World Institute on Disability

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Leveraging the Expertise of Individuals with IDD to Improve Healthcare Provider Capabilities and Provision of Person-Centered Care

Executive Summary

The principle, “those closest to the pain should always be closest to the power” (Ayanna Pressley), influences impactful policy-making but is tragically missing in many systems, including social, medical, emergency, criminal justice, and disability-related services. This absence perpetuates a tiered society that marginalizes and disempowers individuals based on the extent of discrimination they face, disproportionately affecting people with intellectual and developmental disabilities (IDD). These individuals often experience compounded challenges: they are more likely to be victims of sexual abuse, face dismissive or inadequate medical treatment, and are systematically silenced.

Even well-intentioned programs and advocacy organizations often default to speaking for, rather than with, those they serve, distancing marginalized groups further from power—the power to heal, help others, propose solutions, and drive systemic change. The disability community mantra, “Nothing about us without us,” underscores the need for survivors of sexual abuse and individuals with IDD to lead efforts to eliminate violence, dismantle biases, and innovate person-centered, inclusive programs. It is only by the leadership of these groups that the hierarchy in disability services, uneven services, and historic systemic neglect can be address, and complex challenges can be solved.

Systemic change requires slow, evidence-based transformation and redundant modeling of success. A team, predominantly composed of people with disabilities, including survivors of sexual abuse and led by a renowned self-advocate with IDD, prioritized lived experiences to identify actionable changes in medical services. By highlighting challenges, sharing stories, and documenting successes, the team revealed key components necessary, and actionable without significant investment, for progress.

Background

Implicit bias among healthcare providers against individuals with intellectual and developmental disabilities (IDD) persists and is deeply rooted, with Harvard studies predicting over 200 years to achieve neutrality. People with lived experience in the provider patient challenges frequently encounter dismissive attitudes, especially after sexual violence, intensifying their trauma and potential for lifelong pain. For instance, as heard from numerous FG participants, providers often say, “I really don’t know what to do with you. Maybe you should go elsewhere.” This results in the patient without care and more deeply imbedded trauma, especially in the case of sexual assault where the perpetrator is someone in the person’s immediate circle of care.

Dr. Tara Lagu of Northwestern University highlights the need for systemic change, advocating for amplifying the voices of individuals with IDD to reform healthcare practices. Her study, *I Am Not The Doctor For You*, underscores the urgency of addressing discriminatory thinking in medicine.

The medical model, focusing on "fixing" impairments, continues to influence healthcare services while neglecting social and environmental contributors to health disparities. Research from public health and the Administration for Community Living (ACL) identifies health inequity and sexual violence as deeply embedded societal issues.

Addressing these challenges demands provider education, accessible appointments, and collaborative initiatives. Centering the experiences of individuals with IDD and survivors of sexual violence is crucial for dismantling biases and fostering inclusive, equitable healthcare systems.

Project Purpose

The purpose of the project was to gather input from people with intellectual developmental disabilities (IDD) about the quality of healthcare they experience, learn ways to improve person-centered healthcare, and to collect recommendations to improve medical school and healthcare provider training, increasing understanding of the needs of persons with IDD, and particularly related to people with IDD who were also survivors of trauma or abuse.

Building from previous projects funded by WITH that demonstrated deficiencies in medical provider interest abilities to address the needs of persons with IDD who are survivors of abuse, and the potential for individuals with IDD to provide potential options, a qualitative research approach was applied.

The project provided an opportunity to explore the potential of persons with disabilities to provide leadership and facilitation in same or similar situations in medicine and healthcare.

Methodology

Accessing personal and organizational networks of Kecia Weller, The Board Resource Center, The World Institute on Disability, and affiliated individuals, including a pre-screened population of user-testers with disabilities from WID's national cadre, a scripted participation invitation was distributed.

The 21 participants with IDD represented a broad cross section of people with diverse geographic, age, and social sectors, including individuals with intersectional identities and marginalized populations.

Focus groups were virtual and followed best practices for universal access for virtual spaces and inclusive participant engagement, and all accommodation requests were provided. Use of technology resulted in meeting transcripts, meeting notes, and meeting recordings that were then evaluated to create research outputs, summaries, and aggregated outcomes.

Outcomes

Outputs from the focus groups aligned with two primary outcome areas, enhancing leadership and engagement among individuals with IDD and addressing barriers to equitable person-centered care.

1. Enhancing Leadership and Engagement Among Individuals with IDD

1.1. Leadership Capability with Accommodations

Individuals with IDD successfully planned and facilitated information-sharing events when two essential components were present. Open conversations that allowed leaders to identify their needs and request accommodations and flexible to adjust as necessary were critical. Additionally, partnerships between leaders with IDD and others who engage as part of a 'system of support' were critical. These partnerships were unique in that they were built on strategic responses to evolving needs, rather than predictions or assumptions of the individual's needs. This contrasts sharply with the current rigid culture of human and medical services where providers take the lead in identifying and solving problems.

1.2. Safe and Equitable Communication Environments

Participants with IDD effectively shared lived experiences and solutions when accommodations and equitable environments were provided. The potential contributions of individuals with IDD are often untapped, particularly in traditional focus group settings where participants who are perceived as more knowledgeable dominate discussions. In an equitable group environment, many respondents spontaneously proposed solutions to barriers and gaps and expressed interest in collaborating further in other safe environments. Across all focus groups, participants were eager to contribute knowing that their perspectives and opinions were being solicited and valued equitably

2. Addressing Barriers and Promising Practices for Equitable Care

2.1. Barriers and Promising Practices affecting Providers

Barrier**:** Providers face constraints such as time pressures, resource and budget limitations, reporting requirements, billing code restrictions, and systemic issues that limit their ability to provide person-centered care.

Promising Practice**:** Patients with IDD stress the importance of finding providers who are a good match and meet their specific needs. Genuine choice is essential. When there is a good match between patient and provider the patient is able to communicate their needs more effectively, the provider is able to integrate the individual patient accommodations, and there is a higher rate of patient/provider success. Many of the accommodations and needs that were identified by participants did not have significant time or funding costs when they were well understood by providers.

2.2. Absence of Self-Advocacy Mechanisms for Patients to Apply their Expertise

Barrier**:** While individuals with IDD understand their needs and practical solutions, the healthcare system lacks mechanisms for them to contribute their expertise effectively.

Promising Practice: By developing tools like individualized patient portal features, including accommodations needs in patient profiles, integrating patient disability advocate roles within the staffing and process, providers can provide the opportunity for patients to effectively communicate their needs and facilitate problem solving. Additionally, implementing a practice of regular provider education on person-centered planning and related topics would give providers the skills needed to facilitate advocacy and problem-solving.

2.3. Provider Awareness and Education

Barrier**:** Providers often lack the knowledge to identify disabilities, engage effectively, or address the intersection of disability and medical needs without guidance from patients. Providers may have had a patient with IDD early in their career and may be unfamiliar with basic accommodation needs and unable to distinguish the difference between disability related health and current trauma.

Promising Practices**:**

- Strategy 1: Build a healthcare self-advocacy culture with strategies through success stories of positive provider-patient relationships that impacted services along with what it takes to implement and evaluate success. Involve individuals with IDD in staff or advisory roles. [using models such as train the trainer,
- Strategy 2: Create an education curriculum co-developed and delivered by individuals with IDD to directly inform providers and reshape expectations using time sensitive approaches such as video, online access, AI and others.
- Strategy 3: Implement foundational education for providers to improve understanding of disabilities, intersectional identities, trauma, and person-centered care, ensuring these factors

inform care plans, that can ideally integrate with healthcare provider computer networks for quick access to foundational principles and methods.

This structured approach identifies actionable strategies to address systemic barriers and leverages the lived experiences and expertise of individuals with IDD to foster equitable, person-centered healthcare.

Building from the coalition building pilot work being done in current projects, the lessons learned can be combined with strategies to generalize and customize collaborations between healthcare providers and patients that can have national application with communities of all types and structures. In this manner, both the needs of the patient and the needs of the provider can be normalized, and receive appropriate action.

Recommendations

Historical healthcare approaches for individuals with intellectual and developmental disabilities (IDD), especially those with intersectional needs or trauma histories, are rooted in the medical model, which seeks to “fix” the individual and address them addresses PT as an object; this is even more prevalent for those with limited communication abilities. This model conflicts with access and inclusion principles that value disability as an integral and sociological aspect of human diversity. The healthcare system’s multiple layers of accountability further widen the gap between provider capabilities and patient needs, a gap that providers are ill-equipped to close without appropriate training and resources. Within the current climate of limited resources, funding and pressure to see more patients, the tendency increases to dismiss those that require additional education and time.

Focus group participants highlighted both systemic and provider-level shortcomings. Many individuals proposed solutions but struggled to implement their expertise effectively on their own. Challenges navigating advocacy organizations, untrained about how to communicate with people with disabilities, and support systems often left patients sidelined in communication, care planning, and decision-making, with providers deferring to assistants or advocates rather than directly including the individual.

Person-centered care, supportive decision-making and trauma-informed strategies must prioritize the inclusion of individuals with IDD at every stage of process development, implementation, and remediation. Two primary pathways for achieving equitable, person-centered care emerged:

1. Integrating Lived Expertise into Program Development and Delivery

1.1 Reducing Stereotyped Support and Leadership Positions

Individuals with IDD who have had traumatic lived-experiences have a particular expertise that is critical in programmatic development and delivery. By moving beyond tokenized or stereotyped support positions for people with IDD, the needs assessment, problem solving, and remediation process can be streamlined. This can be accomplished by support services learning and understanding the benefits of responsive support as an alternative to managed support. Demonstration projects can provide support services the opportunity to learn and practice interacting with people with IDD as a leader, responding to their evolving needs without overshadowing their leadership, and mastering supportive decision-making skills. In this way, this relationship paradigm can be modeled and taught to healthcare providers.

1.2 Pathways for Entry and Elevation

Establish clear, accessible routes for individuals with IDD to contribute as leaders and care partners to be able to inform providers of their communication, care, and comfort needs before, during and after an appointment. Making information available to healthcare providers can be accomplished through modifications to registration procedures, patient portals, or technology assisted alternative information collection.

1.3 Recognizing Value, Not Charity

Barriers for individuals with IDD in receiving appropriate care can be explicit and implicit, and so should solutions to the barriers. Data collection, information sharing and education on the value added through the lived experience of people with disabilities, can begin to change the assumptions and perceptions of providers and support personnel towards a return-on-investment strategy rather than symbolic inclusion.

2. Leveraging Lived Expertise to Train and Educate Providers

2.1 IDD Leadership in Content Creation:

Individuals with IDD who have had traumatic lived-experiences have insights to elevate, and authority to effectively deliver training and education to healthcare providers. Training content identification, development, revision, and delivery should be accomplished in conjunction with individuals with IDD for all training mechanisms. As the premier experts in the challenges, needs, and individualized solutions, the role of individuals with IDD should be pivotal. This role should go beyond contributions of their stories and impact, but should include real curricula typically saved for 'healthcare consultants. With personalized accommodations content can and should be delivered by people with disabilities.

2.2 Value-Added Contributions:

Acknowledgement of the unique perspectives of individuals with IDD bring to such roles further strengthens both the perceptions of their contributions and deepens the learning for providers. Drawing from an emerging evidence-based practice in adult education, learning is optimized through multiple methods that include 'storytelling'. The opportunity for providers to learn directly from experts, to understand the experiences and engage directly has a notable impact on learning, and people with IDD bring that added value.

2.3 Proactive Budgeting:

Time and funding (from insurance/Federal-state reimbursement) budgeting are known barriers. Training for providers must include an investment rationale that delineates the imperative to invest in competencies in this area at the earliest possible opportunity. Collaboration with patients with IDD can create low expense, high impact policy, procedure, or practice changes that result in improved health for the individual and improved efficiency for the provider. Virtual self-directed and asynchronous training can assist providers to improve their skills at minimum expense or free, technology investments that leverage accessible patient portals, or generative AI assistants can be moderate initial investments that are returned through increased efficiency, and a sustainable resource.

These recommendations highlight the importance of centering the voices, expertise, and authority of individuals with IDD in efforts to reshape healthcare systems, making them inclusive, accessible, and person-centered.