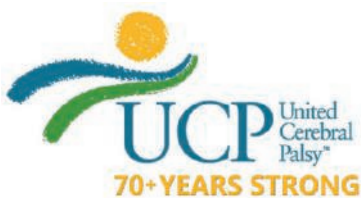


The Case for Inclusion 2020

KEY FINDINGS REPORT

caseforinclusion.org



The Case for Inclusion 2020

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ACKNOWLEDGMENTS

Data for the *Case for Inclusion 2020* and the contents of this key findings report were authored by staff from the ANCOR Foundation and United Cerebral Palsy (UCP). Significant contributions were made by members of the *Case for Inclusion* Steering Committee, to whom the authors extend their deep gratitude: Jeanne De Sa, UCP Board of Trustees; Marybeth Fitzgerald, Gillette Children's; Becky Hansen, UCP of Los Angeles, Ventura & Santa Barbara Counties; Anne Hindrichs, McMains Children's Developmental Center; Ellen Jensby, Alliance Colorado; Fernanda Morrison, UCP Policy Committee; Valdes Snipes-Bennett, Ph.D., UCP of Washington, DC & Northern Virginia; Rita Wiersma, Community Involvement Programs; and Diane Wilush, UCP of Georgia & South Carolina. We

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DEAR INCLUSION ADVOCATE

Thank you for your interest in the *Case for Inclusion 2020* and for your work to ensure that people of all abilities have the opportunity to be included in the community.

In every corner of our country, people with intellectual and developmental disabilities (I/DD) enrich communities and enhance the diversity of the perspectives that make our communities stronger. In part, this is made possible by the thousands of community-based provider organizations that are committed to the idea that a disability shouldn't determine where you can live, work or engage in the community. But too often, underinvestment in the long-term supports and services that facilitate community inclusion mean that people with I/DD are isolated rather than included, segregated rather than supported, and excluded rather than empowered.

To be the best possible advocates we can be for people with disabilities, United Cerebral Palsy and the ANCOR Foundation have partnered to create the *Case for Inclusion 2020*. This investment demonstrates our strong belief that data and stories, when combined, make a compelling case for creating truly inclusive communities. This report and the accompanying online tools have been specially designed to facilitate and strengthen your advocacy, both at the state and federal levels.

As we move into a new decade, one with many opportunities before us, we hope that you will take the opportunity to use the *Case for Inclusion 2020* as an invaluable resource in your efforts to ensure that all facets of our communities invest in creating a life without limits for people with disabilities.

Sincerely,

Armando Contreras
President & CEO
United Cerebral Palsy

Barbara Merrill
CEO
ANCOR & the ANCOR
Foundation

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EXECUTIVE SUMMARY

People with intellectual and developmental disabilities (I/DD), along with the community-based providers that support their inclusion in everyday life, find themselves at an important crossroads as they look ahead to 2020 and beyond.

For a host of reasons, 2020 portends to be a pivotal year for our country's system of long-term supports and services for people with I/DD. How will the 2020 elections impact state and federal governments' commitment to full inclusion, financed in large part by Medicaid as an uncapped federal entitlement, and demonstrated by federal and state legislative and executive branches' fidelity to the Supreme Court's decision in *Olmstead v. LC*, which galvanized the promise of the Americans with Disabilities Act? As this report highlights, how a state is faring—how it stacks up in providing individuals the opportunity to live and work in the community—is increasingly limited by historically high turnover rates among direct support professionals (DSPs).

It is against this backdrop that the key findings presented here and the *Case for Inclusion* more broadly were designed. Each year, the *Case for Inclusion* assesses all 50 states and the District of Columbia on how well states are supporting their residents with I/DD through programs such as Medicaid. One thing longtime users of the *Case for Inclusion* will note is different about this year's report is the lack of rankings. Whereas previous editions of the *Case for Inclusion* have ranked the states to give advocates and lawmakers points of comparison between one another, the ranking methodology was becoming needlessly complex as we sought to diversify the types of measures presented. Therefore, readers will find graphics in this report and charts at caseforinclusion.org that rank states on individual measures, but no overall rankings that aggregate the measures together are included.



This improvement to the methodology has made it possible for the *Case for Inclusion 2020* to assess the states on 58 distinct measures across seven different issue areas. New this year is the issue area you'll find in the center spread of this publication: **ADDRESSING A WORKFORCE IN CRISIS**. The authors of this report chose to include this issue area—which examines turnover rates, vacancy rates, average hourly wages and more—because of the direct impact a dire shortage of DSPs continues to have on opportunities for community inclusion.

Beyond this new issue area, new data for 2020 can be found in three other issue areas:

- **PROMOTING PRODUCTIVITY**
- **REACHING THOSE IN NEED**
- **TRACKING HEALTH, SAFETY & QUALITY OF LIFE**

These data reflect FY 2017 or FY 2018 unless otherwise noted. Due to differences in the collection and publication frequency of the original sources of data from which the *Case for Inclusion* is derived, there are three issue areas for which no new data were available at the time this report went to press: **KEEPING FAMILIES TOGETHER**, **PROMOTING INDEPENDENCE**, and **SERVING AT A REASONABLE COST**.

As a result, measures within those issue areas are not featured in this year's key findings report, but the most recently available data (published in the previous edition of the *Case for Inclusion*) can be found at caseforinclusion.org.



Within the four issue areas for which new data are available, below are the key findings from the *Case for Inclusion 2020*:

- The total number of people with I/DD on **waiting lists for Home and Community Based Services (HCBS)** increased by 49,000, from 424,000 in the last report to 473,000 in this year's report. Ten states saw decreases in the number of people on their HCBS waiting lists, while 23 states saw their waiting lists grow.
- Nationally, the **turnover rate for direct support roles** was 43.8%. In large part, this can be explained by low **median hourly wages for DSPs**, which stood at just \$12.09 nationally.
- The percentage of **people with I/DD working in integrated employment**—meaning they are employed alongside people without disabilities and earn market-driven wages—creeped upward by just one percentage point, from 19% in the *Case for Inclusion 2019* to 20% this year. Across the nation, there were 127,000 people with I/DD working in competitive employment, up from 124,000 in last year's report. Whereas only seven states in the *Case for Inclusion 2019* could boast that more than one-third of their residents with I/DD were engaged in competitive employment, that number increased to 10 states in 2020.
- There was an increase of two percentage points in the number of **people with I/DD engaged in self-direction**, from 11% in FY 2017 to 13% in FY 2018.

These findings and the countless other insights available to inclusion advocates in this year's *Case for Inclusion* reveal a mixed bag. The vast majority of states can claim year-over-year improvements within at least a few measures, illustrating that states and community service providers are committed to improving the quality of long-term supports and services delivered to people with I/DD.

But the corollary is also true: there are no states without room for improvement. No matter how well a state performs on a given measure or within a specific issue area, there is no shortage of ways in which more significant or more efficient investments could help improve quality, expand the reach or deepen the impact of the programs highlighted in this report.

It is for this reason that federal and state governments are also at an important crossroads. They can charge ahead on the current path, continuing a long history of underinvestment in the capacity of people with diverse abilities to enhance our communities. Or, they can choose to take a turn in the right direction—one that puts us closer to our shared vision of truly inclusive communities for all.

As for the rest of us, we can do our part through advocacy. The authors of this report have envisioned this resource to be a helpful place to turn as you lend your voice to this critical cause. We hope you find that we have fulfilled that vision, and that you'll reach out to let us know how we can improve the usefulness of this resource moving forward.

ABOUT THIS REPORT

Since 2006, the *Case for Inclusion* has been one of the nation's leading sources for data about how well states are supporting people with intellectual and developmental disabilities (I/DD) to be part of the community.

Day in and day out, and in every corner of our nation, community providers—the organizations that provide long-term supports and services to people with I/DD—make magic happen.

Through support that enables people to choose where they live, secure and maintain a job, exercise their civic rights, build meaningful and lasting relationships, and a whole lot more, providers are the bridge between people with diverse abilities and the communities where they live, work and play.

But too often, providers lack the investments from federal and state governments to deliver the quality of support that people deserve to the number of people for whom access to that support makes the difference between living in a state-run institution or living a fully inclusive life. This lack of investment is exacerbated by increasing regulatory requirements and economic factors at both the state and federal levels that drive up costs and are typically not accompanied by commensurate increases in reimbursements to allow community-based I/DD service providers to keep pace.

With these challenges as our backdrop, United Cerebral Palsy (UCP) and the ANCOR Foundation partner to publish the *Case for Inclusion*, an annual compendium of data on key measures that assess the extent to which state programs—primarily Medicaid—are meeting the needs of a population of people with I/DD that is growing in both size and complexity.

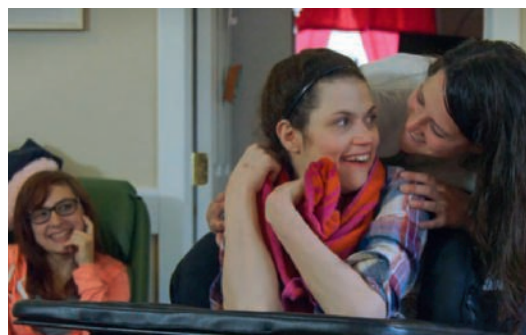
ABOUT OUR METHODOLOGY

The data highlighted in this key findings report are not comprehensive; comprehensive data can be found at caseforinclusion.org. Also available on the website is documentation for each of the data measures, including definitions, original sources, the year data were collected, the year data were published and notes from the original data sources indicating departures from standard methodological practice.

The vast majority of the data in the *Case for Inclusion 2020* have been sourced from the State of the States in Intellectual and Developmental Disabilities Project at the University of Colorado, the Institute for Community Inclusion at the University of Massachusetts Boston, the Kaiser Family Foundation, National Core Indicators and the Residential Information Systems Project at the University of Minnesota. Other credible national sources provided additional data where noted.

For measures where new data were made available after the publication of the *Case for Inclusion 2019* but before the *Case for Inclusion 2020* went to print, data applications at caseforinclusion.org have been updated to reflect the latest available data. For the remaining measures, no updates to these apps have been made since January 2019, but the most recent available data as of January 2020 have been preserved.

Readers are encouraged to use the data documentation section of the methodology page of the website to connect with original data sources to identify whether new information has since become available.



WHAT ABOUT THE TERRITORIES?



People often ask us why the *Case for Inclusion* doesn't include data for the five inhabited U.S. territories: American Samoa, Guam, the Northern Mariana Islands, Puerto Rico and the U.S. Virgin Islands.

The unfortunate answer is that although we'd love to include data for the U.S. territories, insufficient comparison data are available. Although the Americans with Disabilities Act is the law for all of the land—the states and territories alike—there is a significant disparity between federal funding and benefits for Americans that reside in the territories and their counterparts in the states. That disparity and lack of data make it all the more difficult to provide an accurate assessment of unmet need or other indicators of community inclusion included in this report.

Our general lack of understanding about the situation facing people with I/DD in the territories, which are home to more than 4 million Americans, has potentially devastating consequences. Consider, for example, Puerto Rico, where residents of the island are not eligible for Supplemental Security Income (SSI), and the structure of the government's Medicaid program has resulted in a total lack of Medicaid waiver funding for home and community services. The strongest indicator of the lack of progress toward inclusion available is the fact that Puerto Rico is substantially out of compliance with a 20-year-old *Olmstead* consent decree: the 1999 *United States*

of America v. Commonwealth of Puerto Rico, civil case no. 99-1435 (GAG).

To help alleviate this challenge, the authors of the *Case for Inclusion* will be working with our partners to identify avenues for collecting data that ultimately illuminate what investments are needed to ensure community inclusion for residents of U.S. territories with I/DD. If and when data become available, they will be included in subsequent editions of this report.

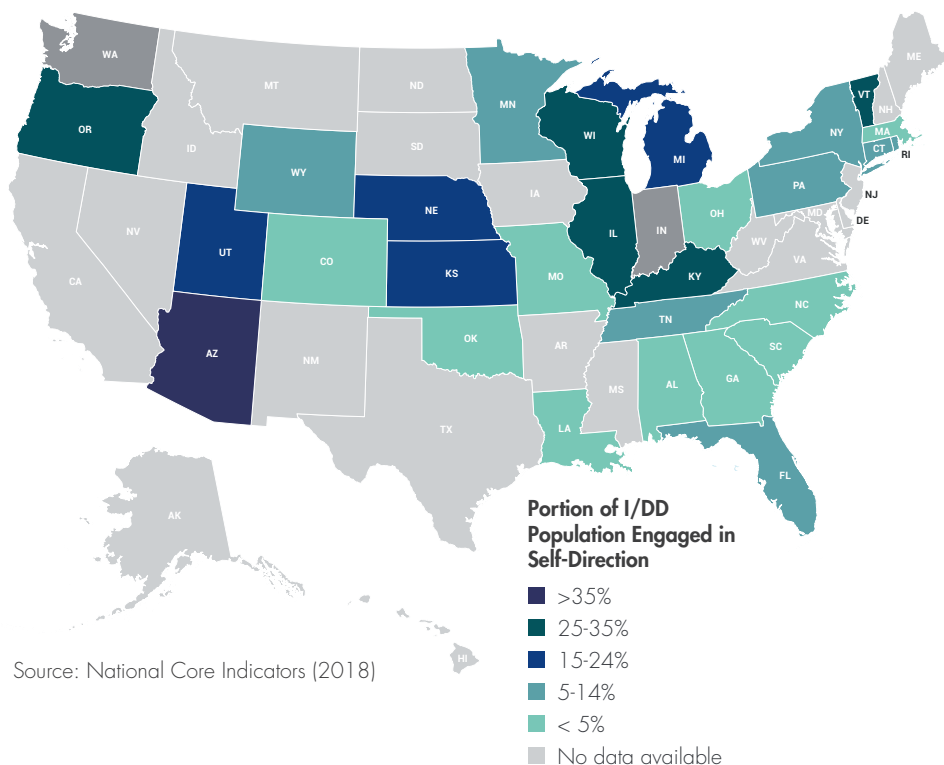
TRACKING HEALTH, SAFETY & QUALITY OF LIFE

From the ability to build and maintain meaningful relationships, to simple things most people take for granted like running errands or going to the dentist, the extent to which people are included in the community has a significant impact on a person's quality of life. This issue area examines several measures that gauge people's ability to be part of the community and, in turn, live a happy, healthy life.

"When I look in the mirror, this is what I see. I see a woman who is proud of her independence.... Other people may see someone with a disability; I see a woman who is absolutely unstoppable."

– Shelly, Self-Advocate in Colorado

IN FOCUS: Rates of Participation in Self-Direction



Defining and measuring the extent to which a person feels included in the community can be difficult. After all, what matters to one person may be less important to another. For that reason, the *Case for Inclusion* examines data from National Core Indicators about self-direction, the percentage of people with I/DD using one of their state's options that enable them to direct their own supports.¹ The vast majority of states offer at least one option for **self-direction**, although there is wide variation between states in terms of the portion of their populations engaged in self-direction.

¹ Readers should note an important distinction between self-direction and person-centered supports. Even when a person does not direct their own services, they should be engaged in making choices about the supports they receive, and those supports should be designed around their unique needs.

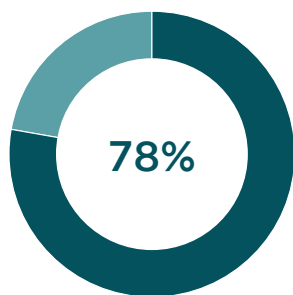
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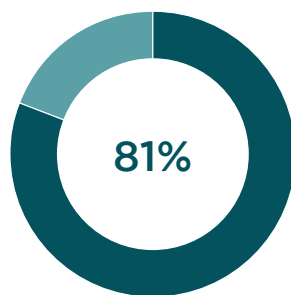
The *Case for Inclusion* reports on a wide range of measures in TRACKING HEALTH, SAFETY & QUALITY OF LIFE, including how many people in a given state **Ran Errands Recently, Don't Often Feel Scared, Have Relationships Beyond Family & Staff, Went Out to Eat Recently, Went Out for Entertainment Recently, Had a Recent Dental Visit, and Attended Religious Services Recently**. No single one of these measures on its own can tell us whether someone is living a truly inclusive life, but together, these measures paint a picture about the opportunities for people to have a higher quality of life.



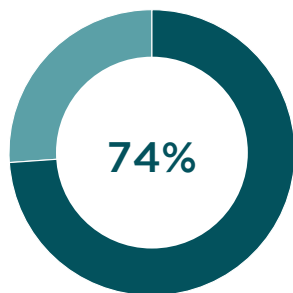
Quality of Life & Person-Centered Supports



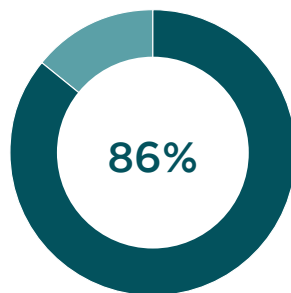
"I have friends who aren't members of my family or staff."



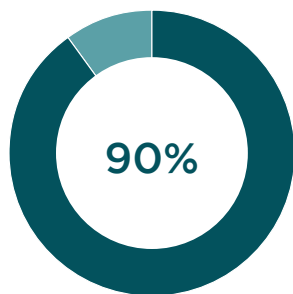
Percentage of people for whom a dentist visit in the past year was reported



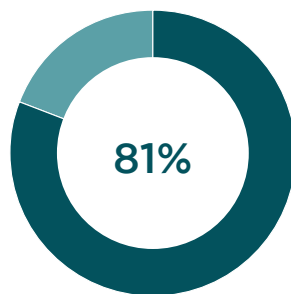
"I have gone out for entertainment at least once in the past month."



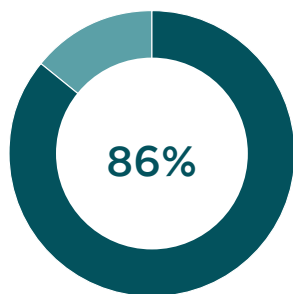
"I have gone out to eat at least once in the past month."



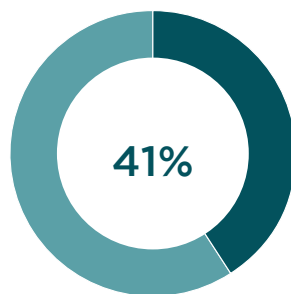
"I do not often feel lonely."



"There is nowhere I regularly go that causes me to feel scared."



"I have gone out to run errands at least once in the past month."



"I have attended religious services at least once in the past month."

ADDRESSING A WORKFORCE IN CRISIS

From their place on the frontlines supporting people of all abilities to be part of the community, direct support professionals, or DSPs, do it all. But nationally, the DSP workforce is in crisis, with high turnover and vacancy rates often leaving community providers unable to support people to thrive in fully inclusive communities.

Having a stable direct support workforce is critical to people being supported, as the highest-quality supports—and thus the highest possible quality of life—are made possible by qualified professionals who have spent time getting to know the people they support. The chart above presents perhaps the most troubling measure from the National Core Indicators (NCI) Staff Stability Survey: **turnover rates**.

States' turnover rates—defined as the number of DSPs who left their positions in the past year divided by the number of DSPs employed at the end of that year—ranged from a low of 24.4% in the District of Columbia to a high of 68.8% in Nebraska. The average turnover rate nationwide was 43.8%.

“To pay my bills, I have to do an extra 16 hours per week [but] sometimes you just want to actually rest or go to a family function—I miss a lot of those. But honestly, I love what I do. I see the impact.”

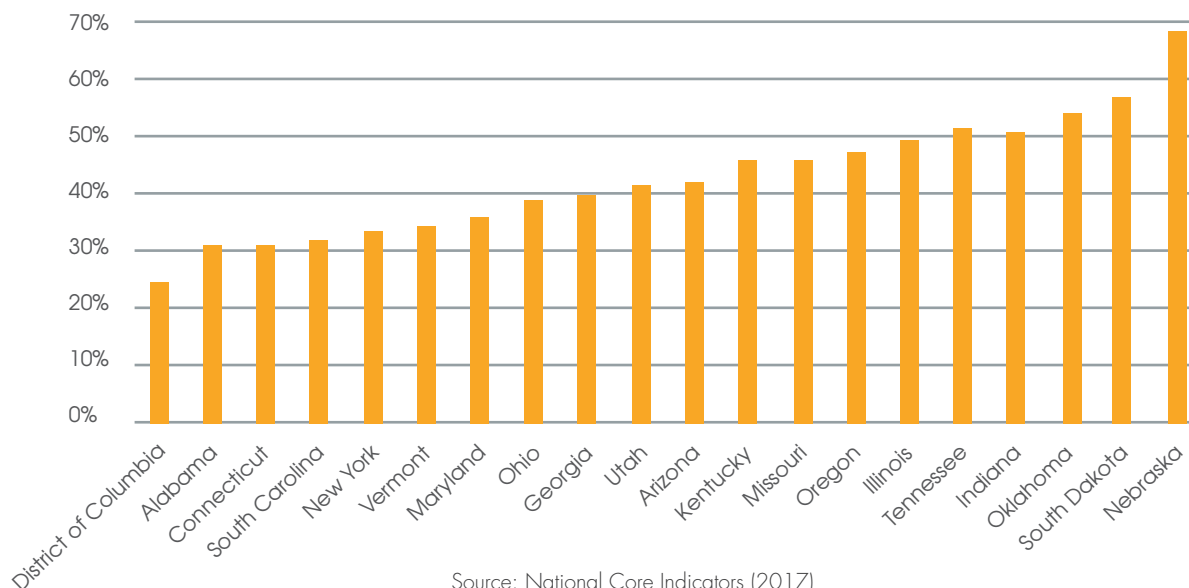
—Nick Smith, Direct Support Professional in Philadelphia

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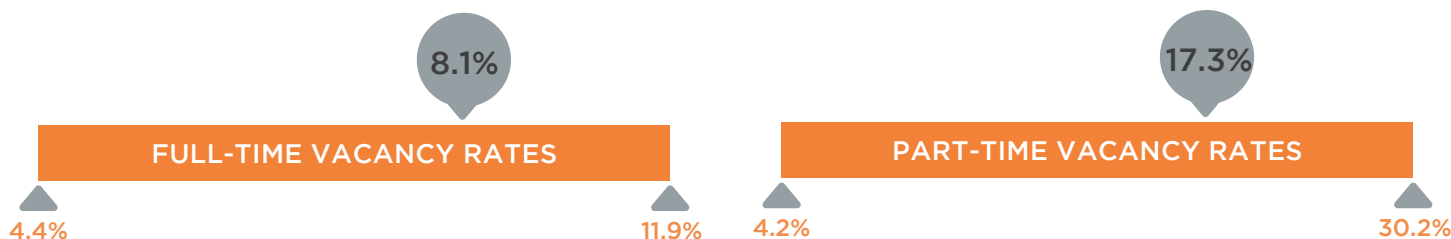
For the first time ever, this year's *Case for Inclusion* offers **ADDRESSING A WORKFORCE IN CRISIS**, an issue area designed to equip advocates, legislators and regulators with data to help respond to the growing DSP workforce crisis. This issue area includes four key measures: **turnover rates**, **vacancy rates** (for both full- and part-time positions), **tenure** (for both employed and separated DSPs), and **median hourly DSP wages**. Unless otherwise noted, the data in this issue area are derived from the 2017 NCI Staff Stability Survey, which gleaned responses from 19 states and DC.

IN FOCUS: Direct Support Turnover Rates



Source: National Core Indicators (2017)

Vacancy Rates Among Direct Support Positions



Median Hourly Wages

Low wages are among the biggest challenges to reducing high turnover and vacancy rates. Nationally, the median hourly wage for direct support professionals was \$12.09 in 2017. Whereas providers generally believe their DSPs deserve more competitive wages, their hands are tied as state Medicaid programs dictate reimbursement rates—the amount of money a provider can request from the state in exchange for delivering a service.

Below are the top three and bottom three states when it comes to median hourly wages earned by DSPs relative to the state minimum wage. It should be noted that even in the states where median hourly DSP wages significantly outpaced state minimums, the median DSP wage remains unlivable in all states. Furthermore, although minimum wages aren't necessarily reliable indicators of cost of living, a smaller gap between the minimum wage and the median hourly wage for DSPs can make it harder for providers to compete for labor against other businesses that offer comparable pay but fewer responsibilities.

DSP WAGES OUTPACE STATE MINIMUMS...

...BY A LONGSHOT

States whose median hourly DSP wage is significantly higher than the state minimum wage

 Utah	In Utah, the median hourly wage of a DSP is \$12.48—72% higher than the state's minimum hourly wage.
 South Carolina	At \$11.55 per hour, South Carolina's DSPs earn, at the median, 59% more per hour than a minimum-wage earner.
 Indiana	A Hoosier working for minimum wage earns about three dollars less per hour than the median DSP in Indiana.

...JUST BARELY

States whose median hourly DSP wage is closer to parity with the state minimum wage

 Arizona	At \$11.24 per hour, the median hourly wage of a DSP in Arizona is only 12% higher than the state's minimum.
 District of Columbia	The nation's capital has one of the highest median wages among DSPs, at \$14.03. However, with a high cost of living, that amount is only 22% more than the District's minimum wage.
 Alabama	Alabama's median hourly DSP wage of \$9.40 is only about 30% higher than the state's minimum wage of \$7.25.

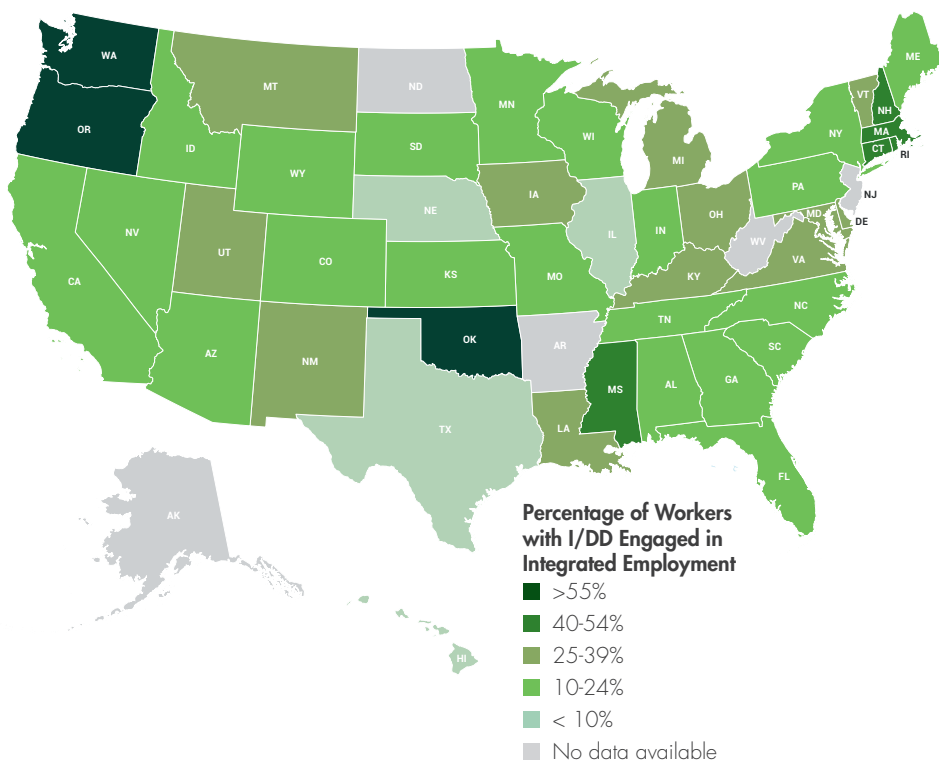
PROMOTING PRODUCTIVITY

For all of us, the opportunity to work means much more than a paycheck. It means appreciating the fruits of our labor. It means feeling like we're contributing. It means being part of a community among our friends and colleagues. But all too often, opportunities to work elude people with I/DD. This issue area explores indicators of how many people are working, and whether that work is translating into the same opportunities enjoyed by workers without disabilities.

**"It is not wealth one asks for,
but just enough to preserve
one's dignity, to work
unhampered, to be generous,
frank and independent."**

- W. Somerset Maugham
English Playwright

IN FOCUS: Integrated Employment



Source: Institute for Community Inclusion at the University of Massachusetts-Boston (2017)

Employment can elude people with disabilities for a number of reasons. Sometimes, a dearth of employers in the community that see the value of hiring people with diverse talents can be the barrier, while in other instances, lack of access to a job coach or employment support specialist can make the difference between working or not. And, even when people with disabilities have the opportunity to

work, it is often in jobs that offer few hours, pay below the minimum wage or fail to provide a clear career pathway. For that reason, the *Case for Inclusion* tracks **participation in services that support integrated employment**—the percentage of a state’s individuals who receive a day or employment service who are supported to work alongside people without disabilities. Despite this being the gold standard for employment

opportunities for people with disabilities, only one in five individuals receiving employment supports were working in competitive employment in 2017.

With job creation rates at record highs and unemployment at record lows, it's high time that states and the federal government commit to meaningful investments in the employment opportunities of workers with I/DD.



Vocational Rehabilitation: A Tale of Two Americas

Funded by the federal government and administered by the states, Vocational Rehabilitation (VR) programs offer a range of supports. From career counseling to training on how to use adaptive technology and everything in between, VR puts employment opportunities within reach for would-be workers with disabilities.

Although VR is far from the only program through which people receive employment supports, data from VR programs can shed light on the situation facing workers with I/DD. However, a close look at these data reveals wide variations between states in terms of participation in and the impact of VR programs.

Nationally, there were 38,642 **participants in Vocational Rehabilitation** in 2017, down from nearly 49,000 in 2013.² Ten states (Alabama, California, Florida, Georgia, New York, North Carolina, Ohio, Oregon, Pennsylvania and Texas) served more than half of all VR participants, with North Carolina serving the most participants (4,252). On the other end of the spectrum, nine states (Alaska, Delaware, Hawaii, Montana, Nevada, New Hampshire, New Mexico, North Dakota and Wyoming) and DC combined to serve just under 1,200 individuals.

Looking at outcomes, we see that a wide gulf also exists in terms of the **rehabilitation rate for VR participants**. Just under half (47%) of VR participants nationally found work, and where you live makes a big difference: while three states (Delaware, Oregon and Washington) reported at least two-thirds of VR participants were rehabilitated, two other states (Alabama and Mississippi) and DC reported rehabilitation rates of less than one in four.

Of course, having a job isn't enough—that job needs to offer competitive wages and full-time working hours for those who want it. Regrettably, the federal Rehabilitation Services Administration no longer shares wage data. It does, however, still share data about the **average number of hours worked per week by VR participants**, and here again, where you live plays a big role in the opportunities before you. At 31 hours per week, the average worker with a disability in the best state for this measure, South Carolina, worked more than twice as much as the average worker with a disability in the worst state for this measure, Maine (14 hours per week). Nationally, the average number of hours worked in 2017 was just under 23.

² Each of the measures referenced here account only for Vocational Rehabilitation participants with an intellectual disability, rather than all VR participants.

FROM THE FIELD

Creating Work Through Entrepreneurship: Hillary's Story



Meet Hillary McFadden, a self-proclaimed foodie from Harrisburg, PA. Hillary has always understood the value of hard work, but because she is blind, she found it difficult to take advantage of job opportunities. Compounding the situation is that only 18% of Pennsylvanians with I/DD work in competitive employment.

By combining her love of food with her experiences as a person with a disability—and with a little support from Keystone Autism Services' Adult Community Autism Program—Hillary decided to start her own business creating braille menus for local restaurants. "I came up with the idea of creating braille menus for restaurants that did not have any menu to accommodate people with visual impairments," Hillary said. "I met with a few of my favorite restaurant owners, explained my concerns and pitched my accommodating ideas."

Beyond enabling herself to be out in the community, checking out the newest coffee shops and farm-to-table offerings, Hillary's work is making it possible for other blind people to be part of the community. Meanwhile, her story teaches the rest of us an important lesson: sometimes, to land your dream job, you have to create it yourself.

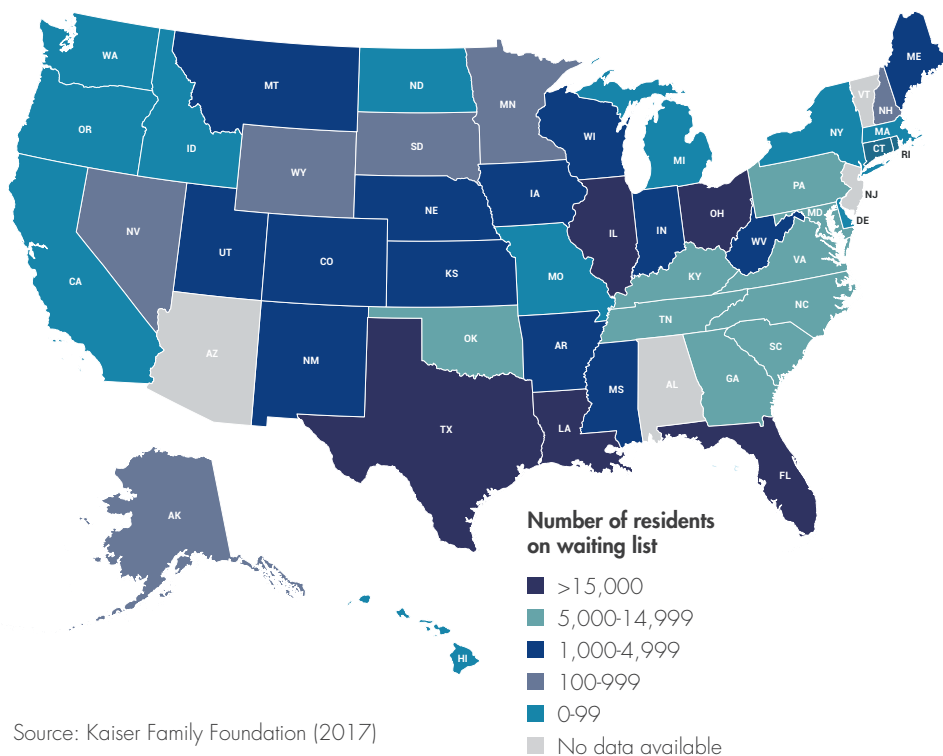
REACHING THOSE IN NEED

What happens when a state can't meet the needs of each of its residents that need long-term supports and services? In too many states, the answer is simple: put them on a waiting list. But while the answer is simple, the problem is far from it—in some states, families sit on waiting lists for years, unsure whether their loved ones will ever gain access to support that makes the difference between inclusion and isolation. Further compounding the challenge is that the number of people on a state's waiting list may not be an accurate reflection of total need in that state.

**"Numbers don't lie—
but they can
obscure the truth."**

—Unknown

IN FOCUS: State Waiting Lists for Home & Community Based Services



The map above reveals the states with the largest and smallest waiting lists for HCBS services. Darker colors represent states with the highest number of individuals on waiting lists, while lighter colors represent states with relatively fewer individuals on waiting lists. On one end of the spectrum, nine states (California, Delaware, Hawaii, Idaho, Massachusetts, Michigan, Missouri, New York and Washington) and the District of Columbia had no waiting list for HCBS services. On the other end of the spectrum, five states (Illinois, Florida, Louisiana, Ohio and Texas) had waiting lists with more than 15,000 individuals.

Waiting Lists BY THE NUMBERS

472,997

Total number of individuals on states' waiting lists nationwide

+49,262

Change in number of people on states' waiting lists since last year's *Case for Inclusion*

217,786

Total number of individuals on Texas' waiting list, the largest in the country

Changes in States' Waiting Lists

The graphic below depicts the states with the biggest increases and decreases in the size of their HCBS waiting lists. The reader should note that although a state's waiting list may have gotten significantly smaller year-over-year, that doesn't necessarily mean all people who are no longer on the list have been removed because they now receive services. Sometimes, these changes are due to adjustments in states' data collection methods or data "clean-up" efforts. Therefore, the reader should be thoughtful in how these data are framed when using them to advance policy change.



IMPRESSIVE IMPROVEMENTS

States with the biggest decreases in the number of people on waiting lists, 2016-2017

 Virginia	In 2017, there were 4,317 fewer Virginians with I/DD on the Commonwealth's waiting list for Home and Community Based Services.
 Kentucky	Kentucky was another commonwealth with big improvements in this area: 2,303 fewer Kentuckians were waiting for services in 2017 than in 2016.
 Georgia	The Peach State's waiting list shrank considerably, from 8,698 people in 2016 to 6,966 people in 2017.



STEEP SLIDES

States with the largest growth in the number of people on waiting lists, 2016-2017

 Texas	The state with the largest waiting list also saw the most growth; 21,538 more Texans with disabilities in 2017 were awaiting support than in 2016.
 Illinois	From 2016 to 2017, the number of people with I/DD waiting for services in the Land of Lincoln grew by nearly 11,000.
 Louisiana	The number of people with I/DD on Louisiana's waiting list grew from 17,590 in 2016 to 27,509 in 2017—an increase of nearly 10,000 people.

When it comes to the ebbs and flows of states' waiting lists, there may be more there than meets the eye. See the following page for a discussion of how smaller waiting lists don't always mean less unmet need.

UNDERSTANDING THE SCOPE OF THE NEED

Waiting lists have traditionally been used as an indicator of the extent to which states are meeting the needs of the full population of people with intellectual and developmental disabilities. Although the authors of this report agree that waiting lists are perhaps the best metric available for our use, it is also clear that this measure doesn't paint the full picture.

Most states do their best to accurately track and report the number of people waiting for services. However, differences in how states track these data can complicate the process of comparing one state to another. For example, one state may only count individuals waiting for a particular type of waiver that doesn't have a direct corollary in the state next door. Likewise, some states may track the number of individuals waiting each month and report an average for the year, while another state may only report the number of individuals waiting at the moment of data collection. And in still other cases, states sometimes engage in data cleanup efforts that can complicate our understanding of who needs supports.

Further compounding the challenge is that some individuals and their families may need long-term supports and services, but don't end up on the waiting list. This can happen for a host of reasons: lack of awareness about the availability of services, fear that they may sit on a waiting list for years, and the ability to pay for services out of pocket are just a few reasons. Therefore, the authors of this report encourage you to use these data with care. Recognize that absent a nationally standardized data collection process that includes technical assistance to states, the number of people on a state's waiting list may or may not reflect the extent to which that state is home to an unmet need.





About United Cerebral Palsy

United Cerebral Palsy (UCP) educates, advocates and provides support services through an affiliate network to ensure a life without limits for people with various disabilities. Together with 60 affiliates, UCP has a mission to be the indispensable resource for individuals with cerebral palsy and other disabilities, their families, and their communities. UCP Affiliates in the US and Canada provide supports to approximately 155,000 children and adults on an annual basis—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.

Learn more at [UCP.org](https://ucp.org).



About the ANCOR Foundation

For nearly 50 years, the American Network of Community Options and Resources (ANCOR) has been a leading advocate for the critical role service providers play in enriching the lives of people with intellectual and developmental disabilities.

As the 501(c)3 charitable arm of ANCOR, the ANCOR Foundation exists to expand the commitment and capacity of providers and communities dedicated to improving quality of life for people with disabilities.

A critical part of this effort, the ANCOR Foundation's *Included. Supported. Empowered.* campaign exists to lift up the successes of people of all abilities and highlight the essential role providers play in bringing those successes to fruition.

Learn more at [WeHaveAStake.org](https://wehaveastake.org).



TAKE ACTION TODAY

Ready to Start Making a Difference in Your Community?

Whether you're just getting your feet wet or want to deepen your commitment to truly inclusive communities for people with intellectual and developmental disabilities, there are a variety of ways you can make a difference starting today using data from the *Case for Inclusion 2020*!



LEARN



See how your state stacks up on the issues you care most about using customizable scorecards, hone your understanding of the policies affecting progress, and share resources with other advocates using the *Case for Inclusion* website.

Visit caseforinclusion.org today to learn more.



CONNECT

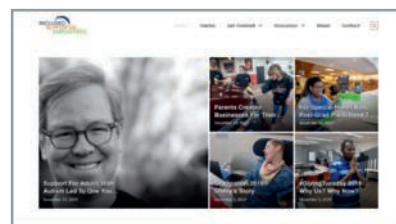


UCP and ANCOR represent substantial networks of providers on the frontlines of community inclusion for people with I/DD. Connecting with these networks can help you identify best practices, glean advice and resources, and more.

Visit ucp.org and ancor.org today to connect with your peers.



ACT



Now that you have the data you need to understand the scope of the challenges we're tackling together, it's time to take action. The *Included. Supported. Empowered.* Toolkit is the perfect resource for honing your advocacy skills.

Visit WeHaveAStake.org/toolkit today to take action.

Ready to Dive Deeper?

The ANCOR Foundation's *Included. Supported. Empowered.* campaign is committed to cultivating a constituency of disability champions—people like YOU—who are committed to the belief that we all have a stake in building opportunities for people with intellectual and developmental disabilities. Joining *Included. Supported. Empowered.* is free, and gives you access to compelling stories, emerging data and opportunities to take action as we work together to celebrate the successes of people with I/DD and highlight the important role providers play in making success possible.

Join *Included. Supported. Empowered.*
WeHaveAStake.org/join.

caseforinclusion.org

