



UCEDD

# Diversity, Equity, and Inclusion Impact Report 2023

At the University Center for Excellence in Developmental Disabilities (UCEDD), we value the diversity of the human experience and intersecting identities and recognize that all communities have knowledge and experiences which contribute to our understanding of health, quality of life, and health care for all people.

Our team is actively working to break down the barriers that people with disabilities face when accessing health care and seeking meaningful participation in the community. These are some accomplishments this year for each action item:

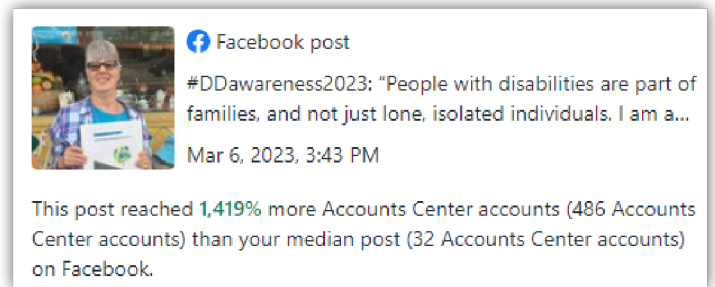
## Elevating the stories and perspectives of people with lived experience and from diverse communities as experts in their own lives, and collaborating with communities to impact change

- We partnered with our advisory council members to celebrate [Developmental Disabilities Awareness Month](#) in March through storytelling and a discussion of ableism, allyship, and access to health care.



**1,412 Reach on Facebook**

*The campaign included the second most popular Facebook post for the year.*



## Partnering with people with disabilities to teach the next generation of healthcare providers and leading by example to promote inclusivity in healthcare, policy, research, and educational spaces, recognizing the harmful history of these spaces and working to ensure people with disabilities are actively welcomed and included as colleagues

- We continued teaching to pre-service learners in the OHSU medical school, dental school, physician assistant program, and school of nursing, expanding this year to the Casey Eye Institute:

- Casey Eye Institute Grand Rounds on inclusive best practices for improving access to eye care for people with I/DD and addressing the ableism of the medical model.
- Two self-advocates shared their experiences as patients with disabilities:



Jan Stahley  
UCEDD Staff Member



Kiersi Coleman  
Community Partners  
Council (CPC) Member

- We led an elective for the OHSU School of Medicine: “Disability Awareness and Clinical Skills Development for Medical Students”, hosting guest speakers with lived experience to provide pre-service education that is culturally affirming and inclusive.



**2**  
Years  
Running



**8**  
Students  
Enrolled  
Annually

### Speakers and highlights this year included:



Tyler Tate, M.D.  
at OHSU: “Ethical  
Issues and  
Disability”



Kara Ayers from  
Cincinnati  
Children’s Hospital  
UCEDD: “Ableism in  
Health Care”



Chennettée  
Jelleberg, Director  
of Student Access at  
OHSU: “Disability  
Awareness and  
Etiquette for Future  
Physicians”



Tina Truong, NP  
at OHSU:  
“Doctors with  
Disabilities –  
Exploring stigma  
and inequality in  
the medical field”



A field trip to  
Community  
Vision’s Assistive  
Technology Lab

## Increasing resources in our community that support self-determination for people with disabilities

- We started a [caregiver training series](#): “Fast Facts and Functional Ideas for Supporting Behavior Over Summer Vacation” with Leadership Education in Neurodevelopmental and related Disabilities (LEND) trainees.
- We continued partnership with Among Friends, a training agency that conducts training for disability professionals, caregivers, and self-advocates through the Sexual Self-Determination and Certification Program.



## Offering information in a variety of formats and languages, as well as research in plain language

- Research articles that were [translated into plain language](#) with key takeaways described:



“An Initial Investigation into the Feasibility of the Communication Matrix Professional Development Program for Educational Professionals Working with Students with Complex Communication Needs”

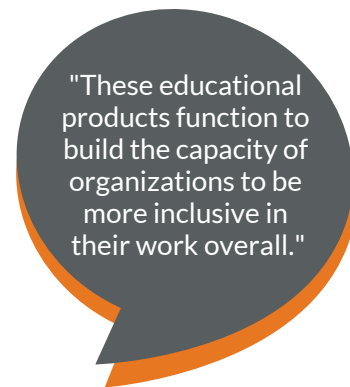


“Teaching Parents Read, Ask, Answer, Prompt Strategies via Telepractice: Effects on Parent Strategy Use and Child Communication”



“A systematic review of research on augmentative and alternative communication brain-computer interface systems for individuals with disabilities”

- In collaboration with our state health authority, created materials including checklists, guides, and videos for improving access to vaccine events. [The culminating website](#) offers support to event organizers for public health events today and in the future beyond the COVID-19 pandemic including an e-learning course that provides an opportunity to be trained as an accessibility lead for an organization.



- We provided Technical Assistance including:



Supporting translation of the [Friendships & Dating](#) curriculum, which is housed at University of Alaska Anchorage.



Assisting Oregon’s Office of Developmental Disabilities Services by facilitating the translation of National Core Indicators (NCI) Child Family Survey, informational letters, and brochures in six languages.

## Hiring and promoting leadership opportunities for people with disabilities and sharing power to create spaces where lived experience guides our work

- We convened a team to develop and begin recruitment for a Young Adult Advisory Board to provide leadership opportunities for young adults with intellectual and developmental disabilities and facilitate a way for them to provide input on program development and service improvement.
- Our summer diversity committee intern gathered resources for supporting diverse trainees and shared them across the Department of Pediatrics.
- We worked with the School of Medicine Diversity Action Plans to ensure people with disabilities were included in providing expertise on the AUCD Multicultural Council.

## Including people with lived experience to create and lead new research ideas

- Based on feedback obtained through partnerships with people with lived experience, we adjusted the recruitment strategy used in a national prevalence study on ID and mental health diagnosis.
- We made an intentional effort to include people with disabilities and their support networks, particularly those from underserved communities, in our research projects.

Examples include:

- ✓ The research team at the [REKNEW research lab](#) continues to include individuals with severe disabilities in the bi-weekly research team meetings and in all research design and implementation tasks. All research conducted in the REKNEW lab follows the principles of Participatory Action Research. Individuals with incomplete locked-in syndrome and/or their formal or informal care providers are included on the research team and data collection sessions are held in their locations of choice.
- ✓ Dr. Emily Quinn recruited community experts to compose a community advisory council, an integral piece of the “Confronting Racism in Down Syndrome Research” project.

## Examining our own beliefs and biases and working to change our perspectives so we can impact change within the systems we work in

- Our [LEND program](#) has worked to develop pre-service education in partnership with diverse communities that address the specific needs of culturally and linguistically diverse people with I/DD and their support networks. Seminar topics included:



OHSU Unconscious Bias Training



Beyond “Born in the Wrong Body”: Challenging out Biases to Provide Inclusive Gender Affirming Care



Grande Ronde: Native American Health & the Modern/Western Medical System



Health Disparities

- The UCEDD Diversity, Equity, and Inclusion workgroup met monthly with the goals of identifying our team's commitment to DEI efforts, formalizing these commitments into work plan action items, and providing support for our team and wider OHSU community to make these efforts feasible. In collaboration with the UCEDD staff and CPC, the work group developed a public-facing [Diversity Statement](#).
- We assisted the Oregon Office of Developmental Disabilities Services in developing a state-wide [National Core Indicators](#) population sampling plan that ensures people from diverse backgrounds are represented.



## Listening to the community on an ongoing basis, especially communities who have experienced oppression, to understand what communities need most



- Continued to build a portfolio of work in emergency preparedness, a community-identified priority, through engaging with community leaders with lived experience.



Convened an emergency prep workgroup that included members from the Oregon Self Advocacy Coalition health care committee, self-advocates, UCEDD staff, and parents of children with disabilities to create an [online emergency preparedness resource hub](#).



- OODH continues to work on addressing health disparities impacting adults with I/DD by [linking adults with I/DD to needed preventive health care](#) services and working with individuals and with health care entities to address barriers.



- Feedback from listening sessions and meetings with Latinx disability groups led to efforts at our Institute and clinics to increase the number of translated documents for families.



- UCEDD completed a data analysis project to identify the needs of diverse communities for the Oregon Center for Children & Youth with Special Health Needs (OCCYSHN) in support of a pilot course for Community Health Workers who work with Latino community members with children with special health care needs.

## Evaluating our current work in response to community needs

- The UCEDD community advisory board, the Community Partners Council (CPC), has led our [Community Engagement Grant program](#), a project awarding grants to community organizations promoting health and wellness for people with disabilities. Recent improvements have aimed to better integrate a DEI lens through the application and review process and increase the amount of funding for future year grants.
- The OODH created additional resources for provider trainings, including a [reference guide](#) for improving intersectional access to mental health care, addressing multiple populations with disabilities and mental health concerns.



The University Center for Excellence in Developmental Disabilities is part of the OHSU Institute on Development and Disability

This work is funded by the Administration on Community Living Grant # 90DDUC0039-02-01



Visit the UCEDD website for more information: [www.ohsu.edu/ucedd](http://www.ohsu.edu/ucedd)