

Inclusion

Direct Support Professional and Frontline Supervisor Perspectives on Work-Life in a Pandemic --Manuscript Draft--

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Abstract:	Direct support professionals (DSPs) and frontline supervisors (FLSs) play an instrumental role in providing home and community-based services for people with intellectual and developmental disabilities. This workforce has been enduring a long-term crisis with recruitment and retention, which has been intensified by the COVID-19 pandemic. This qualitative study aimed to illustrate the most demanding challenges and the biggest positive changes DSPs and FLSs experienced 18 months into the pandemic. Participants included 3,728 DSPs and FLSs across the United States. They answered open-ended questions about the challenges and positive changes they experienced in an online survey. The findings include the challenging working conditions, favorable working conditions, relationships with co-workers and people supported, and the personal impact on DSPs and FLSs.

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Abstract

Direct support professionals (DSPs) and frontline supervisors (FLSs) play an instrumental role in providing home and community-based services for people with intellectual and developmental disabilities. This workforce has been enduring a long-term crisis with recruitment and retention, which has been intensified by the COVID-19 pandemic. This qualitative study aimed to illustrate the most demanding challenges and the biggest positive changes DSPs and FLSs experienced 18 months into the pandemic. Participants included 3,728 DSPs and FLSs across the United States. They answered open-ended questions about the challenges and positive changes they experienced in an online survey. The findings include the challenging working conditions, favorable working conditions, relationships with co-workers and people supported, and the personal impact on DSPs and FLSs.

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DSP & FLS Pandemic Work-Life

Direct support professionals (DSPs) and frontline supervisors (FLSs) play an invaluable role in delivering home and community-based services to individuals with intellectual and developmental disabilities (IDD). DSPs provide support with employment, community living, developing social connections, health and well-being, and many other areas. FLSs' primary responsibility is to provide direction and guidance to DSPs in their work; however, they also frequently provide direct support to individuals with IDD. This workforce has been in crisis with high turnover and vacancy which threaten the inclusion of individuals with disabilities in their communities. The COVID-19 pandemic exacerbated an already fraught situation.

Description of the Workforce and Challenges

The demand for the services provided by the direct support workforce is growing (PHI, 2021). There is an estimated 1.3 million DSPs in the United States (President's Committee for People with Intellectual Disabilities, 2017). DSPs provide supports such as "activities of daily living, household tasks, personal health and safety, community access and integration, relationships, work," and other activities (Bogenschutz et al., 2014, p. 317). DSPs are paid low wages, particularly when required skills and job responsibilities are considered (Hewitt et al., 2021a; Musumeci et al., 2021). For example, DSPs may need to perform medical supports such as caring for feeding tubes or providing behavior supports for individuals with challenging behavior. Many DSPs live in poverty due to low pay, which exacerbates the burnout that has been a long-term issue in the field. Campbell and colleagues (2021) reported 42% of employees in this field received public assistance. FLSs also receive low pay for their level of responsibility (Bogenschutz et al., 2014) and many who are salaried make less than DSPs because when they work beyond 40 hours per week and are not typically paid overtime.

The direct support workforce has had high stress levels and consistently high turnover rates (Bogenschutz et al., 2014; Houseworth et al., 2020; PHI, 2021). Wages, access to health insurance, number of part-time employees, staffing ratios, and Medicaid spending have all been associated with DSP turnover (Houseworth et al., 2020). Pettingell and colleagues (2022) reported that staff wages were a crucial element associated with differences in DSP retention.

Impact of COVID-19 on the Workforce

While direct support workers have faced challenges related to retention and pay for years, the COVID-19 pandemic exacerbated those challenges (National Council on Disabilities, 2020). Workloads increased when staff left their positions, and in some cases when their employers changed staffing patterns so that the fewest people necessary entered the shared space of the people with IDD who were supported. In-home and group home services have been affected by staffing shortages. In a study by McCall and colleagues (2021), 4% (168,370) of DSPs experienced displacement from their positions in the first quarter of the pandemic. Of these displaced DSPs, 9% (14,770) returned to the workforce by March of 2021 but not to direct support work. The outstanding 91% (153,610) had still not re-entered the workforce at the end of the first quarter of 2021.

The 2019 National Core Indicators Staff Stability Survey report provides a snapshot of staffing before the pandemic. Twenty-six states participated in the survey that produced a weighted average 42.8% turnover, however, the vacancy rates averaged 8.5% for full-time positions and 11.2% for part-time positions (NCI, 2020). Twenty-seven states provided data for the 2020 NCI Staff Stability Survey which showed a weighted average turnover of 43.6%, up slightly from 2019 (NCI, 2022). Vacancies were also up an average 12.3% for full-time staff and

16.4% for part-time staff. Indicating that while turnover was high before the pandemic and remained high, backfilling positions was more difficult.

Direct support workers also reported staffing difficulties. Early in the pandemic (spring 2020), 26% of DSPs and FLSs said their workplace was short-staffed (Hewitt et al., 2020). This number had nearly doubled six months later (50%; Hewitt et al., 2021a). Additionally, over half (54%) said their work-life had worsened since the onset of the pandemic (Hewitt et al., 2021b).

Addressing Workforce Challenges

During the pandemic, federal efforts provided states additional funds to deal with essential workers' pandemic-related workforce challenges. The Coronavirus Aid, Relief, and Economic Security (CARES) act was used by some states to temporarily increase pay or provide bonuses to essential workers. Some states offered a temporary hourly pay increase, while others delivered a one-time payment (Kinder, 2020). While these measures were well intended, DSPs did not always benefit. For example, the 2020 Families First Coronavirus Response Act (FFCRA) provided essential workers emergency paid sick leave. The caveat, however, was that some employers were permitted to exclude DSPs if they desired (National Council on Disabilities, 2020). Independent contractors were also excluded from the FFCRA provisions. This means that DSPs hired directly by persons using self-directed programs could not access emergency paid sick leave or other provisions of this act (National Council on Disabilities, 2020).

COVID-19 Work-Related Issues and Environment

As of 2020, women contributed to 81-90%, people of color contributed to 53-63%, and immigrants contributed to 21-31% of the direct support workforce in-home care, residential care, and nursing settings (PHI, 2021). The majority of DSPs had caretaking responsibilities outside of

work as well. Nearly 50% of all DSPs had children, 25-33% of whom had at least one child under age 18, while 10-15% had at least one child under age 5 (Almeida et al., 2020; PHI, 2021). Many DSPs were the primary source of household income, as 23.9% of these professionals were single mothers with no other source of income (Almeida et al., 2020). Additionally, 26.5% of DSPs were over 55, increasing their risk of health complications if infected. The combination of family responsibility and personal risk factors compounded the effects of COVID-19 on DSPs.

The pandemic exacerbated the already problematic DSP turnover rates (Friedman, 2021; Hewitt et al., 2021b). Staff shortages, increased workloads, fear of the disease, childcare difficulty, and other factors led to increased turnover. In a 12-month follow-up survey fielded in summer of 2021, 62% of respondents indicated having coworkers who left their jobs to protect their families or themselves from the disease (Hewitt et al., 2021b). Working hours also significantly increased. Sudden short staffing required employees on-site to stay longer, making the end of their shift time unpredictable (Musumeci et al., 2021).

Purpose of the Current Study

This qualitative study aimed to explore and describe the challenges and positive changes in work-life 18 months after the start of the COVID-19 pandemic for DSPs and FLSs throughout the United States. Understanding both the challenges and positive outcomes was deemed important in order to understand the full experience of providing direct supports during a pandemic. The research questions included:

1. What were the most significant positive work-life changes due to COVID-19?
2. What were the most significant work-life challenges due to COVID-19?

Methods

Qualitative research methods were selected to better understand the experiences of direct support professionals (DSPs) and frontline supervisors (FLSs) 18 months after the beginning of the COVID-19 pandemic. Including the open-ended questions in the survey provided an opportunity for FLSs and DSPs to provide more details and share their stories about providing direct supports during a pandemic. Using qualitative methods allowed for a deeper understanding of their experiences (Creswell, 2013).

Survey

The COVID-19 Direct Support Workforce 12-Month Survey, the 3rd in a series of three online surveys, was fielded in June and July of 2021 via Qualtrics. Information about the survey and a link for access were sent to contacts across the United States and disseminated on social media. Key national organizations endorsed the survey and provided the link directly to DSPs and disability organizations. The survey included 63 total items about participant characteristics and questions about work and personal experiences related to the COVID-19 pandemic (see Hewitt, 2021a; Hewitt, 2021b). The analysis for this study focuses on the survey's two open-ended questions answered by both DSPs and FLSs about their most significant positive change and their most significant challenge in their work-life 18 months after the start of the pandemic.

Participants

5,536 DSPs and FLSs participated in this online survey. The current analysis included only those DSPs (n=2,996) and FLSs (n=732) that answered one or both of the open-ended questions in the survey. Both DSP and FLS groups predominately identified as women, including transgender women (DSPs, 82%; FLSs, 87%) and were the primary wage earners in their households (DSPs, 72%; FLSs, 67%). The average age was 45 years for DSPs and 44 years for FLSs. More FLSs identified as white (81% vs. 70%). More DSPs than FLSs reported being

Black or African American (21% vs. 11%). The remaining 8-9% for both groups included individuals from Asian, Pacific Islander, Native populations, or other groups. Six percent of DSPs and FLSs reported being of Hispanic, Latino, or Spanish heritage. It should be noted that nearly half (44%, DSPs; 49%, FLSs) were working in Midwestern states.

Data Analysis

The data were analyzed using the qualitative data analysis software NVivo. The first two authors analyzed both open-ended questions answered by DSPs and FLSs using a multistage process of open and axial coding guided by the constant comparative method (Creswell, 2013; Strauss & Corbin, 1998). To be systematic and rigorous, an inductive data analysis process was used that compared all data to emerging codes and organized them into categories (Creswell, 2013). Each question was independently coded. The first author coded the DSP data and the second author coded the FLS data to identify initial codes and create a codebook by comparing, combining, and renaming the initial codes. The codebook included 30 codes, grouped into four themes, with descriptions and examples to guide application. The first 10% of each question were recoded for DSPs and FLSs to check for accuracy of the codes and collect inter-rater reliability data using NVivo. A 99.34% overall agreement was achieved and did not add or delete any codes. Relationships and connections within the data were explored during axial coding to group the codes into emerging themes.

Credibility

To establish credibility, data triangulation, researcher triangulation, and peer debriefing (Brantlinger et al., 2005) were used. The data were triangulated across sources (i.e., DSP surveys, FLS surveys). Researcher triangulation included collaboration and discussions about

connections within and between codes and emerging categories during analysis. Peer debriefing occurred during the regular research meetings.

Findings

The findings of this study highlight both the challenges and positive changes experienced by direct support professionals and frontline supervisors 18 months after the beginning of the COVID-19 pandemic. The themes include the challenging working conditions, positive working conditions, relationships with co-workers and people supported, and personal impact on DSPs and FLSs.

The relationships among the themes are illustrated in Figure 1, where the COVID-19 pandemic was the primary context that affected the work-life of DSPs and FLSs. The restrictions of the pandemic impacted the working conditions of DSPs and FLSs. New challenging working conditions stemmed from the pandemic, such as enforcing safety measures, adapting to virtual supports, changes in job duties, schedule changes, and lack of support. There were also increasing positive working conditions resulting from the need to establish flexible work, use technology, and creatively adapt to new ways of doing things. Both of the challenging and positive working conditions affected the relationships that DSPs and FLSs had with their co-workers and the people they support. When they were stressed and overwhelmed, they were more on edge. They had closer relationships when they felt supported at work and got to know the people they support better due to more one-on-one time. The challenging working conditions, positive working conditions, and relationships were all factors that influenced the personal impact of the pandemic on DSPs and FLSs.

Figure 1. *Factors that Affected DSPs and FLSs, During the COVID-19 Pandemic*

Insert Figure 1 about here

Challenging Working Conditions

The pandemic exacerbated the problems of a workforce that was already struggling before the pandemic started. Implementing COVID-19 guidelines added to the workload for FLSs and DSPs. Participants described the effort it took to ensure the people they supported wore masks and practiced social distancing guidelines. Challenges enforcing the guidelines included "balancing the rights of the recipient of services with the health and safety of themselves and those they live with." The new cleaning and hygiene measures also added to their workload: "It's hard to find time to complete all the extra cleaning and still provide the same support to clients." Some FLSs and DSPs were concerned about the lack of attention to COVID-19 guidelines from their employers: "they stated they had procedures/policies (masks, social distancing, cleaning, an isolation room) that less than a month into the pandemic they completely stopped actively enforcing."

Other challenges included not having enough personal protective equipment (PPE). DSPs reported "working with limited PPE supplied from the company and limited protective supplies such as gloves and cleaning supplies." Some DSPs reported having to pay for their own PPE: "a lot of expenses connected to this pandemic came directly from our pockets." Some participants felt like policy makers did not value their efforts. "At the beginning of the pandemic, it seemed like decision-makers respected the work of provider agencies, but now, a year later it seems as though the state is right back to the same sense of 'it will all be taken care of, the provider will deal with it, and we won't have to.' It's sad that that's all the longer we had their respect."

Wearing masks was a negative aspect of following pandemic guidelines. Many participants found them uncomfortable, particularly for specific tasks such as assisting with baths or showers. Others noted that mask-wearing made communicating with the people whom they

supported more difficult by "not being able to see your face or facial expressions." As one DSP explained, "It's hard to communicate with individuals with a mask on."

Staffing Crisis

As one FLS succinctly noted, the staffing crisis "is the new pandemic." One DSP described the problem this way:

Staffing is a huge issue – due to wages and budgets, direct support professionals do not make enough over minimum wages offered in other jobs to make the difficult aspects of our job worth working as a DSP. New staff and old know for a dollar less per hour they can work as a cashier and don't have to be CPR trained, deal with bodily fluids or possibly be in a situation where a client could injure you. There is a lot of turnover and understaffing.”

Participants reported working overtime, including mandated overtime, low staff-to-person ratios, and working in different locations to help cover open shifts. The increase in the number of hours DSPs and FLSs were required to fill to ensure people's needs were met made retention a challenge. FLSs report that they "lost staff because of the amount of hours they were working."

FLSs stated that recruiting new DSPs was difficult. Few people applied for open positions or came for interviews: "Staffing – it is difficult to find staff. We aren't receiving applications when we do – we call for interviews, and of the interviews scheduled, 1/5 of them show."

Low Wages

Many DSPs and FLSs noted that despite the extra work and personal sacrifices they had made to continue to provide supports during the pandemic, they had not received any of the hazard pay that was made available for essential workers:

ONLY getting a .70 raise. Not nearly enough to make an actual difference in finances and currently still caring directly for a person who is covid positive with to my knowledge no hazard pay. Being worried about bringing it home to my autoimmune compromised household. Sleeping in my car due to the company I work for not putting any covid policies in place being unprepared even after 16 months.

Lack of Support

Participants felt unsupported and undervalued despite the extra responsibilities and hours they were working to ensure that supports continued for the people who needed them. One DSP noted, "unappreciative, out of touch and unsupportive upper management. I was directly told by the company's executive director that staff are merely in place to support the members and that staff's welfare is not important." FLSs report that they also experienced a "lack of support from administration in regards to staffing shortage."

Experiences of Frontline Supervisors

While DSPs and FLSs shared many of the same experiences and challenges during the pandemic, FLSs had some additional difficulties that stemmed from their position. FLSs were often responsible for explaining and enforcing COVID-19 guidelines to DSPs, the people they support, and their family members. Finding the balance between protecting people's health and being supportive was challenging. One FLS noted that "watching those I support struggle with guidelines and regulations" was difficult. Other FLSs noted that struggles with enforcing

guidelines came from DSPs unwilling to follow guidelines. One described having "COVID-19 policy fatigue."

FLSs were also negatively affected by the staffing crisis. They are generally salaried employees and often end up covering open shifts. This was exacerbated during the pandemic as the crisis deepened and FLSs were expected to perform their duties and cover shifts and tasks typically done by DSPs: "Due to a decreased staff base, as a supervisor, I'm having to choose between completing paperwork and cover in day hab classrooms ... which provides a huge mental hardship for myself and co-managers." FLSs in residential supports had similar experiences, mainly when individuals supported were home rather than working or going to day programs: "I never get a break. I am on-call for my sites and employees 24/7 without any additional help or compensation." This leads to supervisor and managerial position turnover, leaving few people with the skills and experience needed to manage programs and train new DSPs: "We are experiencing significantly high turnover in supervisors and managers, leaving offices with little to no experienced supervisors to lead the teams."

Positive Working Conditions

Positive changes to the working conditions of DSPs and FLSs since the beginning of the pandemic included the increased support of leadership, improved job skills and responsibilities, more flexible work, and increased health and safety measures.

The increased recognition, support, and care given by an organization's leadership improved the culture of the organization and the well-being of DSPs and FLSs. With increased recognition, DSPs felt genuinely valued by their employers. They found there was also more concern "over employees' wellbeing and mental health." As one DSP shared, "there are monthly check-ins from my direct supervisor, which includes discussion of self-care." DSPs appreciated

the improved communication and supportive responses from their supervisors: “I believe our voices are heard and listened to more.” Due to the pandemic, there was less unnecessary oversight and more flexibility in the work. Many DSPs and FLSs gained greater confidence in their organization’s leadership. As one DSP explained, “I was reassured by the response of my organization's leadership through the pandemic, therefore I am confident that going forward their leadership will meet whatever challenges occur.”

During the pandemic, FLSs also experienced positive changes that improved their job. As one FLS shared, “I believe it pushed me to take a leadership role in my organization.” Many FLSs had to expand their duties and learned new tasks: “I have stepped up more and had to take on more in my role.” They learned to navigate online resources and used technology to assist with a variety of tasks. It was necessary to be more creative when developing activities and curriculum due to the restrictions of the pandemic. For many, this was an “opportunity to look at different ways to provide services.” Though many FLSs enjoyed less travel time, others were looking forward to going back to the office. As the changes from the pandemic slowed down, some were looking forward to a more predictable schedule.

DSPs also experienced positive changes during the pandemic that improved their job. Some DSPs worked in a different location or transferred to a new program where it was a better situation for them. When working with coworkers, DSPs appreciated having “access to communicate with people in more efficient ways utilizing our various platforms.” This gave DSPs more opportunities to consult with coworkers and get support from supervisors. DSPs also valued working with smaller groups to get to know each person they support better and “learn how to provide more individualized care.” DSPs were given more responsibility and autonomy within their work. As one DSP shared, “I have more flexibility to engage in meaningful activities

with the people I support than I did a year ago.” They learned new job skills, increased their adaptability, and took on new roles in different locations. DSPs developed skills in time management, documentation, online teaching, advocacy, and preventive measures for communicable diseases.

The flexibility in work schedules and how work was completed were positive changes caused by the COVID-19 pandemic. Employers began to acknowledge “that flexibility is both important and necessary.” Flexibility in scheduling shifts was important to DSPs, and flexible work hours were helpful for FLSs who completed administrative tasks at home. For many, “working from home has been productive,” and they appreciated the personal choice of whether to work from home or in person if appropriate. The increase in technology use provided DSPs and FLSs more access to trainings and team meetings. Both DSPs and FLSs found that “being able to be creative with how we provide services” was a positive change. With flexible work, one DSP was able “to research training and employment resources and ideas which I am still using.” DSPs were able to be more flexible with the people they support through technology, including virtual check-ins, expanded telehealth, virtual activities, and virtual employment services. Access to virtual appointments was important, “especially for the individuals that travel is hard on or have to go long distances to see certain doctors.” DSPs used online videoconferencing to allow people to see their family and friends.

Another positive change since the beginning of the pandemic was the improvement of health and safety measures at work. DSPs and FLSs became more knowledgeable about preventive healthcare. As one DSP explained, “I’m more aware now about sanitation, cleaning, and the importance about keeping social distance for health reasons.” They had a cleaner work environment because of the “increased focus on hygiene and overall cleanliness.” As one DSP

observed, “all staff take cleaning a little more seriously.” Many staff were provided personal protective equipment by their employer, though often in limited quantities. People wore masks, washed their hands, and practiced social distancing while in the community. Most Staff were relieved when they and the people they supported had been vaccinated: “Being vaccinated gives me much more peace of mind.” They also noticed that people were “not getting sick as frequently from common illnesses.” The vaccines and heightened safety measures helped most staff feel safe as they were getting back to normal.

Relationships

The relationships DSPs and FLSs had with their coworkers and the people they support were both positively and negatively affected by the COVID-19 pandemic, the supports they had, and how they pulled together to get through the difficult times. Repeatedly, DSPs shared that they felt “closer to coworkers” after going through the COVID-19 pandemic together. Many experienced “becoming a better team with my coworkers” with more effective communication. One DSP shared there was even “more teamwork and support from management.” Because teams overcame obstacles during the pandemic, they were a “more cohesive as a team.” They appreciated the commitment of fellow staff and felt more solidarity with each other. As one DSP said, “the team of us 3 long term staff have grown very close and make each other laugh through it all.” DSPs were also able “to connect better with people in other departments/services as we shared online activities.” They built connections through online meetings and appreciated “getting to work collaboratively with different locations.” Even with this, DSPs missed socializing in person with their coworkers.

In contrast, the stress of working through the pandemic strained some staff relationships. They were upset with each other and experienced “disrespect among coworkers” because they

were short staffed and overwhelmed. DSPs felt a strain on their relationships when others did not take COVID-19 seriously and when they did not have the same approvals for flexible work: “employees have a big divide and dislike for one another now based on who is allowed to telework and who isn't.”

Many frontline supervisors also felt closer to their teams. One FLS noted that they became “a closer team of managers and supervisors,” and another FLS “built good relationship with my staff.” When teams pulled together, it developed “camaraderie with coworkers who have had the same experiences.” On the other hand, it was difficult for some FLSs to get to know new DSPs and work through the “tensions between staff who think the other staff are not performing to the level they think is appropriate.”

Throughout the pandemic, DSPs also felt closer to the people they supported. Many have developed a “better relationship with the individuals we serve,” and recognize the importance of meaningful connections. This was largely due to spending “a lot more time in the home with them, finding things to do and talking with one another.” Since they were able to have more one-on-one interactions, they got to know the people “in a much deeper way,” and learned more about their likes and dislikes. Therefore, DSPs were able to provide better support. FLSs also learned more about the people they support and felt a closer relationship to them.

Personal Impact

Throughout the pandemic, DSPs and FLSs experienced both positive changes and challenges in their personal finances, work-life balance, and mental and physical health.

People were affected positively financially by the availability of work, competitive wages, increased wages and bonuses, and more hours to increase their income. Many were thankful that they still had a job and “a steady paycheck” during the pandemic. Some DSPs felt

they had more job security because they were considered essential workers: “therefore being able to continue working without worrying about getting laid off or losing my job.” Others were able to move to a full-time job with benefits or receive a promotion: “I was promoted to a new role based on the need for virtual employment services.” During the pandemic, some DSPs were able to earn more through COVID-19 pay increases, hazard pay, bonuses provided as a “thank you,” and other incentives. This was the first pay increase many DSPs received in a long time: “In the past I have gone years without a pay increase. It is nice to finally make a living wage after 25 years with this agency.” Other DSPs appreciated being able to work more hours to make extra money. As one DSP said about overtime, “it can be draining but at the same time I am a single parent and the extra money has allowed us to stay up on bills.” Even with the pay increase, the future is uncertain: “I’m not sure what to do after it goes away.”

Many DSPs had challenges and concerns regarding their finances. With the increased financial strain on service providers, one DSP shared their “concern about losing my job if my employer goes out of business.” Before and during the pandemic, DSPs did not have competitive pay. As one DSP shared, “our agency does not give increases for longevity staff and the new staff coming in are making as much or more than those of us that have been dedicated over the years.” For the dedicated staff who worked during the pandemic, it hurt morale to know that “unemployment pays better than being a DSP.” The pay raises and bonuses were not provided everywhere, and employees noticed. Many did not receive hazard pay, though they felt they needed “to be financially compensated for being an essential worker.” Others had a reduction in pay, and it was difficult to support families when the “cost of living is increasing with no increase in wages.” As one DSP explained, “the wages I receive are not enough to pay the rent that had increased.” Many DSPs felt they were “overworked and underpaid.” They did not feel

valued: “We are in charge of keeping people safe and healthy and get paid next to nothing to do it.” As one DSP explained,

I love my job, but it is very difficult to support myself. While fast food employees are getting paid 3-4 dollars an hour more, for serving food. We provide a service which is extremely important, to better the lives of our consumers in every aspect of their lives.

Most Direct Caregivers are leaving for higher paying jobs. The shortage of applicants are due to the pay. We are worth more than our hourly rate reflects.

Some workers established a better “balance between work and personal life” after going through the pandemic. As one DSP said, “I personally learned to set more boundaries with my job over the course of the last year.” Many DSPs and FLSs were able to work from home or remotely: “With the option to work remotely becoming common place, I find it much easier to have a work/life balance.” They had more time for activities that were important to them. Some employees had more time for self-care. A few DSPs mentioned that it was now easier to take a sick day: “We're being told to stay home when we're starting to get sick rather than being told to suck it up until we literally can't work anymore.”

Other DSPs and FLSs found that it was difficult to find a healthy work-life balance because they were stressed, overworked, and overwhelmed. It was difficult for them to do basic self-care such as getting enough sleep, finding time to exercise, and catching up on personal medical appointments. Due to overtime, it was difficult to have a social life, go on vacation, or “take care of things outside of work because everything is closed.” It was a challenge to get time with family: “My family and children are suffering because I am never there and always working.” Parents struggled to support their children with virtual learning at home or had difficulty finding childcare. DSPs and FLSs stated that they were overworked because the

organization was short staffed, and they had to cover shifts when coworkers did not show up. As one DSP shared, “I now work 70+ hours, have no life, and hate everything.”

The COVID-19 pandemic affected the mental and physical health of both DSPs and FLSs. Many took steps to strengthen their mental health. As one DSP shared, “I am taking better care of my mental health and recognizing when I feel overwhelmed.” They took steps to control anxiety, learn more positive coping skills, and get support from professionals. Though some organizations had “more compassion around taking time off for mental health,” DSPs who worked at other organizations learned to say no to extra hours when they were overwhelmed “despite pressure to do the opposite.”

The hardships of the pandemic helped staff “view things from a different perspective.” It inspired some DSPs to “live life to the fullest.” Many DSPs voiced gratitude for their job and having meaningful work. As one FLS explained, they had “a renewed sense of how much the people supported mean to us.” They also expressed appreciation for the positive aspects of their lives, such as relationships, family, the freedom to go out, good health, being alive, and the smaller things in life. They expressed appreciation for their coworkers and the people they support. It was also beneficial to their mental health to be appreciated by others and receive acknowledgement that their work was important. The struggles of the pandemic strengthened the resilience of many DSPs and FLSs. They became more adaptive to change and found that “there is always a way to solve a problem.”

Many workers experienced burnout during the pandemic. They felt compassion fatigue, burnout, exhaustion, decreased motivation, and depression. DSPs and FLSs experienced anxiety and fear. They were afraid of being exposed to COVID-19, getting infected, and infecting both the people they support and their families. There was a heightened “anxiety with keeping

everyone safe and healthy” as well as a “fear to return to normal life.” It was difficult to deal with stressed staff: “People have become extremely edgy.” DSPs are also affected by the anxiety and behaviors of the people they support: “the deterioration in their quality of life has been sad.”

Throughout the pandemic, DSPs and FLSs were concerned about staying healthy. Though some of their concerns centered around the effects of being overworked, most of their physical health concerns centered around COVID-19. It was a challenge to get necessary personal protective equipment. DSPs were especially concerned about “exposure to clients who are not vaccinated and require close proximity” or working around people who tested positive for COVID-19. One DSP shared that they were constantly exposed to COVID-19 due to working in a congregate setting. Another DSP with underlying health issues caught COVID-19 two times even with precautions. DSPs and FLSs wanted to make sure they stayed healthy for their families—or at least did not spread it to their families. As one DSP shared, they were “worried about bringing it home to my autoimmune compromised household” and was “sleeping in my car due to the company I work for not putting any COVID policies in place.”

Discussion

Before the COVID-19 pandemic, the direct support workforce was already in a precarious situation (Bogenschutz et al., 2014; Houseworth et al., 2020). The additional responsibilities and demands of ensuring the health and safety of individuals receiving support, paired with low wages and lack of recognition and attention to the needs of the direct support workforce, has caused the situation to reach an untenable level of crisis (Hewitt et al., 2021a; Hewitt et al., 2021b). As described by the participants of this survey, the situation is a self-perpetuating cycle in which overworked and underpaid DSPs burn out and leave the profession (Hewitt et al., 2021a; Hewitt et al., 2021b), leaving even more work for those who stayed. While

the DSP workforce shortage is getting some attention from policy makers, the loss of FLSs is less frequently noted as a concern. However, the loss of significant numbers of experienced leaders in supervisor roles exacerbates the problem. It is likely to make recruiting, training, retaining, and rebuilding a competent workforce even more of a challenge. FLSs are an important factor in the retention of DSPs. DSPs report that problems with supervisors are a primary reason for leaving a position, however, FLS that treat their employees fairly have a better staff retention (Larson et al., 1998).

The workforce crisis has led to negative outcomes for individuals with disabilities, undoing decades of work to improve person-centered services, employment, and social participation (Friedman, 2018). It is threatening the ability of the disability support system to provide even basic services. Programs and services are either curtailing the number of people they support or closing altogether (ANCOR, 2021). For those programs that remain open, the experiences of the DSPs and FLSs in this study show that the quality of services experienced by many individuals is compromised. In a study examining the relationship between DSP turnover and quality of life outcomes for individuals with IDD, Friedman (2018) found that DSP turnover was associated with poorer outcomes related to safety, health, being treated respectfully and fairly, exercising rights, and continuity of supports. Individuals receiving support also had less community participation and poorer relationships with friends and family. Friedman noted that DSPs play a crucial role in supporting these outcomes for people with IDD.

However, the positive changes reported by participants of this study show the way forward in improving the working conditions for DPSs and FLSs. One of the findings of this study was the importance of relationships for DPSs and FLSs in managing the workload and other challenging aspects of providing direct supports during the pandemic. Both DSPs and FLSs

noted that having a team that was supportive of each other as well as support from their supervisors made it easier to do their work. These findings point to three areas of research and practice that have previously been demonstrated to improve recruitment and retention, including increased skills, teamwork, and leadership (Centers for Medicare and Medicaid Services, 2014; Hewitt & Larson, 2007). Bogenschutz and colleagues (2015), for example, found a relationship between competency-based training and lower turnover. DSPs and FLSs responding to the open-ended questions in the present study valued the opportunities they had to increase their skills, which further reinforces previous research showing the benefits of purposeful and meaningful training. Often FLSs are promoted to their role from a DSP position and receive little training on leadership and building teams (Larson et al., 1998; Hewitt et al., 2004). Training for FLS to increase their leadership skills would be an essential part of any systematic training program aimed at retention and supports that improve quality of life (Sedlezky et al., 2013).

However, as noted by the respondents to this survey, wages are a primary concern. In order to stabilize the workforce and provide quality, person-centered supports to participants in LTSS programs, a financial investment in the wages for DSPs and other direct care workers needs to be a priority. This is skilled work and those who provide direct supports that enable people with disabilities to live and participate in their communities deserve a living wage. An analysis of the NCI Staff Stability Survey found that staff wages were the critical factor in DSP retention (NCI, 2022).

Limitations

While the sample was large, survey methods used a convenience sampling approach; therefore, the demographics and characteristics of the survey respondents may not reflect that of the total direct support workforce. Compared to PHI (2021), the participation rate by people of

color was lower than expected, and the length of work tenure was primarily 36 months or more. Results may not reflect well the perspectives of DSPs and FLSs of color and/or those employees who are newer to the field.

Contributions to the Field and Implications for Future Research

The findings in this study added to the body of literature about the conditions that are contributing to the workforce challenges in disability-related long-term supports and services. While these challenges existed before the pandemic, they have intensified since 2020. The DSPs and FLSs responding to this survey identified factors that both cause people to leave the field and what keeps people in their positions. While there have been previous studies about DSPs and workforce challenges, the views and experiences of FLSs have had less attention in the related research. Previous research has shown that FLSs are the key to better retention of DSPs and higher quality supports for people receiving supports. Better understanding of the roles of FLSs and how best to recruit, train, and retain skilled FLSs is an important next step in research.

Implications for Practice and Policy

These challenges described by the DSPs and FLSs in this study are not new; they were present and troublesome before the COVID-19 pandemic. The lack of policymakers' acknowledgment of the direct support workforce crisis also existed before the pandemic. Addressing the workforce crisis will require the implementation of best practices at the provider level as well as policy changes to address systemic problems. Findings from this study, in which DSPs and FLSs identified what was challenging about their work and how they best felt supported by their team and leadership, further reinforces previous work in workforce retention

(e.g., Bogenschultz et al., 2015). Previously tested practices that are effective with DSP and FLS recruitment include:

1. Implementing evidence-based strategies for recruitment and retention such as realistic job previews, targeted marketing, structured behavioral interviewing, career paths, competency-based orientation and training, and mentoring (Hewitt et al., 2019; Liu et al., 2018; Scales, 2018).
2. Making DSP and FLS wages more competitive by increasing base wages to ensure they are livable wages.
3. Providing higher quality training and education support for FLSs from organization leadership on effective supervision and management skills.

While strategies exist for providers to address the workforce crisis, the problem is systemic at its core. Systems level solutions at the federal and state levels are critical. To adequately address the DSP and FLS workforce crisis, critical policy recommendations include:

1. Reimbursement rates for long-term supports and services need to be addressed by policymakers so that DSPs and FLSs who provide this essential work are afforded a living wage and ensured regular cost of living increases.
2. Affordable childcare is an imperative need if this workforce is to continue to effectively provide supports. DSPs are often the primary wage earners in their households and are often single parents (Hewitt et al., 2019). The pandemic has intensified workers' challenges in finding reliable and affordable childcare leading to job losses among low-wage workers (Koltai et al., 2021).
3. Career paths need to be created based on the DSP Core Competencies (NADSP, 2016) and National Frontline Supervisor Competencies (Sedlezky et al., 2013) that provide

opportunities for growth and skill development in community human services that leads to related wage increases.

This workforce has been in a state of crisis for decades, but with added pressures from the pandemic, it is now sitting on the precipice of collapse. States must use funds provided through the American Rescue Plan Act and CARES Act money to offer stability now and strength in the future for this workforce. Other investments in this workforce must be made, including those that provide routine cost of living increases within rate structures. For over 30 years, progress has been made in providing people with disabilities a higher quality of life by supporting and increasing their rights to choose where they live, where they work, whom they spend time with, and how they find enjoyment in life are in jeopardy. These promises, which are made through federal and state policies, are not going to be kept under the current workforce situation. The direct support workforce needs to be respected, well paid, and well trained for this progress to continue. Without substantial workforce investment and change, community providers will continue to decrease the number of people they are able to support, and more people will languish on waiting lists.

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Figure **Context**

Influencing Factors

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Outcomes

