

Question 5 Draft Updates for the IACC 2011 Strategic Plan

This document does not reflect decisions of the IACC and is for discussion purposes only

Question 5. 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 quality measures for adults; 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 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; and a new focus on improved coordination and protection for individuals eligible for both the Medicare and Medicaid programs.
- The Mental Health Parity and Addiction Equity Act of 2008 (MHPAEA), may also impact people with ASD. One article (Barry et al.) examined the history of mental health parity in the U.S. and raised questions about future policymaking in behavioral health. Another article discussed the lack of specialized psychiatric services for people with ID/DD (Munir).
- Three articles focused on oral health issues. The first (Loo et al.) noted that ASD patients with additional factors [e.g. epilepsy, Intellectual/Developmental Disability (ID/DD), behavior history, non-family residence] were more uncooperative during dental procedures, and generally needed supplemental anesthesia. The second study indicates enamel fracture may be more common in people with ASD living in Turkey (Altun et al.). A third article (Altun et al.) reported oral disease is a major health problem among people with developmental disabilities including ASD, suggesting close monitoring and check-ups beginning in childhood.
- Family support issues are the topic of several articles. The first (Thurston et al.) indicates a disabled child’s psychosocial quality of life varies based on environmental conditions. A similar article (Thurston et al.) looked at the interplay between behavior, parenting, and integrated services. Another study (Brookman-Frazee et al.) provides observational data on children with ASD served in community-based mental health clinics. The relationship between sibling adjustment and maternal well-being adds to the literature on caregiving (Quintero et al.).

What gap areas have emerged since last year?

- Access to quality, affordable oral health care services continues to be a challenge for children, youth, and adults with ASD.

Question 5 Draft Updates for the IACC 2011 Strategic Plan

This document does not reflect decisions of the IACC and is for discussion purposes only

- 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. There is greater need during a time when disabled family members are remaining at home longer to coordinate community resources, including mental health services.

What new research opportunities and research objectives have emerged?

- Articles on family function emphasize the need to complete 2010 Short-Term Objective A, aimed at assessing how variations and access to services affect family functioning in diverse populations, including underserved populations.
- A new Federal focus on behavioral health indicates the importance of 2010 New Objective C, which should include a project that proposes to evaluate a model of policy and practice-level coordination among state and local mental health agencies serving people with ASD.
- 2010 Long-Term Objectives A & B suggest methods to improve dissemination, implementation, and sustainability of evidence-based interventions, services and supports in diverse community settings; and testing the efficacy and cost effectiveness of at least four evidence-based services and supports for people with ASD. The following should be identified within these objectives 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 treatment, only and 2) support at least one study focusing on the provision of accessible, person-centered, equitable, effective, safe, and efficient dental services to children with ASD.

References

Altun C, Guven G, Yorbik O, Acikel C. Dental injuries in autistic patients . Pediatric Dentistry 2010 July-August; Vol. 32(4), pp 343-6.

Altun C, Guven G, Akgun O, Akkurt M, Basak F, Akbulut, E. Oral health status of disabled individuals attending special schools. European Journal of Dentistry 2010 October. Vol. 4 (4), pp 361-66.

Barry, C, Huskamp, H, Goldman, H. A political history of federal mental health and addiction insurance parity. Milbank Quarterly, 2010 September, Vol. 88(3), pp. 404-433.

Brookman-Frazer L, Taylor T, Garland A. Characterizing community-based mental health services for children with autism spectrum disorders and disruptive behavior problems. Journal of Autism and Other Developmental Disorders 2010 October, Vol. 40(10), pp. 1188-1201.

Quintero N, McIntyre L. Sibling adjustment and maternal well-being: an examination of families with and without a child with an autism spectrum disorder. Focus on Autism and Other Developmental Disabilities 2010 March, Vol. 25(1), pp. 37-46.

Question 5 Draft Updates for the IACC 2011 Strategic Plan

This document does not reflect decisions of the IACC and is for discussion purposes only

Loo CY, Graham RM, Hughes CV. Behaviour guidance in dental treatment of patients with autism spectrum disorder. International Journal of Paediatric Dentistry 2009 November; Vol. 19(6), pp 390-8.

Munir, K. Psychiatry of intellectual and developmental disability in the US: time for a new beginning. Psychiatry 2009 November, Vol. 8(11), pp. 448-452.

Thurston S, Paul L, Ye C, Loney P, Browne D, Browne G, Wong M, Thabane L, Robenbaum P. System integration and its influence on the quality of life of children with complex needs. International Journal of Pediatrics 2010 October.

Thurston S, Paul L, Chenglin Y, Loney P, Browne G, Thabane L, Rosenbaum P. Interactions among ecological factors that explain the psychosocial quality of life of children with complex needs. International Journal of Pediatrics 2010 June.

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>).