

QUESTION 7: WHAT OTHER INFRASTRUCTURE AND SURVEILLANCE NEEDS MUST BE MET?

2013 Projects: 117
2013 Funding: \$47,404,030

7.A

Conduct a needs assessment to determine how to merge or link administrative and/or surveillance databases that allow for tracking the involvement of people living with ASD in health care, education and social services by 2009. *IACC Recommended Budget: \$520,000 over 1 year.*

2013 Projects: 0
2013 Funding: \$0

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 (revised in 2010).*

2013 Projects: 1
2013 Funding: \$13,495

Project Title	Principal Investigator	Institution	Funding	Funder
State of the states in services and supports for persons with autism spectrum disorder.	L&M Policy Research, Thompson Reuters, and the National Association of State Directors of Developmental Disabilities	Centers for Medicare & Medicaid Services (CMS)	\$13,495	Centers for Medicare & Medicaid

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.*

2013 Projects: 5
2013 Funding: \$1,177,741

Project Title	Principal Investigator	Institution	Funding	Funder
EU-AIMS	n/a	King's College London	\$130,188	Autism Speaks
Simons Simplex Community at the Interactive Autism Network (SSC@IAN)	Law, Paul	Kennedy Krieger Institute	\$97,500	Simons Foundation
Accelerating Autism Research through the Interactive Autism Network (IAN Core)	Law, Paul	Kennedy Krieger Institute	\$453,738	Simons Foundation
Interactive Autism Network Core and Simons Simplex Collection Registry	Lipkin, Paul	Hugo W. Moser Research Institute at Kennedy Krieger, Inc.	\$350,000	Simons Foundation
Characterizing the severely affected autism population	Siegel, Matthew	Maine Medical Center Research Institute	\$146,315	Simons Foundation

7.D

Establish and maintain an international network of biobanks for the collection of brain tissue, 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 (revised in 2011).

2013 Projects: 7

2013 Funding: \$3,369,545

Project Title	Principal Investigator	Institution	Funding	Funder
Autism Genetic Resource Exchange (AGRE)	Staff Member	Autism Speaks (AS)	\$676,333	Autism Speaks
Autism Tissue Program (ATP)	Staff Member	Autism Speaks (AS)	\$236,009	Autism Speaks
Bioinformatics support for AGRE	Staff Member	Autism Speaks (AS)	\$263,552	Autism Speaks

An open resource for autism iPSCs and their derivatives	Schwartz, Philip	Children's Hospital of Orange County	\$545,118	National Institutes of Health
Understanding Cell Heterogeneity In Human Brain Using Droplet Microfluidics And Single-Cell Transcriptomics	McCarroll, Steven	Harvard Medical School	\$0	Simons Foundation
Rhode Island population and genetics study of autism and intellectual disability	Morrow, Eric	Bradley Hospital	\$208,799	Simons Foundation
Rutgers, The State University of New Jersey	No PI listed	Rutgers, The State University of New Jersey	\$1,439,734	Simons Foundation

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.*

2013 Projects: 0
2013 Funding: \$0

7.F

Create funding mechanisms that encourage rapid replication studies of novel or critical finding by 2011. *No recommended budget assigned by the IACC.*

2013 Projects: 0
2013 Funding: \$0

7.G

Develop a web-based tool that provides population estimates of ASD prevalence for States based on the most recent prevalence range and average identified by the ADDM Network by 2012. *IACC Recommended Budget: \$200,000 over 2 years.*

(This objective can be considered completed.)

7.H

Create mechanisms to specifically support the contribution of data from 90% 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.*

2013 Projects: 3

2013 Funding: \$1,026,179

Project Title	Principal Investigator	Institution	Funding	Funder
National Database on Autism Research	No PI listed	Center for Information Technology	\$44,000	National Institutes of Health
To support the ongoing operations of NDAR by providing direction, management and	No Pi Listed	Omnitec Solutions, Inc.	\$635,431	National Institutes of Health
A model integrated data management system for multi-disciplinary autism research	Rozenblit, Leon	Prometheus Research, LLC	\$346,748	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.*

2013 Projects: 13

2013 Funding: \$6,551,583

Project Title	Principal Investigator	Institution	Funding	Funder
Autism and Developmental Disabilities Monitoring Network augmentation with screening and assessment	King, Lydia	Medical University of South Carolina	\$262,621	Autism Speaks
Autism and Developmental Disabilities Monitoring (ADDM) network - South Carolina	Charles, Jane	Medical University of South Carolina	\$552,000	Centers for Disease Control and Prevention
Autism and Developmental Disabilities Monitoring (ADDM) network - Missouri	Constantino, John	Washington University in St. Louis	\$528,177	Centers for Disease Control and Prevention
Autism and Developmental Disabilities Monitoring (ADDM) network - Arizona	Cunniff, Chris	University of Arizona	\$552,000	Centers for Disease Control and Prevention

Autism and Developmental Disabilities Monitoring (ADDM) network - North Carolina	Daniels, Julie	University of North Carolina at Chapel Hill	\$408,000	Centers for Disease Control and Prevention
Autism and Developmental Disabilities Monitoring (ADDM) network - Wisconsin	Durkin, Maureen	University of Wisconsin, Madison	\$552,000	Centers for Disease Control and Prevention
Autism and Developmental Disabilities Monitoring (ADDM) network - Colorado	Ghosh, Tista	Colorado Department of Health and Environment	\$390,000	Centers for Disease Control and Prevention
Autism and Developmental Disabilities Monitoring (ADDM) network - Maryland	Lee, Li-Ching	Johns Hopkins University	\$408,000	Centers for Disease Control and Prevention
Autism and Developmental Disabilities Monitoring (ADDM) network - Utah	McMahon, William	University of Utah	\$545,180	Centers for Disease Control and Prevention
Autism and Developmental Disabilities Monitoring (ADDM) network - Arkansas	Shultz, Eldon	University of Arkansas for Medical Sciences	\$408,000	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)	\$985,604	Centers for Disease Control and Prevention
Autism and Developmental Disabilities Monitoring (ADDM) network - Alabama	Wingate, Martha	University of Alabama, Birmingham	\$408,001	Centers for Disease Control and Prevention
Autism and Developmental Disabilities Monitoring (ADDM) network - New Jersey	Zaharodny, Walter	University of Medicine & Dentistry of New Jersey	\$552,000	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.

2013 Projects: 2

2013 Funding: \$151,545

Project Title	Principal Investigator	Institution	Funding	Funder
Children with autism spectrum disorders in developing countries	Chugani, Harry	Wayne State University	\$30,000	National Institutes of Health
Biological Analysis Core	Van De Water, Judy	University of California, Davis	\$121,545	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.*

2013 Projects: 31

2013 Funding: \$9,560,821

Project Title	Principal Investigator	Institution	Funding	Funder
Meeting grant - International Meeting for Autism Research (IMFAR)	International Meeting for Autism Research (IMFAR)	International Meeting for Autism Research (IMFAR)	\$25,000	Autism Science Foundation
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
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
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	\$253,562	Department of Education
Post-doctoral special education research training in urban communities: A research to practice model	Kamps, Debra	University of Kansas	\$0	Department of Education
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	\$299,910	Department of Education
Leading Excellence for Academic Positions in Special Education (LEAPS)	O'Connor, Rollanda	The Regents Of The University Of California -- Graduate School Of Education - Graduate School Of Education	\$249,990	Department of Education
Post-doctoral training in special education research	Odom, Samuel	University of North Carolina at Chapel Hill	\$0	Department of Education
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	\$313,320	Department of Education
Preparation of leadership personnel to serve infants, toddlers, children, and youth with autism	Wetherby, Amy	Florida State University	\$0	Department of Education
Doctoral Training in Research, Autism, and Interdisciplinary Leadership (TRAIL)	Woods, Juliann	Florida State University	\$249,839	Department of Education
Leadership Education in Developmental-Behavioral Pediatrics	Rappoport, Lenny	The Children's Hospital of Boston	\$15,276	Heath Resources and Services Administration
ACE Center: Research Training and Education Core	Klin, Ami	Emory University	\$48,686	National Institutes of Health
ACE Center: Research Education and Training Core	Kuo, Alice	University of California, Los Angeles	\$220,437	National Institutes of Health

2013 Cerebellum Gordon Research Conference	Raman, Indira	Gordon Research Conferences	\$25,000	National Institutes of Health
Interdisciplinary training for autism researchers	Rogers, Sally	University of California, Davis	\$250,479	National Institutes of Health
ACE Center: Research, training and education	Tager-Flusberg, Helen	Boston University	\$111,353	National Institutes of Health
Inhibition in the CNS (GRS)	Batista-Brito, Renata	Gordon Research Conferences	\$10,000	Simons Foundation
Sponsorship of NeuroDevNet Brain Development Conference	Becker, Bethany	NeuroDevNet	\$7,500	Simons Foundation
International Meeting for Autism Research (IMFAR) Support	Gentry, Jennifer	International Society for Autism Research	\$0	Simons Foundation
Engineering and Autism Workshop	Hamra, Danielle	University of Southern California	\$0	Simons Foundation
Annual SFARI Meeting	No PI listed	N/A	\$545,469	Simons Foundation
Clinical Research Associates	No PI Listed	Clinical Research Associates	\$1,175,000	Simons Foundation
Making Connections: White Matter Malformation in Developmental Disorders Conference	Paul, Lynn	National Organization for Disorders of the Corpus Callosum	\$10,000	Simons Foundation
Infrastructure support for autism research at MIT	Sur, Mriganka	Massachusetts Institute of Technology	\$0	Simons Foundation
The new Simons Center for the Social Brain	Sur, Mriganka	Massachusetts Institute of Technology	\$5,500,000	Simons Foundation
Banbury Center Conference	Witkowski, Jan	Cold Spring Harbor Laboratory	\$0	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.

2013 Projects: 6

2013 Funding: \$3,351,698

Project Title	Principal Investigator	Institution	Funding	Funder
Autism and Developmental Disabilities Monitoring (ADDM) network - South Carolina (expanded)	Charles, Jane	Medical University of South Carolina	\$552,000	Centers for Disease Control and Prevention
Autism and Developmental Disabilities Monitoring (ADDM) network - Missouri (expanded)	Constantino, John	Washington University in St. Louis	\$528,177	Centers for Disease Control and Prevention
Autism and Developmental Disabilities Monitoring (ADDM) network - Wisconsin (expanded)	Durkin, Maureen	University of Wisconsin, Madison	\$622,341	Centers for Disease Control and Prevention
Autism and Developmental Disabilities Monitoring (ADDM) network - Arizona (expanded)	Pettygrove, Sydney	University of Arizona	\$552,000	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	\$552,000	Centers for Disease Control and Prevention
Autism and Developmental Disabilities Monitoring (ADDM) network - Utah (expanded)	Zimmerman, Judith	University of Utah	\$545,180	Centers for Disease Control and Prevention

7.M

Support 10 “Promising Practices” papers that describe innovative and successful services and supports being implemented in communities that benefit the full spectrum of people with ASD, which can be replicated in other communities, by 2015. *IACC Recommended Budget: \$75,000 over 5 years.*

2013 Projects: 0
2013 Funding: \$0

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.*

2013 Projects: 23

2013 Funding: \$7,616,296

Project Title	Principal Investigator	Institution	Funding	Funder
Autism Treatment Network (ATN) 2011-CHOP	Bennett, Amanda	Children's Hospital of Philadelphia	\$140,000	Autism Speaks
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
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	\$113,436	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
Autism Treatment Network (ATN) 2011-MGH/LADDERS	Neumeyer, Ann	Massachusetts General Hospital	\$140,000	Autism Speaks

Autism Treatment Network (ATN) 2011 - MGH Clinical Coordinating Center	Perrin, James	Massachusetts General Hospital	\$445,000	Autism Speaks
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	\$136,664	Autism Speaks
Autism Treatment Network (ATN)	Staff Member	Autism Speaks (AS)	\$732,883	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	\$139,002	Autism Speaks
Healthy Weight Research Network (HW-RN) for Children with Autism Spectrum Disorders and Developmental Disabilities (ASD/DD)	Bandini, Linda G	University of Massachusetts, Worcester	\$200,000	Heath Resources and Services Administration
Creating the Developmental-Behavioral Pediatrics Research Network	Blum, Nathan	Children's Hospital of Philadelphia	\$275,000	Heath Resources and Services Administration
Autism Consortium	Barrett, Peter	Autism Consortium	\$952,306	Simons Foundation
Prometheus Research, LLC	No PI listed	Prometheus Research, LLC	\$3,007,005	Simons Foundation

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.

2013 Projects: 1

2013 Funding: \$728,000

Project Title	Principal Investigator	Institution	Funding	Funder
ATN Registry	No PI listed	N/A	\$728,000	Heath Resources and Services Administration

7.P

Provide resources to centers or facilities that develop promising vertebrate and invertebrate model systems, and make these models more easily available or expand the utility of current model systems, and support new approaches to develop high-throughput screening technologies to evaluate the validity of model systems by 2013. *IACC Recommended Budget: \$1,100,000 over 2 years.*

2013 Projects: 1

2013 Funding: \$125,000

Project Title	Principal Investigator	Institution	Funding	Funder
NMR/cyro-mMR Machine	Zoghbi, Huda	Texas Children's Hospital	\$125,000	Simons Foundation

7.Other

Not specific to Question 7 objectives

2013 Projects: 24

2013 Funding: \$13,732,127

Project Title	Principal Investigator	Institution	Funding	Funder
ADAPTING ELECTRONIC MEDICAL RECORD TO MEASURE MEDICAL OUTCOMES IN ASD POPULATIONS	Bush, Ruth Ann	CHILDREN'S HOSPITAL RESEARCH CENTER	\$138,957	Agency for Healthcare Research Quality
Leveraging national ASD data to advance early access to care & develop research and family capacity	Bethell, Christina	Oregon Health & Science University	\$0	Autism Speaks
Interactive Autism Network-Core Activities	Law, Paul	Hugo W. Moser Research at Kennedy Krieger, Inc.	\$100,000	Autism Speaks
Telehealth System to Improve Medication Management of ASD Remotely	Oberleitner, Ronald	Behavior Imaging Solutions	\$95,480	Autism Speaks

World Health Organization Collaboration	Saxena, Shekhar	World Health Organization	\$400,000	Autism Speaks
Office of the Scientific Director	Amara, Susan	National Institutes of Health	\$8,561,517	National Institutes of Health
Core D: Clinical Neuroscience Services	Anderson, Adam	Vanderbilt University Medical Center	\$200,547	National Institutes of Health
ACE Center: Administrative Core	Bookheimer, Susan	University of California, Los Angeles	\$199,003	National Institutes of Health
ACE Center: Neuroimaging/Neurophysiology Core	Bookheimer, Susan	University of California, Los Angeles	\$181,369	National Institutes of Health
Anatomical and functional modularity of the cerebral cortex	Casanova, Manuel	University of Louisville	\$8,000	National Institutes of Health
ACE Center: Diagnostic and Recruitment Core	Cronin, Pegeen	University of California, Los Angeles	\$225,220	National Institutes of Health
Computational tools to analyze SNP data from patients with mental illness	Downey, Thomas	Partek, Inc.	\$598,866	National Institutes of Health
Core A: Administrative Services	Dykens, Elisabeth	Vanderbilt University Medical Center	\$247,305	National Institutes of Health
Core E: Participant Recruitment & Assessment Services	Dykens, Elisabeth	Vanderbilt University Medical Center	\$269,520	National Institutes of Health
Research Participation Core	Mailick, Marsha	University of Wisconsin - Madison	\$259,801	National Institutes of Health
Fast-as -new experimental medicine studies: Fast-fail trials in autism spectrum	No PI listed	University of California, Los Angeles	\$172,388	National Institutes of Health
Facility Core: Analytical and Environmental Chemistry	Puschner, Birgit	University of California, Davis	\$110,972	National Institutes of Health
ACE Center: Data Management and Analysis Core	Ramsay, Gordon	Emory University	\$40,386	National Institutes of Health
ACE Center: Clinical Assessment Core	Saulnier, Celine	Emory University	\$292,879	National Institutes of Health
ACE Center: Administration and data management	Tager-Flusberg, Helen	Boston University	\$226,572	National Institutes of Health
Administrative Core/Leadership	Van De Water, Judy	University of California, Davis	\$90,193	National Institutes of Health

A multidimensional database for the Simons Simplex Collection	Coppola, Giovanni	Univeristy of California, Los Angeles	\$149,396	Simons Foundation
Mindspec, Inc.	No PI listed	Mindspec, Inc.	\$931,150	Simons Foundation
SFARI Conferences, Workshops & Events	No PI listed	N/A	\$232,606	Simons Foundation