



Report to the President 2017

America's Direct Support Workforce Crisis:
Effects on People with Intellectual Disabilities,
Families, Communities and the U.S. Economy



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ABOUT THE PRESIDENT'S COMMITTEE FOR PEOPLE WITH INTELLECTUAL DISABILITIES

The President's Committee for People with Intellectual Disabilities was started in 1961 by President Kennedy. It advises the President and the Secretary of Health and Human Services (HHS) on matters related to individuals with intellectual disability. Its goal is to help people with disabilities to be valued in their communities.

PEOPLE WITH INTELLECTUAL AND RELATED DEVELOPMENTAL DISABILITIES

People with intellectual and developmental disabilities (ID/DD) are friends, neighbors, co-workers, voters, and taxpayers. They live in and add much to their communities. They have a wide range of limitations, and many need ongoing support from others. There are about 5 million Americans with ID/DD, and about 1.4 million receive services from state agencies.

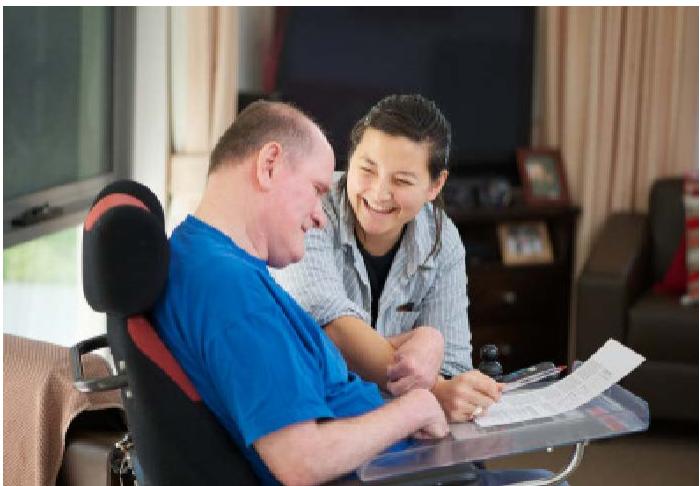
The support needed by persons with ID/ DD is usually provided by family caregivers and paid workers. Most of the paid, hands- on support is done by Direct Support Professionals (DSPs). For most people with ID/DD to participate in all aspects of community life, there must be a well- trained workforce.



THE DIRECT SUPPORT PROFESSIONAL WORKFORCE

Direct Support Professionals, or DSPs, support people with intellectual and developmental disabilities. They help them to live their lives and to enjoy the same benefits as people without disabilities. DSPs work in a range of settings, including a person's own home or family home, large and small care facilities, group homes, training programs, and community job sites.

Most DSPs (70%) work full-time; 30% work part-time. DSPs are part of a larger group of human services workers who provide support to people with serious needs. Some of the people they help are frail older people and people with physical and other kinds of disabilities. More than 4.5 million people do the work of direct support.

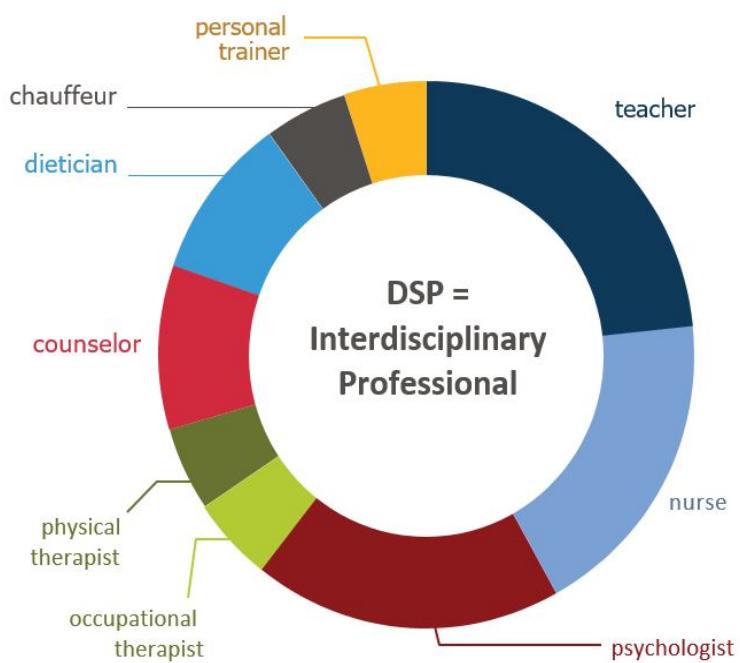


In the past, DSPs usually worked in large settings that served many people together. In those places, trained professionals such as nurses, therapists, psychologists, and social workers also worked on-site. As individuals with ID/DD moved into community settings, DSPs were expected to work more independently with less support from trained professionals. The role of the DSP demanded increased skills and knowledge.

Like teachers, DSPs create ways to teach people new skills. Like nurses, they pass medications, provide treatments, document care, and speak with medical professionals. Like social workers, they get people connected to their communities. Like counselors, they listen, reflect, and offer suggestions. DSPs provide whatever support it takes so people can thrive in their communities.

DSPs must be trained to gain the knowledge, skills, and attitudes required for their work. Unfortunately, there are no federal regulations and little funding for good training programs. In contrast, Certified Nursing Assistants (CNAs) and Home Health Aides (HHAs) must receive 75 hours of training before they start their jobs, training that is provided by most community and technical colleges. The duties of DSPs are much like those of CNAs and HHAs, but DSPs go much further, aiding people with ID/DD in learning new skills, making wise decisions, and becoming active members of their communities. Despite these clear differences, CNAs and HHAs often receive higher wages, and their jobs are seen as valued careers.

Figure 1. DSP Scope of Practice



AMERICA'S DIRECT SUPPORT WORKFORCE CRISIS

Over the past 30 years, there has been high turnover in the direct support workforce. Almost half of DSPs leave their jobs within the first year, and most within the first six months. This is caused in part by low wages, poor

benefits, and lack of training. The average wage for a DSP is \$10.72 per hour, which is below the poverty level for a family of four. Half of DSPs rely on government benefits, and most need to work two or three jobs.

People with ID/DD rely on DSPs for the daily support they need to live in their communities. Their families rely on the DSP workforce to provide sound, quality support so they can work and have respite from the day-to-day stressors of caregiving. Finding, training, and keeping this workforce has reached crisis levels.

The trend has been that more people need supports and services, but fewer people are working as DSPs. At the same time, there is less funding for ID/DD services.

When the economy is doing poorly and people need jobs, agencies can find people to work as DSPs. But when unemployment rates are low, it is harder to find people to provide direct support. Right now, more than 9% of DSP positions are unfilled. This creates extra work and stress for DSPs who remain on the job and results in lower-quality care. DSPs who are tired from working long hours or more than one job are more likely to make mistakes and to face more stressful situations. When DSPs do not know the people they support, they may not recognize signs and symptoms of illness.

When it is hard to find staff to support people in community homes and at job sites, people with ID/DD often have few choices besides group homes or sheltered

work settings. To make sure that people with ID/DD can use all that communities have to offer, they must have skilled support provided by a stable, well-prepared direct support workforce.



Another challenge for the DSP workforce is that direct support is not seen as a valued, professional career, and there is little opportunity for career advancement.

The direct support workforce and the service system that supports it are in crisis. The results will be tragic for people with ID/DD and their families unless important changes are made at once.

Figure 2. DSP Turnover Rate

TURNOVER RATE



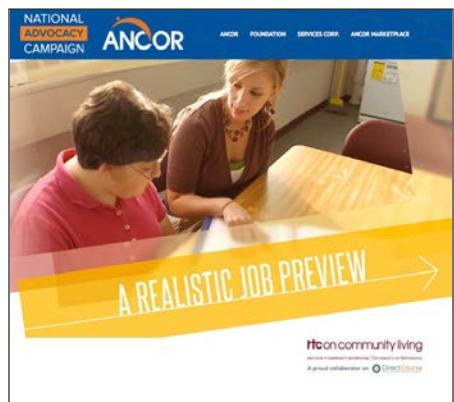
Source: National Core Indicators, 2017.

RECOMMENDATIONS

The direct support workforce crisis can be addressed in the following ways:



Recognizing direct support as a valued career. Programs that recognize direct support as a professional career will be useful in raising awareness of job openings and of the importance of people with ID/DD living valued lives in their communities.



Helping business and organizational leaders learn the skills to improve their ability to find and keep DSPs. A number of tools have helped agencies find and keep DSPs. These tools include flyers and advertisements to find people interested in direct support work; structured interview questions that help agencies find the best workers; and realistic job preview videos that allow people to see what the work will be like before they begin their jobs.



Using self-directed services that allow individuals and families to hire their own DSPs.

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. Currently, 41 states offer some type of self-direction as a support option. Individuals and families who self-direct may pay a higher hourly rate for their DSPs. Some studies have shown lower rates of DSP turnover under such options.



Using worker cooperative and independent provider models.

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 people with ID/DD. The IP model gives people with ID/DD and their families greater choice over who provides services to them. This model also usually costs less.



Provide credentialing for Direct Support Professionals.

One way to add to the value of the DSP position is to provide DPSs credentials. The process reviews the education, training, experience, and competency of each DSP. CNAs and HHAs must have credentials. The National Association for Direct Support Professionals (NADSP) offers a national credentialing program for DSPs, and other agencies offer state-level credentialing programs.

Credentialed employees stay on the job longer and provide higher-quality of services to the people they support. Credentialing should lead to increased wages for DSPs and make direct service a valued career path. Credentialing and training programs specific to the role of DSPs are needed in the community college system in the U.S.



Using technology-enhanced supports.

New technologies are being used to provide support to people with ID/DD who need low levels of on-site direct support. Such supports are sometimes used in addition to, or in the absence of, DSPs. 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 help people find what they need in their communities, and to support their daily schedules.

This direct support workforce crisis has been coming for decades. There is no issue more pressing for people with ID/DD than this serious crisis. Correcting the problems will require bold leadership and immediate action.