New Research Finds Direct Care Workforce Crisis Having Detrimental Impact on Access to Community Disability Services

New data from ANCOR finds that a significant shortage of direct support professionals (DSPs), the frontline workers supporting people with intellectual and developmental disabilities (I/DD), has reached catastrophic levels.

The longstanding workforce crisis, exacerbated by the COVID-19 pandemic, has led to closures of critically needed services and a denial of access to community-based supports. With the conclusion of one-time federal pandemic relief funding, community providers face a fiscal cliff that puts access to community-based services in jeopardy of complete collapse. As a result, immediate legislation to stabilize the DSP workforce is critical to ensuring home- and community-based services remain sustainable and can deliver on the access and inclusion promises of the Americans with Disabilities Act.

There are nearly 6 million people with I/DD living in the United States, many of whom rely on long-term services and supports to live independently and have access to their communities. Thousands of community-based provider organizations together employ more than 1 million DSPs to deliver these crucial, often life-saving services. Unfortunately, the United States has for decades witnessed a severe shortage of DSPs, which has accelerated into a crisis that now threatens access to services.

The direct support workforce crisis is largely attributable to stagnant reimbursement rates and the inability of providers to offer wages that are competitive with those of hourly-wage industries, such as fast food, retail, and convenience stores. Although our research indicates that this was a significant challenge long before the COVID-19 pandemic, data from The State of America’s Direct Support Workforce Crisis 2022 confirms that these problems have not only been amplified by the pandemic but are also at the root of service and program closures, service launch delays, struggles adhering to quality standards and more.

For the third consecutive year, ANCOR has measured the impact of the direct support workforce crisis on community providers and their ability to deliver high-quality community-based I/DD services. When ANCOR surveyed providers in 2021, the results revealed that the workforce crisis had significantly worsened compared to just before the public health emergency. While many employers in the private sector were able to offer increased wages, hiring incentives, hazard pay and bonuses, community providers lacked the resources to fund workforce incentives alongside the range of other previously unanticipated pandemic-related programmatic costs. Community providers rely almost exclusively on Medicaid funding and are thus beholden to paying wages that Medicaid reimbursement rates will permit.

The results of our 2022 survey reveal that this workforce emergency is now to the point of denying access to services and further threatening quality of services for people with I/DD. Over the course of a four-week period beginning in August 2022, ANCOR fielded a survey across its provider network that garnered 718 responses. In the broadest terms, what we found is that providers are unable to attract and retain DSPs at a rate that, if left unaddressed, has the potential to completely collapse the system of services as we know it.

The pages that follow detail the specific findings of the 2022 State of America’s Direct Support Workforce Crisis survey and conclude with a discussion of the policy solutions needed to advance progress toward a more sustainable service delivery system.
83% of Providers are Turning Away New Referrals

**FACT:** More than 8 in 10 respondents indicated that they had turned away or stopped accepting new referrals due to insufficient staffing. This represents a 25.8% increase since the beginning of the pandemic.

**IMPACT:** The limited number of available providers has left individuals with significant or complex support needs traveling long distances outside of their communities—assuming they are able to find a provider at all—thereby heightening their risk of institutionalization or unnecessary hospitalization.

63% of Providers are Discontinuing Programs and Services

**FACT:** More than 6 in 10 respondents indicated that they had discontinued programs or service offerings due to insufficient staffing. This represents a staggering 85.3% increase since the beginning of the pandemic.

**IMPACT:** With programs and services closing at an accelerating rate, the ability of states to maintain an adequate network of community providers and meet federal access standards is at grave risk. Reduced availability of services jeopardizes the safety and well-being of the people relying on them.

55% of Providers are Considering Additional Service Discontinuations

**FACT:** More than half of all respondents indicated that they were considering new and additional discontinuations of programs and service offerings due to the current rate of high turnover and vacancy. Another 37% indicated they were not sure if they would need to close additional services, with only 8% responding they would not.

**IMPACT:** With the infrastructure of services deteriorating as the dearth of adequate staffing grows, there are nearly 700,000 people languishing on states' HCBS waiting lists. Without providers available to deliver supports, families will remain unable to access services, *even after* they are removed from the waiting list.

92% of Providers are Struggling to Achieve Quality Standards

**FACT:** A staggering 92% of respondents indicated that they had experienced difficulties in achieving quality standards due to insufficient staffing. This represents a 33.3% increase since the beginning of the pandemic and a 13.6% increase in the last year alone.

**IMPACT:** When too few workers apply for jobs, providers are reliant 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.

71% of Case Managers are Struggling to Find Available Providers

**FACT:** More than four in 10 respondents (42%) reported that they offer case management services in addition to long-term services and supports. Of those respondents, 71% indicated that it is difficult to connect families with services due to lack of available providers.

**IMPACT:** Case managers work with people with I/DD to coordinate services to meet their needs. Due to their role finding and managing availability of services, case managers are often in a unique position to assess accessibility of the provider network—suggesting there are now fewer services to be offered than before.
66% of Providers are Concerned Vacancy and Turnover Rates Will Increase with the End of the Public Health Emergency

**FACT:** Sixty-six percent of respondents reported being concerned that vacancy and turnover rates will increase when COVID-19 relief funding and regulatory flexibilities related to the COVID-19 public health emergency are terminated.

**IMPACT:** Providers remain reliant on the availability of increased funding and emergency regulatory flexibilities pursuant to the public health emergency to maintain basic operations with reduced staffing. Almost every state included initiatives aimed at stabilizing the direct support workforce in their implementation of enhanced home- and community-based services funding provided by the American Rescue Plan Act (ARPA). However, providers will face a devastating fiscal cliff when that temporary funding expires.

The Most Common Workforce-Related Uses of Federal Pandemic Relief Funding Were Wage Increases and One-Time Bonuses

**FACT:** Eighty-six percent of respondents reported receiving some form of federal pandemic relief funding (e.g., Provider Relief Fund disbursements, increased reimbursement through Appendix K, funding related to ARPA, etc.).

Overwhelmingly, providers indicated that they invested the one-time federal pandemic relief funding in the following DSP workforce initiatives:

- 72.3% of respondents indicated investing relief funding into one-time wage increases
- 75.3% of respondents indicated investing relief funding into one-time workforce bonuses
- 59.1% of respondents indicated investing relief funding into one-time hiring or sign-on incentives
- 26.9% of respondents indicated investing relief funding into training or other professional development programs

Nearly 1 in 7 respondents (13%) indicated investing relief funding to offset additional costs related to personal protective equipment for DSPs throughout the COVID-19 pandemic and other workforce initiatives including, but not limited to, COVID-19 tests, hazard pay, free meals, gift cards for groceries or meals, increased mileage reimbursement rates, referral bonuses and other recruitment incentives.

Respondents also indicated the pressures of increased overtime, turnover rates, and limited availability of federal funds, with 6.2% of providers indicating they were unable to invest in workforce initiatives due to other financial strain.

**IMPACT:** Nearly all respondents used opportunities for written comment to indicate that the short-term availability of federal funding has resulted in one-time use of bonuses and incentives and time-limited wage increases. Without sustainable funding, however, states recognize that federal funding will eventually run out and are therefore reticent to initiate long-term or permanent compensation increases.
Help Save Access to Community-Based Services

Immediate legislation to stabilize the DSP workforce is critical to ensure the home- and community-based services program remains sustainable. ANCOR strongly supports the legislative solutions described below to increase DSP recruitment, strengthen the workforce and ensure the stability of disability supports.

Increase Funding for Workforce Initiatives

ANCOR supports legislation to enhance the Federal Medical Assistance Percentage (FMAP), increasing the federal share of Medicaid funding for Home and Community Based Services (HCBS). An FMAP increase would allow states to address HCBS payment rates to promote recruitment and retention of direct support workers. In particular, ANCOR supports an extension of HCBS temporary funding authorized under the American Rescue Plan Act and passage of the Better Care Better Jobs Act (S. 2210/H.R. 4131).

Create a Standard Occupational Classification for Direct Support Professionals

ANCOR supports legislation to establish a standard occupational classification (SOC) for DSPs. SOCs are used to help all levels of government identify employment trends and design policies, including states’ approaches to rate-setting in their Medicaid programs. Without a SOC that accurately reflects the DSP workforce, there is no comprehensive mechanism for collecting data on DSPs and policymakers cannot make informed decisions to assist with recruiting, retaining or adequately paying DSPs. In particular, ANCOR supports passage of the Recognizing the Role of Direct Support Professionals Act (S. 1437/H.R. 4779).

Supporting Career Pipeline Programs for Direct Support Professionals

ANCOR supports legislation establishing a career pipeline for DSPs. The workforce crisis necessitates additional investments in the training and professionalization of the direct support workforce. Congress should enact legislation that would authorize federal grant programs to support the training, recruitment, retention and advancement of the direct support workforce. In particular, ANCOR supports the Supporting Our Direct Care Workforce and Family Caregivers Act (S. 2344) and Direct CARE Opportunity Act (H.R. 2999).

Get Involved

For opportunities to take action to support investments in community-based I/DD services, visit the ANCOR Amplifier at amplifier.ancor.org. For more information about the data highlighted in this report, please contact Lydia Dawson, Director of Policy, Regulatory & Legal Analysis, at ldawson@ancor.org.

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