

QUESTION 6: WHAT DOES THE FUTURE HOLD, PARTICULARLY FOR ADULTS?		
IACC Strategic Plan Objectives	Conclusions	Funding 2008-2012
<p>6.S.A Launch at least two studies to assess and characterize variation in the quality of life for adults on the ASD spectrum as it relates to characteristics of the service delivery system (e.g., safety, integrated employment, post-secondary educational opportunities, community inclusion, self-determination, relationships, and access to health services and community-based services) and determine best practices by 2012.</p> <p><i>IACC Recommended Budget: \$5,000,000 over 3 years</i></p>	<p>Funding: The recommended budget was partially met. Progress: This area is moving in the right direction as funding and projects have increased over time. Remaining gaps, needs and opportunities: There is a great need to develop standardized measures for quality of life for people with ASD, across both range of ability and lifespan.</p>	\$1,859,186
<p>6.S.B Evaluate at least one model, at the State and local level, in which existing programs to assist people with disabilities (e.g., Social Security Administration, Rehabilitation Services Administration) meet the needs of transitioning youth and adults with ASD by 2013.</p> <p><i>IACC Recommended Budget: \$5,000,000 over 3 years</i></p>	<p>Funding: The recommended budget was partially met. Progress: More than one project was funded, meeting the initial target of this objective. Remaining gaps, needs and opportunities: Little to no work has been done relating to Social Security and this is still needed. Also, looking at one model is too limited in scope, and stronger partnerships among programs would be beneficial for this objective.</p>	\$2,100,000
<p>6.S.C Develop one method to identify adults across the ASD spectrum who may not be diagnosed, or are misdiagnosed, to support service linkage, better understand prevalence, and track outcomes with consideration of ethical issues (insurance, employment, stigma) by 2015.</p> <p><i>IACC Recommended Budget: \$8,400,000 over 5 years</i></p>	<p>Funding: The recommended budget has been only partially met. Progress: One small project to adapt the ADOS modules 1 and 2 for use in adults has been supported in this area, but one project is a minimum, and most likely multiple projects testing various approaches, followed by intense efforts to refine the instruments, would be needed to develop a set of tools that could be used in different settings to diagnose adults. Remaining gaps, needs and opportunities: In addition to developing tools that can be used for diagnosis in adults, it is critical to ensure that diagnosis links to a plan for intervention and /or service provision for diagnosed adults, resulting in improved outcomes.</p>	\$56,000
<p>6.S.D Conduct at least one study to measure and improve the quality of lifelong supports being delivered in community settings to adults across the spectrum with ASD through provision of specialized training for direct care staff, parents, and legal guardians, including assessment and development of ASD-specific training, if necessary, by 2015.</p> <p><i>IACC Recommended Budget: \$7,500,000 over 5 years</i></p>	<p>Funding: The recommended budget has been only partially met. Progress: There is not enough funding or projects for this objective. Also, the few projects do not address the range of issues in this objective. Remaining gaps, needs and opportunities: The projects under this objective focus on secondary students and transition age youth; projects on older adults are missed. No new projects were funded in 2011 and 2012, though the goals of this objective are similar/overlapping to those of 5.L.C., and projects coded there may also represent progress on this objective. There is a need for effective training that can be delivered on a large scale and cost-effectively.</p>	\$619,163
<p>6.L.A Develop at least two individualized community-based interventions that improve quality-of-life or health outcomes for the spectrum of adults with ASD by 2015.</p> <p><i>IACC Recommended Budget: \$12,900,000 over 5 years</i></p>	<p>Funding: The recommended budget was partially met. Progress: 11-18 projects were supported between 2010 and 2012. Progress is being made; however, a sustained effort is needed to fully achieve the goals set forth by this objective. It also appears that funding is decreasing over time, which is a concern. Remaining gaps, needs and opportunities: Work focused on adults with ASD lags behind that focused on children and adolescents. This objective is similar to 6SA – it might be helpful to separate the outcomes of interest. Also, quality of life outcome measures are needed to know if interventions are working.</p>	\$8,036,325
<p>6.L.B Conduct one study that builds on carefully characterized cohorts of children and youth with ASD to determine how interventions, services, and supports delivered during childhood impact adult health and quality of life outcomes by 2015.</p>	<p>Funding: The recommended budget for this objective has been partially met and more than one project was funded. Progress: The projects have not answered all of the questions in this area. More research is needed regarding long-term outcomes. Remaining gaps, needs and opportunities: More than one study would be useful for this objective, including a focus on the benefits of early intervention. The barrier of high cost could be mitigated by capitalizing on partnerships between groups and on existing infrastructure.</p>	\$3,986,983

<p><i>IACC Recommended Budget: \$5,000,000 over 5 years</i></p> <p>6.L.C Conduct 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 by 2018. Topics should include:</p> <ul style="list-style-type: none"> • Community housing for people with ASD; • Successful life transitions for people with ASD, including from post-secondary education to adult services, employment, sibling relationships, and day programs; and • Meeting the service and support needs of older adults with ASD. 	<p>Funding: The recommended budget was only partially met. Progress: Not nearly enough funding and projects have been devoted to this objective. Much more work needs to be done. Remaining gaps, needs and opportunities: Projects regarding service and support needs of older adults are needed; however, there is a question about whether there are yet enough empirically solid adult interventions to make it possible to do comparative effectiveness. It could be useful to separate out specific populations, topics (housing, transitions, etc.) or outcomes in order to better assess progress. A characterization of current resources and how well they're working is needed for this objective, and may be addressed by <i>The State of the States</i> project. The current focus of the field on the transition to adulthood should be expanded to a lifespan focus.</p>	<p style="text-align: right;">\$774,644</p>
<p><i>IACC Recommended Budget: \$6,000,000 over 5 years</i></p> <p>6.L.D Conduct implementation research to test the results from comparative effectiveness research in real-world settings, including a cost-effectiveness component to improve health outcomes and quality of life for adults over 21 on the ASD spectrum by 2023.</p>	<p>Funding: The recommended budget was only partially met. Progress: There is an inadequate amount of projects and funding for this objective. The funded studies are economic analyses, but not implementation of comparative effectiveness studies in real-world settings. Remaining gaps, needs and opportunities: There is a huge gap in adult prevalence research, and in identifying relevant real-world settings for adults with ASD. Identifying the needs of adults with ASD remains important (a needs assessment is needed), and research involving ASD subjects beyond the age of 18 is both lacking and vital.</p>	<p style="text-align: right;">\$135,000</p>
<p><i>IACC Recommended Budget: \$4,000,000 over 5 years</i></p> <p>Not Specific to any Objective (Core Activities)</p>		<p style="text-align: right;">\$2,179,302</p>
<p>Total funding for Question 6</p>		<p style="text-align: right;">\$19,746,603</p>