ADOS at MyWellbrook

Several MyWellbrook clinicians are certified to administer ADOS assessments, if patients qualify for a referral to ADOS. For more questions about ADOS or autism, please direct questions to Dr. Melissa Doyle and Dr. Aleeya Healey.

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Intro to Autism

Autism is a neurodevelopmental diagnosis characterized by difficulties in three primary areas of function.

- Social interactions and communication
- Restrictive Interests or Perseverations
- Repetitive behaviors

Autism is considered a spectrum as individuals may be impacted to varying degrees. It is often useful to view the person's difficulty as compared to what would be neurotypical for age and intellectual ability. For a diagnosis of autism, deficits need to be present prior to age 3. To elicit important diagnostic clues, parents or caregivers are often asked questions about each area, such as:

Social interactions and communication:

- Did the baby make eye contact?
- Did they engage in or respond to a social smile or other affect?
- Did they point to an object to bring it to your attention
- Did they respond when their name was called?

For older children or adults:

- Do they make and sustain eye contact
- Do their social interactions include gestures and facial expressions when talking or responding to others?
- Do they struggle with understanding social norms or idioms (i.e. its raining cats and dogs)
- Do they prefer or seem not bothered by being alone even when engaging in activities that are typically group interactions such as hobbies?
- Do they describe friendships that are primarily online or where there is little ongoing engagement?
- To elicit important diagnostic information, inquire about the friends, do they spend time with them outside of school or work, do they know their favorite food or movie? Those with autism may describe having friends, but for children they may be referring to those they see in the school hallway or on the bus, for adults they are those in a shared lunchroom.

Restrictive Interests or Perseverations

- Did they become overly engaged with things that spin such as the wheels on toys or fans?
- Do they struggle with changes in routine or have a preference for sameness with food or clothing?
- Do they have sensory sensitivities to light, sound or texture of food or clothing?
- Neurotypical children often have areas of interest such as a game or dinosaurs, however, these topics are age/developmentally appropriate and they can be coaxed into a discussion about other things. For those with autism, the conversation largely focuses on their special interest and will keep talking despite a lack of interest from others around them.

Repetitive Behaviors

- Do they rock, flap their hands or pace (for older children) where the behavior does not serve a clear function?
- Patients may describe or engage in repeated movements such as foot shaking, clicking a pen, pacing or even some hand flapping. Noting when this occurs or if it is functional for managing anxiety or while cognitively processing, as often seen for those with other diagnoses such as anxiety or ADHD. This movement functions to relieve stress or to aid with cognitive processing. However, for adults who are trying to mask symptoms, you may see finger taping or other more subtle hand motions.

- Did they line up toys or other items and become distressed if the items were moved?
- We also see some of these behaviors for those with OCD or other anxiety disorders, in those instances the behavior is seen as a mechanism to reduce anxiety and not merely as a preferred activity.

Can a patient have other diagnosis that look like autism?

Many diagnoses co-occur with autism including ADHD, anxiety, Intellectual Disability and several genetic disorders. The APRN should determine that the current symptoms are most likely due to autism and not another disorder prior to referring for an ADOS. If there is a concern for ID, we will verify the IQ on their IEP. Patients with ID are more complicated to assess and are referred to a Developmental Pediatrician for their ADOS.

For ADOS clinicians at MyWellbrook, if you have a concern that the patient's results were more likely due to another psychiatric or developmental diagnosis, please discuss with the APRN.

Diagnosing Autism at MyWellbrook

Any APRN may refer patients for an ADOS assessment if the patient meets criteria for autism during the evaluation. Complete the "ADOS Eligibility" template in Charm, and then notify the Operations team via chat. The patient will then be reviewed for ADOS eligibility and may be approved for an assessment with a MyWellbrook ADOS-certified clinician. **Never promise an ADOS assessment to patients–they may not always be eligible.**

MyWellbrook Health's diagnostic protocol for Autism Spectrum Disorder incorporates medical decision-making and DSM-5 criteria. The ADOS evaluation is often used to substantiate an autism diagnosis when there is significant clinical evidence. ADOS is a gold-standard assessment tool and should be considered a key component of the evaluation, and only administered by ADOS-certified clinicians. It is always administered in-person.

However, to ensure consistency in diagnostic practices, ADOS results are incorporated into overall clinical judgment and do not independently determine diagnosis.

For ADOS clinicians at MyWellbrook, autism is **not** within the diagnostic scope of practice for therapists and social workers. Any patient referred for an ADOS should already have a suspected or provisional autism diagnosis in their chart assigned by the APRN. After a positive ADOS, refer the patient back to the APRN who will formally assign the autism diagnosis.

Therefore, the referring APRN retains ownership of the diagnosis, including:
- Initial documentation (confirmed or provisional)
- Final determination after ADOS

- Any addition, modification, or removal of diagnosis

In contrast, clinicians administering ADOS:
- Provide assessment results and interpretation
- Do not independently assign, remove, or modify diagnoses

If there is a discrepancy between ADOS results and clinical presentation, the APRN should document their clinical reasoning accordingly.

In summary, the process for autism evaluation is below:

1. Initial APRN Evaluation

Criteria fully met → document ASD diagnosis
OR
Criteria substantially met → document provisional ASD diagnosis

ADOS referral is appropriate only when sufficient clinical indication and DSM-5 criteria are present to support an ASD diagnosis.

2. Post-ADOS Follow-Up

All patients who complete an ADOS evaluation are required to have a follow-up appointment with an APRN, regardless of whether the evaluation results in a positive or negative diagnosis.

The ADOS clinician will have conducted a debrief with the patient covering test results; the APRN is not required to re-review all test components but should be prepared to address general questions about autism and ADOS.

Next steps are based on ADOS outcome:
- Positive: Remove provisional status if applicable. Continue addressing all treatment needs. Accommodation letters may be issued as requested.
- Negative — APRN disagrees: Diagnosis is maintained. APRN documents clinical reasoning supporting the diagnosis. Additional support may be obtained via the MGH ASD Checklist or MyWellbrook consultants. Accommodation letters may be issued as requested.
- Negative — APRN agrees: ASD diagnosis is removed. Evaluation for other symptoms should continue, particularly where functional impairments persist.

What ICD-10 code should be in the chart before an ADOS referral?

The referring APRN should add a suspected or provisional autism ICD-10 code to the chart before sending the referral. If this is not present when you receive the referral, use whatever diagnoses are already in the chart and flag the APRN.
The chart should also document early developmental history, behavioral observations and functional impairments due to autism.

What if the patient or family does not speak English?

The ADOS must be administered in the patient's native language. Patients may not use a translator or interpreter for the test. Clinicians may administer testing to a child who speaks English, but the parents do not, if there is informed consent for the test and the child is old enough to remain with the evaluator without distress. For Spanish-speaking patients, Keymi Lorenzo is MyWellbrook's bilingual evaluator.

What if the patient only speaks a few words or appears to have an intellectual disability?

To be eligible for ADOS at MyWellbrook, patients must be verbal. MyWellbrook clinicians only administer Module 2, 3 and 4 for the ADOS. Module 1 (which is not administered at MyWellbrook) is for those who are nonverbal or who do not have "phrase speech". Phrase speech is the use of 3 word functional sentences like "more juice please" or "see my IPad?". These phrases cannot be echolalia, repeating what others say, or scripting, repeating what they heard on tv or online.

ADOS Scoring

What cutoff score should we use for autism on the ADOS Module 3?
Use a score of 7 or above as your cutoff for an autism spectrum finding on Module 3. Do not use the 10-point cutoff — this has been removed from templates as it is no longer clinically relevant and causes confusion for families and professionals unfamiliar with the ADOS.

Should the autism comparison score still be included in reports?
No. The comparison score has been removed from use because it was frequently misunderstood by families and professionals alike. Families sometimes interpreted a "Level 3" comparison score as a fixed, lifelong severity label, when it was only meant to reflect how impairing the signs and symptoms appeared during that specific assessment. Use the total score and consult the severity box (mild/moderate/severe or Level 1/2/3) in the lower left corner of the scoring sheet instead.

When I am unsure whether to give a score of 0 or 1 (or 2 vs. 3), what should I do?
Always go with the lower score. If you are questioning yourself, that uncertainty itself is a signal to score lower. It is better to underscore than to overscore. Overdiagnosis is a significant concern—autism can be a sought-after diagnosis and the ADOS must reflect what you objectively observed, not what the patient or family reports or desires. History including what is in the APRN note does not impact scoring.

How should I score eye contact when I am unsure if it was sufficient?
Score it as a zero. The "1" was removed from that item precisely because evaluators consistently picked it regardless of what they observed, avoiding a clear determination. If you have any doubt about whether adequate eye contact was present, assign a zero.

Can individual high scores on a few items push a client over the threshold?
No. No single item score should be alarming on its own. It is the constellation of scores across all items that brings the total to 7 or above. Do not be afraid to give a 2 on one item — that alone will not incorrectly diagnose someone.

Is it appropriate to ask a client or family why they want an autism diagnosis?
Yes, and it is encouraged. Understanding the purpose of the evaluation helps you provide better context during the results review. It is perfectly valid for someone to say they simply want to understand themselves better. Knowing their goal also helps identify next steps — whether that is school accommodations, ABA services, or personal understanding.

Masking & Adult Assessment

Can I use masking as a reason to score higher?
No. If a patient can articulate that they are masking, that level of self-awareness and insight is itself inconsistent with autism at a scoring threshold. Masking may affect eye contact and some verbalization, but it does not account for emotional understanding questions, offering of information, or other ADOS items. Score what you observe.
Patients may become upset if they believe they have autism and do not score positively on the ADOS. Remind them that the test documents observed behaviors and is not intended to diminish their experience. You can inquire about the goal of a positive score and encourage

them to pursue Cognitive Therapy or social skills training for any of those struggles as those can be very helpful.

A client scored below the cutoff on the ADOS but insists they have autism. How do I handle this?
Be honest and compassionate. Many adults seeking a diagnosis are looking to feel understood or to find an explanation for why they have struggled socially or professionally. Acknowledge that their experiences are real and valid, even if the ADOS does not support an autism diagnosis. Remind them that therapy — including CBT and social skills training — is available and helpful regardless of a formal autism diagnosis. You may also ask what getting the diagnosis would mean to them, which can open a conversation about more appropriate next steps.

How do I handle adult autism evaluations?
Adult autism diagnosis is more complex than childhood assessment. You must establish that signs and symptoms were present in childhood–this requires historical data from caregivers, teachers, or records. Adults presenting with anxiety, OCD, or ADHD may have symptoms that overlap with autism. In those cases, the preferred approach is to treat the comorbid conditions first and then pursue the ADOS if signs and symptoms persist. Do not refer for ADOS solely based on patient self-report.

What historical information is needed to diagnose autism in an adult?
Autism is a pervasive developmental disorder, meaning signs and symptoms must have been present in childhood — not just in recent years. For adults, you need some form of historical evidence such as childhood reports of difficulty making or keeping friends, repetitive behaviors (e.g., lining up toys), or restricted interests (e.g., only talking about one topic). This data typically comes from caregivers or teachers and is harder to obtain for adults, especially if family is not available.

How do I distinguish autism from anxiety, ADHD, or OCD in an adult?
This is one of the most challenging aspects of adult autism assessment. The key question is: are the presenting signs and symptoms better explained by another diagnosis? For example, poor eye contact, social withdrawal, and feeling overwhelmed in social situations can all be symptoms of severe generalized anxiety — not autism. The recommended approach is to address the comorbid condition first (through therapy or psychiatric medication management) and then reassess for autism if signs and symptoms persist. Adults can have both autism and anxiety or ADHD, but each diagnosis must be confirmed independently.

Is the ADOS normed on female presentation of autism?
Not well. The ADOS has a known limitation in that it was largely normed on male presentations of autism. Females often present differently and may not score as clearly on some items. This is a recognized gap in the tool. Despite this, the ADOS still covers enough domains that masking or atypical presentation alone should not prevent a score from reaching the threshold if autism is truly present.

What do I do during the result review with the family?

The result review is the responsibility of the person who administers the ADOS and is mandatory during the ADOS appointment. You should address 3 specific topics:

- **Scoring**: Explain that the numerical scores of 0 through 3 relate to the number of times a specific behavior occurred in response to a prompt. Those scores are added and then compared to the established scores for the test, which determine if the patient's response is consistent with autism.
  Review the specific deficits for autism; social reciprocity, repetitive behaviors and restricted interests and provide an example of each one from the assessment. Keep it focused on what you observed and how that translated to a score.

- **Purpose**: The ADOS does not diagnose autism, it indicates if the patient's responses are consistent with the established symptoms of autism. ADOS results support the evaluation by a medical provider who will diagnose autism.

- **Next Steps**: The patient will meet with the MyWellbrook APRN who will provide the autism diagnosis and address any follow up concerns. Provide resources to the family and remind them their APRN and the office staff can also provide these resources. In New Jersey, the best resource is https://www.everythingautismnj.org/resources. This site will provide support and direction to families, offer advocacy and referrals to other providers. Nationally, we encourage families to connect with autismspeaks.org. Families who consent and are under 20 may receive additional state-provided case management resources.

During the review with the family, do not expand into therapy, advocacy, coaching, or resource navigation — that is the role of the patient's therapist or the APRN. If families need additional support processing the diagnosis, they can be connected to a MyWellbrook therapist or the APRN.

What if a patient becomes dysregulated or unsafe during the ADOS?

Your safety is the priority. If you cannot safely continue, end the session and document "ADOS attempted" in your report and alert onsite staff if you need assistance. Score whatever items you

completed–a partial ADOS can still be clinically informative. Note the reason the session ended in your documentation.

Information on ADOS

The Autism Diagnostic Observation Schedule is a standardized instrument that utilizes interactive activities to observe if behaviors and responses outlined above present to the degree that the individual meets criteria for autism. This tool was developed by Catharine Lord et al in the 1980's and consists of four modules. Any professional can conduct an ADOS evaluation including social workers, educators, psychologists or occupational therapists. To perform an ADOS, you must be trained and certified by an accredited site. Medical providers such as physicians or APRNs can diagnose autism using DSM V criteria. They can also perform ADOS evaluations but must be accredited before doing so. The materials used during the test are highly specialized and can not be substituted with other materials.

The ADOS evaluation is a diagnostic test. However, unlike cognitive test instruments, results can be impacted by the patient's mood and environmental factors such as background noise or other distractions on the day of testing. Score interpretation has greater variability on this test than on other diagnostic test instruments.

Module 1 is for toddlers or non verbal children and adults. The activities in this module are largely interactive and do not require verbal responses to the examiner prompts. The assessment can be complicated as many other diagnostic presentations could better explain the person's difficulties including speech and language disorders, intellectual disabilities or other genetic or developmental diagnosis. As a result, we do not complete Module 1 ADOS evaluations at MyWellbrook, instead referring to other experts in the community.

Module 2 requires that the child have "phrase speech" or is able to use 3 word sentences that are meaningful and goal directed, such as "I want juice" or "mom car now please".
During the test, the child is engaged with various activities to see if they respond to their name, can be redirected from a preferred interest or activity, to see if they use facial expressions or share enjoyment in response to the examiner, to assess engagement in repetitive actions as well as sensory sensitivity. In this module, the parent is permitted to be in the room during testing, but asked to not engage unless the evaluator makes that request.

Module 3 is for children and young adults with fluid speech who can engage in various activities including describing a picture scene, retelling a story from a book and describing and showing the evaluator how they do a daily routine such as brushing their teeth. The score is generated based on the person's ability to use eye contact, gestures and facial expressions, engage in reciprocal or back and forth communication, recognize the affective experiences of others ("why do people marry", "do your actions ever bother anyone"), and not perseverate on the testing materials. No parents or other family members are permitted in the room during testing.

Module 4 is for teens and adults with fluid speech. The test still involves some activity based materials such as retelling a story with affect and gestures, describing a daily routine, responding to the examiner and showing shared enjoyment, as well as awareness of the affective experiences of others ("why do people marry" "do you actions ever bother others and how do you respond"). Activities in this evaluation are somewhat more targeted towards adults. Scoring here is very similar to Module 3. No parents or other family members are permitted in the room during testing.

Note: The ADIR (Autism Diagnostic Interview-Revised) is an interview that is conducted with parents or caregivers of someone with autism. It is frequently utilized when the individual is non verbal or they are not otherwise able to engage in testing. While the ADIR has clinical utility as it provides additional developmental history, it is important to remember that memory is highly subjective. Some centers include the ADIR and ADOS as part of a comprehensive evaluation. We do not use the ADIR at MyWellbrook at this time.

Testing Procedures

The ADOS can take from 30-50 minutes to complete, depending on if the person needs a break in the middle, becomes distressed, frustrated or is disengaged. A patient who is less able or interested in responding to the creativity tasks such as "tell a story" may progress very quickly through the test. After the test, the evaluator immediately scores the results and then returns to discuss the findings with the patient and family. The evaluator is required to document specific examples of interactions or responses to support each score the person achieved.

The test should not be repeated within 1-2 years to avoid the person recalling test activities which can then invalidate the results. For an older teen or adult, once the test is done it does not need to be repeated unless the results are inconsistent with their presentation.

Once the ADOS report is complete the front desk will send it to the patient along with resources if the patient tested positive for ASD.

Cautions and Limitations

The ADOS should only be conducted in the individual's native language.

While the ADOS is considered the "gold standard" of evaluation tools, it is important to remember it is a one hour interaction providing a narrow lens on the person's skills and responses and documents responses to specific tasks or activities.

A person may have other diagnoses that result in a response that appears to be autism, when there may be a better explanation. For example,

- Selective Mutism: may have limited social engagement, eye contact
- Anxiety: may line up items, refuse to touch things or have other avoidance responses

- Intellectual disability or cognitive processing delays: may not be able to comprehend some questions or respond in the time that is permitted.

Autism is often co-morbid with other diagnoses. However, the ADOS needs to indicate that autism is the best explanation for the responses to testing. For this reason, we may suggest that someone with social communication delays wait until language improves before testing or someone with anxiety complete a course of CBT before doing an ADOS. This helps to ensure that the results are most likely due to the presence of autism rather than another diagnosis.

If a child becomes dysregulated or unsafe during the ADOS stop the assessment. Document it as “ADOS attempted” and note that the session ended early due to the child's behavior. Include whatever scoring you were able to complete. In some cases, an early termination is itself diagnostically informative, and the items you did complete may be sufficient to tell a meaningful clinical story.

ABA Therapy & Other Services

Is ABA therapy appropriate for adults with autism?
Rarely. ABA is most appropriate for young children, particularly those with self-injurious behaviors or non-verbal presentations. For adults, the more appropriate resources are social skills groups, CBT, and peer networking programs. If an adult asks about ABA, ask what they are hoping to get from it—the answer usually points toward a more appropriate intervention.

Why might a positive ADOS result not be enough to qualify a client for ABA services?
ABA providers and payers increasingly require a comprehensive evaluation — not just the ADOS. They want documentation that rules out other explanations for the presenting symptoms (e.g., ADHD, anxiety, intellectual disability), a cognitive assessment with IQ scores, and an adaptive functioning assessment. IQ scores can often be found in the client's IEP (schools are required to do these triennially). MyWellbrook's updated templates now include parent-reported and provider-reported observations to strengthen the documentation package.

Are we required to report positive ADOS results to the state?
Yes. The New Jersey Department of Health requires MyWellbrook to report positive ADOS results to the state branch that manages autism. Families are asked whether they consent to be reported with their name or anonymously. If they consent to named reporting and are under age 20, they become eligible for state-provided case management and other resources. This reporting is handled by MyWellbrook staff — not by the evaluator.

Resources for Autism and ADOS

For Providers and Parents

- childmind.org

For Parents

- Everything Autism | New Jersey's Top Resource: Discusses diagnosing in early development, early intervention, ABA and other treatment
- POAC Autism Services in NJ - Autism Events & Training: Parent-led organization with referrals to resources and parent support

For Adults

- Signs of autism in adults | Autism Speaks: Indications of autism in adults
- Planning for Adult Life for People with Disabilities | North Brunswick: Discusses transition to adulthood, services and supports

National Websites With General Information

- Autism Spectrum Disorder | NIMH Information Resource Center
- Autism Spectrum Disorder (ASD) | Autism Spectrum Disorder (ASD) | CDC

ADOS Supplies & Ordering

Contact Alejandra Bryan and send a photo of what needs to be replaced–request snacks, water any items for the ADOS kit, or ask for access to the entire inventory list for reference. **Do not** substitute items without first checking with Alejandra, as some substitutions are acceptable and others are not.