7. What other Infrastructure and Surveillance Needs Must be Met?

- **What infrastructure systems need to be supported, strengthened, or built to support this plan?**
- **How can we ensure that resources and data are shared to support the scientific research process?**
- **How can we ensure that findings are communicated to the public in a responsible and timely manner?**
- **How can we improve autism surveillance efforts?**

What do we know and what do we need?

Current infrastructure may be insufficient to adequately support the research programs outlined in this plan. Additional investment in infrastructure is necessary to collect and share data among researchers, to encourage and enable individuals with ASD and their families to participate in research, and to improve the speed with which findings are disseminated and the extent to which findings are translated into practice and policy.

Data Sharing:

In 2006, the National Institutes of Health (NIH) launched the National Database for Autism Research (NDAR) to improve sample sizes and enable researchers to share data for increased analyses. The NIH-supported national Autism Centers of Excellence (ACE), as well as the grants funded under the "Research to Address the Heterogeneity in Autism Spectrum Disorders" Request for Applications as part of the American Recovery and Reinvestment Act (ARRA), receive funding contingent upon acceptable plans and means for data sharing. Incentives are needed, however, to encourage data submission by other researchers. It will also be necessary to link other significant ASD databases with NDAR. In addition, databases that collect information and coordinate recruitment of people with ASD and their families to participate in research studies need to be enhanced and expanded. Programs to support contribution of data for recruitment, healthcare, education, social services and administrative databases, like the Interactive Autism Network (IAN), should be encouraged. Collecting information about people with ASD will facilitate the study of whether early diagnosis, entry to services and type of intervention affects the course of ASD over time. Multiple data sources from existing research or service systems (e.g., education, Medicaid, etc.) currently operate in isolation. Compiling and sharing data from existing data sources need to address data standardization as well as important privacy and ethical issues. Methods for merging such databases and linking investigator-recruited samples to these merged databases have been used in other populations and in specific locales with success and need to be further developed.

Biobanking:

Many in the field have highlighted the need to establish nationally coordinated strategies for the collection and preservation of post-mortem tissue from both people with and without ASD. The existing brain and tissue bank resources must be expanded to meet the high and continuously increasing demand for post-mortem tissue by scientific investigators. More well-preserved brains are needed from people at various stages of development and particularly from those with few co-occurring disorders. Additional matched controls are needed, as well, to supplement the limited supply in existing repositories.

In addition, it will be necessary to develop methods, standards and protocols for collecting and storing other biological specimens such as blood and urine which might be used to study biological differences or signatures, and skin fibroblasts for creation of pluripotent stem cells.

Surveillance:

Autism surveillance provides important estimates on the numbers of children affected with ASD and helps describe the characteristics of the people with autism spectrum disorders in the general population. Surveillance must be sustained over a period of many years in order to track trends in prevalence estimates over time, and is an essential building block for population-based research - providing clues about potential risk factors that warrant further study. Surveillance provides important data regarding early identification of children with autism, and informs education and health systems regarding areas in which programs can be modified in order to improve early identification and intervention. Surveillance data also provide critically important information for communities to use when planning for services.

In 2007, CDC's Autism and Developmental Disabilities Monitoring (ADDM) network published the first and most comprehensive summary of autism prevalence estimates in the United States (CDC, 2007). These data showed that between 1 in 100 to 1 in 300 (with an average of 1 in 150 children) were identified with ASD. In October 2009, investigators from HRSA and CDC reported that ASD occurs in an estimated 1.1% of children 3 to 17 years, based on parent-report during the National Survey of Children's Health (NSCH), sponsored by HRSA (Kogan et al., 2009) Updated estimates from CDC's ADDM Network, published in December 2009, confirmed that approximately 1% of children were identified with an ASD (between 1 in 80 to 1 in 240 children with an average of 1 in 110) (CDC, 2009). There was an increase of 57% in identified ASD prevalence from 2002 to 2006 in multiple areas of the US. While these data provide important information for service planning, and begin to help us understand that the increases are not fully accounted for by improved identification, many questions related to the multiple causes of ASD increases remain.

There are a number of areas in which prevalence studies could be improved, including the continued estimation and evaluation of prevalence in the same population over time; assessment of ASD prevalence in the context of other neurodevelopmental disorders; further analyses of existing datasets to examine the multiple identification and potential risk factors as they vary by prevalence; collection of data beyond core ASD symptoms, including genetic data and co-occurring medical, dental, and behavioral conditions; and expansion of studies across ages.

Supporting international autism surveillance activities, prevalence estimates, and epidemiologic research will also be important, in order to compare prevalence estimates and epidemiologic characteristics across countries.

Communication and Dissemination:

Research data regarding autism is now being published at a rapid rate. It is critical that new findings are communicated promptly and appropriately to the public so that research findings can be better translated into practice as appropriate. Effective translation is important so that new findings can be utilized to improve risk assessment and implementation of individualized interventions to reduce the disabling symptoms and promote a positive developmental trajectory as early as possible. Additional attention needs to be paid to improving the communication channels between scientists, practitioners, people with ASD and their families.

There is also need to build a system for rapid replication studies concerning key findings. In addition, there is still not agreement about meaningful subtypes or about how to individualize treatment. As more professionals become involved in autism research, there is a need for organized input from established scientists to provide guidance and expertise.

In addition, it will be necessary to identify and address the wide range of ethical and clinical issues related to the diagnosis, assessment, and communication of genetic, environmental, and clinical risk for autism.

Research Workforce Development:

In order to accomplish the necessary research in the field of autism, it will also be important to develop an adequate scientific workforce. While much autism research is already underway, there are several areas of research that are new and growing, including interdisciplinary research, where additional researchers will be needed in the coming years. In fiscal year 2009, there were 92 trainees (graduate students and postdoctoral fellows) supported by specific NIH training and fellowship grants to study autism. These are in addition to the trainees supported on more than 300 NIH research grants focused on autism. The continued expansion and development of this research workforce will be essential to fulfilling the goals laid out in the IACC Strategic Plan.

ASPIRATIONAL GOAL: DEVELOP AND SUPPORT INFRASTRUCTURE AND SURVEILLANCE SYSTEMS THAT ADVANCE THE SPEED, EFFICACY AND DISSEMINATION OF AUTISM RESEARCH.

Short-Term and Long-Term Objectives

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 healthcare, education and social services by 2009*. IACC Recommended Budget: $520,000 over 1 year.*

B. Conduct an annual "State of the States" assessment of existing state programs and supports for people and families living with ASD by 2009. *IACC Recommended Budget: $300,000 each year.*

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.*

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 developing fibroblast repositories to produce pluripotent stem cells. Protocols should be put into place to expand the capacities of ongoing large-scale children's studies to collect and store additional biomaterials, promoting detection of biological signatures. *IACC Recommended Budget for establishing biobanks by 2011: $10,500,000 over 2 years. IACC Recommended Budget for maintaining biobanks: $22,200,000 over 5 years.*

New Objective

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.*

New Objective

F. Create funding mechanisms that encourage rapid replication studies of novel or critical findings by 2011.

New Objective

G. Develop a web-based tool which 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 Budget Recommendations: $200,000 over 2 years.*

New Objective

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.*

New Objective

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.*

New Objective

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.*

New Objective

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.*

New Objective

L. Expand the number of ADDM sites in order to conduct ASD surveillance in younger and older age groups; 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.*

New Objective

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.*

What Progress is Being Made in Fulfilling the Objectives?

(Please provide 1-2 paragraphs to summarize progress.)

***Note:** *Infrastructure objectives that appeared in the 2009 Strategic Plan were moved from other chapters to Question 7. Objectives labeled "New Objective" are either entirely new additions to the 2010 Strategic Plan or significantly modified objectives from the 2009 Strategic Plan. Objectives from the 2009 Strategic Plan that did not change or that have been slightly modified for clarification purposes are unmarked.*

Research Resources

Below is a list of currently available resources for conducting ASD research. It includes government and non-government resources spanning topics such as genetics, bioinformatics, brain and tissue samples, and animal resources, as well as resources related to surveillance, prevalence, and services.

Government Resources

Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE)

http://www.cdc.gov/ncbddd/autism/caddre.html

> *Regional centers of excellence for ASD and other developmental disabilities, which are currently conducting the largest U.S. study of ASD risk factors*

CDC Autism and Developmental Disabilities Monitoring (ADDM) Network

http://www.cdc.gov/ncbddd/autism/addm.html

> *A surveillance network that provides data about ASD prevalence and describes the population of children with ASD*

National Children's Study

www.nationalchildrensstudy.gov/

> *A population-based study of environmental influences on child health and development that could be used to investigate the relationship between genetic and environmental risk markers and ASD diagnosis*

NDAR (National Database for Autism Research)

http://ndar.nih.gov

> *A secure bioinformatics platform for scientific collaboration and data-sharing between ASD investigators*

NDAR Data Definition

http://ndar.nih.gov/ndarpublicweb/standards.go

> *A data definition of ASD research terminology*

NICHD Brain and Tissue Bank

http://medschool.umaryland.edu/BTBank/

A brain tissue repository to support and enhance the acquisition and distribution of tissue samples from deceased individuals diagnosed with intellectual and developmental disabilities for use in research studies

NIF (Neuroscience Information Framework)

http://nif.nih.gov

NeuroLex is a dynamic lexicon to improve communication among neuroscientists about their data

NIH Pediatric MRI Data Repository

http://nih-pediatricmri.org

A multi-site longitudinal study used technologies (anatomical MRI, diffusion tensor imaging [DTI], and MR spectroscopy [MRS]) to map pediatric brain development

NIMH Center for Collaborative Genetic Studies

http://nimhgenetics.org/

A repository of biospecimens from individuals with mental illnesses such as schizophrenia, bipolar disorder, autism spectrum disorders, depression, and obsessive compulsive disorders

NIMH Genetics Repository

http://nimhgenetics.org

A repository to produce, store, and distribute clinical data and biomaterials such as DNA samples and cell lines (includes subjects with ASD)

NITRC (Neuroimaging Informatics Tools and Resources Clearinghouse)

http://www.nitrc.org

A neuroimaging tools repository, NITRC facilitates finding and comparing neuroimaging resources for functional and structural neuroimaging analyses

Non-Human Primate Atlas of Gene Expression through Development

http://www.blueprintnhpatlas.org/nhp

An atlas mapping the expression of particular genes to specific neuroanatomical locations across several timepoints in development in the rhesus monkey

Non-Government Resources

AGRE (Autism Genetic Resource Exchange)

http://www.agre.org

A repository for biomaterials and associated phenotype and genotype information from over 1,000 individuals with an ASD diagnosis and their families

Autism Genome Project

http://www.autismspeaks.org/science/research/initiatives/autism_genome_project.php

A study to find the genes associated with inherited risk for autism

Autism Tissue Program

http://www.brainbank.org

An ASD brain tissue repository

Autism Treatment Network

http://www.autismspeaks.org/science/programs/atn

A network of hospitals and physicians dedicated to developing a model of comprehensive medical care for children and adolescents with autism

Baby Siblings Research Consortium

http://www.autismspeaks.org/science/research/initiatives/babysibs.php

A consortium studying the infant siblings of children with ASD in order to identify early behavioral and biomedical markers of the disorder

IAN (Interactive Autism Network)

http://www.ianproject.org

An online registry of over 35,000 people who have or are related to those with ASD

ISAAC (Internet System for Assessing Autistic Children)

http://www.autismtools.org/index.cfm

A web-based application for administering and managing health research projects/studies and the associated data

RedCap

http://project-redcap.org

Two secure, web-based applications (REDCap and REDCap Survey) designed to support data capture for research studies

SFARI (Simons Foundation Autism Research Initiative)

https://sfari.org/simons-simplex-collection/

A repository of genetic samples and phenotypic data from families where parents without ASD give birth to a child with the disorder