

Welcome to the OHSU University Center for Excellence in Developmental Disabilities, or “UCEDD” as we say, annual report for 2023 through 2024.

So, what did we do last year?

Our work falls into four buckets.

We...

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

## Education

Libby Quinn was a trainee with our UCEDD through the Leadership Education in Neurodevelopmental and Related Disabilities (or LEND) program.

Libby presented about her research at the OHSU Symposium on Educational Excellence.

Libby shared:

“Last year, I explored power differences that exist between health care professionals and patients with disabilities. Through my interviews with both, I learned how impactful sharing one’s story is in this unique relationship. 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!”

In all, we had 35 long-term trainees. 36% of our long-term trainees identify as non-white, 12% of our trainees self-identify as a person with a disability, and 39% have a family member with a disability or special health care need.

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

Jan Staehely, a self-advocate, blogger, and UCEDD communication consultant, contributed to these trainings. She offers students an important perspective on providing effective health care based on her personal experience with cerebral palsy and using an assistive communication device.

Jan shared the following in her blog:

"It's important for health care professionals to have the real experience of communicating with people with disabilities, rather than just talking about it in a classroom or reading a textbook. Communication looks and feels different when you're in the moment with someone like me who uses assistive and augmentative communication."

Service

Personal Responsibility Education Program (or PREP)

Helping Oregon comply with Erin's Law (SB 856) to prevent child sexual abuse, PREP provides training to teachers and community facilitators on implementing evidence-based health education curriculum for youth and young adults with I/DD.

The Oregon Friendships and Dating Program

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

Sexuality for All Abilities (or SfAA)

Sexuality for All Abilities is a sexual health education curriculum designed for high school settings.

A pilot project will be launched next year, expanding the Sexuality for All Abilities curriculum to 10 schools. So far, 17 teachers have been trained in the curriculum.

Community Research Liaison Morrigan Hunter led the development of this project. Morrigan shared that:

"Promoting sexual health education for youth in the I/DD community is so vital. Sexuality education helps young people practice setting boundaries with the knowledge that they deserve to be treated with kindness and respect."

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.

UCEDD faculty member Kim Solondz leads the Lifespan Transition Clinic. Since its creation in 2018, the Lifespan Transition Clinic has provided services for 167 families total, 35 in the last year.

Kim shared the following:

“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.”

## 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.

AAC Peer Support Project Coordinator Sarah Fjeldstad shared how:

“It’s a thrill and an honor to work alongside a consortium of such dedicated, passionate, and brilliant people. I learn from them every time we meet. This work has already positively impacted the lives of those who use or need AAC and their supporters, and I believe our efforts will create even more benefits in the future.”

This work included the first survey to report on a large AAC user base about the tools and techniques they use and their peer support experiences with over 130 responses.

### Research in pregnancy and reproductive health

Professor 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 two papers published, one in press, and three in review.

They presented twice nationally and were recently awarded five more years of funding to continue this collaboration.

#### National Core Indicators data collection

The UCEDD continued its partnership with Oregon's Office of Developmental Disabilities Services (ODDS) to work on the National Core Indicators (or NCI) In-Person Survey (IPS) and Child Family Survey (CFS). This was the NCI team's 10<sup>th</sup> year collecting data for the project!

We conducted 414 interviews for the in-person survey. UCEDD Community Research Liaison Anne Niven was part of the interview team and shared her thoughts about the project:

"What I love about working on the NCI survey is the chance to talk to people living with I/DD directly. These folks don't get enough attention and respect in our culture, and the survey gives me a chance to listen to their stories and report their experiences. That's significant and important."

#### 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.

There were 2,580 visits to the Emergency Preparedness web pages during the year, and 71 participants attended the webinar with 100% of survey respondents reporting knowledge gained.

Some feedback from the webinar included: "This was a fabulous training - I love how the hub is usable and accessible to people across the country."

## Translating clinical reports into other languages

After gathering feedback from meetings with Latinx disability groups to learn how to better serve all communities, Speech-Language Pathologist Hannah Sanford-Keller helped lead an initiative to translate more clinical reports into other languages.

Hannah shared that:

“Providing guidance to families in a language they understand best is so important, especially when supporting their family members during crucial times in development. In clinic, I see how this work is a crucial step in empowering individuals to make important healthcare decisions for their loved ones.”

## Research translation

This year we launched the Research for Everyone Hub, a collection of summaries of published research.

The new webpage format builds on years of research translation in plain language. The online hub features 24 articles with images, organized by topic.

Data and Communication Manager Larissa Yoshino shared that:

“I feel strongly that sharing academic research with communities is part of upholding ‘Nothing about us without us’ in our work.”

Thank you for joining us in celebrating some of the highlights of our last year. If you would like to learn more about our work, please visit our website at [www.ohsu.edu/ucedd](http://www.ohsu.edu/ucedd).