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## **Illinois Ranks 44<sup>th</sup> 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.** – Illinois has taken no significant steps to improve policies that help individuals with intellectual and developmental disabilities lead more independent and productive lives, resulting in a continued poor showing in state rankings compiled by the ANCOR Foundation and United Cerebral Palsy (UCP). The *Case for Inclusion 2019* ranks Illinois 44<sup>th</sup> overall, which is up slightly from 47<sup>th</sup> place in the 2016 report.

[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 Illinois' continued poor showing were in the areas of Promoting Independence (49<sup>th</sup>), Keeping Families Together (44<sup>th</sup>) and Promoting Productivity (45<sup>th</sup>). Factoring into Illinois' near-last ranking in Promoting Independence, 60 percent of Illinoisans with I/DD were living in settings (including their personal home, family home, or care facilities) with six or fewer individuals. This is markedly lower than the national average of 92 percent.

Illinois had a modest ranking in the remaining two areas of Tracking Health, Safety & Quality of Life (14<sup>th</sup>) and Serving Those in Need (25<sup>th</sup>). Thirty-eight percent of Illinoisans with I/DD were on the state's waiting list to receive services, on par with the national average. Additionally, Illinois' quality of life indicators were on par the national average, contributing to the state's middle-of-the-pack performance for that measure.

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 Illinois' performance:

- 1,653 individuals with I/DD were living in Illinois’ seven large, state-run institutions.
- Illinois spent an average of \$425 per person per day on Illinoisans with I/DD living in the state’s institutions, a figure that is slightly more than half the national average of \$762.
- 78 percent of Illinoisans with I/DD were receiving long-term supports and services through Medicaid-funded waivers, putting Illinois in the bottom five in the nation for this metric and well below the national average of 92 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.

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](http://caseforinclusion.org).**

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### **About the ANCOR Foundation**

*The ANCOR Foundation ([ancorfoundation.org](http://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](http://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.*