

PedsCases Podcast Scripts

This is a text version of a podcast from PedsCases.com on “**Post-diagnostic management and follow-up care for autism spectrum disorder – CPS Podcast (Part 3 of ASD series)**” These podcasts are designed to give medical students an overview of key topics in pediatrics. The audio versions are accessible on iTunes or at www.pedcases.com/podcasts.

Post-diagnostic management and follow-up care for autism spectrum disorder – CPS Podcast (Part 3 of ASD series)

Developed by Dr. Nicole Arseneau and Dr. Angie Ip for PedsCases.com.
October 24, 2019

Introduction:

Hello everyone, my name is Nicole Arseneau and I am a second year pediatrics resident from the Stollery Children’s Hospital and the University of Alberta. This podcast was made in conjunction with PedsCases and the Canadian Pediatrics Society. It is part three of a three-part series of statements and podcasts about Autism Spectrum Disorder. It was developed with Dr. Angie Ip, a member of the Autism Spectrum Disorder Guidelines Task Force, and the lead author of the CPS statement we will be reviewing today. For additional information and to view the complete CPS statement, please visit cps.ca. The script for this podcast can be viewed at pedscases.com.

This podcast will review the CPS statement “Post-diagnostic management and follow-up care for autism spectrum disorder” or ASD. After listening, the learner will be able to:

1. Identify the role of the primary health care provider in the care of a child with ASD.
2. Identify and develop management strategies for common comorbid conditions and behavioural challenges that affect children with ASD.
3. Discuss behavioural and developmental interventions for core and associated features of ASD.
4. Discuss complimentary and alternative medicine therapies as they apply to ASD.

Let’s review what we know so far.

Aiden is a young boy we have been following throughout this podcast series who has recently been diagnosed with autism spectrum disorder. He is 3 years old, and his parents’ current main concerns are his behaviours and ability to communicate. He often throws tantrums during transitions and in unfamiliar places and he has few single words. He also uses stereotyped phrases only his family understand. Aiden was diagnosed six weeks ago, but they haven’t been able to access any services yet and are feeling

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overwhelmed. They are back for their follow up appointment and want to know what to do next.

As Aiden's primary care provider, what is your role in his health care?

Generally, primary care providers, including family physicians and pediatricians manage the general health of children with ASD. They also provide specific care related to ASD. This includes managing or making referrals for coexisting medical and psychiatric conditions, regularly monitoring and evaluating the child's health and developmental progress, providing ongoing family education and support, and directing families to appropriate specialists as needed. Additionally, etiologic testing may have been ordered at the time of Aiden's diagnostic assessment, and you should follow up on results and order additional investigations if needed. Please see the companion statement "Standards of Diagnostic Assessment for ASD" for details on the etiologic work-up for ASD.

Aiden and his parents are now in your office. Besides his parents' primary concerns, what other areas of Aiden's health and ASD management should you address at this visit and future visits?

Children with ASD have greater health care service needs than their typically developing peers, and often face barriers to accessing care. Additionally, many children with ASD have communication challenges, and may not present with typical signs and symptoms for medical conditions. For example, a child with an ear infection may present with worsening behaviours during times of transition but may not be able to show that they have pain.

In young children like Aiden, common comorbid health concerns that should be addressed at each visit include sleep, dentition, feeding, and nutrition. These areas should be monitored throughout the lifespan. Later on, psychiatric, mental health, and learning challenges may present including anxiety, depression, and ADHD. We'll talk about those later, but for now, let's talk about those four concerns that should be addressed for 3 year old Aiden.

Sleep: Up to 50-80% of children with ASD will have sleep problems, such as late sleep onset, frequent night and early morning waking, and decreased sleep duration, so this is very important to screen for.

Dentition: All children should have regular dental check-ups, however this may be very challenging for children with ASD who can have sensory sensitivities, anxiety, language impairments or other associated challenges that 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.

Feeding and Nutrition: The prevalence of gastrointestinal disorders is higher in children with ASD than the general population. GI symptoms may relate to constipation, unusual feeding behaviours, restrictive diets, and challenges with toilet training. Additionally, restrictive diets and feeding behaviours can lead to vitamin and mineral deficiencies - iron, for example.

Now that you know what to ask about, let's check in with Aiden and his parents.

On further history, you find out that Aiden has never been to the dentist. He has a fairly consistent bedtime routine, which must be strictly adhered to otherwise he will throw a tantrum. If he wakes up in the middle of the night, he won't fall asleep again unless his parents play a TV show on his tablet while he's in bed. Aiden is also only eating soft pureed foods, and will not tolerate any "chewy" or "crumbly" foods; he will spit them out. He also has constipation and has a bowel movement once every 5-7 days, which is often hard. Aiden will scream and avoid going into the bathroom at all for a bowel movement, which his parents think is likely because he's afraid it will hurt.

Aiden has some sleep trouble with night time waking. In general, as with all children, with or without ASD, education around sleep hygiene is an excellent place to start, including reducing his screen time at night if possible and other behavioural strategies. You may also initiate treatment with melatonin if appropriate.

His parents should also be advised to take him to the dentist, but he may need multiple visits before he becomes accustomed to being examined by a dentist. While many children are able to see their community dentist, some children may need to be referred to a hospital-based dental service.

Aiden also has a restricted diet and constipation. In general, work up and management of constipation, GERD, chronic abdominal pain, and diarrhea should be the same as for children without ASD. Importantly, treating GI conditions like his constipation (and thus eliminating the pain associated with it) may improve both sleep and daytime behaviours. For children with specific feeding problems, like Aiden's texture preference, involvement of allied health professionals including registered dietitians, behavioural therapists, occupational therapists, or speech language pathologists may be helpful.

Let's talk for a minute about how useful these allied health services can be for children with ASD.

Speech-language therapy may be required to improve verbal, non-verbal, 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 help children who are non-verbal or whose speech and language skills are impaired.

Occupational therapy addresses functional challenges in the activities of daily living, including but not limited to specific interventions to improve fine motor or sensory processing impairments. An occupational therapist can help children acquire self-care and play skills.

It is not uncommon for children with ASD to have some challenges with gross motor skills. Physiotherapy can strengthen gross motor skills and improve endurance, strength, balance, coordination, and gait.

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. A child and adolescent psychiatrist should also be consulted to assess and help manage any major psychiatric co-morbidity.

Not every child will need every service I just talked about, however, it's important to note that children with ASD will often need support from a combination of these services and these needs will vary over time. For example, Aiden might benefit from speech language therapy, behavioural therapy, and occupational therapy for his challenges around communication, feeding, sensory sensitivities, and sleep.

Now, you might be wondering, you've talked about managing comorbidities, but what about Aiden's ASD symptoms? What are we going to do to help him with that?

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. Because children with ASD experience varying degrees of impairment in social and behavioural functioning, there is no universal treatment approach

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, or ABA, and use systematic learning principles to teach skills in different learning environments. Current evidence supports the integration of ABA-based models with approaches that are informed by developmental theory, particularly with very young children like Aiden. Since there is no universal approach to treatment, the choice of interventions needs to be based on the child's age and developmental stage, specific strengths and challenges, family needs as well as availability, cost, and location. Also, service delivery models vary greatly across Canada. Paediatricians and other primary care providers should become familiar with services and programs in their communities to best support patients and their families.

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 and we have learnt the following:

- Early intensive behavioural interventions in preschool children has shown evidence of improvement in adaptive skills, IQ, and receptive and expressive language;
- Social skills training can be effective in school-aged children;
- 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;
- And cognitive behavioural therapy can be helpful for treatment of anxiety in verbal children

As there are many ASD interventions for available, and many families use a combination of interventions, guiding a family through this process can be challenging. One resource mentioned in the CPS Statement is the Ontario Association for Behaviour Analysis 2017 report entitled Evidence-based Practices for Individuals with Autism Spectrum Disorder: Recommendations for caregivers, practitioners, and policy makers. This report lists 30 evidence based or emerging ASD interventions, as well as information on what domains they target and what age group they are suited for. More information is available in the online and printed statements.

Let's check back in with Aiden.

Aiden comes back to your office with his family, now six years old. He's been involved with ABA therapy and speech language therapy with some success. However, he recently started attending grade one, and his parents and teachers have been struggling with some of his behaviours. Aiden becomes frustrated very easily, and will often yell very loudly and sometimes hit his teachers when asked to change activities. His parents have also experienced this at home. They come to your office for help.

Behavioural concerns are common with children with ASD. As with all behavioural management, treatment must be individualized to the situation and child and families needs. A general approach to managing maladaptive behaviours starts with identifying and assessing said behaviours. This includes asking about the intensity, duration, and factors associated with worsening or improving the behaviour, and, very importantly, how the behaviour affects the child's functioning. There are many things that can result in an increase in behaviours, some of which include the following:

- 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

As Aiden's primary care provider, you will need to continue to address physical health needs such as managing constipation. Other first line management strategies can involve education for the families on managing behaviours (look into programs in your area), consistent routines and responses to behaviours, and providing augmentative and assistive communication methods for those who are minimally verbal. Behavioural management may need the re-involvement of community therapists such as Aiden's behavioural therapist, occupational therapist, or speech and language therapist. In most cases, medications use should only be considered when nonpharmacological strategies have been exhausted, and they should always be used in combination with behavioural interventions. 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.

Now that Aiden is getting older, what other common co-morbid medical conditions should you screen for and manage?

Children with ASD have higher risk of developing ADHD, anxiety, and depression. These conditions can affect their function and behaviours, and thus are very important to identify and treat.

ADHD can occur in 30-50% of children with ASD. Some behaviours such as "bolting", or running away from caregivers, can be more common in those with ADHD and pose a significant safety concern. First line treatment is always behavioural strategies with the addition of pharmacological treatments if needed. Pharmacological first-line treatment includes methylphenidate or another stimulant medication.. You should refer to CPS Statement : ADHD in children and youth: Part 3; Assessment and treatment with comorbid ASD, ID or prematurity. for more information on treating ADHD in children with comorbid conditions like ASD

Anxiety occurs in up to 50% of children with ASD. Depending on the child's developmental level and intelligence, cognitive behavioural therapy or modified cognitive behavioural therapy may be helpful. 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.

Depression can occur as well, especially as children get older and become more socially aware, and if they experience bullying or find it difficult to fit in socially. Anticipatory guidance or referring to community support may be helpful. Antidepressants, typically SSRIs, may be considered if depressive symptoms persist despite psychosocial interventions.

Aiden's challenges were initially able to be addressed with first line non-pharmacologic therapies. However, when he is 13, he and his parents return to your office because he has had escalating aggressive behaviours, and his school is concerned for the safety of other children and the staff. In going through your history, you find that the behavioural interventions are just not enough anymore. He had been diagnosed with ADHD, and an appropriate stimulant medication was started. He does not appear to have any other medical comorbidities.

What pharmacologic strategies are available to help Aiden now?

When non-pharmacologic strategies have been exhausted, there are two medications approved by the FDA for behavioural management in children with ASD: risperidone and aripiprazole. Remember, medications should always be used in conjunction with behavioural interventions, or in exceptional cases, when awaiting behavioural interventions. Because children with ASD can experience more medication side effects than those without ASD, dosing should "start low, and go slow", often lower and potentially slower than published recommendations. Close monitoring for adverse effects, including weight gain, metabolic syndrome, extrapyramidal symptoms (e.g. muscle stiffness, tremors), and drowsiness is required. There are several resources available for clinicians in the CPS statement addressing this, which should be referred to. For complex cases, a child psychiatrist or developmental paediatrician should be consulted. Again, medications should always be used in conjunction with behavioural interventions.

Aiden's parents mention that they're recently started attending a new support group for parents of children with ASD. They've been hearing a lot about how using vitamin supplements has been helping some children in the group.

What can you tell the parents about complementary and alternative medicine therapies for ASD? I'll call them "CAM" therapies for short.

First of all, it's very common! 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. 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. Clinicians must be ready to help families distinguish between proven and promising therapies and those that are unproven and potentially harmful. Unproven CAM alternatives divert time, emotional energy, and financial resources away from more effective conventional treatments. CAM therapies should not replace conventional ASD therapies. If families wish to try a CAM therapy, care providers should counsel testing only one treatment at a time, and closely monitor and record outcomes.

Some CAM therapies are considered safe, and probably beneficial, though more research is needed. Melatonin for sleep and regular physical exercise fall into this category.

Some CAM therapies are considered safe with appropriate monitoring, though lack supporting evidence. These include supplementing diet with vitamins B6, 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 such as Reiki.

Some therapies that are considered risky and ineffective, and families should be counseled against these therapies. These 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.

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

This is an incomplete list. Clinicians need to stay updated on current CAM therapies in order to provide the most informed care for their patients.

We've talked a lot about Aiden over the last three podcasts, and watched him grow. His family has been there at every clinic visit, every therapy appointment, every stumble and every triumph. 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. Many parents of children with ASD experience greater stress and financial hardship, so clinicians should be familiar with programs such as the Disability Tax Credit (DTC) and the Registered Disability Savings Plan (RDSP).

This brings us to the end of this PedCases podcast on the CPS Statement "Post-diagnostic management and follow-up care for ASD spectrum disorder", and the end of our three part series on Autism Spectrum Disorder. Let's review what we've learned:

1. Paediatricians and other primary care providers play a vital role in providing or coordinating ongoing medical and psychosocial care and support services for children with autism spectrum disorder
2. The management of ASD includes treating medical and psychiatric comorbidities, behavioural and developmental interventions, and providing supportive social care services to enhance quality of life for affected children and families. Management therefore often involves a number of specialists and services including psychologist, speech and language therapists, occupation therapists, physiotherapists, or psychiatrists. Primary care providers, therefore, need to become familiar with the services available in their community.

3. Behavioural interventions for children with or at risk for ASD should be initiated as early as possible, ideally even before a diagnosis is confirmed
4. 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.
5. Children with communication difficulties, such as children with ASD, may not present with common signs and symptoms for medical conditions and physicians often need to take an even more active role in assessment and screening.

Thank you for listening! Please tune in to more podcasts on [PedsCases.com](https://www.pedscases.com)!