Creating a Culture of Respect for Autistic Patients and Families

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The medical field is increasingly effective at diagnosing autism, but practices for building respectful rapport with autistic patients lag behind (Hotez et al., 2024). Patient care works best when the medical team regards the patient as a collaborator: someone who is respected, informed, and involved in their care plan (Wampold & Flückiger, 2023). We offer five practical recommendations for building a culture of respect with autistic patients. Considering that 1 in 31 children now receive an autism diagnosis (Shaw et al., 2025), enhancing the mutual understanding and rapport between autistic patients and their (often non-autistic) service providers will touch the lives of many. We are a team of researchers and aspiring clinicians, united by our personal and professional connections to autism, who share a drive to improve care for autistic people. Many existing resources educate medical providers about autism. Instead, we focus on actionable steps–backed by empirical evidence and reinforced by our lived experiences–to create environments where autistic patients feel included and safe.

Personal Perspective: Briana

While working on my master's degree, I was fortunate to gain experience at a children's inpatient psychiatric facility. On my first day, a receptionist asked my supervisor and I whether we had any experience with autistic children. I replied that I did, but before I could elaborate—to explain that I was an autistic child who grew into an autistic adult—she went on: "We need a cure for that. When I was growing up, there were no autistic kids." My supervisor and I traded uncomfortable looks. Comments like these, even when said without ill intent, carry a harmful implication: that autism is something better off erased, rather than a valued part of one's identity. And if I felt disrespected and unwelcome, how would a young autistic patient, already vulnerable enough to need psychiatric hospitalization, feel?

Choose Your Words Wisely

Words have a bigger impact than you may expect. Psychologists have long documented how language subconsciously shapes a person's thinking. The power of words extends to medical settings. Some common words and phrases in medical lingo (e.g., "suffers from," "symptom," "at risk") implicitly assert that autism is negative, undesirable, and unwanted (Como et al., 2020). Be mindful of the message your words send by choosing neutral words. For example, say that something is "characteristic" of autism, instead of "symptomatic;" say that a child "has a family history of autism," instead of "is at risk for autism."

Personal Perspective: Kelsey

The vocabulary surrounding autism has changed dramatically since I was in graduate school. When I began a PhD program in 2012, I was taught that person-first language ("person with autism") was respectful. The push for person-first language was born out of good intentions–it was an attempt to equalize labels across different groups (e.g., "children with autism" and "children without autism" have the same grammatical structure where personhood leads). But, in practice, person-first language failed to accomplish its intended goal.

It was unequally applied—autistic children were “children with autism,” but non-autistic children were “typical children.” In reality, person-first language worsened the stigma it aimed to address. These days, identity-first language (“autistic person”) is more commonly used to reduce stigma, and I instruct students to use this language. Identity-first language is preferred by the autism community, with the majority of autistic people and their family members endorsing identity-first language (Bottema-Beutel et al., 2021).

Share Information, Not Stigma

Autism is a spectrum, and autistic traits present differently from person to person (American Psychiatric Association, 2022). To illustrate, the diagnostic criteria for one aspect of autism—“restricted repetitive patterns of behavior, interests, or activities”—may be met by a huge range of behaviors, from hand-flapping, to temperature sensitivity, to rigidity in daily routines. Given the variability in autistic traits, passing along person-specific information in addition to the diagnosis is helpful when communicating with other providers. Sharing person-specific information reduces time spent assessing a patient’s abilities and needs, and discourages stereotyping among providers with less knowledge about autism.

Personal Perspective: Briana

A technician once pulled me aside and hesitantly said, “This patient is autistic. I don’t know if you know how to deal with that?” Rather than conveying information about the patient’s needs, the interaction spread stigma by promoting autism as something difficult to “deal with” and lacked helpful information. An alternative might integrate both needs and rapport-building insight, such as: “Claire’s autistic, and sometimes it’s hard for her to find words when she’s overwhelmed. It helps to have some extra time to think about a question and answer, especially if things are busy. She’d love to talk with you about her sketchbook–she’s an expert on drawing dragons!”

Be Mindful That Challenging Behaviors Make Sense to the Patient

When a patient engages in difficult behavior (such as self-injury, aggression, or elopement), with no clear cause, it can be tempting to focus solely on managing the behavior. However, the patient is behaving this way to try and meet a need. For example, they may be desperate for sensory input or struggling to self-regulate. Lashing out or running away may be their way of avoiding overwhelm or distress. In healthcare environments, many autistic patients struggle with harsh lighting, loud noises, crowds, intense smells, crinkly paper lining beds, wearing a gown, and other factors (Keller et al., 2024). Being aware of potential triggers and taking steps to address them when possible can reduce overwhelm and help the patient feel more comfortable. It can be helpful to speak to the patient and family during calm moments to identify upsetting factors, how a particular patient acts when upset, and what helps with calming down.

Personal Perspective: Malerie

When I was a research assistant collecting MRI data, one of our goals was increasing research inclusivity for autistic children, considering that as much as 80% of their data is excluded before it can be analyzed (Nebel et al., 2022). Many autistic individuals avoid participating in MRI studies due to the many sensory challenges involved: the loud sounds of the scanner, the tight space inside, and having equipment close to the face or earplugs in the ears, all while dealing with the unpredictability of a new place. To accommodate, we took on the perspective of our participants. When we noticed something was challenging, we did whatever we could to provide predictability (e.g., by giving participants social stories of what will happen, agendas for the day, and multiple opportunities to "practice" in a mock-scanner), desensitize participants to sensory experiences, and give information, reinforcement, and feedback. Ultimately, once we started improving the MRI experience, we successfully increased participation in our study. You can see some of these efforts on our website.

Include Autistic Patients in their Own Care

Speak to autistic patients directly, rather than directing questions, information, or instructions to their family members only (no one likes to be talked about as if they aren't in the room). Make an effort to help patients understand what will happen and what choices they have. This simple act offers the patient increased dignity and recognition, humanizes the patient for other staff members, and creates an atmosphere where patients are comfortable asking questions to clarify their health options. Building positive rapport has tangible benefits for patients–higher quality communication between patients and service providers results in better health outcomes (Stewart, 1995).

Personal Perspective: Briana

I recall a stressful dentist appointment where every member of staff spoke primarily to my mother, only addressing me to ask infantilizing questions like, "Is there anything you're hoping to get for Christmas?" in a singsong tone–and I was 20 years old at the time. I was excluded from participating in my own care. Worse still, I've heard stories from others who ask questions during their appointment, only to have the provider either ignore them, or deliver their response to a caregiver rather than the person asking. When co-treating with other providers, a simple reminder such as, "Henry would like to know that, too," can go a long way. Even if the patient is non-speaking, addressing them directly shows respect and can increase the patient's and family's comfort.

Remember the Family

It's possible family members have similar processing, communication, or sensory needs to the patient, even if they don't disclose a diagnosis. Many autistic children have parents or siblings also on the autism spectrum (Ozonoff et al., 2024). Accommodations for the family might mean including a parent in procedural prep: what will they experience in terms of sights, sounds, and smells while accompanying their child to a procedure?

It could be a matter of direct communication, remembering that caregivers and siblings may interpret your directions literally (e.g. assuming that “Baths are at six PM” is a hard-and-fast rule rather than a guideline). If a patient is asleep, occupied, or out of the room, continue to be mindful of the way you talk about autism and disability. Don’t assume there are no other autistic people present and listening.

Personal Perspective: Alexandra

I pursued a career in clinical psychology to provide support for families with autistic members, like mine. Overall, I am encouraged by how my colleagues discuss autism and include autistic voices in their research and intervention work. However, on occasion, people talk to me about autism in terms of deficits/“red-flags” or using outdated terms (ex: “low functioning”) without taking a holistic approach to a person’s needs and strengths. This can make me feel uncomfortable for multiple reasons. First, autistic traits are not “red-flags”. Second, while I am not autistic, I still share commonalities with my brother, who is autistic and also one of my favorite people. I sometimes worry that people change how they discuss autism solely because I am in the room. Regardless of a person’s relationship to autism, autism should be discussed beyond a one-dimension spectrum based on “problems.”

Conclusion: Improvement is Achievable

Regardless of your experience working with autistic patients, everyone can take simple steps to create a culture of respect for patients and families. Actions such as using respectful language, sharing information rather than stigma, understanding challenging behaviors, including patients in their own care, and being mindful of the family can go a long way. At the end of the day, everyone is deserving of respect. Patients have the most at stake when seeking care, and by ensuring they feel safe and valued in the healthcare environment, providers can promote well-being and enhance quality of life outcomes.

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