

# 2024

# Annual Report

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# AUCD

Association of University Centers on Disabilities

# Letter from the Executive Director

For AUCD and our Network partners, 2024 has been a year of building upon the progress forged in previous years. While 2023 was a year focused on valuing and strengthening our connections across the Network, 2024 has emphasized further fortifying our core functions as an organization and our Network as a collective force for change.



The AUCD 2024 Conference theme, *Stronger Together: Creating a More Inclusive World*, immersed attendees in the essential role collaboration plays in advancing the rights and opportunities for and with people with disabilities through research, training, education, and service of the AUCD Network. Discussions at the Conference centered around how each University Center for Excellence in Developmental Disabilities (UCEDD), Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Program, and Intellectual and Developmental Disability Research Center (IDDRC) can work together, strategize, and partner to fulfill our joint mission. By uniting around our shared goals as a Network, we are better positioned to drive systemic change and continue promoting pathways across the United States and its territories.

In 2024, AUCD also updated its mission statement to reflect the growing importance of collaboration. Our new mission is to amplify and advance the work of the AUCD Network to promote community inclusion and quality of life for people with developmental and other disabilities and their families.

2024 ended with a significant milestone for AUCD and the Network when President Biden signed the reauthorization of the Autism CARES Act of 2024 into law on December 23. This victory was made possible by the advocacy of our Network members, who contacted their Senators and Representatives to raise awareness and support for this important bill. The year-end accomplishment in policy is a testament to the power of our collective voice and impact we have when our Network comes together for a common cause.

As we head into 2025, AUCD remains excited about the endless opportunities ahead. AUCD is committed to continuing our work *stronger together*, supporting and advancing the rights of individuals with disabilities across the United States and its territories.

Sincerely,

Sandy Root-Elledge  
AUCD Interim Executive Director

# About AUCD and the Network

The Association of University Centers on Disabilities (AUCD) is a national association that supports Network members in their research, training, education, and service so that together, AUCD and Network members can promote the quality of life, health, and well-being of people with disabilities. AUCD's mission is to amplify and advance the work of the AUCD Network to promote community inclusion and quality of life for people with developmental and other disabilities and their families.

- **68 University Centers for Excellence in Developmental Disabilities (UCEDDs)**

The Network of UCEDDs aims to positively affect the lives of all people with disabilities by building and strengthening systems that support full community participation. They work toward a vision of self-determination, independence, productivity, and community inclusion for people with disabilities throughout the lifespan.

- **60 Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Programs**

LEND Programs aim to improve health outcomes for people with autism spectrum disorder (ASD) and other neurodevelopmental disabilities. These programs provide graduate-level training to the next generation of clinical, research, and community leaders. By participating in LEND, trainees learn about the importance of person- and family-centered care (honoring values and culture).

- **15 Intellectual and Developmental Disabilities Research Centers (IDDRCs)**

IDDRCs conduct biomedical and behavioral research to advance understanding of a variety of conditions and topics related to intellectual and developmental disabilities (IDDs). Although each Center differs in their scientific focus, size, and history, they all share a commitment to integrated research opportunities for investigators engaged in basic, clinical, and translational science related to IDDs.

# Stories Across the Network

## Finding the Right Doctors at the Rochester, New York UCEDD and LEND

The new Golisano Intellectual and Developmental Disabilities Institute will drive transformations in intellectual and developmental disabilities (IDD) research, training, care, and advocacy.

When Lisa Latten’s son, Ian, was diagnosed with autism at age two and a half in 2007, she thought, “What am I going to do?” I had this overwhelming need to close ranks—to protect my child, to protect myself. As a parent, you recognize that the world is not set up to support our kids, accept our kids, and love our kids.”



Since 2007, Lisa has found caring doctors and dentists at the University of Rochester Medical Center who are skilled at working with Ian and other children who have IDD. She’s witnessed a significant jump in awareness, as the number of children diagnosed with autism spectrum disorder quadrupled between 2000 and 2020. Lisa and Ian have benefited from research and new approaches to care, including many pioneered and honed at Rochester.

The University of Rochester has long been known as a leader in the field of IDD. It is one of just eight institutions nationwide with three major federally funded programs that support IDD-linked training, research, and advocacy. Over the past decade, the University has invested more than \$80 million in IDD research and care, opening new facilities and expanding research programs. Its pediatric clinicians work with more than 15,000 IDD patients annually, and the school’s dentistry program cares for more than 2,000 patients. The University of Rochester Medical Center houses a UCEDD, LEND, and incoming IDDRC.

# Stories Across the Network

## Utah UCEDD and LEND Promote Resources in the Community

AUCD UCEDD and LEND at Utah State University's Institute for Disability Research, Policy & Practice started the Cache County Maternal, Infant, and Early Childhood Home Visit program in 2024. The program promotes family resilience and healthy child development through home visits, family connection groups, and access to helpful resources from the community.

"It's about empowering parents with knowledge, helping them make an informed decision about what is best for them," said Tressa Johnston, the program administrator.

The focus of the program is on family well-being, supporting both parents and children through the early years of child development, and strengthens families through guiding parents on developmental changes and parenting strategies. The program is able to refer families to other community organizations and resources if a child needs more developmental support.

The program supports a wide variety of families, as long as they have one child in the home who is under the age of six. These could include first-time parents, military families, foster or temporary caregivers, and families of infants with low birth weight.

"Having something research-backed and evidence-based helps them build their family," Johnston said. "It supports child development and helps them make sure their children are ready for school. We all wonder how to balance family and work, school and family. This will help."

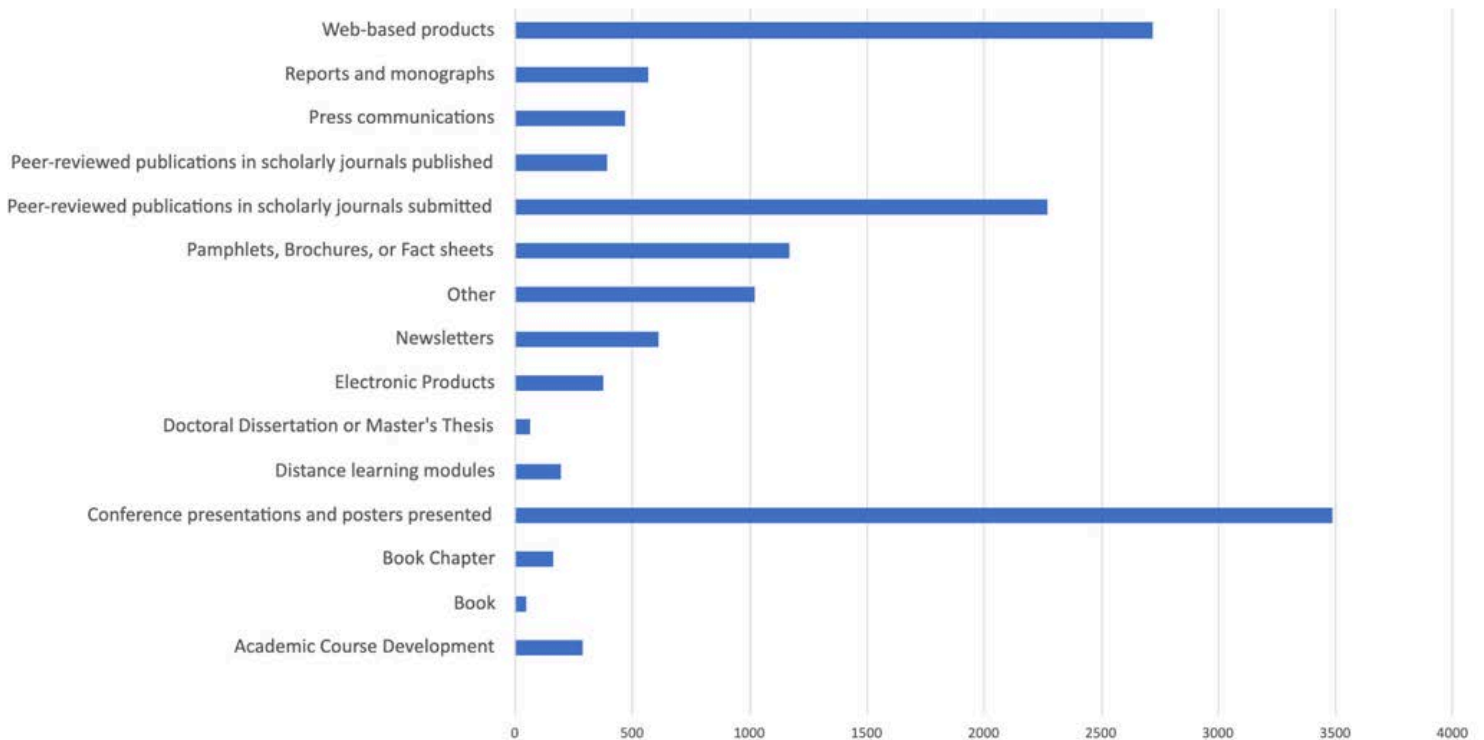


# Our Impact

Members of the AUCD Network engage in a wide variety of activities daily as they work to promote inclusion, justice, health, and respect for all people with disabilities. For data collection purposes, their activities are grouped into three main categories: **technical assistance** (helping people finding resources and answers), **continuing education** (teaching), and **diagnostic services** (clinical medical and research activities).

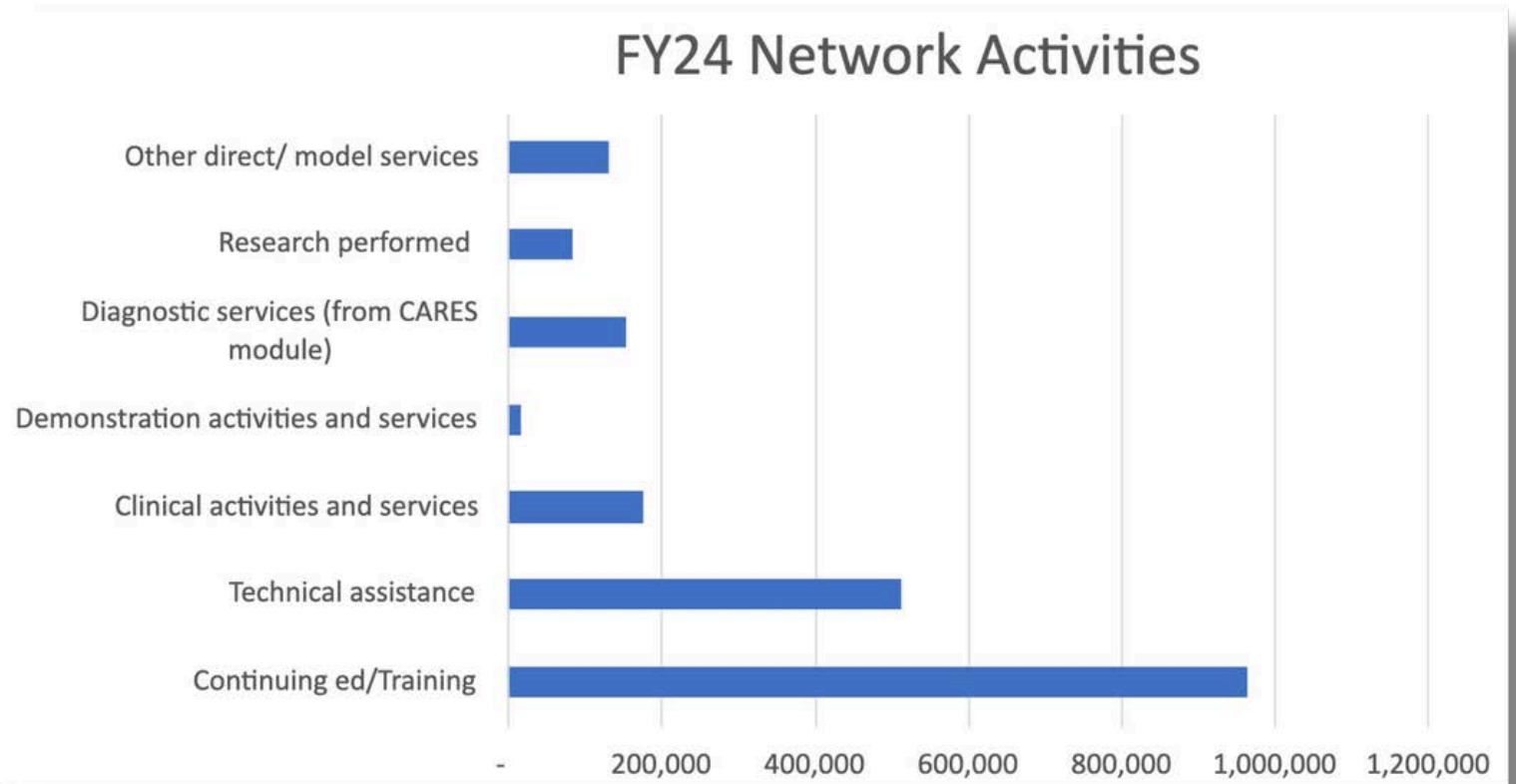
In FY24, more than **513,000 people** and organizations received technical assistance from AUCD members, more than **965,000 people received continuing education**, and more than **177,000 families received clinical services** such as diagnostic evaluations for developmental disabilities, therapies, and more.

FY24 Network Products



# Our Impact

One of the strategic goals of AUCD is to conduct and apply research and share knowledge. Collectively, AUCD Network member Centers and Programs produced more than **13,900 expert products**, including newsletters, books and book chapters, conference presentations, academic and online courses, fact sheets, and press communications. These items reach tens of millions of people, educating them on evidence-based information and guiding them to resources available for people with disabilities and their families.



# Our Impact

In 2024, the AUCD Network trained **4,300 trainees in more than 47 disciplines** such as audiology, physical therapy, social work, dentistry, child development, early intervention, amongst others.

AUCD Emerging Leaders are a part of a community that includes current trainees from AUCD member sites; former (i.e. alumni) trainees; early career professionals from all health and related disciplines, including self-advocates and family members; and others that are relatively new to the disability field. This group of passionate individuals from every U.S. state and territory grows by the thousands each year.

Together, this Emerging Leaders Community shares a passion to serve, research, and educate to make positive changes with and for people with disabilities and their families.



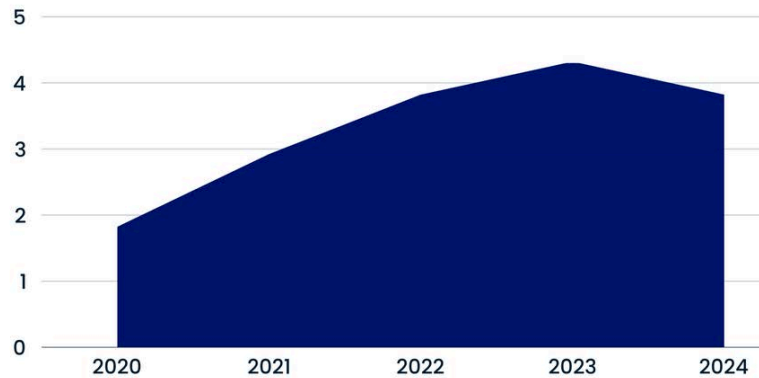


# AUCD Financials

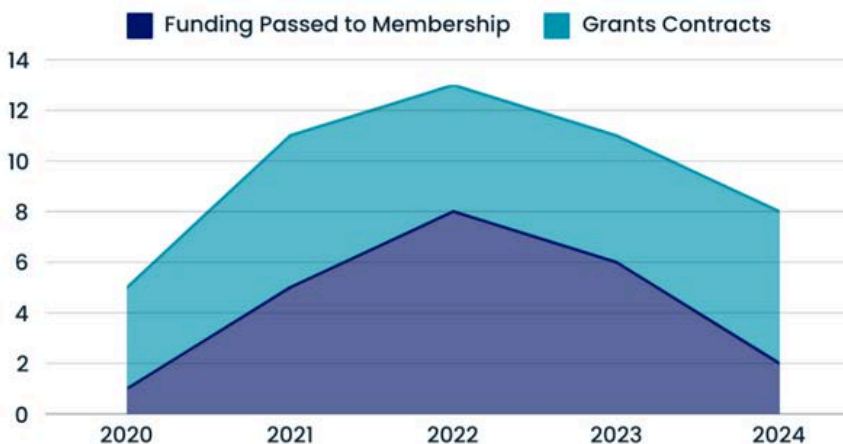
AUCD is a 501(c)3 organization with a \$5.6 million budget. The majority of AUCD's income comes from grants and contracts; and the remainder comes from things like membership dues, event registrations, and private donations. AUCD works to keep our operations efficient, using the maximum available resources to further the goals of our strategic plan.

## 2024 Revenue

- AUCD FY2024 revenue was \$8,000,814 compared to \$12,082,577 in FY2023
- Year-end **unrestricted net assets were \$3,782,396** which is \$529,204 less than the prior year
- AUCD's **reserve fund now exceeds 6 months**



## 2024 Passed through Funding



- AUCD **passed to its members \$2.3 million in funding** compared to \$5.6 million of funding in the previous year (due to expiring grant awards)
- AUCD FY25 projection is over \$0.5 million passed to members
- Membership dues increased by 5% in FY25

# Thank You

Thank you to AUCD's supporters and the thriving Network of researchers, practitioners, educators, professionals, disability stakeholders, students, trainees, and advocates.

## Thank you to AUCD's federal partners

- Administration for Community Living
- Centers for Disease Control and Prevention
- Maternal and Child Health Bureau
- National Institute of Child Health and Human Development

## Thank you to AUCD's top tier sponsors

- JPMorgan Chase & Co
- Walmart
- Elevance Health
- PhRMA
- Microsoft
- Centene
- UAB/Lakeshore Research Collaborative



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