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State Utilization of Direct Support Professionals in Medicaid HCBS Waivers

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# State Utilization of Direct Support Professionals in Medicaid HCBS Waivers

Intellectual and Developmental Disabilities

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## Abstract

Direct support professional (DSPs) are crucial to long term services and supports (LTSS) in the United States for people with intellectual and developmental disabilities (IDD). This study examined how states utilize DSPs' personal care services in Medicaid Home and Community Based Services (HCBS) 1915(c) waivers across the nation. We found extreme variance across states and services; ensuring people with IDD receive quality services demands this lack of standardization is reduced. Not only did the reimbursement rates range widely, the majority of rates were very close to the federal minimum wage. In recognition of this important work, states need to reconsider the waiver reimbursement rates of services provided by DSPs.

*Keywords:* direct support professionals; Medicaid Home and Community Based Services (HCBS) 1915(c) waivers; intellectual and developmental disabilities; community living

#### State Utilization of Direct Support Professionals in Medicaid HCBS Waivers

Direct support professionals (DSPs) (often called direct supports, or personal care aides), support people with disabilities and older adults with activities of daily living (ADLs) as well as other tasks necessary for community integration. DSPs must utilize a complex balance of skills and competencies as they play a variety of different roles, such as assistance with personal care, transportation, financial duties, education, household tasks, and self-determination (Bogenschutz et al., 2014; Hasan, 2013; Hewitt & Lakin, 2001; Hewitt & Larson, 2007; Hewitt et al., 2008; National Direct Service Workforce Resource Center, 2013, n.d.; Robbins et al., 2013; Wright, 2009). As such, DSPs are employed to support people with disabilities in a number of different settings, from residential settings, including individual's homes, group homes, and institutions, to employment and day settings (Bogenschutz et al., 2014).

As a result of an increase in the community living of people with disabilities, including the deinstitutionalization of people with intellectual and developmental disabilities (IDD), and the aging of the baby boomer population, the direct support sector is one of the fastest growing areas of the labor force in the United States (Bogenschutz et al., 2014; Micke, 2015; Robbins et al., 2013). In 2011, there were approximately four-million DSPs in the United States, one-quarter of which were supporting people with IDD (National Direct Service Workforce Resource Center, 2013; Taylor, 2008). By 2020, direct support is estimated to be the largest job in the country (Bogenschutz et al., 2014; Hewitt, 2014).

## **The Direct Support Professional Crisis**

Despite an increased need, there is a DSP crisis, with high turnover rates 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, Wolf-Branigin, & Israel, 2007). The DSP turnover rate is significant, with estimates suggesting organizations that support people with disabilities or older adults may see anywhere from 30% to 70% DSP turnover a year (American Network of Community Options and Resources, 2014; Bogenschutz et al., 2014; Hewitt, 2014; Hewitt & Lakin, 2001; Hewitt & Larson, 2007; Hewitt et al., 2008; Keesler, 2016; Micke, 2015; Taylor, 2008; Wolf-Branigin et al., 2007). The majority of this turnover is due to DSPs quitting rather than being fired because despite the immense and growing need, "DSPs are among the nation's most vulnerable workers" (American Network of Community Options and Resources, 2014, p. 1).

The origins of the DSP crisis go back decades to deinstitutionalization where larger workforces were needed and roles shifted from caretakers of basic needs (e.g., health, safety) to expanded responsibilities wherein DSPs were also responsible for supporting peoples' goals, relationships, and community integration (American Network of Community Options and Resources, 2014; Hewitt & Lakin, 2001). Geographic dispersion, and less direct supervision also resulted in increased isolation and decreased mentorship for DSPs (Edelstein & Seavey, 2009; Hewitt & Lakin, 2001). DSP wages have also not kept up with their increased workloads, the demand for their services, or inflation in the United States (Wachino, 2016). The majority of DSPs receive the federal minimum wage (\$7.25), or just slightly higher. As of May 2015, the national average wage for personal care workers was \$10.48, which is below that needed for basic living – a living wage – for a childless individual, let alone a person with children (Bureau of Labor Statistics, 2016; Glasmeier, 2015; Nadeau, 2016, 2017). Low wages and the rarity of benefit packages – DSPs commonly do not receive fringe benefits such as health coverage,

retirement plans, paid time off, or personal leave – have resulted in many DSPs relying on public assistance (Bogenschutz et al., 2014; Hewitt et al., 2008).

Beyond the direct impact on DSPs themselves, low wages are one of the most significant 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). Research indicates that DSP turnover reduces when DSP wages are increased (Robbins et al., 2013). For example, when DSP wages were increased in San Francisco County, annual turnover decreased by almost half (Robbins et al., 2013). Unfortunately, agencies cannot simply increase rates to alleviate the DSP crisis. The majority of providers receive reimbursement through Medicaid; as such, providers do not have the control or funding to raise prices to increase DSP wages (American Network of Community Options and Resources, 2014). For example, providers in Chicago have been struggling because while the city of Chicago increased the minimum wage, state reimbursement rates have not increased, leaving agencies to make up the difference (Ligas Consent Decree Monitor, 2016).

In addition to low wages and a general lack of benefits, another factor contributing to the DSP crisis is training. The federal government only requires 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 add additional standards, training guidelines are rare, resulting in little consistency and providers trying to determine the best method to train DSPs (Hasan, 2013; Hewitt & Lakin, 2001; National Direct Service Workforce Resource Center, 2013). Sufficient training not only facilitates quality services and supports, it can also result in higher job satisfaction and reduce

turnover as a result (Ejaz, Noelker, & Menne, 2008; National Direct Service Workforce Resource Center, 2013).

In addition to threatening the quality of life and community integration of people with disabilities, DSP turnover puts a considerable financial burden on disability organizations, which already struggle with limited resources (Friedman, 2017a; Hewitt & Larson, 2007; Raustiala et al., 2015). Across the nation, DSP turnover costs an estimated \$784 million annually (Hewitt & Larson, 2007). For agencies that support people with disabilities, because of recruitment and training costs, it can cost up to \$5,000 to fill each DSP vacancy (Raustiala et al., 2015).

## **Medicaid Long Term Services and Supports**

DSPs are crucial to long term services and supports (LTSS) for people with IDD in the United States (Bogenschutz et al., 2014, p. 317; McLaughlin et al., 2015, p. 267). Yet, Medicaid, and the reimbursement rates states provide, can serve as a significant gatekeeper to DSP retention and community integration of people with IDD as a result. As such, one way to better understand DSP utilization for people with IDD is through analysis of Medicaid Home and Community Based Services (HCBS) 1915(c) waivers (henceforth referred to as HCBS waivers), as they are the largest provider of LTSS for people with IDD (Braddock et al., 2017). (Please see Braddock et al. (2017) for more information about LTSS mechanisms, including Medicaid.)

Historically, people with IDD had few options other than segregated institutional settings (e.g., intermediate care facilities for people with developmental disabilities (ICFDD)), or living with family if possible. The HCBS waiver program was introduced to expand community living opportunities by allowing service delivery in integrated community-based settings, including individual, family, and group homes. Unlike Medicaid State Plans (standard statewide-Medicaid programs), Medicaid HCBS waivers allow states to 'waive' the key provisions of the Social

Security Act (i.e., statewideness, comparability of services, and income and resource rules) to provide more flexible LTSS in the community (O'Keefe, 2010). As a result, states can create programs targeted for underserved populations (e.g., people with IDD, traumatic brain injury, HIV/AIDs, etc.) by determining waiver's target groups, services furnished, participant direction, provider qualifications, health and welfare strategies, and cost-effective delivery (Disabled and Elderly Health Programs Group et al., 2015).

As a result of improved community outcomes, cost effectiveness, and preferences of people with IDD, HCBS waiver have grown exponentially, surpassing ICFDD funding in 2000, to become the largest provider LTSS for people with IDD (Braddock et al., 2017; Hemp, Braddock, & King, 2014; Lakin, Larson, & Kim, 2011; Larson & Lakin, 1989; Mansell & Beadle-Brown, 2004; Rizzolo et al., 2013). In fiscal year (FY) 2015, \$25.6 billion in federal funds was projected for HCBS waiver services for 630,000 people with IDD (Friedman, 2017b). However, despite being the largest provider of LTSS today, the flexibility granted to states by HCBS waivers has resulted in wide variance across states and services (Friedman, 2017b; Rizzolo et al., 2013). Moreover, little is known specifically about the national DSP utilization in HCBS waivers. For these reasons, the study examined the following research questions: (1). how do states utilize DSPs for personal care in Medicaid HCBS IDD waivers?; (2). What is the average reimbursement rate provided for DSPs' services across the nation in HCBS waivers for people with IDD?; and, (3). how do reimbursement rates for DSPs' services differ across states and services in HCBS IDD waivers? To do so, Medicaid HCBS waivers from across the nation (FY 2015) were analyzed to determine allocation and utilization of DSPs in personal care services for people with IDD.

## Methods

Medicaid HCBS 1915(c) waivers were obtained from the Centers for Medicare and Medicaid (CMS) Medicaid.gov website over a period of approximately 11 months (May 2015 to April 2016) (n = 498). (If waivers were updated during the collection period, the most current edition was used.) The first inclusion criteria was that waivers be 1915(c) (n = 340); all other waiver types (i.e., 1115, 1915(b)) were excluded. The next inclusion criteria required waivers serve people with IDD – intellectual disability (ID), developmental disability (DD), 'mental retardation' (MR), and/or autism spectrum disorder (ASD) (n = 113). (MR is considered an outdated term; however, it remains in use by some waivers (see (Friedman, 2016) so was a necessary search term.) No age limitations were imposed. Finally, to be included waivers had to include FY 2015 (n = 111). While most often this was the state FY (July 1, 2014 to June 30, 2015), a number of states used the federal FY (October 1, 2014 to September 31, 2015), or the 2015 calendar year (January 1, 2015 to December 31, 2015). The term FY is used for consistency. Waivers that did not include 2015, as well as waivers that were pending or expired, were excluded. This process resulted in the collection of 111 HCBS 1915(c) waivers for people with IDD from 46 states and the District of Columbia.

CMS requires waivers to specify: CMS assurances and requirements; levels of care; waiver administration and operation; participant access and eligibility; participant services, including limitations and restrictions; service planning and delivery; participant direction of services; participant rights; participant safeguards; quality improvement strategies; financial accountability; and cost-neutrality demonstrations (Disabled and Elderly Health Programs Group et al., 2015). CMS defines personal care as, "a range of assistance to enable waiver participants to accomplish tasks that they would normally do for themselves if they did not have a disability" (Disabled and Elderly Health Programs Group et al., 2015, p. 144). Personal care services are provided by a DSP. Waiver service definitions from all 111 waivers were reviewed, and only those related to personal care services based on CMS and Rizzolo et al. (2013)'s guidelines were included in the dataset – all other services were excluded. (It should be noted that although they all belong to the larger service category of 'supports to live in one's own home,' companion, homemaker, and supported living services were not included in the analysis; while they are closely related to personal care they were not included in the study because they were not necessarily provided by DSPs.) In FY 2015, there was a total of 101 personal care services provided by 56 waivers from 32 states and the District of Columbia.

The 101 personal care services' cost-neutrality information, which described units of service, projected numbers of participants per service, total projected spending per service, average cost per unit per service, and average units per user per service were then analyzed using descriptive statistics to determine trends across states and services. We especially focused on total projected spending, including spending per capita and fiscal effort, average projected spending per participant, reimbursement rates, and average annual service provision per participant.

#### Results

In FY 2015, 101 services from 56 HCBS 1915(c) waivers (32 states and the District of Columbia) provided personal care services.

#### **Total Participants**

Approximately 70,000 people with IDD were projected to receive personal care services in FY 2015 (Table 1). The average state projected providing personal care services to 2,091 people. The states that provided personal care to the most people were North Carolina (8,855), Washington (6,478), and Illinois (5,410). The states that provided personal care to the least people were District of Columbia (5), Montana (43), and South Dakota (44).

## **Total Projected Spending**

A total of \$1.5 billion was projected for personal care services in FY 2015. The average state projected spending a total of \$45.96 million on HCBS waiver personal care services for people with IDD. However, total projected spending varied widely by state from \$96,301 in South Dakota to \$253.81 million in Maine. This variance occurred even when state population was controlled via spending per capita (Table 1). The average state projected a spending per capita of \$12.02 on personal care services for people with IDD. The states with the highest spending per capita were Maine (\$190.93), West Virginia (\$30.85), and Oklahoma (\$25.09), and the lowest were New Hampshire (\$0.02), South Dakota (\$0.11), and District of Columbia (\$0.15).

Fiscal effort determines "state's commitment to I/DD services after controlling for state wealth. Fiscal effort is theoretically based on the competitive struggle for government funding described by Key (1949) and Wildavsky (1974) as the essence of politics" (Braddock et al., 2015, p. 14). Fiscal effort was calculated by dividing each state's projected spending on personal care services by the state's total personal income. Total personal income is:

...the income received by, or on behalf of, all persons from all sources: from participation as laborers in production, from owning a home or business, from the ownership of financial assets, and from government and business in the form of transfers. It includes income from domestic sources as well as the rest of world. It does not include realized or unrealized capital gains or losses. (Bureau of Economic Analysis, 2016, n.p.). On average states had a fiscal effort of \$0.27 per \$1,000 of personal income. The largest state fiscal efforts were Maine (\$4.30), West Virginia (\$0.83), and Oklahoma (\$0.55), and the smallest District of Columbia (\$0.002), South Dakota (\$0.002), and Montana (\$0.007) (Table 1).

## **Average Spending Per Participant**

On average waivers projected spending \$15,873 per person for personal care services in FY 2015. Maine (\$75,336), Louisiana (\$65,933), and Oklahoma (\$48,489) projected spending the most per participant on average, while South Dakota (\$2,189), Colorado (\$3,501), and Utah (\$4,204) projected the least per participant on average (Table 1). 30.3% of states (n = 10) projected spending between \$0 and \$10,000 per participant on average, 33.3% (n = 11) between \$10,001 and \$20,000, 21.2% (n = 7) between \$20,001 and \$30,000, 3.0% (n = 1) between \$30,001 and \$40,000, 6.1% (n = 2) between \$40,001 and \$50,000, and 6.1% (n = 2) above \$50,000.

#### **Reimbursement Rates**

HCBS waivers provided personal care services using a variety of different reimbursement rates, including 15-minute (n = 73 services), hour (n = 20 services), day (n = 5 services), week (n = 1 service), and other (n = 2 services). Of those personal care services that were reimbursed by 15-minute rates, the average reimbursement rate per service was \$4.57 per 15-minutes (\$18.26 an hour). Fifteen-minute rate personal care services reimbursement rates ranged by service from \$2.04 per 15-minutes (\$8.16 an hour) to \$13.07 per 15-minutes (\$52.28 an hour) (see figure 1). The average projected hourly personal care services reimbursement rate was \$13.85, the average daily rate \$157.35, weekly rate \$91.47, and 'other' rate \$47.08 (Table 2). HCBS waiver reimbursement rates also varied widely by state (Table 3).

## **Annual Service Provision Per Participant**

The annual service provision per participant for 15-minute rate services ranged by service from 32 units (eight hours) to 17,081 units (4,270.3 hours or 177.9 days) of personal care per year. 15-minute rate services provided an average of 3,239 units (809.8 hours or 33.7 days) of personal care to the average participant per year (figure 2). Hourly rate services provided participants with 1,407.3 hours of personal care a year on average, daily rate 287 days, weekly rate 52 weeks, and 'other' 290 (Table 2).

## Discussion

In wake of the DSP crisis, the aim of this study was to explore how states value the important services DSPs provide, particularly by how they prioritized DSPs' work through projected service allocation. We examined the provision of personal care services in Medicaid HCBS waivers across the nation because they are the largest funders of LTSS for people with IDD. Our analysis of HCBS waiver's personal care services, especially the reimbursement rates states set, served as a proxy analysis as states are required to prioritize the limited resources available to them while designing their waivers and their service allocation.

Our findings revealed although a significant amount of funding (\$1.5 billion) was projected by waivers for personal care services for people with IDD in FY 2015, the total was less than 6% of the total spending projected by HCBS waivers for people with IDD (\$25.6 billion) (Friedman, 2017b). Moreover, we found wide variance across states and services in terms of total projected spending, average spending per participant, reimbursement rates, and annual service provision per participant. This variance remained even when state characteristics, such as population and personal income, were controlled. This lack of standardization can be problematic when trying to ensure people with IDD are receiving quality personal care.

States often have limited resources available to them and therefore must prioritize funding accordingly. However, DSPs not only provide immediate personal care services but are also key to the community integration of millions of people in the United States (American Network of Community Options and Resources, 2014; Britton Laws, Kolomer, & Gallagher, 2014; Smergut, 2007; Venema, Otten, & Vlaskamp, 2015). Research has found that DSP turnover also can significantly hinder quality of life; "a competent and stable workforce is a quality indicator in the lives of people with IDD" (McLaughlin et al., 2015, p. 267). The lack of continuity and security people with IDD experience because of the DSP crisis results in people with IDD being less likely to have human security, such as safety or health (Friedman, 2017a). They are also less likely to integrate into the community, such as participate in the life of the community, or use their environments, as well as less likely to foster and maintain social and interpersonal relationships (American Network of Community Options and Resources, 2014; Britton Laws et al., 2014; Friedman, 2017a; Smergut, 2007; Venema et al., 2015). A consistent DSP workforce also plays a role in person centered services by supporting people with IDD to choose where they live and their services, both of which are significantly less likely to be present when people with IDD experience DSP turnover (Friedman, 2017a).

#### **Implications for Policy and Practice**

In recognition of this important work, states need to reconsider the waiver reimbursement rates of services provided by DSPs. Not only did the reimbursement rates for personal care in FY 2015 range widely, the majority of rates were very close to the federal minimum wage (\$7.25), which annually equates to a full time salary that is below the poverty line for families of two or more (Cooper, 2013). Although mediocre, these reimbursement rates are similar to the national average wage for personal care workers (\$10.48 in May 2015), mirroring a much larger systemic

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issue (Bureau of Labor Statistics, 2016). This is especially problematic given research has found that low wages are one of the leading causes of DSP turnover, meaning states will not have the appropriate infrastructure to support people with IDD in the community, and meet the demands of community services (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 DSP crisis is a threat to community growth because DSPs are necessary to "delay or prevent institutionalization, improve quality of life and keep long-term care costs lower" (Robbins et al., 2013, p. 2). Despite people with IDD, their families, and states wanting smaller settings, due to this crisis, many agencies have begun increasing residential setting sizes because of a lack of workforce infrastructure to support smaller settings (Ligas Consent Decree Monitor, 2016). Since providers often do not "have sufficient staff to support more customized and integrated employment opportunities" there is a "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" (Ligas Consent Decree Monitor, 2017, p. 22).

CMS requires states reimbursement methodologies are not only efficient and cost effective but that they result in "*quality of care* [that is] sufficient" (Centers for Medicare and Medicaid, n.d., n.p.). Thus, to effectively increase rates, when developing rates it is critical for states to "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). Other methods to increase reimbursement rates include CMS or states "establishing minimum percentages of service rates directed to direct labor costs…[and/or] lift[ing] 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). Future research should examine the impact and effectiveness of these alternative techniques, especially on the DSP crisis and the lives of people with IDD.

By comparison personal care services spending per participant is a fraction of the cost of institutional care. We found the majority of states projected spending less than \$20,000 per person on personal care services annually in FY 2015. For comparison, in FY 2015 the average state institutional cost was \$210,110 per person (Braddock et al., 2017). While personal care services are not in and of themselves holistic services, the package of services HCBS waivers provide to support people with IDD in the community are significantly more cost effective than institutional care (average waiver spending per participant in FY 2015 was \$39,989) (Braddock et al., 2017; Friedman, 2017b), suggesting there should be room to increase the reimbursement rates and utilization of the services provided by DSPs so that DSPs are paid a living wage that not only reduces turnover but also recognizes the value of their contributions.

#### **Future Research and Limitations**

Although CMS requires states to meet minimum standards, states are granted wide berth in terms of waiver design, including reimbursement rates, as indicated by the variance in our findings. Yet, states are not required to comprehensively describe why they make the decisions they do in waiver design. For these reasons, future research should examine the motivations behind states' rate methodologies, particularly as a useful mechanism to ensure people with IDD are receiving quality and consistent personal care regardless of where they live across the nation, as well as to reduce threats to deinstitutionalization and community integration (American Network of Community Options and Resources, 2014; Britton Laws et al., 2014; Robbins et al., 2013; Smergut, 2007; Venema et al., 2015). Another useful research avenue would be examining

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the self-directed waiver services, including budget authority, which allows people to direct their budgets for certain services (Friedman, in press), and how they impact DSP reimbursement rates in Medicaid HCBS waivers. This is especially pertinent as the majority of HCBS waivers for people with IDD allowed participant direction in FY 2015 (Friedman, in press).

When interpreting our results, it should be noted that Medicaid HCBS waivers are projections to the federal government rather than actual utilization data. However, they are reasonably accurate proxies as states create their projections based on previous years' utilization data. A national analysis of FY 2013 HCBS waivers for people with IDD by (Rizzolo et al., 2013) also produced similar findings to FY 2013 utilization analyses by Braddock et al. (2015).

Moreover, although HCBS 1915(c) waivers are the largest funding mechanism for people with IDD, they are hardly the only mechanism. While the aim of this study was specifically to examine 1915(c) waivers, future studies should also examine the rest of the IDD landscape and how they utilize and reimburse DSPs.

## Conclusion

DSPs are central to the quality of life of people with IDD (Bogenschutz et al., 2014; Friedman, 2017a). Yet, not only is there little standardization of personal care services in Medicaid HCBS waivers, many of the rates provided to DSPs in waivers were also near the minimum wage. Remedying the DSPs crisis is critical to ensure people with IDD have full access to their civil rights, including community integration. People with IDD, and allies should use the information in this study to advocate for increased utilization of DSP services and reimbursement rates, particularly by using states who ranked highly, such as Maine, or those with similar characteristics to their own states, as benchmarks. As the largest provider of LTSS for people with IDD, Medicaid HCBS waivers are the perfect vehicle to improve the lives of people with IDD *and* 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. Alexandria, VA: Author.
- 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.
- Braddock, D., Hemp, R., Rizzolo, M. C., Tanis, E. S., Haffer, L., & Wu, J. (2015). *The state of the states in intellectual and developmental disabilities: Emerging from the great recession* (10th ed.). Washington, DC: The American Association on Intellectual and Developmental Disabilities.
- Braddock, D., Hemp, R., Tanis, E. S., Wu, J., & Haffer, L. (2017). The state of the states in intellectual and developmental disabilities: 2017 (11th ed.). Washington, DC: The American Association on Intellectual and Developmental Disabilities.
- 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.
- Bureau of Economic Analysis. (2016). Personal income and outlays, July 2016 [Press release]. Retrieved from http://www.bea.gov/newsreleases/national/pi/pinewsrelease.htm
- Bureau of Labor Statistics. (2016). Occupational employment and wages, May 2015: 39-9021 personal care aides. Retrieved from http://www.bls.gov/oes/current/oes399021.htm
- Centers for Medicare and Medicaid. (n.d.). Financing & reimbursement. Retrieved from <u>https://www.medicaid.gov/medicaid/financing-and-reimbursement/</u>

Cooper, D. (2013). The minimum wage used to be enough to keep workers out of poverty—it's not anymore. *Economic Policy Institute*. Retrieved from

http://www.epi.org/publication/minimum-wage-workers-poverty-anymore-raising/

- Disabled and Elderly Health Programs Group, Center for Medicaid and State Operations, Centers for Medicare and Medicaid Services, & Department of Health and Human Services. (2015). Application for a §1915(c) Home and Community-Based Waiver [Version 3.5]: Instructions, technical guide, and review criteria. Retrieved from <u>http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-</u> <u>Topics/Waivers/Downloads/Technical-Guidance.pdf</u>
- Edelstein, S., & Seavey, D. (2009). The need for monitoring the long-term care direct service workforce and recommendations for data collection. *Washington, DC: National Direct Service Workforce Resource Center*.
- 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.
- 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.
- Friedman, C. (2016). Outdated language: Use of "mental retardation" in Medicaid HCBS waivers post-Rosa's Law. *Intellectual and Developmental Disabilities*, 54(5), 342-353. doi:<u>http://dx.doi.org/10.1352/1934-9556-54.5.342</u>
- Friedman, C. (2017a). Direct support professionals and quality of life of people with intellectual and developmental disabilities. *Manuscript submitted for publication*.

- Friedman, C. (2017b). A national analysis of Medicaid Home and Community Based Services waivers for people with intellectual and developmental disabilities: FY 2015. *Intellectual* and Developmental Disabilities, 55(5), 281-302. doi:10.1352/1934-9556-55.5.281
- Friedman, C. (in press). Participant direction for people with intellectual and developmental disabilities in Medicaid Home and Community Based Services waivers. *Intellectual and Developmental Disabilities*. doi:10.1352/1934-9556-56.1
- Glasmeier, A. K. (2015). *Living wage calculator*. Cambridge: Massachusetts Institute of Technology.
- Hasan, S. (2013). *Will there be a direct support professional for me? Looking at what motivates DSPs.* Humboldt State University.
- Hemp, R., Braddock, D., & King, M. (2014). Community-based Medicaid funding for people with intellectual and development disabilities. *NCSL legisbrief*, *22*(7), 1.
- Hewitt, A. (2014). Presidential address, 2014—Embracing complexity: Community inclusion, participation, and citizenship. *Intellectual and Developmental Disabilities*, 52(6), 475-495. doi:10.1352/1934-9556-52.6.475
- Hewitt, A., & Lakin, K. C. (2001). Issues in the direct support workforce and their connections to the growth, sustainability and quality of community supports (Vol. 21). Minneapolis, MN: University Of Minnesota, Research And Training Center On Community Living.
- 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.
- 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.* Minneapolis, MN: University of Minnesota, Institute on Community Integration, Research and Training Center on Community Living.

- Keesler, J. M. (2016). An evaluation of individual and organizational factors in predicting professional quality of life among direct support professionals in intellectual/developmental disability services. State University of New York at Buffalo, Buffalo.
- Lakin, K., Larson, S., & Kim, S. (2011). Behavioral outcomes of deinstitutionalization for people with intellectual and/or developmental disabilities: Third decennial review of US studies, 1977-2010. *Minneapolis, MN: Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota.*
- Larson, S. A., & Lakin, K. C. (1989). Deinstitutionalization of persons with mental retardation:
   Behavioral outcomes. *Journal of the Association for Persons with Severe Handicaps*, 14(4), 324-332.
- Ligas Consent Decree Monitor. (2016). *Stanley Ligas, et al. v. Felicia Norwood, et al.: Fourth annual report of the Monitor.*
- Ligas Consent Decree Monitor. (2017). *Stanley Ligas, et al. v. Felicia Norwood, et al.: Fifth annual report of the Monitor.*
- Mansell, J., & Beadle-Brown, J. (2004). Person-centred planning or person-centred action?
  Policy and practice in intellectual disability services. *Journal of Applied Research in Intellectual Disabilities*, 17(1), 1-9.
- McLaughlin, C., Sedlezky, L., Belcher, H., Marquand, A., & Hewitt, A. (2015). Workforce: Goals for research and innovation. *Inclusion*, *3*(4), 267-273.

- 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, St. Paul, MN.
- Nadeau, C. A. (2016). Living wage calculator. Retrieved from <u>http://livingwage.mit.edu/resources/Living-Wage-User-Guide-and-Technical-Notes-</u> <u>2016.pdf</u>
- Nadeau, C. A. (2017). *A Calculation of the living wage*. Cambridge: Massachusetts Institute of Technology.
- 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 presented at the National HCBS Conference, Arlington, VA.
- National Direct Service Workforce Resource Center. (n.d.). *Direct service worker background handout*. Baltimore, MD: Author.
- O'Keefe, J. S., Paul; Jackson, Beth; Cooper, Robin; McKenney, Ernest; Crisp, Suzanne;
   Moseley, Charles. (2010). Understanding Medicaid Home and Community Services: A Primer, 2010 Edition. Retrieved from <u>https://aspe.hhs.gov/report/understanding-</u> medicaid-home-and-community-services-primer-2010-edition
- 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. New York: 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, and NYSRA.

- Rizzolo, M. C., Friedman, C., Lulinski-Norris, A., & Braddock, D. (2013). Home and Community Based Services (HCBS) Waivers: A nationwide study of the states. *Intellectual and Developmental Disabilities*, 51(1), 1-21. doi:10.1352/1934-9556-51.01.001
- 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. Washington, DC: National Direct Service Workforce Resource Center.
- Smergut, P. (2007). Minimizing turnover among support counselors through a value based culture. *Journal of Nonprofit Management*, *11*(1), 28-39.
- Taylor, S. J. (2008). *The direct support workforce crisis: Can unions help resolve this?* Syracuse, NY: Center on Human Policy, Syracuse University.
- 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.
- Wachino, V. (2016). CMCS informational bulletin: Suggested approaches for strengthening and stabilizing the Medicaid home care workforce. Baltimore, MD: 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.

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

State	Projected participants	Projected spending	Spending per capita	Fiscal effort	Average spending per participant
Alabama	208	\$10,559,360	\$2.17	\$0.06	\$16,320
Colorado	1,865	\$6,529,613	\$1.20	\$0.02	\$3,501
Connecticut	1,021	\$17,326,108	\$4.83	\$0.07	\$16,970
District of Columbia	5	\$100,748	\$0.15	\$0.002	\$20,150
Florida	5,000	\$209,286,000	\$10.32	\$0.22	\$41,857
Georgia	591	\$5,228,790	\$0.51	\$0.01	\$8,847
Hawaii*					
Idaho	324	\$1,541,087	\$0.93	\$0.02	\$4,756
Illinois	5,410	\$67,320,000	\$5.23	\$0.10	\$12,444
Indiana	2,393	\$19,502,711	\$2.95	\$0.07	\$8,150
Iowa	597	\$7,003,083	\$2.24	\$0.05	\$11,730
Kansas	2,995	\$40,236,598	\$13.82	\$0.29	\$13,435
Kentucky	1,882	\$50,702,355	\$11.46	\$0.29	\$26,941
Louisiana	53	\$3,494,431	\$0.75	\$0.02	\$65,933
Maine	3,369	\$253,808,207	\$190.93	\$4.30	\$75,336
Massachusetts	1,842	\$64,635,285	\$9.51	\$0.15	\$35,090
Michigan	419	\$8,175,505	\$0.82	\$0.02	\$19,512
Minnesota	3,898	\$88,389,757	\$16.10	\$0.31	\$22,676
Mississippi	1,425	\$23,298,750	\$7.79	\$0.22	\$16,350
Missouri	4,250	\$34,881,469	\$5.73	\$0.13	\$8,207
Montana	43	\$316,340	\$0.31	\$0.007	\$7,357
New Hampshire	425	\$4,873,900	\$0.02	\$0.06	\$11,468
North Carolina	8,855	\$104,277,652	\$10.38	\$0.24	\$11,776
Ohio*	2,279	\$54,337,614	\$4.68	\$0.10	\$23,843
Oklahoma	2,024	\$98,142,315	\$25.09	\$0.55	\$48,489
Pennsylvania	1,751	\$48,635,648	\$3.80	\$0.07	\$27,776
South Carolina	384	\$1,956,917	\$0.40	\$0.010	\$5,096
South Dakota	44	\$96,301	\$0.11	\$0.002	\$2,189
Tennessee	2,496	\$56,119,622	\$8.50	\$0.19	\$22,484
Utah	592	\$2,488,969	\$0.83	\$0.02	\$4,204
Virginia	2,859	\$69,221,013	\$8.26	\$0.15	\$24,212
Washington	6,478	\$106,631,015	\$14.87	\$0.27	\$16,460
West Virginia	3,090	\$56,900,002	\$30.85	\$0.83	\$18,414
Wyoming	131	\$710,246	\$1.21	\$0.02	\$5,422

Table 1Medicaid HCBS Waiver Personal Care Services (FY 2015)

*Note.* \* = waiver provided combined services which were excluded because they could not be separated out.

# Table 2

	Reimbursement rate type						
	15- minutes	Hour	Day	Week	Other		
n	73	20	5	1	2		
Rate							
Min	\$2.04	\$3.54	\$84.37		\$28.08		
Max	\$13.07	\$23.90	\$285.19		\$66.08		
М	\$4.57	\$13.85	\$157.35	\$91.47	\$47.08		
SD	\$1.89	\$4.18	\$75.71		\$26.87		
Median	\$3.89	\$13.74	\$141.14		\$47.08		
Provision							
Min	32	229	49		229		
Max	17,081	6,599	358		351		
М	3,239	1,407	287	52	290		
SD	2,809	1,432	133		86		
Median	2,289	920	347		290		

Medicaid HCBS Personal Care Reimbursement Rates and Provision Per Participant Per Year

Table 3

Average Reimbursement Rate by State

	Average reimbursement rate						
State	15- minutes	Hour	Day	Week	Other		
Alabama	\$3.85						
Colorado	\$4.87						
Connecticut	\$6.11						
District of Columbia	\$4.72						
Florida	ψ-1.12		\$126.84				
Georgia	\$2.88		φ120.01				
Hawaii*	φ2.00						
Idaho				\$91.47			
Illinois		\$14.50		Ψ/1.47			
Indiana		\$23.90					
Iowa	\$4.38	ψ25.70					
Kansas	\$2.64						
Kentucky	\$5.73						
Louisiana	\$3.86						
Maine	\$6.14		\$285.19				
Massachusetts	\$7.74		\$205.19				
Michigan	ψ <b>/</b> ./ <del>4</del>	\$14.48					
Minnesota	\$4.18	\$3.54			\$66.08		
Mississippi	\$5.45	\$J.J <del>4</del>			φ00.00		
Missouri	\$3.81						
Montana	\$5.61	\$17.94					
New Hampshire		\$17.94					
North Carolina	\$4.15	\$12.20					
Ohio*	\$3.56						
Oklahoma	\$5.50	\$15.68	¢145 17				
	\$4.29	\$13.08	\$145.17				
Pennsylvania South Carolina	\$4.29	\$14.02			¢70 00		
	¢10.70	\$14.03			\$28.08		
South Dakota	\$12.78						
Tennessee	\$3.72		¢01 27				
Utah Vincinia	\$3.28	¢11.40	\$84.37				
Virginia Weshington		\$11.49					
Washington	¢2.27	\$11.59					
West Virginia Wyoming	\$2.27 \$3.87						

*Note.* \* = waiver provided combined services which were excluded because they could not be separated out.

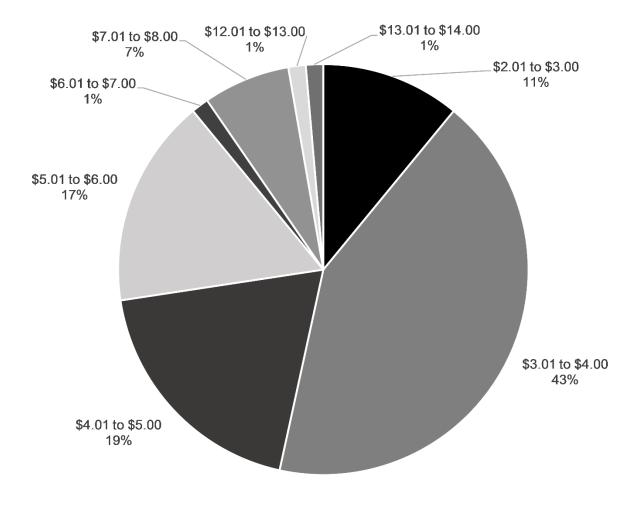


Figure 1. Reimbursement rates by service for 15-minute unit personal care services.

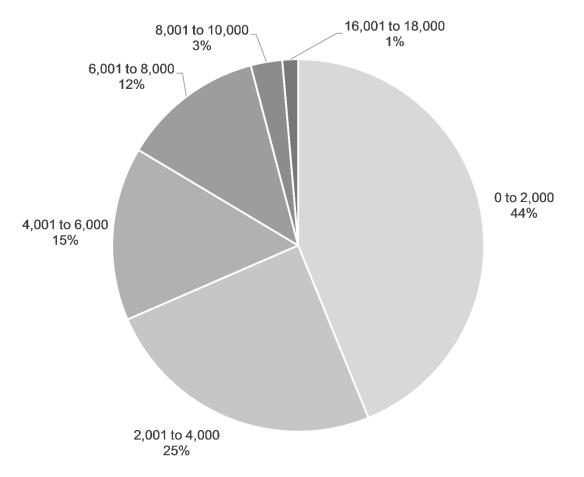


Figure 2. Annual service per participant by service for 15-minute rate personal care services.