

The Implications of the Autism Epidemic

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Regardless of the reason, the prevalence of autism spectrum disorders (ASD) is increasing. Prevalence studies from the 1960s and 70s suggest that approximately 2 per 10,000 children had ASD, while more recent studies suggest the number is closer to 60 to 70 per 10,000. The number of children with autism served by the US Department of Education has increased from 30,000 children a decade ago to almost 225,000 in the 2005/06 academic year.

Federal responses to this alarming trend have fallen into one of two categories. The first response has been to increase funding for research into the causes of autism. The second has consisted of efforts to improve the early identification of children with ASD. These efforts are critically important and have the potential to lead to timely and appropriate intervention for children with ASD, too many of whom are not identified until they are of school age. In general, however, these efforts do not result in improved care for children currently diagnosed with ASD. Other than families, which shoulder the overwhelming bulk of care, supports for children with ASD fall under the purview of local education, developmental disability and behavioral health systems. As the number of children with ASD grows, these systems are becoming overwhelmed. The result is that as more children are diagnosed with autism, they will receive worse, not better care. While there are many sources of these challenges, two critical issues are the high costs of ASD care and lack of system infrastructure. Below I briefly describe these challenges and offer some suggestions for improving the way care is delivered.

The high cost of ASD care is evident in the few cost studies available, which provide evidence of one of the ways in which systems are burdened. Costs of care for a child with ASD from 3 through 22 years of age have been estimated at between \$261,717 and \$881,048, depending on treatment effectiveness, compared with \$140,459 for a typically developing child. Another study estimated average lifetime public expenditures for a person with ASD in the UK to be approximately \$4.7 million. Still a third study found that children with ASD had annual healthcare expenditures more than 3 times those of children with mental retardation. These high costs may cause systems to change the way they provide care. For example, one study found that over time, treatment practices changed so that children with ASD were more likely to receive psychotropic medications and less likely to receive behavioral therapies. Most of these costs are covered by Medicaid, the education system and families themselves, since private insurance companies generally do not cover ASD-related care.

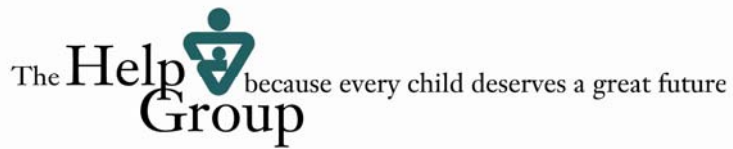
In part because ASD-related services are expensive and not covered by insurance, there are too few clinicians treating children with ASD and those who provide

care are often inappropriately trained. As a glaring example, special education teachers do not require any specific ASD training or certification to work in an autism support classroom. Part of the challenge in increasing clinician capacity is that the missions of the systems in which they work do not create an environment conducive to the best standard of care. For example, the US Supreme Court has specified that a “free and appropriate education” does not mean the best possible care. The children’s public mental health system, through which many children with ASD receive care, is based on an acute model not configured to provide care to children with chronic conditions. Finally, because most states and counties have not established a standard of care for ASD, provider organizations are unwilling to develop services because they don’t know what services they will be reimbursed for and at what payment rate. As a result of insufficient infrastructure, access to care is worse for children with ASD than for children with other special healthcare needs. Parents often are forced to take a lead – and sometimes confrontational – role in obtaining appropriate care,¹⁶⁻¹⁸ and are more likely to experience difficulty in accessing qualified providers for appropriate treatment.

To address these challenges, autism advocates are going to have to take a deep breath, sit down at the same table and make some difficult decisions. The most pressing challenge is to create a predictable and efficient funding stream for autism services. In order to create accountability among public and private health insurers and other public agencies paying for autism services, we must establish a standard of care. Developing this standard of care requires agreeing on acceptable treatment modalities; ancillary supports; the amount of time each should be provided and the qualifications of those who will provide them. It also means deciding on which interventions should not be supported or reimbursed. Without these details, payers will say that there is too much controversy regarding the effectiveness of care for them to pay for it. Providers will be unwilling to develop capacity to serve children with ASD because they can’t determine for what interventions they will be reimbursed.

Once this standard of care is developed, we must develop policies for implementing them. These policies should include minimum standards for ASD clinicians, minimum reimbursement rates, and perhaps most importantly, coordination and delineation among the many payers of autism services about which agencies pay for which services. Developing these standards will create incentives for institutions of higher education to develop programs to create a larger workforce, and for provider organizations to increase their capacity to meet the needs of children with ASD.

I’m sure that many readers will have concerns that there is not enough data to establish a thoughtful standard of care. Certainly, a number of researchers have pointed out that studies of autism intervention effectiveness leave much to be desired. There are examples from other health conditions, however, that offer us a model for thinking about how to develop this standard in the absence of better information. Thirty-five years ago, little was known about treatment of pediatric cancers. In response, cancer centers around the country agreed to collect data in a standardized way and to share information about their successes and failures. The level of scientific inquiry was



accelerated dramatically. Thirty years later, the mortality rate from pediatric cancers had dropped remarkably. We could show similar progress if we agreed on standardized measures of symptoms, functioning, and the nature of the interventions we implement, and then shared that information. This strategy would turn the fact that many different interventions are used by different children into an advantage. We would then have data to target interventions to children as they need them, and help prepare the growing number of children with autism to have meaningful, productive lives.

The data presented in the article is based on a number of studies by the author and other researchers. For specific references, please contact the author at mandelld@mail.med.upenn.edu

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