

Chapter 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. Beginning 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 the IACC Strategic Plan. Over the past x years, a total of x million dollars has been invested in building and maintaining the ASD research infrastructure, including surveillance efforts. Many of the original infrastructure needs identified in 2010 have been accomplished, but continued investment is critical in order to maintain, develop and build on these valuable resources. **Specifically, we must focus on enhancing the biorepository infrastructure, the data infrastructure, the human infrastructure, and surveillance activities in order for autism research to be successful.**

I. Biorepository Infrastructure:

Biological materials repositories collect, process, store, and distribute biospecimens to support scientific investigation. In autism, biorepositories have been developed to support collection and dissemination of brain tissue, fibroblasts and other tissues.

a. Brain Banking:

The NIH NeuroBioBank was formed in 2013 to address the increasing demand for post-mortem human brain tissue for research purposes. Although this resource has a very broad scope, providing 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 but through outreach activities and collaborations with other organizations the collection continues to grow.

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 country (New York, Massachusetts, Texas and California) and one in Great Britain 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 past IACC strategic plans. 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.

b. 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 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 funded clinical projects proposing to collect bio-specimens 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. Whenever possible cryopreserved lymphocytes are derived from whole blood draws and later transformed into LCLs to generate a renewable resource. 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.

Key Priorities: 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.

II. Data Infrastructure

Data infrastructure refers to data collection, storage, sharing and consumption to support autism research, services and policy development. Systems to support qualitative and quantitative data need to be enhanced and expanded.

a. Data Sharing and 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 of a broad and rich view of the health and well-being of those with autism spectrum disorder and their families.

The National Database for Autism Research (NDAR) was implemented in 2008 to harmonize research data and share results for all human subjects research studies by supporting a common data definition, a de-identified research subject identifier—the NDAR GUID - and a precise method for associating research data with publications/results. Initially implemented to support data sharing for the NIH

Autism Centers of Excellence¹, beginning in 2010 NDAR was expanded to support data sharing of the NIH extramurally funded autism research data². In 2013 NDAR was rebranded as the as the NIMH Data Archive (NDA) and now supports data sharing of all human subjects research data related to mental health³. Today, research data from over 600 research projects – representing a public research investment of over \$1.4 Billion - are being shared. Overcoming limitations on restricted use datasets or the sharing of human subjects research data across international borders, the NDA through its federation technologies⁴, makes available research data funded by Autism Speaks, the Simons Foundation and the Autism Science Foundation. Investment is still needed to extend this infrastructure to better support big data analytics and to more fully integrate with the biobanks and genomics data repositories.

The Autism Sequencing Consortium (ASC) currently has whole exome sequencing (WES) data for 29,000 samples, many 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 exists for many of the samples within the ASC, managed by the contributing site

In 2016, the Simons Foundation launched SPARK to recruit, engage and retain a cohort of 50,000 individuals with autism spectrum disorder (ASD) and their family members to participate in autism research. SPARK families enroll online at www.SPARKforAutism.org, 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 research studies of autism. 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 people 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 because of 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.

Key Priorities:

Autism is a highly heterogeneous disorder requiring large sample sizes to make significant findings. 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),

¹ <https://www.nimh.nih.gov/news/science-news/2007/nih-funds-new-program-to-investigate-causes-and-treatment-of-autism.shtml>

² <https://grants.nih.gov/grants/guide/notice-files/NOT-MH-09-005.html>

³ <https://grants.nih.gov/grants/guide/notice-files/NOT-MH-15-012.html>

⁴ <https://www.nimh.nih.gov/news/science-news/2009/major-databases-link-up-to-advance-autism-research.shtml>

new methods of data acquisition (bio-tracking) and the integration of patient directed reporting applications (e.g. IAN⁵ and SPARK⁶). 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 its metadata be shared when a result is published or a significant finding is announced increasing the rigor and reproducibility of findings, a core responsibility of publicly funded research.

When all research projects share their data, its quality increases. For example, when a new subject is enrolled in a research study that very same subject may also have registered in IAN, sent samples to SPARK, or have registered for donation to the NeuroBioBank improving the information available. Data sharing has shifted from a single lab to the research enterprise. Care should be taken to ensure that all stakeholders understand its importance and that those sharing the most used and highest quality datasets be credited for their contributions.

Supporting the changing emphasis on data sharing, the NIH has established a two-tiered approach for the sharing of human subjects research data. 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 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 others are used, it automatically provides a mechanism showing data provenance, 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 our best scientists, and help accelerate research discovery in autism and related disorders. Collectively, open data sharing offers our best opportunity to reach the sample sizes that are likely needed to improve our understanding of autism and related disorders.

The autism research community has established a method for identifying the same subject across various data repositories and biobanks, called the GUID⁷. Most data repositories (NDAR, IAN, SPARK, ABCD) have standardized subject identification using this method. For the biobank repositories, its adoption has been less consistent. Compounding this problem is that most of the biobanks are consented for restricted use (e.g. a study of autism and schizophrenia require separate access) and are shared in separate repositories with different access restrictions and policies. The result being that it is often easier to request a tissue or sample, 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. Regardless of these efforts, 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, even if the data are only available as restricted use datasets (e.g. mss.ng or dbGaP) provide a publicly available manifest of subject GUIDs to files, location, and links to where the phenotypic data are located when publishing. This simple objective will allow data from the same

⁵ Interactive Autism Network (<https://www.ianresearch.org>)

⁶ Simons Spark (<https://sparkforautism.org>)

⁷ guid.nih.gov

individual to be linked across repositories, eliminate data duplication, and help minimize redundant sample and tissue requests conserving precious resources.

Several national surveys and administrative efforts collect information about people with ASD. Many of the 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)] with their own research priorities. Maximizing the utility of and spending on these national data sources necessitates synchronizing them. 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 NHIS participants who use HUD services; and 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, is a key priority in order to vastly expand the information we have on autism from a nationally representative sample.

III. Human Infrastructure

Human infrastructure refers to the development of human resources necessary to support autism research. These include developing a trained workforce to conduct research and encouraging people with autism and their family members to participate in autism research. In addition, we must develop systems to share research findings with community stakeholders and translate research findings into policy and practice.

a. Research Training and Workforce Development Efforts

While there are a number of research and workforce development efforts underway, this is an area on which the IACC should consider doubling-down. Private funding agencies such as Autism Speaks and the Autism Science Foundation support research fellowships that focus on attracting and nurturing early career investigators to pursue innovative ASD research projects that will set them on an ASD-focused career path. Great emphasis is placed on building relationships with experienced mentors and on encouraging multidisciplinary avenues of exploration. The National Institutes of Health also offer 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, a particular area of need and opportunity identified by the IACC is for trainees and early career investigators 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 representing 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 has been done for 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.

b. 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. While there has been an increase in ASD research conducted and published outside of the US and other developed countries, the report, however, also called attention to large imbalance in the number of autism researchers around the world. More attention and investment need be placed in encouraging international research collaborations. International settings can afford unique research opportunities to investigate risk factors (e.g. air pollution) and populations (e.g. genetically homogeneous) that may not be present in countries from which most of ASD research is published. Further, international research not only presents opportunities to disseminate and implement evidence-based science and services in diverse settings around the world, it also allows 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 we continue to promote international research collaboration and better support international research efforts.

c. Dissemination of Science

Mechanisms by which research is disseminated after publication should be a priority for the IACC. It is vital that findings and data become more accessible, not only to scientists, but to the public as well. 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 too often the media provides contradictory information and uses over-sensationalized headlines that confuse the public and risk disenfranchising those who are so important to 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 these types of analysis because they are based on existing data. Much of this work would be more feasible if better data-sharing infrastructure

existed, as discussed earlier. While NDAR strives to make data broadly accessible and is sound in theory, the autism research community must prioritize this resource and share all relevant data supporting reported findings. More attention must be paid to increasing the quality of data shared with NDAR and similar data-sharing efforts helping maximize the return on federal and private investment in autism research made over the last decade.

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 “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. 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, in support of global collaborative efforts, an online information repository and communication forum to promote interaction between researchers, service providers, and advocates around the world would be a welcome initiative.

Key Priority:

People with autism and their families participate in research studies at a rate much lower than stakeholders suffering from other diseases and disorders. 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.

IV. 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. In order 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. There is a pressing need for 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.

Specific Surveillance Programs

--Autism and Developmental Disabilities Monitoring (ADDM) Network

The Autism and Developmental Disabilities Monitoring, or ADDM, Network (<https://www.cdc.gov/ncbddd/autism/documents/addm-fact-sheet--comp508.pdf>) is a population-based surveillance program for autism spectrum disorder 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, and 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. 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. This nationally representative, telephone survey of children's health and development based on parent/caregiver report includes questions on whether a healthcare provider ever told the parent or caregiver that the child had an ASD as well as whether the child currently 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, the child's learning, home and family environment, and

sociodemographic factors. 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 and 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, <https://www.cdc.gov/nchs/nhis/index.htm>), 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 told 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 whether a child has been identified with ASD 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 initiative designed to help improve the precision of US ASD prevalence estimates by addressing the chief limitation of the ADDM Network approach; its reliance upon service records alone to make ASD diagnoses. 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. 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 better estimating 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.

Key Priorities

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 to furthering 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. 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.

V. Specific Objectives:

Objective 1: Biorepositories:

Banks are developed and functional but would benefit from greater coordination, and do not contain enough samples to meet demand from researchers.

- a. Develop and expand programs and outreach campaigns to encourage families to donate brain and other tissues, and to participate in autism research generally.
- b. Create incentives to encourage standardization and sample sharing across banks.

Objective 2: Data Infrastructure:

Research efforts and reliability can be improved by eliminating the barriers to repository integration, improving results reproducibility, and removing ambiguity regarding when and how data should be shared.

- a. Adopt the GUID across all research initiatives in order to reduce the likelihood of sample duplication
- b. Standardize to a common data definition, and responsibly share all the data supporting any findings when those findings are announced.

Objective 3: Human Infrastructure:

An enhanced research and services workforce and acceleration of the pipeline from research to practice are necessary to meet the urgent, growing, and diverse needs of individuals on the autism spectrum and their families.

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

Objective 4: Surveillance:

ASD surveillance systems should be complementary, offering unique strengths and contributions to furthering understanding of the population of individuals with ASD while allowing comparisons and linkages across systems as much as possible.

- a. Surveillance efforts should be expanded to the adult population to better understand needs and concerns over the lifespan.
- b. Surveillance efforts should include more descriptive data regarding co-occurring conditions, including cognitive disability, seizure disorders, anxiety and depression.

VI. Progress Toward Aspirational Goal:

Progress toward the Question 7 aspirational goal, to “develop, enhance and support infrastructure and surveillance systems that advance the speed, efficacy, and dissemination of ASD research and services” has been rapid over the past eight years. The numbers of shared samples have in some cases increased by orders of magnitude and new databases are being built to leverage new genetics findings. This increase in the availability of resources advances the efficacy and speed of ASD research. Increased support for shared resources demonstrates will continue to fuel the cycle of research speed and productivity. In addition, many government and private organizations including Simons Foundation, Autism Science Foundation, Autism Speaks, IAN, the NIH and CDC regularly share lay-audience friendly summaries of research findings to raise community awareness. Future efforts must focus on encouraging more families from diverse backgrounds to participate in ASD research, join registries and donate biological samples. The aspirational goal will be met as long as current support and momentum are maintained.

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 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.