A Family's Journey: Understanding Your Child's Communication, Social Development and Early Signs of Autism

For more information scan this QR code or go to myhealth.alberta.ca/autism-family-and-caregiver-pathway

The information in this guide applies to infants and young children who show early signs related to autism. Autism is a condition that affects how a person's brain develops and works. Children with autism may face difficulty with communication, social interactions, and behaviours.
You are your child's most important support and a key part of their healthcare team. This guide will help you understand what to expect as you work with your child's healthcare team to care for and support your child. If you have any questions along the way, please ask your child's healthcare team.

Getting Help Early (page 7)

All children with developmental delays or concerns can benefit from early support and resources.
- Contact Pediatric Rehabilitation to explore options–self referral is available.
- Consider other available community supports and your natural support network (e.g., playgroups).
- Apply early for Program Unit Funding (PUF) to access early intervention support through Alberta Education.
- Apply for the Family Support for Children with Disabilities (FSCD) to access family support services and, if applicable, child focused services.

Before your child's appointment with their healthcare provider (page 8)

- Consider keeping a journal about your child. Write down or record video of things like daily routines, sleep, eating, changes in communication, activity and place transitions, likes and dislikes, bowel movements, and sensory triggers.
- Collect reports or assessments that have been done and keep them with your journal. Share these with your child's healthcare providers such as your family doctor or the Pediatric Rehabilitation team.
- Write down any changes, questions or concerns about your child's growth and development.
- Consider bringing other caregivers, a family member or friend to support you and your child during your appointment.
- When booking your appointment, you can ask for things that might make the appointment easier for you and your child (e.g., appointment time, quiet room, virtual options etc.)

Visit your child's healthcare provider (page 9)

Your child's health includes physical, emotional, spiritual, financial, social, and environmental elements. In order to better support your child, healthcare providers need to hear from you and understand your family.
- Share what is important to your child and family, what their strengths and needs are, their support system, and what makes your child unique.
- Consider sharing the information collected in your journal, and any other reports and assessments.
- Your healthcare provider will ask you questions and assess your child. This may include:
  - o Questions about your family history with autism.
  - o Measurements of height, weight, head circumference, and reflexes.
  - o Questions about your child's development.
  - o Observing how your child plays or communicates.

Other assessments your child may have (page 12)

- If your primary care provider or pediatric rehabilitation provider think your child would benefit from more evaluation, they may suggest vision, hearing and/or speech and language assessments. In many cases, you can self refer for these assessments, but a referral may still be needed for certain services.
- You may be asked to take information from other appointments back to your healthcare team. You can use your journal to help keep all the information in one place.
- Information from additional assessments will help you and your healthcare team decide what to do next to best support your child.

Review your child's support options (page 13)

- Your healthcare provider might send your child to a clinic that offers therapy and other supports.
- Your healthcare provider may recommend that your child be seen by a pediatrician, a developmental pediatrician or a clinic that specializes in autism assessment.
- Ask who your child is being sent to and what they do.
- Ask how long it will take to be seen and what you should do if you don't hear back in the time you expect.

Keep taking care of yourself and your child (page 18)

- It is important that you take care of yourself and your family while you care for your child.
- Talk with your support network and your healthcare team about your health and support needs.
- Look for or ask your healthcare team for local or online resources and supports.

Important Tips:

Need a clinic, family doctor or nurse practitioner?
https://albertafindaprovider.ca

Need a translator or interpreter?
Let your healthcare provider know.

Need health advice?
Call Health Link at 811 Rehabilitation Advice Line at
1-833-379-0563

Need culturally appropriate care?
Indigenous Support Line at 811

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How to use this resource

This resource is designed to help caregivers of infants and young children who may be experiencing developmental delays in social interactions or communication. This resource also acts as a guide for caregivers to understand what to expect if your child is showing early signs of autism.

The information provided in this resource is based on validated evidence from a variety of sources, including healthcare professionals in Alberta, peer-reviewed journals, current clinical guidelines, validated patient resources, and specialty care recommendations. It is intended as general health information and should not replace the clinical judgment or advice of a qualified healthcare provider. Always consult with your child's healthcare team and follow their recommendations for your child's specific care.

This pathway is a guide, not a one-size-fits all solution. Every family is unique and your family's culture, experiences, and traditions matter. Use this pathway as a starting point and adapt it in ways that work best for you.

Language

We respect the different opinions of people with autism and their families. In this guide, we use two types of language: **person-first** and **identity-first**. This aims to keep a fair and balanced approach. If you prefer a style of language, please discuss this with your healthcare team and others in your life, so they can best support you.

- **Person-first language** puts the person before the condition. It reminds us that each person is more than their diagnosis and helps show respect and inclusion. Example: "child with autism."
- **Identity-first language** puts the condition first. It shows that autism is an important part of who someone is. This is often used by people who speak for themselves and when shorter wording is helpful. Example: "autistic child."

Whole-family health

The whole-family health approach will help you balance the overall needs of your family, while addressing the questions or concerns you have about your child's development.

Whole-family health means thinking about all parts of your family's health and wellness: physical, financial, social, spiritual, emotional, and environmental. All of these parts are connected and influence each other. It's important to be aware of your personal needs, and your family's needs in each part and to share that information with your child's healthcare team.

- **Physical**: the impact of your child's health condition on you and your family's physical well-being
- **Financial**: your ability to meet your family's housing, transportation, food, and health needs
- **Social**: feeling supported to manage your child's daily life, and having meaningful relationships
- **Spiritual**: your family's beliefs, sense of connection, and purpose
- **Emotional**: how your family thinks, feels, and copes with life events
- **Environmental**: the impact of the places where your child and family live, learn and spend time

Whole-family health also reminds us that we are all connected and work together: your child, your family, your child's support systems, and their healthcare providers. Their healthcare providers could be their doctor, nurse practitioner, or a pediatric rehabilitation and early childhood development team that comes together with you to plan and organize-their care.

Your child's healthcare providers need to understand who your child is and what matters to your child and family. This helps to build understanding of your strengths and needs so they can understand how to tailor a program to suit your unique child and family. But it can be hard to know what to share or what to say. Start by asking yourself:

"What are the things in my child's life that are important to them?"

"What are the things in our family or home that may be affecting my child's health and well-being?"

Bringing forward what matters to your child and family is important. Here are some examples of things you may want to talk about with your child's healthcare provider:

Physical

"I am worried we are not getting enough sleep."

"They are hurting themselves or others."

"I have trouble getting my child to eat a variety of foods and I'm worried we are not getting enough healthy food."

"I am tired all the time from trying to help my child cope."

Social

"I can't find childcare to look after my children."

"I feel like we don't have support or people who understand."

"My child doesn't play with their siblings."

"We spend less time with family and friends because it is too much work to manage my child's behaviour."

"Their behaviours are making it hard for us to go to a restaurant or social gathering."

Emotional

"I feel isolated, angry or judged and have no one to talk to."

"My family is overwhelmed and I'm not sure how to manage it."

"I'm constantly anxious about getting a call from my child's daycare/preschool to come pick up my child."

Spiritual

"It is important that our cultural, religious or traditional practices be respected in my child's care."

"I feel disconnected from our religious community or places of worship."

"I feel my child is celebrated in our community and others don't understand."

Environmental

"We avoid crowded spaces because my child is highly sensitive to noise."

"We avoid open water because of safety concerns."

"I'm always worried that my child will wander off."

Financial

"We cannot afford to pay for medical supplies or the things my child needs."

"It's really expensive to pay for therapy sessions and travel to appointments."

"I'm afraid to lose my job because of my child's needs."

"Taking care of my child is a full-time job."

"I don't know how we will pay for communication and sensory tools."

What is Autism?

The information in this guide applies to infants and young children who show early signs related to autism. Autism is a condition that affects how a person's brain develops and works. Autistic children often face challenges with communication, social interactions, and may repeat certain actions and behaviours.

A note for caregivers

This can be a lot. It's okay not to do everything at once. Read this pathway and take steps that feel right for you and your family, at a pace that works for you.

Sometimes called **autism spectrum disorder, autism** is a condition that lasts a lifetime and can have a big impact on your child and your family. Autism is referred to as spectrum because it looks different for each child. Some children have mild signs, while others have more noticeable challenges. Many children with autism also have other health conditions, which can make things more complicated. Because of this, and because every family is different, every autistic child needs different kinds of help and support. Obtaining an early diagnosis of autism can also open the doors to different resources that are important for some children and families. If your child shows signs of autism, it is your choice if and when you consider getting a diagnosis. Many types of support, like pediatric community rehabilitation, will be helpful with or without an autism diagnosis. Autism affects the whole family, including parents, siblings, grandparents, and caregivers.

Doctors don't know exactly what causes autism. No single reason has been identified and investigation of causes is complicated — it can be a mix of genetics, the differences in how our brains work, and things in the environment. Claims that vaccines or Tylenol cause autism lack evidence and are not supported by any recognized autism experts in Canada.

There is no one test or single sign that shows someone has autism. Every autistic person is unique. Autism can look different depending on the person's age, how they learn, and how they communicate. Some signs families might notice include the following (this is not a complete list):

Social Responsiveness

Some children may:

- Smile less often or express emotions differently
- Miss or not respond to social signals, such as facial expressions, body language, or tone of voice
- Use eye contact in their own way, which might mean less eye contact or eye contact that seems different than other children
- Prefer playing alone or with adults, and may take more time before becoming interested in playing with other children
- Not always respond when caregivers try to get their attention, such as when their name is called

Communication
Some children may:

- Take longer to say words or start talking and then stop or reduce speech
- Use words in specific ways, such as repeating sounds, words, or phrases they hear
- Communicate mostly to ask for what they need, rather than to share thoughts or feelings
- Use fewer hand or body gestures, like pointing, waving, or nodding

Behaviour
Some children may:

- Enjoy doing things in repeated ways, such as saying the same words, making certain sounds, playing with objects in familiar patterns, or spinning objects
- Develop strong interests in specific topics or activities that bring them comfort, focus, or joy
- Prefer routines and predictability, and may feel upset when plans or surroundings change
- Experience the world through their senses differently, which may lead them to seek out or avoid certain sounds, textures, lights, or movements. This may look like:
    - Refusing to eat certain food types and textures
    - Extreme or limited sensitivity to temperature or pain
    - Seeking sensory pressure from caregivers to calm down
    - Always on the move
- Need extra time and support to move between activities or places, especially when changes happen quickly

Although children are born with autism, it can take time for signs to develop and be noticed. You may notice signs of autism as early as 6 months. Signs and behaviours are different and unique for every child and children may present differently in different settings (for example, at home versus at daycare). Parents are first to recognize signs and differences in their child that may need further follow-up by their healthcare provider. You also know your family best; it will be up to you to decide your journey and whether you want your child to have an autism assessment. With or without an assessment, there are supports available to you.

Getting Help Early

If you have questions about your child's social development and communication, you can contact the following early support services and programs. All children with developmental delays and concerns can benefit from early support and resources.

- ☐ **Pediatric Rehabilitation**
  www.ahs.ca/pedrehab
- ☐ **Early Childhood Intervention Program** https://www.albertahealthservices.ca/rehab/Page18405.aspx
- ☐ **Rehabilitation Advice Line** at 1-833-379-0563 can help you find the program or service right for your family.
- ☐ **Family Resource Network or your childcare provider**
  https://www.alberta.ca/family-resource-networks
- ☐ **Healthy Parents Healthy Children**
  https://www.healthyparentshealthychildren.ca/

Apply early for the following educational and family supports:

- ☐ **Early education support through Program Unit Funding (PUF)**
  Children must be 2 years+ 6months and less than 6 years of age as of September 1st of the current school year, to qualify. Diagnosis of severe delay (not autism specific) is required.
  Ask a member of your healthcare team for a list of agencies that offer PUF support.
  - Ask for a medical diagnosis letter from the child's primary care provider. This can be helpful to have when applying for additional funding and support programs.
  - You may apply any time of the year

More information about PUF can be found here: https://open.alberta.ca/dataset/499a64b2-65ad-4748-a28f-ceb0f55d8ca6/resource/dde92814-4a6c-4130-98d7-7c1a63505f8c/download/2014-4-completing-a-puf-application.pdf

- ☐ **Family support services through Family Support for Children with Disabilities (FSCD)**
  Family support services include respite, counseling, medical appointment travel supports, clothing and footwear supports.
  - Apply early (autism diagnosis not required) as waits can be long.

More information about FSCD can be found here: https://www.alberta.ca/fscd

Additional support information can be found in resources at the end of the document.

- ☐ Your local community may have additional developmental supports, talk with those in your network about what may be available.

Before your child's appointment with their healthcare provider

Every child and family will have their own unique journey with autism. How you and your child move through your journey, the number of visits with their healthcare team, the healthcare providers they will see, whether you seek a diagnosis and the length of time it takes to get an assessment will all depend on your child's individual needs.

Think of what your goals are for you and your child and what is most important to get out of their appointment. Here is a checklist with some tips to help you get ready for your appointment with your child's healthcare team.

When booking your child's appointment ask for things that might make the appointment easier for you and your child, such as:

- ☐ a virtual option
- ☐ an appointment time in the early and less busy time of the day
- ☐ a quiet room to wait in
- ☐ bring a favourite toy to the appointment to help as a comfort item

Considerations for our visit:

- ☐ A journal can help you remember what behaviour your child is showing, when it started, how often it happens, what makes it better or worse.
- ☐ Bring video recordings of different behaviours to show the healthcare provider.
- ☐ Bring any documents you may have received from other health or childcare providers.
- ☐ Write down a list of your child's strengths, your questions, and concerns. What is going well and what supports do you have in place. When you're done, read your list and mark the most important things.
- ☐ Make a list of the prescription and non-prescription (over the counter) medicines your child uses, including any vitamins, herbs, and supplements.
- ☐ Ask someone you trust to go with you to your child's appointment. They can help you ask questions, write down instructions, and remember explanations.

Helpful tools and resources

- To get the most out of your visit, plan to write notes during the visit or see the Alberta Health Services **My Care Conversations app** (ahs.ca/careapp) website for more information about recording your conversation with your healthcare provider.

Visiting your child's healthcare provider

Your child's healthcare provider (e.g., doctor, nurse practitioner, speech-language pathologist, or early interventionist) will review your child's history of behaviours. They may ask what your child likes to do and if they have any favourite toys or foods. They may also ask what brings on behaviours, how often and how long they last. They may also ask how their behaviours and triggers may impact the things your child does every day like preschool, childcare, hobbies, eating, and sleeping. They will likely ask about how your child's behaviours impact you and your family and what strategies you use to deal with any difficult behaviours. They may also ask what your child's strengths and needs are, what their support system looks like or what makes your child unique.

Seeing a primary care provider (pediatrician, family doctor, or nurse practitioner) is always a good idea when you have questions about your child's development.

Healthcare provider's assessment may include:

- Medical and family history (for example, sibling or aunts and uncles with autism)
- Growth measurement such as weight, height, head circumference
- Examining muscle reflexes
- Child development questionnaires- they may ask that you fill this out on your own or may complete it with you during an office visit
- Observations of your child's play interests in the clinic

What should I watch for if my child is showing early signs of Autism?

Get early support for:

- Talking concerns and how your child talks or interacts with others
- Sleeping problems
- Unusual diet
- Early learning and developmental delays

Contact your healthcare team if your child has:

- Increased aggressive behaviour
- Meltdowns that become more frequent, more intense, or that make daily life very hard to manage
- Increased food aversions, or changes in weight
- Hearing and vision concerns
- Can no longer do/say things that they could before
- Difficult bowel movements

Call 911 any time if urgent medical attention is required:

- If a meltdown becomes a medical emergency such as breathing problems or physical injury
- If your child has wandered off, especially near traffic, water or unfamiliar surroundings

What should I share with my healthcare provider?

"What impact are your child's developmental differences or signs of autism having on things that are important to you and your child, like school, childcare, your job, hobbies and interests, and relationships?"

"What has worked for you in the past to manage your child's triggers?"

"What are your favourite things to do with your child?"

"What types of things help you work better with your healthcare team and what you expect and need from the relationship with your healthcare provider?"

There are lots of things in your life that can impact your ability to manage your child's health, like:

- Challenges with money, housing, and access to transportation
- Not enough support or help
- Not enough sleep and self-care
- Competing demands, like work and other children in the home

It is important to talk about these things with your healthcare provider because they all play a role in your own and your child's health and well-being.

You and your child are the most important part of your child's healthcare team: If you do not understand what your healthcare team is telling you, let them know right away. Be open and honest, they are there to support you.

You might say:

"This is new to me. Could you please explain it slowly, using language that is easier to understand?"

"It sounded like you said that I should… Did I understand that correctly?"

"Can you repeat the next steps to me?"

"Will you please write that down so that I can think about it more later?"

Helpful tools and resources

- Making the most of your appointment: myhealth.alberta.ca/health/pages/conditions.aspx?Hwid=hw226888
- Working with your healthcare team: hqa.ca/info (Health Quality Alberta)

Other assessments your child may have

Every child may benefit from different assessments and screening depending on their individual health needs and your family goals. With your permission, your child's primary care provider may send your child for multiple assessments or to a place where they can all be done at one place.

Self-referral and referral options will be discussed in this section. Information from additional assessments will help you and your healthcare team decide what to do next to best support your child. If you decide to to access them privately, there may be a fee (cost) for some of these assessments.

Vision assessments

Sometimes vision problems may present like autism signs, like being sensitive to bright light or having problems making eye contact or responding to gestures like pointing. Your child's healthcare provider might refer your child to an eye doctor to test their vision. Vision tests are done by special eye doctors called Optometrists or Ophthalmologists. These tests screen for vision problems. Eye examinations for infants can start at 6-9 months. Children 18 years old and younger are eligible for one routine eye exam and one diagnostic procedure per benefit year. More information on vision testing can be found here: https://myhealth.alberta.ca/health/pages/conditions.aspx?hwid=hw235693&lang=en-ca#hw235696

Hearing assessments

Hearing tests help to tell if hearing problems may be causing developmental delays, especially those related to social skills and language use. Your child might be referred to an Audiologist. More information on where to get hearing tests can be found here:

https://myhealth.alberta.ca/topic/Pediatric-Rehabilitation/pages/hearing.aspx?tab=2

Speech and language assessments

These tests might be done to see how your child communicates and understands. Your child's healthcare provider might refer your child to a speech-language pathologist. More information on where to get speech and language assessments can be found here:

https://myhealth.alberta.ca/Topic/Pediatric-Rehabilitation/Pages/communication.aspx?tab=3

Remember to bring your journal to all appointments. Keep assessment and health records with your journal.

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It is important to know what your child's healthcare team finds out. Take time to discuss findings and recommendations. Medical terms can be hard to understand. And even common words like "positive" or "negative" might mean something different. Ask your child's healthcare provider for explanations and examples to make sure you fully understand.

You might ask:

"What does this mean for my child?"

"Is there a current concern? If so, what will I do next?"

Review your child's support options

Developmental Support

Your primary care provider might refer your child to a clinic that offers therapy and support for families and children that require more specialized care. Sometimes clinics have different care providers there to help you and your child. Depending on what you need and where you live, your developmental support might look different.

Pediatric Rehabilitation: Pediatric rehabilitation services support the development of children and youth to participate in meaningful activities of daily life at home and in the community. Focus is on the early years and early intervention to prevent health complications and improve long term health and wellbeing.
https://myhealth.alberta.ca/Topic/Pediatric-Rehabilitation/Pages/default.aspx

Early Childhood Intervention Program (ECIP): The Early Childhood Intervention Program provides information, education and support to families with infants and young children who have developmental delays or disabilities. Early childhood intervention providers and families work together to improve a child's development and their ability to take part in everyday activities at home and in the community. For more information please visit:
https://www.albertahealthservices.ca/rehab/Page18405.aspx#services

Specialized development supports can be provided by various healthcare providers depending on your zone and needs. Below is a list of various healthcare providers and what they do. The following list is in alphabetical order.

Behavioural Health Consultant - They provide brief, evidence-based interventions for a variety of issues, including mental health problems, chronic conditions, and life stresses. Their focus is on the mind-body-behaviour connection and supporting overall health in collaboration with a patient's primary care provider.

Board Certified Behaviour Analyst - They are specialists in Applied Behaviour Analysis (ABA), an intervention technique for individuals with autism and other developmental disabilities.

Child Development Specialist - They help infants, children, youth and families cope with the stress and uncertainty of acute and chronic illness, injury, trauma, disability, loss and bereavement. They provide evidence-based, developmentally and psychologically appropriate interventions including therapeutic play, preparation for procedures, and education to reduce fear, anxiety, and pain. They can help with navigating resources.

Occupational Therapist - They support meaningful participation in daily activities (occupations), through assessment and collaboration with families. This can include supporting skill development, modifying activities as well as adaptations to the physical and social environment.

Physiotherapist - They can work with children to strengthen gross motor skills and improve endurace, strength, balance, gait and coordination.

Psychologist - They can assess or observe and support parent-child responsiveness, attachment and emotional regulation skills. Assessing co-existing conditions to assist with differential diagnosis. They can diagnose autism and may be accessed privately.

Registered Dietitian – They can help you find foods your child might eat and offer suggestions on ways to make mealtimes easier.

Registered Nurse - They care directly for individuals, families, groups, communities to be healthy and well. Nurses will coordinate patient care as part of a team with physicians and other healthcare providers.

Social Worker - A social worker can provide early support to families before diagnostic services by ensuring families are well connected to communuity resources. Social workers can provide emotional support, clarity in the assessment process and answer any question the family may have. They can support your family in navigating the diagnosis process.

Speech-language Pathologist - They assess and help with verbal, non-verbal and social communication skills. This includes helping to figure out what your child understands and how they send messages. They can also provide suggestions for alternative and augmented communication (picture-based communication systems, signs and gestures, device trials, and tablets).

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Autism Assessment

Your primary care provider may also need more advice from a pediatrician or developmental pediatrician or may suggest you visit a clinic that specializes in autism assessment. These require referrals and sometimes medical letters. Keep that medical letter, it can also be used to apply for PUF, FSCD or other supports if they are needed. There is often a fee (cost) associated with obtaining medical documentation.

Pediatrician - They are medical doctors who specialize in the care of children. Pediatricians can treat children who have any type of problem, or they may specialize in specific areas, such as developmental disorders (behaviour, communication, and mental disorders in children).

Developmental Pediatrician – They are a medical specialist who diagnoses, assesses and manages autism spectrum disorder and related conditions, providing comprehensive care for child's developmental, behavioural, and learning needs to improve the quality of life of families.

Autism Assessment Clinics

Child Development Services Clinic/Autism Spectrum Disorder Diagnostic Clinic (Calgary-Alberta Children's Hospital): Provides diagnostic assessment, medical management and consultation services for pediatric patients with a question of Autism Spectrum Disorder. For more information please visit:
https://www.albertahealthservices.ca/findhealth/Service.aspx?serviceAtFacilityID=1110630
https://www.albertahealthservices.ca/findhealth/service.aspx?Id=1071164&facilityId=311

Infant and Preschool Assessment & Outreach Service (Edmonton: Glenrose Rehabilitation Hospital): This program helps children and their families if they have questions about the child's development and they think the child might have Autism Spectrum Disorder that cannot be confirmed in the community. For more information please visit:
https://www.albertahealthservices.ca/findhealth/Service.aspx?id=5768

Pediatric Specialty Clinic (Camrose Professional Centre, Red Deer 49th Street Community Health Centre): Provides developmental assessments (2 years and 6 months old and up) for autism spectrum disorder (ASD), Attention-Deficit/Hyperactivity Disorder (ADHD) and/or Fetal Alcohol Spectrum Disorder (FASD). Diagnosis may be provided directly by the clinic or in collaboration with your Physician or Pediatrician.
https://www.albertahealthservices.ca/findhealth/service.aspx?Id=1041851

West Audiology and Children's Allied Health/Autism Diagnostic Clinic (Lethbridge: Melcor Centre): This service offers skill-building, assessment, and treatment activities for the families of children who have or may develop developmental delays, or disabilities.
https://www.albertahealthservices.ca/findhealth/Service.aspx?id=1085877&serviceAtFacilityID=1138046
https://www.albertahealthservices.ca/findhealth/Service.aspx?serviceAtFacilityId=1101933

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East Audiology and Children's Allied Health/ Developmental and Behavioural Diagnostic Clinic (Medicine Hat Regional Hospital and Brooks Health Centre): This service offers skill-building, assessment, and treatment activities for the families of children who have or may develop developmental delays, or disabilities.
https://www.albertahealthservices.ca/findhealth/service.aspx?Id=1001806
https://www.albertahealthservices.ca/findhealth/Service.aspx?id=1001806&serviceAtFacilityID=1126261

Private options exist for early intervention, support and diagnosis of autism. Call Rehabilitation Advice Line (1-833-379-0563) or ask your primary care provider for more information. In some communities, local agencies may be available to help you explore private healthcare provider options, such as the Centre for Autism Services Alberta, Autism Edmonton, and Autism Calgary. Some private healthcare provider services may be covered by extended health benefits. **See below for local agency web links.**

Asking the following questions can help you make an informed decision about your child's different support options and decide which one(s) will work best for you:

"What are the advantages and disadvantages of each option?"

"Can I use any of these options together?"

"Who is my child being refered to and what do they do?"

"How long will it take to be seen andwhat can we do before we get in?"

"When should we hear back about an appointment, what do we do if we do not hear back from them?"

Helpful tools and resources

To learn about how to prepare for your appointment, check out the QuRE Patient and Caregiver Journal by visiting ahs.ca/qure.

If you want tips and resources on starting the conversation about Autism with friends, family or children visit https://autismalberta.ca/how-to-talk-about-autism/

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If you live far from care:

Social Workers can help with challenges and connect you to supports and resources. Please contact the clinic your child will be attending and ask to speak with a Social Worker. They can help find travel and accommodation options and make referrals if needed. Available supports depend on location and eligibility. The clinic can also tell you if help is available for extra costs related to your child's appointment, such as gas, food vouchers, or parking passes. They can recommend public and private transportation options available in your region.

Virtual Service Options: If you live in a community with limited access to healthcare providers, some appointments and supports may be available virtually. These options can reduce the need for travel and help you stay connected to care and support groups.

- **Pediatric Rehabilitation**- Offers online information, webinars, and parent support groups. https://myhealth.alberta.ca/topic/pediatric-rehabilitation/Pages/default.aspx
- **Alberta Referral Directory**- Helps you find service providers that can meet with you individually and may provide virtual options. https://www.albertahealthservices.ca/info/page14282.aspx (Click on your location and search "autism" or "pediatric rehabilitation")
- **Alberta Indigenous Virtual Care Clinic**- Serves individuals self-identifying as First Nations, Inuit and Metis and their immediate family members. This service is ideal for patients who do not have a primary care provider or those who would like to avoid a wait to receive a consult for a non-urgent issue. www.aivcc.ca

Accommodation Options: If your child needs to travel for care, there may be accommodation options that may help reduce costs:

- **Community and charity organizations-** Service options vary by location; there may be options to offer support by providing accommodations or financial support. A referral from hospital staff may be required.
- **Hotels-** Ask for "hospital, compassion, or medical rates," as many hotels near healthcare facilities offer discounted pricing.

Travel Tips: Planning ahead can help make travel easier for both you and your child:

- Pack your child's favourite snacks and travel-friendly games or activities.
- Bring all medications your child will need and pack extra in case of any delays.
- Plan ahead for rest stops and bathroom breaks.
- Ask the clinic their policy on rescheduling appointments based on transportation needs or inclement weather. It is recommended to stay in contact with the clinic if there are barriers to, or delays with, being able to attend your appointment.

Medical Travel Funding and Financial Supports: You may be eligible for financial help to cover travel costs:

- **Family Support for Children with Disabilities (FSCD)** – ensure that you discuss your travel needs with your FSCD caseworker. Based on your family's needs, you may be eligible for support with mileage, parking, meals, accommodation, and sibling care costs related to attending a medical appointment. Ensure that these supports are included in your FSCD contract prior to attending or travelling for medical appointments. More information about FSCD can be found online https://www.alberta.ca/fscd-supports-and-services
- **Non-Insured Health Benefits (NIHB)-** The NIHB program provides registered First Nation and recognized Inuit residents with coverage for a specified, nationally consistent range of health benefits not otherwise covered through provincial or territorial health insurance, private insurance plans, or other publicly funded plans or programs. Additional information can be found online https://www.sac-isc.gc.ca/eng/1572537161086/1572537234517 or by contacting NIHB Medical transportation Telephone (toll free): 1-800-514-7106
- **Medical expenses on a tax return-** You may be eligible to claim travel expenses if you are needing to travel over 40km (one way) from your home to get medical services. The cost of the travel expenses (including accommodations, meals, and parking) may be eligible when needing to travel at least 80km (one way) from your home to get medical services. Additional information about eligible expenses and how to claim can be found online https://www.canada.ca/en/revenue-agency/services/tax/individuals/topics/about-your-tax-return/tax-return/completing-a-tax-return/deductions-credits-expenses/lines-33099-33199-eligible-medical-expenses-you-claim-on-your-tax-return.html

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Keep taking care of yourself and your child

Taking care of yourself and your family as a parent of an child with developmental differences or a child with autism means paying attention to all parts of your own well-being—physical, emotional, spiritual, financial, and social. These areas are deeply connected, and strengths and challenges in one can easily affect the others, especially when you are working through the ongoing daily commitments of caregiving. Making space for your own needs helps you stay grounded and better able to support your child. This may include helping you stay on top of your own well-being, your family's needs and connecting you with local or online resources and supports that can strengthen your family's overall wellness.

Pediatric Rehabilitation Supports for Parents and Caregivers
https://myhealth.alberta.ca/topic/Pediatric-Rehabilitation/pages/resources.aspx

Pediatric Rehabilitation Caregiver Connection
https://together4health.albertahealthservices.ca/peds-rehab

Healthy Parents Healthy Children
https://www.healthyparentshealthychildren.ca/

Family Resource Networks
https://www.alberta.ca/family-resource-networks

AIDE Canada – Parents and Caregivers Hub with toolkits, webinars, courses, and respite information.
https://aidecanada.ca/community/parents-caregivers-supporters-and-families

Centre for Autism Services Alberta – Family coaching, therapy supports, and caregiver capacity-building.
https://centreforautismab.ca/

Triple P- Stepping Stones Parenting Course- For Parents of a Child with a Disability – Helps you manage problem behaviours and developmental issues common in children with disability. Courses vary as seminars, group sessions, or individual sessions.
https://www.triplep-parenting.ca/alb-en/parenting-courses/stepping-stones-for-parents-of-a-child-with-a-disability/

Financial support is critical as many parents of autistic children experience greater financial stress and hardship.

Disability Tax Credit: Income tax reduction for supporting family members. Medical practitioner certifies severe or prolonged impairment.
https://www.canada.ca/en/revenue-agency/services/tax/individuals/segments/tax-credits-deductions-persons-disabilities/disability-tax-credit.html

Child Disability Benefit: Must be eligible for Canada Child Benefit and Disability Tax Credit. Medical practitioner must certify that the child has a severe and prolonged impairment. https://www.canada.ca/en/revenue-agency/services/child-family-benefits/child-disability-benefit.html

Registered Disability Savings Plan (RDSP): Must be receiving Disability Tax Credit. Canada disability savings grant matches 300-100%, dependent on family net income. https://www.canada.ca/en/revenue-agency/services/tax/individuals/topics/registered-disability-savings-plan-rdsp.html

First Nations Health Consortium (Jordan's Principle): Supports First Nations and Inuit children and families with Jordan's Principle applications in Alberta to ensure children and youth can access required services or supports they need. https://abfnhc.com/jordans-principle-applications/#SupportingDocumentation

Non-Insured Health Benefits (NIHB): Provides registered First Nations and recognized Inuit with coverage for a specified, nationally consistent range of health benefits not otherwise covered through:

- provincial or territorial health insurance
- private insurance plans
- other publicly funded plans or programs

General NIHB inquiries Telephone (toll free): 1-800-232-7301 or additional information found online https://www.sac-isc.gc.ca/eng/1576790320164/1576790364553

Helpful tools and resources

Find programs and resources in your community:
211 connects Albertans to the programs and resources they need, any time, day or night. Whether you're looking for help with mental health, financial assistance, basic needs, or other challenges, 211 is here to help you find supports. It's free, confidential, and available in over 170 languages by phone, making it easy to access help when you need it. To connect with **211 Alberta**:

- Call 211
- Text INFO to 211
- Chat or search at ab.211.ca

Health Information & Tools: myhealth.alberta.ca/Pages/HealthInfoToolsDefault.aspx

Resources

There's lots of information out there, and it can be confusing to know what information is accurate and true. Here are some great resources that may be helpful for you.

My Health Alberta: https://myhealth.alberta.ca/Pages/default.aspx

- **Autism Spectrum Disorder**
https://myhealth.alberta.ca/health/pages/conditions.aspx?Hwid=hw152184
- **Learning Autism Spectrum Disorder**
https://myhealth.alberta.ca/health/AfterCareInformation/pages/conditions.aspx?HwId=abn1051
- **Autism Spectrum Disorder in Children: Care Instructions**
https://myhealth.alberta.ca/health/AfterCareInformation/pages/conditions.aspx?HwId=ut3151
- **Rehabilitation: Being an active partner in your rehabilitation journey**
https://myhealth.alberta.ca/Alberta/Pages/active-partner-rehabilitation-journey.aspx
- **Pediatric Rehabilitation Webinars**
https://myhealth.alberta.ca/Topic/Pediatric-Rehabilitation/Pages/webinars.aspx

Common Resources Available within Alberta and Canada:

Autism Edmonton (formerly the Autism Society of Edmonton Area): Non-profit organization that provides community support, advocacy, and inclusive programs to enhance the lives of autistic individuals and their families through knowledge, services, and opportunities.
https://www.autismedmonton.org/

Autism Calgary: Non-profit organization that provides support, advocacy, and resources for individuals with autism and their families in the Calgary area.
https://autismcalgary.com/

Autism Society of Alberta: Provincial non-profit organization that connects and supports individuals with autism and their families through advocacy, education, and community resources across Alberta.
https://autismalberta.ca/resources/

Easter Seals: Canadian non-profit provider of programs, services and supports of children with a disability.
https://easterseals.ab.ca/family-resource-centre/

navigate for kids™: Online guide for finding disability related resources for children.
https://navigateforkids.com/

Inclusion Alberta: Inclusion Alberta is a family-based non-profit that advocates for children and adults with intellectual disabilities to be fully included in community life across Alberta. https://inclusionalberta.org/

Helpful tip

If you can't print this resource at home, ask a family member, friend, or your healthcare provider to print it for you. You can also use a computer and printer at your local library.

Get help now:

- **Emergency: Call 911**
- Health Link: Call 811

Mental health, addiction, and crisis support:

- 811 or Addiction Helpline: 1-866-332-2322
- 811 or Mental Health Helpline: 1-877-303-2642
- Crisis Text Line: Text CONNECT to 741741
- Crisis Services Canada: Call 988 or visit 988.ca

Community and social support:

- 211 Alberta: Call 211, or visit ab.211.ca
- Family Violence Info Line: 310-1818, or visit alberta.ca/family-violence-find-supports
- Income Support: 1-866-644-5135, or visit alberta.ca/income-support

Alberta Health Services programs:

- Find a Dietitian: ahs.ca/nutrition
  - Health Link has dietitians to answer nutrition questions. Call Health Link at 811 and ask to talk to a dietitian or complete the self-referral form on ahs.ca/811.
- Spiritual Care Services: ahs.ca/spiritualcare

Primary care (family doctors and nurse practitioners):

- Find a doctor or nurse practitioner: https://albertafindaprovider.ca
- Virtual care guide: ahs.ca/virtualhealth

Patient concerns and feedback:

- Office of Alberta Health/Mental Health Patient Advocates: alberta.ca/office-of-alberta-health-advocates
  - Offers coaching to help you advocate for yourself in the health system, and support to learn how the health system works and how to navigate through it.
- Alberta Health Services Patient Relations: 1-855-550-2555, or visit ahs.ca/patientfeedback

Important phone numbers

Name or clinic name:

Phone number:

Name or clinic name:

Phone number:

Name or clinic name:

Phone number:

Notes

Use this space to take notes.

Background

About this Pathway

This pathway was developed in collaboration with patient and family advisors, primary care providers, Specialist Physicians (pediatrician, developmental pediatrician), Pediatric Community Rehabilitation, allied health professions, and Primary Care Alberta (PCA)'s Provincial Pathways Unit.

It is current as of February 2026.

Authors & Conflict of Interest Declaration

This pathway was reviewed and revised by a multi-disciplinary co-design team including specialists and primary care providers from across Alberta. Membership available on request by emailing albertapathways@primarycarealberta.ca.

Pathway Review Process

Patient pathways undergo scheduled review every three years, or earlier if there is a clinically significant change in knowledge or practice. The next scheduled review is May 2029. However, we welcome feedback at any time. Please send us your feedback here.

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Disclaimer

This pathway represents evidence-based best practice but does not override the individual responsibility of healthcare professionals to make decisions appropriate to their patients using their own clinical judgment given their patients' specific clinical conditions, in consultation with patients/alternate decision makers. The pathway is not a substitute for clinical judgment or advice of a qualified healthcare professional. It is expected that all users will seek advice of other appropriately qualified and regulated healthcare providers with any issues transcending their specific knowledge, scope of regulated practice, or professional competence.