



The State of America's Direct Support Workforce 2021

New Research Finds COVID-19 Pandemic Further Decimating a Direct Care Workforce in Crisis

The COVID-19 pandemic drastically changed the landscape of service provision and accelerated the shortage of direct support professionals, or DSPs, the frontline workers who support people with intellectual and developmental disabilities (I/DD) to be included in the community.

For decades, the United States has witnessed a significant shortage of DSPs due to stagnant reimbursement rates and the inability of providers to offer competitive wages with entry-level industries, such as fast food, retail and convenience. In February 2020, ANCOR conducted a survey of providers of community-based I/DD services to glean a deeper understanding of how they experience the human and financial impacts of the DSP workforce crisis. The results of that survey revealed what at the time felt like staggering findings: at alarming rates, providers were discontinuing services, turning away new referrals, delaying the launch of new programs, struggling to adhere to quality standards and more.

And then came the pandemic.

With the onset of COVID-19 and throughout the entire duration of the pandemic to date, we have been fielding desperate calls from our network of more than 1,600 private providers of community-based I/DD services. These calls have made clear the new pressures and hazards of providing essential, close-contact services during the pandemic and how those pressures and hazards have exacerbated the existing workforce crisis. While many in the private sector pivoted by offering increased wages and hazard pay, community providers—who rely almost exclusively on Medicaid funding and are thus beholden to paying wages that Medicaid reimbursement rates will permit—lacked the resources to fund these kinds of unanticipated programmatic costs.

The dire situation we have heard about daily since our last survey led ANCOR to realize the need to further quantify the impact of the COVID-19 pandemic on the DSP workforce. In turn, we fielded a second survey to assess the current state of the direct support workforce crisis. We solicited responses to that survey for a five-week period beginning in August 2021 and garnered 449 responses. The survey measured the same dimensions we asked about in 2020, along with additional measures targeted specifically to the impact of COVID-19 on DSP hiring and retention.

As anticipated, the challenges to maintain services and quality standards have increased dramatically with the immediate and drastic exodus of DSPs from the field. By nearly every count, providers find themselves in a significantly more precarious situation than the ones that described their operations in early 2020.

The findings of this latest study are highlighted in the current report and reveal the significant need for immediate federal response. With the new public health and economic pressures of COVID-19, the very infrastructure of supports and services is held together by a shoestring of dedicated providers nationwide. Without significant investment in the DSP workforce, it is only a matter of time before people with I/DD and their families—many of whom already lacked access to high-quality, community-based supports—completely lose access to the options and resources needed to remain in their homes and in the community.

FACT: 77% of Providers are Turning Away New Referrals

Nearly 8 in 10 respondents indicated that they had turned away or stopped accepting new referrals due to insufficient staffing. This represents a 16.7% increase since the beginning of the pandemic.

- The limited number of available providers has left individuals with high support needs traveling significant distances outside of their communities to seek support and care, thereby furthering their risk of exposure to COVID-19.

FACT: 58% of Providers are Discontinuing Programs and Services

More than half of respondents indicated that they had discontinued programs or service offerings due to insufficient staffing. This represents a 70.6% increase since the beginning of the pandemic, as well as the most pronounced change wrought by the pandemic of all measures included in the survey.

- Without access to services, individuals with disabilities are at a higher risk of hospitalization and institutionalization at a time of limited capacity. As states begin announcing crisis standards of care in hospital settings, there remains a disparate impact to individuals with disabilities left unable to access services in their homes.

FACT: 84% of Providers are Delaying the Launch of New Programs or Services

More than 8 in 10 respondents indicated that they had delayed the launch of new programs or service offerings due to insufficient staffing. This represents a 29.2% increase since the beginning of the pandemic.

- As the infrastructure of services deteriorates without the ability to provide staffing, there are nearly 600,000 people languishing on states' HCBS waiting lists. States will remain unmotivated to reduce waiting lists when no providers are available to provide supports after authorization.

FACT: 81% of Providers are Struggling to Achieve Quality Standards

More than 8 in 10 respondents indicated that they had experienced difficulties in achieving quality standards due to insufficient staffing. This represents a 17.4% increase since the beginning of the pandemic.

- As a result, hiring standards are forced to be lower and providers are more likely to depend on emergency regulatory flexibilities to maintain minimum staffing requirements. When emergency orders are lifted, providers are left unable to comply with staffing requirements, in turn forcing immediate discharge of people who were once supported and, in the worst cases, complete and permanent agency closures.

FACT: 40% of Providers are Seeing Higher Frequencies of Reportable Incidents

More than 4 in 10 respondents indicated they are experiencing higher frequencies of reportable incidents than they had prior to their recruitment and retention challenges. ANCOR attributes the lack of increase in frequency of reportable incidents from pre-pandemic findings to the dedication of community providers to consistently offering quality services despite tremendous pressure and limited resources. It should be noted, however, that although it may be promising that this outcome remained unchanged, it may also be the case that there were the same or fewer reportable incidents due to the dramatic decrease in the number of people being served.

FACT: The Significant Financial Costs of High Turnover are Unsustainable

Nearly 3 in 10 respondents (29%) reported spending more than \$500,000 annually in costs related to high turnover and vacancy rates, while nearly 1 in 6 respondents (18%) reported spending more than \$1 million annually.

- These increased costs, which relate to everything from training to staff overtime and more, simply cannot be sustained by community providers that were significantly underfunded to begin with.

FACT: 92% of Providers Continue to Grapple with the Impact of the Pandemic on Recruitment and Retention

Nearly all providers agree that the COVID-19 pandemic continues to deeply impact the ability for providers to hire and retain DSPs.

Overwhelmingly, providers indicated that the inability to provide comparable wages to the private market has decimated the DSP workforce. Largely reimbursed as a minimum wage position, providers have continuously competed with entry-level industries offering less demanding work for staffing. During the COVID-19 pandemic, private companies and corporations simultaneously increased wages—steps providers simply could not take. Factors contributing to the lingering effects of the pandemic are illustrated by the following findings:

- 92.5% of respondents indicated “Industries that previously paid comparable wages now pay employees more than my organization can afford to pay.”
- 86.2% of respondents indicated “DSP wages are lower than income provided by unemployment or other state or federal safety net benefits.”
- 47.7% of respondents indicated “DSPs who left their positions temporarily due to the pandemic are not yet able to return (e.g., because their children’s schools remain closed, because of fear of contracting COVID-19, etc.).”
- 18.6% of respondents indicated “DSPs who were transferred from day programs to residential settings prefer to continue working in these settings.”

If Not Now, When? The Need to Support Full Funding for HCBS

In his Build Back Better Agenda, President Biden proposed a \$400 billion investment in the Medicaid Home and Community Based Services (HCBS) program. ANCOR strongly encourages the 117th Congress to support this full \$400 billion investment. The relentless challenges evidenced by the data highlighted in this report illustrate why forgoing this investment or reducing its scope would be insufficient in addressing the magnitude of unmet need in our communities.

Without the full investment proposed in the Build Back Better Agenda, states will not be able to support people with disabilities currently receiving Medicaid-funded services, let alone begin clearing the nearly 600,000 families from states’ HCBS waiting lists. A failure to adequately invest will also hinder lawmakers’ efforts to create equity and opportunity in their states and communities, as a failure to invest in the DSP workforce is a failure to invest in a community of more than one million professionals who are predominantly women and people of color. In all, choosing not to stabilize the direct support workforce will have devastating consequences not only for people with disabilities and their families, but also for local economies.

For opportunities to take action to support investments in community-based I/DD services, visit the ANCOR Amplifier at amplifier.ancor.org.