



Disability and Health Across Oregon: Using Community Listening Sessions to Inform Health Promotion Programming

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About us

We are the Oregon Office on Disability and Health (OODH) and the University Center for Excellence in Developmental Disabilities (UCEDD) at Oregon Health & Science University in Portland, OR. We work with each other and partner organizations in Oregon to improve the health and quality of life of people with disabilities.

What we did

In 2018 and 2019, we visited communities in Oregon and held listening sessions with disability service providers, direct support staff, care givers, parents and self-advocates to learn about the health of people with intellectual and developmental disabilities (I/DD). The goals of the listening sessions were to:

- understand the barriers and challenges within communities that contribute to high rates of diabetes and mental and sexual health;
- learn from participants about solutions for improving diabetes, mental health, and sexual health for people with I/DD;
- identify training needs and ways to deliver trainings that would improve services and health equity for people with I/DD.

How we did it

We held five listening sessions, three in rural areas and two in urban areas. We partnered with local disability agencies to help with recruiting participants.

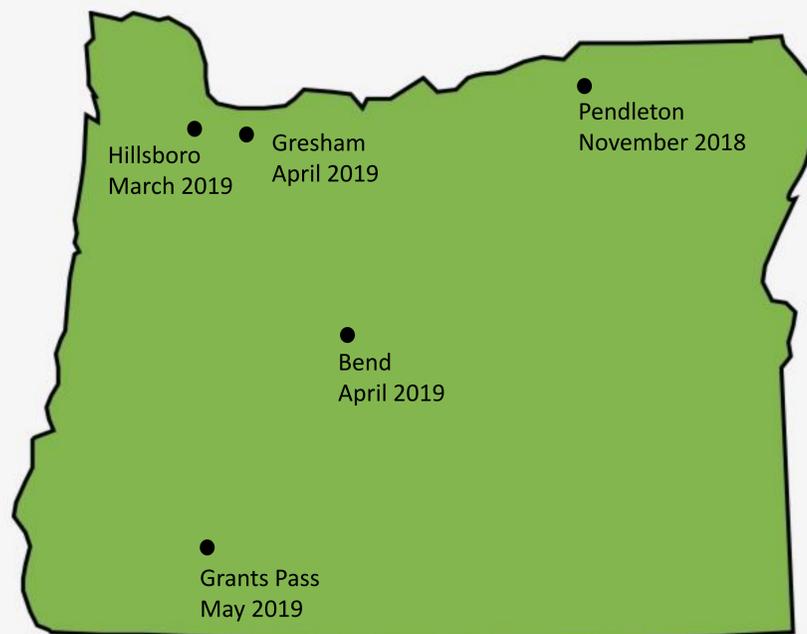
City	County	County population	# of participants
Pendleton	Umatilla	76,985	10
Bend	Deschutes	186,875	15
Hillsboro	Washington	588,957	12
Gresham	Multnomah	807,555	10
Grants Pass	Josephine	86,352	15

Facilitators began the sessions by orienting the participants to the topics of diabetes, mental health, and sexual health by sharing data and research related to disparities. The participants broke out into small groups of 3-4 people with a facilitator and a note taker. The discussion sessions consisted of three 30-minute rounds of questions about diabetes, mental health, and sexual health. After each round, the participants debriefed as a large group to share key discussion points. OODH and UCEDD staff analyzed the data by grouping the discussion points into key themes.

“It’s not always best for diabetes education to come from staff or caregivers. Apps or technology may work better.”

“Holding events like a walk for mental health awareness can help normalize mental health and reduce stigma.”

“Some people are getting no sexual health education at all. No one is bringing it up or talking about it. It’s just not discussed.”



“Health care providers need training on how to explain a diabetes diagnosis in a way that is understandable. Many people don’t know what diabetes is because it’s not explained well.”

“There are few mental health care providers that accept Medicaid and the ones that do have long wait lists. If you miss one appointment, you have to start all over again.”

What we learned

Diabetes findings:

- Health care providers need training on how to explain diabetes management in accessible ways.
- Staff need adequate training supporting someone with diabetes, but some people don’t want to be educated/support about their diabetes by staff and caregivers.
- Rural areas lack accessible exercise opportunities and nutrition education.
- People who live on their own may have less access to coordinated care than those who live in other settings.

Mental health findings:

- There are few mental health providers who accept Medicaid, especially in rural areas, and those that do have long waitlists.
- Mental health stigma along with bad experiences with the system keep people from asking for help and accessing services.
- Training needs: basic mental health first aid training for staff; stress management for people with I/DD.

Sexual health findings:

- Direct support staff have little if any training on how to support sexual health and healthy relationships.
- People are not always provided with privacy to express their sexuality and are sometimes typical sexual behaviors are labeled as “problem” behaviors.
- People don’t always know their rights when it comes to dating, sex, and relationships.
- Training is needed on how to safely use the internet to explore, meet people, and date.

What we did with the information

The information from the listening sessions have helped inform the following projects:

- Partnering with a company to develop a web-based tool to help people with I/DD manage diabetes.
- Revising the Healthy Lifestyles curriculum to incorporate stress management lessons.
- Partnering with two organizations to develop a program that will train disability professionals to become sexual health advocates.

Acknowledgements

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