Autism now affects 1 in 68 children and 1 in 42 boys. Autism is one of the fastest-growing developmental disorders in the U.S. Boys are nearly five times more likely than girls to have autism. One-third of young adults with autism are disconnected from work and continued education after high school.
Drexel University is proud and fortunate to have the A.J. Drexel Autism Institute on its campus. The institute was founded in 2012 and in just a few years has distinguished itself as one of the leading centers for autism research in the country. The institute has built on our Dornsife School of Public Health’s tradition of autism public health science — it is one of only a handful of university-based research groups to have earned the National Institutes of Health’s Autism Center of Excellence Award. Over time, I believe the A.J. Drexel Autism Institute will help to shape policy surrounding autism.

This is especially good news for the estimated 5 million adults in the country who are living with autism and the 1 in 68 newborns who have this disorder. That includes my nephew Jack, a teenage boy who is on the spectrum.

The A.J. Drexel Autism Institute is unique in that its main objective is to discover and implement approaches to prevent the morbidity and disability associated with autism. At the same time, the institute’s focus on population-based strategies is designed to bring more effective treatments and approaches to enable people with autism to lead healthier and more fulfilling lives.

To be sure, these are lofty goals, but the institute is off to a great start, thanks to the world-renowned team of investigators who have come from across the country to do this important work.

The team is led by Director Dr. Craig Newschaffer, a professor in the Department of Epidemiology and Biostatistics at Drexel’s Dornsife School of Public Health; Dr. Diana Robins, program area leader of the Early Detection and Intervention Research Program, and associate professor of Psychology in the College of Arts & Sciences, and Community Health & Prevention in the Dornsife School of Public Health; and Dr. Paul Shattuck, program area leader of the Life Course Outcomes Research Program and an associate professor in Health Management and Policy in the Dornsife School of Public Health. All of the researchers have distinguished themselves through their path-breaking work that is designed to better understand, diagnose and treat those on the autism spectrum.

But don’t just take my word for it. As you read through this report you will see the research team has already attracted national attention and millions in funding. After receiving initial support from Drexel and a generous gift from the Charles and Barbara Close Foundation to launch the institute, our researchers have also received a number of prestigious grants, including more than $3 million from the National Institutes of Health and an anonymous gift of $3.6 million from a generous benefactor. The institute also has an additional $2.8 million in pledged support. Four publications authored or co-authored by institute researchers were included in the top 20 most influential advances in autism research in 2015.

The institute is a jewel here at Drexel. This report details some of the exciting initiatives taking place there. I believe this is just the beginning of the many life-altering advancements to come from the institute.

Sincerely,

John A. Fry

MESSAGE FROM DREXEL’S PRESIDENT

T he A.J. Drexel Autism Institute launched as a free-standing, university-level research institute in July 2012, thanks to the support of President John A. Fry and a generous gift from the Charles and Barbara Close Foundation.

The A.J. Drexel Autism Institute is the first in the country focused on applying public health science to the societal challenges posed by autism spectrum disorder (ASD), a serious set of neurodevelopmental disabilities that fundamentally alter individuals’ abilities to interact and communicate. The institute’s focus is a major shift from most other research centers built around the pursuit of a cure. While biomedical breakthroughs are always welcome, the institute’s mission is to discover, develop, promote and disseminate population-level and community-based approaches that will prevent autism-associated morbidity and disability and improve the quality of life for individuals of all ages on the spectrum.

In a short span, the institute has quickly recruited a leading team of investigators, established staffing and infrastructure, and has implemented an accelerated program of community engagement. Equally impressive, its innovative approach to autism research has attracted more than $5 million in philanthropic support in its first four years.

In addition to the program area leaders highlighted in this first edition of the annual report, the A.J. Drexel Autism Institute has a core of dedicated junior faculty members and senior staff who have taken the lead on exciting projects of their own which will comprise the core of forthcoming reports.

Our researchers work in three research program areas:

- MODIFIABLE AUTISM RISK FACTORS
- EARLY DETECTION AND INTERVENTION
- LIFE COURSE OUTCOMES

Together, these teams are already leading the way in bringing large-scale, population-focused strategies to the autism research landscape in pursuit of the following:

- DISCOVERING PREVENTABLE CAUSES OF AUTISM SPECTRUM DISORDER.
- REDUCING THE AVERAGE AGE OF ASD DIAGNOSIS.
- OPTIMIZING THE ORGANIZATION OF ASD-RELATED SERVICES RECEIVED BY FAMILIES.
- BUILDING EVIDENCE ON THE EFFICACY OF CURRENT AND PROPOSED INTERVENTIONS.
- EDUCATING COMMUNITIES ABOUT EFFECTIVE INTERVENTIONS, ESPECIALLY AMONG THE UNDERSERVED.
- LEARNING HOW ADOLESCENTS AND YOUNG ADULTS WITH AUTISM CAN LEAD MAXIMALLY INDEPENDENT AND FULFILLING LIVES.
- SHARING SCIENTIFICALLY ACCURATE INFORMATION ABOUT AUTISM WHILE RESPECTING COMMUNITY PERSPECTIVES.
- SHAPING PUBLIC POLICY AT ALL LEVELS TO HELP IMPROVE THE LIVES OF THOSE AFFECTED.

To help meet our mission, these programs collaborate with two other groups:

- CLINICAL CORE — a team of licensed psychologists and behavior analysts with the expertise to conduct psycho-social, behavioral and neuropsychological assessments.
- OUTREACH CORE — the institute’s main connector to individuals with autism spectrum disorders, their families and caregivers, service providers and advocacy groups.

The institute also houses a POLICY ANALYSIS CENTER built to support governmental agencies charged with running public service programs assisting those on the spectrum. Examples of initiatives supported by the center include the Pennsylvania Southeast Regional Autism, Services, Education, Resources, and Training (ASERT) Collaborative, a contract with the Commonwealth of Pennsylvania and part of a State Bureau of Autism Services network supporting individuals with autism through expertise in clinical, data and policy projects, and a statewide resource center that connects individuals with autism, their families and professionals to relevant information, events and trainings, and the Philadelphia Autism Project, the first municipal effort of its kind to engage stakeholders across systems and in every corner of the city in specific initiatives that improve the lives of Philadelphians living with autism and their families.

A.J. DREXEL AUTISM INSTITUTE AUTISM RESEARCH FOR SOCIAL CHANGE

- Autism spectrum disorder (ASD) is a set of neurodevelopmental disabilities that fundamentally alter individuals’ abilities to interact and communicate. •
The EARLI study is truly groundbreaking because it is one of the few studies that focuses on the prenatal window. Even though we know that autism is heritable and that genetics are important to the cause of autism, we ultimately can’t change our genetics. We can change other factors that work with genetics to contribute to the brain changes behind autism. Since we’re studying a population that has a higher baseline genetic risk for autism, it’s easier to find these other factors.

Five years after we started the EARLI study, we have a cohort of moms and infants in place, as well as a huge, very rich biologic repository of samples. This rare collection is remarkable because there aren’t a lot of repositories like it in the world, and it gives us the ability to answer a number of research questions going forward.

—Dr. Craig Newschaffer
The Exposure Science Laboratory examines maternal or neonatal samples to detect developmentally related signals.

200 samples come through this lab on a weekly basis and approximately 20,000 tests have been completed since its inception in 2014.
Much of Dr. Diana Robins’ work centers on refining a widely used screening tool for autism spectrum disorders she developed called the Modified Checklist for Autism in Toddlers, Revised, with Follow-Up (M-CHAT-R/F). The M-CHAT-R/F tool can alert caregivers that a child may be displaying early signs of autism spectrum behavior. It is known that children with autism spectrum disorders who receive earlier diagnosis and intervention have better outcomes. However, fewer than 20 percent of the nation’s pediatricians are following all of the early detection recommendations, which call for ongoing surveillance, broad screening at three ages, and ASD screening at 18 and 24 months. This creates a challenge for identifying children on the spectrum earlier so that they can take advantage of treatments while they’re young enough to benefit the most.

Dr. Robins seeks to expand research on early detection to other community settings such as community health centers and preschools as well as to find ways to deliver interventions more quickly and efficiently to families after autism has been diagnosed. She is partnering locally, nationally and internationally with other universities to assess the complex screening and early detection needs of a range of communities. The goal of her research program is to link early screening to early diagnosis, which will lead to earlier and more effective interventions.

"As a scientist, I have seen a lot of folks who focus on basic research, where the acquisition of knowledge is itself the end. For me, it’s always been a bigger picture of what to do with this knowledge to make the world a better place. When we see families struggling to find services, or struggling to get answers about their child, and what we know in the lab doesn’t translate, I feel like we haven’t done our job yet. You want science to have real impact. One of the gaps in the field is taking kids detected through screening and getting them right into treatment studies to show that there’s a connection. That package is what will really shift the standard that’s out there in the world."

-Dr. Diana Robins
Dr. Paul Shattuck’s research seeks to understand the service needs of adults with autism, and the range of health and social outcomes they typically experience. His work explores indicators related to employment, education, services and social participation — going far beyond theory to find practical applications. This work covers largely uncharted waters in autism research.

The “life course” approach looks at the roles an individual assumes and the services systems an individual interacts with over their entire life span. The experiences of receiving a diagnosis, accessing needed services, transitioning into adulthood, finding employment, continuing education and participating in the community are all vital stepping stones on the path to a high-quality life.

Like employment, health and educational outcomes shape our understanding of where we need to improve efforts to help people on the autism spectrum. We build the gauges to see if the billions spent on research and services are moving the needle on these outcomes.

Our work is routinely used by members of Congress, business leaders, advocacy organizations, families, schools and state agency directors to know where problem-solving efforts need to be directed. Our statistics and indicators reveal the scope and magnitude of problems facing people on the autism spectrum and whether we are making progress toward improving outcomes as a nation. Community- and population-level statistics are an essential counterbalance to research that develops interventions.

It’s not enough to know whether a technique creates an effect in a tightly controlled setting. We also need to know if things are getting better or worse for the entire population.

Dr. Paul Shattuck
Little data has been collected and analyzed to date to inform public policies related to adults on the spectrum. The Life Course Outcomes team intends to change that. The team produces a “National Autism Indicators Report” series that examines large national datasets to develop baseline indicators on topics such as transitioning to adulthood and vocational rehabilitation. In 2015, the federal Interagency Autism Coordinating Committee named the team’s report one of the year’s most influential advances in autism research, out of a field of roughly 4,200 autism research publications. The 2016 report focused on Vocational Rehabilitation, a system designed to provide support to states for implementation of services to assist people with disabilities to prepare for, find and keep employment.

Building on the success of the series, Dr. Shattuck and his team are working to create a National Autism Data Center to serve as a one-of-a-kind “census bureau” of autism statistics. The National Autism Data Center will analyze information from around the country to produce meaningful statistics that policymakers can use to advocate for effective programs and services for individuals on the autism spectrum.

An analysis of life outcomes for post-high school adults with ASD

**In 2015, the federal Interagency Autism Coordinating Committee named the team’s report one of the year’s most influential advances in autism research, out of a field of roughly 4,200 autism research publications.**
$14.3M grant to Dr. Craig Newschaffer from the National Institute of Environmental Health, the National Institute of Mental Health, the National Institute of Child Health and Human Development, and the National Institute of Neurological Disorders and Stroke for the EARLI project.

$3.6M anonymous foundation grant to Dr. Paul Shattuck for the Drexel Transition Pathways Initiative project.

$3M grant to Dr. Diana Robins from the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) for her project titled, “Early Detection of Autism Spectrum Disorder.”

$910K grant to Dr. Craig Newschaffer from Autism Speaks to support a 15-month project titled, “Concluding Follow-up of Families Enrolled in the EARLI Cohort.”

$2.5M to Dr. Craig Newschaffer to work with colleagues at Florida State University on a project that is “Mobilizing Community Systems to Engage Families in Early ASD Detection and Services.”

On behalf of the faculty and staff of the A.J. Drexel Autism Institute, we would like to thank our donors and funders who have contributed to the institute since its inception. Your generosity has helped us create a one-of-a-kind public health research institute focused on advancing our knowledge of autism. We are tremendously grateful for your support.

Thank you.

We achieve great things with your support. For more information or to make a gift, please contact:

Meredith Bloom • Project Manager, Philanthropic Initiatives • 215.571.3204 • Mhb54@drexel.edu