

**2012 INTERAGENCY AUTISM COORDINATING COMMITTEE  
STRATEGIC PLAN UPDATE: QUESTION 6  
WHAT DOES THE FUTURE HOLD, PARTICULARLY FOR ADULTS?**

**WHAT IS NEW IN THIS AREA, AND WHAT HAVE WE LEARNED IN THE PAST 18 MONTHS?**

The needs of adults with autism spectrum disorders (ASD) continue to be understudied. Over the last 18 months, relatively few peer-reviewed published studies have examined the needs of adults with ASD or service interventions to improve their functioning and quality of life. Few presented experimental or quasi-experimental evidence, a conclusion supported by the United Kingdom's (U.K.) National Institute for Health and Clinical Excellence (NICE) guidelines for the diagnosis, referral and treatment of adults with ASD (National Collaborating Centre for Mental Health, 2011; Pilling et al., 2012). Because the NICE guidelines were unable to identify high quality evidence, many of the adult autism guidelines in the U.K. are based on the guideline developer group's experience.

**Diagnosis of ASD in Adults**

Several studies have validated strategies to diagnose adults with ASD (Andersen et al., 2011; Bastiaansen et al., 2011; Joshi et al., 2011; Ritvo et al., 2011). However, only one diagnostic instrument was tested in an unselected community sample, which represents a truer test of the instrument's validity (Brugha et al., 2012). This instrument performed only moderately well in the community sample, suggesting the need for more research to identify the best direct observation measures for diagnosis.

**Epidemiology of ASD in Adults**

Recent research has shown that the prevalence of ASD in the adult population is much higher than previously believed. A new study of adults 16 years and older living in the community in England using rigorous survey methodology (the Autism Diagnostic Observation Schedule module-4 [ADOS-4]) found the prevalence of ASD in adults to be 0.98%, with no differences by respondent age. The results of this study suggest that a large portion of the observed increase in prevalence in the U.K. observed over the last two decades is due to improved detection (Brugha et al., 2011). This study also found that adults with ASD were much more likely to be receiving public assistance and have a lower income than their unaffected peers. Interestingly, in the U.S. a similar prevalence of ASD was found among university students (White, Ollendick & Bray, 2011). Finally, new research indicates that in the U.S. as many as 10% of patients in residential psychiatric facilities may have undiagnosed ASD (Mandell et al., 2012).

**Quality of Life/Functional Outcomes**

Free time among adolescents with ASD is frequently spent alone or with their mothers (Orsmond & Kuo, 2011). Furthermore, several new findings suggest that functional skills and quality of life for those with ASD plateau or even diminish during adulthood. For example, research showed that daily living skills improved during adolescence and into the early 20s, but remained static during the late 20s (Smith, Maenner & Seltzer 2012). This plateau may be caused by adolescents leaving the more supportive high school environment, a notion supported by the

recent finding of very low rates of employment and educational activities in young adults immediately following high school (Taylor & Seltzer 2011; Shattuck et al., 2012). In fact, more than 50% of youth with ASD who had left high school in the past two years had no participation in employment or education, a greater percentage than that of any other disability group (Shattuck et al., 2012). While self-care and adaptive behaviors indicated the potential for a high level of independence among a sample of Taiwanese adults with ASD, only 14% were employed, and most of these worked only part-time (Lin, Yu & Yu, 2012).

Approaches to improve outcomes for young adults with ASD have had mixed results. For example, there is evidence that sheltered workshops—currently the most commonly used approach to increase the probability of employment among adults with ASD—do not increase the probability of employment, despite being considerably more expensive than other vocational strategies (Cimera et al., 2012). However, social skills intervention has resulted in improvements across a variety of domains for young adults with ASD. Notably, in a randomized controlled trial studying the effectiveness of an evidence-based, caregiver-assisted social skills intervention, young adults with ASD reported decreased loneliness and improved social skills knowledge, while caregivers reported improvements in young adults' empathy, social skills, and frequency of get-together (Gantman et al., 2012).

### **Service Use**

Based on data from a nationally representative survey in the U.S., it has been shown that 60% of young adults ages 19-23 continue to use mental health services, medical services, and to receive speech and occupational therapies past high school (Shattuck et al., 2011). Rates of service disengagement are very high post high school; African American adolescents with ASD were more than three times as likely as white adolescents to completely disengage from service use, and adolescents in families with incomes less than \$25,000/year were almost six times more likely to completely disengage from service use compared with families with incomes greater than \$75,000/year. This highlights the critical importance of Medicaid entitlements, in that privately insured adolescents were more than twice as likely to disengage from service use as adolescents with public healthcare insurance (Shattuck et al., 2011).

### **WHAT GAPS HAVE EMERGED IN THE PAST TWO YEARS?**

New gaps may not have emerged in the last two years as much as they were systematically quantified and highlighted. A systematic review of vocational interventions for 10-to-52-year olds found only five studies, all of poor quality and all relatively narrowly focused, indicating the urgent need for rigorous development and testing of these types of interventions (Taylor et al., 2012). A review of social skills interventions found only two rigorous studies that included young adults, with both studies including only individuals with average or above average intelligence (Reichow, Steiner & Volkmar, 2012). Again, this review points to the critical lack of tested interventions for adolescents and young adults either to address the core symptoms of ASD (social impairments, communication and repetitive behaviors), or to improve adaptive

behaviors that increase the potential for independence. It is important that interventions be developed and tested that address the needs of individuals with ASD across the spectrum, including those who have greater support needs.

A review of the intersection of ASD and the criminal justice system also highlights a gap in knowledge of the extent to which individuals with ASD exhibit criminal behavior and may end up in the criminal justice system (Lerner et al., 2012). The review points out that while most studies find no link between ASD and criminal behavior, some individuals with ASD do end up in the criminal justice system and may require special treatment. In addition, no research has been conducted on the extent to which individuals with ASD are victims of crimes.

Two published reviews also highlight the lack of understanding of what happens to individuals with ASD as they become older adults (Piven & Rabins, 2011; Happé & Charlton, 2012). In this vein, additional research is needed to identify direct observation measures that can be used in adult diagnosis and validate diagnostic instruments for adults.

Finally, new findings about disparities in service delivery to and outcomes for adults with ASD point to the urgent need for research to understand the reasons for these disparities and to ameliorate them.

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