

2012 Portfolio Analysis Projects

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

Table of Contents

Question	Page Number
Question 1: When should I be concerned?	
Question 2: How can I understand what is happening?	
Question 3: What caused this to happen and can it be prevented?	
Question 4: Which treatments and interventions will help?	
Question 5: Where can I turn for services?	
Question 6: What does the future hold, particularly for adults?	2
Question 7: What other infrastructure and surveillance needs must be met?	

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
Predictors of success in postsecondary STEM education and employment for students with autism	Blackorby, Jose	SRI International	\$217,996	National Science Foundation
Predictive factors of participation in employment for high school leavers with autism	Chiang, Hsu-Min	Columbia University	\$24,622	Organization for Autism Research
Studying the impact of service-learning on career development, self-determination, and social skill building for youth with autism spectrum disorders	Fesko, Sheila	University of Massachusetts Boston	\$300,000	Health Resources and Services Administration
Health-related quality of life and its determinants in adults with ASD	Khanna, Rahul	University of Mississippi	\$20,000	Organization for Autism Research

Survey of services needs of adults with ASD	Law, Paul	Kennedy Krieger Institute	\$25,000	Autism Science Foundation
Quality of life during midlife in adults with ASD	Mailick, Marsha	Waisman Center	\$149,999	Autism Speaks
Examining vocational services for adults with autism	Nicholas, David	University of Calgary	\$59,345	Autism Speaks
Autism in older adults: A pilot, descriptive study	Piven, Joseph	University of North Carolina at Chapel Hill	\$74,000	National Institutes of Health
Why do people with autism spectrum disorders fare so differently in adult life?	Simonoff, Emily	King's College London	\$0	Autism Speaks
Risk and resiliency for youth with autism during the transition to adulthood	Taylor, Julie	Vanderbilt University	\$142,194	National Institutes of Health
<u>6.S.B</u>				
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
Vocational rehabilitation service models for individuals with autism spectrum disorders (VCU ASC Career Links)	Wehman, Paul	Virginia Commonwealth University	\$350,000.00	Department of Education
SEDL's vocational rehabilitation service models for individuals with autism spectrum disorders	Westbrook, John	Southwest Educational Development Corporation	\$350,000.00	Department of Education
<u>6.S.C</u>				
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
Development and refinement of diagnostic instruments for use with adults with ASD	Hus Bal, Vanessa	University of Michigan	\$0	Autism Speaks
<u>6.S.D</u>				
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
Preparation for transition and secondary teachers of students with low-incidence disabilities	Flexer, Robert	Kent State University	\$0	Department of Education

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. *IACC Recommended Budget: \$12,900,000 over 5 years.*

Project Title	Principal Investigator	Institution	Funding	Funder
Evaluating and enhancing driving ability among teens with autism spectrum disorder (ASD)	Brown, Timothy	University of Iowa	\$0	Department of Defense - Autism Research Program
Evaluating and enhancing driving ability among teens with autism spectrum disorder (ASD)	Cox, Daniel	University of Virginia	\$0	Department of Defense - Autism Research Program
Evaluating and enhancing driving skills of individuals with Asperger's and high-functioning autism	Cox, Daniel	University of Virginia	\$0	Department of Defense - Autism Research Program
Training personnel to teach school-age children with autism	Flores, Margaret	Auburn University	\$0	Department of Education
PA Community on Transition: Achieving outcomes through a shared agenda	Hodges, Dana	Pennsylvania Office of Vocational Rehabilitation - Department of Labor & Industry	\$0	Department of Education
Increasing independence and task completion in adolescents and adults with ASD using	Hume, Kara	University of North Carolina at Chapel Hill	\$3,025	Organization for Autism Research

[independent work systems](#)

Transition to adult services for youth with autism spectrum disorder	Kuhlthau, Karen	Massachusetts General Hospital	\$283,935	Health Resources and Services Administration
Increasing functional vocational skills in adolescents and adults with autism using behavioral economics	LaRue, Robert	Rutgers, The State University of New Jersey	\$10,000	Organization for Autism Research
Social-pragmatic treatment for adults with autism spectrum disorder: The Interview Skills Curriculum	Morgan, Lindee	Florida State University	\$0	Autism Speaks
Partnering with autistic adults to develop tools to improve primary healthcare	Nicolaidis, Christina	Oregon Health & Science University	\$300,938	National Institutes of Health
Development of a transportation skills assessment tool for individuals with ASD to aid in finding safe and accessible community transportation services	Szary, Patrick	Rutgers, The State University of New Jersey	\$18,221	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.*

Project Title	Principal Investigator	Institution	Funding	Funder
---------------	------------------------	-------------	---------	--------

Longitudinal studies of autism spectrum disorders: 2 to 23	Lord, Catherine	University of Michigan	\$426,762	National Institutes of Health
Service transitions among youth with autism spectrum disorders	Shattuck, Paul	Washington University	\$212,584	National Institutes of Health
<p><u>6.L.D</u></p> <p>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><i>IACC Recommended Budget: \$4,000,000 over 5 years.</i></p>				
Project Title	Principal Investigator	Institution	Funding	Funder
Estimating the economic costs of autism	Knapp, Martin	London School of Economics	\$0	Autism Speaks
Economic burden of current and future autism	Leigh, Paul	University of California, Davis	\$60,000	Autism Speaks
Estimating the economic costs of autism	Mandell, David	University of Pennsylvania	\$0	Autism Speaks
<p><u>6. Other</u></p> <p>Not specific to any objective</p>				
Project Title	Principal Investigator	Institution	Funding	Funder

LSS postdoctoral fellowship: Autism, social science and law	Francis, Leslie	University of Utah	\$200,000	National Science Foundation
Autism spectrum disorder: Birth cohort 1976-2000, epidemiology and adult status	Katusic, Slavica	Mayo Clinic	\$560,556	National Institutes of Health
Creating a more effective path to housing for people with ASD	Maltby, John	Westchester Institute for Human Development	\$20,000	Organization for Autism Research
Social and occupational outcomes for adults with ASD	Woodruff, Bryan	Mayo Clinic/Southwest Autism Research & Resource Center (SARRC)	\$50,000	Southwest Autism Research & Resource Center

