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Direct Support Professionals: Stress and Resiliency Amidst the COVID-19 Pandemic --Manuscript Draft--

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Abstract

This study reports on the results of an online survey of direct support professionals (DSPs) during the COVID-19 pandemic in June, 2020 to measure their perceived quality of life, stressors, coping/resilience skills, and knowledge of health care rights directly related to the pandemic for the persons that they support. Specifically, we examined direct support workers' perceptions of their quality of life, levels of stress, and their self-reported resilience skills. We found that perceived stress was strongly correlated with both self-reported quality of life and resilience, but not with years of DSP experience. Moreover, while DSPs overwhelmingly knew and affirmed health care rights for individuals with disabilities, they were less knowledgeable about legal rights for individuals with disabilities during hospital stays.

Keywords: COVID-19, direct support professionals, quality of life, stress, resilience, people with disabilities

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Direct Support Professionals: Stress and Resiliency Amidst the COVID-19 Pandemic

The COVID-19 pandemic has had an unprecedented impact upon the United States and the world. Its impact has been particularly pronounced on individuals with intellectual and developmental disabilities and the people who assist them, including direct support workers (DSPs) (Ervin & Hobson-Garcia, 2020; Nygren & Lulinski, 2020; Thompson & Nygren, 2020). Unfortunately, even before the onset of the pandemic, DSPs have frequently experienced high levels of job stress and burn-out, affecting both their professional and personal quality of life (QOL) (Gray-Stanley & Muramatsu, 2011; Kessler & Troxel, in press).

Bradley (2020) has noted several impacts on direct support workers as a result of the COVID-19 pandemic that bear directly upon job-related stress, including increased shifts for many staff, especially those in residential services, the re-assignment of staff to other responsibilities, and a shortage of staff at times as a result of other staff having to go into quarantine. Hewitt et al. (2020) confirmed and expanded Bradley's observations in a national survey of 9,000 direct support workers in April and May of 2020. They found that a full 54% of the respondents reported working extra hours as a result of the pandemic, with one-fourth (25%) of all respondents noting that they were working at least 16 additional hours or more weekly, and 26% reporting that their agency was short-staffed. While turnover has always been an issue in the DSP workforce (due in part to low wages, benefits and lack of recognition – see Bogenschutz et al., 2014), the pandemic has appeared to accelerate this, with 42% of respondents reporting that they knew of a DSP who left the workforce as a direct result of the pandemic. The extent to which the pandemic is impacting DSP turnover, and the stability of this critical workforce, is itself an important issue. In a follow-up survey of approximately 9,000 DSPs conducted later in the pandemic (November, 2020- January 2021), Hewitt (2021) noted that 44% of participating DSPs continued to report working additional hours, with 43% also noting that they were

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performing additional duties. In this follow up survey, 40% of the DSPs indicated that their work-life status was worse than before the pandemic, with 14% indicating that their work-life status was now ‘much worse.’

In a qualitative study of DSP experiences and needs during the early months of the pandemic, Embregts et al. (2020) documented a number of pandemic-related stressors, including a heightened awareness and sense of responsibility for the vulnerability of the people that they supported, sadness that the individuals they supported were unable to see their families, a fear for their own safety in the pandemic, and daily work schedules filled with increased medical and prevention-related tasks. DSPs in this study also noted their use of specific coping or resiliency skills such as reflection, a focus on what is truly essential in their lives, and creative problem-solving in their work as a result of the pandemic.

Only a few studies have focused on the relationship of DSPs coping/resilience skills and stress; the COVID-19 pandemic has only added to the critical importance of addressing this topic. Noonan and Hastings (2009) examined the relationship of a resilience curriculum to DSP perceived job stress and psychological well-being. While their curriculum did not reduce job-related stress, it did impact DSP ratings of their well-being. Keesler and Troxel (in press) examined the relationship between self-care, resilience, and self-care behaviors, DSPs’ professional quality of life was affected both by their self-care behaviors and their resiliency skills, with resilience specifically moderating the relationship between self-care behaviors and secondary traumatic experiences. Resilience may thus play a very important role in dealing with the stress of a world-wide pandemic, which certainly could be considered, at the very minimum, a secondary traumatic experience.

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Finally, given the substantial evidence that DSPs have had to assume additional job responsibilities related to the pandemic (Hewitt et al., 2020; Hewitt, 2021), we were interested if more experienced DSPs would perceive less pandemic-related stress than DSPs who were newer to their positions, and who may still be learning critical on-the-job skills. This mixed methods study extends this work by 1) considering direct support workers' perceptions of their quality of life during the pandemic through both objective and qualitative measures; 2) examining their self-reported resilience skills; 3) examining DSPs perceived levels of stress during the pandemic; and 4) determining if their reported levels of stress were related to their self-reported resilience skills, their years of experience, and their QOL self-perceptions. We hypothesized that perceived stress would be inversely related to resiliency skills, years of experience as a DSP, and perceived, overall quality of life. We used a snapshot in time methodology, conducting a survey of DSPs in one midwestern state in early summer 2020, near the start of the pandemic in the U.S. As a secondary question, we also examined the extent to which DSPs are knowledgeable of the health care rights of individuals with disabilities most relevant to the pandemic. We did not hypothesize about DSPs level knowledge of health care rights, but were simply interested in the extent to which DSPs had the health care knowledge needed for their work in a world-wide pandemic.

Methods

Researchers designed an online survey to measure DSPs perceived quality of life, stressors, coping/resilience skills, and knowledge of healthcare rights directly related to the pandemic for the persons that they support. Upon IRB approval of this research, DSPs who were at least 18 years old and who supported an individual(s) with a disability were eligible to complete the survey which was available in June 2020, approximately three months after states

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began issuing a variety of stay at home orders. The survey remained open for 6 weeks. The state developmental disabilities agency shared the survey through a state-maintained DSP email list. A nominal electronic gift card was offered as incentive.

Measures

Perceived Stress: Participants' stress was measured using the *Perceived Stress Scale* (Hewitt et al., 1992), an 11-item instrument that asks respondents to report how frequently during the previous month they had encountered or dealt with stressful life events. The items were rated on a 5-point Likert scale (i.e., 1 = *never*, 2 = *rarely*, 3 = *occasionally*, 4 = *often*, 5 = *always*). Positively stated items indicate effective coping for a particular type of stressful event (e.g., "How often have you felt that things were going your way?") were reversed to indicate higher stress levels. The scoring metric for negatively stated items (e.g., "How often have you felt that you were unable to control the important things in life?") remained as is. The item scores were summed, and the possible range for the scale was 11–55, with lower scores indicating greater stress. The internal consistency reliability of the perceived stress scale as measured by Cronbach's alpha for this study was .88.

Resilience. The *Brief Resilience Scale (BRCs)* (Smith et al., 2008) is a six-item measure designed to measure individuals' ability to recover effectively from stressful or difficult events. Each item (e.g., "I tend to bounce back quickly after hard times"; "It is hard for me to snap back when something bad happens") is self-rated on a five-point scale with participants asked to rate how well they agree or disagree with each of the statements, with negatively phrased statements reverse-coded. The ratings for each item are summed, with a possible range of scores from 6 to 30, with higher scores indicating increased resilience. The internal consistency reliability of the resilience coping scale as measured by Cronbach's alpha was .87.

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Perceived Quality of Life. Participants were asked to rate the extent to which their life is fulfilling (satisfying) in seven areas that occur in daily life (i.e., social life, family life, hobbies/recreational, educational development, daily living, romantic experience, and expectations/hope for the future) on a Likert scale ranging from 1-7, where 1 represents *totally unsatisfying* and 7 is *completely satisfying*. The ratings for each item were summed, thus, total scores on this measure could range between 7 and 49. The internal consistency reliability of the QOL scale as measured by Cronbach's alpha was .92.

Knowledge Scale. To measure knowledge and concern with health care rights for the people that they serve, we asked DSPs to rate their knowledge of and concern across six areas of healthcare access and rights of people with disabilities which are relevant to COVID-19 (e.g. "People with disabilities have the right to get care just like everyone else;" "State Medicaid Programs must now pay for any help people might need from attendants while they are in the hospital"). For each of the items, we used a four-point scale: 1 (*I don't know about this right*); 2 (*I might know about this right*); 3 (*I know but don't care about this right*); and 4 (*I know and care about this right*). The items were summed, and the knowledge scale scores could thus total between 6 and 24 points. The internal consistency reliability of the knowledge scale as measured by Cronbach's alpha was .58.

Disability Status: We asked DSPs to identify each disabling or functional limitation that they themselves experienced in six areas (vision, hearing, walking/climbing stairs, cognitive/emotional, activities of daily living, community functioning). In other words, six dichotomous items (0 = no and 1 = yes), one for each disabling area, were provided. The sum of the six items were calculated to create a disability status variable that represents the number of disabling conditions/limitations identified by the DSPs for themselves. As a result, our disability

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status scale ranged from 0 (no disabling conditions/limitations) to 6 (disabled/limited in all six areas of vision, hearing, walking/climbing stairs, cognitive/emotional, activities of daily living, community functioning).

Years of Experience: We asked respondents to indicate one of five responses to indicate their experience as a DSP: less than 6 months, 6-12 months, 1-2 years, 2-3 years, and more than 3 years.

Open-Ended Questions: The final three questions of the survey were open-ended, in which participants entered their own responses. Those questions are described below under Qualitative Analysis.

Participants

Two hundred and ninety-five direct support professionals who were being paid to provide supports to people with disabilities at the time of survey provided complete data to the variables utilized in this study. As displayed in Tables 1 and 2, the sample included 246 females (83%) and 49 males (17%) and the majority of the participants were white ($n = 229$; 78%). Although most of the direct support professionals had no disability ($n = 235$), some had disabilities themselves ($M = 0.28$, $SD = 0.69$). About 45% of the direct support professionals had worked as a DSP for more than three years ($n = 133$) at the time of survey; about 6% had worked in the field for two to three years; and the remaining 49% had been in the service for less than two years.

Statistical Analysis

In examining participants' perceptions of their current quality of life (QOL), perceived stress, and self-reported resilience, we used simple descriptive statistics for each of our measures. For our fourth question (determining if participants' perceived levels of stress were related to

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their self-reported resilience skills, their years of experience, and their QOL perceptions), a multiple regression analysis was conducted to examine the collective relationship between the independent variables of self-reported resilience, years of experience, and QOL and the criterion variable of perceived stress. The analysis was carried out in a two-step procedure. In the first step, resilience, years of experience, and QOL with three demographic variables (i.e., race, gender, and disability status) functioning as the covariates were added into the model. In the second step, non-significant covariates were dropped from the analysis to achieve a more parsimonious model. As noted above, years of experience was a five-level categorical variable in the actual survey. It was recoded as a single items scale ranging from 0 to 4, corresponding to the categories of less than 6 months, 6-12 months, 1-2 years, 2-3 years, and more than 3 years. It was then entered into the analysis as a continuous variable to keep the model parsimonious. Therefore, one unit difference in this variable implied one increased level on the experience scale. The analyses were conducted using the statistical computer package SPSS 24 (IBM Corp, 2006), and the significance level of the hypothesis tests was set at .05.

For our secondary research question (the extent to which DSPs were knowledgeable of the health care rights of individuals with disabilities most relevant to the pandemic), we calculated simple frequencies and percentages of participant responses to each question.

Qualitative Analysis

The last three questions of the survey were open-ended (“What kinds of things are causing you stress right now?”, “How are you coping with stress?”, and “What kinds of resources do you need to stay healthy and well while coping with COVID-19?”) in which participants entered their own responses. We used an open coding process to review the data without using predetermined categories and themes (Ezzy, 2002). After numbering all the

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responses, including responses from individuals who had not provided complete data to all of the variables in the study, but who had answered the open-ended questions, we examined the responses, and several themes immediately became apparent. After reviewing the responses a second time, the themes from each question were compiled in a separate Word document, in which the data were cut and pasted from the original list to the coded Word document under its question and theme, and responses were numbered. Some answers encompassed multiple themes, and in these cases, the responses were split and coded under their respective theme. Some responses did not fit under a theme, and the researcher coded those as 'Other.' A total of 363 DSPs, including those who had not provided complete data to all of the survey measures, did provide responses to the open-ended questions, and we included their responses in our qualitative analysis.

Results

Descriptive data related to self-reported resilience, years of experience, QOL and the criterion variable of perceived stress are presented in Table 2. The participants' average total score on the QOL scale was 33.30 ($SD = 9.92$) and their average total score on the self-reported resilience scale was 21.38 ($SD = 4.48$). Participants' average score on the perceived stress scale was 28.75 ($SD = 6.99$). Though, overall, participant responses tended toward responses in the middle of the scale for each of these measures, there was a broad range of individual scores, with participant responses ranging from nearly the absolute minimum to close to the absolute maximum score for each of the three measures of perceived stress, QOL, and resilience. In the first multiple regression analysis, resilience, years of experience, and QOL with three demographic variables were added into the model. None of the three covariates of race, gender, and disability status turned out to be significant. Therefore, they were dropped from the model in

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the second step and a more parsimonious regression model with only resilience, years of experience, and QOL functioning as the independent/predictor variables was performed.

Table 3 presents the results of the multiple regression analysis for the collective relationship between the independent variables of self-reported resilience, years of experience, and QOL and the criterion variable of perceived stress. Our model included all three of these predictor variables. The multiple R-squared for this model was .50, indicating that approximately 50% of the variability in perceived stress could be explained by this set of predictors ($F_{(3, 291)} = 96.81, p < .001$). The significant test results indicated that the three predictor variables collectively related to perceived stress among the direct support professionals, as we had hypothesized.

All slope coefficients except that of the years of experience were significantly different from zero and the two significant predictor variables, self-reported resilience and QOL, were negatively related to perceived stress. Holding all the other variables in the model constant, on average the perceived stress score would decrease by 0.23 points ($t = -7.06, p < .001$) if direct support professionals' QOL score increased by one point; similarly, on average the perceived stress score would decrease by 0.77 points ($t = -10.66, p < .001$) if direct support professionals' self-reported resilience score increased by one point. The relationship between years of experience as a DSP and perceived stress at the time of the survey was not significant.

Participants' self-reported level of knowledge of pandemic-related health care rights for individuals with disabilities is presented in Table 4. For four of the six health care rights included in this survey, DSPs overwhelmingly noted (at least 95%) that they "knew and cared about that right." For two of the health care rights surveyed, there was considerably less knowledge and certainty: "State Medicaid Programs must now pay for any help people might need from

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attendants while they are in the hospital” (only 62.1%) and “Hospitals can make an exception to their visitor policy if people need help with advocating, communicating, understanding or self-care.” (75.4%).

Qualitative Comments. For the question “What kinds of things are causing you stress right now?,” there was a total of 286 individual responses, with reported stressors including work (113 comments), financial (53), family/home/personal life (70), specific COVID-19 concerns (48), other health issues (11), educational issues (16), and concerns about racial tensions (7). Table 5 presents representative comments for each of these themes. For the question “How are you coping with stress?,” we received a total of 272 individual responses, with the most frequently noted themes of self-care/coping strategies (48 comments); hobbies and creative outlets (41); exercise/yoga (39); spirituality, including prayer, faith, and meditation (30); ‘working more/staying busy/dealing with it ‘(29); and talking to friends/coworkers (28 comments). For the final question, “What kinds of resources do you need to stay healthy and well while coping with COVID-19?,” there was a total of 226 individual responses, with personal protective equipment (43 comments) and financial/work support (38) being the most frequently mentioned needs. It is noteworthy that 10 DSPs indicated having food or having sufficient food as a basic concern.

Discussion

We had hypothesized that DSPs perceived level of stress during the COVID-19 pandemic would be related to their self-rated Quality of Life (QOL), self-reported resilience skills, and years of experience as a DSP. While our regression analysis clearly indicated that perceived stress was related to this set of predictor variables, only self-reported resilience and QOL were negatively related to perceived stress. Though we were surprised that more experienced DSPs

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did not report significantly less stress than more newly employed DSPs, it is quite possible that experienced DSPs were more likely to be given additional responsibilities during the crisis.

Clearly, DSPs, as a whole, were given additional pandemic-related responsibilities, as Hewitt et al. (2020) and Hewitt (2021) have reported, and supervisors might have considered their most seasoned DSPs as most capable of handling these additional duties. It is also possible the effects of the pandemic were so global that both new and experienced DSPs were equally impacted by the increased demands.

It is certainly reasonable that DSPs who reported higher QOL also reported less stress. QOL perceptions, of course, go well beyond the work setting (though work-life balance can certainly be considered a part of QOL). Clearly, the practical implications of this finding is that service agencies and supervisors should pay close attention to work-life balance for the DSPs they employ, especially in helping their DSP employees find some semblance of balance even as our country returns to some level of normalcy.

We were further encouraged by DSP responses to COVID-19 related health care rights for the individuals they support. Certainly, the overwhelming majority of our respondents knew and cared about such inherent rights as individuals cannot be denied care because of disability or because they might need extra help. Yet, given the essential role that DSPs may play in supporting individuals with disabilities in hospitals and other health care settings, and especially during health care crises, the fact only 62% of our respondents were confident that “state Medicaid Programs must now pay for any help people might need from attendants while they are in the hospital” and that only 75% of our participants knew that “hospitals can make an exception to their visitor policy if people need help with advocating, communicating,

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understanding or self-care” suggests an important educational need to ensure that DSPs are fully aware of the health care rights of the individuals that they support.

The great majority of our respondents chose to respond to one or more of the open-ended questions, with reported stressors including work, financial, family/home/personal life, COVID-19-related and other health issues, educational issues, and racial tensions. Some of the responses clearly reflected the timing of the survey (racial unrest and demonstrations for racial justice), educational (schools being closed for in-person learning). Some responses reflect long-standing issues for DSPs (work, financial) that have simply been exacerbated as a result of COVID-19. Moreover, consistent with the observations of Ervin and Hobson-Garcia (2020), a key stressor noted by several of our participants was the tension inherent in balancing COVID-19 protections and necessary restrictions with the importance of promoting autonomy and decision-making for the individuals that DSPs supported. While agencies have the absolute responsibility of ensuring the health and safety of the individuals they support, this duty is perhaps made even more acute during a world-wide pandemic. Several of the DSPs in our survey noted the impact of isolation from friends and families that individuals with disabilities experienced, that these individuals had no choice in the matter, and could not always understand the reasons for the magnitude of these changes, poses a delicate dilemma in what Wolfensberger would have called the ‘dignity of risk’ (1972). As one of our respondents noted, “Having those I provide supports for (and their families) upset with the restrictions put on them and lack of choice on how they keep themselves safe when general public have more rights.”

Further, as also noted by Hewitt et al. (2020), there is a profound disparity between the responsibilities DSPs have in the lives of the individuals they support, and their pay and working conditions. Several of our DSPs noted the unfairness of their not being considered “essential

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workers.” Finally, it is a sad commentary that, for at least 10 our respondents, access to sufficient and or healthy food was a concern in their lives.

Implications

One of the key implications of this study is the need to enable DSPs to build resilience skills. There have been formal programs developed to build resiliency skills among DSPs (see Noone & Hastings, 2009), but to what extent such training programs would generalize to a national health crisis is unknown. Certainly, one recommendation is for human service agencies to ensure that DSPs have a greater role in decision-making in their work, and thus a greater sense of their own ability to at least partially control some of the variables they face in adequately supporting the individuals with IDD they serve (Gray-Stanley & Muramatsu, 2011). Our study is also consistent with the findings of Keesler and Troxel’s (in press), that efforts to enable DSPs to build their resilience to reduce levels of stress are greatly needed, even as our service systems return to some semblance of normalcy. As these researchers note:

Organizational strategies to develop a culture that embraces the importance of selfcare and empowers DSPs with opportunities to engage in selfcare may be one strategy to increase DSP resilience and decrease burnout amid the context of significant stressors (in press).

Finally, our findings that resilience skills are significantly correlated with reduced stress has implications for reducing DSP turnover. Reducing DSP turnover is itself an important strategy in promoting the health and safety of individuals with IDD, a concern perhaps even more pronounced in the midst of a world-wide pandemic. For example, Friedman (2021) found that individuals supported by more experienced DSPs had fewer emergency room visits, injuries, and instances of abuse and neglect than those individuals who experienced high DSP turnover.

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While pay commensurate with the essential responsibilities inherent in this work is more than overdue, so also is attention to the essential skills that DSPs need, including coping/resilience skills, to meet the challenges that they face on a daily basis.

Limitations

There are several limitations to this study. First, our measures were simply a snapshot in time. For example, we do not know how individuals would have rated their quality of life and coping/resilience skills outside of the pandemic, or even several months later into the pandemic. Second, our participants reflected individuals who had access to computers and internet, and thus does not capture the perceptions of those who did *not* have this technology. Those individuals may have been even more impacted in their work roles and could have experienced greater stress especially in the context of the pandemic. Third, our measures may not have been sufficiently sensitive to detect real differences in respondents. For example, the BRSC consists of just 6 questions, and the Perceived Stress Scale has 11 items. Our Quality of Life measure asked participants to rate their satisfaction of their lives across seven broad domains. Further, our Knowledge Scale had a lower internal consistency reliability than our other measures. More in-depth measures may have produced different results. Fourth, while our qualitative analysis was rather straightforward, it would have been strengthened by inter-rater reliability checks. Finally, years of experience was a five-level categorical variable in our study, though we treated it as a continuous variable for model parsimony. It is worth exploring in the future how each category or group on this variable would relate to perceived stress. Future studies should also consider measuring years of experience as a true continuous variable that may yield more nuanced findings.

Conclusion

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This study found that perceived stress was strongly correlated with both self-reported quality of life and resilience. Moreover, while DSPs overwhelmingly knew and affirmed health care rights for individuals with disabilities, they were less knowledgeable about legal rights for individuals with disabilities during hospital stays, which can be an important element in at least some DSP job responsibilities. Perhaps the COVID-19 pandemic, as one of the most significant societal stressors of the past century, can be a wake-up call to consider self-care, resilience and quality of life needs of this most essential work force.

References

- Bogenschutz, M. D., Hewitt, A., Nord, D., & Hepperlen, R. (2014). Direct support workforce supporting individuals with IDD: Current wages, benefits, and stability. *Intellectual and Developmental Disabilities, 52*(5), 317-329.
- Bradley, V. (2020). How COVID-19 may change the world of services to people with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities, 58*, 355-360.
- Embregts, P., Tournier, T., & Frielink, N. (2020, September 21). Experiences and needs of direct support staff working with people with intellectual disabilities during the COVID-19 pandemic: A thematic analysis. *Journal of Applied Research in Intellectual Disabilities*. Advance online publication: <https://doi.org/10.1111/jar.12812>
- Ervin, D., & Hobson-Garcia, D. (2020). Community supports and COVID-19: Self-determination in a pandemic. *Intellectual and Developmental Disabilities, 58*, 453-457.
- Ezzy, D. (2002). *Qualitative Analysis: Practice and innovation*. London: Routledge.
- Friedman, C. (2021). The impact of direct support professional turnover on the health and safety of people with intellectual and developmental disabilities. *Inclusion, 9* (1), 63-73.

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- Gray-Stanley, J. A., & Muramatsu, N. (2011). Work stress, burnout, and social and personal resources among direct care workers. *Research in Developmental Disabilities, 32*(3), 1065–1074. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3914885/>
- Hewitt, A., Pettingell, S., Kramme, J., Smith, J., Dean, K., & Kleist, B. (2020). *The Direct Support Workforce and COVID-19 National Survey Report 2020*. Minneapolis: Institute on Community Integration, University of Minnesota.
<https://publications.ici.umn.edu/community-living/covid19-survey/overview>
- Hewitt, A. (2021, March 16). *COVID-19 – Its impact on direct support professionals*. Webinar hosted by the American Association of Intellectual and Developmental Disabilities.
- Hewitt, P. L., Flett, G. L., & Mosher, S. W. (1992). The Perceived Stress Scale: Factor structure and relation to depression symptoms in a psychiatric sample. *Journal of Psychopathology and Behavioral Assessment, 14*(3), 247–257. <https://doi.org/10.1007/bf00962631>
- IBM Corp. *IBM SPSS Statistics for Windows [computer program]. 24.0 Version*. Armonk (NY): IBM Corp; 2016.
- Keesler, J., & Troxel, J. (in press). They care for others, but what about themselves? Understanding selfcare among DSPs' and its relationship to professional quality of life. *Intellectual and Developmental Disabilities*.
- Noone, S., & Hastings, R. (2009). Building psychological resilience in support staff caring for persons with intellectual disabilities: Pilot evaluation of an acceptance-based intervention. *Journal of Intellectual Disabilities, 13*(1) 43–53.
- Nygren, M.A. & Lulinski, A. (2020, December). *State of the Science on COVID-19 and People with IDD [Research brief]*. American Association on Intellectual and Developmental

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Disabilities. https://www.aaidd.org/docs/default-source/publication/state-of-the-science-on-covid-19-and-people-with-idd---dec-2020.pdf?sfvrsn=25893421_0

Smith, B. W., Dalen, J., Wiggins, K., Tooley, E., Christopher, P., & Bernard, J. (2008). The brief resilience scale: assessing the ability to bounce back. *International Journal of Behavioral Medicine, 15*(3), 194-200.

Thompson, J., & Nygren, M. (2020). COVID-19 and the field of intellectual and developmental disabilities: Where have we been? Where are we? Where do we go? *Intellectual and Developmental Disabilities, 58*, 257–261.

Wolfensberger, W. (1972). *The principle of normalization in human services*. Toronto: National Institute on Mental Retardation.

Table 1*Descriptive statistics of participants for categorical independent variables (N = 295)*

		N	%
Gender	Male	49	16.6
	Female	246	83.4
Race	White	229	77.6
	Non-White	66	22.4
Years of experience	Less than 6 months	55	18.6
	6-12 months	44	14.9
	1-2 years	46	15.6
	2-3 years	17	5.8
	More than 3 years	133	45.1

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Table 2*Descriptive statistics of participants for continuous variables (N = 295)*

	Min	Max	M	SD	Cronbach's α
Disability	0.00	6.00	0.28	0.69	
Years of experience	0.00	4.00	2.44	1.60	
Stress	11.00	48.00	28.75	6.99	0.88
QOL	8.00	49.00	33.30	9.92	0.92
Resilience	10.00	30.00	21.38	4.48	0.87
Knowledge	9.00	24.00	21.91	2.77	0.58

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Table 3*Regression analysis for stress as the outcome variable (N = 295)*

	<i>B</i>	<i>SE (B)</i>	β	<i>F(df)</i>	<i>p</i>	<i>R</i> ²
Model				96.81 (3, 291)	< .001	0.50
Years of experience	-0.13	0.18	-0.03			
QOL	-0.23***	0.03	-0.33			
Resilience	-0.77***	0.07	-0.50			

Note. *** $p < .001$.

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Table 4

Knowledge of Healthcare Access and Rights of People with Disabilities (Percentage of Participants)

	I know and care about this right %	I know but don't care about this right %	I might know about this right %	I don't know about this right %
People with disabilities have the right to get care just like everyone else (n=281)	98.2	0.7	1.1	0
People with disabilities cannot be denied care just because you have a disability and may need extra help (n=281)	95.0	1.8	2.1	1.1
State Medicaid Programs must now pay for any help people might need from attendants while they are in the hospital (n=282)	62.1	2.8	11.0	24.1
Hospitals can make an exception to their visitor policy if people need help with advocating, communicating, understanding or self-care (n=280)	75.4	1.8	7.9	15.0
People with disabilities have the right to be treated fairly in the hospital (n=277)	97.1	0	1.8	1.1
Treatment should not be denied because of disability (n=280)	97.1	0.7	1.4	0.7

DSP STRESS AND RESILIENCE DURING COVID-19

Table 5*COVID-19 DSP Stressor Themes and Response Examples (N=286 Total Responses)*

Theme	Response Examples
Work Related (N=113)	<ul style="list-style-type: none"> • <i>“Work is my biggest source of stress now because 2 of us are trying to do the work of 4 people.”</i> • <i>“Low pay, increased risk rate of being an essential employee, concessions for those who don't have to work getting extra pay each week while essential employees get no extra pay...”</i> • <i>“These participants are adults that have been cut off from the world for nearly 3 months, they are feeling disheartened and depressed.”</i> • <i>“Having those I provide supports for (and their families) upset with the restrictions put on them and lack of choice on how they keep themselves safe when general public have more rights.”</i>
Financial Issues (N=53)	<ul style="list-style-type: none"> • <i>“Working constantly and still not making enough money to provide the things we need for my family.”</i> • <i>“Barely making it by with what I make. Penny pinching every paycheck. Worry about not being able to keep the house over our head.”</i> • <i>“The pay that I receive for the work that I do is considerably low (just slightly above minimum wage) which requires me to</i>

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work in excess of 70 hours weekly along with a side business to live comfortably.”

Family/Home/Personal
Life

(N=70)

- *“Worried about parents, that they could get COVID and would not bounce back due to their health.”*
- *“Just getting out of college and being alone as an adult.”*
- *“Raising an infant child during pandemic and shutdowns.”*

Specific COVID-19
Concerns

(N=48)

- *“Not knowing if I have the disease and am unknowingly giving it to my client.”*
- *“When the neurotypical population is allowed to wear masks and go out into the community, our disabled/atypical population is told to stay inside creating two classes of people.”*
- *“Not knowing how COVID will affect the people I care for and how it will change how I'm able to care for them.”*

Personal Health Concerns
(N=11)

- *“Only stressor is my pregnancy. My pregnancy has been more on the rough side. My job can be stressful, but I give 100% so I believe a positive attitude carries me far.”*

Educational Concerns
(N=16)

- *“Having four children and not knowing how school will pan out as far as brick-and-mortar school.”*

Racial Tension/Division
(N=7)

- *“The fact that my mother works in an area that rioting is happening.”*

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- *“I have 3 African American men in my household and the racial tensions with the police and the systemic racism we encounter causes me and my family stress.”*