# Standards and Guidelines for the Assessment and Diagnosis of Young Children with Autism Spectrum Disorder in British Columbia

An Evidence-Based Report prepared for The British Columbia Ministry of Health Planning

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## § 1 Introduction

The field of autism has become of increasing interest to health, social service and education professionals in the last two decades. Dramatically rising rates of identification<sup>246</sup> along with a rapidly changing research milieu has raised a number of pressing questions for government in terms of social policy, funding allocation, and health care initiatives.

As in other jurisdictions, autism services in British Columbia have been the subject of substantial concern and debate in the last decade. <sup>34,272</sup> In 1991, specific services for autism were first introduced in British Columbia as part of the "Enhanced Initiatives for Autism." In 1998, the BC Council on Autism, representing key stakeholders, issued a brief indicating a "crisis" in autism services. This led to a workshop, out of which the Ministry for Children and Families, the Ministry of Education, and the Ministry of Health produced the Autism Action Plan (*AAP*)<sup>13</sup>. The *AAP*, and its follow-up Autism Action Plan – Implementation Plan<sup>14</sup> made recommendations in four categories: 1) early intervention and treatment; 2) assessment, diagnosis, and eligibility; 3) education and training; and 4) transition to adult services. A priority objective was to establish a common definition of autism, and common language, assessment practices, and eligibility for autism services. Another priority was to enhance regional capacities to complete multidisciplinary assessments and diagnoses.

The Ministry of Health Planning (MOHP) is coordinating with the Ministry of Children and Family Development (MCFD) to provide a provincial program of effective early intensive intervention (EII) for children under age six with Autism Spectrum Disorder (ASD; see definition in Section 3). The Ministry of Health Services (MOHS) is responsible for assessment and diagnostic services whereas the MCFD is responsible for treatment, training and research, and program evaluation.

The purpose of this document is to provide minimum standards required in British Columbia to make a diagnosis of ASD in children under the age of six; to assist in establishing eligibility for ASD intervention services; and to establish consistency in the ASD diagnostic process across the province.

## § 2 Overview and Methodology

The current *Standards and Guidelines for the Assessment and Diagnosis of Young Children with Autism Spectrum Disorder* project was planned to ensure assessment and diagnostic services for ASD in children six years old and under adhere to best practice, and are sustainable and practical in British Columbia.

The document contains the following components:

- Introduction (Section 1);
- Overview and Methodology (Section 2);
- Definitions and Terminology (Section 3);
- Clinical Pathway for Diagnosis (Section 4);
- Surveillance and Screening (Section 5);
- Primary Care Assessment and Referral (Section 6);
- Diagnostic Multidisciplinary Assessment (Section 7); and,
- Recommendations for Education and Training (Section 8).

Sections 5, 6, and 7 are each divided into four parts: Preamble, Practice Standards, Clinical Practice Guidelines, and Outcome Objectives and Indicators.

The overall goal for the *Standards and Guidelines for the Assessment and Diagnosis of Young Children with Autism Spectrum Disorder* is:

- to promote the application of evidence-based practices in the identification, assessment and diagnosis of children with ASD;
- to provide health regions with tools that support the identification, assessment, and diagnosis of children with ASD; and,
- to provide health regions and MOHS with an approach to monitoring outcomes.

This document is primarily directed at professionals involved in screening, identification, assessment and diagnosis of young children with ASD. This includes professionals involved in early intervention and education (e.g. Infant Development Program (IDP) and Child Development Centre (CDC) workers, preschool educators), community health services (e.g. primary care physicians, community health nurses, speech-language pathologists, occupational therapists), and other professionals involved in the assessment and diagnosis of children suspected of ASD (e.g. psychologists, pediatricians, child psychiatrists, speech-language pathologists, occupational therapists). It is intended to be used as a reference document by provincial and regional health authorities in developing and expanding assessment and diagnostic services for young children with query ASD.

This document is the culmination of a process that involved several steps. First, the research literature was reviewed and summarized (including primary research as well as several reputable "expert consensus" documents). Next, the evidence from the literature was organized into the areas defined by the project's objectives. Earlier drafts were revised to best reflect an evidence-based and practicable approach to assessing and diagnosing ASD in British Columbia.

This report also represents the substantial contributions of the ASD standards and guidelines working group members. The working group members represented relevant professional associations, agencies and organizations from within B.C., and each had experience and/or expertise with identification, assessment or diagnosis of ASD in children. The working group reviewed three earlier drafts of this report, and provided substantive input in writing and in four telephone conference calls. Two expert reviewers, from outside B.C., provided substantial feedback on the last draft of this report. A substantively larger group of external reviewers, invited based on their profession, experience, or expertise, also contributed input in one telephone conference call. Although this report is primarily an evidence-based document, to the greatest extent possible, an effort to reach consensus was an operating principle.

It is critical that readers recognize that the focus for this document is children suspected of ASD six years old and under. In targeting this age range, this document has a broader focus than some previous consensus documents (e.g. the New York State Guidelines<sup>140</sup> targeting only children under three), but a narrower one than others (e.g. American Academy of Neurology Practice Parameters<sup>64</sup>). Although some of the content is likely to be applicable to children over six years of age, the reader is advised to exercise caution in using the document for older children.

This report does not directly address issues related to service provision, in terms of the settings or other structural elements. It focuses strictly on the diagnostic process for ASD in young children and helps establish eligibility for early intensive intervention for ASD.

## § 3 Definitions and Terminology

In this document several technical terms are used that require clarification. The following definitions represent the working group's understanding and use of the terms for the purposes of this report. In large part these definitions are derived from clinical research and practice, and references are noted.

#### Autism Spectrum Disorders:

Pervasive developmental disorders (PDDs) comprise several related childhood-onset brain disorders including autism, Asperger syndrome, and Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS).<sup>9</sup> Affected children suffer from the core triad of deficits involving communication, reciprocal social interaction, and restricted repetitive patterns of interests and behaviours. It is a life-long disability. The impact of an ASD can range from mild to severe, and may improve or change across the person's life. Individuals with a PDD commonly suffer from a number of comorbid problems,<sup>57</sup> including mental handicap,<sup>98 (j)</sup> language and learning disabilities,<sup>60,122,243</sup> seizures, and neurological dysfunction.<sup>203,225,50,72</sup> They are also at extremely high risk for comorbid psychiatric disturbances, including anxiety and mood disorders, Attention Deficit Hyperactivity Disorder (ADHD), and tics.<sup>191,137</sup>

In clinical practice, different terms are used interchangeably by different professionals to refer to children with similar presentations. For the purposes of this document, the term *Autism Spectrum Disorder*<sup>273</sup> (ASD) has been selected. This is synonymous with the broad category of PDDs described in both DSM-IV<sup>9</sup> and ICD-10<sup>226</sup>. The current classification of PDDs is based on operationalized diagnostic criteria that are identical in both the DSM-IV and ICD-10. The U.S. National Institute of Child Health and Human Development considers a PDD diagnosis using one of these systems to be "one of the most reliable diagnoses in psychiatric or developmental research." <sup>31</sup> Research has shown that although identification of ASD can be done with great confidence (particularly in children over three years of age), identification of sub-types within ASD does not have adequate reliability.<sup>126,263,202,205,220,131,106,183</sup>

ASD includes all of the following DSM-IV and ICD-10 categories<sup>(a)</sup>:

- Autistic Disorder;
- PDD-NOS/Atypical Autism;
- Asperger Disorder/syndrome;
- Rett Syndrome; and,
- Childhood Disintegrative Disorder.

#### **Practice Standard:**<sup>38,64</sup>

A principle of assessment and diagnosis based on strong research support or deemed to be of high clinical importance. A practice standard defines the minimally acceptable procedures for identifying and assessing children with query ASD.

#### Clinical Practice Guidelines (or Practice Parameters):<sup>38,64</sup>

Systematically developed recommendations for assessment and diagnosis based on analysis of available research evidence and the importance of the objective of the procedure. Clinical Practice Guidelines are based on moderate clinical certainty and are not intended to define the standard of care; nor should they be deemed inclusive of all proper methods of care or exclusive of other methods of care directed at obtaining the desired results.

**Practice Option:**<sup>64</sup>

Strategies for identifying and assessing children with ASD for which the evidence is uncertain (inconclusive or conflicting evidence or opinion). Practice options may be considered by the individual clinician in the care of a particular patient. [It should be noted, however, that a "practice option" is not based on any substantive evidence.]

#### Clinical Pathway: 38

Clinical pathways describe the best sequence and timing of procedures for identifying and assessing children with ASD. A clinical pathway describes how to provide the best care. Although any given clinical pathway may be useful in a particular setting, it is important to note that clinical pathways must be tailored to, and some say created by, local service providers who consider their own context.

#### Measures of Outcome Effectiveness: <sup>38</sup>

A proposed activity should result in more good than harm. The strongest evidence that an intervention is beneficial comes from well–designed cohort (prospective) studies with concurrent controls that demonstrate that persons who receive the clinical action experience a significantly better overall clinical outcome than those who do not. With regards to ASD, effectiveness may be based on (1) the ability of the early detection procedure to identify the target condition; and (2) the ability of early identification and diagnosis to achieve a favourable outcome.

#### Developmental Monitoring:

An imprecise term that refers in general to the process of closely watching children's development, without implying any specific process or technique. Monitoring may be periodic or continuous, systematic or informal, and may or may not involve such processes as screening, surveillance, or assessment.<sup>56</sup>

#### Developmental Surveillance:

A flexible, continuous process whereby knowledgeable professionals perform skilled observations of children during the provision of health care and education. The emphasis of developmental surveillance is on eliciting and attending to parental concerns, obtaining a relevant developmental history, making accurate and informative observations of children, and sharing opinions and concerns with other relevant professionals. Primary care practitioners often use age-appropriate developmental checklists to record milestones during preventive care visits as part of developmental surveillance. In contrast to screening at fixed ages, it is a flexible, continuous process, involving input from health professionals, parents, teachers, and others. <sup>56,264</sup>

#### Developmental Screening:

A brief assessment procedure designed to identify children who should receive more intensive and comprehensive assessment. The emphasis is on distinguishing between children at high and low risk for developmental problems, rather than diagnosing such conditions, and typically involves the application of rapidly administered tests, examinations, or other procedures. <sup>56,264</sup> [Valid and reliable screening tests should be used at the appropriate ages as part of developmental surveillance.]

#### Developmental Assessment or Evaluation:

A more detailed investigation of either manifest or suspected delay or abnormality. It may lead to a definitive diagnosis, development of a multidisciplinary comprehensive plan of remediation, realization that there is no significant problem, or a decision that additional observation is warranted.<sup>264, 56</sup>

#### Community:

In this report the term "*community*" is used with reference to all services and supports that exist, and to which there is access, within the child and family's local environment. Community resources would include public health and primary health care services, early intervention and education agencies, and other locally available services. [For the purposes of this report, community resources are distinct from the more specialized ASD assessment services referred to in this document, whether or not they are physically located locally or in the region.]

#### Primary Care Practitioners:

In this report the term "*Primary Care Practitioner*" includes various professionals that come into contact with young children in the community. This includes primary care physicians, educators, infant/child development consultants, community health nurses, and other health care professionals.

#### Primary Care Physician:

In this report, the term "*Primary Care Physician*" refers to family physicians, general practitioners, and any other physicians providing primary care to children.

### § 4 Clinical Pathway for Diagnosis

The early identification, assessment, and diagnostic process is a tiered approach with several decision points. Specifics of each step are detailed below in respective sections on surveillance, screening, primary care assessment and referral, and multidisciplinary assessment and diagnosis. (See Figure 1).

- A) Earliest identification of children with query ASD requires general developmental surveillance of all children under the age of six years in community settings. Multiple points of entry into surveillance and screening assist in early identification. General developmental surveillance can be done by all primary care practitioners. (See Sections 5.2.A, 5.2.B, 5.3.A, 5.3.B).
- B) Selective ASD screening by all primary care practitioners may complement general developmental surveillance of any child where there is heightened concern about the presence of an ASD. (See Sections 5.2.C and 5.3.C).

- C) For children in the primary care setting who are suspected of, or at higher risk for ASD (based on data from A and B above), the following actions should occur (See Sections 6.2.A, 6.2.B, 6.2.C, and 6.3):
  - i) immediate referral for further developmental diagnostic assessment by a community pediatrician, qualified psychologist, or child psychiatrist;
  - ii) additional primary care evaluations; and,
  - iii) referral to appropriate community-based early intervention services (e.g. IDP, developmental preschools, CDCs).
- D) When further evaluation results indicate that ASD is likely, refer the child for further ASD multidisciplinary diagnostic testing.
- E) Detailed clinical diagnostic assessment by a pediatrician, clinical psychologist, or child psychiatrist (See Sections 7.2.1 and 7.3.1). This involves:
  - i) detailed history covering development and presenting concerns;
  - ii) review of all community referral materials and previous assessments;
  - iii) consultation with other professionals and disciplines involved;
  - iv) use of a standardized, structured, caregiver ASD interview; and,
  - v) use of a standardized, structured ASD observation instrument.
- F) If the clinical diagnostic assessment finds a diagnosis of ASD is improbable, the child still requires clarification of the causes for the initial concern. Referral to additional developmental services should be arranged as appropriate.
- G) If the clinical diagnostic assessment finds a diagnosis of ASD is probable, the child requires a comprehensive multi-disciplinary assessment which must include (the order in which any of the diagnostic assessments take place is not important) (See Sections 7.2.2 and 7.3):
  - i) psychological assessment;
  - ii) speech-language-communication assessment; and,
  - iii) medical evaluation.

Results of all diagnostic assessments must support the differential diagnosis.

- H) A diagnosis of ASD may also require one or more of the following:
  - i) occupational therapy assessment;
  - ii) comprehensive family assessment;
  - iii) psychiatric assessment; and,
  - iv) additional specialty assessments.
- I) ASD clinical diagnostic assessment results must be integrated with the findings from the multidisciplinary assessments before a diagnosis of ASD is confirmed. (See Section 7.2).
- J) Abnormal findings at any stage of assessment of a child with query ASD should be thoroughly investigated by adding appropriate elements to the comprehensive assessment. (See Sections 7.2 and 7.3).

- K) If the multidisciplinary assessments find a diagnosis of ASD is improbable, the child still requires clarification of the causes for the initial concern. Referral to additional developmental services should be arranged as appropriate.
- L) To address the variation in the developmental trajectory of ASD, regular review and reassessment of the child's developmental formulation is advised. (See Sections 8.2 and 8.3).

### Figure 1: ASD Clinical Pathway



## § 5 Surveillance and Screening

## § 5.1 Preamble

Although attention to developmental disabilities should be a central component of developmental monitoring for all children,<sup>4,140,156</sup> fewer than 30 per cent of primary care providers conduct routine surveillance/screening.<sup>56,79,25</sup> Numerous studies have established that parental concerns about communication, development and behaviour are highly sensitive and specific and should always receive serious consideration.<sup>77,81,82,84</sup> By contrast, absence of parental concerns has only modest specificity in detecting normal development.<sup>77</sup> Therefore, active surveillance may detect children with developmental disorders at the earliest possible time. As well, surveillance and screening must be seen not as one-time events, but rather ongoing efforts repeated at various ages.<sup>140,6</sup>

It is critical that children with ASD be identified as early as possible. It is possible to identify and diagnose ASD by three years of age and some believe as early as the second year of life. <sup>119,121,179,37,45,127,19,140,261,262</sup> Studies have demonstrated that most parents of children subsequently diagnosed with ASD first became concerned about their child's development around 18 months of age.<sup>96, 97</sup> However, research on surveillance and screening for ASD is at a very early stage. Both the process and tools used for the purpose of detecting previously unidentified cases of ASD continues to be unsettled.<sup>25,90,56</sup>

Presently available screening instruments and known prevalence rates of ASD do not support general population-wide screening. <sup>140,56,246</sup> No single instrument has yet been shown to have the ideal balance of sensitivity and specificity required for the purpose of general screening. <sup>246</sup> Some instruments have shown promise, but only within a narrow age range (e.g. the Checklist for Autism in Toddlers (CHAT) at around 18 months, although even then the sensitivity is not adequate). As well, current methods of screening for ASD may not identify children under 18 months of age, or those with milder or atypical presentations.<sup>64</sup> Overall, the psychometric properties of ASD-specific screening instruments has not been adequately established, particularly for community-based settings.

Selective screening is defined as the use of specific methods and instruments with sub-groups of children identified to be at higher risk for ASD. This would include all children for whom there is clinical suspicion of an ASD, including those who fail general developmental surveillance. It would also include siblings of children with ASD, who have an occurrence risk of 10 to 20 per cent (or approximately 50 times the population baseline risk). <sup>64,230,231,232,233,234,15,159,173,246</sup> At present, there is insufficient evidence to recommend any single procedure to screen for ASD in all children suspected of an ASD in the primary care setting. <sup>56</sup> Therefore screening instruments may be seen as practice options, as a means of further data-gathering or clarification of the clinical situation. "Failing" or "passing" on any single measure should not be the sole determinant of whether or not a child is referred for further assessment.

## § 5.2 Practice Standards

A) Earliest possible identification of ASD requires an ongoing process of general developmental surveillance of all children with specific focus on social-communication delays and deficits.<sup>4,6,64,246,140,90,95</sup>

- B) General developmental surveillance for ASD is conducted by all primary care practitioners. It can include any or all of the following components: <sup>140,107,56</sup>
  - i) serious consideration of <u>all</u> voiced parental concerns about communication, development and behaviour;<sup>77,81,82,84</sup>
  - ii) administration of general developmental screening instruments (see Section 5.3.A);
  - iii) particular attention to developmental milestones related to communication and reciprocal social interaction, two areas central in ASD (See Appendix 1); and, <sup>107,140,249</sup>
  - iv) Ongoing monitoring for the presence of "clinical clues" or "red flags" of ASD at <u>each</u> contact with the child and parents, including scheduled "well-child" visits (See Appendix 2). <sup>246,140,168,251,145,114,22</sup>
- C) Selective ASD screening should be considered by all primary care practitioners as a means of clarifying the clinical presentation or gathering further data whenever a child is suspected of, or at higher risk for an ASD. It includes either or both of the following: <sup>140</sup>
  - i) administration of age-appropriate ASD-specific screening instrument(s) (See Section 5.3(c)); and,
  - ii) review of ASD screening questions with caregiver(s) (See Appendix 3).
- D) Siblings of children with all developmental disabilities and psychiatric syndromes (including, but not limited to ASD) should be carefully monitored not only for ASD-related symptoms but also for language delays, learning difficulties, social problems, and anxiety or depressive symptoms.<sup>64</sup>

### § 5.3 Clinical Practice Guidelines

- A) A number of standardized and norm-referenced general developmental screening instruments are available for primary care practitioners. Recommended developmental screening tools include: <sup>(b)</sup>
  - i) The Parents' Evaluations of Developmental Status;<sup>83</sup>
  - ii) The Ages and Stages Questionnaire;<sup>30</sup>
  - iii) Ages and Stages Questionnaire: Social Emotional;<sup>282</sup>
  - iv) The BRIGANCE Screens; and, <sup>266,267,268</sup>
  - v) The Child Development Inventories.<sup>100</sup>
- B) The following recommendations for general developmental surveillance should be seen as practice options for all primary care physicians in British Columbia: <sup>4,90</sup>
  - i) combining parental concern with a standardized parental report form is an effective means for early behavioural and developmental screening in the primary care setting;<sup>84</sup>
  - ii) periodic health examinations by general medical practitioners provide specific opportunities for routine developmental surveillance in young children; and, <sup>140</sup>
  - iii) the periodic exams at 15, 18, and 24 months may be particularly important since there is often evidence of ASD prior to the child's third birthday.<sup>140</sup>

- C) Selective ASD Screening with a child who is suspected of, or at higher risk for, having an ASD may assist in clarifying the clinical situation or gathering more data. If a screening instrument is used, it is important to make certain that it has been validated by research, and is designed for the age of the child. The following practice options may be used as intended and with requisite cautions by primary care practitioners in British Columbia<sup>(c)</sup>: <sup>140,141</sup>
  - i) the Checklist for Autism in Toddlers (CHAT)<sup>18,20,44,250,251</sup> or the Modified Checklist for Autism in Toddlers (M-CHAT), <sup>155</sup> for children at or near 18 months of age (chronologically);
  - ii) the Screening Test for Autism in Two-Year-Olds (STAT), for children around the age of two years (chronologically);<sup>181</sup>
  - iii) the Autism Screening Questionnaire (ASQ), for children under the age of six years;<sup>28</sup> and,
  - iv) as an alternative to ASD-specific standardized screening tools, the primary care provider may systematically inquire about development of language, social abilities, joint attention skills, and pretend play. Sample questions are listed in Appendix 3.<sup>64,65,246</sup>

### § 5.4 Outcome Objectives and Indicators

### **Objective:**

All British Columbia children with ASD are identified at the earliest possible age.

#### Indicators:

- proportion of children subsequently shown to have an ASD that received some form of *general developmental surveillance* in the primary care setting;
- proportion of children subsequently shown to have an ASD that received some form of *selective ASD screening* in the primary care setting; and,
- proportion of children subsequently shown to have an ASD that were first identified based on:
  - o parent concern;
  - o other caregiver concern; and,
  - o as part of routine preventive developmental surveillance (asymptomatic).

### Target:

Primary care providers identify children subsequently shown to have an ASD as being at high-risk within three months of first voiced parent/caregiver concern, or of first clinically manifested symptom.

## § 6 Primary Care Assessment and Referral

## § 6.1 Preamble

When a child is identified as being at higher risk for an ASD in the primary care setting, referral for further specialized ASD evaluation is required. Prior to the more specialized ASD assessment, a number of community-based investigations and interventions should be initiated. The primary care physician should be knowledgeable about ASD assessment services as well as available local programs (e.g. IDP, developmental preschools, CDCs), and should assist parents in gaining access to both.<sup>90</sup>

## § 6.2 Practice Standards

- A) Referral to specialized diagnostic assessment services should be arranged without delay for all children at higher risk for an ASD (this may require co-ordination between primary care practitioner(s) and the primary care physician). Indications for referral include any of the following:
  - i) clinical suspicion of ASD based on history, presentation, or a combination of factors

#### or;

- ii) whenever a child fails to meet any of the following milestones (these represent a high probability of language and/or developmental disorder): <sup>62,64,65,93,100,30,165</sup>
  - babbling by 12 months;
  - gesturing (e.g. pointing, waving bye-bye) by 12 months;
  - single words by 16 months;
  - two-word spontaneous (not just echolalic) phrases by 24 months; and,
  - loss of any language or social skills at any age;

#### or;

- iii) failure on any ASD-specific screening instrument.
- B) For every child identified to be at higher risk for a developmental disorder <u>including but not</u> <u>limited to ASD</u>, the primary care practitioner should consider the following referrals and procedures:<sup>140</sup>
  - i) a pure-tone audiometric screening for peripheral hearing loss. If reliable screening is not possible, or if there are further concerns about the child's language delay or auditory responses that are not consistent with the developmental level of the child, the child should be referred for a full audiologic assessment to determine auditory status; <sup>11,64,105</sup>
  - ii) every child with a language delay should be referred for a comprehensive speech-language evaluation; and, <sup>64</sup>
  - iii) every child with a developmental delay and pica should have lead screening arranged by the primary care physician. Additional periodic screening of blood lead levels should be considered if the child has persistent pica.<sup>40,64,228,229,140</sup>

C) For children identified to be at higher risk for a developmental disorder including but not limited to ASD, the primary care practitioner should arrange for referral to appropriate community-based early intervention services (e.g. IDP, developmental preschools, CDCs).<sup>140</sup>

### § 6.3 Clinical Practice Guidelines

- A) The primary care practitioners may consider additional assessments by appropriate professionals as deemed necessary (i.e. occupational therapist, physiotherapist, psychologist, and nutritionist-dietitian).
- B) Children for whom there are developmental concerns, but who do not appear to have features suggestive of an ASD, still require further assessment of the causes for the initial concern.
  Primary care practitioners should consider referral to other developmental assessment services.<sup>90</sup>
- C) The primary care physician may consider referral to a community general pediatrician concurrently with referral to specialized ASD assessment services.

### § 6.4 Outcome Objectives and Indicators

#### **Objective:**

All British Columbia children suspected of having an ASD are provided an appropriate work-up and referral for further assessment and intervention in a timely fashion.

#### Indicators:

- proportion of children referred for ASD assessment and diagnostic services who have completed (or been referred for) the following:
  - Speech-Language-Communication Assessment;
  - hearing screening; and,
  - o early intervention services.

#### Target:

Child identified at risk for ASD is referred for specialized assessment within one month of first-noted concern.

## § 7 Diagnostic Multidisciplinary Assessment

## § 7.1 Preamble

The assessment and diagnosis of a child suspected of having an ASD has a number of goals. A clinical diagnostic assessment must take place to ascertain if an ASD is probable. Children believed to have an ASD must also undergo further evaluation to support the probable diagnosis of ASD, to identify potential etiologies, as well as to investigate co-existing functional impairments. For example, children with an ASD commonly have comorbid mental handicap,<sup>(i)</sup> language and learning disabilities, and psychiatric disturbances.<sup>57,98,60,122,243,191,137</sup> As well, a recognizable medical or genetic disorder is found in up to 25 per cent of cases of children showing some abnormality on physical examination.<sup>72,57,98,60,122,243,203,225,50,191,137</sup> Assessment by different disciplines provides for a comprehensive picture of the individual child's functional skills.

Given that earliest identification of and intervention in ASD has positive implications for a child, delays in obtaining assessment and diagnosis need to be avoided. In order to achieve this outcome, specialized ASD assessment services should have clear relationships to points of access in the system.<sup>90</sup>

Assessment of young children can be challenging and clinicians administering standardized tests must understand and adapt procedures to address difficulties children with ASD commonly encounter with such testing. This includes limited language and associated problems in understanding verbal instructions, atypical responses to social reinforcement, and uneven levels of skills between different developmental domains. Operant techniques may be helpful in facilitating assessment. <sup>140,174,256</sup> Scores from standardized tests must be interpreted with caution.

Integration should be a guiding principle for the diagnosis of a child with ASD. The findings of specialized developmental assessments must be incorporated into the diagnostic process. Multidisciplinary assessments of a child with query ASD can be completed in a variety of ways, including concurrent assessments (over the space of a few days) or serial assessments (over a period of weeks). The specific order or sequence in which a child with likely ASD receives multi-disciplinary assessments may vary and could depend on findings from preceding assessments or available community resources. It is not necessary to repeat components of assessment that have already been completed elsewhere (i.e. in the community or elsewhere), and in fact, any duplication of the assessment/diagnostic process must be avoided.

## § 7.2 Practice Standards

### § 7.2.1 Clinical Diagnostic Assessment

- A) A clinical diagnostic assessment must be conducted by a qualified psychologist, pediatrician, or child psychiatrist with broad experience in diagnosing children with autism and developmental disabilities.<sup>140</sup>
- B) The diagnosis of ASD is clinical, based on the most current criteria in the *DSM* or *ICD* (presently DSM-IV–TR and ICD-10). There is no specific test or instrument that either confirms or excludes ASD as a diagnosis.<sup>140,246,263</sup>

- C) A clinical diagnostic assessment must include information from multiple sources and various professionals from different disciplines. Integration of results from multi-disciplinary assessments is necessary and essential. Final synthesis of the information and the decision regarding the appropriate diagnosis needs to be taken by an individual who has been trained to weigh the evidence, integrate the findings, and deal with issues regarding differential diagnosis.
- D) The clinical diagnostic assessment of a child with suspected ASD should include the following components:<sup>64,107,140,246</sup>
  - history from multiple sources, including interview(s) with the caregiver and other involved professionals (e.g. IDP/CDC consultants, teachers, primary care physician, etc.) (See Section 7.3.1(A));
  - ii) consultation with professionals from other disciplines (See Section 7.3.a(B));
  - iii) an evaluation of developmental level based on history and examination, or formal measure (See Section 7.3.1(A));
  - iv) a standardized ASD diagnostic interview with the primary caregiver(s) with at least moderate sensitivity and specificity for ASD <sup>(d)</sup> (See Section 7.3.1(C)); and,
  - v) a standardized observation<sup>(d)</sup> of social and communicative behaviour and play (See Section 7.3.1(c)).

### § 7.2.2 Multidisciplinary Assessments

Assessment of a child with probable ASD must evaluate multiple domains of functioning. This must include: <sup>140,174,256</sup>

- A) Psychological assessment of cognitive level and adaptive functioning<sup>(f)</sup> using standardized norm-referenced instruments (See Section 7.3.2).
- B) A comprehensive speech-language-communication evaluation using standardized norm-referenced instruments (See Section 7.3.3).
- C) A comprehensive medical evaluation by a pediatrician including a detailed physical exam and appropriate laboratory investigations (See Section 7.3.4).
- D) The following additional assessments are required whenever the indicators, listed below, are identified at any stage of the diagnostic process:
  - i) occupational therapy assessment (See Section 7.3.5)
    - evidence of aberrant sensory based behaviours;
    - evidence of motor skill deficits; and,
    - need for adaptive functioning assessment related to child's activities of everyday living;
  - ii) psychiatric assessment for comorbid mental health issues (See Section 7.3.7)
    - prominent self-injurious or aggressive behaviours;
    - significant mood or anxiety symptoms;
    - indications of attentional and/or hyperactive symptoms; and,
    - evidence of tics and/or obsessive-compulsive symptoms;
  - iii) additional specialty assessments, as indicated, should be arranged for children who manifest abnormal findings at any stage of assessment including:
    - neurology;

- nutrition;
- medical genetics; and,
- endocrinology.

## § 7.3 Clinical Practice Guidelines

### § 7.3.1 Diagnosis

- A) *History* obtained from multiple sources of information should include at least the following:
  - i) presenting concerns;
  - ii) development
    - pregnancy and perinatal history (including *in utero* toxin exposures);
    - communicative, motor, and adaptive milestones;
    - history of developmental regression; and,
    - overall developmental level in areas of:
      - ➢ social interaction;
      - communication/play;
      - > restricted and unusual interests and behaviours; and,
      - ➤ adaptive behaviour;
  - iii) primary sensory impairments (hearing or vision);
  - iv) neurological history (seizures, encephalopathic events);
  - v) behavioural issues such as aggression, self-injury, sleep disturbance, eating problems, and pica;
  - vi) family history of developmental, neurologic, or psychiatric disorders;
  - vii) psychosocial stressors and coping; and,
  - viii) intervention history.
- B) Additional information reviewed should include:
  - i) assessments from other disciplines;
  - ii) community assessments and reports; and,
  - iii) reports and observations from other caregivers (i.e. primary care physician, IDP/CDC workers, public health nurse, etc.).
- C) A standardized diagnostic interview with the primary caregiver/parent(s) and a standardized observation of social and communicative behaviour and play are necessary components of a diagnostic assessment for ASD. (See Section 7.2). Currently available instruments that are recommended include: <sup>120,140,49,263</sup>
  - i) the Autism Diagnostic Interview–Revised (ADI-R);<sup>44,113,114,117,118,121,147</sup>
  - ii) the Autism Diagnostic Observation Schedule-Generic (ADOS-G) (modules 1 and 2); and, <sup>116,53,115</sup>
  - iii) the Childhood Autism Rating Scale (CARS).<sup>142,179,182,253,162,52,165,195,147,69,112,121,136</sup>

### § 7.3.2 Psychological Assessment<sup>(e)</sup>

Every child with query ASD should have a psychological assessment. A number of developmental disabilities have associated autistic features. Children with a mental handicap<sup>(j)</sup>, language and learning disorders, or emotional disturbance may manifest autism-like features at some time in their early

development and these children must be distinguished from those with ASD. In order to make a differential diagnosis, it is important that the psychologist doing the assessment has a thorough understanding of how these disabilities present themselves in the very young.

Psychological assessment assists in making or confirming a diagnosis, as well as measuring cognitive skills, adaptive functioning, and behaviour. Although cognitive patterns alone cannot confirm or exclude a diagnosis of ASD, an accurate measure of the child's cognitive ability is essential in the differential diagnosis of mental handicaps<sup>(j)</sup> with and without ASD. <sup>64</sup> It is important in autism to distinguish which aspects of behaviour are characteristic of the disorder and which are due to a lower intellectual level. <sup>174,252,256</sup>

- A) The psychological assessment must use standardized, norm-referenced instruments. A registered psychologist, usually doctoral level, should do the assessment. Any psychologist assessing young children with query ASD must have substantial experience with assessment of both developmental disabilities and preschool children.
- B) The psychologist must obtain an accurate measure of the child's cognitive ability and may also assess language, communication, play, and perceptual skills. The results of such an assessment are also important for identifying a child's strengths and weaknesses, planning treatments, and for prognosis.<sup>64,140</sup>
- C) It is unlikely that any single instrument will assess the full range of skills and deficits. The child's developmental level, language skills, ability to relate, and length of attention span should influence test selection. Selecting a specific instrument is a complex decision and should be individualized for each child. Tests considered should:<sup>140</sup>
  - i) be appropriate to the mental and chronological age of the child;
  - ii) provide an appropriate range of standard scores based on current norms;
  - iii) provide independent measures of verbal and nonverbal abilities;
  - iv) provide an overall index of ability;
  - v) consider the child's ability to remember, solve problems, and develop concepts;
  - vi) measure motor and visual-motor skills; and,
  - vii) assess social cognition.
- D) Greater validity and accuracy of intellectual functioning estimates will be obtained by a wider sampling of cognitive skills.<sup>140</sup> Tests of cognitive functioning suitable for use with preschool children with ASD may include one of:
  - i) Weschler Preschool and Primary Scale of Intelligence-R (WPPSI-R);<sup>283</sup>
  - ii) Stanford Binet Intelligence Scale 4th Edition (SBI-4); <sup>284</sup>
  - iii) Leiter International Performance Scale (revised norms); <sup>285</sup>
  - iv) Bayley Scales of Infant Development, 2nd Edition;
  - v) Mullen Scales of Early Learning; and, <sup>270</sup>
  - vi) The Infant Psychological Development Scale.<sup>271</sup>
- E) Every child with an ASD should have an assessment of adaptive functioning using standardized norm-referenced instruments. Diagnosis of a mental handicap<sup>(j)</sup> requires such a measure. Specific instruments could include<sup>(f)</sup>:
  - i) Vineland Adaptive Behavior Scales;<sup>68,204, 286</sup>
  - ii) Scales of Independent Behavior Revised; and,
  - iii) AAMR Adaptive Behavior Scales.<sup>287</sup>

### § 7.3.3 Speech–Language–Communication Assessment<sup>(g)</sup>

- A) Accurate evaluation of communication ability is central to a comprehensive functional understanding of the child.<sup>213</sup> Formal assessment of aspects of communication is one part of an assessment process, complemented by interviewing, behaviour sampling, and observing the child. The goal of a speech-language-communication assessment should be to provide functional information about the child's communication in meaningful contexts, so that the information can be useful in planning intervention and monitoring the child's progress. <sup>122,256,140,139,196</sup>
- B) Speech-Language-Communication assessment should evaluate the child's functioning in the following areas, as developmentally appropriate: <sup>64,256,122,140,213,295</sup>
  - i) range of communicative functions;
  - ii) sophistication of communicative means;
  - iii) frequency of initiation of communication;
  - iv) use of repair strategies;
  - v) use of social-affective signals (such as directed eye gaze/facial expression);
  - vi) capacity to use symbols in language and play;
  - vii) receptive and expressive abilities in all aspects of language:
    - syntax;
    - semantics;
    - morphology; and,
    - pragmatics;
  - viii) speech articulation/phonology and oral-motor skills, including feeding;
  - ix) voice quality;
  - x) prosody; and,
  - xi) unconventional verbal behaviour (like echolalia or perseverative speech).
- C) Standardized tests constitute only one part of the assessment of communication abilities. Assessment of pre-verbal and very young children will include greater use of parent and other caregiver (e.g. daycare, preschool) interviews, observations and informal assessment measures such as checklists and communication samples. Many current assessment measures include both direct observations of child as well as interview information:
  - i) standardized communication assessment measures may include one of:<sup>256</sup>
    - Communication and Symbolic Behavior Scales;<sup>288</sup>
    - Mullen Scales of Early Learning;<sup>270</sup>
    - MacArthur Communicative Development Inventory;<sup>289</sup>
    - Preschool Language Scales 3;<sup>290</sup>
    - Clinical Evaluation of Language Fundamentals Preschool; and, <sup>291</sup>
    - Reynell Developmental Language Scale.
  - ii) Examples of non-standardized communication assessment measures (may assist but not founded in research) include:
    - Rosetti Infant-Toddler Scale (B-3); <sup>292</sup>
    - Assessment of Social and Communication Skills for Children with Autism; <sup>280</sup>
    - Analysis of spontaneous language sample;
    - Socioemotional Dimensions in Communication Assessment; and, <sup>281</sup>
    - Checklist of Communicative Functions and Means.<sup>281</sup>

### § 7.3.4 Medical Assessment

- A) The medical assessment of children being evaluated for ASD needs to take into consideration both the medical diagnoses that commonly occur as comorbid conditions with autism (e.g. Fragile X, Tuberous Sclerosis) as well as other health problems which might be overlooked when evaluating a child for ASD (e.g. asthma, encopresis, enuresis, etc.).<sup>57,159,255</sup> The goals of the medical evaluation are: <sup>72,95</sup>
  - i) to provide a general profile of the child's health status, particularly as it may impact on the presentation and treatment of the ASD; <sup>140</sup>
  - ii) to ensure that other medical conditions sometimes confused with ASD (such as hearing loss, Landau-Kleffner syndrome, lead and mercury toxicity, etc.) have been adequately ruled out as causal factors in the child's presentation; <sup>192,194</sup>
  - iii) to identify and assess any associated medical conditions, some of which are seen more commonly in children with ASD. It is important to diagnose and treat some comorbid disorders as early as possible (e.g. seizure disorders, hypothyroidism, anemia, metabolic disorders, etc.); and,
  - iv) to ascertain the need for additional specialty consultations (e.g. geneticists, pediatric neurologists, dietitian-nutritionist, etc.) and arrange for follow-up evaluations.
- B) A detailed physical examination should be completed for every child with query ASD. Critical components of the physical examination include the following: <sup>64</sup>
  - i) longitudinal measurements of head circumference (particularly for macrocephaly);<sup>64,236,237,238,254</sup>
  - ii) examination for dysmorphic features (including posteriorly rotated ears,<sup>156</sup> long face, large ears, and large testes associated with Fragile X syndrome (FraX));<sup>246</sup>
  - iii) examination for neurocutaneous abnormalities, including an ultraviolet (Wood's) lamp examination (particularly for hypopigmented lesions/ash leaf macules and facial angiofibromas associated with tuberous sclerosis); and, <sup>239,240,246</sup>
  - iv) neurologic examination<sup>235</sup> of gait, tone, reflexes, cranial nerves (including the ataxic gait and broad mouth with persistent smile associated with Angelman Syndrome<sup>244</sup>).

- C) Specific laboratory studies to search for associated conditions are indicated based on history and physical examination by the pediatrician. <sup>(h) 246</sup> This includes:
  - i) the hearing status of any child with suspected ASD should be conclusively investigated with the following considerations: <sup>105,256</sup>
    - audiologic assessment will require test procedures and facilities designed for the pediatric population, and clinicians with experience testing children. The audiologist's clinical judgement will dictate which test procedures are required;<sup>87,197</sup>
    - formal audiologic assessment should include complete, comprehensive information on auditory status, including middle ear function; and,<sup>105,228</sup>
    - frequency-specific auditory brainstem response (ABR) is the single most useful electrophysiologic procedure for use in estimating hearing thresholds, but should only be used if an experienced audiologist cannot establish pure-tone thresholds.<sup>177</sup>
  - ii) high resolution chromosome studies (karyotype) and DNA analysis for FraX should be performed in any child with query ASD <u>and</u> any of the following:<sup>64,241,242,211,247,248,246,57,140</sup>
    - confirmed/suspected mental handicap;<sup>(j)</sup>
    - dysmorphologic physical features; and,
    - family history of FraX, mental handicap, or learning disability.<sup>(j)</sup>
  - iii) <u>selective</u> metabolic testing (e.g. amino acids, organic acids, thyroid, lactate, pyruvate, carnitine, uric acid, trace metals) should be completed for any child with query ASD and any of the following: <sup>64,57,159,246</sup>
    - lethargy;
    - cyclic vomiting;
    - seizures;
    - dysmorphic or coarse features; and/or,
    - confirmed/suspected mental handicap.<sup>(j)</sup>
  - iv) an EEG is not useful for making the diagnosis of ASD, and is not recommended in the routine assessment of children with possible ASD. A sleep-deprived EEG with appropriate sampling of slow wave sleep should be conducted in the following circumstances:<sup>64,140,135,246,50</sup>
    - presence of clinical seizures;<sup>203,225</sup>
    - a history of developmental regression; and, <sup>193,194</sup>
    - any symptoms suggestive of sub-clinical seizures, such as staring spells.<sup>203,225</sup>
  - v) brain neuroimaging (including MRI and CT) does not assist in making a diagnosis of ASD, and is not recommended in the routine assessment of children with possible ASD, even in the presence of macrocephaly. Brain MRI scans may provide valuable clinical information about a child with ASD in the following circumstances:<sup>65,66,64,140,43</sup>
    - presence of focal neurological problems (including seizures); and,
    - a history of perinatal complications.

### § 7.3.5 Occupational Therapy Assessment(i)

- A) Assessment of Sensorimotor Functioning
  - i) underlying sensorimotor skill impairments are common in children with ASD. Accurate assessment and understanding of the child's sensory processing and how it effects sensorimotor skill development and impacts performance in daily activities provides important clues for diagnosis and intervention planning; <sup>99,102,104,64</sup>
  - many behaviours in children with ASD can be analyzed from a sensory perspective.
    Sensory seeking and/or sensory avoiding behaviours are common in children with ASD and warrant further investigation. The following are common signs in which children with ASD may differ from typical children in their sensory profile related to performance of daily activities:<sup>301</sup>
    - extreme distress in personal care routines (i.e. dressing, hair washing and cutting, tooth brushing);
    - avoidance of eye contact or conversely intense staring at objects/people;
    - high activity level interfering with daily routines;
    - acceptance of limited food textures/temperatures; and,
    - extreme distress with loud noise and/or bright lights;
  - iii) assessment of sensory processing and perception should include a thorough sensory history which examines tactile, proprioceptive, vestibular, visual, auditory, gustatory, and olfactory systems related to functional behaviour and linked to domains of attention, arousal, behaviour, and emotion; and,<sup>104</sup>
  - iv) appropriate measures of underlying sensory and perceptual processing include:
    - Dunn Sensory Profile (3-10 years); <sup>296</sup>
    - Dunn Infant Toddler Sensory Profile (0-3 years); <sup>296</sup>
    - Analysis of Sensory Behaviour Inventory;
    - Motor-Free Visual Perception Test;
    - Developmental Test of Visual Perception; and,
    - Test of Visual Perceptual Skills (non-motor).
- B) Children with ASD often demonstrate delay, deviance, and/or stereotypical patterns of movement, often in combination with sensory processing problems. Evaluation of sensorimotor performance components and skills includes the following:
  - i) neuromuscular abilities including reflex integration, range of motion, muscle tone, strength, endurance, postural control;
  - ii) motor abilities including activity tolerance, gross motor co-ordination, crossing midline, laterality, bilateral integration, praxis, fine motor co-ordination/dexterity, visual motor integration, and oral-motor control;
  - iii) assessment tools chosen address the functional priorities/concerns of the caregivers (parents, teachers, other service providers), and developmental level and chronological age of the child. The underlying performance component skills examined are relative to the goal of improving the child's functional performance and participation within his or her physical, cultural, and social environments. Standardized measures are appropriate only for those who can respond reliably, and in all cases should be combined with interviewing and clinical observations of functional skills. The occupational therapist takes a holistic view of the child through task analysis by addressing the interrelationship between the child, environment, and occupation; and,

- iv) appropriate pediatric evaluation tools which examine sensory and/or motor development include but are not limited to the following:
  - Toddler and Infant Motor Evaluation;
  - Hawaii Early Learning Profile;
  - Bayley Scales of Infant Development; <sup>269</sup>
  - Miller Assessment for Preschoolers;
  - Peabody Developmental Motor Scales;
  - Bruininks-Oseretsky Test of Motor Proficiency;
  - Beery Developmental Test of Visual Motor Integration (3<sup>rd</sup> ed.);
  - Test of Visual-Motor Skills;
  - Movement Assessment Battery for Children;
  - Sensory Integration and Praxis Tests;
  - DeGangi-Berk Test of Sensory Integration;
  - Revised Knox Preschool Play Scale; <sup>297</sup>
  - Transdisciplinary Play-Based Assessment; and, <sup>298</sup>
  - Clinical Observations of Motor and Postural Skills.
- C) Assessment of Adaptive Functioning<sup>(f)</sup>
  - the goal of a comprehensive occupational therapy assessment is to analyze the child's strengths and limitations in the child's occupations of self-care (eating, grooming, hygiene, dressing, and functional mobility), play/leisure, and preschool/educational activities. The occupational therapist uses a process-oriented approach in assessment of these adaptive skills, which identifies underlying component skill deficits that may be interfering with the child's ability to function in activities of everyday living. Deficits in these areas of occupational performance will necessitate further evaluation of component skills, which may be interfering with the child's performance; and,
  - ii) standardized norm-referenced instruments should be supplemented with interview and clinical observations in relevant contexts. Appropriate measures of adaptive functioning include:
    - Canadian Occupational Performance Measure;
    - Wee Functional Independence Measure;
    - Pediatric Evaluation of Disability Index;
    - Vineland Adaptive Behavior Scales; and, <sup>68, 204</sup>
    - Coping Inventory and Early Coping Inventory for Children.<sup>299,300</sup>

### § 7.3.6 Psychiatric Assessment

- A) Children with ASD are at much higher risk for comorbid psychiatric syndromes including mood disorders, anxiety disorders, attention-deficit/hyperactivity disorder, obsessive-compulsive disorders, and tics.<sup>198</sup>
- B) A child psychiatrist familiar with developmental disorders should assess children with ASD or query ASD presenting with any of the following symptoms with particular emphasis on interplay between primary and newly emerging symptoms:
  - i) prominent self-injurious or aggressive behaviours;
  - ii) significant mood or anxiety symptoms;
  - iii) indications of attentional and/or hyperactive symptoms; and,
  - iv) evidence of tics and/or obsessive-compulsive symptoms.

### § 7.3.7 Conflict Resolution

In case of disagreement among professionals regarding the differential diagnosis of ASD for any one child, professionals involved in the dispute are expected to employ a consensual or collaborative model of conflict resolution (using a facilitator or mediator, if necessary).

## § 7.4 Outcome Objectives and Indicators

### **Objective:**

All British Columbia children referred for specialized assessment should receive an individualized and comprehensive assessment as soon after referral as possible.

#### Indicators:

- numbers of children receiving specialized assessment as compared to estimated incidence rates for ASD from epidemiological studies;
- mean age of diagnosis of ASD for children in British Columbia, by community and region, as compared to published figures in other jurisdictions; and,
- mean time from time of referral by primary care provider to time of specialized assessment (by community and health region):
  - o diagnostic assessment; and,
  - o multidisciplinary assessments.

#### Target:

Diagnostic assessment within six weeks, and multidisciplinary assessments within three months of receipt of complete referral from community.

## § 8 Recommendations for Education and Training

## § 8.1 Surveillance, Screening and Primary Care Evaluation

- support each health region in designing a community surveillance/screening program that would include education for primary care professionals;
- provide education and training to regional primary care professionals in the use of developmental surveillance instruments (e.g. the Parents' Evaluations of Developmental Status, the Ages and Stages Questionnaire) and ASD screening instruments (e.g. CHAT, STAT, ASQ);
- develop a "package" of tools which can be used by any community professional involved with a child they suspect may have an ASD; and,
- co-ordinate with existing in-service programs and post-secondary training programs for IDP/CDC consultants, public health nurses, health care professionals, and educators to incorporate ASD-relevant materials.

### § 8.2 Assessment and Diagnosis

- fund a mentoring/training program in diagnostic evaluation for a number of clinicians (pediatricians, child psychiatrists, registered psychologists, speech-language pathologists) for several regional locations in British Columbia. The training program would involve:
  - attending a number of workshops at a magnet centre focussing on diagnostic procedures and instruments;
  - o specialized training in the use of the ADI-R, ADOS-G, and CARS;
  - supervised diagnostic evaluations of a number of children from trainee's own community; and,
  - o ongoing support from the magnet centre via the telehealth network;
- identify and provide additional mentoring/training to professionals from key disciplines involved in multidisciplinary evaluation of ASD;
- fund outreach for experienced autism professionals to work with community teams on individual cases;
- fund attendance of community professionals at training workshops across North America;
- offer short-term fellowship/practicum for students in all disciplines with autism teams;
- work with universities and colleges to revise curriculums for clinical disciplines to better reflect stateof-the-art approaches to ASD; and,
- educate clinicians about the variety of treatment options for ASD.

### § 8.3 Research

• initiate discussions with college and university-based researchers and research-granting agencies (e.g. Canadian Institute for Health Research) to evaluate the effectiveness of the implemented recommendations.

## FOOTNOTES

- (a) ASD also encompasses a number of other diagnostic labels which have not been validated, including: <sup>140, 107</sup>
  - Multisystem Developmental Disorder (Zero to Three Classification); <sup>57,258</sup>
  - Multiplex Developmental Disorder (MDD);<sup>41</sup>
  - Multi-Dimensionally Impaired (MDI); <sup>111</sup>
  - Disorder of Attention, Motor Control, and Perception (DAMP); and, <sup>71</sup>
  - "Autistic tendencies".
- (b) Because of the lack of sensitivity and specificity, the Denver-II (DDST-II) and the Revised Denver Pre-Screening Developmental Questionnaire (R-DPDQ) are not recommended.<sup>56,51,78,89,265</sup>
- (c) The Pervasive Developmental Disorders Screening Test (*PDDST*) appears promising but is not included in this list because of a lack of adequate research.<sup>169</sup>
- (d) All standardized interview and observation instruments have limitations, and no single instrument is completely accurate in all circumstances. Thus, caution must be used in selecting tools and interpreting the resulting scores. For example, no single instrument has shown adequate validity for children under the age of three years chronologically, or with a mental age of less than 18 months. As well, there is insufficient data on the reliability of interview schedules with families for whom English is a second language. In these situations the diagnostician may wish to attempt administering an instrument for the purpose of generating data, without attempting to use the scores for making a diagnosis.
- (e) Substantial authorship of this section by Linda Eaves Ph.D., and Grace Iarocci Ph.D.
- (f) Depending on the clinical situation and available resources, adaptive functioning may be assessed by psychologists or occupational therapists.
- (g) Substantial authorship of this section by Donna Seedorf-Harmoth M.A.
- (h) There is inadequate research support for any of the following investigations in the <u>routine</u> evaluation of a child with ASD:  $^{63, 64, 140}$ 
  - routine clinical use of functional brain imaging technologies (e.g. functional MRI (fMRI), single-photon emission CT (SPECT), or positron-emission tomography (PET));
  - routine clinical use of event-related potentials and magnetoencephalography;
  - hair analysis for trace elements;
  - celiac antibodies;
  - allergy testing (particularly food allergies for gluten, casein, candida, and other molds);
  - immunologic or neurochemical abnormalities;
  - micronutrients such as vitamin levels;
  - intestinal permeability studies;
  - stool analysis;
  - urinary peptides;
  - mitochondrial disorders (including lactate and pyruvate);
  - thyroid function tests; and,

- erythrocyte glutathione peroxidase studies.
- (i) Substantial authorship of this section by Diane Graham OT.
- (j) The term "mental handicap" (and the DSM-IV term "mental retardation") has been the subject of some debate amongst experts. It is argued that the term "intellectual disability" more accurately describes the condition and is less pejorative. In this report, "mental handicap" has been retained because in British Columbia many agencies still use it in determining eligibility for services.

## **APPENDIX 1**

### SOCIAL-COMMUNICATION DEVELOPMENTAL MILESTONES\*

#### 9 Month Developmental Milestones

• will follow a point when the caregiver points and exclaims, "oh, look at the (familiar object)!"

#### 12 Month Developmental Milestones (The above, plus the following)

- will attempt to obtain an object out of reach by getting the caregiver's attention through pointing, verbalizing, and making eye contact (*"protoimperative pointing"*);
- babbling; and,
- gesturing (e.g. pointing, waving bye-bye).

#### 15 Month Developmental Milestones (All of the above, plus the following)

- makes eye contact when spoken to;
- reaches to anticipate being picked up;
- shows joint attention (shared interest in object or activity);
- displays social imitation (for example, reciprocal smile);
- waves "bye-bye";
- responds to spoken name consistently;
- responds to simple verbal request;
- says "mama," "dada"; and,
- other single words (by 16 months).

#### 18 Month Developmental Milestones (All of the above, plus the following)

- points to body parts;
- speaks some words;
- has pretend play (e.g. symbolic play with doll or telephone);
- responds when examiner points out object;
- will point to an interesting object, verbalize, and look alternatively between the object and the caregiver simply to direct the adult's attention to the object ("protodeclarative pointing"); and,
- brings objects to adults just to show them.

#### 24 Month Developmental Milestones (All of the above, plus the following)

- uses two-word phrases;
- imitates household work;
- shows interest in other children; and,
- two-word spontaneous (not just echolalic) phrases) by 24 months.

\*(Adapted from New York State Department of Health. (1999). Clinical Practice Guideline: The Guideline Technical Report. Autism/Pervasive Developmental Disorder<sup>140</sup> and Filipek PA, et al. (2000). "Practice Parameter: Screening and Diagnosis of Autism."<sup>64</sup>)

## **APPENDIX 2**

### CLINICAL CLUES/RED FLAGS FOR POSSIBLE ASD\*

- delay or absence of spoken language;
- looks through people; not aware of others;
- not responsive to other people's facial expressions/feelings;
- lack of pretend play; little or no imagination;
- does not show typical interest in peers, or play near peers purposefully;
- lack of turn taking;
- unable to share pleasure;
- qualitative impairment in nonverbal communication;
- not pointing at an object to direct another person to look at it;
- lack of gaze monitoring;
- lack of initiation of activity or social play;
- unusual or repetitive hand and finger mannerisms; and,
- unusual reactions, or lack of reaction, to sensory stimuli.

\*(Reproduced from New York State Department of Health. (1999). Clinical Practice Guideline: The Guideline Technical Report. Autism/Pervasive Developmental Disorder.<sup>140</sup>)

### **APPENDIX 3**

### ALTERNATIVE TO FORMAL SCREENING\*

### "DOES YOUR CHILD ...

- not speak as well as his or her peers?"
- have poor eye contact?"
- not respond selectively to his or her name?"
- act as if he or she is in his or her own world?"
- seem to 'tune others out'?"
- not have a social smile that can be elicited reciprocally?"
- seem unable to tell you what he or she wants, thus preferring to lead you by the hand or get desired objects on his or her own, even at risk of danger?"
- have difficulty following simple commands?"
- not bring things to you to simply 'show' you?"
- not point to interesting objects to direct your attention to objects or events of interest?"
- have unusually long and severe temper tantrums?"
- have repetitive, odd, or stereotypic behaviours?"
- show an unusual attachment to inanimate objects, especially hard ones (e.g. a flashlight or a chain vs. a teddy bear or a blanket)?"
- prefer to play alone?"
- demonstrate an inability to play with toys in the typical way?"
- not engage in pretend play (if older than two years)?"

\*(Reproduced from American Academy of Pediatrics. Committee On Children With Disabilities. Technical Report: The Pediatrician's Role In The Diagnosis And Management Of Autistic Spectrum Disorder In Children.<sup>246</sup>)

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Standards and Guidelines for the Assessment and Diagnosis of Young Children with Autism Spectrum Disorder in British Columbia

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