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Utah Ranks 17th Among All States in Efforts to Serve Individuals with Intellectual and Developmental Disabilities

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

WASHINGTON, D.C. – Utah has taken steps to improve policies that help individuals with intellectual and developmental disabilities lead more independent and productive lives, moving the state up slightly from 24th place in 2016 to 17th place today in state rankings compiled by the ANCOR Foundation and United Cerebral Palsy (UCP).

[The Case for Inclusion 2019](#) 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). The states are ranked in five key areas critical to the inclusion, support and empowerment of individuals with I/DD and their families: Promoting Independence, Promoting Productivity, Keeping Families Together, Serving Those in Need, and Tracking Health, Safety & Quality of Life.

Utah showed particularly notable improvement in the portion of those with I/DD served through community-based programs, increasing from 86 percent in the 2016 *Case for Inclusion* report to 96 percent in this year's report. The state also saw a slightly higher than average rate of working-age Utahans working in competitive employment (23 percent, compared to the national average of 19 percent), meaning they work alongside individuals without disabilities and earn market-driven wages.

Despite these important improvements, Utah, like most others, struggled in two critical areas: (1) the number of people on waitlists for residential and community services, and (2) the number of individuals living in large, state-run institutions. The number of people on waiting lists for Home and Community-Based Services was 2,387, meaning Utah would need to expand its existing service offerings by 46 percent in order to meet current levels of demand. Meanwhile, 3.3 percent of the state's residents with I/DD—nearly twice the national average of 1.7 percent—lived in Utah's single state-run institution.

Nationally, 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.

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. The ANCOR Foundation joins UCP this year in publishing the report. Among the other findings on Utah’s performance:

- In addition to the 191 Utahans living in a large, state-run institution, there were an additional 836 individuals with I/DD living in large-scale congregate care settings, defined as group homes and Intermediate Care Facilities with seven or more residents.
- One in four (24 percent) Utahans with I/DD self-directed their own services, a rate that is more than twice the national average of 11 percent.
- On average, Utah spent \$8,176 per family to keep families together, lower than the national average of \$11,060 per family. Accordingly, only 29 percent of Utah’s residents with I/DD lived in a family home, compared to the national average of 62 percent.

Nationally, 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—a number that hasn’t budged from the 2016 *Case for Inclusion* findings. And decades after states embarked on efforts to close large institutions that warehouse the intellectually and developmentally disabled, just 15 states have eliminated all such facilities, a number that is also unchanged from 2016.

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 annual *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.”

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 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.

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.