

# 2012 Portfolio Analysis Projects

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

## Table of Contents

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

*This document is for discussion purposes only and does not reflect the decisions of the IACC*

## 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.*

<b>Project Title</b>	<b>Principal Investigator</b>	<b>Institution</b>	<b>Funding</b>	<b>Funder</b>
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)	\$0	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.*

<b>Project Title</b>	<b>Principal Investigator</b>	<b>Institution</b>	<b>Funding</b>	<b>Funder</b>
----------------------	-------------------------------	--------------------	----------------	---------------

*This document is for discussion purposes only and does not reflect the decisions of the IACC*

Interactive Autism Network (IAN) core support	Law, Paul	Kennedy Krieger Institute	\$0	Autism Speaks
Simons Simplex Community at the Interactive Autism Network (SSC@IAN)	Law, Paul	Kennedy Krieger Institute	\$417,500	Simons Foundation
Accelerating Autism Research through the Interactive Autism Network (IAN Core)	Law, Paul	Kennedy Krieger Institute	\$100,000	Simons Foundation
Autism Registry (supplement)	Simon, Gregory	Group Health Cooperative	\$20,045	National Institutes of Health
Autism Registry	Simon, Gregory	Group Health Cooperative	\$447,613	National Institutes of Health
A centralized standard database for the Baby Siblings Research Consortium	Young, Gregory	University of California, Davis	\$0	Autism Speaks

*This document is for discussion purposes only and does not reflect the decisions of the IACC*

## 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.*

<b>Project Title</b>	<b>Principal Investigator</b>	<b>Institution</b>	<b>Funding</b>	<b>Funder</b>
<a href="#">Rutgers, The State University of New Jersey</a>	Contract	Rutgers, The State University of New Jersey	\$368,041	Simons Foundation
<a href="#">An open resource for autism iPSCs and their derivatives</a>	Schwartz, Philip	Children's Hospital of Orange County	\$562,927	National Institutes of Health
<a href="#">Autism Genetic Resource Exchange (AGRE)</a>	Staff Member	Autism Speaks (AS)	\$1,036,843	Autism Speaks
<a href="#">Autism Tissue Program (ATP)</a>	Staff Member	Autism Speaks (AS)	\$560,220	Autism Speaks
<a href="#">Bioinformatics support for AGRE</a>	Staff Member	Autism Speaks (AS)	\$422,519	Autism Speaks

*This document is for discussion purposes only and does not reflect the decisions of the IACC*

## 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.*

<b>Project Title</b>	<b>Principal Investigator</b>	<b>Institution</b>	<b>Funding</b>	<b>Funder</b>
<a href="#">Ethics of communicating scientific findings on autism risk</a>	Newschaffer, Craig	Drexel University School of Public Health	\$0	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.*

<b>Project Title</b>	<b>Principal Investigator</b>	<b>Institution</b>	<b>Funding</b>	<b>Funder</b>
<a href="#">Robot child interactions as an intervention tool for children with autism (supplement)</a>	Bhat, Anjana	University of Connecticut	\$35,325	National Institutes of Health
<a href="#">The microstructural basis of abnormal connectivity in autism (supplement)</a>	Lainhart, Janet	University of Utah	\$226,217	National Institutes of Health
<a href="#">National Database on Autism Research (NDAR)</a>	No PI listed	Center For Information Technology	\$900,000	National Institutes of Health
<a href="#">NIMH IAN with the National Database for Autism Research program</a>	Wang, Philip	National Institutes of Health	\$314,266	National Institutes of Health

*This document is for discussion purposes only and does not reflect the decisions of the IACC*

Omnitec Solution for the NIMH National Database for Autism Research

Wang, Philip

National Institutes of Health

\$2,204,000

National Institutes of Health

## 7.1

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..*

<b>Project Title</b>	<b>Principal Investigator</b>	<b>Institution</b>	<b>Funding</b>	<b>Funder</b>
<a href="#">Autism and Developmental Disabilities Monitoring (ADDM) network - South Carolina</a>	Charles, Jane	Medical University of South Carolina	\$424,999	Centers for Disease Control and Prevention
<a href="#">Autism and Developmental Disabilities Monitoring (ADDM) network - Missouri</a>	Constantino, John	Washington University in St. Louis	\$409,966	Centers for Disease Control and Prevention
<a href="#">Autism and Developmental Disabilities Monitoring (ADDM) network - Arizona</a>	Cunniff, Chris	University of Arizona	\$425,000	Centers for Disease Control and Prevention
<a href="#">Autism and Developmental Disabilities Monitoring (ADDM) network - North Carolina</a>	Daniels, Julie	University of North Carolina at Chapel Hill	\$413,169	Centers for Disease Control and Prevention
<a href="#">Autism and Developmental Disabilities Monitoring (ADDM) network - Wisconsin</a>	Durkin, Maureen	University of Wisconsin - Madison	\$425,000	Centers for Disease Control and Prevention
<a href="#">Autism and Developmental Disabilities Monitoring Network augmentation with screening and assessment</a>	King, Lydia	Medical University of South Carolina	\$275,000	Autism Speaks
<a href="#">Autism and Developmental Disabilities Monitoring (ADDM) network - Maryland</a>	Lee, Li-Ching	Johns Hopkins University	\$425,000	Centers for Disease Control and Prevention

*This document is for discussion purposes only and does not reflect the decisions of the IACC*

Autism and Developmental Disabilities Monitoring (ADDM) network - Colorado	Miller, Lisa	Colorado Department of Health and Environment	\$390,000	Centers for Disease Control and Prevention
Autism and Developmental Disabilities Monitoring (ADDM) network - Arkansas	Shultz, Eldon	University of Arkansas for Medical Sciences	\$423,626	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)	\$1,149,236	Centers for Disease Control and Prevention
Autism and Developmental Disabilities Monitoring (ADDM) network - Alabama	Wingate, Martha	University of Alabama at Birmingham	\$425,000	Centers for Disease Control and Prevention
Autism and Developmental Disabilities Monitoring (ADDM) network - New Jersey	Zaharodny, Walter	University of Medicine & Dentistry of New Jersey	\$425,001	Centers for Disease Control and Prevention
Autism and Developmental Disabilities Monitoring (ADDM) network - Utah	Zimmerman, Judith	University of Utah	\$417,881	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	\$0	Autism Speaks

*This document is for discussion purposes only and does not reflect the decisions of the IACC*

University of Minnesota – Somali Autism Surveillance Project	Jesien, George; Hewitt, Amy	Association of University Centers on Disabilities (AUCD); University of Minnesota	\$108,610	Centers for Disease Control and Prevention
KwaZulu-Natal (KZN) Autism Study	Kauchali, Shuaib	University of KwaZulu-Natal	\$51,000	Autism Speaks
ARTI: The Autism Research & Training Initiative in India	Patel, Vikram	Sangath	\$0	Autism Speaks

## 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
2012 Fragile X and Autism-Related Disorders: From Basic Neuroscience to Improved	Berry-Kravis, Elizabeth	Gordon Research Conferences	\$15,000	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	\$0	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

*This document is for discussion purposes only and does not reflect the decisions of the IACC*



Environmentally Triggered Neurodevelopmental Disorders: Focus on Endocrine Disruption and Sex Differences in Autism, ADHD, and Schizophrenia	Cranmer, Joan	University of Arkansas for Medical Sciences	\$3,000	National Institutes of Health
Recruiting and preparing highly qualified special educators	Dieker, Lisa	University of Central Florida	\$0	Department of Education
Preparation of leaders across the lifespan for autism	Ganz, Jennifer	Texas A&M University	\$250,000	Department of Education
International Meeting for Autism Research (IMFAR) Support	Gentry, Jennifer	International Society for Autism Research	\$100,000	Simons Foundation
Engineering and Autism Workshop	Hamra, Danielle	University of Southern California	\$5,000	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	\$279,803	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	\$163,599	Department of Education

*This document is for discussion purposes only and does not reflect the decisions of the IACC*

Leadership training in severe disabilities/autism	Kennedy, Craig	Vanderbilt University	\$0	Department of Education
ACE Center: Research Training and Education Core	Klin, Ami	Emory University	\$58,382	National Institutes of Health
ACE Center: Research Education and Training Core	Kuo, Alice	University of California, Los Angeles	\$233,017	National Institutes of Health
Project STARS: Systematic Training for Autism Researchers and School Personnel	Mehta, Smita	University of North Texas	\$0	Department of Education
Birth to Kindergarten Professional Preparation: Inclusive Services for Children with Autism Spectrum Disorders	Niemeyer, Judith	University of North Carolina at Greensboro	\$299,9987	Department of Education
AIR-P Research RFAs	No PI listed	N/A	\$1,188,715	Health Resources and Services Administration
2010 Annual SFARI Meeting	No PI listed	N/A	\$411,802	Simons Foundation
Leading Excellence for Academic Positions in Special Education (LEAPS)	O'Connor, Rollanda	The Regents Of The University Of California	\$244,305	Department of Education
Post-doctoral training in special education research	Odom, Samuel	University of North Carolina at Chapel Hill	\$155,777	Department of Education

*This document is for discussion purposes only and does not reflect the decisions of the IACC*

Interdisciplinary training for autism researchers	Rogers, Sally	University of California, Davis	\$353,885	National Institutes of Health
Postdoctoral Research Training Fellowships in Early Intervention and Early Learning in Special Education at the University of Florida	Snyder, Patricia; Conroy, Maureen; Algina, James; Miller, David; Leite, Walter	University of Florida	\$164,760	Department of Education
The Simons Center for Social Brain at MIT	Sur, Mriganka	Massachusetts Institute of Technology	\$6,000,000	Simons Foundation
Infrastructure support for autism research at MIT	Sur, Mriganka	Massachusetts Institute of Technology	\$0	Simons Foundation
ACE Center: Research, training and education	Tager-Flusberg, Helen	Boston University	\$91,207	National Institutes of Health
Preparation of leadership personnel to serve infants, toddlers, children, and youth with autism	Wetherby, Amy	Florida State University	\$0	Department of Education
Banbury Center Conference	Witkowski, Jan	Cold Spring Harbor Laboratory	\$10,000	Simons Foundation
Doctoral Training in Research, Autism, and Interdisciplinary Leadership (TRAIL)	Woods, Juliann	Florida State University	\$249,839	Department of Education

*This document is for discussion purposes only and does not reflect the decisions of the IACC*

## 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	\$150,000	Centers for Disease Control and Prevention
Autism and Developmental Disabilities Monitoring (ADDM) network - Missouri (expanded)	Constantino, John	Washington University in St. Louis	\$97,003	Centers for Disease Control and Prevention
Autism and Developmental Disabilities Monitoring (ADDM) network - Arizona (expanded)	Cunniff, Chris	University of Arizona	\$150,000	Centers for Disease Control and Prevention
Autism and Developmental Disabilities Monitoring (ADDM) network - Wisconsin (expanded)	Durkin, Maureen	University of Wisconsin - Madison	\$150,000	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	\$150,000	Centers for Disease Control and Prevention
Autism and Developmental Disabilities Monitoring (ADDM) network - Utah (expanded)	Zimmerman, Judith	University of Utah	\$149,999	Centers for Disease Control and Prevention

## 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.*

*This document is for discussion purposes only and does not reflect the decisions of the IACC*

<b>Project Title</b>	<b>Principal Investigator</b>	<b>Institution</b>	<b>Funding</b>	<b>Funder</b>
Autism Consortium	Barrett, Peter	Autism Consortium	\$750,346	Simons Foundation
Autism Treatment Network (ATN) 2011- MGH/LADDERS	Bauman, Margaret	Massachusetts General Hospital	\$0	Autism Speaks
Autism Treatment Network (ATN) 2011- CHOP	Bennett, Amanda	Children's Hospital of Philadelphia	\$0	Autism Speaks
Creating the Developmental-Behavioral Pediatrics Research Network	Blum, Nathan	Children's Hospital of Philadelphia	\$250,000	Health Resources and Services Administration
Autism Treatment Network (ATN) 2011- Nationwide Children's Hospital	Butter, Eric	Nationwide Children's Hospital	\$0	Autism Speaks
Autism Treatment Network (ATN) 2011- OHSU	Fombonne, Eric	Oregon Health & Science University	\$0	Autism Speaks
Autism Treatment Network (ATN) 2011- U of Pittsburgh	Handen, Benjamin	University of Pittsburgh	\$0	Autism Speaks
Autism Treatment Network (ATN) 2011- University of Rochester	Hyman, Susan	University of Rochester	\$0	Autism Speaks

*This document is for discussion purposes only and does not reflect the decisions of the IACC*

Autism Treatment Network (ATN) 2011- Children's Hospital Los Angeles	Kipke, Michele	Children's Hospital Los Angeles	\$0	Autism Speaks
Autism Treatment Network (ATN) 2011- KKI	Landa, Rebecca	Kennedy Krieger Institute	\$0	Autism Speaks
Autism Treatment Network (ATN) 2011-Toronto Consortium	Loh, Alvin	Holland Bloorview Kids Rehabilitation Hospital	\$0	Autism Speaks
Autism Treatment Network (ATN) 2011- Arkansas	Lopez, Maya	University of Arkansas for Medical Sciences	\$0	Autism Speaks
Autism Treatment Network (ATN) 2011- Vanderbilt University	Malow, Beth	Vanderbilt University	\$0	Autism Speaks
Autism Treatment Network (ATN) 2011 - Cincinnati Children's Hospital Medical	Manning-Courtney, Patricia	Cincinnati Children's Hospital Medical Center	\$0	Autism Speaks
Prometheus Research, LLC	Contract	Prometheus Research, LLC	\$2,549,095	Simons Foundation
Autism Treatment Network (ATN) 2011 - MGH Clinical Coordinating Center	Perrin, James	Massachusetts General Hospital	\$0	Autism Speaks
Autism Treatment Network (ATN) 2011- University of Colorado Denver	Reynolds, Ann	Children's Hospital Colorado	\$0	Autism Speaks

*This document is for discussion purposes only and does not reflect the decisions of the IACC*

Autism Treatment Network (ATN) 2011- Columbia University	Sidhu, Navreet	Columbia University	\$0	Autism Speaks
Autism Treatment Network (ATN) 2011- University of Missouri	Sohl, Kristin	University of Missouri	\$0	Autism Speaks
Autism Treatment Network (ATN)	Staff Member	Autism Speaks (AS)	\$1,721,387	Autism Speaks
Autism Treatment Network (ATN) 2011- BCM/TCH	Voigt, Robert	Baylor College of Medicine	\$0	Autism Speaks
Autism Treatment Network (ATN) 2011- Glenrose Rehabilitation Hospital	Zwaigenbaum, Lonnie	University of Alberta	\$0	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.*

<b>Project Title</b>	<b>Principal Investigator</b>	<b>Institution</b>	<b>Funding</b>	<b>Funder</b>
ATN Registry	No PI listed	N/A	\$728,000	Health Resources and Services

*This document is for discussion purposes only and does not reflect the decisions of the IACC*

## 7. Other

Not specific to any objective

Project Title	Principal Investigator	Institution	Funding	Funder
Core D: Clinical Neuroscience Services	Anderson, Adam	Vanderbilt University	\$207,706	National Institutes of Health
Core E: Statistical Analysis Core (supplement)	Beckett, Laurel	University of California, Davis	\$30,783	National Institutes of Health
ACE Center: Administrative Core	Bookheimer, Susan	University of California, Los Angeles	\$208,325	National Institutes of Health
ACE Center: Neuroimaging/Neurophysiology Core	Bookheimer, Susan	University of California, Los Angeles	\$195,745	National Institutes of Health
A multidimensional database for the Simons Simplex Collection	Coppola, Giovanni	University of California, Los Angeles	\$88,188	Simons Foundation
ACE Center: Diagnostic and Recruitment Core	Cronin, Pegeen	University of California, Los Angeles	\$236,921	National Institutes of Health

*This document is for discussion purposes only and does not reflect the decisions of the IACC*



Core E: Participant Recruitment & Assessment Services	Dykens, Elisabeth	Vanderbilt University	\$278,269	National Institutes of Health
Core A: Administrative Services	Dykens, Elisabeth	Vanderbilt University	\$255,539	National Institutes of Health
ACE Center: Data Management and Analysis Core	Grigorenko, Elena	Yale University	\$201,589	National Institutes of Health
Core C: Analytical Core (supplement)	Hammock, Bruce	University of California, Davis	\$30,784	National Institutes of Health
Core B: Outreach and Translation (supplement)	Hansen, Robin	University of California, Davis	\$30,783	National Institutes of Health
Comprehensive clinical phenotyping and genetic mapping for the discovery of autism susceptibility genes.	Herman, Gail	Nationwide Children's Hospital	\$0	Department of Defense - Air Force
ACE Center: Clinical Core	Joseph, Robert	Boston University	\$575,083	National Institutes of Health
ACE Center: Administrative Core	Klin, Ami	Yale University	\$114,622	National Institutes of Health

*This document is for discussion purposes only and does not reflect the decisions of the IACC*

ACE Center: Administrative Core	Klin, Ami	Emory University	\$73,923	National Institutes of Health
SFARI Conferences, Workshops & Events	No PI listed	N/A	\$665,195	Simons Foundation
Mindspec, Inc.	No PI listed	N/A	\$924,100	National Institutes of Health
Administrative Core	Piven, Joseph	University of North Carolina at Chapel Hill	\$529,146	National Institutes of Health
ACE Center: Data Management and Analysis Core	Ramsay, Gordon	Emory University	\$97,824	National Institutes of Health
ACE Center: Clinical Assessment Core	Saulnier, Celine	Emory University	\$362,584	National Institutes of Health
Core D: Molecular Genomics Core (supplement)	Sharp, Frank	University of California, Davis	\$30,783	National Institutes of Health
ACE Center: Administration and data management	Tager-Flusberg, Helen	Boston University	\$302,671	National Institutes of Health
Office of the Scientific Director	Wang, Philip	National Institutes of Health	\$11,422,709	National Institutes of Health

*This document is for discussion purposes only and does not reflect the decisions of the IACC*