practices Review**

A review and synthesis of existing evidence-based best practice guidelines formed the basis for the current recommendations. The following is a list of the reviewed documents, which provided a starting point for the current guidelines.

- California Department of Developmental Services (2002). *Autism Spectrum Disorders: Best Practice Guidelines for Screening Diagnosis and Assessment*.
- Lignes directrices concernant les références aux cinq CRDITED de Montréal pour les personnes présentant un Trouble envahissant du développement (TED) (2006)

Each of these documents was carefully reviewed and a list of commonly existing recommendations was synthesized into a summary of best practices and sent to committee members for review. The best practice synthesis is included in Appendix B.
The guidelines of the American Academy of Pediatrics for the Identification and Evaluation of Children with Autism Spectrum Disorders was published following the preparation of the best practice synthesis, and information from that document was integrated during the preparation of this set of guidelines.

**Literature Review and Evidence Tables**

PSYCINFO was used to obtain literature from the years 2000-2007, in order to provide more current material to update the information presented in previous reports. The search consisted of using the keywords Autism OR Asperger OR PDD-NOS AND screening OR assessment OR diagnosis. The search was limited to English-language peer-reviewed journal articles including children under the age of 5 as part of the sample. These search criteria resulted in 678 articles which were manually searched for relevance. Only empirical studies and comprehensive reviews were included in the final review.

The literature was then organized into evidence tables, summarizing bodies of literature on specific topics. Given the importance of early screening and assessment in the identification and diagnoses of children with ASDs, the review focused mainly on research regarding the reliability and validity of available screening and assessment tools. The evidence tables were based on the Health Services/Technology Assessment Text number 7, Criteria for Determining Disabilities in Infants and Children: Low Birth Weight, which were designed to identify outcomes of very low birth weight children. The tables were organized into a book that was provided to the members of the Scientific Subcommittee to review prior to the committee meeting. Fifty-two empirical studies met the above criteria and were included in the evidence table book.

**Committees**

A steering committee was developed consisting of the project coordinator, a representative from the host organization who acted as the chair of the committee, two clinician subcommittee co-chairs (a developmental pediatrician and a psychologist), and two parents of young children with ASDs, who acted as the parent subcommittee co-chairs. Members of the steering committee were chosen by interest and availability. The names of all subcommittee members are listed at the front of the document, except for a small number of parent subcommittee members who did not wish to be identified.

**The Scientific Subcommittee**

Canadian experts in the field of ASDs were invited to participate in a one-day meeting to evaluate the most up-to-date scientific evidence. Experts were chosen based on publication records and involvement in clinical practice. Members of the scientific subcommittees included researchers and practitioners in the fields of psychology, developmental pediatrics, psychiatry, epidemiology, education, occupational therapy, and audiology.

During the meeting, the scientific committee heard reports given by representatives from the parent and clinician subcommittees, who discussed the findings from their meetings. Each of the guidelines listed in the best practice synthesis was discussed in relation to the most current evidence and with regard to the extensive clinical and research experience of the panel members. The meeting was audiotaped and transcribed for accuracy, and the discussion formed the basis of the current document.

**The Parent Subcommittee**

Parents were invited to participate in the parent subcommittee through a mass e-mail campaign that was sent to parent organizations across Canada. An invitation was also
posted on the Autism Central website (www.autismcentral.ca). Parents had the option of coming to a one-day meeting held at the Miriam Foundation in Montreal or completing an online questionnaire. Both options involved answering the following questions:

- What do you see as being the role of parents in the early identification of Autism Spectrum Disorders?
- What do you think are the biggest obstacles preventing the early identification of Autism Spectrum Disorders?
- What has been helpful to you in your efforts to achieve a diagnosis for your child?
- What changes would make the diagnostic process easier for parents?

The parent subcommittee met prior to the scientific subcommittee meeting, to discuss their experiences and opinions regarding early screening, assessment, and diagnosis of ASDs. The background and goals of the project were explained and parents were given an opportunity for discussion. Ten parents attended the evening meeting.

Thirty-six parents completed the online questionnaire about their child. Their children ranged in age from 21 months to 17 years and most had a diagnosis of autistic disorder (n = 26).

The comments, concerns and recommendations from the parent subcommittee are included throughout the document.

The Clinician Subcommittee
Clinicians were invited to participate in the clinician subcommittee through a mass e-mail campaign sent to parent organizations across Canada. An invitation was also posted on the Autism Central website (www.autismcentral.ca). Clinicians had the option of coming to a one-day meeting held at the Miriam Foundation in Montreal or filling in a questionnaire online. Both options involved answering the following questions:

- What are the challenges that you face in regard to the issue of early screening and diagnosis of ASDs?
- What recommendations do you have for overcoming some of the barriers that you face in your profession in screening for and diagnosing ASDs in very young children?
- Do you think that a Canadian document outlining Best Practices guidelines would be helpful to you in your practice? How would it help you? What would be the critical elements?

In addition to the two co-chairs who acted as representatives of the clinician subcommittee at the scientific evaluation day, eleven clinicians were present at the subcommittee meeting, all of whom completed the questionnaire. Fourteen clinicians from across Canada completed the online questionnaire. Overall, the twenty-five clinicians who responded to the questionnaire included seven speech-language pathologists, five ABA therapists, four psychologists, three program / policy developers, two special education teachers, an audiologist, an occupational therapist, a psychoeducator, and an early interventionist. Six clinicians had Ph.D. degrees, twelve had completed a master's level degree, four had a bachelor's level education, and three did
not specify their level of education. Most clinicians had between 3 and 15 years experience (18 clinicians), three had more than 15 years, and two had fewer than 3 years experience.

The comments, concerns and recommendations of the clinician subcommittee are included throughout the document.

**Expert Consensus and Document Review**

A one-day meeting was held in Montreal, Québec for members of the steering committee and the scientific subcommittee. For their reference, all attendees received a document, created specifically for this project, describing the methods of the project and including the evidence tables. The early part of the day consisted of presentations regarding the methodology of the project. The co-chairs of the parent and clinician subcommittees presented a summary of the discussion and recommendations from their respective committee meetings. The synthesis of Best Practice guidelines (Appendix B) provided the basis for the discussion. Each recommendation was presented and discussed concerning its validity with regard to current evidence, Canadian policy, and practicality. Members of the committee discussed recommendations for practice, research, and policy in relation to each of these guidelines. The discussion was audiotaped and transcribed for accuracy.

After incorporating the recommendations from the three committees, a draft of the current document was created, and was sent via e-mail to members of the scientific committee and the co-chairs of the parent and clinician committees for review. The comments and suggestions of the committees were incorporated in the preparation of the second draft, which was also sent for review. A third draft was sent to be evaluated by the external reviewers, who had not participated in any of the committees nor contributed to the development of the document. The final document incorporates their feedback.
Best Practice Guidelines

The following sections are organized into themes representing different aspects of best practices. Each theme is explained with regard to the background and rationale derived from the scientific literature, as well as feedback from the parent, clinician, and scientific committees. Practice recommendations are outlined for clinical purposes, and ideas for research and policy are offered to further expand our knowledge and ability to promote early detection of ASDs.

1. Developmental Surveillance
   • Developmental surveillance should be a continuous process undertaken by physicians and other professionals in contact with young children, with reference to developmental milestones and with knowledge of the symptoms of atypical or delayed development.
   • Parental reports regarding developmental concerns are to be taken into immediate and serious consideration by clinicians. A “wait and see” approach is not supported.

2. Screening
   • Universal (Primary) screening for ASDs is not currently recommended.
   • Targeted (Secondary) screening for ASDs is recommended and requires the use of empirically validated screening tools.
   • The determination that a child is at high-risk for an ASD, based on physician observation, family history, parent report and/or screening tools, should result in immediate referral to an experienced diagnostician or an interdisciplinary assessment team. Referral to available intervention services to promote optimal development should also occur at this time.

3. Diagnosis
   • The diagnosis of ASDs in very young children requires well-trained and experienced professionals.
   • An interdisciplinary team approach is ideal for the diagnostic assessment of ASDs.
   • The clinical diagnosis must be in accordance with the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) and/or International Classification of Diseases (ICD-10) diagnostic criteria.
   • The diagnosis should be made on the basis of a thorough developmental history and structured behavioural observation, in conjunction with clinical judgment. The use of at least one standardized, norm-referenced parent report measure and at least one standardized, norm-referenced behavioural observation measure is recommended.
   • The assessment of cognitive and developmental level is central to the diagnosis of ASDs.
   • A process of differential diagnosis must be undertaken to ensure a comprehensive diagnostic formulation and to rule out other possible causes of the symptoms.
4. **Corollary Assessment Issues**

- A full assessment of areas of strength and weakness, as well as other associated conditions and corollary concerns, is important for intervention purposes and planning.

- Multiple sources of information (parents, teachers, etc.) should be consulted in the assessment and the assessment should take place in varied contexts (home, school, etc.) to heighten validity.

- The delay between the emergence of symptoms, screening, diagnosis and assessment must be as short as possible to prevent delays in treatment.

- The assessment process must be family-centred, focusing on the uniqueness of each child and family and providing all communications, both written and verbal, in a manner that is clear, understandable, useful and respectful.
1. Developmental Surveillance
Developmental surveillance should be a continuous process undertaken by physicians and other professionals in contact with young children, with reference to developmental milestones and with knowledge of the symptoms of ASDs.

**Background and Rationale**

Developmental surveillance is a continuous process undertaken primarily by physicians and public health nurses, but also less formally by other professionals in frequent and regular contact with children (e.g., day care workers, early childhood educators). Sound developmental surveillance requires knowledge of typical developmental milestones and, in specific reference to ASDs, an understanding of the symptoms of ASDs and their patterns of emergence. The American Academy of Pediatrics issued a statement in 2001\(^{46}\), calling on pediatricians to increase their level of knowledge and comfort in working with children with ASDs. In their most recent statement, the AAP\(^{26}\) identifies primary care physicians as being key players in the surveillance of ASDs. According to the AAP the steps of developmental surveillance should include obtaining a family history of ASDs, asking parents about developmental concerns, investigating attainment of typical developmental milestones, especially in the areas of social development and play, and observing the child's behaviour with regard to social and communicative interactions.

Traditionally, health care practitioners employ the 50\(^{th}\) percentile (offering a picture of the average age of skill acquisition) as a standard of comparison for identifying typical and atypical development. In regard to identifying developmental delays, Sices\(^{47}\) argues that sole reliance on the 50\(^{th}\) percentile milestones may not be as useful as the use of 90\(^{th}\) (1.5 standard deviations above the mean, representing an unusually older age of skill acquisition). In the case of language, a lack of novel 2-word combinations by 24 months, or an absence of coordinated pointing and eye contact to share interest or excitement by 18 months is highly unusual. Sices recommends that professionals be aware of the 90\(^{th}\) percentile, ages at which it would be very unusual for children to have not attained specific milestones, in evaluating children for delays.

King and Glascoe\(^{48}\) offer the following explanations for the importance of developmental surveillance in early childhood. First, clinically significant delays in development are common and early intervention is effective and available for children with developmental delays. Further, in addition to children with documented diagnoses, children who are at risk of poor developmental outcomes also benefit from early identification and intervention. King and Glascoe argue that pediatric practitioners are uniquely positioned to identify and refer very young children with developmental delays in a timely manner. They recommend the use of valid screening tools in pediatric practice and urge professionals to have a lower threshold in regard to referral.

Research has shown that the symptoms of ASDs may emerge quite early and remain stable over time\(^{49}\). There is evidence that ASDs can be reliably diagnosed by 18 months of age\(^{50}\). A review of research regarding the early symptoms of ASDs by Goin and Myers\(^{51}\) highlighted the following symptoms: lack of eye contact, affective differences, lack of social skills (including imitative acts and joint-attention behaviours), postural /
motoric / gestural differences, unresponsive to others and/or one’s name, an absence of attention-seeking behaviors, solitary or unusual play patterns, and communication delays. However, the emergence of symptoms is influenced by developmental level. For example, Gray and Tonge emphasize that a lack of repetitive and stereotyped movements in very young children does not exclude the possibility of an ASD diagnosis, as these behaviors tend to emerge later, as children develop physically. Similarly, Stone and colleagues found that several of the DSM-IV criteria did not apply to toddlers with ASDs, including failure to develop peer relationships, impaired conversational ability, stereotyped and repetitive use of language, and inflexible adherence to routines and rituals.

The AAP lists several pre-speech deficits that may serve as possible indications of ASD risk, including lack of appropriate gaze, lack of warm, joyful expressions with gaze, lack of the alternating to-and-fro pattern of vocalizations between infant and parent, lack of recognition of parent’s voice, disregard for vocalizations (e.g. lack of response to name), delayed onset of babbling past 9 months of age, decreased or absent use of pre-speech gestures (e.g. waving, pointing, showing), lack of expressions such as “uh-oh” or “huh,” lack of interest or response of any kind to neutral statements (e.g. “Oh no, it’s raining again!”).

Developmental surveillance can occur at any point of contact between a professional and a child. As well as considering their own observations, the process of developmental surveillance involves eliciting parents’ concerns. Glascoe recommends asking the simple question, “Do you have any concerns about your child?” in order to give the parent an opening for discussion. The AAP recommends inquiring about the development of verbal and nonverbal communication, reciprocal social interaction (including eye contact, joint attention and social referencing, and sharing of interests or achievements), and representational or pretend play skills. Further, the AAP recommends that pediatricians aim to elicit behaviors indicative of the presence of ASDs in the process of routine surveillance, including calling the child’s name and observing the response, pointing to an object of interest to determine whether the child will “follow the point,” and engaging in conversation with the child to observe communication delays or idiosyncrasies.

Feedback from Committees
The parent committee reported that many of them had noticed their children had failed to reach appropriate developmental milestones, prompting their consultation with a physician. Importantly, the behaviors they noted as “red flags,” such as language delay, social skills problems, failure to point and the child’s failure to respond to their name, are those that are recognized and validated by researchers and other professionals. This provides further support for the claim that parents are able to recognize many of the developmental milestones associated with ASDs.

Many types of professionals have frequent contacts with very young children, including public health nurses, daycare workers, and early childhood educators. Members of our clinician committee highlighted the importance of getting these groups involved in the identification of high-risk children, and commented on the need for more education about the signs of ASDs and guidelines regarding appropriate courses of action when a child is identified. It was suggested that there be a direct referral process whereby these professionals could initiate a referral for further assessment, when developmental concerns are noted.
The scientific committee agreed that surveillance should occur on a continual basis, rather than at specific points in time, and should be based on knowledge of developmental milestones and ASDs. It was also emphasized that the expression of ASDs changes with the developmental level of the child. Further, the scientific committee discussed the importance of involving clinical judgment in the evaluation of developmental milestones.

**Recommendations for Practice, Research, and Policy**

**Practice**

- The physician or other professional should note the child’s failure to meet the following developmental milestones.

  **N.B.** A single missed milestone may not be cause for concern (unless it is loss of language), but pay particular attention when more than one of the following milestones has not been met:

  - Diminished, atypical, or no babbling by 12 months
  - Diminished, atypical, or no gesturing (e.g., pointing, waving bye-bye,) by 12 months
  - Lack of response to name by 12 months
  - No single words by 16 months
  - Diminished, atypical, or no two-word spontaneous phrases (excluding echolalia or repetitive speech) by 24 months
  - Loss of any language or social skill at any age
  - Lack of joint attention

  For video examples of symptoms associated with ASDs, see the Video Glossary at Autism Speaks: [www.autismspeaks.org/video/glossary.php](http://www.autismspeaks.org/video/glossary.php)

- Ask parents the question “Do you have any concerns about your child?”
- Inquire about family history of ASDs.
- Engage child in interactions designed to elicit social and communicative behaviours, for example, calling the child’s name or pointing to an object to determine if the child can direct their attention to the indicated object.
- Consider the developmental level of the child, as symptom expression may change within the context of normal development.
- Further use of screening tools and/or referral to an interdisciplinary assessment team should be made based on a combination of parental concern, missed milestones, presence of risk factors and clinical judgement.
**Research**
- Continue research into the early signs of ASDs and changes in their expression over development.
- Examine the effects of the introduction of guidelines on the surveillance and identification of children with ASDs in Canada.
- Investigate the effectiveness of awareness programs for professionals other than physicians who work with very young children.

**Policy**
- Family physicians need more training in developmental surveillance and education around developmental milestones; in particular, training should focus on the 90th percentile as well as the 50th.
- Medical training should require specific training in the early signs of ASDs.
- More education for professionals involved in early child care (public health nurses, daycare workers, early childhood educators) around the early signs and symptoms of ASDs.
- Create links between early child care / education and diagnostic services for informational and referral purposes.
Parental reports regarding developmental concerns are to be taken into immediate and serious consideration by clinicians. A “wait and see” approach is not supported.

**Background and Rationale**
Parents are often the first to notice their child is demonstrating delays in development and there is support for the notions that parent-report may be more accurate than physician observation, which is often very brief and occurs in an artificial setting (pediatrician’s office) which may cause the child to become anxious or behave differently than usual. The most frequently noted “early signs” reported by parents of young children with ASDs include delays in speech and language development and abnormal social responses, as well as other medical and behavioural problems, non-specific to ASDs, such as sleeping, eating, and attention difficulties. Parents in a recent study by Chawarska and colleagues reported recognizing abnormalities in their child’s development by 14 months, on average, with 56% of the parents in this study reporting abnormalities by 18 months of age. De Giacomo and Fombonne found that 90% recognized some abnormality by 24 months. Retrospective analyses of home movies suggest that distinguishing symptoms may be present within the first year of life. Parents may also notice their children regress, losing their previously observed abilities in the areas of verbal and non-verbal communication and social responsiveness; however, researchers have shown that some of these children may not actually have been developing typically before the symptoms were noted by parents. Children with more severe impairments in cognitive abilities and daily living skills, or with concurrent medical problems, may be noticed earlier than children with more subtle impairments. Further, parents may not notice early problems with stereotyped or repetitive movements until older ages, when the child is more physically developed.

Unfortunately, the wait between the parents’ initial reporting and diagnosis is frequently unnecessarily long. The American Academy of Pediatrics urged their members to listen carefully to parental concerns in order to promote early diagnosis. However, research suggests that many medical professionals are reluctant to diagnose ASDs in children under 3.

**Feedback from Committees**
Parents in our committee suggested a number of reasons to explain the length of time between their initial concerns and their child’s diagnosis. They discussed having to fight to have their concerns noted by their primary care physicians, many of whom took a “wait and see” approach. They commented that confusing and sometimes contradictory information frustrated their efforts to receive services for their children. As well, they reported that the pathway between assessment, diagnosis and treatment was often difficult to understand and follow.

Parents’ role in the assessment and treatment of their children with ASDs has expanded considerably over the years, ranging from advocate to interventionist. The parents in our committee reported a sense of responsibility for their children’s treatment and care and felt it was their duty to participate actively by keeping track of their child’s symptoms and development. In response to their increased involvement, they wanted clinicians to take them more seriously and recognize their knowledge and experience. However, they
also felt that more information regarding the signs and symptoms of ASDs is needed and felt that this information should be easily available to all parents. Parents also emphasized the need for accurate information. They commented that they felt a reliable source for clear, concise information regarding ASDs was needed, particularly available in an on-line format, as much of the information available on the internet was misleading or difficult to verify. They felt this kind of information would help them in discussing the needs of their child both with health-care providers and family members.

Our clinician committee also reported frustration upon hearing from parents that they had been ignored or told to “wait and see” by other professionals. They felt that these experiences affected parents’ views of professionals negatively, impacting on their own ability to provide services.

The scientific panel agreed that, when parents notice signs and symptoms of developmental delays in their children, their reports have merit. In addition, it was emphasized that an absence of parental report does not rule out the possibility of an unnoticed delay.

**Recommendations for Practice, Research, and Policy**

**Practice**

- If a parent brings up a concern about his or her child’s development, particularly concerns related to communication and social behaviour, appropriate investigations should be conducted and / or a referral should be made to appropriate services.

- Parents’ concerns about their child’s development should be addressed without delay. A “wait and see” approach is not appropriate.

- Parents’ lack of concern should not rule out the need for further investigations if signs and symptoms are noted by the clinician.

- A guide should be made available to parents undergoing the diagnostic process, including steps to be taken, available resources in their geographic area and a list of reliable websites for self-education. Some recommendations include (in alphabetical order):
  - Autism Central: [www.autismcentral.ca/research/](http://www.autismcentral.ca/research/)
  - Autism Connects: [www.autismconnects.com](http://www.autismconnects.com)
  - Autism Society of Canada: [www.autismsocietycanada.ca/](http://www.autismsocietycanada.ca/)
  - Canadian Autism Intervention Network: [www.cairn-site.com](http://www.cairn-site.com)
  - Health Canada’s Autism website: [www.hc-sc.gc.ca/dc-ma/autism/index_e.html](http://www.hc-sc.gc.ca/dc-ma/autism/index_e.html)

**Research**

- Continue research to understand and circumvent the reasons behind delays in diagnostic referrals and assessments.

- Research is needed regarding the impacts of educational initiatives aimed at educating parents about the symptoms of autistic disorder.

- Further investigations are needed into the nature of regression in ASDs.
When appropriate, researchers should actively involve parents in the process of designing and implementing some research programs.

**Policy**

• Awareness campaigns are needed to provide parents with more information about the signs and symptoms of ASDs, as well as what to do when they notice any developmental concerns.

• Education supported by the Canadian medical associations is needed to provide physicians with more information about the signs and symptoms of ASDs, risk factors that should be considered, as well as specific plans of action when presented with a child with symptoms of an ASD.
2. Screening
Universal (Primary) Screening for ASDs is not currently recommended.

**Background and Rationale**
Early screening for ASDs is considered to be a valuable goal, in light of the need to begin interventions as early as possible. Universal screening involves administering a brief measure to an entire population, regardless of risk status. In regard to ASDs, the goal is to employ a screening tool that could be administered easily and efficiently to all children of a specific age in order to identify those at highest risk. Effective screening tools must be considered in terms of their sensitivity and specificity. A tool with high sensitivity accurately identifies children with ASDs, whereas low sensitivity means that children with ASDs are not identified, resulting in a high rate of false negatives. A tool with high specificity accurately identifies those children who do not have an ASD, whereas low specificity predicts a high rate of false positives, suggesting that children without ASDs may be mistakenly identified as having an ASD (false positives). For a screening tool to be considered appropriate, both sensitivity and specificity must be high to prevent the failure to identify children in need of interventions as well as preventing the misuse of expensive and time-consuming resources with children who do not need them.

Currently, only the Checklist for Autism in Toddlers (CHAT) has been evaluated as a universal screening tool within the general population, administered at 18 months, but it has come up short in regard to sensitivity. Used as a primary screening tool, the CHAT was found to have low sensitivity and high specificity, suggesting that many children with ASDs (approximately 80%) would be missed if this tool was used for primary screening. Further, even a small percentage of false positives would result in large health care expenditures.

In their review of the evidence for universal (primary) screening, Williams and Brayne argue that the current evidence does not support primary screening for ASDs on the basis that no test or screen has been demonstrated to be adequately sensitive or specific. A review by Baird and colleagues argues for the use of the CHAT within the context of a broader surveillance program, as a secondary screening measure for children identified through surveillance.

In their recent clinical report on the identification and evaluation of children with ASDs, the American Academy of Pediatrics recommended primary screening with a standardized developmental screening tool at regular intervals, particularly at the 18-month visit and repeating the screen at 24 months. This recommendation is made in the context of the privatized American healthcare system in which medical investigations are funded through insurance for most citizens. The publicly-funded universal healthcare system of Canada would be unduly taxed by children who score false positives on the universal screen, leading to unnecessary assessments and/or treatments. Waiting lists for assessments by expert diagnosticians or interdisciplinary teams are already unduly long and children with false positive scores would crowd these lists. Therefore, the recommendation for Canada is to not conduct universal screening until screening tools with higher sensitivity and specificity are demonstrated in the scientific literature.
Feedback from Committees
The parent committee suggested that screening all children might result in faster, earlier diagnoses. The clinician and scientific committees agreed that earlier detection through screening was a valuable goal. However, the scientific committee came to a consensus that the current state of the evidence does not support a universal screening program specifically for ASDs. The very low sensitivity of the CHAT, as reported by Baird and colleagues, suggested the possibility of a large number of false negatives, resulting in a false sense of security for parents. Even though specificity of the CHAT was found to be high, a large scale screening process would result in numerous costly false positives. A discussion of a universal screening program for all developmental delays, including ASDs, was considered beyond the scope of the current project.

Recommendations for Practice, Research, and Policy

Practice
• Focus on developmental surveillance, rather than universal screening for ASDs.
• Apply second-level screening to children who have been identified through developmental surveillance or parental report, or who have siblings with ASDs or other developmental disabilities.

Research
• Need further research to develop reliable and valid universal screening tools for ASDs with adequate sensitivity and specificity.
• Continue the evaluation of existing screening tools for the purposes of universal screening.

Policy
• Universal screening is not currently recommended for ASDs, given the limitations of currently available tools.
• Knowledge of the symptoms of ASDs by all individuals in contact with young children is the key to early identification of high risk children; therefore, wider awareness campaigns must be launched in order to educate parents and professionals about the early symptoms of ASDs.
Targeted (Secondary) screening for ASDs is recommended and requires the use of empirically validated screening tools.

**Background and Rationale**
Children considered at high-risk for ASDs should be screened formally, using standardized measures with demonstrated reliability and validity. The tools must demonstrate adequate sensitivity and specificity, which the American Academy of Pediatrics defines as being 70 – 80%.

**Who should be targeted?**
Secondary screening for ASDs should target young children, observed by professionals not to have attained critical developmental milestones relating to communication and/or social behaviour or whose parents have expressed concerns, should be formally screened for ASDs. Another important high-risk group includes children who have at least one sibling diagnosed with an ASD. Research has clearly demonstrated that children with at least one sibling with an ASD are at increased risk for atypical development, including ASDs, up to 20 to 50 times greater risk than the general population. More recent research has demonstrated a familial aggregation of subthreshold autistic social impairment. Therefore, formal screening should occur at regular intervals for children in families in which one or more members have an ASD or other developmental disability.

**Who is conducting screening?**
When parents have concerns regarding the development of their children, they are most likely to contact their family physician or pediatrician to discuss their concerns. The most appropriate venue for targeted screening is in the office of these primary care physicians who see children regularly for physical and developmental check-ups, or by public health nurses/nurse practitioners in some jurisdictions; however, fewer than 30% of primary care providers conduct routine developmental screening, and a recent survey found that only 8% screen specifically for ASDs. Only about 30% of children with developmental disabilities are detected prior to school entrance, at which point they have lost all opportunities for early intervention. The American Academy of Pediatrics recommends that physicians should undertake formal screening whenever concerns are raised by the ongoing surveillance process.

In addition to physicians and public health nurses/nurse practitioners, psychologists are very well equipped to screen for ASDs in children. Children with ASDs are often referred to psychologists for behavioural and emotional issues related to the symptom profile of ASDs.

**Screening Tools (in alphabetical order)**
**The Autism Behaviour Checklist (ABC)** The ABC is a behavioural checklist completed by an interviewer to assess children from 18 months of age. The ABC takes approximately 10-20 minutes to complete. Recent research with a large sample of 4-18 year olds found adequate specificity but low sensitivity. The ABC is not recommended, based on the low sensitivity.
Checklist for Autism in Toddlers (CHAT)\textsuperscript{82} The CHAT is an instrument designed to prospectively identify autistic disorder in children from 18 months of age through the assessment of simple pretend play and joint-attention behaviours using a combination of parent report and behavioural observation. The CHAT was initially found to have high specificity, but low sensitivity\textsuperscript{70,82}. Researchers using the CHAT have employed different sets of criteria including high-risk (failure on 5 key items), medium risk (failure of both protodeclarative pointing, but do not fit into high-risk group) and, more recently, the Denver Modification\textsuperscript{83}, which involves failure on either pretend play or protodeclarative pointing. Research using the Denver Modification has provided the strongest sensitivity and specificity for use as a secondary screening tool\textsuperscript{83,85}; however, research with larger samples and longer follow-up are needed to provide comparable evidence to the regular scoring protocol. There is evidence that the CHAT may be less sensitive to autistic disorder symptoms in children with milder symptoms and in children with more advanced cognitive abilities\textsuperscript{84}. The empirical basis of the CHAT recommends its use in clinical practice, with appropriate care. The Denver modification is tentatively recommended, with a need for further follow-up.

Early Screening for Autistic Traits (ESAT)\textsuperscript{86} The ESAT is a parent-report tool that was developed with an emphasis on screening for behaviours that would alert health professionals to early signs of ASDs in children aged 14-15 months. Two versions of the ESAT exist. The 4-item “pre-screen” version, which is used to identify children in need of more specific screening, was found to identify children with ASDs with a high false-positive rate. The follow-up 14-item version demonstrated both high sensitivity and specificity\textsuperscript{86}. However, a large-scale screening study found a high rate of false positives for the 14-item version, although, many children incorrectly identified as having an ASD were diagnosed with some other developmental or learning disorder\textsuperscript{87}. The ESAT has been used in research on the cognitive abilities of children with ASDs\textsuperscript{88}, but more research is needed to evaluate its use as a practical screening tool for ASDs.

Gilliam Autism Rating Scale (GARS)\textsuperscript{89} The GARS is a 42-item parent- or teacher-report questionnaire for individuals aged 3-22 years, with three subscales developed based on the DSM-IV symptom categories. Although Gilliam\textsuperscript{90} reported psychometric support for the use of the GARS, more recent research has not replicated these initial claims. South and colleagues\textsuperscript{91} found the GARS to have poor convergence with gold standard diagnostic measures and low sensitivity. Research by Mazefsky and Oswald\textsuperscript{92} found that use of the GARS systematically underestimated the likelihood of autistic disorder and misclassified 61 percent of their sample of children with autistic disorder as having a low probability of the diagnosis. Lecavalier\textsuperscript{93} found that the GARS had low sensitivity, and discovered that its internal consistency and inter-rater reliability were

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Range of Sensitivity and Specificity Reported in the Literature:

**Sensitivity:** 0.38 – 0.71

**Specificity:** 0.70 – 0.97

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To obtain permission to use the CHAT for professional, scientific or clinical purposes:

www.autismresearchcentre.com/tests/chat_test.asp
lower in his sample than the estimate reported in the test manual. This measure is not recommended for practice.

**Range of Sensitivity and Specificity Reported in the Literature:**

**Sensitivity:** 0.48  
**Specificity:** Not reported

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**Modified Checklist for Autism in Toddlers (M-CHAT)**

The M-CHAT is a 23-item parent report checklist designed to screen for ASDs between 16 and 30 months of age. It differs from the CHAT in that no direct observation is needed and it includes additional items relating to sensory and motor abnormalities, imitation, and response to name. The critical items on the M-CHAT include showing interest in other children, proto-declarative pointing, bringing objects to show the parent, imitating, responding to name, and following a point. Recent research with a large sample of children has found the M-CHAT to be both highly sensitive and specific with children aged 18 – 30 months. The specificity of the M-CHAT further increases when positive findings are followed up with a telephone interview. This follow-up interview can be used in person as part of the pediatric visit. However, Eaves, Wingert and Ho found low specificity in their examination of the M-CHAT’s agreement with diagnosis in 178 clinic-referred youngsters between the ages of 2 and 6 years. These findings might be explained by the fact that no telephone interview was used and the sample was older than the target age range of the M-CHAT. Due to the generally high estimates of sensitivity and specificity, and ease of administration and scoring, this measure is recommended for practice. More research is needed on this promising measure.

**Range of Sensitivity and Specificity Reported in the Literature:**

**Sensitivity:** 0.77 - 0.97  
**Specificity:** 0.27 - 0.99

To obtain instructions and permission information for free use of the M-CHAT:

[http://www2.gsu.edu/~wwwpsy/faculty/robins.htm](http://www2.gsu.edu/~wwwpsy/faculty/robins.htm)

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**Pervasive Developmental Disorder Screening Test-II (PDDST II)**

The Pervasive Developmental Disorders Screening Test-II is a 3-stage measure designed to detect autistic disorder in very young children. Stage 1, the Primary Care Screener, is appropriate for ages 12 to 18 months and includes 23 items. This measure is intended as a level 1 screening tool screen in primary care settings, but has not been evaluated as such. Stage 2, the Developmental Clinic Screener, can be used from birth to 18 months. It is designed for use as a second level screen with children in whom a developmental delay is already suspected. Stage 3, the Autism Clinic Severity Screener, can be used from birth to 18 months and is designed to distinguish between different ASDs. Initial reports of high sensitivity and specificity require further follow-up. Eaves and Ho found good results in regard to sensitivity; however, their sample was possibly biased, including children with a high likelihood of autistic disorder. Further research is needed on this promising measure.

**Range of Sensitivity and Specificity Reported in the Literature:**

**Sensitivity:** 0.73 - 0.92  
**Specificity:** 0.49 - 0.91
Screening Tool for Autism in Two-Year-Olds (STAT)\textsuperscript{101} The STAT is an empirically-derived behavioural observation measure intended for professional use, with the goal of distinguishing ASDs from other developmental delays in children aged 24-36 months. Use of the STAT requires specific training and takes about 20 minutes to complete. The STAT has been found to be effective in differentiating diagnostic groups even when they are functioning at similar developmental levels\textsuperscript{102}. Stone, Coonrod, Turner, and Pozdol\textsuperscript{103} found the STAT to have high sensitivity, specificity and predictive value in identifying young children at risk for autistic disorder, but not other disorders on the autism spectrum. This measure is recommended for use by trained professionals in distinguishing autistic disorder from other developmental delays, but only for 2-year olds.

**Range of Sensitivity and Specificity Reported in the Literature:**

- **Sensitivity:** 0.83 – 0.92
- **Specificity:** 0.85 – 0.86

To obtain information about the STAT:
http://kc.vanderbilt.edu/kennedy/triad/services_screening.html

Social Communication Questionnaire (SCQ)\textsuperscript{104} The SCQ (formerly known as the Autism Screening Questionnaire), which was developed based on the Autism Diagnostic Interview (ADI-R), is a 40-item, parent-completed, screening questionnaire comprised of questions related to communication, reciprocal social interactions, and restricted and repetitive behaviors and interests. Initial findings revealed higher sensitivity than specificity\textsuperscript{104}. More recently, Eaves, Wingert, Ho, and Mickelson\textsuperscript{105} found that the SCQ was reasonably effective at screening children with autistic disorder from children with other developmental delays (Sensitivity – 0.79, specificity = 0.71); however, the tool was more effective with lower rather than higher functioning children. Corsello and colleagues\textsuperscript{106} found that the SCQ actually identified fewer children than the ADI-R. This is a problem as screening tools should be more inclusive than diagnostic tools. With a small sample of referred children, Wiggins, Bakeman, Adamson, and Robins\textsuperscript{107} found a maximum sensitivity (0.89) and specificity (0.89) for the SCQ using a cut-off score of 11. These divergent findings suggest the need for more research on this promising tool.

**Range of Sensitivity and Specificity Reported in the Literature:**

- **Sensitivity:** 0.79 – 0.96
- **Specificity:** 0.54 – 0.80

The SCQ and related materials are available for purchase in Canada:

**Feedback from Committees**

The parents in our committee reported that they did not recall any specific assessments for ASDs or other developmental delays during their “well-baby” checkups. This is consistent with research by Halfon and colleagues\textsuperscript{108} concluding that physicians are...
either not providing these evaluations or parents are not aware of them when they occur. Barriers to the provision of developmental services include a lack of training; unfamiliarity with new assessment, screening and surveillance measures; insufficient time; insufficient reimbursement; and lack of accountability to patients and payers for the provision of these services.

Members of our clinician committee who were not physicians suggested that they could take a more active role in the process of screening children for ASD risk status. These experienced professionals, included special educators, speech-language pathologists, and audiologists. They felt better equipped to screen children for signs of ASDs than some general practitioners who may see only very few children with ASDs as part of their practice. One difficulty was that they were not recognized as appropriate referral sources, and had no direct link to diagnostic teams.

The scientific committee emphasized the need for screening tools to be administered as a corollary to developmental surveillance. They stressed that the screening tools, when used properly, in combination with parent report and behavioural observation, could assist physicians in improving the confidence with which they referred children to interdisciplinary assessment teams and services. The scientific committee also acknowledged the evidence that physicians do not often engage in screening for ASDs, due to constraints in time and deficiencies in reimbursement. The committee discussed the need to encourage physicians to perform this service, and also the need to find alternative methods of screening by other professional groups. The scientists also discussed the need for those professionals who have developed an “expertise” in this area to be available to other physicians who may come into contact with ASDs more rarely, to offer consultation or for referral purposes.

**Recommendations for Practice, Research, and Policy**

**Practice**

- Children should be formally screened whenever a parent has expressed concern about their development or when the professional has noted signs and symptoms of ASDs.

- Formal screening of siblings of children with ASDs or other developmental disorders should be conducted regularly.

- The M-CHAT is an appropriate parent-report tool for use in second-level screening due to its ease of administration (may be given to parents in the physician waiting room)
  - It is recommended that the follow-up interview is administered in conjunction with the parent-report questionnaire to increase sensitivity.

- The CHAT is the most researched screening tool and may be tentatively recommended for second level screening.
  - The Denver modification is tentatively recommended to increase sensitivity without a loss to specificity. In this scoring criteria, parents can endorse one of two critical items, pretend play AND / OR protodeclarative pointing.

- The STAT is recommended as a second-level screener for use by professionals trained in its administration in distinguishing autistic disorder from other developmental delays.
• The use of the ABC and GARS is not recommended.

• There is a need to develop and utilize the expertise of other professionals (public health nurses, early childhood educators) for the purpose of screening children for ASDs.

**Research**

- More research is needed regarding risk factors for ASDs in order to identify higher risk children.

- Further research is needed on the Denver modification of the CHAT to determine whether the higher rates of sensitivity and specificity are maintained with larger samples over longer follow-up periods.

- Further research is needed on the ESAT, M-CHAT, PDDST-II, the STAT, and the SCQ.

- Innovative research is needed for the development of screening tools that will identify children with more mild symptoms, higher cognitive abilities, or atypical variants of ASDs.

- There is a need for continued research into the development of new sensitive and specific screening tools.

- There is a need for continued research into the development of screening methods that are more time-efficient.

**Policy**

- There is a need for changes to funding models or new approaches to support developmental screening by physicians, possibly including higher reimbursement for developmental screening appointments.

- Pediatricians and general practitioners require more training in recognizing higher risk children and the use of autistic disorder-specific screening tools.

- Other professional groups require more resources directed to their training in the recognition and screening of ASDs.

- The creation of community-based developmental screening centers would lessen the load for medical professionals.

- There is a need for the creation of a bank of experts willing to provide consultation to less experienced physicians in the screening process.
The determination that a child is at high-risk for an ASD, based on physician observation, family history, parent report and / or screening tools, should result in immediate referral to an experienced diagnostician or an interdisciplinary assessment team. Referral to available intervention services to promote optimal development should also occur at this time.

**Background and Rationale**
False negatives (incorrectly identifying a child as not having an ASD) are viewed as more detrimental than false positives (incorrectly identifying a child as having an ASD\(^9\)). Children with ASDs who are overlooked in screens may miss out on critical early intervention services, at a cost to their development, their family's well-being, and, later on, to society. Early intervention is critical to the promotion of independent living in adulthood by fostering skills that allow the adult with an ASD to contribute to the society, rather than depend on it, and to ensure some quality of life. Early identification can help to offset these future costs. On the other hand, children falsely identified as having an ASD may receive unnecessary early intervention services at a high cost to the public and with negative effects on the family. However, evidence has shown that children who screen false-positive for developmental delays perform significantly lower on diagnostic measures of adaptive behaviour, language, intelligence and academic achievement than true negatives\(^10\), and may still benefit from receiving early interventions. This position is echoed in the position statement on developmental surveillance by the American Academy of Pediatrics\(^11\), which states that these children may benefit from community programs as well as continued monitoring.

**Feedback from Committees**
The members of our parent committee fervently asserted that a false positive is more useful and less damaging than a false negative. The parent committee suggested that their family doctors were sometimes reluctant to refer for ASD assessments. Some parents complained about being referred for speech-language or audiology assessments, which resulted in being referred right back to their family doctor for an ASD assessment referral, wasting months of valuable time. Speech and hearing problems may co-occur or be confused with ASDs, and it is critical that these referrals be made simultaneously with a referral to a multidisciplinary ASD assessment team.

The time between the referral and the diagnostic assessment was particularly difficult for the families in our committee, who wanted to know what they could do while they waited. These families asserted the importance of being able to access services during this time, or at least be given some ideas as to how to help their children.

The clinician committee agreed that the wait between assessment and referral was too long, causing stress for families and creating delays in access to services. The clinicians also wanted to be able to offer wait-listed parents some kind of helpful service so that they would not have to search for information on their own, navigating the seas of misinformation available on the internet.
The scientific committee emphasized the need for flexibility in the screening and referral process, in order to enable some sort of triage process. Although all children with suspected ASDs and their families should have access to an assessment by a team of experts, they argued for a possible triage based on the combination of screening and clinical judgement. They argued that some children may have very obvious signs of ASDs, requiring immediate referral to ASD-specific services. For cases in which the diagnosis is clearer, the purpose of the interdisciplinary assessment should be focused more on the investigation of strengths and weaknesses for treatment planning, rather than diagnosis. Conversely, for children whose symptoms are milder or less obvious, or whose cognitive functioning is more intact, achieving an accurate diagnosis will require the efforts of an experienced interdisciplinary team of professionals. In the interim, until the diagnosis is certain, referral to general developmental programs in the community will be helpful.

**Recommendations for Practice, Research, and Policy**

**Practice**

- When an ASD is suspected through developmental surveillance, parent report and/or the use of screening tools, referrals for assessments and services should occur immediately. If unsure, pediatricians and GPs should over- rather than under-refer.

- Referral for audiology assessment should be made concurrently with referral to an interdisciplinary ASD assessment team, unless an audiologist is part of the team.

- Referral to a speech-language pathologist for assessment and intervention should be made concurrently with referral to an interdisciplinary ASD assessment team, unless the SLP is part of the team.

- Consider the child’s cognitive and developmental level, as service needs may differ depending on the child’s developmental level and the severity of cognitive delay.

- The child should receive a referral to early intervention or developmental services upon suspicion that they may have an ASD or other developmental delay.

- Parents should receive a list of available resources including community organizations and parent groups, as well as information about ASDs and a list of websites offering accurate information.

**Research**

- Research is needed regarding the impact, both short- and long-term, of implementing developmental/intervention services for children on the wait-list for assessment, comparing children who are and are not later diagnosed with an ASD.

**Policy**

- Evidence-based interventions should be made available to children who have been identified through a secondary screen as being high-risk, and who are on the wait-list for a formal diagnosis by a multi-disciplinary team.

- There is a need for the creation of a bank of experts who are willing to consult with community-based practitioners concerning the use of screening tools and referral options.

- An accreditation process should be initiated to identify internet resources with reliable and accurate information about ASDs.
3. Diagnosis
The assessment and diagnosis of ASDs in very young children requires well-trained and experienced professionals.

**Background and Rationale**
Different professional disciplines are involved in the assessment and diagnosis of children with ASDs. The process of assessment and the act of diagnosis both require an appropriate level of training and experience, and are regulated differently among the different professional orders and associations, and across provinces.

**Diagnosis**
A professional’s ability to provide a diagnosis of an ASD relies on the regulations of their governing professional body as well as their specific training in developmental disorders. Because diagnoses of ASDs are based on behavioural symptoms, and cannot be identified through a medical test, the diagnosis relies on the ability of the diagnostician to carefully observe, document and evaluate a constellation of symptoms in the context of the child’s overall development.

Technically speaking, all physicians in Canada have the recognized legal right to diagnose a child with an ASD, by virtue of their medical diploma. However, not all physicians have been trained with regard to early development, atypical development, or the symptoms of ASDs specifically. Psychologists in most provinces (except Québec) are also permitted by law to diagnose ASDs; however, many are not specifically trained to do so. Although members of other professional disciplines (particularly speech language pathologists) may be able to identify symptoms of ASDs in young children, their training and their regulatory body exclude them from diagnosing ASDs.

Concerning the act of diagnosis, specific training and experience in ASDs is important for two reasons. First, it ensures that clinicians are able to appropriately conduct and interpret standardized tests, such as the Autism Diagnostic Interview- Revised (ADI-R) and the Autism Diagnostic Observation Schedule (ADOS). These instruments are highly specific in their methods of administration and scoring and often require a graduate-level understanding of psychometrics and statistics, as well as extensive supervised experience to ensure they are correctly administered and that the results are interpreted correctly. The second reason why specific training and experience is critical is that it leads to the development of clinical judgment. Although the ADI-R and the ADOS are standardized tools, the clinician’s judgment is the most important feature of diagnosis. Experienced clinicians have been shown to provide accurate diagnoses of autistic disorder at age 2, with high stability up to age 9.111

**Assessment**
Other professional groups, including speech-language pathologists, special educators, occupational therapists, and other health professionals, are actively involved in the assessment of children with ASDs, despite not being regulated to provide the diagnosis. These professionals must also be trained according to the regulations of their discipline and have adequate training and experience specific to ASDs.

The field of ASDs is rapidly changing, as new scientific developments alter the way we think about the disorder, and affect the policies and practices in early assessment and
treatment. Continued professional education is mandatory to maintain and update clinical skills and knowledge of current research and its implications for practice.

**Feedback from Committees**

Members of the parent committee expressed the view that their family doctors often did not have a sufficient understanding of ASDs and were not equipped to deal with their initial concerns or perform adequate follow-up action. These parents argued that their greatest challenges involved dealing with difficult professionals, and those without specific training in ASDs. Conversely, they expressed that their relationships with helpful and knowledgeable professionals provided them with a great deal of support and hope.

Members of our clinician committee acknowledged that psychologists and physicians were the only professionals with the appropriate training to provide a diagnosis of an ASD, and emphasized that specialized training and experience in ASDs was of utmost importance. They argued that having a medical or doctoral diploma did not imply adequate training and experience to diagnose ASDs and recommended the creation of minimum standards of training, specifying that the training should involve adequate exposure to all that is required in providing reliable and valid ASD diagnoses. The clinician committee stressed that milder variants of ASDs, or complex diagnoses involving co-morbidities, required a high level of expertise in differential diagnosis.

The scientific committee agreed that doctoral-level psychologists and physicians be the only professions with the right to diagnose, and also agreed that specific training and experience with this population is necessary. However, the scientific committee argued for the need for flexibility in cases in which the diagnosis is obvious, or the practitioner cannot access a referral for an interdisciplinary assessment. The possibility of opening the right of diagnosis to other professional groups was discussed, but not recommended as the reliability and validity of such diagnoses is not currently known. The scientific committee agreed on the need for experts in the field to be available to other practitioners for consultations, and for a general increase in developmental and ASD-related information and training for all relevant practitioners.

**Recommendations for Practice, Research, and Policy**

**Practice**

- The diagnosis of ASDs in young children should only be made by a psychologist or a physician under the conditions that they are:
  - Members of a professional order or college that permits the transmission of diagnoses
  - Have graduate (doctoral level) or post-graduate training encompassing specific training in child development and ASDs and other developmental disorders in young children.
  - Have received supervised clinical experience in the assessment and diagnosis of ASDs in young children.
  - Training with the ADOS and the ADI-R is encouraged for those involved in the diagnosis of ASDs; however, this is not mandatory as other assessment protocols involving a detailed-history, parent interview, and direct observation can be sufficient to diagnose ASDs.
The assessment of young children with ASDs should only be conducted by professionals who are:

- Members of a professional order or college.
- Have post-secondary, graduate or post-graduate training encompassing specific training in child development, ASDs and assessment,
- Have received supervised clinical experience in the assessment of ASDs and other developmental disorders in young children,
- Have received training in ASDs as part of continuing education.

Experts in the area of ASDs should act as information and consultation resources for other professionals in the community who encounter children with ASDs in their practice.

Physicians and psychologists who do not frequently see children with ASDs in their practice or who have not had direct training in the field should refer the child to an expert or a multi-disciplinary team or, if they are geographically remote, consult an expert or interdisciplinary team in formulating their diagnosis.

Research

- Research regarding the reliability and validity of early diagnosis made by experts is needed.
- There is a need for more research examining the reliability and validity of early diagnoses made by members of various professional disciplines.
- Research is required to examine the reliability of diagnoses made by experts using telemedicine approaches (video, internet consultation) for children without access to a multidisciplinary team.

Policy

- In order to minimize the waiting times for obtaining a diagnosis of an ASD, the diagnosis of ASDs should be delegated to Ph.D.-level psychologists, in addition to physicians, in the province of Québec.
- There is need to create a bank of experts who are willing to consult with practitioners from remote or rural areas who may not be able to easily refer a family to an interdisciplinary team.
- There is a need for the creation of a system by which experts can consult with remote practitioners, such as video, teleconferencing and internet.
- Continued education specific to the field of ASDs must be mandatory for active professionals in the field.
- More university programs focusing on training various professional groups in the field of ASDs are needed.
- There is a need to encourage more students and professionals to obtain training in the field through financial incentives (i.e., grants, scholarships, etc.) and available positions for trained individuals.
An interdisciplinary team approach is ideal for the comprehensive assessment of ASDs.

**Background and Rationale**
Diagnoses may currently be made by interdisciplinary teams, multidisciplinary teams, or solitary practitioners. Interdisciplinary and multidisciplinary team approaches share the benefit of incorporating information from a variety of perspectives in order to paint a complete picture of the child’s abilities, strengths and weaknesses. Whereas members of interdisciplinary teams work in concert to achieve a diagnosis, members of multidisciplinary teams assess the child and come to conclusions independently, without input from other team members. Each team may include the following professionals: psychologists, psychiatrists, neurologists, pediatricians, other physicians, speech pathologists, audiologists, occupational therapists, social workers and behavioral and educational specialists. Solitary practitioners act on their own, or with consultation as requested, and are usually physicians or psychologists.

**Feedback from Committees**
Parents described the interdisciplinary team approach as being helpful to them in understanding and accepting their child’s condition. They described the value of receiving information regarding various aspects of their child’s functioning and the benefit of talking to different types of professionals; however, they did not like it when they had to provide the same information multiple times.

The clinician committee agreed that the involvement of multiple professionals is important for achieving a differential diagnosis, and for obtaining information relevant for treatment planning. They emphasized that the contributions of different professionals needs to be respected. The scientific committee also identified the need to respectful of parents’ critical contribution to the diagnostic process.

**Recommendations for Practice, Research, and Policy**

**Practice**
- Interdisciplinary teams are recommended above multidisciplinary teams, but either is preferable to a single-practitioner approach.
- Members of the team may include some or all of the following professionals (listed in alphabetical order):
  - Audiologists
  - Behavioural Specialists / Early Interventionists
  - Dietitians
  - Educational Specialists
  - Neurologists
  - Nurse Practitioners
  - Occupational Therapists
• Pediatricians
• Psychiatrists
• Psychologists
• Social Workers
• Speech Pathologists

- The team should be led by a professional who is licensed to diagnose; either a psychologist or a physician.

- Communication and collaboration among team members is necessary to achieve the most accurate diagnosis and to avoid duplication of effort.

- It is important to consider issues of confidentiality and obtain written, legal consent for communication among team members and between other relevant individuals or organizations.

Research
- Research is needed regarding the specific contribution made by each discipline/area of expertise contribution to accurate diagnosis.

Policy
- Increase funding for the creation and maintenance of interdisciplinary diagnostic teams for ASDs.

- Improve access to interdisciplinary teams for families in remote areas.
The clinical diagnosis must be in accordance with Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) and / or International Classification of Diseases (ICD-10) diagnostic criteria.

**Background and Rationale**
The DSM-IV-TR²⁵ and the ICD-10²⁷ represent categorical perspectives on ASDs, suggesting clear boundaries between the presence and absence of the disorder. The categorical perspective, in which a diagnosis is achieved once a certain number of symptoms have been observed, can be contrasted with a dimensional perspective, which holds that characteristics of autistic disorder exist on a continuum in all individuals, ranging from no problems to severe, and that categorical boundaries between the subtypes of ASDs are not clear-cut and may not be clinically useful.

Dimensional approaches are particularly useful for examining developmental change and are useful in research. For example, they have offered a wider and potentially more informative perspective in regard to the heritability of ASD-related traits than focusing only on more narrow, categorically-defined cases. However, for many diagnostic goals (access to services, communication of needs, funding) the categorical approach is necessary and may be more practical and informative.

The DSM-IV-TR²⁵ was developed in collaboration with the developers of ICD-10, resulting in a strong similarity between the two documents, discussed below.

**DSM-IV-TR**
The Diagnostic and Statistical Manual, 4th edition, Text Revision²⁵ provide lists of symptoms used to diagnose various mental disorders. Using clinical judgement, a trained mental health professional employs this list to differentially diagnose ASDs from alternative psychological disorders. The DSM-IV employs a multiaxial system which is designed to evaluate multiple axes of a person’s life, offering a full picture of strengths and weaknesses.

**Multiaxial System**
- **Axis I:** Clinical disorders, including major mental disorders, as well as developmental and learning disorders
  - The ASDs are included under Axis I
  - **Axis II:** underlying pervasive or personality conditions, as well as mental retardation
    - If an intellectual disability is present concurrently with the Pervasive Developmental Disorder, this would be coded on Axis II
  - **Axis III:** Acute medical conditions and physical disorders.
    - If medical conditions including chromosomal abnormalities, congenital infections, seizures, and structural abnormalities of the central nervous system are present, they would be coded in Axis III
• Axis IV: Psychosocial and environmental factors contributing to the disorder

• Axis V: Global Assessment of Functioning or Children's Global Assessment Scale for children under the age of 18. (on a scale from 100 to 0)
  • The traditional Axis V has limited value in regard to its use with very young children with ASDs. This scale is not geared to young children, nor is it set up for individuals with intellectual disabilities.

The DSM-IV-TR diagnostic criteria for ASDs are provided in Appendix A. To summarize, all ASDs include impairments in social reciprocity and communication, in addition to the presence of repetitive stereotyped behaviors, interests, and activities.

ICD-10
The International Statistical Classification of Diseases and Related Health Problems was developed as a system to classify any problems in medicine and includes a section dealing with psychiatric and developmental disorders. It provides codes to classify diseases and a wide variety of signs, symptoms, abnormal findings, complaints, social circumstances and external causes of injury or disease. This system is designed to promote international comparability in disease classification. The most current version, the ICD-10 includes ASDs in the disorders of psychological development, under the subcategory of pervasive developmental disorders. The sub-types Childhood Autism, Atypical Autism, Rett's Syndrome, Other Childhood Disintegrative Disorder, Overactive Disorder Associated with Mental Retardation and Stereotyped Movements, Asperger's Syndrome, Other Pervasive Developmental Disorders, and Pervasive Developmental Disorder- Unspecified are also included.

Differentiating between the Autism Spectrum Disorders
Differentiating between the various subtypes of ASDs has proven to be a difficult task in both research and clinical practice. Research by Cox and colleagues found that neither clinical diagnoses nor the use of the ADI-R resulted in reliable diagnoses for PDD-NOS or Asperger's disorder, whereas diagnoses for autistic disorder were highly stable and reliable for both. Other researchers have also demonstrated unclear boundaries between Asperger's disorder, and PDD-NOS and autistic disorder and suggest that clinical judgement must be used in addition to standardized measures in order to differentiate among the ASDs. Some experts have argued that there is little research to support the clinical differentiation of sub-types within ASDs.

Feedback from Committees
The scientific committee agreed that the clinical diagnosis of ASDs must be in accordance with the symptoms described by the Diagnostic and Statistical Manual of Mental Disorders (DSM)-IV-TR/ International Classification of Diseases (ICD)-10 diagnostic criteria. The scientific and clinical committees both argued that it is more important, clinically, to determine a child’s status with regard to the autism spectrum rather than distinguish between the ASDs. This differentiation remains important for research.
Recommendations for Practice, Research, and Policy

Practice
• Diagnoses of ASDs must be made in reference to the criteria outlined in the DSM-IV-TR or the ICD-10.

• All five DSM axes should be considered in the full diagnostic evaluation of the individual. Although the traditional global functional assessment may not be applicable to very young children with disabilities, an effort must be made to assess the child's general level of functioning in order to paint a more complete picture of the child and provide information relevant to treatment planning.

• Caution should be used when applying the symptoms outlined in the DSM-IV-TR / ICD-10 to very young children.

Research
• Research programs are needed to further investigate the categorical versus dimensional conceptualizations of ASDs.

• More research is needed to examine the differentiation of ASD sub-types, as defined by current classification systems, and their clinical or prognostic significance.

• More research is needed to examine the usefulness of the DSM-IV-TR criteria with regard to very young children.

Policy
• Education and developmental services should be available to all children with ASDs, regardless of the specific diagnostic sub-type.
The diagnosis should be made on the basis of a thorough developmental history and structured behavioural observation, in conjunction with clinical judgment. The use of at least one standardized, norm-referenced parent report measure and at least one standardized, norm-referenced behavioural observation measure is recommended.

**Background and Rationale**

The diagnosis of ASDs requires structured diagnostic history based on the DSM-IV-TR or the ICD-10 as well as an interactive assessment aimed at observing the symptoms of ASDs. These goals are best accomplished through the use of standardized measures in combination with clinical judgment. Much research has focused on the combined use of the ADI-R and the ADOS. In a study with children with intellectual disabilities, de Bildt and colleagues found that using both instruments together resulted in better prediction of ASD status than either instrument alone. Research by Risi and colleagues also found that, used in combination, the ADI-R and the ADOS resulted in more accurate clinical judgement than either tool used alone. In research, the combined use of the ADI-R, ADOS and clinical judgment are often used as a gold standard against which newer screening and assessment tools are measured.

**Parent Report Measures**

**Autism Diagnostic Interview-Revised (ADI-R)**

The ADI-R is a semi-structured interview for parents or caregivers of persons suspected of having an ASD. It includes questions about the child’s family, schooling, developmental history, and communication, social development, play, and restricted, repetitive, and stereotyped behaviors. The ADI-R has a scoring algorithm that is based on the DSM-IV and ICD-10 criteria for autistic disorder. The interview yields separate scores for each of the three diagnostic domains (social interactions, communication, and repetitive and stereotyped behaviors) described in the DSM-IV-TR and the ICD-10. The scoring algorithm requires that the child surpass cut-off scores in each of the three domains to be diagnosed with autistic disorder; as yet, the ADI-R does not provide cut-off scores for Asperger’s disorder or PDD-NOS.

The first study using the ADI-R by Lord, Rutter, and LeCouteur reported high sensitivity and specificity, as well as good inter-rater reliability. Studies have also shown high agreement between the ADI-R and the CARS. Much recent research has provided support for the ADI-R as a valid and reliable tool for assessing for ASDs.

The ADI-R has been found to be less effective in diagnosing children younger than 4 years of age, particularly for non-verbal children with mental ages below 18 months. This is particularly the case for non-verbal children with mental ages below 18 months who do not necessarily demonstrate some of the positive symptoms, representing behavioural excesses, such as restricted interests, maintenance of sameness, or repetitive behaviors, due to their younger developmental level. On the other hand, negative symptoms representing behavioural deficiencies, such as lack of joint attention
and delays in language development may be less easily noticed by parents in the early years.

The ADI-R and related materials are available for purchase in Canada:

**Behavioural Observation Measures**

**Autism Diagnostic Observation Schedule (ADOS)**

The ADOS is a semi-structured observation measure designed to assess communication, socialization, and play skills in children suspected of having ASDs. The tool includes four modules, each requiring just 35 to 40 minutes to administer. The module administered depends on the expressive language level and chronological age of the child being assessed. The procedure involves activities designed to engage the child (or adult) and to elicit social and communicative behaviors. In order to achieve a diagnosis based on the ADOS, children must exceed cut-off scores on three domains: social domain, communication domain, and the social and communication domains combined. The scoring algorithm provides cut-offs for Autism and atypical autism/ASD.

Research has generally found the ADOS to have adequate to high internal consistency and high inter-rater and test-retest reliability. Research has found the ADOS to be highly specific and sensitive, correctly identifying 95 percent of those with autistic disorder and 92 percent not in the autism spectrum. Despite providing diagnostic cut-offs for both disorders, the ADOS has not been found to be very effective at discriminating atypical autism/ASD from autistic disorder, correctly identifying only 33 percent of persons with clinical diagnoses of ASD as having an ASD that was not autistic disorder.

The ADOS and related materials are available for purchase in Canada:

**Childhood Autism Rating Scale (CARS)**

The CARS is an observational rating instrument for children and adults suspected of having an ASD. The CARS includes 15 subscales, including items on socialization, communication, emotional responses, and sensory sensitivities. The manual cites good internal consistency, inter-rater agreement and test-retest reliability. The CARS has been found to have good agreement with the DSM-IV diagnosis, with high sensitivity (0.94) and specificity (0.85). Ventola and colleagues found high levels of agreement between the CARS, the ADOS, and DSM-IV criteria in a sample of toddlers. Findings by Perry and colleagues suggest the possibility that the CARS may be used as a continuous scale representing the severity of the ASD; however, despite significant mean differences between children with autistic disorder versus PDD-NOS, there was still considerable overlap between the distributions. However, Rellini and colleagues found that the CARS identified the children in their sample with Asperger’s disorder and PDD-NOS as being non-autistic, demonstrating limited sensitivity to higher-functioning children with ASDs.

The CARS and related materials are available for purchase in Canada:

3. Diagnosis
Clinical Judgement
Clinical judgment by experienced clinicians is considered to be essential for an ASD diagnosis, and requires appropriate training and experience with the assessment and diagnosis ASDs. Lord and colleagues found that clinical judgement by a specialized group of clinicians outperformed the sole use of standardized measures in predicting a follow-up diagnosis 7 years after the initial judgment. In that study, clinical judgement was informed by the use of either a standardized interview or observation schedule (ADI-R, ADOS), suggesting that standardized tools may serve to structure clinical judgment. Therefore, clinical judgment used in combination with standardized assessment instruments is recommended as the gold standard, rather than clinical judgment alone.

Feedback from Committees
Parents felt that the use of standardized questionnaires in the diagnostic process helped them to “face facts” in regard to their child’s condition, and that the process of completing a standardized assessment lent credence to the results of the assessment. Many parents demonstrated considerable knowledge concerning the assessment tools and procedures that their children had experienced. They described that completing the questionnaires and interviews allowed them to learn about the symptoms of ASDs and face the realities of their child’s behaviour.

The clinician committee suggested that the lack of standardized instruments, both within and between team members and teams, made communication regarding assessment results difficult. They recommended that the Best Practice Guidelines include strong recommendations for the combined use of the ADI-R and ADOS for diagnostic purposes.

The scientific committee stressed that clinical judgment by a trained, experienced professional remained the critical component of diagnosis. There was strong agreement that the use of the ADOS and the ADI-R was recommended; however, it was cautioned that the tools cannot be used by individuals who are not trained in their implementation and use with young children with ASDs. It was also discussed that the CARS, when used properly, can be a useful measure for diagnostic purposes, although caution was expressed about its use with higher-functioning children. The CARS also requires specific training.

Recommendations for Practice, Research, and Policy Practice
- The combined use of the ADI-R and ADOS, in combination with clinical judgment is, at this time, the gold standard for the diagnosis of ASDs; however, a lack of ADI-R, ADOS data should not prevent a child from receiving much needed services if a diagnostician with sufficient expertise conducts the assessment.
- The CARS may also be used in diagnostic assessments.
- Clinical judgment, which requires significant training and experience, is critical when interpreting results of standardized measures and differentiating between the types of ASDs.
- Whether or not empirically-validated assessment tools are used in the diagnostic process, a formal behavioural observation process and a parental interview, including a thorough developmental history, should be conducted and documented.
Research

- There is a need for research aimed at developing and evaluating parent-report and behavioural observation tools that are more time-efficient.
- Research is needed regarding the development and evaluation of algorithms that differentiate between autistic disorder and other forms of ASDs.
- There is a need for continued exploration of the variability and reliability and validity of diagnoses based on clinical judgement.

Policy

- The ADOS and ADI-R should be advanced as the standard assessment protocol in assessment clinics across Canada.
The assessment of cognitive and developmental level is central to the diagnosis of ASDs.

**Background and Rationale**

**Cognitive Development**
Children with ASDs demonstrate a wide variation in cognitive functioning. Recent U.S. estimates by the Centre for Disease Control's 2007\(^1\) report on the prevalence of ASDs in multiple areas of the United States suggest that the percentage of individuals with ASDs concurrent with IDs ranges from 33-59%. The definition of Asperger's disorder stipulates normal intelligence; however, many children with all types of ASDs demonstrate an uneven intellectual profile\(^{134}\). More specifically, individuals with autistic disorder tend to have lower verbal than performance IQ scores, as per a meta-analytic review of 23 studies by Lincoln, Courchesne, Allen, Hanson and Ene\(^{135}\).

Although a cognitive and developmental evaluation is not always necessary for a diagnosis of ASDs, an accurate assessment of cognitive functioning is crucial for prognosis and intervention planning\(^{136}\). Knowledge of a child's cognitive abilities provides important information for treatment planning as researchers have found that children's response to treatment relates to their cognitive functioning\(^{137}\). The assessment of cognitive abilities in children with ASDs requires special consideration of the limitations, which may interfere with their performance. In particular, language difficulties may prevent children with ASDs from performing to their true level. Research using nonverbal tests of intelligence indicates that children with ASDs tended to score higher than would be expected on the basis of classic tests, a discrepancy not observed in children without ASDs\(^{138}\). Further, even cognitive testing with typically developing preschool children is of questionable predictive value due to wide variability among very young children and limited range of testable abilities\(^{139}\). Despite these challenges, cognitive abilities in very young children with ASDs have demonstrated some stability\(^{88}\), and are highly relevant to intervention planning.

**Adaptive Functioning**
The daily living skills of children with ASDs tend to vary widely. Individuals with ASDs tend to have more strengths in motor and daily living than socialization and communication domains. Verbal children tend to have better adaptive functioning than non-verbal children, and younger children outperform older children as compared to their respective norm groups, suggesting a deterioration of skills with age\(^{140}\).

**Feedback from Committees**
Members of our parent committee reported delayed cognitive functioning and overall developmental level as one of the early signs of ASD they noticed in their child. Many parents felt well equipped to observe these problems in their child and wanted some way of effectively communicating these concerns with health professionals.

The scientific committee asserted that a full assessment of cognitive and adaptive functioning should be considered central to an assessment of ASDs. They noted the importance of not including intellectual disability as a core symptom of ASDs, since some children with ASDs do not have an intellectual disability, and the presence of an intellectual disability is an exclusionary criterion for Asperger's disorder. However, the
committee agreed that evidence points to a large proportion of children with ASDs having difficulties in cognitive and adaptive functioning.

**Recommendations for Practice, Research, and Policy**

**Practice**
- Although cognitive assessments are not required for the diagnosis of an ASD, a thorough developmental assessment should be undertaken during or following the assessment process to determine the presence of an intellectual disability and to document the child’s strengths and weaknesses. This is particularly useful for intervention purposes, as the type of intervention and its success may depend on the presence and severity of cognitive delay.

- The developmental assessment must be conducted with the use of standardized, norm-referenced instruments.

**Research**
- Improve the reliability and validity of cognitive testing in very young children, particularly for children with developmental delays.

**Policy**
- It is necessary to include funding for cognitive testing in the diagnostic assessment.
A process of differential diagnosis must be undertaken to ensure a comprehensive diagnostic formulation and to rule out other possible causes for the symptoms.

**Background and Rationale**
The process of differential diagnosis involves distinguishing between two or more disorders with overlapping presentations on the basis of their unique symptom profiles. Differential diagnoses must be undertaken during the assessment process to distinguish between the different types of ASDs and also between ASDs and other disorders, including developmental delays, other psychiatric disorders, hearing problems, other communication disorders, and other medical disorders. The process of differential diagnosis speaks to the need for interdisciplinary cooperation as no single discipline is equipped to assess all possible disorders.

**Intellectual Disabilities**
ASDs occur concurrently with intellectual disabilities at a high rate (35-59%) and a cognitive and developmental evaluation is recommended within the context of an ASD assessment. However, it is also the case that symptoms of IDs may present similarly to symptoms of ASDs, particularly when children are non-verbal. It is important that the assessment determine whether symptoms represent a pure ASD, intellectual disabilities alone, or concurrent ASD and intellectual disability. This task requires clinical judgment in addition to the use of standardized instruments. Lord and colleagues found that many of the 2-year-olds in their sample who were misclassified as having autistic disorder by the use of standardized instruments actually had severe intellectual disabilities. Additionally, there is a behavioural overlap between ASDs and ID, as children with severe ID also demonstrate repetitive behaviours.

**Medical Conditions**
Medical evaluations are important to determine whether the observed symptoms may be better explained by other organic brain disorders, ruling out an ASD diagnosis. Additionally, hearing loss, Landau-Kleffner syndrome, and lead and mercury toxicity must be ruled out. The following section on corollary assessment issues includes a description of medical conditions likely to co-occur with ASDs, but that do not rule out an ASD diagnosis.

**Psychological / emotional / behavioural diagnoses**
Other psychological diagnoses with symptom overlap must be ruled out including social anxieties, selective mutism, ADHD, early symptoms of schizophrenia and behavioural disorders, such as conduct disorder. These disorders may also occur concurrently with ASDs.

**Hearing, Speech, and Language**
Children with specific language impairments (SLI) and hearing deficits may be misdiagnosed as having an ASD, or vice versa.

**Feedback from Committees**
Many of the parents expressed frustration with the variety of diagnoses that their children received from different health professionals. While providing differential
The clinician committee also discussed the importance of conducting a thorough differential diagnosis prior to communicating a diagnosis to the family. This was echoed by the scientific committee, who repeatedly emphasized the importance of employing an interdisciplinary team approach to fully rule out all other possible diagnoses.

**Recommendations for Practice, Research, and Policy**

**Practice**
- An interdisciplinary team approach is recommended in order to conduct a thorough differential diagnosis.
  - A full medical examination is needed to assess for associated medical conditions, as indicated.
    - Genetic testing should be performed when there is presence of intellectual disability or if there is a family history of Fragile X.
    - Selective metabolic testing should be initiated by the presence of suggestive clinical and physical findings (i.e. lethargy, cyclic vomiting, early seizures, the presence of dysmorphic or coarse features; evidence of ID or if ID cannot be ruled out; or if occurrence or adequacy of newborn screening at birth is questionable).
    - A neurology assessment may be needed if seizures are present or if there is a suspicion of other neurological problems.
    - A psychological or psychiatric consultation may be needed to rule out other psychiatric, emotional, or behavioural conditions.
    - An audiology consultation is needed to assess for and rule out the presence of hearing disabilities.
    - A speech-language pathology assessment may be necessary to assess for other communication or language disorders.
    - An occupational therapy evaluation may be necessary to assess for other motor or sensory dysfunctions.
    - The team should compare and contrast findings in an effort to come to a straightforward diagnostic decision.
    - Solitary practitioners should consult with or refer to other professionals, as needed.

**Research**
- More research is needed regarding diagnostic overlap of disorders with common symptoms.
  - Research into the development of tools to distinguish between disorders with common symptomatology is necessary.

**Policy**
- Children with suspected ASDs must have a medical and audiology exam prior to or concurrent with the ASDs assessment.
4. Corollary Assessment Issues
4.1 A full assessment of areas of strength and weakness, as well as other associated conditions and corollary concerns, is important for intervention purposes and planning.

**Background and Rationale**
Although their disorder implies a certain degree of commonality, children with ASDs, like all children, are unique with respect to their individual strengths and weaknesses, likes and dislikes, personalities, and other aspects. Further, children with ASDs may experience a whole host of related and unrelated medical conditions, sensory deficits, and communication difficulties. These problems should be assessed in order to plan for the most appropriate and effective treatment for each child.

**Health and Medical Concerns**
Currently, there is no medical marker for ASDs. Neither the use of EEGs or brain neuroimaging techniques is useful in the diagnosis. However, there are medical conditions with a tendency to occur co-morbidly with ASDs\(^{142}\). Related disorders include epilepsy (10-35%), Fragile X Syndrome (1%), Tuberous Sclerosis (0.2 – 0.8%) and increased head size. The American Academy of Pediatrics\(^{46}\) suggests pediatricians use their judgement to determine the need for lead screening, amino acid screening to detect phenylketonuria, DNA analysis to detect Fragile X syndrome, high resolution chromosome analysis, and prolonged sleep-deprived electroencephalography (in children who have symptoms of developmental regression or clinical seizures or when there is a high suspicion of subclinical seizures).

Further, physicians need to be vigilant concerning regular health concerns, which may be more likely to be missed in children who are non-verbal or demonstrate severe behaviour problems. Research has shown that children with ASDs have more outpatient visits, physician visits, and medications prescribed than children in general\(^{143}\). Volkmar, Wiesner and Westphal\(^{142}\) suggest that the symptoms of ASDs (social difficulties, communication problems, difficulties with novelty, difficulties with organization and attention) may present obstacles for physicians who see children with ASDs as part of their practice. In addition, there is a tendency toward “diagnostic overshadowing” meaning that, rather than investigating other possible causes, the child’s problems are attributed to the ASD.

**Sensory Abilities**
Multiple concurrent sensory issues have been described in the ASD population. Strabismus and myopia are common in children with disabilities. Although deafness may explain ASD-like communication symptoms in a child without an ASD, children with ASDs may also have concurrent hearing impairments. Further, children with ASDs often have sensory defensiveness with regard to auditory, visual, touch, and oral sensory processing\(^{144}\), for example, intolerance to bright lights, loud noises or light touch. Outlining the sensory profile of a child may serve to orient treatment approaches more effectively.

**Speech-Language-Communication**
The verbal communication skills of children with ASDs vary widely. Children with Asperger’s disorder have no clinically significant delay in their verbal abilities, although
their social communication may be unusual. Language abilities of children with ASDs vary from odd to completely absent. Preverbal communication, both gestures and sounds, have been found to be abnormal in children with ASDs.

**Neuropsychological, Psychiatric and Behavioural Functioning**
Filipek and colleagues reviewed research on neuropsychological differences in children with ASDs, and suggested that these children tend to have deficiencies in performance on tasks requiring higher-order conceptual processes, reasoning, interpretation, integration, or abstraction. Additionally, deficiencies in the form of dissociations between simple and complex processing in the areas of language, memory, executive function, motor function, reading, mathematics, and perspective-taking have also been noted. Children with ASDs have been found to have difficulties with selective attention, problems in attending to multiple aspects of stimuli and, in particular, auditory stimuli. Matson and Nebel-Schwalm review research on psychiatric co-morbidities, including mood disorders, which they argue are prevalent but less often studied in very young populations. Young children with ASDs have been shown to be more fearful of thunderstorms, dark places, large crowds, dark rooms or closets, going to bed in the dark, and closed places compared to children without ASDs. However, Matson and Nebel-Schwalm argue that some disorders, including obsessive-compulsive disorder and early onset schizophrenia, may be difficult to distinguish from ASDs due to overlapping symptomatology. In their review of behavioural problems in children with ASDs, Matson and Nebel-Schwalm cite aggression, property destruction, disruptions/tantrums, self-injury, and stereotypies as the primary behavioural issues.

**Sensorimotor Functioning**
Filipek and colleagues suggest that hypotonia, limb apraxia, and motor stereotypies are common in individuals with ASDs, and are more likely to occur in individuals with more severe cognitive impairments.

**Feedback from Committees**
Parents asserted that it was not enough to simply know that their child did or did not have an ASD. In order to understand their child and ably plan for his or her future, parents wanted to know more about their child as a whole person. Parents felt that some of their other concerns about their child were ignored or placed under the ASD umbrella placed under the ASD umbrella (diagnostic overshadowing). Particularly, parents asserted that, just because their child had an ASD, it did not mean that their child couldn't be sick or have other emotional or behavioural problems unrelated to the ASD.

The clinician and scientific committees agreed that a global assessment was important for the purposes of intervention planning.

**Recommendations for Practice, Research, and Policy**

**Practice**
- Considerations for corollary medical investigations and general medical health.
  - Lead screening should be performed in any child with developmental delay and pica.
  - Evaluation for seizure disorders.
- An assessment of hearing and vision is needed to determine presence of co-occurring sensory difficulties.
- Children with ASDs require a full assessment of communication abilities for appropriate treatment planning.
- An assessment by a psychiatrist or psychologist is needed in order to identify any co-morbid psychological, emotional, or behavioural problems.
- An assessment of sensorimotor function by an occupational therapist may be useful for treatment planning.

**Research**
- Further research is needed to examine commonly co-occurring disorders with regard to theories of common causation.

**Policy**
- Functional assessments are part of the overall evaluation process and need to be funded.
Multiple sources of information (parents, teachers, etc.) should be consulted in the assessment. Assessments should take place in varied contexts (home, school, etc.) to heighten validity.

**Background and Rationale**

**Information Sources**
The parents are the most important source of information in the assessment of children with ASDs; however, it is recommended that other individuals who care for or are in contact with the child on a regular basis should be consulted. Interviews should include a health history, a developmental and behavioural history, and a family medical and mental health history.

**Contexts**
Most assessments for ASDs occur in a clinic setting. This tends to occur because the ease and efficiency clinics offer in regard to team communication, access to needed materials, cost, and environmental control. However, children tend to experience changes in behaviour when faced with a novel setting, and children with ASDs tend to be particularly sensitive to changes in their environment. Naturalistic observation, on the other hand, allows the assessor to examine the child’s behaviour within natural environments (e.g., home or daycare), and reduces the influence of setting novelty on the assessment. However, this type of observation involves pragmatic challenges related to less control and less efficient access to other team members and needed materials.

**Recommendations for Practice, Research, and Policy**

**Practice**
- Review information from referral source and all other assessments by other professionals.
- Review detailed developmental history with parents.
- If the child is in an educational or daycare setting, interview or provide questionnaires to teachers or daycare providers. Whenever possible, direct observation is preferred.
- It is critical to conduct assessments in a controlled laboratory setting and, if possible, include naturalistic observation in home and daycare or education setting.

**Research**
- Research on the diagnosis of ASDs in varied contexts (home, school, clinical setting) is needed.

**Policy**
- Formalize links between the family physician, psychologist, assessment team, family and education system, as well as any other involved parties, for ease of communication.
The delay between the emergence of symptoms, screening, assessment and diagnosis must be as short as possible to prevent delays in treatment.

**Background and Rationale**
Researchers have shown that medical professionals are reluctant to diagnose ASDs in children under three years of age. Gray and Tonge suggest that diagnostic delays exist for a number of reasons, including the delayed onset of diagnostic criteria relating to social and communicative development, difficulty in differentiating children with autistic disorder with a mental age of less than 18 months from non-verbal children with developmental delays without autistic disorder or from those with language impairment, lack of specialized training or services, few standardized assessment procedures, concerns over alarming parents or labeling children prematurely, and fear of litigation.

**Feedback from Committees**
“Criminally long” wait lists were described by the members of our parent committee. This is the issue that was perhaps the most salient to the parent committee when discussing their children’s diagnosis and assessment. Our clinician committee also reported frustration with having referrals made “too late,” preventing the child from obtaining early intervention services. The scientific committee agreed that waiting lists for assessments should be made as short as possible, and also stressed that this action needs to be followed up by making treatment programs more easily accessible. The goal of identifying more children at earlier times is questionable when the availability of treatment programs to handle the increased numbers is insufficient. Regardless, all committees felt a need to push for shorter waiting times to reduce parental stress and to obtain earlier access to guidance and interventions for families in need of help.

**Recommendations for Practice, Research, and Policy**

**Practice**
- The time between the referral from a primary practitioner and the beginning of the interdisciplinary assessment should be no longer than three months.
- The assessment results should be available to the family within two months of the beginning of the assessment.

**Research**
- Research is needed to examine methods to reduce or eliminate barriers to the reduction or elimination of wait times.

**Policy**
- In order to be able to meet the increased demand for timely assessment services, policies must be put into place to support the creation and maintenance of interdisciplinary assessment teams.
  - Increased funding for hospital-based interdisciplinary assessment teams.
  - Creation of community-based interdisciplinary assessment teams.
The assessment process must be family-centred, focusing on the uniqueness of each child and family and providing all communications, both written and verbal, in a manner that is clear, understandable, useful and respectful.

Background and Rationale
Canada is comprised of families from a wide variety of different ethnic, cultural, and religious backgrounds. It is critical that assessment protocol consider aspects of each individual family’s background that could impact on the characteristics of the child, the family’s participation in the assessment process, their understanding of the results, and their ability to follow through on recommendations. In Canada, it is critical to consider symptom expression, applicability of diagnostic materials, and response to diagnosis in groups including Franco-Canadians, Aboriginal-Canadians, and recent immigrants.

Although there is little empirical research regarding the expression and identification of ASDs among different cultural groups, it has been observed that most research focuses on ASDs in Anglo-Saxon families. Dyches and colleagues discuss that culture may influence a family’s interpretation of the etiology of the disorder, which in turn affects their appraisal of the stressor, either negative (e.g., as a curse) or positive (e.g., as a gift from God). Religious background, social support, family support and organizational support also vary culturally and may influence a family’s response to their child with an ASD and the professionals who work with them.

Feedback from Committees
The parent committee felt very strongly that clinicians and researchers sometimes forget they are dealing with real families who are going through difficult times. They stressed that the process of assessment is not just about symptoms and questionnaires, but concerns their tears, fears, joy, relief, anguish, and hope. Parents stressed that they wanted to be able to participate in the assessment process and that they wanted to be more actively involved in research programs designed to impact their lives in meaningful ways. They also highlighted the importance of understanding the diagnosis and receiving written material that was appropriate to their level of knowledge and understanding. This was particularly important to parents who discussed being overwhelmed by information at the time of diagnosis, and needing time to process what they had heard.

Clinicians and scientists agreed with the importance of considering cultural differences in practice and research.

Recommendations for Practice, Research, and Policy
Practice
• Consider the cultural context of parental reporting and relationship with professionals. Some cultural and immigrant groups may find it more difficult to voice concerns to professionals. Further, understanding of child development varies widely between cultures.
• Consider the family’s cultural, ethnic, and religious backgrounds. Conduct the assessment and provide feedback in a manner that is sensitive and considers their unique needs.

• All written material provided to parents must be written in language that is easy to understand, without an overuse of jargon or highly technical wording.

• The results of the assessment should also be presented verbally and, when necessary, provided in their first language using an interpreter.

• Sufficient time should be allotted for parents to ask questions, including a follow-up appointment or contact following the first feedback session, in case parents have additional questions.

• Professionals should understand that parents may obtain information from a variety of sources, not all credible, and should be prepared to discuss this information with parents in a manner that is respectful.

Research
• More research is needed to examine cultural variations in symptom expression.

• More research is needed to validate currently available measures in different languages and with different cultural groups.

• Need to research interventions to encourage various cultural groups to pursue early identification.

Policy
• In addition to traditional research programs, funding should be provided to support innovative Participatory Action Research programs, involving individuals with ASDs and their families in the development of applied research programs intended to create immediate, culturally-relevant changes within the community, or social or organizational policy.
References


Appendix A: Diagnostic Criteria

DSM-IV-TR: Pervasive Developmental Disorders


DSM-IV Diagnostic Criteria for 299.00 Autistic Disorder

A. A total of at least six items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

(1) qualitative impairment in social interaction, as manifested by at least two of the following:
   (a) Marked impairment in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
   (b) Failure to develop peer relationships appropriate to developmental level
   (c) A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
   (d) Lack of social or emotional reciprocity

(2) Qualitative impairments in communication as manifested by at least one of the following:
   (a) Delay in or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
   (b) In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
   (c) Stereotyped and repetitive use of language or idiosyncratic language
   (d) Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

(3) Restricted repetitive and stereotyped patterns of behaviour, interests, and activities, as manifested by at least one of the following:
   (a) Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
   (b) Apparently inflexible adherence to specific, nonfunctional routines or rituals
   (c) Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole body movements)
   (d) Persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.
**DSM-IV Diagnostic Criteria for 299.80 Asperger's Disorder***

A. Qualitative impairment in social interaction, as manifested by at least two of the following:

1. Marked impairment in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
2. Failure to develop peer relationships appropriate to developmental level
3. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
4. Lack of social or emotional reciprocity

B. Restricted repetitive and stereotyped patterns of behaviour, interests, and activities, as manifested by at least one of the following:

1. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
2. Apparently inflexible adherence to specific, nonfunctional routines or rituals
3. Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole body movements)
4. Persistent preoccupation with parts of objects

C. The disturbance causes clinically significant impairments in social, occupational, or other important areas of functioning

D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years)

E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behaviour (other than social interaction), and curiosity about the environment in childhood

F. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia

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**ICD-10 Diagnostic Criteria: Pervasive Developmental Disorders**

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**F84.0 Childhood Autism**

A type of pervasive developmental disorder that is defined by: (a) the presence of abnormal or impaired development that is manifest before the age of three years, and (b) the characteristic type of abnormal functioning in all the three areas of psychopathology: reciprocal social interaction, communication, and restricted, stereotyped, repetitive behaviour. In addition to these specific diagnostic features, a
range of other non-specific problems are common, such as phobias, sleeping and eating disturbances, temper tantrums, and (self-directed) aggression.

F84.1 Atypical Autism
A type of pervasive developmental disorder that differs from childhood autism either in age of onset or in failing to fulfil all three sets of diagnostic criteria. This subcategory should be used when there is abnormal and impaired development that is present only after age three years, and a lack of sufficient demonstrable abnormalities in one or two of the three areas of psychopathology required for the diagnosis of autism (namely, reciprocal social interactions, communication, and restricted, stereotyped, repetitive behaviour) in spite of characteristic abnormalities in the other area(s). Atypical autism arises most often in profoundly retarded individuals and in individuals with a severe specific developmental disorder of receptive language.

F84.5 Asperger's Syndrome
A disorder of uncertain nosological validity, characterized by the same type of qualitative abnormalities of reciprocal social interaction that typify autistic disorder, together with a restricted, stereotyped, repetitive repertoire of interests and activities. It differs from autistic disorder primarily in the fact that there is no general delay or retardation in language or in cognitive development. This disorder is often associated with marked clumsiness. There is a strong tendency for the abnormalities to persist into adolescence and adult life. Psychotic episodes occasionally occur in early adult life.
Appendix B: Best Practice Synthesis

Pathways to diagnosis

• Parent report:
  • Are parents accurate in reporting developmental delays in young children?

• Routine Developmental Monitoring
  • Recommended times for developmental monitoring (15, 18, 24 months)
  • Note failure to meet developmental milestones
    • No big smiles or other warm, joyful expressions by 6 months;
    • No back-and-forth sharing of sounds, smiles or facial expressions by 9 months;
    • No babbling by 12 months
    • No gesturing (e.g., pointing, waving bye-bye,) by 12 months
    • No single words by 16 months
    • No two-word spontaneous (not just echolalic) phrases by 24 months
    • loss of any language or social skill at any age

Developmental Surveillance:

• Universal screening for ASDs not possible
  • Have any tools been since shown to be sensitive and specific for universal screening?
    • The Australian Scale For Asperger's Syndrome (A.S.A.S.)
    • Autism Screening Questionnaire (ASQ)
    • Checklist for Autism in Toddlers (CHAT)
    • Communication and Symbolic Behavior Scales Developmental Profile
      • (CSBS DP)
    • Modified Checklist for Autism in Toddlers (M-CHAT)
    • Pervasive Developmental Disorder Screening Test-II (PDDST II)
    • Screening Test for Autism in Two-Year-Olds (STAT)

• Level One Surveillance concerns general developmental level
  • General developmental delay screening tools
    • Ages and Stages Questionnaire
    • the BRIGANCE Screens
    • the Child Development Inventories
    • the Parents' Evaluation of Developmental Status

• Level Two Surveillance
  • Use of Autism specific screening tools
The Australian Scale For Asperger's Syndrome (A.S.A.S.)
Autism Screening Questionnaire (ASQ)
Checklist for Autism in Toddlers (CHAT)
Communication and Symbolic Behavior Scales Developmental Profile
(CSBS DP)
Modified Checklist for Autism in Toddlers (M-CHAT)
Pervasive Developmental Disorder Screening Test-II (PDDST II)
Screening Test for Autism in Two-Year-Olds (STAT)

- Siblings of children already diagnosed with autism are at higher risk and should be closely monitored
- Referral for full diagnostic assessment made on the basis of test results

**Assessment and Diagnosis**

- Review relevant information from referral sources
- For exclusion / inclusion
  - Genetic testing should be performed in presence of intellectual disability or if there is a family history of Fragile X
  - Selective metabolic testing should be initiated by the presence of suggestive clinical and physical findings such as the following: if lethargy, cyclic vomiting, or early seizures are evident; the presence of dysmorphic or coarse features; evidence of mental retardation or if mental retardation cannot be ruled out; or if occurrence or adequacy of newborn screening for a birth is questionable
  - Hearing test to rule out hearing impairments as source of language and communication delay
  - Lead screening should be performed in any child with developmental delay and pica.
  - Seizure disorders
- Comprehensive medical examination
- Review history from multiple sources, including interview(s) with the caregiver and other involved professionals
- Direct behavioural assessment
- Use of empirically validated assessment tools
  - Autism Diagnostic Interview-Revised (ADI-R)
  - Autism Diagnostic Observation Schedule-Generic (ADOS)
  - Childhood Autism Rating Scale (CARS)
  - Gilliam Autism Rating Scale (GARS)
  - Parent Interview for Autism (PIA)
  - Pervasive Developmental Disorders Screening Test-Stage 3 (PDDST-III)
  - Screening Tool for Autism in Two-Year-Olds (STAT)
- Use of multiple instruments is recommended

Appendix A: Diagnostic Criteria
Multidisciplinary Team is ideal
  • Psychologists
  • Neurologist
  • speech-language pathologists and audiologists
  • pediatricians
  • child psychiatrists
  • occupational therapists and physical therapists
  • educators and special educators

Diagnosis can only be made by a psychologist or a physician

Team Members should be trained and experienced in ASDs and should continue to update their skills in regard to early assessment and diagnosis

Clinical diagnosis must be in accordance with Diagnostic and Statistical Manual of Mental Disorders (DSM)-IV/International Classification of Diseases (ICD)-9 diagnostic criteria

Since intellectual disabilities are common in people with ASDs, it is important to assess cognitive level and adaptive behaviour skills using standardized, norm-referenced measures

Full assessment of areas of strength and weakness is important for intervention purposes
  • Sensorimotor and occupational therapy assessment
  • Neuropsychological and behavioural assessment
  • Speech-language assessment
  • Continued medical care

Re-evaluation of diagnosis one year later, ongoing assessment of child for intervention purposes

General Recommendations

  • Assessments must be individualized and age appropriate
  • Process should be efficient and well-organized. Don’t “wait and see”
  • Consider cultural and familial context
  • Consider setting of assessment
    • Use multiple contexts
  • Written reports in lay language so as to be comprehensible to parents
  • Up-to-date referrals to community groups, intervention programs, and other services, resource booklet
  • Children with diagnosed or suspected ASD should be able to enroll in early intervention services
  • Maintain knowledge of alternative therapies for objective discussions with parents
  • Primary health care provider is affiliated with other individuals
Appendix C: Summary of Practice Recommendations

Developmental Surveillance

- The physician or other professional should note the child’s failure to meet the following developmental milestones.

  **N.B. A single missed milestone may not be cause for concern (unless it is loss of language), but pay particular attention when more than one of the following milestones has not been met:**
  - Diminished, atypical, or no babbling by 12 months
  - Diminished, atypical, or no gesturing (e.g., pointing, waving bye-bye,) by 12 months
  - Lack of response to name by 12 months
  - No single words by 16 months
  - Diminished, atypical, or no two-word spontaneous phrases (excluding echolalia or repetitive speech) by 24 months
  - Loss of any language or social skill at any age
  - Lack of joint attention

  For video examples of symptoms associated with ASDs, see the Video Glossary at Autism Speaks: www.autismspeaks.org/video/glossary.php

- Ask parents the question “Do you have any concerns about your child?”
- Inquire about family history of ASDs.
- Engage child in interactions designed to elicit social and communicative behaviours, for example, calling the child’s name or pointing to an object to determine if the child can direct their attention to the indicated object.
- Consider the developmental level of the child, as symptom expression may change within the context of normal development.
- Further use of screening tools and/or referral to an interdisciplinary assessment team should be made based on a combination of parental concern, missed milestones, presence of risk factors and clinical judgement.
- If a parent brings up a concern about his or her child’s development, particularly concerns related to communication and social behaviour, appropriate investigations should be conducted and/or a referral should be made to appropriate services.
- Parents’ concerns about their child’s development should be addressed without delay. A “wait and see” approach is not appropriate.
- Parents’ lack of concern should not rule out the need for further investigations if signs and symptoms are noted by the clinician.
- A guide should be made available to parents undergoing the diagnostic process, including steps to be taken, available resources in their geographic area and a list of reliable websites for self-education. Some recommendations include (in alphabetical order):
Screening

- Focus on developmental surveillance, rather than universal screening for ASDs.
- Apply second-level screening to children who have been identified through developmental surveillance or parental report, or who have siblings with ASDs or other developmental disabilities.
- Children should be formally screened whenever a parent has expressed concern about their development or when the professional has noted signs and symptoms of ASDs.
- Formal screening of siblings of children with ASDs or other developmental disorders should be conducted regularly.
- The M-CHAT is an appropriate parent-report tool for use in second-level screening due to its ease of administration (may be given to parents in the physician waiting room),
  - It is recommended that the follow-up interview is administered in conjunction with the parent-report questionnaire to increase sensitivity.
- The CHAT is the most researched screening tool and may be tentatively recommended for second level screening.
  - The Denver modification is tentatively recommended to increase sensitivity without a loss to specificity. In this scoring criteria, parents can endorse one of two critical items, pretend play AND / OR protodeclarative pointing.
- The STAT is recommended as a second-level screener for use by professionals trained in its administration in distinguishing autistic disorder from other developmental delays.
- The use of the GARS and the ABC is not recommended.
- There is a need to develop and utilize the expertise of other professionals (public health nurses, early childhood educators) for the purpose of screening children for ASDs.
- When an ASD is suspected through developmental surveillance, parent report and / or the use of screening tools, referrals for assessments and services should occur immediately. If unsure, pediatricians and GPs should over- rather than under-refer.
- Referral for audiology assessment should be made concurrently with referral to an interdisciplinary ASD assessment team, unless an audiologist is part of the team.
- Referral to a speech-language pathologist for assessment and intervention should be made concurrently with referral to an interdisciplinary ASD assessment team, unless the SLP is part of the team.
- Consider the child’s cognitive and developmental level, as service needs may differ depending on the child’s developmental level and the severity of cognitive delay.
• The child should receive a referral to early intervention or developmental services upon suspicion that they may have an ASD or other developmental delay.

• Parents should receive a list of available resources including community organizations and parent groups, as well as information about ASDs and a list of websites offering accurate information.

• The diagnosis of ASDs in young children should only be made by a psychologist or a physician under the conditions that they are:
  • Members of a professional order or college that permits the transmission of diagnoses
  • Have graduate (doctoral level) or post-graduate training encompassing specific training in child development and ASDs and other developmental disorders in young children.
  • Have received supervised clinical experience in the assessment and diagnosis of ASDs in young children.

• Training with the ADOS and the ADI-R is encouraged for those involved in the diagnosis of ASDs; however, this is not mandatory as other assessment protocols involving a detailed-history, parent interview, and direct observation can be sufficient to diagnose ASDs.

• The assessment of young children with ASDs should only be conducted by professionals who are:
  • Members of a professional order or college.
  • Have post-secondary, graduate or post-graduate training encompassing specific training in child development, ASDs and assessment,
  • Have received supervised clinical experience in the assessment of ASDs and other developmental disorders in young children,
  • Have received training in ASDs as part of continuing education.

• Experts in the area of ASDs should act as information and consultation resources for other professionals in the community who encounter children with ASDs in their practice.

• Physicians and psychologists who do not frequently see children with ASDs in their practice or who have not had direct training in the field should refer the child to an expert or a multi-disciplinary team or, if they are geographically remote, consult an expert or interdisciplinary team in formulating their diagnosis.

• Interdisciplinary teams are recommended above multidisciplinary teams, but either is preferable to a single-practitioner approach.

• Members of the team may include some or all of the following professionals (listed in alphabetical order):
  • Audiologists
  • Behavioural Specialists / Early Interventionists
  • Dietitians
  • Educational Specialists
  • Neurologists
  • Nurse Practitioners
  • Occupational Therapists
• Pediatricians
• Psychiatrists
• Psychologists
• Social Workers
• Speech Pathologists

The team should be led by a professional who is licensed to diagnose; either a psychologist or a physician.

Communication and collaboration among team members is necessary to achieve the most accurate diagnosis and to avoid duplication of effort.

It is important to consider issues of confidentiality and obtain written, legal consent for communication among team members and between other relevant individuals or organizations.

**Diagnosis**

• Diagnoses of ASDs must be made in reference to the criteria outlined in the DSM-IV-TR or the ICD-10.

• All five DSM axes should be considered in the full diagnostic evaluation of the individual. Although the traditional global functional assessment may not be applicable to very young children with disabilities, an effort must be made to assess the child's general level of functioning in order to paint a more complete picture of the child and provide information relevant to treatment planning.

• Caution should be used when applying the symptoms outlined in the DSM-IV-TR / ICD-10 to very young children.

• The combined use of the ADI-R and ADOS, in combination with clinical judgement is, at this time, the gold standard for the diagnosis of ASDs; however, a lack of ADI-R, ADOS data should not prevent a child from receiving much needed services if a diagnostician with sufficient expertise conducts the assessment.

• The CARS may also be used in diagnostic assessments.

• Clinical judgment, which requires significant training and experience, is critical when interpreting results of standardized measures and differentiating between the types of ASDs.

• Whether or not empirically-validated assessment tools are used in the diagnostic process, a formal behavioural observation process and a parental interview, including a thorough developmental history, should be conducted and documented.

• Although cognitive assessments are not required for the diagnosis of an ASD, a thorough developmental assessment should be undertaken during or following the assessment process to determine the presence of an intellectual disability and to document the child's strengths and weaknesses. This is particularly useful for intervention purposes, as the type of intervention and its success may depend on the presence and severity of cognitive delay.

• The developmental assessment must be conducted with the use of standardized, norm-referenced instruments.

• An interdisciplinary team approach is recommended in order to conduct a thorough differential diagnosis.
• A full medical examination is needed to assess for associated medical conditions, as indicated.
  • Genetic testing should be performed when there is presence of intellectual disability or if there is a family history of Fragile X.
  • Selective metabolic testing should be initiated by the presence of suggestive clinical and physical findings (i.e. lethargy, cyclic vomiting, early seizures, the presence of dysmorphic or coarse features; evidence of ID or if ID cannot be ruled out; or if occurrence or adequacy of newborn screening at birth is questionable).
  • A neurology assessment may be needed if seizures are present or if there is a suspicion of other neurological problems.
  • A psychological or psychiatric consultation may be needed to rule out other psychiatric, emotional, or behavioural conditions.
  • An audiology consultation is needed to assess for and rule out the presence of hearing disabilities.
  • A speech-language pathology assessment may be necessary to assess for other communication or language disorders.
  • An occupational therapy evaluation may be necessary to assess for other motor or sensory dysfunctions.
  • The team should compare and contrast findings in an effort to come to a straightforward diagnostic decision.
  • Solitary practitioners should consult with or refer to other professionals, as needed.

**Corollary Assessment Issues**

• Considerations for corollary medical investigations and general medical health.
  • Lead screening should be performed in any child with developmental delay and pica.
  • Evaluation for seizure disorders.
  • An assessment of hearing and vision is needed to determine presence of co-occurring sensory difficulties.
  • Children with ASDs require a full assessment of communication abilities for appropriate treatment planning.
  • An assessment by a psychiatrist or psychologist is needed in order to identify any co-morbid psychological, emotional, or behavioural problems.
  • An assessment of sensorimotor function by an occupational therapist may be useful for treatment planning.
  • Review information from referral source and all other assessments by other professionals.
  • Review detailed developmental history with parents.
  • If the child is in an educational or day care setting, interview or provide questionnaires to teachers or daycare providers. Whenever possible, direct observation is preferred.
• It is critical to conduct assessments in a controlled laboratory setting and, if possible, include naturalistic observation in home and daycare or education setting.

• The time between the referral from a primary practitioner and the beginning of the interdisciplinary assessment should be no longer than three months.

• The assessment results should be available to the family within two months of the beginning of the assessment.

• Consider the cultural context of parental reporting and relationship with professionals. Some cultural and immigrant groups may find it more difficult to voice concerns to professionals. Further, understanding of child development varies widely between cultures.

• Consider the family’s cultural, ethnic, and religious backgrounds. Conduct the assessment and provide feedback in a manner that is sensitive and considers their unique needs.

• All written material provided to parents must be written in language that is easy to understand, without an overuse of jargon or highly technical wording.

• The results of the assessment should also be presented verbally and, when necessary, provided in their first language using an interpreter.

• Sufficient time should be allotted for parents to ask questions, including a follow-up appointment or contact following the first feedback session, in case parents have additional questions.

• Professionals should understand that parents may obtain information from a variety of sources, not all credible, and should be prepared to discuss this information with parents in a manner that is respectful.
Appendix D: Summary of Research Recommendations

Developmental Surveillance

- Continue research into the early signs of ASDs and changes in their expression over development.
- Examine the effects of the introduction of guidelines on the surveillance and identification of children with ASDs in Canada.
- Investigate the effectiveness of awareness programs for professionals other than physicians who work with very young children.
- Continue research to understand and circumvent the reasons behind delays in diagnostic referrals and assessments.
- Research is needed regarding the impacts of educational initiatives aimed at educating parents about the symptoms of autistic disorder.
- Further investigations are needed into the nature of regression in ASDs.
- When appropriate, researchers should actively involve parents in the process of designing and implementing some research programs.

Screening

- Need further research to develop reliable and valid universal screening tools for ASDs with adequate sensitivity and specificity.
- Continue the evaluation of existing screening tools for the purposes of universal screening.
- More research is needed regarding risk factors for ASDs in order to identify higher risk children.
- Further research is needed on the Denver modification of the CHAT to determine whether the higher rates of sensitivity and specificity are maintained with larger samples over longer follow-up periods.
- Further research is needed on the ESAT, M-CHAT, PDDST-II, the STAT, and the SCQ.
- Innovative research is needed for the development of screening tools that will identify children with more mild symptoms, higher cognitive abilities, or atypical variants of ASDs.
- There is a need for continued research into the development of new sensitive and specific screening tools.
- There is a need for continued research into the development of screening methods that are more time-efficient.
- Research is needed regarding the impact, both short- and long-term, of implementing developmental/intervention services for children on the wait-list for assessment, comparing children who are and are not later diagnosed with an ASD.
- Research regarding the reliability and validity of early diagnosis made by experts is needed.
• There is a need for more research examining the reliability and validity of early diagnoses made by members of various professional disciplines.
• Research is required to examine the reliability of diagnoses made by experts using telemedicine approaches (video, internet consultation) for children without access to a multidisciplinary team.
• Research is needed regarding the specific contribution made by each discipline/area of expertise contribution to accurate diagnosis.

**Diagnosis**

• Research programs are needed to further investigate the categorical versus dimensional conceptualizations of ASDs.
• More research is needed to examine the differentiation of ASD sub-types, as defined by current classification systems, and their clinical or prognostic significance.
• More research is needed to examine the usefulness of the DSM-IV-TR criteria with regard to very young children.
• There is a need for research aimed at developing and evaluating parent-report and behavioural observation tools that are more time-efficient.
• Research is needed regarding the development and evaluation of algorithms that differentiate between autistic disorder and other forms of ASDs.
• There is a need for continued exploration of the variability and reliability and validity of diagnoses based on clinical judgement.
• Improve the reliability and validity of cognitive testing in very young children, particularly for children with developmental delays.
• More research is needed regarding diagnostic overlap of disorders with common symptoms.
• Research into the development of tools to distinguish between disorders with common symptomatology is necessary.

**Corollary Assessment Issues**

• Further research is needed to examine commonly co-occurring disorders with regard to theories of common causation.
• Research on the diagnosis of ASDs in varied contexts (home, school, clinical setting) is needed.
• Research is needed to examine methods to reduce or eliminate barriers to the reduction or elimination of wait times.
• More research is needed to examine cultural variations in symptom expression.
• More research is needed to validate currently available measures in different languages and with different cultural groups.
• Need to research interventions to encourage various cultural groups to pursue early identification.
Appendix E:
Summary of Policy Recommendations

Developmental Surveillance

- Family physicians need more training in developmental surveillance and education around developmental milestones; in particular, training should focus on the 90th percentile as well as the 50th.
- Medical training should require specific training in the early signs of ASDs.
- More education for professionals involved in early child care (public health nurses, daycare workers, early childhood educators) around the early signs and symptoms of ASDs.
- Create links between early child care / education and diagnostic services for informational and referral purposes.
- Awareness campaigns are needed to provide parents with more information about the signs and symptoms of ASDs, as well as what to do when they notice any developmental concerns.
- Education supported by the Canadian medical associations is needed to provide physicians with more information about the signs and symptoms of ASDs, risk factors that should be considered, as well as specific plans of action when presented with a child with symptoms of an ASD.

Screening

- Universal screening is not currently recommended for ASDs, given the limitations of currently available tools.
- Knowledge of the symptoms of ASDs by all individuals in contact with young children is the key to early identification of high risk children; therefore, wider awareness campaigns must be launched in order to educate parents and professionals about the early symptoms of ASDs.
- There is a need for changes to funding models or new approaches to support developmental screening by physicians, possibly including higher reimbursement for developmental screening appointments.
- Pediatricians and general practitioners require more training in recognizing higher risk children and the use of autistic disorder-specific screening tools.
- Other professional groups require more resources directed to their training in the recognition and screening of ASDs.
- The creation of community-based developmental screening centers would lessen the load for medical professionals.
- There is a need for the creation of a bank of experts willing to provide consultation to less experienced physicians in the screening process.
- Evidence-based interventions should be made available to children who have been identified through a secondary screen as being high-risk, and who are on the waitlist for a formal diagnosis by a multi-disciplinary team.
• There is a need for the creation of a bank of experts who are willing to consult with community-based practitioners concerning the use of screening tools and referral options.

• An accreditation process should be initiated to identify internet resources with reliable and accurate information about ASDs.

• In order to minimize the waiting times for obtaining a diagnosis of an ASD, the diagnosis of ASDs should be delegated to Ph.D.-level psychologists, in addition to physicians, in the province of Québec.

• There is need to create a bank of experts who are willing to consult with practitioners from remote or rural areas who may not be able to easily refer a family to a interdisciplinary team.

• There is need for the creation of a system by which experts can consult with remote practitioners, such as video, teleconferencing and internet.

• Continued education specific to the field of ASDs must be mandatory for active professionals in the field.

• More university programs focusing on training various professional groups in the field of ASDs are needed.

• There is a need to encourage more students and professionals to obtain training in the field through financial incentives (i.e., grants, scholarships, etc.) and available positions for trained individuals.

• Increase funding for the creation and maintenance of interdisciplinary diagnostic teams for ASDs.

• Improve access to interdisciplinary teams for families in remote areas.

Diagnosis

• Education and developmental services should be available to all children with ASDs, regardless of the specific diagnostic sub-type.

• The ADOS and ADI-R should be advanced as the standard assessment protocol in assessment clinics across Canada.

• It is necessary to include funding for cognitive testing in the diagnostic assessment.

• Children with suspected ASDs must have a medical and audiology exam prior to or concurrent with the ASDs assessment.

Corollary Assessment Issues

• Functional assessments are part of the overall evaluation process and need to be funded.

• Formalize links between the family physician, psychologist, assessment team, family and education system, as well as any other involved parties, for ease of communication.

• In order to be able to meet the increased demand for timely assessment services, policies must be put into place to support the creation and maintenance of interdisciplinary assessment teams.
  • Increased funding for hospital-based interdisciplinary assessment teams.
  • Creation of community-based interdisciplinary assessment teams.
• In addition to traditional research programs, funding should be provided to support innovative Participatory Action Research programs, involving individuals with ASDs and their families in the development of applied research programs intended to create immediate, culturally-relevant changes within the community, or social or organizational policy.
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For free downloads of this document, as well as a Physician Toolkit, waiting room poster, and Parent Guide to Screening, Assessment and Diagnosis of ASDs, please visit www.autismcentral.ca.

To inquire about ordering multiple copies of the Best Practice Guidelines, Physician Toolkit, waiting room poster, and Parent Guide to Screening, Assessment and Diagnosis of ASDs, please call the Miriam Foundation at (514) 345-1300 or email bestpractices@miriamfoundation.ca.

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ABOUT THIS BOOK

The Best Practices Handbook seeks to establish consistency in the processes used to diagnose Autism Spectrum Disorders by developing standardized Canadian best practices for screening and early diagnosis of individuals with Autism Spectrum Disorders.

The book was published by the Miriam Foundation. Established in 1970, the Foundation is a not-for-profit foundation which supports rehabilitative, vocational and residential services for children and adults living with intellectual disabilities or autism spectrum disorders.