

# 2011 Portfolio Analysis Projects

*Please note that data are not yet final; additional projects may be added.*

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## QUESTION 6: WHAT DOES THE FUTURE HOLD, PARTICULARLY FOR ADULTS?

### 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. *IACC Recommended Budget: \$5,000,000 over 3 years.*

Project Title	Principal Investigator	Institution	Funding	Funder
<a href="#">Transition age young adults with autism: The role of self-determination, social skills, job search, transportation, and rehabilitation services in employment outcomes</a>	Butterworth, John	University of Massachusetts Boston	\$100,000	Health Resources and Services Administration
<a href="#">Studying the impact of service-learning on career development, self-determination, and social skill building for youth with autism spectrum disorders</a>	Fesko, Sheila	University of Massachusetts Boston	\$300,000	Health Resources and Services Administration
<a href="#">Quality of life during midlife in adults with ASD</a>	Mailick, Marsha	Waisman Center	\$0	Autism Speaks
<a href="#">Examining vocational services for adults with autism</a>	Nicholas, David	University of Calgary	\$0	Autism Speaks

<a href="#">Why do people with autism spectrum disorders fare so differently in adult life?</a>	Simonoff, Emily	King's College London	\$0	Autism Speaks
<a href="#">Risk and resiliency for youth with autism during the transition to adulthood</a>	Taylor, Julie	Vanderbilt University	\$142,193	National Institutes of Health
<b><u>6.S.B</u></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. <i>IACC Recommended Budget: \$5,000,000 over 3 years.</i>				
Project Title	Principal Investigator	Institution	Funding	Funder
<a href="#">Vocational rehabilitation service models for individuals with autism spectrum disorders (VCU ASC Career Links)</a>	Wehman, Paul	Virginia Commonwealth University	\$350,000.00	Department of Education
<a href="#">SEDL's vocational rehabilitation service models for individuals with autism spectrum disorders</a>	Westbrook, John	Southwest Educational Development Corporation	\$350,000.00	Department of Education
<b><u>6.S.C</u></b>				
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, track outcomes, with consideration of ethical issues (insurance, employment, stigma) by 2015. <i>IACC Recommended Budget: \$8,400,000 over 5 years.</i>				
Project Title	Principal Investigator	Institution	Funding	Funder

<a href="#">Development and refinement of diagnostic instruments for use with adults with ASD</a>	Hus Bal, Vanessa	University of Michigan	\$28,000.00	Autism Speaks
<b><u>6.S.D</u></b>				
Conduct at least one study to measure and improve the quality of life-long 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. <i>IACC Recommended Budget: \$7,500,000 over 5 years.</i>				
Project Title	Principal Investigator	Institution	Funding	Funder
<a href="#">Preparation for transition and secondary teachers of students with low-incidence disabilities</a>	Flexer, Robert	Kent State University	\$0	Department of Education
<a href="#">A personnel preparation partnership for transition endorsement in low-incidence disability</a>	Flexer, Robert	Kent State University	\$0	Department of Education
<b><u>6.L.A</u></b>				
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. <i>IACC Recommended Budget: \$12,900,000 over 5 years.</i>				
Project Title	Principal Investigator	Institution	Funding	Funder
<a href="#">Supporting teens with autism on relationships</a>	Baker, Cynthia	Danya International, Inc.	\$415,990	National Institutes of Health
<a href="#">Evaluating and enhancing driving ability among teens with autism spectrum disorder (ASD)</a>	Brown, Timothy	University of Iowa	\$214,498	Department of Defense - Autism Research Program

<a href="#">An enhanced performance training and support system for individuals with autism spectrum disorders</a>	Burke, Ray	Prevention Group, LLC	\$0	Department of Education
<a href="#">Evaluating and enhancing driving ability among teens with autism spectrum disorder (ASD)</a>	Cox, Daniel	University of Virginia	\$ 331,421	
<a href="#">Evaluating and enhancing driving skills of individuals with Asperger's and high-functioning autism</a>	Cox, Daniel	University of Virginia	\$0	
<a href="#">Training personnel to teach school-age children with autism</a>	Flores, Margaret	Auburn University	\$200,000	Department of Education
<a href="#">Social skills training for young adults with autism spectrum disorders</a>	Gantman, Alexander	University of California, Los Angeles	\$0	Organization for Autism Research
<a href="#">PA Community on Transition: Achieving outcomes through a shared agenda</a>	Hodges, Dana	Pennsylvania Office of Vocational Rehabilitation - Department of Labor & Industry	\$281,250	Department of Education
<a href="#">Increasing independence and task completion in adolescents and adults with ASD using independent work systems</a>	Hume, Kara	University of North Carolina at Chapel Hill	\$20,000	Organization for Autism Research
<a href="#">Transition to adult services for youth with autism spectrum disorder</a>	Kuhlthau, Karen	Massachusetts General Hospital	\$294,647	Health Resources and Services Administration
<a href="#">Social-pragmatic treatment for adults with autism spectrum disorder: The Interview Skills Curriculum</a>	Morgan, Lindee	Florida State University	\$56,874	Autism Speaks

<a href="#">Partnering with autistic adults to develop tools to improve primary healthcare</a>	Nicolaidis, Christina	Oregon Health & Science University	\$329,490	National Institutes of Health
<a href="#">IDEA Learning Center</a>	Paniccia, Patricia	Intellectual Disabilities Education Association, Inc. - IDEA Learning Center	\$0	Department of Education
<a href="#">Extended School Year/Summer Camp (ESY/SC)</a>	Shadie, George	S.A.F.E., Inc. (Supporting Autism and Families Everywhere)	\$0	Department of Education
<a href="#">Development of a transportation skills assessment tool for individuals with ASD to aid in finding safe and accessible community transportation services</a>	Szary, Patrick	Rutgers, The State University of New Jersey	\$10,000	Organization for Autism Research

### **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. *IACC Recommended Budget: \$5,000,000 over 5 years.*

<b>Project Title</b>	<b>Principal Investigator</b>	<b>Institution</b>	<b>Funding</b>	<b>Funder</b>
<a href="#">Longitudinal studies of autism spectrum disorders: 2 to 23 (supplement)</a>	Lord, Catherine	University of Michigan	\$265,497	National Institutes of Health
<a href="#">Longitudinal studies of autism spectrum disorders: 2 to 23</a>	Lord, Catherine	University of Michigan	\$473,982	National Institutes of Health
<a href="#">Impacts of parenting adolescents &amp; adults with autism</a>	Seltzer, Marsha	University of Wisconsin - Madison	\$396,727	National Institutes of Health

<a href="#">Service transitions among youth with autism spectrum disorders</a>	Shattuck, Paul	Washington University	\$212,351	National Institutes of Health
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### **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.

*IACC Recommended Budget: \$4,000,000 over 5 years.*

Project Title	Principal Investigator	Institution	Funding	Funder
<a href="#">Estimating the economic costs of autism</a>	Knapp, Martin	London School of Economics	\$37,500	Autism Speaks
<a href="#">Estimating the economic costs of autism</a>	Mandell, David	University of Pennsylvania	\$37,500	Autism Speaks

### **6. Other**

Not specific to any objective

Project Title	Principal Investigator	Institution	Funding	Funder
<a href="#">Spectrum Support Program (SSP): A transition and support program for students with autism spectrum disorders pursuing degrees and careers in STEM fields</a>	Boulais, Nicole	Rochester Institute of Technology	\$0	National Science Foundation
<a href="#">Comparative effectiveness of interventions for adolescents and young adults with autism spectrum disorders</a>	Warren, Zachary	Agency for Healthcare Research and Quality and Vanderbilt University	\$0	Agency for Healthcare Research and

				Quality
<a href="#">Social and occupational outcomes for adults with ASD</a>	Woodruff, Bryan	Mayo Clinic/Southwest Autism Research & Resource Center (SARRC)	\$50,000	Southwest Autism Research & Resource Center



