Title Page

Direct Support Professionals' Perspectives on Workplace Support: Underappreciated, Overworked, Stressed Out, and Stretched Thin

(Katherine E. Johnson, Caitlin E. Bailey, Nancy R. Weiss, and Steven M. Eidelman)

Corresponding Author:

Katherine E. Johnson, MPA

Email address: kejohn@udel.edu

University of Delaware

Joseph R. Biden, Jr. School of Public Policy & Administration

110 Alison Hall

Newark, Delaware, 19716 USA

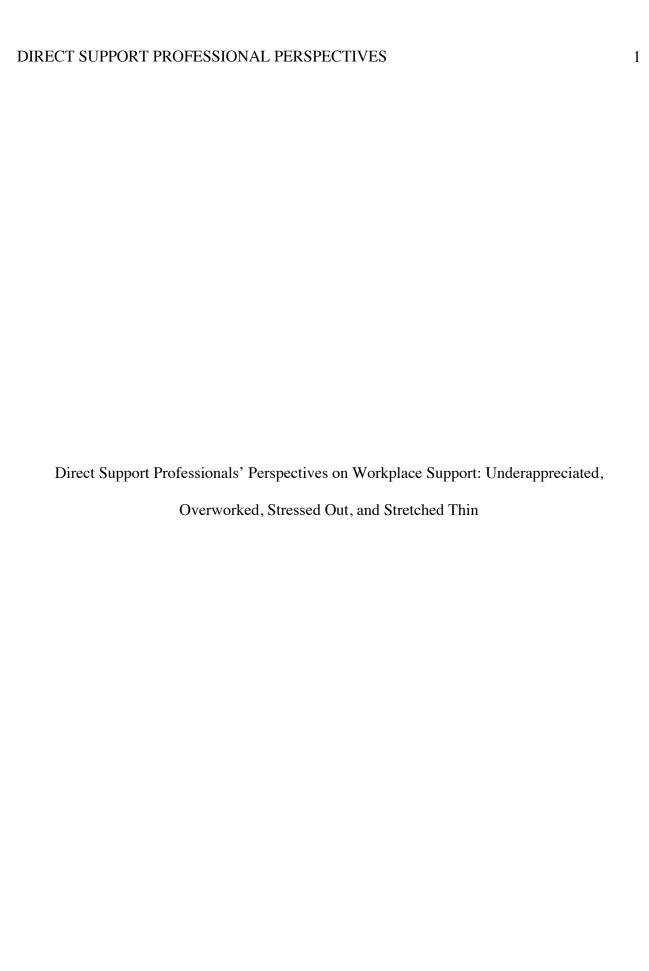
Caitlin E. Bailey, Ph.D., Director of Research and Evaluation, National Leadership Consortium on Developmental Disabilities, Newark, DE, 19716, USA

Nancy R. Weiss, MSW, Director of Disability Initiatives, University of Delaware College of Health Sciences, Newark, DE, 19716, USA

Steven M. Eidelman, MBA, MSW, H. Rodney Sharp Professor of Human Services Policy and Leadership, University of Delaware, Human Development and Family Sciences, Newark, DE, 19716, USA

Acknowledgments

This project was supported by the National Leadership Consortium on Developmental Disabilities and the National Alliance for Direct Support Professionals (NADSP). The University of Delaware Institutional Review Board approved the study protocol. This research was conducted as a portion of Katherine Johnson's undergraduate thesis at the University of Delaware and she would like to thank NADSP for their support in creating and disseminating the survey to their member DSPs.



DIRECT SUPPORT PROFESSIONAL PERSPECTIVES

2

Abstract

The Direct Support Professional (DSP) workforce has experienced a multi-decade period of

disinvestment in the field leading to DSPs being in high demand, while efforts to recruit,

train, and retain these professionals pose challenges. To gain a better understanding of the

needs of DSPs themselves, 440 survey responses and 24 interviews of Direct Support

Professionals were analyzed to understand what would help DSPs do their jobs better and

ensure they feel more supported by their agencies. Results revealed six distinct support

needs: 1) ensure quality participatory management practices; 2) provide fair compensation

and recognition; 3) enhance access to training opportunities; 4) assure reliable and quality

staffing; 5) adequately fund basic needs of both programs and people receiving support; and

6) maintain reasonable job expectations.

Keywords: Direct Support Professional, Workforce, Management

Direct Support Professionals' Perspectives on Workplace Support: Underappreciated,
Overworked, Stressed Out, and Stretched Thin

There is significant knowledge about the systemic, policy and funding pressures that affect the direct support workforce serving people with intellectual and developmental disabilities (IDD) in community service settings (e.g. President's Committee for Persons with Intellectual Disabilities, 2017). However, little has been published about the perspectives of Direct Support Professionals themselves on the current state of the workforce and what they identify as needs to support their work and job functions. The aim of this research is to identify what Direct Support Professionals (DSPs) need from their agencies in order to be successful in their roles, which ultimately may inform paths forward for agencies to address the well-documented workforce "crisis."

According to the best estimates, there are around 4.5 million Direct Support Professionals (Espinoza, 2017; PHI, 2019); the actual number may be even higher. The direct support workforce, while already large, is rapidly expanding. The field has nearly doubled in the last decade and is projected to add an additional 1.3 million new jobs from 2018 to 2028 (PHI, 2019). In addition to the growing need for Direct Support Professionals, there is a lagging ability to recruit, train, and retain skilled staff members to provide supports to people with disabilities. Persistent low wages and benefits (Bogenschutz et al., 2014), poor training, supervision, and limited opportunities for advancement and professional development (Bogenschutz et al., 2015), have resulted in a multi-decade period of high turnover and poor retention among DSPs (President's Committee for People with Intellectual Disabilities, 2017). The current state of the Direct Support Professional workforce has been called a crisis, but some argue that the current situation is far too predictable and persistent to be considered a crisis any longer; experts have

called it a systemic failure of the long-term services and support system (Hewitt et al., 2018). Stakeholders agree that the lack of qualified Direct Support Professionals who can be retained over time is a major barrier to providing high quality supports and promoting person-centered services (Larson & Hewitt, 2005).

Addressing high rates of turnover among direct support staff is critical for people with developmental disabilities since DSP retention is a key indicator of quality of life outcomes (Friedman, 2018; Abbot & McConkey, 2006). For example, it was found that Direct Support Professionals are primary facilitators of community access and integration (Friedman, 2018; Abbot & McConkey, 2006; Venema et al., 2015). Additionally, they play an important role in deterring institutionalization for the people they support (Robbins et al., 2013). Having continuity and stability in the DSP workforce is an important component of providing high quality services that promote the achievement of meaningful life outcomes (Friedman, 2018; Hewitt et al., 2000; Larson et al., 2004).

Studies suggest there are a variety of factors that impact turnover. These include: work/job satisfaction, job strain, perceived lack of respect, inadequate management, work or family conditions, poor social and supervisory support, role ambiguity, and high stress with low autonomy (Acker, 2004; Bogenschutz et al., 2015; Gray Stanley et al., 2010; Hatton et al., 2001; Mittal et al., 2009). There are a variety of stressors that DSPs face in their jobs from heavy workloads, unrealistic expectations, lack of involvement in decision making, and complex client care needs (Gray Stanley et al., 2010).

A variety of studies demonstrate potential avenues to decrease turnover rates for DSPs including increasing wages (Carman et al., 2009), providing applicants with a realistic understanding of the kinds of work they will be doing in advance (Acker, 2004), and providing

strong supervisory support (Nissly et al., 2005). Findings around supervisory support are mirrored in other fields, for instance with supportive job conditions for social workers increasing retention (Kim & Stoner, 2008), supervisory support of frontline hospitality workers increasing their organizational commitment and career satisfaction (Kang et al., 2015), and greater perceived supervisor support for registered nurses correlating with more positive job outcomes (Hall, 2007). We know that employees who feel better understood and supported by their employers are more likely to remain in their positions longer. Quality supervisory support is likely to have positive impact on the DSP workforce.

While the need for a quality DSP workforce is well established in the literature, research on the needs of DSPs is limited. Studies about Direct Support Professionals that exist rarely explore the perspectives and lived experiences of these professionals who are the best experts on the issues they face. This study explores DSP perspectives of their own support needs, in order to identify what agencies can do to help the DSPs they employ thrive in their roles. This information can be useful to identify strategies to retain Direct Support Professionals and promote a more sustainable workforce that better meets the needs of adults with intellectual and developmental disabilities.

Methods

This study employs a phenomenological qualitative design to examine the viewpoints of Direct Support Professionals who work for community agencies serving adults with intellectual and developmental disabilities. The study addresses the question: What would help DSPs do their jobs better and feel better supported by their agencies?

A phenomenological approach (Giorgi & Giorgi, 2003) is ideal because it explores in detail participants' lived experiences and how they understand those lived experiences. This

approach is interpretive (Palmer, 1969), in that the analyst plays a significant role in organizing and understanding information relevant to how the study participant is making sense of their experiences. As far as is possible, this design examines the experience as they are, removing the researcher's own inclinations and the influence of prior research and theory (Smith, 2017). By sourcing knowledge from the subject and their lived experiences, the researcher is able to better understand the phenomenon, in this case the current DSP workforce, using as source material the voices of the individuals who are actually experiencing it.

The purpose of the research was to provide a voice to a workforce that has had little opportunity to be heard, in order to recognize Direct Support Professionals as experts in their own experience. The research recognizes these professionals as knowledgeable about their profession and seeks potential solutions arising from the ideas of the staff themselves. This research is posited within an ongoing social movement, that values workers' rights, especially low-income people, immigrants, women, and people of color who predominantly occupy direct support roles.

This study uses data collected in a national survey of 440 DSPs and from 24 semi-structured interviews with DSPs in Delaware and Maryland. The study protocol was submitted to an Institutional Review Board (IRB) and was deemed exempt from review by the IRB as it posed very little to no risk to participating Direct Support Professionals.

Survey Design

A national DSP survey was developed with the support [Removed for Review] to explore what DSPs express as needed in order to feel supported by their agencies. The survey instrument consists of fourteen questions regarding the respondent's organization, role perception, evaluation, retention factors, and support needs. One open-ended question was analyzed for the

purpose of this study. The open-ended question asked DSPs: "What would help you do your job better? (How could your supervisor or organization better support you to do your job well?)".

Survey Recruitment

Survey recruitment was limited to Direct Support Professionals who were currently working in organizations that provide services and supports to adults with intellectual and developmental disabilities.

The study operationally defines Direct Support Professionals as: "1) someone who provides primarily non-medical hands-on supports, training, and supervision, and personal assistance to adults with intellectual and developmental disabilities; 2) is at least 18 years of age; and 3) works either full-time or part-time as a Direct Support Professional. This definition specifically excludes Direct Support Professionals who have additional duties related to administration or shift supervision (often referred to as "coordinators," "lead staff," or "house managers")."

The incorporation of strict sample inclusion criteria was vital to the phenomenological approach, recognizing DSP's lived experiences as valid and critical to understanding the DSP workforce crisis. The criteria for participation intentionally and specifically excluded DSPs who have additional duties relating to administration or shift supervision, as well as other roles beyond direct support that impact the lives of people with disabilities (ie. therapists, agency administrators, family members, etc.). While the experiences of people in those roles are also valid, this study focuses only on input of Direct Support Professionals themselves.

The survey was created using Qualtrix and disseminated through [Removed from Review] social media networks and through [Removed from Review] Facebook group.

[Removed from Review] also emailed the survey link to their members three times. Additionally,

[Removed from Review] sent the survey link to leaders in the field of IDD who represent different service providers. People receiving the request for study participation were asked to pass along the link to any DSPs working at their agencies.

Sample

1,190 responses to the survey were received. These included partial responses and blank forms (indicating a potential respondent opened the survey but entered no responses). Of the 1,190 total responses received, 750 responses were excluded, leaving 440 responses for the analysis.

a DSP as defined by the criteria for the study. This was determined either by the respondent selecting that they did not meet the qualification criteria or because information provided in the responses indicated the respondents were not DSPs as defined by the criteria for the study, even though they had initially indicated that they qualified. Participants that were excluded identified as having roles such as a house lead, group home manager or assistant manager and a few respondents indicated that they were not providing direct support at all, instead having other job titles or roles such as parent, therapist, and even one CEO. 633 of the total number of responses received were also excluded because the respondent did not complete through at least question number eight regarding the respondent's work role. A vast majority of the 633 excluded were completely blank forms. Ultimately, 440 DSP responses remained and were included in the analysis.

DSP Interviews

24 DSP interviews were conducted in order to further illustrate the findings of the national survey.

Interview Recruitment and Selection. Service providing agencies were contacted, with the goal to gather a variety of agencies providing distinct services, from more traditional day programs to innovative individualized supports. All agencies that were sent a recruitment letter were also selected due to their proximate regional location, being in Delaware, Maryland, and Pennsylvania. [Removed from Review] sent requests for participation in the research study via email to the leaders of eight agencies, representing moderate to more progressive agencies. The research team also recruited outside [Removed from Review] in order to include agencies that provided more traditional services. An additional agency was contacted via personal connections to the interviewer and a one additional agency was contacted as representing a very traditional service delivery approach. Responses were received from all but two of the agencies contacted. Due to scheduling constraints on the part of the agencies that responded to the request to visit and interview staff, DSPs from only five of the eight agencies eventually participated in the study.

At each of the five participating agencies, the agency contact person determined how to best disseminate the request to interview DSPs to participate in the study. All DSPs who volunteered to be interviewed and who were available during the researcher's visit were interviewed. 24 DSPs from five agencies were interviewed in total.

Semi-Structured Interview Protocol. The interviews with the Direct Support Professionals had a semi-structured format. The goal of using a semi-structured approach was to 1) provide consistent format and direction for the interview itself, 2) allow for comparison across agencies, 3) provide flexibility in the interview to explore new ideas that the study had not initially considered, and 4) ask follow-up questions about the content the subjects shared. The interviews each lasted around thirty minutes. Interviews all took place in private rooms, without the observations of other DSPs, other agency staff, or service-users. The interview data was maintained through handwritten notes by the interviewer. All DSPs were informed that their information would remain confidential and that their name and their agency name would be redacted in any reporting. The interview questions and content centered on job responsibilities, training, evaluation, retention factors, and the DSP's support needs from the agency. For the purpose of this study, only responses to the question "what would help you do your job better and how could your supervisor or organization better support you to do your job well?" were included in the analysis.

Analysis

The data from both the 440 survey responses and the 24 semi-structured interviews were analyzed using thematic analysis (Braun & Clarke, 2006). Thematic analysis is an accessible and systematic process for analyzing qualitative data. It calls upon the researcher to identify codes, which are the smallest unit of analysis and group those codes into broader themes. Themes provide a framework to organizing the ideas presented in the data and for reporting the researcher's observations.

The coding process was intentionally entered without preconceived ideas to code for, an inductive approach to the analysis and an essential component of the phenomenological method.

Thus, the entirety of the data in response to the open-ended question regarding support needs, was reviewed before a coding structure was designed. The identified codes were grouped into six broader themes. The data was then reviewed again to ensure the themes captured the data accurately. The interviews served as a way to both expand upon and illustrate the findings of the national survey.

Results

Six significant support needs were identified in response to the open-ended question "what would help you do your job better? (How could your supervisor or organization better support you to do your job well?)". According to the 440 DSPs surveyed and the 24 DSPs interviewed, they would be able to do their jobs better if their supervisors or agencies were to:

1) ensure quality participatory management practices; 2) provide fair compensation and recognition; 3) enhance access to training opportunities; 4) assure reliable and quality staffing; 5) adequately fund basic needs of both programs and people receiving support; and 6) maintain reasonable job expectations.

The themes listed above and described subsequently, illustrate the support needs DSPs themselves identified as important both within the survey and the interviews conducted. While not all the identified needs are surprising, they provide unique insight into the perspectives of these professionals, and potential solutions for organizations who seek to attract, develop, and retain a quality workforce.

Table 1
Support Need Themes, Subthemes, and Illustrative Examples

Themes and Subthemes Quotes

Quality participatory management practices

• Participate in decision- "When I feel like I don't have a voice, I feel discouraged.

 making No micromanaging Effective performance evaluations Improved communication Transparent and fair policies 	For the most part, I see these guys at all times and know what they want and need."
	"Offering support and guidance not micromanaging."
	"the higherups get recognized but not us some of them don't even listen to what you're saying, they think, 'you're just a DSP' DSPs are never invited to the actual meetings. Meetings with DSPs are just Dos and Don'ts if it wasn't for us DSPs some of these companies couldn't run They wouldn't think of this or know what was important to us, unless they asked."
	"We are supposed to have monthly evaluations to let us know how we are performing, but they rarely happen"
	"No picking and choosing when a rule should or shouldn't be followed to convenience management"
 Fair compensation and recognition Wages, work hours, benefits, referral pay Professional development Simple thank-you 	"We're working extra hours and our managers show little to know [sic] appreciation sometimes you're not asked and you're just told you have to. Our lives outside of the building are not being respected."
	"Financial stability and ability to grow in the industry."
	"I've been working there for years but while the agency always has appreciative awards dinners, I've never been nominated."
Access to training opportunities	"better training regarding purpose of the work and commitment to respect and personal independence of people supported."
	"If the state had the trainings so that when I work with more than one agency the trainings work for all agency [sic]."
	"I need more training related to what I do, not CPR, first aid, med administration, OSHA and the other required training"
Reliable and quality staffing • Adequate staffing	"I shouldn't have to do it all. We need more staff to have
 Substitute staff to reduce burnout Demonstrated 	the same reasons for being there. Like really want to be here."

competencies of staffRetention	"Getting substitute staff for vacations to reduce burnout. The staff in our home currently has no one to cover so we cover for each other."	
	"We are short-staffed because no one wants to do this job for so little money. Having short staff causes the current staff stress. We are doing work above our job title and our work is seen as 'women's work' and is not seen as important to the higher ups"	
Funding for basic needs of both programs and people receiving support		
 Generally, more resources Transportation Community based 	"Stop putting billing over the needs and what's best for the people we support."	
 Community-based activities 	"Having money for the individuals for them to have when we go out into the community, whether it's planned or unexpected"	
	"We use our personal vehicles so having more company vehicles would help. I already drive 45 minutes to work."	
Reasonable job expectations		
 Reasonable number of people supported and hours worked 	"We almost constantly have overtime and are pressured into doing more"	
 Stick to job description Less burdensome documentation Don't assume DSPs want overtime 	"I suspect that more can be done to be realistic about what the job really entails up front so that expectations are more aligned with what occurs on average in the position."	

Quality and Participatory Management Practices

The most substantial of the findings indicated that there was a need for management that could better support DSPs in their work and invest more in them as employees. The specific quality practices identified include productive performance evaluations; motivated, engaged, and trusting supervisors; fair and transparent policy enforcement and decision-making; workplace culture; agency and supervisor responsiveness; and participatory management. Participatory management practices refer to management that seeks and considers input from staff at all levels

in decision making and is one component that can contribute to overall quality management.

Many of the comments made by respondents spoke to their desire to be included in decision making and for their input to be sought and valued.

Performance Evaluation. DSPs often noted a desire for productive performance evaluations so they could receive feedback about how they were doing and how they could improve in order to both better support the people with whom they work and to provide opportunities for advancement within their organization. Many DSPs commented that their scheduled supervision and quarterly or annual evaluations did not actually take place.

Motivated, Engaged, and Trusting Supervisors. DSPs recognized that they thrived when their supervisors were motivated and available to them. Many discussed the relationship with their supervisor as either a positive reason they stay, or one of the things they wished they could change. Some DSPs expressed a desire for their manager to stop micro-managing them as this would build trusting environments that would allow them to thrive. DSPs throughout the study mention how "higher ups" do not trust DSPs' expertise or recognize the unique input that DSPs can provide as direct workers.

Fair and Transparent Policy Enforcement and Decision Making. Many DSPs complained about policies being unfairly enforced. They noted that transparency and fairness would help them to feel more respected and appreciated. They want to better understand the "why" behind decisions that are made. Tied to transparency, DSPs expressed a desire for improved communication from their agencies (both from management and co-workers).

Respondents felt that often poor outcomes were due to a lack of communication in the workplace and many DSPs wished that their supervisors were clearer in their communication and more available to interact with direct support staff. One DSP interviewed mentioned that her

supervisor sometimes didn't respond to her: "they didn't respond to you until six hours later, but you need the information right then and there. The protocol says you should call them, but they don't respond, so what do you do?"

Workplace Culture. DSPs were frustrated with a lack of teambuilding. Some DSPs desired more opportunities created by management to interact with their co-workers, learn from and collaborate with one another, and improve the agency culture. One DSP noted: "there is little interaction between coworkers. This can drive a hard workplace environment. We do provide support to each other and communicate regularly through phone and email, but nothing can replace person-to-person interaction."

Participatory Management. DSPs want their voices to be heard and respected.

Respondents mentioned wishing their supervisors would listen to them, would take their suggestions into consideration, and would include them in decision-making. Some DSPs recalled monthly meetings where suggestions were made but felt that nothing came from their suggestions. Some were not even sure that avenues existed through which they could provide feedback at all. One respondent expressed that they wished that management would "listen to what staff is saying rather than assuming you know the answers because of your title."

DSPs also desire more simplified and common-sense practices, which they believe can be created by including DSPs in decision-making. Some DSPs mentioned concerns about things that seemed complicated by what they perceive as unnecessary bureaucracy that is not in the best interests of the people being supported. For example, a DSP mentioned a policy that does not allow people supported to have cellphones. This person believed that administrators failed to recognize that the outcomes for the person being supported could be improved if that person

could use a cell phone to call their own paratransit services. In another interview, a DSP shared how the boyfriend of the person she was supporting was also receiving services from their agency. When the boyfriend's father passed away, agency administrators adjusted his support plan, but since DSPs weren't included in the planning process, they had overlooked the fact that his girlfriend had increased needs as well.

DSPs often noted processes that they felt could be simplified. Many felt that if they were more often included in decision-making, processes would be smoother, and it would better serve the people they support.

Fair Compensation and Recognition

An issue consistently mentioned by DSPs who responded to the survey was the desire for simple recognition for the work they are doing, and that appreciation or recognition should be expressed regularly, throughout the year, rather than just during Direct Support Professional Recognition Week, a week designated by the trade association ANCOR for this purpose. Some survey respondents noted that they would appreciate a simple thank you. Many don't feel as though they are appreciated.

Underappreciated, overworked, stressed out and stretched thin. Some respondents mentioned that they feel that the people who supervise them are taking advantage of them. One DSP shared that DSPs want to "feel as if we were somebody and not just a body to suffice their needs." DSPs feel like their supervisors have little appreciation for their lives outside of work, assign work that interferes with their personal lives and have unfair expectations of their time and tasks. Many DSPs referred to the "people upstairs" and the "higher ups"; the DSPs shared difficult and emotional stories of feeling mistreated and ignored by their agencies.

Fair and appropriate compensation. Issues mentioned included improved wages and fair raises as well as: better and more appealing benefits, allowing for time off, more vacations, and "referral pay" (earning pay for referring candidates who were hired). Additionally, DSPs desire career growth opportunities. Many mentioned wanting their agencies to support their professional development; often in connection with their desire for more and higher quality training. DSPs interviewed from an agency that provided the best compensation, benefits, and supervisory support, raved about the quarterly raises that were for DSPs only, the professional development opportunities, the appreciation picnics, thank you notes, and the payment for their coursework, as major components of their quality work experience. Many of the DSPs from this agency expressed that one reason that this agency treated DSPs better than some other agencies do, is that the agency's Executive Director better understood and better supported DSPs since he himself had been a DSP at one time.

Access to Training Opportunities

The results of the survey found that DSPs are craving access to better, higher quality and more relevant training and professional development opportunities. Many survey respondents suggested having more online options for training as opposed to in-person sessions. One DSP commented: "Having a universal training for all agencies that can be accessed via computer would be very helpful. Especially when you take a day off of work to go to training and they have you watch YouTube videos!"

Broadened topics and topics tied to competency. Many respondents indicated they are bored by the repetitive nature of required trainings and that they wished that advanced topics were more readily available. DSPs suggested a variety of new topics including information about

IDD specifically, dealing with families and conflict, dual-diagnoses, mental health issues, behavioral matters, communication, and dementia.

One DSP expressed frustration at how little training was provided to staff and wished staff would be required to demonstrate competencies before starting their work or at least continue to receive training while working for the agency. This DSP noted, "Our policy states new staff are to shadow three shifts before working, and sometimes this is not enough. New people should have to be evaluated whether they can perform their job duties before expected to work."

Reliable and Quality Staff

DSPs described the harmful impacts that staffing shortages and skill gaps had on them, on the way they performed their jobs, and on the lives of the people they support. They expressed a desire for their employing agencies to hire more reliable and higher quality staff. Some respondents mentioned that there were not enough managers to provide regular, quality supervision and coaching. Some mentioned that there was a lack of enough substitute staff to allow staff to take time off for sickness or vacation. One DSP expressed that they wished that their agencies would "stop creating more residences when the agency can't even staff the ones they have." This concern was echoed in the comments of many other respondents.

Impact of turnover and staffing shortages. DSPs were impacted by the frequency with which co-workers left the job, asking that their agencies invest in reducing turnover and filling vacancies. Many discussed working multiple jobs and still being asked to work overtime. Some DSPs mentioned working 80+ hour weeks at their agencies due to turnover and staffing shortages. One DSP mentioned that the "sudden staff dips place more demands on staff that remain and causes work to encroach on personal lives more." Of most importance, a DSPs notes

that staffing shortages "effect the effectiveness of how well we can provide person-centered support." The significant impact of turnover and staff shortages on direct support staff's lives and work and the negative impact on the lives of people who are supported was mentioned by a number of respondents.

Shortages seemed to exist mostly at the direct care level. Another common theme that was expressed was that the identified staffing shortages were mostly among direct care professionals, while the issue according to the study participants, did not seem to be present for supervisors and administrators. DSPs expressed that they felt that there are too many supervisors and not enough direct care staff. One respondent was clearly frustrated and stated that their organization should "spend less money on 'administrators' who languish behind desks all day and occasionally slither out to condescend to people who are actually doing direct care." Direct Support Professionals feel strongly that they are not being valued for their difficult and essential work, and that people who are being paid more, underappreciate the work they do. This feeling of devaluation can be a contributor to staff making the decision to leave jobs at this level and connects to the theme identified previously of the need for quality management that values its workers.

Adequate funding for basic needs of programs and people receiving support

Direct Support Professionals stated frequently that they understood many of the budgetary limitations that managers and organizations are facing. Still, DSPs are concerned that there is not enough funding for the most basic program needs to be met. Many DSPs, advocating on behalf of the people they support, wished that more resources could be allocated to the people receiving services.

Transportation. DSPs recognized that the people they support could only have full, integrated and engaged lives if they could get to places of interest – stores, recreational areas, restaurants, workplaces, etc. Some DSPs expressed a desire for mileage reimbursement to allow them to use their own vehicles, while others requested more company vehicles, instead of being required to use their personal vehicles. Multiple DSPs interviewed from an agency transitioning from congregate, segregated care, to more individualized care in the community, identified transportation issues as a major barrier to accomplishing these changes.

Technology. DSPs expressed a desire for more current technology to be made available as well as the need to assure adequate numbers of computers, tablets or cell phones so they would be able to complete documentation while away from group homes, day programs or other agency locations. DSPs noted that often billing concerns (what was required in order to bill for their time) seemed to take precedence over the needs of the people being supported. While recognizing that budgetary constraints are a reality, many DSPs were concerned about the lack of funds to purchase items that are important to the people being supported and to promote quality person-directed services. Examples of some of the items for which they wished funds were more available include more recreational equipment and funding for travel and community events and activities.

Reasonable job expectations

DSPs were concerned about their workloads and unfair job expectations. Many asked for reduced workloads, more staffing, as well as reasonable expectations taking into account the number of people they are supporting and the wide range of job duties they are asked to perform.

Skilled DSPs are overworked. One finding that was described by multiple DSPs was the issue of skilled DSPs being overworked to make up for their less skilled co-workers. Many DSPs

expressed that rather than good DSPs being rewarded, they felt that they were being punished by having their tasks and expectations increased without additional time being provided to complete the additional tasks and without additional compensation. A number of DSPs mentioned that they are overworked, and many said that given the choice they would opt for fewer hours of work rather than more hours and more overtime pay.

Additional responsibilities without DSP input. Specifically, it was expressed that adding responsibilities without a DSP's input is a contributor to turnover issues. One DSP provided an example of their work expectations being changed without their control or input:

"[my role description] says 'workout schedule directly with person supported' [but] despite this, my supervisors routinely changed my schedule without the consent of myself or the people I support. This has had a detrimental effect on my customers and my own mental health. I want them to understand that they do not get to pay talented people low wages and shove their schedules and caseload around at will. It's one or the other. Not both."

Burdensome documentation. DSPs mentioned that they felt overwhelmed by the amount of paperwork required of them. Many expressed a desire for the paperwork to be moved online with some mentioning that this would necessitate additional computers or handheld devices. DSPs also called for an overall reduction in required paperwork and documentation. They felt a reduction was particularly needed for documentation that is repetitive, noting that if the documentation requires changes to information that had already been recorded it would be more efficient for this to be done on a computer or by using an app.

Limitations of the Study

It is difficult to fully represent the voices of Direct Support Professionals because unbiased recruitment presents a challenge. The contacts through [Removed from Review] provide one of the best recruitment tools available to researchers studying DSPs. However, it is possible that the DSPs recruited through [Removed from Review] are not representative of Direct Support Professionals nationally.

DSPs are often members of [Removed from Review] because their organization made an investment to become an [Removed from Review] member organization. The organizations that join are likely to be ones that are motivated to invest in their direct support staff and/or are more actively concerned with DSP issues. One might expect that if more DSPs were sampled who were not associated with [Removed from Review], more DSPS from less-invested agencies would have been included as study participants. As a result, different or even more significant concerns may have been reported.

While disseminating the request for survey participants through [Removed from Review] was the primary recruitment method, the survey was also disseminated to managers and administrators who had participated [Removed from Review]. Participants recruited through [Removed from Review] contact list may likely be biased as well. Organizations receiving trainings from [Removed from Review] are often larger, better funded, and/or have a particular values orientation to the field. Of those organizations and supervisors contacted through either [Removed from Review], those motivated to forward the survey to their direct support staff are also likely to be those who are highly invested in the DSPs that work for their agency. Thus, the sample, while sizable, may not be representative of all DSPs.

Discussion

While the field of intellectual and developmental disabilities is constantly evolving, to a great extent, service delivery approaches and the so-called "DSP workforce crisis" have remained stagnant over the last 30 years. The field is in need of innovation and changemaking in order for people with disabilities' lives to be truly self-determined and in order to assure a quality, sustainable DSP workforce. It is vital for organizations to hear and respond to the voices of Direct Support Professionals— as well as and most importantly the people they support—in making organizational and management decisions to assure quality services and lives.

Direct Support Professionals who responded to the survey and who were interviewed, identified potential solutions to the current state of the workforce, that mirror the common practices of strategic human resources management (Berger & Berger, 2018; Pynes, 2013). Examples of such practices include competency assessment, effective and timely performance appraisals, 360-degree evaluations, the use of talent management plans, engaging onboarding practices, transparency in decision-making, and opportunities to solicit feedback from all levels of an organization. Ultimately, in order to retain high quality, talented employees and address the current issues and shortages of the DSP workforce, organizations need to learn from other fields and consider how they as organizations invest strategically in their employees' development, create organizations that foster and retain talent, and emphasize quality supervisory support.

At the core, the data suggest that respecting and appreciating DSPs is of primary importance for the field to move forward. It is not enough for agencies to simply improve wages or hold an annual DSP appreciation picnic; meaningful change will require a revolutionized workspace that genuinely embraces DSPs as valuable team members, trusts DSPs as professionals, and treats DSPs in more just ways, as key, valued employees. Meaningfully

including DSPs in decision-making does not only have implications in DSP retention and development, but is an important and reasonable approach to improve the quality of services being provided. Direct support staff have valuable information and perspectives that are helpful in the delivery of person-directed and individualized supports. Direct Support Professionals play a vital role facilitating community access and integration (Friedman, 2018; Abbot & McConkey, 2006; Venema, Otten & Vlaskamp, 2015) and deterring institutionalization for the people they support (Robbins, Dilla, Sedlezky, & Sirek, 2013).

All agencies should invest in their workforce, and consider the six identified support needs, however supporting DSPs is only a part of the process of changemaking in the field and supporting quality services.

Strategies for Service Provider Agencies

Service provider agencies need to invest in creating a culture that values DSPs in ways that the DSPs themselves judge as meaningful and important. Many organizations may not recognize the cultures they have created, but regardless of the actions organizational leadership think they are taking, DSP perception is still reflecting the reality that DSPs feel underappreciated, overworked, and undervalued. Actions to improve workplace culture and climate that are identified in this study include:

Ensure quality participatory management practices

- Meaningfully include DSPs in *all* organizational decision-making that impacts them and the people they support
- Develop accountability tools to evaluate workplace culture and respect
- Promote transparency in organizational policy and decision-making
- Invest in regular, effective performance evaluation that positively supports DSP development
- Develop career ladders for DSPs providing opportunities for advancement

Fair compensation and recognition

- Find specific, individualized, and tangible ways to authentically appreciate DSPs
- Implement a compensation model based on competencies

Enhanced access to training opportunities

• Develop engaging trainings that are tied to DSP competencies and include more relevant and advanced topics

Reliable and quality staffing

 Establish minimum qualifications prior to entering the workforce backed by demonstration of competencies

Adequately fund basic needs of both programs and people receiving support

- Invest in technology that streamlines administrative processes, allowing for more time available to directly support people
- Advocate for increased resources both for DSP wages and benefits and for program materials and community participation

Maintain reasonable job expectations

- Implement realistic job previews so that DSPs have knowledge of job expectations prior to being hired
- Ensure job descriptions realistically reflect job requirements
- Don't increase job responsibilities without providing increased time to complete additional tasks and accompanying compensation

Conclusion

Seeking and listening to DSPs when addressing the issues that impact them and the people they support is a common-sense practice that is unfortunately often neglected in both organizations and in research. As our results show, DSPs have a lot to provide to the body of knowledge, and their perspectives are vital to better understanding the current state of the DSP workforce and the process through which to address the so-called "workforce crisis." At the root

of what is happening, DSPs are feeling underappreciated, overworked, stressed out and stretched thin. If the field wants to provide quality and person-directed supports to adults with intellectual disabilities, these issues need to be addressed. While unfortunately, but importantly, addressing the issues in the workforce will not be sufficient alone to provide quality and person-directed supports, it is one essential part of being able to do so. Policymakers and organizational leaders need to seek out, listen to and respect DSP voices as one step toward addressing both the shortage of quality DSPs and the provision of quality services.

References

- Acker, G. (2004). The effect of organizational conditions (role conflict, role ambiguity, opportunities for professional development, and social support) on job satisfaction and intention to leave among social workers in mental health care. *Community Mental Health Journal*, 40(1), 65–73. https://doi.org/10.1023/B:COMH.0000015218.12111.26
- Abbott, S., & Mcconkey, R. (2006). The barriers to social inclusion as perceived by people with intellectual disabilities. Journal of Intellectual Disabilities, 10(3), 275–287. https://doi.org/10.1177/1744629506067618
- Berger, L. A., & Berger, D. R. (2018). *The talent management handbook*. New York: McGraw-Hill Education.
- Bogenschutz, M. D., Hewitt, A., Nord, D., & Hepperlen, R. (2014). Direct support workforce supporting individuals with IDD: Current wages, benefits, and stability. *Intellectual & Developmental Disabilities*, *52*(5), 317–329. https://doi.org/ 10.1352/1934-9556-52.5.317.
- Bogenschutz, M. D., Nord, D., & Hewitt, A. (2015). Competency-based training and worker turnover in community supports for people with IDD: Results from a group randomized

- controlled study. *Intellectual and Developmental Disabilities*, *53*(3), 182–195. http://doi.org/10.0.5.72/1934-9556-53.3.182
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. https://doi.org/10.1191/ 1478088706qp063oa
- Carman, R., Mccomb, D., Mccollum, E., & Schroeder, C. (2009). *Direct support professionals wage study*. Retrieved from http://www.paproviders.org/archives/Pages/MR_Archive/ANCOR_2009_Wage_Study.pdf
- Espinoza, R. (2017). Federal Policy Priorities: Strengthening the direct care workforce. Bronx, NY: PHI. Retrieved from https://phinational.org/resource/federal-policy-priorities-strengthening-the-direct-care-workforce/
- Friedman, C. (2018). Direct support professionals and quality of life of people with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities*, *56*(4), 234-250. https://doi.org/10.1352/1934-9556-56.5.234
- Giorgi, A. & Giorgi, B. 2003: Phenomenology. In Smith J.A., editor, *Qualitative psychology: a practical guide to research methods*. Lon- don: Sage.
- Gray Stanley, J. A., Muramatsu, N., Heller, T., Hughes, S., Johnson, T. P., & Ramirez Valles, J. (2010). Work stress and depression among direct support professionals: the role of work support and locus of control. *Journal of Intellectual Disability Research*, *54*(8), 749–761. https://doi.org/10.1111/j.1365-2788.2010.01303.
- Hall, D. S. (2007). The relationship between supervisor support and registered nurse outcoms in nursing care units. *Nursing Administration Quarterly*, *31*(1), 68-80. https://oce-ovid-com.udel.idm.oclc.org/article/00006216-200701000-00015/HTML
- Hatton, C., Emerson, E., Rivers, M., Mason, H., Swarbrick, R., Mason, L., ... Alborz, A. (2001).

- Factors associated with intended staff turnover and job search behaviour in services for people with intellectual disability. *Journal of Intellectual Disability Research*, 45(3), 258–270. https://doi-org.udel.idm.oclc.org/10.1046/j.1365-2788.2001.00321.x
- Hewitt, A., Larson, S.A., & Lakin, K.C. (2000). An independent evaluation of the quality of services and system performance of Minnesota's Medicaid Home and Community Based Services for persons with mental retardation and related conditions: Technical report.

 Minneapolis: University of Minnesota, Institute on Community Integration, Research and Training Center on Community Living. Retrieved from https://rtc.umn.edu/docs/waiver_report.pdf
- Hewitt, A., Macbeth, J., Merrill, B., & Klesit, B. (2018). Feature issue on the direct support workforce and people with intellectual, developmental, and other disabilities. *Impact*, 31(1). Retrieved from https://ici.umn.edu/products/impact/311/#Cover
- Kang, H., Gatling, A., & Kim, J. (2015). The impact of supervisory support on organizational commitment, career satisfaction, and turnover intention for hospitality frontline employees.
 Journal of Human Resources in Hospitality & Tourism, 14(1), 68-89.
 https://doi.org/10.1080/15332845.2014.904176
- Kim, H., & Stoner, M. (2008). Burnout and turnover intention among social workers: Effects of role stress, job autonomy and social support. *Administration in Social Work*, 32(3), 5–25. https://doi.org/10.1080/03643100801922357
- Larson, S. A., & Hewitt, A. S. (2005). Staff recruitment, retention, & training strategies for community human services organizations. Baltimore, Md.: Paul H. Brookes Pub. Co.

- Larson, S.A., Hewitt, A.S., & Lakin, K.C. (2004). Multiperspective analysis of workforce challenges and their effects on consumer and family quality of life. *American Journal on Mental Retardation*, 109, 481–500. https://doi.org/10.1352/0895-8017(2004)109<481:MAOWCA>2.0.CO;2
- Mittal, V., Rosen, J., & Leana, C. (2009). A dual-driver model of retention and turnover in the direct care workforce. *The Gerontologist*, 49(5), 623–634.
 https://doi.org/10.1093/geront/gnp054
- Nissly, J., Mor Barak, M. l, & Levin, A. (2005). Stress, social, support, and workers' intentions to leave their job in public child welfare. *Administration in Social Work*, 29(1), 79–100. https://doi.org/10.1300/J147v29n01_06
- Palmer, R. 1969: Hermeneutics. Evanston: Northwestern University Press.
- PHI. (2019). Workforce Data Center. Retrieved from https://phinational.org/policy-research/workforce-data-center/
- President's Committee for People with Intellectual Disabilites. (2017). Report to the president 2017 America's direct support workforce crisis: Effects on people with intellectual disabilities, families, communities and the U.S. economy. Retrieved from https://www.acl.gov/sites/default/files/programs/2018-02/2017 PCPID Full Report_0.PDF
- Pynes, J. E. (2013). *Human Resources Management for Public and Nonprofit Organizations: A Strate*. John Wiley & Sons.
- Robbins, E., Dilla, B., Sedlezky, L., Sirek, A.J. (2013). Coverage of Direct Service Workforce

 Continuing Education and Training within Medicaid Policy and Rate Setting: A Toolkit for

 State Medicaid Agencies. The Lewin Group. Retrieved from

- https://www.medicaid.gov/medicaid/ltss/downloads/workforce/dsw-training-rates-toolkit.pdf.
- Robinson, O. (2014) Sampling in Interview-Based Qualitative Research: A Theoretical and Practical Guide. *Qualitative Research in Psychology*, 11(1), 25-41. https://doi.org/10.1080/14780887.2013.801543
- Smith, J. (2017) Interpretative phenomenological analysis: Getting at lived experience. *The Journal of Positive Psychology*, *12*(3), 303-304. https://doi.org/10.1080/17439760.2016.1262622
- Venema, E., Otten, S., & Vlaskamp, C. (2015). The efforts of direct support professionals to facilitate inclusion: the role of psychological determinants and work setting. *Journal of Intellectual Disability Research*, 59(10), 970–979. https://doi.org/10.1111/jir.12209

Table 1
Support Need Themes, Subthemes, and Illustrative Examples

Themes and Subthemes	Quotes
 Quality and participatory managem Participate in decision-making No micromanaging Effective performance evaluations Improved communication Transparent and fair policies 	"When I feel like I don't have a voice, I feel discouraged. For the most part, I see these guys at all times and know what they want and need." "Offering support and guidance not micromanaging." "the higherups get recognized but not us some of them don't even listen to what you're saying, they think, 'you're just a DSP' DSPs are never invited to the actual meetings. Meetings with DSPs are just Dos and Don'ts if it wasn't for us DSPs some of these companies couldn't run They wouldn't think of this or know what was important to us, unless they asked."
Fair compensation and recognition • Wages, work hours, benefits, referral pay • Professional development • Simple thank-you	"We are supposed to have monthly evaluations to let us know how we are performing, but they rarely happen" "No picking and choosing when a rule should or shouldn't be followed to convenience management" "We're working extra hours and our managers show little to know [sic] appreciation sometimes you're not asked and you're just told you have to. Our lives outside of the building are not being respected."
	"I've been working there for years but while the agency always has appreciative awards dinners, I've never been nominated."
Access to training opportunities	"better training regarding purpose of the work and commitment to respect and personal independence of people supported."
	"If the state had the trainings so that when I work with more than one agency the trainings work for all agency [sic]." "I need more training related to what I do, not CPR, first

aid, med administration, OSHA and the other required training" "I need more training related to what I do not CPR, first aid, med administration, OSHA and the other required training" Reliable and quality staffing • Adequate staffing "I shouldn't have to do it all. We need more staff to have the same reasons for being there. Like really want to be Substitute staff to reduce here." burnout Demonstrated "Getting substitute staff for vacations to reduce burnout. competencies of staff The staff in our home currently has no one to cover so we Retention cover for each other." "We are short-staffed because no one wants to do this job for so little money. Having short staff causes the current staff stress. We are doing work above our job title and our work is seen as 'women's work' and is not seen as important to the higher ups" Funding for basic needs of both programs and people receiving support "Stop putting billing over the needs and what's best for the • Generally, more resources people we support." Transportation • Community-based "Having money for the individuals for them to have when activities we go out into the community, whether it's planned or unexpected" "We use our personal vehicles so having more company vehicles would help. I already drive 45 minutes to work." Reasonable job expectations "We almost constantly have overtime and are pressured Reasonable number of people supported and into doing more" hours worked "I suspect that more can be done to be realistic about what • Stick to job description the job really entails up front so that expectations are • Less burdensome more aligned with what occurs on average in the documentation position." Don't assume DSPs want

overtime