Screening and diagnosing for autism spectrum disorder (ASD) in pediatric care settings

Nicole Berning and Kimberly Hicks
• Overview of autism spectrum disorder (ASD) and prevalence in MN
• Describe the educational and medical pathways to early intervention
• Share resources on screening, diagnosis and accessing early intervention services
What is autism spectrum disorder (ASD)?

• Autism is a complex, lifelong developmental disability that appears during early childhood and can impact a person’s communication and social skills, relationships and ability to self-regulate.

• Autism is a “spectrum condition” that affects people differently and to varying degrees. For more information and training on ASD, visit MN ASD Resource Portal.
• Since autism is a spectrum, services and supports will likely vary from child to child

• Different eligibility requirements and access points

• A range of services are necessary to support the whole child and family
Prevalence of ASD in Minnesota

- ASD is the fastest-growing developmental disability in the United States.
- MN Autism and Developmental Disabilities Monitoring Network (MN-ADDM) snapshot report and MN-ADDM website
- Average age of first ASD diagnosis was 4 years, 8 months
• Encourage families to **identify medical homes** and **increase awareness of developmental milestones**

• Increase effective and early screening and diagnosis to **lower the average age of diagnosis**

• Ensure providers and families have information they need to **identify, refer and access intervention services**

• Ensure **effective care coordination** between primary care providers and other providers, professionals and community organizations that support children and families
Community collaboration: A key to early identification

• With the rates of ASD drastically increasing, there is a critical shortage of health care providers—namely developmental pediatricians, neurologists, child psychiatrists and specially trained psychologists, who can evaluate and diagnose children with autism (Lynch Barbera, 2021)

• Monitoring a child’s development is the responsibility of all those caring for the child:
  • Caregivers/ guardians
  • Primary care providers
  • Child care providers
  • All health, educational and human service professionals working with children
Screening programs in Minnesota

Child & Teen Check-ups

Help Me Grow

Women, Infants and Children (WIC)

Follow Along

Improved screening, referral and access to intervention

Family home visiting

8/13/2021
Medical diagnosis & educational determination

- Both the **medical system** and the **local school district** play an important role in:
  - evaluating a child’s progress, and
  - determining supports they may be eligible for.
- Some services **require a medical diagnosis**
- Rather than an either/or for education or early intervention services, these systems and professionals must work with each other and tailor the services and recommendations to meet the needs of the child and family.
- Team meets together to develop the right combination of supports.
The Overview of Medical Identification and Educational Determination of ASD resource provides information about the similarities and differences between the medical and educational pathways. Also available in Hmong, Somali and Spanish.

**Overview of Medical Identification and Educational Determination of Autism Spectrum Disorder**

**Do you have a questions about your child’s progress? Don’t wait!**

Both the medical system and your school district of residence play a role in evaluating your child’s progress and finding out what supports they may be eligible for, starting at birth and available whenever your child is diagnosed with or determined to have autism.

**Medical Identification**

- **Make an appointment with your child’s primary care physician and ask for a referral for an autism evaluation.**
- After you receive the referral, contact the relevant clinic and follow their intake process. Check with your insurance provider about coverage and requirements for referrals.
- Depending on the results of assessment, the medical provider and their team can help decide if any therapies, medications, and/or supports could help your child.

**Educational Determination**

- Access HelpMeGrowMN.org online or call 1-866-693-4769, or contact your local school district.
- Someone from the school district may determine that testing is needed for special education services. Your family will participate in the assessment.
- After the assessment, if your child or family is eligible for special education services, a planning team will meet to determine next steps on the types of services or supports your child may need.

**Special Education Services and Resources include...**

- Individualized Education Plans (IEPs), or a similar plan depending on your child’s age and where services are provided, which serve as a blueprint for the different special education services and supports your child will receive from the school at no cost to you (the child’s parents).
- Your child may also be eligible for related services, including things like physical therapy, occupational therapy, speech and language therapy, and school readiness programming, all of which are targeted at helping your child. These therapies are different from those offered in clinical settings, though they share the same name. Children can benefit in different ways from receiving things like speech and language therapy in their school and in clinical settings.

**Tips and Diagnosis of Autism**

- Have autism spectrum disorder (ASD) may experience a range of symptoms and effects. Some people may have very noticeable characteristics, others may not. Autism assessed as early as 18 to 24 months, but can be diagnosed at any age. The earlier intervention begins, the more effective the outcomes. Here are some of the symptoms of autism:

  - Differences in interacting with other people and making or maintaining relationships
  - Differences with back-and-forth conversation
  - Differences using eye contact, gestures, facial expressions, and body language
  - Differences reading social cues
  - Limited meaningful or functional communication

  - In very young children, the first symptoms of autism may include:
    - Limited demonstration of emotions, eye contact, or gestures like waving or pointing
    - No or inconsistent response to name
    - Limited interest in sharing or playing with others
    - Loss of speech
    - Delayed speech and/or no social babbling

**Adaptive behavior, interests, or activities**

- Differences in speech patterns (e.g., saying the same thing over and over in exactly the same way)
- Repeating behaviors like hand-flapping, rocking, jumping, or twirling
- Insistence on specific routines or strong resistance to minor changes
- Sensitivity to light, touch, and sound
- Strong interests in certain areas or objects
- Unusual interest in looking closely at objects, touching, smelling, or tasting objects

For more information, visit mn.gov/autism or contact ASD.DHS@state.mn.us.
## Comparison of the Diagnostic Assessment and Comprehensive Evaluation

### DA requirements & CMDE requirements

<table>
<thead>
<tr>
<th>Requirement</th>
<th>DA</th>
<th>CMDE</th>
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<tbody>
<tr>
<td>Updated annually</td>
<td>✔</td>
<td>✔</td>
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<tr>
<td>Documents medical necessity</td>
<td>✔</td>
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<tr>
<td>Requires the use of specific evaluation tools</td>
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<tr>
<td>Requires the use of a standard form</td>
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<tr>
<td>Determines eligibility</td>
<td>✔</td>
<td>✔</td>
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<tr>
<td>May qualify as a CMDE and DA if all components are included</td>
<td>✗</td>
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<tr>
<td>Requires a wellness/ health screening</td>
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Why make a referral for a CMDE?

• A CMDE is an opportunity to **access intensive early intervention services**

• The CMDE is comprehensive and includes information from variety of sources and professionals, reducing duplicative evaluations and assessments for everyone.

• **Who completes a CMDE?**
  • A licensed mental health professional, physician or APRN who is an enrolled [MHCP CMDE provider](#) or a mental health practitioner who meets the requirements of a [clinical trainee](#)
  • With 2,000 hours of clinical experience or evaluation of people with autism spectrum disorder (ASD) and works within their scope of practice.

• **How do I become a CMDE provider?**
  • If you meet the [criteria](#), you can enroll as a CMDE provider. The process is outlined [here](#).
Who makes the referral?

Refer for comprehensive evaluation

- Caregiver/guardian
- School, child care or other provider
- Primary care provider
Making the connections

1. Identifying developmental milestones
2. Screening and diagnosis
3. Access to early intervention services
Other important components to fill in the gaps

- Establish medical home
- Identifying developmental milestones
- Screening and diagnosis
- Comprehensive referrals
- Access to early intervention services
- Follow up and access to other supports
Why is important to have a medical home?

• Children with special healthcare needs, in particular, benefit from identifying a medical home.

• Studies show improved health outcomes, increased satisfaction and decreased cost of care.

• May particularly help address the needs of children from Black, Indigenous and People of Color (BIPOC) communities and at-risk populations (e.g., homeless, trauma history, etc.)

• Encourage families to identify a medical home
• The American Academy of Pediatrics (AAP) recommends screening all children for ASD at the 18 and 24-month well-child visits, in addition to regular developmental surveillance and screening.

• This type of screening can identify children with significant developmental and behavioral challenges early, when they may benefit most from intervention, as well as those with other developmental difficulties.

• For screening to be effective, it must be applied to all children – not only those with ASD symptoms.
Recommended screening tools

• There are multiple different tools you can choose to screen for ASD:
  • Ages and Stages Questionnaires SE-2 (ASQ-SE2)
  • Pervasive Developmental Disorders Screening Test-II (PDDST-II)
  • Communication and Symbolic Behavior Scales (CSBS)
  • Modified Checklist for Autism in Toddlers – Revised with follow-up (M-CHAT-R/F)

• **M-CHAT-R/F is the most common screening tool used in pediatric offices**
Timing and Frequency of Screening

• It is generally not feasible to complete more than two screenings at a single well visit.

• Clinics should determine their standard screening protocols, aiming for this as a minimum:
  • 3 developmental screenings by age 3 years,
  • 2 ASD-specific screenings by age 2 years,
  • Social-emotional screening every 6-12 months.
The First Steps: Pathway to learning, playing and growing provides a summary of key developmental milestones that babies and toddlers should be achieving. Also available in: Hmong, Karen, Oromo, Russian, Somali, Spanish and Vietnamese.

First Steps: Pathway to Playing, Learning and Growing

Although every child is unique and will learn and grow at their own pace, children are expected to develop in similar ways. By keeping track of developmental milestones, you will be able to support your child as they grow and identify right away if they may need extra help to learn. Don’t wait, early intervention programs can make a big difference! You are your child’s first and most important teacher. Here are tips, tools and guidance to help support your child’s development. Look for these important developmental milestones:

9-12 MONTHS
- Increase gesture, sounds, patterns and facial expressions
- Comprehend
- Gestures by pointing or saving
- Notice you, look at you, and watch you
- Follows a person that moves out of sight
- Begins to recognize faces

12 MONTHS
- Pulls themselves up on feet
- Walks alone
-精细化, adds, and subtraction
- Gestures to describe, or share interest in other children
- Enjoys playing with simple toys
- Follows simple instructions
- Takes part in cooperative games
- Begins to ask questions
-陪你去儿童医院

18 MONTHS
- Builds simple pretend play
- Uses 2-3 words in sentences
- Uses words and phrases to share interest and have short conversations with you
- Shows concern or affection for others
- Plays make-believe with dolls and animals
- Follows simple instructions
- Helps with feeding and dressing
- Begins to follow simple rules
- Makes simple gestures

2 YEARS
- Builds and block towers and puzzles
- Uses 3-4 word sentences
- Uses words and phrases to share interest and have short conversations with you
- Shows concern or affection for others
- Plays make-believe with dolls and animals
- Follows simple instructions

Child and Team Checkups

Your child’s development will be followed at regular checkups. Your child will be evaluated by different professionals to ensure you have a complete picture of your child’s progress.

Don’t wait, early intervention programs can make a big difference! You are your child’s first and most important teacher. Here are tips, tools and guidance to help support your child’s development.

Help Me Grow MN provides resources for families to understand developmental milestones and identify concerns. Resources and support include confidential screening and evaluation at no cost. Visit Help Me Grow online or call 1-866-609-9769 to make a referral. Educational services are free to all who qualify and can include a medical diagnosis. Services typically start within 30-45 business days of evaluation.

For accessible versions of this publication or additional equal access to human services, contact 651-631-4300 or 866-609-9769 (toll-free) or use your relay service.
Monitoring developmental milestones

• Offer resources for families to track their child’s development
  • CDC Milestone checklist
  • CDC Milestone tracker app
  • Pathfinder Health is a collaborative child development tracker for caregivers and their child’s care team
  • MN Learn the Signs, Act Early for free materials and resources
  • Screening and identification / Minnesota Autism Portal (mn.gov)
• **Green light:** child is on track with milestones—share resources to stay on track

• **Yellow light:** approaching milestones—educate caregivers on what they can be doing at home to help *maximize learning opportunities with their child*

• **Red light:** falling behind—refer to early intervention services
Tips for caregivers

• Narrate what you are doing throughout the day—increase practice opportunities by imbedding into routines

• Read to your child and point out pictures in book

• Model language rather than asking them to talk—repetition is key and reinforce all attempts

• Pair gestures with language (e.g., point and label, songs like Head, Shoulders, Knees and Toys, Patty-cake)

• Focus on imitation—if they aren’t imitating words, back up to sounds or gestures
Key indicators of ASD

- Lack of functional communication
  - Child may have language but identify if it’s meaningful (i.e., not rote or repetitive)
  - Can the child communicate their wants and needs?
  - Regression or loss of words or skills
- Avoids eye contact
- No response to name
- Lack of pointing or not following your point
- Sensory issues

- Does not share or engage in pretend play—insists on playing with certain toys or objects in a certain way
- Easily upset by small changes
- Inability to follow directions
- Inability to imitate
- Motor delay
- [Signs and symptoms / Minnesota Autism Portal (mn.gov)](http://mn.gov)
• Prematurity
• Siblings diagnosed with ASD or other familial/genetic risk
• Presence of intellectual disability or language impairment
• Feeding issues or sleep disorders
• “Hand-leading” or taking the adults hand and leading them to what they want
Watch out for “pop-out” skills

• Not uncommon for a child with autism to have “pop-out” skills or skills that they perform beyond their age level

• When people see these skills, they often assume that they are able to demonstrate other age-appropriate skills, but this may not be the case

• May have gaps in “ready-to-learn” behaviors

• May only be able to demonstrate these skills in specific circumstances (e.g., minimal distractions, with prompting, etc.)
When to refer for additional testing

- If you are within your scope of practice to diagnose a child with ASD, then it is important to do so **immediately**
- A diagnosis opens the door to access services and supports
- Keep in mind that EIDBI serves child with ASD and *related conditions*
- In complex cases, it may be necessary to refer the child for additional testing
  - History of trauma
  - Mental health concerns
  - Co-occurring diagnoses
Making referrals

- Refer families to their county/tribal agency to access **healthcare coverage and determine services and supports**
  - Home visiting programs
  - Quality early child care
  - Family support programs

- Refer to **Help Me Grow** to connect to educational services

- Refer to a CMDE provider for **Early Intensive Developmental and Behavioral Intervention (EIDBI) services**

- **Take action at the first sign of a delay—Don’t wait!**
  - Community supports, such as museums, libraries and more
Make a referral to EIDBI services

Click on online referral tool link from the MN Autism Resource Portal or Help Me Connect.

Search the directories for either a CMDE provider or EIDBI agency.

Trouble shoot common barriers

Call to schedule the evaluation. Connect to resources and advocates.
EIDBI referral, continued

Complete the **EIDBI referral form** and submit to the **ASD.DHS@State.mn.us** inbox

EIDBI team will help troubleshoot barrier(s)

Connect child and family to EIDBI provider or other services and supports if no provider is available

8/13/2021
• Explore the Pathway to EIDBI Services for Families online tool to find an EIDBI provider or make a referral to EIDBI services.

• Pathway tool is also available in Hmong, Somali and Spanish.
EIDBI 101

• For families, lead agencies, educators and other interested people to learn about the Early Intensive Developmental and Behavioral Intervention (EIDBI) benefit, as well as other resources for people with autism spectrum disorder (ASD) and related conditions.

• bit.ly/EIDBI-Providers

• bit.ly/EIDBI-Families

• Directions to access on Trainlink
What is the Early Intensive Developmental and Behavioral Intervention (EIDBI) benefit?

- Teaches meaningful communication & social interaction skills
- Addresses interfering behaviors
- Teaches self-management and regulation skills
- Builds independence with self-care and safety skills
- Increases participation in home, school & community life
- Family/caregiver training and counseling
- Child and family centered
Eligibility for EIDBI services

Age
- Birth up to age 21
- Ages served may vary by provider

Medical Necessity
- Determined through a comprehensive evaluation
- Autism spectrum disorder (ASD) or a related condition

Healthcare coverage
- Medical assistance (MA)
- MinnesotaCare
- MA-TEFRA
- Pre-paid health plans
- Private insurance
The Next Steps: Pathway to services and supports for a child recently identified with ASD, helps parents and caregivers understand options for their child in the year after diagnosis. Also available in Hmong, Karen, Oromo, Russian, Somali, Vietnamese and Spanish.
Evaluate the impact of early intervention

• Ask the caregiver how early intervention has helped their child
  • What outcomes are they working on?
  • How is your early intervention provider helping you know what to do to help your child?
  • What progress are you seeing?

• Monitor progress to determine if any new referrals need to be made

• The Navigating Autism Supports and Services: A guidebook for parents and caregivers, is a helpful resource to help families access the right services at the right time for their child and family. Also available in Hmong, Somali and Spanish.
Follow up

• Once the child has begun early intervention services, it is important to continue regular well-child checks

• Maintaining a routine, will help children with ASD continue to receive medical care and stay healthy throughout their life

• Monitor the child’s diet, including any special diet, food allergies or supplements the child is taking

• Ask about toileting and their sleep schedule
Online autism services navigation tool helps make accurate and appropriate referrals to early intervention services and supports based on the needs of the child and family.
Pathway to Services and Supports for Autism provides resources and support information from all the State agencies in Minnesota. Also available in Hmong, Oromo, Somali, Russian, Vietnamese, Karen and Spanish.
Why is it so important for children with autism to access a regular check-up?

• Many children with autism have co-occurring medical conditions, such as sleep apnea, gastrointestinal issues, seizures or allergies

• High pain tolerance

• May not be able to communicate if or where something hurts

• Interfering behaviors, such as biting, hitting or self-injury may be a sign of a serious health condition

• Regular checkups help ensure that any medical conditions, infections or injuries are identified early and properly treated

• When a child is healthy, their ability to learn improves, they have less behavior issues, communicate better, and learn coping skills, among many other improvements.
Strategies to interact and care for a child with ASD in clinic

- **Never hold down or physically restrain the child** unless it’s an emergency
- Assess what is triggering the fear or anxiety
- Task analyze the steps of visiting the doctor
- Practice those steps before the doctor visit
- Use social stories or video modeling
- [Health Care and Wellness / Minnesota Autism Portal (mn.gov)](http://mn.gov)
- [Co-occurring conditions / Minnesota Autism Portal (mn.gov)](http://mn.gov)
Trainings and resources for Primary Care Doctors

- **Developmental and Social-Emotional Screening Trainings**
  
  A training curriculum resource for Minnesota's public screening programs to provide staff training on early childhood developmental and social-emotional screening, referral and linkage to services.

- **Screening – Child and Teen Checkup Fact Sheet for Providers (PDF)**
This introductory module presents information about unique characteristics of ASD. Five simple strategies are introduced that may be used anytime, anywhere with young children, students, and adults with ASD.

Learning objectives:

- Provide an understanding of the spectrum of skills that characterize autism spectrum disorder, or ASD.
- Dispel common misconceptions about ASD.
- Provide simple strategies that may be helpful for individuals with ASD.

Start the module
Autism and Baby Navigator trainings

- **Baby Navigator Conversations** is a free webinar for pediatricians, family physicians, physician assistants, nurses, speech-language pathologists, psychologists, social workers, behavior health specialists, other health care providers in primary care, service coordinators, and other team members in early childhood education and early intervention systems serving babies from birth to 24 months of age.

- This webinar will:
  - Highlight Baby Navigator resources for families,
  - Offer guidance on how you can invite families to Baby Navigator for surveillance & screening, and
  - Provide practical strategies on using Conversational Steps to build consensus with families on the early signs of language delay and autism and to engage families in using Baby Navigator and Autism Navigator online tools and courses.

- This webinar is offered in two monthly series. The content is the same for each series. You can select your preferred day / time. **Please register and share this with colleagues who may be interested.**

- **Series 1:** First Thursday of each month at 4 to 5:30pm (ET)
- **Series 2:** Third Friday of each month from noon to 1:30pm (ET)
- [Registration](#)
Where to refer if you have concerns

- **Help Me Connect**
- **Provider flyer**
- Developmental and behavior concerns
- Disability Services and Resources
The MN Autism Resource Portal is a complete resource guide!

- The portal was created with input from parents, advocates, educators, professionals, and others.
At 2, parent notices developmental concerns. Concerns noted at preschool screening at 4; referred to Help Me Grow.

Starts K but still not at level with peers, in separate classroom. Concerns noted at preschool screening at 4; referred to Help Me Grow.

Parents have no coaching and are struggling at home with no services. Concerns noted at preschool screening at 4; referred to Help Me Grow.

Child’s behavior at home is affecting entire family. School is also seeing increases in needs. Without a medical dx no home services.

Family is overwhelmed and child requires crisis intervention. Referral for diagnostic assessment is made and child is diagnosed at age 13. However, they are unable to access intensive services because of limited providers who work with older children. Eligible for some county services and family support.

Family continues to be the main support. Many times unable to find long term housing and employment that is appropriate. Family is getting home supports but child is still segregated in most environments due to high-level needs.

Continue in adult segregated setting with supports. Many times unable to find long term housing and employment that is appropriate. Family continues to be the main support.

Trajectory when a diagnosis is received later in life.
Parents notice developmental concerns

Pediatrician conducts autism specific screening and makes a referral for additional testing

Child receives a medical diagnosis at age 2

While waiting for the follow up appointment, has evaluation completed through local school district

Child begins going to 40 hours per week of early intervention services, including family caregiver training and support

Family has a team supporting them and the child, including home supports

Child and family are accessing a variety of supports, decreasing caregiver burn out

Supports and services are coordinated and adapted to meet the child and family's changing needs

While waiting for the follow up appointment, has evaluation completed through local school district

Receives special education services, primarily in general education setting with supports. A team, including the case manager, help the family advocate for the right supports at the right time

Supports and services are coordinated and adapted to meet the child and family's changing needs

While waiting for the follow up appointment, has evaluation completed through local school district

Access transition services to find post-secondary education options, work, and a living arrangement in the community

While waiting for the follow up appointment, has evaluation completed through local school district

Trajectory when child accesses early diagnosis and treatment
Two different stories

- A story of a fragmented system in silos
- Receives delayed diagnosis
- Placed in high level settings, isolated, restrictive procedures
- Increased risk of suicide, hospitalizations, run-ins with law enforcement

- A coordinated system where child gets access to diagnosis and services
- Child receive early intervention
- Placed in inclusive setting
- Access to services across a variety of systems
Aligning our policies and practices

• Integrate **recommended screening tools** and **evidence based strategies** into practice

• Provide screening and diagnostic testing to **lower the age of diagnosis**

• Develop **learning communities of practice** or connect regional networks to disseminate knowledge and coordinate services

• Partner to provide resources and promote **sustainable outcomes**
References and resource links

- Autism Navigator
- Help Me Connect
- Turn Autism Around: An Action Guide for Parents of Young Children with Early Signs of Autism by Mary Lynch Barbera, Ph.D., RN, BCBA-D

- Many Faces of Autism Training
- MN Autism Resource Portal
• First Steps: Pathway to learning, playing and growing. Also available in Hmong, Karen, Oromo, Russian, Somali, Spanish and Vietnamese.

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Thank You!

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