

EDITORIAL AND COMMENT

Adults with Autism—A New Minority*David S. Mandell, ScD*

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While autism is generally considered a disorder of childhood, its dramatically increasing prevalence,¹ combined with the lack of known treatment that completely ameliorates associated disabilities,² means that autism is rapidly becoming a disorder of adulthood as well. People with autism will spend the majority of their lives—and receive the overwhelming bulk of their health care—as adults.³

Research on healthcare experiences of individuals with autism has been almost uniformly limited to studies of children and their families, who consistently report more difficulty obtaining health care for their children and less satisfaction with that care, once received.⁴ In recognition of the critical dearth of research regarding adults with autism, the Interagency Autism Coordinating Council, the body charged with advising the Secretary of Health and Human Services on autism research, policy and practice, devoted an entire chapter of its seven-chapter strategic plan to the needs of adults.⁵ That chapter describes the importance of studying and developing community supports, and of including adults with autism in the scientific research process. In the United Kingdom, the National Institute for Health and Clinical Excellence commissioned the development of clinical guidelines for the diagnosis and management of adults with autism.⁶ These guidelines were developed based on expert consensus, but in the absence of a rigorous body of empirical evidence regarding the needs of this growing group.

In this issue of JGIM, Nicolaidis et al. present a groundbreaking study, representing perhaps the first published, comprehensive study of healthcare experiences of adults with autism.⁷ It also is novel in its reliance on a community-based participatory research design, in which adults with autism had input both on the important domains in which to collect data and the nature of the questions asked. The AAPSIRE partnership described in the article provides a model for conducting this kind of research to develop a richer understanding the challenges this group faces.

The findings are in many ways striking in their similarity to what is observed for children. Adults with autism are just as likely as other adults to have a primary care provider, but are more likely to have unmet physical and mental health needs, less likely to receive preventive care, and more likely to end up in the emergency room. The most provocative findings, however, may be the differences in answers to questions regarding satisfaction with healthcare providers, which appear to most directly measure doctor–patient communication. Perceptions of the quality of doctor–patient communication are uniformly poorer among adults with autism, which perhaps is not surprising, given the communication impairments central to the disorder. Working with individuals with receptive and expressive communication impairments may represent a significant challenge within the confines of the often-brief office visit. It is important not to put the burden of improving this communication solely on the shoulders of the individual with autism. Physicians may have to change their strategies both for eliciting information from these patients and for advising them regarding their healthcare. In addition, the nature of the office visit itself may have to change to increase its effectiveness. It will be very interesting to observe the extent to which the tools the authors are developing and mentioned in the manuscript address these issues.

The authors carefully point out the limitations of their study. The Internet and the community partnership may represent a two edge sword for instrument design and data collection. On the one hand, adults with autism are rightly adopting the motto of “nothing about us without us.” Yet who is “us” is sometimes unclear. Autism represents a broad spectrum of disability. Many adults with autism would be very challenged to participate in the process the investigators describe. Different strategies are needed to accurately capture their experiences. Similarly, the Internet, while creating a safe and comfortable environment for some adults with autism to participate in research, may effectively leave many out, resulting in a skewed perspective of healthcare needs.

The number of adults with autism spectrum disorders (ASD) will continue to grow. Some will have a level of independence that allows for full participation in their healthcare decisions; others will have impairments that require dependence on caregivers to mediate the healthcare they receive. Nicolaidis and colleagues offer some insight into the former group. Much more research is needed on both groups. Very little is known about the

healthcare needs that arise as people with autism age; we do know that all-cause mortality is greater in this group than in the general population,⁸ but little about the specific causes of associated morbidity and how best to manage it.

The Affordable Care Act will require the integration of physical and mental health care for all people, including those with autism, which means that primary care physicians will have increased responsibility for managing a myriad of health needs. The concept of a medical home has been operationalized for children with autism to address exactly these sets of issues; there is an urgent need to operationalize a medical home for adults with this increasingly prevalent disorder.

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REFERENCES

1. Autism and Developmental Disabilities Monitoring Network Surveillance Year 2008 Principal Investigators. Prevalence of autism spectrum disorders—Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2008. *MMWR Surveill Summ.* 2012;61(3):1–19.
2. Warren Z, McPheeters M, Sathe N, Foss-Feig J, Glasser A, Veenstra-Vanderweele J. A systematic review of early intensive intervention for autism spectrum disorders. *Pediatrics.* 2011;127(5):e1303–11.
3. Ganz M. The lifetime distribution of the incremental societal costs of autism. *Arch Pediatr Adolesc Med.* 2007;161(4):343–9.
4. Kogan M, Strickland B, Blumberg S, Singh G, Perrin J, van Dyck P. A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States, 2005–2006. *Pediatrics.* 2008;122(6):e1149–58.
5. Committee IAC. 2011 Interagency Autism Coordinating Committee Strategic Plan for Autism Spectrum Disorder Research. 2011; <http://iacc.hhs.gov/strategic-plan/2011/index.shtml>. Accessed March, 2013.
6. National Collaborating Centre for Mental Health. Autism: recognition, Referral, Diagnosis and Management of Adults on the Autism Spectrum—Draft 2011. London: National Institute for Health and Clinical Excellence; 2011.
7. Nicolaidis C, Raymaker D, McDonald K, et al. Comparison of healthcare experiences in autistic and non-autistic adults: a cross-sectional online survey facilitated by an academic–community partnership. *J Gen Intern Med.* 2013. doi:10.1007/s11606-012-2262-7.
8. Shavelle R, Strauss D, Pickett J. Causes of death in autism. *J Autism Dev Disord.* 2001;31(6):569–76.