INDIGENOUS RELATIONS CIRCLE
AUTISM SOCIETY ALBERTA

Autism Knowledge Sharing Series For Indigenous Relations

Walking with Indigenous Autistic Children, Youth & Families in Alberta



"The Autism Society of Alberta would like to introduce the Indigenous Relations Circle. Rooted in respect, the circles' goals are to bring together diverse perspectives on the experiences of Indigenous peoples and autism in Alberta. The circle is a central concept to Indigenous peoples across Turtle Island and the Indigenous Relations Circle will listen, learn, share, connect and advocate for Indigenous Autistic people and families."

– Dr. Grant Bruno, Chair

The Indigenous Relations Circle (IRC) is supporting families at every life stage by participating in the *Enhancing Service Navigation for Individuals with Neurodevelopmental Disability* project.

"Indigenous communities look to the sky for guidance when seeking direction, counsel, prayers and pathways for life journeys. We have viewed the stars as our ancestors and believe we are originally sky people. There are many teachings, stories and ceremonies that embody a celestial connection. In relation to this project, we are exploring navigation through an Indigenous perspective. Metaphorically using the North Star as a reference point to assist Indigenous communities in Autism awareness, education and advocacy. Navigation through systems is challenging for many families. Offering a "North Star" by creating visible and tangible resources, connections and supports to our Indigenous communities can assist our families in their journeys. We look forward to creating culturally relevant resources and nurturing community relationships."



– Dr. Pearl Yellow Old Woman-Healy, IRC Project Lead

Autism Knowledge Sharing Series For Indigenous Relations

Walking with Indigenous Autistic Children, Youth and Families in Alberta

All Our Relations

This knowledge sharing series was created to support Indigenous parents, caregivers, families, and communities who are caring for autistic children and youth. Indigenous caregivers have shared stories, challenges, hopes and dreams for their children.

In reciprocity and respect for the experiences shared, the knowledge gifted was transferred into visible resources to assist families in navigating systems to support their loved ones. The information presented aims to be inclusive, strengths-based, practical and grounded in relationship with community-based needs.

Numerous Indigenous families share stories of their children through their spirits, personality, gifts and strengths first, not with labels or deficit-based language. It is with this understanding that they view children as gifts from Creator and know that difference can come with the child, including Autism. This comes with a responsibility to care for autistic children in how they experience the world.

Indigenous families have shared navigating challenges that include:

- Systemic racism
- Jurisdictional barriers
- Rural or remote access
- Trauma Informed care
- Culturally safe supports
- Funding differences
- Education resources
- Health care
- Mental health
- Respite
- Crisis support
- Culturally safe supports
- Advocacy

This information resource strives to honour the strengths of Indigenous caregiving, nurturing, community supports, and traditional ways of knowing and doing within each of their own ancestral lands.

Understanding Autism Through the Indigenous Caregiver Experience

Caregiver Story

"There is beauty in the difference in how our grandson walks in this world. He doesn't use words, but he shows us how to respect his way of being. We were told he is autistic. To us, he's more than that, we look at his spirit."



Opening Message

In our traditional ways of viewing our children, they are considered gifts from Creator. We accept the child for who they are and the purpose they bring to the physical world. Our children are born with personality traits, physical and biological differences that are embraced and nurtured through our strength-based approach to parenting. We teach belonging and acceptance the moment our children inhale their first sacred breath.

About Autism

Autism is a spectrum of brain differences which may affect communication, social interaction, learning, sensory experiences, regulation, routines and behaviour. In other Indigenous cultures there are various definitions of Autism. The commonality in the meaning shares an inclusiveness of the child's difference and the gifts they bring to community.

Monitor and Screening

In our communities we have relatives who may help us in child rearing and keeping an eye on our children. Caregivers and people who love them, know their children the best. It is helpful to monitor the child's developmental journey as it will assist in understanding the child's progress and identify any concerns. Trust the parental instinct if it feels like your child may need some additional support. There is nothing wrong in seeking more information that will benefit your child's development.

Developmental Milestones



- ✓ Child development stages that most children can do at a certain age range
- ✓ How a child plays, learns, speaks, acts or moves
- ✓ Example of developmental stages:
  - Ages 0-12 months, 12-18 months, 18-24 months, 2 years, 3 years old, 4 years old and 5 years old

Developmental Screening



- ✓ Screenings provide an overview of your child's strengths and needs
- ✓ Screening should ensure that children are up to date on their health checks
- ✓ It can measure early development and academic skills that may serve as the first step in assessing a child's school readiness
- ✓ Help parents, caregivers and teachers know how to best prepare children for school
- ✓ Developmental screenings do not diagnose.

Early Signs

Autism may mean a different developmental timeline, every child is different, and autism may show up in various ways such as:

- ✓ Communicating differently
- ✓ Expressing a need for routines and predictability
- ✓ Having sensory sensitivities
- ✓ Focusing deeply on interests
- ✓ Avoiding eye contact
- ✓ Moving their bodies in unique ways or stimming (rocking, hand flapping)
- ✓ Becoming overwhelmed more easily
- ✓ Experiencing big and strong emotions



Professionals

In Alberta, registered psychologists, psychiatrists, medical doctors and developmental pediatricians can diagnose Autism.



Medical Doctors: family doctors may diagnose autism if they have the expertise



Developmental Pediatricians: medical doctors who specialize in children's health and diagnosis



Psychiatrists: medical doctors who specialize in mental health and diagnosis



Registered Psychologists: licensed mental health professionals who assess, diagnose and provide therapies

There are other professionals who can't diagnose autism but are key in the evaluation process.



Speech-Language Pathologists (SLPs): specialist therapists who assess communication styles and treat communication and swallowing challenges.



Occupational Therapists (OTs): certified therapists who help with movement, play, learning and life skills that improve daily life.

Caregiver Story

"At first, I blamed myself for my child's autism. I felt so lost and confused. I mean, at least now I had answers. I wondered how to support her and where do I go for help?"



Diagnosis

If there are developmental concerns, it is best to reach out to an educator, health provider or family doctor to discuss a possible referral for a specialist or request a developmental evaluation. Talk about your child's progress, development, signs you see, identify any concerns. Your chosen professional may conduct an autism diagnostic assessment to see if your child meets the criteria for autism spectrum disorder (ASD). This can be a lengthy process as they use many tools and information to better understand your child. If your child receives an autism diagnosis, all the information will be written in a comprehensive report.

Diagnostic Report

In Alberta, autism diagnostic reports will vary, and they can be lengthy and detailed documents. It can be helpful to have a support person or advocate with you to clarify terms or language in the report. You may see the following information in the report:



- ✓ Personal identifying information
- ✓ Referral request and reason
- ✓ Background information (medical, developmental, family, education)
- ✓ Assessments and Diagnostic tools
- ✓ Observations and Behavioural results
- ✓ Diagnostic Summary and DSM-5-TR Criteria met and support Levels (1,2,3)
- ✓ Other co-occurring conditions (ADHD, anxiety, medical)
- ✓ Recommendations for support or therapies
- ✓ Get a copy of the report for your records. You will need the report when seeking funding for services and resources.

This can be an emotional time for family, and it may take some time to understand an autism diagnosis and navigate a different path for your child.

Advocacy

Caregivers are the expert witnesses of how their child walks in their life journey. Learning how to advocate in a socially acceptable way, understand the child's needs, and ability to explain these needs takes time. Give yourself grace and have patience. You are allowed to ask for support and request collaborative planning for your child. Celebrate your child's strengths, gifts and interests in the meetings. Share their story.

Discussion questions you can ask:

- [ ] What supports are available for my child? (Level 1, Level 2, Level 3)
- [ ] What therapies are available? (speech, behavioral, occupational, physical, mental)
- [ ] Are there culturally based programming or resources?
- [ ] Are there educational assistants or resource people available?
- [ ] What sensory supports are in place?
- [ ] How are transitions supported?
- [ ] Is there support to apply for funding or other resources that my child may need?
- [ ] Who do I contact if I need further support?

Caregiver Story

"I find the best help are people who listen. I started to talk to other parents who were going through some of the same struggles. I learned from them. I loved connecting with other parents who shared stories, and it felt less lonely."



Walking with our Children

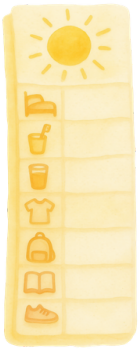
Creator gifted children to us so that we can continue to embrace who we are as Indigenous people and so our identities will remain strong. It is our sacred responsibility to walk with them, nurture, teach and create a safe environment for our children. This includes emotional, relational, cultural, physical, sensory and spiritual safety. Autistic children learn best when they feel safe and can trust others.

What helps my child feel safe and connected?



Routines

Predictability in creating routines helps many autistic children feel safe. Children often feel calmer when they know what is happening, who is coming, where they are going, and what comes next. Speak calmly, clearly and be consistent with the routines as this reduces stress.



Visual routines may help with:

- dressing and hygiene
- toileting
- mealtimes
- school preparation
- bedtime
- appointments or events

Some helpful strategies to use:



Visual Schedules



Calendars



Photos



Verbal Reminders



Some helpful transition cues:

- countdowns
- visual timers
- transition photos
- transition short verbal reminders
- musical cues
- allow extra processing time

Sensory Differences

Many autistic children experience the world very intensely through their senses. Knowing how they sense the world either more or less intensely in a particular sense, helps to support them to feel safe. There are times when we see our children display behaviour that cause concern or experience meltdowns. We must find out what our child is trying to tell us. All behaviour is a form of communication.

Meltdowns

Meltdowns are not tantrums, and they can happen when our child's nervous system becomes overwhelmed. This can happen through various triggers in the environment around them or they are experiencing a sensory overload. They may lose the ability to communicate, stay safe, remain calm, think clearly or regulate their emotions.

Some common **triggers** we may see:

- ✓ unexpected changes in routines
- ✓ transitions
- ✓ demands or tasks
- ✓ hunger, thirst, exhaustion
- ✓ pain or illness
- ✓ fear or anxiety
- ✓ feeling misunderstood



Sensory overload can happen if their brain receives more information from the senses than it can process such as:

- ✓ excessive noise
- ✓ bright or flashing lights
- ✓ big crowds or groups
- ✓ smells
- ✓ clothing textures
- ✓ tastes
- ✓ feeling too hot or cold
- ✓ balance or movement

Keeping a Watchful Eye

Our children show us they may need our help if we see some of these signs:

- ✓ cover their ears
- ✓ scream, yell, or cry
- ✓ repeat verbal scripts or vocal stimming
- ✓ seek movement or sensory input
- ✓ stimming more intensely
- ✓ show big emotions
- ✓ run away, hide or avoid situation
- ✓ throw themselves on the ground
- ✓ show aggression to self or others



Be the Calm

The moment our children enter this world, they are met with love and gentleness. They need us to regulate them and soften their chaotic entrance into this new unfamiliar environment. We create the calm through soft voices, tender touch, kisses, hearing our language being spoken, feeling our heartbeats and wrapping them snug so they feel secure. These initial teachings can be applied and used when our children are seeking sensory support.

During a meltdown, keeping a calm nervous system will help regulate our child. We focus on their physical and emotional safety first. We reduce language and demands. Give our children time to process. We can offer a calm space with supports, activities, and movement to support regulation such as:

- ✓ weighted vests or soft blankets
- ✓ soft twinkle lights or dim lighting
- ✓ favorite toy, plushie, books
- ✓ noise cancelling headphones
- ✓ rocking or spinning chairs, big bean bag chairs
- ✓ sensory tactile tools, fidgets, chewies, squishies, smelly stickers
- ✓ play soft music or powwow songs
- ✓ offer a hand drum
- ✓ breathing or emotional regulation visuals
- ✓ provide movement to jump, swing, walk, dance, stretch, twirl, spin
- ✓ encourage taking deep breaths, blowing bubbles
- ✓ let them take a movement break outside in nature

After a meltdown, a child may feel tired, sad, ashamed or they feel calm and ready to reconnect. We give comfort first and problem solve together later. A regulated child is better able to communicate, learn, and connect.

Caregiver Story

"When he was very little, it was easier to handle his difficult behaviours. He started to grow and get stronger. We had to learn new ways of communicating with him and understand that he is going through changes too. We try to always learn new things to help him."



Communication

Communicating with our autistic children who are non-speaking or speaking require us to adapt to their individual styles. Supporting how they express themselves and understanding them helps to nurture relationships. Communication differences do not mean a child lacks intelligence.

Some children may communicate by using:

- ✓ verbal speech
- ✓ sharing deeply about interests or info dumping
- ✓ echolalia (memorized chunks of language)
- ✓ gestures, pointing, hand leading, body language
- ✓ sounds or vocal stims
- ✓ sign language
- ✓ visual support systems
- ✓ AAC devices (Alternative Augmentative Communication)
- ✓ communication boards
- ✓ behaviours







Supporting Communication

- ✓ provide our children extra time to process language, think, respond
- ✓ speak slower, clear, concise
- ✓ avoid sarcasm or use direct language
- ✓ reduce pressure to speak on demand, use eye contact, or socially interact
- ✓ have readily accessible visual supports

Validating their interactions and expression of communication can reduce stress and frustration for them. Communication is about connection, not perfection.

Caregiver and Family Wellness

In our Indigenous communities, there are helpers who have specific roles when supporting community members. It takes a unique kind of person to raise autistic children with unconditional love, patience, fierce advocacy, determination and acceptance. Being a parent or caregiver to an autistic child can be meaningful and exhausting. Our helpers teach us that all helpers need to practice self-compassion and take care of their own wellness. This benefits everyone. When you are healthy, you can help others. You deserve rest, support, love and wellness without feeling guilt or shame.

Caregiver Story

I love him so much it hurts! But it can feel frustrating doing this all alone. I just want one good night sleep. I am a single parent and there is nobody else I can trust with my child."



Signs of Caregiver Burnout

- [ ] feeling always tired even when you do rest
- [ ] feel alone or lonely
- [ ] filled with big emotions
- [ ] cranky or irritable more often
- [ ] difficulty sleeping or staying asleep
- [ ] feeling not supported

Practice Self-Compassion

You can seek to restore balance in your physical, mental, emotional and spiritual wellness through:

- ✓ having access to respite care services or supports to rest
- ✓ having access to mental health, or counselling supports
- ✓ taking time to regulate yourself through quiet spaces, moving your body, deep breathing, meditation, prayer
- ✓ spending time on the land, connecting with the air, water, sky, animals
- ✓ participating in ceremony or land- based activities
- ✓ visit Elders, knowledge keepers, spiritual helpers
- ✓ find parent support groups to share stories, teachings and laughter
- ✓ create traditional arts or crafts, beading, creating regalia, painting
- ✓ setting boundaries to protect your peace and wellness
- ✓ learning to ask for help and support, we all need help at times

We are walking with our autistic child and learning alongside them. Be gentle with yourself. There is no perfect parent. Nurturing community relationships builds stronger connections, belonging and acceptance of autism. It is a community responsibility.

Closing Message

In our communities, knowing where we come from, who we are, what we practice, and how we do things, embodies our way of being in this world. Our autistic children give us the teaching of autism; they show us their own way of living and leave us with a desire to learn more about who they are. Autistic children have dreams, hopes and infinite possibilities for their future. Our children deserve all parts of their identity and spirit honoured.



Resources and Supports

Support & Care Navigation

- First Nations Health Consortium (Jordan's Principle Intake): Call **1-844-558-8748** to connect with a service coordinator.
- Jordan's Principle Call Centre (24/7): Call **1-855-572-4453**.
- Alberta Indigenous Virtual Care Clinic: Call **1-888-342-4822** to access a patient navigator.
- Autism Calgary - Support & Resource Specialist | **https://autismcalgary.com/**
- Autism Edmonton - Support & Resource Navigation | **https://www.autismedmonton.org/**
- Autism RMWB - Support and Resource Navigation | **https://autismrmwb.org/**
- Autism Alberta - Support & Resource Navigation | **https://autismalberta.ca/**
- Indigenous Disability Canada – National Indigenous Navigation Services (NINS) - support for across Canada for Provincial & Federal benefits, also have case management support | **https://www.bcands.bc.ca**
- Indigenous support line: Call **1-844-944-4744** to access culturally appropriate care
- Family Support for Children with Disabilities (FSCD): **https://www.alberta.ca/fscd**
- Persons with Developmental Disabilities: **https://www.alberta.ca/persons-with-developmental-disabilities-pdd**
- Non-Insured health benefits (NIHB): to access eligible first nations and Inuit health benefits **https://www.sac-isc.gc.ca/eng/1579274812116/1579708265237**
- Express Scripts Canada (NIHB Provider Services): to access coverage for benefits **https://www.express-scripts.ca**

Crisis & Emergency Lines

- Emergency Assistance: Call **911** or visit your nearest emergency department.
- Suicide Crisis Helpline: Call or text **988** (Available 24/7).
- Hope for Wellness Helpline: Call **1-855-242-3310** or chat online at **hopeforwellness.ca** (24/7 Indigenous-focused crisis support).
- Alberta Family Violence Info Line: Call or text **310-1818** (Available 24/7).

Indigenous Connections:

- Connect-Belong-Grow - A non-profit society that organizes social meet ups in the Edmonton area to promote a sense of belonging for families with autistic loved ones. To learn more, contact: **connectbelonggrow@gmail.com**
- Indigenous Relations Circle- **https://autismalberta.ca/alliance/indigenous-relations-circle/**
- Provincial Virtual Children's Rehabilitation- **https://myhealth.alberta.ca/topic/Pediatric-Rehabilitation/Pages/default.aspx**

References

Actify ABA. (2025, June 27). Navigating communication styles in autism: A parent's guide. https://actifyaba.com/communication-styles-in-autism/

AIDE Canada. (n.d.). Parents, caregivers, supporters, and families. https://aidecanada.ca/community/parents-caregivers-supporters-and-families

Alberta Health Services. (n.d.). Autism in infants and young children: Primary care pathway. https://www.albertahealthservices.ca/assets/info/aph/if-aph-prov-autism-in-infants-and-young-children-primary-care-pathway.pdf

Autism Canada. (n.d.). FAQ. https://www.autismcanada.org/about/faq

Autism Caregiver College. (2021, July 7). Autism spectrum disorder fact sheet. https://caregivercollege.ca/mod/page/view.php?id=301

Centre for Autism Services Alberta. (n.d.). Centre for Autism Services Alberta. https://centreforautismab.ca/

Children's Autism Services of Edmonton. (n.d.). Children's Autism Services of Edmonton. https://childrensautism.ca/

Healthy Parents Healthy Children. (n.d.). Development timeline. https://www.healthyparentshealthychildren.ca/resources/tools/development-timeline

MyHealth.Alberta.ca. (n.d.). Autism spectrum disorder (ASD). https://myhealth.alberta.ca/Health/Pages/conditions.aspx?hwid=hw152184

Public Health Agency of Canada. (2024, September 26). Framework for Autism in Canada: Infographic. Government of Canada. https://www.canada.ca/en/public-health/services/publications/diseases-conditions/framework-autism-canada-infographic.html