



# 2017-2022

## UCEDD 5-Year Report



# Table of Contents

3

Message from the UCEDD Directors

4

Our purpose and goals

5

Notable accomplishments

6-7

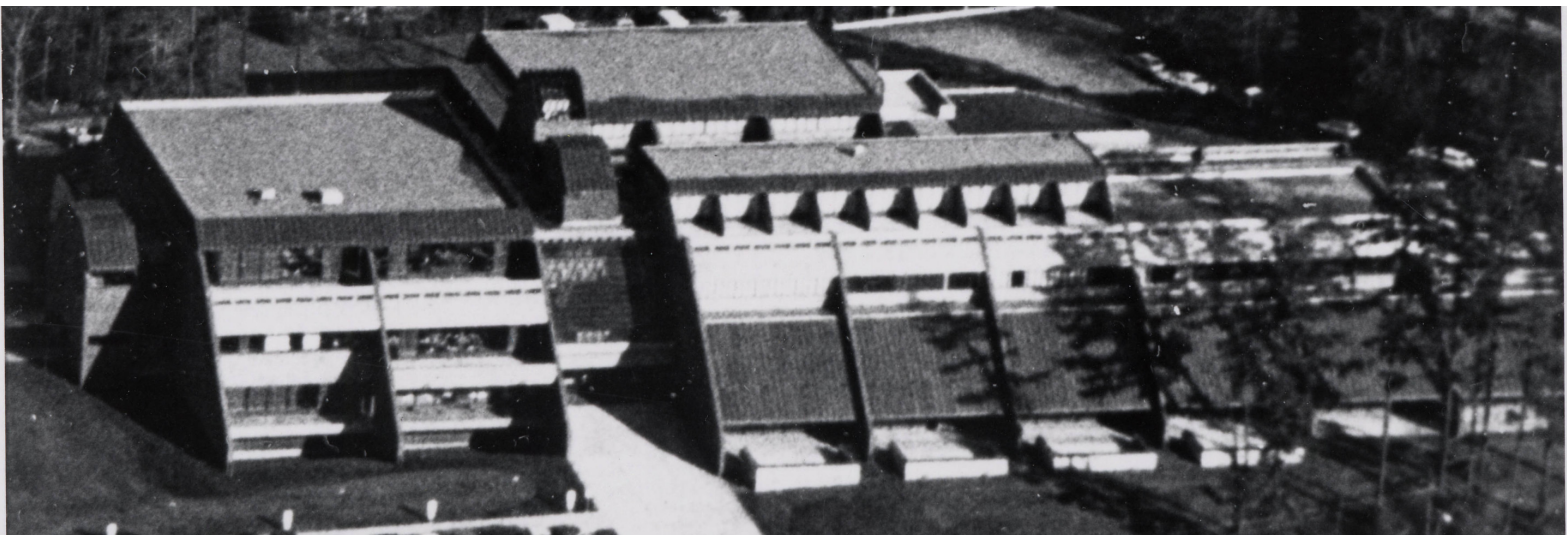
Impact at a glance

8

Selected research publications

9

Where to learn more



Child Development and Rehabilitation Center built in 1971



# Message from The UCEDD Directors



**Rhonda Eppelsheimer,**  
M.S.W., LCSW



**Melanie Fried-Oken,**  
Ph.D., CCC-SLP

For over 50 years the University Center for Excellence in Developmental Disabilities (UCEDD) at OHSU has partnered with people with disabilities and our broader community to promote the health and quality of life for people with intellectual and developmental disabilities and those who support them.

This five-year report highlights our partnerships, education, research, training, and advocacy. It tells the story of the impact our activities have in the community, state, and nation. During these past five years, the nation has faced a global health crisis. In response, we have strengthened our commitment to ensuring that the systems of care for people with disabilities address health disparities, access to critical care and services, and eliminate ableism.

We are thankful for the support of our funders, the Administration for Community Living, our advisory committee – The Community Partners Council, OHSU, and our Developmental Disability Network Partners and community who make this work possible.





# Our Purpose and Goals

The OHSU UCEDD's purpose is to promote health and quality of life for Oregonians with disabilities and their families across the lifespan. We accomplish this through leadership and collaboration with local, state, and national partners, serving as a resource for excellence in education, research and evaluation, community outreach, service, and information sharing.



## GOAL 1

Provide high-quality preservice and continuing education to trainees, professionals and practitioners



## GOAL 2

Increase the skills, knowledge and capacity of individuals and organizations to promote health and quality of life for people with disabilities and their families through services, programs, technical assistance and training



## GOAL 3

Engage in and grow research, evaluation, and policy analysis activities that promote the health and quality of life of people with disabilities



## GOAL 4

Establish the UCEDD as a primary hub of accessible information on disability and health, and disseminate products that are relevant, accessible, and inclusive of diverse audiences

# Notable Accomplishments



## Training professionals for the future

The young professionals we train go on to work in a broad spectrum of professions that impact the lives of people with disabilities. Follow-up trainee survey responses confirm that: 87 percent are working in a field related to Maternal Child Health, 41 percent are working at a public health agency, and 86 percent work with underserved populations.



## Service system improvement

Our collaboration with Oregon ODDS for the National Core Indicators Project, in which we conducted 1,779 quality assurance interviews, has improved the service delivery system, changed policy and practice, advocated and increased funding for Direct Support Professionals and services through legislative efforts for over 33,000 adults and children, their families and service agencies in Oregon.



## Clinical services across the lifespan

We established a Lifespan Transition Clinic serving 100 individuals, with over 40% from underserved populations, which is also a model service in teaching. Each year, trainees from Social Work and Occupational Therapy spend extended time in this clinic learning evaluation procedures, clinical decision-making, and development of recommendations and resources for families. The clinic has also provided training for Speech-Language Pathology and Audiology trainees.



## Inclusive research

The UCEDD's research over the last five years has been focused on advancing science that prioritizes the inclusion of people with disabilities and those who support them as participants in the research process. We conducted national- and international-reaching research emphasizing complex communication needs, health and health care disparities, sexual and reproductive health, mental health, and adolescent health transition.



## Health care advocacy education

Our partnerships with the Oregon Office on Disability and Health (OODH) and Oregon Self Advocacy Coalition (OSAC) have produced a toolkit to provide health and health care advocacy education for people with intellectual and developmental disabilities and those who support them. The OSAC self-advocates led the development of the Taking Charge of My Health Care project, including 12 modules and accompanying resources. The webpage has been visited thousands of times with 2600 downloads and almost 2400 video plays. The toolkit has been disseminated at eight conferences, two trainings, through many community partners, and has been recently translated into Spanish.

# Impact at a Glance



## 541 trainees

---

541 trainees participated in our education programs, including 202 long-term trainees, who spend more than 300 hours training with us.



## 558 research activities

---

The UCEDD had 558 research activities and 50 proposals funded that informed how we train, develop programs, provide technical assistance, and share out new knowledge and science information.



## 752 products developed

---

The UCEDD developed 752 products over the past five-year grant period and our dissemination efforts reached a wide audience, including 548 products designed for professionals, 340 for students, 295 for consumers and families, and 205 for policymakers.



## 58 products translated

---

58 products were translated into languages other than English, including Spanish and ASL.



## 99% satisfaction

---

Our continuing education and training offerings reached more than 9,000 participants including more than 7,000 professionals.



## 103 research publications

---

Over the past five years, our research teams have created 103 publications and 62 presentations.



## 28 projects funded

---

Our Community Engagement Grant program funded 28 projects over the past five years for community based organizations, serving more than 2,000 children and adults with disabilities, family members, caregivers, professionals and students.



## 21,782 pageviews

---

Website pageviews for the Sexual Health Resource Hub pages total over 20,000 (21,782) and are consistently in our top five most popular pages.

# Impact at a Glance



*"I have learned a lot about having hard conversations about what we need to change about ourselves, our ways of practicing, and our ways of thinking. This project gave me practice in how to make these challenging conversations end in growth and constructive new ideas."*

**- Trainee**



*"We had a goal of serving 50 youth with disabilities and their families in Southern Oregon, and we had over 90 participants in our first-ever event!"*

**- Grant recipient**



*"This training has strengthened my confidence and allowed me to start, guide, and contribute to conversations regarding human sexuality in general, instead of just as it pertains to challenging behaviors."*

**- Training participant**



*"Outcomes are best achieved when a diverse interdisciplinary group can work together."*

**- Trainee**



*"I had a fun time participating in the group because I got to know people. This helped me because it was kinda like starting friendships. I hope I can still stay in touch with some of the other kids."*

**- A self advocate in youth leadership program**



*"This work puts into perspective what community members actually want and need and allows the researchers to show cultural humility. Rather than making assumptions about what a community needs, we can center the voices from the community to fulfill the mantra 'nothing about us without us'."*

**- Grant recipient**

# Selected Research Publications

In the past five years, our research teams have created 103 publications, with select articles translated into plain language and published on our website. Plain language summaries make research findings accessible to a broader audience, bridging the gap between researchers and the public.

## Publications authored by Willi Horner-Johnson, Ph.D.:

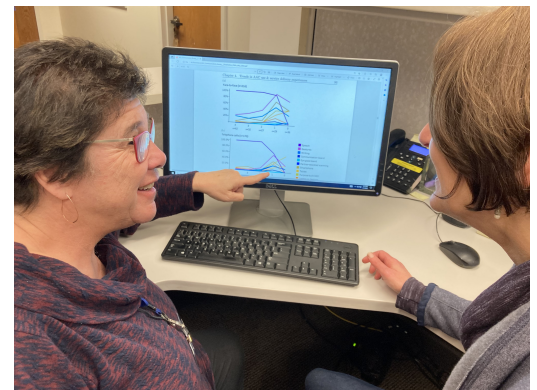
- [Sexual Health Experiences Among High School Students with Disabilities](#)  
Horner-Johnson, W., Senders, A., Tejera, C. H., & McGee, M. G. (2021). Sexual health experiences among high school students with disabilities. *Journal of Adolescent Health, 69*(2), 255-262.
- [Differences in Prenatal Care by Presence and Type of Maternal Disability](#)  
Horner-Johnson, W., Biel, F. M., Caughey, A. B., & Darney, B. G. (2019). Differences in prenatal care by presence and type of maternal disability. *American Journal of Preventive Medicine, 56*(3), 376-382.
- [Contraceptive Knowledge and Use Among Women with Disabilities](#)  
Horner-Johnson, W., Moe, E. L., Stoner, R. C., Klein, K. A., Edelman, A. B., Eden, K. B., ... & Guise, J. M. (2019). Contraceptive knowledge and use among women with intellectual, physical, or sensory disabilities: A systematic review. *Disability and Health Journal, 12*(2), 139-154.

## Publications authored by Melanie Fried-Oken, Ph.D., CCC-SLP:

- [Systematic Review of Research on AAC Brain-Computer Interface Systems](#)  
Peters, B., Eddy, B., Galvin-McLaughlin, D., Betz, G., Oken, B., & Fried-Oken, M. (2022). A systematic review of research on augmentative and alternative communication brain-computer interface systems for individuals with disabilities. *Frontiers in Human Neuroscience, 16*.
- [Trends in Research Participant Categories and Descriptions in Abstracts from the International BCI](#)  
Eddy, B. S., Garrett, S. C., Rajen, S., Peters, B., Wiedrick, J., McLaughlin, D., O'Connor, A., Renda, A., Huggins, J. E., & Fried-Oken, M. (2019). Trends in research participant categories and descriptions in abstracts from the International BCI Meeting series, 1999 to 2016. *Brain-Computer Interfaces, 6*(1-2), 13-24.
- [Mobile Technology Helps Find the Right Words](#)  
Mooney, A., Bedrick, S., Noethe, G., Spaulding, S., & Fried-Oken, M. (2018). Mobile technology to support lexical retrieval during activity retell in primary progressive aphasia. *Aphasiology, 32*(6), 666-692.

## Publications authored by Emily D. Quinn, Ph.D., CCC-SLP:

- [Conducting a Community Engagement Studio to Adapt Enhanced Milieu Teaching](#)  
Quinn, E. D., Cotter, K., Kurin, K., & Brown, K. (2022). Conducting a Community Engagement Studio to Adapt Enhanced Milieu Teaching. *American Journal of Speech-Language Pathology, 31*(3), 1095-1113.
- [Teaching Parents Read, Ask, Answer, Prompt Strategies via Telepractice](#)  
Dodge-Chin, C., Shigetomi-Toyama, S., & Quinn, E. D. (2022). Teaching parents Read, Ask, Answer, Prompt strategies via telepractice: Effects on parent strategy use and child communication. *Language, Speech, and Hearing Services in Schools, 53*(2), 237-255.
- [Hybrid Telepractice Delivery of EMT: Effects on Caregiver and Child Communication](#)  
Quinn, E. D., Kaiser, A. P., & Ledford, J. (2021). Hybrid telepractice delivery of enhanced milieu teaching: Effects on caregiver implementation and child communication. *Journal of Speech, Language, and Hearing Research, 64*(8), 3074-3099.







# Contact Us



## Email

[ucedd@ohsu.edu](mailto:ucedd@ohsu.edu)



## Website

[www.ohsu.edu/ucedd](http://www.ohsu.edu/ucedd)



## Address

Child Development and Rehabilitation Center  
707 SW Gaines Street  
Portland, OR 97239



## Social



@OHSU.UCEDD



@OHSU.UCEDDCPC



@OHSUUCEDD

