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## POLICY FORUM

### **A Life of One's Own: Challenges in the Transition from Childhood to Adulthood with Autism Spectrum Disorder**

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This is a very delicate age for Cameron, with his eighteenth birthday looming like a big exit sign. Should I establish guardianship? Am I limiting his independence if I do? Am I putting him at risk if I don't? Will he be able to earn a meaningful living and be able to support himself? If not, are there supports available for him, aside from me? These questions weigh heavy on my mind, as time seems to speed up the older Cameron gets. I am encouraged by the pride Cameron shows in his independence, and hope that pride continues to grow, along with his independence [1].

Autism spectrum disorders (ASD) have become the focus of researchers, policymakers, and, most of all, the parents of children who are diagnosed with ASD. For years, children have merited the lion's share of attention to people with ASD. This is not surprising. Children in general are vulnerable members of the community and merit special protection. Moreover, children with ASD figure prominently in the broader culture. Witness the popularity of autism memoirs by parents of children with ASD (e.g., *Life, Animated*) or the success of television shows such as *Parenthood* that feature a child character with Asperger syndrome. We are only now, however, beginning to recognize that children with autism will eventually become adults with autism. What are the unique social, ethical, and legal, challenges that this transition poses? In this essay we will examine this set of challenges.

#### **What the Transition to Adult Health Care Entails**

As Hendricks and Wehman have observed, although the transition from childhood to adulthood can be an exciting one for many neurotypical young people as they venture forth seeking new experiences and adventures, it can be a particularly challenging time for young people with ASD [2]. First of all, there are significant differences in the services available to children with autism and those available to adults with autism. Children are entitled to a range of educational, health care, and social services. Public schools are required by federal law to provide free and appropriate education to children with special needs [3]. And many states have laws that mandate some level of insurance coverage for services for children with ASD [4]. The Department of Health and Human Services has compiled a list of some of the services that are available for children with ASD, including descriptions of what is available under the Affordable Care Act (ACA) and the

Combating Autism Act [5, 6]. Adults with ASD, however, are merely *eligible* for housing, health care, and employment. Eligibility rather than entitlement requires that the individual or his or her guardian first be aware of the potential services available and then understand and initiate the process of determining eligibility. The most significant distinction, however, is that eligibility, unlike the entitlements children with ASD have, does not guarantee access to or acceptance in a program for services.

Another key distinction is that parents or guardians are the legal decision makers for children. As the case of Cameron illustrates, unless parents petition for guardianship of their adult children with ASD, an adult with ASD can legally make a number of decisions for himself or herself (including accepting or refusing health care).

Lastly, pediatric health care centers on the child's holistic health needs, but health care for adults with ASD is less integrated; there is little focus on identifying and maintaining a medical home for them and on training internists on how to facilitate the transition. According to a 2010 survey by Patel and O'Hare, "most IMRs [internal medicine residents] had received little or no formal training for how to transition these [ASD] patients" [7].

### **HCT Education and Less Costly Solutions Are Needed**

The need for improved health care transition (HCT) among this population of young people is critical. Less than a quarter of youth with ASD receive appropriate services [8]. This figure is even lower than that for the broader population of youth with special health care needs (YSHCN), suggesting that disparities exist not only between young people with ASD and the general population but also between youth with ASD and those with other special needs [8].

The health care disparities between youth with ASD and both typical youth and YSHCN are striking. In general, young adults have benefited from certain policy innovations, such as the Affordable Care Act (ACA), which allows young adults under 26 to remain on their parents' health insurance. Although this option provides health care coverage well into adulthood, questions loom not only about what will happen after that point, but about whether the care being provided under parents' policies meets the needs of an adult with ASD.

Parents' involvement in the health care transition is essential. Many young adults with ASD still depend upon their parents to identify and provide, directly or through financial means, housing, health care, and postsecondary training or education. And having an educated parent—normally a predictor of greater use of social services—does not necessarily translate into greater use of HCT services for young adults with ASD. Surprisingly, Cheak-Zamora et al. discovered that better educated mothers of young adults with ASD actually "reported lower rates of HCT services than those with less

education” [8]. Thus parents need to be better educated about what HCT services are available in their communities and how to get access to them.

Education and training is also needed for health care professionals working with this population. In a recent study, Kuhlthau et al. cited one respondent who highlighted this need:

I think it would be a really good idea if some curriculum towards family practice training [was developed for]—residents in family practice or—and probably undergraduates in medical school as well. I think there needs to be more in the curriculum about autism and other developmental disabilities [9].

The need for educating and training health care professionals in HCT for patients with ASD has been endorsed by a number of professional organizations and societies. Well over a decade ago, the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians coauthored a joint report on supporting HCT for youth with special care needs, particularly citing the need for greater training [10]. The Maternal and Child Health Bureau in the US Department of Health and Human Services issued a similar report on the services needed for this group of young people [11]. Cheak-Zamora and colleagues are hopeful that the ACA will provide funding to train more health care professionals to address the particular needs of this population of young people [8].

Even if parents and health professionals are educated in HCT, continued financial reliance on parents of adults with ASD may lead to a more complicated and costly solution in the long run. Parents will age. Their own health care needs will increase. They may be on fixed incomes. If, as a society, we rely on parents to meet the needs of their adult children with ASD, considerable financial burdens will extend beyond the parents to the broader society. As Ganz observes:

the substantial costs resulting from lost productivity of both individuals with autism and their parents and from rather large adult care costs...have important implications for those aging members of the baby boom generation approaching retirement. As those individuals retire, many of their adult children with autism will be transitioning into adult care settings. Those costs, combined with very limited to nonexistent income for their adult children with autism combined with potentially lower levels of savings because of decreased income and benefits while employed, may create a large financial burden affecting not only those families but potentially society in general [12].

Ganz recommends financial counseling for parents of young adults with autism as they go through this critical transition time.

Increasing employment and other opportunities for young adults with ASD can also help alleviate this financial burden. Employers are seeking to recruit young adults with ASD [13], and more programs are available to equip these young adults with necessary work skills [14]. There should be more integrated care that addresses not just health and employment but also services to help these young adults maximize their potential. Such services may include continued applied behavioral analysis therapy, occupational therapy, physical therapy, and speech therapy.

### **Ethical and Legal Issues in Facilitating HCT for Patients with ASD**

*Capacity and health care decision making.* Physicians treating young adults with ASD confront fundamental ethical questions. For instance, do traditional ethical rules of patient autonomy apply to caring for a young adult with ASD? Can a physician employ soft paternalism with such a patient if the physician believes that the patient is electing to do something contrary to his or her best interest? Again, many young adults with ASD may need a guardian to help make health care decisions and to assist with the financial aspect of accessing health care. But what happens to those who lack a guardian because they are higher functioning or because a parent or family member is unavailable or unwilling to accept the role of decision maker? Should physicians scrutinize their patients' decision making even more closely because of their ASD? In short, does a diagnosis of ASD presume a lack of capacity?

Although a diagnosis of ASD does not preclude decision-making capacity, young adults with ASD, like other patients, may have capacity that waxes and wanes. Primary care physicians treating young adults with ASD should take greater care to include parents when needed. The medical history should have a robust and detailed account of the patient's psychosocial and family history. Learning about the patient's unique health and social challenges is imperative.

*Employment.* Whether patients are employed is typically seen as beyond the purview of health care professionals. But if we take a broader biopsychosocial approach to care (or even a public health approach), we must recognize the relationship between employment and overall health. The sense of independence that employment brings is a powerful social determinant of health, not just for neurotypical individuals but for the many young adults who have ASD. As the opening quote from Cameron's mother suggests, some level of independence is what all parents of young adults with ASD want for their sons and daughters. Ensuring that these young people are equipped with the appropriate skills to secure and maintain employment is yet another significant milestone in the larger transition from childhood to adulthood.

In sum, we believe the barriers to HCT can be overcome with greater education, communication, and access to and availability of resources. The current generation and future generations of young adults with ASD depend upon it.

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