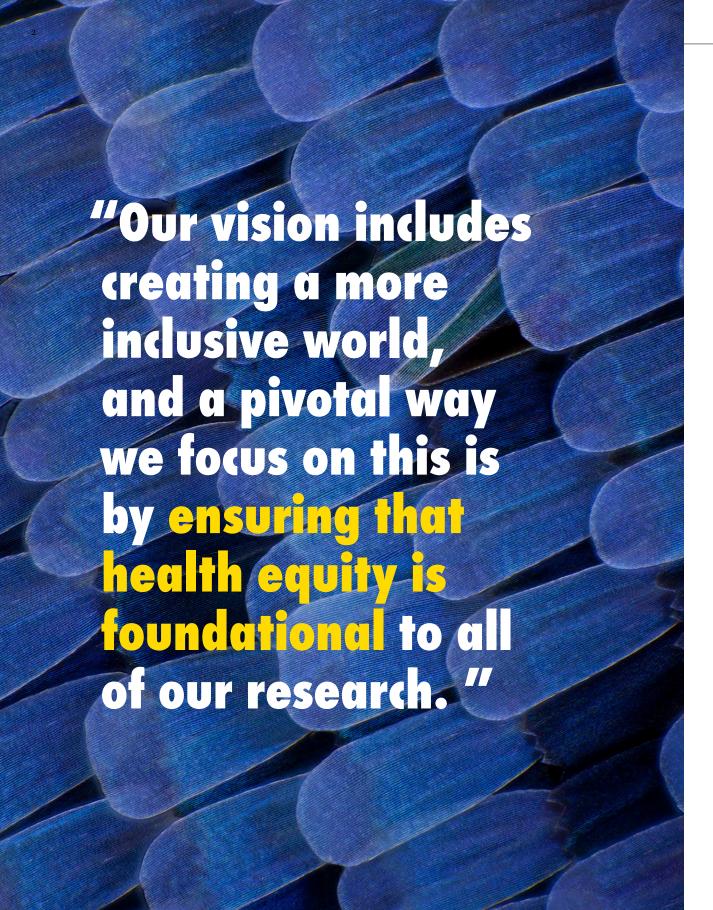


A.J. DREXEL AUTISM INSTITUTE 2023 IMPACT REPORT 1





Diana Robins
DIRECTOR, A.J. DREXEL
AUTISM INSTITUTE

I am honored to present the 2023 Impact Report for the A.J. Drexel Autism Institute. This year, we continued our mission to advance research to better understand autism and drive impactful change in our communities and worldwide. Our vision includes creating a more inclusive world, and a pivotal way we focus on this is by ensuring that health equity is foundational to all of our research.

Our dedicated researchers and professionals work tirelessly to improve the lives of autistic individuals and their loved ones. As a result, last fall we received a 5-year, \$10 million Autism Centers of Excellence (ACE) award from the National Institutes of Health that will help us understand and reduce barriers to good health and healthcare access for people on the autism spectrum. The "Public Health and Autism Science advancing Equitable Strategies across the life course" (PHASES) project will look at health inequity, health determinants, and health services delivery using a public health research framework.

We recognize that autistic people who come from minoritized and economically disadvantaged backgrounds often face additional challenges in accessing quality healthcare, which can significantly negatively impact their overall health and wellbeing. We also are keenly aware that current autism researchers are far less diverse. To be more accessible to participants, it is crucial that we actively contribute to diversifying the next generation of scientists. In 2021, we launched the Summer Scholars program to encourage undergraduate students from underrecognized backgrounds to join us for an immersive research experience. Scholars received holistic exposure to autism research by spending time with multiple areas in our institute and working intensively with 1-2 primary mentors on specific projects. Another way we engage in education is by offering training to the community. Our clinical core has trained more than 700 professionals on ADOS-2 globally, making autism evaluations more accessible worldwide. These professionals came from 17 different countries and across the U.S.

Community engagement is one of the core tenets of our institute. This focus allows researchers to work with and learn from community members, including those traditionally underrecognized in research. Our Fathers' Support Group is now in its fourth year, and the men report valuing the time they spend together. Creating more space for those with lived experience to share their perspectives was the objective of the 2022 Policy Impact Power Lunch webinars. These webinars highlight and feature autistic researchers and self-advocates and focus on policy-related topics. The Drexel Business Inclusion Center, a program operated by Transition Pathways, worked on assisting organizations work towards a more inclusive workforce.

I am proud to report that our team made significant progress toward achieving our goals this year. However, there is still work to do to ensure that every individual with autism has access to the care and support they need to reach their full potential. We remain committed to advancing autism research and promoting health equity for all, and we thank you for your continued support.



2 POLICY IMPACT PROJECT A.J. DREXEL AUTISM INSTITUTE 2023 IMPACT REPORT 3

Launched in August 2021, the Policy Impact Project, led by Dr. Kaitlin Koffer Miller and Anne Roux. MPH, MA, is the latest venture of the Policy, Analytics, and Community research program, led by Dr. Lindsay Shea. The project was created to respond to the urgent need for policy changes that improve the lives of autistic people and their families in the U.S. A profound disconnect exists between the worlds of research and policy. By utilizing research findings to drive systems-level policy solutions, the Policy Impact Project is paving the way for a brighter future for neurodiverse

Bridging
the Gap

How the **Policy Impact Project** translates research into policy action

individuals and making it possible to generate more translation of research into actionable policy. The project works to achieve this by building the infrastructure needed to highlight research findings that can inform policies and decisions that affect the lives of neurodiverse individuals.

One pillar of this project is community engagement. Productive relationships between communities, including those with lived experience, and institutions are necessary to create a forum for multiple voices to be heard, and build more equitable policies. Building more space for those with lived experience to share their perspectives was the objective of the 2022 Power Lunch webinars. These webinars featured autistic researchers and self-advocates sharing their thoughts on vital policy-related topics. Alongside highlighting lived experiences, the project has been conducting

research on policy-relevant issues

research on policy-relevant issues and helping others identify policy recommendations tied to their research. The award-winning National Autism Indicators Reports have a long history of influencing government reports and federal grant applications. The Policy Impact Project believes that data visualization and user-friendly, understandable explanations of complex topics create impact by delivering helpful information to decision-makers.

Generating usable and accessible information from research helps this group target equity through data democratization. Increasing the amount of understandable data for



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"The project is helping to create a more equitable and inclusive society."

autistic individuals and those who

are allies is a crucial element in ensuring health equity. The project often focuses on understanding and improving the safety net programs and benefits on which autistic people and their families rely. This focus on public systems is critical to bolstering equity. According to our report on family financial hardship, one in three children on the autism spectrum lives in very low-income households and may qualify for public benefits. This rate is higher than children with and without other special health needs. The number of autistic people enrolled in Medicaid more than tripled between 2008 and 2016. This research helps communicate the importance of public programs for autistic people and provides statistics to guide public policy. By providing data-driven research and policy solutions, the Policy Impact Project is making a real difference in the lives of autistic people and their families. Through its work, the project is helping to create a more equitable and inclusive society that recognizes the strengths and abilities of neurodiverse individuals and provides them with the necessary supports and services they need to thrive.

AJDAI Leadership Council

The AJ Drexel Autism Institute (AJDAI) leadership council has 17 members and was created to deepen and broaden the Institute's public health impact and promote the excellence of the work and research done here. Council members accomplish this by being actively engaged in the community. Members bring to the Institute what they are seeing and hearing in their various communities, highlighting gaps in services, research needs, and areas of opportunity where the Institute might be able to make a difference. Members also bring the research findings back to their communities, helping implement policy changes and services shown to be effective by the research generated at the Institute.

At AJDAI, commitment to equity shines through this amazing group of individuals. The leadership council includes stakeholders representing diverse racial and ethnic communities, educational and professional backgrounds, and connections to autism, including autistic self-advocates and family members of people on the autism spectrum. The Autism Institute welcomes all voices and encourages them to feel empowered to speak about their experiences.

Leadership Council with President Fry at the Institute's 10 year anniversary celebration



4 AUTISM CENTERS OF EXCELLENCE AWARD 2023 IMPACT REPORT 5





Public Health and Autism Science advancing Equitable Strategies across the life course

The Autism Institute was awarded a 5-year, \$10 million Autism Centers of Excellence (ACE) award from the National Institutes of Health to identify and address barriers to positive health outcomes and health services use for people on the autism spectrum, led by Diana Robins, PhD, director of the Autism Institute, and Diana Schendel, PhD, professor and leader of the Modifiable Factors in Autism research program in the Autism Institute. The project titled "Public Health and Autism Science advancing Equitable Strategies across the life course" (PHASES) will employ a public health research framework to examine health determinants, health services delivery and health inequity especially in under-represented diverse populations — and the impact of these forces on autistic people's health outcomes.

Compared to non-autistic youth, autistic youth are more likely to have co-occurring mental and physical health conditions. We know that social and economic status, race, ethnicity, and sex affect the health of young autistic



Philadelphia
institution
and one of two in
Pennsylvania to
receive the Autism
Centers of Excellence

grant in 2022.

individuals. The researchers will study these issues in people on the autism spectrum during three key life course stages. Robins will lead early detection and diagnosis in toddlers. Patterns of co-occurring health conditions and health services use in adolescence and young adulthood will be led by Schendel. Finally, Lindsay Shea, DrPH, leader of the Policy, Analytics and Community research program in the Autism Institute, will lead mental and physical health in older adulthood.

For example, in one project, researchers will examine Medicaid health data on 1.5 million autistic and neurotypical individuals, ages

Researchers will study key issues in people on the autism spectrum during three key life course stages:

PROJECT

AT A GLANCE



Early detection and diagnosis in **toddlers**.



Patterns of co-occurring health conditions and health services use in adolescence and young adulthood.



Mental and physical health in older adulthood.

10-24 years, over a five-year span to uncover health and health services patterns that make a difference in long-term well-being. Understanding the patterns of health services use over time can better support the management of autistic young persons' health conditions as they age. Co-leads Robins and Schendel noted that this research is novel in that it focuses on examining services and working with underserved populations to generate actionable strategies to improve public health.

Jennifer Plumb, DSW, outreach core director at the Autism Institute, and Elisabeth Sheriden, PhD, clinical core director of the Autism Institute, will lead the dissemination and outreach work. They will facilitate engagement with diverse stakeholders, support training opportunities, and expand the Autism Institute's existing activities to emphasize two-way communication between the research team and the community. Led by co-investigator Elizabeth McGhee Hassrick, associate professor in the Life Course Outcomes research program, PHASES will use community-partnered participatory research across the projects to promote stakeholder engagement.

Drexel is the only Philadelphia institution and one of two in Pennsylvania to receive an ACE grant. This ACE grant is Drexel's third – making it one of only five universities to receive more than one of these awards. PHASES will address preventable adverse outcomes and promote wellbeing in autistic individuals.

6 SUMMER SCHOLARS A.J. DREXEL AUTISM INSTITUTE 2023 IMPACT REPORT 7

"I witnessed firsthand the work it takes to perform honest and ethical research."

Undergraduates Engage in Innovative Autism Research through the **Scholars Program**



Nate Medina



Melissa Rivera

The A.J. Drexel Autism Institute Summer Scholars Program aims to provide talented undergraduate students from diverse ethnic. cultural, socio-economic, and neurodiverse backgrounds with the opportunity to immerse in rich and innovative mentored research experiences in autism with a focus on public health community impact. According to the CDC, autism is similarly prevalent among people of all races. However, the field of autism research is far less diverse. Having a diverse health research workforce allows the research to be more equitable and respectful to the community it serves.

22
applicants

finalists

2 scholars The Summer Scholars
program started in 2021 and
hosted two scholars, Maya Shanker
and Kayleigh Ostberg. Maya came
to the program from Rutgers
University and Kayleigh came from
Rowan University. The inaugural
Summer Scholars were supported
by the Director's Fund.

In its second year, the program was supported by a gift from Quadrant Biosciences. The Autism Institute had a competitive pool of 22 applicants. Melissa Rivera and Nate Medina were chosen for the program and came to the institute from Jefferson University. Melissa spent her summer with the

Life Course Outcomes program, and Nate spent his time with the Modifiable Factors in Autism program. The students also spent time with the Early Detection and Intervention Program and the Clinical Core.

Spending time in multiple areas of the Autism Institute allowed the faculty and staff to provide a holistic experience of autism research for the students' training. In addition, this model offered many opportunities for staff and other student volunteers to join and learn along with the Summer Scholars, which enriched the experience for everyone. The Autism Institute plans to implement this model in future years.

When asked about her

summer scholar experience, Melissa said, "I had the privilege of interning with Dr. Hassrick and her team at the Social Dynamics of Intervention Lab as a summer scholar. I witnessed firsthand the work it takes to perform honest and ethical research. The greatest takeaway for me was that the data would speak for itself. It will reveal where the strengths and weaknesses are, and you have to be ready for it to challenge your own biases or hypothesis. Still. well-done research's value is in how we are inspired to respond to what the data has revealed." The program is currently in its third year and has grown to five scholars, Bineta Brooks, Donald Pressley, Lauren Hino, Rachel Guloy, and Olivia McMullen, thanks to funding from Quadrant Biosciences, the PHASES grant from the Eunice Kennedy Shriver National Institute of Child Health and Human Development, and additional funding supplied by faculty members.

Fathers Support Group

The support group for fathers of autistic people, sponsored by the A.J. Drexel Autism Institute and co-facilitated by Dr. Robert Naseef and Dr. Michael Hannon, is now in its fourth year. The support group was created in response to the need for more resources for fathers of autistic people. Initially, the group began as an in-person initiative in the fall of 2019. The group now continues virtually every month. Since the start of the group, fathers have found comfort in connecting with other fathers who are also navigating similar experiences. In addition, the men report feeling seen, heard, and validated in ways they have not for the entirety of their autism journeys, which is especially helpful given the racial/ethnic, linguistic, spiritual, and neurodiversity of the fathers.

Group counseling can be a powerful tool for promoting health equity by creating a safe, supportive space for members to come together and discuss their shared experiences. Building on community and connection, group counseling can help members to feel less alone. Another benefit of group counseling is that it can be a vehicle for reducing health disparities and creating a more equitable society. The opportunity to engage with each other monthly has become a protective factor for the fathers' mental wellness and continues to support their growth, development, and insight.



Since the start of the group, fathers have found comfort in connecting with other fathers who are also navigating similar experiences.





The Autism Institute has founded a

jointly sponsored autism assessment training program, in collaboration with The Children's Hospital of Philadelphia's Center for Autism Research (CAR), which provides virtual training on the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2). The ADOS-2 is an observational assessment used to aid in the assessment and diagnosis of autism across ages, developmental levels, and language skills. This introductory workshop is designed for clinicians and researchers with some prior background in autism and assessment, including psychologists, physicians, speech-language pathologists, occupational therapists, and other specialists.

The ADOS-2 training program is led by Dr. Elisabeth Sheridan, an Associate Professor and the Director of the Clinical Core at the Autism Institute, and Dr. Whitney Guthrie, an Assistant Professor of Psychiatry and scientist in the CAR program, and an author of the ADOS-2 Toddler Module. The 2-day (Clinical Training) and 3-day (Clinical + Toddler Module) workshops incorporate lectures, videos, demonstrations of administration and coding, and discussions on best practices to equip learners with a fundamental understanding of the ADOS-2 and autism assessment.

This virtual training has had a global impact, training over 700 individuals from all over the United States, including all 50 states, and from 17 countries around the world. The program has grown exponentially since its initial offering in 2021, with an over 200% increase



700

Number of participants trained to date, from 17 countries and all 50 states in the U.S.

in individuals trained in 2022. When asked about the value of the workshop, attendees mentioned appreciation for the presenter's knowledge of the ADOS-2 and their ability to explain the nuances to attendees from a wide range of professional backgrounds. In addition, participants noted that the training is thoughtfully designed and appreciated the speakers' ability to answer attendees' detailed questions. Other feedback has highlighted the impact of these trainings in the community, with one participant saying, "Thank you so much for making autism evaluations more accessible for clinicians in the community and the families that we serve." This program will continue to train clinicians and have a global impact in the coming year.

10 INCLUSIVE HIRING A.J. DREXEL AUTISM INSTITUTE 2023 IMPACT REPORT 11

Best Practices and Strategies to Meet Inclusive Hiring Goals

There is a talent pipeline of individuals with a disability that are looking for a good, well-paying, full-time job with an opportunity for advancement. However, businesses around the country need help to fill their workforce needs. Our team has identified a solution to meet business needs while accelerating inclusive hiring. The Drexel Business Inclusion Center (Drexel BIC) has identified a set of best practices that should be considered when developing a strategy to hire individuals and meet their corporate goals.

- Partner with community organizations.
 Working collaboratively with community organizations allows employers to find individuals that may not be reached through traditional efforts.
- Include disability in Diversity, Equity, and Inclusion (DEI) efforts. DEI efforts that have substance help increase the level and support for diverse individuals working for your organization.
- Adopt and use metrics. To ensure your company's efforts to hire individuals with disabilities are working you must have metrics in place.
- Provide organizational training to promote a culture of inclusion. Training is a way to ensure organizations develop an inclusive environment where all employees can succeed and thrive.
- Empower workers with disabilities within the organization. Employee resource groups (ERGs) are an effective way to empower workers and allow them to offer suggestions to improve the company culture and operations, including developing innovative ideas to help the company meet its goals.

- Support competitive integrated employment. Create opportunities for individuals with disabilities to work alongside their non-disabled peers, for the same wage, as a direct employee with an opportunity to advance their skills and rise within the organization.
- Recognize that workers with disabilities are varied and diverse, like everyone else. Corporations should consider opportunities at all levels of their organization, not just entry level. Individuals with a disability represent a range of talents, skill sets, and experience and should not be categorically ruled out from management and leadership opportunities.
- Muild onramps for candidates with disabilities to ensure equal access to jobs. Corporations can and should even the playing field for a talent pipeline in numerous ways. For example, hire an Inclusion Specialist who works across departments to recruit employees and provide support for making recruitment and onboarding processes more inclusive.

- Make interviewing and onboarding processes more inclusive. One solution would be for corporations to offer working interviews where candidates are invited to perform tasks, so the employer can evaluate them based on their performance to directly evaluate job skills. Other strategies include adjusting processes to reduce the barriers to successfully onboarding after getting a job offer.
- Build natural supports. Mentorship programs, clear identification of unwritten rules (or expected behavior) of the workplace, transparent and effective communication in a variety of modalities to support diverse learning styles, toolkits for supervisors to effectively do their jobs with employees under those diverse learning styles, and the use of universal design principles are examples of natural supports.
- Provide accommodations. Ensure your organization has a straightforward process and that employees are aware and supported throughout any accommodation request.

The above best practices are based on our experience at the Drexel Business Inclusion Center, a program operated by Transition Pathways of the A.J. Drexel Autism Institute in collaboration with Community Integrated Services. Together, we have a team of experts with decades of experience that knows how to provide solutions and eliminate roadblocks for organizations seeking to access the talent pipeline of individuals looking for real, substantive job opportunities. For those seeking solutions, partners like the Drexel BIC are standing by, ready to help.

This article was written by Dianne Malley and Susan Schonfeld who are Senior Consultants at the Drexel Business Inclusion Center, which has engaged more than 250 businesses and trained more than 1300 professionals. Learn more at bit.ly/DrexelBIC



Jamil Osbourne
From Intern to Employee

Jamil Osbourne, is a former Project Career Launch (PCL) participant, one of the job readiness programs run in the Transition Pathways program. Jamil landed a full time job at Tuck-ins thanks to the skills and work ethic he strengthened during the program. He takes pride in his contribution to creating innovative and delectable Inside Out Smores. Jamil began his journey with Tuck-ins as an intern in 2021, graduated from PCL in 2022, and began working at Tuck-ins in December 2022.

Through PCL, Jamil received valuable guidance in various areas, such as resume writing, professionalism, and communication, which prepared him well for his current role at Tuck-ins. Dan Zeplowitz, the owner of Tuck-ins, graduated from Drexel in 2016 and finds the partnership with PCL rewarding. Dan values his employees and is proud to provide employment opportunities to individuals who may have a disability or find it challenging to secure a job. He believes everyone should be given a chance and understands that anyone can succeed with proper support.

Jamil was given the opportunity to thrive thanks to PCL and Tuck-ins. Jamil's story exemplifies how hard work and determination can lead to success and the role that support and guidance can play in helping individuals achieve their goals. Jamil advises those on the spectrum to chase after what they want and not let others limit them. He encourages those on the spectrum facing the job market's challenges to seek PCL assistance to prepare for their careers.

We extend our heartfelt gratitude to our incredible funders, contributors, and partners whose unwavering commitment and generosity have been the driving force behind our success. Your belief in our mission has made a profound impact, and we are deeply thankful for your continued support.

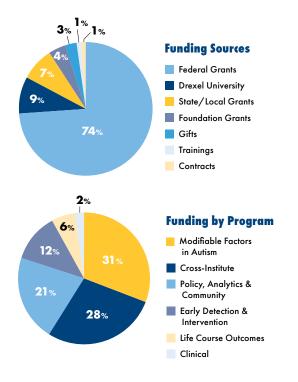
FY23 Grant Highlights

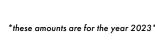
awarded to Diana Robins and Diana
Schendel by the National Institutes of
Health for Public Health and Autism Science advancing
Equitable Strategies across the lifespan

\$690 K awarded to Diana Robins by the National Institutes of Health for Sensitivity of Toddler Screening: Integrating Concurrent and Prospective Strategies to Detect ASD

combined awarded to **Kristen Lyall** by the National Institutes of Health in two areas of study: An ASD Enriched Risk (ASD-ER) ECHO Cohort (UH3 Phase) and Examining Dietary Modifiers of Associations Between Air Pollution and Autism-Related Outcomes in Two Cohorts

awarded to **Lindsay Shea** by the Health Resources and Services Administration for the Autism Transitions Research Project (ATRP)











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