

Two Centers at OHSU's Institute on Development and Disability Partner to Reach Oregonians Across the State:



In a collaborative partnership, Oregon Office on Disability and Health (OODH) and the University Center for Excellence in Developmental Disabilities (UCEDD) are conducting a series of disability and health listening sessions in six communities: Gresham, Hillsboro, Pendleton, Bend, Grants Pass, and Coos Bay. The goal of the listening sessions is to better understand the health and wellness needs of people with intellectual and developmental disabilities (I/DD) by hearing directly from people with I/DD, their case managers, direct support staff, and service providers. Information gathered from the listening sessions will help both centers develop effective and successful health promotion curricula and programs, trainings for professionals and community members, health transition guidance and plans, and targeted wellness media campaigns.

The first two listening sessions were conducted in Pendleton on November 7th and Hillsboro on March 21st. We spoke with disability service providers, community health workers, public health employees and people with I/DD. The topics discussed during the listening session included tobacco use, sexual health, mental health, and diabetes. OODH and UCEDD staff shared information on each of the 4 topics, including prevalence and health disparities data and current trends or needs, and then conducted round table discussions with attendees. We asked questions that addressed:

- what they felt were their community's strengths, gaps and training needs,
- who in their community currently provided supports and/or training,
- who in their community would be best to provide supports and/or training and in what delivery format, and
- what additional information they would like on each topic and how can OODH and the UCEDD help.

The initial results from the listening sessions provided many valuable insights into the health promotion and education resources, supports, gaps, and needs within the communities. One example of a great success of the Pendleton event was the connection that was made between the local public health department (LPHD) and several of the disability agencies' representatives.

It was apparent that the disability agencies' staff and people with I/DD did not know about the wealth of information, supports, and services available to them from their LPHD, especially the tobacco cessation resources. After the LPHD employees shared information about their resources, two participants with I/DD stated how excited they were to go to the LPHD after the listening session to begin their journey to quit tobacco. During the Hillsboro event, we learned from the attendees about the lack of, and thus the need for, high quality training for direct service staff on all four health topics. In addition to the lack of training, it was also shared that there is a gap in communication between the entities that provide the training and direct support workers and others who can benefit from the training. One idea that was shared and embraced by everyone to help with the gap in communication and other resource needs, was to find a way to develop a centralized resource hub that provides a wide variety of information and resources for people with I/DD and their families and support staff.

The lack of mental health services drew significant attention as one of the most pertinent needs at both listening sessions. The issues included the overall lack of mental health providers in rural Oregon compounded by the lack of providers (both in urban and rural Oregon) who are trained to work with people with I/DD and who accept Medicaid. There were also passionate discussions about the need to decrease or eliminate the stigma that still exists for those with a mental health diagnosis and/or those simply wanting to access services. The attendees in Pendleton also shared their frustration regarding the lack of opportunities within their rural community for people with I/DD that offered social connection and promoted a sense of community and belonging.

At the conclusion of the listening sessions it was clear that although there are caring agencies doing their best to provide services, there is a significant need for: 1) affordable, appropriate and high-quality training for professionals providing services to people with IDD; 2) community education and organizing to help address access barriers (including stigmas), bridge the financial gaps, and leverage supports and resources; and 3) collaboration between agencies and community partners to better assist people with I/DD to navigate services.

Upcoming Listening Session Dates:

- April 8-9 – Bend
- April 22 – Gresham
- May 7-8 – Grants Pass
- May 9-10 – Coos Bay

For more information, contact oodh@ohsu.edu.