

Autism Self-Advocacy: Engaging Neurodiverse Patients in Their Care

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Autism is as much a part of humanity as is the capacity to dream.

—Kathleen Seidel (1)

Functional impairments in social reciprocity, restricted interests, and repetitive behaviors are the hallmark diagnostic features of autism spectrum disorder (ASD), a complex neurodevelopmental disorder with an estimated prevalence between 1% and 2% of the U.S. population (2). More recent data from the Centers for Disease Control and Prevention (3) suggest that one in 36 (2.8%) 8-year-old children in the United States have been identified as having ASD. Overall, males are three to four times more likely to be diagnosed with ASD than females. Autism is associated with a wide range of co-occurring developmental, psychiatric, and general medical health conditions (4). About 70% of individuals with ASD may experience one co-occurring mental disorder, and 40% may have two or more co-occurring mental disorders. Anxiety disorders, depression, and attention-deficit hyperactivity disorder are particularly common (2). Other disorders found at higher frequency include intellectual disability, epilepsy, behavioral disturbances and tics, abnormal sleep patterns, motor difficulties, eating and elimination disorders, diabetes, hypertension, and obesity (4–6).

The term “spectrum” highlights the wide range of symptoms, skills, and levels of ability and disability in functioning of individuals diagnosed with ASD. Some children and adults with ASD are fully independent in all activities of daily living and may have gifted learning and cognitive abilities, whereas others require very substantial support to perform basic activities (7). An ASD diagnosis includes six specifiers: 1) the degree of support required—requiring support (Level 1) to requiring very substantial support (Level 3); 2) with or without accompanying intellectual impairment; 3) with or without accompanying language impairment; 4) associated with a genetic or other medical condition or environmental factor; 5) associated with a neurodevelopmental, mental, or behavioral problem; and 6) associated with catatonia (2). It is estimated that about 38% of individuals in the United States who are diagnosed as having ASD also have a co-occurring intellectual developmental disorder (formerly diagnosed as intellectual

disability) (3). In a recent large study by Wolff and colleagues (8), machine learning was utilized to disentangle the role of intelligence in diagnosing ASDs. A bimodal IQ distribution was noted within the ASD group, with 38% with an IQ < 85; 22% with an average IQ (85–115), and 40% with an above-average IQ (> 115). Individuals with higher IQ scores tended to be older at the time of ASD diagnosis (8).

THE NEURODIVERSITY MOVEMENT

The medical model of ASD focuses primarily on impairments and limitations. A shifting perspective on ASD that has been promoted by autistic self-advocates is the neurodiversity model (9). The neurodiversity model asserts that differences in brain development and behavior of autistic or neuroatypical individuals lie within a nonpathological spectrum. In contrast to the medical impairment or deficit model, the neurodiversity perspective describes the neurology and personhood of autistic people through the lens of human diversity, and is akin to other societal forms of diversity, such as gender, sexual orientation, racial-ethnic group, disability, or age (10). Neurodiversity advocates propose a view of autism not as a disease that needs to be treated or cured, but as a form of neurological difference and a disability—one that society should accept and accommodate rather than try to prevent or cure (11).

Under the neurodiversity model, autistic people are viewed as individuals who possess a blend of cognitive strengths and weaknesses in the core domains of communication, sensory processing, motor skill execution, and goal-oriented and reflexive thinking, planning, and self-regulation. The neurodiversity perspective recognizes that difficulties experienced by autistic people are always contextual. Living in a society that is designed for non-autistic people contributes to, and exacerbates, many of the daily living challenges that autistic people experience. For example, social ambiguities, sensory demands, and communication complexities may confuse or overwhelm autistic people (10, 11).

Disability rights advocates have generally promoted the use of “person-first” language to distinguish the person from the disorder—for example, “person with autism.” The autistic self-advocate and neurodiversity community, on the

other hand, points out that “person-first” language suggests that autism is a disease. They propose that autism is just one aspect of human diversity and opt for the identity-inclusive language of “autistic person” to highlight that neurodiversity is part of their identity (9, 11, 12).

The heterogeneity of the population diagnosed with ASD has fueled debates about policy and funding priorities. In what has colloquially been termed “autism wars,” there is an ongoing dispute between those who define autism as a medical condition and those who see it as within the spectrum of human differences (13, 14). Prominent fault lines in this debate have been between self-advocates who focus advocacy on reducing stigma around autism and promoting opportunities and needed accommodations; and groups (often parents of autistic children who have severe disabilities) that view autism through a biomedical lens and support research and the development of behavioral and medical interventions to treat symptoms and search for a cure (15).

More recent dialogue has attempted to resolve this rift through efforts to ensure that representatives of autistic people and their families consult with and represent the entire constituency. McCoy and colleagues (16) argue that both groups (autism advocates and those who advocate for prevention and treatment) are partial representatives of the autism community. The needs of severely developmentally disabled and those of the minimally impaired autism community are quite different. Psychiatrists need to be cognizant of the full spectrum of ASD in order to optimize joint decision-making and empowerment of autistic patients in their care at the level of their patient’s ability (16, 17).

Clinical Vignette

Joanne Brooks is an 18-year-old high school senior who receives special education under the category of autism. She is accompanied by her mother for her first appointment with Dr. Gomez due to symptoms of anxiety that have made it difficult for her to go to school, go to new places, and manage frustrations. She has increasingly experienced “meltdowns” when she feels overwhelmed, which includes bursting into tears at school and yelling or banging things at home—she has even hit herself in the head several times and, in her exasperation, said she wished she were dead.

Joanne’s mother forwarded her psychoeducational evaluation from the school to Dr. Gomez prior to the appointment. Results suggested that Joanne has a complicated learning profile, with above-average verbal skills, nonverbal skills in the low-average range, and very low processing speed. She was given a diagnosis of autism at the age of 7. Joanne has always received her education in mainstream classes with supplemental resource room educational support, social skills group, and speech therapy. She takes her academic studies seriously and is a determined student, albeit taking much longer than her peers to complete her work. She has always struggled with socialization but has several good friends with whom she shares her special interests in anime and drawing. She is active in an online

group of neuroatypical teens who share their struggles and lament the medicalization and stigma of their autism diagnoses.

Dr. Gomez smiled warmly at Joanne and her mother when she met them in the waiting room.

“Please come in,” Dr. Gomez said. When Joanne and her mother were seated in the office, Dr. Gomez spoke to Joanne directly. “Before we get started, I would like to discuss our work together and inquire how I can be helpful. First, what name and pronouns do you prefer?”

Joanne looked somewhat surprised but smiled. “You can call me Joanne, and my pronouns are ‘they, them.’”

Dr. Gomez nodded and did not look away when Joanne peered anxiously at her mother. “OK. You are an adult and what you share with me is confidential unless there are concerns about your safety. How can your family be helpful and how would you like them involved?”

Joanne looked at her mother and said, “She knows me, and I want her to help with decisions, but I want to have the final say. I’ll let you know if there is something I don’t want my parents to know.”

Dr. Gomez nodded and continued, “You have been diagnosed with autism. Some of my patients prefer to be referred to as a person who is diagnosed as having autism spectrum disorder and some patients prefer to be referred to as an autistic person. Or sometimes neuroatypical or neurodiverse. Have you ever considered that?”

Joanne smiled more broadly now and almost yelped, “I can’t believe that you know that! I consider myself proudly neuroatypical,” Joanne announced.

Dr. Gomez smiled. “Joanne, may I ask your mother some questions before we meet privately together?”

“Sure,” Joanne replied. “Joanne, please stop me if there are questions you aren’t comfortable with,” Dr. Gomez said, and turned her attention to Joanne’s mother. “Ms. Brooks, how do you think I can be helpful to Joanne?”

Joanne’s mother described wanting Joanne to be happy and in control of her emotions. She hoped that Dr. Gomez could help her to understand Joanne’s distress, how easily she becomes overwhelmed, and how the family can help her. Adding to the conversation, Joanne described fears about her upcoming graduation and deciding what she would do next.

“I don’t do well with new things,” Joanne acknowledged. “I have my friends and the teachers I like and. . . I might lose all of that.”

Joanne and Dr. Gomez met individually and reviewed her symptoms, her strengths, and her goals for her work with Dr. Gomez. She hoped for help with her anxiety and “meltdowns.” She hoped not to be “labeled,” or to experience attempts to “cure” her autism. She wanted to find ways to make her neuroatypicality an asset. She hoped to have her parents accept her “nonbinary” and “neurodiverse” identity. She did not endorse suicidal ideation or intent or other safety issues.

At the end of the session, Dr. Gomez summarized. “Let me review my assessment and recommendations. You have all of the symptoms of an anxiety disorder. For all of us,

when we get too anxious, we get overwhelmed, and the thinking part of the brain shuts down. We go into ‘fight, flight, or freeze’ mode. Have you heard of that before?”

“Yes. We talked about that in my psychology class,” Joanne noted.

“You have a lot of stress this year,” Dr. Gomez said, “with graduation coming up and the changes that will bring. You are anxious, become overwhelmed, and have meltdowns. This is more common when you are neuroatypical—as you said, change is hard.”

Joanne nodded in agreement.

“I have four recommendations that you can consider,” Dr. Gomez continued. “Let’s discuss and plan next steps. Then, can we call your mother in to review?”

“Sure,” Joanne agreed.

“I am glad you came in. What you are going through is common and there are ways to help. First, I think you will benefit from therapy to help with your anxiety. Second, having some meetings with your parents, as well, can help them to understand and support you. Third, I know of a new group that is starting comprised of teens and young adults who are struggling with similar issues of transitioning to adulthood. You can work through some of these issues with others who are going through the same thing. And last, there are medications to treat anxiety. They don’t work immediately, but they can be very helpful in lowering your overall anxiety so that you don’t go into ‘meltdown’ mode.”

When they had agreed on the plan, Dr. Gomez went to her computer and typed out the recommendations, with referrals. They discussed the plan with Joanne’s mother and set up their next appointment to consider medications.

As Joanne and her mother stood to leave, Joanne looked Dr. Gomez in the eyes for the first time and said, “You’re cool. I think you get me.”

Therapeutic Engagement, Neurodiversity, and Autism Spectrum Disorder

The diagnosis of ASD includes a very large spectrum of individual strengths and functional disabilities—ranging from persons who are cognitively gifted and high achieving to those who have concomitant severe intellectual development disorder and/or who have comorbid medical conditions that require almost constant care. Physicians must keep in mind the full range of this diversity and how this diversity affects access to care when working with autistic patients (10, 18, 19).

Medical training provides knowledge and skills in the diagnosis of disorders and appropriate evidence-based treatments. Conceptualizing ASD not as a disorder, but rather within the range of normal human diversity has not been part of the lexicon. For some neuroatypical individuals, the physician’s understanding of the neurodiversity movement will be important. For others, it will be a foreign concept. Just as preferred pronouns have become integrated into our patient-centered assessments, how an autistic

individual self-identifies will also be an important question for savvy patients. Engagement focused on issues of quality of life, needed accommodations, methods of highlighting strengths, and optimizing patient participation in their treatment decisions is crucial in involving both autistic individuals and their families. Each person is unique. Remaining curious, being open to learning, and working to engage all autistic patients no matter their level of disability will optimize rapport, adherence, and quality of care (12, 17).

Tips for Effective Communication With an Autistic Patient

The following recommendations can be used to enhance effective communication with an autistic patient (19, 20, 21):

1. Consider needed environmental accommodations.
 - a. Long wait times can be stressful. Consider giving patients with ASD the first appointment of the day.
 - b. Offer the option of waiting in a quieter space to avoid overstimulation. If the wait time is expected to be long, give the patient with ASD the option of leaving and coming back at a later specified time. Texting or calling when the physician is available to see the patient may be a good option.
 - c. Ensure that staff understand the special needs of an autistic patient and talk with autistic patients calmly, quietly, and reassuringly.
2. Ascertain the basic level of functioning and communication prior to the visit.
 - a. For patients who are verbal, ask about their understanding of their diagnosis and how that impacts them.
 - b. Some patients have never been told they are autistic. Work with families and other caregivers to determine who and how this will be explained. Clear, matter-of-fact, and honest discussions about the diagnosis with families (for young children) and for the patient (when they are able to understand) helps the individual understand their struggles, appreciate that they are not alone, and puts words to what they have been experiencing.
3. Ask about preferred pronouns. For an individual who understands their diagnosis, ask how the individual identifies regarding the autism diagnosis (as a “person with autism” or “autistic person”).
4. Clarify the nature of confidentiality (and potential limits) in a concrete manner.
5. Communicate a strengths-based approach to autism.
 - a. Highlight strengths throughout the appointment.

- b. This will help to engage the autistic patient and help family members to better understand and support their loved ones.
6. For nonverbal patients, do not assume that their inability to talk means that they do not understand (at least in a basic manner) what is said.
 - a. Use the patient's name and talk directly to them (even with a guardian in the room) as much as possible.
 - b. Use the patient's communication device (if they have one) or pictures to explain, as developmentally appropriate.
7. Use hobbies and interests to engage with and get to know each patient.
 - a. Highlight this as a strength.
8. Processing information: Many autistic individuals require more time to process information and may become confused or overwhelmed when given too much information too quickly.
 - a. Use less verbiage and speak more slowly, without sounding condescending.
 - b. Repeat and emphasize key information.
 - c. Do not ask too many "rapid-fire" questions.
 - d. Use visual supports (symbols, pictures, social stories) as appropriate.
 - e. Try to maintain a quiet and calm environment to avoid overstimulation.
9. Use fewer open-ended questions and keep questions relatively short for more disabled individuals.
 - a. Be specific. For example, "Did you have fun at school today?" instead of "How was your day?"
10. Be clear in communication: Patients with ASD are often quite literal and miss subtlety.
 - a. Avoid using sarcasm, irony, or exaggeration, as many autistic people may take these literally. Explain what you meant if you used an idiom.
11. Distressed behavior: Autistic patients who have minimal language skills or have a difficult time expressing their needs once they are frustrated may need concrete methods of communicating and decreasing frustration.
 - a. If appropriate, give autistic patients a visual help card to use if they are frustrated or want to express "no" or "stop."
 - b. Set boundaries and expectations for the visit in terms of safety and how to communicate distress. Be clear, calm, and matter-of-fact about the rules—such as keeping their hands to themselves, staying in the room, and using words or cards if they need a break or are getting overstimulated.
12. For patients who are seen regularly, set a clear routine of how the appointment is structured to decrease anxiety.
13. For individuals who can meaningfully engage, cognitive-behavioral strategies can be helpful for managing catastrophic thinking and subsequent meltdowns.
 - a. Ongoing psychoeducation and coaching centered on social skills, methods to adaptively manage stress, and executive functioning/organizational skills may be particularly helpful.

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