



Images from ANCOR's national "Cost of Compassion" video. Watch it at [nationaladvocacycampaign.org](http://nationaladvocacycampaign.org).



# Addressing the Disability Services Workforce Crisis of the 21<sup>st</sup> Century

*Electronic Version*

**American Network of Community Options and Resources  
2017**

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## Glossary of Frequently Used Terms

**IDD:** Intellectual and developmental disabilities.

**DSP:** Direct Support Professional. A person who assists an individual with disabilities to lead a fulfilling life in the community through a diverse range of services, including but not limited to helping individuals get ready in the morning, take medication, go to or find work, or participate in social activities, and often offer transportation in their own vehicle. While we use DSP in this paper, various agencies use different titles such as community support staff, day program counselor, assistive technology instructor, or senior advocate.

**Health Paraprofessional:** The umbrella category in which DSPs, CNAs, HHAs and PCAs fall, among others. When referring to statistics or other such data which are based on aggregate information drawn from this entire workforce, we use the term health paraprofessional. When using data drawn specifically from the IDD field, we refer to DSPs.

**PCA:** Personal Care Assistant; a more entry-level care position due to the lower amount of training required. Duties might involve companionship, helping an individual get ready, or running errands.

**HHA:** Home Health Assistant; HHAs receive more training than PCAs so that in addition to personal care, they can perform basic medical procedures such as taking basic vitals, skin care and attending to more complex diet regimens.

**CNA:** Certified Nursing Assistant – CNAs receive more training than HHAs and can perform more advanced medical procedures such as changing catheters, administering treatments or controlling infections. However, they must do so under the supervision of a nurse.

*More information is available in providers' materials explaining the differences between the occupations for their clients, keeping in mind that these materials are often state-specific. Our summaries were drawn from materials by [Ezra Home Care](#) and [Helping Hands Home Care](#).*

**NCI:** National Core Indicators – a well-regarded survey of IDD service providers.

**LTSS:** Long-term Supports and Services.

**LTC:** Long-term Care.

## Index of Frequently Referenced Government Agencies and Programs

**ADA:** Americans with Disabilities Act.

**HHS:** U.S. Department of Health and Human Services.

**CMS:** Centers for Medicare and Medicaid Services (an agency within HHS). Responsible for the management and oversight of the Medicaid home and community based services system.

**HCBS:** Home and Community Based Services. A program governed by the state-federal Medicaid partnership, which funds the majority of IDD services.

**DOJ:** U.S. Department of Justice.

**DOL:** U.S. Department of Labor.

**BLS:** Bureau of Labor Statistics.

## Executive Summary

**Intellectual and developmental disabilities (IDD) services are contending with external market disruptions which severely affect workforce retention and recruitment and are causing a public health crisis. Without qualified staff, agencies are limited in how they offer client-driven services, namely assisting individuals with IDD in living where, with whom and how they choose.**

**IDD services are a unique marriage of the private sector and the public good;** providers, who range from small family-operated agencies to multi-state organizations, offer services funded by the government so that individuals with IDD can live full lives in the community instead of institutions. These services are delivered through dedicated staff called direct service professionals (DSPs). DSPs perform a wide range of work, from coaching individuals so they can find jobs to helping medically fragile individuals eat and get ready for the day. **Agencies use their business acumen to deliver efficiencies** so that services in the community are less costly to the government than institutions, **while increasing the quality of outcomes for individuals because they can decide what help they want.** However, agencies' ability to meet this endeavor is severely hampered by a steadily growing workforce crisis.

### 2015 Median Annual Cost of Care In:

*Nursing Facilities:* **\$91,250**

*Home Services\*:* **\$45,760**

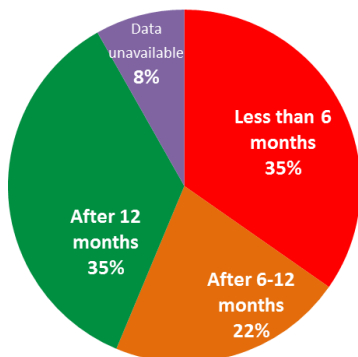
*Adult Day Care\*:* **\$17,940**

\*Fall under the community services umbrella.

Source: Kaiser Family Foundation

Chart 1: DSP Turnover by Tenure Length

### DSP Turnover By Tenure Length



Source: 2016 National Core Indicators study.

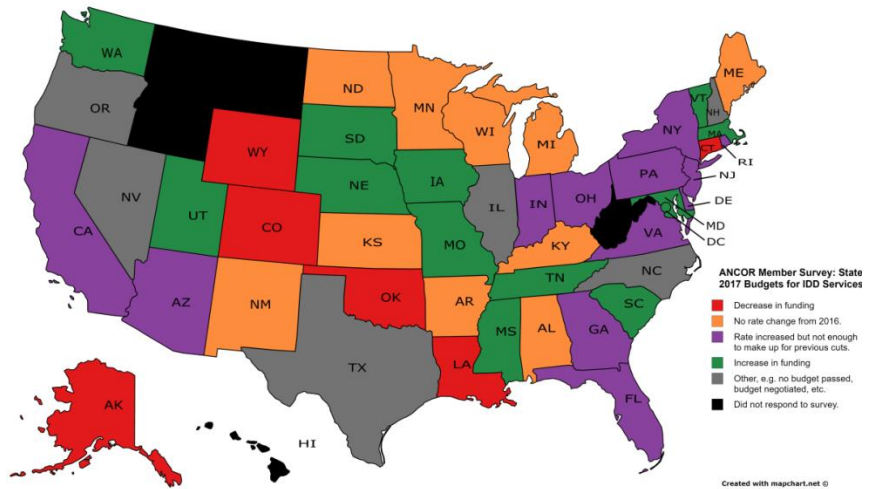
**Turnover is very high in this field and recruitment is difficult, meaning DSP positions stay vacant long enough to cause providers to not be able to take on new clients.** The frequent churn of staff is highly disruptive to individuals with IDD. Federal and state action must be taken before clients' well-being becomes affected – this is a matter of public health. **The workforce crisis stems from federal policy changes which increase demand without increasing funding; stagnant or shrinking state budgets following the great recession; and population trends that mean the workforce will get smaller as the need for services increases.** Combined with the high amount of responsibility called for in this occupation, these factors make it challenging for agencies to remain competitive employers as well as effective service

providers. The American Network of Community Options and Resources (ANCOR) prepared this paper to explore these factors and begin a conversation on solutions. **We seek to foster a discussion between policy-makers, stakeholders and the public that will lead to more workers being hired and individuals with IDD continuing to live the lives they want – namely, lives like those of people without disabilities.**

**Investment in these services is needed to strengthen the employment of DSPs and ensure the stability and quality of services for people with IDD.**

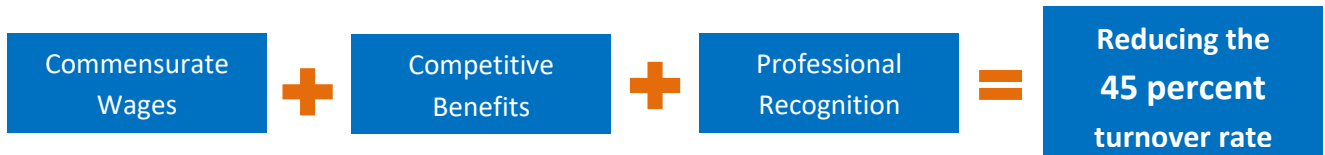
Because a majority of their funding comes from Medicaid, **agencies are price-takers, not price-setters.** The rate at which they are paid is set in advance by their states, since Medicaid is a federal-state partnership. **Providers cannot negotiate these rates, and most state funding does not take into account wage rates in competing occupations, administrative costs, the need for competitive benefits and other such factors.** As a result, rates have remained stagnant for many years despite inflation and absent cost-of-living increases, and in many states rates have been reduced – in part because of decreased revenue from the Great Recession.

Map 1: State 2017 Budgets for IDD Services



Source: ANCOR “State Share” Survey Taken June 2016 of Member State Associations and Board of Representatives.

With current funding levels, providers struggle to recruit and retain a caring, qualified workforce because **wages are not commensurate to the amount of responsibility required.** This results in a **45 percent average DSP turnover rate** and ripples into **wage compression at mid-management levels and above.** This turnover affects continuity of care and quality of services, as staff leave before they have time to **gain their clients’ trust with personal matters and care.** As a Medicaid partner who offers matching funding, the federal government has a vested interest in solving this crisis. **This crisis has economic ramifications since the DSP occupation is one of the fields that will be in the most demand in the coming decade.** The crisis also has legal and moral ramifications, as the future of individuals with IDD’s access to mainstream society and the strength of the DSP occupation are intrinsically tied, particularly since the *Olmstead* Supreme Court decision deemed access to the community to be a right.



This paper will propose solutions to this fiscal challenge, including:

- Improving data on DSP wages so policy-makers have more accurate information;
- Higher funding more reflective of costs;
- Greater coordination between policy-making or regulatory agencies and funding agencies;
- Better-informed rate-setting by states;
- Factoring benefit costs into funding calculations;

- Short-term solutions around struggles with benefits; and
- Addressing policy and financial challenges in accessing technology.

**Low wages also have the secondary effect of affecting public esteem and recognition of this important workforce, making recruitment even more challenging.**

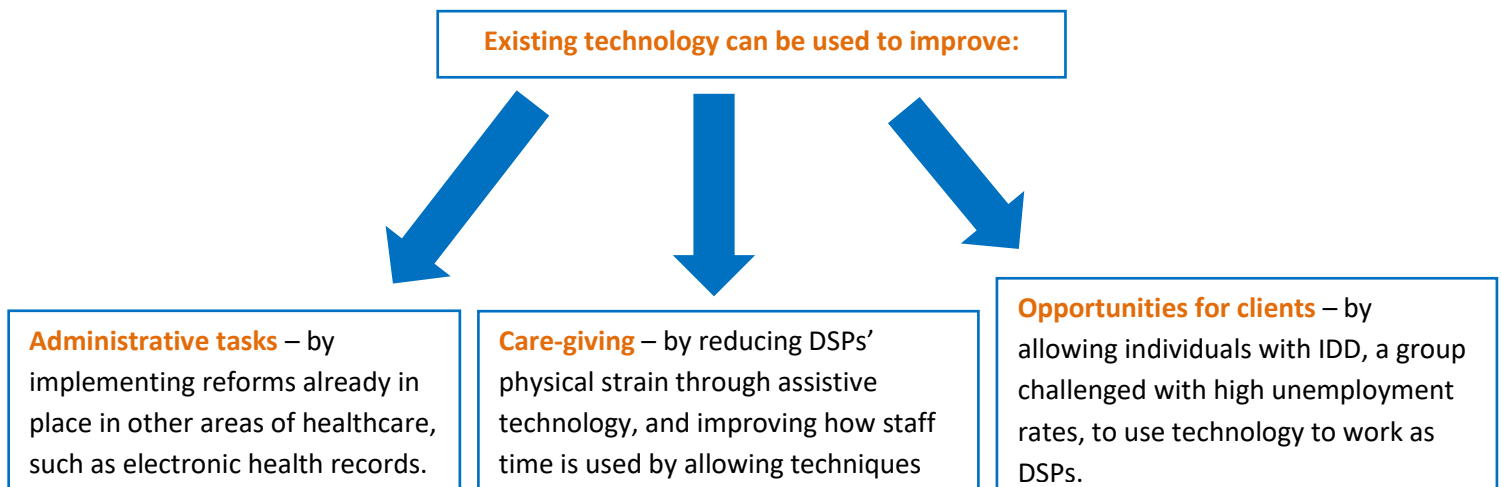
Unfortunately, the general public often assumes that lower wage rates mean that the occupation is not professionalized or does not require many responsibilities. **With regards to the DSP occupation, this assumption is harmful since the position actually requires a lot of training, compliance with regulations and responsibility** – not the least of which is keeping a person alive even in medically complex scenarios. The artificial ceiling imposed on DSP wages creates a false impression that this is not a professional occupation. This problem is further compounded by this workforce’s inherent invisibility – in supporting individuals’ most basic survival needs or loftiest ambitions, DSPs are generally in the background. As a result, people are not aware of the occupation and do not have a good understanding of its role. Given community-based services’ reliance on publically-funded programs such as Medicaid, public recognition of the difficult, morally valuable work is vital to the strengthening of this occupation.

The solutions this paper explores with regards to this facet of the workforce crisis are:

- Improving workplace conditions;
- Public recognition initiatives; and
- Engaging state and local workforce investment boards.

**Existing technologies could assist providers in filling vacancies and more importantly, helping individuals with IDD succeed. Currently, regulations and funding have not caught up to technological innovations, creating inefficiencies, overworking staff and not giving individuals as many opportunities as they deserve.**

The technology challenge, in the words of an ANCOR member, is “a three-legged stool.”





Because technological innovation moves significantly more rapidly than policy-making, regulatory agencies and state legislatures have not approved the use of many tools that would allow for more efficient use of staff time. While technology cannot supplant staff and should not be seen as a full solution to the workforce crisis, adopting existing technologies would relieve demand for DSPs and allow current DSPs to focus their time on the individuals they support rather than administrative tasks. It would also generate savings that could contribute to the long-term stability of IDD services. However, because of the structure of Medicaid which re-routes savings to the state, **it is imperative that providers be able to keep savings generated through technology to re-invest in filling vacancies, thus ensuring that individuals' are staffed where and how they need and desire.**

This paper outlines general principles on the three areas listed above that could be used to guide policy-makers on the topic of technology in IDD services, building on ANCOR's previous work in this area.

**The final component of the workforce crisis is that in the coming decade there will not be enough working-age women (the main DSP demographic) entering the labor force compared to demand for DSPs. This will require creative policies, partnerships, investments and recruitment on the part of all stakeholders to bring new workers into the occupation and ensure its long-term survival.**



*Image from ANCOR's "Cost of Compassion" video.*

Women aged 25 to 64 are the main group of people who enter the DSP profession and similar occupations. However, while in the next decade demand for DSPs will increase by 48 percent, only 2 million additional women aged 25 to 64 will enter the whole labor force in that time, down from 6.3 million in the early 2000s. **This means that unless the field of applicants is broadened and diversified, the shortfall of staff will be a persistent challenge.** This has long-term consequences for preserving individuals with IDD's ability to make choices about their lives.

This paper will suggest the following solutions to this challenge:

- Recruitment of youths through high school, college and recent graduate programs as well as apprenticeships;
- Reaching out to unemployed men;
- Exploring the feasibility of hiring individuals convicted of non-violent crimes who have completed sentences and probation periods;
- Encouraging older workers to stay in the workforce and recruiting them for DSP positions;
- Paying family caregivers;
- Advancing immigration reform;
- Recruiting people with disabilities to provide direct support;
- Expanding the use of shared living services.

## Key Takeaways:

Stakeholders have already given a lot of thought to how to solve the DSP workforce crisis over the past decade. However, the current fiscal climate, low political appetite and lack of public awareness or appreciation of these services make it hard to foster innovation in this field. Fulfilled DSPs who can thrive in their careers and learn new skills are critical to the welfare and personal blossoming of individuals with IDD. Investing in the DSP workforce will:

- Preserve the well-being of individuals with disabilities by keeping those who wish to remain in the community with their friends and family to do so, in the manner that they choose;
- Allow a segment of the private sector, including many family-operated small businesses, to be competitive employers and stay in business;
- Align workers seeking employment with vacancies in the fastest-growing occupation in the nation;
- Create a more financially sustainable future for IDD services while maintaining service quality and meeting ever-growing demand.

## Section 1: Introduction and Background

**Section Highlights:** An increase in diagnoses and other demographic trends, as well as federal policies promoting community-based services for individuals with intellectual and developmental disabilities, are leading to large increases in demand for services at a time when direct service professional turnover and vacancies are persistently high. This section explores the context in which the shortage is occurring and identifies eight factors in the turnover rate which will be explored in the remainder of the paper.

Services for individuals with intellectual and developmental disabilities (IDD) are experiencing a perfect storm of demographic and policy trends which are creating a shortage of direct service professionals (DSPs) and other critical staff. This means individuals with IDD are in danger of not receiving the customized, client-driven assistance they need to succeed, since these services are labor-heavy and service providers run the risk of not meeting strict regulatory requirements which mandate certain levels of staffing. It also means there is a misalignment between the vacancies in one of the fastest-growing occupations in the country, and employees interested in the occupation.



*Image from ANCOR's "Cost of Compassion" video.*

Because the American Network of Community Options and Resources (ANCOR), as part of its National Advocacy Campaign, has committed since 2001 to “enhancing the lives of all people with disabilities who rely on long term supports and services by obtaining the resources to recruit, train and retain a highly qualified and sustainable workforce”, we find it imperative to contribute to the national discussion on this workforce crisis. ANCOR wishes to provide an initial, big-picture overview of critical facets of the workforce crisis, with the goal of generating a discussion on concrete policy proposals. The report will be centered on the topics listed below<sup>1</sup>:

- **Inadequate data on wages that hamper policy discussions;**
- **Low wages that are below a sustainable living, caused principally by low reimbursement rates to providers and resulting in high turnover;**
- **Insufficient benefits (such as health insurance or paid sick leave);**
- **Insufficient professional supports;**
- **Lack of public recognition;**
- **Lack of options for a career;**
- **Insufficient access to necessary technologies for recruitment, employee safety, improved outcomes or streamlined documentation.**
- **Workforce that will not grow as fast as demand.**

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<sup>1</sup> While ANCOR recognizes that pre- and post-onboarding education (training) is a significant factor in staff retention, at this time we believe this important topic merits greater conversation in a standalone document.

However, before launching into these topics it is necessary to explain the confluence of demographic changes and policy trends that led to this crisis and why this is a serious enough problem to warrant intervention by the federal government, state governments and stakeholders.

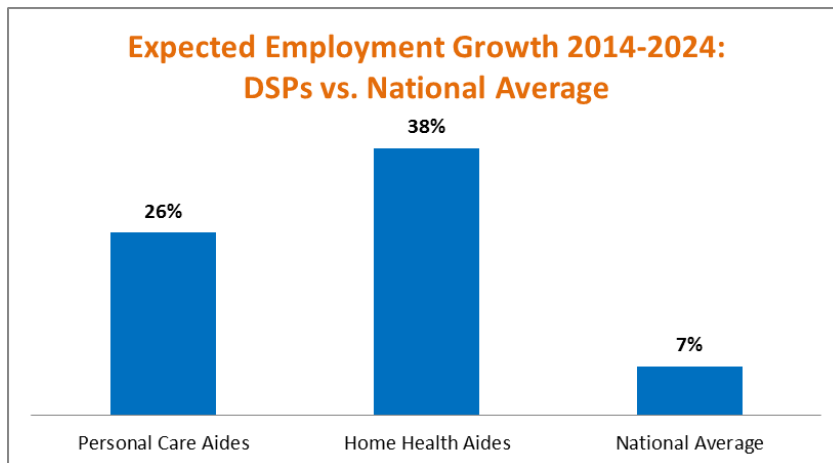
*1. Changing Demographics Are Increasing Demand:*

Demand for services has increased due to changes in national demographics, notably:

- An increase in autism diagnoses;
- Caregivers who need extra help as they age and continue to care for their loved ones with IDD;
- The aging of the Baby Boomer population, which has two-fold consequences: increasing demand on entitlement programs, which in turn stresses the federal budget.

Reflecting these trends, the Bureau of Labor Statistics (BLS) predicts that employment for personal care aides will grow by [26 percent between 2014 and 2024](#), and by [38 percent for home health aides](#), two categories which encompass frontline direct care workers, or direct support professionals. This contrasts to a national average [of 7 percent growth for other occupations](#).

Chart 2: Expected Employment Growth, 2014-2024: DSPs vs. National Average.



*Source: Bureau of Labor Statistics.*

2. Federal policies are solidifying a cultural shift towards community services but not increasing funding:

The Olmstead Case: In 1999, the Supreme Court deemed in the *Olmstead* decision that “unjustified segregation of persons with disabilities constitutes discrimination in violation of Title II of the Americans with Disabilities Act”; the [Court required states to provide community services](#) when doing so is reasonable and desired by individuals with disabilities. The U.S. Department of Justice acted upon this decision shortly thereafter, including filing lawsuits against states it did not deem to be in compliance with the ADA. On the 10<sup>th</sup> anniversary of *Olmstead* in 2009, the Department of Justice increased its enforcement of the *Olmstead* decision, following directives from the President to “vigorously enforce the civil rights of Americans with disabilities” as part of “[The Year of Community Living](#)” initiative.

**As more individuals with complex needs (e.g. medically and/or behaviorally complex or aging needs in addition to an IDD diagnosis) enter the community, offering services in the spirit of *Olmstead* will require greater numbers of qualified and committed staff than the state or federal governments currently fund.**

85

DOJ Olmstead Enforcement Cases Since 1999

10

Different Issues Covered By Enforcement Actions

28

States or Territories Received Olmstead Enforcement

Source: ADA.gov – DOJ Olmstead Enforcement by Circuit Court. Accessible online at: [https://www.ada.gov/olmstead/olmstead\\_enforcement.htm](https://www.ada.gov/olmstead/olmstead_enforcement.htm)

HCBS Settings Rule: the cultural push for integration led the Center for Medicare and Medicaid Services (CMS) to promulgate regulations setting a high bar for the [definition of “community”](#) in Medicaid’s Home and Community Based Services (HCBS) program. The HCBS program is the main funding mechanism for individuals with IDD to receive supports for daily life functions. These guidelines call for more consumer choice and control over the types of services they receive. **Rules such as the HCBS rule not only require more staff for implementation but also put pressure on supervisors and managers to oversee more programs as demand increases for services.**

“Rebalancing” Policies: The previous administration has found that “despite increasing use of home and community based services, the organization, financing and delivery of Medicaid-funded long-term care services remains biased towards institutional care.”<sup>2</sup> As a result, the administration is also seeking to increase the share of community services through “rebalancing” programs such as [Money Follows the Person \(MFP\)](#) and [State Balancing Incentive Payments](#). To give an example of how this increases demand for DSPs, **between when MFP started in 2005 and December 2015 it helped 63,337 individuals with chronic conditions and disabilities leave institutions and moved into the community.** Data on how many additional DSPs are needed to meet this demand were unavailable, but [Mathematica found](#) that MFP has offered mixed blessings on workforce issues<sup>3</sup>, as illustrated by the table below.

<sup>2</sup> Medicaid.gov, *Balancing Long-Term Services & Supports*.

<sup>3</sup> Mathematica, *Money Follows the Person Demonstration: Overview of State Grantee Progress, January to June 2011*. 2011. Pages 33-34.

Table 1: MFP Effects on HCBS Workforce.

MFP Effects on HCBS Workforce		
Category	Number of States	State Names
MFP states increasing DSP employment	5	Not listed in report
MFP states contracting with more HCBS providers	10	Not listed in report
MFP states increasing HCBS Rates	4	CT, KY, LA and ND
MFP states reporting insufficient DSP workforce	5	IA, KY, ND, OH and VA
MFP states reporting insufficient HCBS providers	11	Not listed in report
MFP states reporting being challenged by budget funding requirements or restrictions	6	CA, HI, MI, NC, NH and NY

Source: *Mathematica report*, pages 33-34.

While these policies are laudable in their intent to give individuals greater access to the community, **there has been no additional funding from the federal government or states for implementation of these rules.** The government is asking providers to do more without compensating for additional costs. IDD providers rely almost exclusively on Medicaid funding for revenue and currently do not have the resources for the recruitment and retention of additional staff necessary to meet increased demand, as well as other ancillary costs. To further clarify what it means to have Medicaid as a primary source of funding, IDD providers:

*IDD providers rely almost exclusively on Medicaid funding.*

- Do not receive funding from private insurance companies;
- Do not benefit from other profit-generating sources such as hospitals with prestigious surgery services;
- Do not benefit from private pay.
- Some providers receive state or local contracts for non-Medicaid services, or fundraise through their networks, but these are not core funding streams for this sector.

**The disparity between federal funding, state rates and service demand stemming from federal policies has unfortunate consequences for individuals with IDD who could live in the community but instead remain in larger congregate group settings (institutions) or on waiting lists.** The National Association of State Directors of Developmental Disability Services (NASDDDS) estimates that “at least 20 percent expansion of the current residential system would be necessary to address the demand”.<sup>4</sup>



Image from ANCOR’s “Cost of Compassion” video.

<sup>4</sup> NASDDDS, *Shared Living Guide*. 2011. Page 4.

3. *Federal policies have not integrated healthcare policy with long term services and supports.*

The past decade of policymaking has not aligned long term services and supports (LTSS) with healthcare in a way that has enabled the direct support workforce to thrive. As policy goals to rebalance the system are being put forth, programs like MFP cannot be fully effectuated because of lack of workforce and states currently moving forward on implementation the CMS HCBS Settings Rule are challenged with the deficit in these staff resources. It is essential that the needs of the LTSS program and its workforce are integrated into broader healthcare policy discussions.

#### Medicaid Access Rule

One arena that will be discussed in the solutions section of this paper is how CMS has released rules in accordance with the Access Rule under Section 1903(a)(30)(A) of the Social Security Act. ANCOR has repeatedly requested that the Agency extend coverage of the access rule to home and community-based services (HCBS). One of these official requests was made in January 2016 in response to a Request for Information following issuance of the final rule. ANCOR's comments were fully endorsed by the Arc of the United States, United Cerebral Palsy, the Brain Injury Association and Autism Speaks.

When the initial response was issued to the RFI leaving out HCBS application, ANCOR worked with Members of Congress from the Senate Finance Committee and House Energy and Commerce Committee who shared our dismay of the HCBS exclusion to issue a letter again asking for inclusion of HCBS.

Given the DSP workforce crisis and the expectation for it to worsen over the next ten years as indicated by the Bureau of Labor Statistics, it is imperative that rules like the Medicaid Access rule have application to HCB services and create state accountability measures to create metrics for access. Given the stated goals of the Access rule to address the [Armstrong v. Exceptional Child, Inc. case](#), it would be impossible to do so without addressing the plaintiffs of that case who were in fact HCBS providers.

#### Health and Technology Policy

The arena of technology, a key component of health policy, needs to extend to LTSS procedures but that gap is also growing. For instance, ANCOR provided input to the [five year vision report by the Office of the National Coordinator for Health Information Technology](#) on electronic health information and interoperability of health information technology. ANCOR found that although there are some references to HCBS in the report, the general policy leaves out considerations essential to delivering LTSS. The introduction of better technological coordination could have important implications on strengthening the DSP workforce. For example, electronic health records have been heavily advocated and advanced in recent years at the federal level, but not introduced in the arena of HCBS program.

*"The realization that you can no longer care for your disabled child is a horrific feeling. Wondering if he will be taken care of, who will be there when he is sick or in need, and who will care for him as I do was almost too much to bear. Then along came Joe.... Because of Joe my son was able to graduate high school. I have no doubt this would not have happened if it wasn't for Joe's persistence. Joe has given me such peace knowing my son is safe and happy."*

*-Vicki Welsh, speaking about her son's DSP Joe Cuevas*

Another area that will be essential for greater thought and clarity of process will be how the federal government and states will ensure protection of workforce and in fact strengthen workforce as system change occurs. We continue to see more and more states engaging in discussions about or actually moving forward with providing their Medicaid services for an I/DD population through managed care. Although [CMS issued final regulations on April 21, 2016](#) that clarify stakeholder input, network adequacy standards, and other important details, there is much work to be done to establish how these changes are going to impact workforce development, particularly as managed care organizations seek profits and states seek savings.

### Dual Diagnoses

The area of dual diagnoses (where an individual with IDD also has mental health diagnoses) continues to create an issue in properly developing a well trained workforce. The existence of a [dually diagnosed population often goes unrecognized](#) and thus across the healthcare spectrum the resources and information are challenging to locate and provide. As [autism diagnoses increase](#), providers are preparing to work with an increased amount of complex and multiple diagnoses.

### Health and Labor Policy on LTSS

Finally, legislative attempts to address the workforce crisis seem to fail because of the lack of interagency work between the Departments of Health and Human Services and Labor. ANCOR has formally requested the establishment of this interagency working group in combination with stakeholders to address the issue of workforce. In 2016, when the Department of Labor overtime rule was moving towards implementation, ANCOR responded with the Save Our Services (SOS) Campaign requesting this interagency work and also introducing the [Disability Community Act](#) to provide the support providers needed. Although the bill did not advance, the Departments of HHS and DOL did work together to issue data on the DSP workforce. Other bills like the RAISE Family Caregivers Act and the National Care Corps Act that offered varied solutions to addressing the workforce crisis via the Department of HHS were not successful either in the 114<sup>th</sup> Congress, but hopefully will advance in the 115<sup>th</sup>.

Ultimately, in order for workforce policies to advance, there is a great need for LTSS to be better understood and integrated into healthcare policy. Workforce is an essential aspect of the provision of LTSS and community-based services – to provide long term services in the community requires a significant amount of well-trained, committed staff that may be providing services to as few as one or two individuals. Healthcare policy must incorporate and embrace the LTSS workforce and labor policy in order to achieve real workforce solutions.



#### 4. Direct services struggle to recruit and retain staff:

When people have complex needs, the relationship with their caregivers determines how well their needs are understood and met. Due to high turnover, **individuals do not have the ability to spend enough time with DSPs to develop the understanding relationship needed** to get the best intimate care, administration of medication, supportive career assistance or other such services. The most recent National Core Indicators (NCI) staff stability survey found a nearly 45 percent average DSP turnover rate nationally out of a range of 17.7 percent to 75.6 percent<sup>5</sup>, a conclusion that correlates with [other national findings](#)<sup>6</sup>. Not only is turnover large, it is also frequent: **56 percent of DSPs leave their employment within a year, and roughly 35 percent do so within six months**<sup>7</sup>.

*“We need more people like Jason...He opens doors for me. I can go out and be more active in my church, my community. When people tell me there’s something that I can’t do, he helps me. He tells us that we have our own rights.”*

*-Robert Stephens, speaking about his DSP Jason Pasley.*

The direness of this situation can be illustrated by this field’s recognition that achieving turnover rates around 30 percent or lower constitutes “best practices”. An example can be seen with recipients of the National Alliance of Direct Service Professionals’ (NADSP) [Moving Mountains Best Practices Award](#). Some of these recipients went through great lengths to reduce their turnover from 53 percent to 20 percent or from 49 percent to 37 percent<sup>8</sup>.

In addition to affecting the relationship between individuals and DSPs, high turnover rates affect providers’ ability to allocate resources for consumers’ or programmatic needs and strain remaining employees. **Each vacancy costs agencies between \$4,200 and \$5,200** in direct costs (e.g. separation, training a new employee, etc.) and indirect costs (e.g. lost productivity and client revenue)<sup>9</sup>. Remaining staff find themselves working longer hours, increasing the physical and emotional toll of caregiving to everyone’s detriment. It is unsurprising that the Long Term Care Commission report to Congress found that **“high turnover and workforce shortages have an impact on care quality.”**<sup>10</sup>

<sup>5</sup> National Core Indicators (NCI), *2015 Staff Stability Survey*. 2015. Page 2. Not available online at this time.

<sup>6</sup> U.S. Senate Long Term Care Commission, Report to the Congress. 2013. Page 49.

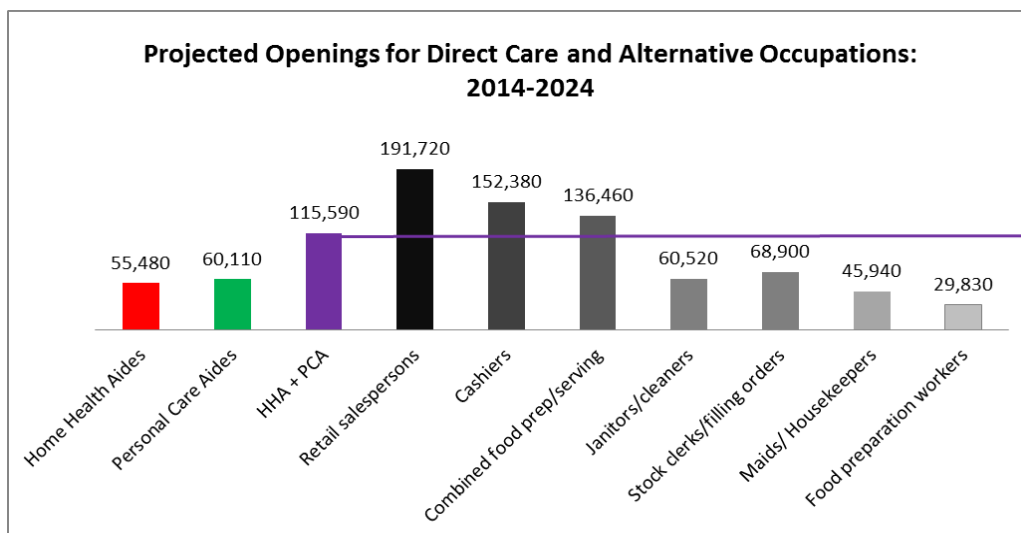
<sup>7</sup> NCI, page 2.

<sup>8</sup> National Association of Direct Service Professionals, *Moving Mountains Best Practices 2009 Award Winner*.

<sup>9</sup> Medisked Connect, *The Staffing Struggle Is Real: New Statistics on I/DD Agencies’ Most Common Staffing Problems +5 Tips for Reducing Employee Turnover*. 2016. Page 6.

<sup>10</sup> The report goes on to state “Though there is little data about the effect of worker turnover in home and community-based settings, studies in nursing homes have shown that higher turnover is associated with poor quality of care as measured by use of restraints, pressure ulcers, psychoactive drug use, and certification survey quality of care deficiencies.”

Chart 3: Projected Openings for Direct Care and Alternative Occupations: 2014-2024



Source: DOL data sent to ANCOR and presented at the President's Committee on Intellectual and Developmental Disabilities

#### Why This Matters:

Agencies cannot remain competitive employers in a policy environment that increases demand but does not give them the tools needed to respond to that demand, leading to large staff shortfalls. This is particularly problematic for client-driven quality of care, which cannot be maintained or improved without a sufficient and fulfilled workforce. Without this workforce, we have a public health crisis because the workforce crisis affects all members of the community, including:

*Agencies cannot remain competitive employers in a policy environment that increases demand but does not give them the tools needed to respond to that demand.*

- Providers who need stability to plan for the future and give their clients the standard of care they require and deserve;
- DSPs performing this emotionally rewarding but difficult work with insufficient relief;
- Consumers and families for whom services are a matter of life or death; and
- Local economies that are not benefiting from full employment because a fast-growing sector is not filling vacancies.

Investing in the workforce so that direct service professionals have fulfilling, financially sustainable and lifelong careers will benefit a large and at times vulnerable segment of society as well as the labor market. **In order to strengthen an entire employment sector and deliver on the promises of the Americans with Disability Act, it is necessary to understand the workforce crisis and intervene before ever-increasing demand reaches tidal wave proportions.**

## Section 2: Insufficient Data on Wages

**Section Highlights:** Policy-makers are using data that is less reflective of the workforce to identify long-term workforce trends, funding levels and other elements that affect the labor market. This is problematic as it leads to decisions that do not meet the needs of individuals nor allow providers to be competitive employers. In response, ANCOR has been advocating for DSPs to be their own category so policy-makers can base their decisions on more accurate information.

### Background

Low wages and their effects on the workforce are an accepted fact - as mentioned by [AAIDD](#), “low wages and limited career opportunities for DSPs have contributed to a workforce supply that is inadequate to meet demand.” However, in attempting to illustrate the precariousness of these wages, **providers face significant data shortages because wage information for DSPs in the IDD field is not readily available or regularly compiled.** For example, BLS and Department of Labor’s (DOL) use three separate databases (NAICS, SIC and SOC) which list health paraprofessional occupations. These lists include occupations which do work akin to but not entirely similar to that of DSPs who care for individuals with IDD, including:

- Home health assistants (HHAs);
- Personal care aides (PCAs);
- Childcare workers;
- Physical therapist assistants; and
- Social and human service assistants.

This is challenging because both these federal agencies send employers surveys or otherwise collect information using the aforementioned classifications to fill those three databases. IDD Providers are not able to fill in their information accurately since the descriptions do not line up with the work their employees perform, further compounding the challenge of finding accurate wage data for this sector.

Additionally, the Paraprofessional Healthcare Institute (PHI) state wage data, while informative because it is extensive, combines all health paraprofessional sectors in its average wage reporting. It is problematic for IDD providers to use wage data that includes other health sectors because: a) other Medicaid providers (such as those offering services to the elderly) benefit from additional funding streams such as private pay or private insurance, so their wages might be higher than the norm in the IDD field; b) the job responsibilities for other paraprofessional occupations might be very different. One of the recruitment challenges for DSPs in the IDD field is that DSPs have to make “on the spot” decisions with life or death consequences for the individuals they support, and current market wages do not reflect this high responsibility.

This data challenge also has long-term consequences for workforce planning, as outlined by the Government Accountability Office’s (GAO) August 2016 report on the long-term care workforce. The report stated that “Federal data sources provide a broad picture of direct care workers – nursing assistants and home health, psychiatric and personal care aides – who provide long-term services and supports (LTSS), but limitations and gaps affect the data’s usefulness for workforce planning.”<sup>11</sup> Focusing on HHS’ Health Resources and Services Administration (HRSA), the report finds that the agency has not attempted to resolve data challenges which prevent it from developing workforce projections. GAO concludes that **“Unless HRSA takes steps to overcome data limitations in order to make projections of supply and demand for direct care workers, policymakers will continue to be hampered in their ability to identify workforce trends and develop appropriate strategies to help ensure a number of qualified direct care workers.”**<sup>12</sup>

### Solution

**To ensure that providers can engage with policy-makers with information that accurately captures the reality of wages in the field, ANCOR urges BLS to designate DSPs as their own category for wage and turnover data collection, and is collaborating with DOL on additional data collection.**

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<sup>11</sup> GAO, *Long-Term Care Workforce. Better Information Needed on Nursing Assistants, Home Health Aides, and Other Direct Care Workers*. August, 2016. Executive Summary. Accessible online at: <http://www.gao.gov/assets/680/679100.pdf>

<sup>12</sup> GAO report, Executive Summary.

## Section 3: Low Wages

**Section Highlights:** Due to states setting low Medicaid rates that providers cannot negotiate, DSP wages are not competitive or commensurate to the level of responsibility required for the occupation. The resulting artificially low wages are the lead reason for turnover, affecting the quality of care and individuals' ability to customize services. ANCOR proposes the following solutions: funding that realistically reflects costs; greater coordination between policy agencies that make demands of providers and funding agencies that do not allocate resources to meet those demands; and improved state rate-setting mechanisms.

### Background

Pending the national collection of DSP wage and turnover data, we can turn to the 2016 NCI survey of IDD providers for a small snapshot of wages in 17 states. This is with the caveat that this survey has a smaller sample size with some states responding at higher rates than others, meaning some state responses have significantly larger margins of error than others. NCI finds that on average a direct service professional earns \$10.72 per hour<sup>13</sup>. This is from a range of \$8.66 to \$13.67<sup>14</sup> per hour for average starting wages and \$9.59 to \$13.97 for average wages, as seen in the chart below.

Table 2: NCI 2016 Wage Data

State	Starting DSP Wage	Average DSP Wage	State Living Wage: 1 Adult	State Living Wage: 1 Adult, 1 Child	State Living Wage: 2 adults (1 working), 2 children	State Living Wage: 2 Working Adults, 2 Children
AL	\$8.66	\$9.59	\$10.17	\$20.52	\$20.12	\$13.99
AZ	\$9.49	\$10.05	\$10.38	\$22.67	\$24.13	\$15.64
DC	\$13.67	\$13.97	\$14.54	\$30.90	\$25.41	\$20.36
GA	\$9.55	\$10.27	\$10.88	\$21.90	\$23.59	\$14.37
IN	\$9.53	\$10.36	\$9.99	\$21.10	\$22.78	\$13.80
KY	\$9.81	\$10.67	\$9.81	\$20.67	\$19.95	\$14.22
MN	\$11.03	\$12.17	\$10.68	\$28.74	\$21.70	\$12.91
MO	\$9.60	\$10.56	\$10.02	\$20.85	\$20.44	\$13.76
OH-HCBS	\$9.84	\$10.56	\$9.58	\$20.87	\$21.98	\$14.14
OH-ICF	\$9.81	\$11.14	\$9.58	\$20.87	\$21.98	\$14.14
OR	\$11.26	\$12.27	\$10.92	\$23.96	\$25.03	\$15.57
PA	\$10.86	\$12.25	\$10.23	\$21.45	\$22.26	\$14.53
SC	\$9.56	\$10.24	\$10.50	\$20.48	\$23.00	\$13.20
SD	\$10.73	\$11.93	\$9.54	\$19.87	\$22.05	\$13.23
TN	\$8.57	\$9.10	\$9.81	\$20.02	\$22.39	\$12.80
TX	\$9.50	\$10.24	\$10.15	\$21.56	\$20.98	\$13.78
UT	\$9.86	\$11.58	\$10.56	\$22.18	\$21.52	\$15.19
VT	\$12.85	\$13.08	\$11.49	\$23.80	\$24.45	\$15.67

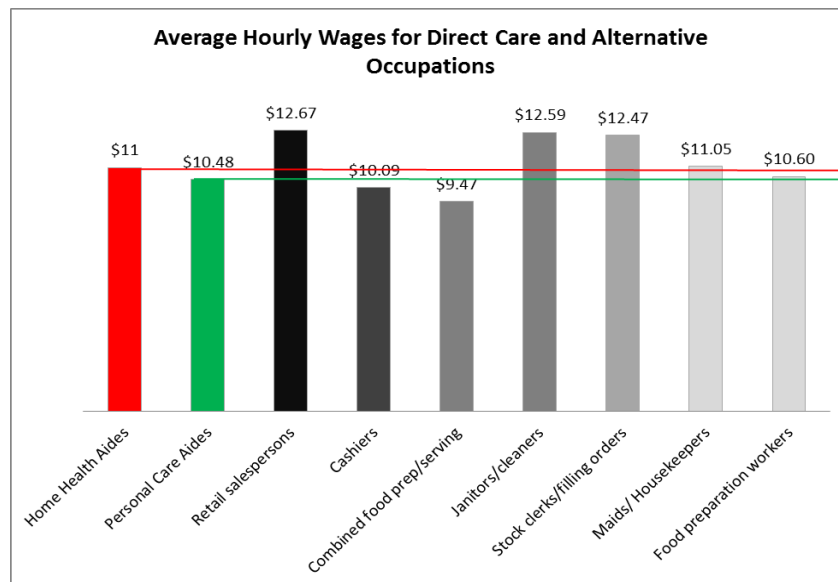
Wage data source: National Core Indicators 2015 Staff Stability Survey, page 24. Living wage estimates: the Massachusetts Institute of Technology's (MIT) living wage calculator. MIT estimates are those needed by an individual, so in the 2 working adults example, both would need to earn at least that wage. Note that ANCOR members from Vermont have commented that these rates are higher than what their experience suggests.

<sup>13</sup> NCI, page 21.

<sup>14</sup> NCI, page 16.

The NCI snapshot makes it easy to understand how current wages for this occupation are not sufficient when one compares them to [MIT's estimates of living wages](#) needed in those states. While ideally we would have statistics specific to DSPs, it is informative that [PHI finds](#) that 1 in 5 paraprofessionals in general are single parents and nearly half of all paraprofessionals (46 percent) rely on public benefits to make ends meet. It illustrates the hardships endured by DSPs that **those who are caring for individuals on Medicaid need public assistance themselves to make ends meet**. Given that DSPs are responsible for individuals' lives, their wages should be commensurate with occupations with a similar level of responsibility. Currently, as shown in the chart below, DSPs' wages match occupations with lower levels of responsibilities, in fields that do not have nearly as much regulatory oversight – and the data used for that chart might not be reflective of lower DSP rates, because the Department of Labor used surveys aggregating DSPs, HHAs and PCAs together.

Chart 4: Average Hourly Wages for Direct Care and Alternative Occupations.



Source: DOL comparison data sent to ANCOR and presented at the President's Committee on Intellectual and Developmental Disabilities

These low wages occur because providers are constrained by low, non-negotiable reimbursement rates set by their states' Medicaid agencies. In essence, DSP wages have an artificially low ceiling that does not reflect market rates. As mentioned earlier, [Medicaid is the primary payer for services for individuals with IDD](#). In many states, Medicaid rates have stayed stagnant or actually decreased in the past decade. **As such, providers do not have enough funding to 1) pay new staff enough to recruit or retain them; 2) raise wages for experienced staff, resulting in wage compression.** This means senior staff who provide needed mentorship and organizational history do not earn noticeably more than inexperienced staff, resulting in turnover at all levels and difficulty in recruiting supervisors from DSP ranks.

Low wages are the primary reason providers reported DSPs leaving (see chart below).<sup>15</sup> When compared to other professions, one can see why these low wages are at the root of other challenges such as the perception of direct service as a low-skilled profession. This also has deep consequences for the IDD community as different rates across the states cause disparities in access to care across the nation.

Table 3: Medisked Survey Results on DSP Reasons for Leaving Employment.

Reason for Leaving	Percentage
Inadequate pay	88.54%
Lack of supervisory support/appreciation	42.04%
Insufficient training/guidance	28.66%
Difficulties/stress of work performed	66.88%
Lack of advancement opportunities	49.68%

Source: Medisked survey. Multiple choice allowed therefore results add up to more than 100 percent.

## Solutions

### Increasing funding:

As price-takers and not price-setters, providers have very little flexibility with how they allocate their resources. **If providers' labor costs increase without additional funding in place to help them adjust, they are placed in a position where they have to reduce wages, lay off staff or make tough decisions about the numbers of new individuals they serve and what kinds of services they are able to offer.** This difficult situation must be remedied by state legislatures and the federal government by prioritizing increased Medicaid rates to IDD services. To achieve this goal, [it will be necessary to continue long-standing efforts to educate lawmakers on Medicaid](#) through coalitions of providers, workers and advocates who propose solutions, particularly in the rapidly changing environment surrounding Medicaid in this new administration and Congress.<sup>16</sup>

The following strategies could help achieve higher funding rates<sup>17</sup>:

- Creating a commission to study the savings generated from shifting acute / long term services and supports (LTSS) to Home and Community Based Settings (HCBS) services and intermediate care facilities (ICFs).<sup>18</sup> This would ideally persuade law-makers of the long-term gains that will follow short-term increases in HCBS Medicaid funding.
- Implementing regular cost of living increases, commonly available to nursing homes, but incredibly rare for waiver funded HCBS services.

<sup>15</sup> Medisked, page 7.

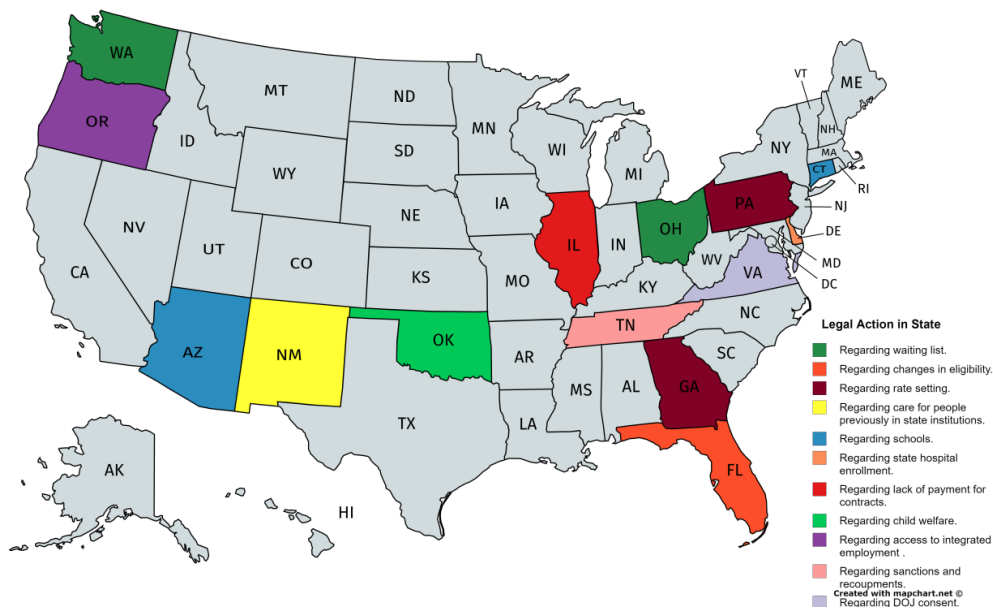
<sup>16</sup> National Direct Service Workforce Resource Center, Research and Training Center on Community Living, PHI, and The Annapolis Coalition on the Behavioral Health Workforce, *A synthesis of direct service workforce demographics and challenges across intellectual/developmental disabilities, aging, physical disabilities and behavioral health*, November 2008, page 28.

<sup>17</sup> This is with the understanding that state and federal sources are the core funding sources of IDD services. Some ANCOR members have mentioned creating a specific revenue source for HCBS services outside of Medicaid.

<sup>18</sup> U.S. Senate Commission on Long Term Care, *Report to the Congress*, September 30, 2013. pages 37-38.

- [Comprehensive Medicaid rate reform](#).<sup>19</sup>
- Greater emphasis by CMS on the need for states to set adequate rates.
- State ballot initiatives and state legislative proposals to increase funding or dedicate specific revenue sources as used in the states of Washington and Maryland.<sup>20</sup>
- Litigation such as the class action lawsuit in Washington State over insufficient access to HCBS services or judicial intervention such as [the Rhode Island district case](#) requiring the state to fund services as requested by the Governor.
- Commissioning additional research into how higher wages lead to greater quality of care.

Map 2: Litigation Occurring in States



Source: ANCOR “State Share” Survey Taken June 2016 of Member State Associations and Board of Representatives.

<sup>19</sup> Vickie Choitz and Matt Helmer, *Improving Jobs to Improve Care: the SEIU Healthcare NW Training Partnership*, March 2015, page 25.

<sup>20</sup> Choitz and Helmer, page 39 for Washington State, and the [Maryland Minimum Wage Act of 2014](#).



### Can Higher Wages Lead to Better Outcomes at Lower Costs?\*

The Hills and Dales agency in Iowa used Money Follows the Person funding for a pilot program designed around 4 men with significant behaviors and histories of hospitalization in psychiatric acute settings. The pilot program pays an extra \$3.50 per hour and requires staff assigned to the men to have Bachelor's degrees and more specialized training – the agency received a rate exception to from the state to enable one-on-one staffing. Since the pilot's inception, the men have not been hospitalized once, their behaviors have reduced (with some spikes at certain times), and two of the men are planning to move into another home where less supervision and oversight is required. While staff in this pilot experienced some turnover, the men's care has been stable. Despite higher wages, the cost of their care is cheaper than it was prior to the pilot due to reduced interventions. This case supports the need for further research into how state/federal investment in wages can yield better health outcomes at lower cost.

*\* Courtesy of an email conversation with Ms. Marilyn Althoff, CEO of Hills and Dales.*

### Greater cohesion between government policy initiatives and funding levels:

As of July 2016, [12 states voted to increase their minimum wages](#). Additionally, [4 states voted for equal pay laws in 2015](#). At the federal level, the past five years have seen two regulations that would grant overtime coverage to more employees (the Department of Labor's Overtime Exemption Rule, and the Home Care Rule) and one regulation that would increase labor costs for community services specifically (the Center for Medicaid and Medicare Services' HCBS Settings Rule). While **providers have strong moral and pragmatic reasons to support the intention behind these initiatives**, the constraints of Medicaid funding put them at risk of being financially unable to comply. This means that policies aimed to raise wages, such as minimum wage increases, have unintended consequences on business operations, IDD services, and affect the availability of staff or programs. Individuals not receiving all the services they need could be vulnerable to abuse or neglect because they are not sufficiently staffed. Additionally, not having the ability to provide authorized services leaves providers at risk of violating their contracts with the state and Medicare, and open to accusations of Medicaid fraud.

In order to avoid this untenable situation, **lawmakers need to develop means of automatically connecting Medicaid funding to policies that would increase expenditures, since it is unlikely that funding and enforcement agencies will coordinate of their own volition**. Past ANCOR members' experiences have demonstrated that whether at the local, state or federal level, the regulatory branches of government do not collaborate with the funding branches of government. This leads to many missed opportunities for coordination which would have insulated providers from unfunded mandates without exempting them from compliance.

Mechanisms that would solve these challenges are:

- [Indexing Medicaid](#) increases to local, state and federal wage increases or the Consumer Price Index - ANCOR members state that this will ideally occur every 2 years;
- Requiring review of financial impact data at the appropriate level of government when state or federal measures would increase costs for Medicaid providers;
- [Wage “pass-throughs”](#) – legislation that allocates extra Medicaid funding on condition that it is used to increase direct support staff wages and benefits when new wage policies are adopted.
- Creating a coordinating or liaison position between departments whose policies affect the IDD community so that they do not inadvertently harm services.
- Using data that reflect actual costs incurred by providers, rather than payment data, as a factor in rate setting.
- Encouraging states to prioritize the quality of delivery rather than low costs contracting with providers. For example, state agencies do not always take into account that some providers might appear to be cheaper than others because they are shifting benefit costs for their staff to Medicaid – so overall the state might still be paying a higher cost for services. Additionally, it skews averages upon which states are based artificially downward.

#### **Elements to Consider When Designing Pass-Throughs:\***

Wage pass-throughs can offer providers needed support, but they can also generate a lot of confusion around implementation. In order to avoid this, states will have to consider practical factors when crafting pass-through legislation to reduce room for error on topics such as:

- What will be used to establish baseline staffing costs against which increases must be spent?
- What will the reporting period be to demonstrate compliance?
- How will providers be required to demonstrate that they are meeting the conditions of the pass-through?
- Can some of the funding go to additional payroll costs that are tied to increased wages?
- Will increases (and attached funding) be retroactive to recent years? Providers might have had to use reserves for wages.
- Will vacancies be factored into how the funds are distributed?
- Can wage/benefit increases be aggregated across all vendor services, or much they be provided on a service code-basis?
- Will the pass-through’s design preclude providers from addressing other cost issues?

*\* Courtesy of an email discussion with Barry Jardini and Chris Rice at the California Disability Services Association and comments from Stan Soby at the Oak Hill agency in Connecticut.*

## Determine state rates using appropriate information and tools:

Currently, states use different mechanisms, assessment tools and consultants to determine their rates, resulting in rates that vary greatly among the states and do not always meet program needs. For example, numerous states are using assessment tools designed to determine what services an individual needs to set reimbursement rates, [creating controversies in some areas](#). **Rate setting based on information that does not reflect the nature of the work done in IDD or expenses incurred can lead to dramatic underfunding of Medicaid services.** This is ultimately problematic for individuals for IDD, who receive different service levels when they move from one state to another, creating access disparities. In order to lead to informed discussions on and accurate evaluations of need during the rate-setting process, ANCOR has listed rate-setting guidance from agency and judicial sources below.

[Guidance from CMS encourages states to:](#)<sup>21</sup>

Base Provider Type, Service Description and Provider Standards	
<b>Provider Type</b>	Direct Service Worker
<b>Service Description</b>	Provides a range of assistance (e.g. Activities of Daily Living such as bathing, dressing, transfers, positioning, range of motion, toileting and Instrumental Activities of Daily Living such as homemaker/chore activities, community integration support, and health maintenance activities) to enable persons to accomplish tasks they would normally do for themselves if they did not have a disability. This assistance may take on the form of hands-on assistance (actually performing a task for the person) or cuing to prompt the person to perform a task.
<b>Provider Standards</b>	<p>Potential Initial Requirements to Obtain a Provider Agreement (varies by state):</p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Minimum age of 18</li> <li><input type="checkbox"/> Some states have requirements regarding whether a parent or spouse (legally responsible adults) can be a Medicaid provider. In addition, states may or may not allow legally responsible adults to enter into a Medicaid Provider agreement.</li> <li><input type="checkbox"/> Many states have policies and procedures governing confidentiality, satisfaction, service monitoring and protections (please note this may not be applicable to individual providers under participant direction).</li> <li><input type="checkbox"/> Some states require potential workers to pass a background check. A "Promising Practice" for states is requiring that a background check be conducted for all workers. It should be noted that under participant direction, a state may allow a program participant to hire a worker who does not pass the background check, however, it is not recommended.</li> <li><input type="checkbox"/> Often states require CPR/First Aide certification.</li> <li><input type="checkbox"/> Often states require training on Medicaid recipient protections and state critical incident reporting procedures.</li> </ul>

- Compare how the home care industry rates in relation to the larger marketplace within a state when forming their rate-setting methodologies;
  - Consider the requirements of the Department of Labor's rule, Application of the Fair Labor Standards Act to Domestic Service from 2013 when setting rates;
    - Consider provider business costs associated with the recruitment, retention and training of skilled workers;
    - Build providers' cost of maintaining status as qualified Medicaid providers;

*Example of a ground-up model in CMS August 2013 state toolkit.*

- Consider other provider costs such as staff tuition payments, higher wages for shift work or performance-based bonuses.
- [Consider "difficulty of care factors"](#) to address the level of provider effort associated with serving individuals with different support needs.<sup>22</sup>
- Consider "ground up" models of rate setting as described in the CMS state toolkit created in August 2013.<sup>23</sup>

<sup>21</sup> Unless otherwise noted, the source is: CMS, *CMCS Information Bulletin: Suggested Approaches for Strengthening and Stabilizing the Medicaid Home Care Workforce*. August 3, 2016. Page 2.

<sup>22</sup> CMS, *Coverage of Direct Service Workforce Continuing Education and Training within Medicaid Policy and Rate-Setting: A Toolkit for State Medicaid Agencies*. August 2013. Page 32.

<sup>23</sup> CMS, *Toolkit for State Medicaid Agencies*, page 33-38.

States can draw further inspiration for rate-setting for the HCBS program from Medicaid's approach in the Access Rule:

- Under the [Access Rule](#), Medicaid encourages states to analyze access to care for covered programs through the following framework:
  - The extent to which enrollee needs are met;
  - The availability of care and providers; and
  - Changes in beneficiary utilization.
- In order to make sure people can receive the services they need, states are required to review access data every 5 years to inform payment changes, including but not limited to:
  - Identified beneficiary needs;
  - Time and distance standards;
  - Payment data;
  - Trends in utilization;
  - Provider enrollment and participation (including providers with open panels and providers accepting new Medicaid beneficiaries);
  - Feedback from providers and beneficiaries, including feedback logs and reviewing access for additional services based on significantly higher levels of beneficiary, provider or stakeholder complaints;
  - Changes in access after payment reductions go into effect, if reductions were instituted – these must also be reported on, along with an analysis of affected stakeholders' information and concerns.
- To effectively monitor access to programs states are required to:
  - Have clearly defined measures and thresholds;
  - Institute feedback mechanisms such as hotlines, surveys, ombudsmen, etc.;
  - Have public comment periods should payments be reduced;
  - Consider input from beneficiaries, providers and stakeholders specifically when reducing or restructuring Medicaid service payment rates.
- In the proposed rule, Medicaid states “we are adjusting our employee hourly wage estimates by a factor of 100 percent. This is necessarily a rough adjustment, both because fringe benefits and overhead costs vary significantly from employer to employer, and because methods of estimating these costs vary widely from study to study. Nonetheless, there is no practical alternative and we believe that doubling the hourly wage to estimate total cost is a reasonably accurate estimation method.”

For further background and provider recommendations specific to incorporating the HCBS program into the Medicaid Access rule, please contact ANCOR staff for a report conducted by HMA on access adequacy.

Court cases also provide criteria states could use as they model new rates:

[Armstrong v. Exceptional Child, Inc.](#) mandated that, despite the state legislature not allocating funding, Idaho Medicaid services comply with a state law requiring the agency to incorporate provider costs in its rate reimbursements. Specifically the court required the agency to:

- Rely on responsible cost studies “that provide reliable data as a basis for its rate setting”;
- Set rates that incorporate providers’ actual costs of providing services – the court found that “[provider] costs are an integral part of the consideration’ that cannot be ignored”;
- Where rates did not substantially reimburse providers their costs, there must be a justification other than purely budgetary reasons.

Explaining why it sided with providers, the court emphasized that it “need not wait for evidence of low quality care or insufficient access to services before intervention.” While *Armstrong v. Exceptional Child, Inc.* was eventually overturned by the U.S. Supreme Court on the grounds of standing, this case offers a useful framework.

[A Rhode Island U.S. District Court](#) ordered the state to comply with an existing order to improve disability employment services<sup>24</sup>. Among other requirements pertaining to service delivery, the court ordered the state to:

- Implement a reimbursement model which would be “sufficiently flexible to allow providers to be reimbursed for services rendered”; and
- Appropriately increase salaries, benefits, training and supervision for DSPs and job coaches.

These administrative and judiciary approaches each mentioned the importance of rates that reflect the true cost of providing services in order to meet individuals’ needs – not the least of which are wages that attract a quality workforce.

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<sup>24</sup> Article with more context accessible online at: <http://ripr.org/post/federal-judge-orders-ri-speed-compliance-consent-decree-developmentally-disabled>

## Section 4: Insufficient Benefits

**Section Highlights:** Because providers cannot offer competitive wages, it is important for them to be able to invest in benefits in order to provide for their employees' well-being and increase retention. This is not feasible under current funding. ANCOR proposes raising the ceiling on benefits in rate setting so that providers can be more appealing employers and short-term solutions to help employees obtain better employment supports pending long-term wage reform.

### Background

While low wages are the primary reason that DSPs seek other employment, it has been widely noted by organizations such as the [Institute of Medicine](#)<sup>25</sup> and the Centers for Medicare and Medicaid Services (CMS)<sup>26</sup> that DSPs also leave because they do not receive adequate benefits. An internal ANCOR membership survey showed that almost all respondents offer health and dental insurance, though at varying levels of coverage depending on the state. NCI's data found that just shy of 67 percent of respondents on average offer health insurance to full-time employees – though 21 percent on average did not offer health insurance at all and only 9

*"In our world, finding someone like her is like finding a diamond in the rough. She has the rare gift of helping parents like me feel at ease and to take the worry out of day to day life challenges. I can't help but feel she has been brought into our lives for a reason."*

*- Karen King, writing about her child's DSP*

percent on average offer health insurance to all DSPs (including part-time employees). NCI reports many providers cannot afford to offer additional benefits which would make up for low wages, such as: paid vacation, paid sick leave, transportation subsidies, child care subsidies or retirement plans<sup>27</sup>. Given the high rate of single parents in this industry and the number of DSPs who work part-time, **the need for sick leave and other such benefits can be particularly consequential and compound pressure for staff to find other employment.** Furthermore, obtaining workers' compensation in case of injuries can be complicated when DSPs change employers<sup>28</sup>.

Table 4: Percentage of Providers Offering Benefits to ALL DSPs (Part-time and Full-Time)

<sup>25</sup> Institute of Medicine (IOM), Committee on the Future Health Care Workforce for Older Americans, *Retooling for an Aging America: Building the Health Care Workforce*. 2008. Page 210.

<sup>26</sup> Centers for Medicare and Medicaid and the Lewin Group report.

<sup>27</sup> NCI, pages 26-30.

<sup>28</sup> IOM, page 212.

State	Health Insurance	Dental Insurance	Vision Insurance	Paid Personal Time*	Paid Vacation**	Paid Sick Time	Paid Time Off ***
AL	15%	14.3%	15%	7.1%	6.7%	6.7%	20%
AZ	5.1%	11.4%	8.9%	0%	1.9%	1.9%	18.4%
DC	16%	8.7%	4.2%	0%	7.7%	38.5%	34.8%
GA	11.3%	15.2%	13.8%	0%	3.8%	3.8%	16.7%
IN	7.1%	13.1%	14.1%	0%	2.4%	2.4%	34.5%
KY	14%	18.8%	16.8%	1.3%	2.4%	3.7%	27.8%
MN	9.2%	12.5%	4.7%	6.5%	16.8%	15.6%	35.2%
MO	9.6%	16.5%	14.3%	0%	4.1%	2.7%	21.6%
OH-HCBS	8.2%	11.8%	11.1%	6.2%	7.9%	8.6%	27.1%
OH-ICF	20%	28.1%	28.1%	33.3%	35%	47.6%	56.3%
OR	12%	19.8%	15%	5.1%	23.8%	59.5%	46%
PA	7.4%	13.5%	15.8%	7.1%	18.6%	13.6%	31.9%
SC	5.1%	15%	14.6%	0%	7.7%	7.7%	14.6%
SD	15.8%	21.1%	20%	20%	25%	15.4%	21.1%
TN	12%	20%	18%	0%	0%	0%	8%
TX	5.1%	9%	10%	0%	5.9%	4.4%	12.4%
UT	5.3%	7.1%	7.1%	0%	0%	0%	14.3%
VT	6.7%	13.3%	13.3%	16.7%	16.7%	16.7%	33.3%
<b>Average</b>	<b>10.3%</b>	<b>14.9%</b>	<b>13.6%</b>	<b>5.7%</b>	<b>10.4%</b>	<b>13.8%</b>	<b>26.3%</b>

Source: NCI report. \*Excludes "Paid Time Off" agencies. \*\*Excludes "Paid Vacation." \*\*\* Pooled sick, vacation and personal leave.

Table 5: Percentage of Providers Offering Benefits Only to Full-Time DSPs

State	Health Insurance	Dental Insurance	Vision Insurance	Paid Personal Time*	Paid Vacation**	Paid Sick Time	Paid Time Off ***
AL	60%	57.1%	40%	35.7%	60%	66.7%	45%
AZ	59.5%	50.6%	39.2%	17.6%	32.7%	24.5%	36.8%
DC	60%	60.9%	54.2%	46.2%	76.9%	53.8%	43.5%
GA	53.8%	43%	37.5%	42%	57.7%	52.8%	46.2%
IN	63.5%	58.3%	50.6%	53.8%	70.7%	58.5%	44%
KY	55.9%	52.1%	49%	48.1%	70.7%	55.6%	56.9%
MN	63.6%	46.8%	26%	30.4%	41.1%	34.4%	34.8%
MO	66.4%	52%	41.3%	45.8%	77%	64.4%	54.4%
OH-HCBS	39.4%	31.7%	27%	25.4%	42.1%	28%	31.3%
OH-ICF	76.9%	67.2%	53.1%	28.6%	50%	33.3%	20.3%
OR	69%	61.4%	48%	28.2%	54.8%	19%	34%
PA	78.7%	64.6%	55.8%	45.2%	62.8%	52.3%	54.3%
SC	89.7%	85%	82.9%	39.1%	80.8%	80.8%	58.5%
SD	84.2%	73.7%	50%	30%	66.7%	76.9%	26.3%
TN	74%	70%	68%	46.9%	68.8%	63.3%	64%
TX	57.6%	40%	34%	45.5%	54.4%	48.5%	57.7%
UT	57.9%	50.9%	33.9%	34.3%	44.1%	36.4%	41.1%
VT	93.3%	86.7%	60%	50%	83.3%	83.3%	40%
<b>Average</b>	<b>66.9%</b>	<b>58.4%</b>	<b>47.3%</b>	<b>38.5%</b>	<b>60.8%</b>	<b>51.8%</b>	<b>43.8%</b>

Source: NCI report. \*Excludes "Paid Time Off" agencies. \*\*Excludes "Paid Vacation." \*\*\* Pooled sick, vacation and personal leave.

Additionally, while ANCOR's internal survey found that a majority of respondents offer employee health and dental insurance, ANCOR members have pointed out that the costs of doing so have increased with their compliance to the Affordable Care Act (ACA). A final concern is that employees opting to benefit from Medicaid expansion under the ACA have less of an employer/employee relationship with providers, increasing the possibility of turnover. Given these challenges, it is critical that governments implement rates that support improved benefits for direct support professionals.

## **Solutions**

### **Raising the artificial ceiling on benefits so providers can be competitive employers:**

In order to offer DSPs the security they need to stay in this field, policy makers need to be persuaded to invest in the workforce sufficiently enough for providers to offer competitive benefits, given how DSPs need strong benefits to be able to provide individuals with IDD the care they deserve without sacrificing their personal well-being. An example of this investment is "pass through" legislation<sup>29</sup> designating funding for benefits or the creation of tax credits for providers offering a certain caliber of benefits.

Alternatively, CMS has recommended that states evaluate how many DSPs are receiving public assistance in their states, and to consider including "fringe benefits" such as healthcare when setting Medicaid rates as a way to "leverage efficiencies and potentially reduce overall state costs."<sup>30</sup>

### **Short-term Solutions:**

Given the urgency of the workforce crisis and that discussions with state legislatures or state and federal Medicaid agencies can be lengthy, below are more short-term solutions providers can consider to assist with the delivery of benefits.

- Obtaining technical assistance so providers can educate DSPs on employment benefits and workforce housing. This way DSPs can better understand what benefits they are eligible for, and learn how to navigate the often confusing enrollment process<sup>31</sup>.
  - This might require a cost estimate.
- Organizing employer purchasing pools to decrease the cost of employer-provided health insurance.<sup>32</sup>
- Researching and compiling a list of grants in this field to obtain outside funding for expenses.<sup>33</sup>
- Exploring public-private partnerships.

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<sup>29</sup> CMS and Lewin Group, page 26.

<sup>30</sup> CMS, Toolkit for State Medicaid Agencies, page 41.

<sup>31</sup> National Direct Service Workforce Resource Center et al, page 26.

<sup>32</sup> National Direct Service Workforce Resource Center et al, page 26.

<sup>33</sup> Texas Health and Human Services, page 15.



## Section 5: Improving Workplace Supports

**Section Highlights:** Given the emotional and physical hardship of the work, DSPs need a proper understanding of the occupation before they start, as well as strong back up from supervisors who comprehend the work, and stable hours. ANCOR proposes guidelines and materials that will assist in giving DSPs strong preparation to the start of hopefully long-term careers.

### ANCOR DSP Recruitment Toolkit

In order to assist providers in recruiting a quality workforce, ANCOR partnered with the University of Minnesota's Research and Training Center to develop the following resources:

- Free public service announcements;
- Customizable DSP recruitment flyers targeted to specific demographics;
- Structured Behavioral Interview Questions with a quick guide and interview template;
- A realistic job preview for DSPs;
- Wage and turnover calculator.



These resources are available at:

[www.ancor.org/toolkit](http://www.ancor.org/toolkit)

Supporting individuals with IDD, while rewarding, can also be emotionally draining and physically exhausting. It is challenging hard work, with irregular scheduling because individuals' needs can vary greatly from week to week, or day to day. In this demanding environment, workplace supports play a critical role in retention.

**According to the Medisked provider survey, 42 percent of respondents stated their employees left because of lack of supervisory support and appreciation.**<sup>34</sup> This points to the importance of a supervisor with a strong understanding of what DSPs do, what they need, and good management principles. Examples of the skills supervisors need to exercise good leadership can be found in the [University of Minnesota's National Frontline Supervisor Competencies guide](#).

Additionally, ANCOR members report that **staff also leave because they feel they spend more time filling out paperwork than actually caring for individuals.** This is due to the rigorous reporting needed to prove that staff comply with Medicaid requirements. Employees have reduced morale when they feel that they are being kept from the meaningful work which originally drew them to the occupation.<sup>35</sup>

<sup>34</sup> Medisked, *The Staffing Struggle Is Real*, 2016, page 7.

<sup>35</sup> From an email conversation with NYSACRA and other members.

The following actions could reduce burnout and increase DSP retention:

- Using realistic previews of the work during recruitment so employees fully understand the work at hand and can decide if it is not right for them before signing on.<sup>36</sup>
- Offering orientation periods and mentoring experiences for new employees.<sup>37</sup> ANCOR members suggest that current employees could also benefit from mentoring.
- Actively engaging DSPs to participate in the person centered planning team for individuals they support. They are in the best position to assist with decisions in daily supports because of their direct interaction with the individuals.<sup>38</sup> This would also provide DSPs with a greater sense of responsibility, ideally increasing retention.
- Actively engaging DSPs in discussions about the direction of the agency so they feel they are valuable members of the team.<sup>39</sup>
- Stressing positive supervision and feedback<sup>40</sup>, including frequent agency wide recognition of accomplishments and excellence.
- Ensuring that supervisors are adequately trained (training will be further discussed in a separate ANCOR document).
- Offering “tenured” or more experienced employees 30 or more guaranteed hours of work per week so they have wage stability.<sup>41</sup>
- Making networking opportunities available to DSPs so they feel less isolated and can recruit each other for vacancies.<sup>42</sup>
- Using more descriptive professional titles such as “Community Integration Specialist”.<sup>43</sup>

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<sup>36</sup> University of Minnesota - Research and Training Center on Community Living, and the Lewin Group, *CMS Direct Service Workforce Demonstration Promising Practices in Marketing, Recruitment and Selections Interventions*, December 2006, page 6.

<sup>37</sup> University of Minnesota and the Lewin Group, page 7.

<sup>38</sup> CMS and the Lewing Group, page 3.

<sup>39</sup> ANCOR Governmental Relations Committee, January 2016 Summit notes.

<sup>40</sup> CMS and the Lewin Group, page 3.

<sup>41</sup> CMS and the Lewin Group, page 2.

<sup>42</sup> Texas Health and Human Services, page 19.

<sup>43</sup> ANCOR Governmental Relations Committee, January 2016 Summit notes.

## Section 6: Obtaining Public Recognition

**Section Highlights:** In order to increase the public support for this critical but largely invisible workforce, which relies on government funding, increasing awareness of the occupation is necessary. ANCOR gives examples of awareness and education campaigns, ways to demonstrate competence to build confidence in the occupation and discusses the involvement of Workforce Investment Bureaus.

### Background

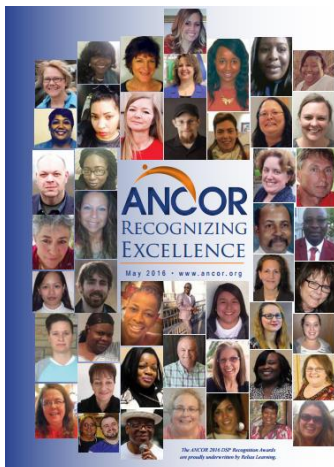
DSPs are a largely invisible workforce. This low public profile began when DSPs worked in large public institutions hidden from the public's eye, but continues because integrated community services are now overwhelmingly provided in many smaller settings in the heart of communities. Unlike Certified Nursing Assistants (CNAs) and hospital employees, DSPs do not work in highly recognizable large community facilities frequented by the general public like nursing homes or hospitals. **Given this sector's overwhelming dependence on Medicaid rates, public education campaigns to educate the public on the contributions DSPs make to their customers' lives are critical to secure support** for increases in public spending on wages and other strategies to professionalize the field.

*"Pam takes good care of me and my diabetes. She helps me when I have low blood sugar and this year she saved my life when my blood sugar was very low on vacation. She cooks me healthy meals...and teaches me about my diabetes."*

*-Eilleen, speaking about her DSP Pam.*

### Solutions

#### Increasing public awareness:



Building upon provider-led advocacy efforts at the state level, ANCOR's National Advocacy Campaign was the early leader in the effort to educate Congress, the Executive Branch and the general public at the national level about the value of DSPs and the need to address the workforce crisis. These public and policy maker education strategies include:

- Producing a national version of the Cost of Compassion video originally created by the Oregon Resource Association (ORA);
- Promotion of DSP Recognition Week;
- Hosting the ANCOR DSP of the Year Awards; and
- Publicizing national studies documenting the impact of low wages on turnover rates and related costs.

ANCOR's NAC efforts led to: the US Senate unanimously designating the first full week in September as National Direct Support Professionals Week every year since 2001; over 45 Governors recognizing the week in their own states; and local and national media coverage – usually linked to DSP Week activities or DSP of the Year recipients. The NAC is in the process of transitioning to the Save Our Services (SOS) Campaign, which promotes the workforce and other provider priorities to federal policy-makers.

Extensive education and advocacy campaigns are also conducted at the state level, such as:

- [IARF's "We Are DSPs"](#) campaign in Illinois, an advocacy effort centered around legislation seeking to improve DSP wages;
- The [New York State Association of Community and Residential Agencies' campaign](#), which educates the public through PSAs and offers employers resources to strengthen the workforce;
- [ORA's Cost of Compassion Public Service Announcement](#) (PSA) on the challenges facing DSPs;
- [Pennsylvania Advocacy and Resources for Autism and Intellectual Disability's \(PAR\) campaigns](#), including the "We Are Worth It" campaign, and their "DSP for a Day" project in which state legislators shadow DSPs.

### Demonstrating competence:

Another way to build up public trust and esteem in this occupation is for DSPs to demonstrate competence. One of the ways to do so is through acquiring core competencies upon which they can build their experience. An example of core competencies are those ANCOR and NADSP, along with other national partners, [collaborated to identify](#) and which have been recognized by DOL and CMS. While ANCOR continues to promote the NADSP core competencies as part of ANCOR's aforementioned [DSP toolkit](#), it is important to note that there is not one sole pathway to demonstrate competency. Other examples include certification programs developed by national trade associations and specialized certification programs such as [the one created by NADD](#).

### Engaging Workforce Investment Boards to invest in direct care services:

Workforce Investment Boards (WIBs) are groups created by the Workforce Investment Act of 1998, which operate at both the state and local level. "[E]ach state establishes a state workforce investment board, which determines strategic priorities, identifies high-growth industries, develops a workforce investment budget, and establishes local workforce investment areas across the state."<sup>44</sup> These groups are composed of [50 percent business owners](#), with the remaining 50 percent a mix of educators, community stakeholders, lawmakers, and workforce program leaders. Their main goal is, [in the words of their national association](#), "to ensure that state and local workforce development and job training programs meet the needs of employers."

IDD providers need to be represented in WIBs. **ANCOR urged this mandatory inclusion in the regulations to the newest workforce legislation, the Workforce Opportunity Innovation Act of 2014, and will continue to advocate for the inclusion of DSPs on the boards.** Ideally, this would help WIBs establish direct care as a high priority occupation<sup>45</sup>. Additionally, it is important that individuals with IDD, as consumers of services and members of the community, be represented on WIBs. Finally, WIBs should prioritize training of common healthcare training requirements such as CPR or first aid, freeing up providers' resources for services or other priorities.

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<sup>44</sup> U.S. Department of Labor Employment and Training Administration, *The Public Workforce System*, November 27, 2015. Accessible online at: <https://www.doleta.gov/business/pws.cfm>

<sup>45</sup> National Direct Service Workforce Resource Center et al, page 27.

## Section 7: Lack of Advancement

**Section Highlights:** Another reason DSPs leave their position is from lack of opportunities for advancement. ANCOR cites career models that either allow for combinations of specialization or advancement (lattice career models) or growth into positions higher in the hierarchy (ladder models), while discussing some of the challenges surrounding career growth in the current environment.

### Background

**The fact that DSPs do not stay in the occupation because they do not see room for growth is not in dispute.** <sup>46</sup> For example, in West Virginia some lawmakers recognized the need for action, prompting the introduction of H.R. 4418 (2014) in the state legislature. The bill requested a report on developing a career plan for DSPs but unfortunately did not become law. <sup>47</sup> Unfortunately, while there is recognition that career development needs improvement, much of the solutions proposed in the literature raise a delicate problem. **Many DSP career paths would promote DSPs out of the IDD field altogether and into occupations such as Certified Nurse Assistant. However, given that in current circumstances there are not enough workers to give individuals with IDD the care they need, ANCOR prefers to suggest career path models that would encourage DSPs to stay in this field.**

As an alternative to paths leading outside of the occupation, below are examples of models that would give DSPs opportunities to form a lifelong career within the IDD niche. ANCOR members voiced the need to take into account opportunities for leadership and specialization as much as advancement when developing models, making lattices which allow for lateral as much as vertical movement of particular interest. If providers are given the tools they need to implement career models to retain employees by giving them options for their future, the occupation will become more appealing to the unemployed who want the opportunity to stay in a field long-term. Just as importantly, this will give individuals with IDD the stability and continuity of care they deserve and demand.



Image from ANCOR's Cost of Compassion video.

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<sup>46</sup> National Direct Service Workforce Resource Center et al, page 9.

<sup>47</sup> H.R. 4418, introduced in 2014 by Delegates Fleischauer, Barrett, Perdue, Staggers, Sponaugle, Eldridge, Hamilton, White, Pethel, Tomblin and Barill on February 5, 2014 to the Committee on Health and Human Resources, did not advance past the committee. Bill accessible online at:

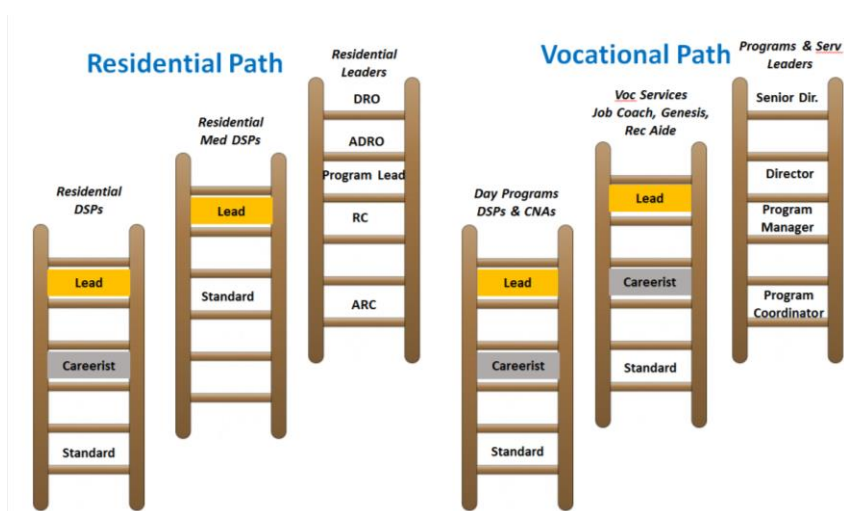
[http://www.legis.state.wv.us/bill\\_status/bills\\_text.cfm?billdoc=hb4418%20intr.htm&yr=2014&sesstype=RS&i=4418](http://www.legis.state.wv.us/bill_status/bills_text.cfm?billdoc=hb4418%20intr.htm&yr=2014&sesstype=RS&i=4418)

## Suggested Career Path Models

1. United Cerebral Palsy in South Florida has found success with its career path model, which allows DSPs to **start at entry-level apprenticeships, develop further skills with certification, and then specialize.** However, the organization finds it challenging to obtain the necessary funding to offer meaningful wages increases as DSPs progress through each step – this highlights the importance of state or federal buy-in for DSP career advancement.<sup>48</sup>

2. In Wisconsin, **St. Coletta created three “tracks” each for its residential and vocational services,** which increases the hourly wage rate for its employees as they demonstrate skill growth. A “standard” DSP position starts at \$13 per hour on the low end, and increases to \$15.50 per hour on the low end at the “Senior/Lead” DSP position, with the possibility of reaching a maximum of \$18.50 per hour. This is in contrast to a minimum wage of \$7.25 in the state. As a result of this career path and wage rate restructuring, St. Coletta experienced full staffing for the first time in 25 years, is actively drawing staff from other industries, and has reduced turnover along with other expenses. When studying this example for replicability, it is important to note that St. Coletta is a 112-year old institution which has multiple partnerships within and outside of its immediate community, allowing it to raise outside funds for higher wages in ways other providers might not be able to imitate. Nonetheless, its career matrix offers promising lessons in vertical and horizontal specialization and advancement for providers seeking to retain and recruit DSPs.

Chart 5: St. Coletta’s Career Ladder.

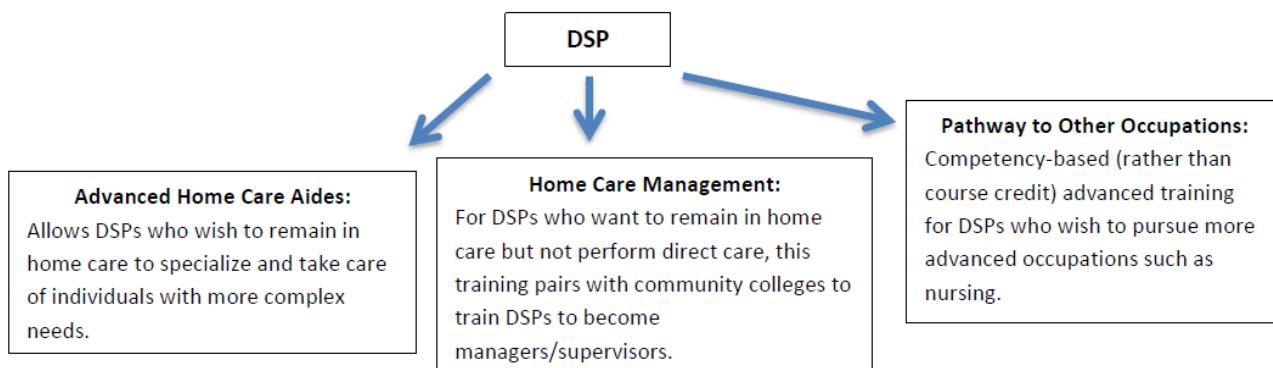


Source: Slide from a presentation by Ted Behncke, President of St. Coletta, September 19, 2016 at ANCOR’s Leadership Summit in Washington, D.C.

<sup>48</sup> From email correspondence with UCP South Florida.

3. In the state of Washington, the Training Partnership offers **additional courses beyond its entry-level training and required yearly continued education for three different tracks which will allow DSPs to specialize and advance in their careers**, as outlined below.<sup>49</sup> Again, ANCOR must note concern about promotion to “other occupations” in the third track, given the vacancy rates that leave individuals with IDD underserved. However, the opportunity to become advanced home care aides or enter management positions through the other two tracks warrants additional consideration because it enables DSPs to further pursue those aspects of the work that most appeal to them while remaining in IDD services. As with UCP Florida, however, funding is a challenge. The case study authors writing about the Training Partnership note that “[a]nother challenge for the apprenticeship program is that graduates earn a relatively small wage increase of just 25 cents per hour in addition to the 25 cents per hour they earn after completing their entry-level training.”<sup>50</sup>

Chart 6: Training Partnership’s Career Path.



4. In New York, the New York State Association of Community and Residential Agencies collaborated with the University of Minnesota and the state Office for People with Developmental Disabilities to design a proposal for voluntary, multi-tiered credentialing model ([GEAR UP](#)).<sup>51</sup> **This proposed model would offer rate incentives to providers if they meet enrollment targets, and wage incentives to DSPs who successfully complete assessments at each level.** In this proposal, the increases would be possible because the state would ideally subsidize half of the cost of the program with the goal of drawing down additional federal funding. As of the time of writing, there was the possibility the state would test this proposal in a pilot program for the next budget year. Proposals of this kind could take longer to achieve in states where administrations are more reluctant to buy into programs or face budget shortfalls.

Chart 7: Proposed GEAR UP Career Path.



<sup>49</sup> Choitt and Helmer, pages 23-24.

<sup>50</sup> Choitt and Helmer, page 35.

<sup>51</sup> NYSACRA, UMN, NYSRA, NYOPDD, *Career GEAR UP* handout.

Additional Commentary:

**In order to be meaningful, career advancement entails increasing a DSP's skillset, level of responsibility, and ultimately, wages.** The four examples above have shown us that while providers and their allies can devise paths for DSPs to increase their professional expertise, current funding levels are insufficient for providers to meaningfully increase wages at each rung of the career ladder or lattice. St. Coletta's program benefits from external funding sources. New York's GEAR UP proposal foresees the need for state investment. UCP South Florida and Washington's Training Partnership show that additional resources are not always obtainable by providers of different sizes and/or in states with different resources. Additionally, ANCOR members have indicated that some rate systems penalize providers who use outside money to cover costs. This is problematic because **career advancement to some extent requires further study, specialization or education – for which DSPs might not want to sacrifice the time for if they will not earn significant wage increases upon completion.**

Furthermore, while they are necessary to increasing retention and further professionalizing the occupation, **promotion plans can also create additional recruitment pressure.** For each DSP promoted to a higher position or moved to a specialized track, another entry-level DSP would need to be hired to maintain continuity of care. As a reminder, currently this occupation faces both high turnover rates and high vacancy rates – employees leave and there are not enough replacements to fill the departures. **Promotion plans can also create wage compression if employees obtain higher salaries by specializing and develop leadership in specific topics, but managers do not receive similar opportunities to earn higher wages.**

**States and the federal government need to recognize the importance of career advancement** and create rates that enable higher wages upon specialization or promotions. This would help IDD services compete for entry-level employees on a more even footing with other services that care for similar populations (such as hospitals and schools). **Investing in this an IDD-specific workforce will not only retain existing employees but also draw more new employees to the field and thus strengthen employment nationwide.** Last but by far not least, **improving retention through career paths will further assist with delivering uniform, stable and quality services regardless of which state individuals live in,** a promise inherent in the Americans with Disabilities Act.



## Section 8: Availability of and Access to Technology<sup>52</sup>

**Section Highlights:** DSPs partially leave because of physical strain from their workload, which existing technology has the potential to resolve. Additionally, by improving administrative processes and giving greater independence to individuals with disabilities, technological innovations can allow DSPs to spend time where they are most needed and thus better meet demand. However, current policies, regulations and funding have not caught up to these innovations. [ANCOR lays out guidelines](#) to help law-makers take technology into account to improve individuals' access to services and reduce DSP workload.

### Background

In terms of DSP recruitment and retention, **technology can play a critical role in:**

- **Improving administrative efficiency**, which will lead to better care and address DSP complaints about paperwork cutting into the time they spend with clients;
- **Reducing the physical strain from providing care (e.g. lifting individuals)** which contributes to injuries and turnover; and
- **Create more opportunities for individuals with IDD.** Technology can fill many needs, ranging from helping someone perform better so they can obtain or keep a job to helping them perform daily functions so they can live more independently and not require as much staff time – without reducing outcomes.



*Image from PAR's Fix the DSP Crisis video, accessible online at [fixthedspcrisis.com](http://fixthedspcrisis.com)*

**However, because of the intimate nature of the care, technology is not a full substitute for staff nor an absolute solution to the staffing crisis. Nonetheless, it can generate savings that providers could reinvest in filling positions if they are allowed to keep the additional funds instead of having to return them to the state.** Additionally, if states participate in cost-sharing for the technology, they will see returns from providers being able to expand services from more efficient use of staff, reducing state liabilities for large waiting lists for services. Because individuals with IDD on waiting lists are frequently waiting for community-based services in institutions, maintaining waiting lists is not optimal for either individual development or state budgets.

Why is access to technology a problem? Currently, the tools exist to assist with independence and help staff work more efficiently. However, maximizing their potential requires review and modification of every aspect of the service system because of the heavy amount of oversight surrounding IDD services. While the safety and well-being of individuals must always be a foremost priority, providers need flexibility to implement new technologies – a flexibility they currently do not have.

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<sup>52</sup> Contents derived from ANCOR's technology paper, *Bringing Long-Term Supports into the 21<sup>st</sup> Century*.

According to ANCOR members, the main challenges surrounding technology are:

- **Policies, regulations and authorizations governing use of technology in IDD spheres which have not caught up with new realities.**
  - This notably includes convincing state legislatures to recognize consumer technology such as iPads so that the HCBS waiver reimburses their purchase. An example of how they would be used is remote consultations with individuals who might not need a staff physically present but do need support for a short amount of time to talk through a momentary anxiety.
- **Securing alternative sources of funding** such as grants to access, purchase and train on technologies.
- **Having the time, resources and know-how to train DSPs on new technology.**
- **Having the proper tools** to gather data for metrics.
- **Securing transmission of electronic health records.**

#### Solutions

- **Funding access to and training for the same technologies that are available in arenas of CMS and health care systems.**
  - Examples are electronic health records, administrative technology and online administrative health records.
- **Funding access to technologies that reduce physical strain of DSP's labor.**
- **Consideration of processes and technologies that have been successful in other areas such as telehealth.**
- **Policymakers recognizing that technology can change the nature of care and its delivery:**
  - Due to advances in technology, on-site DSP time is no longer the only standard or measure of services delivered or determination of a person's need for support and supervision.
  - The workforce shortage will not be filled without the assistance of technology.
  - Exploring how technology could assist individuals with IDD who want to become DSPs. This could address under-employment of individuals with IDD and the workforce shortage.
- **Flexibility for support teams to adjust methodologies as a person's needs and skills change.**
- **Providing incentives for technology companies to design products for use by individuals with IDD, including some of the technologies being made available to injured military members.**
- **Facilitate the inclusion of people with disabilities in the DSP workforce.**

## Section 9: Long-term Population Trends That Will Lead to Workforce Shortfalls

**Section Highlights:** The traditional DSP workforce is comprised of working-age women – a group that in the coming decade will not be entering the labor market in numbers large enough to sustain the occupation. This means that no solution to the DSP workforce crisis is complete without expanding the workforce. To this end, ANCOR explores: youth recruitment; convincing men to become DSPs; exploring the feasibility of employing non-violent former felons; recruiting older workers; paying family caregivers; immigration reform; employing individuals with IDD as DSPs; expanding shared living and finally, leveraging and building capacity for natural supports.

### Background

Demand for DSPs is expected to increase by 48 percent over the next decade<sup>53</sup>, but compared to the past decade far fewer women aged 25 to 64, who form the core of the DSP workforce, will be entering the entire labor force during that time. PHI reports that only [2 million additional women aged 25 to 64](#) will enter the whole labor force in the next ten years, down from 6.3 million in the early 2000s. **This means that even if wages increased enough to recruit and retain more DSPs, there will continue to be a staff shortfall in direct care services unless the pool of people from whom DSPs are recruited can be broadened.** Because of the invisibility of the DSP workforce, educating more groups about the rewards of direct service will take time and creativity. Below, ANCOR has identified promising proposals on expanding recruitment that warrant further research.

### Solutions

#### Recruiting the Next Generation:

By considering alternatives to traditional education, policymakers can help the next generation develop stable careers while also ensuring that individuals receive the support they need to have engaged lives in their communities. For example, the **Ohio Provider Resource Association (OPRA) and the Ohio Alliance of Direct Support Professionals (OADSP) developed the Community Connections Career Partnership<sup>54</sup> as a two-fold solution for the workforce crisis and to assist students who needed alternatives from traditional education.** Juniors at risk of dropping out of their high schools develop work experience by traveling on-site to Provider-Mentor sites four times a week and enrolling in the nationally recognized DSPaths Curriculum. As juniors, students earn Certificates of Initial Proficiency, progressing to Certificates of Advanced Proficiency by their senior year. Participating Provider-Mentors are placed first-in-line for the opportunity to recruit the students upon graduation.

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<sup>53</sup> Congressional Budget Office, *Rising Demand for Long-Term Services and Supports for Elderly People*. June 2013. Page 33.

<sup>54</sup> OPRA and OADSP, *Community Connections Career Partnership* handout –contact Ms. Janice Hall at [jhall@opra.org](mailto:jhall@opra.org) or (740) 260 7278 for more information.

There is also a national apprenticeship program into which youths could be recruited. In 2010 the **Department of Labor approved national guidelines which enable long-term supports and services providers to participate in its [Registered Apprenticeship system](#)**. The apprenticeship program has three stages: the “registration level” completed after training and six months of continuous employment; the “initial certificate level” completed after a year of continuous employment and additional training; and finally “journeyman level” achieved after two years of continuous employment and demonstrated [increases in proficiency](#).

*“Wendy helped me go for my drivers permit and go for my dream. I have my drivers permit and feel happy that I am learning to drive. Wendy wants me to achieve my goals, be successful, healthy, and to go for my dream.”*

*-Amanda, speaking about her DSP Wendy.*

Additionally, **college students could be recruited by being offered a preview into this occupation either before or shortly after they graduate, preferably with some level of loan forgiveness as an incentive**. This could include partnering with existing volunteer programs such as AmeriCorps<sup>55</sup> which offer moderate loan forgiveness. We need to insert the caveat that volunteers should not be considered a replacement for professional staff given the sensitivity of the work involved. Additionally, including programs in direct care in Title IV of the Higher Education

Act would allow students to work while going to school, thus reducing their student debt.<sup>56</sup> Alternatively, programs such the College for Social Innovation offers a [“Semester in the City”](#) which encourages students to depart from the traditional part-time or summer internship approach. Over the course of 15 weeks, students spend: 20 percent of their time shadowing senior leaders; 40 percent of their time performing front line service in the industry; and 40 percent of their time doing a special project. While the College for Social Innovation is currently limited to Boston, one can easily see how partnerships between colleges and provider organizations across the nation could be inspired to customize and replicate this effort.

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<sup>55</sup> ANCOR Governmental Relations Committee, January 2016 Summit notes.

<sup>56</sup> Comments from the audience at the American Society on Aging’s briefing: *America’s Eldercare Workforce: Who Will Be There to Care?* Tuesday, July 12, 2016.

### Partnering with unemployment agencies and similar organizations to direct unemployed men towards direct services:<sup>57</sup>

With 89 percent of the health paraprofessional workforce in general composed of women<sup>58</sup>, recruiting unemployed men presents itself as an obvious solution to the workforce shortage. **Currently, 12 percent of men aged 25-54 are not in the labor force, compared to 2 percent in 1954** - this has effects of long-term decline for individuals and the broader economy and consequences for families and communities.<sup>59</sup> By partnering with unemployment agencies to specifically recruit men, particularly the most affected group of those with high school degrees or less and African-American men<sup>60</sup>, providers can both reduce the workforce shortage and contribute to solving a problem of growing importance to the nation.

### Exploring the feasibility of exempting certain non-violent former felons who have completed their sentences and probation periods:<sup>61</sup>

While the safety and health of individuals served remains providers' priority, offering opportunities to individuals with certain types of previous non-violent convictions who have completed their probation periods could help solve two challenges. **Employment of former felons is crucial to reducing recidivism and crime, and would also expand the applicant pool for direct service professional positions.** This topic has attracted the attention of CMS, which issued a report on employment former felons in long-term care. The [CMS report](#) finds that "most States had legislation addressing these issues. However, State-specific disqualifying convictions and rehabilitation factors varied substantially across States."<sup>62</sup> **The consequence of this is that job applicants are not treated similarly across states, which affects the availability of DSPs able to address the needs of the IDD community.** While the report stemmed from health and safety concerns for the individuals served and has an emphasis on disqualifying factors, it nonetheless offers three different types of rehabilitation factors states and the federal government could consider to develop more consistent guidelines across the nation.<sup>63</sup> These three sets of factors increase in complexity so policymakers would have options to choose from:

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<sup>57</sup> CMS and the Lewin Group, page 4.

<sup>58</sup> PHI, *Home Care Workers: Key Facts*. Page 2.

<sup>59</sup> Office of the President, Council of Economic Advisors (CEA), *The Long-Term Decline in Prime-Age Male Labor Force Participation*. Executive Summary. 2016.

<sup>60</sup> CEA report, executive summary.

<sup>61</sup> CMS, *Report: Centers for Medicare and Medicaid, National Background Check Program, Long Term Care Criminal Convictions Work Group*, December 2012, pages 50-53.

<sup>62</sup> CMS, *Report: Centers for Medicare and Medicaid Services. National Background Check Program. Long Term Care Criminal Workforce Group*. December 2012. Page 2.

<sup>63</sup> CMS Criminal Workforce Group report, pages 5-6.

Table 6: Rehabilitation Factors – 3 Different Options From CMS Work Group.

Consolidated Option	Preliminary Option 1	Preliminary Option 2
<ul style="list-style-type: none"> <li>• Passage of time;</li> <li>• Extenuating circumstances;</li> <li>• Demonstration of rehabilitation;</li> <li>• Nature of the crime in relation to potential job duties.</li> </ul>	<ul style="list-style-type: none"> <li>• Character of the person;</li> <li>• Passage of time;</li> <li>• Completion of sentence;</li> <li>• Nature of the crime in relation to potential job duties.</li> <li>• Age at the time of offense.</li> </ul>	<ul style="list-style-type: none"> <li>• Passage of time;</li> <li>• Person’s complete criminal history;</li> <li>• Age at the time of offense;</li> <li>• Harm to the victim and circumstances of the crime;</li> <li>• Completion of sentence;</li> <li>• Person’s contributions to society (e.g. education level, community involvement);</li> <li>• Participation in rehabilitation programs (e.g. counseling, therapy);</li> <li>• Character references and letters of recommendation;</li> <li>• Similarity between victims and potential persons served, work history, current employment, and nature of position sought.</li> </ul>

**Additionally, providers could be enabled to work with programs participating in the [federal Second Chance Act \(SCA\)](#), which authorizes federal grants to “help state, local and tribal government agencies and community organizations to respond to the rising populations of formerly incarcerated people who return to their communities. [This includes supports such as] housing, education, employment and family relationships, as well as substance abuse and mental health treatment linkages, and therapy that addresses criminal thinking patterns.”<sup>64</sup>**

Other examples of work done on this issue can be seen at the state level. In August 2016, **the Governor of Illinois approved legislation that allowed persons with certain felony convictions to apply to work in health care professions after a post-conviction waiting period.** More specifically, “Senate Bill 42 provides a health care worker who has been convicted of a forcible felony--other than a felony requiring registration under the Sex Offender Registration Act or involuntary sexual servitude of a minor--and whose license was revoked or denied, may petition the Illinois Department of Financial and Professional Regulation to restore the license if more than 5 years have passed since the conviction or more than 3 years have passed since the health care worker's release from confinement for that conviction, whichever is later. This legislation provides that the Department may also consider other evidence of rehabilitation, along with any voluntary remedial actions taken by the health care worker, when determining whether a license shall be restored.”<sup>65</sup>

<sup>64</sup> DOJ, Bureau of Justice Assistance, *Second Chance Act*. Accessible online at:

<sup>65</sup> Illinois Office of the Governor, *News: Governor Rauner Signs Bill to Give Former Offenders a Brighter Future*, August 25, 2016. Accessible online at: <http://www3.illinois.gov/PressReleases/PressReleasesListShow.cfm?RecNum=13776>

**Finally, the state of Pennsylvania has seen recent innovations regarding restrictions on the employment of individuals with certain criminal convictions:**

- Pennsylvania’s Commonwealth Court recently struck down bans against persons with certain criminal records in the long-term healthcare field in the [Peake v. Commonwealth](#) case.
- Starting November 14, 2016 the state will also implement [S.B 166](#), legislation that allows “an individual with a misdemeanor of the 2<sup>nd</sup> or 3<sup>rd</sup> degree to petition to seal the conviction record, as long as the individual does not have another more serious conviction and has been free of arrest for 10 years.”<sup>66</sup>
- The city of Philadelphia updated its “Ban the Box” [law](#) restricting when employers can run background checks or reject candidates because of previous convictions that happened over 7 years before the time of application.

**Future research on how many individuals apply for DSP positions and are turned away because of non-violent convictions, as well as the type of conviction, could lead to constructive discussions<sup>67</sup> on giving providers more discretion in their hiring while preserving the well-being of individuals with IDD.**

**Recruiting older workers with incentives such as tax deductions or flexible schedules:<sup>68</sup>**

With the nation’s aging, older workers will form a larger share of the workforce. This means that in order to be appealing to this demographic, direct service professional postings will need to be adapted to their needs. Part of this evolution requires reducing the physical strains caused by direct care through technology. It also includes proposals such as making working past the retirement age more appealing with tax deductions and flexible schedules. Additional research into what older workers seek in employment would also be of interest.

**Paying Family Caregivers for Their Work:**

Because family caregivers are uniquely placed to offer personalized and flexible services, they are “the single most important element to the sustainability of long term services and supports in the United States.”<sup>69</sup> Unfortunately, family supports only formed 6.7 percent of total IDD spending in 2013, declining from previous years. As a result, **families of individuals with IDD experience higher rates of poverty than other families, often because of out-of-pocket health expenditures.** The support of family services through HCBS is in part hindered due to the Waiver formatting of HCBS services, including:



*Amy and her mother in ANCOR’s Cost of Compassion video, talking about DSPs leaving.*

<sup>66</sup> Pennsylvania General Assembly Session of 2016, No. 2016-5, S.B. 166.

<sup>67</sup> Stemming from an email conversation with IARF.

<sup>68</sup> CMS and the Lewin Group, page 5.

<sup>69</sup> Coleman Institute, *State of the States in Intellectual and Developmental Disabilities*. Tenth Edition 2015. Page 56-57.

- Limited waiver capacity;
- Cost-per participant caps;
- Cost-neutrality requirements; and
- Cost containment measures such as ceilings and service limits.<sup>70</sup>

Initiating state and federal discussions to pay family caregivers would reduce their need to juggle earning a living and caring for their loved one. This would ensure individuals and their families receive the stability, financial security and care they need to thrive.

Equally important, **few public resources are dedicated to educating (training) and counseling family members** – though some states such as Texas actually do so well. Overall, though, family caregivers will suffer from less frustration and burn-out if they receive training while still caring for an individual. Specifically, family caregivers would benefit from programs that are self-paced and customized to the types of services their loved one needs – e.g. how to give specific treatments, how to find relevant medical assistance, how to navigate administrative demands, etc.<sup>71</sup>

### **Advancing immigration reform and expanding and/ or reauthorizing targeted foreign worker visa programs:<sup>72</sup>**

Over a quarter (28 percent) of all health paraprofessionals in general are immigrants.<sup>73</sup> As the United States' native workforce shrinks in size with the Baby Boomer generation retiring, this sector's reliance on an immigrant workforce is likely to continue growing. Advancing immigration reform and allowing foreign worker visa programs will allow individuals to receive stable care without harming job prospects for domestic workers, since there are already not enough to meet demand.

### **Recruiting people with disabilities to provide direct support:**

People with disabilities are the most unemployed population in the United States and with the right technological supports, many could become effective direct care professionals and support themselves financially. Currently many regulations prevent individuals with IDD from working in long term supports and services. Educating policy-makers so they create more opportunities for individuals with IDD could help those seeking employment as much as those struggling to retain professional support.

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<sup>70</sup> Coleman Institute, *State of the States*, page 60.

<sup>71</sup> CMS Leadership Summit on the Direct Service Workforce and Family Caregivers, *Building Capacity and Coordinating Support for Family Caregivers and the Direct Service Workforce: White Paper*, September 16 & 17, 2010, page vi. Accessible online at: <https://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/workforce/downloads/cms-leadership-summit.pdf>

<sup>72</sup> ANCOR, *Testimony on Direct Care Workforce to the National Council on Disability*. February 20, 2016. Page 2.

<sup>73</sup> PHI, *U.S. Home Care Workers: Key Facts*, page 3.



### Expanding the use of shared living services (e.g. host homes, paid roommates, or life sharing):

[Shared living](#) is an approach somewhat akin to foster care, designed so that individuals with IDD can truly experience community life. There is no specific model for shared living, as arrangements vary from case to case. Individuals, couples or families in the community and an individual with a disability discuss together the best way to share their lives. Whatever final agreement both parties reached is then administered by state agencies – either directly or through contracts with providers. The “host” is offered training and information that could allow them to help the individual living with them, including supports from professionals. While some compensation for the “host” is usually involved, this varies from state to state and case to case. Likewise requirements on how to participate in the program vary across states – for example, some states require licensing. Shared living helps with the workforce shortage by requiring less staff than a 24/7 care model and reducing costs without reducing outcomes for individuals with IDD. This does not entirely replace professional supports but allows them to be offered in a more sustainable manner given increasing waiting lists and work shortages.

### Leveraging “natural supports” and developing further capacity through public-private partnerships:

**Natural supports are relationships, networks, programs, and opportunities that exist already outside of Medicaid or government programs that can be leveraged into supporting individuals with IDD, thus reducing demands on DSPs and allowing for staff resources to be allocated where they are needed most.** To illustrate this, siblings, parents, programs at the local YMCA, community service activities and churches all form natural supports around an individual. Involving these networks would make demands on DSPs’ time more manageable, improving the quality of the workplace and ideally increasing retention. However, it cannot be stressed enough that natural supports are not a complete solution to the workforce crisis, in part because they are already being used by the community, in part because individuals’ needs might exceed the natural supports’ capacity. For example, family members who are already heavily involved in their loved ones’ care need the respite offered by professional staff. Nonetheless, because natural supports can be so varied there is a lot of room for innovation and capacity-building, which can be explored through additional investment. This could mean grants from state Councils on Development Disabilities, to name one non-Medicaid source.

## Conclusion

This bird's eye view of the most pressing workforce issues confronting direct care services shows us that stakeholders have already given a lot of thought to how to solve this challenge over the past decade. However, the current fiscal climate, low political appetite and lack of public awareness or appreciation of these services make it hard to foster innovation in this field. Fulfilled DSPs who can thrive in their careers and learn new skills are critical to the welfare and personal blossoming of individuals with IDD. In order to ensure that the IDD community's advancements in civil rights and pursuit of the vision of the Americans with Disabilities Act do not recede due to lack of a supportive workforce, and to ensure that dedicated professionals are enabled to pursue careers in this field, it is imperative that these services receive more funding. ANCOR is eager to examine these topics in greater depth and foster discussion on this topic that could lead to tangible policies and results. We welcome suggestions for future projects.

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[www.wearedsps.com](http://www.wearedsps.com)

<http://www.directsupportprofessional.org/>

[www.valuethework.com](http://www.valuethework.com)

[www.fixthedspcrisis.com](http://www.fixthedspcrisis.com)