



CASE STUDY: OREGON HEALTH AUTHORITY

Inclusion of People With Intellectual Disabilities in Tobacco Cessation Programs

People with intellectual disabilities often face barriers to accessing public health promotion and protection activities, making them particularly vulnerable to preventable disease and injury. In turn, practicing inclusive health not only provides more equitable access to public health resources, but also leads to improved health outcomes and helps health departments meet and maintain a variety of public health accreditation standards. The Public Health Accreditation Board, with funding support and in partnership with Special Olympics International, presents this short case study for the purpose of exploring how the Oregon Health Authority is working to ensure that tobacco cessation resources and assistance are accessible to people with intellectual disabilities. Oregon Health Authority is among a handful of state and local health departments across the nation that are advancing inclusive health for people with intellectual disabilities.

THE PROBLEM

In Oregon, like the rest of the country, tobacco use continues to be a leading cause of preventable death, exacerbating and causing a range of chronic, costly and often-debilitating diseases such as heart disease, stroke and diabetes. Though decades of public health efforts have pushed U.S. smoking rates to historic lows, people with intellectual disabilities use tobacco at disproportionately higher rates than the general population. However, research shows that people with intellectual disabilities who use tobacco are just as likely to want to quit as their tobacco-using peers who do not have intellectual disabilities. Such disparities must be addressed if life-saving cessation resources are to be made accessible to people with intellectual disabilities.

BACKGROUND

Cigarette smoking among Oregon adults has dropped significantly in the last two decades, however big disparities still remain between the general population and those with disabilities. According to data from the Oregon Health Authority, about 17 percent of Oregon's general population reports current smoking; however, among people with disabilities, the rate is closer to 46 percent. To further complicate the matter, there is little research focused on tobacco use by type of disability. What is known, however, is that people with intellectual disabilities who use tobacco products are just as likely to want to quit as their peers without intellectual disabilities.

"When you look at the numbers and see who's using tobacco, it simply can't be ignored," said Kirsten Aird, MPH, Cross Agency Systems Manager in the Health Promotion and Chronic Disease Prevention Section of the Oregon Health Authority Public Health Division. "So the question was how do we make the system available to everyone? How do we make sure everyone knows about our (tobacco cessation) resources and can access them?"

To address the problem, the agency's Tobacco Prevention and Education Program (TPEP) and the Oregon Office on Disability and Health partnered to convene the Tobacco Education Project for People with Disabilities, which officially launched in 2014. Among the project's goals: develop an automatic referral system between disability service organizations and the state's Quit Line; rework Quit Line materials so that they effectively engage and speak to people with intellectual disabilities; and encourage more disability service agencies and campuses to officially go tobacco-free.

This ongoing inclusive health effort relies on key public health competencies to create change, such as facilitating cross-sector partnerships, following the data, and tailoring resources in a way that fosters equitable access to health-promoting opportunities and resources.

"We have to look at the entire system and make sure we're using data to understand where the need is and then make the system responsive," said Aird. "If we can do that together, then we can make the system better for everyone."

The Oregon Office on Disability and Health — a state public health entity funded by the Centers for Disease Control and Prevention and housed at Oregon Health and Science University (OHSU) — led the inclusive tobacco education project, which like most public health efforts began by gathering data on current gaps and needs. In the spring of 2014, organizers fielded a survey among Oregon's disability service provider organizations, hoping to find out more about their participation and interest in tobacco education activities.

Across the state, 140 disability organizations, including those serving people with intellectual disabilities, participated in the survey. Among the results:

- On average, about 22 percent of an agency's staff used tobacco.
- On average, about 19 percent of people with disabilities that the agencies served used tobacco.
- About 49 percent of respondents were not aware of free cessation benefits offered via the Oregon Tobacco Quit Line.
- More than 34 percent said their organization did not have a tobacco-free campus and grounds policy, which can help encourage people to quit tobacco. Nearly 24 percent were not aware whether their organization had such a policy or not.
- Nearly 38 percent of respondents said they were interested in learning how their organizations could participate in a tobacco referral program, which would involve setting up a system to ask people with disabilities about their tobacco use and if they would like the Quit Line to call them.
- More than 81 percent said they would like cessation and prevention materials to disseminate within their organizations.

SOLUTION

With data in hand, organizers began reaching out and inviting disability groups to participate in an educational webinar about tobacco use among people with disabilities and the resources available to help push down tobacco use rates among both staff and clients. In addition to educating and raising awareness, organizers also hoped the webinar would generate interest in building more formal connections between disability service providers and local TPEP coordinators, who help implement and refer people to the state's 24-hour Tobacco Quit Line. According to Angela Weaver, MEd, Program Manager in the Oregon Office on Disability and Health, about 100 people participated in the webinar, which took place in late spring 2014.

"One of our biggest successes so far has been partnership-building," Weaver said. "Facilitating connections, letting disability providers know there's help available in the community, and educating TPEP coordinators that the current system wasn't reaching this vulnerable population."

In the months following the webinar, Weaver and colleagues began connecting interested disability service providers with TPEP coordinators working in local and tribal health agencies. Organizers also began distributing new prevention and cessation materials tailored to speak to people with intellectual disabilities. The revamped materials, based on existing ones available via SmokeFree Oregon, included photos of people with intellectual disabilities, used accessible language and featured the Quit Line number.

Project organizers worked with OHSU's Center for Excellence on Developmental Disabilities — such centers are federally funded and exist in every state — as well as its Community Partners Council to focus group the new materials and ensure the messaging was culturally competent. Weaver said some members of the Community Partners Council even agreed to have their photos featured in the outreach materials.

The Office on Disability and Health printed a range of materials to support the new cessation and education push, including palm cards, brochures and posters, and disseminated hundreds of materials to disability agencies and TPEP coordinators around the state.

“Ensuring that the materials include images of people with intellectual disabilities is so important,” Weaver said. “That’s what makes it relatable.”

On the Public Health Division side, Aird said the agency worked with its Quit Line contractors to make sure services were culturally competent and accessible to people with intellectual disabilities. The agency also worked with the Office on Disability and Health to train caregivers and service providers on how to refer people with intellectual disabilities to the state Quit Line. In fact, Aird noted that training staff on how to effectively serve people with intellectual disabilities is part of its agreement with Quit Line contractors.

“We have resources and so we have leverage,” Aird said of the agency’s role in reaching people with intellectual disabilities and their providers. “It’s a very tactical and tangible example of a long history of intentional efforts to help people live tobacco-free.”

To date, the Tobacco Education Project for People with Disabilities continues to gain traction — for instance, a number of local tobacco prevention programs and disability providers have teamed up to disseminate Quit Line materials. However, Weaver said the effort is still evolving and changing.

For example, one goal of the project was to help disability providers become Quit Line referral agencies. Ideally, the service provider would identify people who want to access cessation services and arrange for the Quit Line to contact the person directly. However, feedback from disability providers shows that connecting and engaging people with intellectual disabilities with Quit Line counselors is still too difficult. In turn, Weaver said the project is working with its partners to explore new options, such as peer-to-peer mentoring or a cessation rewards program. Also in the future, Weaver said the project hopes to include Special Olympics Athletes in its anti-tobacco programming, offer health education at its competitions, and provide coaches with health promotion materials.

“This is such a great example of how — with a minimal amount of money — you can make a huge difference in making sure the system works for everyone,” Aird said. “It’s also an example of how the public health accreditation process pushes us to get creative in responding to the community’s needs.”

CHALLENGES

As is the case with designing and implementing any community health program, a number of challenges had to be addressed, such as:

- **People with disabilities have much higher rates of tobacco use** than their tobacco-using peers, however little research is available on tobacco use by disability.
- **More than 34 percent of disability service organizations surveyed** did not have a tobacco-free campus and grounds policy, which can fuel tobacco use rates.
- **About 49 percent of disability service organizations surveyed** were not aware of free cessation benefits offered via the Oregon Tobacco Quit Line.
- **Feedback from disability providers showed** that connecting and engaging people with intellectual disabilities with Quit Line counselors remained difficult. One goal of the project was to help disability providers become Quit Line referral agencies.
- **Striving for cultural competency** required tailoring new prevention and cessation materials.

LESSONS LEARNED

Best practices for inclusion of people with intellectual disabilities in tobacco cessation programs include:

- **Make your materials relatable.** Include images of people with intellectual disabilities on all outreach materials, such as palm cards, brochures, and posters.
- **Make training a priority.** Don't assume that staff will automatically know how to effectively serve people with intellectual disabilities. Make training part of your agreement with contractors, such as Quit Line counselors.
- **Follow the data.** It is only through data collection that you will gather the quality information needed to ensure that people with intellectual disabilities have access to life-saving resources.
- **Focus group your messaging.** Inviting people with intellectual disabilities to participate in focus groups will give you a better idea of how your messaging and outreach materials resonate with this community.
- **Let the community lead the way.** If the intervention isn't resonating with the intended audience, don't be afraid to make changes or even go back to the drawing board.
- **Fill the gaps.** Use data to understand where the need is throughout the entire system, and then make the system responsive.

ADDITIONAL RESOURCES

Tobacco Education Project for People with Disabilities

Oregon Office on Disability and Health

www.ohsu.edu/xd/research/centers-institutes/oregon-office-on-disability-and-health/programs/building-inclusive-communities.cfm

Disability Quit Resources

SmokeFree Oregon

<http://smokefreeoregon.com/resources/disability-quit-resources/>

Health Promotion Resources

Special Olympics

https://resources.specialolympics.org/Taxonomy/Health/Health_Promotion_INT.aspx

How to Help People with Disabilities Quit Smoking

Centers for Disease Control and Prevention

www.cdc.gov/features/disability-quit-smoking/index.html

QUESTIONS?

If you are interested in learning more about this program or how you can apply some lessons learned to your own organization, please contact Angela Weaver at weaverro@ohsu.edu.