



Cross Agency Collaboration: Creating a Shared Vision for a Healthier Indiana for All

With funding from the Administration on Community Living (ACL) and the Centers for Disease Control and Prevention (CDC) through the American Rescue Plan Act of 2021 (ARPA), the Governor's Council for People with Disabilities (GCPD/the Council) designed and implemented the 5x5 Public Health Internship, a project-based learning internship for five rising public health professionals. As a result of that program, the Council, in partnership with the Indiana Department of Health (IDOH), continued collaborative efforts through the 5x5 Public Health Initiative. The initiative aims to ensure people with intellectual and/or developmental disabilities (ID/DD) have a voice in shaping public health policy and practice. This initiative supports leaders with ID/DD to participate meaningfully in high-level decision-making spaces, such as boards, task forces, and steering committees; where public health priorities, strategies, and funding decisions are made.

This work is grounded in national legislation and supported through state plans. The Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) states that people with intellectual and developmental disabilities (ID/DD) should guide the policies and programs that affect their lives (Administration for Community Living, 2000). The DD Act affirms the right of people with disabilities to self-determination, independence, productivity, and inclusion in all aspects of community life. In Indiana, the GCPD Five-Year State Plan (2022–2026) builds on this mandate by setting goals for leadership, advocacy, and system-level change (Indiana Governor's Council for People with Disabilities, 2021). The plan prioritizes increasing opportunities for people with ID/DD to serve on boards, councils, and workgroups, ensuring their voices guide statewide policy and practice. By linking public health initiatives with these mandates, the 5x5 Public Health Initiative maintains alignment with federal and state commitments. In addition, by partnering with IDOH Tobacco Prevention and Cessation Division (TPC) and Comprehensive Cancer Program, the collaboration ensures there are increased efforts to reduce tobacco use, prevent cancer, and improve healthcare access for Hoosiers with ID/DD who are most impacted by lack of quality healthcare access, a Social Driver of Health.

The heart of this initiative is the belief that incorporating people with disabilities in public health and other initiatives must move beyond a participatory, transactional role to shared transformational leadership. Through intentional mentoring, accessible communication, and relationship-building, these practices transform participation into opportunities where emerging leaders with ID/DD are paired with experienced professionals.



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Introducing the 5x5 Public Health Initiative

In September 2023, the National Institutes of Health formally designated people with disabilities as a population with health disparities (National Institutes of Health, 2023). This decision recognizes that disability is shaped not only by individual health conditions but also by Social Drivers of Health, which include environments, policies, and systems that influence access to care. This designation calls on public health agencies and policymakers to address the conditions that contribute to poor health outcomes and shorter lifespans among people with disabilities. It highlights the need for systematic change across all Social Drivers of Health, such as healthcare access, education, community contexts, economic stability, and the built environment. The 5x5 Public Health Initiative responds directly to this call by embedding disability leadership within Indiana's health systems, aligning state-level public health priorities with national efforts to advance self-determination and participation for people with ID/DD. In response to this national call to action, GCPD is taking concrete steps to strengthen health outcomes for people with disabilities.

The new partnership between the Governor's Council for People with Disabilities (GCPD) and IDOH TPC and Comprehensive Cancer Program is amplifying the voices of people with Intellectual and Developmental Disabilities (ID/DD) by increasing leadership opportunities within public health decision-making. Across Indiana, people with disabilities face greater challenges when it comes to smoking, cancer prevention, and access to health services. Hoosiers with disabilities smoke at higher rates, have fewer opportunities to receive early cancer screenings, and encounter barriers in healthcare settings that make support harder to reach (Hughes et al., 2022; United Health Foundation, 2024). Barriers such as complex communication, lack of tailored resources, and limited provider training mean that the people who need preventive services the most often have difficulty getting them. Recognizing these concerns, the Indiana Department of Health took steps to work alongside community members and partners to find practical ways to improve access, strengthen prevention efforts, and support healthier outcomes for Hoosiers with disabilities.

Through mentorship, accessible communication, and shared leadership, the 5x5 Initiative demonstrates how people with ID/DD in leadership roles can shape policies and programs and address systemic barriers in Indiana communities. At its core, the GCPD 5x5 Public Health Initiative helps people with ID/DD take their place at decision-making tables, such as workgroups, boards, task forces, and steering committees. This helps to ensure the strengthening of public health policies and practices for Hoosiers with ID/DD, which will help to improve health outcomes and include disabled voices from the start. The partnership between GCPD and IDOH TPC and Comprehensive Cancer Programs demonstrated the value of including community members with ID/DD in high-level decision making – value to public health professionals, public health programs, disability programs, and to the community members themselves.



Leaders with Lived Experience

As part of the partnership with IDOH, GCPD staff worked to recruit a person with a disability who is interested in improving health outcomes for people with disabilities to serve on a disability tobacco and cancer prevention program planning workgroup this summer. The 5x5 Public Health Initiative's primary community representative for this project is a coach, health advocate, athlete, and a gold medal winner in the Special Olympics. He believes *"people with disabilities have a voice and deserve to be heard."* He notes that too often, *"people are pushed aside or told they won't succeed,"* but opportunities for leadership change that narrative. A key part of his success has been his collaboration with a seasoned professional, who brings 25 years of experience in public health, prevention, expertise and support. He served alongside 13 other public health professionals and disability experts on a summer workgroup to design a new initiative to address elevated tobacco use and cancer rates among people with disabilities in Indiana.

Early outcomes of the 5x5 Public Health Initiative and the partnership between GCPD and IDOH have demonstrated measurable change across public health divisions. This summer, IDOH TPC and Comprehensive Cancer Program partnered with GCPD to include people with ID/DD in tobacco and cancer prevention program planning and design. Because of this partnership, IDOH staff began shifting how they approached program design, such as by adopting plain language and inclusive data practices. Community participants in the IDOH disability tobacco and cancer prevention workgroup this summer emphasized that accessible communication is key to their participation: *"The use of technical terms in meetings made it hard to follow. Fancy or professional language doesn't help the patient and can make people feel unintelligent."* Plain language avoids jargon in favor of concise everyday language.

Public health professionals within TPC and Comprehensive Cancer Program have been demonstrating new skills in accessibility and communication. For example, IDOH "No Barriers, Just Better Health" program documents (vision, goal, SMART objectives, strategy, and implementation plan) are written using plain language, as well as in the format typically used in public health program design. Additionally, resources are being created to support participation from people with ID/DD in future public health program planning and to ensure their access to chronic disease and prevention programs. Community participants also report meaningful cultural change within TPC and Comprehensive Cancer Programs, including reduced stigma, greater disability awareness, and more openness about disability in leadership spaces. As one leader shared, *"It felt like they were listening to me. I was more than just a seat at the table."*

Centering the leadership of people with ID/DD in this initiative models a sustainable, relational approach to public health. It shows that inclusion works better in systems when it is an ongoing practice that deepens trust, belonging, and accountability. People with ID/DD bring first-hand knowledge of where systems do not meet their needs



(inaccessible communication, lack of transportation, etc.), which helps public health programs to target and close these gaps. When people who use the systems help design them, services, outreach, and messaging reflect real community needs and daily experiences, increasing impact. Shared leadership fosters transparency and mutual responsibility, ensuring that policies and practices are not only well-intentioned but also measurable and responsive to community feedback. Integrating multiple ways of thinking and communicating leads to creative solutions that benefit all community members, not just those with disabilities. When people with ID/DD lead, public health becomes more, relevant, responsive, and effective for everyone.

Leadership Opportunities That Make an Impact

Designing programs for communities with leadership from people with ID/DD helps to shift public health systems to an integrative approach where those affected most by poor health outcomes are included and considered. Additionally, program design and implementation become more accessible, relevant, and effective for communities. This approach also strengthens capacity for health professionals by increasing disability awareness and building the skills needed to respond effectively to diverse community needs. For many, this leadership experience also challenges stigma and expands visibility. As one participant expressed, *"It shows how much of a role model I could be. I'm trying to set a precedent that people with disabilities can do anything they want to do if they just put their mind to it."*

The GCPD Process for Inclusive Leadership

The initiative uses practical strategies to transform participation into leadership. There are five elements to ensure this collaboration becomes a successful daily practice:

- **Mentorship and Collaboration:** Pair emerging leaders with ID/DD and experienced professionals in order to foster mentorship, coaching, and deep understanding of relevant concepts and (when needed) in-field language.
- **Preparation and Reflection:** Engage in regular meetings before and after workgroup sessions to build comfort with meeting processes, build familiarity, and strengthen relationships. These sessions provide space to review materials, create plain language summaries, discuss decisions, clarify key points, gather feedback, and complete action items.
- **Model Inclusion:** Demonstrate accessibility and shared decision-making practices. This includes talking through the outcomes of project meetings, supporting tasks such as developing presentations, conducting research, and shaping ideas for broader systems change.
- **Leadership Development:** Work together to identify opportunities and provide individualized support, such as drafting application materials, biographies, résumés, cover letters, and recommendation letters for participation on advisory committees and other decision-making bodies.



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- **Training and Technical Assistance:** Collaborate to provide tailored guidance to health agencies and partners on implementing accessible practices. Support teams in applying new skills, such as accessible communication methods, that build capacity to sustain meaningful participation by people with ID/DD.

Outcomes of Inclusive Leadership

Early outcomes demonstrate that meaningful participation by people with ID/DD strengthens professional practices, public health systems, and professional culture:

- **Expanded Accessibility Practices:** Public health divisions are now using plain language to clarify goals, strategies, and data.
- **Improved Communication:** More than half of workgroup members reported that disability-led feedback helped make complex topics easier to understand.
- **Capacity Building:** Health professionals strengthened their skills in inclusive communication, accessibility, and data literacy.
- **Resource Redistribution:** Time, training, and financial support were intentionally allocated to support the full participation of leaders with ID/DD.
- **Cultural Shifts:** Participants reported reduced stigma, increased disability pride, and greater openness in disclosing disability within leadership spaces. One participant reflected on this change.

The Perspective of the Indiana Department of Health

The IDOH TPC and Comprehensive Cancer Programs recognized that Hoosiers with disabilities experience higher rates of tobacco use, cancer incidence, and cancer mortality than people with no disability in Indiana (Petty, 2025). Inaccessible healthcare environments and public health materials, limited preventative care, and gaps in data collection and reporting make it difficult to serve community members who need the interventions the most. In response, IDOH's Tobacco Prevention and Cessation and Comprehensive Cancer divisions have partnered with the GCPD to create pathways for change within the public health system.

For IDOH, meaningful progress requires building accessibility into every layer of public health practice. The participating divisions along with internal and external partners are working to develop and test new tools, such as accessibility audits, provider trainings, and inclusive communication materials. These help systems identify and remove barriers to care for people with ID/DD. By focusing on health systems, this approach aims to make preventative care, cancer screenings, and cessation services available and welcoming to all Hoosiers.

This collaboration represents a cultural shift in how public health is practiced in Indiana. Instead of designing programs for people with disabilities, IDOH is designing them with people who have lived experience. This partnership model strengthens accountability,



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builds trust between agencies and communities, and ensures that changes are sustainable and data-informed. Ultimately, IDOH views this work as a critical step toward achieving its broader vision of optimal health for every Hoosier regardless of where they live, learn, work, or play.

The partnership between GCPD and IDOH divisions resulted in the following shared vision for cancer and tobacco programs in Indiana:

An Indiana where health systems support people with disabilities to make informed choices about their health and to access opportunities for cancer and tobacco prevention and treatment.

Plain language:

- We want Indiana to be a place where people with disabilities are healthy.
- All health professionals should help people with disabilities stay healthy.
- People with disabilities should be able to make choices about their healthcare.
- People with disabilities should be able to get services that prevent cancer.
- People with disabilities should be able to get help to quit tobacco products if they need it and they want to.

IDOH and GCPD are advancing a model of public health that values shared leadership and collaborative solutions that are reshaping how agencies plan and implement health programs in Indiana. Working with people who have lived experience ensures Indiana health initiatives will close gaps in health and wellness for people with disabilities.

Conclusion

This process represents a relational approach to public health leadership. Collaboration with communities who are most affected by health disparities is an ongoing process that deepens trust and creates belonging. Empowering leaders with ID/DD in statewide workgroups moves participation beyond representation and creates the conditions for shared power and authentic collaboration. As one participant with ID/DD summarized: *“It felt like they were listening to me. I was more than just a seat at the table. They actually listened to my voice and that helped change their minds on what was going on.”* When people with ID/DD lead, public health systems and the communities they serve become stronger and more responsive to everyone’s needs.

Citations

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