Building Block: An Introduction to AUTISM







Cowessess First Nation and the Autism Resource Centre: Building Block Program

Cowessess First Nation and the Autism Resource Centre believe that all people have gifts to share and that all people should have access to information and opportunity regardless of ability. This partnership was created to explore and begin to address the gap in culturally appropriate autism resources for Indigenous people, families, and communities.

Special thanks are given to the following people for contributing to the Building Block Project:

The sixteen Cowessess Elders/Knowledge Keepers who were fully engaged throughout the project.

Families for sharing their stories:

Kacheena Naytowtow, Myra Delrome, Jeanne Haywahe, Heather Acoose, Cheynna Delorme, and Jeanelle Mandese.

The project Advisory Council:

Chief Cadmus Delorme, Councillor Pat Sparvier, Sandy Pinay-Schindler, Keely Wight-Young, and June Draude.

Community Engagement Coordinators: Geneen Sparvier and Chasity Delorme.

Saskatchewan Indigenous Cultural Centre for Cree language translation; specifically Helen Ben, Julia Ouellette and Priscilla St. John, and Darian Agecoutay with First Nations University for assisting with the Cree translations.



Table of Contents

Wha	at is Autism?	4
	Autism in Canada	4
	Under-Detection of Autism in Indigenous Communities	5
	Common Characteristics of Autism	5
	Social & Communication Differences	6
	Patterns of Behaviour	8
	Sensory Awareness	9
	Autism Strengths and Abilities	10
	Autism is Not	12
	Autism and Other Health Concerns	13
	Similarities Between Autism & Fetal Alcohol Spectrum Disorder	14
	An Indigenous Perspective to Autism	15
ldea	as on How to Support those with Autism	17
	Strategies to Support Social & Communication Differences	18
	Visual Schedules	19
	First / Then Boards	20
	Helping to Support Behaviour	22
	Timers	23
	Breaking Down Steps	24
	Strategies to Support Sensory Sensitivities	25
Livi	ng on the Autism Spectrum	27
	Autism & Resiliency	28
	Culture as a Source of Support	30
	Guide References	32

This resource was created to provide families with information about Autism Spectrum Disorder (also commonly known as ASD or autism), to share strategies for supporting people with autism and to share the stories and perspectives of Indigenous families who experience autism.

You can also find more information about autism on the following websites:

Autism Canada: www.autismcanada.org/

Saskatchewan Ministry of Health: <u>www.saskatchewan.ca/residents/health/accessing-health-care-services/health-services-for-people-with-disabilities/autism-services</u>

Autism Speaks Canada: www.autismspeaks.ca

Geneva Centre for Autism: www.autism.net

Public Health Agency of Canada: www.canada.ca/en/public-health/services/diseases/ autism-spectrum-disorder-asd.html

Autism Community Training (ACT): www.actcommunity.ca

COURAGE LOVE **WISDOM** RESPECT **TRUTH** HONESTY HUMILITY

All Children are Valued in our First Nations Community

The many Indigenous cultures in the Canadian prairies consider the Seven Grandfather Teachings as core values. The stories that accompany these lessons are passed along in a variety of ways, and are as unique as each community and family that lives here. However, a core aspect is that these seven teachings are intended to teach us how to relate to one another in a good way and guide us in living a good life.

These values are reminders of how to approach our relationships in our communities, with families and with children.

It is important to remember these values when discussing autism because all children are valued and bring special gifts into their families and communities.



When children have those special gifts, they actually have a unique relationship with the Creator, with the spiritual world... A child who has a very unique perspective on the world, we can actually learn a lot from them.

- Chief Cadmus Delorme

What is Autism? (aa-ti-zm)

Many First Nations view people with differences as closer to the Creator. The Creator gave each and one of them a unique and spiritual gift and is always protecting them. There are many ways one can use Cree words to describe autism.

ka-kamawaci-iyinisit

pihtos-mânitonihk-iyinisit

(meaning: given different way of thinking in its own spiritual intelligent)

ê-mihkosit pihtos mânitonicihkan

(meaning: given different way of spiritual thinking)

ê-mihkosit pihtos ê-si-waskawiht

(meaning: given the gift of moving a different way or being (characteristic/behavior))

What is Autism?

There are different forms of Autism Spectrum Disorder (ASD/ autism) and each individual with autism is unique.

People with autism experience differences in communication and social interaction. They may have repetitive behaviours and it might affect the way a person perceives their environment. A range of sensory experiences can be difficult for some and affect how they process incoming information.

Autism impacts all races, ethnicities, and socio-economic backgrounds, there is no distinction.

Autism in Canada

Current statistics show that autism occurs in every 1 in 68 births in Canada. There is no known cause and no cure.¹

Autism is typically diagnosed more in males, but that ratio is not as pronounced as once thought.²



If you have met one person with autism, then you have met one person with autism.

 Stephen Shore, autistic professor at Adelphi University

1 Hodges et al., 2020

2 Halladay et al., 2015



Under-detection of Autism in Indigenous Communities

There is under-detection of autism in Indigenous communities. This may be for a variety of reasons, such as:³

- Lack of cultural sensitivity in healthcare assessment tools (i.e. tools that do not reflect the cultural backgrounds of Indigenous people)
- Limited access to mental health services
- Limited awareness about autism in some Indigenous communities

Children may be getting mis-diagnosed with Fetal Alcohol Spectrum Disorder (FASD) and studies have acknowledged that there is an exaggeration of FASD in Indigenous communities. This could be because of lack of accurate data for FASD in Canada, biases in research, or a lack of understanding or consideration of societal context.⁴

Common Characteristicsof Autism

People with autism have unique strengths that are coupled with some common characteristics such as:

- Difference in social interaction
- 2. Difference in verbal and non-verbal communication
- 3. Restricted, repetitive patterns of behaviour
- 4. Sensory sensitivities

3 Bailey & Arciuli, 2020; DiPetro & Illes, 2014, 2016; Fairthorne et al., 2017; Inman, 2019; Lindblom, 2017

4 Aspler et al., 2019; Di Pietro & Illes, 2013



Social & Communication Differences

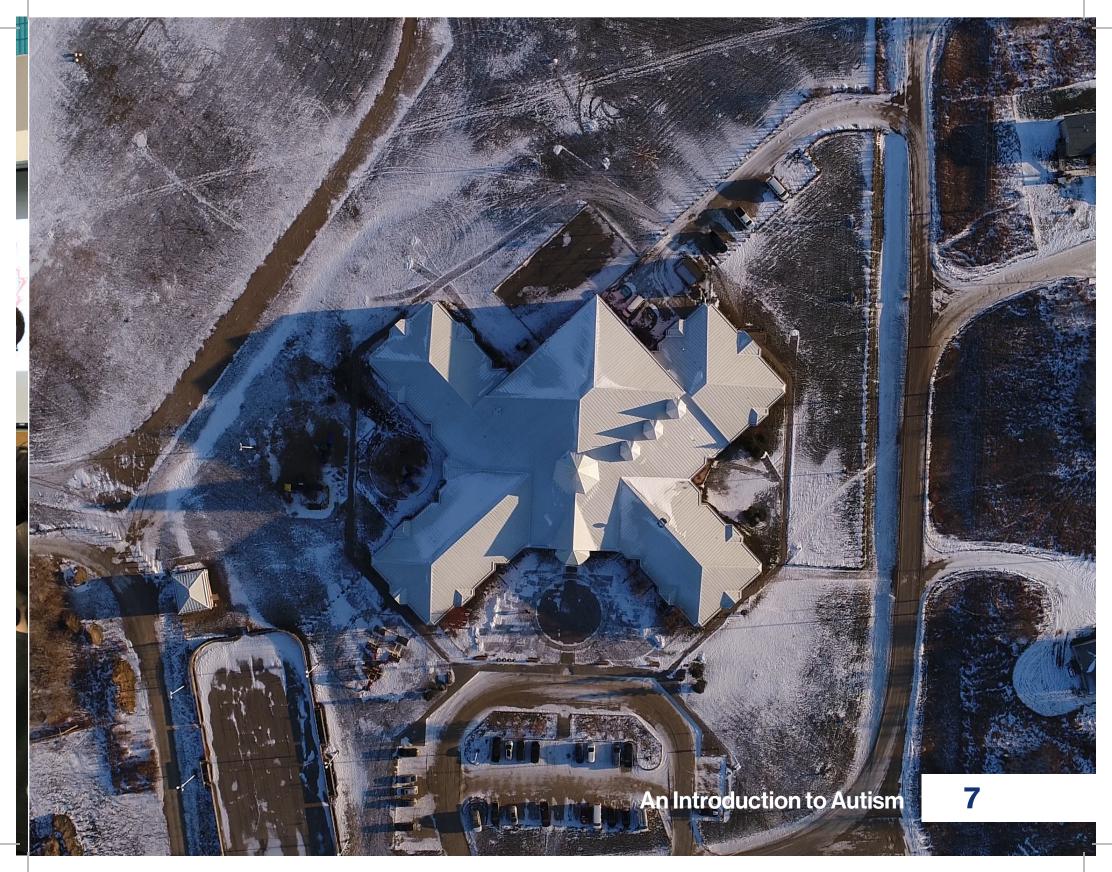
Differences with communication can range from non-verbal to highly verbal with an excellent vocabulary, but with difficulties in give-and-take conversation. The degree of communication and social differences varies from person to person.

People with autism show social/communication differences from an early age that may include:

- Limited eye contact
- Difficulties saying words
- Difficulties with reading facial expressions and body language
- Difficulties starting and maintaining social interactions
- Have trouble making friends
- Socially inappropriate behaviours/interactions

Those with autism can have difficulty understanding those "unwritten" social rules that most of us take for granted. They often use or understand language literally and metaphors (e.g., "your head is in the clouds") are difficult and can be confusing. Ways to interact socially and how to be in different social environments often need to be directly taught and practiced.





Patterns of Behaviour

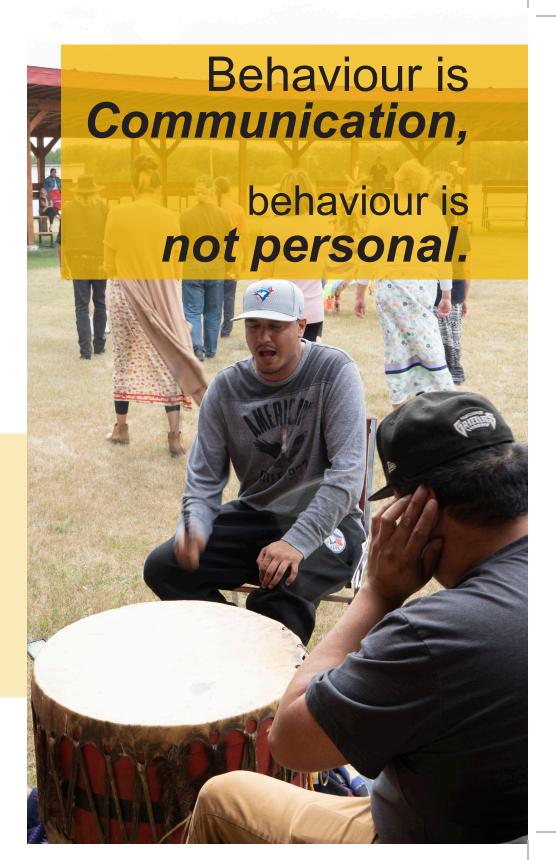
People with autism can have rigid, repetitive types of behaviour, interests, or activities. Similar to social and communication differences, these will vary from person to person.

Rigid and repetitive patterns start at an early age and may include:

- Repetitive motor movements (e.g. lining up toys, flapping hands) or echoing speech
- Requiring sameness, routines, and getting upset with a change in routine
- Highly focused interests
- Focused interest in sensory aspects of the environment (e.g., excessive touching of objects) or types of materials.

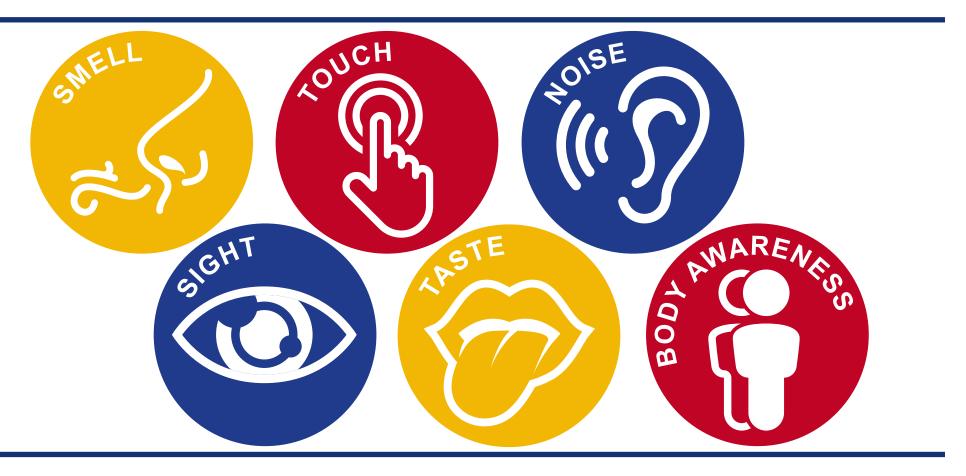
For students with autism...
communication difficulties can be a
primary reason for many behaviour
problems...Inappropriate behaviours
may actually work more effectively
for a student than other forms of
communication

- Linda Hodgdon, 2000, Speech-Language Pathologist



Sensory Awareness

Some people with autism have sensory challenges related to processing things in their environments. For those that do, they are not all the same, and can include sensitivities to things such as:



You do not have to have autism to experience heightened senses. Many people have difficulties with sensory stimulation. Yet, most of people with autism have heightened sensory experiences.

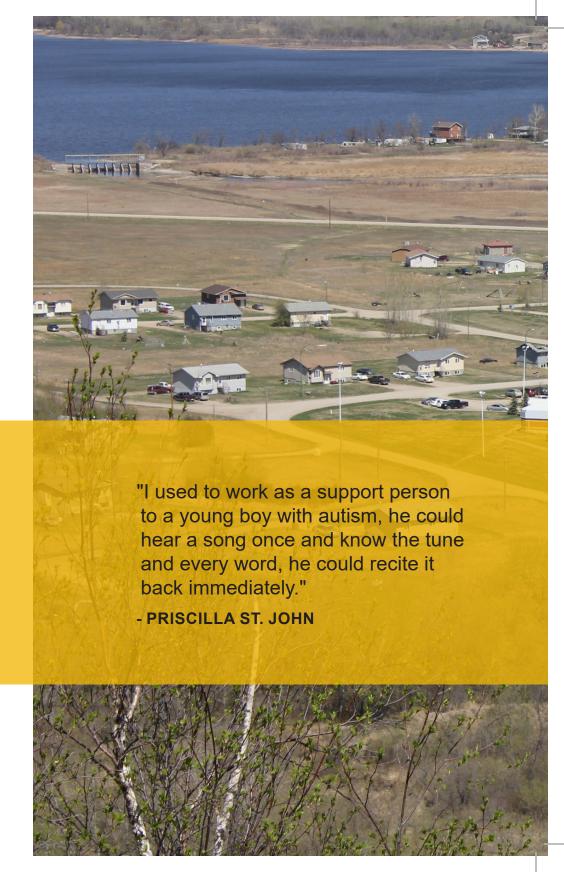
Autism Strengths and Abilities

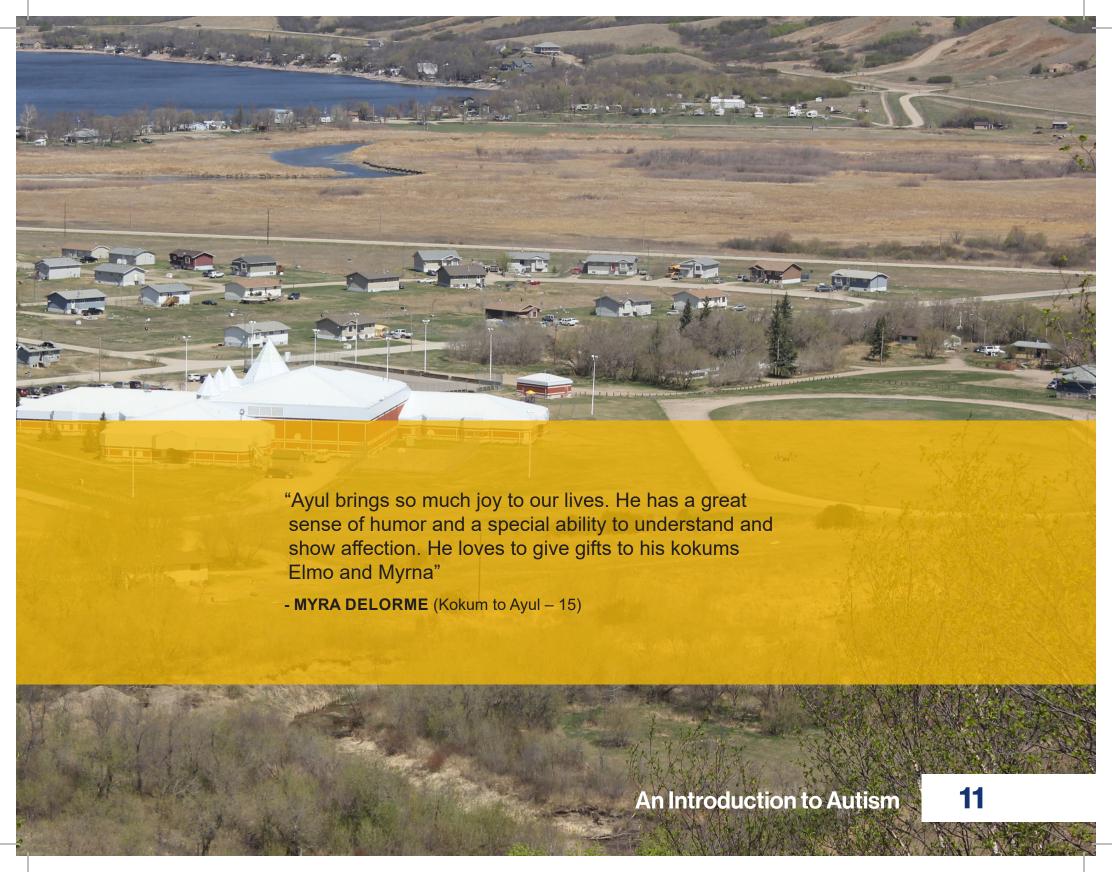
All people with autism have unique strengths. They often showcase some of the following abilities and traits:

- Ability to focus on their special interests
- Exceptional attention to detail
- Visual thinking and learning
- Honesty and reliability
- Thriving on structure and routine
- Strong at following rules and processes
- Solving problems in a unique way
- Seeing the world from a fresh and unique perspective

Autistic Superpowers

Cheynna had concerns and worries when her son was diagnosed with ASD. Until she was inspired by her friend's comment: "Aren't you going to be excited to find out what his gifts are as he grows up? Aren't you going to be excited to find out what his superpowers are?" Re-framing the diagnosis changed her life. She now embraces her son's "different abilities" and she now feels blessed is excited about his future.

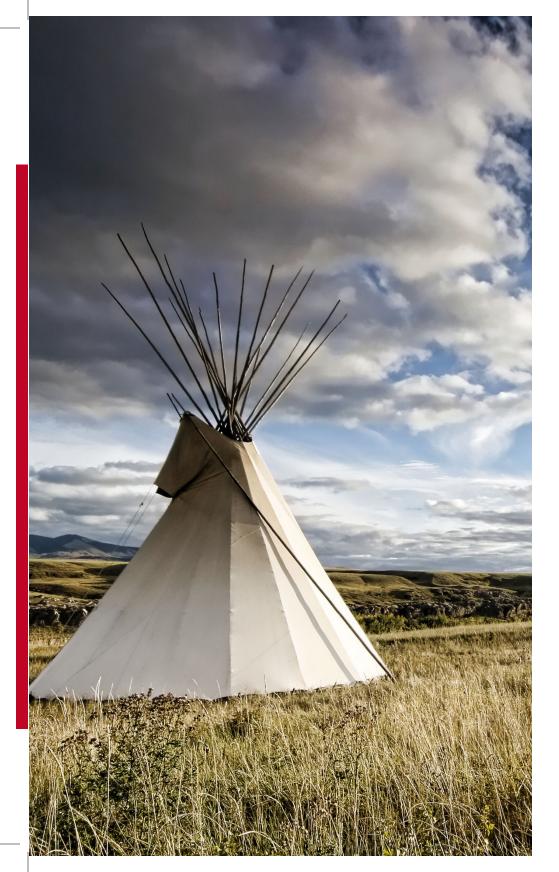




Autism is Not

It's important to remember that autism is not:





Autism and Other Health Concerns

Autism frequently occurs with other health concerns such as:

- Attention difficulties
- Anxiety and depression
- Sleep difficulties
- Eating and food selectivity

Studies have shown that people with autism are four to five times more likely to have at least one other mental health issue than people without autism.⁵

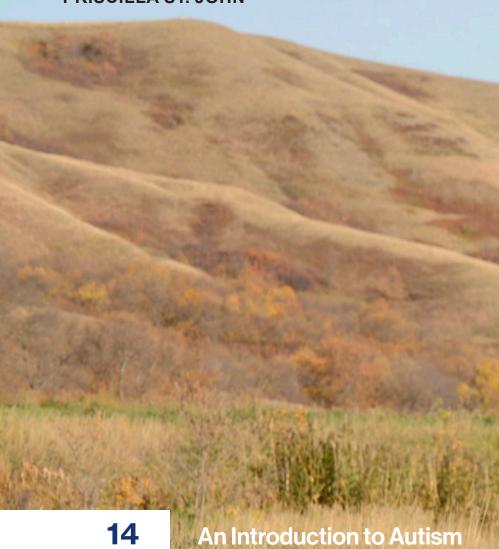
If you have any of these concerns about your child's development, please reach out to your local health care provider, this could be:

- Local health services or health department
- Public health nurse
- Nurse practitioner
- Family doctor
- Mental health professional
- Speech Therapist

⁵ Cummings et al., 2015; Weiss et al., 2017

"I used to work as a support person to two boys that had FASD and ADHD. As children the school system at the time deemed them as "problematic". Their family and community included and surrounded them in culture. Now those two men are lead drummers in the lodge and they are integrated and part of the sacred circle."

- PRISCILLA ST. JOHN

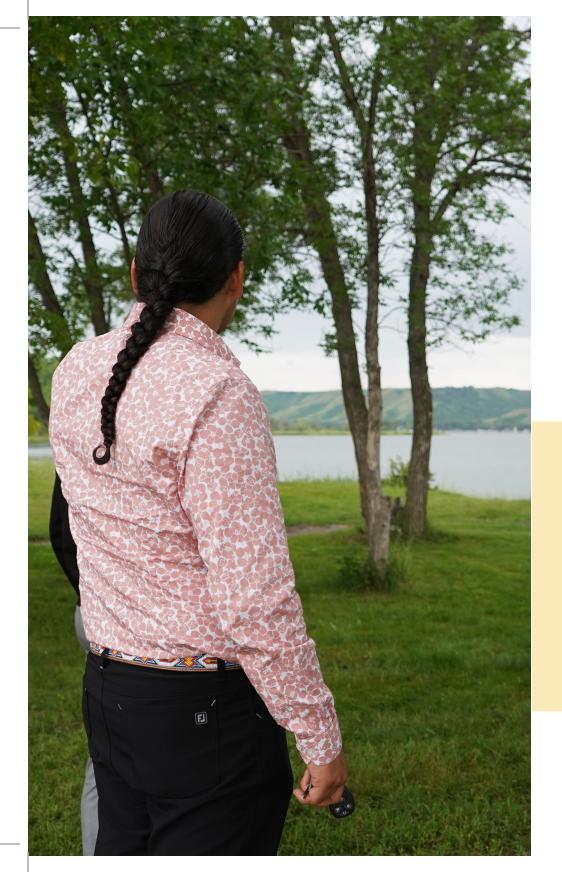


Similarities Between Autism & Fetal Alcohol Spectrum Disorder

It is worth noting that there are similarities between autism and Fetal Alcohol Spectrum Disorder (FASD). Both autism and FASD are on a spectrum and there is wide variability in the ways they may present. They have overlapping characteristics such as:

- Language delays and difficulties
- Restricted interests
- Sensory sensitivities/challenges
- Behavioural issues
- Learning difficulties
- Social challenges
- Delays or concerns with motor development
- Difficulties in everyday self-help skills

It is very important to monitor for early developmental differences. To get a proper diagnosis contact your health care professional, if needed.



An Indigenous Perspective to Autism

It is important to remember that as Indigenous people we can offer our family members or community members with autism, or other differing abilities, many supports including:

- Family support
- A sense of connectedness
- Shared values & teachings
- Empowerment
- Community support
- A sense of well-being and belonging

Children are special gifts; they have special qualities to share with us. They remind us of what is important. They teach us strength and patience.



Ideas on how to Support those with Autism

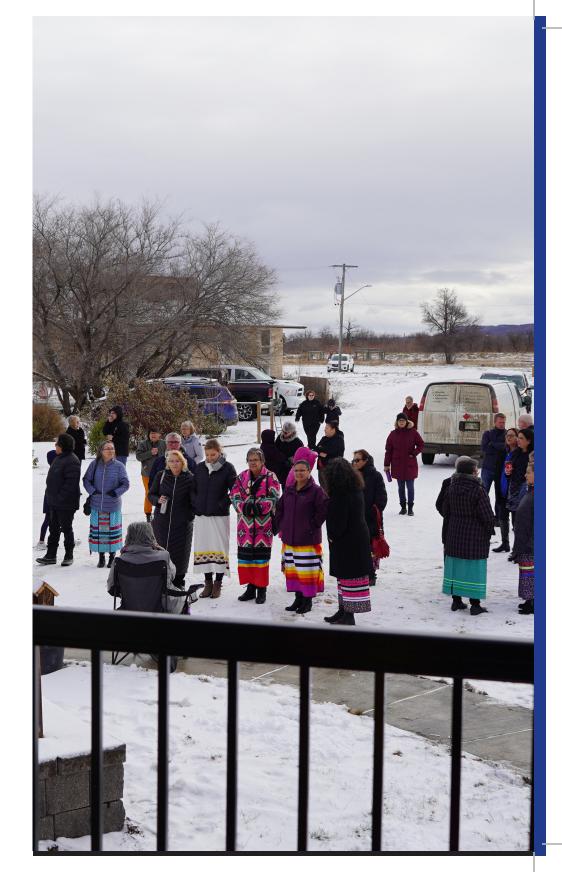
Strategies to Support Social & Communication Differences

People with autism usually have difficulty with communication. There are some ways we can adapt to better support and communicate with them. Such as:

- Use clear, direct language remember often those with autism are black and white thinkers
- ▶ Give directions in smaller steps only one or two at a time
- Use pictures and visual supports
- Avoid sarcasm, metaphors, idioms, and puns
- Give time to process language at least 7 seconds

Know that verbal instructions can be fleeting and change quickly. A more productive communication method could be visual communication.

Visual communication supports such as pictures or words help with understanding activities or instructions. Visuals are helpful as they allow your child to refer to them as often as needed when following their daily routine. Two helpful strategies are to create a visual schedule and use First/Then boards.



Visual Schedules

A visual schedule is a way to accommodate the visual strengths of people with autism. It prepares individuals for transitions, and orders events. This also helps support desired routine, which can lower stress and anxiety.

Getting Ready for School



Get dressed

Postayiwinisê

[post-eye-yih-win-say]

Breakfast

Kîkisêpâ-mîciso

[keeks-say-paa meet-so]

Brush teeth Kistapitêho [kiss-tuh-pit-tay-ho]



Get coat [naa-tuh miss-go-taa-guy]



Get in car Nâta miskotâkay Pôsi sêhkêpayîsihk [poo-sih say-kay-pie-yees-sick]

First / Then Boards:

First/Then boards are similar to visual scheduling and can support individuals for upcoming transitions. This step by step visual can be motivating for individuals to complete non-preferred activities. First/Then boards can lessen stress, anxiety and can direct attention on the task at hand.





Often people with autism do not easily "pick up" subtle social cues including body language or other social cues or norms, by just watching others. Social cues will differ from age, gender, and within cultures. Some examples of this are:

- Interpreting facial expressions
- Tone of voice (sarcasm or telling a joke)
- Following cultural protocol (such as, walking in one direction at feast, speaking during prayer, waiting to be served, etc.)
- Following feast protocol (walking in one direction, waiting to be served, etc.)

People with autism may need extra time to be taught these cues and may need specific support on developing these skills.



Storm's strengths are numbers and math, she can read very well. She notices facial expressions, and is very loving and athletic.

KACHEENA NAYTOWHOW, mom Storm Lawrence (9 years old)

Helping to Support Behaviour

People with autism can have rigid, repetitive types of behaviour, interests, or activities. The intensity will vary from person to person.

Some ways you can support a person with this aspect of their life is to:

- Maintain a predictable routine when possible
- Provide a warning if routine is expected to change
- Use visual scheduling to help explain a task or routine
- Break tasks down into steps using visual step-by-step instructions
- Provide social coaching to help manage anxiety
- Use timers to help prepare for transitions

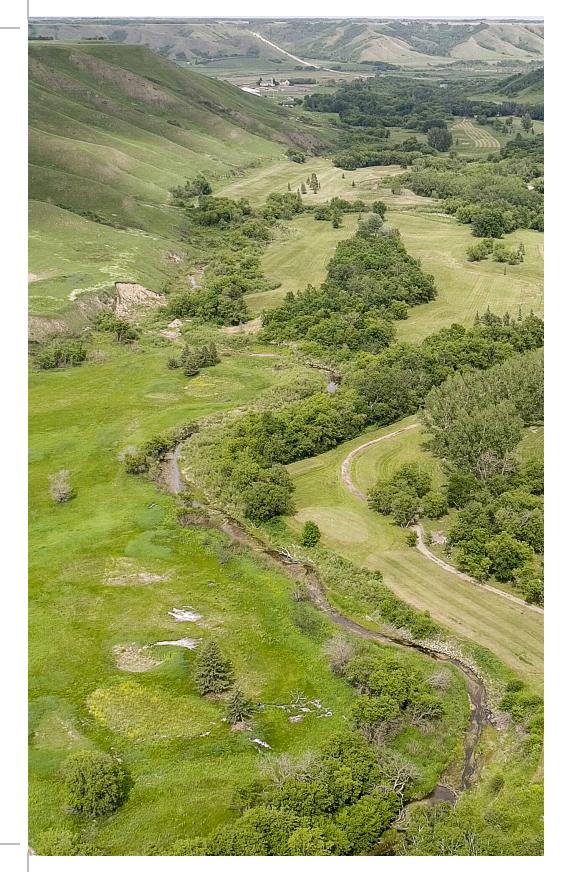




Breaking Down Steps

By getting tasks down to their most simple steps, people with autism may be able to better learn new skills. It is important to communicate steps in words and pictures. This will remove too much language, which may be hard for individuals to process. The number of steps that need to be outlined will vary from person to person.





Strategies to Support Sensory Sensitivities

Not all people with autism have sensory challenges, for those that do, they are not all the same. The support you offer will be specific to the individual.

Some ideas for supporting those with sensitives include:

- Using headphones
- Listening to music
- Dimming lights
- Wearing sunglasses, visor, hat
- Ensuring clothing is comfortable and not itchy or tight (e.g., cut off tags)
- Providing a "heads up" if no will be the response to a question or behaviour
- Modifying activities and environment to reduce sensory overstimulation



Living on the Autism Spectrum

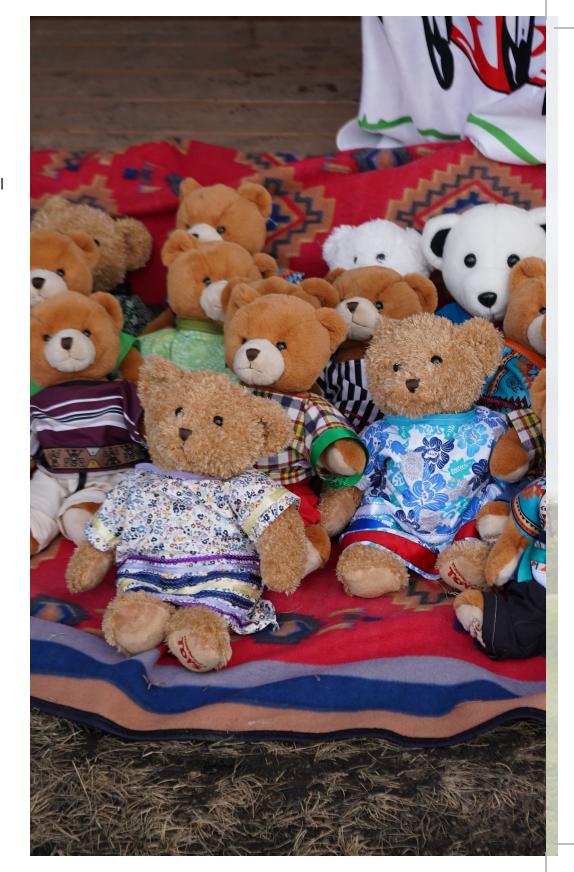
Autism & Resiliency

People with autism may have some struggles, but they can be incredibly resilient. Resilience in people with autism and their families leads to better understanding and good outcomes. In time this can reduce caregiver burden, improve positive emotional wellbeing and develop stronger coping abilities.⁶

Building resiliency leads to finding a greater appreciation of life. Some ways families can support resilient development are:

- Accessing supportive resources
- Gaining spiritual strength
- Connecting with social groups or activities
- Family and/or community support
- Focusing on what one can control
- Being optimistic about the future
- Accepting and celebrating differences

6 Kauhlthau et al., 2019; Palmer et al., 2019; Picardi et al., 2018; Pastor-Cerezuela et al., 2016; Rigles et al., 2017



He loves the land, berry picking and he calls it his land. He talks about ancestors and reminds me that they look after us. Culture has a big part of his heart, being on the land and ceremony will help our autistic kids.

KACHEENA NAYTOWHOW,

9 years old, Storm Lawrence





Culture as a Source of Support

Cultural support, through ceremony, storytelling or other formats can be significant support for families with autistic children in building resiliency and creating supportive environments.

"I would love to see a cultural component to therapy. My mother has passed on and I'm not close to my family. I would love to teach my children my culture but I have no one to ask. My little guy would benefit greatly from exposure as would the rest of my children."

CHEYNNA DELORME, Mom to Omar age 3



"Decolonizing our approach is important. Our children do not need to be in institutional homes. We learn from them. Ayul prepared their family to learn about him. He received his ceremony name when he was two. He was still rolling when he was two and he couldn't get over humps. He learns Lakota with Jeanne, he participates in ceremonies. Children have many gifts and their gift don't come out right away."

JEANNE HAYWAHE AND HEATHER ACOOSE (Kokums to Ayul – 15)

Guide References

- Aspler, J. et al., (2019). Stigmatisation, exaggeration, and contradiction: An analysis of scientific and clinical content in Canadian print media discourse about fetal alcohol spectrum disorder. Canadian Journal of Bioethics, 2(2), 23–35.
- Bailey, B., & Arciuli, J. (2020). Indigenous Australians with autism: A scoping review. Autism, 24(5), 1031–1046.
- Cummings, J. R. et al., (2015). Health services utilization among children with and without autism spectrum disorders. Journal of Autism and Developmental Disorders, 46(3), 910– 920.
- Fairthorne, J., De Klerk, N., & Leonard, H. (2017). The relationship between maternal raceethnicity, immigrant status and country of birth and the risk of having a child with autism spectrum disorder in Western Australia. International Journal of Population Data Science, 1(1).
- ► Halladay, A. K. et al., (2015). Sex and gender differences in autism spectrum disorder: Summarizing evidence gaps and identifying emerging areas of priority. Molecular Autism, 6(1).
- Hodgdon, L. A. (2000). Solving behavior problems in autism: Improving communication with visual strategies. QuirkRoberts Publishing.
- Hodges, H., Fealko, C., & Soares, N. (2020). Autism spectrum disorder: Definition, epidemiology, causes, and clinical evaluation. Translational Pediatrics, 9(S1).
- Inman, C. E. (2019). Absence and epidemic. Canadian Journal of Disability Studies, 8(4), 227–261.
- Kuhlthau, K. A. et al., (2019). A virtual resiliency intervention for parents of children with autism: A randomized pilot trial. Journal of Autism and Developmental Disorders, 50(7), 2513–2526.

- Lindblom, A. (2017). Exploring autism and music interventions through a first nations lens. AlterNative: An International Journal of Indigenous Peoples, 13(4), 202–209.
- Palmer, M. et al., (2019). A Novel Group parenting intervention to reduce emotional and behavioural difficulties in young autistic children: Protocol for the autism spectrum treatment and resilience pilot randomised controlled trial. BMJ Open, 9(6).
- Pastor-Cerezuela, G. et al., (2016). Parental stress and ASD. Focus on Autism and Other Developmental Disabilities, 31(4), 300–311. https://doi.org/10.1177/1088357615583471
- Picardi, A. et al., (2018). Parental burden and its correlates in families of children with autism spectrum disorder: A multicentre study with two comparison groups. Clinical Practice & Epidemiology in Mental Health, 14(1), 143–176.
- Rigles, B. et al., (2016). The relationship between adverse childhood events, resiliency and health among children with autism. Journal of Autism and Developmental Disorders, 47(1),
- Weiss, J. A. et al., (2017). Health concerns and health service utilization in a population cohort of young adults with autism spectrum disorder. Journal of Autism and Developmental Disorders, 48(1), 36–44.

			1

I am deeply grateful to Chief Cadmus Delorme and the Cowessess First Nation community for welcoming the Autism Resource Centre, for inviting us into the community and for sharing their stories with us.

When we began our partnership in 2019, I could not have predicted the learning and growth that would occur over the course of our two years together. The cultural learnings we received opened our awareness to a beautiful worldview which approaches those with autism as powerful, as gifts from the Creator. We cultivated a richer understanding of how we view autism and how we support families. I thank the Cowessess First Nation community and the strength of its people for guiding us toward a more holistic perspective and a kinder approach. It is my hope that this project provides a step toward continued partnerships not only here in Saskatchewan but across Canada.

- Keely Wight-Young, Autism Resource Centre

