Maryland Center for Developmental Disabilities at Kennedy Krieger Institute

ANNUAL REPORT

Fiscal Year 2024 (July 1, 2023 – June 30, 2024)



Our mission is to provide leadership that advances inclusion for people with intellectual, developmental and other disabilities. Kennedy Krieger

Maryland Center for Developmental Disabilities

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Dear Friends and Colleagues,

It is my pleasure to share the annual report of the Maryland Center for Developmental Disabilities (MCDD) at Kennedy Krieger Institute for fiscal year 2024, the second year of the five-year funding cycle (2022–2027) for our core grant from the Administration for Community Living.

This fiscal year, the MCDD welcomed new staff members and trainees, and expanded its programs and projects through new funding sources. The MCDD received a grant from the Maryland State Department of Education's Division of Early Intervention/Special Education Services to partner with Wicomico County Public Schools and the Judy Center Early Learning Hub. Through the partnership, the MCDD, the Judy Center and the school system created a model for inclusive service delivery options by offering early childhood educators innovative opportunities to learn about inclusive practices, thereby building educators' capacity to include children with developmental delays and disabilities in general education classrooms. The MCDD also received a WITH Foundation grant to expand Project HEAL's (Health, Education, Advocacy, and Law) advocacy and civil legal services regarding alternatives to guardianship, Supplemental Security Income and Social Security Disability Insurance.

The MCDD and the Institute's Leadership Education in Neurodevelopmental and Other Related Disabilities (LEND) program; Office for Health, Equity, Inclusion, and Diversity (O-HEID); and government relations department implemented the second year of their advocacy curriculum for staff members and trainees, offering one-hour training sessions from September through April on a variety of advocacy-related topics. The MCDD, LEND and the Institute's Center for Diversity in Public Health Leadership Training also sponsored 64 staff members, trainees and self-advocates to attend Maryland's Developmental Disabilities (DD) Day at the Legislature. Participants attended the formal DD Day event at the Graduate by Hilton Annapolis hotel, met with 14 elected officials and participated in a lunch-and-learn session with speakers from People On the Go (POG), the Maryland Department of Disabilities and the Association of University Centers on Disabilities (AUCD).

Thank you for your ongoing support for our important work.

In gratitude,

Maureen van Stone, Esq., MS Assistant Vice President and MCDD Director

The MCDD at Kennedy Krieger Institute serves as Maryland's University Center for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD). The MCDD is one of the oldest UCEDDs in the nation and is part of the AUCD network.

The MCDD aims to improve the lives of people with disabilities through four core functions: interdisciplinary pre-service preparation, continuing education and training; community services and technical assistance; research and evaluation; and product development and information dissemination.

The MCDD is funded by the U.S. Administration on Intellectual and Developmental Disabilities.

Interdisciplinary Pre-Service Preparation, Continuing Education and Training

The MCDD **partners with local and state agencies**, **people with disabilities and their families, and healthcare professionals** to provide training across a broad spectrum of topics to improve the quality of life of people with disabilities and their families.

The MCDD, including Project HEAL, offered 155 training sessions to Kennedy Krieger staff members and trainees, people with disabilities and their families, and members of the community. Of those attending, 99% reported satisfaction with the training they received.

A diverse group of **20 trainees from eight institutions** of higher education participated in the MCDD's training program. The trainees represented six disciplines; most were studying law or public health. The MCDD hosted two interns from Project SEARCH at Kennedy Krieger Institute. They completed one internship round each with Project HEAL and the MCDD's Resource Finder, and POG offered eight Project STIR[™] (Steps Toward Independence and Responsibility) training sessions to 170 self-advocates.

Trainee Disciplines



- 8 Law
- 1 Health Science
- 1 Political Science
 - 1 Bioethics
- 1 Neuropsychology

"This experience has allowed me to grow in my cultural competence and my knowledge of developmental disabilities. I gained experience and an appreciation for how to conduct a literature review and its critical role in the development of interventions. Dr. Ofonedu shared so much knowledge and was always available despite her very demanding schedule. I learned from our conversations, and I could not have asked for a better supervisor or training experience." Community Services and Technical Assistance

Project HEAL provides **advocacy and civil legal services** for children with intellectual and developmental disabilities who are patients at Kennedy Krieger Institute and their families.

Project HEAL staff members **provided representation to 76 families, limited representation to 787 individuals, and 306 case consultations** for Kennedy Krieger staff members and trainees.

Representatives from POG, a statewide self-advocacy group run for and by people with intellectual and developmental disabilities, delivered 29 presentations and attended seven conferences. POG continuously recruits a diverse group of members and has a total **membership of over 500 individuals from across Maryland**.

During the **2024 Maryland General Assembly** session, the MCDD, Project HEAL and POG provided oral or written testimony for, or signed onto, **53 pieces of proposed legislation** that would affect individuals with disabilities across the lifespan.

Legislative Advocacy

The MCDD tracked 130 pieces of legislation during the 90-day legislative session.

MCDD testified on 4 bills

Project HEAL testified on 35 bills

POG testified on 14 bills

"Thank you for everything you did for my child and the support you gave to me. She is doing fantastic. I cannot thank you enough for being our voice when no one would listen."

– Project HEAL parent from Harford County, Md.

– Trainee



The MCDD works closely with state agencies and organizations, including:

Disability Rights Maryland Johns Hopkins University Disability Health Research Center Maryland Department of Disabilities

Maryland Developmental Disabilities Administration (DDA) Maryland Developmental Disabilities Council (DD Council)

Maryland State Department of Education (MSDE)

Research and Evaluation

Expanding the Public Health Workforce: Our goal is to improve care for the disability community by educating public health professionals, educators and students within the disability and aging networks about challenges brought on by the pandemic.

National Center for Disability, Equity, and

Intersectionality: As part of a national collaborative effort, our goal is to lead the nation's charge to identify and reduce life-limiting inequities in healthcare, community living and justice for people with disabilities, targeting ableism and racism with an intersectional lens.

Our Autism Research and Engagement Core

demonstrates experience and expertise in autism research, community engagement and communicating science to the public. The team published four peer-reviewed journal articles, plus 24 articles and research study summary reports for the SPARK website.

The National Center for Disability, Equity, and Intersectionality:



Product Development and Information Dissemination

Our **Resource Finder** informs individuals, families, trainees and professionals about community services, service providers and other information on intellectual, developmental and other disabilities across the lifespan.

The Resource Finder **responded to 1,316 inquiries**, **helping individuals from 32 states and Washington**, **D.C., and one country outside the U.S**. Of those seeking information from the Resource Finder, **93% reported satisfaction** with the information they received.

The MCDD **hosted 27 resource fair exhibitor tables**, disseminating fact sheets and brochures in English and Spanish.

MCDD staff members **published two peer-reviewed journal articles**.

Top 5 topics about which information was requested:



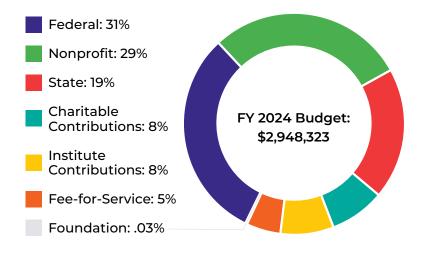
The MCDD's Community Advisory Council (CAC) includes two individuals with disabilities, five family members of people with disabilities, two direct-support professionals and eight members of eight Maryland agencies that provide services and supports for the disability community. The CAC meets in person on a quarterly basis to provide guidance and support for MCDD programs and projects.

| CAC Members | Agency or Role |
|--------------------------|--|
| Rene Averitt-Sanzone, MS | The Parents' Place of Maryland |
| Carol Beatty, MS | Maryland Department of Disabilities |
| Beth Benevides | Hussman Foundation |
| Carmen Brown, LCSW-C | Maryland State Department of Education |
| Meeka Caldwell | Family Member |
| Stephanie Dolamore, DPA | Maryland Developmental Disabilities Council |
| Marianne Doremus | Family Member |
| Justine Duffy | Family Member |
| Triniece Gillom | Self-Advocate |
| Tami Goldsmith | Direct Support Professional |
| Marlana Hutchinson, MBA | Maryland Developmental Disabilities Administration |
| Katherine Jones, EdD | Bay Area Center for Independent Living |
| Rebecca Little, MEd | Direct Support Professional |
| Hunter McIntyre, Esq. | Family Member |
| Matthew Plantz | Self-Advocate |
| Audrey Sellers | Disability Rights Maryland |
| James Williams, Jr. | Family Member |

The MCDD leveraged \$2,948,323 in grants, contracts, charitable contributions, fees for service and Institute funds. New funding in fiscal year 2024 included:

- •\$357,268 in new awards from nonprofit, state and foundation sources
- •\$51,552 from charitable contributions
- •\$140,474 from fees for service
- •\$255,715 from Institute funds

Remaining funding reflects planned grant and contract continuations and other funding carried forward from the previous year to support the MCDD's ongoing efforts to advance inclusion for people with intellectual, developmental and other disabilities.



| MCDD Staff Members | Program |
|-----------------------------|---|
| Cheryl Cohen, MS | Director of Online and Community Programs, Autism Research and Engagement Core |
| Jennifer Falter, Esq. | Contract Attorney, Project HEAL |
| Genevieve Hornik, Esq. | Staff Attorney, Project HEAL |
| Cindy Ibarra | Administrative Services Coordinator |
| J. Kiely Law, MD, MPH | Director, Autism Research and Engagement Core |
| Mallory Legg, Esq. | Director, Project HEAL |
| Alison R. Marvin, PhD | Research Manager, Autism Research and Engagement Core |
| Christopher Mason-Hale | Community Advocate |
| Megan Meck, MS | Project Manager |
| David Mervis, Esq. | Staff Attorney, Project HEAL |
| Kendall Murphy, Esq. | Staff Attorney, Project HEAL |
| Kristine Nellenbach, MS | Program Coordinator, Resource Finder |
| Mirian Ofonedu, PhD, LCSW-C | Director of Training |
| James Orman | Program Coordinator, People On the Go |
| Maria Oven | Manager, Business Operations |
| Mat Rice | Executive Director, People On the Go |
| Marina Sarris, MA | Web Content Manager, Autism Research and Engagement Core |
| Jewell Thompson | Director, Business Operations |
| Jaimie Toroney, MHS | Research Manager, Autism Research and Engagement Core |
| Valeria Tskhay | Training Coordinator |
| Maureen van Stone, Esq., MS | Assistant Vice President and Director |
| Tracy Waller, Esq., MPH | Contract Attorney, MCDD |
| Tracy Wright | Deputy Director, People On the Go |

Honors and Awards

Dr. Mirian Ofonedu received the AUCD Multicultural Council for Leadership in Diversity Award (November 2023) and the Community Advocates 4 You 2024 Outstanding Community Leader Award (May 2024).

Mat Rice received the Gayle Hafner Leadership in Advocacy Award from Disability Rights Maryland (September 2023).

Maureen van Stone received the Relentless Award from the Pediatric Epilepsy Surgery Alliance (October 2023) and was named one of Maryland's Top 100 Women by The Maryland Daily Record, which also inducted van Stone into its Circle of Excellence (May 2024).



MCDD Leadership Roles

MCDD staff members hold various leadership roles at state and national levels.

Mallory Legg, Esq., Project HEAL Director

- Council of Parent Attorneys and Advocates, Inc., Membership Committee Co-Chair
- First Maryland Disability Trust, Secretary

Alison R. Marvin, PhD, Autism Research and Engagement Core Research Manager

Interagency Autism Coordinating Committee, Federal Member

Chris Mason-Hale, MCDD Community Advocate

- Leadership Maryland's Emerging Leaders 2024, Member
- Maryland Commission on Disabilities, Commissioner
- Mayor's Commission on Disability, Representative
- Maryland Disabilities Forum, Co-Chair

Megan Meck, MS, MCDD Project Manager

Association of People Supporting Employment First, Maryland Chapter, Secretary

Kristine Nellenbach, MS, Resource Finder Program Coordinator

- AUCD Community Education and Dissemination Council (CEDC), Vice Chair
- Maryland Assistive Technology Loan Program, Board of Directors
- Maryland Technology Assistance Program (MDTAP) Advisory Council, Member

Mirian Ofonedu, PhD, LCSW-C, MCDD Director of Training

- American Psychological Association (APA), Global Psychology Learning Leadership Institute, Mentor
- AUCD, International Special Interest Group, Co-Chair
- APA Division for the Society of Child and Family Policy and Practice (Division 37), Committee for International Relations in Psychology (CIRP), Liaison Executive Committee
- APA Division 37, Diverse Racial Ethnic and Multicultural Special Interest Group (DREAM SIG), Chair
- Maryland Board of Social Work Examiners, Licensed Clinical Social Work Supervisor
- Maryland Suicide Prevention Conference Planning Committee, Executive Committee

James Orman, People On the Go Program Coordinator

• Maryland Disabilities Forum, Co-Chair

Mat Rice, People On the Go Executive Director

Maryland Developmental Disabilities Administration, Quality Advisory Council, Chair

Maureen van Stone, Esq., MS, Assistant Vice President and MCDD Director

- AUCD, Policy Committee, Co-Chair
- Council of Parent Attorneys and Advocates, Inc., Board of Directors, Executive Committee
- Maryland Developmental Disabilities Administration, Quality Advisory Council
- Maryland Developmental Disabilities Council, Executive Committee
- Maryland State Department of Education, Division of Early Intervention/Special Education Services, State Personnel Development Grant, Advisory Committee
- The Link Center's Maryland State Policy Academy, Member

Tracy Wright, People On the Go Deputy Director and Director of Training

• Maryland Inclusive Housing, Board of Directors



Events and Collaborations

The MCDD organizes and participates in a variety of statewide events that promote advocacy for individuals with intellectual, developmental and other disabilities.

Developmental Disabilities Day at the Legislature

On February 21, several MCDD staff members and trainees participated in Developmental Disabilities Day (DD Day) at the Legislature in Annapolis, Maryland. The MCDD, the LEND program and the Center for Diversity in Public Health Leadership Training co-sponsored a lunch-and-learn event at St. Anne's Parish House for more than 70 people, including our invited speakers, catered by Mission BBQ.

Faith Leaders Conference

On June 26, Dr. Mirian Ofonedu, director of training for the MCDD, hosted the 2024 Faith Community Learning Collaborative Conference for Maryland faith leaders. The event featured presentations and discussions led by experts in disability inclusion and faith-based support. Matthew Plantz, a self-advocate and member of the MCDD's CAC, shared strategies for supporting individuals with disabilities in faith communities. Attendees gained practical strategies and actionable insights to enhance mental health and improve disability accessibility, inclusivity and support. Visit **KennedyKrieger.org/Faith** to learn more.

Special Olympics Maryland

Kennedy Krieger and the MCDD collaborated with Special Olympics Maryland to help launch the Child and Family Health Intervention Pilot program at the Institute's Early Childhood Development and Education Center and Southeast Early Head Start locations. As part of the pilot, more than 20 families participated in Special Olympics Young Athletes, Family Health Forums and Healthy Young Athletes pediatric screenings.

Sponsorships

- The Arc Baltimore: Art in the Round and golf, annual conference and exhibition, and golf tournament
- The Arc Maryland: Annual Conference and Exhibition
- Disability Rights Maryland: Breaking Barriers Awards Gala
- Kennedy Krieger: Neurodiversity in the Workplace National Conference; Center for Autism Services, Science and Innovation Annual Autism Conference; and Room to Grow: Journey to Cultural and Linguistic Competency Conference
- Pathfinders for Autism: Golf tournament

On the cover: MCDD staff members

Back row, left to right: David Mervis, Megan Meck, Mirian Ofonedu, Laura Benjamin, Maureen van Stone, Jewell Thompson, Linna Kuang, James Orman Front row, left to right: Kristine Nellenbach, Chris Mason-Hale, Genevieve Hornik, Mallory Legg, Cindy Ibara

Missing: Cheryl Cohen, Jennifer Falter, J. Kiely Law, Alison Marvin, Kendall Murphy, Maria Oven, Marina Sarris, Jaimie Toroney, Valeria Tskhay, Tracy Waller, Tracy Wright

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