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Promoting Resilience in Direct Support Professionals of Adults with IDD: A Qualitative Descriptive Study --Manuscript Draft--

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Dr. James R. Thompson
Editor
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Dear Dr. Thompson,

We thank the reviewers for their helpful comments on the manuscript. We have made the recommended changes and edits. We feel that the manuscript is strengthened with the changes made, and is now suitable for publication in *Intellectual and Developmental Disabilities*.

Thank you for your consideration!

Sincerely,



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**Promoting Resilience in Direct Support Professionals of Adults with IDD: A Qualitative
Descriptive Study**

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Abstract

The direct support professional (DSP) workforce shortage crisis has reached untenable levels during the COVID-19 pandemic as DSPs rapidly exit the workforce. To gain a better understanding of factors that contribute to DSP resilience during stressful and challenging times, we interviewed 10 DSPs identified by colleagues as resilient, to elicit strategies to promote DSP resilience. Our content analysis revealed nine distinct strategies: (a) communication, (b) self-worth and recognition, (c) authentic, equitable relationships, (d) embracing change and learning, (e) establishing and maintaining boundaries, (f) cultivating an intentional mindset, (g) self-care, (h) spirituality/"the bigger picture", and (i) a daily practice of humor and fun.

Keywords: direct support professional, psychological resilience, intellectual disabilities

Promoting Resilience in Direct Support Professionals of Adults with IDD: A Qualitative Descriptive Study

Direct support professionals (DSPs) work directly with people with intellectual or developmental disabilities (IDD) to help with life's essential everyday activities, enabling people with IDD to live in the community rather than institutional settings. DSPs are called by many titles, including direct care workers, personal care assistants, habilitation specialists, residential counselor, etc. It is estimated that prior to the COVID-19 pandemic, there were approximately 1.3 million DSPs providing supports to people with IDD (Institute on Community Integration, 2022). Difficulties recruiting and retaining DSPs over the past three decades, due to low wages and lack of respect, and a rise in the number of people with ID in need of services has resulted in a DSP workforce shortage crisis (President's Council on Intellectual Disabilities [PCID], 2017). Prior to the COVID-19 pandemic, the average national turnover rate was 43% (National Core Indicators, 2020). With fears of COVID-19 infection and challenges with conflicting family responsibilities, DSPs are now rapidly exiting the workforce (Hewitt et al., 2020). According to a national survey of almost 9,000 DSPs during the spring of 2020, more than 40% of DSPs reported they knew someone in the DSP workforce who left their job due to the pandemic (Hewitt et al., 2020). A Kaiser Family Foundation survey found that two-thirds of responding US states permanently closed at least one community-based provider during COVID-19, which included adult day health, in-home, behavioral, and supported employment services, and group homes, with exacerbation of workforce shortages described as a major contributing factor (Watts et al., 2021). The impact on people with IDD and their families is devastating, as documented by numerous mainstream news media reports (see for example, Brean, 2021; Gaffney, 2021; Tan, 2021). This shortage directly affects the health, safety, and well-being of the approximately 1

million people with IDD in the US and their family members, as they are forced to go without essential care (PCID, 2017). Given the fact that people with IDD are three times as likely to die from COVID-19 (FAIR Health, 2020) and are a population well-known to be vulnerable during disasters and public health crises, it is imperative that people with IDD have access to DSPs to maintain and protect their health during the COVID-19 pandemic and other public health threats.

Compounding the DSP workforce shortage is the fact that DSPs themselves represent a vulnerable population, as the majority of the DSP workforce is female and of color (National Core Indicators, 2022), middle-aged or older, and reliant on some form of public assistance (PHI, 2020). Public health outreach and support for DSPs should be prioritized because DSPs provide critically needed health services to at-risk members of society while being vulnerable themselves. Instead, DSPs remain an “invisible” workforce (Kirschner et al., 2020). They have been deprioritized in the supply chain for personal protective equipment and sanitizers and ignored in policies and support for front line health care workers ([blinded for peer review]). As a result, there is little formal support for DSPs as front-line workers who face increased rates of stress, anxiety, insomnia, burnout, and posttraumatic stress while working during epidemics/pandemics (Magill et al., 2020).

Promoting resilience is a strategy recommended by the National Academy of Medicine (2021) to combat health care worker burnout. Resilience is defined as a process of coping with stressful and challenging circumstances in which the individual learns new skills and self-understanding, thereby strengthening their response to future stressful events (Richardson et al., 1990). In other words, resilience describes a person's ability to thrive in the face of adversity (Connor & Davidson, 2003). Three recent quantitative descriptive studies have explored the

relationships between resilience and other potentially influential factors among DSPs of adults with IDD. Keesler and Troxel (2020) surveyed 153 DSPs from one agency in a midwestern US state to explore the relationships between self-care, resilience, and professional quality of life. Their findings support the concept of resilience as a mediator between self-care and professional quality of life. Crane and Havercamp (2020) conducted an online survey of 195 DSPs at a conference in a midwestern US state and through a DSP Facebook group to examine the relationships between different sources of DSP motivation and indicators of resilience, including low levels of vocational strain and depersonalization and high levels of personal accomplishment. Their findings revealed that DSPs with favorable indicators of resilience were motivated by family, social relationships, and the desire to contribute to the betterment of society. The concept of resilience was not directly investigated; however, resilience was assumed based on low levels of vocational strain and depersonalization and high levels of personal accomplishment. Nevill and Havercamp (2019) explored the relationship between mindfulness, coping style, and resilience as predictors of burnout and short-term turnover in 102 DSPs who support aggressive adults with IDD from one midwestern US county. While resilience was negatively associated with emotional exhaustion, it was not predictive of outcomes, though the authors suggest this finding may be related to the brief, broad measure of resilience used in the study and skew toward higher resilience scores (Nevill & Havercamp, 2019).

Two intervention studies evaluated the effect of brief resilience workshops for DSPs. Noone and Hastings (2009) pilot tested the effect of a 2-day mindfulness and emotional coping training for DSPs on psychological distress, finding a significant reduction in DSPs' psychological distress. Ingham and colleagues (2013) conducted an initial evaluation of a resilience workshop for DSPs who support people with IDD and challenging behavior, finding

that negative emotional reactions to challenging behavior decreased post-intervention, but burnout did not. Neither of these interventions were guided by resilience theory nor employed a specific measure of resilience.

While the perspectives of DSPs related to job needs and agency support has recently been explored (Johnson et al., 2021), there is a notable gap in the literature related to resilience from the perspective of the DSP. Therefore, the purpose of this study is to give voice to resilient DSPs during the COVID-19 pandemic to better understand factors that contribute to DSPs' resilience, for future development of evidence-based interventions to promote the resilience of DSPs.

Methods

The research paradigm underpinning this study is pragmatism, which is directed toward solving real-world problems in everyday life (Kaushik & Walsh, 2019). Pragmatist philosophy avoids the positivist-constructivist dichotomy by acknowledging that while no two individuals can hold identical experiences and worldviews, there are always shared experiences which contribute to shared beliefs and worldviews (Morgan, 2014). For pragmatism, the choice of research design is guided by the design's ability to answer the research question, rather than the researcher's commitment to a philosophical paradigm and method (Kaushik & Walsh, 2019). We employed a qualitative descriptive study design as described by Sandelowski (2000) to answer the research question: What strategies or practices contribute to the resilience of DSPs supporting adults with IDD? Qualitative description is an appropriate research approach when the purpose is to produce a straight description of phenomena comprehensively and accurately in the everyday language of the event (Sandelowski, 2000). As a qualitative method, descriptions are influenced by the describer, though less so than other more interpretive methods

(Sandelowski, 2000). As such, we acknowledge our positionality as nurse researchers which may influence what aspects of the data we highlight, though not intentionally so. The first author is a developmental disabilities nurse researcher who has worked alongside DSPs as a day habilitation nurse for five years. The second author is a nurse researcher who specializes in the study of resilience among non-professional caregivers.

Sample and Recruitment

We used purposive sampling to recruit participants who self-identified, or whom their colleagues identified as being very resilient or the most resilient DSP on the team. Inclusion criteria for the sample were DSPs aged 18-years or older, able to read and speak English, and working a minimum of 32 hours per week supporting an adult with IDD in any setting. Exclusion criteria were DSPs that were related to the adult with IDD and those who did not reside in the United States. We did not include a criterion for length of time in the DSP role as we sought a sample with varied lengths of tenure as a DSP. According to Richardson et al. (1990), resilience is a process that develops over time in response to life experiences, as opposed to a static trait that people possess. We sent email flyers to the listserv of the Developmental Disabilities Nurses Association Research Council, a nationwide group of more than 40 IDD nurses, and to IDD agency directors listed on the Association of Developmental Disabilities Providers website. We also posted the flyer on DSP Facebook groups. The language in the recruitment materials reflected Richardson's et al.'s resilience theory (1990) and a definition of resilience as thriving in the face of adversity (Connor & Davidson, 2003). The flyers asked, "Are you a direct support professional who is thriving through the challenges of the COVID-19 pandemic?" and contained the information about the study and the contact information of the

investigators. We requested that nurses and agency directors widely share the email flyer, and to refer to us any DSP whom they felt met the study criteria.

Upon email or telephone contact by an interested DSP, a member of the research team scheduled a mutually convenient time for a videoconferencing or telephone appointment to discuss study participation and possibly conduct an interview with the DSP if they remained interested after learning more about the study and having the opportunity to ask questions. The researcher also sent the detailed study information sheet to the DSP via email at the time the appointment was scheduled. Twelve DSPs contacted the research team, ten of whom were eligible and who gave consent to participate (see Table 1). Two DSPs did not support adults with IDD and thus were not eligible. To ensure the selection of resilient DSPs, the 10-item Connor-Davidson Resilience Scale (CD-RISC) was used as a screening measure after participants gave consent. The CD-RISC 10 is a single-factor self-report measure of resilience, defined as thriving in the face of adversity (Davidson, *personal communication*). The researcher read and/or shared screen with the CD-RISC items and respondents verbalized their responses using the provided Likert scale. No DSPs were screened out based on their resilience score. The majority of DSPs were female ($n = 9$), from the Northeast US ($n = 7$), and employed in group homes ($n = 5$). After the 10th interview, no new codes were identified from the data, thus it was concluded that data saturation had been reached and no further interviews were conducted.

Ethical Considerations

Institutional review board approval was obtained prior to commencing the study from [blinded for peer review], approval number 21.025. Prior to commencing each interview, the researchers reviewed the study information sheet and answered any questions the potential participant had during the audio/videoconferencing call. The audio recorder was then turned on

and participants gave audio recorded verbal consent. Audio recordings were deleted as soon as transcripts were checked for accuracy and de-identified for confidentiality. All transcripts and study data were stored securely in a password protected University OneDrive.

Data Collection

Data were collected via participant interviews using Zoom audio/videoconferencing, April to August 2021. Zoom was selected because it was widely available, already being used by DSPs during the COVID-19 pandemic in their agencies, provided an option for log in via telephone or the internet, and had the ability to audio record sessions. A semi-structured interview guide (see Appendix A) was developed by the research team based on Richardson et al.'s resilience theory (1990), which defines resilience broadly for applicability to many populations, and from which the CD-RISC-10 was developed. The two researchers met prior to conducting interviews to establish consistency with the study protocol, including the process for obtaining informed consent, administering the CD-RISC-10, and performing the interview. The audio recorded interviews lasted approximately 30-60 minutes and were transcribed verbatim using Zoom auto-transcription. Transcripts were compared against the audio recording for accuracy in their entirety, during which time the transcripts were de-identified with an anonymized participant ID. Participants were given a \$40 gift card in compensation for their time. The researchers took field notes during and immediately after each interview, recording observational, theoretical, and methodological notes in the style of Schatzman and Strauss (1973).

Data Analysis

Qualitative content analysis was employed to analyze the transcripts. Content analysis is the method of choice for qualitative descriptive studies, in which a summary of the informational

contents of the data is sought (Sandelowski, 2000). We employed a 4-stage manifest approach, as outlined by Bengtsson (2016) in which the surface structure of the data is analyzed, asking "What has been said?" (p. 9). In Stage 1, decontextualization, the two researchers independently read each transcript and identified meaning units, or the smallest units of data that are relevant to the research question. Open coding was then employed, meaning that each identified meaning unit was assigned a code generated inductively from the data (Bengtsson, 2016). Each researcher kept their own code list with a list of codes and explanations to minimize cognitive drift during the coding process; the code list was updated by each researcher during the course of data analysis. In Stage 2, recontextualization, the researchers re-read each of the transcripts to ensure all relevant meaning units were identified and that the remaining information in the transcripts was not relevant to the study aim. In Stage 3, categorization, each researcher grouped the similar codes into categories. The researchers then met together and compared categories and constituent codes to reach consensus on a final set of categories and identify representative quotes for each category. In Stage 4, compilation, a summary of findings is presented (see the Results section, below).

We attended to trustworthiness in this qualitative content analysis per the recommendations of Graneheim and Lundman (2004), as follows: 1) We ensured the selection of resilient DSPs by verifying resilience using the CD-RISC-10; 2) We provide an example of how meaning units were coded and condensed (see Table 2) and include illustrative quotes for each category with the study results; and 3) Two researchers independently analyzed the data and reached consensus on the findings. The Standards for Reporting Qualitative Research (SRQR) guided our reporting of the findings (O'Brien et al, 2014).

Results

Nine practices contributing to DSPs' resilience during stressful and challenging times were identified, according to the perspectives of 10 resilient DSPs interviewed during the COVID-19 pandemic. The nine practices were: 1) (a) communication, (b) self-worth and recognition, (c) authentic, equitable relationships, (d) embracing change and learning, (e) establishing and maintaining boundaries, (f) cultivating an intentional mindset, (g) self-care, (h) spirituality/"the bigger picture", and (i) a daily practice of humor and fun. In Table 3, we present illustrative quotes for each category.

Communication

Communication with persons with IDD, families, and other DSPs and staff contributed to success in the DSP role. Learning how to communicate with people with IDD, especially people with IDD who do not use verbal language, was an important skill for new DSPs to learn. Listening, observing, and talking directly to people with IDD as one would any other human being, as well as learning about the person with IDD, were important to making a meaningful connection. The ability to read each other's nonverbal cues, described by one DSP as "vibes", contributed to the tone of the day and even the emotional and behavioral reactions of the person with IDD. Communication with other DSPs, family members and staff was identified as essential for DSPs to be able to do their job and was optimal when the communication promoted an understanding of the bigger picture of what had been going on with the person with IDD, rather than just the events of the previous shift. Communicating with a trusted colleague or peer to briefly vent about a challenge and then move on was also an important strategy DSPs used on a regular basis to cope with stress; this was especially helpful if the colleague was respected by the DSP, had worked in the field for a long time, and could offer perspective.

Communication was a critical component of teamwork, identified as foundational to success in the DSP role. DSPs described the importance of having a consistent team of DSPs, as working with unfamiliar DSPs caused anxiety about the ability of the unfamiliar DSP to perform job functions that also impacted the safety of the regular DSP, for example with two-person physical transfers. DSPs also described how people with IDD were impacted by unfamiliar team members, which led them to feel upset, angry or out of control, due to feelings of stranger danger and mistrust. This prompted the need to facilitate communication and relationship building between the unfamiliar staff and person with IDD, and to ensure they were trained and able to do their jobs. Communication was also important to facilitate teamwork with and between people with IDD, for example, deciding together the day's activities, helping each other with leisure activities, like working together to read words on a game, and spurring each other on to drink fluids and eat fruits and vegetables. Being part of and facilitating such teamwork was described as rewarding: "they're a team... it's just so good to see that stuff. It makes me feel good, makes me feel that I'm doing my job" (Participant D).

Self-Worth and Recognition

Positive recognition from people with IDD, family members, and agency leadership promoted the DSPs' resilience, by enhancing the DSPs' confidence and self-worth. One DSP described the low societal value placed on DSPs, who often don't make very much money, haven't earned a certain title, or are even recognized as essential employees, and how this contributes to "a sort of like blanket feeling...of less of a human being" (Participant G). The opportunity for DSPs to have their voice heard by agency leaders was valued, especially when agency leaders individually followed up with the DSPs after sharing their opinions. Positive feedback from family members and people with IDD themselves further contributed to validation

of the DSP. DSPs also described self-worth and confidence from their own recognition that they were helping others and the positive impact that they were making on the lives of people with IDD whom they supported.

Authentic, Equitable Relationships with People with IDD

DSPs described the importance of knowing the person with IDD as an individual and getting the full picture of who the person is through experience, rather than by relying on what others have told them. The equity, respect, and shared humanness of people with IDD and the DSP was emphasized, which overshadowed differences based on the IDD label. Discernment in communication was an important skill to building authentic relationships. Sharing some details of the DSPs' personal life to make a meaningful connection was described, but not oversharing to the detriment of the person with IDD. "Sugarcoating", or false assurance about challenges faced by the person with IDD was criticized, as was performing activities for the person with IDD to avoid challenge. Instead, DSPs were realistic and ensured that people with IDD had the opportunity to make choices and try, even when a positive outcome was not initially likely.

Embracing Change and Learning

DSPs described the unpredictable nature of their roles and how it was important to be flexible and adaptable. Accepting that change is inevitable and letting go of control for things being done a particular way out of preference was identified as important. A shared characteristic of DSPs in this study was that they were able to put a positive spin on the different changes and challenges identified. Rather than viewing the COVID-19 pandemic only as a threat, the DSPs identified positive effects, including being able to spend more 1:1 time with people with IDD, creating new activities and traditions, and trying new roles. A few DSPs described the use of reflection, internally asking themselves or a higher power if there was something they could

learn from their past experiences and apply to their lives and in their roles as DSPs.

Opportunities for education were valued by the DSPs; one participant described how DSPs "just kind of fall through the cracks" (Participant H) in terms of resources, and another described how a lack of trainings for skills employed in the DSP role contributed to feelings of inadequacy and discomfort. DSPs described the importance of asking questions to have their needs addressed, especially those who were newly employed during the pandemic and did not receive all trainings on policies and procedures. The DSPs also described learning to find their own way, in terms of consistently applying policies and procedures, and at the same time tailoring their approach to the person with IDD, in their own style.

Establishing and Maintaining Boundaries

DSPs in this study reported the need to establish and maintain boundaries, in terms of boundaries between the DSP and people with IDD and their family members, and boundaries around the DSPs' time. Respecting boundaries in the relationship with people with IDD was important for both the DSP and person with IDD. For example, one DSP described how a person with IDD told his mother that the DSP brought a dog to work and let the dog sleep on his bed, which was not true. Instead of pointing this out during the conversation with the person's mother, the DSP waited and spoke to the person with IDD about it directly, out of respect for the person's boundaries of his personal communication with his mother. He was then supported to tell his mother the truth on his own. The same DSP was also cognizant of boundaries when discussing the concept of death while watching a movie with a person with IDD and wanting to be sure they didn't describe life after death in terms of their own spiritual beliefs, that they respected the boundaries of the family (Participant A). Another DSP described how they communicated via text frequently with the people with IDD they supported in the day habilitation setting, but that

they set clear boundaries in terms of expectations for when and how often they would reply (Participant D).

Having clear boundaries around the DSPs' time was discussed by many of the DSPs. This related to the prolific demands on DSPs to work additional shifts or for long periods of time with people with challenging behaviors. DSPs described how they went through a process of learning their own limits and began to recognize their own boundaries in terms of symptoms of burnout. They applied these boundaries with the recognition that they were in the best interests of not only themselves, but also the people with IDD they supported.

Cultivating an Intentional Mindset

An intentional mindset was a common strategy employed by the DSPs when on the job. One specific phrase "leave your problems at the door" was used by several of the DSPs to how they consciously focused on being present in the moment and not bringing problems from their personal life into work. This intentional mindset also involved empathy rather than sympathy, that is, viewing things from the person with IDD's perspective and avoiding pity. Calmness was intentionally cultivated, as opposed to emotional reactivity in response to challenging situations. The DSPs recognized that their mindset directly influenced the tone of the day for the person with IDD, and they were intentional about cultivating a positive atmosphere.

A Daily Practice of Humor and Fun

Many of the DSPs described using fun and humor as a daily practice. This often did not require much effort and was a natural outflow of spending time with people with IDD, whom the DSPs frequently described as possessing good humor and being fun people to be around. Fun was purposively cultivated and incorporated into daily activities, as it motivated people with IDD to meet their needs and goals for the day, especially when people with IDD were in non-work

settings where they were not being incentivized with pay for their time and participation. The DSPs also recognized that having fun helped the day to go by quicker and was good for everyone, DSPs and people with IDD alike.

The DSPs described using humor both with people with IDD and within themselves to cope with challenging situations. When faced with a potential conflict or difficulty with a person with IDD, the DSPs used humor to distract and deflect the negative focus and retain a lighthearted atmosphere. For the DSPs, use of humor allowed them to move from anger and frustration at the circumstances to putting distance between themselves and the situation by making fun of themselves and the situation at hand, as a coping mechanism. To maintain a practice of humor and fun on a daily basis, the DSPs described pulling in jokes they had recently heard, celebrating holidays and special events, asking the people with IDD about what fun ideas they have, and even making fun of the DSP together in a friendly way.

Self-Care

All the DSPs in this study described the importance of self-care, though not all DSPs felt they were adequately meeting their own self-care needs. Self-care was described by the DSPs in terms of time, "me time" or time spent on what mattered most to the DSP, which was often time with loved ones and pets. Self-care strategies employed by the DSPs included exercise, hydration, reading, meditation, personal grooming, and going for a car drive alone to get a coffee. In some cases, self-care like exercise, hydration, and meditation was performed along with people with IDD during the DSPs workday, from the mindset that it was good for both parties. Briefly venting to a colleague, friend, or loved one about daily stressors was also described as a self-care strategy, in that this allowed the person to release stress and move on with their day. Time spent enjoying nature was reported by several of the DSPs, and represented

a break from daily demands, while at the same time providing the opportunity to dwell in the present moment and wonder at nature's marvels.

Spirituality/"The Bigger Picture"

Faith, prayer, and spirituality were identified by some of the DSPs as important coping strategies for daily stress and challenges. Self-reflection was closely linked to prayer and spirituality, in that it provided an opportunity for the DSP to learn about themselves and change and grow, in light of a larger reason for being. Other DSPs who did not directly discuss spirituality used the phrase "at the end of the day", in the context of looking at a bigger picture when interpreting daily challenges, rather than reacting in the moment. A few DSPs also identified the DSP role as being what they were 'meant' to be doing at that time, in metaphysical terms. The COVID-19 pandemic also caused some of the DSPs to have a greater appreciation for time and provided perspective as to what was truly important in life.

Discussion

This study contributes to the literature by offering a first look into DSPs' own perspectives on what contributes to their resilience, using the COVID-19 pandemic as an opportunity for learning. We identified nine practices of resilient DSPs that help them to thrive and be successful in their roles, particularly during times of stress and challenge. These practices included: (a) communication, (b) self-worth and recognition, (c) authentic, equitable relationships, (d) embracing change and learning, (e) establishing and maintaining boundaries, (f) cultivating an intentional mindset, (g) self-care, (h) spirituality/"the bigger picture", and (i) a daily practice of humor and fun. Identification of these practices is an important first step to develop interventions that teach these strategies to new DSPs or DSPs who are struggling in their roles.

We have not found any other studies that have explored the first-hand perspectives of other caregivers of people with disabilities about their resilience. We specifically sought studies of nursing assistants in long-term care, home health aides, and family members of adults with IDD. The lack of the voice of the caregiver in studies of caregiver resilience of people with disabilities is a research gap that needs to be addressed. First-hand perspectives on resilience have been explored among nurses (Cooper et al., 2021; Wei et al., 2019) and among people with IDD themselves (Scheffers et al., 2019). Wei et al. (2019) interviewed 20 nurse leaders across the US about strategies to foster nurse resilience. Seven strategies were identified: "1) facilitating social connections, 2) promoting positivity, 3) capitalizing on nurse strengths, 4) nurturing nurses' growth, 5) encouraging nurses' self-care, 6) fostering mindful practice, and 7) conveying altruism" (p. 681). There are several areas of overlap with our present findings, including focusing on a positive mindset, embracing learning and self-care, and paying attention to the present moment vis a vis mindfulness. Wei et al.'s (2019) strategy of facilitating social connections included activities that promoted bonding among the nurses to improve teamwork, which was also an important factor contributing to resilience in the present study.

Scheffers et al. (2020) summarized the findings of a literature review yielding seven qualitative and mixed-methods studies exploring sources of resilience in adults with IDD, with a focus on the perspective of adults with IDD. This is an important contribution to the literature because people with IDD are at increased risk of experiencing adversity during their lifetime (Scheffers et al., 2020). Three internal sources of resilience included autonomy, self-acceptance, and physical health. Autonomy involved constructing and making choices and feeling in control. It is interesting to consider, in juxtaposition, that letting go of control promoted resilience for the DSP in the present study. Self-acceptance, for the person with IDD, related to accepting

challenges and strengths and facing life with a positive attitude (Scheffers et al., 2020); this is congruent with findings of the present study related to acceptance and putting a positive spin on life's challenges. Physical health for the person with IDD was described as feeling healthy, taking medications, having routine health care visits, and physical activity (Scheffers et al., 2020). For DSPs, physical health was not emphasized; exercise was described as a form of self-care by a few DSPs, but no other mention of physical health was made, which is thought-provoking given that DSPs, as a population, are at higher risk for chronic health conditions due to socioeconomic and racial disparities. Two external sources of resilience identified by people with IDD were a supportive social network and daily activities (Scheffers et al., 2020). The presence of an informal social network along with supportive professional caregivers mirrored the findings of this study in which DSPs benefited from having a strong DSP team, as well as informal support in the form of loved ones and friends to vent to about work-related challenges. Daily activities, mostly described as leisure activities, contributed to resilience in people with IDD, which were important for social interactions and a sense of routine and predictability (Scheffers et al., 2020). The focus on enjoyable leisure activities and socialization is consistent with the DSPs' need to infuse fun into each day; fun daily activities, therefore, should not be seen as an 'extra' in support for people with IDD, but an important strategy to promote resilience of people with IDD and their DSPs.

Limitations

While this is the first study to investigate resilience from the lens of DSPs, it has several limitations. We conducted a single interview with DSPs at one time point during the COVID-19 pandemic thus the extent to which DSPs' perspectives may have changed over time could not be captured. DSP recruitment also posed a challenge during the study. The demands on DSPs

during the COVID-19 pandemic, may have excluded some resilient DSPs who were working so many hours that they were not be able to participate due to time demands. Furthermore, while we sought a nationally representative sample of DSPs, our sample lacked diversity in that it was 90% female, 20% people of color, and predominantly comprised of DSPs from the Northeast US. Compared to the national workforce, the gender profile of the DSP workforce is approximately 71% female and 62% people of color, though wide variation in racial/ethnic diversity of the DSP workforce exists across states (National Core Indicators, 2022). In the present study, all participants were employed 1+ years, therefore they may have been less likely to remember and accurately report what helped them to become resilient earlier in their tenure as DSPs. Future research is needed to determine factors contributing to DSP resilience among a more diverse sample of DSPs.

Implications for Policy and Practice

The findings of this study, when taken into consideration with studies of resilience among nurses and people with IDD, point to two primary recommendations for policy and practice to promote the resilience of DSPs, both of which involve greater investment in the DSP workforce. The first recommendation is for enhanced training of the DSP workforce. DSPs in this study identified a lack of trainings and resources for adequate knowledge to be successful in their roles. This was of particular concern for DSPs who were newer to the DSP role and DSPs with more experience who faced a change in responsibilities. This is consistent with findings of other studies exploring the DSP workforce crisis and the unmet needs of DSPs (Johnson et al., 2021; Pettingill et al., 2022). Existing trainings focus on meeting the needs of people with IDD, and do not address the self-care and resilience needs of DSPs (Nevill & Havercamp, 2019). Ensuring DSPs have access to comprehensive health and wellness programs, inclusive of support

for stress and burnout is an identified need (Pettingell et al., 2022). Given that factors contributing to DSP resilience overlap with those reported by nurses, using or adapting resilience trainings for nurses may be the timeliest available option to disseminate resilience strategies to DSPs. Inclusion of topics unique to the DSP role, including a daily practice of humor and fun, and forming authentic and equitable relationships with people with IDD are necessary if any training is to be adapted. Also, given that the findings of this study reveal that the resilience of DSPs and people with IDD is in many ways intertwined, dyadic interventions involving DSPs and people with IDD may provide maximal impact with fewer resources. Peer support interventions, in which peer specialists are trained to support colleagues and encourage resilience in the workplace is another potential intervention that has been recommended during the COVID-19 pandemic for front-line health care workers (Wu et al., 2020) and to support overall job-related resilience within the sphere of occupational health (Agarwal et al., 2020). A peer support model bears further consideration based on our study findings which identify that the support of a respected and trusted colleague who has worked in the field for a long time can help to offer perspective to newer DSPs, promoting resilience. Creating a pipeline of well-trained DSPs through high school training programs has been proposed by DSP advocacy groups (PHI, 2020). Such pipeline training programs could provide the time necessary to include resilience training along with DSP core competencies, time that is currently not available due to the demands of the workforce shortage.

The second recommendation is to increase the resources and support available to DSPs through policy action. DSPs in this study described a societal devaluation of DSPs, potentiated and closely intertwined with experiences of poverty and low educational attainment. [blinded for peer review] described how DSPs were ignored in initiatives and policies for front-line health

workers during the COVID-19 pandemic, even though both they and the people with IDD they supported were at high risk for poor outcomes from COVID-19. Initiatives and resources for front-line health workers during public health emergencies, like the COVID-19 pandemic, should be inclusive of DSPs. Furthermore, the primary measure of value in society is compensation, and DSPs should be compensated as valued, contributing members of society. Increasing Medicaid reimbursement rates for long-term services and supports, with the requirement that the increase is passed down directly to the DSP, is one potential policy target (PHI, 2020). However, it is also important to consider that increasing salary may negatively affect eligibility for public assistance and lead to a net loss of income (PHI, 2020). This is especially important in light of recent minimum wage increases across the nation (PHI, 2020). For the DSPs in this study, non-monetary forms of recognition were important to feeling valued and confident, including positive verbal feedback from people with IDD, their families, and their employers. Other means of recognizing DSPs' contributions should be explored. Johnson et al. (2021) recommend recognition that is specific, individualized, and tangible, in comparison to general company-wide picnics and celebrations. Future research is needed to identify strategies that help DSPs to feel valued in their roles.

Conclusion

Critics of resilience as a concept argue that a focus on resilience puts the onus of responsibility for dealing with challenges on the individual (Udod et al., 2021); we recognize the value of multi-level interventions consisting of individual, organizational and systems components, to promote maximum effectiveness and impact. This study identified practices contributing to DSP resilience during the COVID-19 pandemic, a time representing the greatest workforce shortage of DSPs in history. The development and testing of educational interventions

and resources to teach these strategies for resilience to DSPs is an important individual-level intervention to be used in conjunction with systems-wide initiatives to reduce the DSP workforce shortage, including increased compensation and recognition. Ensuring access to DSPs, especially those who are resilient and motivated in their work, is critical to the health and quality of life of people with IDD receiving their support.

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Table 1
Demographic characteristics of participants

Participant	CD-RISC 10* score	Gender	Race	Age	Years of Experience as a DSP for adults with IDD	Support Setting	Geographic Region
A	35	Female	Black/Cape Verdean	36	3 years*	Group home	Northeast
B	32	Female	White	Not disclosed	16 years	Day habilitation	Northeast
C	37	Female	White	Not disclosed	6 years*	Day habilitation/Life skills	Northeast
D	32	Female	White	Not disclosed	11 years	Day habilitation/Life skills	Northeast
E	31	Female	White	Not disclosed	6 years*	Life skills/job coach	Northeast
F	24	Male	White	20	7 years	Group home	Midwest
G	32	Female	White	51	8 years	Group home	Northeast
H	27	Female	White	31	5.5 years	Group home/job coach	Midwest
M	35	Female	White	Not disclosed	1 year	Group home	Northeast
N	38	Female	Black	Not disclosed	7 years	Day habilitation	Midwest

Note: Abbreviations: CD-RISC-10 = Connor-Davidson Resilience Scale, 10-item version; DSP = direct support professional; IDD = intellectual/developmental disabilities

* Possible range 0-40, 40 = highest possible resilience score

Table 2*Example of codes and categorization*

Meaning unit	Code	Category
"Something with me, I use humor a lot" (Participant A).	Humor	A daily practice of humor and fun
"We gotta make this fun. It's going to make the day go by quicker, it's gonna make everybody's day better" (Participant B).	Fun	
"You know you heard a joke the night before, and you know, it's kind of like an icebreaker, you know. You got to keep the humor in it, so it kind of breaks the ice when the tension hits" (Participant B).	Humor	
"I feel like I'm fun, I'm outgoing... I'm always taking them out. We do fun activities together" (Participant C).	Fun	
"I'm crazy. I'm fun. They have a great time with me... Everything gets done, all my paperwork gets done, but we have a great time" (Participant D).	Fun	

Table 3*Categories with Illustrative Quotes*

Categories	Illustrative Quotes
Communication	<p data-bbox="862 386 1487 674">"You need to listen, you really need to listen, I listened to the clients, you have to listen to them...I sit back even in our conversations and when they're having conversations amongst each other, I listened to them and that's how I learned and that just different things they say to each other and what their likes and dislikes and I'm like "Hmm"... and I learn" (Participant D).</p> <p data-bbox="862 716 1487 821">"We just vent to one another, real quick, and you know, it's done and over with... we got it off our chest, tomorrow's a new day" (Participant B).</p>
Self-worth and recognition	<p data-bbox="862 863 1487 1041">"At the end of the day, what makes you happy? Don't focus so much on what you're not getting, but what you're getting. You know, are you happy? What can make you happy in this?" (Participant G).</p> <p data-bbox="862 1083 1487 1262">"You know, don't look at it just as a paycheck. I mean granted, yes, it pays my bills, but at the same time, I feel that it's more meaningful than that. Way more meaningful than that" (Participant A).</p>
Authentic, equitable relationship with individuals with IDD	<p data-bbox="862 1304 1487 1440">"I'm gonna be honest, I don't share personal things but I share some things because I...want to make the connection real with these gentlemen" (Participant A).</p> <p data-bbox="862 1482 1487 1587">"They're people, just like we are. You know, they may have a disability, but they're just like we are" (Participant D).</p>

Embracing change and learning

"I just sort of see like whatever situation I'm in, 'How can I make this work?' and if it's difficult, 'okay, what's going on here? what can I work with?' (Participant G).

"And the sooner you learn that the more flexible you are, and you can just roll with it, because every day something new and different is happening... that's just the nature of the job, you've got to roll with it" (Participant G).

Establishing and maintaining boundaries

"What's very important... is that there are boundaries... we can still get along and we can be happy and enjoy each other, you know, but there's just so much you can do. Those boundaries are very important" (Participant N).

"When I first started out as an independent DSP at 18, I was eager to take on as much work as physically possible, and I had bad boundaries. Now I operate from the motto 'You can't pour from an empty cup'. Working yourself to death is going to make things worse for everyone involved" (Participant F).

Cultivating an intentional mindset

"You just got to be calm, even through the most frustrating parts, like you just gotta stay focused and be calm" (Participant B).

"I just come in with my 'hey, we're gonna have a good day, this is what's going to be, guys, and you know, let's get to it" (Participant A).

Self-care

"I have to make time for myself...Self-care is important and you just, you got to take those moments out for you" (Participant B).

"If you can't take care of yourself, you can't take care of nobody else, and guys, also I live by that rule... You represent like who you are, as a person, and self-care is important" (Participant A).

Spirituality/"the bigger picture"

"I did turn more into spirituality. Not just like questioning life, reading or science articles, but also really paying attention... Just really paying attention...[to] what's happening so that actually was an unexpected stress relief" (Participant G).

"I'm a spiritual person, so I do pray a lot on issues like trying to help me figure it out, to be the one to maybe learn" (Participant N)

A daily practice of humor and fun

"And I have to try to make everything fun, because if it's not fun, they don't get, most of them don't get paid, so there's no real incentive to do what I'm encouraging them to do, unless it's something that's fun. Even if it's not fun we have to encourage "We will have fun after" (Participant E).

"And then you move on, you move on to humor because once you get out that anger and frustration then things become funny. You can make fun of yourself, you can make fun of everything that's going on and that helps a lot" (Participant G).



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Supplemental Material
DSP Resilience APPENDIX A.docx



Dear reviewers,

Thank you for your thoughtful review of this manuscript. We feel the manuscript has been strengthened by the changes we made based on your recommendations. Please see your comments below and our response to each comment.

Sincerely,

The authors

Reviewer Comment	Response to Reviewer
Reviewer #1	
1. Direct Support Professional should be listed as a keyword.	Keyword "caregivers" has been changed to "direct support professional".
2. Purposive sampling of participants is appropriate. A bit on how resilience was defined as the primary factor in identifying participants is needed here.	Thank you. We added the following words/sentences (highlighted): "The language in the recruitment materials reflected Richardson's et al.'s resilience theory (1990) and a definition of resilience as thriving in the face of adversity (Connor & Davidson, 2003). The flyers asked, "Are you a direct support professional who is thriving through the challenges of the COVID-19 pandemic?" and contained the information about the study and the contact information of the investigators. We requested that nurses and agency directors widely share the email flyer, and to refer to us any DSP whom they felt met the study criteria."
3. Inclusion criteria did not include tenure or time on the job as a DSP although this is a factor in the process of becoming resilient as defined by the author. It is also noted in Table 1. Some description of the effect of time on resilience in the literature is needed. Implications of time on the job on the findings is needed in the discussion.	<p>We did not choose to exclude participants based on length of experience as we purposively selected participants with varied lengths of experience. We added the following statements to the Methods section following Inclusion/Exclusion criteria: .</p> <p>"We did not include a criterion for length of time in the DSP role as we sought a sample with varied lengths of tenure as a DSP. According to Richardson et al. (1990), resilience is a process that develops over time in response to life experiences, as opposed to a static trait that people possess."</p> <p>We did ask participants for their years of experience as a DSP to characterize our sample (Table 1).</p> <p>We have added a sentence to our limitations section to address tenure:</p> <p>"In the present study, all participants were employed 1+ years, therefore they may have been less likely to remember and accurately report what helped them to become resilient earlier in their tenure as DSPs."</p> <p>We have also added sentences to the discussion section articulating that newer DSPs and those with changes in responsibilities may benefit more from enhanced trainings,</p>

	<p>and that DSPs with more experience can be helpful as mentors to newer DSPs.</p> <p>"DSPs in this study identified a lack of trainings and resources for adequate knowledge to be successful in their roles. This was of particular concern for DSPs who were newer to the DSP role and DSPs with more experience who faced a change in responsibilities."</p> <p>"Peer support interventions, in which peer specialists are trained to support colleagues and encourage resilience in the workplace is another potential intervention that has been recommended during the COVID-19 pandemic for front-line health care workers (Wu et al., 2020) and to support overall job-related resilience within the sphere of occupational health (Agarwal et al., 2020). A peer support model bears further consideration based on our study findings which identify that the support of a respected and trusted colleague who has worked in the field for a long time can help to offer perspective to newer DSPs, promoting resilience."</p>
<p>4. The 10-item Connor-Davidson Resilience Scale (CD-RISC) was used as a screening measure. How is resilience measured by this instrument? How do the factors in this instrument align with the findings?</p>	<p>The following highlighted words/sentences were added to clarify: "To ensure the selection of resilient DSPs, the 10-item Connor-Davidson Resilience Scale (CD-RISC) was used as a screening measure after participants gave consent. The CD-RISC 10 is a single-factor self-report measure of resilience, defined as thriving in the face of adversity (Davidson, <i>personal communication</i>). The researcher read and/or shared screen with the CD-RISC items and respondents verbalized their responses using the provided Likert scale. No DSPs were screened out based on their resilience score."</p> <p>Because this is a single factor measure of resilience, we are not able to discuss how factors in the instrument align with findings.</p>
<p>5. In the data analysis narrative recontextualization is identified as both Stage 2 and Stage 3 (pg. 8).</p>	<p>Thank you for catching this error. Stage 3 has been corrected to read "categorization"/</p>
<p>Reviewer #2</p>	
<p>Abstract: -- Don't need the comma in the second sentence after pandemic.</p>	<p>Comma removed.</p>
<p>Key Words: -- The manuscript focuses on IDD but that is not listed as a</p>	<p>Keyword changed to intellectual disabilities</p>

key word; only developmental disabilities is listed. This seems odd.	
Introduction/Literature Review: The literature review is well written and interesting. It uses recent literature and tells an interesting story. It sets the stage well for the purpose.	Thank you.
-- There are no specific hypotheses listed, just a general paragraph about what the study does. Which is fine. A more specific hypothesis is provided in the Methods.	We made no changes based on this comment.
-- p. 3: first line there is an extra space before 19	Space deleted.
-- p. 3: paragraph starting with "Compounding ... ", the second to last sentence doesn't need a comma after 'workers'	Comma removed.
-- p.4: third line doesn't need a comma after group	Comma removed.
p.4: fourth line ... remove the colon after 'resilience' and add the word 'including'; flows better	Colon removed. The word including was added.
p.4: fifth line ... don't need a comma after 'depersonalization'	Comma removed.
p.4: eighth line ... should be 'investigated; however, ... ' the semi-colon and comma are backwards	Semi-colon and comma placement switched.
p.4: ninth line ... too many spaces before 'Nevill'	Extra spaces deleted.
Methods: The research process and analysis are described well and in detail.	Thank you.
-- There was no report of interrater reliability computed. That would be nice to report.	The following highlighted words/sentences were added to clarify interrater reliability:

	<p>"The following highlighted words/sentences were added to clarify: To ensure the selection of resilient DSPs, the 10-item Connor-Davidson Resilience Scale (CD-RISC) was used as a screening measure after participants gave consent. The CD-RISC 10 is a single-factor self-report measure of resilience, defined as thriving in the face of adversity (Davidson, <i>personal communication</i>). The researcher read and/or shared screen with the CD-RISC items and respondents verbalized their responses using the provided Likert scale. No DSPs were screened out based on their resilience score."</p> <p>The CD-RISC 10 is a self-report scale and observations of the research team members was not included as part of the scale; therefore no interrelater reliability can be calculated. We did already include the following statement on p.8 that describes our process for fidelity to our protocols "The two researchers met prior to conducting interviews to establish consistency with the study protocol, including the process for obtaining informed consent, administering the CD-RISC-10, and performing the interview".</p>
<p>-- p.9: second sentence of Results ... number ten should be 10</p>	<p>Ten has been changed to 10.</p>
<p>Results: -- p.10: line five ... 'what has been ...' should be 'had'</p>	<p>"What has been" has been changed to "what had been".</p>
<p>-- p.10: third line from the bottom ... too many spaces before 'Being part ...'</p>	<p>Extra space prior to "being part" was deleted.</p>
<p>-- p.10: last row ... the (D) is just sitting by itself. Should it be ' ... my job" (D). Had to look at the rest of the paragraphs to realize it was the person's quote.</p>	<p>We added 'Participant' prior to D (Participant D), and shifted the period to after the parentheses, as suggested.</p>
<p>-- p.11: same comment about (G). It's treated as its own sentence (G). But, it's not a sentence and doesn't seem to go with anything. Should it be ' ... human being" (G).</p>	<p>We adjusted the manuscript to follow the same procedure as above for all participant quotes.</p>
<p>-- p.11: second to last line doesn't need a comma after 'realistic'</p>	<p>Comma removed.</p>

<p>-- p. 12: fourth line should be past tense ... was not is (results are always past tense)</p>	<p>We changed "is" to "was".</p>
<p>-- Use of pronouns she/he is used throughout. Does this need to be they/their as we don't know what pronouns the individuals use? Inclusive language.</p>	<p>We adjusted the pronouns to "they" when referring to the DSP. When a DSP identified specifically identified a client as a male or female client, we used the gender-related pronouns. We reviewed the entire manuscript. The changes were made in the "Establishing and Maintaining Boundaries" results section.</p>
<p>-- p. 14: first sentence of first line under heading 'A Daily Practice of Humor and Fun' ... too many spaces before 'This often did not ...'</p>	<p>We deleted this extra space.</p>
<p>-- p. 14: sixth line from the bottom ... they've should be they had ... past tense</p>	<p>We changed "they've" to "they had".</p>
<p>-- p. 14: last line ... 'by' is missing after the word 'described'</p>	<p>We added the word "by" after described.</p>
<p>-- p. 15: fifth line from the bottom ... too many spaces after the word 'terms.'</p>	<p>We deleted the extra space after "terms".</p>
<p>Discussion: -- p. 17: third line from the top ... too many spaces after IDD. and before "This is an ..."</p>	<p>We deleted the extra space before "This is an...".</p>
<p>-- p. 18: Limitations fifth sentence doesn't need a comma after COVID-19 pandemic.</p>	<p>Comma deleted.</p>
<p>-- p. 19: sixth line ... there are too many spaces after adapted 'adapted. Also, given ...'</p>	<p>We deleted the extra space between "adapted" and "Also given".</p>
<p>-- p. 20: last line before Conclusion heading ... too many spaces before 'Future research ...'</p>	<p>We deleted the extra space before "Future research".</p>
<p>Conclusions: -- p.20: third line from the bottom ... too many spaces before 'The development ...'</p>	<p>We deleted the extra space before "The development".</p>
<p>General comment: The field IDD uses the term</p>	<p>- Thank you for this observation. We have focused, when possible, on data specific to DSPs of people with IDD. We</p>

<p>Direct Support Professionals. PHI is used as the comparison for a lot of the paper. PHI focuses on the direct care workforce which is broader than that of IDD. There is other literature that focuses specifically on Direct Support Professionals in the field of IDD. Some is cited, but the primary literature focus seems to be the broader direct care workforce. Consider more sources specific to direct support professionals in the IDD field.</p>	<p>have added data from the following citations in the background and discussion sections: National Core Indicators. (2022). <i>National Core Indicators Intellectual and Developmental Disabilities 2020 Staff Stability Survey Report</i>. https://www.nationalcoreindicators.org/resources/staff-stability-survey/ Pettingell, S., Bershadsky, J., Hewitt, A., Lahti Anderson, L., Hall, S., Smith, J., Sanders, M., Kleist, B., Zhang, A., & Oteman, Q. (2022). <i>Direct Support Workforce and COVID-19 National Survey Report: 24-month Follow-up</i>. Institute on Community Integration, University of Minnesota.</p> <p>We have retained the PHI citation related to DSPs being more likely to receive public assistance as this data was not located specific to IDD. We also retained the PHI citation related to policy recommendations as these are applicable to the IDD DSP population.</p>
<p>Table 3. -- There is (Participant G) and then sometimes (G). Would be good to be consistent throughout the manuscript text and in all tables. Also, it is hard to read the quotes as there is no space between them within the theme. Would be nice to have a space to separate them.</p>	<p>Thank you for noticing this. We have added "Participant" in front of all Participant letter codes for clarity. We added spaces in Table 3 for readability.</p>