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## **New Report Shows Persistent Workforce Crisis, Ballooning Waiting Lists are Jeopardizing Community Inclusion for People with Disabilities**

*Case for Inclusion 2020 Assesses How Well State Programs Support People with Intellectual, Developmental Disabilities*

WASHINGTON, D.C. – A [new report](#) published today by the ANCOR Foundation and United Cerebral Palsy (UCP) finds that a significant shortage of direct support professionals who support people with intellectual and developmental disabilities (I/DD), along with growing waiting lists and insufficient employment opportunities, are inhibiting the ability of people with I/DD to be included in the community.

The *Case for Inclusion 2020* assesses all 50 states and the District of Columbia on 58 measures of how well state programs, primarily Medicaid, serve those with I/DD. The report reveals that the state in which a person with a disability lives can be a significant predictor of that person's life trajectory and whether they have the opportunity to live, work and otherwise be included in the community.

In large part, this challenge stems from a **direct support workforce** in crisis, characterized by low wages and high turnover and vacancy rates among direct support professionals, or DSPs—the professionals who support people with I/DD in everything from completing daily living activities to building job skills to enacting their civic duties, such as voting. While the *Case for Inclusion* finds a national turnover rate among DSPs of 43.8 percent, turnover varies widely between states—from a low of 24.4 percent in the District of Columbia to a high of 68.8 percent in Nebraska. In part, high turnover is explained by low wages—the median wage nationally was just \$12.09 per hour—and closely associated with high vacancy rates. According to the most recent data available, 8.1 percent of full-time and 17.3 percent of part-time direct support positions were vacant.

The challenges associated with a workforce in crisis may help to explain why the *Case for Inclusion* also reveals a significant increase in the number of people with I/DD on states' **waiting lists** for Medicaid-funded Home and Community Based Services (HCBS). In 2017 (the most recent data available used for this report), there were 473,000 people with I/DD—49,000 more than in the year prior—on waiting lists for HCBS waivers to enable them to be supported in community-based settings, rather than in large, state-run institutions with few or no opportunities to lead a full and independent life.

The report ranks states in seven key areas critical to the inclusion, support and empowerment of people with I/DD and their families: Addressing a Workforce in Crisis; Reaching Those in Need; Promoting Productivity; Tracking Health, Safety & Quality of Life; Promoting Independence; Keeping Families Together and Serving at a Reasonable Cost.

For most measures, the report reveals a mixed picture in terms of outcomes for individuals with I/DD. For example, when it comes to **integrated employment**—the percentage of a state’s workers with I/DD participating in services that support their ability to work in the community—10 states (up from seven in the previous edition) reported integrated employment rates of 33 percent or higher. Despite this positive increase across multiple states, other states saw integrated employment rates dip or hover at the same percentage as the previous year. Nationally, there were only 3,000 more workers with I/DD in integrated employment compared to the previous report, marking an increase of only a single percentage point (from 19 percent to 20 percent) and indicating some stagnation in this critical area.

Similarly, the **waiting list** data shows a mix of positive and negative trends that gives overall cause for concern—with the overall number of people with I/DD on waiting lists nationwide jumping nearly 12%. On the one hand, 10 states had no waiting lists for individuals to be able to receive HCBS services and another 10 states saw their waiting lists shrink from 2016 to 2017. However, another 23 states saw their waiting lists grow longer, some significantly so. For example, in Texas—the state with the longest HCBS waiting list—there were more than 218,000 families awaiting long-term supports and services as of the 2020 *Case for Inclusion*.

**“The vast majority of states can claim year-over-year improvements within at least a few measures, illustrating that states and community service providers are committed to improving the quality of long-term supports and services delivered to people with I/DD,”** claim the report’s authors. They go on to explain, **“But the corollary is also true: there are no states without room for improvement.”**

That improvement can be realized, the authors maintain, with smart, sensible public policy solutions that invest in the ability of community providers to support people with I/DD in community-based, rather than institution-based, settings.

“Especially as we head into 2020 and one of the most pivotal election years our nation has seen, it is absolutely critical that lawmakers at all levels of government understand how decades of underinvestment in long-term supports and services for people with I/DD has been one of our generation’s most significant public policy failures,” said **Barbara Merrill, chief executive officer for the ANCOR Foundation**. “At the same time, the *Case for Inclusion* lays out meaningful, manageable ways in which positive movement on the policy front can create opportunities for people with I/DD to be part of the community.”

**Armando Contreras, president and chief executive officer for UCP National**, added: “Nearly 15 years of experience leading the development of the *Case for Inclusion* has proven that advocates in every corner of our country are eager to be the architects of more inclusive communities. The question is simply whether lawmakers are willing to invest in programs that enable community inclusion. If so, UCP and our affiliates look forward to locking arms with ANCOR and its members as willing partners in the journey to create life without limits for people with I/DD.”

The full *Case for Inclusion 2020* report, along with scorecards for each state and additional resources, can be downloaded at [caseforinclusion.org](http://caseforinclusion.org).

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### **About United Cerebral Palsy**

*United Cerebral Palsy ([ucp.org](http://ucp.org)) educates, advocates and provides support services through an affiliate network to ensure a life without limits for people with various disabilities. Together with 60 affiliates, UCP has a mission to be the indispensable resource for individuals with cerebral palsy and other disabilities, their families and their communities. UCP affiliates in the US and Canada provide supports to approximately 155,000 children and adults on an annual basis—one person at a time, one family at a time. UCP works to enact real change—to revolutionize care, raise standards of living and create opportunities—impacting the lives of millions living with disabilities. For 70 years, UCP has worked to ensure the inclusion of individuals with disabilities in every facet of society. Together, with its member affiliates, parents and caregivers, UCP will continue to push for the social, legal and technological changes that increase accessibility and independence, allowing people with disabilities to dream their own dreams, for the next 70 years, and beyond.*

### **About ANCOR, the ANCOR Foundation & *Included. Supported. Empowered.***

*For 50 years, the American Network of Community Options and Resources (ANCOR) has been a leading advocate for the critical role service providers play in enriching the lives of people with intellectual and developmental disabilities. As the 501(c)3 charitable arm of ANCOR, the ANCOR Foundation exists to expand the commitment and capacity of providers and communities dedicated to improving quality of life for people with disabilities. A critical part of this effort, the ANCOR Foundation's *Included. Supported. Empowered.* campaign exists to lift up the successes of people of all abilities and highlight the essential role providers play in bringing those successes to fruition. Learn more at [WeHaveAStake.org](http://WeHaveAStake.org).*