# *Provincial* Autism in Infants and Young Children *Primary Care Clinical Pathway*

Quick Links: Primer & Expanded details | Provider resources | Family resources | Provide feedback

Use this pathway when concerns about pediatric growth and development have been flagged by parents or caregivers, or by a health care provider (e.g., primary care, allied health) and there is **suspicion of autism**. Consideration for autism should be heightened with increasing number of indicators, when there is a family history of autism or other neurodevelopmental conditions and/or there has been developmental regression.

**All parent/caregiver concerns should be taken seriously and acted on promptly**

**Common features of autism:** There is no single diagnostic feature for autism. Individuals present differently based on age, sex, cognitive ability, language, etc. Example indicators may include (not an exhaustive list):

**Communication**
- Delays in language acquisition
- Atypical language development (e.g., echolalia, idiosyncratic language)
- Not seeking attention to show things of interest
- Not responding to social cues
- Not trying to get others attention other than to make requests
- Limited use of gestures

**Social Responsiveness**
- Reduced facial expression
- Limited, unusual or no eye contact
- Limited social interest, play or other interactions with peers
- Inconsistent responding to caregivers' efforts to get their attention (e.g., by calling their name).

**Behaviour**
- Repetitive behaviours, language, use of objects
- Restricted, intense or unusual interests
- Preference for sameness/distress when things change
- Sensory processing differences
- Difficulty transitioning between activities/environments

## 1. If not already done, complete age-appropriate surveillance

(e.g., Rourke baby record)

## 2. Consider whether Urgent Consultation is needed

- Acute/severe developmental regression/skill loss (e.g., neurodegenerative disorders)
- Psychosocial considerations (e.g., trauma)
- Co-existing conditions requiring immediate attention (e.g., failure to thrive)

Yes

Consult Outpatient Specialty Advice, refer to pediatrician/specialist, or send to ER depending on acuity and needs.

**Continue down the pathway concurrently if/when appropriate.**

No

## 3. Initial History, Assessment and Early Intervention

(do not delay referral if unable to complete comprehensive history and assessment)

**History**
- Records review (e.g., birth/medical history)
- Parent/caregiver interview (e.g., challenges, strengths, routines and resources)
- Developmental, medical, family (e.g., sibling with autism) and social history
- A structured age appropriate questionnaire (e.g., M-CHAT R/F, Infant-Toddler Checklist) could be used to gather more detail from caregivers. Results should complement the history and support clinical judgement.
- Encourage families to keep a journal of behaviours/observations.

**Assessment**
- Thorough clinical assessment including height, weight, head circumference.
- Dysmorphic features or neurological signs (e.g., tone and reflexes) as some medical syndromes are associated with higher rates of autism.
- Consider common co-occurring physical and emotional health conditions (e.g., sleep, mental health, GI) and treat/refer as appropriate.

**Observation of specific behaviours and interests**
- Observe how the child interacts in the office visit (e.g., play interests)

Communication and collaboration between families and providers is essential

**Early Intervention:** Many conditions share features with autism.
- All children with developmental delays or concerns can benefit from early intervention.
- Refer to local services while continuing with assessment.
- Families can **self-refer** for Pediatric rehabilitation (PCR), Early Childhood Intervention Program (ECIP) and vision assessment.
- Hearing status needs to be considered for all children with developmental concerns.

**Additional Supports:**
Share diagnosis letter with family as this can be used to apply for additional supports

If another condition better explains developmental delays/concerns (e.g., impaired hearing, language disorders) and the family is interested, refer for assessment, other needs or diagnoses (e.g., PCR/ECIP, specialists).

If developmental concerns persist as the child grows, consider need for an autism assessment.

## 4. Refer to providers that offer more comprehensive medical screening and/or diagnostic assessment

(e.g., community pediatrician, developmental centre).

- Some diagnostic clinics require a physician/NP referral.
- Consider requesting additional community assessments to support the diagnostic process.
- Share available information with the receiving provider/team (do NOT delay making a referral to gather additional information).
- Provide anticipatory guidance on next steps in the assessment process.

## 5. Continue to support family during and after autism diagnosis.

- Follow-up recommended 3-6 months depending on concerns.
- Ongoing collaboration with Pediatric Community Rehabilitation and other care providers and agencies.

***Support family centered care.***
- Actively listen to family's concerns and validate their experience with their child.
- Ensure families are aware of why and where all referrals are being made (especially important if parents did not identify the concern).

*Consider specialist advice*

Primary Care Alberta

**Call to Action:** We need your feedback during this **new** pathway's initial testing phase!

ALBERTA'S PATHWAY HUB

Alberta's Pathway Hub

Background

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*This primary care pathway was co-designed provincially by Primary Care Providers (PCPs), Specialist Physicians (pediatrician, developmental pediatrician), Patient and Family Advisors, Pediatric Community Rehabilitation, Allied Health Professions and Primary Care Alberta (PCA)'s Provincial Pathways Unit. It is intended to be used in conjunction with specialty advice services, when required, to support care within the medical home.*

## EXPANDED DETAILS

Guidance in this pathway applies to infants and children who show early signs of autism. The focus is on children from 6 – 36 months. If the child is 3 years or older, this pathway may still be useful. The primary care provider is advised to ask the caregiver if the child is involved in an educational program (e.g., Early Childhood Services, kindergarten). If this is the case, it will be important to consider and communicate with education providers in addition to those partners detailed here. This pathway attempts to reflect services in the present day within Alberta.

**Language**

We acknowledge and respect the diverse views of those with autism and their families. Both 'person-first' and 'identity-first' language is used throughout this pathway. Wherever possible, being conscious of an individual's preference and respectful in one's approach are seen as recommended practice within this pathway.

**Person-first language** intends to put the person before the condition and emphasizes the individual's humanity, which in turn tries to promote inclusiveness and respect (i.e., people with autism).

**Identity-first language** puts the condition first in a way that embraces the condition as part of a person's identity. It is often used in self-advocacy and where brevity is of value (i.e., autistic child) [1].

### Pathway Primer

Autism spectrum disorder (autism) is a life-long neurodevelopmental condition that significantly impacts the lives of those with autism and their families. Autism is a spectrum condition, and children can present with a wide range of type and intensity of autism characteristics. Children with autism may also have co-occurring conditions that further increase complexity [2]. As a result of this variability, presentation and support needs vary from person to person.

Although the causes of autism are unknown, recent findings point to interplay of genetic, epigenetic and environmental factors. According to the 2019 Canadian Health Survey of Children and Youth (CHSCY), 1 in 50 children and youth aged 1 to 17 in Canada—about 2%—had been diagnosed with autism [3]. Just over half (53.7%) of children are diagnosed before age 5 [3]. Due in part to the increased prevalence of autism over time, pediatricians, primary care providers and other health professionals are now seeing more children with autism.

This clinical pathway intends to support primary care providers with guidance for monitoring for the earliest signs of autism and facilitate earlier referral to pediatric allied health providers and specialized assessment as needed. Information on supporting children and families through early intervention, assessment, diagnosis of autism and beyond is also provided. While this pathway is predominantly intended to support primary care providers provincially, it should also be of benefit for pediatric health care providers.

## Early Identification and Intervention Matters

- Screening for signs of autism should begin as early as 6 months of age during routine visits [4].
- Early intervention leads to better long-term outcomes.
- Some children can be definitively diagnosed by age 2, yet many are not diagnosed until age 4–5 years (or older) [5].
    - The lag in diagnosis may be due to delayed identification of autism symptoms, delays in referral for diagnosis and long wait times for assessment.
    - For some children, characteristics of autism can be subtle in their younger years but become more apparent as the child ages and reaches school aged where they encounter additional demands [4].

## Current Status

- While the Canadian Paediatric Society recommends a **maximum wait time of 3–6 months** for autism assessment, wait times for team-based diagnostic evaluation in many Canadian communities exceed **one year** [5].
- While some primary care physicians, nurse practitioners, and psychologists may be comfortable diagnosing autism, many of these professionals currently refer to pediatricians and/or specialty centers due to the specialized training that may be required to complete a comprehensive autism assessment and due to system-level challenges.
- Supporting primary care providers to diagnose autism is not the focus of this pathway.
- Best practice resources (Canadian) are available and can be accessed to increase provider's competency and confidence in supporting patients and families with autism.
    - Canadian Paediatric Society: Position statements, clinical tools, parent information.
    - Primary Care – ECHO Autism Communities: Program offers twice-monthly program for primary care providers as well as other practice supports. CME credits available.
    - Autism and Neurodiversity in Primary Care (ASD) - Recognize and Refer | Course | UBC CPD: Developed to support primary care providers to deliver high-quality care to autistic and neurodivergent patients across the lifespan. CME credits available.
    - Local programs and supports through autism diagnostic centers.
    - Autism Canada: Resources, advocacy and family support.

## Background

Use this pathway when concerns about pediatric growth and development have been flagged by parents or caregivers, through routine growth and development surveillance, or by a health care provider (e.g. primary care, allied health) and there is suspicion of autism.

**Parents and Caregivers:** It is important to ask parents and caregivers about developmental concerns at every routine visit. Common early concerns presented by parents may include (but are not limited to) language delay, lack of response when the child's name is called and limited eye contact [4]. Examples of prompting questions include:

- Do you notice any differences between your child and their peers?
- Is there something that your child could do before that they can no longer do?

**Note: All parent/caregiver concerns should be taken seriously and acted on promptly** [33]

- Early identification and intervention for autism is associated with better long-term health outcomes. However, there is often a delay between when parents first identify concerns to when they voice these concerns to a healthcare provider and an even longer gap to when a diagnosis is made. To avoid significant impact on long-term health outcomes for children and their families, it is well recognized that improving early access to appropriate services is essential and should be considered a top priority [33].
- Parents' concerns about their child's development should always be taken seriously, as they often signal a need for further assessment - even if the concern does not always result in the diagnosis of autism. It is hoped that this pathway provides further support for prompt intervention and investigation.

**Concerns from health care providers:** This may include primary care physicians, nurse practitioners, public health nurses, community pediatricians, and allied health professionals. If providers have concerns, they may complete developmental surveillance and/or screening and ask children and families to follow-up with their primary care team. Ideally, results from these appointments and assessments should be provided to the primary care provider.

**Heightened consideration for autism when:**

- Family relative with autism: A child with an autistic sibling has a notable increased likelihood of autism (up to 10x greater likelihood than the general population) [6]. Second-degree relatives (e.g., cousins) have a 2x greater likelihood compared to the general population [7].
- Developmental regression occurs (e.g., loss of/reduced speech, social engagement, play).
- Multiple indicators (cluster) of common features of autism are present. Age-appropriate developmental surveillance tools can be used to help identify areas of concern.
- Persistence of symptoms over time and in different settings.

### Common features of autism

There is no single diagnostic feature for autism. Every individual will present differently based on age, sex, cognitive ability, language levels, etc. The following list is not intended to be exhaustive but highlights some common features that should flag the need to consider the possibility of an autism diagnosis to ensure that appropriate supports are put in place [4]. Asking parents and caregivers questions related to the common features listed below can help determine if further investigation is required.

- **Communication:**
    - Delays in language acquisition: Limited use of spoken language (e.g., no single words by 12-18 months and diminished, atypical or no spontaneous/meaningful 2-word phases by 15-24 months) **OR**
    - Atypical language development: What and how the child is saying words is atypical.
        - Echolalia, immediate or delayed
        - Idiosyncratic language: Using phrases or terms that are only meaningful to people who know the child well (e.g., "1, 2, 3, jump" means the child wants to go swimming because that is a game they play at the pool)
        - Non-meaningful and undirected reciting of stories, reenacting scenes from movies, or reenacting an event from the past
    - Not seeking attention to show things of interest
    - Not responding to social cues
    - Not trying to get others' attention (e.g., parents, siblings, peers) other than to make requests
    - Limited use of gestures for the intent of interaction and communication. For example, the child may point to use an iPad but not to show a caregiver an object of interest; child does not wave goodbye, or does so only when prompted.
- **Social responsiveness:**
    - Reduced facial expression directed towards others (e.g., shared smiles)
    - Limited, unusual or no eye contact
    - Limited social interest, play or other interactions with peers (e.g., limited engagement in age-appropriate joint-interactive play)
    - Inconsistent responding to caregiver's efforts to get their attention (e.g., by calling their name)
- **Behaviour:**
    - Repetitive behaviours, language, or use of objects (e.g., hand flapping, rocking, lining up, repetitive vocalization, echolalia)
    - Restricted/intense/unusual interests:
        - Attachment to an unusual inanimate object (e.g., key ring, empty lip chap containers)

  - Advanced knowledge of a specific topic compared to same-aged peers (e.g., can name the hierarchical classification categories for any animal)
  - Interest in an unusual topic or object (e.g., motors, washing machines)
  - Interests restricted to one or two topics, no variety in interest (e.g., will not engage in any activity unless it is related to dinosaurs)
- Preference for sameness/distress when things change
- Sensory processing (registration, seeking, avoidance, sensitivity, and differences) that impacts day to day functioning. This may include:
  - Noticeable difference in how they respond to things like noise, light stimuli, clothing textures
  - Refusing to eat some food types or textures
  - Hypo or hypersensitive to temperature or pain
  - Seeking sensory pressure from caregivers to calm down
  - Always on the move
- Difficulty transitioning between activities/environments (e.g., home, daycare, friend's house, playground)

### 1. Age-appropriate surveillance

Growth and development surveillance should occur during routine health visits and anytime a parent raises concerns about a child's growth and development [4]. If concerns are identified, additional assessment and follow-up are required.

- Monitoring for early signs of autism can begin as early as 6 months of age [8].
- Routine surveillance can help track the progression of characteristics over time (spanning months to years) which can be helpful in the identification of autism.
- See Appendix A: Pediatric Developmental Surveillance Tools and Autism Screening Tools.

### 2. Consider whether Urgent Consultation is needed.

It is important to note that these features can be observed both in those children with autism and those without autism. While these concerns need to be addressed promptly, providers should continue to follow the autism clinical pathway if/when appropriate to ensure early identification and support.

- Acute/severe developmental regression/skill loss: Although 1 in 3 children with autism are reported to have global developmental delay or intellectual disability [9], any child presenting with acute or subacute developmental regression/skill loss, will require further assessment, as such skill loss may be related to underlying neurogenerative disorders [10]. Abnormal movements, seizures, muscle weakness or spasticity, cognitive or adaptive regression or abnormal neurological examination, especially if of new onset.
- Psychosocial considerations (e.g., suspected child neglect, physical or sexual trauma).

- Co-existing conditions requiring immediate attention/intervention while awaiting diagnosis (e.g., failure to thrive): Poor feeding, weight loss, food aversion, suspected nutritional deficiencies.

**Follow-up:**

Depending on clinical presentation, acuity and local resources available:

- Consult Outpatient Specialty Advice, refer to pediatrician/specialist, or send to ER depending on acuity and needs.
- If abuse is suspected, call child intervention 24/7 at 1 (800) 638-0715. If there is immediate danger, call 911.

## 3. Initial History, Assessment and Early Intervention

There are no diagnostic biomarkers for autism [5]. The diagnosis of autism is complex and is ultimately made based on a comprehensive assessment through structured interviews, observations, assessment of behaviour in community settings, developmental assessment, and medical examination to identify co-occurring conditions and/or specific etiologies (e.g., genetic conditions) [11, 5]. Primary care providers play an important role in gathering and sharing information with the family and multidisciplinary teams. This information helps ensure that the child and family can be connected to services/supports and access assessment services in a timely manner.

### History

Elements of history and assessment can be done by or facilitated through the primary care team (e.g., referrals can be made to specialized services, regulated healthcare providers in community, or allied health providers). The list below provides examples of information that can be helpful to collect and share. It is important to note that referrals to early intervention and specialized services should not be delayed if elements of the history or assessment are not or cannot be completed during the visit.

**Complete a record review** [5]**:** This may include previous medical records (e.g., birth and newborn records, well-child visits, prior medical tests and treatments), developmental evaluations, other assessments (e.g., audiology, speech, other allied health), other care provider reports (e.g., daycare worker) and education records if applicable.

**Interview parents, family members, or other caregivers** [5]**:** Using open-ended questions, ask about:

- When the concern first emerged.
- What behaviours they have noticed (can refer to baby books and videos, when available). Pay special attention to common features of autism.
- Any difficulties at home, daycare or other relationships.
- Family functioning, strengths, routines and resources and the family's perceptions about autism. Consider any cultural differences.

**Developmental, medical, family and social history** [5]

- Developmental, behavioural and medical history with a focus on autism-related difficulties (e.g., sleep challenges, diet).
- Family medical and mental health history (three generations, if possible): Ask about developmental disabilities, learning difficulties, behavioural differences, psychosocial history and genetic conditions.
- Hearing and vision concerns: As the prevalence of autism may be higher in those with visual or hearing impairments, autism should be considered in these children [12].

**Structured age appropriate questionnaires** (e.g., M-CHAT R/F, Infant-Toddler Checklist) can be used to gather more detail from caregivers. Results should complement history and support clinical judgement and decision making [5].

- See more information about age-appropriate questionnaires in Appendix A: Pediatric Developmental Surveillance Tools and Autism Screening Tools.

**Encourage families to keep a journal of behaviours and observations**

- Options may include notebooks, digital options, voice recordings and transcription, and videos.
- Include daily observations (e.g., strengths and challenges), medications (e.g., prescription, over the counter, supplements), impacts on day-to-day life.

## Assessment

**NOTE:** Private and public options exist for early intervention, assessment and diagnosis of autism.

### Routine Assessment

- Measure height, weight, and head circumference and plot on growth charts.
    - 20% of individuals with autism are macrocephalic, usually of postnatal onset (not diagnostic) [5].

- Make note of any dysmorphic features (e.g., large or prominent ears) or neurological signs (e.g., tone and reflexes) as some medical syndromes are associated with higher rates of autism [5]. For example:
    - Individuals with fragile X syndrome have low muscle tone and distinctive physical features.
    - Neurofibromatosis or tuberous sclerosis (complete a skin examination).
    - Congenital anomalies (e.g., evidence of a congenital heart condition).

### Common co-occurring conditions

Primary care providers and pediatricians play an important role in providing and coordinating on-going care and support services for children and families with autism. Developmental, mental, medical or psychiatric conditions are reported in more than 70% of individuals living with autism [11]. Addressing co-occurring conditions can have a significant positive impact on the quality of life and functioning of autistic children and their families. Many co-occurring conditions may impact one another, making it critical that a whole-person health approach is considered for children with autism. Special attention should be paid when major life transitions occur (e.g., starting daycare/school, change in family structure).

When assessing for co-occurring conditions, it is important to note that children with autism may present differently than their neurotypical peers. They may experience symptoms differently (e.g., sensory perception) and/or may have challenges expressing their symptoms (e.g., limited verbal ability) [13]. Common co-occurring conditions in **infants and young children aged 6-36 months** may include:
(Note: List is organized from most common/impactful for families to less common/impactful)

- **Sleep:** Sleep problems (e.g., difficulty falling and staying asleep, early awakenings, and decreased sleep duration) are very common, affecting 50-80% of children with autism. Sleep challenges can impact daytime functioning and quality of life for the autistic child and their family (whose sleep is also often impacted) [14] [15].
    - Consider referral for sleep hygiene (behaviour techniques). Counsel families to avoid using screen devices for 1 hour before bedtime as this can disrupt sleep patterns [15].
    - For more information: Sleep matters: Supporting healthy sleep for children and youth with neurodevelopmental disabilities (NDDs) | Canadian Paediatric Society.
- **Gastroenterology:** Children with autism have a higher prevalence of gastrointestinal disorders. GI symptoms may be related to constipation, unusual feeding behaviours, restrictive diets (e.g., food selectivity), and challenges with toilet training [15] [13] [14].
    - Management of GI symptoms for autistic children is the same as in children without autism [13].
    - Effective treatment of GI disturbances may improve other co-occurring conditions and behavioural outcomes (e.g., daytime behaviours and abnormal sleep) [13] [15].

  - For more information: Pediatric Constipation Primary Care Pathway.
- **Nutrition:** Restricted/selective diets may lead to nutritional deficiencies and mealtime struggles.
  - Consider referral to a dietitian and behavioural intervention (e.g., Occupational Therapy, Behavioural Therapy, Speech Language Pathology or community feeding team) [15] [14].
  - For more information: Goodbye Mealtime Struggles Classes | Alberta Health Services and PEAS | Home.
- **Dental**: Like all children, those with autism should have regular, complete dental check-ups but the approach to care may need to be modified due to sensory sensitivities, anxiety, communication difficulties, etc. [15].
  - Some children with autism benefit from seeing a pediatric dentist with expertise working with neurodivergent children.
- **Epilepsy/Seizures:** It has been estimated that approximately 20% of those with autism will develop epilepsy during their lifetime. Age of onset typically in early childhood or adolescence/early adulthood [14].
  - Care is similar to other individuals with epilepsy, but extra attention needs to be taken when selecting medications to minimize behaviour side effects. Refer to pediatric neurology.
- **Emotional Regulation:** Autistic children may also have difficulties with emotional regulation. It is important to monitor for features of mental health conditions which can be common in individuals with autism, over time.
  - Anxiety disorders such as phobias, generalized anxiety disorder and social anxiety are the most common. Attention-Deficit/Hyperactivity Disorder (ADHD) and Oppositional Defiant Disorder are also common. Some behavioural presentations include irritability and self-injurious behaviours. These could also be secondary to sleep disturbances or GI issues [16].
  - Complete a thorough assessment of other underlying causes. Behavioural therapy is first line intervention for psychiatric disorders in children younger than 6 years old.

## Observation of specific behaviours and interests

- Observe how the child interacts during the office visit (e.g., response to caregivers): Observe play with a range of toys (e.g., blocks, puzzles, books, colouring). Ask parents to bring these items in if you do not have them available in your office setting [17].
- Behaviours observed in other settings may not be seen in a short primary care office visit that is structured and predictable. Collect observations from other settings (e.g., daycare, preschool) [5].
- Identified concerns may present over time (some features are gradual to develop/be identified).

## Early Intervention

Many conditions share features with autism. All children with developmental questions, delays or concerns can benefit from early intervention. The goal of intervention is to improve function and well-being. Refer to local services while continuing with assessment.

An interprofessional collaborative approach to early intervention is often needed. Families are able to **self-refer** for Pediatric Community Rehabilitation (PCR) (sometimes also referred to as Children's Allied Health), Early Childhood Intervention Program (ECIP), and vision assessment.

- It is important to determine the family's comfort level with self-referral so that providers can support referrals as needed. Referrals should highlight the family's preferred language and the need for an interpreter when appropriate.

### Pediatric Community Rehabilitation (PCR)

- Pediatric Community Rehabilitation's mandate is to connect with families within 30 days of referral (there is regional variability in the timeline when families are actually seen).
- There is value in a second set of eyes on a child and PCR professionals can provide this.
- Pediatric Community Rehabilitation services may include the following [15]**:**
    - **Occupational Therapy (OT):** 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.
    - **Physiotherapy (PT):** Strengthen gross motor skills and improve endurance, strength, balance, gait and coordination.
    - **Psychology:** Assess or observe and support parent-child responsiveness, attachment and emotional regulation skills. Assessing co-existing conditions to assist with differential diagnosis. Can diagnose and may be accessed privately.
    - **Social Work:** Support children with developmental differences by assisting families to understand and navigate medical, diagnostic, and community systems. They support care coordination by addressing financial or other barriers to services. Social workers provide guidance on service processes, assess eligibility for supports, connect families with resources (e.g., speech-language pathology, OT, PT, early intervention), and advocate for the child and family's needs across settings.
    - **Speech-language Therapy:** Assess and help improve verbal, non-verbal and social communication skills. This includes facilitating access to alternative and augmented communication (picture-based communication systems, signs and gestures, device trials, and tablets).

  - **Virtual Offerings:** All families can access Pediatric Rehabilitation Webinars, Videos and Resources. This service is accessible to all Albertans regardless of their involvement with a specific clinic or program and provides families with opportunities to learn more about topics they are concerned about such as sensory processing, sleep troubles, autism and motor skills, and supports for parents and caregivers.

**Early Childhood Intervention Programs (ECIP)**

- Early Childhood Intervention Programs (ECIP) are available in several areas across Alberta, either as a part of, or separate from PCR. Child Development Specialists in the ECIP program can also help with navigation of resources and provide support to families during the diagnostic process as well as address developmental goals and routines in their home or community. ECIP is specifically for families with children with developmental concerns under the age of 5.

**Hearing and Vision**

- **Vision:** Assessment by an optometrist or ophthalmologist as appropriate.
- **Audiology:** Alberta's Early Hearing Detection and Intervention (EHDI) program screens newborns for hearing loss (HL) and those with risk factors for hearing loss are identified for ongoing follow up. If you have questions about a child's development and they were not screened through EHDI, it is important to refer to an audiologist. Children with autism and other developmental delays are more likely to have hearing loss.
  - Children with hearing or visual impairments often show developmental delays and behaviours that overlap with autism. Identifying autism may be more difficult as a result. Children with signs of autism are also more complex to assess for potential hearing loss. Audiology assessments for suspected autism may use play-based methods or objective tests (OAE, ABR) if participation is limited. Multiple appointments are common due to attention and sensory challenges.
  - Use Alberta Referral Directory to find a public provider → "Community Audiology Services." Parents can self-refer (except in Calgary). Families may also choose to access private audiology clinics at their own expense. When making a referral, provide details of your concerns and behavioural observations. This information will help the audiologist to plan their assessment.

**Health Link (811)**

- Families can call Health Link for health advice and support with wayfinding.

**Rehabilitation Advice Line**

- Families can call the Rehabilitation Advice Line (Alberta wide) to discuss a child's development and well-being and they can provide advice about activities and exercises that help with physical, functional, or developmental concerns. They can also provide strategies to support day-to-day activities and link families to rehabilitation services.

### Additional supports

Providing the family with a medical diagnosis letter (even if they are awaiting a diagnosis) can allow the family to apply for eligible supports [including Family Support for Children with Disabilities (FSCD) and school-based supports]. See Provincial and Federal Supports for additional details.

- Specify the developmental delay and functional impact.
- Families waiting for an autism assessment and diagnosis can still qualify for funding and other supports.
- See Appendix B for a sample letter.

### Other conditions

If another condition better explains developmental delays/concerns (e.g., impaired hearing, language disorders) and family is interested, refer for early intervention (if not previously done), assessment, other needs or diagnoses (e.g., Pediatric Community Rehabilitation, specialists).

## 4. Refer to providers that offer more comprehensive screening and/or diagnostic assessment

In Alberta, there are three levels of medical care for autistic children and families:

1. Primary care: Family physicians and nurse practitioners
2. Community Specialists: Community pediatricians
3. Tertiary Centers: Specialized multidisciplinary teams and specialty physicians, such as developmental pediatricians and child psychiatrists. Diagnosis may also be led by clinical psychologists, or nurse practitioners with specialized training.

Depending on clinical presentation, family readiness, provider involvement, refer to providers that offer a more comprehensive evaluation (e.g., community pediatrician, developmental centre).

- Some diagnostic clinics require a referral from a physician or nurse practitioner. See specific clinic/zone requirements.
- Consider requesting additional community assessments (while the family is waiting to be seen) to support the diagnostic process.

### Helpful information to include in referral

Information that can be helpful to include with the child's referral for an autism assessment includes (Note: Do NOT delay making a referral to gather additional information)**:**

- Referral form/letter based on specific clinic/zone requirements.
    - Where possible, include information about the features observed, developmental concerns, previous findings, and any interventions already attempted. This helps avoid duplication, improves triaging and informs next steps.
- Reports from assessments and observations (e.g., from PCR, developmental screening, childcare settings).
- Status/results of other referrals (e.g., audiology, speech-language therapy).
- Results from age-appropriate screening tools, if available.

#### Prepare family for Diagnostic Process and Potential Diagnosis

The diagnostic process can be stressful for some parents and families. Ask them how they feel about the next steps and potential diagnosis. Care providers have an opportunity to support children and families through the autism assessment and diagnostic process using a child and family centered approach [18].

#### Tertiary assessment clinic (resources available may differ by Zone)

A comprehensive assessment will be conducted by one or more clinicians. Evaluations conducted in autism diagnostic clinics often corroborate prior assessments while spending the time needed to establish the most accurate diagnosis for the child's condition. Because this stage can feel pivotal and overwhelming for children and families, it is essential to provide clear information on what to expect and offer guidance to help them navigate this next phase in care.

#### Comprehensive Autism Diagnostic Assessment [5]

A thorough evaluation by a skilled community provider or diagnostic center typically includes:

- Detailed developmental, medical, family, and social history
- Clinical observation, reports and information about the child in multiple settings
- Use of standardized autism diagnostic tools, as appropriate
- Application of DSM-5 diagnostic criteria
- Screening and assessment for co-occurring conditions

The health-professionals that see a child and the assessments conducted may vary depending on the child and family's needs, as well as the program design and infrastructure within each zone. Families and caregivers should be reassured that all providers in an autism diagnostic facility are specialized in this area and that the priority is making the right diagnosis and then continuing with advancing needs-based evaluation.

**Table 1: Assessments and therapies may include**

- Speech-language Pathology
- Audiology
- Nursing
- Occupational therapy
- Dietitians
- Physiotherapy
- Social Work
- Early childhood development
- Child and adolescent psychiatry/psychology

### 5. Continue to support family during and after autism diagnosis.

- Follow-up recommended every 3-6 months depending on concerns.
- Continue with ongoing collaboration with Pediatric Community Rehabilitation and other care providers and agencies.

**Preparing for office visits with a child suspected of having autism**

Family centered care and simple accommodations can improve experiences (e.g., managing sensory sensitivities, reducing fear/anxiety) for children with autism and families who access the health care system for initial developmental concerns, during the autism assessment and diagnostic process and for post-autism diagnosis care [18]. Work with the family to tailor an approach that will work best for them and their child. Some helpful approaches may include [4] [19] [20]:

- Consider scheduling a virtual health visit with a parent in advance of the first visit, to discuss the child's:
    - Medical and developmental history, with related family factors
    - Strengths and challenges
    - Ask parents what type of set-up might make the visit easier and tailor the clinic room accordingly (e.g., quiet room, no bright lights, room without a window).
- Advise caregiver(s) to bring a couple of their child's favourite toys and/or foods to offer as a distraction or reward, if needed.
- Consider re-arranging the examination room to accommodate sensory sensitivities (i.e., quiet, with dim lights).
- Schedule appointments at the beginning or end of the workday when the office is less busy. This may help to reduce stimulation and decrease the time spent waiting. If possible, ask families to arrive before the clinic opens and have staff direct them directly to the clinic room.
- Schedule longer appointments.
- Strategies that may help support the child and family through multiple aspects of daily living (including medical appointments)
    - **Social stories:** Describe a situation, skill or concept with a goal of sharing accurate social information with a person in a format that is easily understood [21]. They are usually short and simple, and include images. Social stories can be used to support

children and their families to understand the change in routine or new environment and how to advocate for themselves. A video about going to a medical appointment could be another way to help prepare the child.
    - For additional information see: Doctor Visit: A Social Narrative
  - **Visual schedules:** Tools that provide the child with information about what is happening, sequence of events, what changes may occur and when they may need to transition between activities. A visual schedule may include objects, pictures and/or words [22].
    - For additional information see: Visual Schedule Tipsheet

## Support and Connection

The primary goal of support is to increase functional skills, opportunities for community participation, lifelong quality of life and to support families [11]. As every child and family will have different needs, there is no universally accepted approach. Providers should build an awareness of the resources that are available in their communities (local and regional) and support families to connect with them [15]. It is important to note that families may require support in navigating the options available.

**Common resources available within Alberta include:**

Autism Edmonton (formerly the Autism Society of Edmonton Area): Nonprofit organization that provides community support, advocacy, and inclusive programs to enhance the lives of autistic individuals and their families through knowledge, services, and opportunities.

Autism Calgary: Nonprofit organization that provides support, advocacy, and resources for individuals with autism and their families in the Calgary area.

Autism Society of Alberta: Provincial nonprofit organization that connects and supports individuals with autism and their families through advocacy, education, and community resources across Alberta.

Children's Link: Database of available resources. Families and professionals can use the site to explore options and connect with services and supports in their community. Staff are available to assist with searching. Children’s Link Alberta and Easter Seals Alberta have recently merged operations.

navigate for kids™: Online guide for finding disability related resources for children.

Pediatric Rehabilitation: Offered throughout Alberta. Parents and caregivers can find out community/zone specific information at Pediatric Rehabilitation Community Contact Information.

Programs and services can vary throughout the province. Families can connect through Alberta Support by using their online services, myAlbertaSupports, or by contacting Alberta Supports Contact Centre at **1-877-644-9992,** or in Edmonton **780-644-9992.** Additionally, local programs and services can be explored by contacting 211 Alberta.

**Family Centered Care**

- Actively listen to the family's concerns and validate their experience with their child.
- Ensure care delivery incorporates neuro-affirming practices, promoting respect for neurodiversity and individualized support throughout assessment and on-going care.
- Offer coordinated care between other medical and mental health care professionals, allied health care, educators (e.g., childcare and schools), and social and community service providers [15].
- Developmental resources (e.g., Baby Navigator) can be used to facilitate discussions about developmental differences and/or autism.
- Provide anticipatory guidance (e.g., Baby Navigator, Talk Box).
- Ensure families are aware of why and where all referrals are being made (especially important if parents did not identify the concern).
- Connect families with community resources and local autism support groups. Provide personalized recommendations and resources in line with the family's culture, location and priority concerns (e.g., peer support groups).
- Wherever applicable, bring attention and refer patient to the parent and caregiver pathway (developed alongside this clinical pathway and will be available soon).
- Communication between families and providers is critical.
- Discuss concerns and feelings about developmental differences and the possibility of an autism diagnosis (including potential impacts on family life)
- Explain to parents and caregivers what they can expect and advocate for during every stage of the assessment process [18]. The assessment team should be expected to:
    - Invite questions, explore strengths and opportunities, elicit concerns and listen
    - Treat parents as partners
    - Offer information about the team's clinical impression regarding diagnoses and co-occurring conditions, and implications for supports and services.
    - Offer print and online resources (see family resources below).
    - Provide contact information for local family and peer-to-peer support groups.

**Caregiver support**

If family members are also under your care, ask about the family's own self-care and physical/mental health needs and provide appropriate care and referrals to supportive services. If family members receive care from another provider, encourage them to speak with their own care provider about their care needs.

**Provincial and Federal Supports**

Access provincially funded supports and services:

- Family Support for Children with Disabilities (FSCD): Apply early (autism diagnosis not required) as waits can be long. Family support services include respite, counseling, medical appointment supports, clothing and footwear supports. Families can apply for FSCD support while they wait for their assessment. Ongoing services will require a confirmed diagnosis of a chronic disability that significantly limits the child's typical daily living (developmental, physical, sensory, mental or neurological condition or impairment).

  - FSCD eligibility requires age (child must be under 18) and residency criteria (child must be a Canadian citizen or permanent resident; child must reside in Alberta).
  - The person applying for the program must be the child's guardian (professionals cannot submit the applications on behalf of Albertans).
- Program Unit Funding (PUF): Provided to school authorities with Early Childhood Services children with severe disabilities/delays who require additional support. 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 development delay (not necessarily autism specific) is required by a professional specializing in the field.
  - Primary care provider can give the family with a list of service providers (agencies/day cares that offer PUF) based on where they are located in the province.
  - Contact with PUF as soon as possible may result in parents having more choice in available programs. Although programs are generally aligned to the academic year (i.e., start in September), families should be encouraged to apply at any time to optimize opportunities for access.
  - PUF application must be filled out by an Early Childhood Support (ECS) provider on behalf of the family. Families do not complete the PUF application on their own [23].

A diagnosis letter from the child's primary care provider that includes a description of the developmental and functional concerns and that there is a query of autism, can assist the family when applying for additional funding (e.g., PUF and FSCD). Schools/programs can use information in the letter to support their assessment of whether the child qualifies for funding. A sample letter is included in Appendix B.

Additional federal financial support is also available, which can help reduce financial stress for families.

- Disability Tax Credit (DTC): Income tax reduction for supporting family member, medical practitioner certifies severe or prolonged impairment. The T2201 DTC certificate must be completed by both the applicant (Part A) and the medical practitioner (Part B) online or by submitting a paper application.
- 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.
- Registered Disability Savings Plan (RDSP): Must be receiving Disability Tax Credit. Canada disability savings grant matches 300-100% dependent on family net income.

## Dispelling myths

Families may require reassurance that the etiology of autism is not fully known but likely involves a diverse and heterogeneous interplay of genetic, epigenetic and environmental factors [24]. Recent public attention has speculated causative factors which families may ask about. These include but are not limited to:

- Vaccination: No correlation has been found between the use of measles, mumps and rubella (MMR) vaccine or other vaccines and the likelihood of autism [11].
- Acetaminophen use during pregnancy: There is no evidence that supports a link between in utero exposure to acetaminophen and the development of autism in children [11].

## Important considerations for clinical practice in Alberta

In Alberta, it's important to consider how autism intersects with other aspects of a person's identity (such as race, ethnicity, culture, socioeconomic status, gender, and sexuality), as these intersections can shape the types of supports individuals and families may need. Recognizing this diversity helps ensure services are responsive, inclusive, and better aligned with each family's unique circumstances [25]. Families may require tailored support to help them navigate the system and connect with appropriate, high-quality services. This includes considering both potential opportunities (such as family and community-based supports) and barriers (such as transportation, childcare, work schedules, and other factors that may limit their ability to access care) [26]. Populations to consider include (but are not limited to):

### Indigenous Peoples:

Indigenous worldviews often emphasize acceptance, diversity, and inclusion, and some communities view autistic individuals as a gift [27]. However, many families face barriers related to (experience of) racism in the healthcare system, intergenerational trauma, and logistical challenges such as cost, travel, and lack of internet access.

**Additional support strategies:** [25]:

- Provide culturally safe care (e.g., connection over collection, offering choices, inviting traditional practices, seeking to understand system barriers).
- Connect families with extended family and community supports.
- Consider available resources such as Jordan's principle, which provides funding for First Nations Children to access health, social and educational services [28].

### Assigned female sex at birth:

Those assigned female sex at birth may present differently than those assigned male sex at birth and are often more able to mask autism-related characteristics, such as social communication difficulties. Although this is less evident in children under 3, it is still important to be aware of. They may also display more atypical features which could contribute to higher rates of misdiagnosis or underdiagnosis among those assigned female sex at birth [22]. The ratio gap is narrowing as awareness improves and clinicians become better at recognizing autism in individuals assigned female sex at birth.

**Additional support strategies:**

- Autism characteristics in some individuals assigned female at birth may be more subtle in early development. Avoid prematurely ruling out a diagnosis and continue ongoing surveillance and screening throughout early childhood.
- Referring to specialty/tertiary level assessment may be necessary if a child's presentation complicates your clinical impression and/or if further support is needed.

**Culture and language:**

Current evidence suggests that families from racial and ethnic minorities may experience barriers to referral and diagnosis which in turn may present challenges with accessing supports and services [5] [25]. Cultural factors can influence how autism is understood, interpreted and responded to, within families and communities [5].

**Additional support strategies:**

- Offer culturally safe care (e.g. using clear, plain language, asking families about cultural preferences and perspectives).
- Offer interpretation and translation and have materials available in a variety of languages.

**Rural or remote regions:**

Families in remote areas of Alberta may face long travel distances, limited local services, and fewer specialized providers, which can delay assessment and ongoing supports for autistic children. These access challenges, along with fewer community resources and difficulties navigating services from a distance, may contribute to later diagnoses compared with urban peers [5] and can place additional financial and logistical strain on families [25].

**Additional support strategies:**

- Work should be done to enable local providers and specialists/developmental clinics to minimize barriers for families [5].
- Provide patient navigation support, including help identifying available local resources, connecting families to community programs, and offering clear guidance on how to access both in-person and virtual services.
- Leverage virtual care for assessments, follow-up visits, care coordination, and parent coaching to reduce travel burden and improve timely access to specialists.

### Medication

Medications to address behavioural differences should only be considered when non-pharmacological strategies have been exhausted. Use of medications needs to be carefully considered on a case-by-case basis and treatment plans need to be highly individualized [15]. If medications are being discussed with the family, consider a referral to a community pediatrician or specialty clinic.

### Complementary, Alternative and Integrative Medicine (CAIM) approaches

While many families with autism (up to 92%) have used CAIM therapies**,** the evidence for effects of CAIM approaches remains uncertain [this may be especially true for young children (<6 years of age)] [29]**.** CAIMs (e.g., vitamin supplementation, massage therapy, music therapy, pet therapy) aim to complement traditional treatments, but families should approach them with caution, prioritize evidence-informed approaches, and work closely with medical professionals to ensure safety and effectiveness.
If additional support is required, consider a referral to a community pediatrician or specialist.

Primary care providers can support families by opening lines of communication and offering guidance to help distinguish between proven and promising therapies and those that are unproven, potentially harmful (e.g., restrictive diets), and expensive [15]. Ask parents if they have tried, are trying, or are considering trying any CAIM approaches as this information may not be spontaneously shared.

- Support families with informed decision making (e.g., potential benefits and downsides) and planning (e.g., when to start, how long to try and only trying one at a time while monitoring outcomes) [30].
- Use of CAIM therapies should not replace conventional autism therapies and unproven CAIM alternatives can divert time, energy, and resources away from more effective treatment options [15].
- One source that families may find helpful is the Autism Science Foundation.

### When child does not meet diagnostic criteria for autism, but other developmental concerns remain [4].

- Address concerns directly and continue developmental surveillance.
- Continue to refer the child and family for developmental supports and interventions, as appropriate. Assess whether current supports are meeting their needs.
- Revisit the need for autism-focused monitoring and assessment.
- May require referral to a pediatrician or developmental diagnostic team for additional assessment and possible differential diagnosis.

## 6. Advice Options

**If the child needs to be directed to hospital through RAAPID or the ER, call RAAPID for on-call surgeon or 911.**

| Zone | Program | Online Request | Phone Number |
|---|---|---|---|
| **Urgent Telephone** | | | |
| All Zones | RAAPID<br>RAAPID<br>Referral, Access, Advice, Placement, Information & Destination | N/A | **North:**<br>1-800-282-9911 or 780-735-0811<br>**South:**<br>1-800-661-1700 or 403-944-4486 |
| **Non-Urgent Electronic** | | | |
| All Zones | Netcare eReferral<br>eReferral | | N/A |
| **Non-Urgent Telephone** | | | |
| Calgary | Specialist Link<br>Specialist Link<br>Connecting Primary and Specialty Care | Online Request | 403-910-2551 |
| Edmonton, North | ConnectMD<br>ConnectMD | Online Request | 1-844-633-2263 |

You can request non-urgent advice at any point when uncertain about medications, next steps in treatment, imaging or resources available. There are some exceptions to non-urgent telephone program hours of operation and exclusion.

### Rehabilitation Advice Line (RAL)

RAL is available to anyone in Alberta with providers being among the intended users. Support may include guidance on navigating relevant rehabilitation services, guidance on development concerns and possible rehabilitation recommendations, as well as strategies to support families and caregivers. The service can also be accessed by the provider with the family present.

## 7. Referral for Diagnostic Programs

Community pediatricians are often well-placed to make an autism diagnosis. If a child's presentation is considered complex or requires tertiary level of specialized assessment, then referrals can be made to autism diagnostic clinics.

## Zone information

**South Zone (West)**

- Audiology and Children's Allied Health: West Children's Allied Health-Central Access and Triage.
- Autism Diagnostic Clinic (Lethbridge): Any primary care provider (nurse practitioner or family physician) or pediatrician can refer children to the Autism Diagnostic Clinic. The referral is not available online but can be requested by emailing CHI.CCS.INTAKEAdministrativeSupport@albertahealthservices.ca or calling their office at (403) 388-6575.
    - Prior assessments are not required but referring providers must complete the referral form and ensure that the child meets the specified criteria.

**South Zone (East)**

- Audiology and Children's Allied Health: East Children's Allied Health - Central Access and Triage at South Zone and area
- Developmental and Behavioural Diagnostic Clinic (Medicine Hat and Brooks): Any primary care provider (e.g., family physician) or pediatrician can refer children to our differential diagnostic clinic.
- The referral can be requested by calling our Children's Allied Health office at (403) 529-8966.
- Prior assessments are not required but referring providers must complete the referral form to ensure that the child/youth meets the pediatrician's specified criteria for this clinic.

**Calgary Zone**

Most often receive referrals from pediatricians, however, other referral sources considered on case-by-case basis. For additional information, please visit: Child Development Clinic at the Alberta Children's Hospital and Autism Spectrum Disorder Diagnostic Clinic.

**Central Zone**

Most often receive referrals from pediatricians, however, other referral sources considered on case-by-case basis. For additional information, visit: Pediatric Specialty Clinic OR families are sent to the Camrose Specialty Clinic.

**Edmonton Zone**

Pediatricians and primary care providers can refer to the Infant and Preschool Assessment and Outreach Service at the Glenrose Rehabilitation Hospital.

**North Zone**

Pediatrician and primary care provider can refer to Infant and Preschool Assessment and Outreach Service at the Glenrose Rehabilitation Hospital.

# PATHWAY DEVELOPMENT BACKGROUND

## About this pathway

- This pathway was developed in collaboration with Primary Care Providers (PCPs), Specialist Physicians (pediatrician, developmental pediatrician), Patient and Family Advisors, Pediatric Community Rehabilitation, Allied Health Professions and Primary Care Alberta (PCA)'s Provincial Pathways Unit.
- Condition-specific clinical pathways are intended to offer evidence-based guidance to support primary care providers in caring for patients with a range of clinical conditions.

## Authors and conflict of interest declaration

The authors represent a multi-disciplinary team and are listed alphabetically by first name. Names of the content creators and their conflict-of-interest declarations are available on request by emailing albertapathways@primarycarealberta.ca.

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### Pathway review process, timelines

Primary care 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.

**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.

## PROVIDER RESOURCES

| Resource | Link |
|---|---|
| ECHO Autism-Primary Care: Increase access to best practice primary health care for children on the autism spectrum including screening, evaluation and longitudinal care (FREE and CME credits) | Primary Care – ECHO Autism Communities |
| Canadian Pediatric Society: Autism Spectrum Disorder (includes position statements, clinical tools, information for parents and additional resources) | Autism Spectrum Disorder (ASD) \| Canadian Paediatric Society |

## FAMILY RESOURCES

| Resource | Link |
|---|---|
| **Patient Pathway:** On MyHealth Alberta: A webpage and two PDF formats are available to allow for easy printing, download, or scanning a QR code with the patient's smart phone for more information at their convenience. | Will be available March 2026 |
| MyHealth Alberta > Health Information & Topics> Autism. | MyHealth.Alberta.ca |
| Canadian Pediatric Society | Your child's development: What to expect \| Caring for kids |
| First Words Project (16 by 16 series) (e.g., language learning, imagination) | About 16by16 – First Words Project |

|  |  |
|---|---|
| ECHO Autism Communities (e.g., new diagnosis, understanding behaviour, supporting early development resources) | ECHO Autism Communities – Moving Knowledge, Not People |
| Government of Alberta: Family Support for Children with Disabilities | FSCD – How to apply \| Alberta.ca |
| PUF: Program Unit Funding | PUF Infographics |

## Pathway Update Notes

**Date**

- Summary of changes

**Date**

- Summary of changes

# Appendices

## Appendix A: Pediatric Developmental Surveillance Tools and Autism Screening Tools [31]

Resources listed in alphabetical order by category. Please note, additional tools are also available [31].

| | Tool | Specifications | Key information | Pros (+) and Cons (-) |
|---|---|---|---|---|
| Developmental Screening Tools[1] | **Ages and Stages Questionnaires (ASQ), 3rd edition and ASQ Social-Emotional Health, 2nd edition**<br>*Fee required for use and training.*<br>*More information here*<br>*Get a copy of the ASQ from your local Family Resource Network here* | **Ages:** 1mo-6yrs<br>**Length:** 21 questionnaires and scoring sheets aligned to age<br>**Type:** Parent questionnaire | • Parent completes questionnaire (10-15 min); conducted by mail, online, telephone or in person.<br>• Can be completed by early educators and health care professionals.<br>• Highlights child's strengths as well as concerns | + Appropriate for community settings<br>+ Available in multiple languages<br>– Licensed, fee required, not autism specific. |
| | **Infant-Toddler Checklist-Communication sand Symbolic Behaviour Scales Developmental Profile (CSBS DP)**<br>*Free checklist here*<br>*More information here* | **Ages:** 6mo-24mo<br>**Length:** 24 questions<br>**Type:** Parent questionnaire, Free | • Parent, caregiver completes questionnaire (5-10 minutes)<br>• Can be completed by healthcare professionals trained to assess young children.<br>• First step in routine screening to see if developmental evaluation is needed | + Appropriate for community settings<br>+ Claims to be promising way to identify children in need of further evaluation for autism and other developmental delays.<br>– Fee required for easy to score version<br>– Only available in English |
| | **Nippising District Developmental Screen (NDDS)**<br>*Fee required for use and training.*<br>*More information here* | **Ages:** 1mo-5.5yrs<br>**Length:** 13 specific forms aligned to immunization schedule<br>**Type:** Parent questionnaire | • Can be used by parent or health/childcare professionals.<br>• Quick Yes and No questions<br>• Encourages conversation | + Appropriate for community settings<br>+ Available in multiple languages<br>– Licensed, fee required |

|  |  |  |  |  |
|---|---|---|---|---|
|  | **Rouke Baby Record**<br>*Guide I: 0-1 mo*<br>*Guide II: 2-6 mo*<br>*Guide III: 9-15 mo*<br>*Guide IV: 18mo-5yrs*<br>*Free Various English Formats here*<br>*Free Fillable English version here* | **Ages:** 0mo-5yrs<br>**Length:** 1 page per Guide<br>**Type:** Parent questionnaire, Free | • 5 primary concern areas, 2 suggest Autism intervention/ treatment referral (Social/Emotional/Mental Health/Family Issues and Cognitive/Self Help Skills)<br>• Meant to be used as a guide during office visit | + Appropriate for community settings<br>– Only available in French and English |
| Level 1 Autism Screening Tools (universal)[2] | **M-CHAT (R/F)**<br>*Modified Checklist for Autism in Toddlers (Revised with Follow-up)*<br>Free to download in multiple languages here | **Ages:** 16-30 months<br>**Length:** 20 items and follow-up interview for ambiguous scores<br>**Type:** Parent questionnaire | • Lacks specificity to screen children with pre-identified developmental delays.<br>• Make sure to include follow-up interview | + Appropriate for community settings<br>+ Available in multiple languages<br>– High number of false positives (up to half of children who screen positive will go on to get no or different diagnosis). |
|  | **Q-CHAT & Q-CHAT 10**<br>*Quantitative Checklist for Autism in Toddlers*<br>*Free to download in multiple languages in both the full and 10-item version.* | **Ages:** 18-30 months<br>**Length:** 25 items; 10 in the shorter version<br>**Type:** Parent questionnaire | • Parents asked to rate frequency of behaviours (M-CHAT asks whether behaviours present/absent) | + Illustrations for each item<br>+ Brief version is very quick.<br>+ Available in multiple languages |
| Level 2 Autism Screening Tools (targeted)[3] | **Baby-Biscuit**<br>*Baby and Infant Screen for Children with autism Traits.*<br>*Free to download here.* | **Ages:** 17-39 months<br>**Length:** 6 items<br>**Type:** Parent questionnaire | • Has scaled recommendations based on score | + Strong sensitivity<br>+ Very short<br>– Produces many false positives |

[1] Developmental screening tools: Developmental surveillance is an important way for clinicians to identify children at risk for developmental delays and should occur during routine health visits and anytime a parent raises concerns about a child's growth and development [32].

[2] Level 1 autism screening tools: Broad tools that can be used in primary care settings to identify children who may need further evaluation.

[3] Level 2 autism screening tools: More detailed and used by clinicians when concerns have been identified.

Additional information - Level 3 tools: Comprehensive diagnostic assessments administered by specialists such as developmental pediatricians, psychologists, and diagnostic teams trained in their use.

## Appendix B: Sample letter for families

Sample diagnosis letter for families for application for Family Support for Children with Disabilities (FSCD), Program Unit Funding (PUF) and other supports.

I am writing this letter to support the needs of (child's name), DOB.  This child is experiencing significant delays in their development, and they are functionally impacted in the following areas:

-
-
-

Diagnosis:
Date of diagnosis:

The family is currently awaiting further assessment for a query of autism spectrum disorder.  Please consider their application for supports and services for early intervention.

Name of medical professional who diagnosed the child.

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