

INSTITUTE ON DEVELOPMENT AND DISABILITY

University Center for Excellence in Developmental Disabilities

Est. 1971



The University Center for Excellence in Developmental Disabilities, or UCEDD, at the OHSU Institute on Development and Disability was one of the first UCEDDs created nationally, and celebrates a nearly 50-year history in Oregon. We are a federally funded research institution located on OHSU's Marquam Hill Campus in Portland.

Our Mission

To improve the 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.



For more information please scan the QR code or visit us on the web

www.ohsu.edu/ucedd



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About us

The University Center for Excellence in Developmental Disabilities at OHSU works with individuals, families and agencies across Oregon, as well as UCEDDs across the nation, to improve the lives of people with disabilities. Through leadership and effective partnerships the UCEDD serves as a resource for excellence in education, research and evaluation, service and information sharing.

The OHSU UCEDD is a member of the Association of University Centers on Disabilities, a network of 68 independent yet collaborative Centers, with at least one in every U.S. state and territory.

Education

The UCEDD provides high-quality education with an interdisciplinary focus for pre-professionals, professionals and the community. Our pre-professional training is collaborative and coordinated to address issues that affect people with disabilities across systems. In addition, we provide education for the community, policy makers and other professionals on a wide range of issues affecting people with disabilities.

Research and evaluation

The UCEDD engages in innovative research and evaluation that addresses the needs of people with disabilities. Applying the principles of participatory research, we conduct research in areas such as technology, health disparities and communication. Our evaluation efforts look at measuring the effectiveness and impact of programs, policies and services.

Service (technical assistance and training)

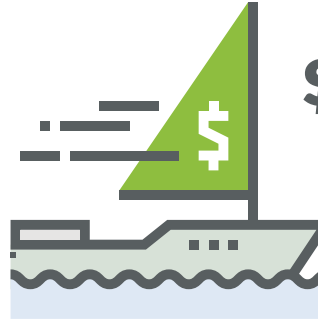
The UCEDD provides direct service to people with disabilities and their families. This includes clinical and other intervention services. We support people with disabilities throughout the lifespan to make successful transitions, receive quality care, and enhance their quality of life.

Information sharing

The UCEDD strives to distribute useful information to the community to enhance services, advocacy, practice and policy and improve quality of life for people with disabilities.

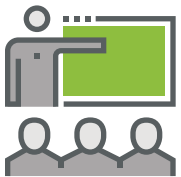
2019 Impact Report

This report reflects our local and national impact and successes in improving health and quality of life for people with IDD (intellectual and developmental disabilities) and their families.



\$7,454,341

**TOTAL FUNDING
LEVERAGED**



1,694

**PARTICIPANTS IN TRAININGS
AND PRESENTATIONS**



3,406

**WEBPAGE VIEWS FOR SUMMER
INTERNSHIP PROGRAM**



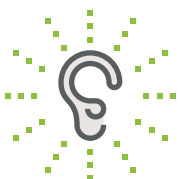
53%

**DIVERSE
TRAINEES**



18

**LEGISLATIVE
VISITS**



5

**LISTENING SESSIONS
ACROSS THE STATE**



18

**RESEARCH
PUBLICATIONS**



761

**PEOPLE WITH IDD INTERVIEWED
ABOUT THEIR SERVICES**



910

**HOURS OF TECHNICAL
ASSISTANCE PROVIDED**

Overview

A sampling of our education, research and community service activities

Educating, serving and listening to the community

Community Engagement Grants

In collaboration with the Community Partners Council, this program supports community-based programming benefiting people with developmental disabilities. Oregon non-profit organizations implement funded projects in areas of sibling support, spirituality and health promotion.

Empowered Youth Leaders

This program promotes self-determination, independence and self-advocacy in youth with disabilities. The program aims to empower youth to become leaders and use their leadership skills to create change in their communities.

Sexual Health Promotion Programs

In partnership with local and state entities including Multnomah County and The Arc Oregon, we provide services and trainings to self-advocates, care providers, and service staff to support healthy relationships and positive sexual health for people with disabilities.

Taking Charge of My Health Care

In partnership with the Oregon Self Advocacy Coalition and the Oregon Office on Disability and Health, this project teaches people with disabilities how to advocate for their health and health care through a series of educational modules to be used for individual learning or in a workshop setting.

Using our research to improve practice and policy

National Core Indicators

A collaborative project between the OHSU UCEDD and the Oregon Department of Human Services in which 400 adults who have IDD and receive one other state service beyond case management are interviewed annually to find out how services and support help people with developmental disabilities.

Translational refinement of adaptive communication system for locked-in patients

Dr. Melanie Fried-Oken and her team partnered with Northeastern University to develop a communication system, also known as a brain-computer interface, for persons with minimal movement and speech. The system uses brain signals to select rapidly displayed letters for message construction in people who are locked-in.

Reproductive health research

Our research examines sexual behaviors and risks among teens with disabilities; contraceptive use and family planning among women with disabilities; health care quality for women with disabilities before and during pregnancy, and pregnancy outcomes.

Training future health care professionals and disability leaders

LEND Program

The Leadership Education in Neurodevelopmental and Related Disabilities training program for future health care leaders is funded by the Maternal and Child Health Bureau. The major goal of this project is to promote the health status of children (and their families) with neurodevelopmental and related disabilities by training health care professionals for leadership roles, collaboration with other agencies, and participation in policy development on health care.

Student internship programs

Opportunities are offered for a wide range of academic levels and abilities, from high school through graduate-level college experiences. Students gain practical experience in the disability field, develop transferable skills, and learn about various career paths in a professional health care setting.

Continuing education for professionals

These Continuing Education Credit events and programs are available to professionals in a variety of specialties seeking knowledge and skills to improve their ability to provide care and services for people with disabilities, and their families.

Data brief

National Core Indicators is a project that gathers health information and a standard set of performance and outcome measures. Oregon is one of 46 states which uses this NCI data to determine services for health and quality of life for individuals experiencing intellectual and developmental disabilities. The indicators are intended to provide a system-level snapshot of how well each state is performing relative to other states, to track their own performance over time, and to establish national benchmarks. Other states use NCI data for a variety of policy development, quality assurance, and strategic planning activities.

In 2018, we interviewed 431 Oregonians across the state. Here is a sample of their responses:

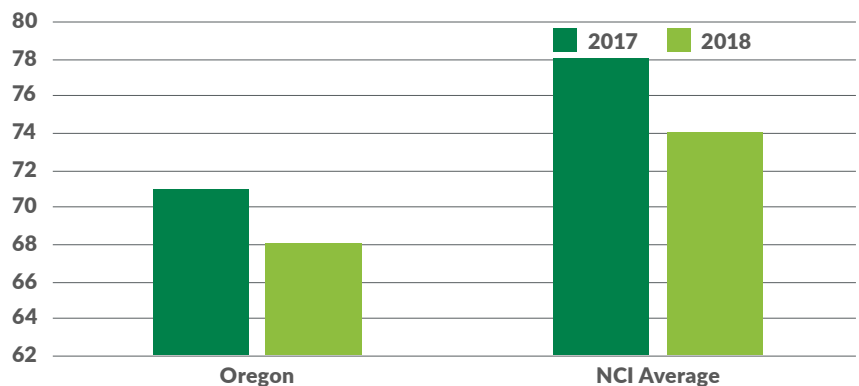
For more information, visit:

www.ohsu.edu/university-center-excellence-development-disability/national-core-indicators

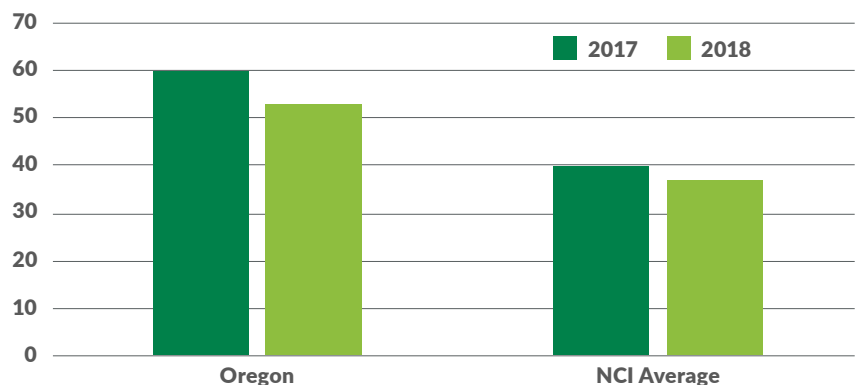
59% of respondents said they wanted more help making friends or keeping friends, compared to the national average of **42%**.

16% of respondents reported feeling lonely often, compared to the national average of **10%**.

Percentage of respondents receiving a flu vaccine in the past year



Percentage of respondents who had the opportunity to vote



Additional services needed most



Community Engagement Grant Program

The Community Engagement Grant Program was created to provide financial support to Oregon-based non-profit organizations to promote full access, capacity building, systemic change and advocacy for people with intellectual and developmental disabilities.

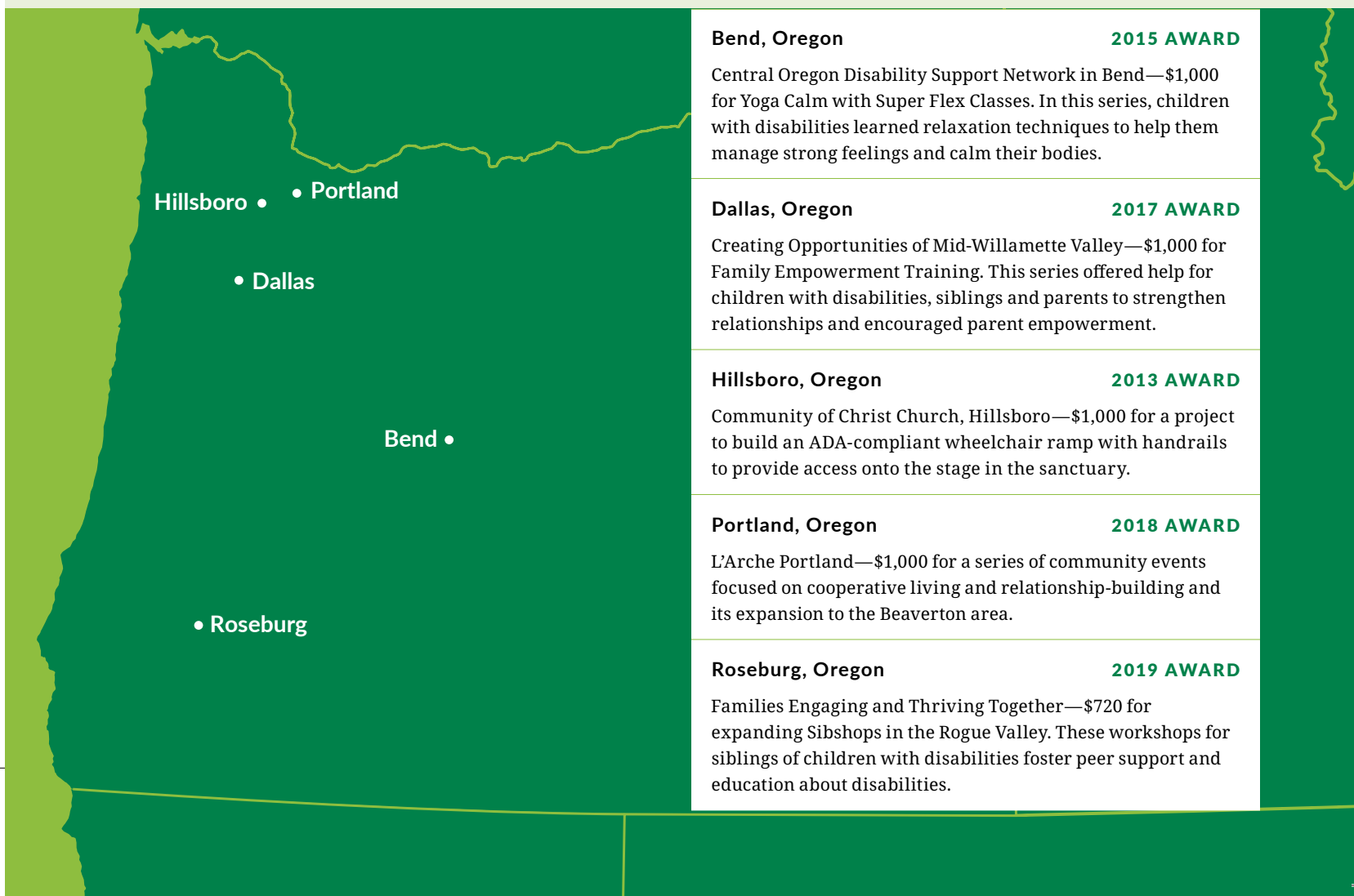
Every UCEDD has a community advisory committee, ours being the Community Partners Council or CPC. Members are individuals who experience disabilities, family members of individuals with disabilities, or anyone who has an interest supporting persons with disabilities and their families.

In collaboration with the CPC, we administer this program to help community-based organizations provide relevant

programming for people with disabilities and their families. Oregon non-profit organizations can apply for grants of up to \$1000 to develop and implement programming in the following areas: family support for people with disabilities, spirituality and disability, and health promotion and disability.

Members of the CPC review grant applications and make funding decisions while the UCEDD provides administrative and technical support for the program.

Grant awardees have expanded programming and completed projects in a wide variety of efforts across the state. A few examples are shown below:



Our research translated to plain language

Keywords

Primary progressive aphasia

PPA is a degenerative disorder in which a person experiences a loss in language expression and understanding.

Group communication treatment

A six-week program held twice weekly to educate about PPA and to introduce new ways to communicate. The program was developed and led by speech-language pathologists and graduate students.

Authors are from OHSU:

Institute on Development and Disability

Mooney, A., Beale, N., & Fried-Oken, M. (2018, July). "Group communication treatment for individuals with PPA and their partners." In *Seminars in Speech and Language* (Vol. 39, No. 03, pp. 257-269). Thieme Medical Publishers. doi: 10.1055/s-0038-1660784



What is the name of the study?

Group Communication Treatment for Individuals with PPA and Their Partners



Who are the authors of the study?

Aimee Mooney, M.S., C.C.C.-S.L.P.; Naomi Beale, M.S.; and Melanie Fried-Oken, Ph.D., C.C.C.-S.L.P.



What was the goal of this study?

The goal of this study was to show the benefits of group communication treatment for people with PPA.

What did we do?

A six-week program provided education on PPA signs and symptoms, and new methods of communication to adjust to living with PPA. It also provided social support by working with a group of people with PPA.

What did we learn?

Communication treatment in a group setting can improve conversational skills, increase social ability, and build community for people with PPA. The group participants in this study showed increased coping skills and their quality of communication improved. There is a beneficial social aspect of group communication treatment that greatly improves the lives of people with PPA.

Why is this important?

People with PPA have a greater risk for depression. They often feel isolated and withdraw from social activities because of their loss of language functions. Group treatment allows them to meet other people facing similar challenges, while learning about coping with PPA and expanding the ways that they can communicate.

Our research translated to plain language

Keywords

Sexual orientation

Being sexually or romantically drawn to persons of the same, or different, sex or gender expression and understanding.

LGB persons

Lesbian, gay, or bisexual people

Suicidal ideation

Wanting to take your own life or thinking about suicide

Authors are from OHSU:

1. Institute on Development and Disability

2. OHSU-PSU School of Public Health

Tejera, C. H., Horner-Johnson, W., & Andresen, E. M. (2019). "Application of an Intersectional Framework to Understanding the Association of Disability and Sexual Orientation with Suicidal Ideation among Oregon Teens." *Disability and Health Journal*. <https://doi.org/10.1016/j.dhjo.2019.05.006>



What is the name of the study?

Application of an intersectional framework to understanding the association of disability and sexual orientation with suicidal ideation among Oregon Teens



Who are the authors of the study?

César Higgins Tejera, M.D., M.P.H., M.S.,¹ Willi Horner-Johnson, Ph.D.,¹ and Elena M. Andresen, Ph.D.²



What was the goal of this study?

The goal of this study was to look at how disability and sexual orientation together relate to suicidal ideation.

What did we find?

Heterosexual (also known as straight) teenagers without a disability had the lowest risk of suicidal ideation. The people at the highest risk of suicidal ideation were LGB teens with disabilities. This was higher than both LGB teens without a disability and heterosexual teenagers with a disability.

What did we learn?

Being both LGB and disabled increases the risk of suicidal ideation beyond either identity by itself. When they occur together, disability and minority sexual orientation may make it more likely that teens will be treated badly by others. Bad experiences could increase the risk of suicide.

Why is this important?

There are ways to make places where teens live, learn and interact with others better for LGB teens and disabled teens. For example, public health efforts and school-based interventions could help lower the risk of suicidal ideation. These could especially help teens who have both of those identities.

Meet our experts

Kiersi Coleman

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Kiersi Coleman is a communication consultant, self-advocate, and program assistant for the UCEDD. Coleman provides expertise for website and social media content, and program implementation and evaluation. She leads efforts across communities within and outside of OHSU to improve the lives of people with disabilities, all while experiencing cerebral palsy herself.

Maureen DeLongis, M.S.W., L.C.S.W.

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Maureen DeLongis, M.S.W., L.C.S.W., is an assistant professor, and the director of social work for the Institute on Development and Disability. DeLongis specializes in providing mental health services to children and families experiencing neurodevelopmental disorders. Her focus includes sibling support, health care transition, and mental health.

Rhonda Eppelsheimer, M.S.W.

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Rhonda Eppelsheimer, M.S.W., is serving as the co-director of the OHSU University Center for Excellence in Developmental Disabilities. Eppelsheimer is credentialed as a licensed clinical social worker focusing on adolescent transition, mental health, and strengthening supports and systems for families who are raising children who experience disability.

Melanie Fried-Oken, Ph.D., C.C.C.-S.P.

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Melanie Fried-Oken, Ph.D., C.C.C.-S.P., the other co-director of the OHSU University Center for Excellence in Developmental Disabilities, is an international expert in the field of assistive technology for children and adults with disabilities. Dr. Fried-Oken conducts federally funded research in the area of augmentative and alternative communication.

Willi Horner-Johnson, Ph.D.

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Willi Horner-Johnson, Ph.D., is an associate professor and researcher at the Institute on Development and Disability. Dr. Horner-Johnson's research focuses on the reproductive health of people with disabilities, and on disparities in access to, and quality of, health care received by people with disabilities. She is also the principal investigator for the Oregon Office on Disability and Health.

Alison Martin, Ph.D.

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Alison Martin, Ph.D., is the assessment and evaluation coordinator for the Oregon Center for Children and Youth with Special Health Needs, the state's Title V block grant agency. Martin is also an evaluation consultant for the UCEDD. Her focus includes evaluation and applied research design for community-based interventions that promote youth well-being.

Alice Miller, M.S.W., M.P.H.

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Alice Miller, M.S.W., M.P.H., is the policy and advocacy program coordinator for the UCEDD. Miller leads research for the National Core Indicators project, an annual survey of adults with developmental disabilities receiving state services. Her areas of expertise include health and disability policy, home and community based services, and health disparities.

Emily Quinn, M.S., C.C.C.-S.L.P.

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Emily Quinn, M.S., C.C.C.-S.L.P., is a speech-language pathologist and researcher at the Institute on Development and Disability. Quinn's research and clinical interests include language interventions for children with neurodevelopmental disabilities, augmentative and alternative communication, and telehealth or telepractice.

Luis Rivas Vazquez

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Luis Rivas Vazquez is a research assistant for the Oregon Office on Disability and Health and for the UCEDD. Rivas Vazquez's work focuses on creating culturally and linguistically appropriate materials for trainings, workshops and curricula for both youth and adults with intellectual and developmental disabilities by providing Spanish translations.

Hannah Sanford-Keller, M.S., C.C.C.-S.L.P.

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Hannah Sanford-Keller, M.S., C.C.C.-S.L.P., is an assistant professor and speech-language pathologist at the Institute on Development and Disability. Sanford-Keller has advanced training in the diagnosis and treatment of autism spectrum disorders, communication disorders, and cleft palate or craniofacial disorders. She specializes in the 0–5 age range.

Lindsay Sauv , M.P.H.

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Lindsay Sauv , M.P.H., is the program and evaluation manager for the UCEDD. Sauv  leads the evaluation activities of the UCEDD's core grant, as well as develops and manages outcome-based model programs for community members with disabilities, with a focus on health promotion for transition-age youth.

Bethany Sloane, P.T., D.P.T.

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Bethany Sloane, P.T., D.P.T., is an assistant professor and a pediatric physical therapist at the Institute on Development and Disability. Sloane is also the diversity coordinator for the Institute on Development and Disability Diversity Committee and works to promote equity within our organization and out in the community.

Kim Solondz, M.S., O.T.R./L.

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Kim Solondz, M.S., O.T.R./L., is director of the Occupational Therapy Program at the Institute on Development and Disability. Solondz has expertise in health care transition for teens and young adults with disabilities. She also directs the AOTA-Accredited Occupational Therapy Fellowship Program training occupational therapists focused on neurodevelopmental and related disabilities.

Janice Staehely

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Janice Staehely is a communication consultant, self-advocate and blogger for the UCEDD and the Institute on Development and Disability. Staehely is also a UCEDD research assistant. While experiencing cerebral palsy and using an assistive communication device, she passionately advocates for disability rights and inclusive access to health care.

Erin Taylor

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Erin Taylor is the health promotion coordinator for the Oregon Office on Disability and Health and for the UCEDD. Taylor's work focuses on creating accessible, universal and age-appropriate materials for trainings, workshops, and curricula for both youth and adults with intellectual and developmental disabilities.

Angela Weaver, M.Ed.

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Angela Weaver, M.Ed., is program manager for the Oregon Office on Disability and Health, a partner and shared office with the UCEDD. Weaver has worked for the past 20 years on policy, system and environmental changes through local partnerships, and education efforts to support access and inclusion of people with disabilities.

Larissa Yoshino, M.P.H.

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Larissa Yoshino, M.P.H., is the data and dissemination coordinator for the UCEDD. Yoshino oversees the UCEDD's core grant-specific National Information Reporting System database, and assists with grant reporting, product development and community outreach. Her expertise is in public health issue-framing, policy advocacy, and communication strategy.



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