The Impact of Direct Support Professional Turnover on the Health and

Safety of People with Intellectual and Developmental Disabilities

Carli Friedman, PhD
CQL | The Council on Quality and Leadership
100 West Road, Suite 300
Towson, MD 21204
cfriedman@thecouncil.org

The Impact of Direct Support Professional Turnover on the Health and

Safety of People with Intellectual and Developmental Disabilities

Abstract

Direct support professional (DSP) turnover significantly impacts both human service providers and people with intellectual and developmental disabilities (IDD). This study explored how DSP turnover impacts people with IDD's health and safety. We analyzed secondary data regarding DSP turnover and health and safety (i.e., emergency room visits, incidents of abuse and neglect, injuries, and behavioral events) from a random sample of 251 people with IDD. Findings revealed, regardless of their support needs, people who experienced DSP turnover had more emergency room visits, experienced more instances of abuse and neglect, and had more injuries than people who did not experience DSP turnover. Our findings suggest extended tenure of DSPs can help promote the health and safety of people with IDD.

Keywords: direct support professionals (DSPs); health and safety; emergency room visits; abuse and neglect

The Impact of Direct Support Professional Turnover on the Health and

Safety of People with Intellectual and Developmental Disabilities

Direct support professionals (DSPs) provide individualized personal assistance to people with disabilities and older adults in a wide variety of settings (e.g., people's homes, group homes, institutions, employment settings, etc.). DSP's job duties may include offering assistance with: personal care; health and safety; communication; relationships and networking; community living; transportation; advocacy; household tasks; promoting self-determination; and financial duties (Hasan, 2013; Hewitt & Larson, 2007; Hewitt et al., 2008; Robbins et al., 2013; Wright, 2009). As DSPs provide a wide range of services, they are often required to balance a complex set of competencies, in addition to participating in labor intensive work (National Direct Service Workforce Resource Center, 2013).

As of 2017, there were 4.4 million people working as DSPs in the United States; an estimated one-quarter of which work with people with intellectual and developmental disabilities (IDD) (Espinoza, 2017; National Direct Service Workforce Resource Center, 2013; Taylor, 2008). Although direct support is one of the fastest growing sectors of the labor force in the United States, in large part due to an increase in prevalence as well as people with IDD living longer (Centers for Disease Control, n.d.; Lauer & McCallion, 2015; McCallion et al., 2012), with it estimated to become the largest job in the country by 2020, there is a high annual turnover rate for DSPs (American Network of Community Options and Resources, 2014; Bogenschutz et al., 2014; Hewitt, 2014; Micke, 2015; Robbins et al., 2013). In fact, human service organizations supporting people with disabilities and/or older adults experience DSP turnover rates ranging from 30-70% annually (Bogenschutz et al., 2014; Taylor, 2008). Research suggests people with IDD with complex support needs in particular may be more likely to experience DSP turnover

(Friedman, 2018a). This phenomenon may be due to DSPs receiving less training about people with complex needs, and/or because of increased burnout (Britton Laws et al., 2014; Hasan, 2013; Hewitt & Larson, 2007; Taylor, 2008).

Reasons for the Direct Support Professional Turnover

There are a number of factors contributing to the decades-long issue of DSP turnover. One of the most prominent contributors to DSP turnover is DSP wages (Bogenschutz et al., 2014; Firmin et al., 2013; Hasan, 2013; Hewitt et al., 2008; Micke, 2015; Taylor, 2008; Wolf-Branigin et al., 2007). DSP wages have remained extremely low and have often not kept up with inflation (Edelstein & Seavey, 2009; Hasan, 2013; Wachino, 2016). In fact, DSP wages are typically relatively close to the federal minimum wage. As a result of low reimbursement rates, many human service organizations find themselves competing with the fast food industry for employees as fast food industry wages have been increasing at a quicker rate than the wages of DSPs (Raustiala et al., 2015). DSPs also often do not receive benefits, such as paid leave or healthcare (Bogenschutz et al., 2014; Hewitt et al., 2008).

A lack of training also contributes to DSP turnover (Hasan, 2013; Hewitt, 2014; National Direct Service Workforce Resource Center, 2013). Not only is there a lack of standardization across training, a lack of adequate training can also harm people with IDD's health and safety and hinder community integration. For example, one of the leading reasons people with disabilities are kept at home is a fear that something might happen to them and staff would not be prepared for those risks (Britton Laws et al., 2014). DSPs' self-efficacy impacts their job satisfaction; those DSPs who have more self-efficacy and confidence not only have higher job satisfaction, they also leave their jobs less often (Britton Laws et al., 2014; Ejaz et al., 2008; National Direct Service Workforce Resource Center, 2013).

A lack of career path and advancement opportunities, as well as organizational cultures can also lead to increased DSP turnover (Hasan, 2013; Hewitt & Larson, 2007; Hewitt et al., 2008; Wolf-Branigin et al., 2007). Furthermore, being a DSP is taxing, with a significant workload, which can cause burnout, stress, and depression, all of which can lead to turnover (Britton Laws et al., 2014; Hasan, 2013; Hewitt & Larson, 2007; Taylor, 2008).

The Impact of Direct Support Professional Turnover

In addition to the toll the taxing workload, lack of training, low wages, and organizational culture can take on DSPs themselves, DSP turnover also significantly impacts both human service providers and people with IDD. For example, as a result of constantly needing to fill vacancies, recruit for new DSPs, train new DSPs, and pay overtime to current DSPs to make up for vacancies, turnover can have a tremendous financial burden on disability organizations, many of which are already operating on a limited budget (Hewitt & Larson, 2007; Raustiala et al., 2015). Turnover can also hinder the community integration of people with IDD. DSPs provide quality support to millions of people in the United States; as such, a lack of DSPs can prevent people from accessing their communities (American Network of Community Options and Resources, 2014; Britton Laws et al., 2014; Smergut, 2007; Venema et al., 2015).

Not only do they facilitate community integration, DSPs can also help improve people with IDD's quality of life (Friedman, 2018a, 2020; Robbins et al., 2013). Quality of life typically includes emotional, material, and physical well-being, interpersonal relations, personal development, self-determination, social inclusion, and rights (Cummins, 1991; Cummins et al., 1997; Schalock, 2004; Schalock et al., 2002; Schalock et al., 2010). In fact, those people with IDD who experience DSP turnover are less likely to have a wide range of quality of outcomes present, such as having relationships, performing social roles, choosing their services, being safe

and free from abuse and neglect, and many others (Friedman, 2018a). Moreover, DSP turnover hinders provider organizations' ability to provide supports to people with IDD (Friedman, 2018a). People with complex support needs in particular not only are more likely to face DSP turnover, but also have disparities in outcomes and organizational supports (Friedman, 2018a).

Research suggests DSPs help facilitate the quality of life of people with IDD and DSP turnover can hinder people's quality of life. The aim of this study is to further this line of research by exploring how DSP turnover specifically impacts the health and safety of people with IDD. Our research question was: What is the impact of DSP turnover and complex support needs on the health and safety outcomes of people with IDD? We explored this question by analyzing secondary data regarding DSP turnover from Personal Outcome Measures® interviews, and data regarding health and safety (i.e., emergency room visits, incidents of abuse and neglect, injuries, and behavioral events) from 251 people with IDD.

Methods

Data

This was a secondary data analysis; the data were originally collected from adults with IDD who received services from a single state's developmental disabilities department. The state developmental disabilities department service recipients were randomly selected to participate in Personal Outcome Measures® interviews in 2018. The state developmental disabilities department then pulled the applicable incident reporting data about the sample that human service organizations in the state are required to provide them, particularly emergency room visit data, abuse and neglect incident data, injury data, and behavioral incident/event data from 2016 through 2018. All personal identifiers were removed, and the data were coded with identifiers; the data were then transferred to the research team.

Participants

In total, the secondary dataset included 251 people with IDD. Gender was relatively evenly distributed amongst men (52.19%) and women (47.81%; Table 1). The most common disabilities (in addition to IDD) were seizure disorder/neurological problems (29.96%), anxiety disorders (25.10%), and mood disorder (22.27%). Most participants were White (72.65%) and had a primary communication method of verbal/spoken language (80.08%). Participants most often resided in provider-owned or -operated homes (38.25%), their own home/apartment (31.08%), and family homes (22.71%). The mean age of participants was 47.47 (*SD* = 14.75). Almost a quarter (24.30%) of participants had independent decision-making, 48.21% assisted decision-making, 24.70% full/plenary guardianship, and 2.79% used an 'other' form of decision-making.

Measures and Variables

Dependent Variables: Health and Safety

The following variables served as dependent variables (DVs): emergency room visits; incidents of abuse and neglect; injuries; and behavioral events. Emergency room visits was comprised of every single time a person in the sample visited an emergency room, regardless of the type of incident or severity. Incidents of abuse and neglect included every single allegation of abuse, neglect, and exploitation, both physical and emotional, regardless of if they were substantiated or not. Injuries included every single time a person was injured, regardless of the severity of the injury; examples include burns, lacerations, loss of consciousness, fractures, and so on. Behavioral events included any time there was a documented behavioral event, regardless of the type of incident, where the incident occurred, or if the incident resulted in an injury. Each of the DVs were comprised of three years of data: 2016 through 2018.

Independent Variable: DSP Turnover

The first independent variable (IV) was if people experienced DSP turnover within the past two-years (yes (1); no (0)). This data was derived from Personal Outcome Measures® interviews conducted in 2018. The Personal Outcome Measures® (The Council on Quality and Leadership, 2017) is a person-centered quality of life tool which emphasizes choice, self-advocacy, self-determination, and community inclusion. The Personal Outcome Measures®, which has been continually refined through initial pilot testing, over 25 years of administration, research and content experts, a Delphi survey, and feedback from advisory groups, has construct validity and reliability (Friedman, 2018b; The Council on Quality and Leadership, 2017). This question about people experiencing DSP turnover is part of the Personal Outcome Measures® section on continuity and security.

Independent Variable: Complex Support Needs

Because people with complex support needs can have poorer outcomes as well as experience turnover more often, it was also important to both examine interactions with complex support needs to determine if health outcomes differ depending on these needs, and to control for complex support needs to examine across people with IDD. For this reason, complex support needs (yes (1); no (0)) was also used as an IV. Complex support needs, which also came from the Personal Outcome Measures® data, includes people who have complex medical support needs – those people who needed skilled nursing care twelve or more hours per day – and/or those with comprehensive behavioral support needs – people that required twenty-four hour supervision particularly due to risk of dangerous behavior, such as harm to themselves or others. In our sample, 22.95% of people (*n* = 56) had complex support needs, while 77.05% did not (*n* = 188).

Analysis

We had the following research question: What is the impact of DSP turnover and complex support needs on the health and safety outcomes of people with IDD? After analyzing the data using descriptive statistics, we conducted a 2 x 2 multivariate analysis of variance (MANOVA) to determine the effect of DSP turnover and complex support needs (IVs) on the four health outcomes (DVs): emergency room visits; incidents of abuse and neglect; injuries; and behavioral events. We utilized Pillai's Trace instead of Wilks' Lambda because of unequal cell size and failed homogeneity of variance-covariance. Following the MANOVA, we conducted analyses of variance (ANOVAs) for each of the DVs as follow-up tests. Bonferroni correction (p = 0.013) was utilized because of the large number of analyses and risk of Type I error.

Results

The majority of people with IDD in our sample experienced DSP turnover within the past two-years (65.6%, n = 162), with only slightly more than one-third of participants (34.4%, n = 85) not experiencing turnover within two-years.

The number of emergency room visits ranged from 0 to 64 per person in the three-year period, with an average of 3.73 visits (SD = 6.93). The number of abuse and neglect incidents ranged from 0 to 29 per person in the three-year period, with an average of 1.23 incidents (equivalent to 0.41 per year; SD = 2.77). The number of injuries ranged from 0 to 44 per person in the three-year period, with an average of 1.63 injuries (equivalent to 0.54 per year; SD = 3.83). The number of behavioral events ranged from 0 to 162 per person in the three-year period, with an average of 3.02 (equivalent to 1.01 per year; SD = 13.57).

We conducted a 2 x 2 MANOVA to determine the effect of DSP turnover and complex support needs (IVs) on the four health outcomes (DVs): emergency room visits; incidents of abuse and neglect; injuries; and behavioral events. There was a significant main effect for DSP

turnover, $F (4, 233) = 3.34$, $p = 0.01$, Pillai's trace = 0.05, partial η^2 = .05 and complex support

needs, $F (4, 233) = 4.68$, $p = 0.001$, Pillai's trace = 0.07, partial $\eta^2 = 0.07$. However, there was

not a significant interaction effect, $F (4, 233) = 2.16$, $p = 0.07$, Pillai's trace = 0.04, partial $\eta^2 = $

0.04.

We conducted ANOVAs on the DVs as follow-up tests to the MANOVA for the

significant main effects for DSP turnover and complex support needs (Bonferroni $p = 0.013$).

The following ANOVAs were significant with DSP turnover: emergency room visits; incidents

of abuse and neglect; and injuries (Table 2). Behavioral events was reaching significance but not

significant using Bonferroni method. Regardless of complex support needs, people with IDD

who experienced turnover visited the hospital significantly more often, experienced more abuse

and neglect, and had more injuries than people who did not experience DSP turnover (Figure 1).

The following ANOVAs were significant with complex support needs: emergency room

visits; incidents of abuse and neglect; injuries; and behavioral events (Table 2). Regardless of

DSP turnover, people with IDD who had complex support needs visited the hospital significantly

more often, experienced more abuse and neglect, had more injuries, and had more behavioral

events than people without complex support needs (Figure 2).

Discussion

DSP turnover can significantly hinder the community integration of people with IDD. In

order to detail the important roles DSPs play, the aim of this study was to explore how DSP

turnover impacts the health and safety of people with IDD. Findings revealed, regardless of their

support needs, people who experienced DSP turnover visited the emergency room more often,

experienced more instances of abuse and neglect, and had more injuries than people who did not

experience DSP turnover. As such, our findings suggest DSP continuity helps promote the health and safety of people with IDD.

Our findings suggest continuity of DSPs may result in fewer injuries and emergency room visits. Not only does increased DSP tenure likely result in better care and therefore fewer injuries and emergency room visits, as emergency room visits and hospitalizations are a leading cause of expenditures, a reduction in emergency room visits may also lead to reduced costs (Blaskowitz et al., 2019; Centers for Medicare and Medicaid, n.d.). This reduction in costs as a result of increased DSP tenure would be twofold; not only because of a possible reduction in emergency room visits, but also because of a reduction in expenditures related to recruitment and training as a result of DSP turnover itself, which costs an estimated $960 million annually in the United States as of 2020 (inflation adjusted; Hewitt & Larson, 2007). The hundreds of millions of dollars saved from reduced DSP turnover and reduced emergency room visits and injuries could then be reinvested towards increasing DSP wages and expanding the professionalization of the direct support workforce, as well as used to strengthen the community infrastructure for people with IDD.

In addition, abuse and neglect of people with IDD is a rampant issue that requires attention – people with IDD are significantly more likely to be victims of abuse, neglect, mistreatment, and exploitation than nondisabled people and people with other disabilities (Baladerian et al., 2013). For example, people with IDD are seven times more likely to be victims of sexual assault than nondisabled people (Shapiro, 2018). As people with IDD face a serious risk of harm due to a plethora of abuse and neglect, the U.S. Department of Health and Human Services (HHS), Office of Inspector General, Administration on Community Living, and Office for Civil Rights (2018) have concluded, incidences of abuse and neglect "are not isolated

incidents but a systemic problem" (p. 3). Our findings suggest that the continuity of DSPs may help reduce instances of abuse and neglect.

While not the main aim of our study, our findings also revealed, controlling for DSP turnover, people with complex support needs visited the emergency room more often, experienced more instances of abuse and neglect, had more injuries, and had more behavioral events than people without complex support needs. Not only is this problematic as people with complex support needs are likely to have reduced health and safety, and quality of life as a result, but also because the very medical and psychiatric injuries and needs which result in emergency room visits, can also lead to re/institutionalization for people with complex support needs (Causby & York, 1991; Intagliata & Willer, 1982; Lulinski-Norris, 2014; Lulinski-Norris et al., 2012; Trent, 1994). And because people with complex support needs are more likely to be susceptible to abuse and neglect, injuries, behavioral events, and emergency room visits, we believe it is particularly important that there be strengthened DSP training about supporting people with complex needs; doing so could both improve people with complex support needs' outcomes, and lead to more self-efficacy and less burnout, and therefore less turnover, amongst DSPs.

Implications for Policy and Practice

As DSP turnover can hinder both the health and safety, and the quality of life of people with IDD, attention to issues that cause turnover is necessary. First, as it is one of the leading reasons for turnover, DSP wages must be increased (Bogenschutz et al., 2014; Firmin et al., 2013; Hasan, 2013; Hewitt et al., 2008; Micke, 2015; Robbins et al., 2013; Taylor, 2008; Wolf-Branigin et al., 2007). States cannot continue providing DSP reimbursement rates that are near poverty; by continuing to do so, DSP turnover will not only continue, but states will also fail to

have an appropriate infrastructure to meet the demands of community services, and support

people with IDD in the community. Not only do states need to increase DSP reimbursement

rates, according to the Centers for Medicaid and Medicare Services (CMS), it is critical when

doing so they "also consider [in their reimbursement methodologies] business costs incurred by

a provider – whether a home care agency or an individually employed worker – associated with

the recruitment, skills training, and retention of qualified workers" (Wachino, 2016, p. 3). It may

also be useful to "establish minimum percentages of service rates directed to direct labor

costs…[and/or] lift wages for a broader group of workers, for example indexing the state

minimum wage to inflation or passing living wage laws" (Wright, 2009, p. 2). As research

suggests sexism also plays a significant role in lower DSP wages (Friedman, 2019a), attention

should also be drawn to ending systemic pay gaps between men and women.

Another mechanism to reduce DSP turnover is increasing training and self-efficacy

(Britton Laws et al., 2014; Hasan, 2013; Hewitt & Larson, 2007; Taylor, 2008). The current lack

of state training guidelines can result in gaps, which can hinder the quality of support DSPs

provide (Hasan, 2013; National Direct Service Workforce Resource Center, 2013). Increased

training can not only increase the self-efficacy of DSPs, which reduces turnover, it can also help

promote professional growth and advancement opportunities; moreover, 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). The

professionalization of the direct support workforce could also not only reduce turnover but

improve DSPs' lives (Friedman, 2019b; National Alliance for Direct Support Professionals,

2013; National Association for the Dually Diagnosed, 2018; Smith et al., 2015). According to

Smith et al. (2019), the professionalization of DSPs will result in wage stabilization, expanded

tenure of DSPs as a result of a career ladder, and enhanced quality supports as a result of competency-based training.

Research also suggests that provider organizations may be able to reduce DSP burnout and stress by encouraging DSPs to participate in self-care (Keesler & Troxel, 2019). Keesler and Troxel (2019) found participating in self-care is associated with DSPs having less burnout and secondary traumatic stress – "engaging in selfcare is both preventative and restorative" (p. 18). As organizations can play an important role in encouraging DSPs to participate in self-care, they need to develop an organizational culture that encourages self-care amongst its employees as well as one that empowers employees (Keesler & Troxel, 2019; Lee & Miller, 2013; Orellana-Rios et al., 2018). One such mechanism to encourage self-care amongst DSPs is to train people about self-care. To do so, "it is critical for organizations: to understand the importance of selfcare to professional quality of life; to foster awareness of selfcare among DSPs through education; to promote and reward selfcare practices among DSPs; and, to provide opportunities for the integration of selfcare into daily routines" (Keesler & Troxel, 2019, pp. 20-21).

Limitations

A number of limitations should be noted when interpreting our findings. While the sample was randomly selected, the participants represented one state and were all receiving services from the state developmental disabilities department. Since this was a secondary data analysis, we did not have the ability to add additional questions or variables. It should also be noted that Bonferroni correction is a conservative measure.

Conclusion

Despite an immense and growing need for their services, DSPs are "are among the nation's most vulnerable workers" (American Network of Community Options and Resources,

2014, p. 1). DSPs not only have low wages and a lack of benefits, they also have a taxing

workload that requires them to master a complex set of skills. The systemic treatment of DSPs,

such as the poor reimbursement rates set for their services, simply does not reflect the critically

important services they provide. As indicated by our findings, extended tenure of DSPs can help

promote the health and safety of people with IDD. Reducing DSP turnover we believe can result

in a reduction in injuries, instances of abuse and neglect, and emergency room visits among

people with IDD. Remedying the DSP turnover epidemic is necessary not only to improve the

lives of people with IDD, but also the lives of DSPs.

References

American Network of Community Options and Resources. (2014). *Ensuring a sustainable work force for people with disabilities: Minimum wage increases can not leave direct support professionals behind*. Author.

Baladerian, N., Coleman, T. F., & Stream, J. (2013). *Abuse of people with disabilities: Victims and their families speak out*. *A report on the 2012 national survey on abuse of people with disabilities*. Spectrum Institute. http://disabilityandabuse.org/survey/findings.pdf

Blaskowitz, M. G., Hernandez, B., & Scott, P. W. (2019). Predictors of emergency room and hospital utilization among adults with intellectual and developmental disabilities (IDD). *Intellectual and Developmental Disabilities*, *57*(2), 127-145. https://doi.org/10.1352/1934-9556-57.2.127

Bogenschutz, M. D., Hewitt, A., Nord, D., & Hepperlen, R. (2014). Direct support workforce supporting individuals with IDD: Current wages, benefits, and stability. *Intellectual and Developmental Disabilities*, *52*(5), 317-329. https://doi.org/10.1352/1934-9556-52.5.317

Britton Laws, C., Kolomer, S. R., & Gallagher, M. J. (2014). Age of persons supported and factors predicting intended staff turnover: A comparative study. *Inclusion*, *2*(4), 316-328. https://doi.org/10.1352/2326-6988-2.4.316

Causby, V. D., & York, R. O. (1991). Predictors of success in community placement of persons with mental retardation. *The British Journal of Mental Subnormality*, *37*(72), 25-34. https://doi.org/10.1179/bjms.1991.004

Centers for Disease Control. (n.d.). *Increase in developmental disabilities*. Centers for Disease Control. https://www.cdc.gov/ncbddd/developmentaldisabilities/features/increase-in-developmental-disabilities.html

Centers for Medicare and Medicaid. (n.d.). *Pay-for-performance rate methodologies in a HCBS FFS environment*. Centers for Medicare and Medicaid.

https://www.medicaid.gov/medicaid/hcbs/downloads/training/pay-for-performance.pdf

Cummins, R. A. (1991). The comprehensive quality of life scale—intellectual disability: An instrument under development. *Australia and New Zealand Journal of Developmental Disabilities*, *17*(2), 259-264. https://doi.org/10.1080/07263869100034481

Cummins, R. A., McCabe, M. P., Romeo, Y., Reid, S., & Waters, L. (1997). An initial evaluation of the comprehensive quality of life scale: Intellectual disability. *International Journal of Disability, Development and Education*, *44*(1), 7-19.

https://doi.org/10.1080/0156655970440102

Edelstein, S., & Seavey, D. (2009). *The need for monitoring the long-term care direct service workforce and recommendations for data collection*. National Direct Service Workforce Resource Center. https://phinational.org/wp-content/uploads/legacy/research-report/dsw_dcrrptfeb09.pdf

Ejaz, F. K., Noelker, L. S., & Menne, H. L. (2008). The impact of stress and support on direct care workers' job satisfaction. *The Gerontologist*, *48*(suppl 1), 60-70.

https://doi.org/10.1093/geront/48.Supplement_1.60

Espinoza, R. (2017). *Federal policy priorities: Strengthening the direct care workforce*. PHI.

https://phinational.org/wp-content/uploads/2017/07/phi_federal_report_web_0.pdf

Firmin, M. W., Orient, K. M., Steiner, H., & Firmin, R. L. (2013). Factors affect the employment longevity of staff working with clients possessing intellectual disabilities. *International Journal of Business Anthropology*, *4*(2), 54-65. https://doi.org/10.33423/ijba.v4i2.1150

Friedman, C. (2018a). 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

Friedman, C. (2018b). The Personal Outcome Measures®. *Disability and health journal*, *11*(3),

351–358. https://doi.org/10.1016/j.dhjo.2017.12.003

Friedman, C. (2019a). Gendered jobs and gendered pay: The relationship between sexism and

personal care aide wages. *Manuscript submitted for publication*.

Friedman, C. (2019b). *The move to managed care for intellectual and developmental disability

services: Guidance for state Medicaid and DD Directors, and payers*. CQL | The Council

on Quality and Leadership.

Friedman, C. (2020). *There's no place like home: A national study of how people with

intellectual and/or developmental disabilities and their families choose where to live*. The

Arc of the United States, & CQL | The Council on Quality and Leadership.

https://futureplanning.thearc.org/assets/CFP_Housing_Survey_Technical_Report-

80e6eb718c816d07a15a9972df06a6e73b1393d5b56ae145acc058fce243cd93.pdf

Hasan, S. (2013). *Will there be a direct support professional for me? Looking at what motivates

DSPs [Unpublished Master's thesis]*. Humboldt State University.

Hewitt, A. (2014). Presidential address, 2014—Embracing complexity: Community inclusion,

participation, and citizenship. *Intellectual and Developmental Disabilities*, *52*(6), 475-

495. https://doi.org/10.1352/1934-9556-52.6.475

Hewitt, A., & Larson, S. (2007). The direct support workforce in community supports to

individuals with developmental disabilities: Issues, implications, and promising pactices.

Mental Retardation and Developmental Disabilities Research Reviews, *13*(2), 178-187.

https://doi.org/10.1002/mrdd.20151

Hewitt, A., Larson, S., Edelstein, S., Seavey, D., Hoge, M., & Morris, J. (2008). *A synthesis of direct service workforce demographics and challenges across intellectual/developmental disabilities, aging, physical disabilities, and behavioral health*. University of Minnesota, Institute on Community Integration, Research and Training Center on Community Living. https://nadsp.org/wp-content/uploads/2016/08/Cross-DisabilitySynthesisWhitePaperFinal.pdf

Intagliata, J., & Willer, B. (1982). Reinstitutionalization of mentally retarded persons successfully placed into family-care and group homes. *American Journal of Mental Deficiency*, *8*(1), 34-49.

Keesler, J. M., & Troxel, J. (2019). They care for others, but what about themselves? Understanding selfcare among DSPs' and its relationship to professional quality of life. *Intellectual and Developmental Disabilities*. Advance online publication.

Lauer, E., & McCallion, P. (2015). Mortality of people with intellectual and developmental disabilities from select US state disability service systems and medical claims data. *Journal of Applied Research in Intellectual Disabilities*, *28*(5), 394-405. https://doi.org/10.1111/jar.12191

Lee, J. J., & Miller, S. E. (2013). A self-care framework for social workers: Building a strong foundation for practice. *Families in Society*, *94*(2), 96-103. https://doi.org/10.1606/1044-3894.4289

Lulinski-Norris, A. (2014). *Community capacity to provide mental and behavioral health services to people with developmental disabilities [Unpublished dissertation]*. University of Illinois at Chicago.

Lulinski-Norris, A., Rizzolo, M., & Heller, T. (2012). *An analysis of movement from state operated developmental centers in Illinois*. Institute on Disability and Human Development, University of lllinois at Chicago.

McCallion, P., McCarron, M., Fahey-McCarthy, E., & Connaire, K. (2012). Meeting the end of life needs of older adults with intellectual disabilities. In E. Chang & A. Johnson (Eds.), *Contemporary and innovative practice in palliative care* (pp. 255-270). IntechOpen. https://doi.org/10.5772/29438

Micke, H. (2015). *Causes and solutions for high direct care staff turnover [Master of Social Work Clinical Research Paper]*. St. Catherine University & University of St. Thomas.

National Alliance for Direct Support Professionals. (2013). *credentialing guidebook for direct support professionals*. National Alliance for Direct Support Professionals. https://www.nadsp.org/wp-content/uploads/2016/08/NADSP_Credentialing_Guidebook_FINAL_8.23.13.pdf

National Association for the Dually Diagnosed. (2018). *The NADD Accreditation and Certification Programs*. National Association for the Dually Diagnosed. http://acp.thenadd.org/index.htm

National Direct Service Workforce Resource Center. (2013). *Understanding your HCBS direct service workforce's strengths and preparing the workforce to serve all populations with core competency training* [Paper presentation]. National HCBS Conference, Arlington, VA.

Orellana-Rios, C. L., Radbruch, L., Kern, M., Regel, Y. U., Anton, A., Sinclair, S., & Schmidt,

      S. (2018). Mindfulness and compassion-oriented practices at work reduce distress and

      enhance self-care of palliative care teams: a mixed-method evaluation of an "on the job

      "program. *BMC palliative care, 17*(3), 1-15. https://doi.org/10.1186/s12904-017-0219-7

Raustiala, M., Crosier, B., Drexelius, J. R. j., Schiff, W., Mayo, K., Golden, B., & Seereiter, M.

      (2015). *Supporting people with developmental disabilities: The impact of low wages and

      the minimum wage debate on the direct support professionals workforce*. The Alliance of

      Long Island Agencies for Persons with Developmental Disabilities, Cerebral Palsy

      Association of New York State, Developmental Disabilities Alliance of WNY,

      Interagency council of developmental disabilities agencies inc., NYSACRA, NYSARC,

      & NYSRA. http://50.31.98.189/~ddawny/wp-content/uploads/2015/12/Minimum-Wage-

      Issue-Paper-final-November-27.pdf

Robbins, E., Dilla, B., Sedlezky, L., & Johnson Sirek, A. (2013). *Coverage of direct service

      workforce continuing education and training within medicaid policy and rate setting: A

      toolkit for state medicaid agencies*. National Direct Service Workforce Resource Center.

      https://www.medicaid.gov/sites/default/files/2019-12/dsw-training-rates-toolkit.pdf

Schalock, R. L. (2004). The concept of quality of life: What we know and do not know. *Journal

      of Intellectual Disability Research, 48*(3), 203-216. https://doi.org/10.1111/j.1365-

      2788.2003.00558.x

Schalock, R. L., Brown, I., Brown, R., Cummins, R. A., Felce, D., Matikka, L., Keith, K. D., &

      Parmenter, T. (2002). Conceptualization, measurement, and application of quality of life

      for persons with intellectual disabilities: Report of an international panel of experts.

Mental Retardation, *40*(6), 457-470. https://doi.org/10.1352/0047-
6765(2002)040<0457:CMAAOQ>2.0.CO;2

Schalock, R. L., Keith, K. D., Verdugo, M. Á., & Gómez, L. E. (2010). Quality of life model
development and use in the field of intellectual disability. In *Enhancing the quality of life
of people with intellectual disabilities* (pp. 17-32). Springer Netherlands.
https://doi.org/10.1007/978-90-481-9650-0_2

Shapiro, J. (2018). *The sexual assault epidemic no one talks about*. National Public Radio
(NPR). https://www.npr.org/2018/01/08/570224090/the-sexual-assault-epidemic-no-one-
talks-about

Smergut, P. (2007). Minimizing turnover among support counselors through a value based
culture. *Journal of Nonprofit Management*, *11*(1), 28-39.

Smith, D., Macbeth, J., & Bailey, C. (2019). *Moving from crisis to stabilitzation: The case for
professionalizing the direct support workforce through credentialing*. Community
Bridges Consulting Group, National Alliance for Direct Support Professionals, &
National Leadership Consortium on Developmental Disabilities.
https://www.nadsp.org/wp-content/uploads/2019/02/Moving-from-Crisis-to-
Stabilization-Credentialing-Report.pdf

Smith, V. K., Gifford, K., Ellis, E., Rudowitz, R., Snyder, L., & Hinton, E. (2015). *Medicaid
reforms to expand coverage, control costs and improve care: Results from a 50-state
Medicaid budget survey for state fiscal years 2015 and 2016*. The Kaiser Family
Foundation & National Association of Medicaid Directors.
http://files.kff.org/attachment/report-medicaid-reforms-to-expand-coverage-control-costs-

and-improve-care-results-from-a-50-state-medicaid-budget-survey-for-state-fiscal-years-2015-and-2016

Taylor, S. J. (2008). *The direct support workforce crisis: Can unions help resolve this?* Center on Human Policy: Syracuse University. https://files.eric.ed.gov/fulltext/ED503912.pdf

The Council on Quality and Leadership. (2017). *Personal Outcome Measures: Measuring personal quality of life* (3rd ed.). Author.

Trent, J. W. J. (1994). *Inventing the feeble mind: A history of mental retardation in the United States*. University of California Press.

U.S. Department of Health and Human Services, Office of Inspector General, Administration on Community Living, & Office for Civil Rights. (2018). *Joint Report: Ensuring beneficiary health and safety in group homes through state implementation of comprehensive compliance oversight*. Authors. https://oig.hhs.gov/reports-and-publications/featured-topics/group-homes/group-homes-joint-report.pdf

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

Wachino, V. (2016). *CMCS informational bulletin: Suggested approaches for strengthening and stabilizing the Medicaid home care workforce*. Centers for Medicare and Medicaid Services.

Wolf-Branigin, M., Wolf-Branigin, K., & Israel, N. (2007). Complexities in attracting and retaining direct support professionals. *Journal of Social Work in Disability & Rehabilitation, 6*(4), 15-30. https://doi.org/10.1300/J198v06n04_02

Wright, B. (2009). *Strategies for improving DSW recruitment, retention, and quality: What we know about what works, what doesn't, and research gaps*. National Direct Service Workforce Resource Center.

http://www.advancingstates.org/sites/nasuad/files/hcbs/files/179/8930/Strategies_Improving_Recruitment_Retention.pdf

Figure 1. The impact of direct support professional turnover on emergency room visits, incidents of abuse and neglect, injuries, and behavioral events.

Figure 2. The impact of complex support on emergency room visits, incidents of abuse and neglect, injuries, and behavioral events.

Table 1

Participant Demographics (n = 251)

Variable	*n*	%
Disabilities other than intellectual disability (*n* = 247)		
Seizure disorder/neurological problems	74	29.96
Anxiety disorders	62	25.10
Mood disorder	55	22.27
Personality/psychotic disorder	46	18.62
Cerebral palsy	41	16.60
Behavioral challenges	33	13.36
Autism spectrum disorder	30	12.15
Impulse-control disorder	29	11.74
Limited or no vision - legally blind	15	6.07
Physical disability	11	4.45
Down syndrome	9	3.64
Hearing loss - severe or profound	8	3.24
Alzheimer's disease	2	0.81
Brain injury	2	0.81
Other psychiatric diagnosis	35	14.17
Gender		
Man	131	52.19
Woman	120	47.81
Guardianship status		
Independent decision making	61	24.30
Assisted decision making	121	48.21
Full/plenary guardianship	62	24.70
Other	7	2.79
Primary method of communication		
Verbal/spoken language	201	80.08
Face/body expression	43	17.13

Sign language	3	1.20
Communication device	1	0.40
Other	3	1.20
Race (*n* = 245)		
White	178	72.65
Black	63	25.71
Latinx	5	2.04
Asian	1	0.41
Other	1	0.41
Residence type		
Provider-owned or -operated home	96	38.25
Own home/apartment	78	31.08
Family's house	57	22.71
Host family/family foster care	14	5.58
State-operated HCBS group home	4	1.59
Other	2	0.80
Complex support needs (*n* = 244)		
Yes	56	22.95
No	188	77.05

Note. Participants could have more than one disability or race. HCBS = Home and Community Based Services.

Table 2

Univariate Follow-up Tests (ANOVAs)

Model	F	df	p	partial η^2
DSP Turnover				
Emergency room visits	12.05	1, 240	< 0.001	0.05
Incidents of abuse and neglect	9.95	1, 240	0.002	0.04
Injuries	6.63	1, 240	0.01	0.03
Behavioral events	4.97	1, 240	0.03	0.02
Complex support needs				
Emergency room visits	13.27	1, 240	< 0.001	0.05
Incidents of abuse and neglect	7.71	1, 240	0.006	0.03
Injuries	9.15	1, 240	0.003	0.04
Behavioral events	14.91	1, 240	< 0.001	0.06

Note. Bonferroni correction (p = 0.013) utilized.