

January 9, 2017

Centers for Medicare & Medicaid Services  
Department of Health and Human Services  
Attention: CMS-2404-NC, P.O. Box 8013  
Baltimore, MD 21244-8013

*Submitted via [www.regulations.gov](http://www.regulations.gov)*

**RE: Request for Information: Federal Government Interventions To Ensure the Provision of Timely and Quality Home and Community Based Services (CMS-2404-NC)**

Dear Mr. Slavitt,

The National Alliance for Direct Support Professionals, Inc. (NADSP) appreciates the opportunity to inform CMS' thinking around federal government interventions that would help improve access to Home and Community Based Services (HCBS). The NADSP's mission is to enhance the quality of support provided to people with disabilities through the provision of products, services, and certifications which elevate the status of direct support workers, improve practice standards, promote systems reform and, most importantly, advance the knowledge, skills, and values of direct support workers.

Individuals with intellectual and developmental disabilities (I/DD) 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 and 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. 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.

A number of demographic and social trends suggest that the United States will experience a dramatic increase in the number of people needing long-term services and supports over the next 30 years. This need is projected to outpace the number of workers available to provide these services resulting in a severe shortage of direct service workers.

Building and promoting an adequate, well-qualified, and competent direct service workforce has proven to be a particularly challenging task. Providing recognition for continuing education and training as an allowable Medicaid service expense supports states' efforts to develop direct service worker qualifications and continuing education and training requirements. This is an important step in developing a quality direct service workforce (DSW) that is prepared to meet the growing demand.

Please see attached our recommendations for specific steps CMS could take to strengthen the HCBS home care workforce, including establishing requirements, standards or procedures to ensure rates paid to home care providers are sufficient to attract enough providers to meet service needs of beneficiaries and that wages supported by those rates are sufficient to attract enough qualified home care workers.

National Alliance for Direct Support Professionals  
1971 Western Avenue #261 - Albany, NY 12203

•(844) 44NADSP

•[www.nadsp.org](http://www.nadsp.org)

Joseph M. Macbeth • Executive Director

Christine Burnett • President



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Executive Director  
National Alliance for Direct Support Professionals

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## INTRODUCTION TO THE 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 I/DD 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.

### 1. 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 that results in ineffective and inconsistent support for people with I/DD.

***Recommendation: Pay a living wage that exceeds the poverty thresholds and minimum wage comparisons.***

Enabling providers to pay a living wage that exceeds the poverty thresholds and minimum wage comparisons is the first and most important step to ensure an adequate supply of workers to meet the demands for their important services. The Massachusetts Institute of Technology (MIT) has disseminated a study that illustrates the criteria for a living wage by region. The study results can be found at <http://livingwage.mit.edu/articles/19-new-data-calculating-the-living-wage-for-u-s-states-counties-and-metro-areas>. A wage calculator created by the Massachusetts Institute of Technology Department of Urban Studies and Planning points out in their study (<http://livingwage.mit.edu/counties/36001>):

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The living wage model is an alternative measure of basic needs. It is a market-based approach that draws upon geographically specific expenditure data related to a family's likely minimum food, child care, health insurance, housing, transportation, and other basic necessities (e.g. clothing, personal care items, etc.) costs. The living wage draws on these cost elements and the rough effects of income and payroll taxes to determine the minimum employment earnings necessary to meet a family's basic needs while also maintaining self-sufficiency.

After determining a starting living wage, that amount should be adjusted upward for experience, credentials, and other salary compression issues as with any other profession. After that, all wages should be adjusted further for inflation.

## 2. LIMITED TRAINING, CAREER PATHS AND CREDENTIALING OPPORTUNITIES

The DSP role is complex because it is about supporting each individual in a person-centered way within his or her 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 be healthy, safe, valued and participating members of their communities. 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 are 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 and Medicaid Services (CMS) have identified nationally validated competencies for DSPs that recognize the knowledge, skills and abilities need by DSPs to effectively support individuals with disabilities in the community. 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<sup>1</sup> from Medicaid about how to build training into HCBS reimbursement rates<sup>2</sup>, use of established competencies to set workforce development and training standards is not widespread.

***Recommendation: As required by the CMS Home and Community-Based Services Settings Rules (2014), assist states to provide all direct support professionals advanced training on supporting and understanding the processes of Informed Decisions Making (IDM).***

Each day, direct support professionals support scores of thousands of people with intellectual and developmental disabilities whose needs and desires are as multiple and varied as is their number. Central to this effort is a vast direct support workforce whose members have diverse ethnic, racial and

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<sup>1</sup> 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>

<sup>2</sup> Centers for Medicare and 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>



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educational backgrounds and whose different life experiences shape what they bring to the job. Their personal beliefs and values certainly guide each of them in their personal lives, but it gets tricky once they enter their place of work because what they believe is “right or wrong” and what the person they support believes is “right or wrong” is often quite different.

As a direct support professional, being “person-centered” is more than an ideal or the next mandatory training. It is the heart and soul of the work of a direct support professional. Being “person-centered” is a yardstick against which all other activities they perform must be measured. In the National Alliance for Direct Support Professionals’ (NADSP) Code of Ethics, we define person-centered supports, “as a direct support professional, my first allegiance is to the person I support; all other activities and functions I perform flow from this allegiance”. Of course, this presents a significant challenge, because as we write in the Preamble to our Code of Ethics, “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. Direct Support Professionals face ethical decisions on a daily basis and consistently feel the tension between the ideals of the profession and its practice”.

Often, a direct support professional’s primary duty and responsibility is to protect people from harm, but that often puts direct support professional in the position of imposing their values, judgment and concerns before those of the person being supported. It also can create ethical dilemmas via the perception of power and control over another person. Where does one draw the line? How do DSPs promote the dignity of those they support to assess and take risks, understand the consequences of a bad decision and learn from those mistakes? After all, regardless of cognitive abilities, everyone learns from previous mistakes.

In January of 2014, the United States Centers for Medicare and Medicaid Services, promulgated new rules for those receiving services under the federal Home and Community-based Services Waivers. These new rules provide emphasis on personal autonomy and allowing greater access to integrated settings. The regulation also will ensure that people who receive the supports will be able to make informed choices. Given that direct support professionals will have a major role in ensuring that people with disabilities will be better prepared to understand the choice making process and associated risk and responsibility that goes along with making ones’ decision, the NADSP created a training program that is geared towards training direct support professionals to support the Informed Decision Making process.

People with intellectual and developmental disabilities can be helped in how to make informed decisions, but they have been traditionally limited in the opportunities to make their own choices. In many cases, the people being supported are ‘experience poor’ and need to have opportunities to experience different options in order to establish a preference. The NADSP believes that people with disabilities should be offered training about the IDM process and by using scenarios and real life experiences, everyone will be able to learn how to make informed choices and understand the risk and responsibility that goes along with decision making.

Until now, service systems across the country have been geared towards overprotection, which is counter-productive to allowing for the dignity of risk. To be truly person-centered, service settings will have to balance associated risk that is part and parcel of decision making, with its traditional regulations on incident management regarding abuse and neglect. I think you’ll agree that in many service settings, direct support professionals will be the key lynchpin in meeting these new guidelines.

National Alliance for Direct Support Professionals  
1971 Western Avenue #261 - Albany, NY 12203

•(844) 44NADSP

•www.nadsp.org

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In all regions of the world, people with intellectual disabilities say that having control in their lives is essential to being seen and treated equally in the community. Perhaps people with disabilities from Inclusion International say it best in their [\*“Global Report on the Right to Decide” \(2014\)\*](#), “Making choices and decisions for ourselves is an important part of who we are. It is fundamental to having control over our own lives and important for securing all other rights: if we are not allowed to make our own decisions, how can we have a voice in anything else that is important to us”? Lastly, the report states this powerful assessment on the Right to Decide, “When people are supported to make decisions for themselves, they are seen as more capable by others. When we are not allowed to make our own decisions or when someone else makes our decisions for us, we are seen as less capable and as having less value in community”.

In our experience, aside from family members, direct support professionals are often the lynchpin to helping people understand the decision-making process and frankly, what’s more important than helping someone direct the course of his or her own life?

*Informed Decision Making (IDM) Training Learning Objectives:*

- Understand the similarities and differences between substituted, supported, and informed decision-making
- Increase awareness of why having choice in one’s life is vital to community living and to recognizing the civil rights of the person
- Think practically about how a lack of choice may hurt or hinder personal growth and development
- Think critically about the amount of knowledge a person has regarding a choice, context of the choice, and what he/she needs to know in order to make a good choice
- Demonstrate how the skills under the NADSP competency “Participant Empowerment” apply to informed decision-making
- Connect the ability to support choice to recognizing that person’s civil rights and personhood
- Recognize informed decision-making as essential to person-centered support
- Develop an understanding of what it may feel like to be ‘experience poor’.
- Learn that the opinions one brings into the relationship can be coercive or negatively impact the choices of others
- Develop the values needed to support decision and provide ethical support
- Come to see oneself as an advocate for the right to make choices
- Identify resources & advanced training opportunities to enhance your ability to support informed decision-making.

***Recommendation: Adopt a universal Code of Ethics for the Direct Support Workforce.***

Direct support professionals 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.

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

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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.

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.

The Code of Ethics for direct support professionals was developed, validated and promulgated by the National Alliance for Direct Support Professionals (NADSP). The beliefs and attitudes expressed in the Code of Ethics is not the handbook of the profession, but rather a roadmap to assist DSPs in staying the course of securing freedom, justice, and equality for all.

*NADSP Code of Ethics contains the following statement areas:*

- Person-Centered Supports
- Promoting Physical and Emotional Well-Being
- Integrity and Responsibility
- Confidentiality
- Justice, Fairness and Equity
- Respect
- Relationships
- Self-Determination
- Advocacy

***Recommendation: Adopt the universal and nationally validated set of competency areas for the Direct Support Workforce.***

If the Code of Ethics is the roadmap for direct support professionals, the Competency areas are the bricks & mortar that provide the framework by which direct support professionals meet industry demand for quality by setting expectations for job performance and a basis for objective performance evaluation. The competency areas ultimately create the foundation of our national certifications that require the practical demonstration of knowledge, intentional execution of skill, and an opportunity for reflection from the direct support professional.

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Developed through extensive research and nationally validated through an external process, these competency areas closely align with the Center for Medicare and Medicaid Services (CMS) Home and Community Based Services Settings Rule (2014) and provided the anchor for the CMS Road Map of Core Competencies for the Direct Service Workforce which were developed in 2014 to identify a common set of core competencies across community-based Long-Term Support and Service (LTSS) sectors for the purpose of informing direct support service delivery and promote best practices in community-based LTSS.

The U.S. Department of Labor's Employment and Training Administration's Competency Model identify the NADSP competency areas for Long-Term Care Supports & Services as providing industry sector technical competencies - the first and only set of LTSS competencies to receive such approval by the United States Department of Labor.

In addition to the fifteen general competency areas, which are broad categories that describe effective work performance, each area contains corresponding skill statements that provide highly specific, observable skills that may be demonstrated by a worker.

*The NADSP's Competency Areas include the following general domains:*

- Participant Empowerment
- Communication
- Assessment
- Community and Service Networking
- Facilitation of Services
- Community Living Skills & Supports
- Education, Training & Self-Development
- Advocacy
- Vocational, Educational & Career Support
- Crisis Prevention and Intervention
- Organizational Participation
- Documentation
- Building and Maintaining Friendships and Relationships
- Provide Person Centered Supports
- Supporting Health and Wellness

***Recommendation: Ensure that direct support professional training is based on sound research and embeds the Code of Ethics and nationally validated direct support professional competency areas.***

NADSP provides accreditation to curricula from educational programs, which meet their guidelines for training direct support professionals in the 15 necessary core competencies needed to receive a certified credential or in an area of specialization appropriate for a specialist credential. The 15 core competencies believed to be essential to a direct support professional are: participant empowerment, communication, assessment, community and service networking, facilitation of services, community living skills and supports, education training and self-development, advocacy, vocational educational and career support, crisis prevention and intervention, organizational participation, documentation, building and maintaining friendships and relationships, providing person-centered supports, and

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supporting health and wellness. Skills required to achieve competency in each of these areas is outlined in the Competency Areas Guideline released by NADSP and can be used to tailor educational programs to meet accreditation standards.

There are currently ten (10) training curricula that have met the standards of NADSP accreditation. These curricula cover a wide variety of training methodology; on-line, classroom-based and a blended learning environment of on-line and classroom.

***Recommendation: Provide states with a framework for career advancements through certifications and credentialing for direct support professionals.***

We encourage CMS and States to hardwire a deeper commitment to improve and stabilize the direct support workforce by introducing competency-based credentials for direct support workers and frontline supervisors.

A competency is the ability to apply knowledge, skills, and ethics required to perform critical work functions. Competencies are the way to verify that a person has learned that which is intended in the learning objectives in any job.

Every profession uses credentialing to establish criteria for competence and quality. A credential is not a self-declared achievement; rather, it is defined and governed by the profession and usually a nationally recognized credentialing entity. Credentialing is a voluntary, advanced step beyond core competencies and is rewarded by recognition and compensation. The purpose of credentialing is to establish a standard for professional knowledge gained through education or training, assuring that the professionals have met the knowledge base and demonstrated proficiency in standards of practice and skills, and certifying a person's commitment to the profession and to life-long learning.

Because of its commitment to excellence, credentialing solidifies and stabilizes a profession and provides within the profession growing opportunities for career lattices/ ladders and skill mentoring. For community supports to be successful, direct support must engage in sophisticated relationships that are both personal and professional. They are personal in that the work is about participating in human growth and development; they are professional because the relationships are based on defined ethical behavior that articulates to a set of complicated skills. Community services are improved because the workforce who provides the services is improved. Credentialing is a systemic commitment to service improvement.

Currently, training direct support workers is most often left to the employer's discretion and in the case of personal care assistant training, the content, like that of the nurse assistant training, focuses primarily on body care with scant attention to other important skills that support self-determination, choice, person-centered support and teamwork.

The national gold standard of direct support professional credentials is the NADSP DSP-Certified credential <https://www.nadsp.org/dsp-credentialing/about-dsp-credentialing.html> . Established in 2007, it is a portfolio-based process that includes related instruction related to the NADSP Code of Ethics, competency-based work samples reflecting CSSS and ethics, career commitment statement, and references from the employer/service recipient.

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### 3. INEFFECTIVE SUPERVISION AND ORGANIZATIONAL CULTURE

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.

***Recommendation: Provide frontline supervisors with training on national competency areas.***

The University of Minnesota's Research and Training Center released the Frontline Supervisor (FLS) Core Competency Set in 2013 [http://rtc.umn.edu/docs/National\\_Frontline\\_Supervisor\\_comp\\_7-2-13.pdf](http://rtc.umn.edu/docs/National_Frontline_Supervisor_comp_7-2-13.pdf) and submitted them for successful national validation in 2014. Arguably one of the most difficult jobs in community services, FLSs represent both administrative policy and day-to-day services. In a sense, they are the carriers and interpreters of organizational culture.

Responsible for supervision and oversight of direct services, FLSs have many roles: direct support itself, supervision, team leadership, hiring, mentoring, evaluating, disciplining, advocacy, etc.—all within the eleven core competencies and one hundred twenty accompanying skills.

*The National Frontline Supervisor Competency Areas include the following general domains:*

1. Direct support
2. Health, wellness and safety
3. Support plan development, monitoring and assessment
4. Facilitating community inclusion across the lifespan
5. Promoting professional relations and teamwork
6. Staff recruitment, selection, and hiring
7. Staff supervision, training, and development
8. Service management and quality assurance
9. Advocacy and public relations
10. Leadership, professionalism and self-development
11. Cultural awareness and responsiveness

***Recommendation: Work with National and State Departments of Labor to establish a Standardized Occupational Code – Direct Support Professional.***

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1971 Western Avenue #261 - Albany, NY 12203

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A standardized federal and state occupational code (SOC) must be developed for the Direct Support Professional. This would assist in the collection of data about this occupation and would allow it to be recognized as requiring far different competency areas and skill requirements from certified nursing assistants, personal care aides and home health aides - the occupation codes that currently are used by I/DD providers to report personnel. While there are certainly some crossover skill requirements, the direct support professional requirements vastly exceed the other occupations.

***Recommendation: Provide technical assistance to service provider organizations to develop DSP-Centric organizations.***

*“We have a DSP Problem.”* We hear it all of the time. Home and Community-based Support Providers experience a crushingly high percentage of staff turnover, poor morale, and an inability to provide the high-quality supports that people with disabilities and their families want and deserve. We are working to enhance the status of direct support professionals and promote the development of a highly competent human services workforce. We recognize that people needing support are more likely to fulfill their life dreams if they have well-trained, experienced, and motivated people at their side in long-term, stable, compatible, support relationships. But direct support professionals, to do their jobs well, must be treated well, recognized as the key lynchpin to quality supports and given authority to practice their craft as true “professionals”.

Over the years, NADSP trainers have had the opportunity to work with hundreds of organizations and including their executive and administrative staff, as well as more than thirty thousand direct support professionals. NADSP has also held listening sessions all over the country, and we have learned a lot about DSPs across many important areas.

Most importantly, we’ve learned that:

- Direct support professionals play a vital role in promoting quality of life for people with intellectual and developmental disabilities.
- Direct support professionals can play a major role in facilitating true person-centered and self-directed supports and social connections. However, generally, DSPs are not taught or supported well in assisting people with disabilities to make their own choices and direct their own lives.
- Direct support professionals are dedicated to the people they support, often that dedication keeps them in underpaid, overworked positions.
- To provide quality supports, direct support professionals must feel empowered to make critical decisions within their role and have the support needed to do their job well.
- Both administrators and direct support staff report a greater need for training across the many core competencies needed by DSPs to support people well.
- Direct support professionals want to feel empowered to make critical and needed decisions within their role.
- Direct support professionals must understand, more thoroughly, the rights of those they support; specifically in the context of representative payee, power of attorney and guardianship.
- To be effective practitioners:
  - Direct support professionals must become more connected to leadership/management and the formal structure of an organization.
  - Direct support professionals must have the necessary resources to do their jobs well.
  - Direct support professionals must have access to modern technology.
  - Direct support professionals must have the confidence to self-motivate within their role.

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- Direct support professionals must have a have a broad understanding of the service industry and their vital role within it.

## 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.

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