

Health Watch Table – Autism Spectrum Disorder (ASD)

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This ASD Health Watch Table (HWT) is a tool to assist primary care providers (general practitioners, family physicians, nurses, and nurse practitioners) in improving the primary care of their patients with autism spectrum disorder (ASD). The tool was developed within the Developmental Disabilities Primary Care Initiative (DDPCI).

This ASD tool, like the other DDPCI HWTs, is intended to summarize outlooks in a manner enabling busy primary health care providers to undertake responsible health measures without an unduly time-consuming requirement of having to review in detail and compare the multiple texts concerned. It reflects a broad consensus in extensive published texts by specialists in the spheres under consideration. It includes concerns applicable to the life span from childhood through to adulthood, but unlike the other DDPCI tools which focus on those with DD, this HWT covers all abilities and severity of ASD.

The recommendations are not meant to impose a rigid formula as to what must be done and when, irrespective of the primary health care provider's judgment as to what is judicious and reasonable in given circumstances. Furthermore, the HWT is not proposed to differentiate anyone's health needs from those of others in the general population. Rather, it is an attempt to highlight particular health concerns that are prone to occur more frequently among persons with ASD than in the population as a whole.

Key websites that the primary health care provider, families and caregivers may find helpful have been included.

About the Developmental Disabilities Primary Care Initiative

The [Developmental Disabilities Primary Care Initiative](#) has brought together clinicians with expertise in the care of adults with developmental disabilities (DD) to improve primary care and quality of life for these persons. An array of tools has been developed to assist primary care providers (general practitioners, family physicians, nurses, nurse practitioners) in caring for adults with developmental disabilities (DD) by helping them to implement various recommendations in the [Primary care of adults with developmental disabilities: Canadian consensus guidelines](#).¹

With leadership and coordination from Surrey Place Centre and funding from the Ontario Ministry of Community and Social Services, the Ontario Ministry of Health and Long-Term Care, and Surrey Place Centre Foundation, Guidelines and Tools have been developed to help primary care providers follow best practices in the care of these patients.

¹ Sullivan WF, Berg JM, Bradley E, Cheetham T, Denton R, Heng J, et al. Primary care of adults with developmental disabilities: Canadian consensus guidelines. *Can Fam Physician*. 2011 May;57(5):541-53.

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i) Checklist for confirmed diagnosis of ASDPreparation for office visit:

- [Check out autism needs with care provider prior to visit \(Section 5\)](#)
- [Are office accommodations in place to ensure optimal clinical encounter? \(5\)](#)

Clinical review

- [Is the aetiology known – review need for genetic reappraisal? \(6.1\)](#)
- [Hearing and vision review \(6.2\)](#)
- [Seizures? – review as required \(6.3\)](#)
- [GI: constipation, eating and nutritional needs? \(6.4\)](#)
- [Sleep review \(6.5\)](#)
- [Sensory sensitivities? \(7.4\)](#)
- [Behaviours of concern? \(6.7\)](#)
- [Concerns about mental health? \(6.7\)](#)
- [Review psychotropic medications – are they still needed? \(6.8\)](#)
- [Are supports and expectations appropriate to individual developmental needs and capacities \(are recommendations from psychological and communication assessments being implemented\)? \(7.2 & 7.3\)](#)
- [Has an autism friendly environment been implemented with appropriate attention to sensory and emotional needs? \(6.7\)](#)
- [Review age and stage transitions \(9\)](#)
- [Role of complementary and alternative therapies \(10\)](#)
- [Support to care providers and care provider resources \(11\)](#)

ii) Checklist for suspected/possible ASD

- [What are parental/care provider concerns?\(1 & 2\)](#)
- [Administer developmental screen for children or screening tool for adults \(4\)](#)
- [Refer to specialist team for diagnostic appraisal \(6 & 7\)](#)
- [Parallel referrals to developmental services for children and adults to determine developmental needs and available services; implement autism friendly environment \(6 & 7\)](#)
- [Share parent education resources for Early Intervention \(7.1\)](#)

1. INTRODUCTION

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition underpinned by recognizable anatomical and functional neurological differences^{1,2}. [DSM-5 diagnostic criteria](#)³ are available from Autism Speaks. ASD is characterized by difficulties in social interaction and communication and by rigid or repetitive behaviours typically manifested early in development and usually apparent by 3 years of age. Sensory sensitivities and motor atypicalities are also common. ASD affects people of all ability levels (more than 50% may have intellectual disability [ID]) and patterns of behaviour meeting criteria for ASD varies from individual to individual and may become more or less apparent or alter in any given person over time.

Even with early intervention and appropriate supports, the majority of individuals remain significantly affected and dependent on some degree of support throughout life⁴. Early intervention for ASD (see section 7.1) helps to promote positive and more typical developmental trajectories and prevents secondary functional disabilities.

The condition may influence the presentation of medical conditions (including mental distress and psychiatric disorder), as well as the nature of clinical encounters with health care providers.

When considering intervention and treatment for people with ASD, it is important to differentiate between the core features of ASD and behaviours caused by physical (e.g., sleep or GI disturbances) and/or mental health comorbidities (e.g., anxiety, ADHD), as this understanding significantly influences intervention and treatment options and effective outcomes. There is no cure for the core features of ASD as we currently understand the condition. Social and communication disabilities benefit from interventions that promote skills in these areas and from supportive autism-friendly environments that include attention to sensory needs⁵.

For optimal outcomes, variable levels of interventions and supports (e.g., sensory, communication, behavioural, psychological, educational and appropriate environments) usually need to be lifelong. Psychotropic medication may be helpful for some ASD-related behaviours during childhood, but not recommended as a first line of treatment for adults. As such, medication at this time has a limited role to play in the treatment of core ASD symptoms.

To assist clinicians in supporting people with ASD and their families, several comprehensive practice guidelines have now been developed (a) for children⁶⁻¹³ and (b) for adults¹⁴.

The focus of the [Primary Care Initiative](#), within which this HWT was developed, is on adults with developmental disabilities (DD), now referred to as intellectual developmental disorder (IDD)³, of whom as many as one third are now considered to have co-existing ASD¹⁵. Additionally, while there is accumulating evidence concerning health issues in adults with ASD, the majority of clinical evidence arises from studies in the population under 18 years of age across the ability range.

This HWT covers health issues described in the population with ASD across the lifespan with and without IDD. In the table to follow, children and adults are combined unless unique aspects are relevant for one or other age group only. The recognition of health conditions and provision of appropriate health care for such a diverse population of individuals is complex and may challenge primary care providers.

People with IDD and ASD often present with unusual or seemingly bizarre behaviours. The task of the primary care provider is to determine whether these behaviours constitute manifestations of ASD or concurrent medical and/or mental health conditions that need to be identified and treated (see section [6.7](#)).

When conventional communication (e.g., speech) is compromised, individuals with ASD may communicate their physical and mental distress through their behaviours. The aetiology of these behaviours needs to be evaluated systematically and robustly in order to undertake appropriate treatment.

In the case of less able individuals with ASD, who cannot communicate verbally their inner experience (e.g., thoughts, feelings, physical discomforts), there is a risk of making erroneous assumptions about their behaviours (taking an “Outside-in” perspective¹⁶), which can lead to wrongly prescribing psychotropic medication to eliminate the behaviour(s) of concern, rather than recommending more appropriate and effective measures based on the circumstances giving rise to this behaviour. In clinical practice, understanding unusual behaviours of these individuals may benefit from being informed by autobiographical accounts of people with ASD (such as [Donna Williams](#), [Temple Grandin](#), [Naoki Higashida](#) and [Tito Mukhopadhyay](#)), who are able to write about their experience (the “Inside-out” perspective). These accounts point to issues not previously recognized but which can impact greatly on the clinical encounter (e.g., disruptive behaviours in the fluorescent-lit meeting room associated with sensory hypersensitivity), ongoing medical care (e.g., tactile defensiveness associated with touch sensitivities) and the understanding of mental health issues (e.g., the impact of stress and anxiety leading to previously unrecognized conditions, such as catatonia).

Our publication on [primary care of adults with IDD](#) identifies thirty-one practice guidelines¹⁷ and provides an accompanying set of [tools](#)¹⁸. Many guidelines and tools are also applicable to individuals with ASD and, where this is the case, the guideline number will be referenced.

Given the complexity of ASD, we envisage this HWT will be most helpful within a shared care model between a primary care physician (paediatrician or family doctor), other medical specialists and allied health care professionals.

2. THE 'ESSENCE' OF AUTISM (ADAPTED FROM: [Autism in general practice](#), an e-learning course offered by the Royal College of General Practitioners, UK 2013)

Social difficulties arise from deficits in:

- **social communication** (problems with understanding and using verbal and non-verbal forms of communication, such as tone of voice, body language and facial expression)
- **social imagination** (difficulty understanding other people's intentions and behaviours, with inability to predict outcomes of interactions outside of routines) and
- **social interaction** (difficulty understanding that the beliefs, desires, plans, hopes, and intentions of others may differ from one's own ['theory of mind'] and difficulty managing their own thoughts and feelings)

Social difficulties may not be noted until school age or later.

Difficulty in understanding social rules can lead to social isolation and even aggressive responses or being bullied; in adolescence, this difficulty in navigating the social environment can lead to anxiety and/or depression.

Failing to make and keep friends can be compensated for by solitary activity, but will result in problems later on in life with social situations, the workplace or relationships.

Social oddness can stem from incorrect understanding of social rules. This might make the person with ASD appear insensitive or rude.

'Mindblindness', the consequence of lacking 'theory of mind', leads to difficulties in perspective taking, expressing empathy for others and building relationships.

Communication difficulties include the patient having difficulties recognizing and using body language, facial expression and tone of voice. Direct eye contact can be uncomfortable and gaze aversion can give the impression of ignoring anyone talking.

Conversation lacks reciprocity and can be disrupted by literal interpretation of words, use of idiomatic speech and perseverative thoughts and interests. In the event of 'vague' instructions, a person with ASD can become muddled.

Alexithymia (lack of words to describe emotions) can result in sudden outbursts of extreme emotion due to inability to communicate how they feel and then being overwhelmed with their feelings.

Difficulty understanding language and auditory processing can also impact the ability to communicate.

A pattern of immediate or delayed repetition of language can indicate anxiety, lack of understanding about the situation, or, as we begin to better understand from people with ASD (e.g., Higashida, page 23)¹⁹, may, depending on the individual, represent different memory processes or even play with the sound and rhythm of familiar words.

Repetitive behaviours (and stereotypies) may include flapping hands, spinning around ('stimming') or ordering objects in particular ways. Some repetitive behaviours are responses to sensory issues; others may be attempts to gain control and establish some predictability within their environment and day-to-day life.

In older children, these repetitive behaviours may manifest as rigid play routines, often copied verbatim, such as from TV scripts. The focus of attention might shift to the collection of information, usually of objects. This can range from dinosaurs to bus or train timetables or other properties of the physical world.

The consequences of these behaviours are:

- Arranging their physical environments or possessions in particular ways
- Carrying out tasks at a certain time and in a particular sequence
- Engaging in scripted social exchanges from which deviations are poorly, if at all, tolerated

Note: Changes to the patient's routines or environment that are not initiated by them might create distress and anxiety and result in problem behaviours. These latter behaviours, and indeed some repetitive behaviours, may be caused by problems with executive function in the autistic brain or be a way of regulating stress levels for the patient.

Sensory issues: Sensory sensitivities and distortions affect 90% of individuals with ASD²⁰. Pain sensation may be heightened or reduced. Inability to filter out multiple stimuli (auditory, visual, tactile, taste, smell, vestibular and proprioceptive) may limit the person’s processing capacity. In addition, sensory distortions and hyper- and hypo-sensitivities may give rise to unusual behaviours (e.g., stamping gait to ensure contact with what the person with ASD might perceive as shifting ground, toe walking to increase proprioceptive input, painful reactions to fluorescent/flickering lights or electronic beeping, certain clothing materials being extremely uncomfortable to bear).

3. PREVALENCE

Children & Adults:

The most recent CDC report estimates the prevalence rate of ASD in children aged 8 years is 14.7 per 1,000 (1 in 68; 1 in 42 boys and 1 in 189 girls)²¹. This supersedes their 2012 estimate of 1/88 (1/54 boys; 1/252 girls)²². Multiple factors influence the identification of children with ASD and there were significant variations in ASD prevalence by geographic area, sex, race/ethnicity, and level of intellectual ability. Experts are unsure whether the actual prevalence of ASD has increased or whether changes in concepts, definitions, service availability and professional and public awareness of ASD account for increased rates reported.

The most commonly quoted estimate for adults is 1%²³.

Baron-Cohen²⁴ estimated that 40% of children had undiagnosed ASD (study in a school-based population across the range of functioning, in the UK); Nylander and Gillberg²⁵, surveying an adult, psychiatric, out-patient population with an ASD assessment tool, found that of the group identified with ASD, 17 out of 19 individuals (91%), had not been previously diagnosed as such, but instead, had a diagnosis of psychiatric disorder, primarily schizophrenia.

4. SCREENING AND DIAGNOSIS

Using a screening tool can help clarify the need to refer for further assessment. Diagnosis of ASD facilitates explanation of the symptoms and helps patients, families, and others to accept differences. In addition, it opens possibilities for early intervention and informs about associated physical and mental health vulnerabilities.

Notes:

- (a) Females with ASD may present differently from males (e.g., social characteristics) as described by Gould and Ashton-Smith²⁶ – also available at www.autism.org.uk/about-autism/autism-and-asperger-syndrome-an-introduction/gender-and-autism/women-and-girls-on-the-autism-spectrum.aspx.
- (b) Communication and social impairments, defined as separate criteria in previous iterations of DSM, are now combined in DSM-5 and sensory sensitivities are included for the first time.

CONSIDERATIONS	RECOMMENDATIONS
<p><i>Children:</i></p> <p>Early recognition of ASD and prompt intensive intervention can result in substantially improved outcomes.</p> <p>Concerns about development or behaviour, especially delayed speech and language development, lack of responsiveness, disruption in the social-communicative, play, sensory and motor domains of development, may be indicative of ASD²⁷.</p> <p>It is prudent for physicians unfamiliar with ASD to adopt a low threshold for seeking expert consultation.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Take parents’, carers’ or patients’ concerns about development and behaviour seriously. <input type="checkbox"/> Administer a developmental screen, including a screen of social development, at well-baby and well-child visits (e.g., Rourke [one week to 5 years of age], http://rourkebabyrecord.ca/downloads.asp). <input type="checkbox"/> Perform ASD-specific screening using the <i>Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT-R/F)</i> www.m-chat.org/print.php²⁸ at 18 and 24 months (AAP). It can be used in children 16 to 30 months of age. <input type="checkbox"/> Older children, age 4 to 18 years, can be screened with the Social Communication Questionnaire²⁹. <input type="checkbox"/> Refer any child who fails the M-CHAT-R/F for a formal evaluation by an experienced clinician or team of professionals. <input type="checkbox"/> Prior to a confirmed diagnosis of ASD, and to prevent unnecessary delays in the diagnostic and treatment process, Carbone recommends prompt, simultaneous referrals to 1) an audiologist, 2) an interdisciplinary autism team, 3a) an early intervention program (for children younger than 3 years), or 3b) the special education department of the local school district (for children 3 years and

CONSIDERATIONS	RECOMMENDATIONS
	<p>older)³⁰. In some Canadian jurisdictions, referral by a paediatrician may be required to access early intervention programs. Some practitioners also recommend referral to Speech and Language Pathologist (SLP) and Occupational Therapist (OT) and Ophthalmologist in this context.</p> <ul style="list-style-type: none"> □ Anagnostou (Table 1)¹⁰ outlines a recommended clinical work-up for patients diagnosed with ASD. □ A formal diagnostic evaluation would include the use of standardized interview and observational tools such as the 3di, ADI-R, ADOS and DISCO⁶, and information from multiple sources as a part of expert clinical opinion, using the framework of the DSM-5 criteria. (Note: the above tools have not been validated in children who are hearing and visually impaired, reinforcing the importance of excluding these sensory impairments as part of the diagnostic workup.)
<p><i>Adults:</i> The rate of undiagnosed ASD is high. (Please see Section 3.)</p>	<ul style="list-style-type: none"> □ While currently there are no widely accepted tools to screen for autism in adults, questionnaires such as the Autism Spectrum Disorder in Adults Screening Questionnaire – ASDASQ²⁵, Autism Spectrum Quotient – AQ test online http://aq.server8.org/ (Baron-Cohen), Social Communication Questionnaire – SCQ (based on items from the ADI³¹, and Gilliam Autism Rating Scale – GARS³² may be helpful. □ The tools a specialist would use in a formal diagnostic evaluation for adults may include the Diagnostic Interview Guide for the Assessment of Adults with Autism Spectrum Disorder www.rcpsych.ac.uk/pdf/asperger_interview_use_this_one.pdf (Royal College of Psychiatrists, UK) for Asperger’s syndrome/higher functioning autism. The DISCO can be used for adults across the age span and all levels of ability and the ADI, ADOS and 3Di may be used effectively for adults by the experienced ASD clinician¹⁴.

5. MANAGING THE CLINICAL ENCOUNTER AND OFFICE ACCOMMODATIONS (See also Tools for the Primary Care of People with Developmental Disabilities – [Office organizational tips](#))

CONSIDERATIONS

Children & Adults:

Medical and dental visits can be very stressful for individuals with ASD. Unfamiliar places and people may elicit fear and panic responses.

Attention to individual-specific comfort needs will identify the office as a “safe” place and should help avoid ‘meltdowns’ resulting from overstimulation, heightened anxiety, difficulties with affect regulation and managing emotional upsets.

Presence of familiar and informed care providers (e.g., group home workers, family) will enhance the clinical process.

Eye contact may be extremely uncomfortable, even painful for persons with ASD.

Even when not engaging in eye contact themselves, many individuals with ASD experience the eye contact of others as distressing.

Lack of eye contact does not mean they are not listening.

Patient response: may be overstimulated by his/her own emotions (positive or negative) and/or the emotions they sense in others.

Physical examination and medical procedures may be extremely stressful, and even painful, especially if patient has tactile sensitivity.

RECOMMENDATIONS**Planning the visit**

Key sources: the [National Autistic Society](#) and several print publications³³⁻³⁵

- Promote [autism-friendly environments](#)⁵ to optimize and achieve good, proactive health care.
- Schedule first or last appointment of the day, because people with ASD find waiting, especially in a busy area, extremely stressful.
- Prior to appointment, contact a knowledgeable care provider to identify any known specific needs, e.g., sensory sensitivities; verify need for visual supports (e.g., communication boards such as the NHS, UK [Communication Passport](#), [PECS](#), [Books Beyond Words](#)) if verbal communication is limited.
- Where possible, arrange for appropriate accommodations, e.g., pay attention to noise levels, presence and proximity to other people.
- Be alert to potential triggers in the office environment (e.g., flickering fluorescent lights).
- Encourage the caregiver to fill out the “[Today’s Visit](#)”¹⁸ form prior to office visits and use [Social Stories](#)^{36, 37} and visuals as mentioned above (some may benefit from seeing pictures of the doctor’s office) to prepare their client for the doctor’s visit.
- Consider asking for the individual to prepare his/her own questions or concerns ahead of time, in writing.
- Ensure that the person accompanying the patient to the appointment is familiar with the patient and knowledgeable about the presenting issues.
- If possible, find a small, quiet, uncluttered room or suggest they wait in the car. Enquire regarding strategies to manage anxiety, e.g., weighted vest, squeezies to hold in hand, walking and pacing, which might have been used successfully in the past and be prepared to support use of these during the meeting; opportunity to move and walk about is often helpful.
- Be prepared to schedule a longer time for appointments.

Engagement strategies

- Pay attention to keeping to time and don’t make promises you cannot keep, e.g., “please wait a minute” – some will expect attention in exactly one minute.
- Maintain a clear sense of structure; explain what is happening and what will happen, then keep to the plan. Sharing a visual display of the agenda, crossing off each item as they are discussed, is helpful.
- Slow down your agenda and take your time.
- Ask directly for the information you need, as vital information might not be volunteered.
- Be aware that language comprehension may be overestimated in highly verbal individuals or underestimated in non-verbal individuals.
- Make direct requests, e.g., “please lie on the couch” NOT “can you lie on the couch” – the latter may result in the person not doing anything as they may not understand that you are asking them to do something.
- Give extra time to allow the person to ask questions.
- Adopt a neutral emotional stance and body language to avoid overwhelming the patient with positive or negative emotions.
- Patient may not understand personal space; may invade your personal space or need more personal space than is usual.
- Without sensitive, careful explanation and forewarning of what to expect, the patient may interpret your actions as an attack or sensory intrusion resulting in fear, panic and defensive behaviours (e.g., running away).
- May find it difficult to understand another’s perspective. May not understand your intentions but may expect you to know what they are thinking.
- Enlist care providers’ assistance wherever possible, especially if patient is nonverbal or uses alternative communication aids.
- Listening with interest and attention and appreciating parent, care provider and patient difficulties and anxieties, enhances understanding the patient and the working relationships with care providers.
- Provide names and contact details of local support groups and other resources.

Use of language

- Be aware of the nuanced impairment of communication (verbal and non-verbal) in ASD and Asperger syndrome (DSM-5).
- Be aware of difficulties processing verbal information, especially when the patient is anxious.
- Slow down your speech, lower your voice in volume and pitch; don't ask a lot of questions. Often it is useful to talk in the same manner as the person to whom the patient is closest.
- Use short sentences and simple language; avoid using idioms and metaphors because people with ASD tend to take everything literally, e.g., "it looks like your throat is on fire"; they might try to put the fire out with water (reported by a care provider).
- Ask questions to make sure they have understood what has been said – may speak clearly but lack full understanding.
- Support verbal requests, e.g., during physical examination and explanation of the problem, use visuals to aid understanding, e.g., it may help to write things down, use drawings, pictures (e.g., *Books Beyond Words* by Sheila Hollins www.booksbeyondwords.co.uk)³⁸.
- Use actual objects to demonstrate meaning, e.g., doll or yourself, to demonstrate a procedure. Simple gestures may help, but avoid complex gestures or facial expression without verbal instructions, as these may not be understood.
- Give patients time to process what you have said.
- Don't assume a nonverbal patient does not understand what you are saying.

Physical examination

- Always explain what you are going to do (using visuals as required), before starting any procedure or examination. Waiting for permission to begin may avoid possible meltdowns.
- Avoid speaking negatively in front of the patient with ASD, as even if they have trouble processing language, they will certainly understand tone.
- Some individuals may have a disproportional response to pain. For painful procedures, e.g., venipuncture, it may be wise to assume the person will feel pain and use local anaesthetic cream³⁹.
(**Note:** some individuals with tactile sensitivity may not tolerate having cream applied to their skin.)

6. MEDICAL ASSESSMENTS/EVALUATIONS AND INTERVENTIONS

6.1 AETIOLOGY

CONSIDERATIONS	RECOMMENDATIONS
<p><i>Children & Adults:</i></p> <p>Current evidence supports a strong genetic role in the aetiology of ASD. Additional support for the association of ASD with known genetic disorders arises from its recognition in conditions such as fragile X, Smith-Lemli-Opitz, 22q11del syndromes and tuberous sclerosis complex, among many other conditions with detectable genetic alterations⁴⁰.</p> <p>An identified genetic aetiology may be made for as many as 30-40% of ASD cases⁴¹.</p> <p>Advances in genetic testing, such as chromosomal microarray (CMA), permit detection of very small genomic changes in patients already evaluated using traditional cytogenetic tools.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> A genetic consultation is recommended for individuals with diagnosed ASD in the 2013 revision of the American College of Medical Genetics & Genomics⁴¹ practice guideline. Contact your local genetics centre for referral criteria for aetiologic assessment of individuals with ASD, especially those who have relatively severe developmental delays, dysmorphic features, congenital anomalies or a family history of ASD⁴². Some centres recommend obtaining chromosomal microarray and fragile X testing prior to genetic consultation. <input type="checkbox"/> Undertake a <i>Wood's lamp</i> exam to detect hypopigmented macules associated with tuberous sclerosis, especially in persons with a seizure disorder. <input type="checkbox"/> Consider referral for genetic evaluation, even in individuals who have undergone a genetic appraisal in childhood with negative results.

CONSIDERATIONS	RECOMMENDATIONS
6.2 HEARING AND VISION (PC GUIDELINE # 11)	
<p><i>Children & Adults:</i></p> <p>Hearing deficits are common and can be a factor in delay of speech development^{43, 44}.</p> <p>Visual deficits include higher incidence of refractive error, strabismus and differences in ocular motility function. Visual differences include hyper- and hypo-sensitivity to visual stimuli, photosensitivity, colour perception and hypersensitivity to colour, differences in visual-spatial and visual-motor processing and spatial awareness including visual neglect which in turn may result in poorer processing of peripheral stimuli⁴⁵.</p> <p>Hearing and vision difficulties can manifest as a change in behaviour at any age.</p> <p>In some with ASD, attentional issues, auditory processing problems and auditory and visual sensory sensitivities give rise to atypical perceptions. These need to be differentiated from typical concerns such as hearing loss associated with otitis media and squint associated with astigmatism. These latter concerns are normally addressed by standard audiology and ophthalmology evaluations in both children and adults⁴⁵.</p>	<ul style="list-style-type: none"> □ Audiological assessment prior to diagnosis of ASD and periodically throughout the lifespan and whenever a concern in this regard arises. Audiological assessments will be comprised of an individualized battery of tests depending on the profile of the individual and may include an audiogram and test for hyperacuity at different frequencies. Current state of auditory physiologic testing enables audiologists to assess auditory function accurately at all ages⁴⁶. □ Review hearing and vision and assess as required when changes in behaviour are noted. □ Consider referral for central auditory processing and behavioural optometry where available, in order to promote appropriate supportive environments. □ Be aware that sensory distortions, atypicalities or hypersensitivities are common and poorly understood and can mislead clinical understanding⁴⁵.
6.3 NEUROLOGICAL (PC GUIDELINE #18)	
<p>Neurological, Mental Health and Behavioural Concerns (section 6.7), Psychopharmacological Interventions (section 6.8), Sensory Sensitivities (section 7.4) and Motor Difficulties (section 7.5) overlap in both understanding, clinical presentations and treatment considerations.</p>	
<p><i>Children & Adults:</i></p> <p>~30% have epilepsy (with greater prevalence in those with severe IDD). Onset of seizure disorder may not occur until adolescence or adulthood. Accurate diagnosis of the particular seizure type is important⁴⁷.</p> <p>Keep in mind that penlights or otoscopes can trigger seizures in susceptible individuals.</p> <p>A small but significant proportion of young people develop catatonia-like behaviour. Aetiology remains unclear,</p>	<ul style="list-style-type: none"> □ Maintain a high index of clinical suspicion for development of epilepsy, as presentation may be subtle. □ Consider EEG and/or referral to a specialist in the context of “spells” or when there is a dramatic fluctuation or regression in language. □ In individuals with a seizure disorder, ensure periodic review by a neurologist for reassessment of diagnosis and treatment regime. □ Individualize treatment: if control cannot be achieved, weigh the risks of an occasional seizure against the risk of intolerable side-effects with high dose anticonvulsants. □ Multidisciplinary approach is crucial for assessment of catatonia-like behaviour and treatment.

CONSIDERATIONS	RECOMMENDATIONS
<p>but sometimes may be related to stress⁴⁸⁻⁵⁰.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> ASD per se is not an indication for brain imaging. Consider only if typical red flags for neuroimaging are present (e.g., localizing symptoms). <input type="checkbox"/> Keep in mind that some anticonvulsants in some individuals may contribute to problem behaviours.
<p>6.4 GASTROINTESTINAL (GI) (PC GUIDELINE # 15)</p>	
<p><i>Children & Adults:</i> GI problems, including constipation, diarrhea, abdominal pain, Gastroesophageal Reflux Disease (GERD), dysphagia, aspiration, Helicobacter pylori (H. pylori) infection, celiac disease, lactose intolerance and pica, are more common than in the general population. GI-associated distress may present as sleep disturbance or other behavioural problems such as aggression or self-injury. Under-nutrition, possibly due to odd food preferences or oral hypersensitivity (including to taste and smell) and nutritional deficiencies, are also common, especially among patients on chronic anti-convulsant therapy^{51, 52}. Eating problems may be associated with oral motor delays or sensory sensitivities. Food selectivity may be due to dental pain or caries as well as sensory sensitivities.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Have a low threshold for GI evaluation, including celiac disease, when there is concern about unusual or a change in behaviours. <input type="checkbox"/> Consider GI pathology such as GERD or ulcers (possibly causing pain) if there are night wakings with pain behaviour (see Pain 6.6). <input type="checkbox"/> Check for <i>H. pylori</i> infection if persistent signs of dyspepsia or unexplained behaviour changes are noted; retest in 3 to 5 years after treatment. <input type="checkbox"/> Screen for dysphagia and aspiration if neuromuscular dysfunction is present. <input type="checkbox"/> Screen regularly for constipation. Guidance for the Management of constipation in children and adolescents with autism spectrum disorders was developed by the Gastroenterology Committee of the Autism Speaks Autism Treatment Network (ATN), and Guide for Managing Constipation in Children Tool Kit for Parents is available at Autism Speaks (free, but requires registration). PEG 3350, which is well-tolerated, tasteless, odorless and colourless, may be a good medication option for constipation in people with ASD. <input type="checkbox"/> Screen for pica and ascertain serum lead levels when pica exists. <input type="checkbox"/> If food selectivity or food refusal is present, patient should be closely monitored for sub-optimal growth and nutritional deficiencies. <input type="checkbox"/> Ascertain history of mealtime behaviour and dietary intake; undertake dietary assessment including weight for height or BMI. <input type="checkbox"/> Involve a nutritionist, OT, SLP and behavioural consultant as needed^{53, 54}.
<p>6.5 SLEEP DISORDERS</p>	
<p><i>Children:</i> ~ 80% show sleep problems, most commonly delayed sleep onset, night wakings, and early awakenings. In general, more evidence supports the use of behavioural interventions than medications.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Rule out underlying medical and pain-related conditions contributing to the sleep disturbance, such as GERD, sleep apnea, seizures, erupting teeth and medication side-effects. <input type="checkbox"/> Consider first non-pharmacological approaches, e.g., parent education, sleep hygiene and behavioural interventions⁵⁵. In the context of sensory sensitivities, a weighted blanket has been found to be effective for some. Also see <i>ATN/AIR-P Sleep Tool Kit-Parent Booklet and Quick Tips</i>¹¹ (free, but requires registration). <input type="checkbox"/> Melatonin is safe and often effective for children with ASD and sleep difficulties. <input type="checkbox"/> When considering medication, give preference to medications that do not change sleep architecture and are not anti-cholinergic.
<p><i>Adults:</i> A new onset of a sleep disturbance can arise.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Consider a full investigation for new onset of sleep disturbance, including recent changes in the environment, relationships, daily

CONSIDERATIONS	RECOMMENDATIONS
<p>In view of paucity of sleep studies in adults with ASD, consult guidelines developed for children cited above and adult sleep literature in the general population.</p> <p>Sensory sensitivities may contribute to sleep disruption in both children and adults (e.g., even changes in position or due to a small sensory event such as sounds [a car driving by], lights, textures [bedding, pyjamas]).</p>	<p>programs, as well as underlying medical, emotional or psychiatric explanation(s).</p> <ul style="list-style-type: none"> <input type="checkbox"/> Consider GI conditions (GERD, constipation), pain, dental problems, seizures, sensory deficits, depression, fears and anxiety, or other psychological or emotional distress (e.g., abuse). <input type="checkbox"/> Consider role of sensory sensitivities and consult an OT trained in sensory integration. <input type="checkbox"/> Consider Melatonin as in children.
<p>6.6 PAIN (PC GUIDELINE #4)</p>	
<p><i>Children & Adults:</i></p> <p>Pain may not be recognized if it presents atypically and instead is seen as problem behaviour.</p> <p>Atypical experiences of pain and responses to pain may include laughing, humming, singing, removal of clothing and self-injury which could mask the seriousness of the medical condition.</p> <p>Agitation and an increase in problem behaviours may be the only clues that the child or adult is in pain.</p> <p>Pain may also manifest as changes in food and fluid consumption.</p> <p>There is no evidence that people with ASD suffer any less from the presence of a noxious experience⁵⁶.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Use tools to ascertain presence of pain as outlined in Primary Care Guidelines (e.g., DisDat for adults)⁵⁷. <input type="checkbox"/> Experience of pain may be decreased with music, movement and deep pressure activities (massage). <input type="checkbox"/> Consider symptomatic treatment for perceived pain (e.g., acetaminophen or ibuprofen). In individuals with minimal communication, a trial of analgesia, 3 to 4 times a day for 1 to 2 days may be helpful, with monitoring of pain or target behaviours associated with pain. <input type="checkbox"/> Even if target behaviour resolves with analgesia, the underlying cause of the pain needs to be identified and treated.
<p>6.7 MENTAL HEALTH AND BEHAVIOURAL CONCERNS (PC GUIDELINES # 22-26)</p>	
<p>Unique neurobiology and consequent processing problems, atypical sensory and perceptual experiences in daily life give rise to mental distress; this is eloquently described by self-advocates (“Inside-out” perspective). (Please see Introduction, p. 3.)</p> <p>In children, psychiatric and behavioural disorders are common and frequently multiple; high level of anxiety, mood, disruptive disorders and ADHD are reported^{58, 59}.</p> <p>Adolescents with ASD and DD, compared to those with ASD only, have higher rates of new onset psychiatric disorder (e.g., adjustment, depressive) as well as higher rates of compulsive behaviours and stereotypies, and are prone to specific manifestations of anxiety, fears and phobias^{60, 61}.</p> <p>Stoddart et al. reviewed the Canadian context of mental health needs of this population and the adequacy of services to meet them www.asperger-manitoba.ca/wp-content/uploads/2013/02/2013-Diversity-Youth.pdf.</p> <p>There are no epidemiological studies of mental ill-health in adults. However, two long-term follow-up studies have shown high rates of mood (53%), anxiety (50%), especially OCD (20%), chronic tic disorder (20%), psychotic disorders (12%) and ADHD (43%)⁶²; 16% are reported to develop new-onset disorders falling into two main groups – OCD (some with catatonia) and affective disorders⁶³. Increased rates of anxiety and depression are described in adults with Asperger syndrome⁶⁴.</p>	
<p><i>Children & Adults:</i></p> <p>Mental health disturbances can present as problem behaviours (PBs).</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Refer to an interdisciplinary mental health team (ideally including behaviour therapist, speech-language pathologist, nurse, occupational therapist, physiotherapist, psychiatrist, pharmacist and

CONSIDERATIONS	RECOMMENDATIONS
<p>As ID increases, assessing and treating mental ill-health and PBs assumes greater complexity.</p> <p>Problem behaviours from an assessment/treatment perspective might be divided into two categories (a) communication of “distress” and (b) “antisocial” behaviours.</p> <p>(a) “Distress behaviours” are underpinned by pain or discomfort (e.g., GERD, emotional loss or insufficient and inadequate supports or psychiatric disorder)]. Distress PBs include aggression to self, others and property; tantrums; pica; head-banging; wrist-biting; hair-tearing; and running away.</p> <p>(b) Antisocial behaviours are a problem for care providers, but may not be distressing to the individual. They include inappropriate touching, sniffing, tasting, repetitive behaviours, stereotypies, spitting and smearing.</p> <p>Sometimes there is overlap between these two categories; repetitive behaviours can be pleasurable; on the other hand, repetitive behaviours giving rise to self-injury may be underpinned by a medical condition or it may be a way to self-soothe in an environment that is too stressful.</p> <p>Distinguishing between (a) and (b) is crucial to formulating effective and ethical interventions.</p> <p>Psychiatric illness and disorder</p> <p>Mental distress may escalate and contribute to psychiatric disorders (“Outside-in” perspectives)</p> <p>Psychiatric disorder may arise during childhood (e.g., ADHD, tic disorder) or occur later as new onset and may be episodic (e.g., depressive episode). More than one psychiatric disorder can coexist (along with behaviour problems).</p> <p>It is important to distinguish behaviours associated with psychiatric disorder from PBs associated with other aetiologies, as treatment may be different.</p>	<p>psychologist), whenever possible, to assist in assessing and managing behavioural and mental health concerns.</p> <p>Problem behaviours</p> <ul style="list-style-type: none"> □ Refer to the Diagnostic Formulation of Behavioural Concerns (Figure, p. 67)⁶⁵. □ An evaluation of the individual, as well as his support environment, should be undertaken as problem behaviours are co-constructed. A functional analysis of the behaviour (antecedent-behaviour-consequence) is often crucial⁶⁶, as is a communication assessment. Before considering psychiatric diagnosis, review the following possible causal factors (pp 68-69)⁶⁵: <ul style="list-style-type: none"> a) Medical factors, such as GI conditions, physical pain (e.g., from injury or infections), dental problems, medication side-effects, allergies and sensory deficits; seizures can be sub-clinical and present as problem behaviours and/or fluctuations in affect/attention/mood. b) Environmental factors, inadequate supports and inappropriate expectations, such as those related to sensory sensitivities, communication needs, transitions, changes (e.g., in supports, routines, residence), sexuality. c) Emotional factors, such as life events, trauma, loss, grief and stress. □ PBs are usually managed best by less intrusive non-pharmacological means, such as: <ul style="list-style-type: none"> ○ A combination of interrelated programs focusing on communication interventions and individual or group-oriented social skills training with the goal to enhance quality of life ○ Environmental modifications and increased behavioural supports with greater emphasis on positive behavioural strategies □ Some maladaptive behaviours may be amenable to adjunctive pharmacologic interventions. □ Consider pharmacologic interventions in the context of physical, environmental and emotional needs having been evaluated and necessary supports optimized⁵. <p>Psychiatric illness and disorder</p> <ul style="list-style-type: none"> □ Autism-friendly environments (identified through assessment of autism needs), will diminish potential for mental distress⁵. □ Having established that a, b and c above, are not the cause of the behaviours and symptoms of concern, the likelihood of psychiatric disorder increases. □ Consider referral to a specialist psychiatrist with expertise in ASD⁶⁷. □ Given the unique behaviours in people with ASD, establishing baseline symptoms and behaviours prior to the onset of concerns about psychiatric disturbance is crucial. □ Criteria (DSM-5) for psychiatric disorder are based on any significant changes in symptoms and behaviours from the individual’s unique baseline. □ Understanding the individual over time and any unique ways of communicating contributes greatly to the psychiatric diagnostic formulation and opportunities for effective intervention.

CONSIDERATIONS	RECOMMENDATIONS
<p>With greater severity of autism and ID, it may be difficult to sub-type specific psychiatric disorders and in these situations, treatment of symptoms may be considered.</p> <p>Caution: People with ASD can behave in ways that may be misinterpreted as psychotic disorder. Consequently, misdiagnosis of psychotic disorder occurs, in particular when ASD and ID coexist.</p>	<ul style="list-style-type: none"> □ Treat according to best practices for specific psychiatric disorder. □ Attention to triggers and precipitants (e.g., life events, transitions, absence of needed ASD accommodations) is especially important and offers treatment opportunities. □ Therapeutic approaches include the following interventions: <ol style="list-style-type: none"> 1. psychological (e.g., behavioural support, CBT) 2. social (e.g., social skills training, educational and employment supports, structured leisure and supported group activities) 3. support to care providers⁶⁷
<h3>6.8 PSYCHOPHARMACOLOGICAL INTERVENTIONS (PC GUIDELINES #5 AND 27)</h3>	
<p>CONSIDERATIONS</p> <p><i>Children & Adults:</i></p> <p>Data show that people with IDD, including ASD, are ‘overmedicated and undertreated’⁶⁸. Polypharmacy is common and, once psychotropic medications are started, they are hard to stop. Sensitivity to medications may be a concern. Medications are often used to manage PBs rather than treat the underlying cause of PBs.</p>	
<p>RECOMMENDATIONS</p> <p>Psychiatric illness and disorder – when to use medication</p> <ul style="list-style-type: none"> □ Medicate according to evidence-based practice for the specific psychiatric disorder. Refer to an IDD/Autism mental health specialist to ensure robust diagnostic evaluation, because it is imperative to have an accurate psychiatric diagnosis. <p>Problem Behaviours – when to use medication</p> <ul style="list-style-type: none"> □ Base pharmacological interventions on the following criteria⁶⁹: <ul style="list-style-type: none"> ▪ Evidence that the target symptoms are interfering substantially with learning, socialization, health or quality of life ▪ Suboptimal response to behavioural interventions and environmental modifications ▪ Evidence that the problem behaviour (or coexisting psychiatric disorder) is amenable to pharmacological intervention <p>In the absence of consensus on the pharmacological treatment of PBs in ASD, the following international perspectives are offered from Canada, the UK and US:</p> <ul style="list-style-type: none"> □ Anagnostou et al (Canada)¹⁰ outline medications used to treat ASD behaviours and symptoms (Table 2). □ Barrett (UK)⁷⁰ offers drug treatment algorithms for adults displaying the following behaviours (1) Aggression, (2) Self Injury, (3) Sleep disturbance, and (4) “Core Difficulties” of ASD, which they describe as (4a) Social anxiety and withdrawal (4b) Stereotypies and (4c) Rituals and obsessive behaviour. □ Myers et al (US) (Table 1 p. 1169)⁷¹ identify target symptom clusters in children as follows: (1) Repetitive behaviour, behavioural rigidity, obsessive compulsive symptoms; (2) Hyperactivity, impulsivity, inattention; (3) Aggression, explosive outbursts, self-injury; (4) Sleep dysfunction; (5) Anxiety; (6) Depressive phenotype; (7) Bipolar phenotype; consider medication based on identified clinical circumstances. Myers et al (Table 2, p. 47)⁷² focus on medication classes to address target symptoms and describe important adverse side effects. □ There is one expert consensus about practice pathway for ASD and ADHD symptoms in children⁷³. □ Please keep in mind the following: The primary cause giving rise to the symptom (e.g., mood, anxiety) and behaviour clusters should be determined whenever possible and medication (or other interventions) targeted to this aetiology according to best practice. □ Antipsychotic medications are sometimes used in the management of behaviours for which underlying aetiology has not been identified with the following recommendations from NICE guidelines^{9, 14}: 	

- Best practice recommends shared care between the specialist who initiates antipsychotic treatment (paediatrician or psychiatrist) and family doctor, with relative roles as follows below. In the absence of a specialist, care often defaults to a family doctor.
- The **prescriber** should:
 - Identify the target behaviour
 - Monitor effectiveness
 - Review effectiveness and side-effects after 3 to 4 weeks
 - Stop treatment if there is no indication of clinically important response at 6 weeks
- Precautions:
 - Start with a low dose
 - Use the minimum effective dose needed
 - Regularly review benefits and any adverse events
- The **physician with responsibility for continued treatment** with antipsychotic medication should:
 - Collaborate with a Behaviour Therapist or mental health professional in monitoring target behaviour(s); changes in these behaviours, monitored pre- and post-treatment, will determine effectiveness
- Monitor side-effects with an agreed-upon duration of treatment and plans for stopping treatment.

General medication management

- Routinely review medications being used for mental health symptoms and behavioural problems.
- Consider careful withdrawal of medication after 6 to 12 months of therapy to determine whether the drug is still needed.
- Monitor for side effects (e.g., drug-specific guidance for children are available at <http://comesaguideline.org/> under 'Information for Doctors').
- If PRN medication is being used, ensure a clear PRN administrative protocol is in place⁷⁴ and consider advice provided by [Deb](#) (page 29)⁷⁵.

7. DEVELOPMENTAL ASSESSMENT AND INTERVENTIONS

7.1 EARLY INTERVENTION

CONSIDERATIONS	RECOMMENDATIONS
<p><i>Children:</i> Early intervention (EI) programs can result in substantially better outcomes. EI, ideally offered before age 5 years, uses a multitude of behavioural and educational approaches outlined at websites below: http://researchautism.net/pages/autism_treatments_therapies_interventions/autism-interventions-children; EI strategies are further described by Volkmar at http://autism.yale.edu/sites/default/files/Class2-Volkmar_CLEAR.pdf and outcomes reviewed by Magiati et al ⁷⁶.</p>	<ul style="list-style-type: none"> □ Ensure referral for early intervention program which would include strategies such as: <ul style="list-style-type: none"> ▪ parental education and support ▪ behavioural therapy ▪ developmental education ▪ communication therapy ▪ occupational and physical therapy ▪ highly structured social play interventions □ Offer parents information about effective evidenced-based early intervention programs: <ul style="list-style-type: none"> ▪ Early Start Denver Model “An early start for your child” for parents by Rogers Dawson and Vismara (2012) www.autismspeaks.org/what-autism/treatment/early-start-denver-model-esdm ▪ Other EI strategies are described at www.autismspeaks.org/what-autism/treatment

7.2 PSYCHOLOGICAL

CONSIDERATIONS

Children & Adults:
 Psychologists screen and diagnose ASD (ideally in early childhood, but at any age when concerns are raised), as well as intellectual disability and behavioural and mental health issues, by providing comprehensive assessments that ascertain:

- learning styles
- cognitive adaptive language and social communication abilities
- social-emotional functioning
- academic and vocational skills
- behavioural challenges
- attention and memory
- skill development
- psychosocial and environmental issues

Determining baseline functioning is important, particularly when there is concern about changes in behaviour or deterioration in cognition or adaptive functioning.

Identifying the individual's current strengths can be used as a platform for development of other skills.

Creating, with the individual and those who know them well, an 'about me' book which can provide an autobiographical journey of the person's life and can alert providers to optimal communication issues.

Behaviour problems occur in a broader context and assessment of the physical and social environment is as important as assessment of the individual.

The diagnostic process should:

- identify key areas for individualized behavioural, psychosocial and educational interventions
- specify measurable goals
- collect data to ascertain effectiveness of interventions and monitor over time
- expedite access to services and supports

Selection of psychosocial interventions for youth and adults are outlined at:

http://researchautism.net/pages/autism_treatments_therapies_interventions/autism-interventions-adults

RECOMMENDATIONS

- Refer to an autism-informed psychologist for assessment of strengths and needs, identify appropriate expectations of the individual from preschool through to adult life and ensure prevention and management/treatment of emotional and behavioural problems.
- Work with a psychologist, behaviour therapist and multidisciplinary team to assess daily supports (environmental and care provider) and ensure they are appropriate.
- Ensure access to evidence-informed therapeutic interventions for behavioural and emotional issues that arise (e.g., therapeutic counselling or cognitive behaviour therapy [CBT] for anxiety; psychotherapy for trauma; behavioural support around problem behaviour [e.g., functional analysis, consistency of supports across environments]). Remain available and informed about intervention outcomes, many of which can have a bearing and impact on medical care⁷⁷.

7.3 LANGUAGE AND COMMUNICATION

CONSIDERATIONS	RECOMMENDATIONS
<p><i>Children & Adults:</i> Up to 25% do not develop functional spoken language and communicate through their behaviour⁷⁸. Significant language difficulties increase likelihood of mental ill-health. Available early intervention (EI) strategies can markedly improve communication skills. A speech-language assessment can provide a more comprehensive view of communication needs and lead to specific intervention recommendations. Advances in literacy instruction and technology have resulted in enhanced</p>	<ul style="list-style-type: none"> □ Ensure early enrollment in a speech and language program as soon as delays in communication are identified. If not available, refer to a Speech Language Pathologist (SLP) to identify the nature of the language and communication difficulties and to recommend optimal interventions. □ In the absence of speech, alternative ways to communicate might be explored, such as Augmentative and Alternative Communication (AAC) methods⁷⁷. Use of AAC methods does not prevent the emergence of talking, but rather increases that possibility. □ Other tools and strategies likely used will include: <ul style="list-style-type: none"> • Visual aids such as the Picture Exchange Communication System (PECS) are effective to increase child adult-initiated communication. Additional suggestions are described at www.autism.org.uk/24388 (download pdf).

CONSIDERATIONS	RECOMMENDATIONS
<p>communication and learning potentials for many.</p> <p>Language and communication difficulties include altered onset, rate and means of language acquisition and some combination of speech and receptive and expressive language problems. Expressive language includes flat intonation, rote utterances, idiosyncratic word use, low volume and/or rapid speed, as well as stereotyped speech patterns. Verbal expression can mask underlying receptive difficulties. Poor motor control can mask strong language comprehension abilities.</p> <p>Social aspects of language use, such as reciprocal conversation skills, turn-taking and understanding nonliteral language (i.e., metaphor, irony, sarcasm and humour) are characteristic difficulties.</p> <p>Loss of language skills – regression – also noted to often occur between 20 to 23 months, in 20-40% of children with ASD. This should serve as a red flag for clinicians to undertake autism screening⁷⁹.</p> <p>The social use of language, interaction and friendship skills are best learned in natural environments with skilled supports.</p> <p>While language problems persist into adulthood, adults can continue to develop communication skills lifelong. Sometimes behaviours are labelled as challenging, but the individual may have no alternative strategy, other than through problem behaviour, to express need, discomfort or intent.</p>	<ul style="list-style-type: none"> • There are new and emerging technologies to assist people who are non-verbal – e.g.: <ul style="list-style-type: none"> ▪ Pragmatic Organization Dynamic Display (PODD) ▪ Floortime ▪ Prologue2go • Video modeling can assist an individual to learn new concepts, learn to manage change, develop social communication skills and regulate their own behaviour. • Books Beyond Words offers both physicians and care providers ways to engage meaningfully in a variety of health-related situations⁸⁰. • Social Stories help teach social skills to people with autism. These stories are short descriptions of a particular situation, event or activity, which include specific information about what to expect in that situation and why^{36,37}. • Recommend resources to parents (e.g., Pivotal Response Therapy – www.autismprthelp.com/; “More Than Words”, or “Talkability”, available from Hanen Centre, www.hanen.org) • In those with greater communication impairment, ways to engage include Intensive Interaction (Phoebe Caldwell)⁸¹ <ul style="list-style-type: none"> □ Because language skills continue to develop in older children, intervention should be continued to at least the end of adolescence and beyond, if possible⁸². □ Consider referral for a joint SLP and Psychologist assessment, especially when problem behaviours arise. Problem behaviours may require a more comprehensive team approach. □ Language Regression: If some language skills were well-established and completely lost, without recovery of skills a few months after, referral for assessment and further investigations, such as an EEG during sleep and MRI/MRS brain scans, may be warranted. □ Learn what needs (and/or distress) are being communicated through the unique body language of people with ASD. Where possible, teach alternative strategies to communicate these needs and/or assist care providers to understand this communication of distress through body language.

7.4 SENSORY (AND MOTOR-RELATED) ISSUES

CONSIDERATIONS

Children & Adults:

~90% may have unusual hyper- and/or hypo-sensory sensitivities or responses in all sensory domains including: hearing, vision, tactile, olfactory, taste, proprioceptive and vestibular²⁰. These can give rise to substantial problems in their daily lives and may not always be apparent (e.g., some report sensitivities to barometric pressure)⁸³.

Certain unusual behaviours can indicate sensory hypersensitivities, e.g., fingers in ears in response to sounds, squinting, hands over eyes with flickering and buzzing fluorescent lighting; squirming to touch may indicate tactile defensiveness⁸⁴. Such sensory sensitivities and difficulties modulating sensory input can negatively impact activities of daily living and hygiene.

Over-stimulation, related to difficulties processing sensory input, especially verbal, but also other information, can give rise to sensory overload and present as:

- “meltdowns” (sudden, apparently inexplicable, acute behaviour distress and disturbance);
- autonomic nervous system (ANS) hyper-arousal states and Fight (e.g., aggression) – Flight (e.g., withdrawing) – Freeze (e.g., posturing, catatonic-like) responses^{5, 85}.

Engaging in repetitive behaviours (e.g., pacing) and “self-stimming” behaviours (e.g., rocking) may be a way to self-calm and avoid going into an ANS hyper-arousal state⁸⁶.

Hypo-sensitivities may manifest in antisocial behaviours, e.g., pressure-seeking behaviours by squeezing self or others. Unusual gait, such as tiptoe walking, kicking at surfaces and hyperactivity, may indicate proprioceptive and vestibular deficits or distortions⁸⁷.

RECOMMENDATIONS

- Refer to OT for assessment of the individual’s unique profiles of hyper- and hypo-sensory sensitivities (to light, sound, touch, as well as assessment of proprioceptive and vestibular deficits or distortions) and responses. Support implementation of a sensory diet as required^{88, 89}.
- For many individuals, the right balance of sensory stimuli is important and may be calming (e.g., deep pressure is calming, while light touch may be distressing).
- Strategies are also available to manage sensory stimuli that are overwhelming, e.g., wearing noise-muting headphones, chewelry, fidget toys or objects and bouncing on a ball (proprioceptive and vestibular).
- Recommend helpful online resources such as *Sensory Processing Disorders: Information for Families*, compiled by Michael Cheng, Child Psychiatrist, and Jennifer Boggett-Carsjens, Registered Occupational Therapist, available at www.drcheng.ca/resources/Articles/self-regulation-info_for_families.doc and e-mentalhealth.ca section www.ementalhealth.ca/Toronto/Sensory-Processing-Problems-in-Children-and-Youth/index.php?m=article&ID=8890.
- Be aware of symptoms and behaviours that have sensory underpinnings exemplified by:
 - dizziness, nausea and vomiting associated with changes in position from heightened vestibular sensitivity
 - fear and avoiding movement experiences due to immature balance reactions and poor bilateral co-ordination
 - difficulty planning oral/fine/gross motor activities due to distortions in proprioceptive feedback
 - difficulty grading the force of movements may be interpreted as aggressive behaviours

7.5 MOTOR DIFFICULTIES

CONSIDERATIONS	RECOMMENDATIONS
<p><i>Children & Adults:</i></p> <p>Motor clumsiness has often been noted in individuals with ASD (e.g., difficulty mastering complex motor tasks; “clumsy”, difficulty tying shoelaces, holding pen/pencil and writing). The aetiology of motor difficulties (e.g., fine and gross motor movement, praxis and motor planning) is not well-understood.</p> <p>Executive functioning difficulties (difficulties organizing, setting goals and completing tasks) are described by von Hahn & Bentley at www.autismconsortium.org/blog/detail/executive-functions-in-children-with-asds and by Hill⁹⁰ at www.ucd.ie/artspgs/langimp/autismexecdysf.pdf.</p>	<ul style="list-style-type: none"> □ Physical activity should be encouraged according to the individual’s interests. Sports with less demand on co-ordination and social functioning, such as bicycling, swimming, running, fitness routines or martial arts, may be preferable. □ OT, PT and BT may provide some helpful and pragmatic recommendations for fine and gross motor difficulties. □ Refer to neurologist or neuropsychiatrist if concerns remain or there is a change in gait or motor behaviours, e.g., catatonic-like behaviours or regression in skills.

CONSIDERATIONS	RECOMMENDATIONS
<p>Difficulties in starting, stopping, continuing, combining and switching motor action, speech, thought, memory and emotion are often described by people with autism and are considered by several clinicians and researchers to be associated with sensory-motor (neurobiological) differences in autism⁹¹⁻⁹³.</p> <p>Hypotonia (usually noted by physiotherapists or neurologists), may be a consequence of cerebellar or proprioceptive impairment⁹⁴.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Arrange sensory assessment by OT, as required.
8. REFLECTIONS ON EMOTIONAL NEEDS	
<p><i>Children & Adults</i></p> <p>Emotional needs may be unrecognized and neglected because of communication difficulties. A sense of belonging and relationships with significant people in their lives is critical in managing fear and feeling connected.</p> <p>Lowering high arousal levels assists communication.</p> <p>Self-narrative accounts, such as <i>The reason I jump</i> (Naoki Higashida) help us to understand better the perspective of individuals with ASD. This understanding will help inform clinicians as to the aetiology of seemingly bizarre behaviours. Additional examples of self-narratives are available at http://researchautism.net/pages/autism_autistic_asperger_spectrum/personal_accounts_autism/index.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Encourage care providers to help the individual develop supportive friendship networks. <input type="checkbox"/> Work with the individual and family to optimize opportunities for inclusion, participation and friendship. <input type="checkbox"/> Consider an intensive interaction approach to facilitate the communication of emotional needs in individuals with little or no spoken language, e.g., www.phoebecalldwell.co.uk/. <input type="checkbox"/> Recommend low arousal approach www.lowarousal.com/ (please see videos under “Resources”). <input type="checkbox"/> Alert care providers to the availability of autobiographies of people with ASD to promote acceptance of uniqueness rather than pathologizing. <input type="checkbox"/> Involvement in the expressive arts (dance, visual arts, music) may be helpful for some.
9. TRANSITIONS	
<p><i>Children & Adults:</i></p> <p>Change and transitions (e.g., change in a daily routine; starting, leaving, changing schools; caregiver turnover; age-related service changes; arrival of new or loss of a family member) are difficult for people with ASD. Even slight changes in usual routines can cause enormous stress, contributing to anxiety.</p> <p>Intentional, supported, incremental changes, using advance warning and joint problem-solving techniques, along with visual supports and rehearsal</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Educate and assist the family to navigate times of transition. <input type="checkbox"/> Anticipated change should be carefully planned well in advance of the transition. <input type="checkbox"/> Commonplace situations may be a source of unique stress and anxiety and these situations should be identified so as to anticipate, avoid where possible, or plan to manage these effectively (e.g., attention to coping strategies). <input type="checkbox"/> Planning for transition to adult community living should start in school, at the latest age 16 years and as early as 13 years. (Transition Toolkit – free, requires registration) www.autismspeaks.org/family-services/tool-kits/transition-tool-kit.

CONSIDERATIONS	RECOMMENDATIONS
<p>strategies, can help many learn to manage unexpected changes in their lives.</p> <p>Puberty and transition into adulthood are particularly vulnerable times where difficulties and psychological distress should be anticipated and managed proactively.</p> <p>Specialist services for adults are generally less available, giving rise to problems in getting health needs met as described in a recent Ontario study⁹⁵.</p>	<ul style="list-style-type: none"> □ Initiate transition of care from paediatricians to family physicians, internal medicine specialists, and adult psychiatrists. □ Discuss issues of guardianship and power-of-attorney, if indicated. □ Ensure that beneficial interdisciplinary support and care continues throughout the lifespan.
<h3>9.1 ABOUT SEXUALITY</h3>	
<p>Address issues of sexuality, including sexual and relationship education, contraception, when appropriate, protection from infections, including immunization, sexual assault, and abuse⁹⁶.</p> <p>Guidance related to this key concern in teenagers and young adults is helpfully addressed at the following selected websites:</p> <ul style="list-style-type: none"> • Davida Hartman (Educational Psychologist, Irish Health Service Executive) developed a website devoted to autism sex education: www.autismsexeducation.com/#!/about/component_14104 • Lindsey Nebeker: http://nakedbrainink.com/ 	
<h2>10. OTHER</h2>	
<p>CONSIDERATIONS</p> <p>Complementary and alternative medicine (CAM) – An ever-expanding array of complementary and alternative therapies is available, often with limited evidence of efficacy and occasionally with evidence of significant harm⁹⁶. ASD is likely comprised of a heterogeneous group of diverse neurodevelopmental disorders with varying genetic susceptibility and environmental contributors⁹⁸. As a result, some therapies may be helpful for some children, depending on the specific underlying cause of their ASD. At present, most treatments do not have specific biomarkers that are able to predict a positive response.</p> <p>Widely-reported controversy concerning MMR vaccine association with ASD has resulted in continuing reluctance by parents to vaccinate children against serious communicable diseases of measles, mumps and rubella.</p> <p>Examples of sites outlining evidence to refute these claims include:</p> <p>www.immunize.org/autism/ www.cdc.gov/vaccinesafety/Concerns/Autism/Index.html</p>	
<p>RECOMMENDATIONS</p> <ul style="list-style-type: none"> □ Families may be hesitant to discuss CAM treatment they are considering or trying. Primary care providers should approach CAM objectively and compassionately. To help evaluate risk and benefits based on available evidence, they should regularly inquire about and initiate discussion of alternative treatments. □ Assessment of the effectiveness of a therapy could be undertaken in a similar fashion to a psychopharmacological intervention, identify target symptoms or behaviours or skills, and monitor to see if these improve significantly with the therapy. Stopping and then restarting the therapy with careful observation can be informative. Asking teachers or therapists who are blind to treatment, for a brief assessment of the target symptoms/behaviours, weekly or monthly as treatments are introduced, can also be informative. □ Information for Parents: <ul style="list-style-type: none"> • http://researchautism.net/pages/autism_treatments_therapies_interventions/autism_treatments_biomedical • www.asatonline.org/ • http://autism.asu.edu/Docs/2013/Summary_of_Treatments_for_Autism-2013.pdf • www.autismspeaks.org/what-autism/treatment/complementary-treatments-autism 	

11. CAREGIVER (*) AND PROFESSIONAL (#) RESOURCES

- *# *Interacting with Autism* is a video-based website that presents the most reliable evidence-based information currently available on Autism Spectrum Disorder (ASD).
Designed primarily for those on the spectrum and their families, as well as educators and healthcare workers, to help them make informed choices about what approaches might be most effective for any specific individual diagnosed with autism.
www.interactingwithautism.com/about
- *# Autism spectrum disorder homepage at the Centers for Disease Control (CDC).
www.cdc.gov/ncbddd/autism/addm.html
- *# Autism Speaks/Autism Treatment Network (ATN) – Tool kits (20+ to date) for families and professionals to help manage issues from dental procedures to haircuts (free or may require registration).
www.autismspeaks.org/family-services/tool-kits
- *# *Autism spectrum knowledge path* at the Maternal and Child Health Library at Georgetown University.
www.mchlibrary.info/KnowledgePaths/kp_autism.html
- *# Yale seminars on autism with Fred Volkmar, Ami Klin and colleagues, 2010.
www.youtube.com/playlist?list=PL27FAF837577D180A
- # An open access site devoted to the use of research in policy and practice.
www.autismrpaphub.org/
- *# The NCMHI site offers materials, technical assistance and tools to physicians, families, and other medical and non-medical providers.
www.medicalhomeinfo.org/about/cocwd/autism.aspx
- # American Academy of Pediatrics – November 2012, vol 13, Supplement 2 reviewed management guidelines for children and youth with ASD (constipation, insomnia, and medications for attention-deficit/hyperactivity) and other key clinical concerns – free, full-text.
http://pediatrics.aappublications.org/content/130/Supplement_2.toc
- *# National Autistic Society – Health.
www.autism.org.uk/working-with/health
- # *Autism in general practice* – Royal College of General Practitioners, UK – fee-based online training module.
www.rcgp.org.uk/courses-and-events/online-learning/ole/autism-in-general-practice.aspx
- *# *Surveillance and screening for ASDs in very young children: physician toolkit, 2008*.
www.autismcentral.ca/new/images/physician_toolkit_en_web.pdf
- *# Autism Central – Canada – Resources in each province/territory, nationwide and local/regional (Montreal, Ottawa, Toronto).
www.autismcentral.ca/new/index.php/en/resources/provincial
www.autismcentral.ca/new/index.php/en/resources/local-and-regional
- *# The Gray Center – Carol Gray created *Social Stories* in 1991 to help teach social skills to people with autism. These stories are short descriptions of a particular situation, event or activity, which include specific information about what to expect in that situation and why.
<http://carolgraysocialstories.com/>
- Key autism-related organizations offering a multitude of resources for parents, caregivers and professionals.
www.autismspeaks.ca/
www.autism.net/
www.autismsocietycanada.ca
www.togetherforautism.ca
www.autismontario.ca
www.autismcanada.org
www.autism.ca
www.cairn-site.com/en/links.html
www.autismspeaks.org/

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