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New York Ranks 18th 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. – Despite showing strong support for policies that help individuals with intellectual and developmental disabilities lead more independent and productive lives, New York continued a gradual slide that began in 2012, coming in 18th place this year 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.

The strengths in New York's performance in this year's rankings were most notable in the area of Serving Those in Need, where the state tied for first in the nation, in large part due to the fact that New York has no individuals on a waiting list to receive Home and Community-Based Services. The state also earned high marks for meeting the coveted 80/80 standard, meaning at least 80 percent of the state's residents with I/DD receive HCBS services and at least 80 percent of the state's I/DD expenditures are allocated to support individuals in community-like settings. New York fared better than the national averages on both of these measures, at 93 percent and 90 percent, respectively.

Despite these important improvements, New York, like most others, struggled in two critical areas: (1) the number of residents in large-scale congregate care settings, 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 number of residents in congregate care facilities—defined as group homes and Intermediate Care Facilities with at least seven residents—was 19,852, a number significantly higher than all other states. Moreover, with only 13 percent of working-age individuals with I/DD working in competitive employment—meaning they work alongside individuals without disabilities and earn market-driven wages—New York's performance on this measure is significantly lower than the national average of 19 percent.

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 New York’s performance:

- Whereas the state has a high number of individuals living in large-scale congregate care settings, it has a comparably lower percentage of residents living in large, state-run institutions. At 0.3 percent, or 436 residents, New York has a significantly smaller portion of individuals with I/DD living in institutions than the national average of 1.7 percent.
- The percentage of individuals participating in Vocational Rehabilitation who found a job was 58 percent, four percentage points higher than the national average.
- Only three other states spent more than New York to keep families together. However, despite spending \$488 million, New York spent an average of only \$8,847 per family, lower than the national average of \$11,060.

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.