

Research

Direct Support Professionals and Quality of Life
of People with Intellectual and
Developmental Disabilities



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**Direct Support Professionals and Quality of Life of People
with Intellectual and Developmental Disabilities**

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Abstract

DSPs are the “backbone” of long term services and supports (LTSS) in the United States (Bogenschutz et al., 2014, p. 317). This study examined the relationship between direct support professionals (DSPs) and people with intellectual and developmental disabilities’ (IDD) quality of life. To do so, we utilized Personal Outcome Measures[®] interviews from over 1,300 people with IDD to examine the impact DSP change has at individual and organizational levels. We found DSP continuity is central to quality of life of people, including human security, community, relationships, choice, and goals. States cannot continue to provide near-poverty level reimbursement rates for DSPs and still ensure quality of life.

Keywords: direct support professionals; quality of life; organizational supports; community living

Direct Support Professionals and Quality of Life of People with Intellectual and Developmental Disabilities

Direct support professionals (DSPs), also often called direct supports or personal care aides (or hundreds of other job titles (Hewitt & Lakin, 2001; Hewitt & Larson, 2007)), provide personal, often individual, assistance to people with disabilities and older adults. DSPs provide a wide and complex range of services, including aiding people with activities of daily living, and promoting physical and emotional well-being. Examples of job duties include assistance with: health and safety, relationships, networking, communication, personal care, transportation, advocacy, financial duties, community living, crisis prevention, household tasks, education on self-care skills, promoting self-determination, and managing finances (Bogenschutz et al., 2014; Hasan, 2013; Hewitt & Lakin, 2001; Hewitt & Larson, 2007; Hewitt et al., 2008; National Direct Service Workforce Resource Center, n.d.; Robbins et al., 2013; Wright, 2009). These tasks are not only labor intensive but also require a complex balance of competencies (Hewitt & Lakin, 2001; National Direct Service Workforce Resource Center, 2013).

DSPs work in a variety of settings, including participant's homes, group homes, private and public institutions, nursing homes, and job support programs (Bogenschutz et al., 2014). In 2011 there were approximately four-million DSPs in the United States, approximately one-million of which were working with people with intellectual and developmental disabilities (IDD) (National Direct Service Workforce Resource Center, 2013; Taylor, 2008). DSP opportunities are growing faster than any other sector of the labor force due to deinstitutionalization of people with IDD, community living of people with disabilities, and aging of the baby boomer population ((Bogenschutz et al., 2014; Micke, 2015; Robbins et al., 2013). Estimates suggest by 2020 direct support will be the largest job in the country, with

approximately five-million DSP positions (Bogenschutz et al., 2014; Hewitt, 2014). Yet, “DSPs are among the nation’s most vulnerable workers” (American Network of Community Options and Resources, 2014, p. 1).

There is an astronomically high annual turnover rate for DSPs (American Network of Community Options and Resources, 2014; Hewitt, 2014; Hewitt & Lakin, 2001; Hewitt & Larson, 2007; Hewitt et al., 2008; Keesler, 2016; Micke, 2015; Wolf-Branigin, Wolf-Branigin, & Israel, 2007). Recent estimates suggest the average organization supporting people with disabilities or older adults may see anywhere from 30% to 70% DSP turnover a year (Bogenschutz et al., 2014; Taylor, 2008). Almost all of this turnover is due to DSPs quitting rather than being fired (Firmin et al., 2013).

Reasons for the Direct Support Professional Crisis

DSP turnover, and the crisis it creates, is a decades-long issue (American Network of Community Options and Resources, 2014). The origins of the crisis date back to the deinstitutionalization and community living movements of the 1970s where smaller ratios were needed in the community and therefore a larger workforce (Hewitt & Lakin, 2001). The roles of DSPs also shifted from caretakers of basic needs, such as health and safety, to continuing to partake in these roles while also supporting peoples’ goals, relationships, and community integration (Hewitt & Lakin, 2001). At the same time, as there is more geographic dispersion than in institutions, community settings also lead to less direct supervision and mentorship, and more isolation for DSPs (Edelstein & Seavey, 2009; Hewitt & Lakin, 2001).

Despite an increased need for community-based DSPs and an increased workload for DSPs, wages for DSPs have remained extremely low, often lower than institutional wages (Edelstein & Seavey, 2009; Hasan, 2013). DSP wages are rarely significantly higher than the

federal minimum wage (\$7.25); as of May 2015 the national minimum wage for personal care workers was \$10.48 (Bureau of Labor Statistics, 2016). Low wages, combined with a lack of benefits, often causes those DSPs to rely on public assistance (Bogenschutz et al., 2014; Hewitt et al., 2008). Low wages are also one of the top reasons for the high turnover rate and recruitment problems (Bogenschutz et al., 2014; Firmin et al., 2013; Hasan, 2013; Hewitt & Lakin, 2001; Hewitt & Larson, 2007; Hewitt et al., 2008; Ligas Consent Decree Monitor, 2017; Micke, 2015; Smergut, 2007; Taylor, 2008; Wolf-Branigin et al., 2007). The Centers for Medicare and Medicaid Services (CMS) acknowledges, DSP “wages paid to individual workers are often slow to be adjusted in response to inflation and economic growth, and can lag behind wage increases in other health and service sectors” (Wachino, 2016, p. 3). Low reimbursement rates often leave disability organizations competing with the fast food industry because of similar wages; in fact wages in the fast food industry have been increasing at a quicker rate than wages for DSPs (Raustiala et al., 2015).

Research reinforces that with increased wages there is less DSP turnover (Robbins et al., 2013). For example, when San Francisco County increased their DSP wages, annual DSP turnover decreased by almost half (Robbins et al., 2013). Yet, this wage issue is not as simple as agencies increasing their rates. Since reimbursement is through Medicaid, community providers cannot simply raise prices to increase DSP wages because they do not have the funding to do so (American Network of Community Options and Resources, 2014). For example, agencies in the city of Chicago are struggling because Chicago increased minimum wage throughout the city, yet the reimbursement rates agencies receive from the state of Illinois have not kept pace leaving agencies struggling to make up the difference (Ligas Consent Decree Monitor, 2016).

Another issue in the DSP crisis is training; those DSPs who provide the most support typically have the fewest qualifications (Hewitt, 2014). The federal government only requires that DSPs have a driver's license, a high school diploma or equivalent, and the ability to pass a criminal background check with no felony convictions (Hasan, 2013; Hewitt, 2014; Hewitt & Larson, 2007; Wachino, 2016). While states may have their own standards, few states provide training guidelines so there is little consistency, and training is often left to providers to figure out (Hasan, 2013; Hewitt & Lakin, 2001; National Direct Service Workforce Resource Center, 2013). When DSPs are not prepared enough, people with disabilities suffer. Not only is health and safety a concern, but so is community inclusion as one of the top reasons people with disabilities are kept at home is out of fear that something might happen because staff do not have enough training to be prepared for those risks (Britton Laws, Kolomer, & Gallagher, 2014).

Training not only addresses concerns about quality (National Direct Service Workforce Resource Center, 2013), but a study by Ejaz, Noelker, and Menne (2008) determined that DSPs had higher job satisfaction when they believed they were "more in control of the stressors of their work due to useful on-the-job training and ongoing continuing education" (Britton Laws et al., 2014, p. 322). Extended training not only increases the self-efficacy and confidence of DSPs, both of which reduce turnover, it also allows a path for professional growth and advancement opportunities as benefits and wages typically increase when jobs require more qualifications (Britton Laws et al., 2014; Firmin et al., 2013; Hasan, 2013; National Direct Service Workforce Resource Center, 2013). As it stands there are limited advancement opportunities – DSPs have no career paths or room to advance – which also impacts their wages, and ultimately turnover (Hasan, 2013; Hewitt & Lakin, 2001; Hewitt & Larson, 2007; Hewitt et al., 2008; Wolf-Branigin et al., 2007). For example, when the state of Wyoming placed more emphasis on training and

career development of DSPs and increased wages the turnover rate dropped significantly in the state (Lynch et al., 2005).

Another large factor in the DSP crisis is job and organizational culture (Keesler, 2016; Wolf-Branigin et al., 2007). Being a DSP is a taxing job given the workload and the low pay. DSPs often suffer from burnout, stress, and depression, which is amplified by the increased burden due to turnover (Britton Laws et al., 2014; Hasan, 2013; Hewitt & Lakin, 2001; Hewitt & Larson, 2007; Keesler, 2016; Taylor, 2008). Coupled with this stress, research has found a lack of support from supervisors (Micke, 2015). Thus, DSPs are often required to utilize complex skills with little direct oversight or mentoring (Britton Laws et al., 2014; Hewitt & Larson, 2007).

The Impact of the Direct Support Professional Crisis

Beyond the direct impact on DSPs themselves, the impact of the DSP crisis – the “revolving door” of DSPs (Bogenschutz et al., 2014, p. 320) – is twofold. First, turnover has put a tremendous financial burden on disability organizations, which often already have limited resources available to them. Filling vacancies can cost up to \$5,000 per DSP because of recruitment and training costs (Raustiala et al., 2015). Estimates suggest DSP turnover costs \$784 million annually in the United States (Hewitt & Larson, 2007). However, the DSP crisis has a much higher cost than its financial burden – DSPs are critical for the community integration of people with disabilities. Not only are DSPs key to the quality care of millions of people in the United States, a lack of staff can also keep people from going into, and being integrated in the community (American Network of Community Options and Resources, 2014; Britton Laws et al., 2014; Smergut, 2007; Venema, Otten, & Vlaskamp, 2015). The DSP crisis also threatens community growth as DSPs are necessary to “delay or prevent

institutionalization... and keep long-term care costs lower” (Robbins et al., 2013, p. 2). For example, in Illinois there is a Consent Decree (*Ligas v Norwood*) noting people with IDD living in private intermediate care facilities for persons with developmental disabilities (ICFDD) have the right to live in the community if they choose. To be appropriately implemented, the Decree requires an increased community infrastructure to meet the demands of community services. The lead council for the people with IDD explains,

while the State has so far met its quantitative requirements under the Consent Decree, we do have serious concerns about the quality of the services being provided.... From our perspective, many of the quality issues arise from the low wages paid to DSPs. The main issues for our clients are: lack of person-centered planning to allow our clients to live in the most integrated setting...; difficulty placing and supporting people in the community who have significant medical or behavioral needs...; lack of meaningful participation in the community...; [and] lack of integrated, competitive employment opportunities as providers are often taking a one-size fits all approach...because they don't have sufficient staff to support more customized and integrated employment opportunities. (Ligas Consent Decree Monitor, 2017, p. 22).

Moreover, due to the DSP crisis, some agencies have already considered increasing setting sizes because they do not have the workforce infrastructure to support smaller settings despite state and family interest (Ligas Consent Decree Monitor, 2016).

In addition to their role in facilitating and expanding community living, DSPs are also necessary to “improve quality of life” of people with IDD (Robbins et al., 2013, p. 2). Quality of life is based on “common human experiences and unique, individual life experiences” (Schalock

et al., 2002, p. 462) while also giving “sense of reference and guidance from the individual’s perspective, focusing on the person and the individual’s environment” (Brown, Schalock, & Brown, 2009, p. 2). Quality of life includes: emotional well-being; interpersonal relations; material well-being; personal development; physical well-being; self-determination; social inclusion; and, rights (Cummins, 1991; Cummins et al., 1997; Schalock, 2004; Schalock et al., 2002; Schalock et al., 2010). As such, quality of life is a particularly important construct to demonstrate the effectiveness of the quality of supports people receive (Hoffman et al., 2006; Lee et al., 2008).

DSPs are the “backbone” of long term services and supports (LTSS) in the United States (Bogenschutz et al., 2014, p. 317). In addition to impacting the growth and sustainability of community services (Hewitt & Lakin, 2001), “a competent and stable workforce is a quality indicator in the lives of people with IDD” (McLaughlin et al., 2015, p. 267). A holistic examination of the role DSPs play in the quality of life of people with IDD that pays attention to the individual and organizational is necessary to provide evidence of the valuable contributions of DSPs. Both are necessary to provide support for an expansion of the development and positive treatment of the profession. To do so, this study examines the following research questions :

- 1) what factors impact the odds of people with IDD experiencing changes in DSPs?;
- 2) How do changes in DSPs impact the outcomes of people with IDD?; and,
- 3) How do changes in DSPs impact the organizational supports that are in place for people with IDD?

This study utilizes the Personal Outcome Measures[®], a comprehensive measure of person-centered quality of life, interviews from over 1,300 people with IDD to examine the impact DSP change has at individual and organizational levels.

Methods

Participants

The secondary survey data utilized in this survey were transferred to the researchers with no identifiers; as such the author's institutional research board (IRB) determined it was exempt from full review. Participants were originally recruited over approximately two years (January 2015 to December 2016) through organizations, including local, county, and state governments, in the United States that provide any of the following services to people with disabilities: service coordination; case management; family or individual supports; behavioral health care; employment and other work services; residential services; non-traditional supports (micro-boards and co-ops); and, human services systems. This process resulted in the data from 1,443 people with disabilities (Table 1).

Measure

The Personal Outcome Measures[®] (The Council on Quality and Leadership, 2017a) was developed to comprehensively measure quality of life of people with disabilities while also paying attention to the key role support can play in improving individual outcomes. Unlike other quality of life measures that are based on organizational standards, the Personal Outcome Measures[®] focuses on a person-centered definition of quality of life, including choice, self-advocacy, self-determination, and community inclusion. The Personal Outcome Measures[®] has been continually refined through initial pilot testing, 24 years of administration, research and content experts, a Delphi survey, and feedback from advisory groups (The Council on Quality and Leadership, 2017a). All certified interviewers are required to have at least 85% reliability with an expert interviewer from The Council on Quality and Leadership before being certified to administer the Personal Outcome Measures[®] (The Council on Quality and Leadership, 2017b).

The Personal Outcome Measures[®] has been found to have reliability and construct validity (Citation removed for review; The Council on Quality and Leadership, 2017b).

The current version of the Personal Outcome Measures[®] includes 21 indicators divided into five factors: human security; community; relationships; choice; and, goals. *Human security* includes the following indicators: people are safe; people are free from abuse and neglect; people have the best possible health; people are treated fairly; people are respected; people experience continuity and security; and, people exercise rights. *Community* includes the following indicators: people interact with other members of the community; people live in integrated environments; people participate in community life; and people use their environments. *Relationships* includes the following indicators: people have intimate relationships; people have friends; people remain connected to natural support networks; people decide when to share personal information; and, people perform social roles. *Choice* includes the following indicators: people choose where and with whom to live; people choose services; and, people choose where to work. Finally, *goals* includes the following indicators: people realize personal goals; and, people choose personal goals. Each 21 indicators are measured in terms of personal outcomes and organizational supports. While the outcomes examine the presence of each of the 21 indicators, organizational supports examine if individualized organizational practices are in place to support the person to achieve said outcomes.

The Personal Outcome Measures[®] is administered in three stages. In the first stage a certified interviewer has an open-ended conversation with the person with IDD about each of the Personal Outcome Measures[®] indicators. During the second stage the interviewer asks someone who knows the participant best (e.g., friend, family) follow-up questions about outcomes and individual supports to fill in any gaps from the initial interview. During the final stage the

interviewer completes decision trees based on the information gathered from the first two steps, and observations of the participant in a variety of settings and record reviews, if necessary, to determine if the outcomes are present, and if the organizational supports are in place. (See the Personal Outcome Measures® manual (The Council on Quality and Leadership, 2017a) for more details about the decision trees for each of the 21 indicators.) Each are dichotomously coded as present (1) or not present (0) for outcomes, or in place (1) or not in place (0) for organizational supports.

Variables

The main variable of this study was the Personal Outcome Measures® item that looked at changes in DSP staff. The item is a probe under the “continuity and security” area of the Personal Outcome Measures® which examines the type of control people have over their lives, and disruptions of their lives due to factors such as personal decision making, economic security, and, most frequently, the services and supports they receive from organizations. Relying on organizations for services and supports, “often links changes in people’s lives to organizational changes. Organizations provide continuity and security for people through the service process” (The Council on Quality and Leadership, 2017a, p. 25). As such, one of the areas determined is changes in DSP staff in the past two years. Following the above administration procedure, suggested questions for information gathering with the participant regarding DSP staff included:

- How long have your support staff worked with you?
- Do you have the consistency you need in the staff who work with you?
- What would cause you to make changes in your current situation?
- Is there anything you do not want to change?
- Have you experienced any changes? and,

- How do you feel about these changes? (The Council on Quality and Leadership, 2017a, p. 26)

During the follow-up interview with someone who knows the participant well, suggested questions for information gathering about DSP staff included:

- What does the person consider to be important issues that would affect his or her continuity and security?
- Does the person feel secure in his or her living and working situations?
- What has the person told you is important for continuity and security?
- If the person has indicated concerns, what are they and what was done about them?
- How is the importance of staff continuity defined for the person and addressed through the support process? (The Council on Quality and Leadership, 2017a, p. 26)

Using this information, the certified interviewer decides if the person has experienced changes in DSP staff in the past two years (no (0); yes (1)) as a probe for the larger continuity and security determination. This particular probe about DSP staff change was the main variable utilized in our study. The other variables included demographic variables as well as variables about the 21 quality of life outcomes and the 21 quality of life organizational supports. (See the Personal Outcome Measures[®] manual (The Council on Quality and Leadership, 2017a) for in depth description of each of the 21 indicators.)

Research Questions and Analysis

The aim of the study was to explore what types of people with IDD are most likely to experience changes in DSPs, as well as how DSP changes affect outcomes and supports of people with IDD. Analysis was completed using IBM SPSS 23. After applicable items were dummy coded descriptive statistics were run. Then, to determine what types of people experience changes in DSPs, our first research question examined: what factors impact the odds

of people with IDD experiencing changes in DSPs? To answer the first question, the dependent variable (DV) was changes in DSP staff. Independent variables (IVs), which are listed in Table 1, were selected after reviewing the literature on DSPs and people with disabilities. Separate binary logistic regression models were run with each of the IVs, and the DV change in DSP staff. We ran univariate analyses to determine odds ratios for each of the IVs.

We also wanted to explore how DSP changes impact people with IDD's quality of life; for this reason, our second research question was: how do changes in DSPs impact the outcomes of people with IDD? For questions two, changes in DSP staff was used as the IV. Binary logistic regression models were then run with each of the 21 quality of life outcomes described above serving as the DVs in the models. Univariate analyses were then run for significant models.

Our final aim was to explore how DSP changes impact the supports organizations provide to people with IDD. Therefore, our third research question was: how do changes in DSPs impact the organizational supports that are in place for people with IDD? Changes in DSP staff was used as the IV. Binary logistic regression models were then run with each of the 21 organizational supports described above (DVs) for each of the models. Univariate analyses were then run.

Results

The majority of participants ($n = 750, 55.9\%$) experienced a change in DSPs in the past two years (Table 1). Of those who experienced a change, provider organizations/support staff were the most responsible ($n = 549, 40.9\%$), followed by the person with IDD ($n = 31, 2.3\%$), employers/co-workers ($n = 9, 0.7\%$), family ($n = 9, 0.7\%$), guardians ($n = 6, 0.4\%$).

People Most Likely to Experience Direct Support Professional Change

At the individual level, we aimed to explore what factors impacted the odds of people with IDD experiencing DSP change in the past two years. Binary logistic regression analyses were run with each of the IVs to determine if any of the variables significantly predicted changes in DSPs. The following variables produced significant relationships: diagnosis; race; guardianship status; residence type; housemates; complex needs; daily support; and, supports received (Table 2).

According to univariate analyses, when all other diagnoses are controlled, people with IDD with behavioral challenges have 2.68 times higher odds of experiencing changes in DSPs in the past two years than people with IDD with all other types of diagnoses. Conversely, when all other diagnoses are controlled, people with Down Syndrome, intellectual disability, or seizure disorder/neurological problems have lower odds of experiencing DSP change (2.38, 2.50, and 1.42 times lower respectively) compared to those with IDD who have other diagnoses.

In our study, there was a significant relationship between race and DSP change. According to univariate analyses, people who are Black or African American have 1.67 times lower odds of experiencing change than White people.

There was a relationship between guardianship and DSP change; people who have assisted decision making have 1.47 times lower odds of DSP change than people who have independent decision making.

People who live in family homes have 2.70 times lower odds of experiencing DSP change than people in their own homes. However, people in provider operated homes and private ICFDD have 2.02 times and 14.02 times higher odds of DSP change respectively than people in their own homes. Similarly, as the number of housemates increases (both with and without disabilities), the odds of experiencing DSP change increases.

Those who receive three to six hours, twelve to twenty-three hours, or twenty-four hours of daily support all have higher odds of experiencing DSP changes (2.71, 4.07, and 6.81 times respectively) than people who receive support on call as needed.

Controlling for all other services, people with IDD who receive staffed residential supports (2.25 times), recreational activity supports (1.56 times), or nursing services (1.50 times) have higher odds of experiencing DSP change than those who do not receive these services. Those who receive enclave services (1.67 times) or community-based day activity services (1.35 times) have lower odds of experiencing DSP change than those that do not receive these services.

Impact of Direct Support Professional Change on Outcomes

To explore how DSP change impacts the outcomes of people with IDD, binary logistic regression models were run with between the IV ‘change in DSP’ and each of the 21 *Personal Outcome Measures*[®] outcomes as the DV. DSP change significantly predicted the following outcomes: natural support networks; intimate relationships; are safe; best possible health; exercise rights; treated fairly; experience continuity and security; decide when to share personal information; choose with whom and where to live; use environments; live in integrated environments; interact with others in the community; perform social roles; choose services; participate in community life; have friends; and, are respected (17 out of 21 outcomes) (Table 3). With each of the models, people with IDD that experience DSP change have lower odds of having each of these outcomes than people who do not experience DSP change (odds ratios are displayed in Table 3).

The following outcomes were not significant, suggesting for these indicators DSP change does not significantly impact the likelihood of the outcomes being present: free from abuse and neglect; choose where to work; realize personal goals; and choose personal goals.

Impact of Direct Support Professional Change on Organizational Supports

To determine how DSP change impacts the organizational supports that are in place for people with IDD, binary logistic regression models were run with the IV ‘change in DSP staff.’ The Personal Outcome Measures[®] organizational supports for each of the 21 indicators were used as the DVs for each of the models. DSP change significantly predicted the following DVs: natural support networks; intimate relationships; are safe; best possible health; treated fairly; continuity and security; decide when to share personal information; choose with whom and where to live; use environments; live in integrated environments; interact with others in the community; perform social roles; choose services; realize personal goals; participate in community life; have friends; and, are respected (18 out of 21 supports) (Table 4). In all of the models, each of these organizational supports are less likely to be in place for people who IDD that have experienced DSP change than people who have not experienced this change (odds ratios are displayed in Table 4).

The following outcomes were not significant, suggesting for these indicators DSP change does not significantly impact the likelihood of the organizational supports being in place: free from abuse and neglect; choose where to work; and choose personal goals

Discussion

The aim of this study was to explore the impact of DSPs on quality of life of people with IDD. In doing so we explored the impact of DSP change on outcomes of people with IDD as well as organizations’ ability to provide supports – the ways DSPs are crucial to the community integration of people with IDD. We also examined who was most likely to be impacted by IDD change – those areas that can be targeted for additional supports to help maintain DSP placement and reduce DSP change.

Our results reinforced previous literature's findings about the key role DSPs play in the lives of people with IDD. Particularly, those people with IDD who experience DSP change are less likely to successfully achieve quality of life outcomes than people not experiencing DSP change. These impacts are wide ranging, from safety to choice making opportunities.

Compared to people with IDD who did not experience change, people who experienced DSP change in the past two years are less likely to experience human security – “non-negotiable human and civil rights” (The Council on Quality and Leadership, 2017b, p. 5) – including being safe, having the best possible health, exercising rights, being treated fairly, being respected, and experiencing continuity and security. When there is DSP change, organizational supports regarding important aspects of human security (i.e., are safe; best possible health; treated fairly; are respected; continuity and security) are also less likely to be in place, indicating the roles DSPs play in supporting human security.

According to our findings DSP change also impacts community, including people with IDD's right to “be in the community, and to access and interact with the world around them” (The Council on Quality and Leadership, 2017b, p. 5). Those with IDD who experience DSP change are less likely to have community outcomes present, including: use environments; live in integrated environments; interact with others in the community; and, participate in the community. From our findings it appears there is a bidirectional relationship between DSPs and community where those people with IDD not in the community are more likely to experience change, as evidenced by people in more segregated residence types and larger settings being more likely to experience DSP change than those in smaller and more community-based settings, and those who experience change are less likely to be in the community, as evidenced by the

decreased likelihood of community organizational supports being in place when there is DSP change.

DSP change also impacts the relationships of people with IDD. People with IDD who experience DSP change are less likely to have intimate relationships, have friends, have natural supports, perform social roles, and decide when to share personal information than people who do not experience change. DSPs appear to play a key role in facilitating these outcomes, especially in terms of providing supports for those who need it most, as organizational supports are less likely to be in place when there is change. This is problematic as relationships “are links to the greater world that create a blanket of security and help people who receive supports play social roles” (The Council on Quality and Leadership, 2017b, p. 5). Moreover, the social capital created by relationships helps promote quality of life.

Choice, “the ability to make decisions that affect one’s life and community,” is also impacted by DSP change (The Council on Quality and Leadership, 2017b, p. 5). Compared to those who do not experience change, those people with IDD who experience DSP change are less likely to choose services, and choose with whom and where to live. Organizational supports regarding choice (i.e. choose services; choose with whom and where to live) are also less likely to be in place when there is DSP change compared to when there is not. This is problematic as choice is important for participation, autonomy, and self-determination (The Council on Quality and Leadership, 2017b).

When there is DSP change there are also lower odds of organizational supports being in place to help people with IDD realize personal goals. Organizations can serve as gatekeepers that either help people with IDD meet personal milestones or make it more difficult for them to have these experiences.

Together human security, community, relationships, choice, and goals comprise a holistic quality of life. Excellence in person-centered services, especially through the services DSPs provide, is necessary to ensure people achieve these outcomes. We recognize states often have limited resources available to them and must prioritize funding accordingly. However, according to our findings, DSPs not only provide immediate personal care services but can also impact larger aspects of quality of life, such as people with IDD's ability to maintain intimate relationships or experience continuity and security. An expansion of personal care services for people with IDD in LTSS for people with IDD, would then provide twofold.

People who Experience the Most Change

According to our findings, in order to maximize the quality of life of people with IDD, more training and/or support may also be needed for DSPs who work with people with IDD with behavioral challenges and/or complex behavioral support needs, people who need nursing services, and people with the highest support needs (daily support), as they are more likely to experience DSP change. This is especially true as burnout and less DSP self-efficacy contribute to DSP turnover (Britton Laws et al., 2014; Hasan, 2013; Hewitt & Lakin, 2001; Hewitt & Larson, 2007; Keesler, 2016; Taylor, 2008).

We also found that people who live in provider owned or operated homes, and private ICFDD, as well as those that live in larger settings, are more likely to experience DSP change. This is particularly true for those receiving residential supports, and supports for recreational activities, which very likely are also provided by residential staff. It is likely that there is higher turnover in these settings because providing supports in these settings may require juggling more tasks than other settings, such as day settings, and be more taxing as a result. In contrast, when

there are natural supports – people with IDD live in family homes – they are less likely to experience DSP change than when people with IDD live in their own homes.

Our findings also revealed a number of people with IDD who are *less* likely to experience DSP change, such as people with Down Syndrome, intellectual disability, or seizure disorder/neurological problems compared to people with other disabilities, Black people compared to White people, and people with assisted decision making compared to people with independent decision making. More research is needed to explore why these groups in particular are less likely to experience change. We believe it may be particularly fruitful to look at interactions, as they may be the reason for some of these findings. Future research could also examine if any of these findings are sample specific.

Limitations

When interpreting our results, a number of limitations should be noted. First, the data were from the United States only; while generalizations to other countries or cultures cannot be made, we believe this is also a potential avenue for future research. Another limitation is that the data were not representative of people with IDD in the United States as a whole. Most of the sample was white. Moreover, participants were recruited through organizations that provide LTSS, particularly those organizations who partner with the Council on Quality and Leadership to conduct Personal Outcome Measures[®] interviews. As a result, this sample may not be representative of all people with IDD, or all service providers. It should also be noted that although the literature suggests DSPs quitting organizations is the most prominent for DSP change (Firmin et al., 2013), our variable regarding DSP change did not differentiate between other potential reasons people with IDD experienced change, such as organizational

restructuring. As this was a secondary data analysis, the researcher did not have the ability to ask additional questions or add additional research variables.

Implications and Conclusions

As indicated by our findings, DSPs are central to the quality of life of people with IDD, including human security, community, relationships, choice, and goals. Those people with IDD who experience DSP change are less likely to achieve individualized outcomes. They are also less likely to have organizational supports in place to help them achieve their outcomes. Because of their importance, not only for health and safety, but also for community integration, systemic change is needed to address the causes of the DSP crisis and its exponential turnover rates (Britton Laws et al., 2014).

One of the first steps in doing so is by increasing DSP wages, as they are one of the leading causes of turnover (Bogenschutz et al., 2014; Firmin et al., 2013; Hasan, 2013; Hewitt & Lakin, 2001; Hewitt & Larson, 2007; Hewitt et al., 2008; Ligas Consent Decree Monitor, 2017; Micke, 2015; Smergut, 2007; Taylor, 2008; Wolf-Branigin et al., 2007). States cannot continue to provide near-poverty level reimbursement rates for DSPs, and still ensure people with IDD have the rights granted to people with them by the Americans with Disabilities Act (1990) and *Olmstead v LC* (1999). States must invest in DSPs in recognition of their critical role in a successful community infrastructure, particularly as deinstitutionalization continues to increase (Braddock et al., 2017). Doing so requires not only significantly increasing meager wages, but also addressing the lack of standardization of reimbursement rates across states and programs (*citation removed for review*). As they are the largest provider of LTSS for people with IDD, Medicaid Home and Community Based Services (HCBS) waivers, may be a fruitful avenue to begin this change (Braddock et al., 2017).

In order to maximize the quality of life of people with IDD, DSPs must also have more training. The common lack of state training guidelines may result in gaps which hinder the quality of supports people receive (Hasan, 2013; Hewitt & Lakin, 2001; National Direct Service Workforce Resource Center, 2013). Moreover, training and the self-efficacy it produces, is another way to address DSP turnover as it reduces burnout (Britton Laws et al., 2014; Hasan, 2013; Hewitt & Lakin, 2001; Hewitt & Larson, 2007; Keesler, 2016; Taylor, 2008). This is especially pertinent as we found those with more complex disabilities are more likely to experience DSP change. Those DSPs who provide the most support typically have the fewest qualifications, potentially leading to more burnout, increases in turnover, and as a result, fewer quality supports for people with IDD (Hewitt, 2014).

Finally, there must also be a larger cultural shift to one that recognizes the value of DSPs. Despite the low pay, and the demanding work, the support DSPs provide directly facilitates the quality of life of people with IDD, both in terms of their personal outcomes, and the organizational supports that are in place. “If quality assurance is to enhance the quality of services to people with disabilities it makes no sense to ignore the skills and stability of the people who provide these services” (Hewitt & Lakin, 2001, p. 12). The quality of life of people with disabilities is at stake.

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Table 1
Demographics and Descriptive Statistics (n = 1,341)

Variable	n	%	Variable (continued)	n	%	m (SD)
Age range			Residence type			
18 to 24	95	7.1%	Own home/apartment	284	21.2%	
25 to 34	250	18.6%	Family's house	213	15.9%	
35 to 44	223	16.6%	Host family/family foster care	24	1.8%	
45 to 54	279	20.8%	Provider operated house or apartment	677	50.5%	
55 to 64	252	18.8%	Private ICF/DD	22	1.6%	
65 to 74	122	9.1%	State operated HCBS group home	43	3.2%	
75+	39	2.9%	State operated ICF/DD	25	1.9%	
Gender			Other	22	1.6%	
Man	719	53.6%	Complex medical needs	159	11.9%	
Woman	613	45.7%	Behavioral support needs	270	20.1%	
Diagnosis			Weekly support			
Intellectual disability	1,059	79.0%	On call - support as needed	28	2.1%	
Seizure disorder/neurological problems	285	21.3%	0 to 3 hours/day	60	4.5%	
Mood disorder	189	14.1%	3 to 6 hours/day	94	7.0%	
Cerebral palsy	187	13.9%	6 to 12 hours/day	155	11.6%	
Anxiety disorders	166	12.4%	12 to 23 hours/day	76	5.7%	
Behavioral challenges	162	12.1%	24/7 - around the clock	819	61.1%	
Autism spectrum disorder	147	11.0%	Other	46	3.4%	
Other mental illness/psychiatric diagnosis	146	10.9%	Housemates with disabilities			3.83 (2.45)
Personality/psychotic disorder	141	10.5%	Nondisabled housemates			0.53 (1.24)
Obesity	95	7.1%	Services received (yes)			
Physical disability	92	6.9%	Transportation	987	73.6%	
Impulse-control disorder	83	6.2%	Staffed residential supports	810	60.4%	
Down syndrome	81	6.0%	Recreational activities	781	58.2%	
Hearing loss - severe or profound	62	4.6%	Community-based day activities	736	54.9%	
Limited or no vision - legally blind	45	3.4%	Day program/activities	725	54.1%	
Alzheimer's disease or other dementia	30	2.2%	Nursing services	549	40.9%	
Brain injury	20	1.5%	In-home supports	361	26.9%	
Race			Sheltered work	281	21.0%	
White	998	74.4%	Supported community employment	200	14.9%	
Black or African American	246	18.3%	Competitive employment (follow-along supports)	100	7.5%	
American Indian or Alaska Native	54	4.0%	Enclave work	80	6.0%	
Hispanic, Latino, or Spanish Origin	29	2.2%	Respite care	40	3.0%	
Other (Asian, Native Hawaiian, other Pacific Islander, or other)	16	1.2%	Change in direct support staff in past 2 years (yes)	750	55.9%	
Primary method of communication			Who is primarily responsible for the change in direct support staff?			
Verbal/spoken language	1,102	82.2%	Provider organization/support staff	549	40.9%	
Face/body expression	169	12.6%	Individual with disabilities	31	2.3%	
Communication device	16	1.2%	Employer/co-worker	9	0.7%	
Sign language	14	1.0%	Family	9	0.7%	
Other	33	2.5%	Guardian	6	0.4%	
Guardianship status			other	32	2.4%	
Independent decision making	370	27.6%				
Assisted decision making	494	36.8%				
Full/plenary guardianship	423	31.5%				
Other	35	2.6%				

Table 2

Results of the Binary Logistic Regressions for Change in Direct Support Staff

Model	-2LL	df	χ^2	O. R.	95% C.I.
Diagnosis***	1274.89	17	44.60		
Alzheimer's disease or other dementia				1.38	0.53 - 3.60
Anxiety disorders				1.19	0.79 - 1.80
Autism spectrum disorder				0.73	0.46 - 1.14
Behavioral challenges				2.68***	1.70 - 4.21
Brain injury				0.99	0.31 - 3.14
Cerebral palsy				0.91	0.60 - 1.38
Down syndrome				0.42**	0.23 - 0.75
Hearing loss - severe or profound				0.86	0.46 - 1.59
Impulse-control disorder				1.12	0.62 - 2.04
Intellectual disability				0.40*	0.18 - 0.88
Limited or no vision - legally blind				1.25	0.61 - 2.58
Mood disorder				0.88	0.61 - 1.28
Obesity				1.27	0.75 - 2.15
Other mental illness/psychiatric diagnosis				1.10	0.71 - 1.72
Personality/psychotic disorder				1.15	0.74 - 1.77
Physical disability				1.03	0.62 - 1.71
Seizure disorder/neurological problems				0.70*	0.51 - 0.96
Race (ref: White)***	1552.86	4	25.05		
Black/African American				0.60***	0.45 - 0.80
Hispanic, Latino, or Spanish origin				2.60	0.98 - 6.90
American Indian or Alaska Native				1.85	0.96 - 3.59
Other (Asian, Native Hawaiian, other Pacific Islander, or other)				3.13	0.69 - 14.28
Guardianship status (ref: independent decision making)***	1540.77	3	16.9		
Assisted decision making (supported and limited guardianship)				0.68**	0.50 - 0.91
Full/plenary guardianship				1.06	0.78 - 1.45
Other				2.29	0.92 - 5.73
Residence type (ref: own home/apartment)***	1444.07	7	121.49		
Family's house				0.37***	0.25 - 0.53
Host family/family foster care				0.49	0.20 - 1.19
Provider operated house or apartment				2.02***	1.49 - 2.74
Private ICFDD				14.21*	1.88 - 107.45
State operated HCBS group home				1.07	0.54 - 2.10
State operated ICFDD				1.26	0.54 - 2.96
Other				1.71	0.59 - 4.98
Housemates***	1539.44	2	115.9		
Housemates with disabilities				1.22***	1.16 - 1.28
Nondisabled housemates				0.80***	0.72 - 0.89

Complex needs (ref: none)***	1536.71	2	41.2		
Complex medical needs				1.24	0.84 - 1.83
Complex behavioral support needs				2.72***	1.94 - 3.81
Daily support (ref: on call - as needed)***	1470.12	6	78.01		
0 to 3 hours/day				2.53	0.92 - 6.96
3 to 6 hours/day				2.71*	1.04 - 7.10
6 to 12 hours/day				1.94	0.77 - 4.90
12 to 23 hours/day				4.07**	1.51 - 11.00
24/7 - around the clock				6.81***	2.81 - 16.43
Other				3.47*	1.20 - 10.05
Services received***	1450.19	11	127.72		
In-home supports				1.07	0.77 - 1.49
Staffed residential supports				2.25***	1.63 - 3.13
Competitive employment (follow-along supports)				0.81	0.50 - 1.29
Supported community employment				1.00	0.72 - 1.41
Sheltered work				0.89	0.66 - 1.20
Enclave work				0.60*	0.37 - 0.99
Day program/activities				1.08	0.62 - 1.41
Community-based day activities				0.74*	0.57 - 0.97
Recreational activities				1.56**	1.16 - 2.10
Transportation				1.36	0.98 - 1.88
Nursing services				1.50**	1.11 - 2.02

Note. *= $p < .05$. **= $p < .01$. ***= $p < .001$. Only significant models are shown.

Table 3

Impact of Direct Support Professional Turnover on Outcomes

Models	-2LL	df	χ^2	O. R.	95% C.I.
Outcomes					
Are safe**	1034.83	1	8.31	0.61**	0.44 - 0.86
Best possible health**	1389.59	1	7.82	0.68**	0.52 - 0.89
Treated fairly***	1594.17	1	31.5	0.50***	0.39 - 0.64
Are respected***	1561.1	1	48.08	0.42***	0.33 - 0.54
Experience continuity and security***	1444.89	1	206.82	0.16***	0.12 - 0.21
Exercise rights***	1612.12	1	16.95	0.61***	0.48 - 0.77
Interact with others in the community***	1522.56	1	30.82	0.49***	0.38 - 0.63
Live in integrated environments***	1507.16	1	110.87	0.27***	0.21 - 0.35
Participate in community life***	1609.42	1	34.61	0.49***	0.38 - 0.62
Use environments***	1438.79	1	17.95	0.57***	0.43 - 0.74
Intimate relationships***	1633.08	1	11.38	0.67***	0.53 - 0.84
Have friends***	1592.08	1	33.07	0.50***	0.39 - 0.63
Natural supports***	1614.1	1	38.09	0.47***	0.37 - 0.60
Decide when to share personal information***	1625.72	1	18.7	0.59***	0.47 - 0.75
Perform social roles***	1578.74	1	17.1	0.60***	0.48 - 0.77
Choose with whom and where to live***	1339.8	1	30.33	0.48***	0.37 - 0.62
Choose services**	1433.89	1	7.55	0.70**	0.54 - 0.90

Note. *= $p < .05$. **= $p < .01$. ***= $p < .001$. Independent variable for all models is 'change in DSP in past two years'.

Table 4

Impact of Direct Support Professional Turnover on Organizational Supports

Models	-2LL	df	χ^2	O. R.	95% C.I.
Organizational Supports					
Are safe**	948.79	1	10.9	0.55**	0.38 - 0.79
Best possible health*	1533.68	1	5.76	0.74*	0.57 - 0.95
Treated fairly***	1582.22	1	31.95	0.50***	0.39 - 0.64
Are respected***	1512.79	1	42.82	0.42***	0.33 - 0.56
Continuity and Security***	1392	1	153.22	0.18***	0.13 - 0.24
Interact with others in the community***	1530.59	1	26.83	0.52***	0.40 - 0.67
Live in integrated environments***	1581.13	1	57.89	0.40***	0.31 - 0.51
Participate in community life***	1572.19	1	18.16	0.59***	0.46 - 0.75
Use environments***	1412.99	1	11.57	0.63***	0.48 - 0.83
Intimate relationships***	1635.25	1	12.5	0.65***	0.52 - 0.83
Have friends***	1620.27	1	22.39	0.57***	0.45 - 0.72
Natural supports***	1430.36	1	22.07	0.53***	0.41 - 0.70
Decide when to share personal information***	1615.69	1	17.08	0.60***	0.48 - 0.77
Perform social roles***	1539.87	1	14.41	0.62***	0.49 - 0.80
Choose with whom and where to live***	1481.62	1	16.38	0.60***	0.47 - 0.77
Choose Services*	1450.38	1	6.57	0.72*	0.56 - 0.92
Realize personal goals*	1632.59	1	5.8	0.75*	0.59 - 0.95

Note. *= $p < .05$. **= $p < .01$. ***= $p < .001$. Independent variable for all models is 'change in DSP in past two years'.