Question 6 Draft Updates for the IACC 2011 Strategic Plan
This document does not reflect decisions of the IACC and is for discussion purposes only

Question 6. What Does The Future Hold, Particularly for Adults?

What is new in this research area and what have we learned this past year?

Only a few studies and reviews related to youth and adults with ASD and the trajectory of aging were published during the past year. These focused on: parenting, behaviors, high-functioning autism, differences between people with ASD and those with other disabilities, high-functioning ASD, recreation, mortality, medication, and prevalence.

- A 2010 study indicated that mothers of youth and adults with ASD experience greater stress, invest less time in personal leisure activities, and are impacted in various domains (work, home, social). The study indicates increased access to respite care and family and flexible work policies are indicated. (Smith et al).

- Several recent studies examined behaviors in adults with ASD, focusing on symptom abatement over time; the increase in behaviors in adults diagnosed with ASD and epilepsy; and degree of intellectual disability related to behavior, including unique behavioral characteristics of adult females (Chowdhury et al.; Smith et al.; Hove et al.; and Cohen et al.). One 2010 study (Esbensen et al.) discussed overall adult functioning, comparing adults with Down syndrome and adults with ASD. The study concluded the ASD group had additional deficits in independence and overall quality of life.

- A 2010 report from Japan suggested education in high-functioning adults with ASD may be associated with greater educational attainment and employment. (Yokotani, K.) A journal article from the UK discussed constructs associated with high functioning adults with ASD negotiating neurotypical society. A third article (Becker et al.) noted health-related quality of life in this group is associated with better living skills. A late 2009 article (Marriage et al.) found adult functioning in persons with ASD and concurrent mental disorders poorest for those with ASD and ID.

- An article from Spain supported the notion that participation in recreational activities decreases stress and increases quality of life for adults with ASD (Garcia-Villamisar et al.).

- A 2010 Swedish study examining risk factors and causes of death in young adulthood indicated ASD death rates are high; significantly higher in females, and in people with ASD and associated disorders including epilepsy and ID/DD (Gillberg et al.).

- A study over time of psychotropic medication use in youth and adults with ASD showed an increasingly high likelihood of staying medicated across the life course (Esbensen et al).

- A 2010 article on the prevalence of ASD in Iceland indicated ASD may be about 50 percent under diagnosed in adults, especially in people who have been diagnosed with ID as their primary diagnosis. This finding is consistent with recent state data specific to ASD from the National Core Indicators (http://www2.hsri.org/nci/).
An environmental scan of interventions for people with ASD performed on behalf of the Centers for Medicare & Medicaid Services (Young et al.) examined interventions for adults with ASD, finding effectiveness for only nine interventions for adults. Only a third ranked as “evidence-based.” The report also highlighted the need for further research on effective community-based services for adults.

What gap areas have emerged since last year?

The continuing dearth of research on youth and adults diagnosed with ASD (as well as those not diagnosed with ASD), and the IACC’s Portfolio Analyses continue to highlight the urgent need for additional scientific research specific to this group. In 2010, advocacy groups including the Autism Society of America and Autism Speaks devoted resources to initiatives on adult services and supports.

State budget cuts over the course of the past year, somewhat mediated by ongoing Federal financial assistance, have resulted in fewer optional services in state Medicaid programs that provide many poor adults who have ASD with health, institutional, and HCBS. A wide range of services, mostly mandated in Medicaid for children through the Early, Periodic, Screening, Diagnostic, and Treatment (EPSDT) service, have been impacted for adults. These include rehabilitative services such as speech, physical therapy, and occupational therapy and mental health; and hearing, vision, and oral health services. The lack of dental services, particularly for adults with ASD who present with behavioral challenges, is of particular concern.

There is little information on older adults with autism. There may be unexplored service opportunities for the Administration on Aging (AoA), that operates some programs that include people with concurrent disorders (Alzheimer’s disease, diabetes, Aging and Disability Resource Centers, chronic disease and disability) to provide support.

A gap continues to exist regarding scientific research related to day habilitation services for adults with ASD, and other developmental disabilities. The 2010 CMS environmental scan revealed no published research on this topic. There is also a paucity of research related to supported employment for adults with ASD – most is directed at high-functioning people with autism. Day habilitation, or community-based day programs, are traditionally used by state Medicaid programs as a mechanism to provide organized day activities, generally in center-based settings and during community outings to people who no longer qualify for school services, or who need day care-like support. These programs are typically aimed at older adults or people with disabilities. Day habilitation does not include supported employment, sheltered work, educational, or prevocational services. Some day programs specialize in providing services for adults diagnosed with ASD. Because most Medicaid programs include this service in HCBS programs for people with ID/DD including ASD, and significant amounts of Federal and State funding is designated for day supports, it is critical to construct a body of evidence surrounding its cost-effectiveness, use and efficacy.
Question 6 Draft Updates for the IACC 2011 Strategic Plan
This document does not reflect decisions of the IACC and is for discussion purposes only

- Although some research is focused on high-functioning adults on the ASD spectrum, more is needed, including greater participation in research by this group.

What new research opportunities and research objectives have emerged?

- 2010 New Objective C suggests comparative effectiveness research that includes a cost-effectiveness component to examine community-based interventions, services and supports to improve health outcomes and quality of life for adults on the ASD spectrum over age 21. Day programs for ASD should be prioritized as a service targeted through Objective C.

- The Research Opportunities section should be modified to indicate the importance of including direct input from people with ASD throughout the scientific research process.

References


Question 6 Draft Updates for the IACC 2011 Strategic Plan
This document does not reflect decisions of the IACC and is for discussion purposes only


Young J, Corea C, Kimani J, Mandell D. Autism spectrum disorders (ASDs) services final report on environmental scan, CMS. (http://www.impaqint.com/files/4-content/1-6-publications/1-6-2-project-reports/finalasdreport.pdf)