

FOR IMMEDIATE RELEASE

January 10, 2019

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Massachusetts Ranks 35th 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. – Stagnant or declining investments in state programs that help individuals with intellectual and developmental disabilities lead more independent and productive lives have resulted in Massachusetts dropping from 4th place in 2007 to 35th place this year in state rankings, according to the *Case for Inclusion 2019*, 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 biggest factors affecting Massachusetts' poor performance were its low marks in Reaching Those in Need and Tracking Health, Safety & Quality of Life; Massachusetts ranked 41st in both categories. In the latter of those categories, Massachusetts performed at or below the national average in five out of eight measures, including the percentage of people with I/DD reporting that they don't often feel lonely (57 percent of Bay Staters with I/DD, compared to the national average of 89 percent) and the percentage of people with I/DD reporting they had gone out in the community for entertainment purposes in the last month (69 percent in Massachusetts, compared with the national average of 77 percent).

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 key findings on Massachusetts' performance:

- There were 409 individuals in Massachusetts—1.9 percent of those with I/DD in the state—living in a large, state-run institution. In addition, there were 912 individuals living in a large-scale congregate care setting—defined as group homes and Intermediate Care Facilities with at least seven residents.

- On average, Massachusetts spent \$3,066 per family on efforts to keep families together—less than one-third of the national average of \$11,060.
- A relative bright spot for Massachusetts was in the area of Promoting Productivity, where the state ranked 10th in the nation. Thirty-eight percent of the state’s working-age residents with I/DD worked in a competitive employment setting, meaning they worked alongside people without disabilities at market-driven wages. Only three states outperformed Massachusetts on this measure.

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.

The report documented downward trends in two critical 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 2019* 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 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 or 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.