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# Autism: Current practices and controversies

The medical profession and society should learn to celebrate neurodivergence and ensure that neurodivergent individuals receive the supports and accommodations they need to realize their full potential.

ABSTRACT: The DSM-5 condition known as autism spectrum disorder is usually a lifelong diverse condition whose etiology is not fully elucidated. Over the past few decades, its prevalence has increased, and the relationship with other neurodevelopmental disorders has evolved. In BC, there is a well-defined process for making the diagnosis. Treatment interventions are available for both the core symptoms of autism in early childhood and comorbid conditions throughout the lifespan. Supports are available through provincial programs and the health care sector but may be difficult for families to access. We discuss the advocacy burden for the families whose children have the most complex needs and impairment.

tism is a neurodevelopmental disorder that typically presents in early childhood and is characterized by impaired social communication and

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restricted and repetitive patterns of behavior and interests. Although considered a specific disorder, autism is one of a number of neurodevelopmental disorders, with which it shares many aspects.<sup>1</sup> We review evolving aspects of diagnosing autism spectrum disorder in BC and in clinical practice, as informed by recent developments in the field. While we may touch on areas of evolving knowledge, it is beyond the scope of this article to provide a comprehensive review of more controversial aspects of autism.

#### **Diagnosing autism**

The gold standard for diagnosing autism involves obtaining a child's history by conducting a thorough diagnostic interview with the child and their parents and a mental status examination. Some jurisdictions, such as BC, have a prescribed diagnostic process, in part to standardize who may access limited therapeutic and support resources. The BC Autism Assessment Network (www .phsa.ca/our-services/programs-services/ bc-autism-assessment-network) and its affiliated centres see children who have a query of autism and designate the required assessment process for the diagnosis to be recognized by the Ministry of Children and Family Development, and for these children to be allocated individualized funding for treatment intervention. The same process is followed by both publicly funded assessors in BC Autism Assessment Network centres and private fee-for-service assessors. There are long wait lists for assessments conducted by publicly funded developmental clinics in

BC (such as Sunny Hill Health Centre), but the wait list is often shorter for private fee-for-service assessors.

In addition to a history and mental status examination obtained by a trained clinician, a BC Autism Assessment Network assessment requires a semistructured interview with the parents—the Autism Diagnostic Interview—and a semistructured interaction with the child—the Autism Diagnostic Observation Schedule.<sup>2</sup>

# *DSM-5* diagnostic criteria for autism spectrum disorder<sup>3</sup>

- A. Persistent deficits in social communication and interaction across multiple contexts.
- B. Restricted, repetitive patterns of behavior, interests, or activities.
- C. Onset in the early developmental period (although may not be manifest until social demands exceed capacity).
- D. Causes significant impairment in functioning.
- E. Symptoms not better explained by intellectual disability/global developmental delay.

#### Autism today

## Increasing prevalence, broadening phenotype, and relationship to other neurodevelopmental disorders

Experienced clinicians have traditionally been able to fairly quickly assess whether a child has autism. However, we are increasingly seeing children with autism diagnoses

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in whom the classic diagnostic features are not readily apparent. This is likely because the diagnostic boundaries of the behavioral phenotype that defines autism have broadened over the past 30 years, and there is now large variability in symptom types, onset, and degree of severity.<sup>1,4</sup> Whereas it is true that the contemporary cohort of patients with autism may include fewer individuals with comorbid intellectual disability, data also indicate a secular trend toward less severe features of autism in subjects with this diagnosis.<sup>5</sup>

From the 1970s onward, the reported prevalence of autism has increased substantially. The condition was previously considered rare and affected less than 0.05% of the population, but by 2015, the prevalence was estimated as at least 1% in both children and adults.<sup>1</sup> In 2022, the proportion of children and youth in BC between the ages of 6 and 18 years with an autism diagnosis was 1 in 32 (3%).<sup>6</sup> This rate is somewhat higher than that reported by the Public Health Agency of Canada, which noted that in 2019, 1 in 50 (2%) of Canadian children and youth aged 1 to 17 years were diagnosed with autism.<sup>7</sup>

The increased rate of diagnosis is controversial because there is no evidence that the autism phenotype, the symptoms on which the diagnostic criteria are based, is occurring with increased frequency. Lundström and colleagues followed more than 4000 children born in Sweden over a 10-year period, from 1993 to 2002, and found that the year-over-year prevalence of the autism phenotype was stable during that period.<sup>1</sup> In contrast, there was a significant increase in the prevalence of registered diagnoses of autism spectrum disorder in the Swedish national patient register.1 Lundström and colleagues<sup>1</sup> postulated that this was due to three factors:

• There may have been an implicit broadening of potentially overlapping diagnostic criteria. The considerable overlap of symptoms between autism and other neurodevelopmental and psychiatric diagnoses may have contributed to the rapid rise in autism diagnoses in recent years.  Increasing awareness of autism may have been associated with diagnostic substitution (e.g., the increased prevalence of autism diagnosis has corresponded, to an extent, with a parallel decrease in diagnosis of intellectual disability documented in the literature, but also, in our practice, of other psychiatric and neurodevelopmental disorders).

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• Diagnosis and prevalence may be sensitive to funding and availability of therapeutic and support services. Dedicated funding and specific interventions for autism may have contributed to an increase in the likelihood of referral for diagnosis. Similar hypotheses have been made in the Canadian context.

Dr Anton Miller, a developmental pediatrician at Sunny Hill Health Centre, responded to Lundström's article with a letter to the British Medical Journal, noting that in BC, a substantial proportion of referred cases now consist of children aged 2 to 3 years for whom autism-related clinical observation of such things as social reciprocity and social communication may be mild, and whose low-level restricted and repetitive behaviors may be difficult to distinguish from those exhibited by typical children.8 Dr Miller also noted that for many of these children, it can remain clinically subjective whether to attribute impairment to symptoms of autism or to delays or impairment in language or executive functioning skills, which are frequently also present.

Indeed, in our respective practices, comparatively few children with autism present with autism traits in isolation. Most also experience other comorbid cognitive and mental health issues, such as intellectual disability, learning disorders, tics, anxiety, and attention deficit hyperactivity disorder. This clinical presentation is sometimes called "autism plus" and often accounts for a large part of the impairment in children with autism.9 Due to the considerable overlap of symptoms between autism and other neurodevelopmental disorders, children diagnosed with autism frequently have concurrent neurodevelopmental and/ or psychiatric disorders, such that comorbidity is the rule rather than the exception. Given the spectrum of severity in autism itself and the spectrum of comorbidities, patients with a diagnosis of autism have heterogeneous needs, including psychiatric needs. The broader recognition of autism continues to be associated with significant diagnostic overshadowing of other psychiatric comorbidities. A diagnosis of autism may not, for a particular patient and at a particular point in time in their life, be the primary source of psychiatric impairment.<sup>10</sup>

#### Ambiguous language

The term "high-functioning autism" does not have a consistently agreed upon definition but is generally used to refer to individuals with autism who are of average or above average intellectual functioning (such as patients with autism without intellectual disability). The term, as commonly used, does not refer to the severity of the autistic symptoms in a specific individual and may be misleading, because some patients with "high-functioning" autism may be substantially impaired in their functioning. In the past, such individuals may have been assigned a diagnosis of Asperger syndrome. However, studies have not been able to clearly distinguish Asperger syndrome from other forms of autism, and in the DSM-5, such individuals are classified as part of the autism spectrum.<sup>3</sup>

Also plagued with inconsistent definition, though less frequently used, is the phrase "low-functioning autism," which is generally assumed to mean that the affected individual has comorbid intellectual disability or may be nonverbal or minimally verbal. In a multisite study conducted in the US between 2000 and 2016, 27% of 8-year-old children with autism were assessed to have profound autism (defined as being nonverbal or minimally verbal or having an IQ < 50).<sup>11</sup> Children with profound autism are more likely to be born preterm or with low birth weight; to be female; to be from ethnic minority groups; to have lower socioeconomic status, a seizure disorder, and lower adaptive functioning scores; and to present with self-injurious behaviors.<sup>11</sup>

#### Autism through the lifespan

In most cases, autism persists throughout the lifespan. One of the benefits of the increased awareness about autism is that a number of adults who were previously undiagnosed and misunderstood have recognized characteristics of autism in themselves. Having a label for their neurodivergence can be very helpful for these individuals. For example, Mary Doherty, an Irish physician, recognized in her mid-40s that she had autism, and in 2019 she founded Autistic Doctors International, a peer support and advocacy group.<sup>12</sup>

The increased media interest in autism has generally focused on milder forms of the disorder. However, individuals with more severe and less visible forms of autism may be more likely to have behavioral/mental health challenges and to require clinical attention (medical and psychiatric). In the US, families of individuals who are more impaired with autism have formed an advocacy group, the National Council on Severe Autism, to focus attention on those individuals with autism who, by virtue of any combination of cognitive and functional impairments, require continuous or near-continuous lifelong services.

### **Evolving knowledge**

### Etiology

Genetic factors play a consistently larger role than environmental factors in etiology.<sup>4</sup> Approximately 85% of individuals with autism have idiopathic autism, whereas approximately 15% are diagnosed with syndromic or secondary autism.<sup>4</sup> Well-documented causes of secondary autism include conditions such as tuberous sclerosis, fragile X syndrome, and some congenital infections (e.g., rubella). In some cases, secondary autism may be associated with more severe behavioral problems than is idiopathic autism.

#### Gender and socioeconomic factors

In BC, approximately three times more males than females receive funding from the Ministry of Children and Family Development's Autism Funding Unit, despite a greater increase in the diagnosis of autism in girls in recent years.<sup>6</sup>

Studies from different countries have suggested that the prevalence of autism, especially in combination with intellectual disability, is higher among children of immigrant women. Such children are more likely to be diagnosed with autism at a younger age and to present with more severe traits of autism and associated intellectual disability than are children of non-immigrant women. Etiological factors associated with immigrant mothers could include vitamin D deficiency, socioeconomic disadvantage, and less access to medical care during the prenatal period.<sup>13</sup>

#### Autistic regression

Two forms of developmental regression are sometimes seen in pediatric patients with autism:

Most children show symptoms of autism before 18 months of age. However, a subset of children with autism appear to have relatively normal development, followed by the appearance of autistic features in the second or third year of life. A case example is a child we treated who had relatively normal development until about the age of 2 or 3 years, when he started losing skills, became very quiet, and appeared reluctant to even to say his name until the age of 4 years. The onset of autism in such children is temporally correlated with public immunization schedules (the measles, mumps, and rubella vaccine in the second year of life). This may contribute to the erroneous but persistent belief that this vaccine could be the cause of the autism.

In the 1960s and 1970s, it was first noted that some children with autism lose skills and develop behavioral symptoms in adolescence. In 2006, in a community-based sample in Ontario, Bradley and Bolton identified patients with autism who, in adolescence, developed complex psychiatric symptoms associated with loss of functioning.<sup>14</sup> In the authors' experience, such regression and behavioral change can often be attributed to adolescent onset of comorbid psychiatric disorders, such as catatonia or mood disorders.<sup>14</sup>

#### Pathological demand avoidance

Pathological demand avoidance is a concept that recently emerged to describe a group of children who are driven to avoid everyday demands and expectations to an extreme extent.<sup>15</sup> Such children are typically passive in their first year of life. As more is expected of them, the child becomes "actively passive" and strongly objects to normal demands in the family or school environment. The child seems to feel under intolerable pressure from normal expectations and, over time, develops strategies that allow avoidance of such expectations but may be experienced as disruptive or distressing by the family or school. Such children have a high rate of mood lability and anxiety. The behavior tends to persist into adulthood.<sup>15</sup> It is hypothesized that underlying anxiety drives pathological demand avoidance. Symptoms can overlap with those of oppositional defiant disorder, which may also occur in children with autism and is often related to underlying attention deficit hyperactivity disorder, anxiety, or depression. In our clinical opinion, a diagnosis of pathological demand avoidance should not obscure consideration of treatable comorbid disorders, such as anxiety and attention deficit hyperactivity disorder.

# Avoidant/restrictive food intake disorder

This is a new diagnostic category in the *DSM-5* and is characterized by avoiding or restricting food intake, without the body

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image disturbance that would be seen in anorexia nervosa.<sup>3</sup> Children with autism are often noted to be fussy and rigid eaters and may have extreme sensitivity to the appearance, texture, or taste of food. Avoidant/restrictive food intake disorder can be understood as a particularly severe form of food sensitivity in such children and would be diagnosed when the child has significant weight loss or faltering growth. Treatment may include behavioral desensitization.

# Treatments and interventions for children with autism

#### Early intervention

For many years, autism was considered to be an intractable neurodevelopmental disorder with few effective treatment options. However, a few decades ago, quality university-led trials of psychosocial interventions in early childhood demonstrated positive changes in young children with autism.<sup>16</sup>

Historically, such early intervention focused on instructor-led high-intensity applied behavioral analysis and discrete trial training that relied on external rewards, based on principles of applied behavior analysis. Other validated early intervention models have emerged in parallel to applied behavior analysis, which focus on teaching parents to support the child in early communication and social interaction, sometimes with delivery intensity that is lower than was initially anticipated to be necessary for effectiveness. Early intervention can successfully teach the child practical skills for day-to-day living, such as asking for help, saying no, and improving emotional regulation, as well as the basic building blocks for future socially mediated learning, such as joint attention and imitation.<sup>17</sup>

As is often the case in many areas of medicine, the early enthusiasm of initial landmark efficacy studies has been dampened over the years by subsequent real-world effectiveness and observational data. It was initially believed that intensive early intervention during the preschool period would dramatically improve long-term outcomes for most children with autism.<sup>16</sup> However, a multisite Canadian study showed limited change in the trajectory of autism for most children diagnosed during the preschool years, even though all the children had received some degree of early intervention.<sup>18</sup> In that study, Szatmari and colleagues followed 421 children with autism from diagnosis, at between 2 and 4 years of age, up to 6 years of age. Approximately 11% of the children improved in terms of autism severity and adaptive functioning. However,

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90% continued to have severe symptoms of autism and showed little change in adaptive functioning at 6 years of age. The children who had improved the most were often those who presented with less severe symptoms at the time of diagnosis.

A follow-up study of the same cohort of Canadian children at 10 years of age showed that approximately 25% of the children displayed less severe symptoms of autism over time.<sup>19</sup> The group that showed favorable symptom evolution over time tended to have lower autism severity and better cognitive, language, and adaptive living skills at the time of diagnosis.

The early childhood period provides many opportunities for growth and learning. Although it is generally accepted that early intervention is a benefit to young patients with autism, it has become apparent that the nature, specific target symptoms, and intensity of intervention must be tailored to the needs of each child and their family.

### Psychotherapy

Psychotherapy may be helpful for children who are verbal and youth with comorbid anxiety, depression, obsessive-compulsive

disorder, or tic disorders. Good-quality literature supports the benefits of modified cognitive-behavioral therapy in children and youth with autism and comorbid anxiety disorders.<sup>20</sup> Modifications may include helping the child identify and label emotions and having greater involvement of the parents in the treatment. Modified cognitive-behavioral therapy for comorbid anxiety disorder involves graduated and sustained exposures to anxiety-provoking situations and positive reinforcement for exposing oneself to feared situations.<sup>20</sup> However, it can be difficult to find a clinical counselor or psychologist with skills in the area of anxiety disorders comorbid with autism.

# Behavioral therapy for challenging behaviors

In many cases, challenging behaviors in patients with autism stem from a mixture of biological and environmental contributors, but the precise mix varies greatly between cases.

Even infrequent and sporadic aggressive or self-injurious behaviors can lead to substantial restrictions on an individual's access to school and the community. This may limit the child's access to important treatments and interventions. Challenging behaviors can result in injury to the child or family members. Such behaviors can result in families feeling anxious and unsafe and can reduce the quality of life. Families often learn to cope by restricting their lifestyle in anticipation of the next episode of challenging behavior. In severe cases, challenging behaviors may become a factor in a child having to live away from their family.

Challenging behaviors commonly result in, and are perpetuated by, reinforcement over time. Behavioral treatment may be needed to improve such behaviors; there is substantial literature on the effectiveness of such behavioral intervention in treating irritable/aggressive behavior in children with autism. The current approach to addressing problem behavior requires a functional behavior assessment, followed

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by implementation of a function-based intervention. The goal is to reduce the rate and prevalence of problem behaviors while teaching functional, socially desired alternatives (e.g., if the function of the problem behavior is determined to be accessing attention, the functionally equivalent target behavior would yield access to attention; if it is escape from a difficult task, the task would be modified, or a break response would be taught).<sup>21</sup>

Parent management training uses parents as agents of behavioral change in the child to promote skill acquisition and generalization of the acquired skills to the home, the school, and various community settings. Common elements of parent management training include formal instruction in general principles of behavioral psychology and in specific management techniques, role-playing, homework assignments, teaching of play and social skills, and use of visual communication techniques. Parent management training can be supplemented with home visits and telephone consultation.

#### **Psychotropic medications**

Psychotropic medications used judiciously in line with a limited but increasing evidence base to address common psychiatric comorbidities, such as attention deficit hyperactivity disorder and anxiety disorders, can improve functioning in some children. Off-label use of psychotropic medications to address challenging behaviors is fraught with significant drawbacks and limitations but can become necessary in some cases. A companion article in this issue reviews the psychopharmacological treatment of irritability in autism (see page 291).

### Alternative treatments

A number of open, nonplacebo, controlled studies published between 2010 and 2019 suggested there was significant improvement in challenging behaviors, sleep, and symptoms of anxiety in children and youth with autism who were treated with cannabis-derived products. The first randomized, double-blind, placebo-controlled trial was conducted in Israel:<sup>22</sup> 150 children and youths with autism who were 5 to 21 years of age were given either placebo, whole-plant cannabis extract, or cannabidiol. Improvement in challenging behavior was suggested for whole-plant cannabis but not for cannabidiol. One of the main adverse effects was somnolence. The authors were cautious in their conclusions, noting that evidence for efficacy was mixed and

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insufficient. In a 2019 policy statement, the American Academy of Child and Adolescent Psychiatry advised "against the use of medical marijuana or isolated cannabinoids for core symptoms or co-occurring emotional or behavioral problems in children and adolescents with autism spectrum disorder."<sup>23</sup>

A systematic review of 19 randomized controlled trials evaluated dietary supplements (such as digestive enzymes and vitamin B12) and variations of the gluten-/ casein-free diet. The studies were small and short-term, and there was little evidence to support the use of nutritional supplements or dietary therapies for autism.<sup>24</sup>

# Government supports and psychiatric care

### Funding

Children and youth. In BC, funding for treatment and community support for children and youth with autism is administered by the Ministry of Children and Family Development: Children and Youth with Support Needs. Funding for treatment interventions is individualized to each child and is ultimately managed by the family, within the parameters set by the Ministry. Funding can be disbursed for certain devices or services provided by approved treatment providers who are contracted by families. In BC, children with autism who are under 6 years of age are allocated \$22 000/year. Between 6 and 18 years of age, children and youth with autism receive \$6000/year.

A diagnosis of autism also allows the school to receive additional funding from the Ministry of Education and Child Care, which may allow for the provision of 1:1 educational assistance, if needed. Personal communication with teachers in special education indicates that some are concerned that the increased focus on autism within the education system may have resulted in comparatively less funding and attention dedicated to children with specific learning disorders (neurodevelopmental disorders associated with specific impairment in reading, mathematics, or writing). Some patients with psychiatric diagnoses other than autism, including other neurodevelopmental disorders, can present with functional impairment equal to or greater than some children with autism but do not receive the level of funding available to children with autism. The Representative for Children and Youth of BC notes that there are "thousands of children with [fetal alcohol spectrum disorder], Down syndrome and a wide range of other neurocognitive developmental needs who receive little or no support from the Province of BC."25

Adults. Adults with autism may receive publicly funded community supports that are contracted to community agencies by Community Living British Columbia if they meet either of two eligible pathways:

- They have a concurrent diagnosis of intellectual disability (whose psychometric definition has classically consisted of cognitive and adaptive functioning at more than two standard deviations below the mean or lower on standardized psychometric assessment).
- Adults with autism, but without comorbid intellectual disability, may

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still be eligible for Community Living British Columbia supports if their adaptive functioning is more than three standard deviations below the mean (a much narrower statistical definition), through the Personalized Supports Initiative.

### Psychiatric care and behavioral therapy

Psychiatric care. Despite the high rates of psychiatric comorbidity in autism, Child and Youth Mental Health teams in the province may be reluctant to see such children because they already have large caseloads and may lack the skills to assist such complex children. It is difficult to access child psychiatrists in BC, although BC Children's Hospital has a Neuropsychiatry Clinic that can provide consultation for such children. In the Lower Mainland. youth 12 years of age and older (14 years of age and older elsewhere in the province) can be seen by their local Developmental Disabilities Mental Health Service team only if they have a comorbid diagnosis of intellectual disability. Most of the care of these children is provided by community physicians, particularly pediatricians. Community physicians, nurse practitioners, and mental health clinicians can obtain advice from a child psychiatrist regarding management of such children via the BC Children's Hospital Compass Mental Health program (https://compassbc.ca).

Behavioral therapy. In BC, behavioral consultants are available to families who have children with autism. However, the training and experience of behavioral consultants varies, and some may lack the expertise to provide evidence-based behavioral treatment for challenging behaviors such as aggression. If the behavioral problem is severe and more intensive behavioral treatment is required, the \$500 per month of individualized funding available to families of school-aged children may not be sufficient.

There is often an expectation that the family will implement the behavior therapy plan by themselves within their home environment. This may not be realistic in some situations, such as when implementation of the plan is expected to cause an initial debilitating increase in challenging behaviors (the "extinction burst"), or in situations where a family's time and resources may be pulled in various directions. The competing priorities and needs of all family members, and the limitations on their time and resources, have to be balanced against caregiver burnout.

> For families of children with significant behavioral challenges, there is a need to constantly advocate to receive the necessary enhanced supports and respite.

#### Supporting families

In clinical practice, the unmet support needs of the most behaviorally complex children with autism and their families are of particular concern. Many of these children and youth are relatively nonverbal and exhibit severe challenging behavior, aggression, or self-injury. Families of such children need respite. Whereas all families of children with autism receive limited funding to access respite care, the public funding for respite is the same for all families, irrespective of need. Finding a provider who can offer respite to the families of children with the most challenging behaviors can be very difficult because of safety concerns.

When the institutions in BC that historically housed individuals with neurodevelopmental disorders were closed in the 1980s and 1990s, the belief was that families would be able to access publicly funded supports in the community. However, respite for families has become progressively less available over time. One of us started working in the field in 1993, at which time families of children with neurodevelopmental disorders still had access to staffed respite homes where their child could receive respite care on select days of the month.

For families of children with significant behavioral challenges, there is a need to constantly advocate to receive the necessary enhanced supports and respite. Even the most competent parents of such children will likely find the task of advocating with the Ministry of Children and Family Development both daunting and draining. This is even more so for parents from historically marginalized groups, such as parents with their own disabilities or immigrant families.

In our clinic, we recommend that families contact the Family Support Institute of BC (https://familysupportbc.com), which provides invaluable advice and assistance to parents and siblings regarding advocacy.

# Meeting the needs of the most severely impaired patients

A minority of patients who have autism with severe and refractory challenging behaviors may use disproportionate amounts of emergency and inpatient medical and psychiatric care. The severe symptoms of this most significantly impaired group of patients can cause great distress in the patients themselves, in their families, and in their community care providers. It may impair the patients' ability to participate in school and their family's ability to work. Patients who have autism with severe and refractory psychiatric symptoms can benefit from specialized multidisciplinary residential assessment and treatment. Currently, the only option for this in BC is Community Living British Columbia's Provincial Assessment Centre, which serves youths 14 years of age and older and adults with a diagnosis of intellectual disability. However, the Provincial Assessment Centre has stopped accepting patients with a history of aggression, even though it is considered one of the strongest predictors of inpatient psychiatric care in youths with autism.<sup>26</sup>

### **Case histories**

#### Early intervention

A 4-year-old child recently diagnosed with autism presented to primary care

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with challenging outbursts of anger and physical aggression. Such outbursts were in excess of what would be expected at his developmental stage and were the cause of a number of significant injuries that were sustained by his parents. Outbursts and physical aggression impaired the family as a whole: one parent had to leave their job and forgo part of the family's income, and various early childhood education settings had refused to care for the child due to his behavioral challenges. A primary care assessment did not reveal any cause of pain or discomfort that could be contributing to such outbursts in this child with impaired adaptive skills.

Concurrently with the child being referred to a preschool psychiatry clinic, the family used their individualized autism funding to contract a behavior analyst, a team of behavior interventionists, and a speech and language therapist. After 4 months of treatment intervention, the goal of which was to teach the child functional communication and more adaptive behavior scripts, the outbursts and physical aggression had decreased to such a degree that by the time the child was finally assessed at the early childhood psychiatry clinic, he was functioning well at home and in his new early childhood education centre (with educational assistance provided by their catchment's Supported Child Development team). Off-label use of psychotropic medications to control aggression and irritability was no longer a consideration.

# Autism and attention deficit hyperactivity disorder

An 8-year-old boy had been asked to leave day care at 3 years of age because of hyperactivity, including jumping on tables and throwing objects. Autistic symptoms identified at the time included echolalia, spinning ribbons, hyperacusis, and missing social cues. He was diagnosed with autism at 5 years of age. Behavioral problems persisted, and at 8 years of age, he was refusing to do schoolwork and would bolt out of class, touch peers inappropriately, and hit the bus driver and educational assistant. The parents were unable to find someone to provide respite care because of his significant challenging behaviors. In the consulting room, he was extremely wriggly and distractible and pulled at his mother's clothing to get her attention. Mood was overall good. Lisdexamfetamine, 30 mg daily, for treatment of comorbid attention

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deficit hyperactivity disorder was helpful but wore off by noon. An increase in lisdexamfetamine to 60 mg daily led to a dramatic response, and behavior became manageable throughout the day.

### Autism and social anxiety

A 16-year-old male was diagnosed with autism at 8 years of age when the school noted that he would not play with other children and talked to himself. He was overly self-aware and constantly compared himself to his peers. He would not use the washroom or eat in front of others at school. He avoided answering questions in class and was placed in a separate room with the educational assistant. He eventually refused to go to school altogether. He was seeing a counselor, but the psychotherapy was mostly supportive and did not consist of modified cognitive-behavioral therapy, which is the evidence-based treatment for anxiety. Treatment with 40 mg of fluoxetine daily was very helpful for the social anxiety and allowed the child to return to school with support.

# Autism, intellectual disability, and obsessive-compulsive disorder

An 11-year-old boy had a history of prematurity and significant developmental delays (nonverbal until 6 years of age) and was diagnosed with autism at 2 years of age. He had a history of attention deficit hyperactivity disorder and complex tics. At 8 years of age, he started to exhibit severe behavioral outbursts related to rituals. A certain blanket had to be folded in a particular way and placed in a certain corner, he had to hold certain objects in a particular manner, and he repeatedly touched walls at a particular spot. Brushing his teeth became rigid and time-consuming because there had to be a particular amount of toothpaste on the toothbrush or he would need to start again. If saliva came out of his mouth when brushing his teeth, he would need to wipe his mouth a certain number of times. When getting dressed, his mother had to stand in a particular spot and not move while he adjusted his clothing. Showers took 60 to 90 minutes, and the soap had to be applied to his hands in a particular way.

Rituals would take more than 3 hours per day to perform, and he would need to persist at them until he was satisfied they were done correctly. He was diagnosed with comorbid obsessive-compulsive disorder and was treated with 50 mg of sertraline daily, which partially reduced the compulsions and outbursts. He could not tolerate a higher dose.

## Conclusions

Autism exists across a spectrum of severity throughout the lifespan and with a constellation of comorbidities. Supports for patients and their families and treatments for challenging behaviors and comorbid conditions exist but may be difficult to access. Most community pediatricians and family physicians, and indeed most physicians, in BC will encounter individuals with autism in their practice, be it as patients or co-workers or in their personal lives and families. As a profession and as a society, we should learn to celebrate neurodivergence, while recognizing that impairment and distress often exist and that supports and accommodations may be needed for such individuals to realize their full potential. ■

#### **Competing interests**

#### None declared.

#### References

- Lundström S, Reichenberg A, Anckarsäter H, et al. Autism phenotype versus registered diagnosis in Swedish children: Prevalence trends over 10 years in general population samples. BMJ 2015; 350:h1961.
- 2. Lord CE. Autism: From research to practice. Am Psychol 2010;65:815-826.
- American Psychiatric Association. Diagnostic and statistical manual of mental disorders. Text revision: DSM-5-TR. 5th ed. Washington, DC: American Psychiatric Association; 2022.
- Casanova MF, Casanova EL, Frye RE, et al. Editorial: Secondary vs. idiopathic autism. Front Psychiatry 2020;11:297.
- Rødgaard E-M, Jensen K, Vergnes J-N, et al. Temporal changes in effect sizes of studies comparing individuals with and without autism: A metaanalysis. JAMA Psychiatry 2019;76:1124-1132.
- Ministry of Children and Family Development. Autism Funding Program service rate: British Columbia. Vancouver, BC: University of British Columbia; 2020.
- Public Health Agency of Canada. Autism spectrum disorder: Highlights from the 2019 Canadian health survey on children and youth. Ottawa, ON: Public Health Agency of Canada, 2002. Accessed 10 June 2023. www.canada.ca/en/public-health/ services/publications/diseases-conditions/autism -spectrum-disorder-canadian-health-survey -children-youth-2019.html.
- Miller A. What does it mean to be diagnosed with autism spectrum disorder in 2015? BMJ 2015;350: h1961.

- Posserud M, Hysing M, Helland W, et al. Autism traits: The importance of "co-morbid" problems for impairment and contact with services. Data from the Bergen Child Study. Res Dev Disabil 2018; 72:275-283.
- Defresne P, Mottron L. Clinical situations in which the diagnosis of autism is debatable: An analysis and recommendations. Can J Psychiatry 2022; 67:331-335.
- Hughes MM, Shaw KA, DiRienzo M, et al. The prevalence and characteristics of children with profound autism, 15 sites, United States, 2000–2016. Public Health Rep 2023. doi:10.1177/0033354923 1163551.
- Duong D, Vogel L. Untapped potential: Embracing neurodiversity in medicine. CMAJ 2022;194: E951-E952.
- Linnsand P, Gillberg C, Nilses Å, et al. A high prevalence of autism spectrum disorder in preschool children in an immigrant, multiethnic population in Sweden: Challenges for health care. J Autism Dev Disord 2021;51:538-549.
- Bradley E, Bolton P. Episodic psychiatric disorders in teenagers with learning disabilities with and without autism. Br J Psychiatry 2006;189:361-366.
- Newson E, Le Maréchal K, David C. Pathological demand avoidance syndrome: A necessary distinction within the pervasive developmental disorders. Arch Dis Child 2003;88:595-600.
- McEachin JJ, Smith T, Lovaas OI. Long-term outcome for children with autism who received early intensive behavioral treatment. Am J Ment Retard 1993;97:359-372.
- Lord C, Charman T, Havdahl A, et al. The Lancet Commission on the future of care and clinical research in autism. Lancet 2022;399(10321):271-334.
- Szatmari P, Georgiades S, Duku E, et al. Developmental trajectories of symptom severity and adaptive functioning in an inception cohort of preschool children with autism spectrum disorder. JAMA Psychiatry 2015;72:276-283.

- Georgiades S, Tait PA, McNicholas PD, et al. Trajectories of symptom severity in children with autism: Variability and turning points through the transition to school. J Autism Dev Disord 2022; 52:392-401.
- 20. National Institute for Health and Care Excellence. Autism spectrum disorder in under 19s: Support and management. Updated 14 June 2021. Accessed 10 June 2023. www.nice.org.uk/guidance/ cg170/chapter/Recommendations.
- 21. Ala'i-Rosales S, Cihon JH, Currier TDR, et al. The big four: Functional assessment research informs preventative behavior analysis. Behav Anal Pract 2018;12:222-234.
- 22. Aran A, Harel M, Cassuto H, et al. Cannabinoid treatment for autism: A proof-of-concept randomized trial. Mol Autism 2021;12:6.
- American Academy of Child and Adolescent Psychiatry. Use of medical marijuana in children and adolescents with autism spectrum disorder for core autism symptoms or co-occurring emotional or behavioral problems. 2019. Accessed 14 May 2023. www.aacap.org/AACAP/Policy \_Statements/2019/Use\_of\_Medical\_Marijuana \_in\_Children\_and\_Adolescents\_with\_Autism \_Spectrum\_Disorder\_for\_Core\_Autism\_S.aspx.
- Sathe N, Andrews JC, McPheeters ML, Warren ZE. Nutritional and dietary interventions for autism spectrum disorder: A systematic review. Pediatrics 2017;139:e20170346.
- 25. Canadian Press. B.C.'s representative for children, youth urges immediate help for kids with special needs. CBC News. 2 December 2022. Accessed 10 June 2023. www.cbc.ca/news/canada/british -columbia/bc-representative-children-youth -urges-immediate-help-kids-special-needs -1.6673317.
- Mandell DS. Psychiatric hospitalization among children with autism spectrum disorders. J Autism Dev Disord 2008;38:1059-1065.