

**TESTIMONY ON WORKFORCE TO THE PRESIDENT'S COMMITTEE FOR PEOPLE  
WITH INTELLECTUAL DISABILITIES (PCPID)**

**Thursday, December 1, 2016**

Dear Distinguished Members of the President's Committee for People with Intellectual Disabilities:

The American Network of Community Options and Resources (ANCOR) appreciates the opportunity to present on the important issue of the direct care workforce and the dedicated men and women who are employed by our members in the provision of services to individuals with disabilities. ANCOR is a national trade association representing more than 1,200 private providers of community living and employment services to primarily individuals with intellectual and developmental disabilities across the country. Together, our members employ more than half a million direct support professionals (DSPs) and other staff.

Let me begin this presentation with a portion of the annual bipartisan Senate resolution we lead each year which recognizes the work of DSPs. "Direct support professionals are hardworking, taxpaying citizens who provide an important service to people with disabilities in the United States, yet many continue to earn low wages, receive inadequate benefits, and have limited opportunities for advancement, resulting in high turnover and vacancy rates that adversely affect the quality of support, safety, and health of individuals with disabilities."

This section of the Senate resolution, etched forever in the Congressional record, summarizes the issue so well. While providers have prioritized strengthening this invaluable workforce, they face significant challenges – which include availability of workers, administrative requirements, and adequate funding. The main and usually only source of funding for our members is Medicaid, primarily through the Medicaid Home and Community-Based Services (HCBS) program. This means providers do not have the ability to negotiate or enforce the rates they are provided for services and importantly, for fairly compensating their DSPs. As more individuals with disabilities are living typical lives in their communities, the need for direct support professionals has risen. Yet nationally, Medicaid rates have not kept pace with this increase. This leaves providers to answer the impossible question of whether to serve fewer people and preserve the safety and quality of their services, or attempt to serve more people in the community, but with fewer, less qualified staff and higher risks.

Today, in this limited time period, I want to share with you a few key points. The first is the importance of the direct support professional workforce to achieving community integration for individuals with intellectual disabilities. Secondly, I want to touch upon the latest numbers and figures that truly display the crisis that we are in. Finally, I want to share with you what's at stake and why we can no longer wait to solve this issue.

I will begin my first point by saying that as a sibling to both a brother and sister with intellectual and developmental disabilities, the workforce issue is at the forefront of my mind each day, as I know it is for families throughout the country. I acutely understand that the existence of a dedicated and effective workforce is key to ensuring that my siblings have the same opportunities to live in society as myself and the supports they need to access the lives that they want to live.

When I joined ANCOR in 2015, I did so because I see providers as key players in implementing the Americans with Disabilities Act. I wanted to be a part of creating the policies to help them achieve the goals of the ADA serving individuals like my siblings. I was also quite excited to join the association at the time when a major federal rule had also just been finalized a year before, one that continues to be in its first years of implementation today. That rule, that many of us call the Home and Community-Based Services (HCBS) Settings rule, defines “community” for the first time and requires states to undergo a rigorous and transparent process to ensure that HCBS services are being provided in line with that definition. This includes the requirement that individuals have access to more integrated services and that their person-centered planning and individual decision making leads their service provision.

I also joined ANCOR just as the Workforce Innovation and Opportunity Act (WIOA) passed, amending how employment services are provided to people with disabilities and ensuring greater access to competitive integrated employment. While it was a very exciting time to begin my new role at ANCOR, something struck me immediately. Each of these laws and federal rules required staff supports to truly achieve the goals. ANCOR has supported every one of these pieces of legislation and rules – sending letters to Congress and the Administration stating just that. However, we have always made the point that the direct support professional deficit cannot be overlooked when moving forward on these policies. So in summary, it is my strong opinion that integration, competitive integrated employment, and the other policy goals that we all stand for cannot be fully achieved for people with disabilities until we solve the workforce crisis.

Someone recently asked me what a workforce crisis looks like. Although it is felt more strongly on the ground than anywhere, it is data that illustrates the national and future implications of this issue best. Data is so key in telling the story of the DSP workforce, but it is unfortunately incomplete. I am grateful for my colleagues in the room and on the phone that have taken on new approaches to quantifying the reality of the crisis before us. Based on what current data does tell us, direct support professionals do some of the most important work in our country but our investment in them is the form of compensation and benefits is woefully inadequate. For instance, it is found that over half, 56%, of the direct support professionals rely on public assistance to make ends meet. 37% of these workers are uninsured and another 21% rely on public insurance like Medicaid. Direct support professionals are often the main breadwinners in the family, 91% are women and 21% are single parents.

In September ANCOR held its Annual Leadership Summit and welcomed the Secretary of Labor as well as the Commissioner of the Bureau of Labor Statistics to discuss the workforce crisis and get the latest data on the outlook for this essential workforce. What they shared was staggering.

Since 2014 there has been a dramatic spike in the number of vacancies of these jobs compared to hires. There has simultaneously been a spike in the number of individuals in this profession quitting. But perhaps the most staggering figure that BLS revealed was that while in the course of the next decade other occupations are slated to grow around 7%, our need for workers is growing between 26% and 38%. These numbers, mind you, are quantified for personal care services and home health aides, the category in which direct support professionals fall. It is my assumption that if DSPs were to be identified alone in this data set, the outcomes would look even more dire. So what does this data ultimately reveal? There are not enough individuals entering the entire U.S. workforce in the next decade to meet the needs of the future of the direct care workforce. It’s statistically impossible to meet the need.

This all brings us to why we cannot wait and why it is essential that the President’s Committee immediately look at the workforce crisis and offer solutions to the incoming Administration to address this emergency. We do not have time to wait. People with disabilities need to know that they can be

supported by one or two individuals that earn their trust instead of the ten or more that they are becoming accustomed to. Even worse, individuals are being told there are no direct support professionals to support them. This was my most recent experience just this past month with my own brother who lives in California. Justin has cerebral palsy and endured a traumatic fall last year inhibiting his mobility even further. He was told, in a state where the California Lanterman Act creates a state right to community services, that there was no staff available to support him in the community. Instead, he had the choice of a congregate setting or having a psychologist issue medication to address his need to get out in the community. Neither of these options supported his right to live as a full participant in the community, which is not only what is legally required by the ADA, but is also what our values require.

The risks presented by the DSP workforce crisis are not simply forecasts of what could happen. The dangers of not having an adequate workforce in place are already playing out. Many of you may have seen the Chicago Tribune series issued this November highlighting abuse and neglect in Illinois group homes. While much of the feedback from the community and families to this story aimed to point out that the vast majority of individuals have wonderful and positive experiences with their Illinois providers, the story gives examples of how individuals with significant intellectual and developmental disabilities are at major risk when the appropriate staff are not in place. Many of the incidents highlighted by the article cite significant harm to an individual and in some instances, deaths that could have been prevented with adequate staffing.

I do not sit before you and claim that solving the workforce crisis is going to eliminate all instances of abuse and neglect. However, as with any business, an adequate, professional workforce is a major factor in addressing the possibility of misconduct. Ironically, the day before the first of the Chicago Tribune stories was released, the Illinois State Legislature refused to override a veto by the Governor restricting additional pay for direct support professionals. So DSPs in Illinois will continue to earn an average of \$9.35 an hour. This is below the federal poverty level for a family of three. As the story cites one provider saying, they are “scraping the barrel” for workers and workers who were previously disqualified from serving as a DSP are now being hired because that is the only option.

Another reality that we are seeing emerging is that an inadequate workforce is sustaining the institutionalization of people with intellectual disabilities. This year the Protection & Advocacy agency of Washington, Disability Rights Washington, sued the state for violation of the Americans with Disabilities Act. Specifically, the suit alleges that 91 people have been identified in the state as either wanting to leave an institutional setting or being at great risk of becoming institutionalized, but none have community options because of the state’s inability to support them. The suit claims, in part, that the state does not have enough staffing to meet the demand in the community and thus these individuals either remain institutionalized or likely to enter an institutional setting to receive services.

It is with great respect that I implore your honorable Committee to address the workforce crisis in 2017. While it is stating the obvious that enhanced provider reimbursement is a critical element in addressing this crisis, it must be coupled with other solutions that need greater exploration. Creating interest in the profession through volunteerism, employing individuals with disabilities as DSPs, reforming immigration law to target foreign worker visa programs, reducing administrative burden, drawing in those who have been outside the workforce since the recession with training and programs, expanding models like self-direction, host homes, and shared living and enhancing technology solutions have all been offered as possible fixes. However, we need you, the Members of the President’s Committee, to recognize the challenges, the various solutions, and help lead the new Administration and the country in addressing the crisis.

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