

When All Are Counted

Closing the Health
Surveillance Gap
in West Virginia

Community Leading the Way

Think Kids, a child health and well-being advocacy organization in West Virginia, in partnership with West Virginia University and a community-based advisory board, talked with residents who identified with a marginalized identity—Black/African American, LGBTQIA+, and/or people with disabilities—to **understand how West Virginia collects and reports health surveillance data to build a more inclusive surveillance system.**

The project team wanted to understand how data are collected and shared, how marginalized groups are left out or harmed in the current system, and what structural changes could be made for a more representative system.

The project focused on residents' stories and experiences. It showed how living in rural areas, combined with being part of a marginalized community, can make it even harder to get needed care.



What Did This Research Reveal?

The research found that when someone with a marginalized identity lived in a rural area, it created barriers such as transportation issues, provider shortages, long travel time, and lack of accessible equipment and services.

Participants shared feelings of powerlessness, distrust, and stigma in care, including biased assumptions and non-affirming treatment, that often lead to emergency room avoidance and reluctance to seek care.

The project mapped these problems from individual to societal levels and highlighted **community-informed solutions to improve access, representation, and trust.**



“The [medical] resident immediately came in and said, ‘We're going to have a problem with the medication because you're probably...’

In other words, she was telling me I wouldn't be able to afford it.

She assumed that I was on welfare [because of my race]. She never looked at my chart, and she never made that connection, and I caught on.”

— Focus group participant



The research found **more similarities than differences across marginalized groups**, with shared experiences of discrimination, provider shortages, long travel times, financial burden, and lack of accessible services.

A central question participants identified was, **“Who has the ultimate decision-making power regarding how health care is provided?”**

Why Do These Findings Matter?

These findings show that **marginalized rural residents are undercounted and underserved unless surveillance, policy, and health systems prioritize their experiences.** Addressing these gaps requires representative providers, inclusive training, expanded local services, and policy changes to reduce barriers and rebuild trust.

The findings also demonstrate the **potential for solidarity** amongst marginalized groups, as **shared experiences can build a larger collective voice for change.**

The study produced **community-informed recommendations**, from **individual empowerment and relationship-building to organizational changes, community resources, policy advocacy, and societal stigma reduction.**



How the Research is Shaping the Future

In March 2024, Think Kids held a convening in Charleston, West Virginia to present the project findings to community members, policymakers, the media, and other local leaders. The event, part-conference, part-exhibit, included discussions with study participants, a Data Walk with the team detailing research findings, and panels on how to use the research recommendations and coalitions formed to make substantive policy changes in West Virginia.

Although Think Kids ceased operations in 2024, **these recommendations have been shared with local policymakers, community leaders, and health systems to inform workforce development, local planning, and advocacy for improved surveillance, access, and services in West Virginia.**



Learn More

AcademyHealth supports community-led researchers producing evidence for community-driven solutions. Learn more about all Community Research for Health Equity grantees at:

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