Report to the President 2017

America's Direct Support Workforce Crisis:

Effects on People with Intellectual Disabilities, Families, Communities and the U.S. Economy

PRESIDENT'S COMMITTEE FOR PEOPLE WITH INTELLECTUAL DISABILITIES

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President's Committee for People with Intellectual Disabilities
Washington, D.C. 20447

President Donald J. Trump
The White House
1600 Pennsylvania Avenue, NW
Washington, D.C. 20500

Dear Mr. President:

On behalf of the President's Committee for People with Intellectual Disabilities (PCPID), it is an honor to bring this important issue to you and your Administration. As Chair, I have a developmental disability, and I am fortunate to lead a dedicated group of committee members to serve your Administration and the American people. For many of us, a personal relationship with an individual with an intellectual disability inspires us to work to improve the quality of life experienced by all people with intellectual disabilities and their families.

The members of the President's Committee appreciate the opportunity to submit for your consideration the 2017 Report, *America's Direct Support Workforce Crisis: Effects on People with Intellectual Disabilities, Families, Communities and the U.S. Economy*. The intended outcome of this Report is to ensure that you and the Administration are fully aware of and understand the effects of the direct support workforce crisis and the opportunities to address it in ways that strengthen the ability of people with intellectual disability to both participate in and contribute to their communities and the American economy. Not only does the crisis facing this workforce threaten people with intellectual disability and their families; it also undermines the stability, efficiency and ability to grow much needed long-term services and supports and, therefore, undermines the overall U.S. economy.

Highlighting this critical issue continues the tradition established by President John F. Kennedy in 1961 when he established a blue-ribbon panel to address the needs of people with intellectual disability and their families. The Report specifically examines the following areas to determine how the direct support workforce crisis can be corrected and this workforce sustained so people with intellectual disability are included and engaged in all aspects of society:

- Overview of the direct support workforce
- Critical challenges faced by the long-term services and supports industry
- Effects of the workforce crisis
- Economic and other factors that have influenced the crisis
- Promising practices to address the direct support workforce crisis

We are hopeful that this Report will provide strategies to strengthen federal policies for the direct support workforce and, by extension, the overall U.S. economy.

Sincerely,

Jack Brandt, Chair

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COMMITTEE PROFILE

In 1961, President John F. Kennedy called the nation's attention to the limited opportunities for people with an intellectual disability (ID) in the U.S. He sought recommendations on how this nation could better respond to inadequate and often deplorable treatment of individuals with ID. In 1966, President Lyndon B. Johnson established the President's Committee on Mental Retardation to ensure the right of a "decent, dignified place in society" for people with ID. The panel has been maintained by every administration since, although to underscore the importance of respect and elimination of negative labeling, in April 2003, the Committee was renamed the President's Committee for People with Intellectual Disabilities (PCPID).

PCPID serves in an advisory capacity to the President of the United States of America and the Secretary of Health and Human Services (HHS) on matters related to individuals with intellectual disability. The Committee upholds the right of all people with ID to pursue a quality of life that promotes independence, self-determination and economic self-sufficiency. Our goal is to ensure opportunities for people with ID and related developmental disabilities (DD) to live and participate in American communities each and every day by going to school, being active members of faith communities, working and paying taxes, and being friends, neighbors and co-workers. Presidential Executive Order 12994, as amended by Executive Orders 13309, 13446 and 13708, stipulates that the Committee shall provide advice to the President concerning expansion of educational opportunities, promotion of homeownership, assurances of workplace integration, improvement of transportation options, expansion of full access to community living, and increased access to technology.

The Committee currently consists of 13 citizen members appointed by the President, including a Chair who is responsible for planning the PCPID strategic direction. There are also 12 ex officio (federal government) members designated by the President. The ex officio members are the Secretary of Health and Human Services, the Secretary of Education, the Secretary of Labor, the Secretary of Housing and Urban Development, the Secretary of Commerce, the Secretary of Transportation, the Secretary of the Interior, the Secretary of Homeland Security, the Attorney General of the United States, the CEO of the Corporation for National and Community Service, the Chair of the Equal Employment Opportunity Commission, the Chair of the National Council on Disability, and the Commissioner of the Social Security Administration.

PCPID is supported by federal employees, including the Commissioner of the Administration on Disabilities (AoD), who serves as the Committee's Designated Federal Officer. Within the AoD, the Administration on Intellectual and Developmental Disabilities (AIDD) is the federal agency responsible for implementation and administration of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act). Organizationally, AoD is located within the Administration for Community Living (ACL) at the U.S. Department of Health and Human Services.

SELECTING DIRECT SUPPORT WORKFORCE CRISIS AS OUR PRIORITY

In August 2016, the President's Committee for People with Intellectual Disabilities (PCPID) identified possible topics for the 2017 Report to the President (RTP). Among the topics identified were Direct Support Professionals (DSPs); integrated employment; social integration; intersectionality (e.g., disability and LGBTQ); and the Supreme Court's Olmstead decision and its mandate to reduce segregation in service systems. The PCPID polled its members about the most pressing topic for the 2017 Report, with the majority (56 percent) of votes cast for the Direct Support Professional workforce, and a sizeable number (28 percent) voting to address the relatively slow progress in increasing integrated employment for people with intellectual and developmental disabilities.

Since the topics of direct support workforce and integrated employment both had considerable support, panels of federal and community partners were assembled to make the case for the importance of each. After the panels presented

and Committee discussion occurred, a vote was conducted. The final tally yielded overwhelming support (87percent) for addressing the crisis in the Direct Support Professional workforce as the topic of the 2017 Report to the President.

A work group was formed to discuss the outline for the 2017 RTP, and the initial draft was developed by the Chair and ex officio members. The outline was shared with the full Committee in January 2017. PCPID members then formed two work groups, focusing on (1) the economic impact of DSPs and (2) the individual and family impact of DSPs. Each work group met twice to discuss the outline, identify resources and consider recommendations.

During the March 2017 PCPID meeting, the work groups met to discuss their respective sections and develop recommendations for the 2017 RTP. The full Committee heard work groups' reports and then finalized Recommendations conveyed in this Report. Subsequently, the full Committee reviewed drafts of the report and approved its transmittal to the White House through the Secretary of Health and Human Services, the Honorable Tom Price.

EXECUTIVE SUMMARY

People with an intellectual disability (ID) rely on Direct Support Professionals (DSPs) for daily support that enables them to live in U.S. communities. Their families rely on the DSP workforce to provide reliable quality support so they can work and have respite from the day-to-day stressors of caregiving. Challenges in finding, keeping and training this workforce persist and have reached crisis levels in the long-term services and supports (LTSS) industry.

The direct support workforce is one of the highest in demand in the U.S. The expansion needed in this workforce is unlikely to take place without significant changes in how direct support professionals are recruited, trained and supported. The pipeline for people entering the Direct Support Profession is not keeping pace with the number of DSPs needed by Americans with ID and their families. Low wages, scant benefits, limited training and lack of career advancement opportunities have led over the past 30 years to the following nationwide results:

- average DSP wages of $10.72 per hour
- average DSP wages below the federal poverty level for a family of four
- half of DSPs relying on government-funded and means-tested benefits
- most DSPs working two or three jobs
- average annual DSP turnover rates of 45 percent (range 18–76 percent)
- average vacancy rates of more than 9 percent

This currently untenable crisis stems from the following factors:

- high staff turnover;
- growing demand for services due to the growth and aging of the U.S. population in general;
- increased survival rates for people with ID;
- demographic shifts resulting in fewer people moving into the DSP workforce;
- persistently non-competitive aspects of direct support employment, including low wages, poor access to health insurance, and lack of paid time off (PTO) and other benefits;
- high stress and demands of direct support employment, including round-the-clock, seven-days-a-week work;
- insufficient training and preparation for DSP roles; and
- lack of professional recognition and status for skilled DSPs.

Not only does the DSP crisis impact individuals and families, but it is also extremely costly to the human services system and the overall U.S. economy.

These realities put people with ID who need assistance at great risk of harm, contribute to unreasonably long waiting lists for services and are leading many people to reconsider more expensive institutional models of segregated care outside their home. The direct support workforce and the service system that supports it are in a crisis that will result in catastrophic outcomes for people with ID and their families unless significant and immediate responses are implemented.

Solutions to the direct support workforce crisis are critical to ensuring that people with ID can live, work and contribute to their communities. Such solutions are also important because of their significant economic implications. Simply put, responding to the direct support workforce crisis makes economic sense.

Over the past two decades, small-scale efforts have been made to find solutions, with small investments provided by federal, state and local governments. Most of these efforts have been grant-funded demonstration projects that don't prove fully sustainable after the grant funding ends. Practices that would address the workforce crisis include:

- improving professional identity and recognition;
- teaching business and organization leaders skills to improve their ability to recruit, select and retain direct service employees;
- using self-directed services that permit individuals and families to recruit, select and retain their own DSPs;
- using worker cooperative and independent provider models;

- using competency-based training models that lead to credentialing or certification of staff and yield wage increases; and
- using technology-enhanced supports.

Finding solutions to this crisis requires bold leadership and commitment from the Administration and its many federal agencies with important roles to play in keeping promises made to persons with ID. It will also require bipartisan action on the part of Congress. The direct support workforce is where the rubber hits the road in the LTSS industry, and there is no issue more pressing in regard to sustainability of service provision for people with ID than responding to the serious crisis it now faces.

RECOMMENDATIONS

This direct support workforce crisis has been coming for decades. Policy makers and their allies have been slow to make finding and implementing solutions a priority. It will take courageous leadership within the Administration and Congress to fund and ensure implementation of targeted solutions to address this crisis. Without bold and swift action, the LTSS system is threatened for all people with ID who rely on it to meet their most basic needs. The President's Committee for People with Intellectual Disabilities encourages the Administration to consider the following Recommendations as possible contributions to resolving the direct support workforce crisis. We urge that the actions and programs presented here be developed and implemented, and that their outcomes be evaluated.

1. The U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services should ensure through review of Home and Community-Based Services Waivers or regulation that states include sufficient Direct Support Professional wages and compensation packages in their rate-setting methodologies for long-term services and supports to people with intellectual and developmental disabilities.

2. The U.S. Department of Health and Human Services, Administration for Community Living should provide technical assistance and financial or programmatic incentives to states to promote the use of technology solutions in long-term services and supports, such as remote monitoring, sensors, robotics, and smart homes, to create efficiencies, reduce costs and support community living for people with intellectual disabilities.

3. The U.S. Department of Health and Human Services, Administration for Community Living should provide funding to states through grants and contracts to develop, implement and evaluate comprehensive programs designed to provide training and technical assistance to employers that focus on improving business acumen to reduce Direct Support Professional vacancy rates, improve retention and promote efficient, high-quality long-term services and supports for people with intellectual and developmental disabilities.

4. The U.S. Departments of Education, Health and Human Services, and Labor should create grant programs and financial incentives for states to expand the pool of Direct Support Professionals through recognition programs, grassroots campaigns and training efforts designed to expand awareness about the profession and encourage greater participation by people with disabilities, men, retirees, and young adults across diverse racial, ethnic and cultural groups.

5. The U.S. Department of Health and Human Services should work with states to expand utilization of self-direction in long-term services and supports so that family, friends and neighbors can be hired as Direct Support Professionals.

6. The U.S. Department of Labor through the Bureau of Labor Statistics should investigate ways to recognize "Direct Support Professional" as a distinct occupation title and provide routine labor statistical reporting on this occupation.

7. The U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services (CMS) should ensure through regulation and review of Home and Community-Based Services Waivers that states identify provider qualifications that recognize Direct Support Professionals as skilled practitioners who are community navigators, facilitating greater community and economic involvement for people with intellectual and developmental disabilities. Additionally, CMS and states should

ensure that compensation rates are aligned with appropriate status, value, respect, a living wage and benefits.

8. The U.S. Department of Health and Human Services, Administration for Community Living and Centers for Medicare & Medicaid Services should develop federal standards and work with the Department of Labor to implement specialized credentials and professional development opportunities for Direct Support Professionals, ensuring: (a) that people with intellectual disabilities are trainers and mentors, (b) that programs are focused on competencies specifically identified for DSPs, (c) that completion of training to meet standards is voluntary and occurs post-hire, and (d) that the credentials result in increased wages and access to benefits for DSPs.

9. The U.S. Department of Labor should engage the broader American workforce system to find solutions to this crisis by using community colleges and American job centers to develop and invest in career training and credentialing for Direct Support Professionals.

10. The U.S. Department of Health and Human Services and the U.S. Department of Labor should engage the business community and provide grants and other incentives to states to develop online matching registry services and other creative options to match people with intellectual disabilities and their families who need help finding available DSPs.

OVERVIEW AND INTRODUCTION

People with intellectual disabilities (ID) rely on Direct Support Professionals (DSPs) for daily support that enables them to live in U.S. communities. Their families rely on this workforce to provide reliable quality support so they can work and have respite from the day-to-day stressors of caregiving. Challenges in finding, keeping and training this workforce persist and have reached crisis levels.

WHO ARE PEOPLE WITH INTELLECTUAL AND RELATED DEVELOPMENTAL DISABILITIES?

In the United States, people with intellectual and related developmental disability (ID/DD) live, participate in and contribute to their communities as friends, neighbors, co-workers, voters and taxpayers. These individuals have a wide range of limitations, and many have lifelong needs that require ongoing assistance from others. People with ID/DD have substantial and lasting mental or physical impairments that are evident at birth or in the developmental period and require assistance and support in areas of learning, language, self-care, making decisions, independent living and finding and keeping employment.

Developmental disability (DD) is a broader term that includes most people with ID but also individuals with substantial limitations first evident in the developmental period but that may derive from conditions other than ID (e.g., autism, cerebral palsy and others). Importantly, people with ID and people with DD receive the same types of services from the same types of agencies; therefore, these terms are often used interchangeably to describe the individuals who are the focus of this Report. Based on a sample of more than 17,000 users of state ID/DD services in 35 states, about 93 percent of the persons served had either a primary or a secondary diagnosis of ID (Hiersteiner, 2016). The best estimate of the prevalence of ID/DD (Larson et al., 2001) suggests there are about 5 million Americans with ID/DD. Of these individuals, about 1.4 million are receiving or formally waiting for services from state developmental disabilities program agencies (Anderson et al., 2016).

PROMISES MADE TO PEOPLE WITH INTELLECTUAL AND RELATED DEVELOPMENTAL DISABILITIES

In many ways and places, the U.S. Congress, acting on behalf of the American people, has made serious and important promises to people with ID/DD. These promises have derived in large measure from the landmark Rehabilitation Act of 1973 (as amended), in which Congress affirmed that disability "in no way diminishes the right of individuals to: (a) live independently, (b) enjoy self-determination, (c) make choices, (d) contribute to society, (e) pursue meaningful careers, and (f) enjoy full inclusion and integration in the economic, political, social, cultural and educational mainstream of American society" (29 USC 701(a) (2)). In the Developmental Disabilities Assistance and Bill of Rights Act (DD Act – Public Law 106-402), Congress mandated that "individuals with developmental disabilities have access to opportunities and necessary support to be included in community life, have interdependent relationships… [and] access to and use of recreational, leisure and social opportunities to enrich their participation in community life" (Sec. 101(c) (8) & (12)).

THE CONNECTION BETWEEN NATIONAL PROMISES AND THE DIRECT SUPPORT WORKFORCE

The support needed by persons with ID/DD is primarily provided by family caregivers and paid workers. Most of the paid, hands-on support that is provided is done by DSPs. Due to the relatively high levels of need for assistance among people with ID/DD, Congress has found that "as increasing numbers of individuals with developmental disabilities are living, learning, working and participating in all aspects of community life, there is an increasing need for a well-trained workforce… to provide the services, supports and other forms of assistance required to enable the individuals to carry out those activities" (Sec. 101(a)(14)). Title III of the DD Act, which focuses on a program for direct support workers who provide assistance to individuals with DD, indicates that these workers have played essential roles in supporting people with ID/DD and expanding their community options. Congress also found that individuals

with ID/DD benefit from assistance from direct support workers who are well trained, and from receiving services from professionals who have spent time as direct support workers (Public Law 106-402, Sec. 301. FINDINGS [42 USC 15111]). In short, for people with ID/DD to live in their communities, they must have available to them DSPs who are well trained in and will provide them with individualized supports in all facets of community life: home, work, education, faith, family, friendship, activity and the responsibilities of citizenship (e.g., paying taxes and voting).

THE DIRECT SUPPORT WORKFORCE CRISIS

The direct support workforce is one of the highest-demand workforces in the U.S. The expansion needed in this workforce is unlikely to happen without significant changes in how professionals are recruited, trained and supported. Low wages, scant benefits, limited training and lack of career advancement opportunities have resulted over the past 30 years in high turnover and vacancy rates throughout the long-term services and supports (LTSS) industry. This is a persistent and growing crisis that has worsened considerably in the 20 years since the PCPID last noted it in its 1998 Report to the President, *Opportunities for Excellence* (HHS, 1998). Individuals, families and businesses find it increasingly difficult, and sometimes impossible, to find and keep good employees. These realities put people with ID who need assistance at great risk of harm, contribute to unreasonably long waiting lists for services and are leading many people to reconsider more expensive institutional models of segregated care outside their home. The direct support workforce and the service system that supports it are in a crisis that will result in catastrophic outcomes for people with ID and their families unless significant and immediate responses are implemented.

The pipeline of people entering the Direct Support Profession is not keeping pace with the number of DSPs needed by Americans with ID and their families. With annual DSP turnover rates nearing 50 percent nationally, human services programs each year must recruit and train a number of new employees equal to more than half of their current workforce just to support their current clientele, and even more new DSPs to meet the growing demand of new entrants into human services programs. This currently untenable crisis stems from the following factors:

1. high staff turnover;
2. growing demand for services due to the growth and aging of the U.S. population in general;
3. increased survival rates for people with the complex health needs found among persons with ID/DD;
4. demographic shifts resulting in fewer people moving into the DSP workforce;
5. the persistently non-competitive aspects of direct support employment, including low wages, poor access to health insurance and lack of paid time off (PTO) and other benefits;
6. the high stress and demands of direct support employment, including round-the-clock, seven-days-a-week work;
7. insufficient training and preparation for DSP roles; and
8. lack of professional recognition and status for skilled DSPs.

Not only does the DSP crisis impact individuals and families, but it is also extremely costly to the human services system. Solutions to the direct support workforce crisis are critical to ensuring that people with an ID can live, work and contribute to their communities. Such solutions are also important because of the significant economic implications. Simply put, responding to the direct support workforce crisis makes economic sense, as it will achieve the following:

1. Promote job growth and related economic development by filling critical vacancies and supporting the continued growth needed in the long-term services and support industry to meet the growing demand.
2. Enhance cost-effectiveness and savings by increasing retention and reducing the costs associated with turnover (e.g., worker recruitment, selection and training; overtime pay to remaining employees).
3. Provide support to family caregivers who are often unemployed or underemployed due to the need to provide care and support to family members with an ID, enabling them to increase

their participation in the labor force and their contributions to the economy.

4. Improve quality of supports and services by ensuring a qualified, competent and stable workforce reducing injuries, illnesses and critical incidents of abuse and neglect.

Addressing the direct support workforce crisis will sustain and improve opportunities for individuals with ID/DD to participate in and contribute meaningfully to all facets of society, including the economy of the U.S., its territories and tribal nations. Finding solutions will also constitute a response to real human needs. When direct support workers are not available, are poorly trained, lack understanding of an individual's needs or are unfamiliar with effective ways to support individuals in living and working in their communities, people with ID/DD and their families suffer. They lose heart about achieving the quality of experiences and daily life that government leaders have promised them. Families despair over what the crisis of commitment will mean to their loved ones with disability as they (family members who provide assistance) grow older and are no longer able to help. People feel real danger in the present crisis because they know the current workforce is not sufficient to do what is required, and they know that without concerted action, the future looks even worse.

Finding solutions to this crisis requires bold leadership and commitment from the Administration and its many federal agencies with important roles to play in keeping promises made to persons with ID/DD. It will also require bipartisan action on the part of Congress. The direct support workforce is where the rubber hits the road in the LTSS industry, and there is no issue more pressing in regard to sustainability of service provision for people with ID/DD than responding to the serious crisis it now faces.

THE DIRECT SUPPORT WORKFORCE

WHO ARE DIRECT SUPPORT PROFESSIONALS?

Direct Support Professionals (DSPs) support individuals with an intellectual disability (ID) who need assistance to live their lives and enjoy the same benefits as people without disabilities. They support people in ways that enhance inclusion and independence. More specifically, as defined in the Congressional Direct Support Professional Recognition Resolution in 2003 (S. Con. Res. 21/H. Con. Res. 94), DSPs are individuals who are employed to "provide a wide range of supportive services to individuals with an ID on a day-to-day basis, including habilitation, health needs, personal care and hygiene, employment, transportation, recreation, housekeeping and other home management-related supports, so that these individuals can live and work in their communities" and "lead self-directed, community and social lives" (Congressional Record, November 4, 2003, p. H10301).

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. They include full-time (70 percent) and part-time (30 percent) employees (Hewitt et al., 2015). Employers assign a wide range of job titles for Direct Support Professionals, such as direct support specialist, habilitation specialist, job coach, residential counselor, family care provider, personal assistant and others. The vast majority of DSPs work in the private sector for both for-profit and nonprofit companies. In some states, large numbers of DSPs work for state agencies that still deliver services directly to people with an ID. A small percentage of the DSP workforce is represented by organized labor.

SIZE OF THE DIRECT SUPPORT WORKFORCE

Direct Support Professionals (DSPs) for persons with ID are one segment of a vast human services industry that provides long-term services and supports (LTSS) to many people with significant needs, including frail elders, people with behavioral health needs and people with physical and other types of disabilities. The Bureau of Labor Statistics (BLS) does not have a specific occupational category for DSPs who provide supports for people with an ID. The U.S. Department of Labor (DOL) subsumes DSPs under three primary Standard Occupational Classifications: (1) Personal Care Assistant, (2) Home Health Aide and (3) Nursing

Assistant. In 2015 there were nearly 4.5 million direct support workers in these three occupational categories (Espinoza, 2017; BLS, 2015), which are among the top five fastest growing occupations in the U.S. (BLS, 2015). However, given the range and variation of job titles assigned to DSPs for persons with an ID, these DSPs may be uncounted or undercounted by the current BLS classification.

Given the difficulty of using BLS data to specifically identify the direct support workforce that supports people with an ID, estimates are made based on the number of people who receive services and what is known about staffing ratios. Using average staffing ratios per person served as drawn from state-specific studies, it is possible to make reasonable estimates. As indicated in Table 1, it is estimated that in 2013 there were about 880,000 full-time equivalent (FTE) Direct Support Professional positions allocated to providing assistance to the 1.4 million individuals with ID/ DD receiving services under the auspices of state ID/DD program agencies. Given that 30 percent of the DSP workforce is part-time, and estimating that 2.5 part-time workers are needed to fill one full-time equivalency, there were an estimated 1,276,000 DSPs working to support individuals with ID/DD on June 30, 2013. The estimated 880,000 FTEs in 2013 reflect an increase of about 89,000 (11.3 percent) in the decade between 2003 and 20113. Importantly, because of shifts in how services and supports are typically provided to individuals with ID/DD, the ratio of DSPs to service users decreased from an estimated 0.564 to 0.496 over the decade.

Simply to sustain services as they are, and given current turnover rates, every year 574,200 new DSPs need to take new jobs in the workforce. Notably, too, it would require an additional 167,001 new DSPs to meet the needs of the more than 200,000 individuals wait-listed for services. With projected growth in demand, worsening workforce issues and a strong U.S. economy, this number is expected to grow yearly between now and 2030.

DIRECT SUPPORT PROFESSIONAL SCOPE OF WORK

DSPs provide assistance in a wide range of life activities across the lifespan. They work with children, youth, young adults, adults in midlife and elderly individuals. They help people make informed decisions and exercise choice by teaching, training and supporting them in all aspects of life. DSPs are charged with keeping people with an ID safe and healthy, and in doing so, they follow health and

Table 1. Change in demand for DSPs for persons with ID/DD, 2003–2013

	2003			2013		
SERVICE TYPE	Users	FTE	DSPS	Users	FTE	DSPS
State Services	42,835	1.34	57,399	35,602	1.34	47,706
Private/Community	359,446	1.13	406,174	350,990	1.13	398,618
In-Home/Family	500,004	0.25	125,001	758,031	0.25	194,508
Vocational/Day	465,000	0.35	162,750	605,301	0.35	211,855
Persons in Nursing Facilities	35,005	1.13	39,556	24,021	1.13	27,144
Total Current Recipients	1,403,290	0.56	790,820	1,773.945	0.50	879,831
People with ID/IDD Who Are Wait-listed	75,288	0.56	42,161	232,204	0.50	115,173

Table notes

1 The ratios of DSPs to service users were computed as part of the 2006 Report to Congress: The Supply of Direct Support Professionals Serving Individuals with Intellectual and Developmental Disabilities, prepared by the Office of the Assistant Secretary for Planning and Evaluation (available at https://aspe.hhs.gov/basic-report/supply-direct-support-professionals-serving-individuals-intellectual-disabilities-and-other-developmental-disabilities-report-congress). Data on service users for the years shown come from Residential Services for Persons with Developmental Disabilities: Status and Trends (University of Minnesota) and The National Report on Employment Services and Outcomes (University of Massachusetts-Boston).

2 The wait-list ratio of DSPs to users is computed at 0.71 based on the 2003 estimated ratios of DSPs to own home and family home users (0.25) and the ratio of DSPs to private/community home users (1.13) and the assumption that those on waiting lists would go to each of those categories of home, in roughly equal distribution.

3 There are 4.2 FTE shifts per week (168 hours/40), so a staffing ratio of 1:1 means that on average there are 4.2 persons with ID/DD supported by one DSP at any one time.

4 The count of service users is a duplicated count because some users use more than one service type.

A Day in the Work Life of a DSP

I have been a DSP for almost 14 years. This is a day in my life as a Direct Support Professional. I start my day at 7 a.m. The person I support is incontinent and I assist him to clean his bedding and start his laundry. Then I have to process his food because he can't eat solid food. When eating, he has to be watched at all times so he won't choke on his food and aspirate. If staff are not trained on how to support him, he could aspirate and get pneumonia and die. After he eats, I prompt him to brush his teeth. I administer his medications. Afterwards, he cleans the bathroom. Then I transport him to his daily activities in the community. He goes to the gym for a one-hour workout. Then I take him for lunch and coffee. At the restaurant, I have to process his food and thicken his drink to honey consistency so he won't aspirate and choke. I guide him through stores; he is also blind. I have supported him for almost 14 years to adapt to his environment and to be as independent as possible. We head home and make dinner and again process food and thicken his drinks. I watch him eat so he won't choke or aspirate. After, I assist him with completing breathing exercises to help prevent aspiration pneumonia I prompt him to brush his teeth and get ready for bed. I administer his medications.

When he goes to bed at 8 p.m., his day is done but mine is not. I still have to document what I have done to support him throughout the day. I have to coordinate with doctors and make sure all his consents are up-to-date and that his record is complete so that we comply with all licensing standards.

I do this all for $10 per hour. My nephew works at Walmart and makes $11 an hour, just to be a cashier. This does not make sense to me. Right now, I am working in two homes, traveling 50 miles a day because we don't have enough staff to cover the support hours needed for everyone. I get pulled from home to home because all of our staff are leaving for other jobs that pay more. I am worried that the person I support will end up with inexperienced staff that do not know his protocols and will give him solid food, not realizing that he could aspirate and possibly die.

The staff shortage is real. In the last few months I have had to work more and see less of my family to provide the support needed. I feel if there was an increase in pay, we would be able to keep staff and provide better support for everyone we support in the state of Maine.

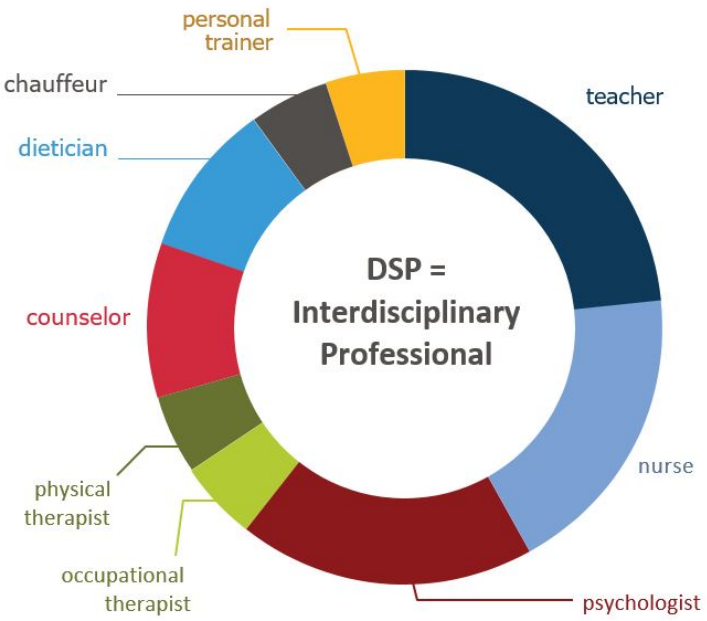
—Randall Howard, DSP

wellness routines, dispense medications and implement significant treatments and medical intervention protocols. They take people to appointments with various health care and specialty providers and often play important roles in communicating with medical professionals about health-related observations and records. DSPs are integral to supporting overall well-being and prevention of costly acute care by identifying emerging signs and symptoms of illness or disease, encouraging healthy lifestyles, fostering connections to caring family and friends and monitoring changes in health status. DSPs may also provide daily living skills support, such as getting people out of bed, helping them bathe and get dressed, preparing meals and assisting people in feeding themselves. Many DSPs help people with an ID to communicate and to use complex assistive technology devices. Importantly, DSPs support people with an ID in finding and keeping jobs and working toward their personal career goals. They get people socially connected to and support their participation in recreation activities, education, cultural events, spiritual activities and civic functions. DSP job duties are diverse, ever-changing and based on each individual's needs and abilities.

The role of a DSP is increasingly complex. The independent nature of the job requires significant skill, judgment, independent problem-solving and decision-making. Many DSPs work alone with a person with an ID in individual or family homes, small group homes, the community and employment settings. As such, they are often isolated and do not have co-workers, supervisors or clinical professionals (e.g., nurses or medical personnel, social workers, occupational therapists, physical therapists) on site to turn to for assistance or guidance. As the shift from congregate care to home- and family-based services continues, DSPs will take on ever-greater responsibility and accountability. The nature, intensity and frequency of contact between DSPs and the people they support make their work different from the roles filled by clinicians, service coordinators, administrators and supervisors. DSPs spend a lot of time with the people they support, and this gives them a unique lens into the lives of such individuals.

In many ways, 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.

Figure 1. DSP Scope of Practice



Like various allied health professionals, they assess needs, implement specific treatment plans and document progress. Like social workers, they get people connected to community resources and benefits. Like counselors, they listen, reflect and offer suggestions. DSPs provide whatever support it takes so people can live and participate in their communities with greater independence and dignity.

COMPETENCIES NEEDED BY DIRECT SUPPORT PROFESSIONALS

Over the past 20 years (as indicated in Figure 2), numerous sets of national and state DSP-specific competencies have been identified and refined. Their development has included stakeholder input from service recipients, family members, DSPs, supervisors and agency administrators, as well as the use of validation processes. Modifications have been made over time to reflect needed attention to self-direction (people with ID making decisions about their own services, related budgets and

Figure 2. Direct Support Professional competency sets over time

Source: Hewitt, 2017

JOANNE MURRAY, DIRECT SUPPORT PROFESSIONAL – CERTIFIED AT LEVEL 1 BY NADSP

Joanne Murray is a 30-year veteran in providing direct support to adults with developmental disabilities. She chose "vocational support" as an area to illustrate her DSP competence and skill. Joanne has worked with Vicki for 30 years. Vicki is a 96-year-old woman with intellectual disability who, for most of her life, has had a passion for making jewelry. Joanne saw that Vicki had great potential in jewelry design and could probably make jewelry to sell for profit.

Vicki had recently "aged-out" of a sheltered workshop where she made a modest income. Vicki was unhappy about this, but Joanne had the idea to transform Vicki's love of jewelry making into an income-producing vocation. Joanne and Vicki went on a learning journey together over the course of a year. Together, they designed business cards, created a catalog of jewelry designs, launched an advertising campaign in their local area and ultimately produced a plethora of "real" jewelry (made from authentic metal and gemstones).

Vicki was supported and encouraged by a highly skilled DSP to pursue an actual business as an artist and entrepreneur. Vicki started selling her beautiful works and is about to launch a business website.

Figure 3. New York Career Gear Up credential model and framework

Source: Hewitt et al, 2015

staffing) and the important role DSPs play in supporting people in developing and maintaining relationships.

DIRECT SUPPORT PROFESSIONAL TRAINING AND CAREER PREPARATION

Direct Support Professionals need training to gain the knowledge, skills and attitudes required of their roles. Unfortunately, widespread, well-funded systems of training and support do not exist for DSPs. Federal regulations are largely silent about the pre-service and in-service training necessary for DSPs to provide quality community support to people with ID. Some states require that employers provide a minimal number of pre-service training hours (often around 40), but these regulations rarely are competency based; instead they focus on topics or basic skills that must be taught within a certain number of hours post-hire (e.g., CPR, first aid, documentation, bloodborne pathogens) and at regular intervals after hire.

It is often difficult for service-providing agencies to offer complete courses of training to their DSPs because of the following realities: (1) reimbursement rates that cover little more than personnel costs, (2) the dispersal of DSPs across many work sites and the centralized location of training, (3) the widely varying hours worked by DSPs and the difficulty of finding convenient times for training, and (4) the high rate of DSP position vacancies, making it difficult to cover work shifts while DSPs attend training. A recent statewide provider survey in New York found that DSPs received an average of 50 pre-service training hours, only half of the 100 hours required by the state, and an average of 33 hours in subsequent years (Hewitt et al., 2015). Yet, a series of focus groups conducted during this same study indicated that DSPs are anxious to learn more, develop skills and continue their careers in the field. More information about these findings and the recommendations from New York can be found in Appendix D.

NIKEETA SMITH, DIRECT SUPPORT PROFESSIONAL – CERTIFIED AT LEVEL 1 BY NADSP

Nikeeta is a DSP who has worked for four years in a group home that supports people with disabilities. She supports LaToya, a woman with intellectual disability and limited verbal communication skills.

LaToya often uses physical aggression (e.g., hitting, head butting, kicking) to communicate her feelings. This can be a difficult way to get one's message across, and Nikeeta assessed the need for LaToya to learn more appropriate methods. To help LaToya with this, Nikeeta spent many hours assembling communication books and visual aids, learned sign language and even used an electronic tablet in order to devise ways in which she and others could best communicate with LaToya. Over the course of approximately a year, LaToya's challenging behavior diminished and she was more comfortably able to shop, dine out and live with her roommates.

Prior to Nikeeta's tenure, no staff had taken the initiative to spend time with LaToya. Many found her too aggressive and did not have the patience or will to assist her in developing better communication skills. Nikeeta had gone through the College of Direct Support online learning program and participated in the NADSP certification initiative sponsored by her employer. Nikeeta's newfound insights and knowledge prompted her to work closely with LaToya to open up new horizons of communication and relationships for a woman who might otherwise have remained neither understood nor respected. Nikeeta made sure this wasn't the case.

In contrast to the typically less specific and demanding pre-service training required of DSPs, there is a 75-hour pre-service educational requirement for Nursing Assistants and Home Health Aides (Marquand, 2013). This training requirement has resulted in most community/technical colleges in the U.S. having pre-service training programs for these occupational titles. However, these programs are not required for nor aligned with the training needs of DSPs.

The Certified Nursing Assistant (CNA) and Home Health Aide (HHA) training programs emphasize physical health and a "medical model," and are less comprehensive than the training needed by DSPs to provide home and community-based supports. While DSPs need the skills required of a CNA and an HHA to support people with health, self-care and home-living needs, they require much more training focused on supporting independence, learning new skills and teaching people with an ID how to make informed decisions about their own lives, community living and social participation. DSPs have all the duties and responsibilities of caregiving occupations, but their role is much more focused on being community navigators. As such, their training and career development needs should be focused much more on a social model (civil rights and social justice) than on a medical model (treat and cure) of disability. Despite these clear differences, CNAs and HHAs often benefit from higher wages and increased visibility due to the credentialed nature of their work.

While certification or credentialing programs similar to those for CNAs do not exist widely for DSPs, examples of promising practices do (e.g., National Alliance for Direct Support Professionals national credential, Ohio Alliance for Direct Support Professionals state-level credential and many organization-level credentialing programs). Attainment of certifications through credentialing is one way to improve the quality of care; it is also likely to contribute to higher levels of professionalism, increased occupational pride, improved work performance, higher job satisfaction and reduced injuries for DSPs and the people they support. Employees who complete rigorous credential programs may stay on the job longer and provide a higher quality of support (Bogenshutz, Nord, & Hewitt, 2015). Credentialing has the potential to justify improved compensation for DSPs and to establish recognition and career pathways in an occupation that historically has been undervalued. Widely accessible credentialing and training programs specific to the role of DSPs are needed throughout the community college system in the U.S.

RELIANCE ON DIRECT SUPPORT PROFESSIONALS FOR QUALITY OUTCOMES

Service systems that expect quality outcomes in exchange for public investment in them must rely on DSPs to deliver system-and individual-level outcomes. The connection between quality in long-term Home and Community-Based Services (HCBS) and the direct support workforce was recently identified by the National Quality Forum (2016). In their newly developed quality framework, the direct support workforce was identified as a quality domain. Aspects of workforce quality include these:

1. DSPs have a person-centered approach to services;
2. DSPs have demonstrated competencies;
3. the organization and state ensure safety and respect for the worker;
4. there are sufficient workforce numbers, dispersion and availability;
5. DSPs are adequately compensated with benefits;
6. DSPs are culturally competent; and
7. DSPs are engaged and participate in the organization and system.

An increasing number of states are paying attention to the need to know more about their direct support workforce. As a result, National Core Indicators (NCI) created a staff stability survey, which is currently being used in 19 states and obtains information about turnover and vacancy rates as predictors of individual outcomes (see Figure 5, p. 21).

DIRECT SUPPORT WORKFORCE AND THE U.S. ECONOMY

The direct support workforce promotes participation in the U.S. economy in two ways: (1) by helping people with an ID get jobs and (2) by enabling family members to work. A national priority identified in the Workforce Innovation and Opportunity Act (2014) is to increase employment among people with an ID. Given the low number of people with ID/DD currently employed in competitive community jobs (only about 16 percent), and the slow growth in that number, DSPs are needed who can help increase that number by effectively supporting people in finding and keeping paid competitive employment. Another major

contribution DSPs make to our communities is to support families so that members (e.g., parents, siblings and extended-family members) are able to work and maintain their careers and businesses. When inconsistent support is provided for their loved one with an ID, it is difficult for a family member to maintain employment, accept promotions and establish a career. When consistent and quality support is available from DSPs, family members are more likely to participate in employment, work more hours and accept promotions and additional responsibilities, all generating tax revenue and reducing reliance on public benefits.

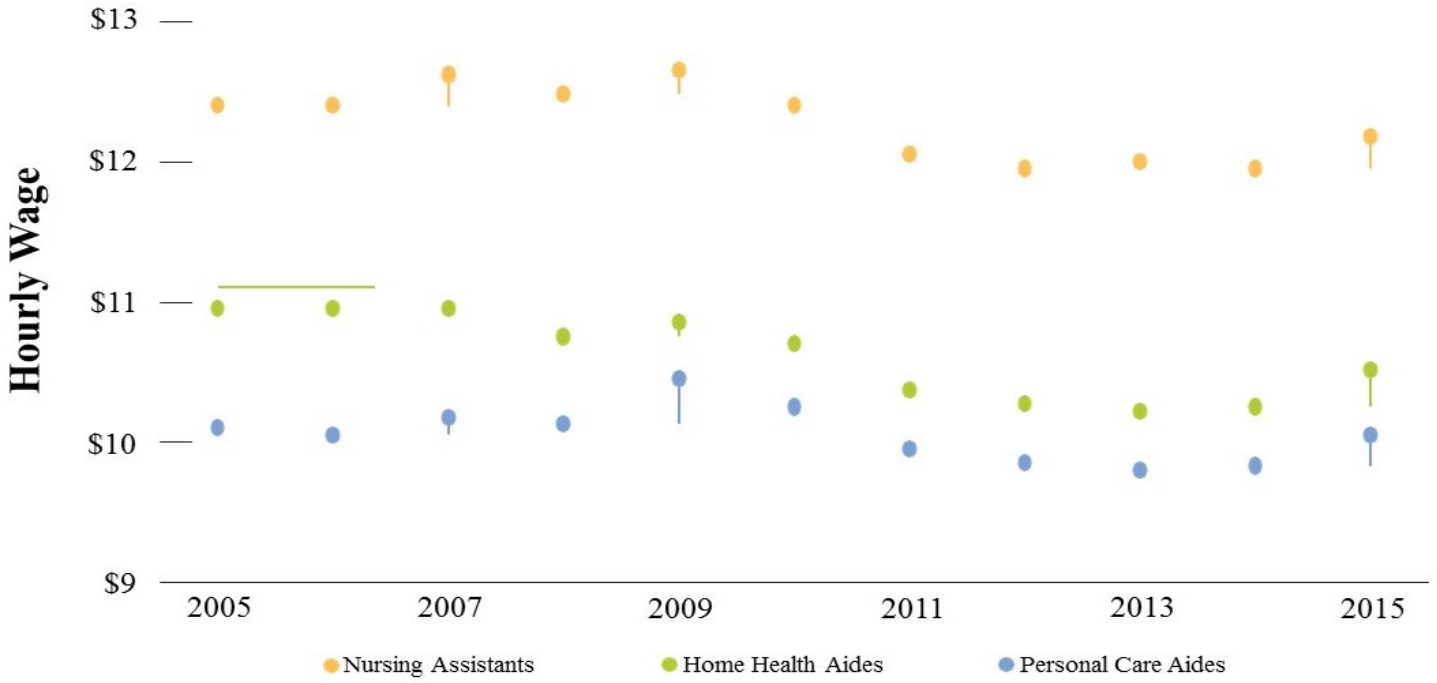
PERVASIVE WORKFORCE CHALLENGES RESULT IN CRISIS

The matters of availability, skills and sufficiency among Direct Support Professionals (DSPs) present a growing public health concern. The following factors affect this workforce crisis: (1) the projected increase in demand for DSPs to support the rapidly growing number of people with disabilities, driven primarily by growth in the elderly population; (2) the nature of the supports provided by DSPs, which are essential to health, safety and overall well-being; and (3) the persistent, substandard work conditions and rewards that undermine the ability to recruit and retain DSPs (Hewitt et al., 2008). Substantial investments in community-based long-term services and supports (LTSS) are urgently needed in order to avert a public health crisis by supporting recruitment, sustaining experienced DSPs and providing adequate pre-service preparation and in-service training to ensure quality in the services provided.

WAGES AND BENEFITS

The national average wage for DSPs is $10.72 per hour (Hiersteiner, 2016). As shown in Figure 4, adjusting for inflation, this workforce has actually seen their wages decline over time (PHI, 2015). At $10.72, the average DSP who works full time makes below the federal poverty level for a family of four (HHS, 2015). Many, but not all, organizations provide health insurance and paid time off to DSPs (e.g., Hewitt et al., 2015). Often part-time workers have no paid benefits. Almost half of DSPs receive publicly funded benefits, such as medical, food or housing assistance (PHI, 2017). Most DSPs work a second (or third) job to earn enough money to pay their bills (Test et al., 2003). Perpetually low wages and limited benefits ultimately make it difficult to recruit and retain DSPs. Most DSPs who leave the profession do so not because of the nature of the work, but because they cannot support their families on the available wages.

Figure 4. Direct support wages over time, 2005–2015



Note: In 2016, the average U.S. wage for a DSP was $10.72

Source: PHI, 2017.

HIGH TURNOVER AND VACANCY RATES

A high turnover rate is well documented in the DSP workforce (Bogenshutz et al., 2014; Braddock & Mitchell, 1992; Larson, Lakin & Bruininks, 1998; Larson et al, 2005; ANCOR, 2010; Hewitt et al., 2015). Nationally, the average annual turnover for DSP positions is an estimated 45 percent, with a range of 18–76 percent (Hiersteiner, 2016). About 35 percent of DSPs leave their positions in less than six months, and approximately 22 percent leave within 6–12 months. As a point of comparison, across all industries, as reported by BLS (2017), the national average separation (turnover) rate is 3.5 percent. The magnitude of this workforce issue is hardly seen in any other industry, thus making running an efficient and effective direct support business nearly impossible. The costs of replacing a DSP in ID/DD services have been reported to be between $2,413 and $5,200 (Hewitt & Larson, 2007; ANCOR, 2010; Medisked Connect, 2016). The aggregated cost is substantial; in New York State alone, the cost of replacing DSP workers using an average cost per person of $4,073 was estimated at $79,804,549 in 2015 (Hewitt et al., 2015). Nationally, these costs are estimated at $2,338,716,600.

Vacancy rates are another indicator of workforce insufficiency. Current vacancy rates within LTSS for people with ID/DD are more than 9 percent (Hewitt et al., 2015; Hiersteiner, 2016). This means that 9 percent of all available positions go unfilled. Vacancy rates are created by service growth resulting from increased need and demand, as well as high DSP turnover. Unfilled positions undermine the quality of care, overburden DSPs remaining on the job and are a clear symbol of the crisis of providing sufficient numbers of DSPs to meet the needs of persons with ID/DD and their families.

CONSEQUENCES OF THE DIRECT SUPPORT WORKFORCE CRISIS

The Direct Support Professional (DSP) workforce crisis results in substantial negative and lasting effects that diminish quality of service, reduce progress toward individual goals and harm individuals. To emphasize the nature of these consequences, stories from people with an ID, their families, DSPs and organizations are included throughout this Report. These stories provide a vivid picture of the effects of the growing workforce crisis on people with an ID who receive services, families, direct support professionals and organizations.

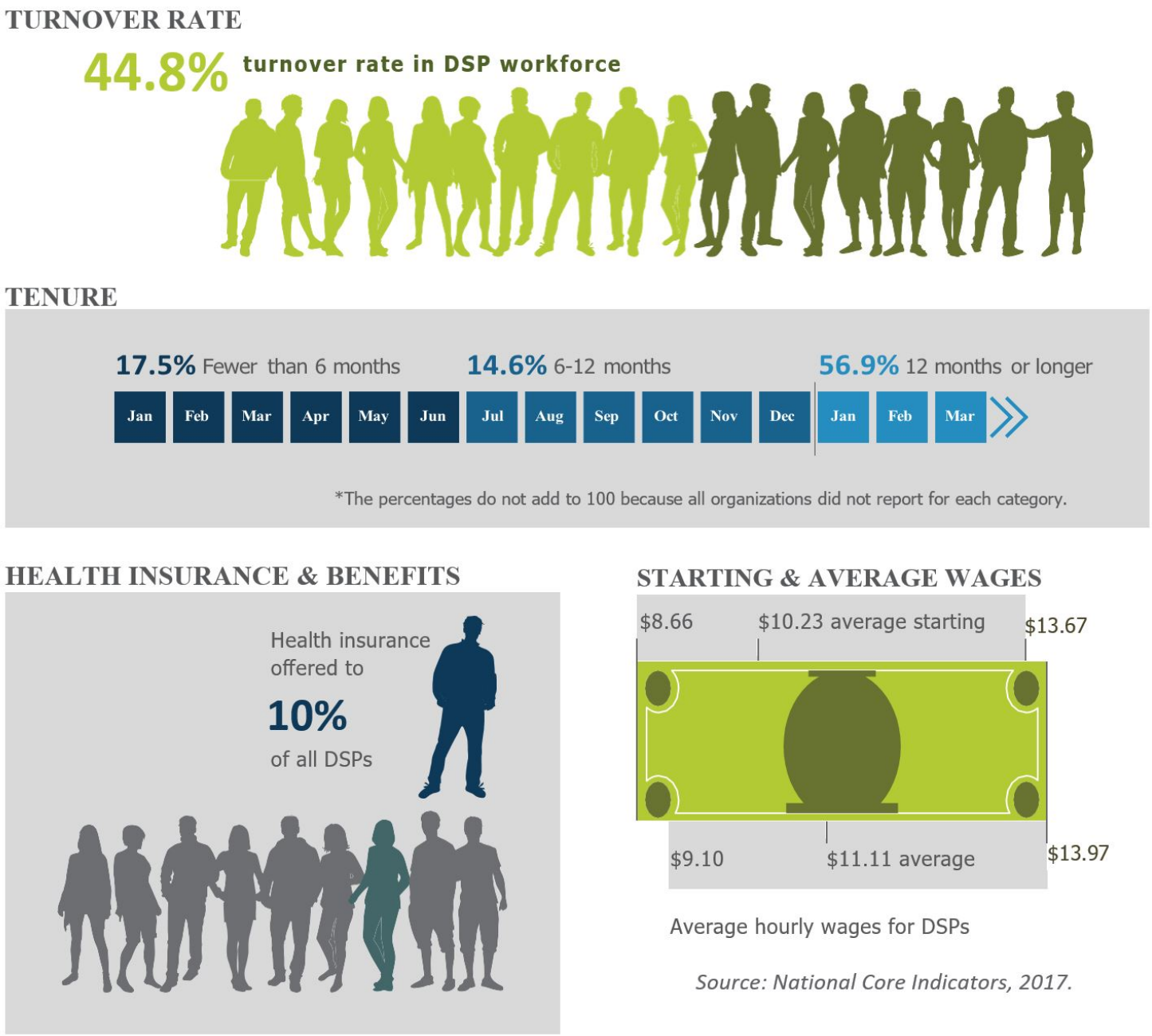
EFFECT OF THE WORKFORCE CRISIS ON INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

The current workforce crisis threatens the health, safety and well-being of people with ID/DD. DSPs who are tired from working long hours or multiple jobs are much more likely to make mistakes and have lower tolerance for stressful situations. When DSPs do not know the person for whom they are providing support, they may not recognize signs and symptoms of illness. The consequences of the direct support turnover and vacancy rate impact the independence and opportunities experienced by people supported. When organizations cannot find staff to support people in more integrated and individualized community homes and job sites, people with an ID must often rely more on congregate models, such as group homes or sheltered work settings. Ensuring that people with an ID can experience all that communities have to offer depends on consistent, dependable, skilled support provided by a stable, well-prepared DSP workforce.

EFFECT OF THE WORKFORCE CRISIS ON FAMILIES

The impact of the workforce crisis is also evident in the lives and well-being of family members. Being able to entrust loved ones to skilled, committed and well-known support providers is vitally important in order for family members to maintain employment and engage in community outside the family. In the National Health Interview Survey – Disability Supplement of 1994–1995, 53 percent of parents interviewed reported major career concessions (e.g., not taking a job, working fewer hours, dropping out of the workforce, turning down a promotion) related to having a child with ID/DD (Anderson et al., 2002). Another concern is that families and individuals have to get to know a new DSP every time one enters their life. This can cause frustration because they have to train so many staff each year.

Figure 5. A summary of National Core Indicator Staff Stability key statistics



Source: National Core Indicators, 2017.

"Living on my own hasn't always been easy. I've had my fair share of direct support professionals who took advantage of me because literally depended on them in order to live . . . I've been placed in unsafe situations, disappointed by being unable to go somewhere with family and friends and forced to overlook things that people without disabilities would never consider." —Ed Bartz

ORGANIZATIONAL PROFILE UCP SEGUIN SERVICES, ILLINOIS

Organization, size, scope, and length of time in business.
Established in 1976, UCP Seguin believes that all people, regardless of ability, deserve to achieve their potential, advance their independence, and live as full members of the community. We provide life skills training, assistive technology, meaningful employment, and a place to call home for people with disabilities, as well as specialized foster care for children. Our goal: life without limits for people with disabilities.

UCP Seguin took root in 1949 when a group of parents in the western suburbs of Chicago began providing day school classes for their children in a church basement – the first pilot program for community-based special education in Illinois. From this early alliance evolved Mentally Retarded Children's Aid, which transferred all programs to Seguin Services, Inc., in the mid-1970s. Granted 501(c)(3) status in April 1977, Seguin was one of the first agencies in Illinois to establish community-based employment and group homes for adults with disabilities and specialized foster care for children with disabilities.

On July 9, 2013, United Cerebral Palsy of Greater Chicago merged with Seguin to become UCP Seguin, which now serves an unduplicated total of more than 24,000 persons with disabilities each year.

Current DSP vacancy and turnover rates.
We currently have nearly 160 vacancies among 800 positions, equaling a 20 percent vacancy rate. Residential Services and Day Services – two of the most critical service and support departments – have been the hardest hit, with 115 of the 160 vacancies. During the most recent reporting, the year-to-date turnover was 24.7 percent.

Current wages and benefits.
The average hourly wage paid to DSPs between July 1, 2016, and December 31, 2016, was $11.80 per hour, which includes overtime paid. This pay is comparable to other nonprofit ID/DD service providers.

The City of Chicago's minimum wage is $10.50 per hour, rising to $11 per hour on July 1, 2017, and $13 per hour on July 1, 2019. This severely impacts the ability of suburban providers to recruit employees who are able to work within the city limits at a higher wage. There is an effort to work with the City of Chicago to get a release from the minimum wage requirements for nonprofit organizations since this wage requirement adds further financial distress to already stretched budgets.

Though UCP Seguin provides many benefits (e.g., medical, dental, vision, flexible spending accounts), DSPs regularly rely on public benefits of medical coverage for their dependent children, vouchers for care for their children, Section 8 housing vouchers and other benefits. Many DSPs have made tough decisions to work limited hours and/or forgo promotions in order to avoid losing these public benefits.

Biggest workforce challenges.
Overtime costs and an inability to hire competent staff are draining financial resources, and this, combined with a 4.7 percent national unemployment rate, impacts negatively on staff recruitment and retention and is an extreme challenge affecting delivery of services to the people we support. The safety and well-being of the people we support is compromised by the vacancy rates of 20 percent or more.

We are no longer able to accept referrals of individuals who at present have higher support needs (e.g., health or behavioral). Even with added funding, we are unable to recruit the staff at current reimbursement rates to provide needed support services and have to turn away referrals.

Risks related to the workforce crisis. With the low unemployment rate and the lack of state and federal funds to support higher wages, community organizations serving people with developmental disabilities face a major crisis: recruiting, hiring and retaining capable direct support staff. We need more dedicated individuals who believe in our mission. We need an infusion of additional dollars to support these staff in performing their mission-driven duties.

ORGANIZATIONAL PROFILE
STONE BELT ARC, INCORPORATED - BLOOMINGTON, INDIANA

Organization, size, scope, and length of time in business.
Stone Belt Arc, Inc., is a nonprofit disabilities service provider in south central Indiana, headquartered in Bloomington. We serve about 1,600 people with ID/DD annually and have a staff of about 500 (when all positions are filled). Our annual budget is about $18M with about 90 percent of that being Medicaid funded. We were incorporated in 1959. Our services include employment, adult education (facility- and community-based), residential services, psychiatry, therapy, behavior supports and facility-based work services.

Current vacancy and turnover rates.
Stone Belt's current vacancy rate is 13 percent, and our current turnover rate is 33.4 percent.

Current wages and benefits.
Our starting salary for DSPs is $9 per hour, though anyone with experience comes in higher than that. We have health insurance for full-time staff, and we recently were able to add a 2 percent match on the 401(k)-retirement program. We have a fairly generous paid time off program and observe eight paid holidays. We have been competitive with similar service providers, though most have been pushing wages up a bit, so we are probably starting to fall behind.

Numerous Stone Belt staff rely on HIP [Healthy Indiana Plan, an affordable health insurance plan for adults] for their personal health insurance as they cannot afford coverage even through our agency's plan or marketplace. They also rely on Hoosier Healthwise for their children's health insurance; SNAP for food stamps, along with local food banks and charities that provide free food; and HUD income-contingent affordable housing. Staff also often request help from city and county support funds to assist in paying utilities.

Biggest workforce challenges.
Indiana University and the hospital – the two largest employers in the area – have minimum wages of $10 per hour. This has reduced the number of students who apply [to work at Stone Belt], as well as tightening the general employee pool. As with many similar businesses, the high turnover rate and difficulty with recruitment require extensive administrative resources. The employee pool is generally not as qualified as it was in years past, and we find we have had to accept applicants that we would not have considered in the past. This creates other issues, such as longer training, less dependability, lack of engagement/commitment to the mission and so forth. If we had enough staff, we could provide support to many new people. We don't officially have a "waiting list," but we cannot readily admit new clients – some have to wait for us to get to them.

Risks related to the workforce crisis. Employee behavior is a concern, especially with the rise in illicit drug use. Employee honesty is also a concern, and we worry that the people with ID/DD we support are at more risk of abuse and exploitation. The lower professionalism level may also impact the community perception of our agency. Operating programs at less than full staffing also puts people supported at risk for their health and safety. There are also lost-opportunity costs. Individuals with ID/DD and their families will go to the provider that can admit them the most quickly. This doesn't always meet their best interests.

The lack of consistent care is evident in countless stories from family members. Many families find that they can prepare, plan for and execute plans for their family member with an ID to live independently with support, only to face the reality of their family member having to move back home shortly after moving out because consistent direct support could not be maintained. Other family members report they have never been on a vacation together and find it extremely hard to get any respite from their responsibilities of supporting their family member. This causes stress, health issues, burnout and, ultimately, added societal costs.

Despite earning low wages and working long hours, many DSPs remain in this work as long as they can afford to because they love it and they recognize the importance of their jobs. Watching the small steps, and sometimes the very notable progress, that people with an ID make toward independence and personal satisfaction is highly motivating to most DSPs. Certainly this is driven by personal values rather than by any hopes for lofty economic benefit. DSPs typically find their highest motivation in their relationships with the people they support. When a personal connection and commitment are made, progress often follows. Yet, high turnover rates, DSPs being overworked and the

"Despite our best efforts to create a wonderful life for our son, we know it could crumble in a moment. Everything, absolutely everything, depends upon the stability and quality of his support staff. In our state of Pennsylvania, DSPs are being paid wages that are 25–50 percent below a living wage, and they have not had an increase in over 10 years. Many work two or three jobs, and nearly half are dependent on public benefits. Until recently, there were no nationally validated competencies for DSPs, no common professional code of ethics, no career ladder and, sadly, little recognition for the important work they do. Our son's DSPs deserve more. As my husband and I approach our seventies, we need to feel we are fulfilling our responsibility to provide a safe and secure future for our son. We're doing all we possibly can."

—Cheryl Dougan, mother of a 33-year-old man living and working in the community in Bethlehem, PA

"Even though I'm working extra hours and doing meaningful work, I am still always behind on household bills and am unable to keep our car running. What's even worse, no matter how frugal we are and how hard we work supporting people with disabilities [so they can] live their lives, my wife and I find it difficult to provide extracurricular opportunities for our three kids. My wife is a preschool teacher at a low-income school. She is also in a 'helping' profession that is just as devalued and underpaid as direct support. It is shameful that in our society, important careers that support people with disabilities to achieve a decent quality of life are so underpaid."

—Adam D. Braun, DSP-C1, Dallas, Oregon

economic stresses of employment can undermine such trusting relationships between DSPs providing support and the people receiving it.

Many DSPs are able to stay in their jobs only by working two or three jobs and up to 80 hours a week to have enough income to put food on their tables. These demands put DSPs and the people they support at greater risk because the DSPs are tired, potentially less alert and more susceptible to error while working. In the U.S., workers often feel value, respect and status based on their rate of pay; however, DSPs' wages are so low that they do not bring forth the sense of value and respect this highly skilled profession deserves.

EFFECT OF THE WORKFORCE CRISIS ON ORGANIZATIONS AND BUSINESSES THAT EMPLOY DIRECT SUPPORT PROFESSIONALS

Organizations face real challenges in addressing the current workforce crisis. Unlike most businesses, providers in this industry cannot simply increase their fees to pay their staff more. Delivery of long-term services and supports happens under a ceiling of funding that is dependent on state legislative actions. The costs and wasted resources of such high rates of turnover over decades have serious consequences for businesses that employ DSPs: does this work as a means of getting rich. These individuals that truly care about people and want to.

Changes in recruitment pool qualifications and experience. A 45 percent annual turnover rate is debilitating in any industry. The relatively low unemployment rate across industries since the Great Recession has negatively impacted staff stability and the ability to meet the demand for services. Organizations cannot find enough qualified individuals to fill positions. A tightening pool of potential employees, along with greater competition from other businesses and industries that pay more competitive wages, results in businesses being forced to consider applicants they would not have previously considered. A fallout of this "lowering of the bar" is that service agencies experience less dependability among DSPs, and they see an increase in disturbing workplace behavior among some employees (e.g., theft, illicit drug use, neglect, poor decision-making).

Business acumen challenges. It is difficult for service-providing agencies to use effective business acumen when they are focused on replacing nearly half of their

"It is hard to watch the effect that high turnover has on the people that we support. So many Direct Support Professionals that I've known over the last eight years are leaving jobs that they love because of low wages and the inability to support their own families. It makes it even harder for those of us who continue in the job to properly support the people when we are understaffed and unable to find good people for these really important jobs."

—Adam D. Braun, Partnerships in Community Living, Dallas, Oregon

"I support many DSPs in a supervisory role. I am regularly informed of the financial burdens they carry. Many are trying to manage a family, home and safe transportation with their very low-level wages. Many have student loans and/or medical challenges of their own they are trying to balance. Nobody does this work as a means of getting rich. These are individuals that truly care about people and want to give back in a meaningful way. More often than not people are being faced with the difficult decision of having to choose a better-paying position versus one that they have a heart for. Because they have to consider their families and their livelihood, they must move on, and this contributes dramatically to our current workforce shortage."

—Michelle Paige-Buttoli

"One [parent] goes away while the other stands by for a week. The next week, the other spouse takes their vacation. We would love to take a vacation together."

—Parks family

workforce each year. Their attention is mostly on hiring and getting new people into vacant positions, as opposed to developing the other half of their workforce that wants to stay in the profession. Supervisors and managers devote most of their attention to new hires, even as they recognize they are neglecting the support and development of the organization's most valuable employees. Supervisors also spend large percentages of their time working direct support shifts themselves, which leaves less time for them to actually supervise their employees. Additionally, supervisors report that the time they do have available to support their DSP employees is often spent on problem-solving in regard to difficult life situations caused by poverty and related stress.

Financial costs and wasted resources. The role of the DSP is complex. The skills of DSPs, as in most professional roles, accumulate and are refined over time. High levels of instability within a workforce require substantial ongoing investments in recruitment and training of staff. In addition to the replacement costs of recruiting and selecting new employees, high levels of staff instability require substantial payouts of overtime as current DSPs fill in for DSPs who vacate positions. In New York State alone, on average, organizations across that state paid for 2,541 hours of overtime in a 30-day period during 2014. Total estimated annual overtime expenditures were $206,276,508 (Hewitt et al., 2015).

Risks for and the high cost of injuries. DSPs perform jobs that place them at risk for injury. Many DSPs provide support by positioning, lifting or transferring people who are unable to do these tasks independently. DSPs may also mediate emotional or behavior challenges, which can result in injury. According to the Bureau of Labor Statistics (2016), among all occupational categories, nursing assistants had the fourth-greatest number of occupational injuries and illnesses per year requiring days away from work. Their rate of significant injuries and illnesses was exceeded only by law enforcement, correctional officers and firefighters. This risk is seen in the high cost of worker compensation insurance premiums paid by DSP employers based on the actual claims experience of insurance companies. The multiple locations and circumstances in which human service provider agencies place DSPs often make it more difficult to institute programs and policies that control injuries, thus resulting in increased rates (Hutcherson, 2017).

EFFECT OF THE WORKFORCE CRISIS ON OUR COMMUNITIES AND THE ECONOMY

This workforce crisis has a multifaceted impact on the community. When there are not enough staff, and when those who are present are not well trained, the people they support use more of the community's police, ambulance, firefighter, emergency department, acute care and other resources. Availability of more experienced and better-trained DSPs could reduce this cost to communities. Additionally, given that nearly half of all DSPs use some form of government-funded, means-tested public assistance, the current crisis' foundation in low-wage, limited-advancement employment results in communities and taxpayers picking up the costs of income replacement supports for health care, housing, food, child care and other necessities.

FACTORS INFLUENCING THE CRISIS

Over the last 20 years, the conditions of concern identified by Congress in their enactment of the DD Act (Public Law 106-402) have worsened into what is now considered by all industry stakeholders to be a national workforce crisis. At the heart of this threat is the increasing difficulty of securing and sustaining a direct support workforce of sufficient size and quality to meet needs of people with an ID. The following factors have the greatest impact: (1) growth in the number of people with ID/DD who need and receive services, (2) major shifts in the type of services desired and delivered to people with ID, (3) steadily increasing longevity of people with ID/ DD, (4) changing U.S. population demographics, (5) changes in the overall U.S. labor force and economy and, above all, (6) the failure to create an occupation of direct support with sufficient pay, benefits, training, career trajectories and status to recruit and retain a stable, skilled workforce to deliver on the promises made.

GROWTH IN THE NUMBER OF PEOPLE WITH ID/DD WHO NEED AND RECEIVE SERVICES AND RELATED INVESTMENTS

Between June 1991 and June 2014, the total number of individuals served under the auspices of state ID/DD service agencies increased by nearly four times (390 percent), from 289,370 to 1,128,530. In 2015, total spending for ID/DD services and supports reached $65.21 billion, a growth of 4.1 percent from FY 2013–2015 (see Figure 6). As a result of the Great Recession, state/local funding declined 4.9 percent between 2009 and 2010, which was counter-balanced by "enhanced" Federal Medical Assistance Percentage (FMAP) rates. In 2011, the U.S. experienced the first reduction in total ID/DD spending, dropping 0.8 percent to $60.2 billion.

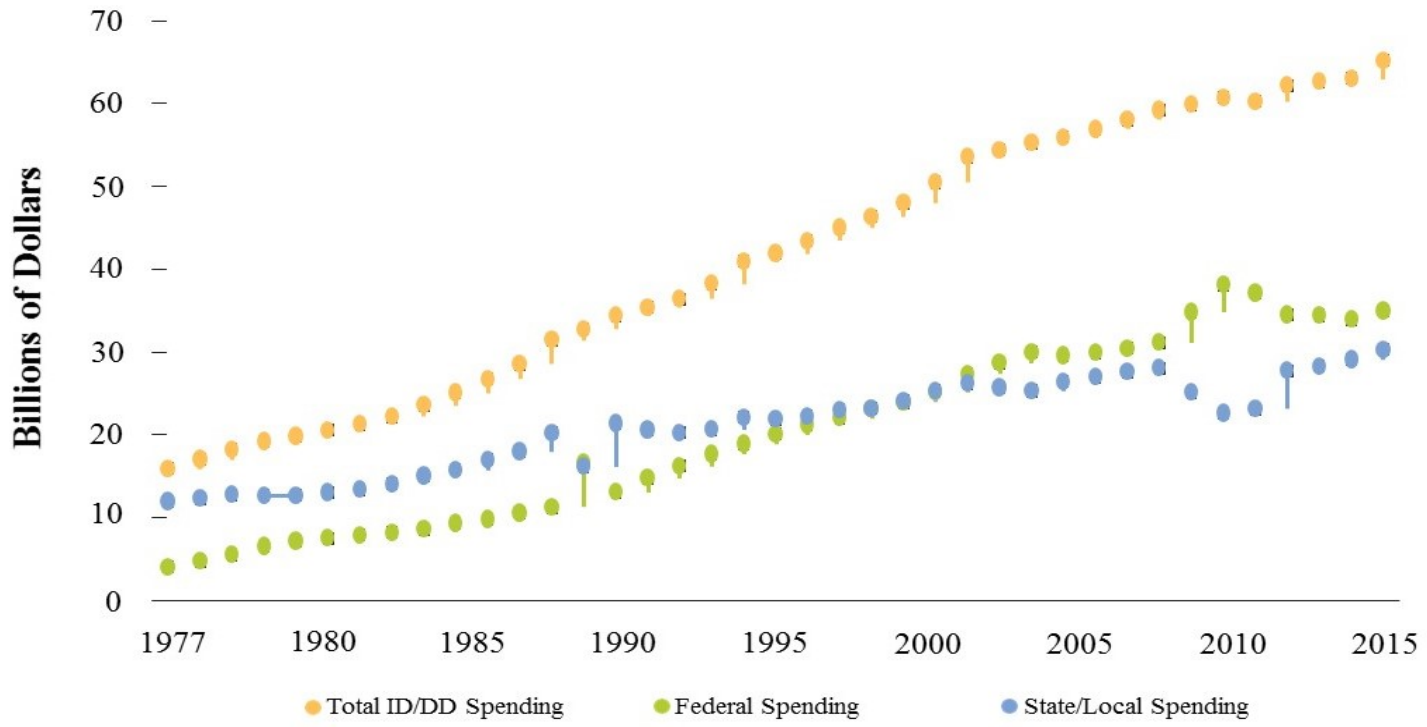
MAJOR SHIFTS IN THE SERVICE SYSTEM

The growth in services delivered represents not only increased numbers of people with ID/DD who receive services but also steady changes in the types of services they receive, which influences the workforce crisis. Over the past two decades, as children educated in more inclusive school settings have grown up, they (and their families) expect to live and be included in their communities. These changing expectations and our commitments to them have resulted in people receiving increasingly individualized services and supports in their homes and community instead of in congregate care facilities.

Where people with ID/DD live. Of the people with ID/DD known to state agencies, 1,170,190 receive some type of Medicaid-funded long-term residential support. These services support people in family homes, their own homes or group settings of varied sizes (1–6, 7–15 and 16+). As Figure 7 indicates, the majority of people with ID/DD who receive services get them in their family home, and the smallest portion receives them in larger settings where 16 or more people live.

Where people with ID/DD spend their days and are employed. People with ID/DD also receive LTSS that provide them with employment and daytime activity. While most people with ID/DD want to participate in integrated community employment, the majority are not doing so (Butterworth et al., 2015); only about 16 percent of people with ID/DD have paid integrated employment in community jobs.

Figure 6. ID/DD expenditures over time, 1977–2015



Note: all dollar values inflation-adjusted for 2015 dollars

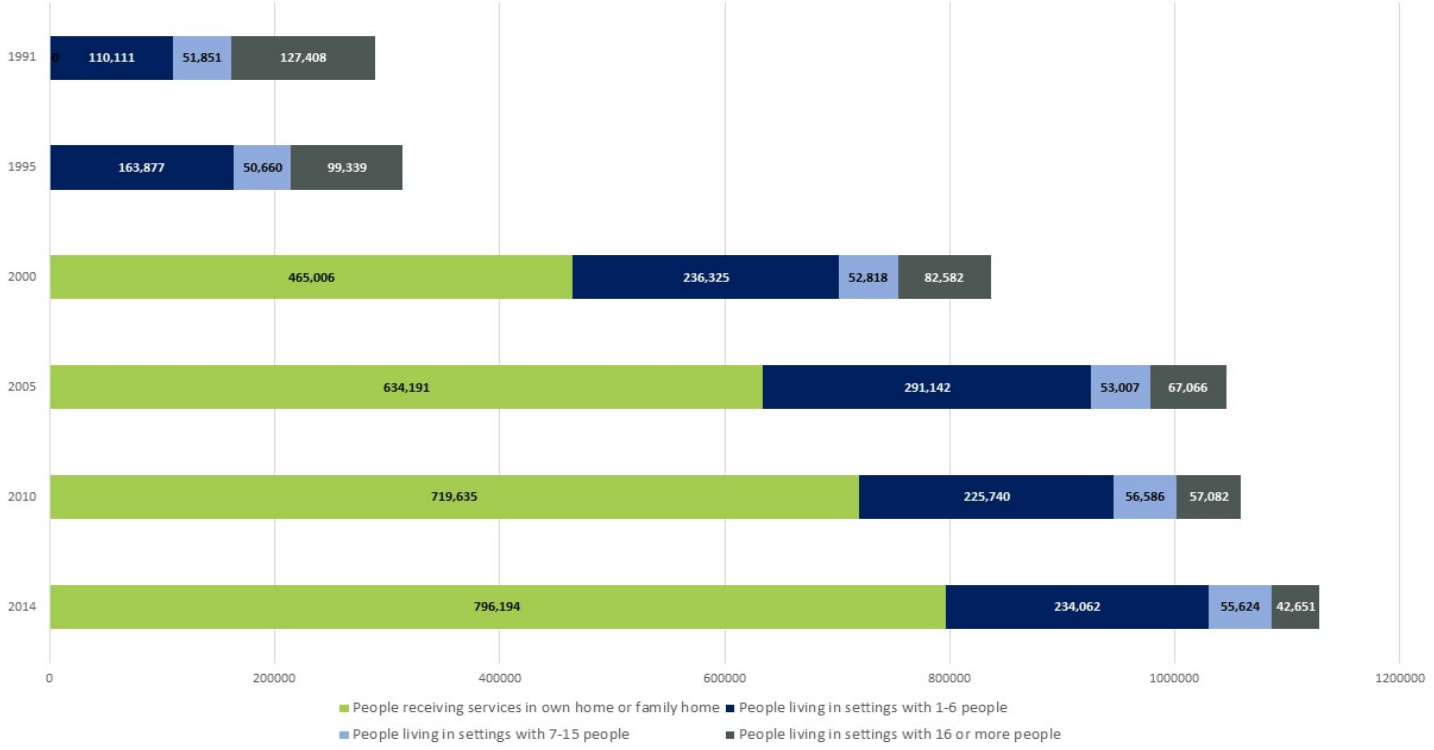
Source: Braddock et al. (In Press). State of the States in Intellectual and Developmental Disabilities: 2017. Washington, DC: American Association on Intellectual and Developmental Disabilities.

As indicated in Figure 8, there was tremendous growth in the number of people receiving daytime non-work and employment services between 1990, when 314,488 people were supported by DSPs, and 2015, when 610,188 people were supported. However, the overwhelming majority participate in non-work activities (e.g., volunteer work, community engagement, entertainment) or facility-based ("sheltered") employment. To increase integrated employment for people with ID/DD, sufficient numbers of well-trained DSPs must be available.

Changing expectations toward more person-centered supports. Over the past several decades, rapid deinstitutionalization and community integration of people with ID/DD have resulted in remarkable systems transformation. In decades past, DSPs were much more likely to work in relatively large residential settings in which university-trained professionals and other experienced personnel (e.g., nurses, therapists, psychologists, social workers) were likely to be on-site. As individuals with an ID and their families have sought more physically and socially integrated lifestyles, DSPs are expected to accommodate these changes by working much more independently and responsibly. They are called on to support the aspirations of individuals to be more fully integrated in their communities through social, recreational and employment roles. It is difficult to overstate the extent to which the rapid shift from congregate care to home- and family-based services has demanded not only increased skill, but also increased sophistication and flexibility, on the part of DSPs. Increasingly, the focus of LTSS is on providing personalized services with a strong commitment to greater independence by providing individuals with an ID just what they need when they need it.

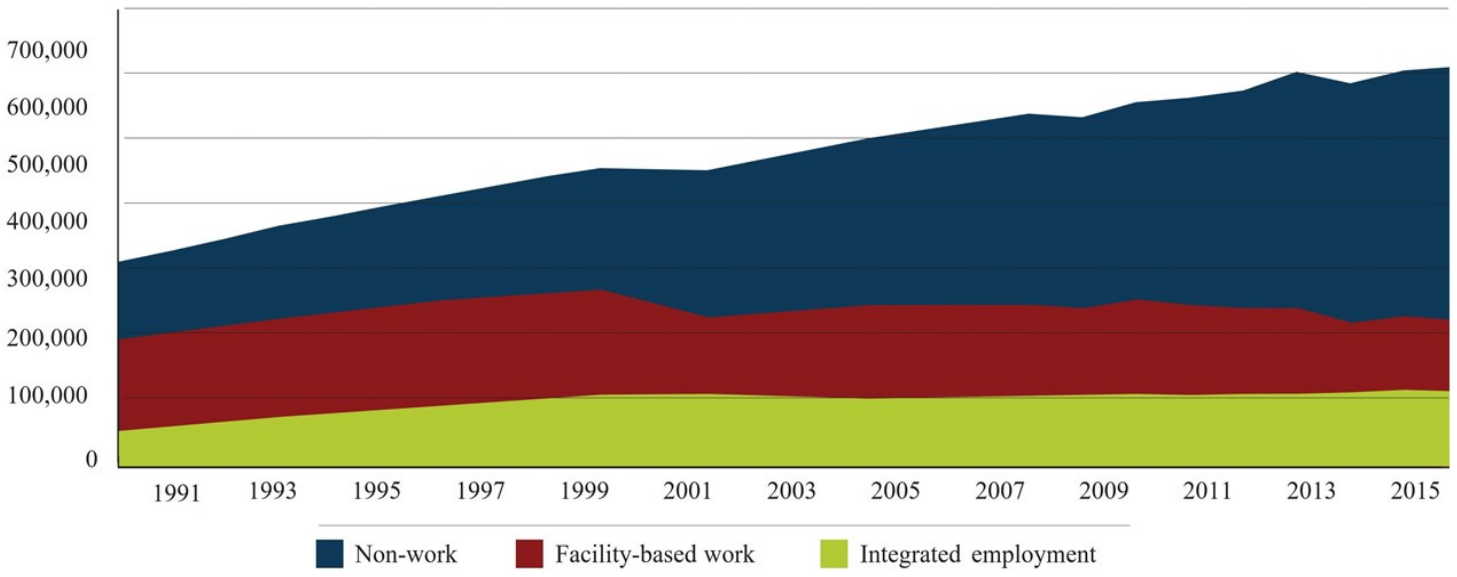
States and the provider organizations that employ DSPs have responded quickly to demands and the desire for more person-centered supports. For example, in the decade between 2003 and 2013, the average annual cost per person of providing Medicaid-funded LTSS increased only from $50,237 to $52,999, which in inflation-adjusted dollars represented a 16.7 percent decrease in per-person costs (Anderson et al., 2015; Lakin, et al., 2004). But the economic and social benefits of shifts in DSP roles have yielded little benefit to DSPs in terms of wages and benefits. Rather, the economic gains associated with such increased productivity have been used to provide services (albeit not fully) to the steadily growing number of individuals with ID seeking and needing community-based services and supports.

Figure 7. Living settings of people with ID/DD



Source: Residential Information Systems Project (2017), Research and Training Center on Community Living, University of Minnesota

Figure 8. Types of employment and day services received by people with ID/DD



Source: StateData.info (2016), Institute on Community Inclusion, University of Massachusetts-Boston.

PEOPLE WITH ID/DD LIVE LONGER

One of the most positive and celebrated reasons for the high demand of Direct Support Professionals is that the life expectancy for individuals with ID/DD has increased from an average of 19 years in the 1930s to 66 years today (Coppus, 2013). There are many reasons for this, including (a) advances in medicine, (b) improved healthcare, (c) better nutrition, (d) decreases in institutionalization and (e) the inclusion of people with ID/DD in society. Although the severity of a person's disability, certain genetic conditions, mobility impairments and having feeding difficulties are all associated with shorter average life expectancies, all subpopulations of persons with ID/DD are living longer. Today, people with mild intellectual disabilities have life expectancies similar to the general population (74 years).

Many people with ID/DD require lifelong support and in some cases 24-hour supervision. As people with ID/DD live longer, the total number of service-years they will require increases. This creates additional demand for DSPs.

CHANGING DEMOGRAPHICS IN THE UNITED STATES

The population demographics in the United States are changing and significantly influencing the direct support workforce crisis by creating competition for employees between populations with needs and by reducing the number of new entrants into the workforce.

Aging of Americans. In 2014 there were 46.2 million Americans 65 years or older, making them roughly 15 percent of the U.S. population (one in every seven people). This number is expected to double by 2060, to approximately 98 million (ACL, 2017). Among this demographic, roughly 30 percent of those who live in the community report having difficulty with activities of daily living (ADLs), and 95 percent of those who receive institutional care report needing such support. The growth of the older American population places added demand on the labor force and increases competition for potential workers between older Americans and Americans with ID/DD (ACL, 2017).

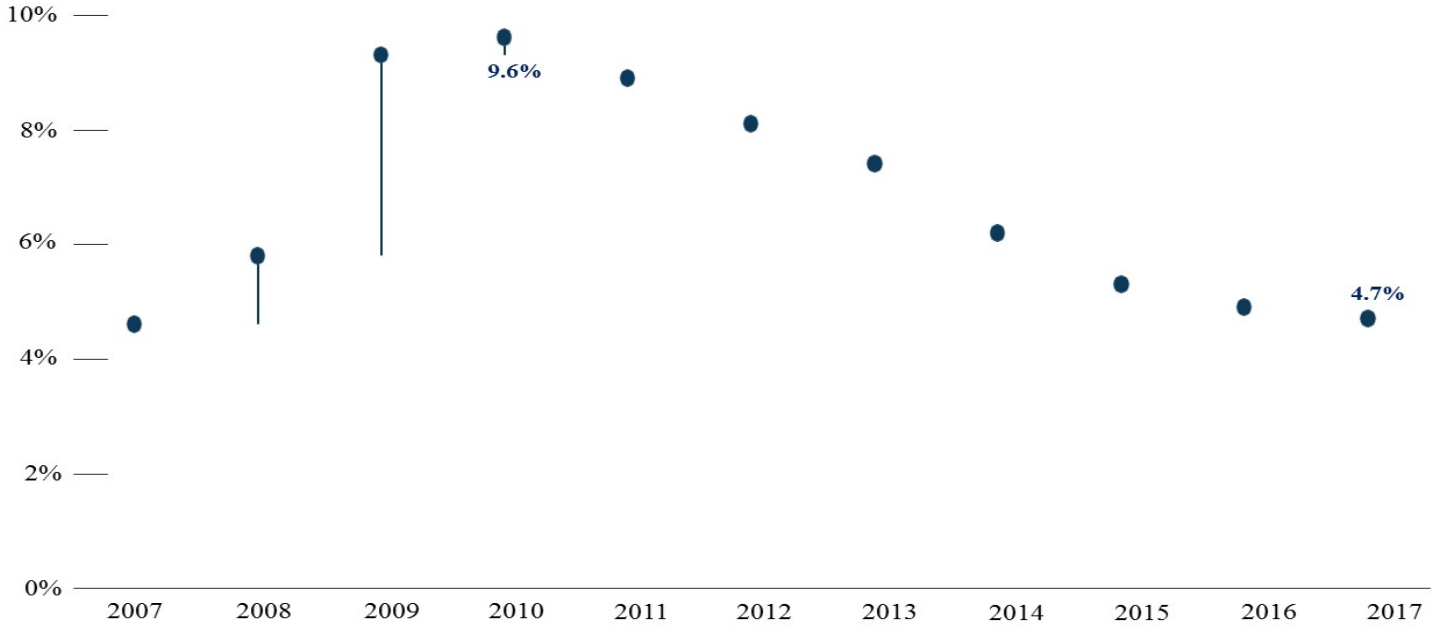
Fewer younger Americans. The number of people age 16+ entering the workforce is not keeping pace with the increased demand for LTSS to serve the aging U.S. population. While the labor force will likely grow over the next decade, it will do so at a slow average annual rate of 0.5 percent. It is projected that only 18,498,000 youth/young adults age 16–24 and 104,697,000 adults age 25–54 will enter the workforce in 2020, representing a projected decline since 1994 of 13 percent and 4 percent respectively. 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 an overall decrease in the

Figure 9. Workforce conditions that deter entry into the profession

percentage of the population participating in the labor force.

These projected changes create competition for workers across all industries. One cannot go shopping or watch the news without seeing clear signs that employers all over the U.S. are looking for new workers and are competing by offering higher wages. The high level of accountability, job stresses and round-the-clock, 365 days a year nature of DSP work, coupled with low wages and poor benefits, do not make the field enticing for most new workforce entrants. The rapidly growing demand for employees to support older adults outstrips the demand for workers to support persons with an ID. This increased demand is occurring in an economy in which 80 percent of all U.S. jobs are in service sectors. As the number of new entrants into the workforce fails to keep pace with demand, especially in the service and support sectors, the crisis in recruiting and retaining DSPs for people with an ID will most likely worsen. Thus, it is important to

Figure 10. U.S. unemployment rate over time, 2007–2017



Source: Bureau of Labor Statistics, 2017.

"Despite the degree of professionalism, technical expertise and compassion our staff are required to possess, insufficient agency funding means we are unable to pay them a living wage. At $12.50/ hour to start, all our staff, even those who work 39 hours per week, have second jobs in order to make ends meet."

—The Arc New London

maximize strategies to bring new entrants into the DSP field from non-traditional pools.

Growing diversity. The U.S. population is increasingly diverse, and by 2055, the U.S. will not have a single racial or ethnic majority. This significant projected change has been and will continue to be driven by immigration and increases of diverse racial and ethnic groups already residing in the United States. According to a recent Pew Research Center report, nearly 59 million immigrants have arrived in the U.S. in the past 50 years, mostly from Central and South America, the Caribbean and Asia. Roughly 14 percent of the U.S. population is foreign-born, compared with just 5 percent in 1965 (Pew Research Center, 2016). In the upcoming decades, it is anticipated that most of the U.S. population growth will be linked to new Asian and Hispanic immigration and to growth in the population the U.S. Census calls "native-born," who may also be of Asian, Hispanic/ Latino and other ethnicities.

An increased number of DSPs are first-generation Americans, many of whom speak fluent English in addition to their language of origin. It is not uncommon for these DSPs to have been employed in health care (e.g., as doctors or nurses), education or other allied professions in their countries of origin and to now be working as DSPs while pursuing credentials to practice their profession in the U.S. As the DSP workforce shortage has intensified, businesses have employed more immigrant workers. It is estimated that 20–25 percent of direct support workers employed by nursing homes and home health organizations are foreign-born. While percentages vary based on geographic region, multiple studies reviewed by The Lewin Group (2008) estimated that in some parts of the U.S., over half of all DSPs are non-white.

The cultural and linguistic diversity in the LTSS industry is a significant strength. The DSP workforce resembles the current and emerging demographic makeup of the United States. This workforce brings a wealth of knowledge and skills, including the capacity to understand and respond to racial, ethnic and cultural differences among the U.S. population, and to speak languages beyond English. The U.S. Census Bureau estimates that 21.5 percent of the U.S. population 5 years and older speak a language other than English at home (U.S. Census Bureau, 2017).

U.S. ECONOMIC STABILITY AND GROWTH

The stability and growth of the U.S. economy dramatically affects the direct support workforce in the LTSS industry. When the economy is doing poorly and unemployment rates are higher, employers of DSPs have some reprieve in terms of being able to fill vacant positions because more people are looking for jobs. When unemployment rates are lower, it is more difficult to fill vacancies. During and immediately following the Great Recession, with unemployment rates hovering around 10 percent (as shown in Figure 10), most service providers experienced substantial relief from the pressure of high vacancy rates. As economic conditions have improved and general workforce participation has decreased (from 66 percent of all residents 16 years and older in March 2007, to 63 percent in March 2017), employers of DSPs have felt the workforce crunch more than ever. At trade association meetings and in boardrooms where leaders of service-providing agencies make decisions, it is broadly recognized that this crisis can't be solved by simply hiring more people. The direct support workforce is the most pressing issue discussed by LTSS business owners today.

LOW WAGES AND LACK OF AFFORDABLE BENEFITS

Without question, and as previously discussed, a strong influence on this workforce crisis is the low wages and lack of affordable benefits available to DSPs. No matter how appealing the work itself is, employees need to be able to live and support their families. This is universally recognized by employers, workers and clients within the LTSS industry.

RAPID, INTENSE, FULL-SCALE RESPONSES NEEDED THROUGHOUT THE U.S.

People with an ID and their family members have always known and experienced the effects of the ever-revolving door with DSPs. Yet, employers, advocates, policy makers and allies have been slow to make this their highest issue and to identify it as a threat to quality in LTSS. Unfortunately, like death by a thousand cuts, there has been no single event to rally society to do what needs to be done – to actually keep the promises made to people with an ID and their families. It will take bold leadership within the Administration to work in collaboration with Congress and industry to implement solutions to these challenges. Without such leadership, the LTSS system is threatened for all people with an ID who rely on it to meet their most basic needs. Fortunately, there are promising practices that offer solutions that can be adopted. When implemented, these practices will create efficiencies and cost-effectiveness.

"I left that agency for a higher-paying job so that I could make ends meet and work less hours. While that job was good money, it was not as meaningful as being a direct support professional. I decided to go back to what made me happy in life and what made me feel like I was making a difference in someone's life."

—Clarice Davis (DSP 4 years OHIO)

MOVING TOWARD SOLUTIONS USING PROMISING PRACTICE

Significant changes are needed in the nation's approach to the workforce that supports people with an intellectual disability if we are to sustain the commitments made to them and to their families. Over the past two decades, small-scale efforts have been made to find solutions, with small investments provided by federal, state and local governments. Most of these efforts have been grant-funded demonstration projects that don't prove fully sustainable after the grant funding ends. Practices that would address the workforce crisis include:

1. improving professional identity and recognition;
2. teaching business and organizational leaders skills to improve their ability to recruit, select and retain employees;
3. the use of self-directed services that permit individuals and families to recruit, select and retain their own DSPs;
4. using worker cooperative and independent provider models;
5. using competency-based training models that lead to credentialing or certification of staff and yield wage increases; and
6. using technology-enhanced supports.
7. This section of the Report highlights some of these practices.

PROFESSIONAL IDENTITY AND RECOGNITION

In order for young adults and others to be recruited into DSP positions, they have to know who these professionals are and what they do. Programs that recognize and create professional identity will prove useful in letting Americans know about the jobs and the field of community supports for people with an ID.

National Professional Association. The National Alliance for Direct Support Professionals (NADSP) is a professional association for this workforce. Its aims are to (1) enhance the status and recognition of DSPs, provide opportunities for training and education, support the development and implementation of a voluntary credentialing program, (4) create a national professional organization for DSPs, (5) support public policy initiatives that increase the wages and overall compensation for DSPs and (6) determine an occupational title that best matches the role and responsibilities of DSPs. The work of NADSP has resulted in the wide use and industry acceptance of the occupational title "Direct Support Professional," a national Code of Ethics, adoption of the 15 NADSP Competency Areas and associated skill statements for the DSP role, and a voluntary credentialing program based on the NADSP competency and skills areas.

Recognition Programs. Raising awareness about the complexity and importance of the DSP role is an important first step toward recognizing and rewarding DSPs in a manner they deserve. A number of recognition and awareness campaigns have been launched in states and local communities throughout the U.S. to highlight the importance of DSPs to the lives of the people they support. DSPs are nationally recognized and honored in September during Direct Support Professional Week, first formally authorized in 2003 through a Congressional Resolution. This week is now also recognized by many state governors and organizations as an opportunity to celebrate and acknowledge the profession of direct support. Several national associations have developed award programs to recognize exemplary contributions of individual DSPs. NADSP also recognizes effective organizational practices through its Moving Mountains award program. Combined, these programs bring attention to who DSPs are, what they do and effective strategies for recruitment and retention.

Grassroots and Public Awareness Campaigns. Grassroots campaigns have successfully increased awareness about the important work done by DSPs. These campaigns are most often connected to efforts to increase wages and/or provider rates within LTSS. They strive to mobilize DSPs, individuals with an ID, family members and disability advocates to join forces to share stories and ask for change. Campaigns of this nature do not happen in every state or community, and they vary with regard to visibility. Various videos that have been used in these campaigns to illustrate the work of DSPs and the effect of the workforce crisis are available on Facebook and other social media outlets. Recent examples include: (a) Befair2directcare – https://www.youtube.com/watch?v=J52Zl7-Fcjw/; (b) Value the Work, Raise the Wage – http://www.oregonresource.org/value-the-work.html; (c) The Pennsylvania Advocacy and Resource for Autism and Intellectual Disability (PAR) –

http://www.fixthedspcrisis.com/; and (d) ANCOR National Advocacy Campaign – http://www.nationaladvocacycampaign.org/

BUSINESS ACUMEN FOCUSED ON WORKFORCE RECRUITMENT AND RETENTION STRATEGIES

Direct Support Professional workforce challenges are pervasive, and all service-providing organizations struggle to find and keep their DSP employees.
Yet, some organizations do better than others in managing DSP recruitment and retention. The variability across organizations is likely a product of organizational business practices. While systemic issues strongly influence workforce challenges (e.g., wages, unemployment rates), there are evidence-based strategies that organizations can use that will help them maximize retention. Both the American Network of Community Options and Resources (ANCOR) and The Arc of the United States have developed workforce recruitment and retention toolkits to support their member organizations. These tools were developed and used in pilot demonstrations conducted by the Research and Training Center on Community Living at the University of Minnesota. When used in combination with a specific recruitment and retention organizational plan, these tools have assisted participating organizations in reducing turnover by as much as 15 percent for DSPs and 29 percent for their supervisors. The toolkits include:

- Targeted Marketing Flyers developed with feedback from members and stakeholders
- Structured Behavioral Interview Questions and Interviewers Guide
- Access to the National Frontline Supervisor Competencies (NFSC) – http://rtc.umn.edu/docs/National_Frontline_Supervisor_comp_7-2-13.pdf
- Customized and Branded Public Service Announcements (PSAs) to be used on multiple media platforms
- Customized Realistic Job Previews (RJPs)

These toolkits are designed to provide maximum impact in the digital age while still taking advantage of opportunities for advertising in printed publications and on job notice boards. The targeted marketing flyers can be printed, or they can be posted on social media or organization webpages. The public service announcements (PSAs) are designed as short (30-second) clips to raise awareness and provide a call to action. They are available in digital download for members to use for marketing and outreach and can be posted to social media and organization webpages. The Realistic Job Previews (RJPs) are customized for organizations and provide a snapshot of a day in the work life of a DSP, visually illustrating the positive aspects of the work balanced with the challenges from the perspective of DSPs. The ANCOR toolkit can be found at http://www.nationaladvocacycampaign.org/welcome/, and The Arc of the United States toolkit, at http://www.thearc.org/.

"We must do something to attract more qualified people to do this important and noble work. Now more than ever, direct support professionals will be front and center in helping people like me to build social capital, helping us in finding and keeping meaningful employment, promoting social inclusion – all the while still supporting safety, assessing risk and promoting choice."

—Ed Bartz (a person who previously self-directed and now uses an agency-with-choice model)

SELF-DIRECTED SERVICES

Self-directed services allow a person with an ID and/ or their family to determine their own goals and support needs and the services they want, and to find, choose and train their own staff. Self-directed services promote people's independence and control over their own lives. While this model works for many individuals and families, it is not yet widely used within the ID/DD service system. Varying models of fiscal accountability are used in self-directed services. Within ID/DD programs, the vast majority use fiscal intermediaries approved by their state to manage their accounts and serve as employers of record for staff. Currently, 41 states offer some type of self-direction as a support option through their Home and Community-Based Services, and increasingly, self-directed options are offered through state-plan Medicaid services. A recent nationwide review of self-direction found that at least 96,796 individuals with ID/DD participated in it across 33 states (DeCarlo, et al., 2017).

It is not uncommon for individuals and families who self-direct to pay a higher hourly rate for their DSPs (though often fewer benefits are provided these same DSPs). Some studies have shown that self-directed models have lower rates of DSP turnover (Timberlake et al, 2014; Gross et al., 2013). Using self-direction allows individuals and families to more easily integrate the natural support of family and friends, and it is sometimes easier to arrange intermittent or temporary supports when they are needed because of the program flexibility (Melda et al., 2009). In some self-direction models, family members can serve as paid DSPs. A benefit of individuals and families being engaged in finding, training and supporting their own direct support staff is the pressure it relieves on the traditional service system that struggles to maintain its current workforce. It also brings new entrants into the DSP workforce who otherwise might not have considered DSP work.

THE USE OF INDEPENDENT PROVIDERS (OR CONTRACTORS)

Several states have begun using an independent provider (IP) model for direct support staff. Independent providers, or independent contractors, are self-employed and provide services directly to individuals with an ID. These contractors can be affiliated with a community organization that acts as a fiscal intermediary, or they can be self-employed. IPs find employment through advertising, through recommendations from other people in the industry and, in some cases, through registries. The IP model gives people with an ID and their families greater choice over who provides services to them. There is typically lower overall cost associated with independent providers, as there is less overhead.

The IP model has proven to be a viable alternative to the standard model of agency-controlled staffing. Allowing DSPs to direct their own career can result in increased wages and improved retention. In states that use the IP model, education and certification are typically available to help DSPs establish themselves as IPs and to support their training needs. Examples of states with LTSS models that use independent contractors as Personal Care Assistants (and some DSPs) are Arizona, California, Oregon, Minnesota and Washington.

WORKER COOPERATIVES

Worker cooperatives (co-ops) are autonomous associations of direct support workers who are united voluntarily to meet their common economic, social and cultural needs and aspirations by developing, jointly owning and democratically controlling the organizations in which they are employed. Across all types of industries, co-ops have shown capacity to reduce poverty and increase employment opportunities and work experiences for employees. Within cooperative models, DSPs become business owners and manage all

Workforce Cooperatives

Cooperative Home Care Associates

Established in New York City in 1985 with the initial goals of reducing staff turnover, improving the quality of supports and services provided, and increasing compensation for DSPs and other home care professionals. http://www.chcany.org/

Home Care Associates

Established in Philadelphia in 1993 and funded by a private foundation. Within this organization, all home care aids are shareholders. www.homecareassociatespa.com/home.html

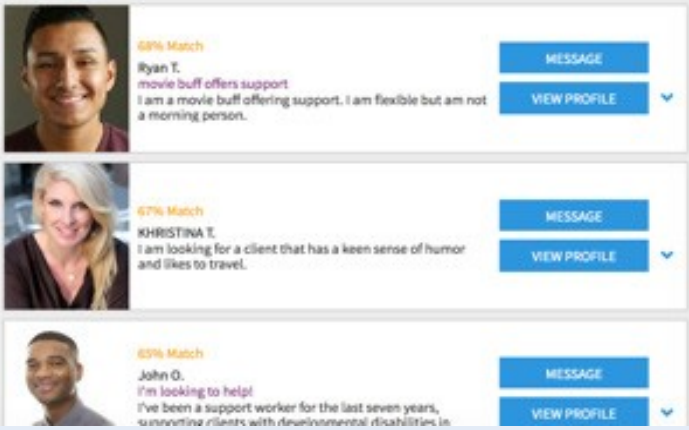
Workforce registry and matching service example

MySupport was founded in 2014 by a group of disability rights activists, former state Medicaid officials and leaders in the aging and disability policy community seeking to expand Medicaid-funded self-directed services. MySupport connects seniors, families and people with disabilities with direct support workers and the tools to manage them.

MySupport allows workers and those seeking support to create profiles, which are then matched using a proprietary matching algorithm focused on personality and values in a direct support relationship. Users are asked questions about how preferred responses to different support-related scenarios, general personality queries and other relevant information, enabling the MySupport platform to assign a compatibility score between each worker and each person with a disability on the platform.

"Too much of the conversation on direct support assumes it's just about putting a warm body in the right place at the right time," said Ari Ne'eman, MySupport's Chief Executive Officer and co-founder. "We designed MySupport to let people find workers based on their own personal definition of quality. Every person with a disability deserves the right worker for them. Our matching algorithms work like online dating – you get to see what people value and believe in before sitting down for an interview or first home visit."

In addition, MySupport offers fiscal intermediaries and agencies tools to manage time and attendance, documentation and note-keeping and other tools necessary to manage the worker-employer relationship. The platform can be customized to reflect employer or budget authority systems and



includes a comprehensive back end system that lets program administrators at the agency/FI, health plan or state level set service-authorizations, overtime requirements, joint employer considerations and other relevant components of platform operations.
At request, the company offers other forms of customization, including workforce analytics and integration with established eLearning offerings.

My Support typically is contracted with state governments, managed care organizations, agencies and fiscal intermediaries to set up operations in a particular area. My Support works collaboratively with its clients and local community-based organizations to recruit workers, assist them in creating profiles and provide technical support and assistance to those seeking support on the platform and program administrators seeking to customize platform operations, set service authorizations, access analytics data or otherwise interface with the platform. My Support is currently live in California, Iowa and New York and will soon launch in Virginia, Maryland and several other states.

aspects of the organization's operation. As such, they have more control over their wages, benefits, training and workplace culture. While the cooperative model is currently most often used in home health services, it has potential for a positive effect in the direct support workforce because so many DSPs live in poverty and want more influence on organizational culture.

DIRECT SUPPORT WORKFORCE REGISTRIES AND MATCHING SERVICES

Across the U.S., more people are hiring, managing, supervising and discharging their own support staff. Many people who self-direct hire family members or friends, but others benefit from services that link them to qualified and appropriate DSPs. Workforce registries and matching services provide a mechanism through which this linking can occur. Such registries facilitate connections between DSPs and individuals who are looking for new employees.

Workforce registries are intended to connect supply with demand, and many strive to ensure compatibility between DSPs and the individual supported, with the hope that a good match will reduce turnover (Dilla, Robbins & Blakeway, 2013).

COMPETENCY-BASED TRAINING PROGRAMS

Competency-based training (CBT) is designed to teach people knowledge (what a person knows), skills (what a person can do) and attitudes (the way in which a person thinks about something). CBT usually includes a combination of classroom and/or online didactic training delivery, on-the-job training and skills demonstration and measurement (Hewitt, 1998). Training that uses a competency-based approach is purposefully designed to result in the learner being able to demonstrate skills based on a specific set of competencies, such as those identified earlier in Figure 2 (p. 16). There is a growing, yet still limited, number of competency-based training programs that target DSPs as learners. The National Alliance for Direct Support Professionals accredits training programs that are designed to support DSPs who complete their national credentialing program. Currently, there are 11 NADSP-accredited programs.

DirectCourse is an example of an accredited online training curriculum that was developed with grant funding from the Administration on Intellectual and Developmental Disabilities, was successfully scaled up and became self-sustaining post-funding. It is currently used by 34 states, and has over 600,000 active learners engaged each day and over 7 million competency-based lessons completed each year. This program has an emerging research base that shows that when DirectCourse is combined with classroom discussion, mentoring and on-the-job skill demonstration, organizations experience reduced DSP turnover, DSPs gain skill and report better relationships with their supervisors, and individuals with ID/DD experience better quality-of-life outcomes in areas such as employment, home living and health and safety (Bogenshutz et al., 2015; Hewitt et al., 2017).

CAREER LATTICE AND CREDENTIALING

Career paths and credentials such as certificates are common strategies across industries in the U.S. to improve the skills of workers and to differentiate and reward them for completing training and developing additional skills. Several models of career latticing exist in the direct support workforce to encourage workers to stay in direct support roles (vs. moving up and out into supervisory roles). Most are multi-level programs that offer specialized skills based on (1) specialized needs experienced by people with an ID (e.g., complex health, behavioral support, aging), (2) service type (e.g., in-home, employment, residential, community) or (3) degrees of autonomy and independent decision-making specific to the role of a DSP (initial, proficient or advanced). Providing a pathway for advancement through DSP credential programs has proven challenging within the LTSS industry, especially for the group of workers who support people with an ID. Three primary reasons are at the foundation of the lack of expansion and widespread use of credentialing and career pathway programs: (1) There are few incentives (e.g., increased wages, opportunities for advancement) for DSPs to complete such programs; (2) state and federal regulations do not require them; and (3) the reliance on Medicaid funding for LTSS requires that wage incentives be built into provider rates, which requires legislative appropriation at the state level.

In response to some of these barriers, in 2011 the Centers for Medicare & Medicaid Services (CMS) issued a bulletin (CMS, 2011) to states that clarified allowable training within Medicaid rate-setting and provided guidance on Medicaid reimbursement policy for direct service worker continuing education and training costs. To further clarify their intent, CMS issued a toolkit (Robbins, Dilla, Sedlezky & Johnson Sirek, 2013) that provides strategies and methods states can use to cover costs of continuing education for the direct support workforce, including training, apprenticeship, credentialing and certification. The toolkit was created to ensure that state Medicaid administrators had information about strategies they can use to establish and provide accessible continuing education and training to further the skills, knowledge and competencies of the workforce providing services to Medicaid-eligible service recipients.

Using a comprehensive multi-stakeholder engagement process, the New York State Office for People With Developmental Disabilities (OPWDD) identified six critical components of effective credentialing programs: They should be (1) sufficiently funded so as to be developed, implemented, sustained and evaluated; (2) accessible to DSPs in ways that enable participation irrespective of where DSPs live and where the

program is offered; (3) designed academically for learner success and to include mentoring and other types of learner support; (4) designed to promote adult learning and use of a hybrid methodology including both online and classroom training to accommodate DSP schedules and the need to learn at varying times; (5) inclusive of work-based learning opportunities where learners can develop and practice skills in real work settings; and 6) designed to ensure that wage and promotional opportunities are built into the infrastructure of LTSS through Medicaid rates.

Examples of credential programs for the direct support workforce that supports people with an intellectual disability

Association of People Supporting Employment (APSE) – http://apse.org/certified-employment-support-professional/

The Ohio Alliance of Direct Support Professionals (OADSP): DSPaths – http://www.oadsp.org/?page_id=34

National Alliance for Direct Support Professionals (NADSP) – https://nadsp.org/about-dsp-credentialing/

National NADD Competency-Based Direct-Support Certification – http://acp.thenadd.org/ dsp.htm

USING TECHNOLOGY AS SUPPORT

As long-term services and supports change, new technologies are emerging and being used to provide support to people with an ID who demand lower levels of on-site direct support staffing. These technology supports are sometimes used as a supplement to direct support staffing and at other times used in the absence of direct support staffing. They are used in individual homes, family homes and group living situations to monitor the safety and support the independence of people with ID/DD. Technology is also used to support people with transportation, to help them navigate their community and to support their daily schedule. Many states now allow for the use of technology supports through Home and Community-Based Services.

In providing individuals and their legal representatives with choice and control over the use of technology, person-centered planning and support are critical to ensure ethical decisions that support privacy and autonomy (Braddock et al., 2013). For many people with an ID, technology facilitates greater independence and reduces the need for more restrictive, supervised settings (PCPID, 2015). Several types of technology are used in LTSS:

Sensors. Sensor technology is used to monitor the health and safety of people with an ID. The most widely known sensor technology is alert systems that people wear around their neck so that, if they fall or need help, they push a button and someone will either call or come to assist. Other commonly used sensor technologies are sensors on doorways so that a person who is responsible for monitoring can know if a person with an ID has arrived home or left their house. These sensors also provide an alert if someone enters a home or room when they are not expected. Sensors can be used on beds and in bathrooms to monitor whether a person gets up in the middle of the night and if they are using the restroom. These sensors can identify health conditions such as sleep apnea (identified by sensor data that shows unusual sleep patterns and restlessness) or diabetes (identified by unusually high frequency of urination). Each sensor is monitored by an organization or designated person who responds on an as-needed basis if alerted to do so.

Remote Monitoring. Remote monitoring technology is used by installing cameras that project images through secure internet connections, allowing DSPs (or others) to monitor a person with an ID from a remote location. In these situations, protocols are put in place that instruct the remote monitoring DSPs about what to look for; if anything of concern is noted, the remote DSP will call the individual being supported or deploy a paid staff or family member to intervene.

Computer-Assisted Devices (Tablets, Smartphones). There is a variety of personal technology that supports learning and can lessen reliance on DSPs. These tools include voice interfaces (Barker, 2002), computer training and teaching programs (Davies, Stock, & Wehmeyer, 2004) and picture-based email programs. Despite their potential, these technologies are not readily available to most people with ID/DD.

Transportation Technologies. Technology has the potential to dramatically enhance independence and mobility in the community for people with ID/ DD, meaning they can enjoy better access to the services and opportunities that they need in order to live most fully. Devices with Global Positioning Systems and voice-activated instructions are used to support community navigation. With the availability of application-assisted transportation services (e.g., Uber and Lyft), some people with an ID are using technology to request and manage transportation. The Accessible Transportation Technologies Research Initiative (ATTRI), a multimodal effort at the Department of Transportation, seeks to remove barriers to independent travel by developing technologies that (a) make wayfinding easier for people with a variety of disabilities (sensory, cognitive and others), (b) make crossing intersections safer, (c) provide concierge-style services to assist travelers along their journeys and (d) utilize advances in robotics and automation to provide additional transportation options. After extensive research and public engagement to help understand the needs of stakeholders, the ATTRI program is entering the first stage of prototype development.

Electronic Medication Dispensers. A key role most DSPs have is to support individuals with an ID in taking their medications as prescribed by physicians. DSPs prepare, administer and document the delivery of medications. There are technology-enhanced devices on the market that can be programmed to open at the correct time each day and offer one dose of medication at a time. Some models provide verbal prompts that it is time to take medication. While these devices rely on caregivers to program and fill them with medications, for some people with an ID this technology reduces the need for a DSP or family caregiver to be present to administer medications.

Smart Homes. Using technology systems in homes can provide numerous benefits for people with disabilities, their families and DSPs. Tracking systems can provide feedback to family and staff on daily-living activities such as cooking, cleaning and laundry. Pattern recognition and learning software can be used to alert direct support employees of impending risks or adverse events, including social isolation and challenging behavior (Elite Care, 2002). Environmental automation can control operation of household systems, including disabling an appliance, or unlocking a door when a person is ready to enter and locking it after they enter or leave.

Personal Robots and Assistants. Robots and electronic assistants (e.g., Siri and Alexa) are becoming more commonly available and used in the U.S. These technologies have the potential to supplement the role of DSPs and family caregivers (Dario et al., 1999; Excell, 2004). Analysis of data from the National Long-Term Care Survey showed that utilization of assistive technologies was associated with fewer hours of personal assistance (Hoenig, Taylor & Sloan, 2003). Other advances have also been utilized to assist people with activities of daily living (Rotstein, 2004; Stresing, 2003).

Technology-Enhanced Staffing Providers

Night Owl – https://nossllc.com/

Rest Assured LLC – https://restassuredsystem.com/

Sengistix – https://www.sengistix.com/

Simply Home – http://www.simply-home.com/

EXPANDING THE WORKFORCE PIPELINE

Given the rapidly growing need for direct support workers to fill positions, interventions have been utilized to expand the workforce pipeline. The goal of these interventions is to reach out to and recruit employees from among populations that have not traditionally fit the profile of a typical direct support worker.

Pathways for People with Disabilities. At Texas A&M University, the Center on Disability and Development offers the Bridge to Career in Human Services program, which provides pathways for people with disabilities to access postsecondary education opportunities specifically leading to careers as DSPs. Coursework is carried out in one semester, and the second semester includes a supervised practicum experience during which students learn and utilize skills that prepare them for employment as DSPs. More information on this program is available at http://b2c.tamu.edu/.

Pathways for High School Students. In Grove City, Ohio, the South-Western City School District Career Tech Community Career Connections Program–Ohio (C3PO) gives high school students the opportunity to gain knowledge and skills for, and provides a pathway to, a credential to become a certified DSP. Juniors and seniors in high school gain access to the components of a credentialing program and have the opportunity to earn a

Certificate of Initial Proficiency or Certificate of Advanced Proficiency that they can utilize to gain employment in the workforce post-high school. More information on this program is available at http://www.swcsdcareertech.com/c3po.html.

RECOMMENDATIONS

This direct support workforce crisis has been coming for decades. Policy makers and their allies have been slow to make finding and implementing solutions a priority. It will take courageous leadership within the Administration to ensure implementation of targeted solutions to address this crisis. Without bold and swift action, the LTSS system is threatened for all people with ID/DD who rely on it to meet their most basic needs. The President's Committee for People with Intellectual Disabilities proposes the following Recommendations to help resolve the direct support workforce crisis. We urge that the actions and programs presented here be developed and implemented, and that their outcomes be evaluated.

1. The U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services should ensure through review of Home and Community-Based Services Waivers or regulation that states include sufficient Direct Support Professional wages and compensation packages in their rate-setting methodologies for long-term services and supports to people with intellectual and developmental disabilities.
2. The U.S. Department of Health and Human Services, Administration for Community Living should provide technical assistance and financial or programmatic incentives to states to promote the use of technology solutions in long-term services and supports, such as remote monitoring, sensors, robotics, and smart homes, to create efficiencies, reduce costs and support community living for people with intellectual disabilities.
3. The U.S. Department of Health and Human Services, Administration for Community Living should provide funding to states through grants and contracts to develop, implement and evaluate comprehensive programs designed to provide training and technical assistance to employers that focus on improving business acumen to reduce Direct Support Professional vacancy rates, improve retention and promote efficient, high-quality long-term services and supports for people with intellectual and developmental disabilities.
4. The U.S. Departments of Education, Health and Human Services, and Labor should create grant programs and financial incentives for states to expand the pool of Direct Support Professionals through recognition programs, grassroots campaigns and training efforts designed to expand awareness about the profession and encourage greater participation by people with disabilities, men, retirees, and young adults across diverse racial, ethnic and cultural groups.
5. The U.S. Department of Health and Human Services should work with states to expand utilization of self-direction in long-term services and supports so that family, friends and neighbors can be hired as Direct Support Professionals.
6. The U.S. Department of Labor through the Bureau of Labor Statistics should investigate ways to recognize "Direct Support Professional" as a distinct occupation title and provide routine labor statistical reporting on this occupation.

7. The U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services (CMS) should ensure through regulation and review of Home and Community-Based Services Waivers that states identify provider qualifications that recognize Direct Support Professionals as skilled practitioners who are community navigators, facilitating greater community and economic involvement for people with intellectual and developmental disabilities. Additionally, CMS and states should ensure that compensation rates are aligned with appropriate status, value, respect, a living wage and benefits.

8. The U.S. Department of Health and Human Services, Administration for Community Living and Centers for Medicare & Medicaid Services should develop federal standards and work with the Department of Labor to implement specialized credentials and professional development opportunities for Direct Support Professionals, ensuring: (a) that people with intellectual disabilities are trainers and mentors, (b) that programs are focused on competencies specifically identified for DSPs, (c) that completion of training to meet standards is voluntary and occurs post-hire, and (d) that the credentials result in increased wages and access to benefits for DSPs.

9. The U.S. Department of Labor should engage the broader American workforce system to find solutions to this crisis by using community colleges and American job centers to develop and invest in career training and credentialing for Direct Support Professionals.

10. The U.S. Department of Health and Human Services and the U.S. Department of Labor should engage the business community and provide grants and other incentives to states to develop online matching registry services and other creative options to match people with intellectual disabilities and their families who need help finding available DSPs.

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FREQUENTLY USED ACRONYMS

AAIDD	American Association on Intellectual and Developmental Disabilities
ACL	Administration for Community Living
ADA	Americans with Disabilities Act
ADL	activities of daily living
AIDD	Administration on Intellectual and Developmental Disabilities
ANCOR	American Network of Community Options and Resources
AOD	Administration on Disabilities
APSE	Association of People Supporting Employment
ATTRI	Accessible Transportation Technologies Research Initiative
BLS	Bureau of Labor Statistics
CBT	competency-based training
CDS	College of Direct Support
CMS	Centers for Medicare & Medicaid Services CNA Certified Nursing Assistant
CPR	cardiopulmonary resuscitation
DD	developmental disabilities
DD Act	Developmental Disabilities Assistance and Bill of Rights Act of 2000
DOL	U.S. Department of Labor
DSP	Direct Support Professional
FMAP	Federal Medical Assistance Percentage
HCBS	Home and Community-Based Services
HHA	Home Health Aide
HHS	U.S. Department of Health and Human Services
HSRI	Human Service Research Institute
IC	independent contractor
ICA	International Cooperative Alliance
ID	intellectual disability
IDD	intellectual and developmental disability
IP	independent provider
LTSS	long-term services and supports
NADD	National Association for Persons with Developmental Disabilities and Mental Health Needs
NADSP	National Alliance for Direct Support Professionals
NYSACRA	New York State Association of Community and Residential Agencies
OADSP	Ohio Alliance of Direct Support Professionals
OPWDD	New York State Office for People With Developmental Disabilities
PCA	Personal Care Attendant
PCPID	President's Committee for People with Intellectual Disabilities
RTP	Report to the President

APPENDIX A - NADSP COMPETENCIES

15 NADSP COMPETENCY AREAS

The following is a list of fifteen competency areas that have been approved by the NADSP Executive Committee. Each Competency area has corresponding skill statements. These skill statements describe the knowledge and skills DSPs must have to demonstrate competency in each area (see below). In deciding on which competency areas to focus, applicants should think about the things they currently do in their everyday work or areas in which they would like to become more knowledgeable and skillful. Through each competency area, DSPs have the opportunities to address challenges, work on issues identified by the person they support or assist a person in looking in a particular goal. For example, an applicant may provide support to a person with a communication challenge. The applicant could use a work sample to demonstrate how they helped the person they support to develop a picture communication board.

AREA 1: PARTICIPANT EMPOWERMENT

The Direct Support Professional enhances the ability of the participant to lead a self-determining life by providing the support and information necessary to build self-esteem, and assertiveness; and to make decisions.

Skill Statements

- The competent DSP assists and supports the participant to develop strategies, make informed choices, follow through on responsibilities, and take risks.
- The competent DSP promotes participant partnership in the design of support services, consulting the person and involving him or her in the support process.
- The competent DSP provides opportunities for the participant to be aself-advocate by increasing awareness of self-advocacy methods and techniques, encouraging and assisting the participant to speak on his or her own behalf, and providing information on peer support and self-advocacy groups.
- The competent DSP provides information about human, legal, civil rights and other resources; facilitates access to such information; and assists the participant to use information for self-advocacy and decision making about living, work, and social relationships.

AREA 2: COMMUNICATION

The Direct Support Professional should be knowledgeable about the range of effective communication strategies and skills necessary to establish a collaborative relationship with the participant.

Skill Statements

- The competent DSP uses effective, sensitive communication skills to build rapport and channels of communication by recognizing and adapting to the range of participant communication styles.
- The competent DSP has knowledge of and uses modes of communication that are appropriate to the communication needs of participants.
- The skilled DSP learns and uses terminology appropriately, explaining as necessary to ensure participant understanding.

AREA 3: ASSESSMENT

The Direct Support Professional should be knowledgeable about formal and informal assessment practices in order to respond to the needs, desires and interests of the participants.

Skill Statements

- The competent DSP initiates or assists in the initiation of an assessment process by gathering information (e.g., participant's self-assessment and history, prior records, test results, additional evaluation) and informing the participant about what to expect throughout the assessment process.
- The competent DSP conducts or arranges for assessments to determine the needs, preferences, and capabilities of the participants using appropriate assessment tools and strategies, reviewing the process for inconsistencies, and making corrections as necessary.

- The competent DSP discusses findings and recommendations with the participant in a clear and understandable manner, following up on results and reevaluating the findings as necessary

AREA 4: COMMUNITY AND SERVICE NETWORKING

The Direct Support Professional should be knowledgeable about the formal and informal supports available in his or her community and skilled in assisting the participant to identify and gain access to such supports.

Skill Statements

- The competent DSP helps to identify the needs of the participant for community supports, working with the participant's informal support system, and assisting with, or initiating identified community connections.
- The competent DSP researches, develops, and maintains information on community and other resources relevant to the needs of participants.
- The competent DSP ensures participant access to needed and available community resources coordinating supports across agencies.
- The competent DSP participates in outreach to potential participants.

AREA 5: FACILITATION OF SERVICES

The Direct Support Professional is knowledgeable about a range of participatory planning techniques and is skilled in implementing plans in a collaborative and expeditious manner.

Skill Statements

- The competent DSP maintains collaborative professional relationships with the participant and all support team members (including family/ friends), follows ethical standards of practice (e.g., confidentiality, informed consent, etc.), and recognizes his or her own personallimitations.
- The competent DSP assists and/or facilitates the development of an individualized plan based on participant preferences, needs, and interests.
- The competent DSP assists and/or facilitates the implementation of an individualized plan to achieve specific outcomes derived from participants' preferences, needs and interests.
- The competent DSP assists and/or facilitates the review of the achievement of individual participant outcomes.

AREA 6: COMMUNITY LIVING SKILLS & SUPPORTS

The Direct Support Professional has the ability to match specific supports and interventions to the unique needs of individual participants and recognizes the importance of friends, family and community relationships.

Skill Statements

- The competent DSP assists the participant to meet his or her physical (e.g., health, grooming, toileting, eating) and personal management needs (e.g., human development, human sexuality), by teaching skills, providing supports, and building on individual strengths and capabilities.
- The competent DSP assists the participant with household management (e.g., meal prep, laundry, cleaning, decorating) and with transportation needs to maximize his or her skills, abilities and independence.
- The competent DSP assists with identifying, securing and using needed equipment (e.g., adaptive equipment) and therapies (e.g., physical, occupational and communication).
- The competent DSP supports the participant in the development of friendships and other relationships.
- The competent community-based support worker assists the participant to recruit and train service providers as needed.

AREA 7: EDUCATION, TRAINING & SELF-DEVELOPMENT

The Direct Support Professional should be able to identify areas for self-improvement, pursue necessary educational/training resources, and share knowledge with others.

Skill Statements

- The competent DSP completes required training education/certification, continues professional development, and keeps abreast of relevant resources and information.

- The competent DSP educates participants, co-workers and community members about issues by providing information and support and facilitating training.

AREA 8: ADVOCACY

The Direct Support Professional should be knowledgeable about the diverse challenges facing participants (e.g., human rights, legal, administrative and financial) and should be able to identify and use effective advocacy strategies to overcome such challenges.

Skill Statements

- The competent DSP and the participant identify advocacy issues by gathering information, reviewing and analyzing all aspects of the issue.
- The competent DSP has current knowledge of laws, services, and community resources to assist and educate participants to secure needed supports.
- The competent DSP facilitates, assists, and/ or represents the participant when there are barriers to his or her service needs and lobbies decision-makers when appropriate to overcome barriers to services.
- The competent DSP interacts with and educates community members and organizations (e.g., employer, landlord, civic organization) when relevant to participant's needs or services.

AREA 9: VOCATIONAL, EDUCATIONAL & CAREER SUPPORT

The Direct Support Professional should be knowledgeable about the career and education related concerns of the participant and should be able to mobilize the resources and support necessary to assist the participant to reach his or her goals.

Skill Statements

- The competent DSP explores with the participant his/her vocational interests and aptitudes, assists in preparing for job or school entry, and reviews opportunities for continued career growth.
- The competent DSP assists the participant in identifying job/training opportunities and marketing his/her capabilities and services.
- The competent DSP collaborates with employers and school personnel to support the participant, adapting the environment, and providing job retention supports.

AREA 10: CRISIS PREVENTION AND INTERVENTION

The Direct Support Professional should be knowledgeable about crisis prevention, intervention and resolution techniques and should match such techniques to particular circumstances and individuals.

Skill Statements

- The competent DSP identifies the crisis, defuses the situation, evaluates and determines an intervention strategy and contacts necessary supports.
- The competent DSP continues to monitor crisis situations, discussing the incident with authorized staff and participant(s), adjusting supports and the environment, and complying with regulations for reporting.

AREA 11: ORGANIZATIONAL PARTICIPATION

The Direct Support Professional is familiar with the mission and practices of the support organization and participates in the life of the organization.

Skill Statements

- The competent DSP contributes to program evaluations, and helps to set organizational priorities to ensure quality.
- The competent DSP incorporates sensitivity to cultural, religious, racial, disability, and gender issues into daily practices and interactions.
- The competent DSP provides and accepts co-worker support, participating in supportive supervision, performance evaluation, and contributing to the screening of potential employees.
- The competent DSP provides input into budget priorities, identifying ways to provide services in a more cost-effective manner.

AREA 12: DOCUMENTATION

The Direct Support Professional is aware of the requirements for documentation in his or her organization and is able to manage these requirements efficiently.

Skill Statements

- The competent DSP maintains accurate records, collecting, compiling and evaluating data, and submitting records to appropriate sources in a timely fashion.
- The competent DSP maintains standards of confidentiality and ethical practice.
- The competent DSP learns and remains current with appropriate documentation systems, setting priorities and developing a system to manage documentation.

AREA 13: BUILDING AND MAINTAINING FRIENDSHIPS AND RELATIONSHIPS

Support the participant in the development of friendships and other relationships.

Skill Statements

- The competent DSP assists the individual as needed in planning for community activities and events (e.g., making reservation, staff needs, money, materials, accessibility).
- The competent DSP assists the individual as needed in arranging transportation for community events.
- The competent DSP documents community activities and events.
- The competent DSP encourages and assists the individual as needed in facilitating friendships and peer interactions.
- The competent DSP encourages and assists the individual as needed in communication with parents/family (e.g., phone calls, visits, letters).
- The competent DSP implements individual supports regarding community activities.
- The competent DSP provides incentive or motivation for consumer involvement in community outings.
- The competent DSP assists the individual as needed in getting to know and interacting with his/her neighbors.
- The competent DSP encourages and assists the individual as needed in dating.
- The competent DSP encourages and assists the individual as needed in communicating with social workers and financial workers.

AREA 14: PROVIDE PERSON CENTERED SUPPORTS

Skill Statements

- The competent DSP provides support to people using a person-centered approach.
- The competent DSP modifies support programs and interventions to ensure they are person centered.
- The competent DSP challenges co-workers and supervisors to use person centered practices.
- The competent DSP is knowledgeable about person centered planning techniques.
- The competent DSP assists individuals in developing person-centered plans.

AREA 15: SUPPORTING HEALTH AND WELLNESS

Promotes the health and wellness of all consumers.

Skill Statements

- Administers medications accurately and in accordance with agency policy and procedures.
- Observes and implements appropriate actions to promote healthy living and to prevent illness and accidents.
- Uses appropriate first aid/safety procedures when responding to emergencies.
- Assists individuals in scheduling, keeping, and following through on all health appointments.
- Assists individuals in completing personal care (e.g., hygiene and grooming) activities.
- Assists with identifying, securing and using needed adaptive equipment (i.e. adaptive equipment) and therapies (e.g., physical, occupational, speech, respiratory, psychological).
- Assists individuals in implementing health and medical treatments.
- Assists individuals to take an active role in their health care decisions.

APPENDIX B - NADSP CODE OF ETHICS

NATIONAL ALLIANCE FOR DIRECT SUPPORT PROFESSIONALS CODE OF ETHICS

The following is the complete text of the NADSP Code of Ethics as approved by the NADSP board in April of 2016. The College of Direct Support (CDS) and the College of Frontline Supervision, Management, and Leadership (CFSM) embed the principles of this ethical code into every course. We encourage all learners and leaders in human service organizations to be familiar with these and support DSPs in aligning their practices to this code.

PREAMBLE

Vision. Direct Support Professionals (DSPs) who support people in their communities are called upon to make independent judgments on a frequent basis that involve both practical and ethical reasoning. The people who assume this complex role must examine their own values and beliefs while honoring those of the people they support.

Purpose. A primary purpose of the DSP is to assist people who need support to lead self-directed lives and to participate fully in our nation's communities. This emphasis on empowerment and participation is critical. There are numerous pressures coming from organizations, government, social policy, and societal prejudice that can shift focus and allegiance away from the people who are being supported. DSPs face ethical decisions on a daily basis and consistently feel the tension between the ideals of the profession and its practice.

In order to maintain the promise of partnership and respect that must exist in a supportive relationship, a strong ethical foundation is critical to help DSPs navigate the maze of influences that bombard them. The prejudices of society form powerful barriers, yet too often, the very social policies and service systems designed to help can create additional barriers that prevent many people with intellectual, developmental or physical disabilities from enjoying a rich and fulfilling life.

Mission. Therefore, it must be the mission of the DSP to honor the individual path suggested by the unique gifts, preferences, and needs of each person they support. DSPs will walk in partnership with the person, and those who are significant to them, toward a life of opportunity, well-being, freedom, and contribution. While other professional groups (such as doctors, nurses, service coordinators, and social workers) are directed by clearly defined criteria, the DSP is directed by the person they support. Therefore, the DSP must exemplify ethical practice, high standards, and creative vision as they partner with those they support in order to engage community and make everyday choices about their personal finances, physical well-being, social and intimate relationships, and employment. The entire landscape of a person's life can change through ethical and intentional direct support services.

Values, Skills and Knowledge. The knowledge and skills of community support practice must be joined with the ethical principles to create the environment needed to fully support people in making life choices. To do so effectively, we must all recognize DSPs as professionals who have values, skills, and knowledge that constitute a unique and important profession, and who can infuse these beliefs into practice. Furthermore, there must be a commitment to hiring, developing, and supporting DSPs to create a healthy sense of their own worth and potential. Direct Support Professionals must embrace their role to foster a spirit of cooperation and mutual responsibility with other DSPs regarding ethical practice.

NADSP Code of Ethics. In 2000, these issues led the National Alliance for Direct Support Professionals (NADSP) to bring together a national panel that included direct support professionals, self-advocates, family members, human service professionals and researchers to identify the kinds of ethical situations that direct support professionals face and to develop a set of ethical guidelines to address them. In 2016, the NADSP reconvened a new and diverse stakeholder group to review the language of our original document. The revised Code of Ethics has not changed in content; it remains to serve as a straightforward and relevant ethical guide, shedding light on the shared path to a self-directed life. It is intended to guide direct support professionals in resolving ethical dilemmas they face every day and to encourage them to achieve the highest ideals of the profession.

Direct support professionals, agency leaders, policymakers, and people receiving support are urged to read the Code of Ethics and to consider ways that

these ethical statements can be incorporated into daily practice. The beliefs and attitudes expressed in the Code of Ethics are a cornerstone of the profession.This Code of Ethics is not the handbook of the profession, but rather a roadmap to assist us in staying the course of securing freedom, justice, and equality for all.

Person-Centered Supports:

As a DSP, my first allegiance is to the person I support; all other activities and functions I perform flow from this allegiance.

Furthermore, as a DSP, I will:

- Commit to person-centered supports as best practice.
- Focus first on the person and understand that my role in direct supports will require flexibility, creativity and commitment.
- Recognize that each person is capable of directing their own life.
- Honor those who cannot speak by seeking other ways of understanding them.
- Recognize that the unique culture, social network, circumstances, personality, preferences, needs and gifts of each person I support must be the primary guides for the selection, structure, and use of supports for that person.
- Advocate with the person I support and others when the demands of the system override the needs of those I support, or when individual preferences, needs or gifts are neglected for any reason.

Promoting Physical and Emotional Well-Being:

As a DSP, I will commit to promote the emotional, physical, and personal well-being of the people I support. I will encourage growth and recognize the autonomy of those receiving support while being attentive and energetic in reducing the risk of harm.

Furthermore, as a DSP, I will:

- Develop a respectful relationship with the people I support that are based on mutual trust and maintains professional boundaries.
- Understand and respect the values of the people I support and facilitate their expression of choices related to those values.
- Assist the people I support to prevent illness, avoid unnecessary risk, and understand their options and possible consequences that relate to their physical health, safety, and emotional well-being.
- Partner with each person and their support network to identify areas of risk and create safeguards specific to these concerns.
- Challenge other support team members, such as doctors, nurses, therapists, coworkers, and family members, to recognize and support the rights of people to make informed decisions even when these decisions involve personal risk.
- Be vigilant in identifying and reporting any situation in which the people I support are at risk of abuse, neglect, exploitation or harm.
- Address challenging behaviors proactively and respectfully. If aversive or deprivation intervention techniques are included in an approved support plan, I will work diligently to find alternatives and pursue the elimination of these techniques from the person's plan.

Integrity and Responsibility:

As a DSP, I will support the mission and vitality of my profession to assist people in leading self-directed lives and to foster a spirit of partnership with the people I support, other professionals, and the community.

Furthermore, as a DSP, I will:

- Be aware of my own values and how they influence my professional decisions.
- Maintain competency in my profession through learning and ongoing collaboration with others.
- Assume responsibility and accountability for my decisions and actions.
- Advance my knowledge and skills through ongoing professional development and lifelong learning.
- Seek advice and guidance on ethical issues from others as needed to inform decision-making.
- Recognize the importance of modeling valued behaviors to co-workers, people I support, and the community at-large.
- Practice responsible work habits.

Confidentiality:

As a DSP, I will safeguard and respect the confidentiality and privacy of the people I support.

Furthermore, as a DSP, I will:

- Seek information directly from those I support regarding their wishes in how, when and with whom privileged information should be shared.
- Recognize that confidentiality agreements are subject to federal and state laws and regulations, as well as agency policies.
- Recognize that it may be necessary to disclose confidential information in order to prevent serious or imminent harm to the person I support or others.
- Seek out qualified guidance to help clarify situations where the correct course of action is unclear to me.

Justice, Fairness and Equity:

As a DSP, I will affirm the human rights as well as the civil rights and responsibilities of the people I support. I will promote and practice justice, fairness, and equity for the people I support and the community as a whole.

Furthermore, as a DSP, I will:

- Assist the people I support to access opportunities and resources in the community that are available to everyone.
- Facilitate the expression and understanding of rights and responsibilities with the people I support.
- Understand the guardianship or other legal representation of the people I support, and work in partnership with legal representatives to assure that the person's preferences and interests are honored.

Respect:

As a DSP, I will respect the human dignity and uniqueness of the people I support. I will recognize each person I support as valuable and promote their value within communities.

Furthermore, as a DSP, I will:

- Seek to understand the people I support today in the context of their personal history, their social and family networks, and their hopes and dreams for the future.
- Recognize and respect the cultural context (such as gender, disability, religion, sexual orientation, ethnicity, socio-economic class) of the person supported and his/her social network.
- Honor the choices, preferences, abilities and opinions of the people I support.
- Protect the privacy of the people I support.
- Interact with the people I support in a manner that is respectful to them.
- Provide opportunities for the people I support to be viewed and treated with respect and embraced as integral, contributing members of their communities.
- Promote the use of language that is respectful, sensitive and contemporary.
- Practice positive intention and transparency in my interactions.

Relationships:

As a DSP, I will assist the people I support to develop and maintain relationships.

Furthermore, as a DSP, I will:

- Advocate with the people I support when they do not have opportunities to build and maintain relationships.
- Recognize the importance of maintaining reciprocal relationships and proactively facilitate relationships between the people I support, their family and friends.
- Assure that people have the opportunity to make informed choices in safely expressing their sexuality.
- Separate my personal beliefs and expectations regarding relationships (including sexual relationships) from those of the people I support. If I am unable to separate my own beliefs and preferences in a given situation, I will remove myself from the situation and seek the assistance of a qualified coworker.
- Refrain from expressing negative views, harsh judgments, and stereotyping of people.

Self-Determination:

As a DSP, I will assist the people I support to direct the course of their own lives.

Furthermore, as a DSP, I will:

- Support the rights of individuals to lead self-directed lives, working in partnership with other members of the person's support network.
- Promote self-determination in physical, intellectual, emotional, social and spiritual pursuits.
- Honor a person's right to assume risk in an informed manner.
- Recognize that each individual has potential for lifelong learning and growth.
- Celebrate, accept and learn from life's rich experiences with people through triumphs and failures.

Advocacy:

As a DSP, I will advocate with the people I support for justice, inclusion, and full community participation.

Furthermore, as a DSP, I will:

- Support people to speak for themselves in all matters, and offer my assistance when needed.
- Represent the best interests of people who cannot speak for themselves by partnering with the individual and their support team to gather information and find alternative means of expression.
- Advocate for laws, regulations, policies, and procedures that promote justice and inclusion for all people with disabilities.
- Promote human, legal, and civil rights for all people and help those I encounter to understand these rights.
- Seek additional advocacy services when those that I provide are not sufficient.
- Seek out qualified guidance when I am unsure of the appropriate course of action in my advocacy efforts.
- Recognize that those who victimize people with disabilities must be held accountable.

Revised & Approved, NADSP Board of Directors
April 12, 2016

APPENDIX C - JOINT POSITION STATEMENT ON THE DSP WORKFORCE ON BEHALF OF AAIDD AND NADSP

STATEMENT

Individuals with intellectual and developmental disabilities (IDD) have long sought lives where they can be fully contributing and valued members of their communities. Federal regulations including the Americans with Disabilities Act (ADA), and more recently the Centers for Medicare & Medicaid Services (CMS) Home and Community-Based Services (HCBS) Settings Rule and the US Department of Labor Workforce Innovation and Opportunity Act (WIOA) have set forth standards aimed at making inclusion and employment a reality. The availability of a qualified, competent and stable Direct Support Workforce plays an important role in supporting people to accomplish these goals. To be successful, it is critical that Direct Support Professionals (DSPs) have the competence, confidence, ethical decision-making skills and guidance necessary to provide quality support, receive compensation that is commensurate with job responsibilities and have access to a career path aligned with ongoing professional development.

ISSUES

The stability of the direct support workforce has been a long-standing issue across disability service systems. The field is plagued with high turnover at a time when demand for additional direct support professionals to support both disability and aging populations in the United States is peaking. It is estimated that nationally more than one million new direct support positions will need to be filled by 2022. This growing demand combined with limited availability of training and education and increased expectations and requirements make it essential that there be increased investment in this vital workforce.

The United States is at a critical juncture where workforce development, education and disability service systems must implement strategies to increase the capacity and quality of the direct support workforce. Action is necessary if we are to provide the support people with IDD need to live and participate in their communities. Self-advocates and family-advocates have fought hard for decades to ensure that supports provided are person-centered, increase inclusion, and lead to valued lives for people with intellectual and developmental disabilities. Researchers, practitioners, providers and policy-makers have recommended recruitment, retention, and education strategies to address this critical workforce need; however, they have yet to be sufficiently funded or brought to scale. If the charge to address the workforce crisis is not acted upon, the entire disability service system is at risk of going back to days of institutionalization, segregation, and stigmatization, turning the clock back on decades of advocacy and disregarding the voice of people with developmental disabilities across the country.

LOW WAGES

Wages paid to direct support professionals are comparable to those paid for entry level low wage positions in nearly all service industries. Insufficient wages affect workforce retention and the quality of support provided. There is a significant discrepancy between the job responsibilities and skill expectations required of DSPs and their low wages. Nearly half of direct support workers in the U.S. rely on public benefits. Others often work two to three jobs to support themselves and their families. Wages need to be increased. This, combined with other work-related stressors, lead to DSP turnover which results in ineffective and inconsistent support for people with IDD.

LIMITED TRAINING, CAREER PATH AND CREDENTIALING OPPORTUNITIES

The DSP role is complex because it is about supporting each individual in a person-centered way within their unique context. The workforce must have the knowledge, skills, and ethical compass to perform a wide array of tasks that support people with intellectual and developmental disabilities to be healthy, safe, valued and participating members of their communities. To achieve this, it is important that DSPs receive sufficient, high-quality training and opportunities for paid professional development on an ongoing basis.

No federal minimum training requirements exist for DSPs. Career pathways that provide DSPs an opportunity to increase competency and

professionalism is a recommended strategy to improve retention of the workforce and quality of support. The National Alliance for Direct Support Professionals (NADSP) and the Centers for Medicare & 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. Several national organizations offer credential programs for DSPs who support people with IDD in varied roles. Despite the identification of required competencies, related credentialing and guidance [1] from Medicaid about how to build training into HCBS reimbursement rates [2], use of established competencies to set workforce development and training standards is not widespread.

INEFFECTIVE SUPERVISION AND ORGANIZATIONAL SUPPORT

DSPs are faced with fulfilling an increasing number of responsibilities in more autonomous situations. This will require that they be provided the professional development opportunities and have the support they need to ensure they are competent to provide support and be successful in their work. The supervision they receive is frequently inconsistent and ineffective. This can result from frontline supervision being the default career ladder for DSPs, often achieved without the requisite preparation necessary to succeed. It is important that supervisors are competent in critical skills to being an effective supervisor in long term services and supports for people with disabilities.

DSPs must be supported to effectively understand and utilize person-centered approaches designed to increase community inclusion for people with intellectual and developmental disabilities. Often systems and organizations promote these concepts but do not shift their organizational culture and practices to align with them. These changes may include increased use of technologies, flexible staffing patterns, and providing DSPs with the education and resources they need to make connections and build capacity within the community.

POSITION

Evidence-based practice must be widely implemented to increase the ability of individuals, families and employers to recruit, retain, and ensure the competence of DSPs to improve the quality of life and outcomes of supports provided to people with IDD. A comprehensive approach to address the need to build capacity within the direct support workforce, which should include the following:

- Allocate federal and state funding at levels sufficient to provide living wages and the benefits necessary to attract and retain qualified DSPs in home and community-based services.
- Provide credentialing opportunities, career pathways, and ongoing competency-based training and mentoring, embedded in public policy and sufficiently funded to create incentives for DSP participation.
- Ensure frontline supervisors are adequately trained and support to effectively recruit, retain and support DSPs.
- Implement and evaluate the use of technologies as a universally-designed option for support while simultaneously providing relief to the increased demand for support and support workers.
- Ensure DSPs have opportunities for needed training, mentoring and professional development to effectively assist people with IDD to be fully included, valued, and participating members of their communities.

Adopted:
Board of Directors,
American Association on Intellectual and Developmental Disabilities
May 18, 2016

Board of Directors,
National Alliance for Direct Support Professionals
May12, 2016

[1] Robbins, E., Dilla, B., Sedlezky, L., Sirek, A.J. (2013). Coverage of Direct Service Workforce Continuing Education and Training within Medicaid Policy and Rate Setting: A Toolkit for State Medicaid Agencies. The Lewin Group. Retrieved from: https://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/workforce/downloads/ dsw-training-rates-toolkit.pdf

[2] Centers for Medicare & Medicaid Services (2015). Questions and Answers: Administrative Claiming Related to Training and Registry Costs. Retrieved from: https://www. medicaid.gov/medicaid-chip-program-information/by-topics/ financing-and-reimbursement/downloads/qa-training-registry-costs-071015.pdf

APPENDIX D - IMPLEMENTING DIRECT SUPPORT PROFESSIONAL CREDENTIALING IN NEW YORK

KEY DESIGN ELEMENTS OF THE NEW YORK DIRECT SUPPORT PROFESSIONAL (DSP) CREDENTIALING MODEL

1. Multi-tiered credential with a hybrid model of learning methods. The Credentials must be achieved in sequence, beginning with DSP Credential I. Proposed training opportunities include on-line training, interactive classroom learning and work-based learning opportunities—

   a. DSP Credential I includes 50 hours of training: 20 hours on-line, 10 hours classroom training, and 20 hours of work-based learning

   b. DSP Credential II includes 100 hours of training: 40 hours on-line, 20 hours classroom training, and 40 hours of work-based learning

      - Includes a specialization emphasis in one of four areas: Supporting Older Adults, Behavioral Support, Autism Spectrum Disorders, or Complex Medical Needs.

   c. DSP Credential III (Mentor) includes 40 hours of training: 12 hours on-line, 8 hours classroom training, and 20 hours of work-based learning.

      - Includes an emphasis on person-centered planning, as well as preparing mentors to support other learners through credentialing.

   d. Frontline Supervision and Management Credential includes 40 hours of training: 20 hours on-line, 5 hours classroom, and 15 hours work-based learning. It may be completed after achieving the DSP Credential

2. Valid, recognized competency-based skills and knowledge requirements. These are the identified outcomes that will be assessed across the credential program. The competencies used as the basis of the credentialing program are —

   a. New York State DSP Core Competency Goals

      - Putting people first
      - Building & maintaining positive relationships
      - Demonstrating professionalism
      - Supporting good health
      - Supporting safety
      - Having a home
      - Being active and productive in society

   b. National Frontline Supervisor (FLSs) Competencies. These also used in NADSP's Credentialing for Frontline Supervisors

      - Direct support
      - Health, wellness, and safety
      - Participant support plan development, monitoring, and assessment
      - Facilitating community inclusion across the lifespan
      - Promoting professional relations and teamwork
      - Staff recruitment, selection, and hiring

- Staff supervision, training, and development
- Service management and quality assurance
    - Advocacy and public relations
    - Leadership, professionalism, and self-development
    - Cultural awareness and responsiveness

3. Voluntary enrollment at employer's discretion. DSPs will not be mandated to complete credentials in order to serve as a DSP. DSPs must satisfactorily complete their employer's required probationary period before beginning credential training. Additionally, DSPs must complete the following years of service to qualify for credential assessments —

    a. DSP Credential I Assessments may be completed only after the DSP has clocked at least 1 year of full-time employment as a DSP.

    b. DSP Credential II Assessments may be completed only after the DSP has clocked at least 2 years of full-time employment as a DSP.

4. Incremental annual enrollment growth targets over five years —

    Annual targeted growth —

    1st Cohort = Yrs. 1 & 2 = 3 percent of DSPs statewide

    2nd Cohort = Yrs. 2 &3 = add 2 percent of DSPs statewide

    3rd Cohort = Yrs. 3 &4 = add 5 percent of DSPs statewide

    4th Cohort = Yrs. 4& 5 = add 5 percent of DSPs statewide

    5th Cohort = Yrs. 5 & 6 = add 5 percent of DSPs statewide

5. Employers will receive rate incentives to cover educational costs and increased DSP wages. Employers will be awarded these incentives if they meet per-determined enrollment thresholds (e.g. 3 percent, 5 percent, 10 percent). Wage incentives will be awarded to DSPs with successful completion of assessments at each credential level.

6. Individuals with disabilities will be involved in on-line, classroom, and work-based educational components.

7. Program governance will be overseen by an independent, third-party credentialing program body. This will be a newly established governing body who will provide recommendations for curriculum and assessment at each level of the credential —

    a. Assessment will include on-the-job skill demonstration by the supervisor or skill mentor (initial, proficient and advanced levels), response to scenario testing (initial and proficient levels) and written test (advanced and specialized levels).

    b. The governing body will also provide guidance on curriculum by identifying required instructional criteria for approved instructional programs.

    c. A Request for Proposal could be released by the Office for People with Developmental Disabilities (OPWDD) to determine credentialing organization.

8. A Board of Directors will guide and inform the governing body. The Board of Directors will include DSPs, FLSs, provider organizations, individuals with intellectual and developmental disabilities, family members, content experts and individuals with expertise in credentialing/ certification and instructional design.

9. A Grandperson Clause will allow experienced DSPs and FLSs chosen by their employers to be assessed for the credential without coursework. Such experienced DSPs and FLSs must complete the probationary period at least two years prior to the implementation of the credential program.

10. Completion of continuing education requirement of 36 hours every three years in order to keep the credential active. Certified DSPs and FLSs submit qualifying activities to the governing body. Acceptable continuing education units are those whose topics are directly aligned with the content of the New York DSP Core Competencies published by OPWDD. This requirement applies to newly certified DSPs after they renew their registration for the first time.

11. Overall evaluation of credentialing program on service quality. Program effectiveness will be monitored on a statewide and organizational level using longitudinal indicators, such as retention rates, injury rates, and reduction of avoidable hospitalizations.

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