

Question 4 Draft Updates for the IACC 2011 Strategic Plan

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Question 4. Which Treatments and Interventions Will Help?

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

Several notable studies and reviews on the efficacy of specific interventions for improving outcomes of individuals with ASD were published in 2010:

- A 2010 study showed that medications, such as risperidone, are most effective for reducing irritability and aggression when they are combined with intensive behavioral intervention (Frazier et al., 2010).
- A randomized controlled trial demonstrated the efficacy of a comprehensive early intensive behavioral intervention, based on the Early Start Denver Model, which integrated developmental approaches with principles of ABA for improving IQ, language, and adaptive behavior, and reducing severity of autism diagnosis, in toddlers with ASD (Dawson et al., 2010).
- Positive benefits from social skills training for improving social interaction and peer relationships were reported (Frankel, Myatt, Sugar et al., 2010).
- A systematic review concluded that modified cognitive behavioral interventions are efficacious for reducing anxiety in individuals with Asperger syndrome (Lang et al., 2010).
- An environmental scan of interventions for children, youth, and adults with ASD performed on behalf of the Centers for Medicare & Medicaid Services (Young, Mandell, et al., 2010), examined interventions for children, youth, and adults with ASD (<http://www.impaqint.com/files/4-content/1-6-publications/1-6-2-project-reports/finalasdreport.pdf>). The scan included services to address the core impairments associated with ASD and other support services such as behavioral interventions, peer training, and supported employment. For children, 15 interventions met the “evidence-based” criteria established, while the other 16 interventions studied met only the criteria for emerging or unestablished interventions. Far less evidence was available on services and supports for transitioning youth and adults, underscoring the need for more research in this area.

What gap areas have emerged since last year?

Recent data (e.g. Pinto et al., 2010) indicate that several rare and highly-penetrant gene variants and copy number variations (e.g. NLGN3, NLGN4, NRXN1, SHANK 2 and 3, PTCHD1, maternally-inherited 15q11-q13, among others) are involved in ASD. There is a need for translational research that can take advantage of these new genetic findings to (1) identify subgroups of individuals with ASD who respond well to specific medications and intervention approaches, (2) inform which signaling pathways are affected in ASD, (3) develop animal models to explore the down-stream effects of these genetic variants on brain function, and (4) discover targets for development of therapeutics. In order to develop effective medical and behavioral interventions, there is a continuing need for autism intervention networks which can provide platforms for conducting clinical trials and comparative effectiveness

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research using genetic and other biomarkers for specific subtypes, other individual characteristics, and their relationship to response to specific treatments for people with ASD.

In a 2010 presentation to the IACC, data were presented from the Autism Treatment Network, a system of 14 academic health centers throughout the US and Canada that provide care to over 5,000 individuals with ASD, which showed that 65% of individuals with ASD experience sleep disturbances and 14% of those with sleep problems also have seizures. Gastrointestinal (GI) problems were also reported in 50%, and those with gastrointestinal problems were more likely to have sleep disturbances, behavioral problems, and a lower health related quality of life. Other health issues identified include seizures, food sensitivities, anxiety and depression. We do not know whether these medical conditions are a primary aspect of some forms of autism or whether they are secondary features. Recent consensus statements and expert reviews indicate that assessment and treatment of such conditions can lead to improvement in behavior and quality of life (Buie et al., 2010a, b; Coury, 2010), and represent a critical unmet need and great opportunity for improving overall health and quality of life of individuals with ASD. The existence of co-occurring medical conditions in ASD underscores the importance of identifying subgroups of individuals with specific medical conditions who might respond favorably to a particular targeted treatment. In addition, it will be necessary to develop and test multifaceted treatment approaches (e.g. combined behavioral and medical) that address medical co-morbidities.

In April of 2010, an NIH-sponsored workshop (<http://www.nidcd.nih.gov/funding/programs/10autism/>) identified the urgent need for more research on children with ASD who have not developed functional verbal language by five years of age. Among the topics discussed was the development of new intervention approaches that directly teach spoken communication skills and Augmentative and Alternative Communication (AAC). More research is needed on the efficacy of novel service-provision, education, and treatment approaches that facilitate communication skills in people with ASD who are nonverbal and in individuals with challenges in verbal ability, including the need for evidence on the utility of AAC for specific subpopulations of persons with ASD. Potential areas of investigation include oral-motor skills, auditory/speech processing, social attention mechanisms, and impairments in intentional communication. In addition, research is needed on ways to improve access to AAC and the most appropriate means of AAC to utilize with specific subpopulations of individuals on the autism spectrum, including both individuals who are nonspeaking and individuals with speech which is partially or periodically limited. Comprehensive studies focusing on both adults and school-aged children on the autism spectrum should address the components of the most effective AAC approaches and factors which enhance or moderate improvements in communication, behavior and quality of life as a result of AAC usage.

Additional focus is needed to identify and address health disparities for people with ASD. While attention has been given to closing disparities in access to health care and health outcomes on the basis of race and income, little has been done to close this gap for people with developmental and intellectual disabilities, including autism. Recent legislative initiatives, including the Children's Health Insurance Program Reauthorization Act (CHIPRA) and the Affordable Care Act support this research, as well as the refinement of quality of life measures for children, and the development of quality of life measures for

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adults. Data generated from the National Core Indicators (<http://www2.hsri.org/nci/>) has revealed some data regarding quality of life specifically for people with ASD enrolled in state programs. Furthermore, a 2010 congressional briefing held as part of the Advancing Futures for Adults with Autism Initiative identified an urgent need for treatment research to address the needs of adults with ASD, particularly treatments focused on improving health, social relationships, adaptive behavior, communication, and cognitive functioning.

What new research opportunities and research objectives have emerged?

- O Support at least 5 community based studies that assess the effectiveness of interventions and services in broader community settings by 2015. Such studies may include comparative effectiveness research studies that assess the relative effectiveness of different and/or combined medical, pharmacological, nutritional, behavioral, service-provision, and parent or caregiver – implemented treatments, scalable early intervention programs for implementation in underserved, low resource, and low literacy populations, and studies of widely used community intervention models for which extensive published data are not available.
- O Support at least 5 studies on interventions for nonverbal individuals with ASD by 2010. Such studies may include (1) projects examining service-provision models that enhance access to Augmentative and Alternative Communication (AAC) supports in both classroom and adult service-provision settings, such as residential service-provision and the impact of such access on quality of life, communication and behavior, (2) studies of novel treatment approaches that facilitate communication skills in individuals who are nonverbal, including the components of effective ACC approaches for specific subpopulations of persons with ASD, and (3) studies assessing access to AAC for children and adults with ASD who have limited or partially limited speech and the impact on functional outcomes of access. Outcome measures should include assessment of potential harm as a result of autism treatments, as well as positive outcomes.
- O Support at least 2 studies that focus on research on health promotion and prevention of secondary conditions in people with ASD. Secondary conditions of interest include overweight and obesity, injury, and co-occurring psychiatric and medical conditions.

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