IOWA MEDICAID EPSDT Care FOR Kids

Volume 31 • Number 2 Spring 2024

In-Clinic Screening for Autism Spectrum Disorder

Dianne McBrien, MD,
Clinical Professor,
Center for Disabilities and Development,
University of Iowa
Stead Family Children's Hospital

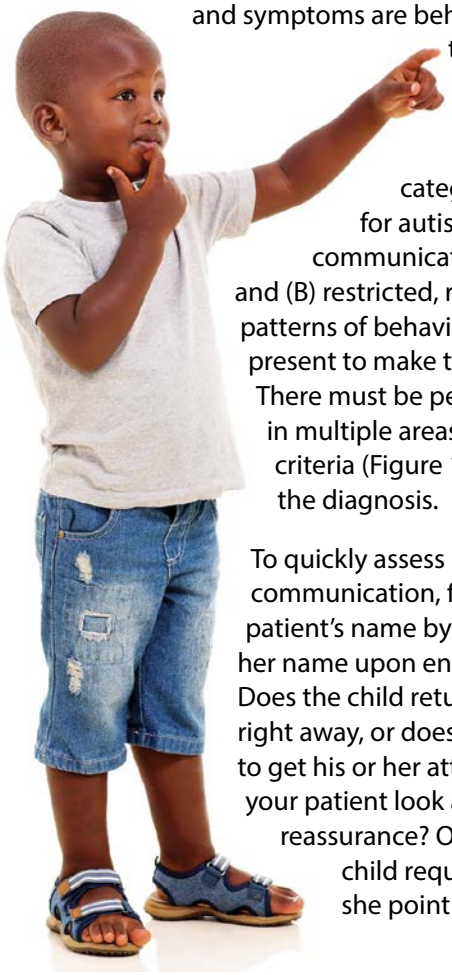
In 2020, the Centers for Disease Control and Prevention reported that the prevalence of autism in children was 1 in 36.[1] The demand for services, including diagnostic evaluations and therapies, is high; families and referring providers alike are frustrated by long waiting lists. Primary care and other community providers, however, may assist these children and their families significantly as they wait. The following article is a broad review of basic elements of the autism

(continues on page 2)

evaluation in young children, including screening, risk factors, and pertinent observations on the physical exam.

The American Academy of Pediatrics recommends the use of an autism-specific screening measure at the 18- and 24-month well-child visits. While there are several options for screening, the easiest to administer and score is the Modified Checklist for Autism in Toddlers-Revised with Follow-up (M-CHAT R/F), which is designed to be used with the M-CHAT-R and is valid for screening toddlers ages 16 to 30 months to assess risk for autism spectrum disorder.[2] Studies of the M-CHAT R/F have determined that, performed once, it is sensitive but not very specific at screening cases of autism in young children.[3,4] In other words, it is good at detecting possible cases of autism, but many children who screen positive do not have autism. Older children may be screened using the Ages and Stages Questionnaires: Social Emotional (ASQ: SE-2), which can be used for children up to 60 months of age, or the Social Communication Questionnaire (SCQ), which was developed for individuals 4 years and older.

While autism is a neurologically based disorder, its signs and symptoms are behavioral. As of 2011, the DSM-V specified that deficits in two different categories of criteria for autism — (A) social communication impairment and (B) restricted, repetitive patterns of behavior — must be present to make the diagnosis.[5] There must be persistent deficits in multiple areas of **both** sets of criteria (Figure 1) to make the diagnosis.



To quickly assess social communication, first say your patient's name by calling his or her name upon entering the room. Does the child return your gaze right away, or does it take extra effort to get his or her attention? Does your patient look at their parent for reassurance? Observe how the child requests items. Does she point with a finger?

Figure 1

DSM-5 Criteria for Autism Spectrum Disorder

Currently, or by history, must meet criteria A, B, C, and D

A. Persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays, and manifested by all 3 of the following:
   1. Deficits in social-emotional reciprocity.
   2. Deficits in nonverbal communicative behaviors used for social interaction.
   3. Deficits in developing and maintaining relationships.

B. Restricted, repetitive patterns of behavior, interests, or activities as manifested by at least two of the following:
   1. Stereotyped or repetitive speech, motor movements, or use of objects.
   2. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change.
   3. Highly restricted, fixated interests that are abnormal in intensity or focus.
   4. Hyperactivity or hypoactivity to sensory input or unusual sensory aspects of environment.

C. Symptoms must be present in early childhood (but may not become fully manifested until social demands exceed limited capacities).

D. Symptoms together limit and impair everyday functioning.

Does she shake her head no or nod her head yes in response to questions? Does your patient smile easily in response to playful overtures, like pretending to hide? All of the aforementioned behaviors are examples of typical social communication, which are seen less often or not seen in young children with autism. Refer to Figure 2 for a list of common social communication milestones with corresponding timing.

To evaluate for restricted, repetitive patterns of behavior, observe your patient with simple toys, such as a baby doll with a bottle or a set of toy cars. Does the child demonstrate typical imitative play with the toys (feeding or rocking the baby, "driving" the cars)? Or is there anything unusual in the child's play, i.e., peering closely at the wheels and spinning them, flapping the doll by its leg, sniffing and tasting the toys? Note any repetitive sounds or words the child produces. This category also includes delayed echolalia, which often consists of scripted speech from TV shows or movies ("No job too big, no paw too small!") or immediate echolalia, in which the child repeats the end of the last phrase he heard. Observe for any unusual movements, including hand flapping, repetitive ear covering, toe walking, and rocking.

This category of criteria also includes sensory issues, which can be difficult to evaluate. While pediatric care providers commonly hear reports of picky eating or a child disliking certain clothing items, sensory issues associated with autism tend to be disruptive to family life. A child may tolerate so few foods that parents need to pack her preferred meals for trips and family visits. Sensitivity to sound may be so acute that the family avoids loud public spaces such as parades, movie theaters, or big box stores. Sensory issues can also be associated with ADHD, anxiety, and global developmental delay.

While several risk factors have been identified for autism, including prematurity, various genetic syndromes, and advanced parental age, the greatest single risk factor for autism is being a sibling of an individual with autism. Siblings may run up to an eightfold risk compared to the siblings of typical children. Even nonautistic siblings are at elevated risk for speech delay, anxiety disorders, and attentional problems.[6]

The differential diagnosis is broad but most commonly sorts into two categories: children in whom social communication delays are a part of a pattern of overall developmental delay, and those whose social struggles are related to primary attentional or social anxiety issues.

What should you do if you think one of your patients has autism? Most importantly, don't wait for the results of the autism clinical evaluation to refer to services, including speech and occupational therapy. To refer patients under 3 for intervention, contact Early ACCESS at 888-IAKIDS1 or email **iafamilysupportnetwork@everystep.org**.

Figure 2

Social Communication Milestones

1 year

Waves bye-bye

Understands "no" (child pauses briefly or stops play)

Enjoys simple games like peekaboo or patty-cake

18 months

Points with finger to show parent something interesting

Demonstrates simple imitative play, like pushing a toy car

Copies parent doing chores, like sweeping with a broom

2 years

Looks at parent's face to see how to react in a new situation

Points to at least two body parts upon request

Can play with more than one toy at the same time, like giving a baby doll a bottle

3 years

Notices other children and joins them in play

Talks with parent in conversation using at least two back-and-forth exchanges. Asks "who," "what," "where," or "why" questions, like "Where is mommy/daddy?"

4 years

Pretends to be something else during play (teacher, superhero, dog)

Likes to be a "helper"

Answers simple questions like "What is a coat for?" or "What is a crayon for?"

In-Clinic Screening for Autism Spectrum Disorder *(continued from previous page)*

While several risk factors have been identified for autism, including prematurity, various genetic syndromes, and advanced parental age, the greatest single risk factor for autism is being a sibling of an individual with autism.

Early ACCESS services are in home and are not associated with special education. Refer children ages 3 to 5 to the Area Education Agency (AEA), which works closely with school districts to provide the services that children need. Find local AEAs at **https://iowaaea.org/**.

Autism-specific treatments, such as applied behavioral analysis and floor time, require both an autism diagnosis and a score above cutoff on an evidence-based autism diagnostic tool (ADOS-2, CARS, RITA-T). Contact the Regional Autism Assistance Program at **Iowa-RAP@uiowa.edu** or call 866-219-9119 ext. 2. RAP can provide a link to autism family navigators, who are experienced parents of children with autism. Family navigators are trained to provide peer support, as well as to inform the family about community-based resources. If you are experiencing challenges treating an autism-related comorbidity while waiting, such as sleep disruption, disruptive behavior, or anxiety, call the UIHC Integrated Call Center at 800-322-8442 and ask to speak to the developmental/behavioral pediatrician on call.

References

1. Maenner MJ, Warren Z, Williams AR, et al. Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020. MMWR Surveill Summ. 2023;72(No. SS-2):1–14.

2. Robins D, Fein D, Barton, M. Modified Checklist for Autism in Toddlers, Revised, with Follow-up (M-CHAT-R/F™). 2018. **https://www.mchatscreen.com/wp-content/uploads/2015/09/M-CHAT-R_F_Rev_Aug2018.pdf**. Accessed March 4, 2024.

3. Hyman SL, et al. Identification, Evaluation, and Management of Children With Autism Spectrum Disorder. Pediatrics. January 2020. 145(1): e20193447. 10.1542/peds.2019-3447.

4. Wieckowski AT, Williams LN, Rando J, Lyall K, Robins DL. Sensitivity and Specificity of the Modified Checklist for Autism in Toddlers (Original and Revised): A Systematic Review and Meta-analysis. JAMA Pediatr. 2023.177(4): 373–383. doi:10.1001/jamapediatrics.2022.5975.

5. American Psychiatric Association. Diagnostic and statistical manual of mental disorders (5th ed.). 2013. **https://doi.org/10.1176/appi.books.9780890425596**.

6. Hansen S, et al. Recurrence Risk of Autism in Siblings and Cousins: A Multinational, Population-Based Study J Am Acad Child Adolesc Psychiatry. 2019.58(9):866–875.

Common Medical Interventions for Children with ASD

Early Access Services

If your child is younger than 3 years old, call Early ACCESS at 888-425-4371. For more information about Early ACCESS visit **https://educateiowa.gov/pk-12/early-childhood/early-access**.

Area Education Agency Services

If your child is 3 years or older, call your local school or Area Education Agency. To find your AEA visit **https://www.iowaaea.org/find-my-aea/.**

Speech Language Therapy

- Used to help children understand speech processes and language use in social situations.
- Can be beneficial for children who may struggle with communication or have difficulty understanding social cues when talking with others.

Occupational therapy

- Involves physical and motor skills.
- Develops age-appropriate independence and self-care skills.

Physical therapy

- Focuses on problems with movement that can cause limitations in daily life.
- Addresses challenges with sitting, walking, running, and jumping.
- Can improve coordination, poor muscle tone, and balance, leading to better overall movement.

Applied behavior analysis (ABA)

- Depending on a child's needs, therapy can focus on teaching self-help skills, social skills, academic skills, communication, or appropriate behavior.
- A therapist determines how a child's surroundings, including people, may influence their behavior.
- Focuses on positive reinforcement.
- Teaches children how to increase useful behaviors and decrease behaviors that may cause harm or interfere with learning.
- Uses rewards for positive behaviors rather than recognition of negative behaviors.

Behavioral health services

- Typically provided by social workers, psychologists, and mental health counselors.
- May be helpful for children with difficult behaviors or co-occurring disorders like ADHD, disruptive behavior disorders, depression, or anxiety.
- Can involve just the child or the entire family.
- Can help children learn new skills/behaviors or strengthen existing skills to address problematic behaviors.

ABA resources

Help is in Your Hands – Free, online resources with 16 web-based video modules with ABA-based activities to help parents add simple intervention practices to their everyday routines at home. It is best for infants through kindergarten and is based on the Early Start Denver Model. Emphasis on following the lead of the child when teaching/reinforcing social and communication skills. It also offers webinars for providers on coaching parents to support their young children with autism or social communication problems. Visit **https://helpisinyourhands.org/course**.

MIND Institute ADEPT (Autism Distance Education Parent Training) Interactive Learning – A 10-lesson interactive, self-paced, online learning module providing parents with free tools and training to more effectively teach their child with autism functional skills using ABA techniques. UC Davis Mind Institute: **https://www.ucdmc.ucdavis.edu/mindinstitute/centers/cedd/adept.html**.

Vanderbilt University provides free online trainings for parents of children with autism. To create a free account to access trainings, visit **https://triad.vkclearning.org**. For early intervention, ages 0 to 3, online modules are available for the ABCs of Behavior, Communication, Challenging Behavior, Social Play, Toilet Training, and Addressing Sleep Challenges. For early childhood, pre-kindergarten, the following modules are offered: Play, Circle Time, Communication, and Inclusion. For school-ages, grades kindergarten-12, modules addressing the following topics are available: Communication, Challenging Behavior, Visual Supports, Environmental Supports, Transition to Adulthood, and Social Skills.

Source: Iowa Regional Autism Assistance Program

Navigating Behavior Challenges in Toddler and Preschool Age Children

Gretchen Vigil, MD, Clinical Associate Professor,
Stead Family Department of Pediatrics, University of Iowa Stead Family Children's Hospital

Even if behavioral management of preschool-age children isn't your expertise, this article provides tips to address parental concerns in the clinic. All providers have to address parenting questions, ranging from handling toddler tantrums to poor listening skills. For many parents, a toddler's terrible twos are the first time they have had to consider discipline. When a child is biting, hitting, or pinching, this can make parents fearful that their child will have a lifetime of violence or have difficulty getting along with others. When talking with parents, listen and don't try to rush. Keep track of your time as it is billable.

Routine

Toddlers and preschool-age children love a routine. Their life, to them, is very unpredictable and seems out of their control. They are being told what to wear, what to do, where to go, etc. Their behavior can easily be thrown off by fatigue and hunger. They don't have the ability to understand their emotions, and they don't have the words to explain their wants and needs.

A stable routine with predictable sleep times and mealtimes can tame many a crazed 2- to 4-year-old — and their parent. Children find comfort in knowing what is going to happen and when, and that their sleep and food needs will be addressed. Parents are also better able to plan outings and errands. Many families post their daily routine using pictures and move a clip to indicate where they are in the schedule.

Choice

Look for opportunities to give children a choice and control when possible. For example, "Do you want the blue shirt or red shirt?" or "Do you want to put your coat on, or do you want me to do it?" Offer **only** two choices that are acceptable to you. Otherwise, they are sure to pick one that you don't want and then you're stuck. The unsaid third choice if they don't pick, is the parent picks. Be neutral. Only offer the choice once and stick with the choice with no lengthy discussions or explanation. If there is no choice, do not offer a choice.

Sometimes there is no apparent choice, for example, car seat compliance or other safety issues. But, can you make something in that a choice? "You have to sit in your car seat, but do you want to hold your bear or your book?" "You have to hold my hand, but should we walk or skip?" Finally, sometimes stating this favorite is necessary: Do you want to do it the hard way or the easy way? " The flu shot is going to be done. Do you want it done the easy way or the hard way?"

Transitions

Transitions, especially unexpected ones, can trigger behavioral issues. Provide a warning about upcoming transitions. Timers can be helpful. "In two minutes, when the timer goes off, we need to clean up and start lunch." "Ok, that was the timer, time to clean up." "In two minutes we need to leave the park, do you want to swing or slide one more time before we go." Children this age live in the moment. They do not have a concept of time. They don't understand the terms later, tomorrow, or next year. They often cannot conceive of leaving the here and now; even to go do something positive like getting ice cream. Don't we all like a warning of an upcoming change?

Positive attention

Be positive! Someone once told me that a parent should give 10 positives to counteract each negative. Praise and kind words make us feel good and more likely to repeat our actions or try harder. Praise the things you want to see more. Ignore what you want to extinguish. Thank them for compliance or for doing the right thing. Parents can be positive with more than just words: use smiles, high fives, hugs, kisses, stickers, sprinkles, etc.

Parents should remember that discipline is really teaching, not punishing. Manners, safety, and managing emotions are taught, like learning to walk and talk. Children feel more secure when they know their limits and that their parents are in control.

Parents need to consider therapy for themselves, addressing their experience with discipline as a child and recognizing their emotional response or reaction to their child's behaviors. Therapy with the child-parent dyad can improve bonding and compliance.

Resources

www.kidshealth.org — includes discipline basics or for specific issues, such as biting.

www.healthychildren.org — American Academy of Pediatrics parenting information.

www.psychologytoday.org — up-to-date listing of therapists that can be filtered for location, age, etc.

IOWA MEDICAID EPSDT Care FOR Kids

University of Iowa Stead Family Children's Hospital
Center for Disabilities and Development
University Center for Excellence in Developmental Disabilities
100 Hawkins Drive
Iowa City, IA 52242-1011

What's in this issue

If you have questions about **billing** related to EPSDT Care for Kids services, please call Provider Services: **1- 800-338-7909**. If you have questions about **clinical issues** and EPSDT Care for Kids services, please call **1- 800-383-3826.** Please note: Due to budget restraints, the *EPSDT Care for Kids Newsletter* is sent to offices and organizations, rather than to individuals. **The newsletter is also available online at www.iowaepsdt.org**. Readers are welcome to photocopy or download material from the newsletter to share with others. If you wish to reproduce material from the newsletter in another publication, whether print or electronic, please obtain permission prior to publication by contacting Michelle Johnston at **michelle-johnston@uiowa.edu**. Please include the following acknowledgment with reprinted material: Reprinted by permission of the Iowa *EPSDT Care for Kids Newsletter.*

The ***EPSDT Care for Kids Newsletter*** is published three times a year, in print and online, as a joint effort of the Iowa Department of Human Services, the Iowa Department of Public Health, and the Center for Disabilities and Development, which is nationally designated as Iowa's University Center for Excellence in Developmental Disabilities. The goal of this newsletter is to inform Iowa health care professionals about the EPSDT Care for Kids program, to encourage them to make use of this important resource, and to provide them with information about a wide range of developments in the field of health care.

Please send correspondence concerning **content** to:
Temitope Awelewa, MD
UI Stead Family Children's Hospital
Department of Pediatrics
200 Hawkins Drive – BT 1300-2
Iowa City, IA 52242
temitope-awelewa@uiowa.edu

Please send **change of address** information to:
Michelle Johnston
University of Iowa Stead Family Children's Hospital
Center for Disabilities and Development
100 Hawkins Drive, Iowa City, IA 52242-1011
michelle-johnston@uiowa.edu