

**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 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 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 are based on the guideline developer group's experience.

Diagnosis of ASD in Adults

Several studies validated diagnostic strategies (Andersen et al., 2011; Bastiaansen et al., 2011; Joshi et al., 2011; Ritvo et al., 2011) but only one instrument was tested in an unselected community sample, which represents a truer test of the instrument's validity (Brugha et al., 2012). The instrument studied performed only moderately well in the community sample, suggesting the need for more research modifying direct observation measures for diagnosis.

Epidemiology of ASD in Adults

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 observed over the last two decades is due to improved detection (Brugha et al., 2011). The study also found that individuals with ASD were considerably socially disadvantaged, on average, compared with unaffected peers. A second study in a single U.S. university found a similar prevalence of ASD among college students (White et al., 2011). A third study in the United States found that as many as 10% of patients in residential psychiatric facilities may have undiagnosed ASD (Mandell et al., 2012).

Quality of Life/Functional Outcomes

Several studies suggest a plateauing or diminishment of functional skills and quality of life during adulthood. Smith et al. (2012) found that daily living skills improved during adolescence and into their early 20s, but remained static during their late 20s. This plateau may be caused by adolescents leaving the more supportive high school environment. In support of this hypothesis, Taylor and Seltzer (2011) found very low rates of employment and educational activities in young adults immediately following high school, as did Shattuck et al. (2012), with more than 50% of youth with ASD who had left high school in the past two years having no participation in employment or education, a greater percentage than that of any other disability group. Lin and colleagues (2012) found that 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, mostly part time. Free time among adolescents with ASD is frequently spent alone or with their mothers (Orsmond and Kuo, 2011). Cimera and colleagues (2012) found that sheltered workshops, the most common strategy to enhance employment outcomes for adults with ASD, do not increase the probability of employment, despite their considerably greater expense than other vocational

strategies. Notably, a randomized trial conducted by Gantman et al. (2012), which found that their social skills intervention resulted in improvements across a variety of domains for young adults with ASD.

Service Use

Using data from a nationally representative survey in the U.S., Shattuck and colleagues (2011) found that about 60% of young adults ages 19-23 continue to use mental health services, medical services, and to receive functional therapies past high school. Rates of service disengagement are very high post high school. African American adolescents with ASD were more than 3 times as likely as white adolescents to completely disengage from service use. Adolescents in families with incomes less than \$25,000/year were almost 6 times more likely to completely disengage from service use compared with families with incomes greater than \$75,000/year. The study also 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.

WHAT GAPS HAVE EMERGED IN THE PAST 18 MONTHS?

New gaps may not have emerged since last year as much as they were systematically quantified and highlighted. A systematic review of vocational interventions for 10-52 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 et al., 2012). Again, this review points to the critical lack of tested interventions for adolescents and young adults to address core symptom or functional domains. A review of the intersection of ASD and the criminal justice system also highlights a gap in our 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). Two published reviews also highlight the lack of understanding of what happens to individuals with ASD as they become older adults (Piven et al., 2012; Happe and Charlton, 2011). Additional research is needed to validate diagnostic instruments for adults.

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