

EDUCATIONAL & EMPLOYMENT CHALLENGES IN YOUNG ADULTS WITH AUTISM

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Abstract:

The prevalence of autism spectrum disorders (ASD) is increasing at a rapid rate. Over the years, the perception, diagnosis, assessment, care, and educational practices with children on the spectrum have evolved. However, many parents, educators, and medical professionals are still searching for quality care and resources for those diagnosed with ASD. The number of high-functioning ASD students entering into higher education is also on the rise, and the resources available to this age group are limited. The benefits of early childhood intervention are widely acknowledged yet the services provided for transitioning young adults, and adults with ASD are severely lacking. We aim to identify unmet needs of individuals with ASD and other neurodevelopmental disorders. We also emphasize the importance of physicians to educate, discuss, and utilize community resources available while also being a knowledgeable, compassionate, and creative primary resource. Finally, we advocate for an interdisciplinary diagnostic and therapeutic approach and present the benefits of this model. By understanding the limitations posed to the patient from his or her disability, physicians can be an additional resource while leading a diverse multidisciplinary team to assist autistic patients in living a better quality of life.

***Keywords:** Autism Spectrum Disorders; ASD; neurodevelopmental disabilities*

1. AUTISM SPECTRUM DISORDERS

Autism Spectrum Disorders (ASD) is a class of complex neurodevelopmental disorders impairing social and communication skills, behavior, and cognitive development. Under the Diagnostic and Statistical Manual of Mental Disorders, individuals with a diagnosis of Autistic disorder, Asperger's disorder, or Pervasive Developmental Disorder not otherwise specified should be given the diagnosis of ASD (American Psychiatric Association. and American Psychiatric Association 2013). The diagnostic criteria include deficits in social communication and restricted, repetitive patterns of behavior and interests. ASDs are caused by genetic or neurobiological factors and not psychological or environmental ones (Kim 2015). Symptoms of ASD are marked by significant heterogeneity and fall along a spectrum ranging from mild to severe. Approximately 50% of individuals falling in the above-average range on intelligence tests are referred to as higher-functioning and may represent the fastest growing sector of the autism population (Rao, Beidel, and Murray 2008). ASD itself represents one of the fastest-growing disability categories in the world, affecting nearly 1.5 million individuals in the United States alone (Developmental Disabilities Monitoring Network Surveillance Year Principal, Centers for Disease, and Prevention 2014). The increased prevalence of ASD can be attributed to heightened public awareness, improved screening, changes in the diagnostic specification, and improved ability to recognize and diagnose higher-functioning individuals with ASD who may have been overlooked in the past (Adreon and Durocher 2007).

1.1.Educational Services

Individuals with autism demonstrate a variety of symptoms within and across the diagnostic criteria, and therefore, each individual is unique in his or her specific symptoms, strengths, response to early intervention, and areas of need (Lincoln et al. 1988) (Lord and Bishop 2015). This poses a challenge to educators providing educational programming for students with autism. As part of the Individuals with Disabilities Education Act (IDEA) of 1990 Part B, students between the ages of 3-21 receive educational services in their local public schools. The number of these students that go on as adults to graduate with a diploma or certificate, drop out, or reach the maximum mandated age of services has increased since the implementation of these services. Much attention has been focused on preparing and supporting children, teachers, and families in the move from primary to middle school to secondary school (Dente and Parkinson 2012, Thorpe). However, a growing number of students who meet diagnostic criteria for ASD enter college systems undiagnosed and consequently disconnected from disability services and other critical resources (White, Ollendick, and Bray 2011).

1.2. Higher Education after High School

Upon exiting high school, only a small minority of students with ASD transition to higher education programs, with more transitioning into employment settings; others are not engaged in either. Taylor and Seltzer found that of 66 young adults (ages 19-26) with ASD who completed high school, 6% were in competitive employment, 12% were in supported employment, 14% had earned a

postsecondary degree, 56% participated in sheltered workshops of day activity centers, and 12% had no regular activities (Taylor and Seltzer 2011). Adults with ASD were less likely to pursue postsecondary education than peers with learning disabilities (LD), specific language impairments (SLI), or hearing, visual, orthopedic, or other health impairments, although the overall rates of employment were highest for those young adults who did participate in postsecondary education (Newman and Contreras 2011). When compared to LD or SLI peers, ASD young adults had much higher rate of “no participation” in either education or employment (Shattuck, Narendorf, et al. 2012).

1.3.Challenges in Pursuing Higher Education

Although many high-functioning ASD students are intellectually capable of pursuing higher education, they are likely to encounter an array of psychosocial challenges in transitioning from high school to college (Vanbergeijk, Klin, and Volkmar 2008). These difficulties may be compounded by challenges faced by all autistic patients, such as difficulty engaging in reciprocal social interaction and relationship development, problems maintaining conversation in social settings, perseverative or obsessive thought patterns, fixated or restricted behaviors and interests, and difficulty interpreting nonverbal cues or the perspective of others. Additional problems such as behaving in age and interpersonally appropriate ways with members of the opposite sex are also a hindrance. In addition, it is also difficult for these individuals to develop a meaningful personal understanding of ASD. All of

these challenges are further exacerbated by dysregulation in visual, tactile, auditory, or other sensory modalities, difficulty processing or remembering oral instructions, fine-motor impairments, unusual movements or clumsiness, and emotional dysregulation. Collectively, these features present great barriers to ASD students hoping to forge meaningful peer, work, and intimate relationships as part of their college experience.

In addition, the sexual development and behavior of individuals with ASD poses a unique challenge for students entering campus environments (Vanbergeijk, Klin, and Volkmar 2008). A study on sexual behavior in high-functioning male adolescents ages 12-21, found that a third needed intervention due to lack of hygiene, speaking too frankly about sexuality, touching genitals in public, and masturbating in the presence of others (Hellemans et al. 2007). This may be due to children with ASD having less awareness of socially acceptable practices led to inappropriate behavior in public more often than those without ASD, had less sex education, displayed more behaviors such as touching others and self, as well as disrobing (Stokes and Kaur 2005). At a time when sensitivity to sexual misconduct on campuses has heightened, transitioning ASD individuals who lack crucial sexual education and skills can pose many consequences for the mental health of all students.

1.4.Employment Outcomes after High School

ASD adults who were employed earned lower wages (by 37.2%), had fewer skills, and had the lowest rate of paid employment (63.2%) when compared these peers with LD and SLI (Shattuck,

Narendorf, et al. 2012). These findings were supported by Smith and Lugas, with 63% of ASD adults with employment compared to 55.6% of those with other disabilities, working fewer hours (24 hours/week versus 32 hours/week), and earning lower weekly wages (\$196 versus \$316) (Lugas 2010). While vocational rehabilitation services have assisted 53% of adults with ASD to find employment (Cimera and Cowan 2009), due to the underemployed in the number of hours worked (mean of 18.5 hours/week), they have proved to be an expensive group to serve.

1.5. Economic and Caregiver Burden

Adult outcomes are poor, especially with regard to employment. Although there is variability based on personal characteristics, the increasing numbers of adolescents/young adults with ASD transitioning into adult services requires an emphasis on the need to ensure that the resources utilized to support these individuals result in positive outcomes. Because the financial cost of supporting an individual with ASD is high, an estimated 1.4 to 2.3 million dollars over the lifespan of an affected individual, it is more important to ensure that the services being provided results in positive outcomes for both the individual and society (Barrett 2014). This entails increased independence, enhanced quality of life, and decreased social burden. It has been found that the odds of ever having had a paid job were higher for those ASD patients who were older, from higher-income households, and with better conversational abilities and functional skills (Roux et al. 2013, Shattuck, Narendorf, et al. 2012). Families are likely bearing increased financial and emotional

burden for continued dependent support of young adults, especially those who do not meet the above criteria. Ji et al found that a multidisciplinary parent education program, designed for the caregivers of children with ASD, may have positive effects on caregivers' mental health-related quality of life, while having little effect on their physical health-related quality of life (Ji et al. 2014). Although the eight-week interval used in this study may not be enough to assess physical health-related quality of life, it is nevertheless an important aspect of caregiving and determines whether long term support can be provided to ASD patients. Because 76% of caregivers were unemployed in order to take care of children with ASD, it placed a greater burden on personal development, time, as well as finances for these families.

1.6. Improving Employment Outcomes & Quality of Life

Strategies for improving employment outcomes might include providing work experiences during high school, deliberate matching of capabilities to job types during transition planning, attention to the vulnerabilities of disadvantaged youth with ASD during and beyond transition, and increased flexibility of institutional supports provided over the occupational life course (Shattuck, Roux, et al. 2012). By giving these adults adequate preparation for employment that is consistent with the current labor market, the costs to society can be minimized since the number and expectations of young adults with ASD entering adulthood is increasing. In addition, current clinical, education, and familial support methods that are already in place for transitioning between various school levels can be applied to transitioning into the real world.

Although a greater degree of independence is required for an adult to succeed in the real world, ASD patients must be provided with resources that can support them in times of failed independence. Perhaps the goal of complete independence may also be an unrealistic as well as unhealthy one for these individuals. The literature has only recently began to identify the needs of young adults with ASD and in proposing appropriate accommodations, models, and recommendations for supporting personal aspiration and postsecondary education of these individuals. Thus, further studies are needed to determine the long term success rates and/or consequences of these interventions.

1.7. The role of the Physician

It is important for physicians to screen for autism-related impairment, especially during transitional periods which are especially stressful for these patients. ASD symptoms have been found to be correlated with social anxiety, depression, and aggression (Gadow et al. 2015). Patients must be encouraged by their physicians to seek help when needed. This can be done by reducing stigma, educating the patient, family, and friends on mental health, gatekeeper training, and referral to psychiatry (Eisenberg, Hunt, and Speer 2012). Attention-deficit/hyperactivity disorder (ADHD) and ASD frequently co-occur (Berenguer-Fornier et al. 2015). Increased liability to ADHD, which has been shown to increase the risk of substance use disorders (Lee et al. 2011), and elevated autistic trait scores were associated with substance use and misuse, with the exception of alcohol use (De Alwis et al. 2014). While ASD patients were less likely to engage in drinking, upon engagement, their

vulnerability to alcohol dependence was found to be elevated. Thus, physicians must also screen for substance abuse and be competent in providing counseling where needed. Physicians must also emphasize continued screening and monitoring at institutions of higher education, especially those attracting students in engineering, technology, and computer science as ASD students are disproportionately represented there (Baron-Cohen et al. 2001, Wei et al. 2013). Because it may not be possible for the patient to return to their pediatrician once in college, due to age and location restrictions, continuity of care must be established with adult primary care providers to decrease the amount of change encountered by the patient as well as to establish a better patient-physician relationship.

1.8. Multidisciplinary Approach & its Benefits

Although many multidisciplinary models and interventional approaches exist for children with ASD, there remains a significant lack of services provided for adults. The current services provided for adults with ASD focus on vocational rehabilitation services, which often denies them services, because they are considered severely disabled (Lawer et al. 2009). Current methods also under emphasize the importance of other social, emotional, and psychological needs of these adults, as seen above during their transition to college. Since autism is characterized by a heterogeneous clinical profile, it challenges patients in multiple aspects of their life. The pervasive nature of the disorder thus requires positively pervasive support spanning multiple disciplines. A multidisciplinary approach to treatment

and support is necessary in order to ensure patients' optimal function within society. It is increasingly important to emphasize that multiple disciplinary teams aim to treat a singular patients; requiring ample communication between expert members. While each team member specializes in one aspect of a patients care, the team as a whole should collaborate to create a set of "shared expertise". Each member of the intervention team should have knowledge of their colleagues' skills, and responsibilities towards their respective ASD patient. Since adequate communication is an obstacle in most ASD patients, other members of the team can help facilitate communication between the physician and patient. The physician in turn can lead the team with his or her clinical reasoning, examination, and awareness of potential resources, especially with regards to employment and higher education, which can be allocated to the patient. This evolved "transdisciplinary approach" serves and supports the patient at a higher level. The intervention team is able to reflect on various layers of the patient's life with equal time, attention, and importance given to each by the expert in that area. Patients benefit from the variety of viewpoints and options offered.

2. CONCLUSION

Because there is much variability in IQ, ASD severity, socioeconomic status, and ongoing parental involvement, there is variability in employment and educational outcomes for adults with ASD. Physicians must place an emphasis on building long-term relationships with ASD patients so they can serve as a primary source of facilitating many of the importance transitions that take place in the life of a young adult. By leading a team of experts

from multiple disciplines, physicians can fulfill the various areas of need in an ASD patient, and also enhance the essential patient-physician relationship.

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