

2011 Portfolio Analysis Projects

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

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7.B

Conduct an annual "State of the States" assessment of existing State programs and supports for people and families living with ASD by 2011.
IACC Recommended Budget: \$300,000 each year.

Project Title	Principal Investigator	Institution	Funding	Funder
State of the States for people with ASD	L&M Policy Research, Thompson Reuters, and the National Association of State Directors of Developmental Disabilities	Centers for Medicare & Medicaid Services (CMS)	\$88,154	Centers for Medicare & Medicaid Services

7.C

Develop and have available to the research community means by which to merge or link databases that allow for tracking the involvement of people in ASD research by 2010. *IACC Recommended Budget: \$1,300,000 over 2 years.*

Project Title	Principal Investigator	Institution	Funding	Funder
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Interactive Autism Network (IAN) core support	Law, Paul	Kennedy Krieger Institute	\$100,000	Autism Speaks
Interactive Autism Network (IAN)	Law, Paul	Kennedy Krieger Institute	\$0	Autism Speaks
Accelerating autism research through the Interactive Autism Network	Law, Paul	Kennedy Krieger Institute	\$0	Simons Foundation
Simons Simplex Community at the Interactive Autism Network (SSC@IAN)	Law, Paul	Kennedy Krieger Institute	\$375,000	Simons Foundation
Accelerating Autism Research through the Interactive Autism Network (IAN Core)	Law, Paul	Kennedy Krieger Institute	\$100,000	Simons Foundation
Autism Registry	Simon, Gregory	Group Health Cooperative	\$730,343	National Institutes of Health
A centralized standard database for the Baby Siblings Research Consortium	Young, Gregory	University of California, Davis	\$81,803	Autism Speaks

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7.D

Establish and maintain an international network of biobanks for the collection of brain, fibroblasts for pluripotent stem cells, and other tissue or biological material, by acquisition sites that use standardized protocols for phenotyping, collection, and regulated distribution of limited samples by 2011.

- This includes support for post-processing of tissue, such as genotyping, RNA expression profiling, and MRI.
- Protocols should be put into place to expand the capacities of ongoing large-scale children's studies to collect and store additional biomaterials, including newborn bloodspots, promoting detection of biological signatures.
- Support should also be provided to develop an international web-based digital brain atlas that would provide high-resolution 3-D images and quantitative anatomical data from tissue of patients with ASD and disease controls across the lifespan, which could serve as an online resource for quantitative morphological studies, by 2014.

IACC Recommended Budget: \$82,700,000 over 5 years.

Project Title	Principal Investigator	Institution	Funding	Funder
Autism Celloidin Library	Hof, Patrick	Mount Sinai School of Medicine	\$0	Autism Speaks
Rutgers, The State University of New Jersey	No PI listed	Rutgers, The State University of New Jersey	\$4,930,840	Simons Foundation
An open resource for autism iPSCs and their derivatives	Schwartz, Philip	Children's Hospital of Orange County	\$561,337	National Institutes of Health
Autism Genetic Resource Exchange (AGRE)	Staff Member	Autism Speaks (AS)	\$1,615,308	Autism Speaks
Autism Tissue Program (ATP)	Staff Member	Autism Speaks (AS)	\$470,603	Autism Speaks

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Bioinformatics support for AGRE	Staff Member	Autism Speaks (AS)	\$550,514	Autism Speaks
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7.E

Begin development of a web-based toolbox to assist researchers in effectively and responsibly disseminating their finding to the community, including people with ASD, their families, and health practitioners by 2011. *IACC Recommended Budget: \$400,000 over 2 years.* Begin development of a web-based toolbox to assist researchers in effectively and responsibly disseminating their finding to the community, including people with ASD, their families, and health practitioners by 2011. *IACC Recommended Budget: \$400,000 over 2 years.*

Project Title	Principal Investigator	Institution	Funding	Funder
Ethics of communicating scientific findings on autism risk	Newschaffer, Craig	Drexel University School of Public Health	\$533,354	Autism Speaks

7.H

Create mechanisms to specifically support the contribution of data from 90 percent of newly initiated projects to the National Database for Autism Research (NDAR) and link NDAR with other existing data resources by 2012. *IACC Recommended Budget: \$6,800,000 over 2 years.*

Project Title	Principal Investigator	Institution	Funding	Funder
National Database on Autism Research (NDAR)	No PI listed	Center For Information Technology	\$1,517,596	National Institutes of Health

7.I

Supplement existing ADDM Network sites to use population-based surveillance data to conduct at least 5 hypothesis-driven analyses evaluating factors that may contribute to changes in ASD prevalence by 2012. *IACC Recommended Budget: \$660,000 over 2 years..*

Project Title	Principal Investigator	Institution	Funding	Funder
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Autism and Developmental Disabilities Monitoring (ADDM) network - South Carolina	Charles, Jane	Medical University of South Carolina	\$354,024	Centers for Disease Control and Prevention
Autism and Developmental Disabilities Monitoring (ADDM) network - Missouri	Constantino, John	Washington University in St. Louis	\$341,502	Centers for Disease Control and Prevention
Autism and Developmental Disabilities Monitoring (ADDM) network - Arizona	Cunniff, Chris	University of Arizona	\$354,025	Centers for Disease Control and Prevention
Autism and Developmental Disabilities Monitoring (ADDM) network - North Carolina	Daniels, Julie	University of North Carolina at Chapel Hill	\$344,170	Centers for Disease Control and Prevention
Autism and Developmental Disabilities Monitoring (ADDM) network - Wisconsin	Durkin, Maureen	University of Wisconsin - Madison	\$354,025	Centers for Disease Control and Prevention
Autism and Developmental Disabilities Monitoring Network augmentation with screening and assessment	King, Lydia	Medical University of South Carolina	\$0	Autism Speaks
Autism and Developmental Disabilities Monitoring (ADDM) network - Maryland	Lee, Li-Ching	Johns Hopkins University	\$354,025	Centers for Disease Control and Prevention
Autism and Developmental Disabilities Monitoring (ADDM) network - Colorado	Miller, Lisa	Colorado Department of Health and Environment	\$324,870	Centers for Disease Control and Prevention
Autism and Developmental Disabilities Monitoring (ADDM) network - Arkansas	Shultz, Eldon	University of Arkansas for Medical Sciences	\$352,880	Centers for Disease Control and Prevention
Metropolitan Atlanta Developmental Disabilities Surveillance Program/Autism and Developmental Disabilities Monitoring (ADDM) network - Georgia	Van Naarden Braun, Kim; Rice, Cathy; Baio, Jon	Centers for Disease Control and Prevention (CDC)	\$1,092,786	Centers for Disease Control and Prevention

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Autism and Developmental Disabilities Monitoring (ADDM) network - Alabama	Wingate, Martha	University of Alabama at Birmingham	\$354,025	Centers for Disease Control and Prevention
Autism and Developmental Disabilities Monitoring (ADDM) network - New Jersey	Zaharodny, Walter	University of Medicine & Dentistry of New Jersey	\$354,026	Centers for Disease Control and Prevention
Autism and Developmental Disabilities Monitoring (ADDM) network - Utah	Zimmerman, Judith	University of Utah	\$348,095	Centers for Disease Control and Prevention

7.J

Develop the personnel and technical infrastructure to assist states, territories, and other countries who request assistance describing and investigating potential changes in the prevalence of ASD and other developmental disabilities by 2013. *IACC Recommended Budget: \$1,650,000 over 3 years*

Project Title	Principal Investigator	Institution	Funding	Funder
Epidemiological study of pervasive developmental disorders in Mexico	Fombonne, Eric	McGill University	\$60,000.00	Autism Speaks
University of Minnesota – Somali Autism Surveillance Project	Jesien, George; Hewitt, Amy	Association of University Centers on Disabilities (AUCD); University of Minnesota	\$215,462	Centers for Disease Control and Prevention
KwaZulu-Natal (KZN) Autism Study	Kauchali, Shuaib	University of KwaZulu-Natal	\$60,000.00	Autism Speaks

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A large scale, two phase study to estimate prevalence, and raise awareness, about autism spectrum conditions in India	Mukerji, Shaneel	Action for Autism/Creating Connections	\$0.00	Autism Speaks
ARTI: The Autism Research & Training Initiative in India	Patel, Vikram	Sangath	\$59,952	Autism Speaks
Surveillance of Autism Spectrum Disorders (ASD) in select children in Minneapolis and of Somali descent	Reiff, Michael; Hewitt Amy	University of Minnesota	\$150,000	National Institutes of Health

7.K

Encourage programs and funding mechanisms that expand the research workforce, enhance interdisciplinary research training, and recruit early career scientists into the ASD field by 2013. *IACC Recommended Budget: \$5,000,000 over 3 years.*

Project Title	Principal Investigator	Institution	Funding	Funder
Interdisciplinary Training Conference in Developmental Disabilities	Abbeduto, Leonard	University of Wisconsin - Madison	\$20,000.00	National Institutes of Health
Preparing tomorrow's school psychology faculty to meet the needs of children with disabilities using evidence-based practices	Clark, Elaine	University of Utah	\$196,402.00	Department of Education
Preparing SLPs, OTs, early childhood special educators, and developmental psychologists for leadership roles in teaching, research, and service focused on young children with autism and their families	Crais, Elizabeth	University of North Carolina at Chapel Hill	\$0	Department of Education
Environmentally Triggered Neurodevelopmental Disorders: Focus on Endocrine Disruption and Sex Differences in Autism, ADHD, and Schizophrenia	Cranmer, Joan	University of Arkansas for Medical Sciences	\$25,000	National Institutes of Health

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Recruiting and preparing highly qualified special educators	Dieker, Lisa	University of Central Florida	\$200,000.00	Department of Education
Preparation of leaders across the lifespan for autism	Ganz, Jennifer	Texas A&M University	\$500,000	Department of Education
International Meeting for Autism Research (IMFAR) Support	Gentry, Jennifer	International Society for Autism Research	\$50,000.00	Simons Foundation
Amygdala in Health and Disease	Graveline, Darlene	Gordon Research Conferences	\$1,000	Simons Foundation
Leadership in Family-Centered Early Intervention (LIFE) personnel preparation program	Hanline, Mary	Florida State University	\$0	Department of Education
Leadership training in high-need students with severe disabilities/autism	Hughes, Carolyn	Vanderbilt University	\$287,590	Department of Education
Meeting grant - International Meeting for Autism Research (IMFAR)	International Meeting for Autism Research (IMFAR)	International Meeting for Autism Research (IMFAR)	\$25,000.00	Autism Science Foundation
Post-doctoral special education research training in urban communities: A research to practice model	Kamps, Debra	University of Kansas	\$163,459	Department of Education

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Leadership training in severe disabilities/autism	Kennedy, Craig	Vanderbilt University	\$0	Department of Education
2011 Cerebellum Gordon Research Conference	Khodakhah, Kamran	Gordon Research Conferences	\$20,000	National Institutes of Health
Project STARS: Systematic Training for Autism Researchers and School Personnel	Mehta, Smita	University of North Texas	\$0	Department of Education
International Mental Health/Developmental Disabilities Research Training Program	Munir, Kerim	Children's Hospital Boston	\$138,232	National Institutes of Health
Mental Health/Disabilities (MHDD) Research Education Program	Munir, Kerim	Children's Hospital Boston	\$148,926	National Institutes of Health
Birth to Kindergarten Professional Preparation: Inclusive Services for Children with Autism Spectrum Disorders	Niemeyer, Judith	University of North Carolina at Greensboro	\$299,998	Department of Education
AIR-P Research RFAs	No PI listed	N/A	\$649,013	Health Resources and Services Administration
2010 Annual SFARI Meeting	No PI listed	n/a	\$463,909	Simons Foundation
Leading Excellence for Academic Positions in Special Education (LEAPS)	O'Connor, Rollanda	The Regents Of The University Of California	\$244,984	Department of Education

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Post-doctoral training in special education research	Odom, Samuel	University of North Carolina at Chapel Hill	\$159,737	Department of Education
OPAM: A conference on Object Perception Attention and Memory	Palomares, Melanie	University of South Carolina	\$7,200	National Institutes of Health
Environmental Epigenomics and Disease Susceptibility	Robertson, Andrew	Keystone Symposia	\$12,200	National Institutes of Health
Interdisciplinary training for autism researchers	Rogers, Sally	University of California, Davis	\$344,214	National Institutes of Health
International Meeting for Autism Research (IMFAR)	Rogers, Sally	University of California, Davis	\$47,822.00	National Institutes of Health
Early Childhood Special Education Leadership (ECSEL)	Smith, Barbara	University of Colorado Denver	\$0	Department of Education
Innovative Technology for Autism	Staff Member	Autism Speaks (AS)	\$0.00	Autism Speaks
Infrastructure support for autism research at MIT	Sur, Mriganka	Massachusetts Institute of Technology	\$1,500,000.00	Simons Foundation
Preparation of leadership personnel to serve infants, toddlers, children, and youth with autism	Wetherby, Amy	Florida State University	\$0	Department of Education

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Disorders of Synaptic Dysfunction Symposium
and Workshop

Zoghbi, Huda

Baylor College of Medicine

\$5,000

Simons
Foundation

7.L

Expand the number of ADDM sites in order to conduct ASD surveillance in children and adults; conduct complementary direct screening to inform completeness of ongoing surveillance; and expand efforts to include autism subtypes by 2015. *IACC Recommended Budget: \$16,200,000 over 5 years.*

Project Title	Principal Investigator	Institution	Funding	Funder
Autism and Developmental Disabilities Monitoring (ADDM) network - South Carolina (expanded)	Charles, Jane	Medical University of South Carolina	\$124,950	Centers for Disease Control and Prevention
Autism and Developmental Disabilities Monitoring (ADDM) network - Missouri (expanded)	Constantino, John	Washington University in St. Louis	\$80,803	Centers for Disease Control and Prevention
Autism and Developmental Disabilities Monitoring (ADDM) network - Arizona (expanded)	Cunniff, Chris	University of Arizona	\$124,950	Centers for Disease Control and Prevention
Autism and Developmental Disabilities Monitoring (ADDM) network - Wisconsin (expanded)	Durkin, Maureen	University of Wisconsin - Madison	\$124,950	Centers for Disease Control and Prevention
Autism and Developmental Disabilities Monitoring (ADDM) network - New Jersey (expanded)	Zaharodny, Walter	University of Medicine & Dentistry of New Jersey	\$124,950	Centers for Disease Control and Prevention
Autism and Developmental Disabilities Monitoring (ADDM) network - Utah (expanded)	Zimmerman, Judith	University of Utah	\$124,949	Centers for Disease Control and Prevention

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7.N

Enhance networks of clinical research sites offering clinical care in real-world settings that can collect and coordinate standardized and comprehensive diagnostic, biological (e.g., DNA, plasma, fibroblasts, urine), medical, and treatment history data that would provide a platform for conducting comparative effectiveness research and clinical trials of novel autism treatments by 2012. *IACC Recommended Budget: \$1,850,000 over 1 year.*

Project Title	Principal Investigator	Institution	Funding	Funder
Autism Consortium	Barrett, Peter	Autism Consortium	\$300,000	Simons Foundation
Autism Treatment Network (ATN) 2011- MGH/LADDERS	Bauman, Margaret	Massachusetts General Hospital	\$140,000	Autism Speaks
Autism Treatment Network (ATN) 2011- CHOP	Bennett, Amanda	Children's Hospital of Philadelphia	\$140,000	Autism Speaks
Creating the Developmental-Behavioral Pediatrics Research Network	Blum, Nathan	Children's Hospital of Philadelphia	\$220,000.00	Health Resources and Services Administration
Autism Treatment Network (ATN) 2011- Nationwide Children's Hospital	Butter, Eric	Nationwide Children's Hospital	\$140,000	Autism Speaks
Autism Treatment Network (ATN) 2011- OHSU	Fombonne, Eric	Oregon Health & Science University	\$140,000	Autism Speaks
Autism Treatment Network (ATN) 2011- U of Pittsburgh	Handen, Benjamin	University of Pittsburgh	\$140,000	Autism Speaks

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Autism Treatment Network (ATN) 2011- University of Rochester	Hyman, Susan	University of Rochester	\$140,000	Autism Speaks
Autism Treatment Network (ATN) 2011- Children's Hospital Los Angeles	Kipke, Michele	Children's Hospital Los Angeles	\$140,000	Autism Speaks
Autism Treatment Network (ATN) 2011- KKI	Landa, Rebecca	Kennedy Krieger Institute	\$25,000	Autism Speaks
Autism Treatment Network (ATN) 2011-Toronto Consortium	Loh, Alvin	Holland Bloorview Kids Rehabilitation Hospital	\$140,000	Autism Speaks
Autism Treatment Network (ATN) 2011- Arkansas	Lopez, Maya	University of Arkansas for Medical Sciences	\$140,000	Autism Speaks
Autism Treatment Network (ATN) 2011- Vanderbilt University	Malow, Beth	Vanderbilt University	\$140,000	Autism Speaks
Autism Treatment Network (ATN) 2011 - Cincinnati Children's Hospital Medical	Manning-Courtney, Patricia	Cincinnati Children's Hospital Medical Center	\$140,000	Autism Speaks
Prometheus Research, LLC	Contract	Prometheus Research, LLC	\$3,392,463	Simons Foundation
Autism Treatment Network (ATN) 2011 - MGH Clinical Coordinating Center	Perrin, James	Massachusetts General Hospital	\$445,000	Autism Speaks

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Autism Treatment Network (ATN) 2011- University of Colorado Denver	Reynolds, Ann	Children's Hospital Colorado	\$140,000	Autism Speaks
Autism Treatment Network (ATN) 2011- Columbia University	Sidhu, Navreet	Columbia University	\$25,000	Autism Speaks
Autism Treatment Network (ATN) 2011- University of Missouri	Sohl, Kristin	University of Missouri	\$139,996	Autism Speaks
Autism Treatment Network (ATN)	Staff Member	Autism Speaks (AS)	\$1,028,052	Autism Speaks
Autism Treatment Network (ATN) 2011- BCM/TCH	Voigt, Robert	Baylor College of Medicine	\$25,000	Autism Speaks
Autism Treatment Network (ATN) 2011- Glenrose Rehabilitation Hospital	Zwaigenbaum, Lonnie	University of Alberta	\$139,376	Autism Speaks

7.0

Create an information resource for ASD researchers (e.g., PhenX Project) to share information to facilitate data sharing and standardization of methods across projects by 2013.

- This includes common protocols, instruments, designs, and other procedural documents and should include updates on new technology and links to information on how to acquire and utilize technology in development.
- This can serve as a bidirectional information reference, with autism research driving the development of new resources and technologies, including new model systems, screening tools, and analytic techniques.

IACC Recommended Budget: \$2,000,000 over 2 years.

Project Title	Principal Investigator	Institution	Funding	Funder
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CRCNS: Ontology-based multi-scale integration of the autism phenome	Das, Amarendra	Stanford University	\$323,887	National Institutes of Health
Cognitive usability evaluation of the SFARI system	Kaufman, David	Columbia University	\$33,054	Simons Foundation
ATN Registry	No PI listed	N/A	\$714,000	Health Resources and Services Administration

7. Other

Not specific to any objective

Project Title	Principal Investigator	Institution	Funding	Funder
ACE Center: Data Management/Statistical Core	Abbott, Robert	University of Washington	\$46	National Institutes of Health
Core D: Clinical Neuroscience Services	Anderson, Adam	Vanderbilt University	\$207,782	National Institutes of Health
ACE Center: The Imaging Core	Bookheimer, Susan	University of California, Los Angeles	\$326,257	National Institutes of Health
Infant Primate Research Laboratory	Burbacher, Thomas	University of Washington	\$156,634	National Institutes of Health

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Core E: Participant Recruitment & Assessment Services	Dykens, Elisabeth	Vanderbilt University	\$277,512	National Institutes of Health
Core A: Administrative Services	Dykens, Elisabeth	Vanderbilt University	\$255,048	National Institutes of Health
ACE Center: Administrative Core	Eichenbaum, Howard	University of California, San Diego	\$32,936	National Institutes of Health
ACE Center: Data and Statistics Core	Gibbons, Robert	University of Illinois at Chicago	\$378,379	National Institutes of Health
ACE Center: Data Management and Analysis Core	Grigorenko, Elena	Yale University	\$190,870	National Institutes of Health
Comprehensive clinical phenotyping and genetic mapping for the discovery of autism susceptibility genes.	Herman, Gail	Nationwide Children's Hospital	\$0	National Institutes of Health
ACE Center: Administrative Core	Klin, Ami	Yale University	\$118,056	National Institutes of Health
ACE Center: Assessment Core	Leventhal, Bennett	University of Illinois at Chicago	\$378,379	National Institutes of Health
ACE Center: Subject Assessment and Recruitment Core	Minshew, Nancy	University of Pittsburgh	\$845,682	National Institutes of Health

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Office of the Scientific Director	Nakamura, Richard	National Institutes of Health	\$6,957,996	National Institutes of Health
2010 SFARI Workshops	No PI listed	n/a	\$579,228	Simons Foundation
Mindspec, Inc.	No PI listed	N/A	\$768,400	National Institutes of Health
ACE Center: The Diagnostic and Assessment Core	Piggot, Judith	University of California, Los Angeles	\$310,925	National Institutes of Health
Administrative Core	Piven, Joseph	University of North Carolina at Chapel Hill	\$529,954	National Institutes of Health

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