

2013 Portfolio Analysis Projects

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

2013 Projects: 28

2013 Funding: \$3,152,885

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.

2013 Projects: 9

2013 Funding: \$1,118,557

Project Title	Principal Investigator	Institution	Funding	Funder
Survey of services needs of adults with ASD	Law, Paul	Kennedy Krieger Institute	\$0	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	\$59,755	Autism Speaks
Why do people with autism spectrum disorders fare so differently in adult life?	Simonoff, Emily	King's College London	\$146,546	Autism Speaks
IMPROVING HEALTHCARE TRANSITION PLANNING AND HEALTH-RELATED INDEPENDENCE FOR YOUTH WITH ASD AND THEIR FAMILIES	Cheak-Zamora, Nancy	University of Missouri	\$308,685	Department of Defense
Autism in older adults: A pilot, descriptive study	Piven, Joseph	University of North Carolina at Chapel Hill	\$71,040	National Institutes of Health
Risk and resiliency for youth with autism during the transition to adulthood	Taylor, Julie	Vanderbilt University Medical Center	\$142,194	National Institutes of Health

Predictors of success in postsecondary STEM education and employment for students with autism	Blackorby, Jose	SRI International	\$231,970	National Science Foundation
Health-related quality of life and its determinants in adults with ASD	Khanna, Rahul	University of Mississippi	\$8,367.57	Organization for Autism Research

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) meets the needs of transitioning youth and adults with ASD by 2013. *IACC Recommended Budget: \$5,000,000 over 3 years.*
2013 Projects: 0
2013 Funding: \$0

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. *IACC Recommended Budget: \$8,400,000 over 5 years.*
2013 Projects: 1
2013 Funding: \$240,000

Project Title	Principal Investigator	Institution	Funding	Funder
Clinical algorithm for identifying adult autism	Mandell, David	University of Pennsylvania	\$240,000	National Institutes of Health

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. *IACC Recommended Budget: \$7,500,000 over 5 years.*
2013 Projects: 1
2013 Funding: \$0

Project Title	Principal Investigator	Institution	Funding	Funder
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[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.*

2013 Projects: 5

2013 Funding: \$290,180

Project Title	Principal Investigator	Institution	Funding	Funder
Social-pragmatic treatment for adults with autism spectrum disorder: The Interview Skills Curriculum	Morgan, Lindee	Florida State University	\$0	Autism Speaks
Evaluating and enhancing driving ability among teens with autism spectrum disorder (ASD)	Brown, Timothy	University of Iowa	\$0	Department of Defense
Evaluating and enhancing driving ability among teens with autism spectrum disorder (ASD)	Cox, Daniel	University of Virginia	\$0	Department of Defense
Supporting teens with autism on relationships	Baker, Cynthia	Danya International, Inc.	\$270,180	National Institutes of Health
Increasing functional vocational skills in adolescents and adults with autism using behavioral economics	LaRue, Robert	Rutgers, The State University of New Jersey	\$20,000	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.*

2013 Projects: 2

2013 Funding: \$353,910

Project Title	Principal Investigator	Institution	Funding	Funder
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ASD in Mid-Adulthood: A 40 Year Follow-Up of Individuals Served by the TEACCH Autism Program	Klinger, Laura	University of North Carolina	\$149,995	Autism Speaks
Service transitions among youth with autism spectrum disorders	Shattuck, Paul	Washington University in St. Louis	\$203,915	National Institutes of Health

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:

- 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

IACC Recommended Budget: \$6,000,000 over 5 years.

2013 Projects: 0

2013 Funding: \$0

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.

2013 Projects: 2

2013 Funding: \$60,000

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

6.Other

Not specific to Question 6 objectives

2013 Projects: 8

2013 Funding: \$1,090,239

Project Title	Principal Investigator	Institution	Funding	Funder
Stress as a Predictor of Outcomes for Adults with Autism Spectrum Disorders	Bishop-Fitzpatrick, Lauren	University of Pittsburgh	\$29,500	Autism Speaks
Resilience Education for Increasing Success in Postsecondary Education	DeRosier, Melissa	3-C Institute for Social Development	\$67,250	Autism Speaks
Using Structured Teaching to Promote Employment Skills in Adolescents with ASD	Klinger, Mark	University of North Carolina	\$0	Autism Speaks
Quality of Life During Midlife in Adults with ASD: Supplement on Dementia	Mailick, Marsha	Waisman Center	\$44,589	Autism Speaks
Assessing Self-Determination in the Era of Evidence-Based Practices: The Development and Validation of Student and Adult Measures of Self Dertermination	Wehmeyer, Michael	University Of Kansas Center For Research, Inc.	\$396,360	Department of Education
Autism spectrum disorder: Birth cohort 1976-2000, epidemiology and adult status	Katusic, Slavica	Mayo Clinic	\$542,540	National Institutes of Health
LSS postdoctoral fellowship: Autism, social science and law	Francis, Leslie	University of Utah	\$0	National Science Foundation
Creating a more effective path to housing for people with ASD	Maltby, John	Westchester Institute for Human Development	\$10,000	Organization for Autism Research