

Providing Support During the COVID-19 Pandemic

# Direct Support Workforce and COVID-19 National Report: Six-Month Follow-up

April 2, 2021


The aim of this study was to gather evidence about the experiences of the direct support workforce during the COVID-19 pandemic and to inform efforts to better prepare for future waves of this pandemic. This is a six-month follow-up to the [initial report \(/community-living/covid19-survey/overview\)](#) published in fall of 2020.

This survey was conducted by the [Institute on Community Integration \(https://ici.umn.edu\)](https://ici.umn.edu) at the University of Minnesota in partnership with the [National Alliance for Direct Support Professionals \(https://nadsp.org/\)](https://nadsp.org/).



The development of reports and manuscripts was supported by Grant #90RTCP0003 to the Rehabilitation Research and Training Center for Community Living for Persons with Intellectual Disabilities from the National Institute on Disability Independent Living and Rehabilitation Research, U.S. Department of Health and Human Services. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not therefore necessarily represent official NIDILRR policy.

Please contact [Jerry Smith \(mailto:smith495@umn.edu\)](mailto:smith495@umn.edu) with questions.

**SHORT REPORT:** Download the three-page PDF version of the Direct Support Workforce and COVID-19 National Report: Six-Month Follow-up.  ([https://ici-s.umn.edu/files/\\_9-neK-xR6/national\\_dsp-covid-6-month.pdf](https://ici-s.umn.edu/files/_9-neK-xR6/national_dsp-covid-6-month.pdf))

Suggested Citation:

Hewitt, A., Pettingell, S., Kramme, J., Smith, J., Dean, K., Kleist, B., Sanders, M., & Bershadsky, J. (2021). Direct Support Workforce and COVID-19 National Report: Six-Month Follow-up. Minneapolis: Institute on Community Integration, University of Minnesota.

## Introduction and Background

In March 2020, many businesses and schools followed safety protocols, closed their doors, and began working and participating remotely because of the COVID-19 pandemic. For the vast majority of direct support professionals (DSPs), this was not an option. Friends and colleagues from across the country shared stories of the mounting challenges in providing supports safely to individuals with intellectual and developmental disabilities during the COVID-19 pandemic. The National Alliance for Direct Support Professionals (NADSP) and the University of Minnesota's Institute on Community Integration (ICI) staff knew it was important to hear directly from DSPs about their experiences in supporting people with disabilities during a global pandemic. In response, ICI developed an online survey and collaborated with NADSP to reach DSPs from across the country. The initial survey was launched in April 2020 and surveys were completed by 8,914 participants. Based on the results of the initial survey, some items on the initial questionnaire were slightly modified and a few questions were added to a second, six-month follow-up survey that was launched in November 2020 and completed by 8,846 participants. Both surveys, completed by DSPs, were intended to gather information about their experiences during the COVID-19 pandemic to inform effective policy and practice decisions about what is needed and to better prepare for potential future waves of this or other pandemics.

## Background

The direct support workforce provides an array of critical supports making it possible for people with intellectual and developmental disabilities (IDD) to live, work, and thrive in their communities. These professionals perform multiple tasks which, at any given time during the course of their work, may be similar to those of teachers, nurses, psychologists, occupational therapists, physical therapists, counselors, dieticians, chauffeurs, personal trainers, and others (Centers for Medicare and Medicaid Services, 2014; President's Committee for People with Intellectual Disabilities, 2018). There is no Bureau of Labor Statistics occupational classification for direct support professionals and they are often categorized with home health aides, personal care assistants, certified nurse assistants, and others. Providing home and community-based supports for people with IDD, however, requires specialized skills and competencies; unfortunately, this is not reflected in their low wages, limited access to benefits, and lack of respect afforded to this essential workforce.

The shortage of direct support workers is well documented. Over 43% of DSPs left their positions in 2019 with one-third leaving in the first six months of employment (National Core Indicators, 2020). Vacancy rates were 8.5% for full-time and 11% for part-time positions. As a result of high vacancies, many DSPs, supervisors, and other staff consistently have to work overtime to provide supports (Hewitt et al., 2019; Test et al., 2003). Another consequence of high vacancies in DSP positions is that sometimes people with IDD go without supports that they need and that have been authorized. Family members often end up providing these supports themselves, which affects their availability to maintain their own employment (Anderson et al., 2002). The threat of contracting COVID-19, social distancing guidelines, and stay-at-home orders affected people with IDD and DSPs. People with IDD are more likely to contract COVID-19 (Gleason et al., 2021) and are at greater risk of mortality from COVID-19 than nearly any other diagnosis type (Kaye, 2021). During the pandemic, they have experienced loss of employment and social isolation. DSPs are most often their primary supports. The purpose of the COVID-19 DSP initial and six-month follow-up surveys was to gather information about the experiences of DSPs related to the COVID-19 pandemic to inform efforts to prepare for future waves of the pandemic. The first round of data collection took place in the early months of the pandemic response when there were many unknowns about how to support people with IDD and DSPs. Almost 9,000 direct support workers from the U.S. completed the survey between April and May 2020 with at least one survey received from every state. Results

of the first survey round are available at [www.ici.umn.edu/covid19-survey](http://www.ici.umn.edu/covid19-survey) (<http://www.ici.umn.edu/covid19-survey>). This report covers the second round of data collection, which took place between November 2020 and January 2021. The second survey, administered online six months after the first, examined how workforce systems are supporting DSPs and frontline supervisors during the COVID-19 pandemic. The second survey was completed by 8,846 participants. The results of the second survey are presented in the current report. A 12-month follow-up study will be fielded in May 2021 and focus on vaccinations, return to work, and social inclusion.

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The purpose of the COVID-19 DSP initial and six-month follow-up surveys was to gather information about the experiences of DSPs related to the COVID-19 pandemic to inform efforts to prepare for future waves of the pandemic.

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## Method

The second survey was administered using an online survey platform called Qualtrics. Information on the survey and how to access the link was posted on ICI's website, sent to ICI's contacts across the United States, and circulated on social media. The National Alliance for Direct Support Professionals promoted the survey and distributed the link to DSPs and disability organizations across the country.

Of the 12,003 six-month follow-up surveys opened in Qualtrics, no questions were answered in 1,617 of them; 1,241 respondents indicated they were DSPs but answered fewer than six questions; 280 indicated they were not a DSP or frontline supervisor (FLS); and 19 did not reside in the USA. This left 8,846 completed surveys in the six-month follow-up sample. Of those, 193 did not provide the state in which they worked. Analyses at the state level were reported for only those who provided the state item; those without state were reported only in the total sample results. Just over one-quarter of the sample (26%) indicated they had taken the survey in both the first and second rounds of administration. An attempt was made to match participants who participated in both rounds of administration. However, since providing names and/or email addresses was optional, there were insufficient matches to conduct change-over-time analyses. Thus, the two reports provide information from two different samples at two different points in time.

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The final sample contained 8,846 participants.

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## Analysis

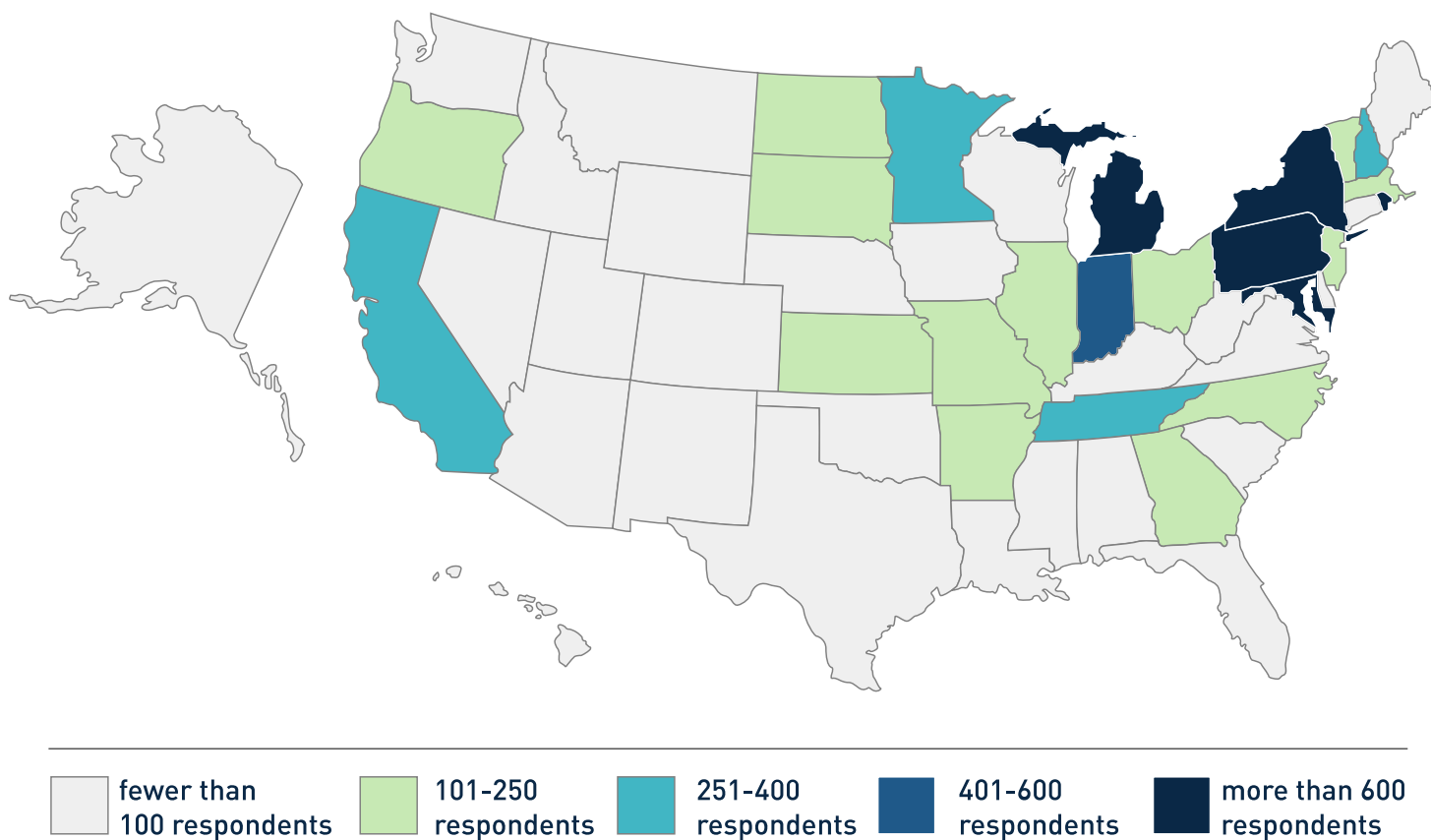
## Quantitative Analysis

Descriptive statistics were provided for individual items. Using SPSS version 24 (IBM Corp, 2016), crosstabulation tables with Chi-square statistics and Oneway ANOVAs were run to look at relationships between two variables. These included an examination of the relationships between the primary setting where participants worked and whether they had been exposed to COVID-19, the number of people they served who had been diagnosed with COVID-19, and the types of personal protective equipment (PPE) provided by their employer. To better understand the differences between setting types, the "other" category was excluded from analysis as it was small and included a variety of setting types. Setting types compared included agencies or facilities, family or individual's homes, and community job or employment. Race groups were collapsed into Black or African American, white, and other to explore relationships with working additional hours due to COVID-19, hourly wages, annual household income, and work life status. Finally, additional consideration was given to the relationship between annual household income and whether the participant was the primary wage earner. Significant differences are described in the text and are indicated in charts and tables when applicable with an "\*" .

## Qualitative Analysis

Key words and terms were identified that described each subtheme and frequencies were calculated using NVivo (QSR International Pty Ltd, 2018). The responses were read by two researchers to reduce bias when choosing themes. Narrative summaries were written for the themes in each of the two questions followed by quotes from participants.

**Figure 1. Number of participants by state of employment**



The 8,653 participants who reported the state in which they worked were located in all 50 United States and the District of Columbia (see figure 1). There were 28 states (55%) that had fewer than 100 participants, 13 (25%) had 101-250 participants, 4 (8%) had 251-400 participants, 2 (4%) had 401-600 participants, and 4 (8%) had more than 600 participants. Individual state reports are available for states with at least 200 respondents (see [www.ici.umn.edu/covid19-survey](http://www.ici.umn.edu/covid19-survey)) (<https://ici.umn.edu/covid19-survey>).

## Results – Employment Information

### Job Titles

A direct support professional (DSP) was defined as an employee who spends at least 50% of their time providing direct support (support, training, personal assistance, community integration) for a person with intellectual or developmental disabilities (IDD). DSPs may perform some supervisory tasks, but the primary focus of their job is direct support. They have titles such as direct care worker, house managers with primarily direct care duties, residential aide, job coach, home health aide, personal care assistant, certified nursing assistant, and many others. A frontline supervisor (FLS) was defined as an employee whose primary responsibility (more than 50% of their role) is the supervision of DSPs. While an FLS may perform direct support tasks, their primary job duty is to supervise employees and manage programs; they are not viewed by the organization as DSPs and their titles may include house managers if

their duties are not primarily direct support. An FLS may or may not be in a licensed or degreed position (such as a nurse) but the organization views their role as guiding and directing the work of the direct support worker more than 50% of their time. The job titles of the 8,806 employees who answered the question about role included:

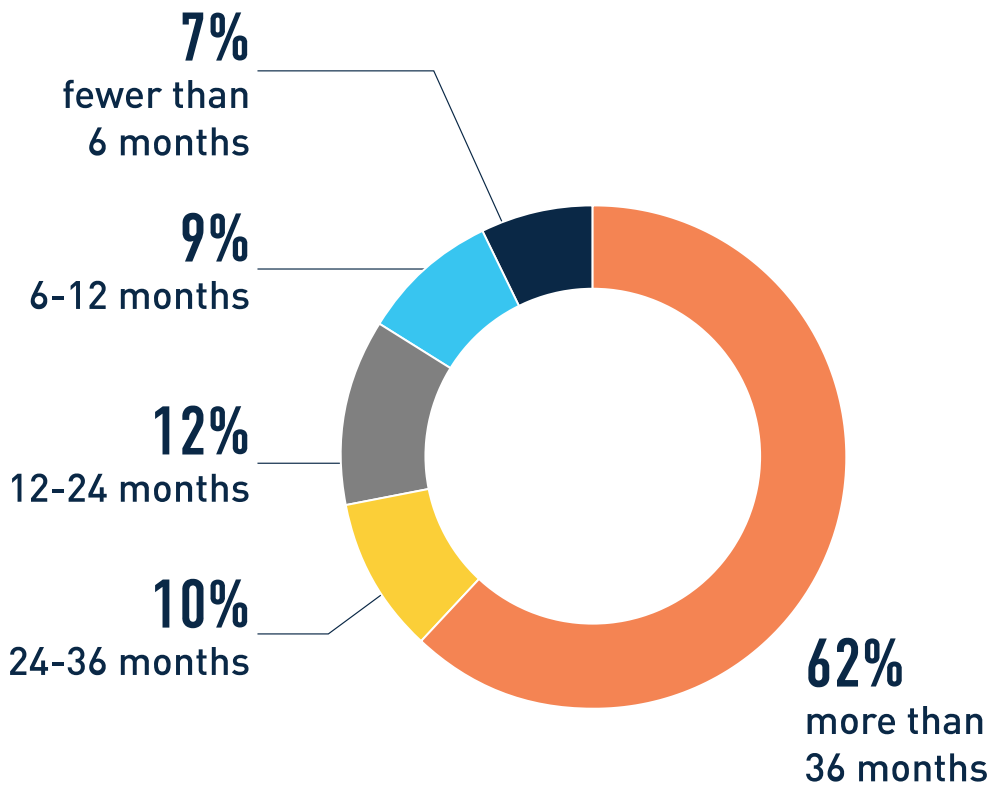
- 81% Direct Support Professionals,
- 17% Frontline Supervisors,
- 1% Certified Nursing Assistant (CNA), and
- 1% Other, including, ABA Therapist, Behavior Analyst/Clinician, Day Care Provider, Entitlement Specialist, Family Life/Lifestyle Teacher, Founder/Owner/CEO, LPN, Medical Liaison/Medical Tech/Medical Needs Manager, Recovery Specialist, RCA, Registered Nurse, Occupational Therapist, PCT, Quality Assurance, Support Broker, Teacher, and Youth Specialist.

The primary participants in the survey were DSPs, although FLSs comprised nearly one-fifth of the participants. A small number of participants were CNAs or other positions providing direct support to people with IDD.

## Job Tenure

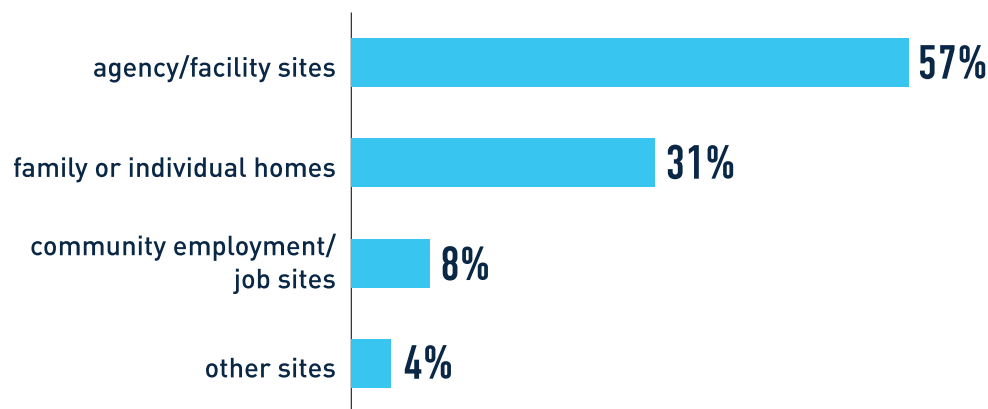
The majority of participants (78%) had worked in direct support for more than 36 months. Three percent had worked in direct support for less than 6 months, 4% had worked 6 to 12 months, 7% had worked 12 to 24 months, and 8% had worked 24 to 36 months. The participants who completed the survey also had longer tenure with their primary employer with the majority working for more than 36 months at their primary employer (62%). Ten percent had worked at their primary employer for 24–36 months, 12% for 12–24 months, 9% for 6–12 months, and 7% for less than six months. The results are presented in figure 2.

**Figure 2. Percentage of participants by length of time working in direct support at their primary employer**



## Settings where Supports were Provided

Participants reported the primary setting where they provided supports (figure 3). Fifty-seven percent provided support primarily in agency or facility settings (e.g., group home, sheltered workshop), 31% in family or individual homes, 8% in community employment or job sites, and 4% in other sites. Other sites included a mixture of places or multiple places, community non-employment (e.g., fun, volunteer, recreation, etc.), hospital, remote/telehealth/virtual, and school (high school, college, pre-K, elementary school). Nearly half of the participants (46%) provided services in more than one setting.

**Figure 3. Percentage of participants working primarily in service setting types.**

## Results – Demographic Characteristics

### Gender, age, race, ethnicity, immigration status

Participants provided information about their gender, age, race, ethnicity, and immigration status. The majority were female (83%), with the average age of 45 years. Participants reported their race as:

- 73% white,
- 17% Black or African American,
- 5% two or more races,
- 2% American Indian or Native American,
- 2% another race not listed, and
- 1% Asian.

Seven percent indicated their ethnicity as Hispanic, Latinx, or Spanish background. Of those, 3% said they were Mexican, Mexican American, or Chicano; 2% said Puerto Rican; 2% said a Hispanic, Latinx or Spanish origin not listed; and 0.5% said Cuban. Nine percent of participants indicated they were first- or second-generation immigrants to the U.S.

The demographics reflected in this study of DSPs supporting people with intellectual and developmental disabilities are not congruent with other studies in the aging and physical disability sectors where 60% of the workforce is identified as being people of color and 29% immigrants (PHI, 2019).

### Wages Paid and Primary Wage Earner Status

Seventy percent of respondents were the primary wage earner in the household. Participants were asked to report their hourly wage rate as it was on January 1, 2020. The purpose of this was to distinguish the base rate paid to DSPs without salary augmentations added for essential workers by some states due to COVID-19. Wage-related information was

summarized by employee type, whether DSP, FLS, CNA, or other. For DSP positions, the average hourly wage was \$13.92 (median = \$13.46, range \$6.25 to \$40.00). The other types of workers were paid higher wages on average. Managers, supervisors, directors, and coordinators made, on average, \$18.25 per hour (median = \$17.61, range \$8.00 to \$60.00). CNAs made, on average, \$13.39 per hour (median = \$13.00, range \$8.30 to \$20.00). Other positions made, on average, \$17.43 per hour (median = \$16.00, range \$9.00 to \$38.50). See the “Job Titles” section for the description of “other positions.” Table 1 details wage and primary wage earner information for DSPs.

### Wage and primary wage earner status for DSPs\*

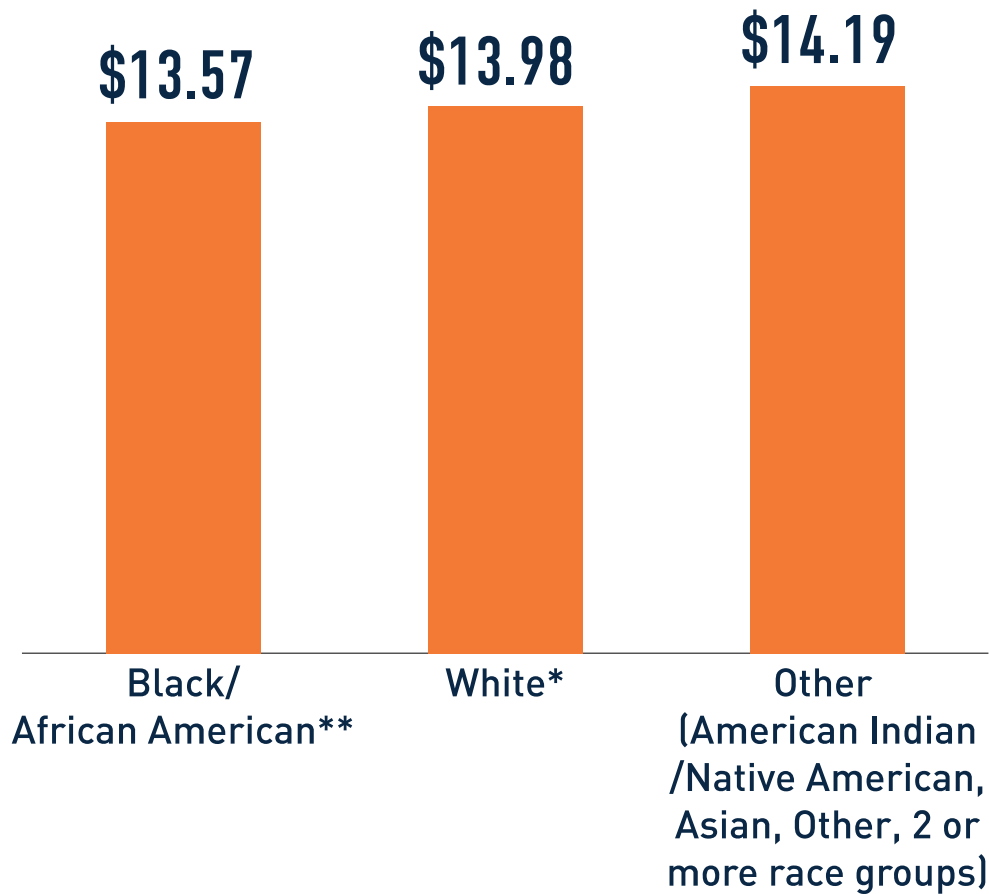
<b>Average hourly wage of DSPs*</b>	\$13.92
<b>Received salary augmentation as Essential Worker</b>	30%
<b>Self-identified as the primary wage earner in their household</b>	70%

\* Managers/supervisor, directors/coordinators, and other licensed staff (a total of 18% of the sample) were excluded from calculation of average wages in this report.

### Hourly Wages by Race and Ethnicity

As seen in figure 4, there were significant differences between DSPs of different race groups with respect to hourly wage. DSPs identifying as Black/African American made, on average, \$13.57, which was \$0.41 and \$0.62 less per hour than white (\$13.98) and other (e.g., American Indian/Native American, Asian, other group not listed, 2 or more race groups) (\$14.19) DSPs. White DSPs made, on average, \$0.21 less per hour than other DSPs. Additionally, there were significant differences when comparing those with and without a Hispanic origin. Those of Hispanic origin made, on average, \$14.30, which was \$0.39 more per hour than those not of Hispanic origin (\$13.91).

**Figure 4. Wages by race group**



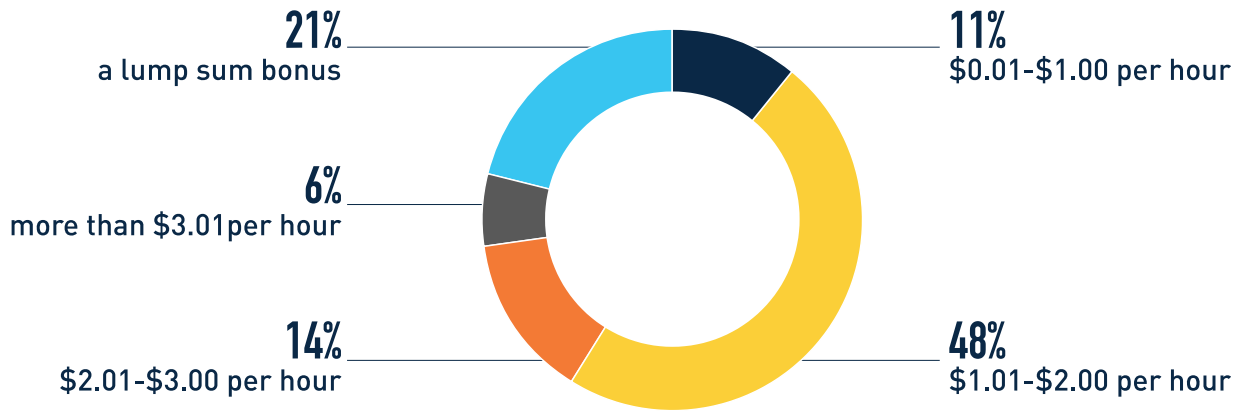
\*\* Black/African American participants make significantly less than individuals identifying as white or other. \* White participants make significantly less than individuals identifying as other.

## Salary Augmentation for Essential Workers

Ninety-seven percent of participants self-identified as essential workers. In most industries, one benefit of “essential worker” status was access to essential worker salary augmentation. In community supports for persons with disabilities, only 30% of participants in this six-month follow-up survey were paid more during the COVID-19 pandemic through salary augmentation. In the initial survey, this number was 24%. The amount of the wage increase for participants is depicted in figure 5. Of the 30% who received a salary augmentation, 11% received an increase of \$0.01 to \$1.00 per hour, 48% received \$1.01 to \$2.00 per hour, 14% received \$2.01 to \$3.00 per hour, 6% received \$3.01 or more per hour, and 21% received a lump-sum bonus.

**Figure 5. Percentage of participants receiving extra pay due to COVID-19 risks**

Of those receiving extra pay:



## Household Size and Income

Including themselves, the average number of people living in participant households was three. Participants reported their average household annual income which included their income plus others in the household. Household income ranges were:

- 5% said \$14,999 or less,
- 12% said \$15,000 to \$21,999,
- 36% said \$22,000 to \$39,999,
- 40% said \$40,000 to \$99,999,
- 7% said over \$100,000

For a family of three, the federal poverty level is considered \$21,960 or less (US Department of Health and Human Services, 2021). Seventeen percent of participants fell into this bracket. It is important to note that to qualify for most federal and state benefits household incomes can be 125 - 150% of the federal poverty level and this puts the income threshold at \$27,450 to \$32,580 which includes roughly half of the participants in this survey.

## Education

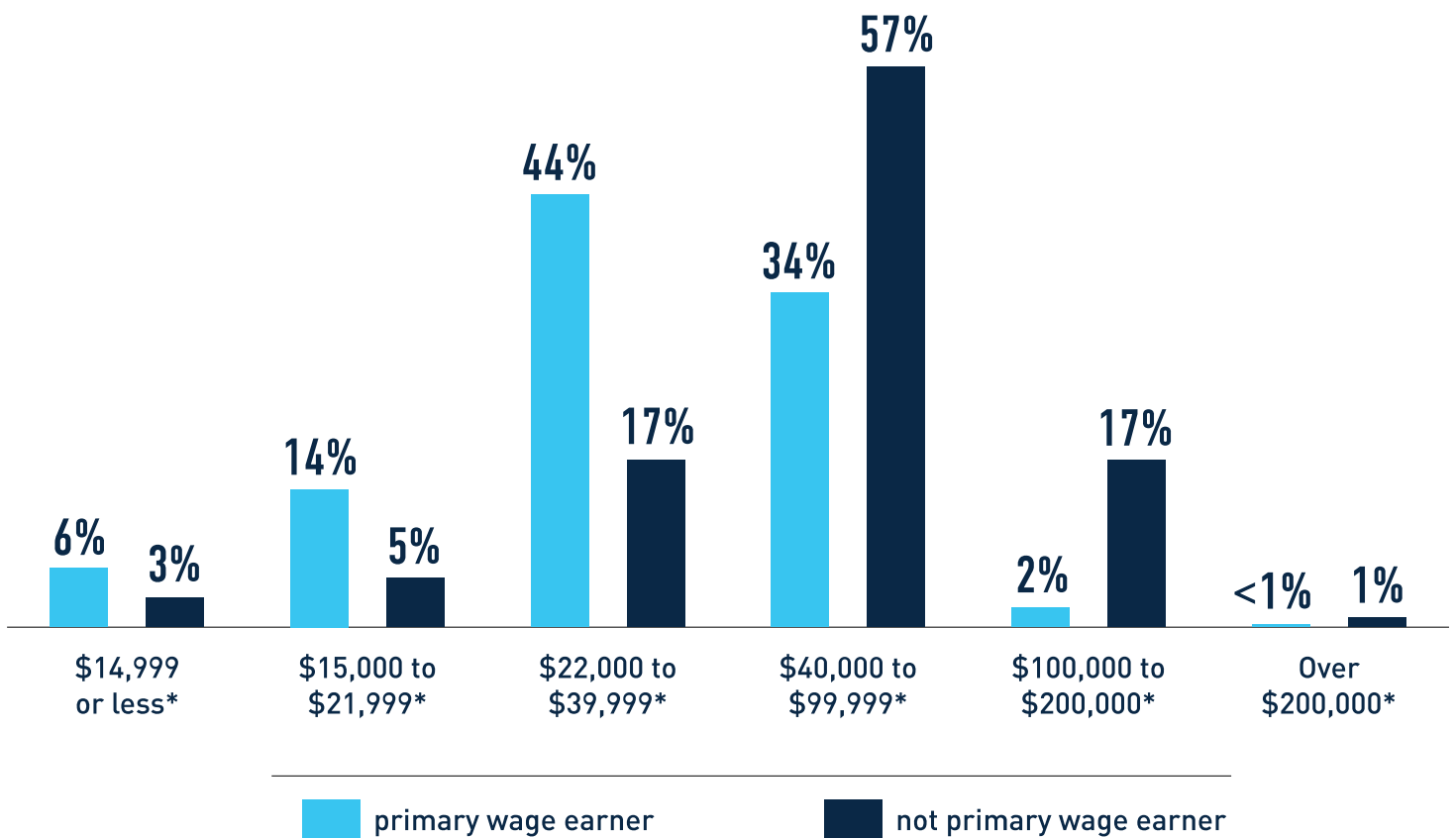
Most participants (73%) have education beyond high school. Fifteen percent have a two-year degree, 31% have some college, 19% have a four-year bachelor's degree, and 8% have a graduate degree. Another 27% have a high school diploma, 1% completed 12th grade but have no diploma, and 0.5% have an 11th grade education or less.

**73% of participants have education beyond high school.**

## Annual Household Income by Primary Wage Earner

There were significant differences between those who were and were not primary wage earners and annual household income (see figure 6). Sixty-four percent of those who were the primary wage earners in their households reported \$39,999 or less for their annual household income compared to 25% of those who were not the primary wage earners in their households. There were significant differences between primary wage earner status and annual household income for each income level. There was a significantly higher percentage of primary wage earners (44%) with household incomes of \$22,000 to \$39,999 compared to households where the participant was not the primary wage earner. A significantly higher percentage of households in which participants were not the primary wage earner (57%) had incomes of \$40,000 to \$99,999, compared to households where the participant was the primary wage earner (34%).

**Figure 6. Primary wage earner by annual household income**



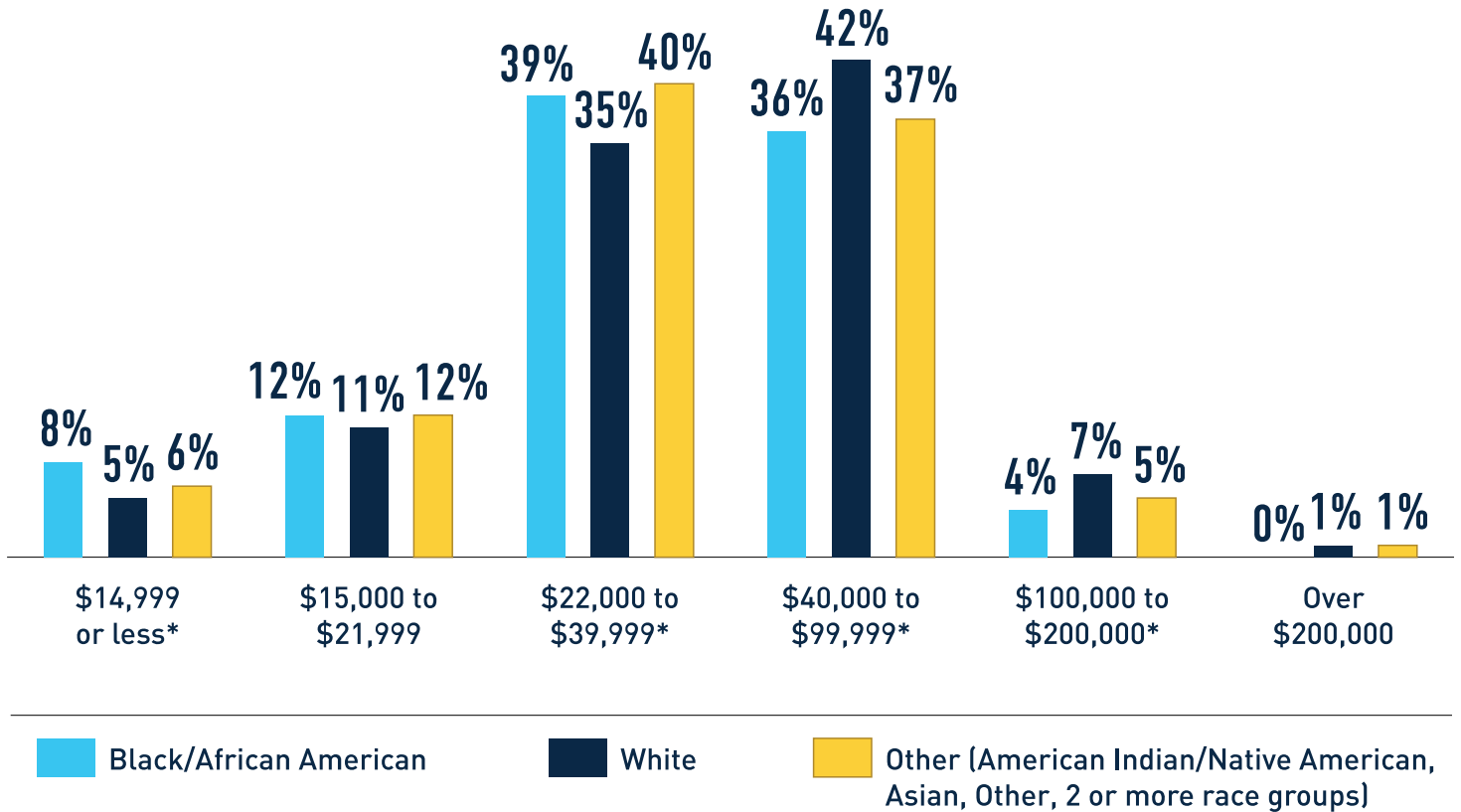
\*There were significant differences between primary wage earner status and annual household income for each income level.

## Annual Household Income by Race and Ethnicity

As seen in figure 7, there were significant differences between race groups and annual household income. A slightly higher percentage of participants identifying as Black/African American (8%) had a household income of \$14,999 or less than white (5%) or other (6%) participants. A higher percentage of participants identifying as white (42%) had annual household incomes of \$40,000 to \$99,999 compared to Black/African Americans (36%) and other (37%). And,

similarly, a higher percentage of white (7%) participants reported \$100,000 to \$200,000 in their annual household income than Black/African American (4%) and other (5%). There were no significant differences in annual household income between those of Hispanic origin and those who were not of Hispanic origin.

**Figure 7. Race by annual household income**

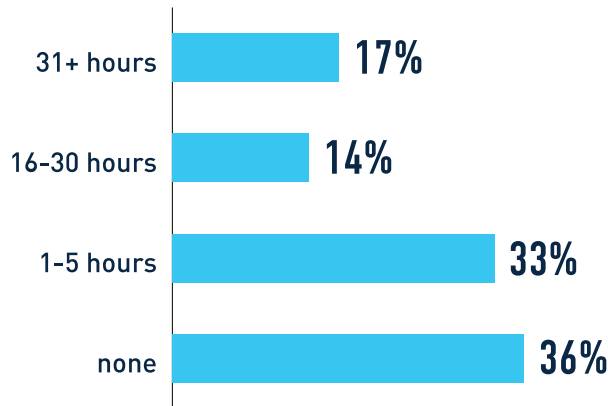


\* Black/African American participants had a significantly higher percentage annual household income of \$14,999 or less. Black/African American and Other participants had significantly higher percentages of annual household income of \$22,000 to \$39,999. White participants had a significantly higher percentage of annual household income of \$40,000 to \$99,999. Black/African American participants had a significantly lower percentage of annual household income of \$100,000 to \$200,000 than white participants.

## Additional Work Hours Due to COVID-19 by Race and Ethnicity

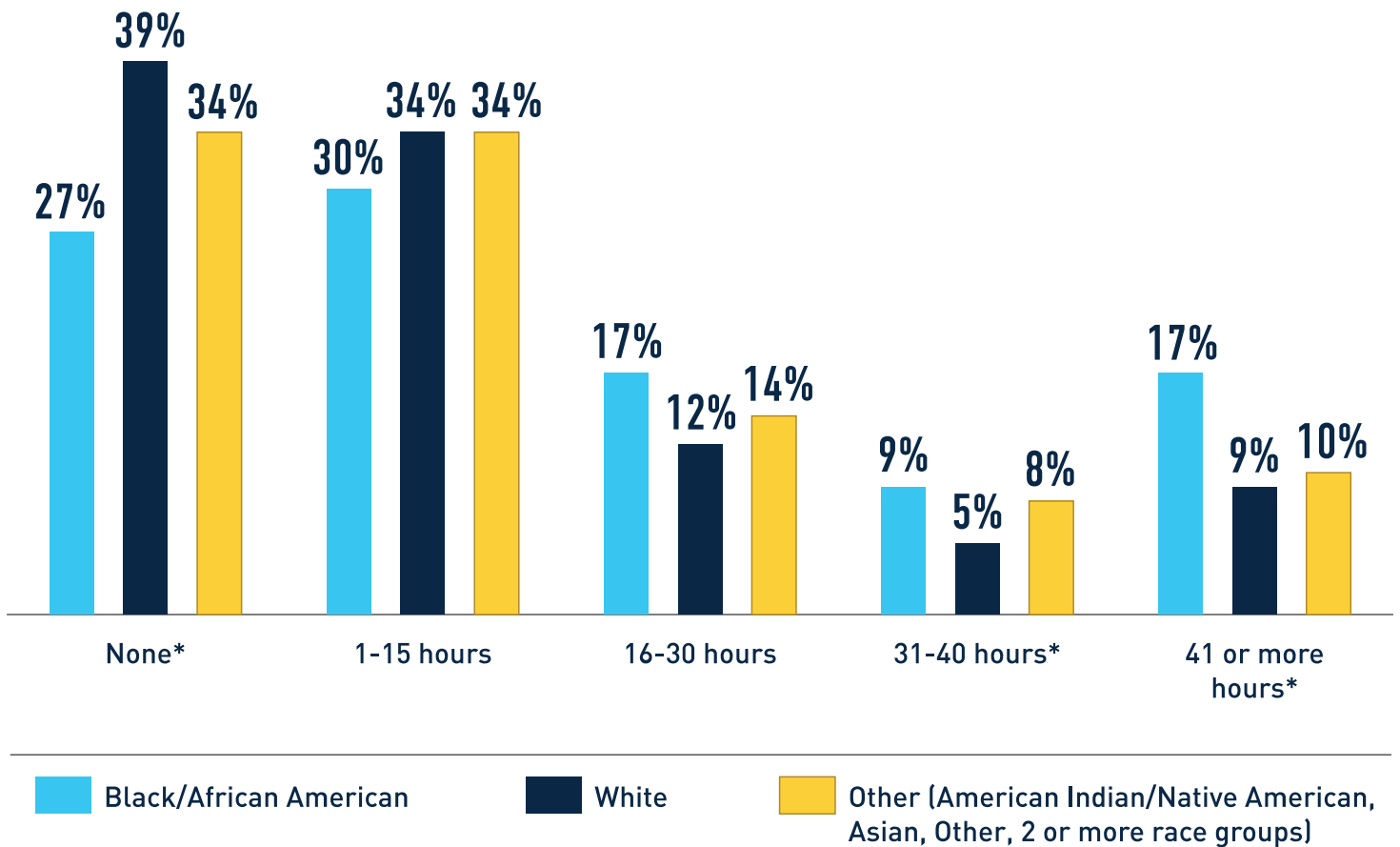
Thirty-three percent worked one to 15 additional hours per week, 14% worked 16 to 30 additional hours per week, and 17% worked 31+ additional hours per week. Thirty-six percent did not work any additional hours per week due to the COVID-19 pandemic. See figure 8.

**Figure 8. Percentage of participants working additional hours per week due to the COVID-19 pandemic**



There were significant differences between race groups and the number of additional hours worked weekly due to COVID-19 (see figure 9). Higher percentages of participants identifying as white (39%) or other (34%) worked no additional hours compared to Black/African Americans (27%). Both participants who identified as Black/African American (9%) and other (8%) had higher percentages of working an additional 31-40 hours weekly due to COVID-19 compared to white participants (5%). A higher percentage of participants who identified as Black/African American (17%) worked more than 40 additional hours a week due to COVID-19 compared to white (9%) and other (10%) participants. There were no significant differences in additional hours worked due to COVID-19 between those of Hispanic origin and those who were not of Hispanic origin.

**Figure 9. Extra hours worked by race**



\* White participants had a significantly higher percentage of not working additional hours due to COVID-19. Black/African American and other participants had a significantly higher percentages of working an additional 31-40 hours per week due to COVID-19, and Black/African Americans had a significantly higher percentage of working 40 or more additional hours per week due to COVID-19.

## Changes in Work Schedule

Participants were also asked to check all that apply from a list of ways that the pandemic had affected their work schedule. The following reasons were offered:

- 44% working more hours per week,
- 43% additional responsibilities/different roles,
- 35% working different shifts,
- 28% working in different settings,
- 24% working the same hours per week,
- 12% working less hours per week,
- 12% working remotely/telehealth/virtual,
- 6% furloughed/laid off/unemployed/facility closed,
- 4% had other work schedule changes,
- 3% became live-in staff in the residence, and

- 1% left their position by choice due to the COVID-19 pandemic.

## Results – Impact of Pandemic on Staffing Patterns and Practices

### Pandemic Impact on Turnover and Vacancy

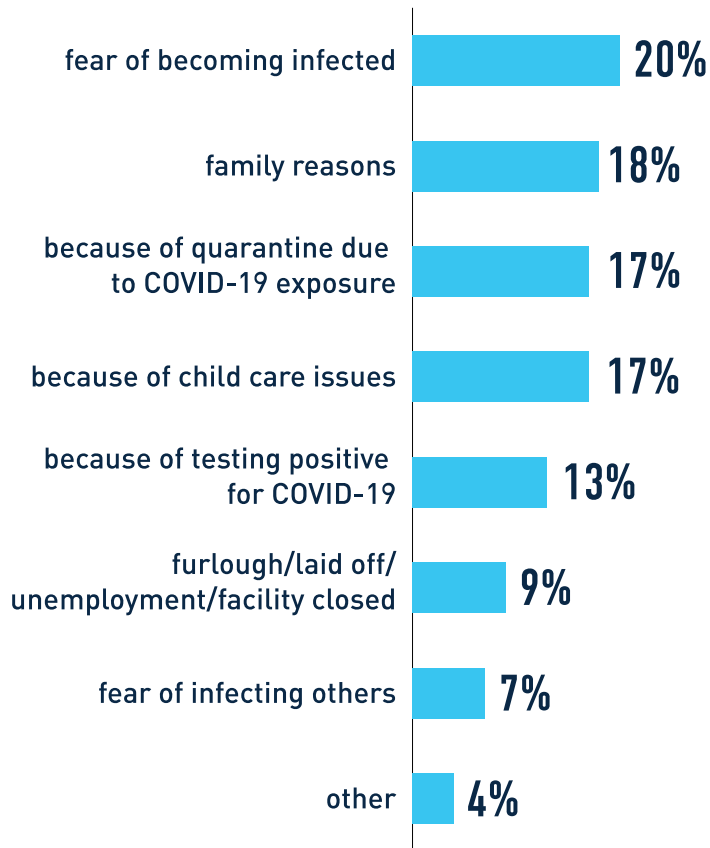
When asked about whether they were short-staffed as a result of the COVID-19 pandemic, 50% of participants said their organization was more short-staffed than before the COVID-19 pandemic. Another 28% were short-staffed before the COVID-19 pandemic and continued to be equally short-staffed. Twenty-two percent were not short-staffed due to the COVID-19 pandemic. The percent of participants indicating that their organization was more short-staffed now than before the pandemic is almost double the results from the first study conducted in April 2020 in which this number was reported as 26%.

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**Fifty percent of participants said their organization was more short-staffed than before the COVID-19 pandemic.**

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Over half (55%) of participants said that they know of staff who left their jobs due to the COVID-19 pandemic. When asked about the reason(s) their coworkers were no longer working, 20% of respondents noted fear of becoming infected with COVID-19, 18% had family reasons (e.g., caring for someone with health issues, homeschooling kids), 17% had to quarantine due to COVID-19 exposure, 17% had childcare issues (e.g., no daycare available), 13% tested positive for COVID-19, 9% were furloughed/laid off/unemployed/facility closed, and 7% feared they would infect others. These reasons are depicted in figure 10. Four percent selected other reasons than those listed. In April 2020 only 3% of participants indicated that their coworkers left positions due to being laid off or furloughed and this number rose to 9% by November 2020.

**Figure 10. Reasons cited by participants that their coworkers were no longer working**

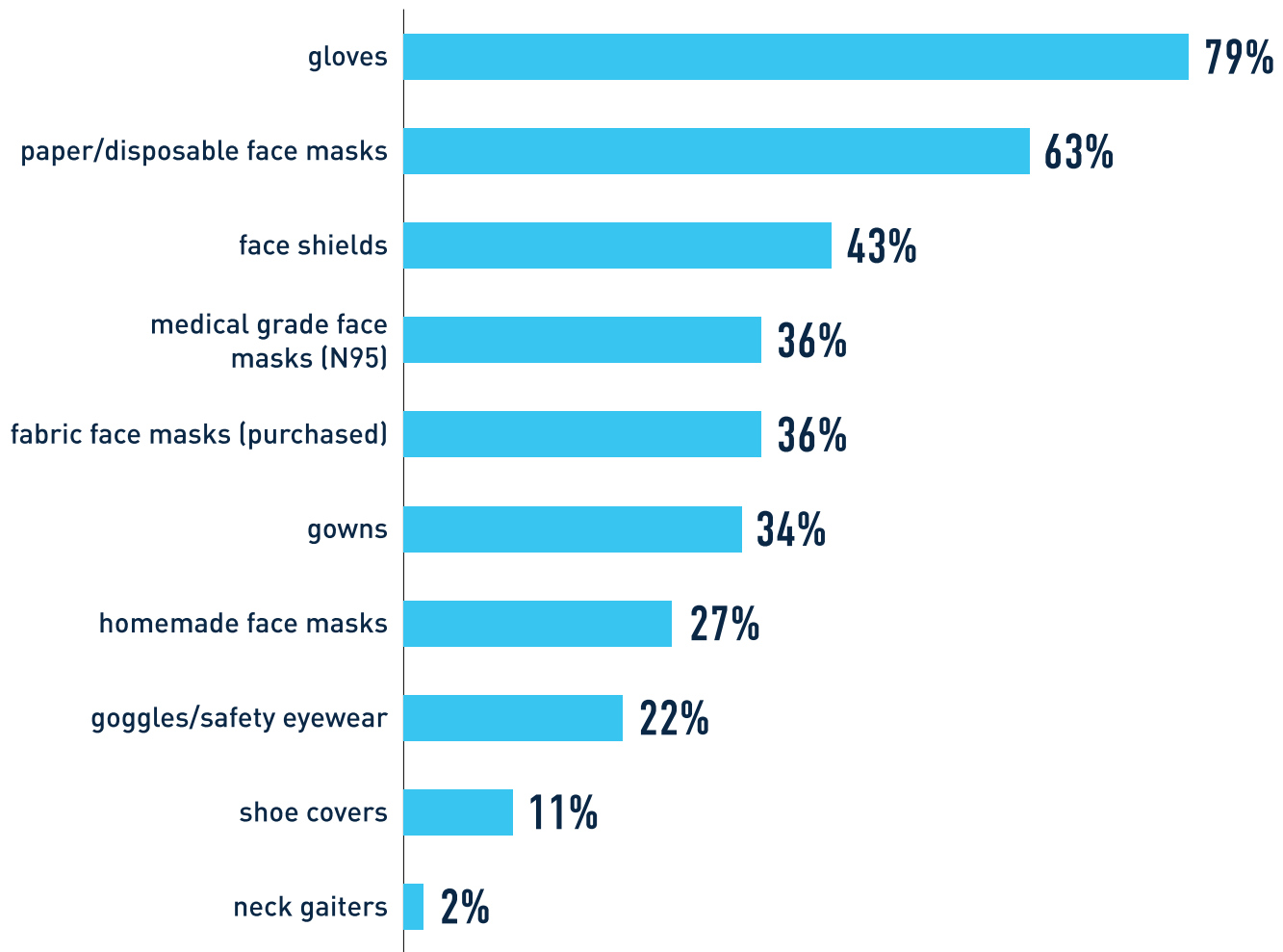
## Hiring Practices During the COVID-19 Pandemic

With staff shortages and additional stresses caused by staff leaving their positions due to the pandemic, nearly half of participants (46%) reported new staff had been hired during the COVID-19 pandemic. When new staff were hired because of the pandemic, 30% of participants said new staff received typical orientation and preservice training, 53% said they received the typical orientation and preservice training as well as safety training related to the pandemic, and 17% said that typical orientation and preservice training were not provided.

## Provision of Personal Protective Equipment and Safety Measures

Personal protective equipment (PPE) was in short supply when the pandemic began. Participants were asked to report on the provision of various types of PPE provided by their employer. Figure 11 depicts the provision of these types of PPE as reported by participants.

**Figure 11. Types of personal protective equipment (PPE) provided to participants**



Nearly 80% of participants said their employer provided gloves, 63% received paper/disposable face masks, 43% received face shields, 36% received medical grade face masks (N95), 36% received fabric face masks (purchased, not homemade), 34% received gowns, 27% received homemade face masks, 22% received goggles or safety eyewear, 11% received shoe covers, and 2% received neck gaiters. Three percent said other types of personal protective equipment were provided by their employer, while 5% said their employer does not provide PPE. This compares to 84% of participants reporting they received gloves, 46% received medical grade face masks (N95), and 53% received homemade masks in the first survey conducted in April 2020. The other PPE types were not asked in the first survey.

### Types of PPE Provided by Employer by Setting Type

As seen in Table 2, there were significant differences between setting type where the participant primarily worked and the availability of personal protective equipment. A higher percentage of participants working in agency/facility sites were provided all types of PPE, except fabric masks, compared to those working in community job/employment and family/individual homes. Participants working in community job/employment settings had the highest percentage of having fabric masks. Otherwise, the general pattern seen across PPE types showed participants in agency/facility sites

with the highest access to PPE, those in community job/employment next, and those in family/individual homes with the lowest percentages of PPE provided to them. With respect to participants who were provided no PPE, the percentage was highest for those supporting people in family/individual homes (10% compared to 1% in agency/facility sites and 4% in community job/employment sites).

**Table 2. Personal Protective Equipment (PPE) by Setting Type**

	<b>Agency/Facility</b>	<b>Family/Individual Home</b>	<b>Community Job/Employment</b>
<b>PPE</b>	<b>%</b>	<b>%</b>	<b>%</b>
<b>Gloves</b>	88% *	65% *	75% *
<b>Medical grade face masks (N95)</b>	45% *	24% *	31% *
<b>Fabric face masks</b>	38% *	32% *	46% *
<b>Paper/disposable masks</b>	70% *	51% *	64% *
<b>Homemade face masks</b>	30%	23% *	29%
<b>Face shields</b>	52% *	29% *	39% *
<b>Neck gaiters</b>	2%	2%	4% *
<b>Gowns</b>	46% *	19%	16%
<b>Shoe covers</b>	15% *	6%	7%
<b>Goggles/eyewear</b>	29% *	12%	14%
<b>None provided</b>	1% *	10% *	4% *

\* Indicates group is significantly different from the others.

## Safety Measures Put in Place in Response to COVID-19

Safety measures were provided by employers. Participants reported on the types of safety measures put into place by their employers. The safety measures reported included:

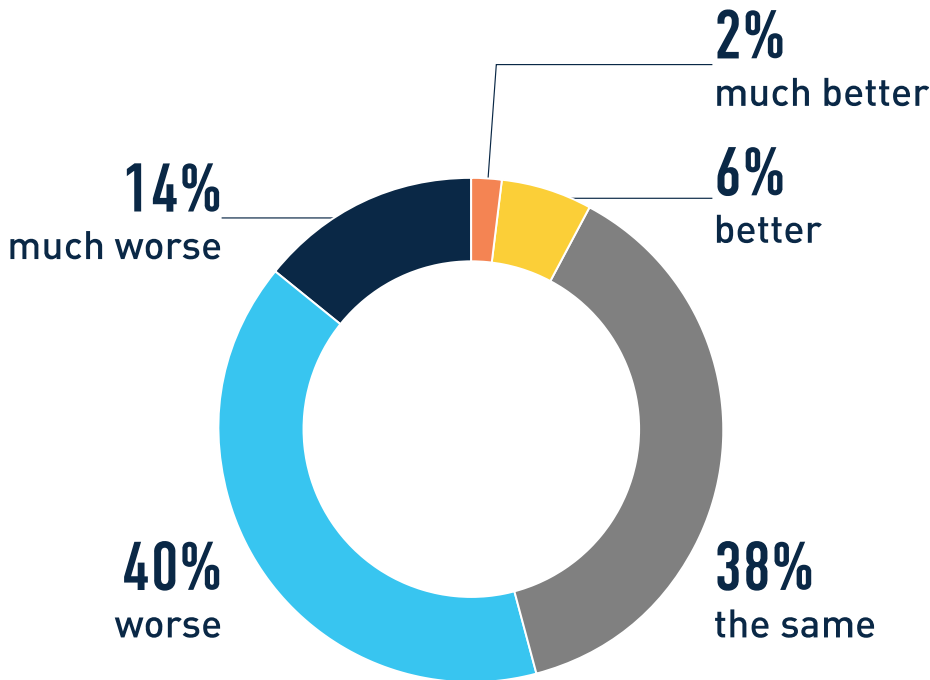
- 72% reported that workers had their temperatures taken before shifts,
- 70% reported posted signs on proper handwashing,
- 69% reported taking client temperatures,
- 69% reported restrictions on visitors,
- 67% reported additional cleaning required,
- 66% reported having internal communications (e.g., information emails, blogs, hotline),
- 65% were provided training on health and safety,
- 64% reported posted signs on social distancing,
- 55% reported that checklists were provided for additional cleaning procedures,
- 53% reported enforcing social distancing,
- 48% took surveys/questionnaires about staff health and symptoms,
- 36% reported being provided access to COVID-19 testing, and
- 2% said other safety measures were provided by their employer.

Some (2.0%) said no safety measures had been put into place. In the first survey conducted in April 2020, 72% reported signs posted on proper handwashing, 67% were provided training on health and safety, 66% had their temperatures taken before their shifts, and 59% reported signs posted on social distancing. The other safety measures were not asked in the first survey.

## Results – Participant Work Life

As participants found themselves six months further into COVID-19, they were asked how they were feeling about their work life. As shown in figure 12, 2% indicated their work life was much better, 6% said better, 38% said the same, 40% said worse, and 14% said much worse.

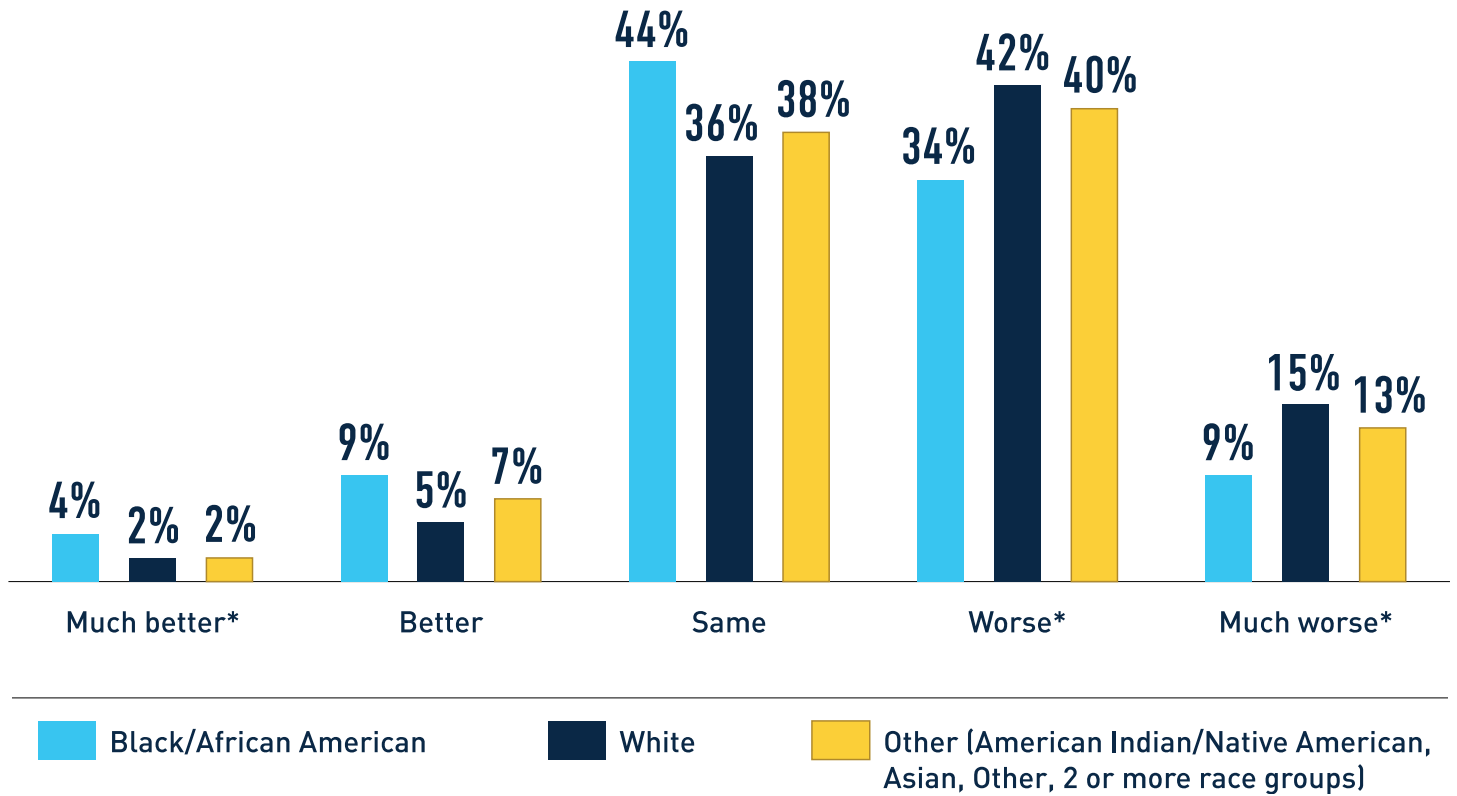
**Figure 12. Participant work life status six-months into COVID-19**



### Impact on Work Life Status by Race and Ethnicity

As seen in figure 13, there were significant differences between race groups and whether their work life status had changed since the beginning of COVID-19. A higher percentage of participants identifying as Black/African American (13%) said their work life was much better or better compared to white (7%) or other (9%) DSPs. White (57%) participants had a higher percentage of feeling their work life was worse or much worse than Black/African American (43%) and other (53%) participants. There were significant differences in whether work life status had changed since the beginning of COVID-19 between those with a Hispanic origin and those who were not of Hispanic origin. Fifty-one percent of those who were of Hispanic origin felt their work life was much better, better or the same compared to those who were not of Hispanic origin (45%).

**Figure 13. Work life status six-months into COVID-19 by race**



\* Black/African American participants had a significantly higher percentage of feeling work life was much better, white and other participants had higher percentages of feeling work life was worse or much worse.

## Results – Participant Exposure to COVID-19 by Setting Type

Nearly half (47%) of participants said they had been exposed to COVID-19 through their work. As seen in figure 14, there were significant differences between setting type where the participant worked and whether they had been exposed to COVID-19. Participants working in agency/facility sites had a higher percentage of exposure (52%) compared to those in community job/employment sites (44%) and family or individual homes (38%).

**Figure 14. Exposure to COVID-19 by setting type**

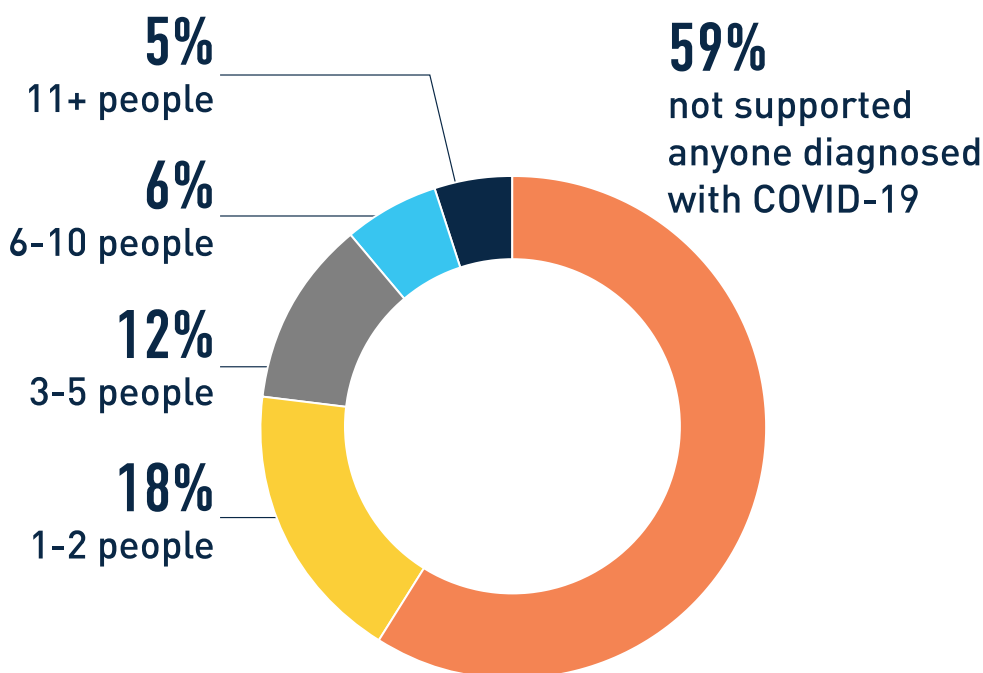


\*Agency/facility sites had a higher percentage of exposure to COVID-19.

## Results – Impact of COVID-19 on People Receiving Supports

At the time of this survey, 59% participants had not supported anyone diagnosed with COVID-19. Eighteen percent had supported 1-2 people diagnosed with COVID-19, 12% supported 3-5 people, 6% supported 6-10 people, and 5% supported 11 or more people. Figure 15 details the percentage of participants by number of people supported who had been diagnosed with COVID-19. This compares to 91% of participants in the initial survey who had not yet supported anyone with a diagnosis of COVID-19.

**Figure 15. Number of people with COVID-19 diagnosis supported**



## Number of people supported who had COVID-19 diagnosis by Setting Type

Similarly, this analysis examined the setting type where the participant worked the majority of their time and the number of people they supported who had a COVID-19 diagnosis. As seen in Table 3, there were significant differences between setting type where the participant worked the majority of their time and the number of people they supported who had a COVID-19 diagnosis. Those working in family/individual homes had a higher percent (70%) of supporting no individuals with COVID-19 and lower percentages of supporting 3-5 people (7%) and 11 or more people (2%).

Participants supporting people in community job/employment sites supported a higher percentage of 1-2 people who had been diagnosed with COVID-19 (22%), and those in agency/facility sites supported a higher percentage of 6-10 people.

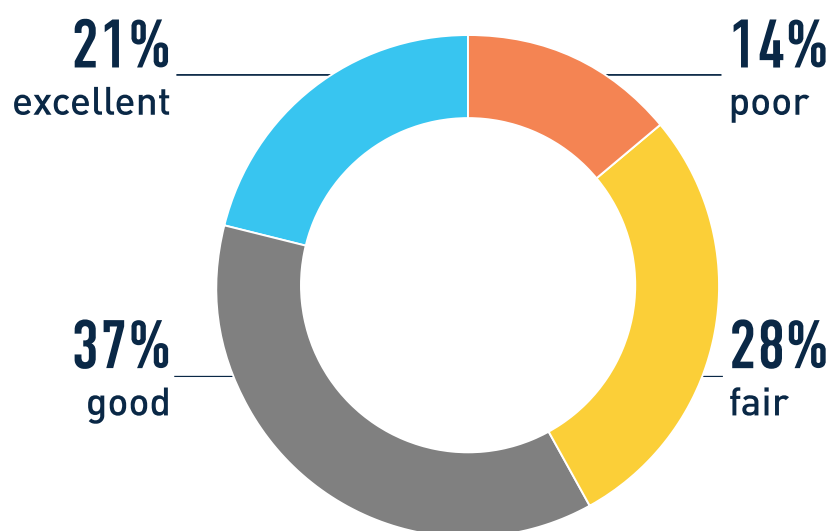
**Table 3. Number of People Supported with COVID-19 by Setting Type**

	Setting Type		
	Agency/Facility	Family/Individual Home	Community Job/Employment
<b>Number of People Supported</b>	%	%	%
<b>None</b>	54%	70%*	53%
<b>1-2 people</b>	18%	17%	22%*
<b>3-5 people</b>	14%	7%*	15%
<b>6-10 people</b>	8%*	4%	5%
<b>11 or more people</b>	6%	2%*	5%
<b>Total</b>	100	100	100

\* Family/Individual Home had a significantly higher percentage of supporting no people with COVID-19 and lower percentages of supporting 3-5 and 11 or more people. Community job/employment sites had higher percentage of supporting 1-2 people with COVID-19. And, agency/facility sites had a higher percentage of supporting 6-10 people with COVID-19.

When asked how the people who received supports were doing with following social distancing measures, 21% of participants said excellent, 37% good, 28% fair, and 14% poor. Figure 16 details these perceptions about people supported following guidelines for social distancing. These numbers did not substantially change over the six-month

**Figure 16. Participant perceptions on social distancing of people they supported**



Participants also reported on the frequency the people they supported were allowed in-person visits with their family members or friends. Eighteen percent of participants said that the people they supported were often allowed to visit with their family members or friends in-person, 26% said sometimes, 29% said seldom, and 27% said never as they were not allowed to have visitors in their home. This compares to 64% of participants reporting that the people they supported were not able to have visitors in the first survey conducted in April 2020.

Participants were asked about the consequences the people they supported were experiencing due to the social isolation from the COVID-19 pandemic. Of all participants,

- 79% said missed going out into the community,
- 71% said boredom,
- 56% said decreased exercise,
- 52% said more anxiety,
- 51% said increased mood swings and/or depression,
- 48% said increased behavior issues,
- 46% said loneliness,
- 40% said sleeping more than usual,
- 25% said regression,
- 14% said difficulty addressing dietary issues,
- 11% said other health issues,
- 10% said sleeping less than usual,
- 6% said difficulty addressing pain management, and
- 6% said academic concerns.

Two percent listed other consequences experienced due to COVID-19, and 4% said they had seen no negative consequences from social isolation. In the first survey conducted in April 2020, 80% reported boredom, 57% increased mood swings and/or depression, 52% increased behavior issues, 48% loneliness, 47% more sleep than usual, 15% dietary issues, and 5% difficulty addressing pain management issues. The other consequences of social isolation measures were not asked in the first survey.

## Participant Perspectives

Two questions were included on the six-month follow-up survey that allowed participants to respond in an open-ended format. The questions were: *What is the worst thing you have experienced in your role as a DSP during COVID-19?* and *What is the most important thing your employer has done to support you during the COVID-19 pandemic?*

### What was the worst thing experienced as a DSP during COVID-19?

Two responses were the most prominent worst things experienced as a DSP during COVID-19. The first was issues DSPs were experiencing with pay, representing 15% of the 6,613 responses. Some DSPs experienced a loss in hours, were furloughed, or their pay was cut, while others asserted that DSPs deserve “hazard pay,” continued “hero pay,” or higher pay due to the risks of exposure that they took daily to do their job. Many experienced a loss in pay after being forced to quarantine at home when exposed to COVID-19 while at work.

*“I have picked up many hours with people who are COVID+, don’t know if I get paid more for it, GOT COVID myself, and am now out of work without any kind of pay.” [Direct Support Professional]*

*“Being around individuals that have the COVID-19 and not getting paid enough money. And worrying about if you was to catch the COVID-19 you would not have enough PTO time to use for a family member being sick or your child being out of school.” [Direct Support Professional]*

An equally prominent response to the question about the worst thing experienced as a DSP was their own, or their coworkers’, mental health. DSPs listed symptoms of burnout, stress, anxiety, depression, and isolation.

*“I have experienced compassion fatigue. Dealing with the stress of added mental health issues with the people I serve. Everything I do takes longer, and my clients are scared, bored, don’t like being isolated, have more behaviors. I have not been given extra compensation like others at my company, which makes me feel unappreciated and unimportant.” [Direct Support Professional]*

*“Poor wages and increased risks with COVID caused staff to quit. Staff shortages leads to less staff doing a ton of extra overtime. Mandatory overtime leads to caregiver burnout. Caregiver burnout causes low morale. And low morale causes lack of care for the folks. (Borderline neglectful doing the bare minimum for the folks, but staff can't pour from an empty cup if you know what I mean). Many of the staff are looking for other jobs and it is absolutely terrible for the individuals I support. It’s nearly impossible to balance this work with family and trying to raise a kid who has ADHD and is in a hybrid learning model...” [Direct Support Professional]*

Eleven percent of DSPs also reported struggling to help the people they support with their mental health or to understand the pandemic. DSPs repeatedly reported struggling to explain COVID-19 and various policies to reduce the spread of COVID-19 to the people they support. According to DSPs, people supported have experienced isolation, depression, and anxiety. DSPs also stated that the people they support responded to COVID-19 with an increase in challenging behaviors or a regression in skills the person had previously used.

*“The stress of wearing a mask. Trying to understand a ... person speaking through a mask is difficult. It’s frustrating for them and me. Having a halt on their routines is difficult and no interactions in person is very hard. Depression and anxiety are a daily struggle. It is very difficult to help explain why, how, and when all of the COVID issues will be resolved.” [Direct Support Professional]*

People supported *“telling us how isolated and forgotten they feel.” [Other Care Role]*

Many DSPs described fear of contracting or spreading COVID-19 as the worst thing they have experienced during the pandemic. While 5% of DSPs listed actually contracting COVID-19 as the worst part of being a DSP during the pandemic, 12% were fearful of spreading or contracting COVID-19.

*“The worst thing is when we had a client test positive. It meant my family also had to quarantine until I had a negative COVID-19 test result. The fear of passing illness to my family was the worst feeling.” [Certified Nursing Assistant]*

*“Fear that the medically fragile person I serve will contract COVID. Fear that I will contract it and not be able to work with them and that will cause them fear. I am the longest serving staff person with them (16 years) and understand their communication style the best and we are understaffed as it is. I also worry about other staff not taking necessary social distancing and mask guidelines seriously in their personal lives and bringing COVID into our consumer’s life.” [Direct Support Professional]*

Some DSPs also reported not feeling supported by the organization they work for (10%), issues related to wearing PPE for extended periods of time (5%), and personally experiencing a death (not necessarily due to COVID-19) (3.6%), as the worst thing experienced during the pandemic. 184 DSPs (2.8%) stated they did not experience any worst thing as a DSP.

## What was the most important thing your employer has done to support you during COVID?

The overall best thing employers did to support participants six months after the pandemic began, reported by 63% of respondents, was to look out for their health and safety by providing personal protective equipment and offering medical checks, making their safety and that of the people they supported a priority.

*“The agency listened to our health and safety concerns and responded to our requests for PPE, cleaning supplies, and stricter safety protocols.” [Direct Support Professional]*

*“They are very diligent in following CDC guidelines about screening and getting people tested and following quarantine procedures.” [Direct Support Professional]*

Twenty percent of participants said that their employers supported them through good communication, providing informative updates and making themselves available to staff, listening to their concerns. Checking in with staff through calls, emails, texts, and Zoom meetings was appreciated.

*“My employer continues weekly COVID emails throughout our agency and also each program site director sends constant communication and answers all concerns related to COVID.” [Direct Support Professional]*

*“During that time of quarantine my supervisor called me constantly to check on me, how I was doing. That meant a lot to me.” [Direct Support Professional]*

Approximately 16% of participants cited additional pay as the best thing their employer did to support them. For some, this was a one-time bonus. For others, the increase was more than \$2 per hour. For many, the increased pay was only temporary.

*“They have increased our wages and I hope we continue to receive raises because we all deserve it.” [Direct Support Professional]*

*“We did receive two bonus checks of \$500 each during this pandemic, but with added expenses of providing our own masks and other supplies, increased gas for more shifts needing covered, and having no employee support system for therapy, the money did not go nearly as far as we needed it to.” [Direct Support Professional]*

Approximately 9% of participants indicated that their employers provided very little or no support to them during the first six months of the pandemic. Many noted a lack of appreciation from management and little concern for their well-being. Offering survey participants a bottle of hand sanitizer or a pizza party was described by some as disrespectful.

*“Honestly there is a lack of support from the company. A lot of us have felt underappreciated during the pandemic.” [Direct Support Professional]*

*“Nothing. We have been exposed multiple times, but it was up to us to get tested.” [Direct Support Professional]*

*“They made me feel guilty for quarantining myself after being exposed and I'm a breast cancer survivor with a weakened immune system due to chemo. They don't care.” [Direct Support Professional]*

Participants also cited job flexibility – working from home and offering time off (7.2%), providing training and education (5%), and showing appreciation (2.5%) – as the best things their employers did for them during this period.

## Key reflections on COVID-19 and DSP Experiences Over Time

DSPs and FLSs continued to provide critical supports for people with IDD throughout 2020 in the midst of the COVID-19 pandemic. About a quarter of participants (26%) indicated on the survey that they took both versions of the survey, but there was insufficient data to match these participants to analyze results across time. For this reason, the results are regarded as snapshots of DSP perspectives across time.

## Participant tenure

Similar to the first survey sample, a large majority of the sample (62%) reported that they had worked in direct support for 36+ months, while only 7% had worked in direct support for less than six months. This is compared to organizations reporting that 37% of their DSP workforce had been employed for 36+ months and 18% for six months or less, as reported by their employer in 2019 (National Core Indicators, 2020). Given their tenure in the workforce, they bring a unique perspective related to their expertise in the field and their commitment to direct support.

## Participant Demographics

This survey gathered information about participant demographics. The initial survey did not gather this information to keep the survey as short as possible. The demographics of the participants indicated that 83% were female with a median age of 45 years. This is close to the national average of 87% and 46 years reflected in a national sample of home care workers across service sectors (PHI, 2019). Seventy-three percent of respondents identified as white, 17% as Black/African American, 7% as Hispanic, 2% as American Indian/Native American, 1% as Asian, 2% as another race, and 4% as two or more races. These demographics likely do not reflect the diversity of the direct support workforce as in other studies that included the aging and physical disability sectors, where 60% of the workforce is identified as being people of color and 29% as immigrants (PHI, 2019).

Wages are also an important finding. In this study the average wage was \$13.92 per hour. This group of survey participants had a much longer tenure than typical DSPs, given that 62% had been in their positions for 36 or more months. This likely influences the hourly rate being higher than in other studies (National Core Indicators, 2020). That said, a family of three cannot live on this wage and meet expenses. It is important to note that Black/African American participants were more likely to have lower salaries and household incomes than other groups. Over half of participants indicated that their household income fell below 125–150% of the federal poverty level for a family of three. This means they are eligible for many federal and state governmental benefits available to poor people. Furthermore, 73% of DSPs reported that they have education beyond high school, indicating that these are not entry-level workers.

## Working many hours per week

Prior to the COVID-19 pandemic in January 2020, over one-third of participants reported working 41+ hours per week. The need to work additional jobs or overtime hours has been documented for decades in the direct support workforce (Hewitt et al., 2019; Test et al., 2003). Although there were many changes in the workforce in 2020, 44% of participants indicated that they are working more hours per week and 43% had additional responsibilities or different roles. Participants reported that the additional overtime and work in different roles and locations added to symptoms of burnout, stress, anxiety, depression, and isolation. Continuing to rely on DSPs to pick up additional hours, modify their work life and hours and add new roles and responsibilities will not promote health and wellness within this workforce. More systems-level solutions that build pipelines, pay wages that align with the skills required of the job, and create workplace cultures that attend to the symptoms of burnout, stress, anxiety, depression, and isolation are critical.

## Work life is getting worse

The majority of participants (54%) indicated that their work life is getting worse. Few said that it is getting better. While 97% of participants self-identified as essential workers, only 30% reported receiving salary augmentations as an essential worker. This is comparable to the results of the earlier survey, in which 24% reported receiving salary augmentations. Sixteen percent of participants reported on the increased financial stress they experienced from reduced work hours or being laid off. Additional expenses for family and childcare added to participants' financial burden, and was a common reason many direct support workers in other sectors left their jobs (Cimarolli & Bryant, 2021). Fifteen percent of participants indicated increased mental health issues resulting from working during the COVID-19 pandemic. These issues included stress, isolation, depression, exhaustion, worry, anxiety, and others. And thirteen percent of participants reported they were in fear of contracting or spreading COVID-19. It is important to recognize these stressors and to consider their effect on the workforce. DSPs may benefit from access to counseling and support, as has been recommended for direct support workers in other sectors (Clarke et al., 2020).

## Staffing challenges

Participants reported that staffing challenges continued to be a significant problem for their organization. In November 2020, six months into the pandemic, 50% of the respondents said that their organization was more short-staffed than before the COVID-19 pandemic. Staffing challenges appear to have become more widespread in the six months between the surveys, as this was reported as 26% in the previous survey. In November 2020, 9% of participants reported that staff left their positions due to being laid off or furloughed, which compares to only 3% in April 2020. Forty-six percent of participants reported that new staff had been hired during the COVID-19 pandemic; in April 2020 this was reported as 22%. For those who reported new staff had been hired, the majority (53%) indicated that new staff received typical orientation and preservice training as well as safety training related to the pandemic. This is similar to what was reported in the previous report – an area where we hoped to see improvement. Intentional programs and strategies will need to be developed and used to promote entry into this workforce as high vacancies have always been an issue in the field and a worsening of them will make what was already a serious problem much worse to pull out of.

## Diagnosis with COVID-19

DSPs were asked about their exposure to COVID-19 at work. Nearly half (47%) said they had been exposed to COVID-19 at work in November 2020. The number of participants who had supported people who had been diagnosed with COVID-19 increased significantly during the six months since the previous survey, in which 91% of participants had not supported anyone diagnosed with COVID-19. At the time of this second survey, 18% had supported 1–2 people diagnosed with COVID-19, 12% supported 3–5 people, 6% supported 6–10 people, and 5% supported 11 or more people. Only 59% of participants had not supported someone diagnosed with COVID-19. These findings make it clear that DSPs take significant risks in their roles of supporting people with IDD. People with IDD are at great risk of getting COVID-19 compared to others in the population, and many die from it (Gleason et al., 2021). As such, the people who provide their support need to be identified and paid as essential workers as long as the pandemic continues. This is important information for preparing for future national crises or pandemics.

## Safety measures

Some level of safety measures was provided by 98% of employers. Overall, there was greater adherence to safety measures after six months, including enforcement of social distancing practices, in part because of clear guidelines from states and the Center for Disease Control. A notable change in safety measures reported by participants included access to COVID-19 testing (10% in initial survey, 36% in six-month follow-up survey). Sixty-three of participants reported that health and safety was an area where their employers supported them during the COVID-19 pandemic.

## Disproportional Impact of COVID-19 for People from Diverse Racial and Ethnic Backgrounds

There were significant differences between participants of different race groups with respect to hourly wage. Participants identifying as Black/African American made, on average, \$13.57, which was \$0.41 less per hour than those identifying as white (\$13.98) and \$0.62 less than those identifying as other (\$14.19). Additionally, there were significant differences when comparing those with and without a Hispanic origin. Those of Hispanic origin made, on average, \$14.30, which was \$0.39 more per hour than those not of Hispanic origin (\$13.91). These wage disparities need to be further explored to better understand why they exist and what actions will need to be taken to reduce them.

There were also significant differences between race groups and the number of additional hours worked weekly due to the COVID-19 pandemic. Participants who identified as Black/African American (9%) and other (8%) had higher percentages of working an additional 31-40 hours weekly due to COVID-19 compared to white participants (5%). And, participants who identified as Black/African American (17%) worked more than 40 hours a week due to COVID-19 compared to white (9%) and other (10%) participants. A higher percentage of participants identifying as white (39%) or other (34%) worked no additional hours compared to Black/African Americans (27%). There were no significant differences in additional hours worked due to COVID-19 between those of Hispanic origin and those who were not of Hispanic origin. The wage differences between Black/African American participants and white/other participants and the reality that they were also more likely to be the primary wage earner in their household and had lower household incomes likely contributes to their need to work more hours. Additional exploration of these disparities must be explored and actions identified to remediate them.

Significant differences were identified between race groups and whether their work life status had changed since the beginning of the COVID-19 pandemic. A higher percentage of participants identifying as Black/African American (13%) said their work life was much better or better compared to those identifying as white (7%) or other (9%). White (57%) participants had a higher percentage of feeling their work life was worse or much worse than Black/African American (43%) and other (53%) participants. There were significant differences in whether work life status had changed since the beginning of COVID-19 between those with a Hispanic origin and those who were not of Hispanic origin. Fifty-one percent of those who were of Hispanic origin felt their work life was much better, better, or the same compared to those who were not of Hispanic origin (45%). It is difficult to understand what underlies the report from Black/African Americans that their work life was much better or from white and other participants that theirs were much worse. Clearly, participants faced many changes in their lives and these likely contributed to their experiences and perceptions. For example, for some people, working more hours might be viewed as positive because it means more money is coming into the household. For others, the pressure of working more or fewer hours could be viewed as very stressful.

## Setting Size, Exposure to COVID-19, and PPE Access

There were significant differences between setting type where participants worked the majority of their time and the percent of participants exposed to COVID-19 and the number of people they supported who had a COVID-19 diagnosis. Almost half (47%) of participants were exposed to COVID-19 through their work. Higher percentages of participants working in agency/facility sites (46%) and community job/employment sites (47%) were supporting at least one individual with a COVID-19 diagnosis compared to those working in family or individuals' homes (30%). Participants supporting people in community job/employment sites were more likely to support 1–2 people who had been diagnosed with COVID-19 (22% vs. 18% and 17%, respectively, for agency/facility sites and family/individual homes). However, participants working in agency/facility and community job/employment sites had higher percentages of supporting 6 or more individuals with COVID-19 diagnoses. There were also significant differences between setting type and the availability of personal protective equipment (PPE). The general pattern seen across PPE types (gloves, masks, face shields, gowns, goggles, other) showed participants in agency/facility sites with the highest access to PPE, those in community job/employment next, and those in family/individual homes with the lowest percentages of PPE provided to them. The more congregated the site, the more likely survey participants were exposed to COVID-19, supported people with IDD who tested positive for COVID-19, and had greater access to PPE.

## Key Reflections on COVID-19 and Experiences of DSPs Supporting People with Intellectual and Developmental Disabilities Over Time

The COVID-19 pandemic has been hard on people with IDD. Only 4% of participants reported that the people they support showed no negative consequences from the social isolation they have endured. However, among all of the consequences of social isolation reported in both the initial and the six-month follow-up survey, the percentages decreased slightly over time: boredom went from 80% to 71%, mood swings/depression from 57% to 51%, behavior issues from 52% to 48%, and loneliness from 48% to 44%. The reason for the decrease in negative consequences may be the result of an increase in social interactions. As reported in the initial survey, people supported were allowed to see family and friends in person sometimes (10%), seldom (16%), and never (64%). In the six-month follow-up survey, “sometimes” increased to 26%, “seldom” increased to 29%, and “never” decreased to 27%.

## Moving Forward – What is Needed for DSPs

**Ensure DSPs are identified as essential workers in comprehensive, organized, and funded response plans at national and state levels for additional waves of COVID-19 and future pandemics.** This workforce needs to be officially identified as essential workers in order to retain DSPs in their jobs. Some DSPs left work to care for children or other family members. Access to essential worker status and pay may give DSPs childcare and financial support needed to remain in their jobs. An important way to support and recognize this workforce and ensure they are listed as essential workers is to establish a standard occupational classification (SOC) code for DSPs.

**Access to childcare and support if schools or daycares close.** Ensuring essential worker status specific to this occupation would prioritize childcare availability for these families in most states. A large percentage of the workforce are single mothers with children (PHI, 2019; Hewitt, Pettingell & Kramme, 2019). Access to childcare ensures that DSPs can continue coming to work.

**Wage increases for essential workers commensurate with the increased level of exposure.** Direct support depends largely on human interaction, placing workers at increased risk for contracting COVID-19. Only 30% of respondents indicated they were paid higher wages during the pandemic and many employees were working a high number of overtime hours. Wages for DSPs need to be augmented like other healthcare and essential workers during national crises and future pandemics. Work needs to happen now to ensure these state-level and national policies are changed and clearly include DSPs.

**Access to career ladders that lead to increased skills and compensation.** Seventy percent of respondents indicated they were primary wage earners in their household, earning an average of \$13.92 per hour. Over half of the participants in this survey had household incomes low enough to qualify for federal and state relief programs such as energy assistance, food insecurity programs, and housing assistance. This workforce should have access to career ladders and credentialing programs that result in increased wages and access to affordable benefits. Credentialing programs provide opportunities for DSPs to increase their skills, resulting in the provision of higher-quality supports and providing a clear and equitable framework on which pay increases can be grounded.

**Create systems-level pipelines and incentives to enter this workforce.** Vacancy and turnover rates have historically been high in this industry. During the pandemic many DSPs lost their jobs due to layoffs or furloughs and others left the field for personal or safety reasons. This retrenchment will most likely have long-term effects on the workforce. Creating intentional pipelines through educational and workforce development programs will be needed to ensure vacancies in the developmental disabilities sector can be filled.

**Increased training on health and safety for DSPs.** Only 53% of new hires during the COVID-19 pandemic received typical orientation and preservice training that included safety training on the pandemic. Comprehensive safety training needs to be provided at the onset of a public health crisis. New hires need comprehensive orientation and onboarding to enter this line of work, in addition to knowledge about practices to manage health and safety related to the prevention of COVID-19 and care for those infected by it.

**Professional recognition and wage equity for direct support.** Direct support workers have always provided critical, essential supports. The average wage of \$13.92 per hour for participants prior to the pandemic – and only \$12.36 nationally (National Core Indicators, 2020) – is not reflective of the skilled nature of the work. Moreover, this study showed that Black/African American DSPs made significantly lower hourly wages than white/other groups. These disparities must be explored and resolved. All DSPs need to make a livable wage and have access to affordable healthcare benefits. They should not have to work multiple jobs or excess overtime to be able to live above the poverty line.

## Moving Forward – What is Needed for People with IDD

**Prioritize people with IDD living in the community in the administration of vaccinations.** As essential workers, DSPs were among healthcare professionals who received vaccinations early. People with IDD living in long-term care facilities were also prioritized as a vulnerable population. People with IDD who are living independently in the community or with family must also be a priority for COVID-19 vaccinations.

**People with IDD need education and training on handwashing, hygiene, and social distancing.** While 58% of participants reported that people with IDD were good or very good at following social distancing practices, 42% were reportedly fair or poor at this. These numbers were almost the same as when the survey was first administered indicating there was no change in skill over time. Some participants reported that the people they supported had difficulties understanding the changes and restrictions to their lifestyle resulting from the COVID-19 pandemic. People with IDD need access to ongoing, effective education and training on health and safety practices. Efforts to identify effective instruction strategies using universal design for learning approaches should be tested and materials disseminated and implemented.

**Ensure access to technology for people with IDD that allows social interaction with others.** Many participants reported boredom, loneliness and depression among the people they support related to lifestyle changes from the COVID-19 pandemic. Improvements were made in the percentage of people who were never allowed to see friends and family between the initial survey (64%) and the six-month follow-up survey (27%). Technology and other forms of safe socializing are a plausible explanation for this improvement. Investments in technologies that help people have greater control over their lives and access to virtual social interaction can help them maintain friendships and social contacts in future waves of COVID-19 or other pandemics or related crises.

**Develop evidence-based strategies for accessing and using telehealth.** In addition to mental health issues, some participants reported that people supported had increased difficulties managing their diet and pain. Access to telehealth could make it easier to access supports and help alleviate these issues. Work with the medical community is needed to eliminate disparities and ensure people get the healthcare they need.

**Review of policies to ensure person- and family-centered practices with informed decision-making regarding social contacts during a pandemic.** People with IDD and their families should be involved in decisions affecting them. Person-centered services seek to balance peoples' safety with their preferences. Alongside training on safety, people who receive supports and their families need to have a say in how and when they participate in community activities.

## Conclusion

A national emergency was declared on March 13, 2020, concerning the COVID-19 pandemic. One year later, the crisis remains. This study sheds light on the work experiences of DSPs during this challenging time. The study results underscore a number of systemic problems with the provision of services for people with intellectual and developmental disabilities and the vulnerability of the direct support workforce. It is critical that systemic challenges of high turnover, high vacancies, low wages, and the effects these challenges have on the lives of people with intellectual and developmental disabilities be addressed through significant policy change. And the equity issues identified for Black/African American DSPs with regard to wage equity must be resolved.

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