

OHSU University Center for Excellence in Developmental Disabilities

2023-2024 Annual Report Highlights

Our work falls into four buckets.

We educated students and trained professionals, provided community services, conducted research, and shared information.

We had **35** long-term trainees:

- 36% of our long-term trainees identify as non-white and come from diverse backgrounds
- 12% of our trainees self-identify as a person with a disability
- 39% have a family member with a disability or special health care need.



Libby Quinn, Health Administration Trainee:

"Including individuals and families with lived disability experience in health education programs can help health care professionals collaborate with patients. Patients have great power and perspective — and it's about time we value it!"

We provided training to over **624** health care students and professionals across multiple disciplines, including the Medical School, Dental School, Physician Associate Program, School of Nursing, and Casey Eye Institute.

The **Personal Responsibility Education Program (or PREP)** program provides training to teachers and community facilitators on implementing sexual health education for youth and young adults with I/DD through two curricula:

Oregon Friendships and Dating Program

This curriculum provided training for **37** facilitators in **15** new settings.

Sexuality for All Abilities

Designed for high school settings, **17** teachers have been trained in this curriculum and a pilot project will expand the curriculum to **10** schools.

Kim Solondz, M.S., OTR/L Director of Occupational Therapy

"In clinic, many of the youth and families we meet do not even know what questions to ask about transition to adulthood. The Lifespan Transition Clinic provides them with the tools to set goals and learn about what is available to support them in the future."



The **Lifespan Transition Clinic** provides resources and action plans for families to help prepare youth aged 14-24 for transition in all areas, including health care, vocation, post-school, and community participation. Since its creation in 2018, the Lifespan Transition Clinic has provided services for **167** families total, **35** in the last year.

Research

Research in complex communication needs

UCEDD co-Director Dr. Melanie Fried-Oken leads a project in collaboration with CommunicationFIRST to create a national plan to develop and advance peer-support models for augmentative and alternative communication (or AAC). This project established a consortium of over **50** people including AAC users and other representatives from agencies and organizations to work together toward that goal.

Quote from Consortium member:

"It feels like we have gotten a lot done, and also this is just the beginning of a movement across the U.S. and probably further to open doors for AAC users to get more than language supports."

Other projects:

- Optimizing Brain-Computer Interfaces with a Functional Implementation Toolkit

Research in sexual and reproductive health

Professor Dr. Willi Horner-Johnson worked on four federally funded research projects addressing pregnancy and reproductive health. In her work, she co-directs the National Center for Disability and Pregnancy Research with Dr. Mitra at Brandeis University. In the last year they have had **2** papers published, **1** in press, and **3** in review.

Other projects:

- Understanding and Supporting Reproductive Decisions among Women with Developmental Disabilities that Affect Cognition
- Disparities in Perinatal Care and Outcomes among Black Women and Latinas with Physical Disabilities
- Addressing Sexual and Reproductive Health Care Disparities and Barriers among Adolescents and Young Adults with Disabilities

National Core Indicators data collection

The UCEDD continued its partnership with Oregon's Office of Developmental Disabilities Services to work on the National Core Indicators (or NCI) In-Person Survey and Child Family Survey.



414 interviews
for the in-person survey



10 years
collecting data for the program

Information sharing

This year we published an online resource hub, "**Emergency Preparedness for People with Disabilities.**" We also updated the **Ready Now! Toolkit**, now available in Spanish, and hosted a webinar to help people access and use these resources.

Resource hub and webinar training results:



2,580 visits

to the Emergency Preparedness web pages during the year



71 participants

attended the webinar



100% success

all surveyed webinar participants reported knowledge gained

If you would like to learn more about our work, please visit our website at: www.ohsu.edu/ucedd.

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