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Position Statement

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Position Statement

Post-diagnostic management and follow-up care for autism spectrum disorder

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Abstract

Paediatricians and other primary care providers are well positioned to provide or coordinate ongoing medical and psychosocial care and support services for children with autism spectrum disorder (ASD). This statement provides recommendations and information on a range of interventions and resources, to help paediatric care providers optimize care for children with ASD and support their families. The management of ASD includes treating medical and psychiatric co-morbidities, behavioural and developmental interventions, and providing supportive social care services to enhance quality of life for affected children and families.

Keywords: *Autism spectrum disorder; Behavioural interventions; Complementary and alternative medicine; Developmental interventions; Pharmacological management*

GENERAL PRINCIPLES AND GOALS OF CARE

Children with autism spectrum disorder (ASD) require individualized medical, behavioural and developmental interventions, and support from social care services, to maximize their full potential. Managing ASD requires coordinated care among medical and mental health care professionals, therapists, educators, and social and community service providers. Families should be informed about different treatment options and evidence for their effectiveness. They should also be referred to supportive resources, especially when major life transitions occur (e.g., starting or changing schools, the birth of a sibling, or a separation or divorce).

Paediatricians, family physicians, and other primary care providers typically manage or make referrals for coexisting medical and psychiatric conditions in children with ASD. They should also regularly monitor and evaluate the child's health and developmental progress, provide ongoing family education and support, and direct families to appropriate specialists, as needed (Table 1).

The overall goals of treatment are to target the core features of ASD, along with associated developmental, behavioural, and learning challenges, and enhance quality of life for the entire family. Specific treatment goals include improving social functioning, play, verbal and nonverbal communication, and functional adaptive skills, as well as reducing maladaptive behaviours, and promoting learning and cognition (1–6).

ADDITIONAL ETIOLOGICAL TESTING AND ASSESSMENT FOR ASSOCIATED MEDICAL CONDITIONS

After an ASD diagnosis has been confirmed, paediatric health care providers may order additional etiological testing or assessments for associated medical conditions (3). Investigations are often ordered during the ASD diagnostic assessment, and

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Table 1. Checklist of approaches to post-diagnostic management of ASD

1. Etiological testing for associated medical conditions

☐ Physical and neurological exam
☐ Hearing assessment (with formal audiology assessment, if indicated)
☐ Vision assessment
☐ Dental assessment
☐ Genetic testing, if indicated (e.g., chromosomal microarray)
☐ Metabolic testing, if indicated

2. Assessment and management of co-morbid conditions. Refer to specialists when appropriate.

☐ Gastrointestinal conditions
☐ Nutrition
☐ Sleep
☐ Anxiety, depression, and other mood and psychiatric disorders
☐ ADHD
☐ Other child-specific conditions

3. Other assessments and therapies that address ASD-associated functional challenges

☐ Speech-language therapy
☐ Psycho-educational assessment
☐ Occupational therapy
☐ Physical therapy
☐ Individualized educational supports

4. Behavioural and developmental interventions for core and associated features of ASD. Refer to specialists when appropriate.

☐ Become familiar with available community programs
☐ Provide information about essential components and effectiveness of treatment interventions and programs
☐ Facilitate enrolment into behavioural and developmental intervention programs (therapist-delivered or parent-mediated approaches)

5. Management of challenging behaviours

☐ Offer anticipatory guidance on safety issues (e.g., wandering, bolting, vulnerability to bullying or abuse)
☐ Identify and assess target behaviours
☐ Assess existing and available supports including behavioural and developmental interventions described above
☐ Offer first- or second-line treatment, as appropriate
☐ Refer for parent training

6. CAM approaches

☐ Become familiar with CAM therapies
☐ Inquire and provide guidance about using CAM therapies

7. Family and other support interventions

☐ Provide parents with educational resources about ASD and local community supports
☐ Provide information about in-home supports and interventions and help with securing respite care and social assistance
☐ Inquire about family and sibling support and parental physical and mental health issues and unmet needs, and refer appropriately
☐ Assist with application for the Disability Tax Credit, and provide information regarding opening a Registered Disability Savings Plan
☐ Advocate for local services and education programs
☐ Obtain and share information, with parental consent, with schools, program staff, and health and social service personnel (especially during major transition periods)

ADHD Attention-deficit hyperactivity disorder; ASD Autism spectrum disorder; CAM Complementary and alternative medicine.

it is important that paediatric care providers confirm and follow-up on pending investigations, and initiate additional ones, as needed. For more information on medical investigations, see the companion statement, Standards of Diagnostic Assessment for ASD, published in this issue.

SURVEILLANCE AND FOLLOW-UP CARE FOR CO-MORBIDITIES

Children with ASD have greater health care service needs than their typically developing peers, but often face barriers to accessing care (7). Children with ASD may have or develop co-morbid conditions and should be monitored routinely. Be mindful that children with communication difficulties, such as children with ASD, may not present with common signs and symptoms (3). Additional online resources for follow-up care for co-morbidites are listed at the end of this statement.

Dental

Children with ASD should have regular, complete dental check-ups. However, sensory sensitivities, anxiety, language impairments or other associated challenges, may require a modified approach to routine care, or referral to a hospital-based dental service. In some jurisdictions, public health units offer specialized in-home or school-based dental screening programs for children with ASD. Helpful resources are available for community dentists caring for children with ASD (8,9).

Gastroenterology

The prevalence of gastrointestinal disorders is higher in children with ASD than the general population (3,4). Gastrointestinal symptoms may relate to constipation, unusual feeding behaviours, restrictive diets and challenges with toilet training. Specific workup for gastroesophageal reflux disease (GERD) or celiac disease should be considered, when medically indicated. Managing constipation, GERD, chronic abdominal pain, and diarrhea should be the same as for children without ASD. Treating gastrointestinal disturbances may improve abnormal sleep and daytime behaviours (4).

Nutrition

Nutrition can be challenging because some children with ASD have very restricted diets, leading to deficiencies (in iron, for example) and maladaptive mealtime behaviours. Consider nutrition counselling and referral to a dietitian, as well as behavioural interventions to target specific feeding problems. A behavioural therapist, occupational therapist, speech-language pathologist, or community feeding team may all be helpful resources.

Sleep

Sleep problems, such as late onset, frequent night and early morning waking, and decreased sleep duration, affect 50% to 80% of children with ASD. Sleep problems negatively impact daytime behaviours and quality of life for both child and family (10). Consider counselling to improve sleep hygiene and reinforce behavioural techniques (possibly in collaboration with a behavioural therapist, and possibly combined with melatonin therapy). Counsel families to avoid using screen devices, which can disrupt sleep patterns, 1 hour before bedtime.

Anxiety

Up to one-half of children with ASD also experience an anxiety disorder or phobia, conditions which may contribute to aggressive or self-injurious behaviours (7,10). Children with ASD who are verbal, and whose cognitive abilities are at an 8-year-old's level or greater, may benefit from group or individual cognitive behavioural therapy (CBT) sessions (7,10). Modified CBT approaches may be appropriate for some younger children.

Attention-deficit hyperactivity disorder (ADHD)

In 30% to 53% of children with ASD, ADHD is a co-occurring condition. Many young children with ADHD are overtly inattentive, hyperactive, or impulsive. With or without ADHD, 'bolting' (suddenly running away from caregivers), and wandering in children with ASD, can pose further safety concerns (10). For more on co-morbid ADHD, see the CPS position statement ADHD in children and youth: Part 3; Assessment and treatment with co-morbid ASD, ID or prematurity.

Depression

If depression co-occurs with ASD, it is generally in older children as they become more socially aware. Children with ASD may be bullied or find it difficult to fit in socially or to establish and maintain relationships (7,10). Counselling with anticipatory guidance, including referral to community support services or referring a child for psychological intervention, can be helpful.

OTHER ASSESSMENTS AND THERAPIES TO ADDRESS ASD-ASSOCIATED CHALLENGES

Alongside behavioural and developmental therapies, children with ASD often need other supportive services. Paediatric care providers can assist families by coordinating appropriate assessments and care.

- Speech-language therapy may be required to improve verbal, nonverbal, and social communication skills. A speech-language pathologist can offer alternative and augmentative communication aids, such as picture-based communication systems, signs and gestures, or specialized devices and software, to children who are nonverbal or whose language skills are impaired.
- A psychologist can perform a psychological assessment to evaluate for cognitive, adaptive, and learning skills as well as

co-morbid conditions (such as anxiety, ADHD). These findings may help with treatment planning and supporting specific needs.
- Occupational therapy addresses functional challenges in the activities of daily living, including specific interventions to improve fine motor or sensory processing impairments. An occupational therapist can help children acquire self-care and play skills.
- Physiotherapy can strengthen gross motor skills and improve endurance, strength, balance, coordination, and gait.
- A child and adolescent psychiatrist should be consulted to assess and help manage any major psychiatric co-morbidity.

BEHAVIOURAL AND DEVELOPMENTAL INTERVENTIONS FOR ASD

One constant guiding principle is that behavioural interventions for children with or at risk for ASD should be initiated as early as possible, ideally even before a diagnosis is confirmed (11,12). Because children with ASD experience varying degrees of impairment in social and behavioural functioning, there is no universal treatment approach (13,14). Also, service delivery models vary greatly across Canada. Paediatricians and other primary care providers should become familiar with services and programs in their communities, and be prepared to discuss wait times for publicly funded services and other navigational issues with parents and caregivers.

Behavioural interventions have emerged as the main evidence-based treatment for children with ASD. These interventions are mostly based on the science of applied behaviour analysis (ABA) and use systematic learning principles to teach skills in different learning environments (13,15–18). Current evidence supports the integration of ABA-based models with approaches that are informed by developmental theory, particularly with very young children (4,19). For example, the understanding that affective engagement plays an important role in developing social relationships, informs models that foster positive affective exchanges between child and therapist or caregiver (12). Naturalistic developmental behavioural interventions blend behavioural and developmental treatment approaches, and integrating them into daily activities is recommended for preschoolers (14,19).

A comprehensive review of behavioural interventions for ASD is beyond the scope of this position statement. Within the last decade, however, there has been a significant increase in the quantity and quality of studies (i.e., with larger sample sizes, lower risk of bias, randomized controlled trials) to investigate interventions for ASD, especially in preschoolers, with at least one high-quality study to determine effectiveness (16–27). Study findings have established the following intervention principles:

- Early intensive behavioural interventions are commonly used with young children (2 to 5 years of age), with some evidence of improvement in adaptive skills, IQ, and receptive and expressive language (14,17).
- Parent-mediated interventions are effective in helping parents to be more responsive and engaged with helping children to acquire communication skills or manage challenging behaviours. Reported outcomes include improved parent–child interactions, increased parental knowledge and skill levels when teaching social communication and managing behaviour, gains in children's communication skills, and reduced autism-related symptom severity (20,22).
- Social skills training has been shown to improve social behaviour in children aged 7 to 12 years who have average or above average intelligence (23).
- Cognitive behavioural therapy can be used effectively to treat anxiety disorders in children with ASD who are verbal (7,10,23).
- One systematic review reported significant positive effects on parent–child interactions, regardless of the intervention models studied (i.e., behavioural, social-communication focused, or multicomponent developmental) (25).

However, it is still not known which specific interventions or approaches are most likely to be effective for an individual child, based on age and developmental stage, specific strengths and challenges, and family needs. The choice of intervention or program may depend on availability, proximity, and cost (25,26).

Countless ASD-targeted interventions and approaches exist in the literature under many different names, and they often overlap in practice. Families commonly use a combination of interventions. Primary care providers could consider the Ontario Association for Behaviour Analysis (ONTABA's) 2017 report entitled Evidence-based Practices for Individuals with Autism Spectrum Disorder: Recommendations for caregivers, practitioners, and policy makers (16), as a starting point. The report provides tabulated information on 30 evidence-based or emerging ASD interventions, based on targeted domains (Table 12) and age group (Table 13). Definitions of intervention methods and domains appear in Appendices D and E, respectively.

Significant positive features of effective interventions or programs are listed below (4,13–15):

- Teachers and therapists are trained and experienced, and work in supportive environments (e.g., classes with appropriate child-to-educator ratios).
- Teachers and therapists are supervised by professionals with extensive ASD expertise.
- Interventions support ongoing child development, including social communication, language, emotional and behavioural regulation, cognitive, and adaptive skills.
- The child's progress is monitored and evaluated regularly, and adjustments are made accordingly.
- Evidence-based protocols are followed closely, to ensure overall program effectiveness.

- Parents are actively involved, and learning opportunities are incorporated into daily experiences.

MANAGING MALADAPTIVE BEHAVIOURS

Community paediatricians and physicians are often the first-line for helping families manage challenging behaviour, such as aggression or self-injury (4,7). A trained behaviour specialist can be consulted to help identify reasons for disruptive behaviours (usually based on a functional behaviour assessment), which then inform first-line treatment planning. Treatment plans may include specific behavioural interventions, an evidence-based parent training program, and environmental modifications, or a combination of approaches. Disruptive behaviours that are pervasive, severe, or interfere substantively with a child's learning, socialization, health or safety, or the quality of family life, may require using medication concurrently with nonpharmacologic interventions.

A general approach to managing maladaptive behaviours is offered below.

1. Identify and assess target behaviours

- Ask parents or other caregivers (e.g., relatives or a child care provider) about intensity, duration, and factors that appear to worsen or improve the behaviour to be targeted. Ask about the effect of a specific behaviour on the child's daily functioning.
- Factors that can increase risk for having challenging behaviours include:
  - Communication deficits, making it difficult for a child to understand or express needs and wants
  - Coexisting medical disorders, which can cause pain or discomfort
  - Coexisting mental health problems or neurodevelopmental conditions
  - Physical (e.g., lighting or noise levels) and social environments (e.g., home, child care, school)
  - Changes in daily routines or personal circumstances
  - Developmental changes (e.g., puberty)
  - Bullying and other forms of maltreatment

2. Offer first-line management strategies

- Ensure that families receive adequate education and consistent support for behavioural strategies. Recommend evidence-based parenting programs or classes, when they are available in your community. Helpful online toolkits are also available (see below).
- Provide ongoing medical treatment for a co-occurring physical disorder, and psychotherapeutic intervention for any coexisting mental health problem.
- Counsel families on strategies and interventions that can positively impact a child's physical environments (e.g., structured, predictable routines) and social life (e.g., consistent caregivers and approaches to behaviour management, and supportive, family-centred care for parents).
- Use augmentative and alternative communication systems, devices or software to help minimally verbal children communicate at home or in school.

PHARMACOLOGICAL MANAGEMENT

Co-occurring behavioural symptoms and mental health disorders are common in children with ASD. In most cases, medication use should only be considered when nonpharmacological strategies have been exhausted, and they should always be used in combination with behavioural interventions for children with ASD. Sometimes, starting a medication while awaiting access to services may be necessary, but such decisions must be considered carefully on a case-by-case basis. Because children with ASD can experience more medication side effects than those without ASD, dosing should "start low [often lower than published recommendations], and go slow". Strict monitoring for adverse effects and drug interactions is essential (28–31).

A comprehensive review of pharmacological options for managing challenging behaviours and mental health disorders is beyond the scope of this statement. However, a brief summary of some psycho-pharmacological medications currently in use is provided below, with recommended resources. Physicians are encouraged to review current guidelines when prescribing and monitoring psychotropic medications (28–31). For complex cases, a child psychiatrist or developmental paediatrician should be consulted.

Challenging behaviours

For treating irritability and aggression in children with ASD who are 5 years of age and older, the Food and Drug Administration (FDA) in the USA has only approved two medications: risperidone and aripiprazole. Close monitoring for adverse effects, including weight gain, metabolic syndrome, extrapyramidal symptoms (e.g., muscle stiffness, tremors), and drowsiness is required (30). Please also refer to the resources below.

Associated behavioural and mental health disorders

Anxiety

Debilitating anxiety can be treated with a cautious trial of a selective serotonin reuptake inhibitor (SSRI), such as fluoxetine or sertraline. Treatment-resistant children should be referred to a tertiary-care specialist (28,29,31).

ADHD

First-line treatment is with methylphenidate or another stimulant medication. Atomoxetine and alpha-2 adrenergic receptor agonists (e.g., clonidine or long-acting guanfacine) are appropriate alternatives, when combined with parent training in ADHD behavioural management (28,29,31).

Depression

Antidepressants, typically SSRIs, may be considered if depressive symptoms persist despite psychosocial interventions (28).

Sleep disturbances

Melatonin, when combined with appropriate sleep hygiene and behavioural modification strategies, appears to be effective in reducing sleep onset times and increasing sleep duration, but may not reduce nocturnal or early waking (2,32). Side effects may include difficulty waking, daytime sleepiness, or enuresis.

Recommended resources for pharmacological management of ASD

- Canadian Alliance for Monitoring Effectiveness and Safety of Antipsychotics in Children (CAMESA) guidelines: http://camesaguideline.org/information-for-doctors.
- Canadian ADHD Resource Alliance (CADDRA) provides ADHD practice guidelines for physicians: https://www.caddra.ca/.
- American Academy of Child and Adolescent Pscyhiatry (AACDAP) Autism Parents' Medication Guide: https://www.aacap.org/App_Themes/AACAP/Docs/resource_centers/autism/Autism_Spectrum_Disorder_Parents_Medication_Guide.pdf.

COMPLEMENTARY AND ALTERNATIVE MEDICINE (CAM) APPROACHES

An estimated 28% to 95% of families affected by ASD have used CAM therapies, and roughly 25% have tried special diets to augment conventional therapies (33,34). Families are more likely to try CAM therapies when children are diagnosed at a younger age or experience severe ASD symptoms, gastrointestinal issues, or seizures (33). Clinicians must remain familiar with current evidence in the rapidly evolving field of CAM therapies, and be ready to help families distinguish between proven and promising therapies and those that are unproven, potentially harmful, and expensive. Unproven CAM alternatives divert time, emotional energy, and financial resources away from more effective conventional treatments. At every office visit, clinicians should ask parents, without judgment, about present or past use of CAMs, and advise that current evidence for many CAM therapies is based on low quality studies. CAM therapies should not replace conventional ASD therapies. If families wish to try a CAM, care providers should counsel testing only one treatment at a time, and closely monitor and record outcomes (33). And while some CAM approaches are considered safe, additional research is needed before they can be recommended. Melatonin use for sleep issues and regular physical exercise have both shown some positive effects for children with ASD (33–37).

Therapies that are considered risky and ineffective include hyperbaric oxygen therapy, chelation, secretin, and the use of certain herbal products. Antibiotics, antifungals, and facilitated communication strategies are also considered to be ineffective for treating ASD (33–37).

Parents of children with severe ASD symptoms may inquire about the use of cannabidiol oil. There is insufficient efficacy or safety data at the present time to support the use of medical cannabis to treat any condition in children (38), and the ethical implications for paediatric care providers regarding its use in children with ASD are considerable (39).

Although some CAM therapies are considered safe with appropriate monitoring, many lack supporting evidence. Such approaches include supplementing diet with vitamins B_6, C, D, and Mg, or omega-3 fatty acids, or dietary interventions, such as gluten- or casein-free diets. Other tolerated though unproven approaches include massage therapy, music and expressive therapies, therapeutic touch, therapeutic horse-back riding, other types of animal or pet therapy, yoga, and energy therapies (e.g., healing touch, Reiki) (33–37).

FAMILY SUPPORT

The primary health care provider has an important role in the long-term care management of children with ASD and their families, especially as developmental and other needs change over time. Many parents of children with ASD experience greater stress and financial hardship than parents of typically developing children (2–4). Health care providers should be familiar with federal and provincial programs that provide financial services for families, including the Disability Tax Credit and the Registered Disability Savings Plan.

Family physicians and other primary care providers should regularly ask the parents of children with ASD about their own self-care and physical and mental health needs, and provide appropriate care and referral to supportive services, as needed. As with the diagnostic process, be sensitive to the possibility that parents often experience distress related to their child's developmental issues and the impacts this can have on family life.

PROGNOSIS: FACTORS ASSOCIATED WITH POSITIVE OUTCOMES

Predicting treatment outcomes, especially in children younger than 3 years of age, is difficult. However, factors associated with positive developmental and behavioural outcomes include early identification, timely access to behavioural interventions, and higher cognitive abilities. Interventions should focus on

each child's specific needs as they evolve, support parents and families, and ensure that children with ASD can participate fully in life at home, in school, and in the community (17).

RECOMMENDED ONLINE RESOURCES

For primary care providers and families learning to access ASD intervention services in their communities, the following resources are a first step:

- Guide to government provincial/territorial funding programs and school support services: https://www.autismspeaks.ca/science-services-resources/resources/accessing-government-services/
- Guide to provincial/territorial funding programs for ASD therapy: https://www.autismcanada.org/resources/
- Additional information for Quebec: https://www.quebec.ca/en/health/health-system-and-services/assistive-devices-disabilities-and-handicaps/services-for-persons-with-a-disability/
- Online autism service directory: http://www.autismjunction.ca/
- Ontario Association for Behaviour Analysis (ONTABA) Evidence-based practices for individuals with autism spectrum disorder: Recommendations for caregivers, practitioners, and policy makers, 2017: http://www.ontaba.org/pdf/ONTABA%20OSETT-ASD%20REPORT%20WEB.pdf

Information about provincial/territorial and national ASD organizations, with education and support groups for children with ASD and their families:

- Autism Canada lists provincial/territorial autism organizations and societies, and regional branch offices: http://www.autismcanada.org/about-us/provincial-territorial-council-3/
- Autism Speaks Canada: http://www.autismspeaks.ca/
- Autism Community Training has a database of ASD resources and online training materials: http://www.actcommunity.ca/

Other resources for health care professionals and families:

- Autism Canada. Autism Physician Handbook, Canadian Edition. https://autismcanada.org/resources/physician-handbook/
- Tool kits from Autism Speaks, including tool kits on dental care, feeding, challenging behaviours, and sleep: https://www.autismspeaks.org/tool-kit
- Spectrum: A source for news and analysis of research advances. Individuals can be on a mailing list for updates: https://www.spectrumnews.org/

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