

Question 5 Draft Updates for the IACC 2011 Strategic Plan

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Where Can I Turn For Services?

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

- Recent legislative initiatives, including the Affordable Care Act, passed by the Congress in 2010, support research and state and Federal programs that will positively impact health and quality of life for people with ASD. These include: expanded opportunities in 2014 for individuals at 133 percent of the Federal Poverty Line to access health care; increased attention to health and medical home care coordination; expanded Health Information Technology; a national quality improvement strategy that will develop and refine quality measures; the expansion of Medicaid options to provide home and community based services (HCBS) through several new venues, including “targeting” to people who do not meet traditional institutional level of care program requirements, and Community First Choice services; the extension of the Centers for Medicare and Medicaid Services’ (CMS) Money Follows the Person Rebalancing Demonstration Program; the CLASS Act; increased opportunities surrounding the removal of barriers to providing HCBS; incentives to offer HCBS as an alternative to nursing homes; a new focus on improved coordination for individuals eligible for both the Medicare and Medicaid programs through the Federal Coordinated Health Care Office; and establishment of the Center for Medicare and Medicaid Innovation.
[\(http://www.innovations.cms.gov/\)](http://www.innovations.cms.gov/).
- The Mental Health Parity and Addiction Equity Act of 2008 (MHPAEA), went into effect in 2010. Details of how parity will be implemented are still being resolved, but the concept of comparable coverage for mental health and substance use disorder benefits and physical health services has broad implications for children and adults with ASD. An interim final rule was published in February, 2010 by the Departments of Labor and Treasury, and HHS:
<http://edocket.access.gpo.gov/2010/pdf/2010-2167.pdf>.
- Several recent articles focused on oral health issues, highlighting a need to further investigate the impact of dental treatment on people with ASD throughout the life course. Oral disease is a major health challenge for people with developmental disabilities including ASD (Arun et al.; Loo et al.). In 2010 and 2011, many State Medicaid programs that support adults with ASD have or will substantially reduce optional adult dental care services (Smith et al.).
- A 2010 Swedish study examining risk factors and causes of death in [a cohort of 120](#) people with ASD [found that](#) co-occurring disorders (including Sudden Unexplained Death in Epilepsy), [accidents,](#) [and](#) [deaths](#) occurred at a higher than expected rate (Gillberg et al., 2010). In addition, information was presented in 2010 to the IACC regarding wandering incidents, some that resulted in death. In response, the IACC formed a Safety Subcommittee to gather information and make recommendations.

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• What gap areas have emerged since last year?

- Access to quality and affordable oral health care services continue to be a challenge for children, youth, and adults with ASD.
- Access to psychiatric expertise specific to ID/DD and ASD in state mental health systems is poor, overall capacity is lacking, and issues of seclusion and restraint persist (Munir; Barry et al.; Prouty et al.). There is greater need during a time when disabled family members are remaining at home longer to coordinate community resources, including mental health services.

Comment [OARC1]: Reference needed

• What new research opportunities and research objectives have emerged?

- (SPECIFIED PROJECT WITHIN PRESENT OBJECTIVE) The Federal focus on behavioral health highlights the importance of 2010 Short-Term Objective C, which should include a specific project aimed at care coordination: support at least one study to evaluate a model of policy and practice-level coordination among state and local mental health agencies serving persons with ASD.
- (NEW) Develop and test the effectiveness of at least two strategies or programs to increase the health and safety of people with ASD (e.g., parent, caregiver, individual training to prevent wandering; early warning system for wandering; emergency preparedness; elimination of seclusion and restraint; reduction of unnecessary incarceration) that consider principles of self-determination and personal autonomy.
- (SPECIFIED PROJECTS WITHIN PRESENT OBJECTIVES) 2010 Long-Term Objectives A, B, and C indicate the following as targets for study: 1) support at least one study on the cost-benefit of providing comprehensive dental services, including routine, non-emergency medical and surgical dental services, denture coverage, and sedation dentistry to adults with ASD as compared to emergency and/or no treatment; 2) support at least one study focusing on the provision of accessible, person-centered, equitable, effective, safe, and efficient dental services to people with ASD; and 3) evaluate at least one new and existing pre-service and in-service training program to increase skill levels in oral health professionals to benefit people with ASD and promote interdisciplinary practice.
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Comment [OARC2]: Draft objective and add language in the “what’s new” section on peer-supports (Alison, Ellen, Ari, Lee); Add language explaining that peer-supports cross both interventions and services arenas (Jennifer)

Comment [OARC3]: Currently Plan calls for 2 models of policy and practice coordination – discussed increasing number of studies

Comment [OARC4]: Needs timeline

Comment [OARC5]: The Subcommittee discussed adding both “dental health” and “mental health” services specifically into current Long-Term Objectives.

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