Intellectual and Developmental Disabilities

Direct Support Professionals: Diversity, Disparities, and Deepening Crisis

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Abstract:	Direct support professionals (DSPs) support people with intellectual and developmental disabilities (IDD/DD) so they can live in the community. Thirty years of deinstitutionalization and development community living options would not have been possible without DSPs. While life for people with IDD improved greatly, working conditions, wages/benefits, demands, stress/burnout, and trauma experienced by DSPs has worsened. Turnover and vacancy rates threaten availability of community supports for too many people with IDD. DSPs from diverse racial, ethnic, linguistic, and cultural backgrounds face significant workplace disparities. These issues and solutions were discussed during the Research and Training Center on Community Living's 2022 State of the Science Conference. We propose important research questions needing solutions to continue constructively addressing these critical issues.

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Abstract

In the United States, Direct support professionals (DSPs) support people with intellectual and developmental disabilities (IDD) so they can live in the community. Thirty years of deinstitutionalization and the development of community living options would not have been possible without DSPs. While life for people with IDD improved greatly, working conditions, wages/benefits, demands, stress/burnout, and trauma experienced by DSPs have worsened. Turnover and vacancy rates threaten the availability of community supports for too many people with IDD. DSPs from diverse racial, ethnic, linguistic, and cultural backgrounds face significant workplace disparities. These issues were discussed during the Research and Training Center on Community Living's 2022 State of the Science Conference. We propose important research questions needing solutions to continue constructively addressing these critical issues.

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Direct Support Professionals: Diversity, Disparities, and Deepening Crisis

Direct support professionals (DSPs) are individuals who support people with intellectual and developmental disabilities (IDD) who need assistance to live the most integrated, interdependent, fulfilling, and self-directed life in the community. In the history of disability and community inclusion in the United States, DSPs have played an integral role. Deinstitutionalization and the development of community living options for people with IDD would not have been possible without DSPs. The shift from institutions to community inclusion for people with IDD over the last 30 years happened in large part due to the dedication, skills, and flexibility of DSPs (Lawson, et al., 2021). Their work has had a direct impact on the definition of success in the community changing from not being in an institution to being of the community and belonging (Lawson, et al., 2021). When the work is done well, DSPs advocate for individual enrichment through community participation, inclusion practices, supported decision making, and interdependence. In this article, we provide a summary of the literature reviewed and critical questions that emerged, during the Research and Training Center on Community Living's 2022 State of the Science Conference. This strand focused on the sufficiency and stability of the direct support workforce with a special focus on racial, ethnic, linguistic, and cultural diversity and disparities in the workforce in the United States (U.S.). Several national policy and practice solutions, such as the implementation of competency-based training, are promising to address some issues but require more research with a focus on diversity. We conclude with a list of important unanswered questions. These questions may be addressed through research and policy that considers the diversity of the workforce.

Composition of the Direct Support Professional Workforce

The direct care workforce in the United States is very large, with approximately 4.5 million direct care workers supporting aging adults and people with disabilities (McCall & Scales, 2022). Of direct care workers, about 1.4 million are DSPs supporting people with IDD. Healthcare support occupations (such as personal care assistants [PCAs], home health aides [HHAs], and nursing assistants [NAs]) which are largely comprised of direct care workers are projected to grow nearly 18 percent between 2021-2031, gaining nearly a million jobs. With this influx of workers, this workforce would become the largest occupation in the economy (Bureau of Labor Statistics [BLS], 2022). While the demand for services is quickly growing, recruitment and hiring of new workers are not meeting the demand. This is one factor that contributes to a large number of vacancies or unfilled open positions (National Core Indicators Intellectual and Developmental Disabilities [NCI-IDD], 2022) and people with disabilities waiting for services. Further, many DSPs who are hired are not met with sufficient support, access to career ladders, and adequate wages and benefits to stay in their jobs over time (Institute of Community Integration [ICI], et al., 2022).

Diversity Amongst Direct Support Professionals

The National Core Indicators (NCI) State of the Workforce Survey, formerly the NCI Staff Stability Survey, is administered annually to organizations in participating states employing DSPs and providing home and community-based services for people with IDD and other disabilities. There were over 3,800 provider organizations from 29 states and the District of Columbia who participated in the 2021 survey, which included demographic questions about their workers (NCI-IDD, 2022). The workforce is predominantly female, with the average breakdown of gender identity as 71.2% female, 24.1% male, 0.3% non-conforming/other, and

4.4% don't know gender identity, although these rates vary by state. According to the Bureau of Labor Statistics, the median age across direct care workers is 43 (PHI, 2023). However, the aging of the workforce is a rising issue with many workers getting older and nearing retirement (PHI, 2022).

The direct support workforce is overrepresented by people of color compared to the U.S. population. Across states participating in the NCI State of the Workforce Survey (2022) agencies reported the average racial/ethnic breakdown of their DSP workforce included about equal percentages of Black and African American DSPs compared to white DSPs. There was 40.1% Black or African American, 38.6% White, 5.4% Hispanic/Latinx, and 1.5% Asian, although there was variation by state. The number of people of color in the workforce grew between 2009 and 2019 from 1.7 million workers in 2009 (52 percent of the workforce) to 2.8 million workers in 2019 (61 percent; McCall & Scales, 2022). The number of Black/African American workers grew the most, from 906,000 workers in 2009 to 1.4 million in 2019. However, Hispanic/Latino workers grew at the fastest rate, more than doubling in number from 418,000 workers in 2009 to 889,000 in 2019. Additionally, the proportion of direct care workers who are women of color increased from 45 to 53 percent of the workforce between 2009 and 2019—growing from 1.4 million to 2.4 million workers (McCall & Scales, 2022). The cultural and linguistic diversity of the DSP workforce brings a wealth of knowledge and skills, including the capacity to understand and respond to racial, ethnic, and cultural differences among the U.S. population, and to speak languages in addition to English which could be assets to the field. However, this research has yet to be conducted.

Disparities Amongst Direct Support Professionals

In a recent survey of over 8,600 direct support workers, 70% indicated that they were the primary wage earners in their homes with an average household size of three (Hewitt et al., 2021). Given an average wage in 2021 of $14.41 per hour (NCI-IDD, 2022), many workers are struggling to get by on low wages. Women of color comprise over half of the direct care workforce and experience more economic insecurity than their white or male counterparts (McCall & Scales, 2022). McCall and Scales (2022) also reported discrepancies in the percentage of workers working full-time. Black/African American workers are most likely to work full time (74 percent), compared to 65 percent of white workers, 64 percent of Hispanic/Latino workers, 60 percent of Asian/Pacific Islander workers, and 57 percent of workers of another race. Median annual personal earnings are $22,200 for Black/African American workers; $20,200 for Asian/Pacific Islander workers, white workers, and workers of another race; and $18,200 for Hispanic/Latino workers. Forty-seven percent of women of color in the direct care workforce live in or near poverty (defined as below 200 percent of the federal poverty level), with variation among racial/ethnic groups. Women and most people of color are also more likely than men and white workers to live below 100 percent of the federal poverty level. In terms of household size, amongst racial and ethnic groups, Asian/Pacific Islanders have the largest households: 31 percent of these households have four or more other family members. Twenty-six percent of Hispanic/Latino workers, 22 percent of workers of another race, 17 percent of Black/African workers, and 13 percent of white workers live with four or more family members, indicating the prevalence of DSPs supporting children on their salary. Further, the proportion of workers living with at least one non-family member ranges from 8 percent for Hispanic/Latino workers to 13 percent for Asian/Pacific Islander workers (McCall & Scales, 2022).

Immigrants in the Direct Support Workforce

Immigrants make up a substantial portion of the long-term care sector (28%) and are more likely to stay in their jobs longer than U.S.-born citizens (Rapp & Sicsic, 2020). People of color in the direct care workforce are significantly more likely to be immigrants than white workers (McCall & Scales, 2022). Forty-three percent of men and 40 percent of women of color are immigrants, compared to 7 percent of white men and 6 percent of women. More specifically, nearly nine in ten (89 percent) Asian/Pacific Islander direct care workers are immigrants, as well as 46 percent of Hispanic/Latino workers, 29 percent of Black/African American workers, and 18 percent of workers of another race, compared to 6 percent of white workers. These workers bring important experiences to their work in direct support. An increasing number of DSPs are first-generation Americans, many of whom speak fluent English in addition to their language of origin. Further, it is not uncommon for DSPs who are immigrants to have been employed in health care (e.g., as doctors or nurses), education, or other allied professions in their countries of origin and now are working as DSPs while pursuing credentials to practice their profession in the U.S. (President's Committee for People with Intellectual Disabilities, 2018). Rapp and Sicsic (2020) pooled data from the Annual Social and Economic Supplement with the Current Population Survey for the years 2003–2019 and compared US-born and immigrant long-term care (LTC) workers' propensity to stay in the workforce over one year. Naturalized citizens, legal noncitizen immigrants, and unauthorized immigrants have a 7.6 percent point (pp) increased probability of staying in the LTC workforce, compared to US-born citizens ($p < 0.01$). especially among personal care workers (Rapp and Sicsic, 2020).

Conceptualizations of Direct Support Professional Work

Direct support professionals are interdisciplinary workforce as they have job duties that resemble aspects of many different professions (President's Committee for People with Intellectual Disabilities, 2018). Like teachers, they spend time developing and implementing effective strategies to help people develop new skills and enrich current ones. Like social workers, they connect people with IDD and families to the resources and benefits provided by government and community organizations. Like nurses, DSPs dispense medications, administer treatments, document care provided, coordinate with various medical teams, and implement plans of care (President's Committee for People with Intellectual Disabilities, 2018). DSPs, through their various and robust skills, work in a wide range of settings from family homes, intermediate care facilities, small community residential settings, supported living, vocational or day training programs, and community job sites to promote quality, equity, diversity, and community (Lawson, et. al., 2021).

The DSP role is complex because it is about supporting each individual in a person-centered way and requires a broad set of competencies to be done well. The National Alliance for Direct Support Professionals (NADSP) and the Centers for Medicare and Medicaid Services (CMS) have identified nationally validated competencies for DSPs that recognize the knowledge, skills, and abilities needed by DSPs to effectively support individuals with disabilities in the community (Centers for Medicare and Medicaid Services [CMS], 2014; National Alliance for Direct Support Professionals [NADSP], 2016a). These include competencies in person-centered practices, assessment and evaluation, crisis prevention and intervention, supporting health and wellness, and community living skills and supports among others. The use of established competencies to set workforce development and training standards is not widespread (Bershadsky et al., 2022), and yet, the ideal workforce must have

the knowledge, skills, and ethical compass to perform a wide array of tasks that support people with IDD to be healthy, safe, valued, and engaged members of their communities.

As values have progressed over time toward - person-centeredness, employment first, shared decision making, self-determination and efficacy, community inclusion and belonging, and preservation of autonomy, - the nature of DSPs work often makes them responsible for the implementation of these policy and programmatic changes (Lawson, et. al., 2021). As the point of contact with persons receiving support, DSPs are instrumental in ensuring that the values embraced by the field of IDD are the foundation of the support they provide. When the work is performed well, DSPs provide whatever support it takes for people to live and participate in their communities with greater independence and dignity.

The role of a DSP is growing increasingly complex and difficult (ICI et al., 2022). The nature of the job requires personal judgment, independent problem-solving, and decision-making. In addition to the competencies already described, the complex demands for ethical decision-making and subsequent skilled support are demonstrated through the National Alliance of Direct Support Professional's Code of Ethics (NADSP, 2016b). The Code of Ethics emphasizes that DSPs must do the work to understand the interplay of their values and beliefs and with the demands of their job to honor the values and beliefs of the people they support. Further, many DSPs work alone supporting people in individual or family homes, small group homes, the community, and employer settings (ICI et al., 2022). As such, they are often isolated and do not have co-workers that work alongside them, nor do they have ready access to supervisors or clinical professionals (e.g., nurses or medical personnel, social workers, occupational therapists, physical therapists) on-site to turn to for assistance or guidance (ICI et al., 2022).

Challenges faced by DSPs are increasing as more and more people with complex disabilities live and work in the communities of their choosing (ICI et al., 2022). National Core Indicators In-Person Survey data for the five survey periods from 2012-2013 through 2018-2019 show that the proportion of individuals with behavior challenges living in the community more than doubled during that span, from 15% to 31%, the proportion with anxiety disorder grew from 14% to 29%, and the proportion with a mood disorder increased from 23% to 31% (ICI et al., 2022). At the same time, fewer people now choose to live in large congregate settings, with most people choosing to live in small community settings.

Workforce Challenges and Impacts on People with Intellectual and Developmental Disabilities

Despite the high level of skill and decision-making required of DSPs, the work is often described as entry-level caregiving and is unrecognized as a career in national databases (ICI et al., 2022). The nature, intensity, and frequency of contact between DSPs and the people they support make their work different from the roles filled by clinicians, service coordinators, administrators, and supervisors. The Bureau of Labor Statistics does not recognize the role of a "direct support professional" with a standard occupational classification, as it does with most professions. DSPs are subsumed under three primary Standard Occupational Classifications: PCA, HHA, and NA (ICI et al., 2022). They are also often referred to under the heading of direct care workers who are essential workers whose physical and emotional labor as home care workers, personal care aides, and certified nursing assistants support older adults and people with disabilities living with dignity (Betts, 2022). Direct care workers who work as independent providers in private homes whose clients take on all employer-related roles including pay and tax reporting, as well as those employed in the "gray market" (i.e., are paid cash or "off the

record" in private households), are also often not counted in national datasets (Betts, 2022). Limited data on the direct support workforce is collected on a national basis containing sufficient demographic indicators for analysts and policymakers to parse out inequities experienced by people with intersecting marginalized identities. Those gaps in demographic data and inconsistencies across how datasets account for workers' identities make addressing the labor market issues through targeted, equity-based policymaking challenging. It is vitally important to examine and address issues of demographic disparities that arise. Further, examining the intersections of multiple identity factors related to gender, race/ethnicity, and immigrant status can shed light on systemic issues that need solutions that take these factors into account (ICI et al., 2022).

Direct Support Professional Wages

The quality of life for people with IDD has improved significantly over the past 30 years (Larson, et. al; 2021), but the same cannot be said for the work-life balance of DSPs. The unfortunate truth is that the system of community-based services was built on the promise that it would cost less than the cost of institutional services (Larson, et. al; 2021). These savings came through lower wages and benefits paid to direct support staff resulting in a 30-year history of wages that are not commensurate with the skills needed to be an effective DSP (ICI et al., 2022). To underscore the significance of low wages in direct support, 43% of the workforce rely on public assistance to provide for themselves and their families (PHI, 2023). In the 2021 NCI State of the Workforce Survey (2022), the median hourly wage for DSPs is $14.50 (range $8.50 to $17.00). For comparison, the federal poverty level in 2021 for a family of four was $26,500 per year ($12.74 per hour) (Office of the Assistant Secretary for Planning and Evaluation,

2021). With wages in this range, home and community-based service agencies compete with other entry-level industries (for example retail and hospitality) for workers.

Direct Support Professional Turnover and Vacancy Rates

To understand the full consequences of low wages combined with high skill demands, it is important to explore the current turnover and vacancy rates across DSP positions. In the 2021 NCI State of the Workforce Survey (2022), the average state turnover rate for DSPs was 43.3% (with a range of 28.5% to 59%). The average vacancy rate was 16.5% for full-time positions and 20.3% for part-time positions. This has increased tremendously since 2019 which showed 8.5% for full-time positions and 11.2% for part-time positions (National Core Indicators [NCI], 2020), an increase of 94% for full time positions and 81% for part time positions. The inequity between high-skill requirements and low pay has been a major contributing factor to turnover within the DSP workforce and turnover results in vacancies. Recent increases in inflation and wage across other professions are only making the problem worse for an already struggling workforce (Bershadsky et al., 2022).

The many workforce stressors experienced by DSPs are compounded by working in a profession that is undervalued, underpaid, and underappreciated. The lack of a recognized occupational title, few training requirements, and insufficient wages are all indicators of an invisible and undervalued workforce. Using data from provider organizations that employed DSPs in 2018, Pettingell et al. (2022) examined how wages, different types of incentives, and benefits (e.g., paid time off, access to health insurance, disability insurance, wage bonuses, health incentives programs, etc.) impacted annual turnover. Results indicated that incentives were not positively associated with DSP retention. Higher wages paid to DSPs were the most

notable factor associated with differences in DSP retention rates, along with the state in which the organization was located and organization vacancy rates.

Direct Support Professionals and Stress

In recent years, there have been studies that highlight differing considerations of diverse DSPs. Job stress was found to predict burnout and depression in African immigrants working as DSPs in the United States (Onyejose, 2021). Additionally, DSPs may be exposed to the traumatic experiences of people with IDD with potential psychological implications. Boamah and Barbee (2022) examined the prevalence of post-traumatic stress disorder (PTSD) and Secondary Traumatic Stress (STS) in a sample of DSPs. STS describes the immediate adverse reactions people can have to trauma survivors that they are helping. The symptoms of STS are the same as those experiencing direct trauma and PTSD and include heightened arousal, avoidance, and intrusive thoughts, although in the case of STS, the arousal is due to exposure to the trauma of others (Boamah & Barbee, 2022). The results suggested that DSPs are exposed to traumatic experiences, and exposure to a greater number of traumatized clients is significantly correlated with symptoms of STS. At least 12.4% of DSPs in this sample met the diagnostic criteria for experiencing post-traumatic stress disorder (PTSD) symptoms. Risk factors associated with DSPs' propensity to develop STS include those who are exposed to client trauma history, experienced high frequency of client challenging behaviors, and those with history of personal trauma (Boamah et al., 2022). DSPs who discover the traumatic experiences of a client through documents, in conversation with the client or staff, guardians, or family members, and those who experience high rates of aggressive challenging behaviors or who have their own traumatic experiences are more likely to develop STS. Rich and colleagues (2021) found that most organizations reported that their staff do not fully understand trauma, and most

organizations did not provide formal training on understanding trauma or trauma-informed care. In examining predictors of STS, Boamah et al. (2022) found a significant inverse relationship between perceived organizational support and STS. Likewise, personal resilience was a significant buffer to STS among DSPs. Keesler & Troxel (2020) explored self-care behaviors among DSPs and the relationship between self-care, resilience, and professional quality of life. Fostering a culture within the provider sector of self-care and support for DSPs through various forms of training on self-care, regular community events focused on appreciation for DSPs, and stronger efforts to promote resilience through mental health practice can improve the professional quality of life. Further, there is correlation between DSP's work-related stressors - burnout and STS- and staff outcomes, including staff satisfaction and general health; organizational outcomes (i.e., work satisfaction, turnover intent); and client outcomes, like client success (Boamah, 2020). These studies highlight additional dimensions that may contribute to workforce stability, and the need for further investigations into the intersection of gender, race/ethnicity, job stress, self-care, and trauma in DSPs to effectively increase retention.

Challenges Related to the COVID-19 Pandemic

The issue of recruitment and retention of DSPs reached crisis proportions well before the onset of the COVID-19 pandemic, and the crisis deepened during the pandemic (Bershadsky, 2021). During the COVID-19 pandemic, the intimate nature of DSP work amplified the challenges faced by the workforce (Institute on Community Integration, 2022). DSPs were essential (even though the majority of states did not recognize this status at the onset of the pandemic), and the nature of their work put them at high risk for COVID-19 infection (Bershadsky, 2021). Turnover rates increased substantially (ranging from 19.8% to 35%) from pre-COVID baselines in 2019 (NCI-IDD,, 2022). High rates of turnover among DSPs contribute

to job stress among staff who remain, which in turn contributes to more turnover and higher rates of reportable incidents of abuse or neglect (American Network of Community Options and Resources [ANCOR], 2021). High rates of turnover among DSPs have also been linked to injuries and hospital admissions among people with intellectual and developmental disabilities (Friedman, 2021). DSP continuity is central to quality of life, including security, community, relationships, choice, and goals.

During the COVID-19 pandemic, working conditions for DSPs and life for both staff and people with IDD became increasingly challenging (Institute on Community Integration [ICI], 2022). Staff shortages increased and people's routines were disrupted, compounded by mandatory lockdowns which for many people meant they were not allowed to leave their homes nor have any visitors. Many organizations reduced the number of people working in any given program to limit exposure and some DSPs began providing virtual supports. For the vast majority of DSPs, it was not an option to stop working once the pandemic began because of their commitment to the people they supported and also the realization that they were primary heads of households and needed to earn money. Nearly all DSPs continued to work, but in different ways and in many situations, different places. Many DSPs worked longer shifts during the pandemic with Black and African American DSPs shouldering extra hours disproportionately (Bershadsky, 2021). Approximately two years after the start of the COVID-19 pandemic, studies conducted by the Institute on Community Integration and the National Alliance for Direct Support Professionals found that direct support workers experienced significant mental and physical health concerns because of the pandemic (ICI, 2022). Half of the respondents had experienced physical and or emotional burnout, 47% experienced anxiety, 38% had difficulty sleeping, 18% had physical health complications, and 4% experienced

suicidal thoughts. The number of additional hours worked also increased over time, with 26% having worked 1-15 hours more per week than before the COVID-19 pandemic, 12% worked 16-30 additional hours per week and 24% of DSPs reported working 31+ additional hours per week. DSPs were and continue to be exposed to work stress and traumatic experiences (ICI, 2022).

The crisis in the workforce significantly impacted organizations that employ DSPs throughout the pandemic. In 2021, ANCOR (2021) found that two-thirds of provider respondents turned away referrals for people with higher support needs (medical, behavioral, etc.) or those that require 1:1 staffing. Several respondents indicated that they have waiting lists for services due to a lack of staff. Even with approved services and sufficient program capacity, many people with IDD lack support because there is no one to support them. Further, providers have delayed the launch of new programs or services due to insufficient staffing. Nearly seven in 10 respondents indicated that they had experienced difficulties in achieving quality standards due to insufficient staffing. In a constant cycle of hiring and orientation, provider organizations struggle to focus on quality because too many of their resources are directed to recruitment, hiring, onboarding and required training. Meeting the present and future needs of people with IDD and their families requires a stable, supported, and sustainable workforce.

Effects of Workforce Churning on People with Intellectual and Developmental Disabilities

High turnover and vacancy rates are difficult for the people receiving support. In 2021 ANCOR surveyed providers of IDD services and found that short staffing means that people have limited choice of who they live with and where; 40% of providers are seeing higher frequencies of reportable incidents and 69% are struggling to achieve quality standards (ANCOR, 2021). The importance of a sustainable workforce was explored by Friedman (2018)

who analyzed the impact that DSP turnover has on the quality of life of the people supported. Using Personal Outcome Measures of data collected from over 1,300 people with IDD, Friedman found that DSP continuity is central to the quality of life, including security, community, relationships, choice, and goals. People who had experienced staff turnover in the last two years were more likely to have difficulty obtaining these dimensions of quality of life. The difficulty in finding and keeping DSPs has lengthened the waiting lists for community services and, increasingly, signaled a return to segregated and institutional care with some states increasing the allowable size of programs and new private gated communities and campuses emerging in many states (ICI, HSRI, NASDDS, 2022). Service provider agencies struggle to attract and retain skilled DSPs as frontline workers face the increasing challenges of working with the rising number of people with more complex disabilities who live and work in communities of their choosing (ANCOR, 2021).

Finding Solutions to Chronic Direct Support Workforce Challenges

Over the past two decades, there have been small-scale efforts to address these direct support workforce issues with effective solutions (e.g., Hewitt & Larson, 2004; Institute on Community Integration [ICI], 2021; Hewitt et al., 2008). These have been supported by investments from federal, state, and local governments. Many efforts have been grant-funded demonstration projects that are not fully sustainable after the grant funding ends. Sustainability is particularly difficult if the interventions include funding staff positions or wage increases for DSPs if there is not a long-term strategy in place to support these funding streams.

Practices that have demonstrated promise in addressing the workforce crisis include: improving professional identity and recognition; teaching business and organization leaders skills to improve their ability to recruit, select and retain direct service employees (Hewitt &

Larson, 2004; ICI, 2021); using self-directed services that permit individuals and families to recruit, select and retain their own DSPs; using worker cooperative and independent provider models (Institute on Community Integration [ICI], n.d.); using competency-based training models that lead to credentialing or certification of staff and yield wage increases (Bogenschutz et al., 2015; Hewitt et al., 2023; Kramme & Hewitt, 2018, 2021); and using technology-enhanced supports (President's Committee for People with Intellectual Disabilities, 2018). However, most of these studies did not focus on the unique needs or perspectives of women of color who are the largest group within the direct support workforce. As future studies evaluate the effectiveness of interventions, it will be important to assess demographic differences to ensure that strategies address issues more comprehensively.

Important Unanswered Questions

As described above, recent research demonstrates the challenges faced by the DSP workforce and the disproportionate representation from minority groups in the United States. Given that this workforce comprises mainly of women and people of color, poor job quality, and low wages for direct care workers will perpetuate longstanding societal disadvantages for these staff. A better understanding of the effects of being from a diverse background and being a DSP is needed.

To better understand DSPs and people with IDD receiving support from diverse racial, ethnic, linguistic, and cultural backgrounds, the 2022 State of the Science DSP strand participants identified a need to pursue answers to the following questions:

1. How is community living experienced by people with IDD from diverse backgrounds and what are the implications of that on DSP competencies?

- What competencies are needed by DSPs to best support people from diverse racial, ethnic, linguistic, and cultural backgrounds?
- How can these identified competencies best be validated by people with IDD from diverse racial, ethnic, linguistic, and cultural backgrounds who are receiving supports?

2. What is known about how to best engage DSPs, particularly those from diverse backgrounds, early in research?
    - What will enable research teams to gather information directly from DSPs, rather than provider agencies, to be sure that their stories and experiences are captured from their voice as opposed to filtered through their employers?
    - What is needed to get representative samples of DSPs from diverse racial, ethnic, linguistic, and cultural backgrounds in all research?
3. What are the characteristics of a healthy workplace culture?
    - What are the attributes?
    - How does this impact DSPs, particularly those from diverse backgrounds?
    - What actions support wellness and positive mental health?
    - What discrepancies exist between DSP and organizational perspectives on organizational culture?
4. What are the Home and Community-Based Services system drivers and pressures?
    - What supports and moves the Home and Community Based Services (HCBS) system forward and what strains the system?
    - What is needed regarding the direct support workforce to align with these drivers and reduce or eliminate the pressures?

5. What does the community system designed to provide supports to people with intellectual and developmental disabilities need to do to better support DSPs from diverse backgrounds?
6. How do we best support families from diverse backgrounds and cultures who may be self-directing and how do we increase informed choice on support options?
    - What kinds of new models can be developed that are reflective of what people and families from diverse backgrounds prefer (given the workforce shortage)?
    - What are the direct support workforce implications of the answers to these questions?
7. How do we best support DSPs from diverse racial, ethnic, linguistic, and cultural backgrounds working with individuals and families in their own home?
    - What are the rights and responsibilities of the family and the individual to engage in respectful communication and interactions with DSPs so that their level of trauma is reduced?
    - What mediation strategies are best for improving these working relationships, and what intervention research will help?

Researchers exploring these questions should make methodological considerations for frameworks and models that show promise in supporting the linguistic and ethnic diversity of the workforce and people receiving support to fully participate in research. These may include participatory action research, anti-racist frameworks, DisCrit, and the Gelberg and Andersen Behavioral Model for Vulnerable Populations. Finding answers to these important questions has

strong implications for DSPs and the Home and Community-Based Services sector in research, policy, and practice.

Implications for Research

Comprehensive supports for the direct support workforce would be enhanced by intentional engagement with workers themselves, with an emphasis on consulting workers from a wide range of identities. It can be challenging to assess the needs of the workforce when many workers are working in remote locations. The role of unions on DSP wages and working conditions should be considered. Some workers prefer to communicate in languages other than English and may not have sufficient resources to participate in research without provision for childcare or caregiving if data collection happens outside the workday. Data collection and analysis to fill broad knowledge gaps at the employer and systems levels are needed. Data need to be able to better identify and address disparities within the workforce, which will require disaggregating data by gender, race/ethnicity, and more (Betts, 2022). A federal standard dataset should include collecting individualized, raw data on race, ethnicity, gender, sexuality, age, immigration status, disability status, and any additional identity categories that workers and stakeholders determine to be relevant, alongside basic job quality data on compensation rates, benefits, service duration and turnover, etc. This could include attention toward how to fill knowledge gaps regarding undocumented immigrants and other groups that are underrepresented in public datasets.

Interventions need to include strategies to collect demographic data to document among whom the interventions are most helpful and to point towards strategies that more comprehensively meet the needs of all DSPs, particularly for DSPs of color. Workforce interventions designed to improve working conditions, change organizational cultures, and

reduce high turnover and vacancy rates need to consider the diversity of the workforce and ensure samples large enough that differences in outcomes based on the race, ethnicity, linguistic, and cultural backgrounds of the DSPs can be identified. Careful attention to collecting data using strategies to reach these workers is needed. Additionally, studies need to find out from the perspective of the DSPs themselves what are their top challenges, and their ideas to find solutions to them. This is particularly important when trying to understand the types of experiences DSPs encounter that they find disrespectful, harmful, and/or that lead to trauma and related health and wellness challenges.

Implications for Policy

The long-term services and supports (LTSS) sector, including community-based support for adults with IDD, has a serious shortage of workers. The consequences are already visible with waiting lists, organizations turning down opportunities for increased services, and some programs downsizing. Over time these issues will intensify if well designed comprehensive approaches are not put in place. There is an urgent need to design policies aiming at reducing the turnover and vacancy rates of the direct support workforce. Additionally, the disparities that exist among the workforce with regard to wages must be rectified. People of color and immigrant workers are an important part of the workforce. Women in the direct care workforce tend to have lower earnings than men and women of color are more likely than their male and white counterparts to live in or near poverty, need public assistance, and lack access to affordable housing (McCall & Scales, 2022). The same study highlights that there are also disparities among people of color. For example, Black/African American workers have particularly low family incomes, and many Hispanic/Latino workers are uninsured (McCall & Scales, 2022).

"Black Women Best" is a foundational economic framework that says when Black women's economic well-being is centered in policy, everyone's well-being is better off, and the entire economy ultimately thrives. The federal standard dataset and worker engagement strategy should be designed to ensure Black women are set up to succeed and be counted (Betts, 2022). Immigration policies must be examined to determine how they impact this important segment of the workforce across states. Employers can address wage inequities by standardizing entry-level wages and adding wage tiers tied to training, job tenure, and other factors. This issue could also be addressed by providing workers with employer-sponsored benefits (e.g., health insurance, retirement savings programs); connecting them with community supports and resources (e.g., financial counseling, affordable childcare, immigration assistance); and reforming public benefits (e.g., changing eligibility requirements, expanding tax credits, removing immigration-related barriers).

Rate setting methodologies used by states to identify the rates paid to organizations for community LTSS must be reviewed and updated on an ongoing basis to ensure that all costs associated with the delivery of services are included (President's Committee for People with Intellectual Disabilities, 2018). Relying on data that is known to not accurately reflect the work done by DSPs should be prohibited and consistency in what is included as a component of these costs should be enforced, including livable wages and benefits that are affordable based on the demographics of the workforce and the wage being paid. Additionally, it is critical that once new rates are set, they are automatically increased using a standard inflation and cost of living calculation. In far too many states rates are not adjusted routinely and within reasonable timeframes.

Implications for Practice

To address the deepening crisis of community supports, the pool of DSPs must be expanded through recognition programs, grassroots campaigns, and training efforts designed to expand awareness about the profession and encourage greater participation by people with disabilities, men, retirees, and young adults across diverse racial, ethnic and cultural groups (President's Committee for People with Intellectual Disabilities, 2018). However, DSP experiences may vary within the same job classifications, settings in which services are provided, in similar geographic areas regionally and across states, and based on their intersectional identities. Research must be conducted to explore and understand these experiences. This impacts the different wraparound supports that DSPs need to stay in emotionally and physically grueling frontline care jobs, such as reliable transportation, childcare, mechanisms to prevent and respond to harassment and discrimination, and culturally responsive management (Betts, 2022). One example is the development of specific training and interventions that target stress and burnout in African immigrants, as well as other DSPs in human services (Onyejose, 2021). To promote equity in the workplace, employers can adopt race- and gender-explicit workforce supports, such as organization-wide training on addressing unconscious biases related to gender, race/ethnicity, and other identities (McCall & Scales, 2022). Recommendations from Keesler and Troxel (2020) include fostering a culture within the provider sector of self-care and support for DSPs. This may manifest through training on self-care, regular community events focused on appreciation for DSPs, and stronger efforts to promote resiliency through mental health practice.

Trauma-informed care (TIC) is a philosophy of service provision that is committed to preventing traumatization and re-traumatization and promoting healing of all those in a system. TIC is a framework for service provision that integrates knowledge of the nature, prevalence,

and effects of trauma across all layers of an organizational system. This includes organizational policies, procedures, and practices at all levels. TIC is not a method of clinical treatment of trauma, but rather a philosophy of service delivery which recognizes that preventing traumatization, re-traumatization, and promoting healing is the responsibility of everyone involved in the organization (Rich et al., 2021).

To reflect and support the growing number of people of color in the direct care workforce, diversity is needed at every level of long-term care organizations, especially among trainers, supervisors, managers, administrative staff, and executive leadership. More diverse long-term care organizations will be better positioned to address the unique needs of women, people of color, and immigrants in direct care—and the needs of the diverse older adults and people with disabilities that they support (McCall & Scales, 2022).

Conclusion

Given what has been known for three decades, and all that was learned during the pandemic, attending to the needs of DSPs and people receiving support from diverse backgrounds is critical for the vision of community living to be fully realized. Livable wages and affordable benefits must become the norm for DSPs, not the exception. Disparities within the workforce must be eliminated. Continued efforts to reduce stress and burnout experienced by DSPs so that their well-being is enhanced is essential. Combined, these steps can lead to improved quality of community support experienced by individuals with IDD.

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