INTERLUDE: WHY IT MATTERS THAT MOST OF THE NATION’S DISABILITY SUPPORT PROFESSIONALS ARE WOMEN OF COLOR

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As in previous years, the Case for Inclusion 2022 reports on the major industry and workplace challenges that for decades have plagued the country’s estimated 1.3 million direct support professionals, while also recommending solutions on how to improve employment conditions for this critically important segment of our nation’s overtaxed health care system.

As a supplement to this year’s Case for Inclusion, this article takes a closer look at why it should matter to policymakers, advocates, researchers, politicians, people with disabilities and the public at large that nearly 60% of DSPs are people of color, mainly Black or Latino, and the great majority are women.

According to PHI, a national nonprofit that researches and advocates for direct care workers and the people they support, women were 87% of the nation’s direct care workforce in 2019. This includes people who serve older adults and other populations, but also the DSPs who support people with intellectual and developmental disabilities, such as cerebral palsy, Down syndrome, spina bifida and a range of others.

According to PHI, a growing percentage of the country’s direct care workforce consists of people of color. In 2019, direct care workers were 39% white, 32% Black, 19% Latino and seven percent Asian American Pacific Islander, with three percent from other groups. Notably, the percentage of white DSPs in this workforce dropped by 10% from 2009 to 2019.

PHI Data & Policy Analyst Steven McCall indicates that among direct care workers, Hispanic women make up the fastest-growing segment. While the number of Black female direct care workers increased from about 906,000 to 1.4 million, or 60%, between 2009 and 2019, the number of Hispanic women in the field more than doubled, from about 418,000 to 888,000, a jump of 112%.

The percentage of immigrants is growing fast as well. They now account for at least one in four direct care workers in the United States, said McCall, and a large majority of that segment are women of color. McCall adds that the percentage of immigrant workers is almost certainly higher, given how difficult it is to count undocumented immigrants who get hired off the books.

**Growing Intersections & “Data Oppression”**

In a series of recent interviews about the expanding presence of DSPs of color, the range of topics discussed touched on the intersections between race, ethnicity, gender, poverty, education, employment, disability and the lack of sufficient data in many of these categories.

Dr. Bonnielin Swenor is Director of the Disability Health Research Center (DHRC) at Johns Hopkins University. She’s been a vocal critic, especially during the pandemic, of what she labels “data oppression,” which she defines as the unwillingness of many researchers to acknowledge, much less track, the growing importance of gathering comprehensive data about historically disenfranchised communities.

“Who counts depends on who is counted” is a common refrain at DHRC, said Swenor. “The idea being that when you don’t have data about these groups [referring to communities of color or people with disabilities], it is as if these inequities
are absent. [But] the lack of data collection removes the opportunity for good policy [and] strategies to address inequities. It’s actually a question in my mind of social justice and human rights to collect the data.”

The irony is that data related to race or ethnicity is often collected but not disseminated, said Swenor. That’s what happened when health officials across the country began tracking COVID-19 infections and deaths during the early days of the pandemic. At first, relatively little was known, from a data standpoint, about how severely communities of color were being ravaged by the spread of the virus.

It was not until civil rights organizations and other advocates for communities of color, especially Latino, Black and Native American communities, began demanding answers that data collection began to shift. These advocates sought to understand why so many people in their neighborhoods were being sickened or killed by the coronavirus, and their advocacy led to state and federal health authorities, including the White House, to improve the processes used to gather and deliver that information to the Centers for Disease Control and Prevention.

Incomplete data and “data gatekeeping,” said Swenor, can result in social inequities that hinder the ability of health officials to address public health threats in marginalized communities. But as incomplete as data on communities of color can sometimes be, Swenor said data about people with disabilities is often far less comprehensive—if it’s gathered at all.

“For the disability community, we still don’t have that data [about the full impact of COVID-19] and the community is still fighting to collect it,” she said.

Data deficiencies regarding people with disabilities and communities of color also make it difficult to determine what happens when populations like this intersect with each other, as well as a variety of other economic and social factors, such as poverty, discrimination, education, housing, employment and politics.

Although it has been more than 30 years since the Americans with Disabilities Act became law, identifying a disability is still not a standardized, core component of most health records, said Swenor, because a person’s disability is still viewed by many policymakers, health officials and researchers only as a medical condition. Disability is infrequently viewed through a social framework or a civil or human rights lens.

“There was a day, decades ago, when race wasn’t a part of those medical questionnaires either,” said Swenor, “but that’s still where we are today with the disability community. That’s why we still can’t [accurately] track COVID-19 in the disability community’ or fully understand the impact of the pandemic on people with disabilities, including those who also are part of communities of color.

DSPs of Color Matter

Brandiss Pearson, a former social worker who is now a nurse practitioner, hosted an online lecture last year for the National Alliance for Direct Support Professionals. Her presentation was part of a three-part series of webinars titled “Black DSPs Matter.”

Pearson said her research found that “[Direct support professionals] felt unseen. Like many other frontline workers, they didn’t think they were being given the same regard as nurses, who had people standing outside of hospitals cheering and saying thank you.”
As a parent of a child who has Down syndrome, Pearson added, “I don’t think the work [DSPs] do is elevated enough.” Like their fellow DSPs and other essential workers nationwide, DSPs of color have had little choice but to work longer hours and put themselves at greater risk of infection from the coronavirus.

Black DSPs, while deeply committed to caring for the people they support, confided to Pearson about having to face inequitable workloads, microaggressions, tokenism, and race and gender-based pay gaps.

“These were all things that were pervasive before COVID-19,” Pearson said in an interview for this report. But now these factors are colliding with the trauma of living through the pandemic and trying to keep up the “superwoman” persona that compels Black women to come off as strong and stoic. “I’m a Black woman, therefore I can carry a heavier load. [At the same time] I have to cross my t’s and dot all of my i’s. And I have to show up in a larger way to be seen as equal.”

Pearson said many Black DSPs believed they didn’t have the option to quit their jobs or even call in sick. “So, when other people didn’t come to work, they had to take on the extra workload.”

Adding to their stress, despite the low wages most DSPs receive (the national average is about $12.36 an hour), DSPs of color and those who are immigrants are often the main or even lone breadwinners for their families.

In a 2021 survey of nearly 9,000 DSPs across the country, the Institute on Community Integration (ICI) at the University of Minnesota identified a range of inequities between Black DSPs and their white colleagues. The survey found 43% of Black DSPs, compared to 26% of white DSPs, worked an additional 16 hours per week during the pandemic. The survey also found that 60% of Black DSPs versus 40% of white DSPs reported living in households that earned under $40,000 annually.

At the same time, according to PHI, about 45% of the nation’s DSPs live near the poverty line, which for a single person in 2021 was $12,880. PHI also found that the median pay for a direct care worker is about $20,000 per year. These dynamics have cascading effects beyond the direct support professionals themselves; without a living wage, these full-time workers are often forced to rely on public benefits programs, such as SNAP and TANF.

“I often get the question of why is it that this workforce is so underpaid and undervalued,” said PHI Vice President of Policy Robert Espinoza. “One of the answers is that the primary demographic of this workforce are people of color and especially women of color who have long been excluded and marginalized, not just in direct care but in society at large.”

**Pursuing Equity**

As the U.S. population and the number of people with IDD continue to grow—and as the elderly become a bigger share of the country—the need for DSPs will also increase. PHI estimates the direct care workforce will need to fill nearly 8 million jobs, including 1 million new positions, by the end of this decade. About one in four of those new jobs will have to be filled by DSPs.

The nation’s population, meanwhile, is also growing more diverse. About 40% of people born in the US today are people of color, and Census figures show non-Hispanic white people will comprise a minority in the US by 2045.

Dr. Leonor Vanik is a co-founder of the National Coalition of Latinx with Disabilities. She says direct support professionals need to be better valued.
and formally trained for the important roles they play in providing a vital health care service for people with IDD. But Vanik, whose sister has Down syndrome, said the industry also needs to stop pigeonholing Latinos and other people of color, as well as immigrants, into what have been unjustifiably regarded for too long as low-wage, entry-level jobs that promise little chance for advancement. Treating jobs in the field as if they should be low-paying perpetuates employers’ practice of underpaying DSPs, said Vanik.

Back at Johns Hopkins, Dr. Swenor points out that while women of color make up most of the DSP workforce, it’s also important to understand that “People are more than one thing. The equation to address inequities includes many variables. And if you’re only including one variable, like race or gender, you’re not going to solve that equation.”

Swenor said employers and society at large also need to respond, for instance, to the needs and interests of LGBT workers and people with disabilities who are DSPs.

The DSP workforce is also, on average, attracting older workers, even as they spend more time caring for aging individuals in the IDD community.

“I firmly believe that whenever you’re collecting data about race, gender, ethnicity, age and so on, you should also be including disability questions in all surveys. This is the type of thing where there is no [final] destination. You’re always striving to gather better data. In the pursuit of equity, better democracy and social justice, there is no end game.”