

A close-up photograph of a purple flower, likely a gerbera, with many layers of petals. The center of the flower is dark and textured. The background is blurred green foliage.

Springing into Action: Autism Screening and ASD Resources for North Dakota

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Disclosures:

Whitney Rolling:

- Dr. Rolling works for Sanford Health.
- Sanford Health does not endorse any specific service providers.
- MCHAT-R/F is a copyrighted instrument. Please see guidelines for use at their website: <https://mchatscreen.com/>.

Trisha Stibbe:

- Mrs. Stibbe has no disclosures.

- Acronyms used today:

ASD = autism spectrum disorder

CDC = Center for Disease Control and Prevention

AAP = American Academy of Pediatrics



Objectives:

1. Understand autism spectrum disorder screening tools and the importance of early intervention.
2. Identify resources for families awaiting an autism evaluation.
3. Identify locations for autism evaluation sites.
4. Acknowledge what families want to know about an autism diagnosis.
5. Acknowledge the importance of a multi-disciplinary approach to management of autism spectrum disorder.
6. Identify resources for families after their child receives an autism diagnosis.



Autism Prevalence Data

Identified Prevalence of Autism Spectrum Disorder
ADDM Network 2000-2020 Combining Data from All Sites

Surveillance Year	Birth Year	Number of ADDM Sites Reporting	Combined Prevalence per 1,000 Children (Range Across ADDM Sites)	This is about 1 in X children
2020	2012	11	27.6 (23.1-44.9)	1 in 36
2018	2010	11	23.0 (16.5-38.9)	1 in 44
2016	2008	11	18.5 (18.0-19.1)	1 in 54
2014	2006	11	16.8 (13.1-29.3)	1 in 59
2012	2004	11	14.5 (8.2-24.6)	1 in 69
2010	2002	11	14.7 (5.7-21.9)	1 in 68
2008	2000	14	11.3 (4.8-21.2)	1 in 88
2006	1998	11	9.0 (4.2-12.1)	1 in 110
2004	1996	8	8.0 (4.6-9.8)	1 in 125
2002	1994	14	6.6 (3.3-10.6)	1 in 150
2000	1992	6	6.7 (4.5-9.9)	1 in 150

- New data from the CDC now estimates ASD prevalence as 1/36 children or 2.8% of children.

<https://www.cdc.gov/ncbddd/autism/data.html>

Autism Screening



- AAP guidelines recommend ASD screenings at the 18 and 24 month well child visits.
- Screening tests are designed to have high sensitivity rates so that children with the disorder or disease are not missed. Therefore some children may screen positive on an ASD screening questionnaire that don't have ASD but may also have concerns for developmental delays.
- Early screening and identification is important for ASD because studies have shown reduced impairment from autism symptoms with early interventions.



- A common ASD screener is the M-CHAT-R/F (Modified Checklist for Autism in Toddlers-Revised/Follow-up).
- Website: <https://mchatscreen.com/>. ©2009 Diana Robins, Deborah Fein, & Marianne Barton
- ASD screening questionnaire for children aged 16-30 months of age.
- <https://www.autismspeaks.org/screen-your-child> (electronic version on Autism Speaks)
- https://mchatscreen.com/wp-content/uploads/2015/09/M-CHAT-R_F_Rev_Aug2018.pdf (full instructions).
- MCHAT-R/F is a 20 question screen that are YES or NO responses.

M-CHAT-R™

Please answer these questions about your child. Keep in mind how your child usually behaves. If you have seen your child do the behavior a few times, but he or she does not usually do it, then please answer **no**. Please circle **yes** or **no** for every question. Thank you very much.

- | | | |
|---|-----|----|
| 1. If you point at something across the room, does your child look at it?
(FOR EXAMPLE, if you point at a toy or an animal, does your child look at the toy or animal?) | Yes | No |
| 2. Have you ever wondered if your child might be deaf? | Yes | No |
| 3. Does your child play pretend or make-believe? (FOR EXAMPLE, pretend to drink from an empty cup, pretend to talk on a phone, or pretend to feed a doll or stuffed animal?) | Yes | No |
| 4. Does your child like climbing on things? (FOR EXAMPLE, furniture, playground equipment, or stairs) | Yes | No |
| 5. Does your child make <u>unusual</u> finger movements near his or her eyes?
(FOR EXAMPLE, does your child wiggle his or her fingers close to his or her eyes?) | Yes | No |
| 6. Does your child point with one finger to ask for something or to get help?
(FOR EXAMPLE, pointing to a snack or toy that is out of reach) | Yes | No |
| 7. Does your child point with one finger to show you something interesting?
(FOR EXAMPLE, pointing to an airplane in the sky or a big truck in the road) | Yes | No |
| 8. Is your child interested in other children? (FOR EXAMPLE, does your child watch other children, smile at them, or go to them?) | Yes | No |
| 9. Does your child show you things by bringing them to you or holding them up for you to see – not to get help, but just to share? (FOR EXAMPLE, showing you a flower, a stuffed animal, or a toy truck) | Yes | No |
| 10. Does your child respond when you call his or her name? (FOR EXAMPLE, does he or she look up, talk or babble, or stop what he or she is doing when you call his or her name?) | Yes | No |
| 11. When you smile at your child, does he or she smile back at you? | Yes | No |
| 12. Does your child get upset by everyday noises? (FOR EXAMPLE, does your child scream or cry to noise such as a vacuum cleaner or loud music?) | Yes | No |
| 13. Does your child walk? | Yes | No |
| 14. Does your child look you in the eye when you are talking to him or her, playing with him or her, or dressing him or her? | Yes | No |
| 15. Does your child try to copy what you do? (FOR EXAMPLE, wave bye-bye, clap, or make a funny noise when you do) | Yes | No |
| 16. If you turn your head to look at something, does your child look around to see what you are looking at? | Yes | No |
| 17. Does your child try to get you to watch him or her? (FOR EXAMPLE, does your child look at you for praise, or say "look" or "watch me"?) | Yes | No |
| 18. Does your child understand when you tell him or her to do something?
(FOR EXAMPLE, if you don't point, can your child understand "put the book on the chair" or "bring me the blanket"?) | Yes | No |
| 19. If something new happens, does your child look at your face to see how you feel about it?
(FOR EXAMPLE, if he or she hears a strange or funny noise, or sees a new toy, will he or she look at your face?) | Yes | No |
| 20. Does your child like movement activities?
(FOR EXAMPLE, being swung or bounced on your knee) | Yes | No |

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M-CHAT-R Follow-Up™ Scoring Sheet

Please note: Yes/No has been replaced with Pass/Fail

- | | | |
|---|------|------|
| 1. If you point at something across the room, does your child look at it?
(FOR EXAMPLE, if you point at a toy or an animal, does your child look at the toy or animal?) | Pass | Fail |
| 2. Have you ever wondered if your child might be deaf? | Pass | Fail |
| 3. Does your child play pretend or make-believe?
(FOR EXAMPLE, pretend to drink from an empty cup, pretend to talk on a phone, or pretend to feed a doll or stuffed animal) | Pass | Fail |
| 4. Does your child like climbing on things?
(FOR EXAMPLE, furniture, playground equipment, or stairs) | Pass | Fail |
| 5. Does your child make <u>unusual</u> finger movements near his or her eyes?
(FOR EXAMPLE, does your child wiggle his or her fingers close to his or her eyes?) | Pass | Fail |
| 6. Does your child point with one finger to ask for something or to get help?
(FOR EXAMPLE, pointing to a snack or toy that is out of reach) | Pass | Fail |
| 7. Does your child point with one finger to show you something interesting?
(FOR EXAMPLE, pointing to an airplane in the sky or a big truck in the road) | Pass | Fail |
| 8. Is your child interested in other children?
(FOR EXAMPLE, does your child watch other children, smile at them, or go to them?) | Pass | Fail |
| 9. Does your child show you things by bringing them to you or holding them up for you to see – not to get help, but just to share?
(FOR EXAMPLE, showing you a flower, a stuffed animal, or a toy truck) | Pass | Fail |
| 10. Does your child respond when you call his or her name?
(FOR EXAMPLE, does he or she look up, talk or babble, or stop what he or she is doing when you call his or her name?) | Pass | Fail |
| 11. When you smile at your child, does he or she smile back at you? | Pass | Fail |
| 12. Does your child get upset by everyday noises?
(FOR EXAMPLE, a vacuum cleaner or loud music) | Pass | Fail |
| 13. Does your child walk? | Pass | Fail |
| 14. Does your child look you in the eye when you are talking to him or her, playing with him or her, or dressing him or her? | Pass | Fail |
| 15. Does your child try to copy what you do?
(FOR EXAMPLE, wave bye-bye, clap, or make a funny noise when you do) | Pass | Fail |
| 16. If you turn your head to look at something, does your child look around to see what you are looking at? | Pass | Fail |
| 17. Does your child try to get you to watch him or her?
(FOR EXAMPLE, does your child look at you for praise, or say "look" or "watch me") | Pass | Fail |
| 18. Does your child understand when you tell him or her to do something?
(FOR EXAMPLE, if you don't point, can your child understand "put the book on the chair" or "bring me the blanket") | Pass | Fail |
| 19. If something new happens, does your child look at your face to see how you feel about it?
(FOR EXAMPLE, if he or she hears a strange or funny noise, or sees a new toy, will he or she look at your face?) | Pass | Fail |
| 20. Does your child like movement activities?
(FOR EXAMPLE, being swung or bounced on your knee) | Pass | Fail |

Total Score: _____

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Most items "YES" is the desired response (negative for autism) except there is reverse scoring for 2,5,12 ("NO" is typical response).

YES=0, NO=1 except for questions 2,5,12 where NO=0 and YES=1

Scoring:

Scoring Algorithm

For all items except 2, 5, and 12, the response "NO" indicates ASD risk; for items 2, 5, and 12, "YES" indicates ASD risk. The following algorithm maximizes psychometric properties of the M-CHAT-R:

- LOW-RISK: Total Score is 0-2;** if child is younger than 24 months, screen again after second birthday. No further action required unless surveillance indicates risk for ASD.
- MEDIUM-RISK: Total Score is 3-7;** Administer the Follow-Up (second stage of M-CHAT-R/F) to get additional information about at-risk responses. If M-CHAT-R/F score remains at 2 or higher, the child has screened positive. Action required: refer child for diagnostic evaluation and eligibility evaluation for early intervention. If score on Follow-Up is 0-1, child has screened negative. No further action required unless surveillance indicates risk for ASD. Child should be rescreened at future well-child visits.
- HIGH-RISK: Total Score is 8-20;** It is acceptable to bypass the Follow-Up and refer immediately for diagnostic evaluation and eligibility evaluation for early intervention.

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What to do Next?

- If screening is positive or if significant concerns arise, a formal autism evaluation is indicated.
- Autism evaluations can be scheduled at academic institutions or private service providers.
- Some larger school districts perform autism testing but the testing establishes a educational autism diagnosis. A medical autism diagnosis must come from a medical provider.
- Many times wait lists are long, so if a concern is present, encourage families to seek out evaluations as soon as possible.



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Autism Diagnostic Clinics

(ND locations primarily--not comprehensive but the best I have.)

Anne Carlsen Therapy Center
Jamestown
701-252-3850

Benson Psychological Services
Fargo
701-297-7540

Caravel Autism Health (TH available*)
Moorhead
218-275-6602

Dakota Family Services
Fargo
(Minot location only medication management)
(Bismarck only has in-patient services)
701-419-6734

Neuropsychology Associates
Fargo
701-297-7588

Sanford Health
Developmental-Behavioral Pediatric Clinic (701-234-2431)
Developmental CTC Clinic (701-234-6600)
Fargo

Solutions Behavioral Health
Bismarck
Moorhead, Detroit Lakes, Fergus Falls
218-287-4338

Southeast Human Service Center (ND Residents)
Fargo
701-298-4500

Great Plains Interdisciplinary Autism Diagnostic Clinic
Minot, Williston
701-858-3286

(Minnesota is not included in full on this list but the Minnesota Autism Center is a great resource for evaluations.

<https://www.mnautism.org/>

Current ASD diagnostic clinics for MAC are at Duluth and Minnetonka)



Resources and Recommendations for those awaiting an Evaluation

- Reach out to Early Intervention (children 0 months up until 3rd birthday).
- Reach out to the public school district for an evaluation for an IEP (individualized education plan) for children aged 3 and older.
- Enroll children in developmental therapies if appropriate (speech therapy, and/or occupational therapy, and/or physical therapy).
- Referral for audiology or ophthalmology evaluations if indicated.
- Prepare for the appointment. Ensure all documents (parents/guardians and school/daycare reports) are returned if there is intake paperwork. Have daycare or school provide some behavioral observations or concerns.
- Write down questions about your child you would like answered.
- Review your child's development. (age of developmental milestones such as sitting, walking, first words, etc.)



RESEARCH STUDY OPPORTUNITY

Autism FIRST PROJECT

TELEOUTREACH
CENTER

STUDY PURPOSE

Researchers at the University of Minnesota, Twin Cities are looking for research participants for a study about the efficacy of early intervention services provided over telehealth (video conferencing) for kids with Autism Spectrum Disorder (ASD) and their families. Parents will receive coaching to provide interventions to support their child's communication and other skills.

YOU AND YOUR CHILD MAY BE ELIGIBLE IF:

Your child is between 1 and 5 years old and is either on a waitlist to be evaluated for ASD or has received an ASD diagnosis in the last 3 months & is waiting for services.

WHAT DOES THIS STUDY INVOLVE?

Participants receive parent coaching for 30-60 minutes 3x weekly for 9-12 weeks through video conferencing home visits. Questionnaires and interviews are given before and after the intervention. Overall, parents commit to 18 months of participation. Research staff will connect with participants via a webcam and a computer, tablet, or smartphone. Training is provided. Compensation is up to \$275 per child/family.

Please contact telehealthstudy@umn.edu for more information about the study.

 INSTITUTE on COMMUNITY INTEGRATION | UNIVERSITY OF MINNESOTA

Approved for use by UMN IRB
Effective on 4/7/2022
IRB Study Number: STUDY00013893

Research Opportunity for children 1-5 years of age that are awaiting an ASD diagnostic evaluation or have gotten an ASD diagnosis in the last 3 months and are awaiting services.

Contact: telehealthstudy@umn.edu

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ASD Management and Treatment

Medical Recommendations	Medication Management	Developmental Supports	Behavioral	Educational	Family Support	State Supports	Other
<ul style="list-style-type: none"> •Genetic Testing •Eye Evaluation •Hearing Evaluation •Dental Services 	<ul style="list-style-type: none"> •No specific medications for ASD. •FDA approved medications for irritability in ASD. •Medications to target comorbidities (anxiety, ADHD, esp.) 	<ul style="list-style-type: none"> •PT, OT, ST •AAC Device if have language impairment 	<ul style="list-style-type: none"> •ABA therapy •Social Skills through speech therapy 	<ul style="list-style-type: none"> •IFSP/IEP •Educational Advocacy 	<ul style="list-style-type: none"> •FV North Dakota •Developmental Disabilities Offices 	<ul style="list-style-type: none"> •Developmental Disabilities Office-SSI, respite, etc. •FV North Dakota •Autism Speaks •Local Autism Chapters with Family supports •Activities/Events locally 	<ul style="list-style-type: none"> •ASD is a mandatory reportable disorder in the state of ND.

ABA Resources: (Not fully comprehensive but the best I have.)

Pediatric Partners	Fargo, Bismarck, Grand Forks, Thief River Falls	1-888-875-5262	https://www.pediatricpartnersclinic.com/services/applied-behavior-analysis/
Full Circle Pediatric Solutions	Fargo	701-478-0221	https://fullcirclepediatric.com/en/applied-behavior/
North Dakota Autism Center	Fargo	701-277-8844	https://ndautismcenter.org/behavior/
Solutions Behavioral Healthcare Professionals	Fargo, Moorhead	701.412.2973	http://www.solutionsinpractice.org/
Family Institute PC	Fargo, Grand Forks	701-282-8510	https://www.familyipc.com/psychotherapy-counseling-services/behavior-analysis/
Anne Carlson Therapy Center	Fargo, Jamestown, Bismarck, Grand Forks, Minot , Bottineau	701-402-5569	https://annecarlson.org/behavior-health-autism/
Caravel Autism Health	Moorhead	218-748-8737	https://caravelautism.com/?
Total Behavioral Support	Minot	701-852-6154	https://www.totalbehaviorsupport.com/about
Poppy's Promise	Bismarck	701-204-7870	https://www.poppyspromise.com/
Wonderment Therapies	Dickinson	701-483-3899	https://wondermenttherapies.com/
Iron Range Behavioral Services	Virginia	218-748-8500	https://www.irbehavioralservices.com/eidbi-services
Catalyst (TH in MN for some insurances)	St. Cloud, Perham	866-569-7395	https://catalystbehavior.com/personalized_aba/#
Minnesota Autism Center (MAC)	Virginia, Bemidji, Red Wing, Hutchinson, Duluth, Mankato, Rochester, Cambridge, Medford	(952) 767-4200	https://www.mnautism.org/
Milestone Health Partners	Williston	(701)-651-6437	https://www.milestonehealthpartners.com/behavioral-health

Parent Resources:

Family Voices of North Dakota

Web Site: <http://fvnd.org/>

Electronic Referral: <http://fvnd.org/contact-us/>

1-888-522-9654

Autism Services Unit

Katherine Barchenger, State Autism Coordinator

N.D. Department of Human Services

1237 W. Divide Avenue, Suite 1C

Bismarck, ND 58501-1208

Phone: (701) 328-4630

Toll-Free: (800) 755-2719

ND Relay TTY: (800) 366-6888

Fax: (701) 328-8969

Email: kbarchenger@nd.gov

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ASD Written Resources

(Thank you Dr. Quanrud.)

Play and engagement in early autism: The Early Start Denver Model by Sally Rogers, PhD and Geraldine Dawson, PhD. Publisher: New York: Guilford Publishing, 2009)

A Practical Guide to Autism: What Every Parent, Family Member, and Teacher Needs to Know By Fred R. Volkmar and Lisa A. Wiesner (Wiley, 2009)

Ten Things Every Child with Autism Wishes You Knew By Ellen Notbohm (Future Horizons, 2005)

The Complete Guide to Asperger's Syndrome By Tony Attwood (Jessica Kingsley Publishers, 2008)

Thinking in Pictures, Expanded Edition: My Life with Autism By Temple Grandin (Vintage, 2006)

The Out-of-Sync Child, Third Edition: Recognizing and Coping with Sensory Processing Differences By Carol Kranowitz (Perigree, 2022)

Autism Education & Resources | Autism Speaks <https://www.autismspeaks.org/>
· 100 Day Kit for Young Children | Autism Speaks <https://www.autismspeaks.org/tool-kit/100-day-kit-young-children>
· 100 Day Kit for School Age Children | Autism Speaks <https://www.autismspeaks.org/tool-kit/100-day-kit-school-age-children>

Autism Research Institute <https://www.autism.org/>
"Learn the Signs. Act Early." | CDC <https://www.cdc.gov/ncbddd/actearly/index.html>
CDC's Milestone Tracker App | CDC <https://www.cdc.gov/ncbddd/actearly/milestones-app.html>

National Autism Association | Providing real help and hope for the autism community since 2003.
<https://nationalautismassociation.org/>
Autism - HealthyChildren.org <https://www.healthychildren.org/English/health-issues/conditions/Autism/Pages/default.aspx>

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- Robins, Diana, et al. The Modified Checklist for Autism in Toddlers, Revised with Follow-Up. M-Chat™ Web Site. <https://mchatscreen.com/>. Accessed April 26, 2023.
- Autism Spectrum Disorder. American Academy of Pediatrics Web Site. <https://www.aap.org/en/patient-care/autism/>. Last Updated April 5, 2023. Accessed April 26, 2023.



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