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New Report Shows State Efforts to Serve Individuals with Intellectual and Developmental Disabilities Have Stalled or Backslid

Case for Inclusion 2019 Ranks States on Policies and Programs that Encourage Employment and Community Living

WASHINGTON, D.C. – Despite significant progress over the past decade to help individuals with intellectual and developmental disabilities integrate into the larger community, the ANCOR Foundation joins United Cerebral Palsy (UCP) on a new report that finds those efforts have stagnated or even moved backwards in recent years.

The *Case for Inclusion 2019*, which ranks all 50 states and the District of Columbia on how well state programs, primarily Medicaid, serve those with intellectual and developmental disabilities (I/DD), shows that where these individuals live has an enormous impact on their life trajectory. For example, a person born with Down syndrome in a high-ranked state such as Arizona (1st place) or Oregon (2nd place) is likely employed, earning a competitive wage and residing with roommates in a community setting. By contrast, in low-ranked states such as Texas (49th place) or Arkansas (50th place), the same individual is most often living in a large state institution with few or no opportunities to lead a full and independent life.

The report ranks states in five key areas critical to the inclusion, support and empowerment of I/DD Americans and their families: Promoting Independence, Promoting Productivity, Keeping Families Together, Serving Those in Need, and Tracking Health, Safety & Quality of Life.

In most areas, the report found that notable advances in the support of individuals with I/DD have stalled. For instance, just 29 states—two more than in the 2016 *Case for Inclusion*—report that at least 80 percent of these Americans are served in home-like settings, such as a family home, their own home or a small group setting. And decades after states embarked on efforts to close large state institutions that warehouse the intellectually and developmentally disabled, just 15 states have eliminated all such facilities, a number that is unchanged from 2016.

The report documented downward trends in two areas: (1) the number of people on waitlists for residential and community services, and (2) the number of individuals with I/DD working in competitive employment, meaning they work alongside people without disabilities at a market-driven wage. The *Case for Inclusion 2018* found the number of people on waiting lists for Home and Community-Based Services was up 75,000 from the 2016 report to almost 424,000. Just seven states, down from 10 in 2016, reported at least 33 percent of working-age individuals with I/DD working in competitive employment.

“Individuals with I/DD, including the young and the aging, want and deserve the same opportunities and quality of life as all Americans. Yet some states do much better than others in demonstrating the needed political will and implementing the sound policies and focused funding necessary to achieve this ideal,” the report states.

Factors driving the stagnating or downward trends include states forgoing Medicaid expansion and growing shortages in Direct Support Professionals (DSPs), the frontline workers who help those with disabilities integrate into the community. “The DSP workforce crisis may be the most significant challenge we face in improving the outcomes tracked by the *Case for Inclusion*,” said ANCOR and ANCOR Foundation CEO Barbara Merrill. “Without the professional staff needed to provide the supports and services that enable people with I/DD to be integrated into the community, provider agencies have little hope of maintaining and expanding on any progress they’ve seen in the past decade.”

The *Case for Inclusion*, which has been published regularly since 2006 by UCP, compiles the most recent data available (generally from 2016 for this report) and analyzes 30 outcome measures in the five major categories. Among the other key findings from this year’s report:

- Thirty-three states, one more than in 2016, meet what’s known as the 80/80 Home and Community Standard, meaning that at least 80 percent of all individuals with I/DD are served in the community and 80 percent of all resources support their ability to live in homes with fewer than seven residents and participate in the broader community.
- Just 16 states, up from 15 in 2016, support a large share of families (at least 200 families per 100,000 of population) through family support services that help them care for children with disabilities at home and adults with disabilities living in a community setting.
- Only 15 states, the same as in 2016, successfully placed at least 60 percent of individuals in vocational rehabilitation jobs.
- Just 15 states report that at least 10 percent of individuals use self-directed services, which allow them to design the supports they receive based on their specific needs. This number is also unchanged since 2016.

The report shows how several states have driven reforms during the past decade. Between 2007 and 2019, Ohio jumped from 48th to 8th place in the rankings by dramatically increasing the share of individuals served in the community (from 63 percent to 86 percent) and reducing by half the portion of those served in a state institution. Maryland moved from 33rd to 11th place by increasing the portion of people served in home-like settings (from 74 percent to 99 percent), closing two state institutions and adding a Medicaid Buy-In program.

The report highlights states that have been models for the rest of the country. For example, in 2006, Washington State developed a policy that prioritized employment for individuals with I/DD. The impact of Washington’s “Employment First” policy was profound, with the number of individuals working for pay increasing 81 percent from 2,322 in 2007 to 4,200 in May 2018. At 85 percent, Washington now has the highest rate in the country of individuals with I/DD participating in competitive employment, compared to the national average of just 19 percent.

By contrast, several states that have remained stuck at or near the bottom of the rankings perform similarly on certain important measures, such as a failure to serve a substantial portion of the state’s population with I/DD and an insufficient commitment of funding to individuals served. For example, North Dakota (46th place) and Oklahoma (47th place) both failed to meet the aforementioned 80/80 Home and Community Standard, and have seen rankings at or near the bottom of the *Case for Inclusion* rankings since its inception in 2006.

It is notable that during a period of polarization on many issues, policies that support individuals with I/DD have support from stakeholders across the political spectrum. For example, the 10 highest-ranked states are a political mix, including deep-blue Oregon and California and deep-red Kentucky and South Dakota. Armando Contreras, President & CEO of UCP, notes that “across the country we see efforts by state policymakers to enhance their approach to Medicaid services and supports and related programs for the I/DD population by making the best use of existing and scarce resources. Of course, additional funding to keep pace with the diverse needs of this population would help, but new ideas and shared best practices from successful states have the potential to drive improvements even absent additional funding.”

The full *Case for Inclusion 2019* report, along with scorecards for each state and additional resources, can be downloaded at caseforinclusion.org.

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About United Cerebral Palsy

United Cerebral Palsy (ucp.org) educates, advocates and provides support services through an affiliate network to ensure a life without limits for people with a spectrum of disabilities. Together with 64 affiliates, UCP has a mission to advance the independence, productivity and full citizenship of people with disabilities by supporting more than 176,000 children and adults every day—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 the ANCOR Foundation

The ANCOR Foundation (ancorfoundation.org) exists to expand the commitment and capacity of providers and communities dedicated to improving the quality of life of people with intellectual and developmental disabilities. The Foundation works to amplify the impact of service providers whose programs and resources empower people of all abilities to live independently, enjoy greater accessibility, and experience the self-confidence and self-satisfaction that comes with being an included and valued part of the community.