

Autism Spectrum Disorder in the Northwest Territories

ALL YOU NEED TO KNOW
BEFORE A DIAGNOSIS





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A recent report completed by the Public Health Agency of Canada showed that 1 out of 66 children aged 5-17 in Canada are diagnosed with Autism Spectrum Disorder (ASD).

If you're reading this document, perhaps you're concerned that a family member, or someone that you care for, has ASD. Often, caregivers aren't sure if they should pursue an official diagnosis. Many families don't want their loved one to be given a "label."

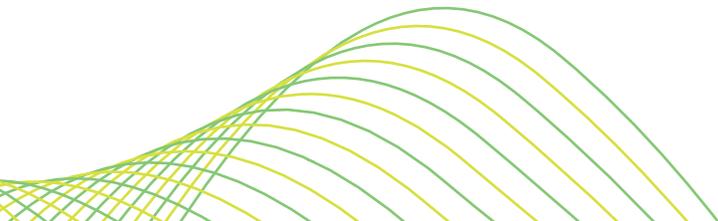
While making your decision, here are some things that you should consider:

- 1. If you receive a diagnosis, you (the parents or individuals) are in control of who knows about the diagnosis. Diagnostic professionals will inform you and the referring physician (if applicable), and no one else. Going forward, your written permission is required before sharing the diagnosis.*
- 2. Professionals report that many children are relieved to know of their diagnosis. Often, children can tell when they're considered "different," or when they struggle at things. Finding out "why" can be reassuring to a child.*
- 3. A diagnosis document gives you a lot of information about your child and includes ways you can help. It contains information about many different developmental domains, including: speech, social development, physical development, and others.*

It's important to understand that testing for autism is a lengthy, arduous and often stressful process. It shouldn't be done "just in case." After testing, it's common for the family to be exhausted. They may need to take a few days to rest and process the experience.

Don't forget that, above all, your child or loved one is a unique individual. If you get a diagnosis of autism or something else, your loved one will always be more than a diagnosis to you. Continue to think of them as a person first. The diagnosis is merely a description of some aspects of your special person.

For those who do have serious concerns about whether or not autism may be present, we want to help make the assessment process clear and accessible.



General Information

You may have heard terms like Autism, Asperger's Syndrome, or Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). These are now all referred to as Autism Spectrum Disorder (ASD).

What is Autism Spectrum Disorder (ASD)?

Autism Spectrum Disorder (ASD) is a complex, lifelong neurological disorder that affects how the brain develops and leads to varying levels of developmental delay. It is currently the most commonly diagnosed neurological disorder in Canada. ASD is equally prevalent across all ethnic, racial, and socio-economic groups. ASD is diagnosed approximately 4 times more often in males than in females.

It is called a spectrum disorder because there is a wide range of symptoms and degrees of severity. Every person with ASD has their own unique strengths and challenges. The degree to which each individual is developmentally delayed will vary from one person to the next. A spectrum means that no two individuals with ASD are the same and that an individual with ASD is dynamic. The needs and skills of the individual will evolve across the spectrum over time.

People with ASD can:

- have difficulty with social communication
- have limited, repetitive patterns of behaviours and interests
- struggle with sensory processing, sensing the passage of time, and executive functioning skills (Appendix D)
- sometimes also have autoimmune conditions, seizure disorders, asthma, eczema, migraines, allergies and ear infections

They may also have the following strengths:

- be detail-oriented in sensory processing (how messages are received from the various senses by the nervous system and then responded to)
- have exceptional memories
- above average visuo-spatial skills (involving visual images and patterns)
- strong non-verbal reasoning skills (understand, analyze and solve problems visually rather than verbally)
- a heightened interest in and strong skills in computers and other technology

- an ability to thrive in organized and structured environments

ASD is a life-long diagnosis. With diagnosis and effective support many people who live with ASD gain many skills and abilities, make important contributions to their community and live fulfilling, happy lives.

Signs of ASD

If your child is not reaching developmental milestones, it's important to visit a doctor to discuss your concerns. Not all developmental delays mean a child has ASD, and a professional can recommend which path to take. ASD is defined by a certain set of behaviours. There is no definitive blood test, brain scan or other medical test for autism. Children with ASD can have any combination of the behaviours in any amount. Even if not all signs are present, a child still may have ASD.

If you have any concerns do not ignore them, ask a professional. Some "red flags" that should be explored further are listed on the Autism Speaks website and indicated below – www.autismspeaks.ca

The following signs may indicate that your baby or toddler is at risk for ASD:

- No big smiles or other warm, joyful expressions by 6 months or thereafter
- No back-and-forth sharing of sounds, smiles or other facial expressions by 9 months
- No babbling by 12 months
- No back-and-forth gestures such as pointing, showing, reaching or waving by 12 months
- No words by 16 months
- No meaningful 2-word phrases (not including imitating or repeating) by 24 months
- Any loss of speech, babbling or social skills at any age
- Extreme avoidance to touch
- Extreme sensitivity to light, sound or other sensory input

At any age the following signs may indicate an individual has ASD:

- Avoiding eye contact and preferring to be alone
- Struggles with understanding other people's feelings
- Remains non-verbal or has delayed language development
- Repeats words or phrases over and over
- Gets upset by minor changes in routine or surroundings
- Has highly restricted interests
- Performs repetitive behaviours such as flapping, rocking or spinning
- Has unusual and often intense reactions to sounds, smells, tastes, textures, lights and/or colors

The signs listed above are a few signs of ASD. Autism Speaks also offers online ASD screening tools on their website. **PLEASE** remember that a screen is **NOT** a diagnosis! It is simply a tool that can help you to decide if an assessment might be a good idea.

Initial Steps

If you suspect your child may have Autism Spectrum Disorder (ASD), or suspect a developmental delay or learning disability it is important that they are seen and assessed by a professional in order for them to receive proper support. ASD can be diagnosed accurately beginning at age two. An earlier diagnosis and assessment leads to better outcomes throughout life. While an official diagnosis of ASD may not be a requirement for starting to access some services in NWT, having a diagnosis can open doors to many more types of support and more rapid implementation of services that can support your child's development. It is also important to note that the majority of services outside of the NWT, including national programs and funding require an official diagnosis.

If you live in Yellowknife:

The first step is to see a primary care physician or allied health professional to voice your concerns. They can then make a referral to the Stanton Child Development Team (CDT).

The professionals that can make this referral may be an Occupational Therapist (OT), Physiotherapist (PT), Speech-Language Pathologist (SLP), Audiologist, Psychologist, Nurse or Doctor.

Once a referral has been made to the Stanton Child Development Team the Coordinator will schedule an appointment for your family with a Paediatrician. The Paediatrician will meet with you and your child to discuss your concerns, to do some basic screening tests and then if appropriate will make a further referral for further developmental support and/or to a diagnostic specialist. This referral will most likely be to the Glenrose Autism Centre in Edmonton, Alberta. Staff from Glenrose will then contact you to arrange the visit and facilitate an assessment of your child.

In other NWT communities:

In a community, the first person you will need to meet with is the Nurse in Charge at your local health centre. You will discuss the concerns that you have about your child and their development and request a referral to see a Paediatrician. You will then be contacted regarding an appointment with the Paediatrician which will either happen in a regional centre or in Yellowknife.

The Paediatrician will meet with you and your child to discuss your concerns, to do some basic screening tests and then will make a further referral for further developmental support and/or to a diagnostic specialist. This referral will most likely be to the Glenrose Autism Centre in Edmonton, Alberta. Staff from Glenrose will then contact you to arrange the visit and facilitate an assessment of your child.

Your Role

You will play an important role in your child's diagnosis process. At times you may come across medical professionals who are not familiar with or a specialist in Autism Spectrum Disorder. In these situations, you may have to advocate for your child and be persistent about getting a referral to a specialist.

A resource that may be helpful is the "Autism Physician's Handbook" produced by Autism Canada in 2015. This resource provides information about developmental milestones and discussing your concerns with medical professionals. This resource is available at: www.autismcanada.org/wp-content/uploads/2015/11/PhysicianHandbook_2015.pdf

Referral and advocacy support can be obtained at the NWT Disabilities Council or NWT Autism Society (contact information on page 9 or 11).

Diagnostic Process

To diagnose ASD, several health professionals are needed. It's not a quick diagnosis involving just you and your doctor. Typically, assessments are completed by a team that includes a pediatrician, a psychologist, a speech language pathologist, and an occupational therapist. Assessments may vary by the age and ability of the child.

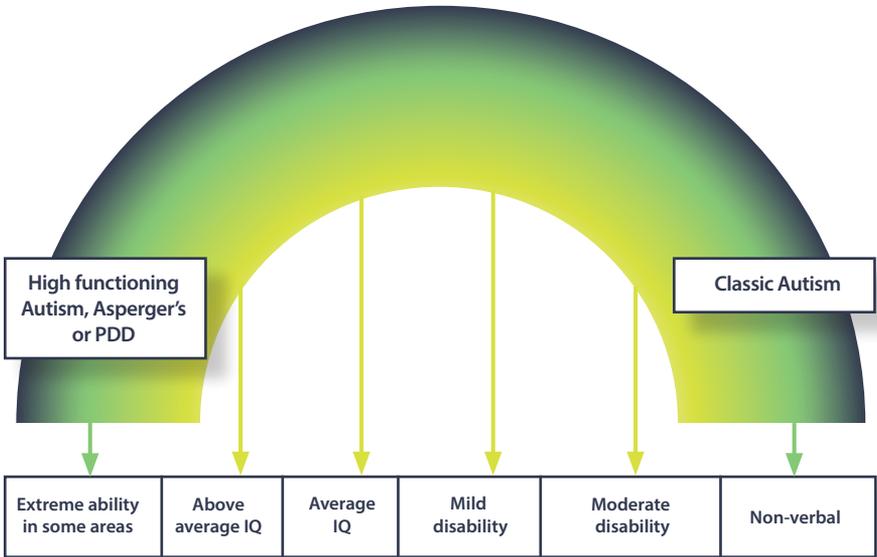
As a parent or caregiver, you will travel with your child to the diagnostic centre where your child will be assessed. Your child will be assessed in all areas of development in order to gain a full picture of them. You may be asked to fill in questionnaires/checklists and/or complete an interview so the professionals can gain a bigger picture of your child's development and behaviour. This process might seem overwhelming but it helps ensure that your child receives a correct diagnosis, and accurate recommendations and therapy options. If your child does not receive a positive diagnosis for ASD through this process it is still likely that you will learn valuable information about them and how to support their development.

Some parents are concerned when their child doesn't "act themselves" during diagnostic tests, especially when travel to unfamiliar surroundings is part of the process. Please be assured that the professional team at Glenrose is aware of the stress involved with travelling south for medical appointments and will accommodate for this.

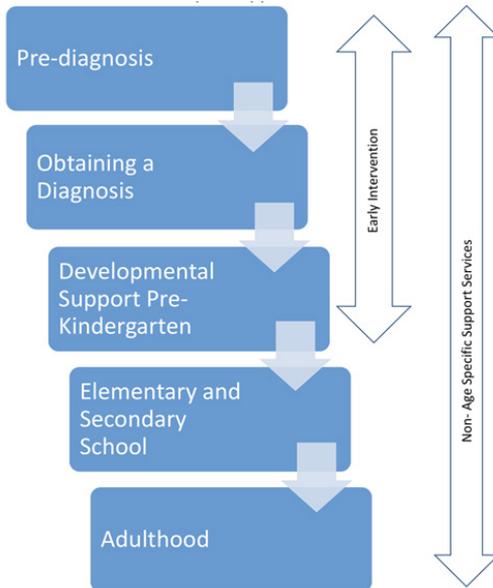
They also understand that children with ASD especially do not perform as well in different environments and when there is a lot of change. If you notice this happening with your child, you can mention it to the professionals who are doing the assessments.

Following you will find a graphic that illustrates how autism presents in many different ways. This graphic, while helpful, in some ways is inaccurate. Instead of displaying a continuous spectrum with "high functioning" at one end and "lower functioning" at the other, it would be more accurate to have a circle with different combinations of "high" and "low" for each unique person.

Autism is a Spectrum



Breakdown of Lifespan Support in the NWT



Early Intervention: When to Start Accessing Supports

The period from 0-4 years is a critical period of development for a child. During this period of time a child experiences the fastest rates of learning and growth in all domains from language, motor, communication, emotion and socialization. It is important to act as early as possible to access support and begin different developmental therapy to take advantage of this critical period of growth. The earlier developmental support begins, the more effective it is for the child and the greater the impact will be later in life; this is especially true for a child with ASD.

It can take months and even years to obtain an official diagnosis of ASD. The time frame can vary greatly depending on what services are available in your community. However, you do not have to wait until you receive a diagnosis to begin to access services. When you notice any delay in your child's development talk to a Nurse in Charge or a doctor about getting a referral to specific services that can support the development of your child. Different services that you can talk about accessing include:

- Stanton Childhood Development Team (CDT)
- Occupational Therapy (OT)
- Speech Language Pathology (SLP)
- Physical Therapy (PT)
- Audiology
- Early Childhood Intervention Program

The following pages will present agencies and services available to support you through the diagnostic process.

Glenrose Rehabilitation Hospital

About: Diagnoses are performed at Glenrose Rehabilitation Hospital in Edmonton. These diagnostic processes take a few days once you arrive at the centre. Your child will be seen by a variety of professionals for a complete team diagnosis.

Referrals can be made by:

- A physician
- A pediatrician

Glenrose Rehabilitation Hospital requires that your child have previous assessments completed before the appointment. These may include:

occupational therapy, speech language pathology, physiotherapy, psychology. Talk to your physician or pediatrician about having these assessments completed.

Cost: The diagnosis is free. Some travel costs are covered by the Government of the Northwest Territories, as long as you do not have similar coverage through an employer or other program. Please refer to the Medical Travel page on the Government website at <https://www.hss.gov.nt.ca/en/services/medical-travel>. A medical travel guide and travel forms can also be downloaded from this website.

Wait time: Varies, but can be 18 – 24 months after a referral is sent. Once the referral is made you will be provided with a better estimated wait time.

***A note of caution:** Many studies have indicated that when children on the spectrum are away from their familiar surroundings (which would be the case while travelling), they tend not to perform accurately for diagnostic tests. Some parents do not mind this, and many others find this fact quite distressing. Whatever your outlook, it is important to keep this possibility in mind.

Contact Information:

10230 111 Avenue NW, Edmonton, AB, T5G 0B7

Phone: (780) 735-6134

Other Methods

Some families take other pathways to access ASD diagnostics for many reasons including shorter waitlists or knowing someone who provides ASD diagnosis elsewhere. These routes include both private and publicly funded diagnoses in Canada or in the United States. These diagnosis pathways are not organized through anyone in the NWT and therefore parents and caregivers seek out these avenues on their own.

It is important that if you decide to take a route to diagnosis that is not listed above that you are aware that not all diagnoses are equal in cost or quality. Although many centres may offer a diagnosis by one single professional, a team diagnosis approach is the gold standard.

Before you access services, it is important to assess the quality of the diagnosis as well as the potential costs. Receiving a diagnosis is only one small aspect of the assessment. A team diagnosis will include information about your child as well as recommendations for treatment that are valuable. The more detailed that the information from the

assessment is, the more specific service provision can be for your child. The NWT Disabilities Council, as well as your health care providers should be able to provide you guidance on whether a different diagnosis pathway is acceptable.

NWT Disabilities Council

About: The Council supports any person living with a disability in any community in the Northwest Territories.

Vision: The NWT Disabilities Council envisions that all individuals living with disability have equal access to full citizenship, as guaranteed under the Charter of Rights and Freedoms, toward the achievement of a self-determined, fulfilling, and meaningful life.

Mission: The NWT Disabilities Council exists to educate, advocate, and support the self-determination of all individuals with disabilities.

Contact Information:

Suite 116, 5102 50th Avenue, Yellowknife, NT, X1A 3S8

Phone: (867) 873-8230 or Toll Free: 1 (800) 491-8885

admin@nwtcdc.net

Available programs and services including contact information:

Information, Referral and Support Coordinator:

- Providing information about disabilities and related services currently available in the NWT
- Linking clients with existing services
- Assisting clients to apply for disability related programs such as CPP Disability, Private Long Term Disability, Income Support and Learning Supports for Persons with Disabilities
- Attending meetings or appeals related to disability issues as a neutral third party or advocate if required
- Writing letters of support
- Researching programs that you may qualify for and providing a referral if required

Phone: 1 (800) 491-8885 or (867) 873-8230

Email: info@nwtcdc.net

Website: <https://www.nwtcdc.net/information-referral-and-support>

Hay River Committee for Persons with Disabilities

Phone: (867) 875-4448

Email: hrcpd@northwestel.net

ECIP Program: The Early Childhood Intervention Program (ECIP) provides early intervention services for children between birth and school entry who have disabilities and/or development delays. Our Early Childhood Intervention Coordinator and Workers partner with parents/caregivers and other professionals to provide optimum 1:1 support for each child enrolled in this program based on individual needs. Entry into the ECIP is granted based on three criteria – level of need, age, and order of referral/request of the service. These services are provided until a child begins kindergarten.

Phone: 1 (800) 491-8885 or (867) 873-8230

Email: csm@nwtcdc.net

Website: <https://www.nwtcdc.net/early-childhood-intervention>

Snoezelen Room: Snoezelen or controlled multisensory environment (MSE) is a therapy for people with autism and other developmental disabilities. It consists of placing the person in a soothing and stimulating environment, called the “Snoezelen room”. These rooms are specially designed to deliver stimuli to various senses, using lighting effects, color, sounds, music, scents, etc.

Phone: 1 (800) 491-8885 or (867) 873-8230

Email: csm@nwtcdc.net

Website: <https://www.nwtcdc.net/early-childhood-intervention>

Community Outreach: Our Community Outreach Program focuses on traveling to communities and developing relationships with people across the NWT. Community Outreach also aids in projects or awareness events throughout the NWT.

Phone: 1 (800) 491-8885 or (867) 873-8230

Email: info@nwtcdc.net

Website: <https://www.nwtcdc.net/information-referral-and-support>

Autism Society NWT

About: Autism Society NWT is committed to giving caregivers the tools they need to better support individuals with ASD in their communities.

Vision: Autism Society NWT envisions families and individuals, living with autism spectrum disorder (ASD), achieving their full potential within THEIR home community.

Mission: Autism Society NWT achieves this vision through advocacy and empowerment, educational resources and system navigation, and promoting safety/awareness for the individual, family and community.

Contact Information:

5204 54th Avenue, Yellowknife, NT, X1A 1W8

Phone: (867) 446-0985

Email: president@nwtautismsociety.org

Website: <https://www.nwtautismsociety.org/>

Available programs and services:

Navigating Autism Across the Lifespan – Guidebook: This toolkit gives caregivers an opportunity to reflect on the individual being supported and adapt resources provided to best suit his or her needs. Resources in this toolkit include: background information on ASD and wandering and creating an Emergency Prevention Plan.

Website: <https://www.nwtautismsociety.org/resources>

Autism Wandering Emergency and Prevention Plan - Caregiver Toolkit:

This resource is intended for parents, caregivers and other vested partners interested in learning more about what supports are available to people with ASD across the lifespan in the Northwest Territories. It is the mission of the Autism Society NWT that all individuals with ASD are able to reach their full potential and have universal access to the services they require.

Website: <https://www.nwtautismsociety.org/resources>

Government of the Northwest Territories

P.O. Box 130, Yellowknife, NT X1A 2L9
Switchboard: (867) 767-9000

Available programs and services:

Speech Language Pathology: Speech-Language Pathology (SLP) is a rehabilitation service that provides speech and language therapy to people with communication disorders. Our Speech Language Pathologists provide a full range of SLP services, including the identification, evaluation, diagnosis, treatment, and management of speech delay, language development and communication disorders.

Location: Stanton Medical Centre, 419 Byrne Road,
Yellowknife, NT, X1A 2N1

Phone: (867) 767-9299

Email: sth_rehab@gov.nt.ca

Website: <https://www.nthssa.ca/en/services/rehabilitation-services/speech-language-pathology>

Occupational Therapy: Occupational Therapists are therapists that help to solve problems that are interfering with an individual's ability to do daily activities or occupations that are important to them. These problems may be the result of an injury, disease, developmental delays, congenital disabilities, or environment.

Location: Centre Square Tower, 2nd Floor, 5022 – 49th Street, P.O. Box 10,
Yellowknife, NT, X1A 2N1

Phone: (867) 767-9299

Email: sth_rehab@gov.nt.ca

Website: <https://www.nthssa.ca/en/services/rehabilitation-services/occupational-therapy>

Occupational Therapy (Pediatrics):

Location: Stanton Medical Centre, 419 Byrne Rd.,
Yellowknife, NT, X1A 2N1

Phone: (867) 669-3130

Email: sth_rehab@gov.nt.ca

Website: <https://www.nthssa.ca/en/services/rehabilitation-services/occupational-therapy>

Early Childhood Program – Early Childhood Development: The Early Childhood Program supports early learning and child care programs for children 0-11 years of age under the Child Day Care Act. Early learning and child care programs are delivered in a variety of settings in the NWT including, child day care centres and family day homes. These can be in the form of full and part time early childhood education programs, preschools, nursery schools and after school/out-of-school programs. These programs provide play-based exploratory environments that support children’s development and where required, enable parents to access employment or training opportunities.

Location: Education, Culture and Employment, Early Childhood and School Services, P.O. Box 1320, Yellowknife, NT, X1A 2L9

Phone: (867) 767-9354

Website: <https://www.ece.gov.nt.ca/en/services/early-childhood-development/early-childhood-program>

Health and Social Services System Navigator: The Navigator helps you with your questions and concerns as you access services provided by the Health and Social Services system. The Navigator can help by:

- Resolving concerns
- Providing information on all health and social services in the NWT
- Connecting you with your health and social services provider
- Helping you find commonly used forms

Phone: 1 (855) 846-9601

Email: HSS_Navigator@gov.nt.ca

Programs and Services for Persons with Disabilities Inventory: The inventory provides a list of programs and services available for persons with disabilities and their caregivers through GNWT Departments, agencies, and those delivered through our partners. The inventory is a tool that can be used to help persons with disabilities and their caregivers maximize their use of the supports available in the NWT.

Email: hsscommunications@gov.nt.ca

Website: www.hss.gov.nt.ca/sites/www.hss.gov.nt.ca/files/resources/gnwt-disabilities-inventory.pdf

YWCA NWT

Box 1679, Yellowknife, NT, X1A 2P3

Phone: (867) 920-2777 or 1 (866) 223-7775 (crisis line)

Email: giving@ywcan7wt.ca

Mission: To create a safe Northern society for women and families to reach their full potential.

Available programs and services including contact information:

Family Centre – Parent Support: The YWCA Family Centre offers parents support to address the challenges of parenting in an isolated community and parenting children with unique social, emotional, and physical needs.

Location: 4902 Franklin Ave., Yellowknife, NT, X1A 0C1

Phone: (867) 920-2777

Email: giving@ywcanwt.ca

Website: <https://www.ywcanwt.ca/family-centre>

Family Centre – Toy Lending Library: This amazing FREE resource allows families to borrow toys, books and games for free! Keep the borrowed items for 2 weeks and we'll send you a reminder email when you need to return them.

Location: 4902 Franklin Ave. Yellowknife, NT, X1A 0C1

Phone: (867) 920-2777

Email: giving@ywcanwt.ca

Website: <https://www.ywcanwt.ca/family-centre>

Family Centre – Drop-in: YWCA NWT Family Centre is for children up to age 5. We focus on mental and physical wellness for every family. Our program is intended to serve families and parents in need of a space to engage with their children through play and learning. We go on fun community outings and provide two snacks daily.

Location: 4902 Franklin Ave. Yellowknife, NT, X1A 0C1

Phone: (867) 920-2777

Email: giving@ywcanwt.ca

Website: <https://www.ywcanwt.ca/family-centre>

AIDE (Autism and/or Intellectual Disability Knowledge Exchange Network) Canada

Website: www.aidecanada.ca

AIDE Canada aims to connect Canadians nationwide to credible, reliable, and evidence-informed resources that are geared specifically towards the autism and/or intellectual disability community.

Available programs and services including contact information:

Asset Map: This free tool allows individuals across Canada to look up nearby resources and services by location, needs (e.g.: behavioral supports, community inclusion, financial help, etc.), journey (e.g.: diagnosis, adulthood, seniors), and service types. New assets are being added all the time, so check back often!

Website: <https://aidecanada.ca/locate/asset-maps>

Library: The AIDE Canada library is a new and growing collection of over 3000 online and physical lending resources related to autism, intellectual disability, and developmental disabilities. The library is free and also provides a "Borrow by Mail" service to all Canadians.

Location: The Pacific Autism Family Network, 3688 Cessna Drive, Richmond, BC, V7B 1C7

Phone: 604-207-1980, extension 2006

Email: library@aidecanada.ca

Website: <https://library.aidecanada.ca/>

Live Chat: If you would like assistance accessing tools or resources on the AIDE website, or being directed to services in your area, you can chat with AIDE staff between 9AM Atlantic to 5PM Pacific, Monday - Friday. If no one is available to chat, you can fill out an email contact form.

Website: <https://aidecanada.ca/connect/chat-with-us>

Toolkits: AIDE Canada has created almost 200 free toolkits and infographics so far on various topics related to autism and/or intellectual disabilities and resources (e.g.: how to access funding across Canada, benefits of certain therapies, information on ASD/ID's, etc.).

Website: <https://aidecanada.ca/learn>

Webinars: AIDE frequently hosts free webinars with its 6 regional hubs (Miriam Foundation in Quebec, Autism Calgary, Autism Yukon, Autism Ontario, Autism Nova Scotia and the Pacific Autism Family Network in British Columbia). All events are recorded and available online for future reference.

Website: <https://aidecanada.ca/connect/events>

Is it possible to get diagnosis costs covered?

Medical Travel

“The Government of the Northwest Territories will provide medical travel benefits to eligible persons in the NWT who must travel in order to access necessary and appropriate insured health services. To be eligible for this benefit, travel must originate in the NWT and service must not be available within the resident's home community. Furthermore, the medical referral from the resident's home community must be to the nearest insured centre that offers the required treatment.

The medical travel benefit extends only to individuals who do not have similar coverage through an employer or some other program. The benefit provides for return airfare, inter-facility ambulance services on emergency medical evacuations, and limited support for meals, accommodation and ground transportation.

Medical Travel will make all arrangements for travel once the medical referral is received and travel is approved. Clients may choose to make their own arrangements and claim their expenses after the fact.

Clients who choose to submit a claim must contact Medical Travel for guidance. The staff at Medical Travel will provide the proper claim forms and verify the current daily rates for meals, accommodations and transportation to and from appointments.”

<https://www.hss.gov.nt.ca/en/services/medical-travel>

More information can be found in the Medical Travel Guide:
<https://www.nthssa.ca/sites/nthssa/files/resources/medical-travel-guide-final.pdf>

Private Insurance

If you choose to get a diagnosis through a private service provider, your extended health insurance may cover some of the cost. Contact your provider directly to ask about coverage.

Some people choose to get insurance to help with this expense. There are many health insurance providers, the three below are a few of the most common.

Canada Life (formerly known as Great-West Life)

Phone Number: 1 (800) 957-9777

Website: www.canadalife.com

Manulife

Phone Number: 1 (888) 790-4387

Website: www.manulife.ca

Sun Life

Phone Number: 1 (877) 786-5433

Website: www.sunlife.ca

Jordan's Principle

Jordan's Principle aims to ensure all First Nations children are able to access health, social and educational services. Under Jordan's Principle, private diagnosis and treatment may be covered. Services covered under Jordan's Principle include, but are not limited to, respite care, speech therapy, schooling supports, medical equipment and mental health services.

Contact within Canada

For more information, including how to access Jordan's Principle or submit a request visit <https://www.sac-isc.gc.ca/eng/1568396042341/1568396159824>

Phone: 1 (855) 572-4453 (available 24 hours a day, 7 days a week)

Contact within the NWT

Phone: 1 (866) 848-5846

Email: sac.principedejordanrn-nrjordanprinciple.isc@canada.ca

It is recommended that you prepare the following prior to making contact:

- your child's name and birthday
- proof your child is eligible (First Nations or Inuit)
- a description of their needs
- what product or service they need
- what you think the cost will be
- how often the support is going to be needed

Ronald McDonald House

If your child is receiving an assessment outside of the NWT, you may be able to stay at the Ronald McDonald House to help reduce the cost of travelling.

Website: <https://rmhcalberta.org/stay/edmonton-house/>

What results can you expect?

Going into an assessment, it is important to know your child may not receive a diagnosis of ASD. However, there is still valuable information that may be learned from the diagnosis process, including the possibility of different diagnoses (sensory processing disorder or a learning disability, for example). The professionals involved will help to reveal information that is important for services your child may need later on.

If your child does receive a diagnosis of ASD they will receive a diagnosis based on the severity level of ASD ranging from Level 1: 'Requiring Support' to Level 3: 'Requiring Substantial Support.' For more information about the different severity levels of ASD take a look at the Diagnostic Criteria Page on the Autism Speaks website:

<https://www.autismspeaks.org/autism-diagnosis-criteria-dsm-5>.

Remember, a child can display more symptoms in some domains and less in others. It's also encouraging to note that a child is not "stuck" in a level. With support, many children with ASD will make enough progress to change levels. Also, some children may require more support for temporary periods that include transitions and/or increased stress loads.

It is important for you to keep all of the papers and assessments that are given to you in one file in a safe location at home. This will help you when you access services in the future. If you choose to share them with another professional such as a teacher, always give them a photocopy and keep the original. These assessments are also important "baseline" assessments to which future assessments may be compared.

Whom do you have to share the results with?

Once a diagnosis is made the results are only shared with parents or caregivers and the physician who made the referral. As a parent or caregiver you can choose to tell people about the diagnosis or choose not to do so. In school, your child will still qualify for support without disclosing the diagnosis. However, you may want to let individuals from the Department of Education know about the diagnosis so your child receives more specific support in the school setting. It is likely that you will be requested to disclose a diagnosis to any therapeutic services you access as well so that they are better able to meet your child's needs. Your doctor or school (or any other individual) is required by law to obtain your signed permission before disclosing a diagnosis to any other professionals.

As your child grows, be sure to also consult your child and to give your child a voice when making disclosure decisions.

What next?

Now that you have a diagnosis, what next? Research shows that the earlier a child receives a diagnosis and begins therapies, the better the long-term outcomes for that child. You may want to look at the companion document to this document: ***We Have an ASD Diagnosis: Now What?***

In 2017, a parent named Ronnie Koenig wrote a great article titled, "Things I wish I'd known about having a child with autism." (<https://www.today.com/%20series/things-i-wish-i-knew/things-i-wish-i-d-known-about-having-child-%20autism-t110323>).

This article is worth reading.

Here is a summary of her main points:

1. Don't worry about what other people are thinking.
2. When it comes to autism, one size doesn't fit all.
3. Medical issues may be involved.
4. Be grateful for the strong connection you and your child will forge.
5. Focus on independence and communication.
6. Trust your instincts, even with a doctor's advice.
7. Seek out a mentor.
8. Watch for depression in older children and young adults.
9. As you change your expectations, the world will grow.
10. Celebrate all of your child's achievements.

Remember, there are many NWT families who have forged the way for you. Although every individual with ASD is unique, and every situation is unique, there are many compassionate individuals who would love to share in your journey if this is something that you feel would help you.



Appendix A:

NWT Indigenous Government Contact Information

If you or the person you are caring for with ASD is a citizen of an NWT First Nation, there may be other supports or services available. Contact your First Nation for more information.

Akaiicho Dene First Nations

Mail: P.O. Box 1768, Yellowknife, NT, X1A 2P3

Phone: (867) 394-3313

Akaiicho Territory Government

Mail: General Delivery, Fort Resolution, NT, X0E 0M0

Phone: (867) 394-3313

Decho First Nations

Mail: P.O. Box 89, Fort Simpson, NT, X0E 0N0

Phone: (867) 695-2355

Gwich'in Tribal Council

Mail: P.O. Box 1509, Inuvik, NT, X0E 0T0

Phone: (867) 777-7900

Inuvialuit Regional Corporation

Mail: Bag Service 21, Inuvik, NT, X0E 0T0

Phone: (867) 777-7000

Northern Territory Métis Nation

Mail: P.O. Box 720, Fort Smith, NT, X0E 0P0

Phone: (867) 872-2770

Sahtu Secretariat Incorporated

Mail: P.O. Box 155, Déljine, NT, X1A 0G0

Phone: (867) 589-4719

Tłjicho Government

Mail: P.O. Box 412, Behchokò, NT, X0E 0Y0

Phone: (867) 392-6381 ext. 1302

Community Governments

Acho Dene Koe First Nation

Mail: General Delivery, Fort Liard, NT, X0G A0A

Phone: (867) 770-4571 Ext. 265

Déljine Got'ineḡ Government

Mail: P.O. Box 156, Déljine, NT, X1A 0G0

Phone: (867) 589-8100

Kát'odeeche First Nation

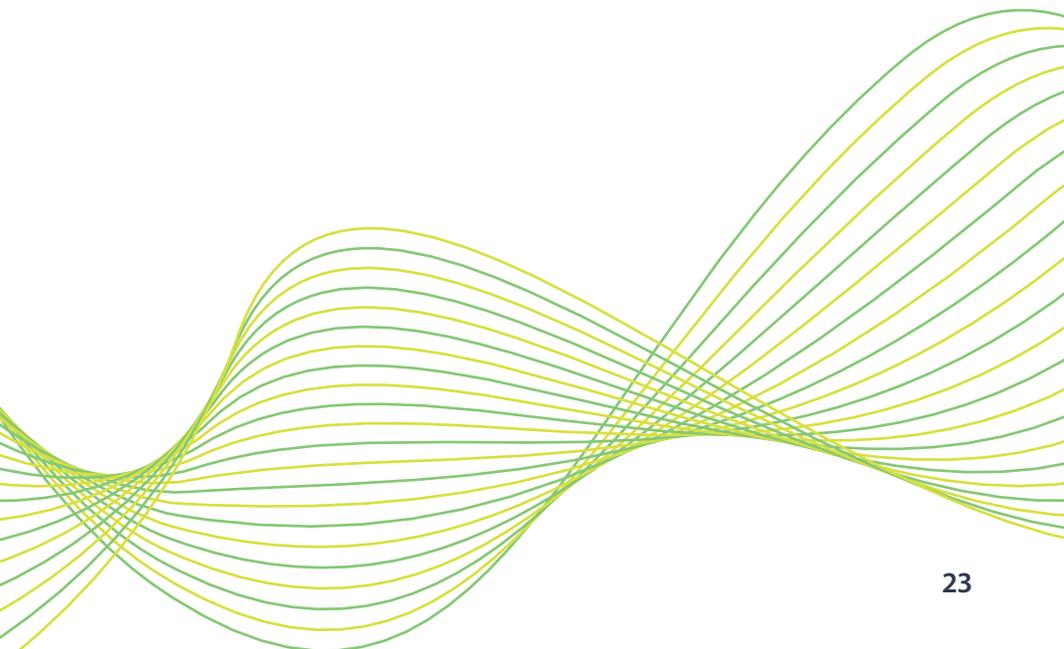
Mail: P.O. Box 3060, Hay River, NT, X0E 1G4

Phone: (867) 874-6701

Salt River First Nation

Mail: P.O. Box 960, Fort Smith, NT, X0E 0P0

Phone: (867) 872-2986



Appendix B:

Community Nursing Services Contact Information

Aklavik

Phone: (867) 978-2516

Fax: 867-978-2160

Address: 2 Airport Road, P.O. Box 114, Aklavik, NT X0E 0A0

Behchokò

Phone: (867) 392-6075

Fax: 867-392-6612

Address: Bag #5, Behchokò, NT X0E 0Y0

Colville Lake

Phone: (867) 709-2409

Fax: 867-709-2504

Address: General Delivery, Colville Lake, NT X0E 1L0

Déliné

Phone: (867) 589-5555

Fax: 867-589-5570

Address: General Delivery, Déliné, NT X0E 0G0

Fort Good Hope

Phone: (867) 598-3333

Fax: 867-598-2605

Address: P.O. Box 9, Fort Good Hope, NT X0E 0H0

Fort Liard

Phone: (867) 770-4301

Fax: 867-770-3235

Address: General Delivery, Fort Liard, NT X0G 0A0

Fort McPherson

Phone: (867) 952-2586

Fax: 867-952-2620

Address: P.O. Box 56, Fort McPherson, NT X0E 0J0

Fort Providence

Phone: (867) 699-4311

Fax: 867-699-3811

Address: P.O. Box 260, Fort Providence, NT X0E 0L0

Fort Resolution

Phone: (867) 394-4511

Fax: 867-394-3117

Address: P.O. Box 1997, Fort Resolution, NT X0E 0M0

Fort Simpson

Phone: (867) 695-7000

Fax: 867-695-7017

Address: P.O. Box 246, Fort Simpson, NT X0E 0N0

Fort Smith

Medical Clinic

Phone: (867) 872-6205

Fax: 867-872-6260

Address: P.O. Box 1080, Fort Smith, NT X0E 0P0

Health Centre (Public Health)

Phone: (867) 872-6203

Fax: 867-872-6251

Address: 41 Breyne Street, P.O. Box 1080, Fort Smith, NT X0E 0P0

Gamètì

Phone: (867) 997-3141

Fax: 867-997-3045

Address: General Delivery, Gamètì, NT X0E 1R0

Hay River

Regional Health Centre

Phone: (867) 874-8000

Fax: 867-874-8016

Address: 37911 MacKenzie Highway, Hay River, NT X0E 0R6

Medical Clinic

Phone: (867) 874-8100

Fax: 867-874-8099

Address: 37911 MacKenzie Highway, Hay River, NT X0E 0R6

Inuvik

Inuvik Regional Hospital

Phone: (867) 777-8000

Fax: 867-777-8054

Address: Bag Service #2, 285 MacKenzie Rd, Inuvik, NT X0E 0T0

Public Health

Phone: (867) 777-7246

Fax: 867-777-8054

Address: 106 Veterans Way (1st Floor)

Jean Marie River

Phone: (867) 809-2900

Fax: 867-809-2902

Address: General Delivery, Jean Marie River, NT X0E 0N0

Łutselk'e

Phone: (867) 370-3115

Fax: 867-370-3022

Address: P.O. Box 56, Łutselk'e, NT X0E 1A0

Nahanni Butte

Phone: (867) 602-2203

Fax: 867-602-2021

Address: General Delivery, Nahanni Butte, NT X0E 0N0

Norman Wells

Phone: (867) 587-3333

Fax: 867-587-2934

Address: 26 Woodland Avenue, P.O. Box 340, Norman Wells, NT X0E 0V0

Paulatuk

Phone: (867) 580-3231

Fax: 867-580-3300

Address: General Delivery, Paulatuk, NT X0E 1N0

Sachs Harbour

Phone: (867) 690-4181

Fax: 867-690-3802

Address: General Delivery, Sachs Harbour, NT X0E 0Z0

Sambaa K'e

Phone: (867) 206-2838

Fax: 867-206-2024

Address: General Delivery, Sambaa K'e, NT X0E 1Z0

Tsiigehtchic

Phone: (867) 953-3361

Fax: 867-953-3408

Address: General Delivery, Tsiigehtchic, NT X0E 0B0

Tuktoyaktuk

Phone: (867) 977-2321

Fax: 867-977-2535

Address: Bag 1000, Tuktoyaktuk, NT X0E 1C0

Tulita

Phone: (867) 588-3333

Fax: 867-588-3000

Address: P.O. Box 145, Tulita, NT X0E 0K0

Ulukhaktok

Phone: (867) 396-3111

Fax: 867-396-3221

Address: P.O. Box 160, Ulukhaktok, NT X0E 0S0

Wekweètì

Phone: (867) 713-2904

Fax: 867-713-2903

Address: General Delivery, Wekweètì, NT X0E 1W0

Whatì

Phone: (867) 573-3261

Fax: 867-573-3701

Address: General Delivery, Whatì, NT X0E 1P0

Wrigley

Phone: (867) 581-3441

Fax: 867-581-3200

Address: General Delivery, Wrigley, NT X0E 1E0

Yellowknife

Ambulatory Care Centre (previously called Stanton Medical Clinic)

Phone: (867) 669-4122 and (867) 669-3100

Fax: 867-669-4139

Address: 548 Byrne Rd, Yellowknife, NT X1A 2N1

Audiology Clinic

Phone: (867) 669-3130

Fax: 867-669-4128

Address: 550 Byrne Rd, Yellowknife, NT X1A 2N1

Eye Clinic

Phone: (867) 873-3577

Fax: 867-920-7992

Address: 4916 47 St, Yellowknife, NT X1A 1L8

Frame Lake Community Health Clinic

Phone: (867) 767-9125

Fax: 867-920-2210

Address: 312 Old Airport Rd, Yellowknife, NT X1A 3T3

Public Health

Phone: (867) 767-9120

Fax: 867-873-0158

Address: 4702 Franklin Ave, Yellowknife, NT X1A 1N2

Stanton Medical Centre

Phone: (867) 669-3100

Fax: 867-920-4271

Address: 419 Byrne Rd, Yellowknife, NT X1A 2N1

Stanton Territorial Hospital

Phone: (867) 669-4111

Fax: 867-669-4128

Address: 548 Byrne Rd, Yellowknife, NT X1A 2N1

Yellowknife Primary Care Centre

Phone: (867) 920-7777

Fax: 867-920-7711

Address: 4915 48 St, Yellowknife, NT X1A 1N2

Appendix C:

Professionals on the Therapy and Diagnostic Team

Different professionals play different roles in both the diagnosis and therapy process for people with ASD. The following section outlines who the professionals are, what they do and what you should ask them.

Behaviour Analyst: A Board Certified Behaviour Analyst (BCBA) is a licensed practitioner who helps to determine the functions of (reasons for) behaviours. Then they design client-specific behaviour programs and therapies to help families and children to manage and improve behaviour. Behaviour analysts typically become more involved with families after a diagnosis, but they may also be helpful while a family is on a waiting list or for those who simply want consultation and/or advice. For more information on what to expect visit: www.bacb.com/

Community Nurse: If you live in a smaller community within the NWT you may not have frequent access to a general practitioner. In this case you may have to visit the closest health centre (Appendix B). They will be able to direct you to the services you should access. You should bring all your concerns to them and it is recommended that you even write them down so you remember. Depending on your child's age and the community you or your child may be able to access services within your community or you may have to travel to Yellowknife or even outside of the NWT.

Developmental Therapist: looks at children's play, behaviour, social and emotional development. They provide support to families regarding parenting issues and child development.

Diagnostic Coordinator: In a diagnostic process within or outside of the NWT you or your child may be assigned a diagnostic coordinator. While this person may not actually perform diagnostic assessments they are a point of a contact for families and an organizational coordinator of the different components of the assessment. They will be able to answer any questions you may have about the diagnostic process and potentially be able to link your child to services as a part of their therapy.

General Practitioner: A general practitioner is also commonly called a family doctor. General practitioners are usually the first point of contact for patients when there is a concern. If you are not sure where to go with your health concerns they are a good place to start. Even while they may not be able to provide you with a diagnosis or support needed they are able to provide you with a referral or support in accessing services that will. It is important to bring all of your concerns to them and it is recommended that you even write them down so you do not forget.

Occupational Therapist (also commonly called an OT): provides care and therapy to help solve problems that interfere with everyday life. They help to promote skills for independent living. They also provide supports surrounding sensory integration (anything to do with the senses and balance perception). Any concerns about behaviours that affect everyday life of you or your child should be brought to your OT (ex. teaching a child to tolerate teeth brushing or to brush their teeth independently). For more information on what to expect visit: www.autismontario.com/node/484

Pediatrician: A pediatrician is a doctor that specializes in childhood health and wellness. For your child to see pediatrician in the NWT you will need a referral from a general practitioner to see a pediatrician. It is recommended that you bring all concerns to the pediatrician. They may be able to help you directly or refer you to another specialist or a team that will be able to address the concerns with your child.

Psychiatrist: A psychiatrist is a medical doctor that specializes in psychological diagnoses. They are able to provide assessments and therapy but also prescribe medications. It is important to bring any concerning behaviours, mental development or emotion to your psychiatrist.

Psychologist: A psychologist studies the human mind, emotions and behaviour. If you or your child is seeing a psychologist for either an assessment or therapy it is important to inform them of any behaviours that you are concerned about. In terms of a diagnosis they will perform cognitive assessments and play based assessments.

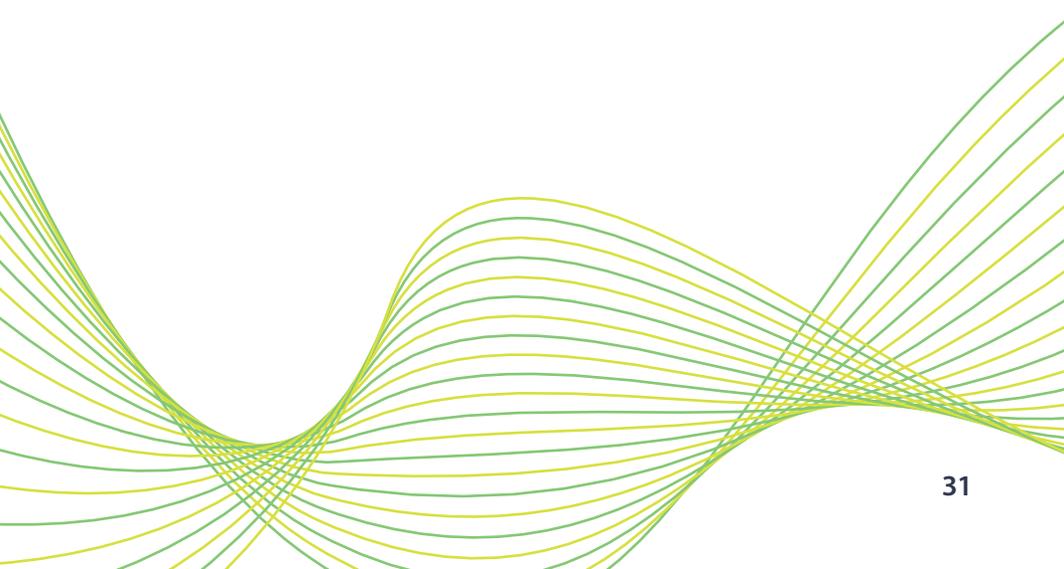
Physiotherapist: A physiotherapist (also called a PT) specializes in physical movements. They can help to address a person's behaviours or illnesses that may affect their ability to perform functional activities in their daily lives. They may be a part of a diagnosis team or you or your child's therapy. Be sure to tell them if you have any concerns with your child's movement.

Social Worker: A social worker may be helpful throughout the lifespan of an individual with ASD. They can help by providing a variety of services not limited to information regarding diagnosis and treatment, explaining the diagnosis and treatment processes to family members and working with a person with ASD on relationships, social skills and transitions. For more information on what to expect visit:

www.autismontario.com/node/497

Speech Language Pathologist: A speech language pathologist (also known as an SLP) specializes in the evaluation, diagnosis and treatment of communication disorders. ASD can affect speech, language development, and social communication. They also can help with eating and swallowing issues. An SLP may play a crucial player in both a diagnosis and therapy. In a diagnosis an SLP may evaluate language delay and social language use. Any language-related or communication related concerns should be brought to your SLP. For more information on what to expect visit:

www.autismontario.com/node/496



Appendix D:

Glossary of Important Terms

Echolalia: Echolalia is the repetition of words, phrases, intonation, or sounds of the speech of others. Children with ASD often display echolalia in the process of learning to talk. *Immediate echolalia* is the exact repetition of someone else's speech, immediately or soon after the child hears it. *Delayed echolalia* may occur several minutes, hours, days, or even weeks or years after the original speech was heard. Echolalia is sometimes referred to as "movie talk" because the child can remember and repeat chunks of speech like repeating a movie script. Echolalia was once thought to be non-functional, but is now understood to often serve a communicative or regulatory purpose for the child.

Executive functioning: Executive functioning is a broad term that refers to the cognitive processes that help us regulate, control and manage our thoughts and actions. It includes planning, working memory, attention, problem solving, verbal reasoning, inhibition, cognitive flexibility, initiation of actions and monitoring of actions.

Language delay: A language delay occurs when a child's language is developing slower than other children of the same age, but it is following the typical pattern of development. For example, a child may be 4 years of age, but understanding and/or using language typical of a child who may be only 2.5 years of age. A child may have a receptive language (understanding of language) delay or an expressive language (use of language) delay. Language development can be affected by the complex interaction of genetic and environmental influences.

Nonverbal communication: Nonverbal behaviors are those things people do to convey or exchange information or express emotions without the use of words. These include eye gaze (looking at the face of others to check and see what they are looking at and to signal interest in interacting), facial expressions (movements of the face used to express emotion and to communicate with others nonverbally), body postures (movements and positioning of the body in relation to others), and gestures (hand and head movements to signal, such as a give, reach, wave, point, or head shake). In the first year of life, children learn to coordinate nonverbal behaviors to regulate social interaction so that they can use their eyes, face, body, and hands together to interact. At the same time, children learn to read or understand the nonverbal behaviors of others.

For example, they learn to follow gaze and look where someone else is looking, understand if others show with their face or tone of their voice that they are happy, sad, or angry, or look at what someone is pointing at. Before learning to talk, children can take turns with nonverbal behaviors in back-and-forth interactions.

Rigidity/Repetitive Behaviours and Interests: Repetitive behaviors and restricted interests are common in children with ASD. Children with ASD may appear to have odd or unusual behaviors such as a very strong interest in a particular kind of object (e.g., lint, people's hair) or parts of objects, or certain activities. They may have repetitive and unusual movements with their body or with objects, or repetitive thoughts about specific, unusual topics.

Screening vs. diagnosis: The Field Epidemiology Manual describes the difference between diagnostic and screening tests as: Screening tests are offered to asymptomatic people who may or may not have early disease or disease precursors and test results are used to guide whether or not a diagnostic test should be offered. Diagnostic tests are offered to people who have a specific indication of possible illness (a history, symptom, sign or positive screening test result) to determine whether or not they have the disease in question.

Self-stimulation (stimming): Self-stimulating behaviors or "stimming" are stereotyped or repetitive movements or posturing of the body. They include mannerisms of the hands (such as handflapping, finger twisting or flicking, rubbing, or wringing hands), body (such as rocking, swaying, or pacing), and odd posturing (such as posturing of the fingers, hands, or arms). Sometimes they involve objects such as tossing string in the air or twisting pieces of lint. These mannerisms may appear not to have any meaning or function, although they may have significance for the child, such as providing sensory stimulation (also referred to as self-stimulating behavior), communicating to avoid demands, or request a desired object or attention, or soothing when wary or anxious. These repetitive mannerisms are common in children with ASD.

Sensory Processing Disorder (SPD): SPD is a condition where the brain and nervous system have trouble processing or integrating stimulus. SPD is a condition in which sensory input either from the environment or one's body is poorly detected or interpreted and/or to which atypical responses are observed.

For a child with SPD, processing the feelings of hot or cold, tired, hungry, lights and sound can be challenging or overwhelming. SPD can show up as an either an over or lesser response to stimulation.

- **Hypersensitivity:** Over reactivity to sensory input is abnormal sensitivity or hyperresponsiveness. This is the state of feeling overwhelmed by what most people would consider common or ordinary stimuli of sound, sight, taste, touch, or smell. Many children with ASD are over reactive to ordinary sensory input and may exhibit sensory defensiveness - a strong negative response to their overload, such as screaming at the sound of a telephone.
- **Hyposensitivity:** Under reactivity to sensory input is one aspect of abnormal insensitivity to sensory input, or hyporesponsiveness, in which a child does not respond to sensory stimulation. A child who appears as if deaf, but whose hearing has tested as normal, is under reactive. A child who is under reactive to sensory input may have a high tolerance to pain, may be clumsy, sensation-seeking, and may act aggressively.

Social Communication: Social interaction is the use of nonverbal or verbal behavior to engage in interaction with people. This can involve eye gaze, speech, gestures, and facial expressions used to initiate and respond to interactions with others.

This document is updated yearly.

If you have any suggestions for edits or would like to suggest new information, please email yukonhub@aidecanada.ca.

This material is designed for information purposes only.

It should not be used in place of medical advice, instruction and/or therapy.

If you have specific questions, please contact your doctor or appropriate health care professional.

This document was produced through the collaboration between AIDE Canada (Autism and/or Intellectual Disability Knowledge Exchange Network), Autism Yukon, and the NWT Disabilities Council.

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