Building Disability-Led Public Health Systems in Indiana

Public health programs do not always work well for people with disabilities, especially people with intellectual and developmental disabilities. During the coronavirus pandemic (COVID-19), many disability advocates saw that people with disabilities were often left out of emergency planning, healthcare and public health information.

Tony Lee Gunter, a community leader and Special Olympics Health Ambassador, described the challenge this way:

"Trying to navigate health services is hard for regular people. It's twice as hard for a person with a disability."

To address the higher rates of cancer and tobacco use among people with disabilities , the Indiana Department of Health partnered with the Indiana Governor's Council for People with Disabilities' 5x5 Public Health project, disability advocates, and community leaders to form a new project called No Barriers Just Better Health. . The goal was to ensure that people with disabilities helped shape public health decisions rather than simply receiving services.

No Barriers Just Better Health focuses initially on getting people to stop using tobacco. Now its broader impact extends far beyond a single health issue and can inform public health professionals and policymakers about disability-led practices.

Shared Decisionmaking

Rather than asking community members to review plans after decisions had already been made, people with disabilities helped shape the project from the beginning. They participated in planning meetings, helped set goals, reviewed materials and contributed to evaluation activities.

The No Barriers Just Better Health project also included supports that made participation easier, such as:

- Plain-language materials
- Flexible meeting formats
- Communication support
- Preparation meetings
- Supported decisionmaking

Cierra Olivia Thomas Williams, a workgroup member and founder of the Nothing Without Us Collective, explained:

"It's really about helping people who usually have all the power learn how to share that power."

Participants repeatedly noted that disability leadership influenced both project priorities and implementation decisions. Community members helped shape outreach strategies, communication approaches, project goals and evaluation activities. As one participant reflected, "This is not something they would have done before Tony was a leader in this project."

Making Communication Easier to Understand

Participants explained that public health information is often difficult to understand because it uses technical language, acronyms and complicated data. To address this challenge, community members and public health staff worked together to simplify communication.

They reviewed educational materials, redesigned presentations, simplified planning documents and created outreach tools using plain language. These changes helped people with disabilities better understand information and make informed decisions about their health. Staff also found that clearer communication benefited not only people with disabilities, but also public health professionals and community partners.

Changing Public Health Practice

The No Barriers Just Better Health project not only involved more people in planning; it also changed how public health work was done.

Public health staff adapted meeting structures, communication practices and decisionmaking processes to support broader participation. The team began conducting accessibility reviews for public-facing materials. They redesigned educational resources, simplified data displays and added disability-related questions to Quitline systems – a free, confidential coaching and support to help you quit smoking, vaping, or using tobacco products.

The project also increased awareness of the need for better disability-related data. Participants emphasized that public health agencies need accurate information on disability status, barriers to care and health outcomes to identify gaps and improve services. The project helped elevate conversations about disability data collection within public health planning and evaluation.

Healthcare organizations participating in the project — including community advocates, volunteers and service providers — reviewed their accessibility practices and developed plans to improve services for people with disabilities.

Participants said these changes improved communication, teamwork and accessibility across agencies and organizations.

Early Results

Although long-term health outcomes are still being studied, participant interviews share that the project has already produced important changes. These include:

- Increased participation in public health planning by people with disabilities
- Stronger partnerships across organizations
- Improved accessibility practices
- More accessible communication
- Greater awareness of disability-related issues in public health

Participants also reported a greater understanding of supported decisionmaking and the importance of including disability perspectives in public health systems. Disability leaders helped shape outreach strategies, project goals, communication approaches and evaluation activities throughout the project.

Challenges and Lessons Learned

Participants described the project as both rewarding and challenging. Meaningful participation from people with IDD required additional planning, accessibility supports, communication changes and ongoing relationship-building. Public health professionals often had to rethink traditional ways of working and decisionmaking.

As Sally Petty, regional program director of the Indiana Department of Health's Tobacco Prevention & Cessation Program reflected:

"It is hard to share power."

The project also helped healthcare organizations assess the accessibility of their services for people with disabilities. Partner organizations tested provider review tools that examined accessibility, cancer screening, tobacco prevention, guardianship issues, violence prevention and service navigation. Participating organizations re-

viewed their practices, developed improvement plans and committed to making at least one organizational change. These efforts helped move disability inclusion beyond meetings and into healthcare delivery. The project also required dedicated staff, facilitation support, accessibility tools and funding. Participants noted that expanding the work will require continued investment and organizational commitment. Despite these challenges, participants consistently said the process led to stronger programs and better outcomes.

Lessons for Other Public Health Agencies

Participants identified several lessons for other agencies:

- Build trusted relationships first
- Budget time and money for accessibility and facilitation
- Collaborate across teams and organizations
- Include people with disabilities from the beginning
- Treat lived experience as expertise
- Reduce communication barriers
- Allow time for collaboration and shared decision-making

Community participants who were involved in the project also recommended starting with smaller projects and partnerships before expanding to greater efforts. Building relationships and establishing accessibility practices early can help create stronger programs over time.

Participants emphasized that sustaining this work will require continued investment. The project relied on dedicated staff, facilitation support, accessibility resources and ongoing relationship-building. Several participants noted that long-term success will depend on continued funding and organizational commitment.

Conclusion

The No Barriers Just Better Health project shows that disability inclusion requires more than inviting people with disabilities to participate. It requires accessible communication, shared decisionmaking, strong partnerships and a willingness to redesign how public health work is done.

By placing lived experience, accessibility and supported decisionmaking at the center of planning, the project offers a practical model for creating public health systems that are more responsive, collaborative and effective for everyone.