Adolescents and Young Adults with Autism: Transitions to Adulthood

The NIHCM Foundation recently awarded its Health Care Television and Radio Journalism Award to a documentary film, Autism: Coming of Age, which offers an in-depth look inside the lives of three young adults with autism and shares their struggles finding meaningful employment and educational opportunities. The documentary underscores the need for additional transition planning and services for individuals with autism. NIHCM’s independent panel of Television and Radio Award judges noted the importance of this growing population of children and the necessity for future planning. The following article provides background information on this important issue as well as resources for health plans, journalists and other stakeholders in maternal and child health to share with parents and families in need of assistance with autism transition planning.

Autism

Autism spectrum disorders (ASDs), commonly referred to simply as autism, are a group of developmental disabilities that can cause significant behavior challenges, impede an individual’s ability to communicate, understand and respond to social cues.1 While people with autism can share similar characteristics, individual symptoms vary widely. Autism is typically diagnosed in early childhood and is marked by delayed childhood development, repetitive actions and in some cases a regression of previously gained skills. While there is no cure for autism, research indicates that early intervention services, such as applied behavior analysis (ABA), may be helpful in improving development for some children.2

Autism diagnoses have been steadily increasing in recent years, and the Centers for Disease Control and Prevention (CDC) estimate that one in eighty-eight children have been diagnosed with autism.3 As autism awareness increases, so do the number of advocacy and support groups for families and individuals with autism. Since autism is typically diagnosed in younger children, policymakers and the media generally pay less attention to teenagers and young adults with autism.

Children with Autism Transitioning to Adulthood

Roughly 50,000 children with autism will turn 18 this year in the United States,4 and 500,000 are expected to reach adulthood within the next ten years.5 A recent nationwide study of individuals with autism between the ages of 19 and 23 revealed that youth with autism experience lower rates of employment and post secondary schooling relative to individuals with mental retardation or other speech, language or learning disabilities, putting them at a unique risk for being completely disengaged from work or schooling after high school.6 The authors of this study note that these findings point to probable cracks in transition planning for youth with autism. Furthermore, most states determine whether an individual with a developmental disability is eligible to receive support services as an adult based on his or her IQ. Because autism is not necessarily associated with severely reduced IQ
levels, many individuals with autism do not qualify for state-sponsored support services as adults.7

Currently, 80 percent of adults with autism are living at home with aging parents.8 Increasing numbers of young adults with autism coupled with low rates of employment and educational studies post-high school make this a critical age group on which to focus time and resources.

Support Programs for Young Adults with Autism
Several organizations are dedicating resources to help prepare young adults with autism for life after high school.

The Dan Marino Foundation – Marino Vocational College
The Dan Marino Foundation (DMF) has been working to create opportunities for individuals with autism and other special needs to become independent since 1992. The DMF provides treatment programs, outreach services and daily-living transition programs in addition to raising money for quality-of-life research. The DMF has also raised funds to build the Miami Children's Hospital Dan Marino Center and the Dan Marino Foundation Vocational College.

The Marino Vocational College is scheduled to open in the Fall of 2014 and will serve as the first-of-its-kind vocational college where young adults with autism and other disabilities can learn valuable life, employability, business-etiquette, and social skills, attain occupational proficiency and socialize while gaining independence. Students at the campus will have access to a broad, evidence-based curriculum, including academic and functional education programs, career and job placement centers, fine arts classes, and employability skills. The campus will also include a health and wellness center and a virtual technologies institute. This inclusionary campus will encourage students to take classes at its partner vocational centers, specialty colleges, and universities and will also open classes to students of its partner universities. The college will offer courses that fit each individual's needs. In addition, students can earn certification for specific vocations through local partnerships or practice life skills toward learning to live independently at a four-year college.

Advancing Futures for Adults with Autism
Advancing Futures for Adults with Autism (AFAA) is a national group of organizations that collaborate to improve the lives of adults with autism. AFAA’s dedicated members operate with the conviction that working together will provide much greater impact than any organization working independently. AFAA has worked closely with a variety of stakeholders from around the country including individuals with autism to learn about the challenges of adult life for individuals with autism. AFAA uses this information to form their policy agenda that strives to create and drive public policies that will support adults with autism in becoming fully integrated, participating members of society. AFAA also offers information for families on a variety of subjects including residential, recreation and community
integration, and vocational resources, as well as information about adolescents and young adults with autism transitioning out of high school.

*Autism Speaks*

Autism Speaks is the largest autism science and advocacy organization in the country. Autism Speaks has created a transition tool kit for families and caregivers of adolescents with autism. The transition tool kit contains information about how to create a transition plan and includes access to information about the different laws that impact the transition process for each state.

2 Ibid.
3 Ibid.
5 Tanner L. “1 in 3 young adults with autism lack jobs, education; they fare worse than other disabled kids.” *Chicago Tribune* May 14, 2012.
6 Shattuck et al. 2012
8 Ibid.