

ASD Office Prep Tip Sheet


People with autism often have needs or preferences that make getting medical care difficult or stressful. Some people avoid seeking medical care because the process of getting care is too overwhelming. The organization and layout of an office can make that process easier, and we have advice for providers who want to make their spaces and staff better equipped to help people with ASD get care.

The following office and visit preparation recommendations have been developed by members of this project's Patient Experience Board. Pull quotes have been contributed by members.

Pre-visit

Key take-away: A successful visit is detail-dependent and requires a coordinated effort among clinicians, practice staff, patients, families, and group home staff to prepare and execute well.

- Prepare for visits by consulting with **patients and families**.
 - Perform accommodations planning and share information with staff. The **Patient Accommodations Care Plan** is a useful resource.
 - Obtain diagnostic priming information
 - “We sent a photo of his back in advance, so the dermatologist had already seen it.”
 - Ask if the patient will be accompanied and whether they would prefer to be addressed directly, or would prefer the clinician to communicate with the person accompanying them.
 - Meet with office staff to discuss office organization and possible accommodations for visits by specific patients
 - Schedule health visits as early in the day as possible to avoid the environmental stressors of the waiting room.
 - For patients who are quite anxious about visits to the doctor:
 - Have patients visit the office at least once to get accustomed to the office and for an introductory session.
 - Consider creating a **visual support** that describes what your patient can expect during the visit, including photos of you and your office staff.
- **Coordinate logistics with patients, families, and group home staff**, as needed.
 - “The hospital's autism patient navigator connected with the doctor, practice manager, and security ahead of time to strategize.”
 - “15 minutes prior to arriving, the group home staff called hospital security to let them know the ETA.”

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- “Two security guards and the practice manager met me, my son, and the group home staff in the lobby, accompanied us up to the appointment, and stayed until my son was finished and left. The escort also allowed us to avoid a problem with lobby security that would have been caused by my son's inability to wear a mask.”

Key take-away: Optimize digital patient tools to offer multiple methods for patients to make appointments, and post relevant information to help patients prepare and feel reassured before their visit.

- Consider optimizing scheduling and patient portal capabilities to enable individuals to:
 - Navigate and perform necessary tasks easily, with clear instructions
 - Make an appointment online, by telephone, or in-person
 - See all available dates, times, and providers
 - Elect to be waitlisted for specific schedule slots
 - Schedule appointments months in advance
 - Choose an email reminder or a phone call (or both)
 - Pay in advance, or opt into payment plan (upon request)
 - Provide options for patient feedback about experience with the practice/provider
 - Appointment-specific reminder with preparation details (e.g., you will get a shot, so make sure to wear a shirt that the sleeve can roll up; you will be changing into a gown for this exam, so please bring comfortable clothing that is easy to change in and out of)

Visit arrival and check in

Key take-away: Be mindful of and accommodate potential environmental and sensory stressors

- **Practice provides the option to check in online, or via tablet/phone**
- Encourage office staff to **take the patient and caregiver(s) directly to an appropriate exam room.**
- **Wait times are provided and displayed clearly, are updated; if delays, notifications are sent**
- **Offer opportunity for patient to wait in the lobby, or in their car (if preferred), instead of the waiting room**
 - “[My] son will leave if there is a delay in being seen and won't return from the parking lot or garage. His geneticist once had to examine him in the vehicle as he wouldn't leave the vehicle and enter the office because there had been a delay. On one occasion, his refusal to reenter the building meant a delay in being seen for a problem that resulted in a five-week hospitalization.”
- **Ensure that the lights aren't bright, and the music isn't loud**
- **Provide partitions between people to control the spread of germs and offer some privacy**
- **Provide masks, tissues, and sanitizer in the waiting room**

Vitals

Key take-away: Remain flexible and respect patients' limits.

- **Greet the patient first**
- Seek to **establish rapport** with the patient

- Take time to **check the patient's communication skills** and whether the patient uses an augmentative and alternative communication system or device
- **Explain procedures** before beginning
- **Show and demonstrate equipment** to patient before procedure where possible
 - "A common issue with visits is fear, often not knowing what exactly will be going on, and this can lead to adverse reactions. Medical professionals would do well to inform their patients and walk them through each step."
- **Always announce the intention to touch patients** before doing so, and give them time to process this information
- Patients **should be able to opt out of non-essential routine data collection**. For example, collecting weight and height information may not be relevant for all appointments.
- Recognize the need to reduce stress by respecting the patient's limits.


Interview

Key take-away: Use time available wisely to focus on the patient's and family's chief concerns.

- **Agree on an agenda** at the start of the visit with all present.
- **Minimize how long patients must be undressed** or in a gown
- **Allow extra time for patients to process information**, and allow ample time for a response so they do not feel rushed
- **Use plain, literal language** when asking questions, and be aware that relevant information might not be provided unless specifically elicited
- While the focus of relationship building and communication should be on the patient, it is also important to **establish a relationship with, and obtain information from, the patient's main caregiver if the patient has difficulties with communication**.
- **Do not make assumptions about what a patient might expect** to happen during the appointment. Upon greeting from clinician, patients will be given an overview of what to expect during the appointment, especially details about the examination (e.g., "in this appointment, typically we will confirm medication you are currently taking, ask about your diet and exercise...")
- Make efforts to **personally connect with patients** and acknowledge their successes.
 - "Our current dentist is not a pediatric dentist. Every time we are there, all of the providers will stop in and talk with the boys for a quick chat. I believe they also write down notes about each one so they are reminded of what they can chat about (interests, etc.) the next time. I think the connection is key."
 - "[A positive experience has been] nurses and doctors congratulating me for having survived anorexia and gotten healthy."

Physical exam

Key take-away: Be mindful of the hallmarks of reassuring, respectful care for people with ASD.

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- **Discuss accommodations that will provide comfort** for patients. For example, if any action during the appointment causes pain, offer a squeeze ball, pain relief medication. Offer sunglasses or headphones for patients to wear, in circumstances where there are intense sensory experiences (e.g., strong lights at dental exam).
 - **Be prepared to end an appointment early** if it becomes distressing to the patient. The patient sets the agenda.
 - **Consider telehealth.**
 - Avoiding in-person exams, when possible, is a boon for patients with ASD. “Prior to COVID-19, if [my son] had an abscess, he couldn't get a script for antibiotics without being seen at urgent care, which was a huge production.”
 - Transportation to and from an in-person exam can be a stressful proposition. Navigating public transit and dealing with its delays is a nuisance, and it can be challenging to manage time away with other commitments, such as jobs and family.
 - “Actually, getting to the physical appointment can often be far more stressful for me than the in-person consultation itself.”

Phlebotomy

- Do the minimum amount of required blood work, and group tests together to minimize number of blood draws
- Permit the patient to lie down during blood drawing
- If the patient can tolerate the sensation, use a numbing spray or cream for blood work
- Give a precise indication of how long it will take
- Allow patients to prepare themselves by giving sufficient warning before beginning

Post-visit follow up

- It may take a few visits to adequately understand a complicated medical history and to establish mutual trust in order to allow uncomfortable or invasive examinations; be prepared for follow ups
- Send written communication (e.g., email or text) with a reminder for a follow-up appointment

Practice personnel changes

- Let a patient know if a doctor has left the practice before they schedule their next appointment.
- Communicate a contingency plan to a patient about staffing changes.
- If a certain doctor is out, let them know about other doctors. Ensure that the doctor who is covering can prescribe the necessary medications.
- If a provider leaves their practice, they should transfer the care to another provider with the relevant experience and disposition to effectively support an individual.