



**TESTIMONY ON FRAMING THE ID/DD WORKFORCE CRISIS**  
**MOVING TO WORKABLE SOLUTIONS**  
**Tuesday, April 11, 2017**

Dear Distinguished Members of the Committee:

It is my honor to present this testimony before you today and on behalf of the American Network of Community Options and Resources (ANCOR), we sincerely thank you for focusing this morning's discussion on the topic of direct support professionals for individuals with intellectual and developmental disabilities (ID/DD). ANCOR has been in the Washington, DC area for almost half a century serving as the major national trade association representing more than 1,200 private providers of community living and employment services to individuals with intellectual and developmental disabilities across the country. Together, our members employ more than 600,000 direct support professionals (DSPs) and other staff. We are proud to have IARF as an active member of our association and are privileged to represent them at the national level.

As the association's head of our government relations department, it is my job to interface with Congress, the White House and the federal agencies to ensure that services for people with ID/DD are protected and that states are afforded the best opportunities to ensure they can partner with our members to effectively provide their service. In 2016 ANCOR provided testimony on the direct support workforce to the National Council on Disability, the President's Committee for People with Intellectual Disabilities (that is now doing its first report on the topic), and we worked directly with the U.S. Secretary of Labor, the U.S. Commissioner for the Bureau of Labor Statistics and the U.S. Director of the Centers for Medicaid and Medicare Services on issues specific to our workforce. Just last month, ANCOR issued a workforce report "[Addressing the Disability Services Workforce Crisis of the 21<sup>st</sup> Century](#)."<sup>1</sup> It is my hope that I can highlight much of this work and share the solutions that we have developed.

Before I speak to the broader spectrum of our findings, I want to share that as someone whose work is based in Washington, DC it is important for you to know those of us in the nation's capital have for many years paid a significant amount of attention to how disability issues are managed in Illinois. Our fellow national disability organizations based in Washington, DC have watched the deinstitutionalization efforts within Illinois, many of the major historical disability rights activists are Illinoisans and I have worked personally with Senators Durbin and Duckworth and former Senator Kirk on a variety of disability issues. Furthermore, as home to our most recent president, the focus on Illinois was strengthened as President Obama showed strong support for disability issues and even declared 2009 the Year of Community Living in honor of the Olmstead decision's 10<sup>th</sup> anniversary. Needless to say, Illinois sets an example in all that it does in this arena and it is ANCOR's hope that Illinois will serve as a national example of how to solve the workforce crisis that providers are facing.

In September 2011, a Chicago Tribune editorial piece spoke to the deinstitutionalization efforts of Illinois, noting that, "Illinois' treatment of the developmentally disabled lags way behind the times. Other states have proved convincingly that in most cases, institutionalizing people in big government-

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<sup>11</sup> Found at <http://www.ancor.org/newsroom/news/ancor-announces-release-its-workforce-paper> (April 10, 2017)

run facilities hurts everyone concerned and wastes money. Community-based organizations offer small neighborhood group homes and other varied options for care and generally provide better results at a much lower cost.” ANCOR agrees and many national studies have proven that community living is a better, more cost-effective option for individuals with intellectual and developmental disabilities. However, the workforce that supports these services is facing a greater crisis than ever and the stability of the workforce depends on significant solutions that must be triggered in order for any community system to survive.

As you are aware, home and community-based services (HCBS) are provided through the state and federal Medicaid program and partnership. Our members, including our Illinois members, rely almost solely on Medicaid funding to provide disability services. As a result of the funding mechanism, the workforce crisis faces unique stresses that have been more injurious in the 21<sup>st</sup> century than ever. The crisis stems from three key factors – first, that federal policy changes encouraging community services have increased demand for these services without increasing funding, second, that state budgets have been stagnant or shrinking since the great recession leaving many provider reimbursement rates without change in over a decade, and third, the complex issue that there are simply not going to be enough workers in the next decade to fill the gaping holes in the DSP workforce fully. These factors have currently left the direct support professional workforce with a national average turnover rate of 45%. Quits and layoffs exceed hires, our members are constantly spending precious Medicaid dollars on the training and hiring process, and people with disabilities are not getting what they deserve from the program. As a sibling of two individuals with intellectual and developmental disabilities myself, I can attest that the DSP workforce crisis directly harms people with disabilities and their families. Most recently, my brother who has significant physical and developmental disabilities and requires assistance to leave home and be in the community, waited for years for a DSP, recently was assigned one for one week before she left. He has received no services since and is waiting until another one is retained. Currently he relies instead on my eighty year old father for his daily life supports.

My family is not alone in this experience. In 2014, the Kaiser Family Foundation, a respected national health research foundation based in DC, quantified that Illinois had over 15,000 individuals with intellectual and developmental disabilities waiting for community services, waiting for either the funding or the workforce or both to be in place in order to provide it. As much as this is a matter of funding, it is also one of human capital. The reality is, as the Bureau of Labor Statistics leadership informed ANCOR last year, that while on average, every other career field is set to grow between 2014-2024 at a rate of 7%, DSPs and similar roles are expected to grow by up to 38% during that time period. There are simply not enough people of working age entering the workforce at that same time to fill that need. Combined with the fact that wages are not commensurate to the work, this leaves room for a significant disaster in the provision of community services.

Having covered the daunting issues facing the DSP workforce, I would like to put forth several solutions as outlined in ANCOR’s newly released workforce report earlier referenced.

On the wage end of the discussion, wages for DSPs are woefully below what they should be given the skills and expectations of this workforce. Around 80% of what our members receive in Medicaid funding goes directly to paying the frontline workforce who then make around \$8-11/hour. As I share with Members of Congress on Capitol Hill, our services are in many ways, the provision of staff supports. In a study we were provided from the U.S. Departments of Labor and Health and Human Services, it was demonstrated that in many states the hourly wages for janitorial staff, retail and fast food restaurant staff are above that of the DSP workforce. There is no question in my mind that the lack of a sufficient wage for DSPs has led to the workforce crisis currently at hand. There are additional solutions I will discuss that are not funding focused, but I want to be absolutely clear, especially because of the role that the state plays in the rates, that without stabilizing the rates that providers receive to pay their workers, the workforce crisis does not go away.

As the state of Illinois considers a new minimum wage level this year, it is of utmost importance to think of how this impacts the DSP workforce crisis. As the raising of the minimum wage can prove to be a positive in many ways and is a noble goal to support, the state must consider how it will manage a new minimum wage for its Medicaid-funded workforce. ANCOR recommends that at the very least, states look at a targeted pass-through directed to DSPs to avoid any further trauma to already underfunded rates.

In addition to wage stabilization, states need to ensure that providers have resources that would provide adequate benefits to DSPs in order to support their ongoing employment. Studies have found that workers do not just leave their jobs because of low wages, but also for poor benefits and other workplace supports that could have been used to retain them. It is important to note that if a DSP leaves an agency, it costs around four to five thousand dollars to replace them, inclusive of the new training costs for that individual. All costs aside, the greatest one is to the person who receives the services and now has to face the challenge of a new individual entering their lives.

One of the non-monetary solutions that ANCOR's workforce report puts forward is the state and federal policy support for technology to help fill the deficit in the DSP workforce. We have encouraged the U.S. Department of Health and Human Services to embrace integrating more technology into the provision of HCBS services. The use of remote technology can not only be cost effective and provide a partial solution to the human capital problem, but it can also provide greater independence for the person receiving the services. In fact, at a recent event at the White House that ANCOR helped to arrange that focused on technology for people with disabilities, individuals with disabilities showcased how smart home devices like Amazon's Alexa can address some of the needs that historically a staff person would provide. In order to take advantage of the benefits, however, states need to be clear that they reimburse providers for their use of technological advancements. Only a few states have taken full advantage of CMS' allowance for greater innovation in services, but far more should be taking grander leaps to use technology for a variety of purposes including improving administrative efficiency, reducing the physical strain of the provision of service, and creating more independent opportunities for the individual with ID/DD.

Another way to address the human capital issue is to creatively address who is getting paid for supports. Family caregivers are woefully underused as a formal piece of the workforce but necessary to solving the workforce crisis. Family supports only formed 6.7 percent of total ID/DD spending in 2013, declining from previous years. Yet over 75 percent of individuals with ID/DD live with their families. A state must ensure its waiver allows for ease of paid family caregivers while also directing them to training and resources that service providers can help to provide and manage. Furthermore, the development of shared living, which I believe requires a license in Illinois, can be another effective solution and needs to be expanded to provide fully integrated opportunities for individuals.

We are beginning to see success in many states from Wyoming to Ohio to New York that focus on targeting at-risk youth and young adults for careers in the direct care workforce as early as high school. ANCOR supports the National Care Corps Act which is a federal bill that would provide educational and other incentives for more workers to enter the direct support professional workforce. Ultimately, targeting and actively recruiting young individuals will be a key aim of any state's agenda that hopes to impact the crisis. This workforce development must take shape within the goals of the state and local workforce boards that have historically not addressed the direct support professional career field. I hope that your leadership can help to activate those discussions.

I am fully aware that the state and federal government need reliable data in order to make significant policy changes. Unfortunately the Medicaid program does not have a plethora of public data available. We cannot fully understand the need for the direct support professional workforce because the Bureau

of Labor Statistics combines the data in what it calls a standard occupational classification (SOC) with a much larger workforce that does not necessarily face the same stresses, primarily the classifications of personal care aides and home health assistants. In order to truly capture the real data for the workforce crisis, ANCOR has requested that the Bureau of Labor Statistics create an individual SOC for the DSP workforce. ANCOR is extremely pleased to see that states like Illinois are seeking to encourage the BLS to create this SOC with active bills like HR 272. Although it may seem like an insignificant accomplishment, a unique SOC at the BLS can translate to substantial policy change.

I will end my testimony by saying that my journey in becoming an attorney was activated by my appreciation and admiration for the Americans with Disabilities Act (ADA) and what that civil rights law meant for my two siblings with disabilities. When folks ask what ANCOR members do, I often share that disability service providers are the folks that help to implement the ADA and constitutional equal protection rights of the individuals that law protects. The Medicaid HCBS program in Illinois that you all support makes it possible for thousands of individuals with ID/DD to thrive in the community and outside of institutions and for that you should be extraordinarily proud. We are facing a particularly frightening crisis currently, but the solution is not out of our reach yet. With wage modification, proper funding supports, creative use of technology, innovative human capital solutions, and increased data tracking, we can create real solutions to the workforce crisis and the quality of services that individuals receive.

Thank you for your consideration of my testimony today and I look forward to working with you to advance the future of the direct support professional workforce.

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