



Community Supports in Crisis: No Staff, No Services

June 2022

Authors: **Institute on Community Integration (ICI), University of Minnesota**

Julie Bershadsky, PhD

Amy Hewitt, PhD

Human Services Research Institute (HSRI)

Valerie Bradley, MA

Alexandra Bonardi, MS, OT, MHA

National Association of State Directors of Developmental Disabilities Services (NASDDDS)

Laura Vegas, MS

Mary Sowers

ICI improves policies and practices to ensure that all children, youth, and adults with disabilities, and those receiving educational supports, are valued by and contribute to their communities of choice. ICI is a designated University Center for Excellence in Developmental Disabilities, part of a national network of similar programs in major universities and teaching hospitals across the country. The Institute is home to over 70 projects and six affiliated centers, addressing disability issues across the lifespan.

HSRI is a non-profit organization that is celebrating 45 years as a leader in the field of disabilities. Over the decades, HSRI had combined rigorous quantitative research with community-based participatory research to help develop more effective and responsive service systems and policies to support people with disabilities and their families.

NASDDDS represents the nation's agencies in 50 states, Puerto Rico, and the District of Columbia providing services to children and adults with intellectual and developmental disabilities and their families. NASDDDS promotes visionary leadership, systems innovation, and the development of national policies that support home and community-based services for individuals with disabilities and their families.

Recommended citation:

ICI, HSRI, & NASDDDS. (2022). *Community supports in crisis: No staff, no services*. Minneapolis, MN: University of Minnesota, Institute on Community Integration.

This document was funded in part by grant #90RTC0003 from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), U.S. Department of Health and Human Services, awarded to the Research and Training Center on Community Living (RTC-CL), Institute on Community Integration (ICI), University of Minnesota.

The opinions expressed herein are those of the author and do not necessarily reflect the policy or position of NIDILRR, ICI, or the University of Minnesota or their funding sources and no official endorsement should be inferred.

The University of Minnesota is an equal opportunity educator and employer. This document is available in alternate formats upon request.

© 2022 University of Minnesota Regents. All rights reserved.

For alternate formats, please contact —

Institute on Community Integration
2025 East River Parkway
University of Minnesota
Minneapolis, MN 55414

ici.umn.edu
icipub@umn.edu
612-624-6328

The Institute on Community Integration (ICI) collectively acknowledges that Minnesota is located on the traditional, ancestral, and contemporary lands of Indigenous people. As people residing on this land, we also acknowledge that it was cared for and is called home by the Anishinaabe, Chippewa, Ojibwe, Dakota, or Northern Cheyenne peoples, and other Native peoples from time immemorial. This land holds great historical, spiritual, and personal significance for its original stewards, the Native nations and peoples of this region. We recognize, continually support and advocate for the sovereignty of the Native nations in this territory and beyond. By offering this land acknowledgment, we affirm tribal sovereignty and will work to hold ourselves and affiliations accountable to American Indian peoples and Nations.

We acknowledge that the United States emerged out of profound historical, spiritual, and personal trauma for indigenous, minoritized, and oppressed communities in the United States, including people with disabilities. We hold this moment as a way to remember the generations of people who have endured systemic oppression since the nation's founding, including the forced institutionalization of people with disabilities. We recognize and continually support the need for community specific reparations and healing processes needed for healing to take place for violation of systematic policies against people. By offering this acknowledgment of trauma, we affirm the right of people to bring their whole selves and stories into this space and aim to use our resources and time to arrive at a more connected and respectful place in the world.

Contents

Introduction: Sounding the Alarm p. 1

Background: What Do We Know About the Direct Support Professional Network? p. 2

U.S. Department of Labor occupational categories p. 2

Demographics of the direct support workforce p. 2

Pay levels p. 3

Training and competencies p. 3

Nature and breadth of settings where DSPs work p. 3

Drivers of the DSP Crisis p. 4

Demographic shifts in the U.S. p. 4

Nature of people with IDD receiving long-term services and supports p. 4

Range of competencies required p. 5

Increasing numbers of older adults p. 6

System changes p. 7

Low wages, limited benefits, lack of career p. 7

Inflation p. 7

Impact of the Workforce Crisis p. 7

Impact on providers p. 7

Impact on DSPs p. 8

Impact on people with IDD p. 9

Initiatives to Enhance Workforce Stability and Competence p. 10

Employee Resource Networks (ERNs) and Employee Assistance Programs (EAPs) p. 11

Staff/participants matching (Collaborative for Self-Directed Supports) p. 11

Time is of the Essence! What We Need to Do Now p. 11

Create an occupational category at the U.S. Department of Labor p. 11

Ensure that the DSP workforce is recognized as a distinct cohort within the overall caregiving and direct support workforce p. 12

Pass federal legislation to increase wages and access to affordable benefits, institutionalize training and credentialing programs, and recognize the direct support workforce p. 12

Embed training and other workforce enhancement requirements in value-based purchasing schemes p. 12

Simplify self-direction programs p. 12

Increase the use of technology to enhance LTSS p. 13

Establish federal and state interagency taskforces p. 13

References p. 13

Appendix A p. 15

State Initiatives p. 15



Introduction: Sounding the Alarm

The system of services for people with intellectual and developmental disabilities (IDD) has come a long way in the last 30 years — from segregated care in remote institutions to a robust and varied network of community supports. This progress took decades and was not inevitable. It was achieved through persistent advocacy on multiple levels. It took lifting the voices of people with disabilities and family members, litigation and legal action to secure rights, federal legislation that codified the values of inclusion and access, and building a body of research and evidence-based best practices.

All the progress toward community living that has been made in services for people with IDD over decades is now in jeopardy — because of catastrophic labor shortages and pervasive high turnover rates among the workforce that supports them, direct support professionals (DSPs).

Because of these shortages and high turnover rates, community programs for people with IDD across the country have started closing — many permanently. People in smaller residences are being moved to larger congregate facilities or back home to live with elderly parents. Far too many providers are seeking to increase the size of their existing programs or to consolidate them. Waiting lists are growing because there are no staff to open new programs, deliver support to new people with IDD in their homes or staff old ones. Many providers have undertaken burdensome debt to keep their doors open (ANCOR, 2021). Most importantly, people with IDD, as well as their families, are experiencing dangerous disruptions that put them at risk of losing their hard-won lives in the community. The gains made over decades are being reversed. This dire picture is the result of a rapidly worsening workforce crisis which was exacerbated by the COVID-19 pandemic.

DSPs are the backbone and beating heart of the system of supports for people with IDD. They are directly responsible for assisting people with IDD to live and fully participate in their communities. They perform varied and complex tasks and bear a high level of responsibility. However, attracting and retaining skilled DSPs has become a daily

challenge to service provider agencies around the country. At the same time, the challenges faced by DSPs themselves are increasing, as more and more people with complex disabilities live and work in the communities and neighborhoods of their choosing. With the onset of the COVID-19 pandemic, the complexity and burden of the DSP has only increased.

Though DSPs are essential to the well-being of people with IDD and a well-functioning service system, most DSPs experience low wages that are equivalent to or less than an entry-level retail or hospitality service job, and fringe benefits are minimal, and for DSPs, often unaffordable. This inequity between high-skill requirements and low pay has been a major contributing factor to turnover within the DSP workforce. Recent increasing inflation and wage increases in other professions are only making the problem worse.

Meeting the present and future needs of people with IDD and their families requires a stable, supported, and sustainable workforce. The integrity of the long-term services and supports system (LTSS), and the ability to achieve positive outcomes for participants, depends on it.

The purpose of this paper is to —

- Sound the alarm about the nature and scope of the workforce crisis in the IDD service system,
- Clarify the unique characteristics and responsibilities of this workforce, compared to caregivers in other LTSS sectors,
- Provide an overview of the depth of the crisis in the workforce and the impact on people with IDD,
- Identify state and provider initiatives that have shown success in addressing the crisis, and
- Suggest urgent policy changes to enhance the stability of the workforce.



Background: What Do We Know About the Direct Support Professional Network?

This section will introduce the overall scope of the caregiving network providing long-term services and supports (LTSS). It will describe who provides services and supports in the aging, IDD, behavioral health, and nursing fields, and what distinguishes these professions.

U.S. Department of Labor occupational categories

The 2018 Bureau of Labor Statistics (BLS) Standard Occupational Classification system is a federal statistical standard used by federal agencies to classify workers into occupational categories for the purpose of collecting, calculating, or disseminating data. All workers in the United States are classified into one of 867 detailed occupations according to their occupational definition. Though DSPs are part of a vast network of services and supports to people with IDD and their families, BLS does not have a specific occupational category for DSPs. DSPs are subsumed under three primary Standard Occupational Classifications: (1) Personal Care Assistant (PCA), (2) Home Health Aide (HHA), and (3) Nursing Assistant (NA). While some DSPs do provide health-related functions, they need to master a broader array of competencies, including facilitating community inclusion, supporting choice-making, supporting employment, and teaching life skills.

Because of the lack of a Standard Occupational Classification for DSPs, it is difficult to identify DSPs in the BLS data. There is no data collection at the federal level, and no consistent data collection at the state level. Estimates must be made even about basic things such as the size of the workforce, and it is difficult to collect or track dependable data on their work conditions and outcomes.

Demographics of the direct support workforce

The direct support workforce has historically been largely comprised of women. Data from the National Core Indicators Staff Stability Survey (2020) indicate that approximately 70% of the DSP workforce are women. Of those, roughly 70% are prima-

ry wage earners and head of households (Hewitt et al., 2021) with an average household size of three persons. The average age of DSPs has increased over the past 30 years and is now 46 (Zippia, 2022). When compared to general population data, the direct support workforce is disproportionately comprised of Black, Latino and other persons of color (NCI, 2020). An increasing number of DSPs are first-generation Americans, many of whom speak fluent English in addition to their language of origin and previously held health care positions in their country of origin (President's Committee on People with Intellectual Disabilities [PCPID], 2017).

Before the COVID-19 pandemic, there were 4.6 million people in the direct support workforce in 2019 (Campbell et al., 2021). The growth in the aging population from 47.8 million to 88 million by 2050 will increase the number of workers needed to provide these services (PCPID, 2017; Campbell et al., 2021). It is estimated that there will be an additional 1.3 million in-home care jobs created between 2016 and 2028 (Campbell et al., 2021). This will be the largest growing occupation in the United States economy (Campbell et al., 2021).

Pay levels

Compared to DSPs, other direct care professionals consistently earn a higher wage. According to the Bureau of Labor Statistics (2020), Home Health Aids and Personal Care attendants earned an average of \$13.49 per hour, Nursing Assistants earned \$15.41 per hour, Residential Advisors earned a mean hourly wage of \$16.07, and Psychiatric Aides earned \$16.01 per hour. According to NCI Staff Stability data (2020), the mean hourly wage for DSPs was \$13.28. Despite the fact that DSPs need to have a bigger skill portfolio, other direct care professionals often benefit from higher wages and increased visibility due to the credentialed nature of their work.

Training and competencies

For PCAs, HHAs, and NAs, there are well-defined federal training and competency requirements. For example, there is a 75-hour pre-service educational requirement for Nursing Assistants and Home Health Aides. Federal training requirements have resulted in pre-service training programs for these occupational titles in most community/technical colleges in the U.S. However, there are no federal training requirements for DSPs and training programs for other direct care personnel are neither required nor aligned with the training needs of DSPs.



While DSPs may need skills similar to PCAs, HHAs, and NAs (e.g., to support people with medical, self-care, and other activities of daily living), they also require training that supports independence, supports people to learn new skills, teaches people with an ID how to make informed decisions, and facilitates community involvement and social participation. Because there are no federal requirements, training requirements for DSPs vary from state to state but typically include 40 hours of post-hire training.

Nature and breadth of settings where DSPs work

DSPs work in a range of settings, including family homes, people's own homes, intermediate care facilities, small community residential group homes, community job sites, vocational and day training programs, and others. Many DSPs work alone with a person with an IDD in individual or family homes, small group homes, the community, and employment settings. As the shift from congregate care to home- and family-based services continues, DSPs will take on ever-greater responsibility and accountability.

Drivers of the DSP Crisis

There are many factors that coalesced to create a DSP recruitment and retention crisis in HCBS services and supports for people with IDD. These factors include changing demographics of the workforce, challenging needs of people served, and the scope of competencies that DSPs need to do their jobs.

Demographic shifts in the U.S.

The number of people age 18+ entering the workforce is not keeping pace with the increased demand for LTSS to serve the U.S. population. Many demographic factors are influencing this decline, including a slower growth rate in our overall population, more of the U.S. population entering retirement years — and needing support — and an overall decrease in the percentage of the population participating in the labor force. As employers compete, they bid up wages, leaving publicly-funded IDD providers at a disadvantage.

Nature of people with IDD receiving long-term services and supports

To understand the work that DSPs do, it is important to understand the characteristics of the people with IDD with whom they work. National

Core Indicators® (NCI) IDD In-Person Survey (IPS) data provide an overview of the needs and characteristics of people served in home and community-based services (HCBS). These data highlight the challenges faced by DSPs as more and more people with complex disabilities live and work in the communities and neighborhoods of their choosing. NCI data for the five survey periods from 2012-2013 through 2018-2019 show that the proportion of individuals with behavior challenges living in the community more than doubled during that span, from 15% to 31%, the proportion with anxiety disorder grew from 14% to 29%, and the proportion with a mood disorder increased from 23% to 31%. In terms of the level of support needed to address these various challenges that people face, the NCI data indicate that of the total sample across the country, 67% require round-the-clock supervision and support or daily support.

At the same time, fewer people now choose to live in large congregate settings, with most people choosing to live in small community settings. While there are many benefits to this shift, it also results in many DSPs working in teams of two or three staff or on their own, with only intermittent face-to-face interaction with supervisors or other organizational management. The following table shows the places where people with IDD receiving long-term services and supports live.

Figure 1. DSPs provide supports across all these settings.

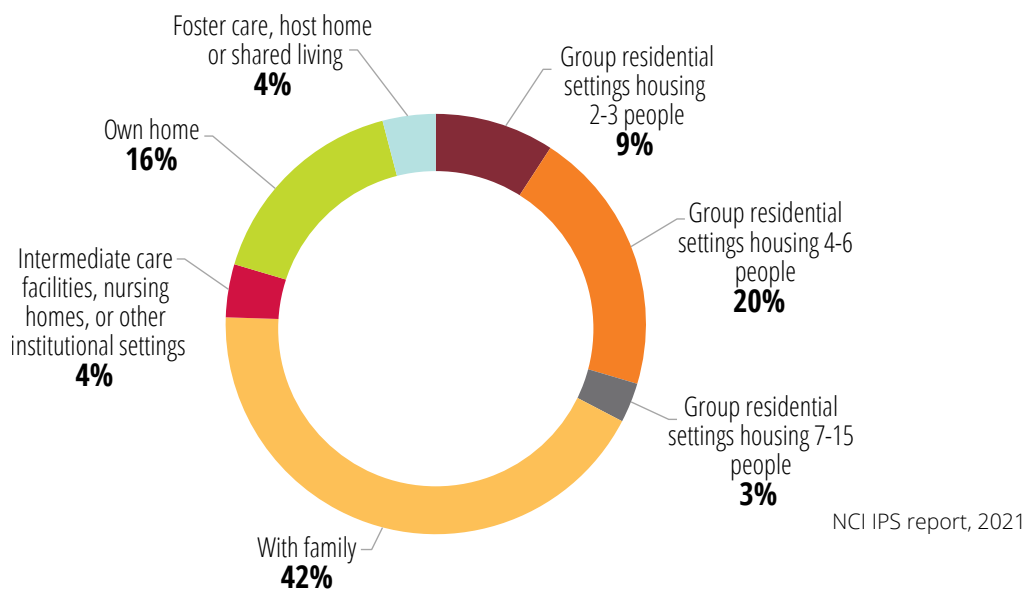
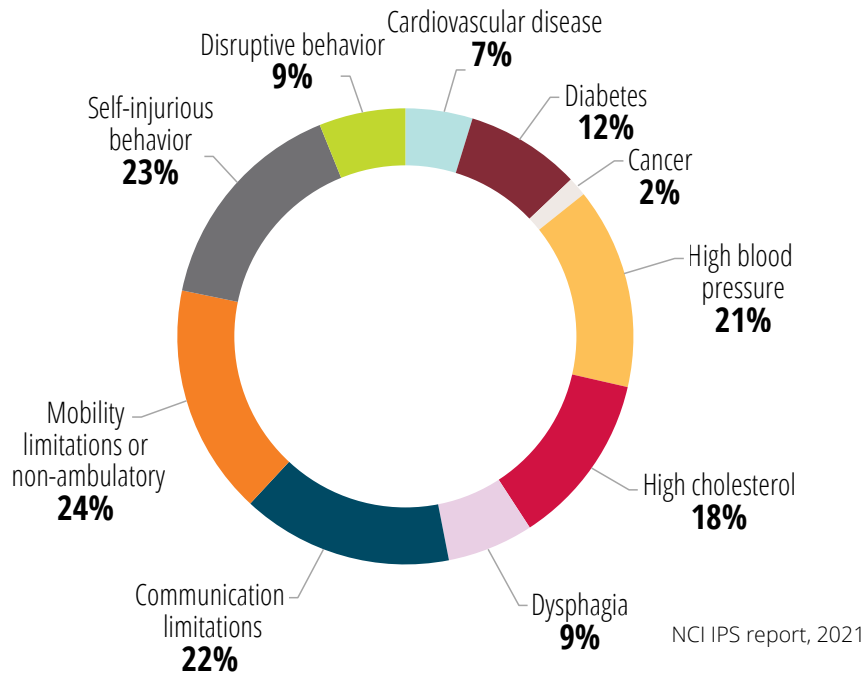


Figure 2. Health challenges among people with IDD receiving services

These data paint a broad picture of people with IDD that suggests their need for a varied range of supports, including but not limited to behavioral, medical, clinical, social, community engagement, relationship building, decision-making, and with activities and instrumental activities of daily living. To successfully provide these supports requires that DSPs bring a wide range of skills and knowledge to their job — a level of mastery that is not reflected in their pay.

Range of competencies required

The DSP role is complex because it is about supporting each individual in a person-centered fashion. The workforce must have the knowledge, skills, and ethical compass to perform a wide array of tasks that support people with IDD to be healthy, safe, valued, and engaged members of their communities. DSPs are interdisciplinary professionals. They have job duties that resemble aspects of many different professions. Like teachers, they develop and implement effective strategies to teach people new skills. Like nurses, they dispense medications, administer treatments, document care, and communicate with medical professionals (PCPID, 2017). To achieve this, it is important that DSPs receive sufficient, high-quality training and opportunities for paid professional development on an ongoing basis.

As noted earlier, there are no federal minimum training requirements for DSPs. Career pathways that provide DSPs an opportunity to increase competency and professionalism are a recommended strategy to improve retention of the workforce and quality of support. In spite of the lack of federal requirements, numerous sets of national and state DSP-specific competencies have been identified and refined over the past 25 years. The National Alliance for Direct Support Professionals (NADSP) and the Centers for Medicare and Medicaid Services (CMS) have identified nationally-validated competencies for DSPs that recognize the knowledge, skills, and abilities need by DSPs to effectively support individuals with disabilities in the community. However, use of established competencies to set workforce development and training standards is not widespread.

Credentialing has the potential to increase quality of services, justify improved compensation for DSPs, and establish recognition and career pathways in an occupation that historically has been undervalued. Much like those available for CNAs and HHAs, widely accessible credentialing and training programs specific to the role of DSPs are needed throughout the community college system in the U.S.



Increasing numbers of older adults

There are many factors that contributed to the escalating workforce crisis in the IDD field, characterized by high turnover, high vacancies, and low wages. One overarching factor is the aging of the U.S. population. In a 10-year period from 2006 to 2016, the population age 65 and over increased from 37.2 million to 49.2 million in 2016 (a 33% increase) and is projected to almost double to 98 million in 2060 (Administration on Community Living, 2017). Currently, one in every seven individuals in the U.S. is over age 65. This means there is a growing number of people who require support. More people needing support means more competition for workers in LTSS. Likewise, the life expectancy of people with IDD is growing, which can be attributed to better medical care and health surveillance, as well as improved living conditions. The average lifespan of people with IDD is now similar to the general population (Bittles et al., 2002; Janicki, Dalton, Henderson, & Davidson, 1999, as cited

in Heller 2010). The number of adults with IDD age 60 years and older is projected to nearly double from 641,860 in 2000 to 1.2 million by 2030 (when all of the Baby Boom generation will be over 65). While this is something to be celebrated, it means that people with IDD will require additional years of support.

Further, as parents and informal caregivers of adult family members with IDD age and become infirm, the demand for services increases — a demand that will continue to grow over the next several years. Data from the National Core Indicators Adult Family Survey (2021) indicate that 67% of family members with an adult with IDD living at home were over 55 and 12% were 75 and older.

To cap it off, the aging trends are affecting the DSP workforce itself as well — people working in these positions are also getting older and nearing retirement, which will add to the number of people exiting the workforce and increase the DSP turnover rate.

System changes

Changes in the structure of the IDD service system have also changed demands on the workforce. Over decades, the average size of residential arrangements has continued to decline. According to data from the Residential Information Systems Project (RISP), for example, the proportion of people receiving services in group settings has been declining, whereas the proportion of people receiving services in their own, family, or foster family homes has been growing. In 2015, for example, the proportion of people receiving services living in a group setting was 28%; by 2018, it had decreased to 25%. Similarly, people are less likely to spend their days in large congregate programs and are increasingly taking advantage of more inclusive community experiences (RISP). A rule by the Centers for Medicare and Medicaid Services in 2014 referred to as the Settings Rule provided additional impetus for the deconstruction of larger residential and day services. This more individualized and person-centered approach is in keeping with a consensus in the IDD field about how to enhance quality of life but requires more one-to-one coverage and less group support, which requires more staff.

Low wages, limited benefits, lack of career

The crisis is also driven by low wages, which means that HCBS provider agencies compete with other entry-level industries (e.g. retail, hospitality) for employees. To understand the full consequences of low wages combined with high skill demands, it is important to note the vacancy rates in DSP positions. According to the 2020 NCI Staff Stability Survey, the average vacancy rate for full-time staff was 12.3% nationally, while the states ranged from 2% to 17.2%. For part-time staff, the national average was 11.2%, with states ranging from 2.4% to 29.8% (based on 2,987 provider agencies that submitted data).

Additional factors contribute to the revolving door of people in and out of these positions. In its *Report to the President 2017*, the President's Committee on People with Intellectual Disabilities (2017) focused on the workforce challenges in the IDD field. In addition to low compensation and meager benefits (often offered but not utilized), the Committee also highlighted a high rate of injury due to the physical demands of their positions, sanctions for the consequences of their actions, isolation from other workers and supervisors given the decentralized nature of the system, the lack of a career ladder,

and insufficient training and professional development.

In addition to low wages, DSPs do not receive adequate and affordable workplace benefits, such as health and/or dental insurance, daycare, etc. According to the latest (2020) NCI Staff Stability Survey, while 80% of providers offered some type of Paid Time Off (PTO), only 70% of providers offered health insurance, and 65% offered dental insurance and/or vision coverage. Furthermore, these offered benefits were often out of reach of most DSPs — only 50% of eligible employees were enrolled in the insurance benefit, even though it was offered.

Inflation

The recent high inflation has exacerbated the low wage and lack-of-benefit problem. The annual inflation rate for the United States as of April 2022 was 8.2%. This high inflation is eating away at already low DSP wages, and provider agencies cannot increase DSP wages to keep up without increased service rates controlled by the government.

Impact of the Workforce Crisis

The DSP workforce crisis significantly impacts providers, workers and the people they support. The COVID-19 pandemic exacerbated the crisis and brought the system to the brink of imploding.

Impact on providers

As noted, the labor shortage in the IDD field was already a crisis prior to the pandemic. In the past two years, the crisis has become even more desperate, given the disruption caused by COVID-19. To gain a better understanding of the impact of the pandemic on the DSP workforce, NCI developed a COVID-19 supplement to its annual Staff Stability survey. Supplement data were collected between January 1 and December 31, 2020. Below are some of the findings —

- Slightly over half (53%) of responding providers across states reported that the number of DSPs on their payroll decreased over the course of 2020.
- Slightly less than half (41%) reported a decrease in the number of adults with IDD enrolled or approved for services over the course of 2020.

8 • Community Supports in Crisis: No Staff, No Services

- Of those whose DSP numbers dropped by more than 10% in 2020, more than half (57%) experienced a decrease in numbers of adults with IDD enrolled in or approved for services.
- Almost one fifth (19%) of providers put DSPs on furlough at some point during 2020. This percentage varied by state, ranging from 5% of agencies in one state to 31% of agencies in another.
- One third (33%) of agencies reported having closed locations/sites in response to the COVID-19 pandemic.
- Almost half (47%) reported stopping the delivery of some supports, either temporarily or permanently.
- About 15% reported paying family members to serve as support providers during the pandemic.

Providers also noted changes in the nature of services and supports provided. More than half (62%) of providers altered the delivery of certain “non-residential” supports and stopped providing other “non-residential” supports. Specifically, 33% closed locations/sites, 37% limited the number of DSPs rotating into a location by increasing the hours per shift, 6% began live-in services, 56% altered how some supports were delivered, 47% stopped delivering some supports temporarily or permanently, and 37% limited the number of sites/locations/addresses at which a DSP could work.

During the pandemic, to retain and reward staff, 38.3% of providers reported implementing at least one bonus for all DSPs and 25.5% reported implementing temporary wage increases to all DSPs supporting adults with IDD. Roughly one quarter (24.8%) reported that no wage bonuses or wage increases were implemented for the purposes of retaining DSPs during the pandemic.

Across states, the turnover rate for DSPs in 2020 ranged from 27% to 80%; the weighted average turnover rate was 44%. Vacancy rates for full-time positions among responding providers ranged from 2% to 17% with an average of 12%. Vacancy rates for part-time positions ranged from 2% to 30% with an average of 16%.

Additional data on the impact of the workforce crisis was collected by ANCOR (2021) through a survey of providers of community IDD services to determine the impact of the workforce crisis on their programs and on their ability to deliver quality

supports to people in need in their communities. The survey was conducted in February 2020 and generated responses from 805 organizations. Findings included —

- 66% of providers turned away new referrals, particularly those with higher staffing needs,
- 34% of providers are discontinuing programs and services, and waiting lists are increasing,
- 65% of providers are delaying the launch of new programs or services,
- 69% of providers are struggling to achieve quality standards, including complying with the settings rule,
- Short staffing means people have limited choice of who they live with and where,
- 40% of providers are seeing higher frequencies of reportable incidents, and
- The average provider spends an additional \$904,000 annually to fill vacancies and train new staff.

Finally, a survey of state Medicaid agencies, completed by the Kaiser Family Foundation (Watts et al., 2021) in July 2021, documented that impact of staff shortages on agencies providing HCBS services and supports —

“The Medicaid HCBS provider infrastructure declined during the pandemic, with two-thirds of responding states reporting a permanent closure of at least one provider. Most of these states reported permanent closures among more than one HCBS provider type. States most frequently cited workforce shortages as the pandemic’s primary impact on in-home and group home services, while closures due to social distancing measures was the most frequently reported primary impact on adult day health and supported employment programs.”

Impact on DSPs

The challenges faced by the DSP workforce worsened during the pandemic. Staff shortages increased, people’s routines were disrupted during lockdowns, staff and the people they served confronted new hygiene protocols, DSPs were deployed to unfamiliar settings, and personal protective equipment was in short supply. Many DSPs left their jobs to care for children out of school and



family members. The first round of a survey on the effects of COVID-19 on the DSP workforce (Hewitt et al., 2020) conducted in April and May of 2020 documented the impact of the pandemic in the early months of the spread of the disease. Using a convenience sample of 9,000 DSPs, the survey found —

- Among the respondents:
 - » 74% were primary wage earners
 - » Median wage was \$13.54 on 1/1/20
 - » 76% were not getting paid more during COVID-19
- Of those who worked extra hours per week:
 - » 29% worked 1-15 hours more
 - » 10% worked 16-30 hours more
 - » 15% worked 31+ hours more

Additionally, 30% worked different shifts and 29% worked in different settings. With respect to the availability of staff, 25% of respondents said that they were more short-staffed than they were before the pandemic. To underscore the last point, 42% of respondents knew a DSP who had left their job due to COVID-19 (e.g., because of a childcare issue, fear of becoming infected). With respect to personal protective equipment, less than half of the respondents reported that they had medical-grade face masks.

Hewitt and colleagues conducted two more rounds of the survey from November 2020 to January 2021 and June to July 2021. By the final round, 50% of respondents had experienced physical and or emo-

tional burnout, 47% experienced anxiety, 38% had difficulty sleeping, 18% had physical health complications, and 4% experienced suicidal thoughts. The number of additional hours worked also increased significantly over time, with 26% worked 1-15 hours more per week, 12% worked 16-30 additional hours per week and 24% of DSPs reported working 31+ additional hours per week.

Impact on people with IDD

Workforce disruptions have a direct and negative effect on the well-being of people with IDD. High rates of turnover among DSPs have been linked to injuries and hospital admissions among people with intellectual and developmental disabilities, and also contribute to job stress among staff who remain, which in turn contributes to more turnover and higher rates of incidences (ANCOR, 2021). Turnover also undermines consistent and sustainable training protocols which are critical to ensuring that people with IDD receive the health, behavioral, nutritional, and other support that they need. A review of Personal Outcome Measures interviews conducted with over 1,300 people with IDD revealed that DSP continuity is central to quality of life, including security, community, relationships, choice, and goals.



Initiatives to Enhance Workforce Stability and Competence

Due to the dire circumstances with staff shortages experienced in every state and the District of Columbia, states are seeking strategies to turn the tide and may have undertaken efforts to improve recruitment, retention, and job satisfactions among DSPs. An important recent tool in these efforts is the American Rescue Plan Act of 2021 (ARPA).

As noted on Medicaid.gov¹, on March 11, 2021, President Biden signed the ARPA legislation (Pub. L. 117-2). Section 9817 of ARPA provides qualifying states with a temporary 10% increase to the federal medical assistance percentage (FMAP) for certain HCBS Medicaid expenditures. States were required to submit plans to CMS detailing how they will enhance HCBS in their states using ARPA funds. The single largest investment area by states in their ARPA Spending plan is workforce². These investments have included one-time payments in the

form of retention and recruitment bonuses, wage increases, training and certification efforts, and workforce registries.

These ARPA investments build upon the strong efforts and early learning from some states who initiated work in these areas even prior to the pandemic. Following is a summary of the actions taken by states with ARPA funds —

- 44 of 49 states included provider payment enhancements in their initial spending ARPA plans including:
 - » Increased compensation
 - » Workforce development strategies
- Wage increases:
 - » Bonus payments for recruitment and retention
- Additional innovations:
 - » Student loan forgiveness
 - » Rate methodology changes to include DSP transportation payments
 - » Childcare stipends
 - » Scholarships and reimbursement rate enhancements with requirement for DSP wage increase for DSP advanced education
 - » Value Based Payments based on training completion

1 <https://www.medicaid.gov/medicaid/home-community-based-services/guidance/strengthening-and-investing-home-and-community-based-services-for-medicaid-beneficiaries-american-rescue-plan-act-of-2021-section-9817-spending-plans-and-narratives/index.html>

2 <https://www.medicaid.gov/medicaid/home-community-based-services/downloads/arp-sec9817-overview-infographic.pdf>

These changes are fairly recent and it is not yet clear what impact they will have on the workforce crisis. It will be important to track whether provider vacancy rates decline over time. See Appendix A for a description of specific state initiatives and innovations.

Employee Resource Networks (ERNs) and Employee Assistance Programs (EAPs)

One innovative model is the Employee Resource Networks (ERNs). ERNs pull together job retention services, work supports, education, and training. While the focus is on entry-level and low wage employees, the services are available to all who work for ERN member companies.

The goal of the ERN programs is for: (1) workers to gain economic self-sufficiency for themselves and their families, (2) employers to retain an engaged and skilled workforce, (3) public agencies and nonprofits get better outcomes from programs that advance economic independence, and (4) community colleges to add students and build closer ties to area businesses.

Another innovative model is the Employee Assistance Program (EAP). An EAP is an employee benefit program that assists employees with personal problems and/or work-related problems that may impact their job performance, health, mental, and emotional well-being.

Staff/participants matching (Collaborative for Self-Directed Supports)

An emerging model is staff/participants using online platforms that match people looking for services with people who provide such services. One such program is the Interactive DSP Map, which works to connect available DSPs and SDEs (Self-Directed Employees) with people who need their services in the state of New Jersey. The initiative includes an interactive virtual map indicating where DSPs and SDEs are available for work now so that people and families can contact them directly for an immediate start date. People and families in need of services can also post their request for support on the [Map](https://www.thecollaborativenj.org/nj-interactive-map.html) (<https://www.thecollaborativenj.org/nj-interactive-map.html>).



Time is of the Essence! What We Need to Do Now

The challenges related to high turnover, high vacancy rates, and limited career pathways have existed for the direct support professional workforce for decades. Warnings were provided over two decades ago about how changes in U.S. demographics by 2020 would seriously heighten the challenges faced regarding this LTSS workforce. A global pandemic catapulted the anticipated worsening workforce challenges into a situation that is untenable for state systems, organizations, DSPs, and most importantly, individuals with IDD and their families. A coordinated national workforce plan must be implemented and sufficiently funded to remedy the decades-long crisis in community LTSS.

Create an occupational category at the U.S. Department of Labor

To accurately count the size and scope of the direct support professional (DSP) workforce, it is critical that it be accurately counted. None of the existing occupational categories accurately or adequately describe the work of DSPs. The occupational categories of Home Health Aid (HHA), Personal Care Assistant (PCA), and Certified Nursing Assistant (CNA) are primarily focused on health care. DSPs do provide health care and all the skills required of these other LTSS. However, they provide many additional skills focused on supporting people with disabilities to be connected to and engaged in their communities. These additional skills need to be recognized by the U.S. Department of Labor (DOL) and identified with a unique occupational code. To ensure that the DOL effectively describes this workforce and understands the required skills and competencies, the Department should be advised by a national group of key stakeholders. Additional-



ly, should a new DOL occupational code be developed, targeted training and information should be provided to state-level labor department staff who have previously coded this group of workers.

Ensure that the DSP workforce is recognized as a distinct cohort within the overall caregiving and direct support workforce

The direct support workforce is not homogenous. There are common skills used and aspects of the work performed by the overall workforce. However, there are differences in the types of places they work, people to whom they provide support, and the actual supports provided to each group of individuals who receive LTSS. The unique aspects of this workforce must be recognized to ensure sufficient training, support, clear expectations, and adequate compensation.

Pass federal legislation to increase wages and access to affordable benefits, institutionalize training and credentialing programs, and recognize the direct support workforce

States often take their lead and can gain state-level legislative support for their long-term services and supports from federal agencies. As such, it is imperative that federal legislation is developed and passed that instructs federal agencies to create a funded national plan of action to ensure wages that align with skills, access to affordable benefits, and

training requirements that lead to credentialing programs. Legislation needs to mandate that the U.S. Departments of Health and Human Services, Labor, and Education work together to develop and implement the national plan that includes stakeholder engagement in its development. Additionally, states should be provided incentives to encourage similar state-level activities.

Embed training and other workforce enhancement requirements in value-based purchasing schemes

As LTSS moves more toward the use of value-based purchasing schemes, efforts to ensure that workforce stability is embedded in these schemes is essential. This should include expectations of reducing turnover and vacancy rates while simultaneously uplifting the skills and stability of the workforce.

Simplify self-direction programs

Self-direction is a slow but steadily growing community service option under Home and Community Based Services in the U.S. There is promise that by increasing utilization of this service type, fewer people with IDD will be in out-of-home placements that require 24-hour care and needed staffing. When individuals and families direct their own services, they often rely on other family members and friends to provide support. Additionally, individuals and families often have greater flexibility in establishing base

pay rates and increases in wages over time. One effective method for addressing the workforce crisis is to increase the use of self-direction options. One barrier to increasing use of self-directed community supports is that in many states the access is overly burdensome and paperwork reporting requirements can be intimidating. Many individuals and families do not want to become the legal employers of their DSPs. Efforts should be made to simplify processes and encourage growth in self-directed supports.

Increase the use of technology to enhance LTSS

Technology cannot supplant human beings in community human services offered through long term services and supports. However, technology can make support more efficient and, in some cases, more effective to the individuals who receive services and to their DSPs as well. Federal incentives to states and incentives from states to provider organizations to promote smart home, adaptive, and everyday technology for persons with IDD is important.

Establish federal and state interagency taskforces

The federal government should establish an interagency task force on the direct support workforce with participation minimally from: (1) U.S. Department of Health and Human Services – Administration on Community Living, Assistant Secretary of Planning and Evaluation, Centers for Medicare and Medicaid Services, Health Resources and Services Administration, President's Committee on People with Intellectual Disabilities; (2) U.S. Department of Labor; and (3) U.S. Department of Education. This task force should include staff members from these agencies who have expertise in the direct support workforce or will learn more about this workforce and how their agency can address threats to the sustainability and growth of community long-term services and supports. Additionally, the federal interagency taskforce should intentionally seek engagement from other key stakeholders (e.g. individuals who receive LTSS, direct support professionals, families, employers, state IDD agencies). States should be provided incentives to create similar state-level interagency taskforces on the direct support workforce.

References

- Administration on Community Living. (2017). *2017 profile of older Americans*. <https://acl.gov/sites/default/files/Aging%20and%20Disability%20in%20America/2017OlderAmericansProfile.pdf>
- ANCOR. (2021). *The state of America's direct support workforce*. https://www.ancor.org/sites/default/files/issue_brief_the_state_of_americas_direct_support_workforce.pdf
- Bittles, A., Petterson, B., Sullivan, S., Hussain, R., Glasson, E., & Montgomery, P. (2002). The influence of intellectual disability on life expectancy. *The Journals of Gerontology: Series A: Biological Science and Medical Science*, 57, pp. 470–472.
- Campbell, S., Del Rio Drake, A., Espinoza, R., & Scales, K. (2021). *Caring for the future: The power and potential of America's direct care workforce*. Bronx, NY: PHI.
- Hewitt, A., Pettingell, S., Kramme, J., Smith, J., Dean, K., & Kleist, B. (2020). *The direct support workforce and COVID-19 national survey report 2020*. Minneapolis, MN: Institute on Community Integration, University of Minnesota.
- Hewitt, A., Pettingell, S., Bershadsky, J., Smith, J., Kleist, B., Sanders, M., Zhang, A., Dean, K., & Kramme, J. (2021). *Direct support workforce and COVID-19 national survey report: Twelve-month follow-up*. Minneapolis, MN: Institute on Community Integration, University of Minnesota.
- Janicki, M. P., Dalton, A. J., Henderson, C., & Davidson, P. (1999). Mortality and morbidity among older adults with intellectual disability: Health services considerations. *Disability and Rehabilitation*, 21(5/6), 284–294, as cited in Heller, T. (2010). Heller, T. (2010). People with intellectual and developmental disabilities growing old: An overview. *Impact*, (23)1, pp. 2–3. University of Minnesota, Institute on Community Integration.
- National Core Indicators. (2020). *2020 staff stability survey*. Human Services Research Institute and the National Association of Directors of Developmental Disabilities Services. https://www.nationalcoreindicators.org/upload/core-indicators/2020StaffStabilitySurveyReport_FINAL.pdf

14 • Community Supports in Crisis: No Staff, No Services

National Core Indicators. (2021). *Adult family survey*. Human Services Research Institute and the National Association of Directors of Developmental Disabilities Services. https://www.nationalcoreindicators.org/upload/core-indicators/2020-2021_AFS_National_Report.pdf

President's Committee on People with Intellectual Disabilities. (2017). *Report to the President 2017. America's direct support workforce crisis: Effects on people with intellectual disabilities, families, communities and the U.S. economy*. https://acl.gov/sites/default/files/programs/2018-02/2017%20PCPID%20Full%20Report_0.PDF

Residential Information Systems Project. (2015). *In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends 2015*. https://ici-s.umn.edu/files/mPje9JQGac/2015_risp-web

Residential Information Systems Project. (2018). *In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends 2018*. <https://ici-s.umn.edu/files/yFXkkmRteg/2018-risp-full-report>

U.S. Bureau of Labor Statistics. (2020). *Occupational employment statistics*. <https://www.bls.gov/oes/>

U.S. Bureau of Labor Statistics Standard Occupational Classification. (2018). https://www.bls.gov/soc/2018/major_groups.htm

Watts, M. O., Musumeci, M. B., & Ammula, M. (2021). *State Medicaid Home & Community-Based Services (HCBS) programs respond to COVID-19: Early findings from a 50-state survey*. Kaiser Family Foundation.

Zippia. (2022). *Direct support professional demographic and statistics in the U.S.* <https://www.zippia.com/direct-support-professional-jobs/demographics/>

Appendix A

State Initiatives

Tennessee

TennCare and the QuILTTS initiative

With the recognition that quality services and supports are dependent upon a well-trained, qualified and stable workforce, TennCare, the Tennessee state Medicaid agency is invested in multiple workforce stabilization initiatives. During 2013-2014, TennCare engaged with technical assistance opportunities funded by a grant from the Robert Wood Johnson Foundation's State Quality and Value Strategies Program for the purposes of promoting high-quality LTSS for TennCare members. The funding award to Lipscomb University via a contract with Princeton University provided technical assistance which includes facilitation of opportunities for broad stakeholder review and input regarding proposed quality improvements, the engagement of key stakeholders in the program design process, assistance in gathering input/information, review of the literature, interviews regarding best practices, program design and effectiveness of pay for performance (P4P) programs, and recommendations to TennCare regarding the quality framework and implementation process. The result of the technical assistance engagement was the design and implementation of the QuILTTS initiative.

The Quality Improvement in Long-Term Services and Supports (QuILTSS) is a value-based purchasing initiative to promote the delivery of high-quality long-term services and supports. The QuILTSS initiative includes outcome-based reimbursement for services such as Nursing Facility Care and Home and Community Based Services among others, as well as a program dedicated to the development of the LTSS workforce. Tennessee identified that one of the most critical aspects of LTSS value pertains to the level of training and competency of professionals delivering direct supports — whether in a Nursing Facility or in the community. The QuILTSS Institute, a virtual online training center, offers staff training and professional development courses based on the CMS Direct Service Workforce Competencies.³

The CMS Direct Service Workforce Core Competencies, finalized in 2014, is designed to inform direct service delivery and promote promising and best practices in community based LTSS. The Competency set is intended to serve as the foundation for career lattices and ladders that further recognize the many competencies needed for direct service workers across service populations. The DSW Core Competencies are designed to be customized in practice to reflect the specific needs of people supported in community based LTSS. The competencies are also designed to form the basis for practical tools to strengthen the Direct Support Workforce: workforce development tools, such as individualized learning plans, coaching guidelines, performance evaluation tools, recruitment, hiring selection strategies, and post-secondary certificate and degree programs.

Based on the foundation of the CMS DSW Core Competencies, the Tennessee QuILTSS institute's mission is to build a more competent workforce includes college-worthy, competency-based training programs, training content designed by national subject matter experts who are the leading thinkers in their field, a mobile-ready online delivery platform offering an in-person training program option, and the ability for DSWs to earn micro-credential badges for each competency. The competency-based courses are designed to strengthen and enhance Tennessee's direct service workforce through ongoing development of the DSP's knowledge, skills, abilities, and intellectual behaviors. In addition, through partnerships with higher education institutions, there are opportunities for DSWs to earn college credit and advance along career pathways.

An alignment of goals and solid partnerships between TennCare, the state Medicaid agency, and the Department of Intellectual and Developmental Disabilities (DIDD), the operating agency, has resulted in the QuILTSS Institute being utilized by DSW's supporting people with IDD in their communities.

Finally, through a partnership between TennCare and TN DIDD, and including TNCO, the TN IDD provider trade association, the state engaged in a multi-year comprehensive effort to address workforce challenges, with the Institute on Community Integration at the University of Minnesota.⁴ Participating organizations received training and technical assistance to identify and address at least one

³ <https://quiltss.org/>

⁴ <https://tenncare.ici.umn.edu/>

key challenge that their organization faces aimed at improving DSP turnover and retention rates. As part of the engagement, ICI created an online DSP Workforce Toolkit, which is a collection of evidence-based tools and strategies that support provider organizations in finding, choosing, and keeping quality DSPs.

Using the American Rescue Plan Act of 2021 (ARPA) as a tool to further address DSP workforce shortages, Tennessee's approved plan includes a pilot using a directed quality incentive payment to HCBS providers. The pilot will incentivize HCBS providers to offer value-based wage increases to their front-line HCBS workers who successfully complete a competency-based training program. These could include quality incentive payments to help cover the cost of training and to incentivize timely completion in areas such as —

- Competitive integrated employment,
- Use of Enabling Technology to support independence,
- Critical incident (reportable event) management, and
- Benefits counseling.

For more information click [here](#)

Core Services

Over the past few years, Core Services of Northeast TN, a non-profit organization supporting people with IDD, has been on a mission to improve DSP retention. Through the creation of a DSP Career Ladder, the integration of the NADSP Certification Program, the implementation of a DSP Mentorship program, and more, there have been transformative results not only for the DSP workforce, but for the whole organization. In addition, the organization applied the same person-centered concepts used with people supported to the direct support professionals (DSPs) of the organization. As a result, the DSP turnover rate was cut in half, with the vacancy rate averaging around 4%. This helped to reduce overtime rates 35% and allowed Core Services to reinvest the savings in wages and to add benefits like a 401(k). As of September 2021, 22% of the DSP workforce at Core Services held some type of professional credentials and those numbers continue to rise. Finally, because DSPs love their jobs

at Core Services, 75% of job applicants are referrals from current employees, producing a higher caliber of applicant.⁵

For more information, click [here](#)

Ohio

In August of 2019, Ohio's Department of Developmental Disabilities (DODD) announced a historic state-local partnership that resulted in the first meaningful wage increase for DSPs in over a decade. With the support of Ohio's Governor Dewine and the Ohio legislature, a state budget was proposed that specified investments of \$370 million for Ohioans with developmental disabilities and over \$250 million for DSP wage increases. The proposed budget included a first of its kind partnership of DODD with Ohio County Boards of Developmental Disabilities to jointly invest in higher wages for DSPs. Specifically aimed at supporting the Ohio DSP workforce, this proposal was the largest investment in system history.

The Department formed the Ohio DD Workforce Crisis Task Force, beginning in May 2020. The Workforce Crisis Task Force is made up of diverse stakeholders, including Advocacy and Protective Services, The Arc of Ohio, Association of People Supporting Employment First (APSE), Ohio Association of County Boards (OACB), Ohio Association of Direct Support Professionals (OADSP), among many external entities.⁶ The task force is charged with developing short-term and long-term solutions in order to attract, recruit, and maintain a DD workforce large enough to meet adequate staffing levels in the face of a highly competitive job market. In support of Ohio's workforce, strategies may warrant attention to —

- professional capacity development in support of DSPs,
- promote adaptable skills, cultures, and empathy to meet modern service delivery challenges,
- educate people with disabilities and their families on how to best understand their roles and responsibilities within a home-care model, including how to supervise and manage support functions, and

⁵ Retrieved from CQL website

⁶ www.dodd.ohio.gov/about-us/our-programs/resource-DSP-Workforce

- foster a workforce that maximizes positive relationships with people receiving services and their families as they move toward their goals.

Using funding approved as part of Ohio's ARPA plan, DODD plans to work with partners across the state to identify innovative approaches to addressing the DSP workforce crisis in ways that are sustainable and have long-term positive impacts.

For more information click [here](#)

Missouri

On April 4, 2022, Governor Mike Parson of Missouri announced an initiative aimed at recruiting and maintaining a highly-skilled and dedicated workforce. In response to the continuing challenges of stabilizing a skilled workforce of DSPs, Missouri Talent Pathways has been developed by the Missouri Department of Mental Health, Division of Developmental Disabilities (DD).

Missouri Talent Pathways is the first of its kind in the nation. Recently approved by the U.S. Department of Labor, the initiative is now a registered apprenticeship program that blends on-the-job mentoring with technical instruction and culminates in participants receiving a certificate as a Certified Direct Support Professional. As a U.S. Department of Labor-registered apprenticeship intermediary, the Division and community partners will have access to expanded applicant pools, traditional workforce development programs, and a career ladder framework for DSPs.

A piece of a larger solution to support stabilization of the DSP workforce in the state, Missouri Talent Pathways' other objectives include increasing competency of national best practices, statewide applicability and portability, improving cost and efficiencies, and expanding talent pipelines for community providers to recruit DSPs.

Missouri's Department of DD Services is also deeply engaged in developing Value-Based Purchasing (VBP) approaches. VBP is a payment approach that offers a way for the system to transition from fee-for-service to paying providers based on the quality vs. quantity of services they provide. In a fee-for-service structure, enhanced/increased staffing has long been a tactic utilized by DD systems to improve quality of services or to solve problems in service delivery where financial incentives appeared to be tied to increasing staffing for people using

IDD services; this exacerbates the DSP workforce instability. Missouri is planning a waiver amendment to launch January 1, 2023 that will include VBP strategies.

To track the progress and success of Missouri's workforce initiatives, the Division relies heavily on the NCI-IDD Staff Stability tool as one of their premier sources of data. The NCI-IDD Staff Stability Survey is a mechanism whereby critical data about the DSP workforce data is collected directly from the provider network. The results of the survey will help Missouri to develop DSP workforce initiatives; compare state results with other states; and build systems to more effectively collect, analyze, and utilize workforce data. Most recently, Missouri used the data collected in the staff stability survey to measure the stabilization of DSP workforce throughout the COVID-19 pandemic.

For more information regarding Missouri's VBP, click [here](#)

For more information regarding Missouri Talent Pathways, click [here](#)

New York

In 2013, the New York State Office of People with Developmental Disabilities (OPWDD) funded the establishment of Regional Centers for Workforce Transformation (RCWT). Coordinated by the New York State Alliance for Innovation and Inclusion (The Alliance), a New York provider trade association, the Centers' mission is to develop the professionalism and capacity of New York State DSPs by educating and empowering them and frontline supervisors in validated competency standards. Core Competencies, in combination with the National Association of Direct Support Professionals (NADSP) Code of Ethics, became required for service providers in 2016 to help them build DSP capacity in the changing service landscape within the field.

With cooperation and funding from the New York State Developmental Disabilities Planning Council, OPWDD formed six RCWTs to provide assistance to providers, while incorporating the NADSP Code of Ethics and the New York State DSP Core Competencies into agency practice.

Moving forward, New York State has committed to using a significant amount of the funds approved in their ARPA plan to develop Workforce Development Grants for the purposes of improving the quality and skills of the DSP workforce. Through a one-time grant program, providers that demonstrate increased DSP completion of standardized credentials or demonstrated competencies will receive financial incentives to better support DSP workforce recruitment, retention, and competency. ARPA investments in New York State also include the development of pipeline programs in K-12 and post-secondary education and a statewide marketing program. In addition, New York State is providing a one-time payment to providers through grants that include the commitment that all monies will be paid to qualified DSPs. Payments will be tiered based on tenure and vaccine status. This would support over 100,000 current DSPs and family care providers who worked during the COVID-19 pandemic.

There are also many provider organizations that employ DSPs who are implementing innovative practices.

For more information regarding New York State, click [here](#)