



Drexel University

A.J. DREXEL AUTISM INSTITUTE | 2018-2019 REPORT

# IMPACT



# WHAT WE DO

The A.J. Drexel Autism Institute launched in 2012 as the first research organization dedicated to bringing a public health approach to understanding and addressing the challenges of autism spectrum disorders. The Institute's interdisciplinary team of world-class researchers explores autism's characteristics, causes and consequences in order to develop community-based action to improve the quality of life for individuals of all ages with autism. Our research is rooted in the community and involves diverse populations; the science is broad-based, with our team including epidemiologists, psychologists, environmental health scientists, sociologists, and health and education policy research specialists.

# WHO WE ARE

The Institute is structured around three research programs and one center that work together to discover avoidable causes, identify symptoms and effective interventions as early as possible, promote quality of life for those living with autism, and support the development of effective social and health policy.



## MODIFIABLE RISK FACTORS RESEARCH PROGRAM

discovers exposures or behaviors that if reduced, eliminated or changed would lessen autism spectrum disorder disability, impairment and morbidity.

**Faculty:** Dr. Kristen Lyall and Dr. Nathaniel Snyder



## EARLY DETECTION AND INTERVENTION RESEARCH PROGRAM

evaluates methods of improving screening, diagnosis and treatment to children in the community and ways to adapt existing interventions to the needs of underserved children and families.

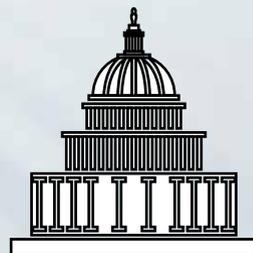
**Leader:** Dr. Diana Robins  
**Faculty:** Dr. Giacomo Vivanti



## LIFE COURSE OUTCOMES PROGRAM

improves quality of life for people on the autism spectrum and their families by informing and assessing programs, policies and support systems.

**Leader:** Dr. Paul Shattuck  
**Faculty:** Dr. Elizabeth McGhee Hassrick



## POLICY AND ANALYTICS CENTER

supports the development of effective social and health policy in cities, states, and across the United States.

**Leader:** Dr. Lindsay Shea



## Welcome

**The A.J. Drexel Autism Institute takes a public health approach to autism research: our science focuses on populations as a whole, and we bring research into the community, for immediate real-world impact.**

We study complex phenomena that often require large sample sizes followed over long periods of time and consequently, the payoff often isn't immediate. So we're excited to have the opportunity in this year's annual report to share ways our work – some of which has been more than a decade in the making – has affected individuals, communities, and entire populations, with ripples felt across the world.

Launched in 2008, the Early Autism Risk Longitudinal Investigation (EARLI) is a unique, long-term, prospective study of prenatal autism spectrum disorder risk factors and markers. The study follows hundreds of mothers who previously had a child with autism, from the start of a subsequent pregnancy through delivery, and then follows the children through age three to evaluate for autism and identify any associated environmental factors. Recently published research using EARLI data sheds light on how epigenetic changes to paternal sperm or the formation of veins and arteries in the placenta during pregnancy relate to autism risk – all part of a kaleidoscope of complex factors contributing to autism's underlying biologic causes that the Autism Institute's **Modifiable Risk Factors Research Program** investigates.

Clinicians at the Autism Institute work with Elwyn, Philadelphia's largest publicly-funded early intervention provider, to evaluate young children whose parents, pediatricians, or teachers suspect may have autism. The A.J. Drexel Autism Institute **Clinical Core** provides diagnostic evaluations to inner-city preschool children already enrolled in services at Elwyn, as soon as a few weeks to three months after initially being flagged with autism concerns – an impressive feat in an age when wait times for diagnosis can stretch to a year or longer. Early diagnosis can be key to beginning critical autism-specific interventions, such as behavioral approaches to learning. Researchers here are also working directly with parents on how they can implement interventions with children recently diagnosed with autism.

In the Philadelphia neighborhoods that Drexel is very much a part of, the **Early Detection and Intervention (EDI) Research Program** team continues to change lives every day through studies seeking to improve early autism diagnosis and treatment. Their record of early autism diagnosis has inspired parents to support Drexel's autism research and advocate for autism awareness. The EDI Program's work has crossed international boundaries as well: our screening tool has been used in more than 125 studies in 32 countries around the globe.

The Institute's **Policy and Analytics Center (PAC)** has helped the City's Philadelphia Autism Project work with local Philadelphia libraries to help make a range of autism awareness programs and autism resources available to all, regardless of language or background. To date, the PAC has also reached more than 4,000 Philadelphia police officers with trainings designed to increase their understanding of persons with autism and promote positive interactions with individuals on the autism spectrum.

Drexel's Project SEARCH, run by the Autism Institute's **Life Course Outcomes Research Program**, now in its third year, offers internships and vocational training on Drexel's campus. Students on the autism spectrum in their last year of high school in the Philadelphia School District participate to help them prepare for competitive employment after graduation. In addition to inspiring stories like one intern's first experience with employment at the Philadelphia Airport, Project SEARCH is changing the culture at host employers and creating impact that extends beyond the students who work there.

In addition to emerging as a thought leader for public health science in autism research since its launch in 2012, the Autism Institute has had tangible impact on the autism community in Philadelphia and beyond. We anticipate that our work will yield additional impact benefiting even more communities down the road. We hope you'll join us on our journey.

*Diana Robins*

*Interim Director, A.J. Drexel Autism Institute*

# Clinical Core

## Partnership with Elwyn

**Three years ago, the A.J. Drexel Autism Institute Clinical Core partnered with Elwyn, one of the oldest providers of educational and behavioral services for children with special needs,** to follow up with children who had autism concerns in multi-disciplinary evaluations. The Autism Institute doesn't directly enroll children for immediate evaluation – clinicians at the Autism Institute see children who are already enrolled in Elwyn's early intervention services. Drexel clinicians see children as soon as a few weeks to three months after their referral for an autism diagnostic assessment – almost unheard of in the world of autism diagnoses where wait times can drag on for a year or more.

Clinicians started off seeing two families a week. Now, they see eight families, using the gold standard in autism diagnostics while limiting wait time to under three months in ideal situations. Clinicians provide more than just a diagnosis - the service partnership with Elwyn has also created opportunities for research. For example, clinicians listened to parents' immediate needs, and the question that parents of children diagnosed with autism most often asked was, "What can I do when I go home today?" Parents wanted to help their children with communication, and that's where the Functional Communication Study was born. This study is the first of its kind to use video modeling and in-vivo feedback to determine if video modeling alone can help parents effectively implement autism interventions with their children.

As part of the study, parents come in weekly for twelve weeks and engage in an evidence-based protocol called Functional Communication Training that has been adapted specifically for parents. Parents learned to observe behaviors in order to help their children express their wants or needs with language, rather than other forms of communication such as tantrums. Parents also receive videos that go along with their weekly lessons. Video trainings and guidance by clinicians empower parents to implement interventions at home.

“The Functional Communication Study was an amazing experience. I met some really genuine people who cared about children and their development. The study gave me tools on how to work with my child and teach him how to talk to me when he wanted something. The most helpful thing I learned was patience.”

-Shayna Martin



ELWYN FAMILIES HAVE COME FROM:

- NORTH AMERICA**  
MEXICO
- CENTRAL AMERICA**  
GUATEMALA  
EL SALVADOR  
HONDURAS  
NICARAGUA  
COSTA RICA
- SOUTH AMERICA**  
ECUADOR  
COLOMBIA  
PERU  
BRAZIL  
VENEZUELA
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- AFRICA**  
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KENYA  
LIBERIA  
SENEGAL

## ABA Program

The Drexel University School of Education Applied Behavior Analysis (ABA) graduate program was founded and launched in 2014 under the leadership of the Autism Institute's Clinical Core Director, Dr. James Connell. The nationally accredited ABA program provides students with the knowledge and skills to design, implement, monitor, analyze, and disseminate evidence-based assessments and interventions for the treatment of symptoms associated with an autism spectrum disorder. Treatment areas include language acquisition, academic, social and functional skill development, job support and problem behavior reduction. ABA is the most effective therapy for individuals with autism spectrum disorder. Drexel students are exposed to a technology of human behavior change as they work towards an M.S. degree as well as national certification as a Board Certified Behavior Analyst.

The certification requires students to complete hands-on internships under the guidance of experienced supervisors. The A.J. Drexel Autism Institute, the program's largest placement site, hosts four to five students in the ABA program every year. Students interact directly with individuals on the autism spectrum while being supervised by the Autism Institute's behavior analysts. Drexel's ABA students have worked as assessors, interventionists, and project coordinators on many of the Autism Institute's initiatives and have supported projects within the Early Detection and Intervention and Life Course Outcomes Research Programs.



**Past students of Drexel's ABA program form an integral part of the Clinical Core team.**

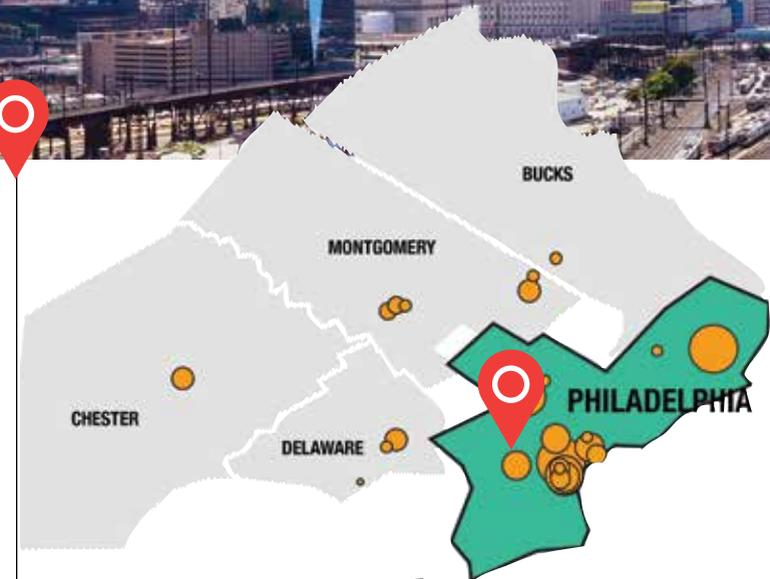
JONATHAN KOLBE

# Policy and Analytics Center



## Providing autism resources at local libraries

As one of the largest libraries in the country, the Free Library System of Philadelphia provides unparalleled access to resources and programming to diverse communities across the city. The Philadelphia Autism Project, a project of the Policy and Analytics Center, collaborates with the library system to provide people on the autism spectrum in every corner of the city with the resources they need to navigate critical systems and services, regardless of their language or background. The partnership with the library system has created and expanded programs, such as cooking classes and sensory story times. The Philadelphia Autism Project has also conducted trainings for library staff making them aware of what autism might look like in library patrons and providing pointers on ways to effectively interact with those individuals.



## Training police to be autism aware

The Philadelphia Autism Project and the Autism Services, Education, Resources, and Training Collaborative (ASERT) Eastern Region work with local police departments to train officers and first responders to ensure positive interactions with people on the autism spectrum. To date, more than 6,000 individuals have been trained, including 2,000 officers. From spreading the word about how to register an individual with autism with the local office to visiting autism support groups with canines in tow, police officers work with the Philadelphia Autism Project and ASERT to actively improve police-public interactions and the public's access to resources that can enhance law enforcement's important role when it comes to the needs of those on the autism spectrum.

# Life Course Outcomes



## A pipeline to employment for youth with autism



**Transition Pathways** explores different strategies to help young adults on the autism spectrum achieve a successful transition from high school. **Project SEARCH** is its flagship program. Dianne

Malley, who heads Transition Pathways and Project SEARCH at Drexel University, says that the goal of Project SEARCH is to have the last day of school look like the first day of the rest of your life. The program hosts a cohort of eight students in a series of internships and vocational training designed to prepare students in their last year of high school on the autism spectrum for competitive employment after graduation. The program will begin its fourth year in the fall. Of the sixteen students who completed the program in the first two years, fifteen went onto the job search with program partners and are currently employed. Project SEARCH's successes have inspired similar programming and new initiatives around the city.



**Yasom Davis** leaves his house at 6:30 am every day to spend more than an hour on trains and buses to get to his job as “warehouse extraordinaire” at the Philadelphia International Airport. Although this may sound like a typical Philadelphia commute, it’s remarkable because Davis was diagnosed with autism at age three. Research has shown that only about one-third of young adults with autism are employed the first two years after high school.

Davis was part of the first cohort of students to go through Project SEARCH at the A.J. Drexel Autism Institute at Drexel University, and is one of four interns who went on to full time employment at the airport after completing the program. Housed within the Life Course Outcomes Research Program, Project SEARCH offers vocational training and internships to young adults diagnosed with autism spectrum disorder and an intellectual disability with the goal of competitive, integrated employment. The program at Drexel is one of the first specifically for young adults on the autism spectrum.

When the Philadelphia School District contacted Davis and his mother, Latrece Nicols, to participate in Project SEARCH, she was impressed by their offerings and the success of the program in other cities.

Davis was about to enter his last year of public school before aging out of the Philadelphia School District, and he had no concrete plans for steps after high school. Project SEARCH looked like a great opportunity for him. Nicols says Davis was hesitant at first and wanted to finish his last year of high school, but became more enthusiastic about participating after talking in depth about job training and going to work. “Our motivation was to get him all of the support he can to fulfill his dream and goals,” Nicols says.

Davis – a thoughtful, soft-spoken young man – says, “If it wasn’t for Project SEARCH, I wouldn’t be working.”

Nicols says that Project SEARCH helped her son achieve full time employment and the confidence to do the job

well. “I am certain that he would not have been this open and receptive to the changes had he not gone through the Project SEARCH program first,” she says. Davis traveled on his own using public transportation for the first time during his time with the program. “That alone was liberating for him,” Nicols says.

As an intern with Project SEARCH, Davis worked at the campus Barnes & Noble, Printing and Mailing Services, and Parking Services doing things like stocking and sorting through mail. He says that though he enjoyed working at all three locations, Barnes & Noble was his favorite. He uses the stocking skills he picked up there at his current job. At the airport, his work includes helping shred paper, working the ride-on floor buffer, labeling boxes, and completing other service tasks. He enjoys being part of a team and likes his 9-5 hours.

His enthusiasm for his job is matched by his mother’s commitment to Davis ultimately flourishing as an independent adult. “I just want him to have the ability to live up to his full potential. One day, and I stress one day, I would like for Yasom to live on his own or with limited assistance,” Nicols says.

When asked what his goals are when it comes to employment, Davis says, “I’ll stay at the airport and never retire. I mean, until I retire.”



Latrece Nichols & Yasom Davis

Students enrolled in Drexel’s Transition Pathways programs

# Modifiable Risk Factors



## EARLI data unravels some of the mysteries of autism risk

The Early Autism Risk Longitudinal Investigation (EARLI) is a unique, long-term prospective study of prenatal autism spectrum disorder risk factors and markers based in the Autism Institute's Modifiable Risk Factors Research Program. Launched in 2008, the EARLI study is one of the most extensive ongoing epidemiologic studies to understand the complex causes of autism. The study follows hundreds of mothers who have previously had a child with autism, from the start of a subsequent pregnancy through delivery. Researchers have followed these children through age three to assess behaviors indicative of autism and to identify any associated environmental factors. A recent grant that makes EARLI part of the National Institutes of Health's signature Environmental Risk of Child Health Outcomes (ECHO) initiative will bring back the children for additional follow-up at older ages. Findings from the first round of analyses of EARLI data are now being published.

### IMPACT OF EARLI STUDY

#### 2008

Sept.-EARLI study receives Autism Center of Excellence grant from the National Institute of Health

Aug.-Study website [earlistudy.org](http://earlistudy.org) launched

#### 2009

Feb.-Sites launch first public awareness campaigns

Mar.-Recruitment begins

Mar.-Pre-pregnancy follow-up and enrollment begins

#### 2012

Aug.- Enrollment in EARLI ends, with 220 mothers enrolled

#### 2015

Aug.- Findings on the role paternal sperm plays in a child's autism risk published in the *International Journal of Epidemiology*

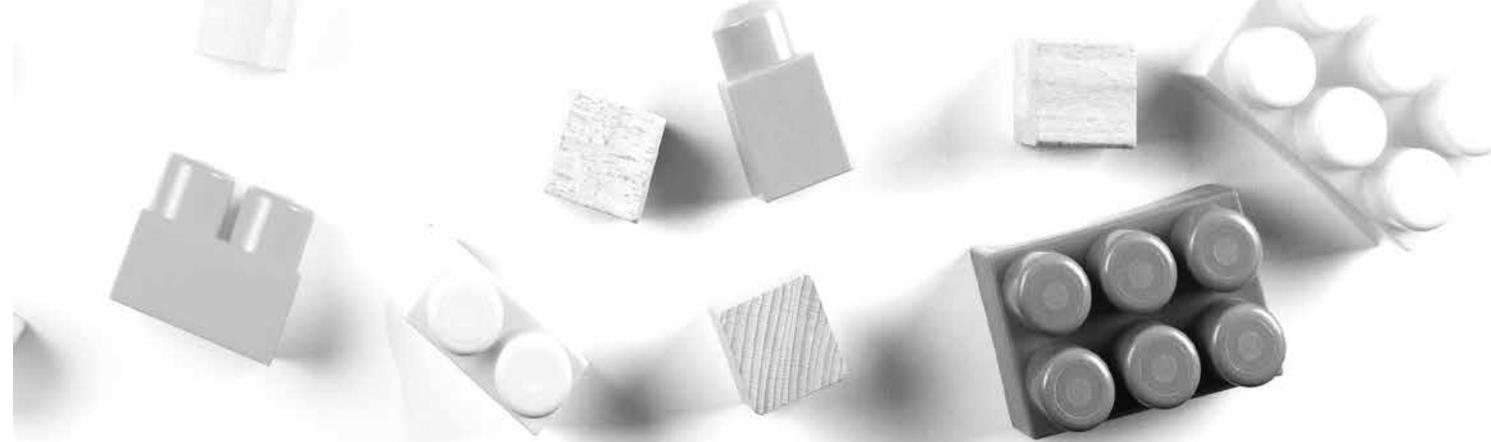
#### 2016

Sept.- EARLI and other research projects that study high autism-risk siblings collaborate under Dr. Newschaffer's leadership, to secure funding from NIH ECHO initiative to study biomarkers of environmental exposure in baby teeth and to follow up on EARLI babies at older ages.

Dec.-Study published in *Journal of Coupled Systems and Multiscale Dynamics* on differences between veins and arteries in placentas of EARLI mothers

#### 2017

Jan.- Study published in *Molecular Autism* on the role of male sex hormones on autism risk



## What a father's sperm tells us about his child's risk of autism

Can biochemical changes to the genes in a father's sperm increase the risk of autism in offspring? Researchers examined DNA methylation in semen samples from the EARLI study to learn more, and found 193 regions in paternal sperm that were associated with early signs of autism in 1-year-old offspring. Some of these regions were also associated with genes linked to Prader-Willi syndrome – a complex genetic condition with symptoms including intellectual impairment and learning disabilities. This research suggests that these biochemical changes—which are different than the sequence of the amino acids that make up our genetic code and, very importantly, can be altered by environmental influences—may indeed contribute to autism risk.

## Mapping placental veins and arteries to gauge autism risk

The placenta is the temporary organ that controls the fetal environment yet, despite this all important role, has rarely been considered in studies of neurodevelopmental disabilities. An innovative study recently looked at the vascular networks of placentas from EARLI moms and compared them with those from a general population of births. Since autism appears to start in early fetal life, the placental functioning might influence risk for early developmental processes going awry. EARLI researchers measured the placenta size, shape and depth and mapped out the thickness, length, and geometric locations of its veins and arteries. They discovered that placentas from EARLI mothers had lower transport efficiencies, which could affect the delivery of nutrients, oxygen and other molecules to the fetus, when compared to the general population. More research now needs to be done to determine if the vascular networks of placentas can be considered a biomarker of autism risk, and how they might be related to neurodevelopment of autism and other conditions.



# Early Detection and Intervention

## Making a Difference

**“For once a doctor was seeing all these concerns we saw in our daughter and agreeing with us.”**

**-Amanda Crouse**

### **Amanda and Dennis Crouse began to have concerns about their daughter, Violet, when she was five months old.**

She wouldn't look at them, even when they were nose to nose with her. They grew increasingly worried when she flapped her hands. By age one, Violet didn't speak many words or engage with other children around her.

Amanda completed the Modified Checklist for Autism in Toddlers, Revised, with Follow-Up, also known as the M-CHAT-R/F – the most commonly used survey for autism spectrum disorder (ASD) screening – in Violet's pediatrician's office. Soon after, researchers at Drexel contacted her to complete a full evaluation as part of the Early Detection Project (EDP) led by Dr. Diana Robins, the author of the M-CHAT-R/F, leader of the Early Detection and Intervention Research Program, and Interim Director at the A.J. Drexel Autism Institute.

After a comprehensive evaluation, clinicians confirmed Violet's autism diagnosis. Amanda's first reaction was relief. “My husband and I had these concerns for months and no one listened to us,” she says. “For once a doctor was seeing all these concerns we saw in our daughter and agreeing with us.”

The EDP aims to examine the optimal schedule for routine ASD screening, better integrate screening with surveillance and other strategies to detect ASD, and evaluate whether training improves screening practices in pediatric primary care. Evidence shows that if pediatric providers screen patients at 18 and

24 months and immediately refer those children who demonstrate autism risk, they can reduce the age of diagnosis reduced by two years compared to the national average; this study is testing even younger ages for universal screening. Early intervention services are key to improving outcomes in children diagnosed with autism, and often the formal diagnosis opens the door to more intensive, evidence-based ASD treatment.

Amanda recognizes the importance of the work being done at Drexel's Autism Institute, and says early diagnosis and intervention is life-changing. “If the team at Drexel never saw Violet and diagnosed her, I'm not confident we would have received a diagnosis this early from any other doctor. Because we did, we were able to get Violet started with Applied Behavior Analysis (ABA) and speech therapy,” Amanda says.

Now, Amanda is also part of the Parent Training Study at Drexel, a web-based training that teaches parents behavioral strategies to encourage communication in their child. Amanda learns evidence-based tips and techniques that she uses on a daily basis to improve Violet's communication skills – things like holding objects next to her eye to encourage eye contact.

Besides the skills she's learned, Amanda has developed a better understanding of the services Violet receives through her therapies, and is comforted that Violet isn't facing this alone.

Right after Violet's diagnosis, Amanda signed up for the 5K at the first Eagles Autism Challenge to raise money for autism research at beneficiary organizations including the A.J. Drexel Autism Institute. Her reasons for signing up were many: to support her daughter and her diagnosis, to raise money and awareness so other families had the same opportunities she had, and to give back and show support for Drexel. Not a novice racer, Amanda completed the Broad Street Run several times as well as the Rock 'n' Roll Philadelphia Half Marathon. She never thought any other race would top crossing those finish lines: “Crossing the finish line carrying my daughter at the Eagles Autism Challenge did just that. It was an overwhelmingly emotional experience,” she says.

Amanda and her husband count themselves as truly thankful and fortunate to have participated in the Early Detection Project. “Autism awareness has become our life and every day is a learning opportunity for all of us.”

# The **M-CHAT** has been referenced by over **125 studies** in **32 countries**

## How the M-CHAT changes lives

The Modified Checklist for Autism in Toddlers (M-CHAT) is the world's most widely used parent report autism risk screener for toddlers. It was developed by Dr. Diana Robins of the Autism Institute along with her colleagues, Drs. Deborah Fein and Marianne Barton. In the current version of the M-CHAT, parents answer a series of 20 yes or no questions about their child's usual behavior. A child that screens positive is further screened through a structured set of follow-up questions that determine whether or not a child should be referred for an autism evaluation and for early intervention. The M-CHAT has become a common addition to well-child visits, as it is both simple for healthcare providers to administer, and sensitive enough to help detect many children with ASD two years earlier than the national average.

TALKS THAT THE EDI TEAM (GIACOMO VIVANTI, DIANA ROBINS) HAVE GIVEN WORLDWIDE:



- Brazil
- Poland
- Italy
- Guam
- Bhutan
- Greece
- Israel
- Canada
- Austria
- Australia
- China
- Switzerland
- Hungary



- Italy
- Greece
- China
- Spain
- Chile
- Mexico
- Kazakhstan
- Portugal
- Canada

- Mexico
- Italy
- England
- Turkey
- France
- Israel
- Czech Republic
- Netherlands
- United States
- Albania
- Spain
- Serbia
- Lebanon
- Australia
- Canada
- Democratic Republic of Congo
- Belgium
- Japan
- Republic of Singapore
- Brazil
- Taiwan
- Egypt
- Sweden
- Norway
- France
- Sri Lanka
- Ireland
- Korea
- Thailand
- Malaysia
- China
- India



Thank you to all who participated in the Eagles Autism Challenge on May 18th at Lincoln Financial Field. In its second year, the Eagles Autism Challenge had 3,600 participants and raised over \$3.5 million for autism research at the A.J. Drexel Autism Institute, Jefferson, and CHOP. Thank you for your support and participation!



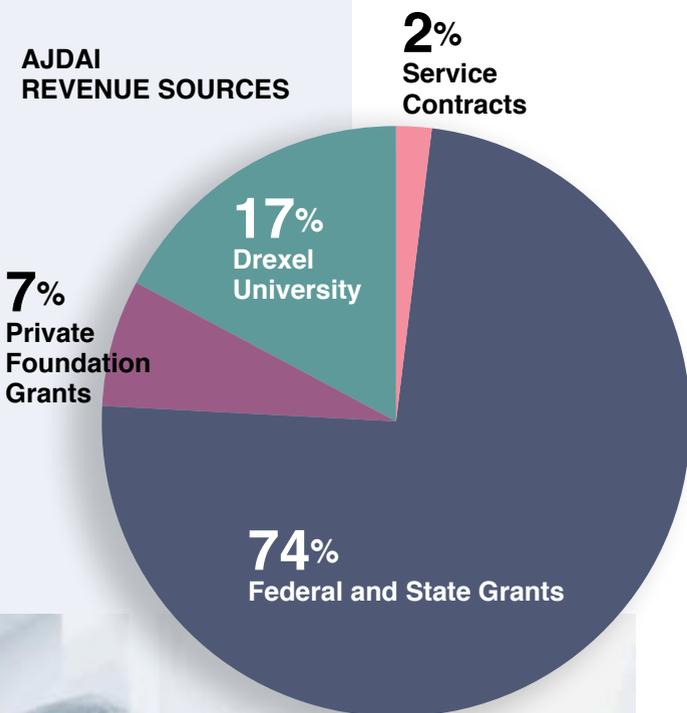
[eaglesautismchallenge.org](http://eaglesautismchallenge.org)



# Fundraising

## Grant Highlights

THE A.J. DREXEL AUTISM INSTITUTE WAS AWARDED THESE GRANTS IN FISCAL YEAR 2018.



**\$11.4M** awarded to Dr. Diana Robins as part of the National Institute of Mental Health's Autism Center of Excellence to determine if screening lowers the average age of ASD diagnosis, leads to earlier interventions, and improves outcomes.

**\$2.5M** awarded to Dr. Paul Shattuck from the Health Resource & Services Administration for the Autism Transitions Research Project.

**\$1.1M** awarded to Dr. Craig Newschaffer by the National Institute of Environmental Health Sciences to study prenatal exposures that disrupt the endocrine system and may affect brain development.

**\$430k** awarded to Dr. Giacomo Vivanti by the National Institutes of Health to improve the determination of which interventions would have the greatest likelihood of success for children with autism.

## Thank you to supporters

On behalf of the faculty and staff of the A.J. Drexel Autism Institute, we would like to thank our donors for their continued philanthropic support. It's your generosity that allows us to advance groundbreaking research that serves the community at large. Your support allows our team of scientists, researchers and clinicians to work towards changing the face of autism every day.

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Thank you to our sponsors and attendees for making our second annual benefit concert a success! We hope to see you at this year's concert on October 12, 2019 at **World Café Live.**

*If you wish to discuss support for the A.J. Drexel Autism Institute, please contact:*

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[drexel.edu/autisminstitute/contact/giving-opportunities/](http://drexel.edu/autisminstitute/contact/giving-opportunities/)

## GIVING OPPORTUNITIES



### AUTISM INSTITUTE RESEARCH FUND

Gifts to the Research Fund will be used to fund pilot research projects that Institute investigators typically need to conduct before they can compete for federal or foundation grants. Preliminary results are often a required component of grant applications. This fund will also be used to support unanticipated research expenses that emerge during the course of completing studies.



### PUBLIC HEALTH LECTURE SERIES

Our Public Health Lecture is an annual event that is open to the public. With support of this program, your gifts could help to strengthen and grow this series which serves as a cornerstone of our community outreach. This series could be enhanced by it occurring more than once a year, by attracting the most influential and engaging speakers, and by addressing topical issues which families and communities members are most affected by.



### AUTISM EDUCATION AND OUTREACH FUND

Contributions to the Autism Education and Outreach Fund help to support the education of community members to aid them in their learning of ASD and ways to best guide those on spectrum. Learning centers, day cares, schools and community centers may not have the financial means to receive a formal training however with support of this fund, it will provide the means for those institutions in order to train their caregivers and families on best practices regarding ASD.



### DREXEL AUTISM SUPPORT PROGRAM (DASP) SCHOLARSHIP AWARD

The Drexel Autism Support Program is a student-centered program for current Drexel students with the goal of promoting academic competency, self-advocacy, interpersonal skills, independent living and social integration. Gifts to this fund support deserving undergraduate students participating in DASP as they pursue their Drexel education.



### TRANSITION PATHWAYS

Contribute to our efforts to support young adults to transition to meaningful careers and reach their full potential.



### AUTISM INSTITUTE GIFT FUND

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