

## Data Snapshot: Reaching Those in Need

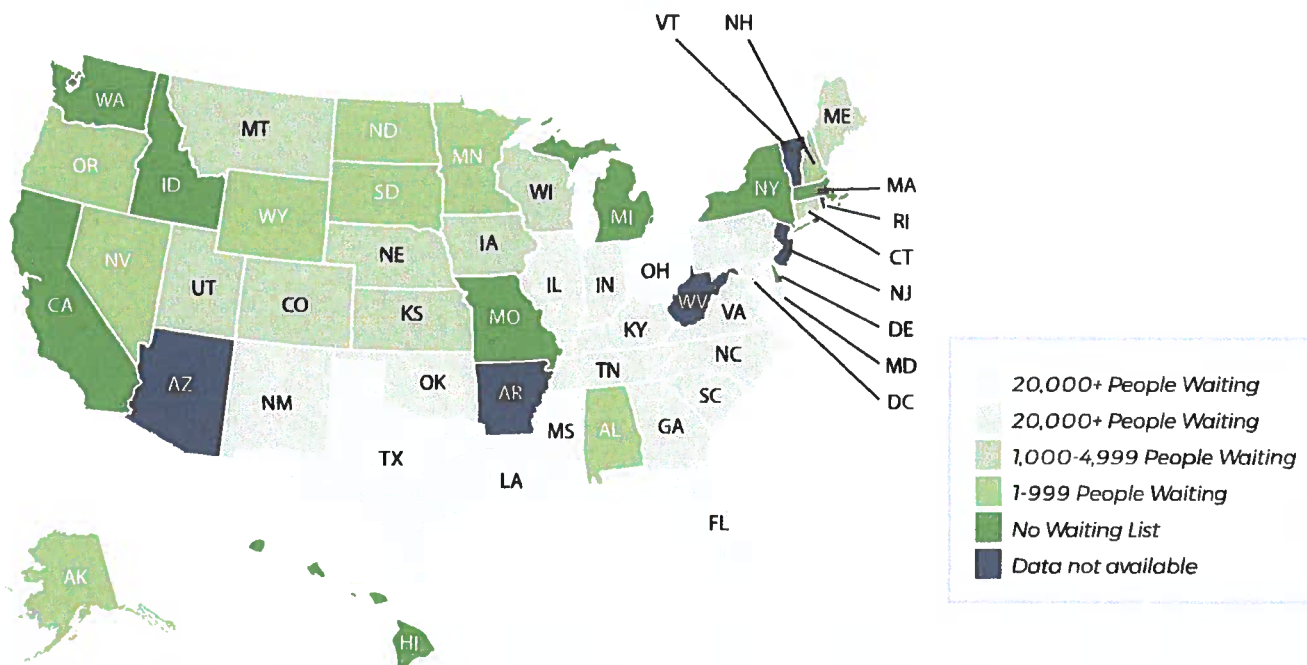
Elsewhere in this report, we have described how inadequate staffing inhibits providers' ability to support the full number of people in need in their communities. In these circumstances, states are often forced to create waiting lists for Home and Community Based Services. But even when a state allocates additional funding to serve the people languishing on the waiting list, that doesn't necessarily mean those in need of services can access them. When too few community providers have too few staff to support those being cleared from waiting lists, people are forced to either forgo services altogether or live in hospitals and institutions—assuming such settings are even available to them.

People on states' waiting lists can find themselves there for months and, more commonly, years, waiting for authorization to seek services. Families are rarely, if ever, provided a timeframe for when they can expect support to become available. How states manage their waiting lists to determine who gets cleared varies across the country; some states operate on a first-come, first-served basis, while others consider the extent to which people waiting are at risk for abuse, neglect and exploitation.

Meanwhile, states' waiting lists aren't a perfect measure of the scope of unmet need in a particular place. Confusion and fear can prevent families from undertaking the application process in the first place, while states' efforts to clean up their waiting lists or adjust eligibility standards can lead those in need to be removed from lists despite not receiving services after years of waiting. In other words, we use waiting lists to assess how many people would likely take advantage of community IDD services if offered them today, but we acknowledge that doing so underestimates the number of families in need.

As of the 2022 edition of the *Case for Inclusion*, there were 589,940 people on states' waiting lists for Home and Community Based Services according to the Kaiser Family Foundation.<sup>15</sup> This marks an increase of nearly 117,000 since the publication of the *Case for Inclusion 2020*. Strikingly, more than 78% of people on states' waiting lists live in the five states with the largest waiting lists: Texas (323,434), Ohio (68,644), Louisiana (27,509), Florida (21,864) and Illinois (19,354).

**NUMBER OF PEOPLE ON STATES' WAITING LISTS FOR HCBS (IDD) SERVICES**



It should be noted that in addition to waiting lists being an imperfect measure of unmet need, waiting lists can obscure another reality, which is that the size of a waiting list isn't necessarily correlated to the number of people being supported. For example, a state that spends considerably less per person can maintain a smaller waiting list or none at all by offering less support to more people. Meanwhile, a state could offer higher levels of support to those receiving services, but in turn be forced to keep more people on the waiting list.

Further complicating the barriers to understanding the scope of unmet need in a state is the fact that waiting list data don't always permit apples-to-apples comparisons. For instance, some states might count all people with IDD awaiting services, while others may only count those waiting who have already been deemed eligible to receive services. Similarly, some states may not operate a waiting list in the traditional sense of the term but may have "planning lists" or "priority lists" that reveal there are, in fact, individuals and families seeking to receive some level of long-term services and supports.

Therefore, it is essential that states not only make investments that enable them to support more people, but also to enhance the support being offered to those already being served. But here again, states' ability to do so will demand a larger pool of qualified direct support workers, which will itself require deeper investments in the provider workforce.

## FROM THE FIELD



### Longer Waiting Lists, Longer Waits

A survey of 450 community providers fielded by ANCOR in 2021 found that 77% of providers were turning away new "referrals," meaning they were unable to support additional people beyond those already being supported, due to the direct support workforce crisis.

One such provider is United Cerebral Palsy of Stanislaus County. Chris Martin, the agency's Executive Director, explained that, "During the beginning of COVID, we closed all programs down and transitioned to an online model [for day supports]. We developed a plan to phase back into in-person supports, but we have yet to move onto Phase 2 because we cannot hire enough staff." Like so many providers, UCP of Stanislaus County has lost many long-time staff members who found better-paying opportunities elsewhere, and is finding it close to impossible to attract new staff who can find other industries where they can work fewer hours while earning better pay and benefits.

Providers being unable to take on new referrals means longer waiting lists—and longer waits for those waiting. Although Martin's organization supports people with IDD in California, which doesn't have a waiting list for HCBS services, UCP of Stanislaus County has had to start its own waiting list. "We are trying to keep in contact with people through technology, remote supports and home visits, but it's not the level of service we want to offer."

# The Case for Inclusion 2022

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