

Question 6 Draft Updates for the IACC 2011 Strategic Plan

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What Does the Future Hold, Particularly For Adults?

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

- In September, 2010 HHS announced a joint grant program administered by CMS and the Administration on Aging, in part to expand the Aging and Disability Research Centers to better assist people with disabilities, older adults, and their caregivers. As greater numbers of adults with disabilities including ASD access the strengthened infrastructure, more research is needed regarding their support needs (www.hhs.gov/news/press/2009pres/06/20090622b.html).
 - Several articles related to transitioning from entitlement-based education services to the adult services system and higher education (Chappel et al.; Shogren et al.; Schall et al., McDonough et al.) were published in 2010. These indicated that early collaboration between services system partners greatly increased access to adult services and employment. People with ASD may need more assistance and oversight than those with other developmental disabilities, and additional research is needed on efficacious strategies to foster vocational success. One report from Japan suggested ASD adults absent ID may achieve greater educational attainment and employment. (Yokotani, K.). However, a study from the United States indicated that the transition from high school may actually have the most negative impact on individuals with higher cognitive levels who are more likely to lose services (Taylor et al.). In July, 2010 President Obama indicated the Administration's commitment to expand disability employment in the Federal workforce, emphasizing the need for additional research in the area of ASD employment across the spectrum.
 - Recent studies examined the role of behaviors and co-occurring conditions in adults with ASD, indicating many people with ASD, especially those with ID/DD, have ongoing deficits related to independence and quality of life (Chowdhury et al.; Smith et al.; Hove et al.; and Cohen et al; 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. There was no evidence on "day programs" for adults with ASD.
- **What gap areas have emerged since last year?**
 - The continuing lack of research on youth and adults diagnosed with ASD (as well as those that go undiagnosed), public comment received by the IACC in 2010, and the IACC's Portfolio Analyses

Comment [OARC1]: And the needs of their aging caregivers

Potentially reference information on aging process based on NC meeting (Dawson)

Comment [OARC2]: Subcommittee discussed striking this language

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continue to highlight the urgent need for additional scientific research specific to this group. In 2010, several national advocacy groups devoted private resources to initiatives on adult services that have been brought to the IACC's attention.

Comment [OARC3]: Move entire passage to "what's new?"

- Although some minimal improvement is predicted for state budgets in 2011, state and local governments are anticipated to face continuing fiscal stress. Budget cuts, somewhat mitigated by ongoing Federal financial assistance, have resulted in fewer optional services in programs including Medicaid, that provide many poor adults who have ASD with acute care, HCBS, and other supports (National Governors Association, National Association of State Budget Officers).
- There is little research specific to older adults with autism and their caregivers, although some research from the University Centers of Excellence in Developmental Disabilities (<http://www.aucd.org/directory/directory.cfm?program=UCEDD>) is directed at cross-disability aging issues.
- Although some research is focused on adults on the ASD spectrum and their families, more is needed, including greater utilization of the Participatory Action Research (PAR) and [Community-Based Participatory Research \(CBPR\)](#) models. The Administration on Developmental Disabilities supported development of a PAR Toolkit: <http://www.acf.hhs.gov/programs/add/areas/HealthArea.html>.

Comment [OARC4]: Cite Services Workshop? Need specific references

Comment [OARC5]: Expand to include end of life issues for caregivers and transitioning into new living facility

• What new research opportunities and research objectives have emerged?

- (SPECIFIED PROJECTS WITHIN PRESENT OBJECTIVE)2010 New Long-Term Objective C recommends "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." The following topics should be targeted for study: 1) community housing for people with ASD (previously identified as a Research Opportunity); and 2) successful life transitions for people with ASD, including from post-secondary education to adult services; aging; employment; sibling relationships; and day programs.
- The Research Opportunities section should be modified to include the following: "It is important to include people with ASD and their families in the scientific research process. The use of models such as Participatory Action Research (PAR) [and Community-Based Participatory Research \(CBPR\)](#) will ~~facilitate~~ full participation by people with disabilities and their family members in the planning, implementation, and evaluation of research."

Deleted: that

Deleted: encourage

Deleted: are encouraged

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