

Autism Spectrum Disorder in the Yukon

ALL YOU NEED TO KNOW
BEFORE A DIAGNOSIS

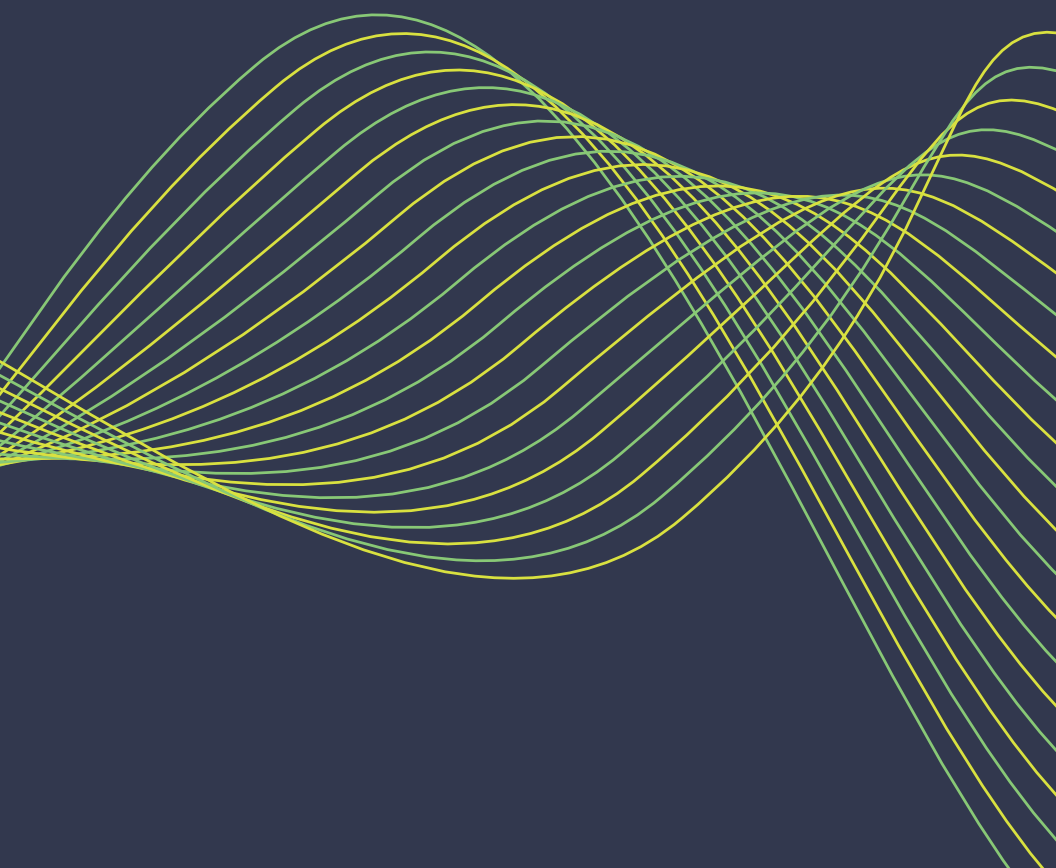




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A recent report completed by the Public Health Agency of Canada showed that 1 out of 66 children aged 5-17 in Canada are diagnosed with Autism Spectrum Disorder (ASD).

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."

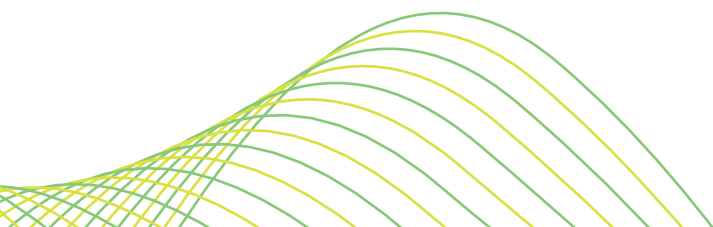
While making your decision, here are some things that you should consider:

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 ASD?

Autism Spectrum Disorder (ASD) is a neurological disorder that affects how the brain develops and leads to developmental disability. It is called a spectrum disorder because there is a wide range of symptoms and degrees of severity. ASD is diagnosed approximately 4 times more often in males than in females.

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.

Signs of ASD are typically first noticed by a parent or caregiver. ASD can be diagnosed as early as age two, and at any point after.

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

To find out more contact:

- **Autism Yukon: (867) 667- 6406**

Autism Yukon is a non-profit, non-governmental organization that exists to improve the quality of life for those affected by Autism in the Yukon. Their mandate includes supporting families as they navigate the assessment process. They also provide education to families, teachers, employers and therapists. They provide a lending library and hold occasional workshops. Autism Yukon is also responsible for raising public awareness concerning issues related to autism and for identifying and alerting appropriate government departments of gaps in service.

- **Child Development Centre: (867) 456-8182**
The Child Development Centre is a non-profit, non-governmental organization. They work with families and community members to provide therapeutic services and support the developmental needs of all Yukon children from birth to kindergarten. The Child and Youth Diagnostic and Support Team provides assessment in the areas of Autism Spectrum Disorder, Fetal Alcohol Spectrum Disorder and Complex Behaviour for children in this age range.
- **Student Supports, Department of Education: (867) 667-8000**
The special supports teams at each individual school may refer school-aged children to this department for further assessments and recommendations. Student Supports does NOT diagnose autism or other neurodevelopmental diagnoses. Student supports also makes decisions about education assistants and other supports provided to schools.
- **Disability Services: (867) 393-7464**
Disability Services provides support to children with a query of ASD or who have received an ASD diagnosis. Disability Services also provides assessment and diagnosis to children ages 5 – 19 through their Developmental Diagnostic and Support Clinic.
- **Autism Speaks webpage: www.autismspeaks.ca/**
Autism Speaks is a leading national autism organization in Canada. They have an excellent website which includes many downloadable “tool kits” that have been quite helpful to Yukon families.
- **Canadian Autism Spectrum Disorders Association (CASDA) webpage: www.casda.ca/**
CASDA is Canada’s leading advocacy organization and is responsible for speaking to the federal government and raising awareness nationally. Consisting of leading representatives from across Canada, they are constantly reminding the federal government about the need for a national autism strategy so that coverage is not as fractured from province-province-territory.

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. 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 may indicate an individual may have ASD are listed on the Autism Speaks website, above.

For babies and toddlers signs of ASD include:

- 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

For ASD at any age signs of ASD include:

- 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.

The first step is to see a primary care physician and voice your concerns. It may be helpful for you to write down important information to say during the appointment. The physician may do some basic screening tests or may refer you and your child to other services for further assessment.

In communities throughout the Yukon the process is similar but instead of voicing concerns to a physician you may have to see a community nurse first. Teams from the Child Development Centre travel to all Yukon communities. If your child is under five you can contact them directly and they will arrange to visit you in your community.

If you don't have a family doctor, you can call (867) 393-6980 to see if any physicians in Whitehorse are accepting new patients or visit a walk-in clinic for a referral to a pediatrician. If you do not live in Whitehorse you can visit your community health centre.

If the physician, nurse or other professional suspects ASD, your child will have the option to see a diagnostic team. It is possible to be referred to some diagnostic services without first seeing a physician or nurse. In some cases, teachers, parents or caregivers can refer the child directly to diagnostic services (see diagnostic map on page 6).

Please note that screening tests done online or by your doctor are not a diagnosis and are only used to determine if further assessment is needed. You can speak to Autism Yukon for support during this process. Part of their mandate includes family navigation, which includes helping families know what to do when. They can also help you know who to call with your questions.

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 may be asked to fill in questionnaires/checklists or complete an interview so the professionals can understand a bigger picture of your child's development. This process might seem daunting 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.

Diagnostic services are available both within and outside of the Yukon. Where a child accesses an assessment is dependant on a variety of factors.

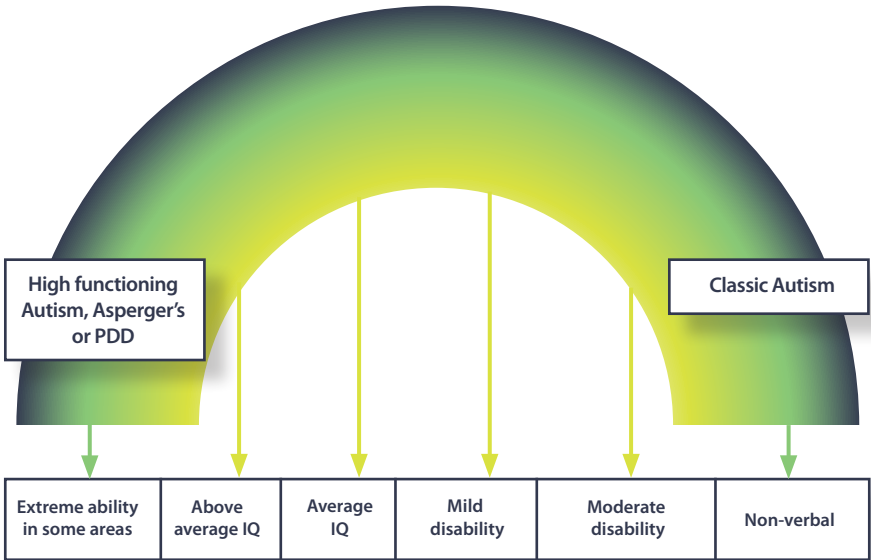
Including:

- The age of the child at the time that they are seeking diagnosis (under/over the age of 5)
- Whether the parent/caregiver has the ability to access private diagnosis either by paying independently, through private insurance coverage or through Jordan's Principle.
- Whether or not there are other medical conditions/diagnoses present as well. Many children have additional diagnoses along with ASD (digestive struggles or epilepsy, for example).

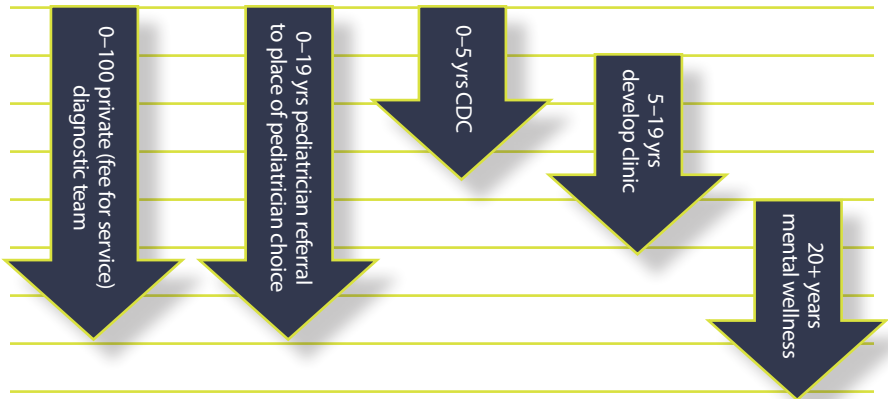
ASD Assessment Standards:

While there are currently no assessment standards in the Yukon, you may want to refer to the British Columbia assessment standards for ASD to ensure that your child is receiving an adequate diagnosis. You can download the document here: http://www.phsa.ca/autism-site/Documents/asd_standards_0318.pdf. This document was published in 2003 but it is still current. This document focuses on standards for children who are six and under.

Autism is a Spectrum



Yukon ASD Diagnosis and Therapy



Therapy

0-5: CDC and Disability Services • 6-19: Disability Services
20+: Mental Wellness (limited)

The Child Development Centre

If your child is under the age of five they can receive a diagnostic assessment through the Child Development Centre's team of professionals.

About: The Child Development Centre (CDC) is a not-for-profit agency that provides therapeutic services for children from birth to kindergarten. They use a family-centred approach and the family's involvement is integral to the assessment process. The main office is located in Whitehorse, with other offices in Watson Lake and Kwanlin Dün. They visit all rural Yukon communities.

Referrals can be made by:

- Parents and caregivers
- With the parent's permission, any other person involved with the family (caregiver, doctors, public health nurses, social workers, educators etc.)
- The CDC itself, if your child is already accessing their services

Referrals can be made by contacting the CDC or filling out the referral form (can be found online). Please note this form is different from the referral form for accessing general CDC services.

Cost: Free

Wait time: Varies, but typically less than a year.

Website and Contact Information:

Website: www.cdcyukon.ca/

Contact Information:

1000 Lewes Blvd, Whitehorse YT

Phone: (867) 456-8182

Toll-Free Phone: 1 (866) 835-8386

Email: info@cdcyukon.ca

Diagnostic coordinator: (867) 456-8182 ext. 193

Other Information: The CDC follows a similar year to the school system and is closed in the summer months (mid-June to mid-August). During this time minimal services are provided.

Disability Services Developmental Diagnostic and Support Clinic

The Developmental Diagnosis and Support Clinic can provide a publicly-funded diagnosis for children ages 5 through 19. You may be referred to this clinic, or you may self refer.

About: The Developmental Diagnostic and Support Clinic is a service of the Yukon government's Department of Health and Social Services. The clinic is made up of a multi-disciplinary team that includes a pediatrician, psychologist, occupational therapist, speech language pathologist, child/youth and family counsellor, and clinic coordinator. They provide Autism Spectrum Disorder diagnostic services to children and youth, as well as referrals to appropriate supports and services for children, youth and their families as part of the assessment process.

Referrals can be made by:

- Parents and caregivers
- Physicians
- Department of Education

Disability Services will complete an intake assessment before the full ASD diagnostic assessment. A diagnostic coordinator will work with the family to organize the different assessments that are needed.

Cost: Free

Website and Contact Information:

Website: <https://yukon.ca/en/health-and-wellness/babies-and-childrens-health/find-supports-your-child-disability>

Contact Information:

49B Waterfront Place, Whitehorse YT

Phone: (867) 393-7464

Toll free in Yukon 1 (800) 661-0408, ext. 7464

Private Services within the Yukon

If you are able to self-fund a diagnosis it is possible to receive an assessment from private services located within Whitehorse.

About: Private diagnostic services in Whitehorse are performed by a psychologist, an occupational therapist and a speech language pathologist. Together, information from these assessments can be used to make a conclusive diagnosis. If the person is a child, the team will also include a pediatrician.

Referral Process:

Referrals can be made by:

- Parents and caregivers
- Physicians or pediatricians
- Mental Wellness and Substance Use Services

Cost: \$4000-\$5000 before insurance coverage.

Wait time: Approximately 2-4 weeks. The assessment itself takes approximately 6-8 weeks. Therefore, the entire private assessment process is expected to take approximately 3 months.

Website and Contact Information:

Website: www.trailheadhealth.ca/

Contact Information:

Charlene Bradford

Suite 202, 104 Elliot Street, Whitehorse YT

Phone: (867) 668-2612

Email: info@trailheadhealth.ca

Other Information: If you have private health insurance, you may want to check if the services are covered by your policy before accessing private services. Jordan's Principle (see page 12) may cover some, or all, of the private diagnosis fees for First Nations children.

Diagnostics Outside of the Yukon

Diagnostic services in B.C. or Alberta are not a common route but may be used in complex cases. Most often, it's better to get a diagnosis in your home province or territory. The transition from the diagnostic team to local therapists and programs will be smoother, and can sometimes even include some of the same professionals. Travelling away from home can cause children to perform differently than they normally would on some developmental tests.

About: Diagnoses are performed at Sunnyhill Health Centre in Vancouver or Glenrose Rehabilitation Hospital in Edmonton. Both of 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:

- Physician or pediatrician

For travel costs to be covered, your child may need to see a pediatrician in the Yukon first.

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 doctor about getting these assessments completed).

Cost: Diagnosis is free and some travel costs are covered. See page 13 for more information about Medical Treatment Travel. You may be able to stay at the Ronald McDonald House or Easter Seal House while your child has appointments at the children's hospitals (see page 13).

Wait time: 18-24 months after a referral is sent. A better estimate of a wait time is given at the time that the appointment is booked.

Contact Information:

Sunnyhill Health Centre

4500 Oak St Entrance 5

Vancouver, BC V6H 3N1

Phone: (604) 875-2345

Glenrose Rehabilitation Hospital

10230 111 Avenue NW

Edmonton, Alberta T5G 0B7

Phone: (780) 735-6134

Other Information: Sunnyhill provides services for children up to the age of 19. Glenrose Rehabilitation Hospital provide services for children up to the age of 17. Your child may also have other specialist appointments outside of the Yukon. You may want to ask your doctor if it is possible to have the specialist appointments and diagnosis at the same centre and around the same time so you do not have to make multiple trips. Make sure to review information from Medical Treatment Travel before making any travel plans (page 13).

***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.

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 publically funded diagnoses in Canada or in the United States. These diagnosis pathways are not organized through anyone in the Yukon 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. The information about your child as well as recommendations for treatment are valuable. The more detailed that the information from the assessment is, the more specific service provision can be for your child. Autism Yukon, as well as your health care providers should be able to provide you guidance on whether a different diagnosis pathway is acceptable.

Is it possible to get diagnosis costs covered?

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.

Great-West Life

Phone Number: 1 (800) 957-9777, Website: www.greatwestlife.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: www.canada.ca/en/indigenous-services-canada/services/jordans-principle.html

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

Contact within the Yukon

Council of Yukon First Nations

Phone: (867) 393-9200

Website: www.cyfn.ca/services/jordansprinciple/

Child Development Centre

Phone: (867) 465-8182 ext. 190

Medical Treatment Travel

In order to receive diagnosis or treatment for ASD or related conditions, you may have to travel to Edmonton, Calgary or Vancouver for services that are not available within the Yukon. The Application for Medical Travel must be completed by a practitioner who is licensed within the Yukon and approved by the Medical Travel Program (practitioners include doctors, and community nurses where there is no doctor available).

After the practitioner sends the referral to the Medical Travel Program, one of their travel agents will call you to organize travel. Services covered are outlined on the website and include travel expenses and a \$75 per day reimbursement after the second day of receiving out-patient services outside of the Yukon, to a maximum of 90 days. For more information, please visit their website.

Website: <https://yukon.ca/en/medical-treatment-travel>

Contact:

Phone: (867) 667-5203 or (867) 667-5233

Toll Free: 1 (800) 661-0408 ext. 5203

Ronald McDonald House

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

Website: www.rmhc.ca

Easter Seal House

If your child is receiving assessment outside of the Yukon, you may be able to stay at the Easter Seal House to reduce the cost of travelling.

Website: www.eastersealsbcy.ca/how-we-help/easter-seals-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/what-autism/diagnosis/dsm-5-diagnostic-criteria>). In 2013 diagnosis standards for ASD changed. Before 2013, parents and caregivers could expect diagnosis of either Autism, Asperger's or Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). This is not the type of results that you will receive today.

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 receive services in the future. If you chose to share them with another professional such as a teacher, always give away a photocopy. 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.

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?*** It would also be a good idea to register as a member with Autism Yukon so that you can receive regular information about workshops and other events.

In 2017, a parent named Ronnie Koenig wrote a great article titled, “Things I wish I’d known about having a child with autism.” (today.com/series/things-i-wish-i-knew/things-i-wish-i-d-known-about-having-child-autism-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 Yukon 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:

Yukon First Nations Contact Information

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

Council of Yukon First Nations

2166-2nd Avenue, Whitehorse

Phone: (867) 393-9200

Website: www.cyfn.ca/

Carcross Tagish First Nation

Carcross

Phone: (867) 821-4251

Website: www.ctfn.ca/

Champagne and Aishihik First Nation

Haines Junction and Whitehorse

Phone: (867) 634-4200 or (867) 456-6888

Website: www.cafn.ca/

Kluane First Nation

Burwash Landing

Phone: (867) 841-4274

Website: www.kfn.ca/

Kwanlin Dun First Nation

Whitehorse

Phone: (867) 633-7800

Website: www.kwanlindun.com/

Liard First Nation

Watson Lake

Phone: (867) 536-5200

Website: www.liardfirstnation.ca/

Little Salmon Carmacks First Nation

Carmacks

Phone: (867) 863-5576

Website: www.lscfn.ca/

Na-Cho Nyak Dun First Nation

Mayo

Phone: (867) 996-2265

Website: www.nndfn.com/

Ross River Dena Council

Ross River

Phone: (867) 969-2277

Website: www.rossriverdenacouncil.com/

Selkirk First Nation

Pelly Crossing

Phone: (867) 537-3331

Website: www.selkirkfn.com/

Ta'an Kwach'an Council

Whitehorse

Phone: (867) 668-3613

Website: www.taan.ca/

Teslin Tlingit Council

Teslin

Phone: (867) 390-2532

Website: www.ttc-teslin.com/

Tr'ondek Hwech'in First Nation

Dawson City

Phone: (867) 993-7100

Website: www.trondek.ca/

Vuntut Gwutchin First Nation

Old Crow

Phone: (867) 966-3261

Website: www.oldcrow.ca/

White River First Nation

Beaver Creek

Phone: (867) 862-7802

Website: www.whiteriverfirstnation.com/

Appendix B:

Community Nursing Services Contact Information

For free, confidential 24-hour health information by registered nurses you can call the **Yukon HealthLine 811**.

Beaver Creek Health Centre

Mile 1202 Alaska Highway

Phone: (867) 862-4444

Carcross Health Centre

1952 Tagish Avenue

Phone: (867) 821-4444

Carmacks Health Centre

106 River Drive

Phone: (867) 863-4444

Dawson City Health Centre

501- 6th Avenue (2nd Floor)

Phone: (867) 993-4300

Destruction Bay Health Centre

Mile 1083 Alaska Highway

Phone: (867) 841-4444

Faro Health Centre

111 Bell Avenue

Phone: (867) 994-4444

Haines Junction Health Centre

131 Bates Street

Phone: (867) 634-4444

Mayo Health Centre

Location: 21 Centre Street

Phone: (867) 996-4444

Old Crow Health Centre

Location: Building 200

Phone: (867) 966-4444

Pelly Crossing Health Centre

Location: Kilometre 464 Klondike Highway

Phone: (867) 537-4444

Ross River Health Centre

Location: 14 Kulan Street

Phone: (867) 969-4444

Teslin Health Centre

Location: 27 Dawson Avenue

Phone: (867) 390-4444

Watson Lake Health Centre

Location: 817 Raven Hill Drive

Phone: (867) 536-5255

Whitehorse Health Centre

Location: 9010 Quartz Road

Phone: (867) 667-8864

Dawson Medical Clinic

Location: 501-6th Avenue

(1st floor Dawson Hospital)

Phone: (867) 993-5744

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 Yukon you may not have frequent access to a general practitioner. In this case you may have to visit the closest nursing station (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 Whitehorse or even outside of the Yukon.

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 Yukon you or your child may be assigned a diagnostic coordinator. While this person may not actually perform diagnostic assessments they are a point of 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 Yukon 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.

autismawarenesscentre.com/does-my-child-have-sensory-processing-disorder/

musingsofanaspie.com/executive-function-series/

www.autismspeaks.org/what-autism/video-glossary/glossary-terms

childdevelopment.com.au/areas-of-concern/diagnoses/language-delay/

This document is updated yearly.

If you have any suggestions for edits or would like to suggest new information, please email info@autismyukon.org.

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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.

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