

The Autism Spectrum: Human Rights Perspectives

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In the next decade, approximately half a million teenagers on the autism spectrum will transition to adulthood. Unlike earlier generations, who were institutionalized as children in state psychiatric hospitals or hidden by their families, many of today's young adults with autism spectrum disorders grew up at home and attended school in their communities. This was a major accomplishment of strong and tireless advocacy on the part of families who challenged powerful governmental and bureaucratic forces. Whether teenagers will succeed as adults in their communities depends in part on the strength and tirelessness of their families and the responses of our society. We are at the beginning of a massive social experiment.

MILLENNIALS AND NEURODIVERSITY

Much of the outcome hinges on the attitudes of the over 70 million “neurotypical” (nonautistic) millennials, many of whom had opportunities to meet neurodiverse classmates in inclusive programs at school and may be more accepting of neurodiversity than are their parents. But now that the autism community is “aging out” of school, they will need to interact with the broader community, including older generations of neurotypical doctors, who had never seen peers with autism and who may be uncomfortable. This will come as a surprise.

PHYSICIAN AWARENESS

To pediatricians, the emergence of an adult population on the spectrum is no surprise. They have watched for decades the rapid expansion of the diagnostic criteria and the rapid evolution of

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therapeutic approaches. Pediatricians have been learning about autism for decades from experts and, perhaps mostly, from their patients. In contrast, their physician colleagues in adult medicine and other fields, such as urology, typically have limited exposure to adults diagnosed with autism. Because parents (or whoever is responsible for care) realize this, many still cling to their adult children's pediatricians, begging them to continue providing care long after their children reach age 18. But physicians outside of pediatrics are already starting to see the enormous surge in patients diagnosed with autism: a rate of ~1 a week.

Physicians caring for adults have much to learn, and they may turn to pediatricians for help. They will need to learn how to communicate with neurodiverse patients who, like stroke patients, may have language but not speech. For such patients, physicians may need to take histories through an assistive device, such as a computer tablet. They will need to learn some new terms, such as meltdowns, restricted interests, "stimming," sensory defensiveness, applied behavioral analysis, concrete language interpretation, "Aspies," synesthesia, prosopagnosia, and neurodiversity, as well as new attitudes, such as the notion that disability is contextual.

It is important for physicians to appreciate the significance of rapid changes in diagnostic criteria for autism. The expansion in diagnostic criteria has been suggested as an explanation for the apparent surge in diagnoses. One implication is that physicians in adult medicine may have had, all along, adult patients with autism in their practices. They were just never recognized and diagnosed with autism.

RAPID SHIFTS IN UNDERSTANDING

It is also important for physicians to appreciate the history and rapid

changes in therapeutic approaches in autism. In just a few decades, the approach has evolved from institutionalization to assimilation and, more recently, to acceptance with assistance. During the era focused on assimilation, parents were told they must extinguish their children's autistic behaviors. Strict behaviorism was used widely to promote age-appropriate, publicly acceptable behaviors, regardless of the children's objections and tears. Parents were also exposed to fads of medicinal "cures." More recently, strict behaviorism is being replaced with the recognition that behavior is a form of communication, and the trend is toward greater understanding and compassion for autism and even appreciation of it as a form of neurodiversity. Many, if not most, of the paradigm shifts in the field of autism were accomplished not by professional experts but by grassroots efforts from parents. Recent ones are often driven by "self-advocates," a term for adults on the spectrum.

OBJECTIONS TO PERSON-FIRST LANGUAGE

Many self-advocates, such as leaders of the Autistic Self Advocacy Network, object to "person-first language" and prefer the term "autistic" because they consider autism a positive attribute, and person-first language is used for disorders, not for positive attributes. How often does one hear the phrase "man with athleticism?" However, the style for this journal requires person-first language.

HUMAN RIGHTS IMPACT OF LEGAL CAPACITY DECISIONS

Informed consent and guardianship (or conservatorship) are 2 human rights issues that physicians will face in caring for patients with autism spectrum disorders. Once teenagers reach the age of majority,

they ordinarily have the power to make their medical, educational, financial, social-sexual, contractual, and other personal decisions, such as voting. Many parents wish to delay adult rights until their teenager is more mature, and some physicians are unsure about informed consent. Physicians may ask parents to put their adult child under a legal guardianship (also known as conservatorship in some states), which removes the teenager's rights and gives them to another person, usually a family member or a professional fiduciary. Because physicians will be asked to sign a capacity assessment to authorize it, they need to know the human rights consequences. Adults in guardianships often have fewer rights than convicted felons, and the process is rarely reversible. Parents may not realize that not only their children but their own lives (and potentially their personal funds) will fall under control of the courts and, in some cases, of professional guardians. According to a report by *The Wall Street Journal*,¹ allegations of exploitation and abuse are rife in guardianship systems despite public and legislative efforts at overhaul and oversight. Recognizing the relationship of absolute power to corruption and, as described by Dohn Hoyle of The Arc Michigan, "the incongruity of removing individuals' rights in order to protect them," advocates are now speaking out against guardianship. According to a nationwide survey, parents are rarely offered alternatives other than full guardianship.² In response, organizations such as TASH, the Autistic Self Advocacy Network, Spectrum Institute, the National Association to Stop Guardian Abuse, and the American Civil Liberties Union are leading a movement to reform the guardianship system, protect conservatees, and develop alternatives, such as a mechanism known as supported decision-making. Physicians may be asked to

allow such alternatives in obtaining informed consent, and they will need to be considerate of the wishes of the self-advocates and, at the same time, alert to any potential for abuse in either guardianship or its alternatives. Legislative changes are ongoing.

Possibly the most important and unspoken issue is abuse, which is rampant among people with disabilities, especially the developmentally disabled. In a national survey of over 7000 respondents, more than 70% of people with disabilities reported experiencing abuse, and most said they did not report it because of fear.³ Such reluctance is understandable given their vulnerability and the likelihood that an abuser may easily dismiss the claims of a victim with limited communication skills or discredit the victim simply on the basis of the disability itself. Developmentally disabled adults are at the mercy of caregivers, who may include abusive family members or minimum-wage employees with little screening or supervision. Anytime a guardian has absolute power over even one of a person's human rights, the opportunities for abuse and retaliation are extreme. Physicians may be the only ones in a position to protect vulnerable adults from abuse, and they can do so only if they recognize subtle signs and remember to include abuse in the differential diagnosis when a vulnerable adult presents with signs of regression, depression, or "behavior problems" that may result from unsuccessful efforts to report victimization.⁴

Physicians may also have a role in identifying and rescuing millions of older adult patients who have undiagnosed autism. Their presence can be deduced from the prevalence statistics. During ~1980–1990, autism was reported to have a prevalence of 1:10 000. It was considered a childhood disorder, with essentially no mention of

autism in adults. A decade later, the prevalence of childhood autism was reported as 1:1000.⁵ Another decade later, the Centers for Disease Control and Prevention reported a rate of 1:68 and, 1 year later, a rate of 1:45.⁶ Many experts believe this is not a true increase but simply a result of improved diagnosis and/or broadened diagnostic criteria. If so, it follows that although ~2% of adults of all ages probably have autism, fewer than ~5% of adults over age 30 have had their autism diagnosed, with the oldest having the highest prevalence of unrecognized autism. Without correcting for the increased mortality associated with autism, there should be approximately half a million people with autism in every decade of age, including almost 2 million from age 30 to 70. Where are they now?

One place we may find the missing adults with undiagnosed autism is in prison. Common behaviors, although innocent in a child, may, in an adult, easily draw the attention of law enforcement. If older adults with undiagnosed autism, often misdiagnosed as schizophrenia, outlived their family caregivers or were released from psychiatric institutions, it is conceivable that they ended up homeless, arrested, and incarcerated in the "mental health" wards of prisons.⁷ A number of misunderstandings about autism resulted in police shootings of unarmed innocent adults or their caregivers,⁸ some of which were fatal, as in the case of Steven Eugene Washington. Even legal guardianship may not protect individuals from criminal charges for unintentional behaviors, as evidenced by the case of Paul Gordo in 2016 in California. There is evidence to suggest that people on the autism spectrum are overrepresented in prison populations.⁹ Interestingly, autism appears to be underdiagnosed in nonwhite children,¹⁰ a disparity potentially contributing to the

corresponding racial disparities in prison populations.

Pediatricians will be important leaders in promoting autism awareness, acceptance, assistance, and advocacy among our nation's health systems. A lack of awareness among health professionals may constitute a danger to the health, safety, and human rights of adults on the spectrum, whose mortality rate is reported to be 10 times that of the general population.¹¹ Training medical students and physicians in the management of patients with autism is needed to avert tragedy and bring efficient and successful outcomes in health care systems. Training resources designed for this purpose are readily available from organizations such as the American Academy of Developmental Medicine and Dentistry, the American Academy for Cerebral Palsy and Developmental Medicine, and the Office of Developmental Primary Care of the University of California, San Francisco. Clearly, such information needs to be incorporated into medical school curricula. As observed by Ari Ne'eman, a self-advocate and former head of the Autistic Self Advocacy Network, "autism is not a tragedy, ignorance is."

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