



TIP SHEET

For Medical Professionals

Our network of OHC families have been navigating the healthcare system for many years, from routine wellness visits to life-threatening emergencies. What follows are some common themes they have shared based on those experiences. We hope these will help you feel ready to provide excellent care to individuals with autism and/or intellectual and developmental disabilities (IDD).

Take a whole person approach

- **Embrace the whole person mindset.** The individual in your office with autism or IDD is so much more than their specific diagnosis or disability. They also likely have different needs and preferences than others with that same diagnosis or disability – so getting to know them as a person is critical.
- **Beware of diagnostic overshadowing.** Rather than automatically attributing symptoms or behaviors to the disability when they could be independent issues, first ask yourself, “how would I approach any patient presenting with this set of symptoms?” Then consider whether their disability should impact your assessment and your treatment plan.
- **Be curious and open-minded about ‘behaviors.’** Some patients may demonstrate behaviors, whether conscious or involuntary, that may seem unusual but can be an important means of self-regulation or communication. Many patients may “stim”, i.e. engage in repetitive behaviors such as vocalizing, hand flapping, fidgeting, or rocking.
 - Try to understand the function the behavior serves, respect its value, and determine ways to increase the individual’s comfort in the setting (see accommodations section below).
 - Anxiety is common among patients with autism and IDD, and can also cause increases in challenging behaviors (including aggressive behaviors towards self or others).
 - If a patient presents as aggressive, there’s a good chance that aggression is a way of communicating that something is wrong, or that a person is experiencing pain
- **Try to learn as much as you can about the patient upfront, before you dive specifically into a given medical issue.** This is important for all patients, but especially those with special needs.
 - Ask questions about the individual’s interests, strengths, challenges, what they like to do when they’re feeling well, etc. This helps you establish a connection as well as a baseline understanding.
 - Lean in to what you learn about interests to build rapport. For example, invite a patient to tell you some more facts about elevators, or ask them about the collection of pencils they brought to the appointment. Validating their interests shows that you are seeing them as you would any patient.
 - Try to check in ahead of time in case there are topics to avoid that might trigger intense emotion, challenging behavior or perseveration.
- **Partner with parents and caregivers.** They may not be medical professionals, but they are the expert in their child’s daily experience, and can share invaluable information that will help you to see your patients in a holistic way.
 - Parents/caregivers can help you understand their child’s baseline, to help you put the symptoms or behaviors you see in context, including when something that might seem inconsequential to you is out of the norm for the individual.
 - For a non-verbal patient in particular, parents and caregivers are often the translator, able to explain what sounds, gestures, and/or behaviors mean, and can share medical history, etc.

Build trust and rapport through effective communication

- **Greet and address the patient directly whenever possible.** (They are the patient, and should be the most important person in the room, even if they have a caregiver there to support them.)
 - Some patients with IDD or autism will speak directly with you, others may use alternative forms of communication (sign language, iPad or other device, pictures/writing).
 - Even when a caregiver is the one who will do most of the talking, show the patient you are interested in them by continuing to check in with them - a reassuring glance, a smile, letting them play with your stethoscope, etc.
- **Begin by engaging based on the patient's chronological age - and then adapt if needed.**
 - One of the most frequent complaints from individuals with autism and/or IDD is that people (including medical professionals) often assume they will engage like a child.
 - Interest in topics that seem suited for someone younger doesn't necessarily correlate to the patient's intellect. For instance, you might observe a young adult listening to a Wiggles song when you come into the exam room, but that doesn't mean the next song on their playlist isn't Green Day.
 - Some patients will, in fact, engage in a way that is "younger" than their chronological age; take the family's cue on the best way to interact in these cases.
- **Meet the patient where they are.**
 - Some patients might engage in behaviors that are noisy or distracting while you are speaking, or might not make eye contact. Some may invade others' personal space or require increased personal space for themselves. This is a reality for many families, so unless they signal otherwise, they are fully expecting to continue on with the appointment as thoroughly as you would with any patient.
 - Be ready to do a little more "detective work" when the patient has more difficulty communicating their symptoms (e.g., a patient might not be able to tell you what hurts, so you may have to go head to toe and watch expressions to figure it out).
- **Recognize that patients may have challenges processing information,** and/or might have a gap between their expressive and receptive language levels. Begin by presuming competence. You might also try to:
 - Explain what you will do before starting any examination or procedure, so they know what is coming next. Use their parent or a toy to demonstrate first what you are about to do.
 - Incorporate the use of visuals, social stories and gestures; for example, you may provide a picture illustrating what will happen. Many individuals with IDD are visual first learners.
 - Give the patient time to process and respond. Or pause to check in and ask a patient to share back what you have said, to assess understanding of what you have shared.
 - Use clear, concrete language and examples. Individuals with autism and/or IDD may interpret things very literally.
 - Recognize that language from an individual might not always be reliable (e.g., some individuals always answer "yes," or can script language without understanding it, etc.) Parents and caregivers can help guide you on this as well.
 - When possible, give the patient some choices (e.g., "I can look in your ears first, or your mouth, which do you prefer"), which may give them a sense of autonomy and help reduce anxiety.

Offer accommodations suited to the individual

Many patients with autism or IDD have sensory sensitivities, anxiety around medical visits, or other challenges; accommodations can sometimes help. Ideally, you would learn about helpful accommodations before their first visit, but you can also offer them in the moment.

- **Offer to adapt the environment to respond to sensory sensitivity or anxiety.**
 - Some patients may be light sensitive, sound sensitive, smell sensitive, etc. Some may prefer you not touch them or make eye contact unless absolutely necessary. Ask the patient and/or caregiver whether there are any sensory accommodations you can make, such as dimming the lights in the exam room, or allowing headphone wearing, or offering that they wait in a quiet area vs. the main waiting room.
 - Likewise, there are also patients who are under-sensitive and therefore may be sensory-seeking. For these individuals, things like the use of animated language, bright colors, stimulating noise, or deep-pressure touch might be helpful. They may prefer the energy of the main waiting room so it's important to find the right fit.
 - Allow options for distraction and self-soothing for patients who may need them. Soothing or sensory friendly toys are often helpful (recognizing any shared toys will need to be cleaned often), and many patients will bring their own. For technology lovers, easy access to WiFi is a real plus.
- **Set parents and caregivers up for success** so that they can set you up for success.
 - It might be difficult for them to complete paperwork when they also need to be supervising their child. Allow the option to complete it ahead of time.
 - Try to limit the paperwork to just what you really need - and limit their need to provide the same information over and over again - as this population of parents/caregivers is typically overburdened with paperwork.
 - Provide as much information as you can ahead of time (e.g. the flow of the appointment, what procedures to expect, whether there will be waiting in between parts of the appointment, etc.) so that parents & caregivers can preview the experience with the patient.
 - Offer to send the family images of your office or any equipment that will be used. Many individuals benefit from seeing things ahead of time; the family may use these images to create a custom social story for their child.
 - It can be very stressful to have to wait or meet in a room where the patient isn't allowed to touch things and expecting the parent to enforce these rules could lead to challenging behaviors from the patient that could be avoided by providing a more appropriate space.
- **Provide flexibility** where possible, to optimize the visit process and schedule for families.
 - Allow the patient and family or caregiver to arrange informal trips to the healthcare setting before the first appointment, if desired, to help prepare for the actual visit.
 - Offer to schedule appointments when the waiting time might be the shortest — such as first thing in the morning, or right after returning from your lunch break. Individuals with I/DD and autism often have a hard time waiting, and may be prone to anxiety or challenging behaviors.
 - Allow families to call ahead and inquire as to whether a doctor is running behind schedule, so they will be able to adequately plan and prepare for the wait time. Some may do better waiting in their car until you are ready for them; others may just need updates on 'how much longer' to help them manage the waiting time.
 - Determine if it's preferable to get many things done in one appointment to minimize the number of visits - or whether it would be better to spread things out for multiple visits to make each visit shorter/more manageable.
 - There are likely considerably more logistics involved to attend an appointment than for most patients, and for many, the disruption from their usual schedule can be very difficult. Offer virtual options when possible if that's better for the patient & family.

OHC Program Overview

- The Arc of Massachusetts' Operation House Call (OHC) program equips young medical professionals with essential skills and mindsets to provide quality health care for individuals with autism and intellectual and developmental disabilities (IDDs).
- OHC centers the perspectives of families, parents, and individual self-advocates, who serve as educators in the program. Our teaching objectives include shifting mindsets to reduce bias and promote health equity, enhancing communication skills, raising awareness of potential accommodations, and broadly promoting disability competency.
- The program has a network of over 200 volunteer families teaching over 1,200 medical professionals every year. It is regularly offered at Boston University School of Medicine, Tufts University School of Medicine, UMass Chan Medical School, and Harvard Medical School, as well as the Simmons School of Health Sciences, UMASS Graduate School of Nursing, and the Yale School of Nursing.
- OHC hit a very exciting milestone in 2023 when OHC was signed into law and funded through the Massachusetts state budget signed by Governor Maura Healy.

About IDD and Autism

- Intellectual and developmental disabilities (IDDs) are disorders that typically present at birth or in the first few years of life, and that uniquely affect the trajectory of the individual's physical, intellectual, and/or emotional development. Examples include Down syndrome, cerebral palsy, and autism.
- Autism spectrum disorder (ASD) is often characterized by communication difficulties, repetitive behaviors, deep special interests or restricted interests, sensory processing challenges, and distinctive learning styles. The presentations of ASD span a broad range and are unique to each individual. Intellectual disability may or may not be present in individuals with ASD.
- Along almost every measure, individuals with IDD face poorer health outcomes compared to the general population. This disparity is exacerbated by factors such as race, ethnicity, or socioeconomic status (the concept of intersectionality). Lack of provider education or disability awareness is one of the greatest barriers to care access and quality faced by people with IDD.