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Perspective
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Providing Effective Medical Care to Autistic People

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Dr. Schiff recently saw a new gynecology patient who was having heavy and painful periods. She noticed that the patient appeared to be very anxious; the patient was pacing, not making eye contact, and giving short responses to questions. Her chart included a diagnosis of autism spectrum disorder, and the doctor realized she could use strategies she had learned by helping her own autistic son feel more comfortable in new situations. She grabbed paper and a pen and started drawing checkboxes: *1) Talk about your problem; 2) Get undressed for pelvic exam; 3) Sit on exam table and put feet in stirrups; 4) Do pelvic exam; 5) Get dressed; 6) Talk about treatment plan.* As Dr. Schiff wrote down each step, she pointed to it and read it aloud. Then she showed the patient that they were at the first checkbox; when they got to the last box, the visit would be over. The patient relaxed: she sat down, dropped her shoulders, unclenched her hands, and looked intently at the paper. The doctor waited until the patient said she was ready to start. Dr. Schiff's medical training hadn't prepared her for this encounter, and if not for her personal experience with autism, the appointment most likely wouldn't have gone well.

When Dr. Schiff conferred with her colleagues, we realized that physicians are often underprepared to provide routine medical care to autistic patients, and this lack of preparation can have profound effects on care quality and outcomes. (Although physicians have often been taught to use person-first language, such as "person with autism," many autistic adults prefer identity-first language, such as "autistic person"; in clinical care, clinicians should use the patient's preferred language.)

Recognition of autism and autism diagnoses have increased substantially in recent years, with the Centers for Disease Control and Prevention now estimating that 1 in 36 children in the United States have been identified as having autism. Autism affects how people learn, communicate, and interact with their environment; because it lies on a spectrum, autistic people have a wide range of skills and abilities. Although clinicians have become more aware of autism, most nonautistic physicians don't have the skills to effectively engage with autistic patients, despite the efforts of many autistic physicians and others to advocate for education and skill development.

Medical trainees are taught how to gain a patient's trust, respect patient autonomy, avoid judgmental questioning, and make patients feel comfortable. But not every patient develops trust in the same way, has the same priorities, advocates for their needs in the same way, or derives comfort from the same approaches. In particular, members of marginalized racial and ethnic groups, women, people who have experienced trauma, LGBTQ+ people, people with intellectual or developmental disabilities, and autistic people may each have specific needs that differ from those of other patients.

Clinicians overwhelmingly report a lack of training in the care of autistic patients.[1] The National Council on Disability has urged the Accreditation Council for Graduate Medical Education (ACGME) to require all residency programs to adopt disability competency training, and the IIDDEAL (Individuals with Intellectual and Developmental Disabilities Engaged, Aligned, and Leading) project — funded by the Patient-Centered Outcomes Research Institute and comprising autistic people, advocates, clinicians, and researchers — has called for requiring certification and training throughout the health care workforce in providing patient-centered care for people with autism and other intellectual disabilities.[2] But our review of publications from many major medical societies and the ACGME uncovered little guidance on the treatment of autistic patients presenting for nonautism-related care and few examples of related training requirements.

Lack of training and comfort in treating autistic people has implications for the quality of care. Autistic people have higher rates of coexisting physical and mental health conditions than nonautistic people, and the rate of premature death is twice as high among autistic people as among nonautistic people.[1,3] But autistic people frequently report feeling dismissed, ignored, infantilized, and traumatized during health care experiences. They also encounter substantial barriers to obtaining access to care.[4] Health care systems are often challenging to navigate, and executive-function differences in autistic patients can exacerbate these challenges.

Autistic adults report having more unmet health care needs than nonautistic adults. For example, autistic women are significantly less likely to have had a recent Pap smear than nonautistic women.[3] Advocacy groups have taken steps to address these issues. The Autistic Women and Nonbinary Network publishes a list of clinicians offering “sensory-considerate” care. But placing the burden of improving access to care on autistic people is inappropriate.

When it comes to developing accommodations for autistic patients, Dr. Stephen Shore has said, “If you have met one autistic person, you have met one autistic person.” Each autistic person has particular strengths and needs. Clinicians should ask patients what accommodations may be helpful to them during medical encounters and understand that a strategy that helps one autistic person may harm another. The SPACE (sensory needs, predictability, acceptance, communication, and empathy) framework, developed by autistic physicians, orients clinicians toward areas of potentially needed accommodations.[4] The AASPIRE Healthcare Toolkit includes resources for physicians and allows patients to create a letter outlining their desired accommodations.[5]

Although accommodations shouldn’t be applied uniformly, certain strategies may be helpful for addressing common health care barriers. Uncertainty, such as not knowing what will happen during a visit and when it will end, can be an important source of anxiety for many autistic people. For these patients, a schedule outlining a visit’s steps may reduce anxiety.

Autistic people often experience sensory input differently from nonautistic people and may be overwhelmed or overstimulated or “shut down” in response to certain smells, sounds, or types of light exposure or touch. Adjusting to a person’s sensory needs (e.g., by lowering lights) may reduce these effects.

Executive-function differences may make scheduling appointments challenging. If a patient reports scheduling difficulties, providing alternative methods for interacting with staff (e.g., a patient portal) may be helpful.

Patients may express their comfort level in various ways. It’s important for clinicians to interpret behaviors with empathy and not assign patients negative labels such as “noncompliant” or “uncooperative.” Actions that might otherwise signal “noncompliance” may reflect self-regulatory behaviors for managing stress and should be supported if they are safe in the context of the care environment. People may not use spoken language or make eye contact; may have difficulty completing requested movements; may pace, rock, fidget, or cover their eyes or ears; or may leave an appointment. Such behaviors don’t necessarily mean that the person doesn’t understand the situation or want care. Some autistic people have said that not making eye contact during conversation helps them focus on the other person; lack of eye contact is an adaptive approach to participating in the encounter.

Physicians should seek ways to clearly present patients with choices about their care and use supported decision making. It’s important to use the patient’s preferred method of communication (e.g., spoken or written language, pictures, or models) to discuss medical concepts so they can fully engage in their care. Such approaches may include using assistive and augmentative communication tools or involving a care partner in interactions.

Autism isn't something that needs to be fixed; rather, it creates challenges for people who must navigate environments that aren't built for the way they learn and process information. Many of these challenges aren't exclusive to autism, and not every autistic person may have the diagnosis listed in their medical record prompting clinicians to ask about desired accommodations. Being flexible should therefore be the standard of care.

We have seen the anxiety and discomfort that can result when clinicians insist that patients get their blood pressure taken or sit on an elevated exam table, simply because "that's how we do it." We must learn to center our care-delivery methods not on the approaches that are the most convenient and efficient for us, but on those that meet the needs of individual patients and support the best possible care experiences and outcomes. Requiring education at all levels of medical training about the neurocognitive processing, support needs, and possible preferences of autistic people and about potential environmental stressors could facilitate more equitable health care. Without national training mandates, the provision of equitable care will continue to depend on individual clinicians' interest and investment.

An audio interview with Lauren Schiff is available at NEJM.org

Clinicians have an obligation to strive for successful outcomes for all patients. Ignoring the needs of autistic people denies them access to excellent care and undermines their health.

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Independent Physician Associations — A Bulwark against Corporate Control?

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Hospitals, health systems, and other corporate entities — such as insurers, private equity firms, and retailers — now employ about 80% of U.S. physicians.[1] Although corporate ownership may generate administrative and operational efficiencies, help standardize care processes, and increase institutional knowledge and capital, it can also have adverse effects on prices and spending, quality of care, and workforce retention. It is in this context that physicians in smaller, independent practices — those that are owned by one or more physicians — have sought alternative forms of practice affiliation to leverage the advantages of being part of a larger organization while honoring the ability of physicians to practice as they see fit. These physician-led structures include independent physician associations (IPAs) and physician-owned clinically integrated networks (CINs). Yet recent legal and regulatory uncertainty has led to concerns about the long-term viability and efficacy of these organizational structures as an alternative to corporate control.

There is a continuum of forms of practice affiliation with varying degrees of financial and clinical integration and centralization of operations and management. At one end, after fully independent practices, are IPAs consisting of loosely affiliated practitioners and practices; at the other end are fully integrated group practices operating under a single tax identification number (see figure). Moving along this continuum may yield contracting advantages and negotiating leverage with insurers, possibly at a