

## 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-Villamizar 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/>).

## 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*

- 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**

Becker I, Schroder J, Remschmidt H, Bachman C. Health-related quality of life in adolescents and young adults with high-functioning autism-spectrum disorder. Psychosocial Medicine 2010 August.

Brownlow C. Presenting the self: negotiating a label of autism. Journal of Intellectual & Developmental Disability March 2010; Vol. 35(1), pp 14-21.

Chowdhury, M, Benson B, Hilier, A. Changes in restricted repetitive behaviors with age: a study of high-functioning adults with autism spectrum disorders. Research in Autism Spectrum Disorders 2009 September.

Cohen IL, Tsiouris JA, Flory MJ, Kim SY, Freedland R, Heaney G, Pettinger J, Ted-Brown W. A large-scale study of the psychometric characteristics of IBR modified overt aggression scale: findings and evidence for increased self-destructive behaviors in adult females with autism spectrum disorder. Journal of Autism and Developmental Disorders 2010 May; Vol. 40 (5) pp599-609.

Esbensen AJ, bishop S, Seltzer MM, Greenberg JS, Taylor JL. Comparisons between individuals with autism spectrum disorders and individuals with Down Syndrome in adulthood. American Journal on Intellectual and Developmental Disabilities 2010 July; Vol. 115(4), pp. 277-90.

Esbensen AJ, Greenberg J, Seltzer M. A longitudinal investigation of psychotropic and non-psychotropic medication use among adolescents and adults with autism spectrum disorders. Journal of Autism and Developmental Disorders 2009 September, Vol. 39(9), pp. 1339-1349.

Garcia-Villamizar DA, Dattilo J. Effects of a leisure programme on quality of life and stress of individuals with ASD. Journal of Intellectual Disability Research 2010 May; Vol. 54 (7) pp 611-9.

Gillberg C, Billstedt E, Sundah V, Gillberg IC. Mortality in autism: a prospective longitudinal community-based study. Journal of Autism and Developmental Disorders 2010 March, Vol. 40(3) pp. 352-7.

## 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*

Hove O, Havik OE. Developmental level and other factors associated with symptoms of mental disorders and problem behaviour in adults with intellectual disabilities living in the community. Social Psychiatry and Psychiatric Epidemiology 2010 January; Vol. 45(1), pp 105-13.

Marriage S, Wolverson A, Marriage K. Autism Spectrum Disorders Grown Up: A Chart Review of Adult Functioning. Journal of Canadian Adolescent Psychiatry 2009 November, Vol. 18(4), pp. 322-28.

Saemundsen E, Juliussen H, Hjaltestad S, Gunnarsdottir T, Halldorsdottir T, Hreidarsson S, Magnusson P. Prevalence of autism in an urban population of adults with severe intellectual disabilities – a preliminary study. Journal of Intellectual Disability Research 2010 August; Vol. 54(8), pp 727-35.

Smith KR, Matson JL. Psychopathology: differences among adults with intellectually disabled, comorbid autism spectrum disorders and epilepsy. Research in Developmental Disabilities 2010 May-June; Vol. 31(3), pp 743-9.

Smith KR, Matson, JL. Behavior problems: differences among intellectually disabled adults with comorbid autism spectrum disorders and epilepsy. Research in Developmental Disabilities 2010 September-October, Vol. 31 (5), pp 1062-9.

Smith LE, Hone J, Seltzer MM, Greenberg JS, Almeida DM, Bishop SL. Daily experience among mothers of adolescents and adults with autism spectrum disorder. Journal of Autism and Developmental Disorders 2009 August; Vol. 40(2), pp 167-68.

Wasserman S, Weisman de Mamani A, Mundy P. Parents' criticisms and attributions about their adult children with high functioning autism or schizophrenia. Autism: The International Journal of Research and Practice 2010 March; Vol. 14(2), pp 127-37.

Yokotani K. Educational level signals unobserved abilities of people with high functioning autism spectrum disorders. Psychological Reports 2010 August; Vol. 107 (1), pp 227-35.

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>).