

## Webinar Focus

The Partners for Advancing Health Equity Collaborative hosted the webinar, *Access for All: Centering the Perspectives of Individuals with Intellectual and Developmental Disabilities in Health Equity* on July 16, 2024. Panelists engaged in discussions about health inequities experienced by people with intellectual and developmental disabilities, highlighting the importance of centering the voices and expressed needs of people with IDD. This report provides a synthesis of key takeaways, solutions, and action steps identified from the webinar.

## Webinar Voices

- › **Caryn Bell**, Associate Director, P4HE, [Tulane School of Public Health & Tropical Medicine](#)
- › **Beth Marlow**, Professor, Departments of Neurology and Pediatrics; Burry Chair in Cognitive Childhood Development, [Vanderbilt University Medical Center](#)
- › **Darcy Milburn**, Director of Social Security and Healthcare Policy, [The Arc](#)
- › **Margaret Nygren**, Executive Director and CEO, [American Association of Intellectual and Developmental Disabilities](#)

## Key Resources

- [Barriers to Health for People with IDD](#)
- [Communicating with People with IDD](#)
- [IDD Toolkit for Primary Care Providers](#)

## Your Voice

P4HE values collaboration. If there is a resource on this topic that you would like to share with us, provide it [here](#).

## Key Takeaways

Individuals with [intellectual and developmental disabilities \(IDD\)](#) face various structural barriers to attaining positive health outcomes, including challenges in accessing quality care and bias against people with disabilities. These health inequities are exacerbated for people with IDD with intersectional marginalized identities. It is critical for organizations across sectors to collaborate in prioritizing and addressing the unique experiences and needs of individuals with IDD. Collaborations should aim to provide equitable services and individualized supports while simultaneously dismantling unjust systems and institutions that drive inequities for this population.



The majority of webinar participants indicated that they were somewhat familiar with IDD. Attendees also suggested ways that we can work

together to address equity for people with IDD, including **actively listening to and uplifting people with IDD, conducting more interdisciplinary research, increasing funding, expanding education and advocacy on IDD, and offering better training on IDD for health care providers.**

## Call To Action



*“Every person with a disability, or without a disability, has unique strengths and weaknesses. If you’ve met one*

*person with a disability, you’ve met one person with a disability.”* Margaret Nygren, Executive Director and CEO, American Association of Intellectual and Developmental Disabilities

Below we've summarized immediate action steps shared by the panelists and identified by webinar participants to be taken to advance health equity.

› **Cultivate a culture of self-advocacy.**

To learn about the health concerns of people with IDD, listen to them directly. People with IDD have the lived experience to self-advocate and inform others on everyday health problems. When an individual with IDD (or anyone for that matter) tells you something is a problem, believe them. Some people with IDD can have [difficulties communicating their perspectives and experiences with health issues](#) and can feel [dismissed by health care providers](#), redirecting attention to parents or caregivers to explain instead and preventing individuals with IDD the chance to self-advocate. One example of this is [pain management](#) in which people with IDD may have difficulties adequately communicating pain levels using traditional self-report pain scales, leaving clinicians to make decisions about treatment which usually involves [undermedication](#). Instead of relying on traditional diagnostic tools, utilize effective [communication methods](#) and [assessments](#) that will allow people with IDD to convey their needs and advocate for their health.

[Intellectual and developmental disabilities \(IDD\)](#) encompass several different conditions that affect one's development. While the conditions fall under a single umbrella of IDD, every individual with IDD has unique [experiences and challenges](#). Due to the individualized health needs of this population, tailored services are more effective to address such health challenges, rather than one-size-fits-all solutions.



*"We really need to encourage [self-advocates] to participate in this work and share their voices. When you hear people tell their stories of what they've been through, it's impactful to all of us in a way [that is not when] just reading it."* Beth Marlow, Professor, Departments of Neurology and Pediatrics; Burry Chair in Cognitive Childhood Development, Vanderbilt University Medical Center

Cultivate a culture of [self-advocacy](#) that uplifts the health priorities of people with IDD, positioning them as experts on their own health. Amplify their voices in decision-making on best practices to treat people with IDD. Through cross-sector collaborations, [involve people with IDD](#) in the design and implementation of health initiatives aimed to provide accessible and equitable care to meet their health needs. People with IDD possess strengths that can be extremely valuable in promoting effective solutions that center the expressed needs and desires of people with IDD.

› **Acknowledge and address the systemic barriers to health that disproportionately affect people with IDD.**



*“People with IDD experience all the barriers that everyone else does but to a higher degree in a lot of cases. That can also be complicated by multiple marginalized identities.”* Darcy Milburn, Director of Social Security and Healthcare Policy, The Arc

With the unique health challenges that people with IDD face, it is important to consider the [root causes of such health issues](#). Receiving quality health care involves several steps that can limit access and lead to health disparities. It begins when someone decides to see a provider and includes setting up appointments, checking insurance, arranging transport, waiting, communicating needs, and following post-appointment care plans. For individuals with IDD, performing many of these tasks can be [especially challenging](#). The ease of completing these actions and the level of comfort experienced play significant roles in determining whether services will be sought out again. Acknowledge how such factors may be obstacles for people with IDD to access health care, and propose ways to make these processes and practices [easier and more accessible](#). Systemic issues require systemic solutions, so people and organizations across sectors must work together to collectively address the underlying causes of poor health outcomes for people with IDD in pursuit of health equity.

› **Keep intersectional marginalization at the forefront of discussions on designing health initiatives for people with IDD.**

Individuals with IDD are multifaceted people who disproportionately face barriers to health and longevity. The negative determinants of health and subsequent health inequities are compounded for people with IDD of [intersectional marginalized identities](#), including [race](#), ethnicity, gender, sexuality, and socioeconomic status among others. Many individuals with IDD experience poverty, exacerbating struggles due to [insufficient health insurance coverage](#) and [inability to pay for costly, specialized services](#) needed to treat chronic conditions. When devising solutions, it is crucial to consider the unique needs of people with IDD, including [expanding Medicaid](#) to target the drivers of poor health outcomes among low-income communities. Both income and the [social marginalization associated with having a disability](#) impact the quality of care received and thereby, health outcomes. It is essential to acknowledge the stigmas, biases, and discrimination that people with IDD face within [healthcare](#) systems and broader societal structures. [Enhancing education and awareness of IDD](#) and providing [training for staff across all sectors](#) will enable better understanding and support of individuals with IDD.

## Unique Challenges Experienced by People with IDD



› **Collaborate across sectors to employ a multipronged approach to develop and implement solutions that advance health equity for people with IDD.**



*“Actions [should have] a multi-pronged approach, from the micro to the macro. They’re not simple; this is not a simple problem. It’s not a one-size, one action. Do it over and over and over again until things change. Work together until things change and keep [progress] from*

*slipping back.”* Margaret Nygren, Executive Director and CEO, American Association of Intellectual and Developmental Disabilities

As with any efforts toward widespread change, health equity work must involve cross-sector, collective actions that aim to address health concerns and disparities in all avenues of society. In such collaborations, partners can share and uplift each other’s strengths and resources to have further reach across communities and to tackle structural obstacles that inhibit healthy outcomes, including for people with IDD. The [history of marginalization for people with disabilities](#) leaves a lot of areas for improvement for partnerships to act on to promote health equity. For example, limited data

and research on the [effects of race, ethnicity](#), and gender on health for people with IDD results in low awareness of inequities and a lack of actions taken to improve health outcomes. Incorporate the expertise of researchers to identify and employ [better ways to collect and analyze data on disparities for people with IDD](#), particularly disaggregated data by demographic characteristics of interest and IDD status, to [expand research](#), and to inform policies and initiatives undertaken by cross-sector collaborations. Given the vast determinants of health that negatively impact people with IDD, there also needs to be increased funding for [patient-centered, equitable service provision and health resources](#) to target such barriers to accessing quality care. Leverage funds from [philanthropies](#), [the private sector](#), and government agencies to develop and implement health initiatives, [train health care providers](#) in treating IDD, and [offer affordable health care services](#) in underserved areas. Inciting systemic change also requires engaging with policymakers and making a case for new policies or policy changes that will dismantle the unjust systems and institutions that perpetuate health inequities. [Advocate to policymakers](#), alongside various influential partners from the collaborative, such as [grassroots advocacy groups](#), on the health disparities experienced by people with IDD and the changes needed to transform health for this population. Most importantly, allow people with lived experience with IDD to [self-advocate](#), offering first-hand knowledge and perspectives to all efforts of the partnerships on the most pressing health issues. [Amplify voices](#), grant leadership opportunities, and decision-making power to individuals with IDD to truly center their health priorities in initiatives. With so many issues to confront in pursuit of health equity, it may be difficult to determine the best actions to take. Thus, partners from various sectors must unite to employ a multipronged approach to continuously design and execute various far-reaching solutions that eliminate structural barriers to health and meet the unique needs of people with IDD.

## Deeper Dive

### IDD Toolkit for Primary Care Providers

The [Vanderbilt Kennedy Center for Research on Human Development](#), in partnership with [Surrey Place](#) of Toronto, Canada, developed the [IDD Toolkit](#) to aid primary care providers in serving people with intellectual and developmental disabilities. The toolkit includes: information and resources on different approaches to care, tools for various physical health issues among people with IDD, [Health Watch Tables](#) on specific IDDs, tools for assessing and addressing mental health issues among people with IDD, and additional fact sheets for specific audiences. Nearly all tools were developed alongside the [2018 Canadian consensus guidelines on primary care for adults with IDD](#). The toolkit aims to offer resources to help reduce barriers to quality health care for people with IDD, including the promotion of preventative care – something that is often overlooked for this population. Health care providers and cross-sector partners can utilize this toolkit to better understand best practices for treating people with IDD and providing them patient-centered health care.

## Project ECHO

[Project ECHO](#) is an initiative run by the [University of New Mexico Health Sciences Center](#) with nearly 7,000 programs across the world and includes communities specifically focused on serving individuals with different disabilities. Project ECHO's IDD communities are networks that help to share knowledge from specialist teams to local care teams to people with IDD through telementoring, aiming to expand individuals' access to quality speciality care. These networks include interdisciplinary teams to provide training for providers on treating IDD and resources for individuals with IDD and their families. In addition to the IDD communities, Project ECHO is providing spaces for individuals with lived experience to self-advocate and serve as experts. For example, the ECHO Autism communities are of [the first ECHO programs to center lived experience](#) in sessions with providers, with these individuals offering perspectives on challenges faced and recommendations for change. Through cross-sector collaborations, care providers and other partners can join an ECHO IDD community or learn how to incorporate components of the [ECHO model](#) into their work for treating people with IDD, or other disabilities, in pursuit of advancing health equity for these populations.

## About P4HE

The P4HE Collaborative harmonizes goals, advances learning, and facilitates collaboration to improve health equity. It is led by the Tulane University School of Public Health and Tropical Medicine and is part of the Tulane Institute for Innovations in Health Equity. Support for this program is provided by ICF. Funding is provided by a grant from the Robert Wood Johnson Foundation.



### Foster

the co-creation and spread of knowledge.



### Sharpen

our research tools to focus on solutions, facts and stories.



### Disrupt

traditional research approaches.



### Harmonize

our voices.



### Challenge

the status quo.



### Shine

light on practices that are indefensible, irrational and inconsistent.

To learn more about these issues, or Partners for Health Equity's calls to action, a resource library including a full recording of this, and all previous P4HE Webinars, can be found on the P4HE [website](#).