Question 7: How do we continue to build, expand, and enhance the infrastructure system to meet the needs of the ASD community?

Aspirational Goal: Develop, enhance and support infrastructure and surveillance systems that advance the speed, efficacy, and dissemination of ASD research and services.

Introduction: Appropriate research infrastructure is critically important to the success of the IACC Strategic Plan, and progress toward the aspirational goal has been rapid over the past eight years. New databases are being built to leverage recent genetics findings and efforts to share biospecimens among multiple research efforts are intensifying. This increased availability of resources has advanced the efficacy and speed of ASD research. Surveillance systems have also progressed over the past 8 years, with new efforts focused on tracking more descriptive symptoms as well as a binary diagnosis. As the diagnosis of autism has broadened, more children are being identified who do not have co-morbid cognitive disability and additional resources have been focused on serving the needs of people across a diverse spectrum. Furthermore, many government and private organizations regularly share lay-audience friendly summaries of research findings to raise community awareness, including Simons Foundation, Autism Science Foundation, Autism Speaks, the Interactive Autism Network (IAN), the National Institutes of Health (NIH), and the Centers for Disease Control and Prevention (CDC).

In 2010, the IACC decided to track investments and evaluate progress in this area in the same organized, rigorous manner that is used in the rest of its Strategic Plan. From 2009-2015, a total of $302 million dollars has been invested in building and maintaining ASD research infrastructure, including surveillance efforts. While many of the original infrastructure needs identified in 2010 have been accomplished, continued investment is critical in order to maintain, develop and build on these valuable resources**.** Specifically, there must be a focus on enhancing the biorepository infrastructure, the data infrastructure, the human infrastructure, and surveillance activities in order for autism research to be successful.

Biorepository Infrastructure

Biological materials repositories collect, process, store, and distribute biospecimens to support scientific investigation. In the autism research community, biorepositories have been developed to support collection and dissemination of brain tissue, fibroblasts and other tissues. Greater participation in brain and tissue banking is needed from members of the autism community in order to obtain enough samples to meet research requests. Outreach campaigns to encourage families to donate brain and other tissue need to be expanded and enhanced.

Brain Banking

The NIH NeuroBioBank was formed in 2013 to address the increasing demand for post-mortem human brain tissue for research purposes[1]. Although this resource provides tissues for wide-ranging neurological and neurodevelopmental disorders, there is high demand for tissue from donors diagnosed with autism spectrum disorders. The NIH NeuroBioBank supports six independent brain and tissue repositories; the University of Maryland site collects and distributes the majority of ASD tissue. The collection has been highly sampled over the years and continues to grow through outreach activities and collaborations with other organizations.

A more autism-focused effort was undertaken in 2015 by the Autism BrainNet, supported by the Simons Foundation. Autism BrainNet is focused exclusively on creating a collection of ASD and control brains. The program supports four nodes throughout the United States (New York, Massachusetts, Texas and California) and one in the United Kingdom that share standardized protocols for tissue harvesting, storage and tissue dissemination. Autism BrainNet has a robust public awareness campaign to encourage donation, led by the Autism Science Foundation, fulfilling one of the longstanding goals of the IACC Strategic Plan. The NIH NeuroBioBank and Autism BrainNet work closely together to ensure that tissue acquisition, processing and distribution from both resources are conducted with the highest standards possible.

Tissue Banking

The NIMH Repository and Genomics Resource (NRGR) provides a centralized national biorepository that plays a key role in facilitating ASD research. The repository contains thousands of biospecimens from ASD families, and accompanying genotypic and phenotypic data are available to qualified researchers worldwide. Biomaterials are stored at the Rutgers University Cell and DNA Repository, supported through a cooperative agreement from the National Institute of Mental Health (NIMH). Clinical projects funded by NIMH that propose to collect biospecimens are strongly encouraged to submit the samples to NRGR. Submissions typically consist of whole blood draws along with the necessary phenotypic data relevant to these samples. The NRGR also accepts plasma, DNA/RNA/cDNA, biopsied material, and human-derived cell lines such as induced pluripotent stem cells (iPSCs) and lymphoblastoid cell lines (LCLs). Other types of biospecimens (e.g. saliva) may be accepted on a case-by-case basis. There are currently 18,822 ASD samples across all diagnoses of ASD in the NRGR Autism distribution. Another 12,606 have been received and will be released in future distributions.

Data Infrastructure

Data infrastructure refers to data collection, storage, sharing and consumption to support autism research, services and policy development. Autism is a highly heterogeneous disorder requiring large sample sizes to make significant findings. Thus far, tens of thousands of research subjects have consented to make their genomics, imaging, and clinical research data available to scientists in the hope that those data will help lead to important research discoveries. These datasets have become very large (i.e. millions of gigabytes) and will likely grow exponentially in the coming years with the rapid advances in technology (e.g. raw imaging, whole genome sequencing), new methods of data acquisition (bio-tracking) and the integration of patient directed reporting applications (e.g. IAN and SPARK). Other research communities have established related data repositories and funded data sharing initiatives making those datasets broadly available for use by the autism research community. Given the size of these data and the complexity of the software, algorithms and analytic methods used, it is essential that all the data and associated metadata be shared when a result is published or a significant finding is announced. Ensuring that all data is shared will increase the rigor and reproducibility of findings, a core responsibility of publicly-funded research.

Data Banks

New findings, technologies and research methods have emerged that can drive autism research forward, capitalizing on advances in participant engagement through electronic portals and the collection of large data sets. Together, these participant-powered and clinical data networks can be further leveraged for rapid research on large numbers of participants throughout the country, offering the potential for a broad and rich view of the health and well-being of those with ASD and their families.

The National Database for Autism Research (NDAR) was implemented in 2008 to harmonize research data and share results for all human subject research studies, by supporting a de-identified research subject identifier – the NDAR Global Unique Identifier (GUID), and a precise method for associating research data with publications/results[2]. NDAR also supports common data definitions, a standardized set of data collection measures ensuring that results across studies can be accurately combined or compared. Initially implemented to support data sharing for the NIH Autism Centers of Excellence, NDAR was expanded to support data sharing of any autism research data funded by NIH extramural programs beginning in 2010. In 2013, NDAR was rebranded as the NIMH Data Archive (NDA) and now supports data sharing of all human subject research data related to mental health. Today, research data from over 600 research projects, representing a public research investment of over $1.4B, are being shared. Overcoming limitations on restricted use datasets or the sharing of human subject research data across international borders, the NDA allows for the availability of research data funded by Autism Speaks, the Simons Foundation and the Autism Science Foundation. Investment is still needed to extend this infrastructure to support big data analytics better and to integrate with biobanks and genomics data repositories more fully.

Another mechanism for data sharing is the Autism Sequencing Consortium (ASC), an international group of scientists who share autism samples and genetic data[3]. Currently, ASC has whole exome sequencing (WES) data for 29,000 samples, many of which are derived from DNA samples in the NIMH repository. Summary data is available for all samples, as is raw and called data for samples with appropriate consents. Permission to re-contact research participants from completed studies exists for many of the samples within the ASC, managed by the contributing site.

In 2016, the Simons Foundation launched SPARK (Simons Foundation Powering Autism Research for Knowledge) to recruit, engage and retain a cohort of 50,000 individuals with ASD, as well as their family members, to participate in autism research. To participate in SPARK, families enroll online, provide saliva samples for genetic analysis and agree to be re-contacted for future research opportunities. SPARK participants are being sequenced and genotyped to identify new genes associated with autism risk. Clinical, behavioral, and genetic data on the SPARK cohort are available to all qualified investigators, and SPARK participants can be invited to participate in other ASD research studies. Thus far, SPARK has enrolled over 48,000 individuals, including 19,000 individuals with ASD.

In 2016, the Autism Science Foundation launched the Autism Sisters Project to collect and distribute DNA from the unaffected female siblings of individuals with autism. Current research suggests that genes implicated in autism are equally distributed in boys and girls, but that many girls who carry the autism genes do not express clinical symptoms of autism due to a “female protective effect”. The goal of this new project is to collect DNA samples to enable researchers to discover and characterize this “female protective effect”[4,5].

Data Sharing

When all research projects share their data, the quality of the accumulated data increases. For example, when a new research participant is enrolled in a research study, that person may also have registered previously with one or more data or biorepositories. If the data are linked and widely accessible to researchers (with appropriate privacy protections in place), the potential richness of the information available on that participant is thereby enhanced. Care should be taken to ensure that all stakeholders across the research enterprise understand the importance of data sharing and that those sharing the most used and highest quality datasets be credited for their contributions. To facilitate data sharing

in research involving human participants, an identifier or code is used to identify and link each individual to his or her specimens and perhaps also to associated medical information; use of a de-identified code (i.e., a code that does not reveal the identity of the individual) maintains privacy of the individual's information. The Global Unique Identifier (GUID) was developed to provide an easy method of identifying the same research participant across various data repositories and biobanks while maintaining the privacy of their personal information. The advantage of the GUID is that it enables linkage of data and specimens for a given individual over multiple studies, which can enrich the data set and prevent unnecessarily repeating the collection of the same types of samples from a given individual for multiple studies. While most data repositories have standardized identification of research participants using the GUID, adoption of this method has been less consistent across biobank repositories. Compounding this problem is the fact that most of the biobanks hold samples that are consented for restricted use (e.g. a study of autism and schizophrenia would require separate access) and are shared in separate repositories with different access restrictions and policies. The result is that it is often easier to request a tissue or sample from a biobank, re-sequence or re-analyze it, and then share the data with a new and different identifier, causing unnecessary (and often undetectable) duplication. For genomics, tools have been developed to eliminate this duplication, and attempts have been made to provide similar safeguards for imaging data. Though these additional tools exist, it is strongly encouraged that all data and biobank repositories maintain the use of the GUID and that those publishing genomics- or biobank-related studies provide a publicly-available manifest of subject GUIDs and links to phenotypic data locations when publishing, even if the data are only available as restricted use datasets. This action will provide standardization allowing data from the same individual to be linked across repositories, eliminate data duplication, and will help minimize redundant sample and tissue requests, thereby conserving precious resources.

Supporting the increasing emphasis on the importance of data sharing, the NIH has established a two-tiered approach for the sharing of NDA research data involving human subjects. First, observational and raw data is to be defined and shared using established data standards (data dictionary and a GUID). All data related to research results are expected to be submitted prior to publication. Data supporting other aims remain embargoed until publication, protecting ongoing research. This approach directly follows the long-established research process of sharing results and data at the time of publication. Where data collected by other researchers are used, this system automatically provides a mechanism showing data provenance and providing credit. All repositories supporting autism research should implement a similar program, even if the datasets shared are summary datasets, are not easily harmonized with established data repositories, or have restricted use limitations. As a community, by responsibly sharing high quality data at the appropriate times, it will increase the return on the collective research investment, protect the intellectual contribution of the best scientists, and help accelerate research discovery in autism and related disorders. Collectively, open data sharing offers the best opportunity to reach the sample sizes that are likely needed to improve understanding of autism and related disorders.

Several national surveys and administrative efforts collect information about people with ASD. Many of these surveys are federally funded through agencies such as the CDC [National Health Interview Survey (NHIS), National Survey of Children Health (NSCH)] or the Department of Education [National Longitudinal Transition Study-2 (NLTS2)]. Although each responsible agency may focus on its own research priorities when collecting and analyzing the data, synchronization of the national data sources will maximize their utility. Concordance of questions and sampling across surveys and administrative data could add greatly to the comparability of research undertaken across these national platforms. Additionally, infrastructure for linking these surveys to one another and to other sources of data is essential. The precedent for linkage already exists: for example, the CDC links the NHIS to administrative

records from the Department of Housing and Urban Development (HUD), which allows for the addition of detailed housing information for those NHIS participants who use HUD services. Additionally, Federal Statistical Research Data Centers make national data from the Census bureau, the CDC, and AHRQ available to researchers in one place. More projects like these, and additional means of capitalizing on the data that has already been collected and funded, are a key priority in order to generate a vast expansion of the information available on autism to a nationally-representative sample.

Human Infrastructure

Human infrastructure refers to the development of human resources necessary to support autism research. These include developing a professional workforce to conduct research and provide services, as well as encouraging individuals with autism and their family members to participate in autism research. In addition, systems must be developed to share research findings with community stakeholders and translate research findings into policy and practice.

Individuals with autism and their families participate in research studies at relatively low rates, hampering the ability of researchers to fully understand ASD and develop interventions. Coordinated efforts are needed to educate stakeholders from diverse backgrounds on the importance of participating in research. Research should also be conducted to understand the barriers that discourage participation. Efforts should also be made to encourage families from diverse backgrounds to donate biological samples for research.

Research Training and Workforce Development Efforts

There are a number of efforts underway to enhance research training and workforce development. Private funding agencies such as Autism Speaks and the Autism Science Foundation support research fellowships that focus on attracting and nurturing early career investigators as they pursue innovative ASD research projects and begin their careers. Great emphasis is placed on building relationships with experienced mentors and on encouraging multidisciplinary avenues of exploration. The NIH also offers research training opportunities including, but not limited to, training and career development grants and travel awards for early career investigators to attend research conferences.

While these initiatives represent mechanisms for the general support of trainees and early career ASD investigators, an area of need and opportunity identified by the IACC is these up-and-coming researchers to have better access to existing datasets for conducting secondary data analysis. Hundreds of millions of federal and private donor dollars have been spent on ASD research, which has led to the collection or federation of data on tens of thousands of ASD cases. A modest investment aimed at improving access to these data would not only maximize the return on substantial financial and human capital investments represented by decades of ASD research, but would also provide a fast-tracked training mechanism ideally suited to early career investigators, who often lack the resources to collect primary data.

Workforce development is an area of immense need as the number of identified individuals with autism continues to grow. While progress has been made in the area of early detection and intervention, and in the support of children on the spectrum, much less effort has been expended on adult services, as tens of thousands of children with autism transition to adulthood. Further, there is a dearth of trained medical professionals that are knowledgeable in providing care to the autism community, particularly the adult community. The Autism CARES Act, IDEA Part C, and Title V Maternal and Child Health Block

Grants all provide some amount of federal funding intended to target workforce training and development programs. However, resources remain scarce and it is not immediately clear how some of those resources are being utilized, particularly whether there is any standardization in the delivery of workforce development efforts across communities. In some cases, it is unclear what training programs are being implemented, if they are evidence-based, and how they are evaluated. There seems to be an immediate need for evidence-based best-practice guidelines in the development and implementation of such training programs.

International Collaboration

A 2012 IACC report titled Autism Spectrum Disorder Research Publication Analysis: The Global Landscape of Autism Research highlighted the expanding web of ASD research collaboration and publications across the globe; researchers from over 50 countries published papers during the analysis period. While there has been an increase in ASD research conducted and published outside of the US and other developed countries, the report also called attention to the fact that while research efforts are robust in the U.S., Canada, Europe, Australia, and China, many other countries around the world are lacking in capacity to conduct or opportunities to participate in research. More attention and investment toward fostering international research collaborations have the potential to change this situation and provide benefits for people with autism and other developmental disabilities worldwide. Diverse settings can afford unique research opportunities to investigate risk factors (e.g. air pollution) and populations (e.g. higher genetic homogeneity) that may not be present in countries from which most of ASD research is currently published. Further, international research collaborations not only present opportunities to disseminate and implement evidence-based science and services in diverse settings around the world, but also allow the ASD research community to learn about how diverse populations, including those from low-resource settings, have addressed issues such as limited research infrastructure and large service gaps. For these reasons, it is imperative that international research efforts and collaborations continue to be promoted and supported.

Dissemination of Science

Increasing and improving mechanisms for dissemination of research findings after publication should be a priority for the autism community. It is vital that findings and data become more accessible to researchers, practitioners, families, and the general public. Training to improve science communication skills should be more readily available to researchers who wish to share their work with lay audiences. Particularly important is risk communication in the interpretation of research findings, as the information disseminated to the public is sometimes contradictory, oversimplified, overstated or sensationalized. This misinformation can confuse the risk disenfranchising members of the public and have a negative impact on research participation. Mechanisms that allow for the summation of the evidence base into actionable recommendations such as systematic reviews and meta-analysis are encouraged, though research funders often overlook the potential for these types of analyses because they are based on existing rather than new data. Much of this work will be more feasible as the data-sharing infrastructure further develops and expands. NDAR provides an infrastructure to make data broadly accessible through a universal platform and federation with other data sources. To make NDAR the most useful resource possible for the community, autism researchers must improve both the consistency and quality of data shared, especially those data supporting published results, allowing the infrastructure to be better utilized supporting the dissemination of scientific advances. More attention must be NDAR and similar data-sharing efforts can help maximize the return on federal and private investment in autism research made over the last decade by providing the research community with richer datasets and opportunities for research that would not have been possible without the coordination of these data.

Technology can play a key role in improving the dissemination of science, and advances in technology have made it increasingly possible to handle the troves of "big data" that have been collected in ASD research. In addition to combining, storing, and analyzing data, technology affords new avenues of information collection and dissemination, for example, in the form of mobile applications (apps). Researchers can better collect data and do so more consistently across research studies by utilizing technology-based research platforms. Similarly, practitioners can better collect clinical data using the same or similar platforms. Making this technology more accessible and promoting the development of new technology for data collection and sharing should be prioritized by the research community to help optimize autism research studies. Further, technology to promote dissemination and implementation of intervention and support services, via telehealth or e-learning, is critically important to improving the capacity to deliver the latest in evidence-based services throughout the US and around the world. Lastly, with growing awareness of ASD around the world and an increase in the number of local organizations supporting people with ASD in their communities, it is an opportune time to begin building stronger international collaborative efforts around ASD. Such initiatives have the potential to enhance communication and cooperation between governments, researchers, service providers, and advocates and to aid in dissemination of research findings and best practices globally.

Surveillance

Population-based surveillance for autism spectrum disorder is essential for monitoring time trends in prevalence, assessing patterns by demographic factors and level of support necessary, characterizing co-occurring conditions, estimating resource needs, and stimulating research into potential risk factors. For the data provided to be used effectively, surveillance should be as complete and valid as possible. Population-based studies of the prevalence and characteristics of autism spectrum disorder in the United States have been conducted among children, but continued collection is necessary to monitor trends. In addition, there is a pressing need for surveillance studies among adults.

There are several different methodologies currently used for estimating the prevalence and characteristics of autism spectrum disorder among children, including: 1) use of administrative records; 2) parent or caregiver surveys; 3) expert review of records from multiple sources; and, 4) screening and examination of children. Each of these methodologies has strengths and limitations. Administrative records are readily available and cost-effective to use, but are collected for other purposes and do not always contain adequate and pertinent information. Health surveys are nationally representative, generate data relatively quickly, include extensive questions on service needs and utilization, include a comprehensive age range of children, and are cost-effective in terms of the marginal cost of adding ASD-related questions; however, the validity of parent/caregiver-reported ASD has not been established and declining response rates have raised concerns about bias. Expert review of records from multiple sources, including healthcare and education records, can ascertain records-based data on a number of factors such as demographics, educational placement, intellectual and adaptive function, and behavioral phenotype. However, this methodology is dependent on data in children's records, focuses on a few specific ages, and is resource- and time-intensive and so currently cannot be done at a national level. Finally, screening and examination of children using a standardized and validated ASD diagnostic tool is a rigorous methodology that attempts to give all children in the selected population an opportunity for ascertainment. However, this methodology is resource- and time-intensive, so cannot currently be done on a national level. In addition, low response rates in previous studies suggest a potential for bias.

Continued ASD surveillance among children is essential to monitor prevalence trends (including disparities in prevalence by demographic factors), characterize co-occurring conditions, estimate resource needs, and stimulate research into potential risk factors. ASD surveillance systems should be complementary, offering unique strengths and contributions that will further the understanding of the population of individuals with ASD. Where appropriate, data collection should be designed to allow comparisons across systems. Linkage of surveillance data with other state and federal datasets should be encouraged to leverage the surveillance efforts and expand the scope and utility of the information collected.

While many research studies are focused on understanding and meeting the needs of children with ASD, much less effort has been expended on adults. There is an urgent need to expand ASD surveillance to adults to characterize prevalence, adolescent/young adult transition needs, employment and housing, co-occurring conditions, premature mortality, and other lifespan issues. In particular, investigating ASD prevalence in adults will help researchers understand how the interaction of ASD and co-occurring conditions impacts the ability to adults with ASD to live and work.

A systematic community survey in the United Kingdom estimated that approximately 1% of adults surveyed met the criteria for ASD, a rate similar to that in children[6,7]. None of the adults with ASD identified in this study had been previously screened or diagnosed, further confirming the need for ASD surveillance in adults. The researchers involved in the study noted several challenges to their methodology, including low response rates to the survey and the potential high cost of initial screening. Nevertheless, a comprehensive adult surveillance in the United States would be desirable, subject to available funding.

Current Surveillance Programs

Autism and Developmental Disabilities Monitoring Network

The Autism and Developmental Disabilities Monitoring (ADDM) Network is a population-based surveillance program for ASD and other developmental disabilities based on expert review of behavioral characteristics documented in developmental evaluations contained in children's healthcare and educational records. The Centers for Disease Control and Prevention (CDC) has been conducting surveillance for ASD among 8-year-old children through the ADDM Network every two years since 2000 at between 6 and 14 sites throughout the United States. Recent surveillance cohorts have included approximately 350,000 8-year-old children. In 2010, the ADDM Network was expanded to include surveillance for ASD among 4-year-old children in six sites of the ADDM Network. Data have been linked to various sources such as environmental pollutant monitoring, juvenile justice records, and others. Additional linkages to data from state and federal agencies would enhance the usefulness of the ADDM Network data. The ADDM Network methodology has remained stable over time and so is able to assess prevalence trends. The most recent prevalence estimate for 2012 was 14.6 per 1,000 8-year-old children[8]. The ADDM Network methodology also allows for assessment of the effect of changes in diagnostic criteria for ASD, and an evaluation of the effect on ASD prevalence and characteristics of the change from DSM-IV-TR to DSM-5 is underway.

National Survey of Children's Health

The National Survey of Children's Health (NSCH) is currently administered by the Maternal and Child Bureau of the US Health Resources and Services Administration (HRSA). This nationally representative, telephone survey of children's health and development based on parent/caregiver report includes questions on whether the child currently had an ASD as well as whether a healthcare provider ever informed the parent or caregiver that the child had an ASD. Data are also collected on a variety of topics

including the child's health, health as an infant, recent healthcare service, experiences with healthcare providers, health insurance coverage, sociodemographic factors, and the child's learning, home and family environment. The most recently published report presented data for over 90,000 children aged 6-17 years; ASD prevalence was 2.00% for children aged 6-17 years in 2011/2012. Beginning in 2016, this survey was moved to a mail-invitation, online survey based on a US Census Bureau sampling platform. This survey has been combined with the previously fielded National Survey of Children with Special Healthcare Needs. The new combined survey will be conducted every year and include approximately 100,000 children aged 0-17 years. It is anticipated that state-level estimates will be available for many variables, and for other variables data will be combined from several study years to provide state-level estimates. Linkages to data from other federal agencies should be encouraged to expand the scope and usefulness of the data collected.

National Health Interview Study

CDC conducts the National Health Interview Survey (NHIS), a nationally-representative survey of parents/caregivers that provides data on the health of children in the United States, including information on whether a healthcare provider ever informed the parent or caregiver that the child had an ASD. The US Census Bureau is the data collection agent and the data are collected through personal household interviews. Data are collected on children aged 0-17 years every year; the most recently published survey year, 2014, presented data on ASD prevalence and characteristics for approximately 13,000 children aged 3-17 years. Data are also gathered on a variety of topics including the child's health status, healthcare access and utilization, and a mental health screener (the Strengths and Difficulties Questionnaire), as well as family factors, including sociodemographic factors. ASD prevalence was 2.24% for children aged 3-17 years in 2014. The questions that establish a child's ASD status were recently revised to be the same as those in the NSCH. As with NSCH, linkages to data from other federal agencies should be encouraged to expand the scope and usefulness of the data.

South Carolina SUCCESS

The South Carolina Children's Educational Surveillance Study (SUCCESS) is an Autism Speaks-funded screening-based initiative designed to help improve the precision of US ASD prevalence estimates by reducing reliance on service records alone to make ASD diagnoses, addressing the chief limitation of the ADDM Network approach. It has been suggested that this methodological approach is subject to missed cases, particularly among populations with less access to services, and in sites with fewer record types. SUCCESS was designed as a replication of the first-ever total population study of ASD prevalence in South Korea which found 2.64 percent of 7-9 year-old children, or 1 in 38, had an ASD[9]. SUCCESS similarly implements a direct-screening protocol of all eligible school children in the catchment area, to both augment and compare to the records-based case ascertainment methodology of the South Carolina ADDM Network site. In addition to improving the estimation of the prevalence of ASD within a US site, SUCCESS intends to characterize the factors contributing to why cases may be missed using current best surveillance practices. It is also the first study to compare DSM-IV and DSM-5 prevalence using a population-based methodology in the US. The findings, currently in preparation, will better guide ASD surveillance practices in the US, including resource and infrastructure needs, moving forward.

Summary

Continuing to build the infrastructure necessary for autism research is an important priority. In particular, researchers must make efforts to standardize their data collection and share with others in order to build higher-powered studies across multiple areas of research. Research institutions must continue to support biobanks and databanks, and to work towards integrating common collection and processing methods. Efforts to increase the participation of individuals with autism and their families in

research and contributions to biorepositories, as information and samples gathered have the potential to make significant contributions to our understanding of ASD. Inclusion of people on the autism spectrum and their families in research planning is also important, as it will help ensure that studies maintain a focus on issues that matter most to those who are impacted by ASD. Finally, funding agencies should continue to devote resources to ensuring dissemination of research findings and best practices, gaining better understanding of ASD prevalence across the lifespan, and training the next generation autism researchers, clinicians, and care providers.

Objectives

Objective 1: Promote growth, integration, and coordination of biorepository infrastructure.

a. Promote biological sample donation to ensure that demand for research studies is met.
b. Develop and expand programs and outreach campaigns to encourage families from diverse backgrounds to participate in ASD research, join registries and donate biological samples.
c. Create incentives to encourage standardization and sample sharing across data and biorepository banks.

Objective 2: Develop, enhance and link data repositories.

a. Adopt a de-identified research participant/subject identifier, such as the GUID, across all research initiatives in order to reduce the likelihood of sample duplication.
b. Use common data definitions in order to standardize data collection, and responsibly share all the data supporting any findings when those findings are announced.

Objective 3: Expand and enhance the research and services workforce and accelerate the pipeline from research to practice.

a. Expand and enhance programs that provide funds to train current and future researchers on innovative research techniques.
b. Provide service providers with training in evidence-based ASD services across multiple settings from clinics to communities.
c. Develop programs to translate and disseminate ASD research findings into actionable recommendations and real-world practice.

Objective 4: Strengthen ASD surveillance systems to further understanding of the population of individuals with ASD, while allowing comparisons and linkages across systems as much as possible.

a. Expand surveillance efforts to include the adult population in order to gain a better understanding of needs and concerns over the lifespan.
b. Expand surveillance efforts to collect more descriptive data regarding co-occurring conditions, including cognitive disability, seizure disorders, anxiety and depression to increase understanding of the prevalence of these conditions in the ASD population.

References

[1] Nichols L, Freund M, Ng C, Kau A, Parisi M, Taylor A, Armstrong D, Avenilla F, Joseph J, Meinecke D, Wagner A, Roger Little A. The National Institutes of Health Neurobiobank: a federated national network of human brain and tissue repositories. Biol Psychiatry. 2014 Jun 15;75(12):e21-2. [PMID: 24074636]

[2] Johnson SB, Whitney G, McAuliffe M, Wang H, McCreedy E, Rozenblit L, Evans CC. Using global unique identifiers to link autism collections. J Am Med Inform Assoc. 2010 Nov-Dec;17(6):689-95. [PMID: 20962132]

[3] Buxbaum JD, Daly MJ, Devlin B, Lehner T, Roeder K, State MW; Autism Sequencing Consortium. The autism sequencing consortium: large-scale, high-throughput sequencing in autism spectrum disorders. Neuron. 2012 Dec 20;76(6):1052-6. [PMID: 23259942]

[4] Werling DM, Parikshak NN, Geschwind DH. Gene expression in human brain implicates sexually dimorphic pathways in autism spectrum disorders. Nat Commun. 2016 Feb 19;7:10717. [PMID: 26892004]

[5] Werling DM. The role of sex-differential biology in risk for autism spectrum disorder. Biol Sex Differ. 2016 Nov 16;7:58. eCollection 2016. [PMID: 27891212]

[6] Brugha T, McManus S, Meltzer H, Smith J, Scott FJ, Purdon S, Harris J, Bankart J. Autism Spectrum Disorders in Adults Living in Households Throughout England—Report From the Adult Psychiatric Morbidity Survey 2007. Leeds, England NHS Information Centre. 2009. http://content.digital.nhs.uk/pubs/asdpsychiatricmorbidity07

[7] Brugha TS, McManus S, Bankart J, Scott F, Purdon S, Smith J, Bebbington P, Jenkins R, Meltzer H. Epidemiology of autism spectrum disorders in adults in the community in England. Arch Gen Psychiatry. 2011 May;68(5):459-65. [PMID: 21536975]

[8] Christensen DL, Baio J, Van Naarden Braun K, Bilder D, Charles J, Constantino JN, Daniels J, Durkin MS, Fitzgerald RT, Kurzius-Spencer M, Lee LC, Pettygrove S, Robinson C, Schulz E, Wells C, Wingate MS, Zahorodny W, Yeargin-Allsopp M; Centers for Disease Control and Prevention (CDC). Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years--Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2012. MMWR Surveill Summ. 2016 Apr 1;65(3):1-23. [PMID: 27031587]

[9] Kim YS, Leventhal BL, Koh YJ, Fombonne E, Laska E, Lim EC, Cheon KA, Kim SJ, Kim YK, Lee H, Song DH, Grinker RR. Prevalence of autism spectrum disorders in a total population sample. Am J Psychiatry. 2011 Sep;168(9):904-12. [PMID: 21558103]