The California Gatherings

Special Edition Newsletter

Putting Person Centered Practices to Work

2020 August

The focus of this special issue is on the need for advocacy on the issues of economic and healthcare equity for people with disabilities.

Ultimately, the ability of the disability rights movement to transform Olmstead into its Brown v. Board of Education and to ensure that people with disabilities have the civil and economic protections that every other American has will depend on several factors: additional legal victories, increased political power, and greater focus by those who have supported other civil rights movements.

Alexander Wohl
Adjunct Professor at American University Washington College of Law

Excerpt from

Poverty, Employment, and Disability: The Next Great Civil Rights Battle

by Alexander Wohl

At a time when many U.S. policymakers increasingly are focused on the issue of poverty and economic disparity as an important and neglected social problem (not to mention a perceived potent political tool), a particularly striking set of statistics is one often ignored—the disproportionately high level of poverty among Americans with disabilities.

Persons with disabilities experience the highest rates of poverty of any subcategory of Americans charted by the Census Bureau. Of the nearly 30 million individuals with disabilities ages 18–64, 27 percent, or more than 4 million people, live in poverty. This is more than double the rate of 12.5 percent for the entire population. Equally troubling and certainly related is the disproportionate labor force participation rate: For people with disabilities, it is 19.5 percent and for people without disabilities it is 68.7 percent. Office of Disability Employment Policy, Department of Labor, **http://www.dol.gov/odep**.

Though these numbers are revealing, they also do not tell us much about the causes and effects of this economic disparity, particularly those involving the relationship of poverty to underemployment of individuals with disabilities; the inadequate and often regressive role of government programs intended to provide support and assistance, including health care; and the underlying history of discrimination experienced by people with disabilities that has prolonged and exacerbated these problems. (Read the complete article **here**)

The Gatherings Archive is here. Thanks to Tina and her cohorts at Tri Counties Regional Center, you'll find that some editions of the newsletter are now available in Spanish.

E3TC

Educate Empower Employ:

The Elephant in the Room: Poverty, Disability, and Employment

At-a-Glance

Research has shown that adults with even severe disabilities are often able to have successful careers and be self-sufficient. But, many of these people are un- or under-employed and living in poverty. This study explains some of the reasons for this and offers solutions for change.

Key Findings

- Poverty and disability are often interrelated and cyclical. Poor living conditions and lack of insurance can cause disabilities. Medical and adaptive equipment expenses related to disability can cause poverty. Stressors of poverty survival often compound the obstacles presented by the disability itself.
- The federal definition of poverty is outdated and does not include expenses such as child care, health insurance, transportation, and disability treatment, to name a few.
- Students with disabilities in high-poverty schools spend less time getting job training, in general education classes, and receiving community-based instruction than students in other schools. This puts them at a disadvantage.
- Minorities are especially at risk due to the intersection of racial bias, disability, and poverty. These children have fewer opportunities to engage with their communities, gain job skills, and can lead to unemployment, underemployment, dropping out, substance abuse, and incarceration.

Practitioners who work closely with people with disabilities living in poverty can use their knowledge and experience to create change. They can both advocate for consumers and work toward public policy changes that empower people with disabilities who want to work.

Raise Public Awareness

Talk about the relationship between poverty and disability, and how they feed into one another. Create awareness of the complex inter-relationship between the two.

Share Information with Other Professionals

Cross-disciplinary sharing between poverty and disability studies would strengthen the advocacy power of both, and would help provide a research basis for changes to policy and legislation.

Empower and Hold Schools Accountable

Give schools the the means to provide job training – and even job placement – before graduation for students with disabilities. Hold schools accountable for post-school outcomes of students with disabilities.

Need for Health Literacy

The National Quality Forum's Person Centered Planning and Practice defines health literacy as ***improving the ability of the person to obtain, process, and understand health information and services needed to make decisions***. It's considered one of the core competencies of facilitation.

The challenge: What can we do to become *health literate* and support advocacy efforts in our communities for healthcare reform?

Some Healthcare Research Facts for People with Intellectual and Developmental Disabilities

- People with IDD, by almost any measure, are in poorer health than people without disabilities. As a group, they engage in low levels of physical activity (Hsieh, Hilgenkamp, Murthy, Heller, & Rimmer, 2017), eat unhealthy diets lacking in essential nutrients (Taggart, Truesdale, Dunkley, House, & Russell, 2018), and have high levels of chronic disease (Havercamp & Scott, 2015).
- Nearly 27% of Missourians with IDD report engaging in no physical activity (National Core Indicators, 2017).
- Health care providers often have inadequate training related to the unique needs of people with IDD (Anderson et al., 2013).
- Individuals with IDD also face an overall lack of accessible health care service options, especially appropriate mental health services (Whittle, Fisher, Reppermund, & Trollor, 2019).
- They receive less frequent preventative visits with healthcare providers and are more likely to have undetected health issues than the general population (Krahn & Fox, 2014).
- Despite these and other health inequities experienced by individuals with IDD, rarely are they included in health policy initiatives for those facing health disparities. In fact, Krahn and colleagues point out that the presence of people with IDD "in these…groups is not recognized nor accommodated" (Krahn, Walker, & Correa-De-Araujo, 2015, p. S204).
- In order to be fully comprehensive, health equity research should include participants of all demographics including individuals with IDD, as disability is now generally regarded as a demographic attribute (National Academies of Sciences, Engineering, and Medicine, 2018).

Compiled by **The Institute of Human Development, University of Missouri at Kansas City**

Service Providers and Advocacy at the Intersection of Healthcare and Disability

Note: Service providers have long realized the correlation between the two and are initiating and supporting healthcare advocacy reforms. Amanda George, a long-standing member of the Learning Community, offers an excerpt of a grant effort* in Missouri, aimed at increasing healthcare advocacy:

We propose to develop a **Health Equity Collaborative** that will build grassroots community-organizing capacity to address critical health issues affecting individuals with intellectual/developmental disabilities (IDD) in the greater Kansas City metro area. The project will train individuals with IDD, family members and professionals from a range of sectors in grassroots organizing principles and skills. They will collectively identify key issues and develop approaches and action plans to address them. Through the organizing process, participants will learn to mobilize around health policy issues, influence policy decisions, and inject the voice of people with IDD into local health equity efforts.

Because people with IDD are often left out of health policy discussions, this project's goal is to build a group of dedicated individuals with a passion for grassroots organizing around health issues related to people with IDD. Though little research exists related to grassroots community organizing around health policy by individuals with IDD, other populations use grassroots organizing extensively and successfully. Research has indicated grassroots community organizing has the potential to unleash "the collective power necessary to uproot socioeconomic inequities at the core of health disparities" (Pastor, Terriquez, & Lin, 2018, p. 358). Moreover, a case study analysis of community organizing and its impact on health policy concluded that when groups most impacted by health disparities participate in research, they can "influence policy change for health equity" (Cacari-Stone, Wallerstein, Garcia, & Minkler, 2014, p. 1621).

By bringing together individuals with IDD, their families, direct support workers, and community partners from the IDD, social service, and health fields in Kansas City, this project will facilitate the use of grassroots community organizing to influence health policy issues. Health Equity Collaborative members will participate in trainings focused on advocacy and community organizing, engage in health policy discussions, choose priority focus areas, develop strategies, and take action for change.

*** Note:** This is a joint effort by ***Eitas*** and **The Institute of Human Development (UMKC),** successfully funded by **Health Forward Foundation.**