UCP United Cerebral Palsy™

ANCOR FOUNDATION

INCLUDED. SUPPORTED. EMPOWERED.

THE CASE FOR

INCLUSION

REPORT 2019

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I N T R O D U C T I O N

Today in America, a person born with intellectual and developmental disabilities (I/DD) has a great opportunity for a long, healthy, full and meaningful life.

This didn't happen by accident.

It happened over decades as a direct result of advocacy and successful policy reforms at the federal and state levels, led in large part by the work of United Cerebral Palsy (UCP) and the American Network of Community Options and Resources (ANCOR), their members and affiliates at the local, state and federal levels, and other stakeholders. The momentum for these reforms were fueled by family members and people with disabilities.

That success continues to be true due to two things: vigilance and progress.

UCP has historically published the Case for Inclusion report. For the first time this year, UCP and the ANCOR Foundation—through its Included. Supported. Empowered. campaign—have joined together to publish a comprehensive set of data for our nation, plus all 50 states and the District of Columbia, to protect the gains we've made and identify areas in which more progress is needed.

VIGILANCE

Protect the gains that have been achieved in the states and at the federal level with policy and funding to effectively support individuals.

PROGRESS

Showcase the areas that need attention, reform and improvement to provide further opportunity and inclusion.

Since 2006, The Case for Inclusion has been the preeminent annual ranking of how well state Medicaid programs serve people with intellectual and developmental disabilities (I/DD) and their families.

Individuals with I/DD, including the young and the aging, want and deserve the same opportunities and quality of life as everyone else in our country.

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.

Notably, the Case for Inclusion ranks all 50 States and the District of Columbia (DC) on their outcomes for individuals with I/DD.

The Case for Inclusion is a tool that gives us glimpses at how well each individual state is performing overall, how each state matches up against other states regarding key data measures and, most importantly, the policies and practices of top-performing states that may be considered as best practices.

A significant addition to the 2019 report includes incredibly sobering data about the magnitude of the Direct Support Professional workforce crisis. The inclusion of this issue recognizes that in the absence of a stable, qualified direct support workforce, states will struggle to reduce waiting lists, and to support people to experience community integration – to be included, supported and empowered.

ABOUT UCP

United Cerebral Palsy (UCP) may be one of the largest health nonprofits in the U.S. today, but that was not the case in 1949. In the 1940s, there were not many options for families of and people with cerebral palsy and other disabilities.

Faced with fear and a lack of understanding by both the medical community and the general public, individuals with a disability were relegated to second-class status. Medical professionals frequently urged parents to warehouse their children in institutions where they lived out their lives, segregated from the rest of society. Parents who chose to raise their children at home learned that few services and supports were available to help their children lead full, productive lives in the community. With little contact between families of children with cerebral palsy, many parents felt isolated, helpless and alone.

In 1948, Leonard H. Goldenson, then-President of United Paramount Theaters and ABC Television, and his wife, Isabelle, joined forces with prominent New York businessman Jack Hausman, and his wife, Ethel, to improve the quality of life for their children with cerebral palsy and for others like them. The two families placed an advertisement in the *New York Herald Tribune* to recruit families interested in improving available services to children with disabilities so that families could stay together, and people with disabilities could be part of the community.

Hundreds of parents of children with cerebral palsy and other disabilities responded to the advertisement and joined the Goldensons and Hausmans in their crusade to create an organization to improve service for people with disabilities. It was from this humble, grassroots beginning that UCP was born as a national organization in 1949. Several UCP affiliates opened across the country, quickly establishing the organization. Right at its inception, UCP brought issues about cerebral palsy and other developmental disabilities to the forefront of the national media.

UCP would not be where it is today — assisting thousands of people with disabilities and their families — if it had not been for a group of parents who were committed to pioneering an effort to change the world for their children.

Today, UCP continues to work closely with its affiliates on issues that open doors for people with disabilities. From home ownership to health care reform, inclusive education to competitive employment, UCP has established itself as a leader in the disability community and as a strong voice for individuals with disabilities and their families.

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 (I/DD). As a national nonprofit association, ANCOR represents 1,600+ organizations employing more than a half-million professionals who together serve more than a million individuals. Our mission is to advance the ability of our members to support people with I/DD to fully participate in their communities.

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 the quality of life for people with disabilities.

Through its work, the Foundation recognizes and assists those who provide the programs, resources and information that empower people with disabilities to live more independently, enjoy greater accessibility and build self-reliance, self-confidence and self-satisfaction.

ABOUT *INCLUDED. SUPPORTED. EMPOWERED.*

The skill, commitment and hard work of supporting individuals with intellectual and developmental disabilities (I/DD) has for too long gone unrecognized. Their untold stories—of lifting the human spirit beyond all expectations—inspired the ANCOR Foundation to launch a three-year national public awareness campaign. Included. Supported. Empowered. is focused on celebrating and educating our society about the successes of people with intellectual and developmental disabilities and the providers who make success possible.

Learn more at wehaveastake.org.

ABOUT ANCOR

A DECADE OF
THE CASE FOR INCLUSION

2006-2019

Since 2006, the Case for Inclusion has ranked the states. The impact of this annual ranking has been substantial.

Since its inception, the Case for Inclusion has:

SHAPED FEDERAL POLICY FOR SERVICES to those with I/DD.

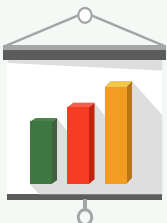**SERVED AS A TOOL FOR PROVIDERS** to track similar outcomes for the individuals

INFORMED FEDERAL MEDICAID & WAIVER SCORECARD conversations.

BECOME A GO-TO MEDIA RESOURCE FOR REPORTERS covering I/DD, state institutions closing, and waiting lists in the states.

SHAPED CONGRESSIONAL DEBATES on Medicaid reform and funding.

PROVIDED CONTEXT FOR STATE LEGISLATORS & ADVOCATES on how their states measure up to peer and neighbor states.

INSPIRED INCREASED STATE PARTICIPATION in the National Core Indicators, providing a much more personal look at individual outcomes.

At a high level, this snapshot shows how Medicaid services have changed over the past decade (from 2005 to 2016). For the most part, services for people with I/DD served by Medicaid have grown and outcomes have improved significantly.

☑ **Recipients of Home and Community-Based Services have increased** from 433,000 served to 807,000 individuals (86 percent increase).

☑ **Spending for HCBS has doubled** from $17.2 billion to $35.4 billion. Institutional spending has dropped from $12.1 billion to $10.5 billion.

☑ **Medicaid Buy-In programs have expanded** from 33 to 48 states.

☑ **Family support services have increased** from 396,000 to 594,000 families served (up 32 percent).

☑ **Participation in National Core Indicators has doubled,** from 24 states to 47 states for the quality assurance program.

☑ **Large, isolating state institutions have decreased in number** from 176 to 140, and the **number of individuals living in these institutions has been cut in half,** from 39,000 to 19,000 people.

☑ **The number of individuals served in their own homes has increased** from 101,000 to 147,000 (45 percent increase).

☑ **The number of individuals served in their families' homes has increased** from 533,000 to 714,000 (33 percent increase).

☑ **The number of individuals served in shared living/host homes has increased** from 35,000 to 64,000 (82 percent increase).

However, a couple negative trends are evident over the last decade (2005 to 2016):

❗ **Competitive employment participation has dropped** from 24 percent to 19 percent of individuals served.

❗ **Waiting lists have tripled** from 138,000 to 424,000.

Certainly, there is more work to be done, but advocates should step back and celebrate the significant improvements and promising trends over the past decade before continuing their tireless work to make community inclusion a cornerstone of the experience of people with I/DD in America.

THE CASE **FOR ACTION**

The tireless work of advocates locking arms with principled elected officials or, when advocacy failed, seeking justice through the nation's judicial system, achieved unprecedented progress.

In a few decades, thousands of Americans moved from isolation in large state institutions to living in the community. In the process, individuals have been supported to experience, often for the first time, a life full of richness and participation in work, friendships, and all aspects of the community.

WHY THE **CASE MATTERS**

Data matters. Data is not the sum of anecdotes or stories. But behind the numbers in the Case are real Americans.

But the fact is elected officials respond to rankings and comparisons. This gets their attention and focuses them on what outcomes matter the most. Let's face it: it is hard to find facts about how Medicaid services impact the lives of Americas with I/DD. The Case pulls that data together in one place, provides links and references to more extensive reports, and combines multiple data measures to paint a complete picture of what the state is doing, doing well or not doing.

The Case gets the attention of the media and elected officials on these issues and the people they affect every year. More importantly, it provides an annual scorecard of where a state is going on supporting people with I/DD. No other report does this.

WHAT THE **CASE DOES**

The annual Case for Inclusion provides the framework and facts for continued advocacy, for the protection of the accomplishments achieved and for providing clear direction in those areas that need further improvement.

The Case does this by holistically ranking the states, showing the sub-rankings of each state in 5 key outcome areas (to showcase the best in class and those states needing improvement) and by highlighting key policy reforms or narrative case studies to point the way to further state-level progress. UCP and its state affiliates, along with ANCOR and the ANCOR Foundation's Included. Supported. Empowered. campaign, are your partners in that advocacy journey.

HOW YOU **CAN USE IT**

Facts matter. Context matters. Comparisons matter.

The Case for Inclusion gives all three to advocates so that data can inform their advocacy and prevent defenders of the status quo from pretending that a better way is not possible. There are always states doing a better job. The Case shows which states stand out and showcases that improvement is possible and attainable with focused attention, the necessary resources and sound public policy.

HOW IT **MAKES A DIFFERENCE**

This approach works. Numerous states have adopted policy reforms directly related to measures that the Case tracks, scores, and ranks – from participation in the quality assurance surveys of the National Core Indicators, to promoting work and competitive employment with Employment First policies, to reductions in waiting lists and improved waiting list tracking in numerous states.

The combination of data, advocacy and proven reforms have a huge impact on real people. These reforms are profoundly transformative for the Americans with I/DD living in those states.

PROMOTING
INDEPENDENCE

All states still have room for improvement, but some states have consistently remained at the bottom since 2007, including Arkansas (#50), Illinois (#44), Mississippi (#51) and Texas (#49), primarily due to the small portion of people living in and resources dedicated to small or home-like settings in these four states.

Thirty-three states, one more (Kentucky) than in 2016, meet the 80/80 Home and Community Standard, which means that at least 80 percent of all individuals with I/DD are served in the community and 80 percent of all resources spent on those with I/DD are for home (less than 7 residents per setting) and community support. Those that do not meet the 80/80 standard are Arkansas, Delaware, Florida, Illinois, Indiana, Iowa, Louisiana, Mississippi, New Jersey, North Carolina, North Dakota, Ohio, Oklahoma, South Carolina, South Dakota, Texas, Utah and Virginia. Delaware, Oklahoma, Utah and Virginia are very close to meeting this standard. In fact, 46 states serve at least 80% of all individuals in the community (on the Home and Community-Based Services waiver).

Twenty-nine states, up 2 from the 2016 Case, report meeting the 80 percent Home-Like Setting Standard, which means that at least 80 percent of all individuals with I/DD are served in settings such as their own home, a family home, in a shared living /host home setting or small group settings with fewer than four residents. The U.S. average for this standard is 82 percent. Eleven states, up from eight, meet a top-performing 90 percent Home-like Setting Standard: Arizona, California, Colorado, Kentucky, Michigan, Nevada, New Hampshire, Ohio, Vermont, Washington, and Wisconsin.

As of 2016, fifteen states report having no state institutions to seclude those with I/DD, including Alabama, Alaska, Hawaii, Indiana, Maine, Michigan, Minnesota, New Hampshire, New Mexico, Oklahoma, Oregon, Rhode Island, Vermont, West Virginia and Washington, D.C. Another 10 States have only one institution each (Arizona, Delaware, Idaho, Montana, Nevada, North Dakota, South Dakota, Tennessee, Utah and Wyoming). Since 1960, 234 of 374 state institutions have been closed, including 10 in 2015 alone, according to the University of Minnesota's Research and Training Center on Community Living. Another 12 are projected to close by summer 2021, of the 140 still operating in 2016.

Fifteen states report at least 10 percent of individuals using self-directed services, according to the National Core Indicators survey in 44 states. Nine states report at least 20 percent being self-directed. These states include Florida, Idaho, Illinois, Kentucky, New Hampshire, New Jersey, Oregon, Utah, and Wisconsin.

SIGNIFICANT TAKEAWAYS

PROMOTING PRODUCTIVITY

Fifteen states report successfully placing at least 60 percent of individuals in vocational rehabilitation in jobs, with nineteen states reporting the average number of hours worked for those individuals placed being at least 25 hours and four States reporting at least half of those served getting a job within one year. No states met the standard on all three success measures: placement in jobs, average hours worked, and getting a job within a year.

Only seven states, down from 10 in 2016, report having at least 33 percent of individuals with I/DD working in competitive employment. These states include Connecticut, Maryland, Massachusetts, New Hampshire, Oklahoma, Vermont, and Washington.

KEEPING FAMILIES TOGETHER
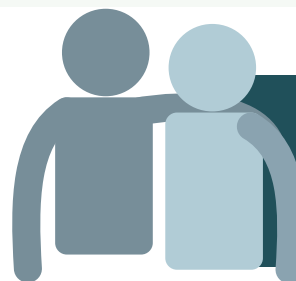
SERVING THOSE IN NEED

Only sixteen states, up from fifteen in 2016, report that they are supporting a large share of families through family support (at least 200 families per 100,000 of population). These support services help families that are caring for children with disabilities at home, which helps keep families together, and people with disabilities living in a community setting. These family-focused state programs were in Arizona, California, Delaware, Kentucky, Louisiana, Minnesota, Montana, New Hampshire, New Mexico, New York, Ohio, Pennsylvania, South Carolina, South Dakota, Vermont, and Wyoming. Mississippi is very close (199).

Waiting lists for residential and community services are high and illustrate the scope of an unmet need. Nearly 424,000 people, up almost 75,000 people since 2016, are on a waiting list for Home and Community-Based Services. This requires a daunting 55 percent increase in states' HCBS programs. Fourteen states, down from 18 in 2016, report no waiting list or a small waiting list (requiring less than 10 percent program growth).

TRACKING HEALTH, SAFETY & QUALITY OF LIFE

Forty-seven states participate in the National Core Indicators (NCI) survey, a comprehensive quality-assurance program that includes standard measurements to assess outcomes of services. A total of 44 states, up from 36 in 2016, reported data outcomes in 2014-2017, giving us a more comprehensive look at how states are truly doing to improve outcomes for people with I/DD.

2019 | STATE RANKINGS

The Case for Inclusion has ranked all 50 states and D.C. on their performance serving individuals with I/DD since 2006. The impact of this annual ranking is significant, shaping congressional debates and on Medicaid reform and funding and influencing federal policy for services to those with I/DD, serving as the go-to media resource for reporters, and providing much needed context for state legislators and advocates on how their states measure up to peer and neighbor states.

#1 ARIZONA

#2 OREGON

#3 VERMONT

#4 MISSOURI

#5 KENTUCKY

#6 HAWAII

#7 NEW HAMPSHIRE

#8 OHIO

#9 CALIFORNIA

#10 SOUTH DAKOTA

#11 MARYLAND

#12 SOUTH CAROLINA

#13 MICHIGAN	#14 WISCONSIN	#15 DISTRICT OF COLUMBIA
#16 INDIANA	#17 UTAH	#18 NEW YORK
#19 PENNSYLVANIA	#20 DELAWARE	#21 MINNESOTA
#22 GEORGIA	#23 NEBRASKA	#24 MAINE
#25 NEVADA	#26 TENNESSEE	#27 COLORADO

#28 **IDAHO**

#29 **ALABAMA**

#30 **WASHINGTON**

#31 **CONNECTICUT**

#32 **RHODE ISLAND**

#33 **WYOMING**

#34 **FLORIDA**

#35 **MASSACHUSETTS**

#36 **LOUISIANA**

#37 **KANSAS**

#38 **NEW JERSEY**

#39 **VIRGINIA**

#40 **ALASKA**

#41 **NORTH CAROLINA**

#42 **WEST VIRGINIA**

#43 NEW MEXICO	#44 ILLINOIS	#45 IOWA
#46 NORTH DAKOTA	#47 OKLAHOMA	#48 MONTANA
#49 TEXAS	#50 ARKANSAS	#51 MISSISSIPPI

ALPHABETICAL STATE RANKINGS

State	Rank	State	Rank	State	Rank
Alabama	29	Kentucky	5	North Dakota	46
Alaska	40	Louisiana	36	Ohio	8
Arizona	1	Maine	24	Oklahoma	47
Arkansas	50	Maryland	11	Oregon	2
California	9	Massachusetts	35	Pennsylvania	19
Colorado	27	Michigan	13	Rhode Island	32
Connecticut	31	Minnesota	21	South Carolina	12
Delaware	20	Mississippi	51	South Dakota	10
Dist. of Columbia	15	Missouri	4	Tennessee	26
Florida	34	Montana	48	Texas	49
Georgia	22	Nebraska	23	Utah	17
Hawaii	6	Nevada	25	Vermont	3
Idaho	28	New Hampshire	7	Virginia	39
Illinois	44	New Jersey	38	Washington	30
Indiana	16	New Mexico	43	West Virginia	42
Iowa	45	New York	18	Wisconsin	14
Kansas	37	North Carolina	41	Wyoming	33

MOST IMPROVED STATES

	2019	2007	+/- change
Ohio	8	48	+40
Missouri	4	41	+37
Kentucky	5	40	+35
District of Columbia	15	49	+34
Maryland	11	33	+22
Nebraska	23	43	+20
Oregon	2	21	+19

STATES WITH BIGGEST DROPS

	2019	2007	+/- change
Connecticut	31	6	-25
West Virginia	42	16	-26
Montana	48	19	-29
New Mexico	43	13	-30
Massachusetts	35	4	-31
Alaska	40	2	-38

(Most improved and biggest drop states are those with more than a 20 place change)

MARYLAND
UP 22 PLACES

Dramatically increased the portion of people served in home-like settings (from 74 percent to 90 percent), closed two state institutions, started participating and reporting outcomes for the NCI, and added a Medicaid Buy-In program.

MISSOURI
UP 37 PLACES

Closed three state institutions, reducing by 64 percent the number of individuals isolated in large state institutions, and started participating in and reporting outcomes for the NCI.

OHIO
UP 40 PLACES

Dramatically increased the share of individuals (from 63 percent to 85 percent) served in the community, closed a state institution, reduced by half the portion of individuals served in large state institutions, and started participating in and reporting outcomes for the NCI.

DISTRICT OF COLUMBIA
UP 34 PLACES

Reports a significant increase in the share of individuals (from 44 percent to 83 percent) served with home and community-based services. Now reports 88% of those served are in home-like settings.

KENTUCKY
UP 35 PLACES

Reports an increase in the share of individuals (from 79 percent to 97 percent) served in the community and reduced the population at state institutions in half. It also added a Medicaid Buy-In program to support coverage when individuals work and increase their income.

NEBRASKA
UP 20 PLACES

Increased portion of individuals served in the community (from 82 percent to 92 percent), started participating in the National Core Indicators, and dramatically reduced the population at its large state institution.
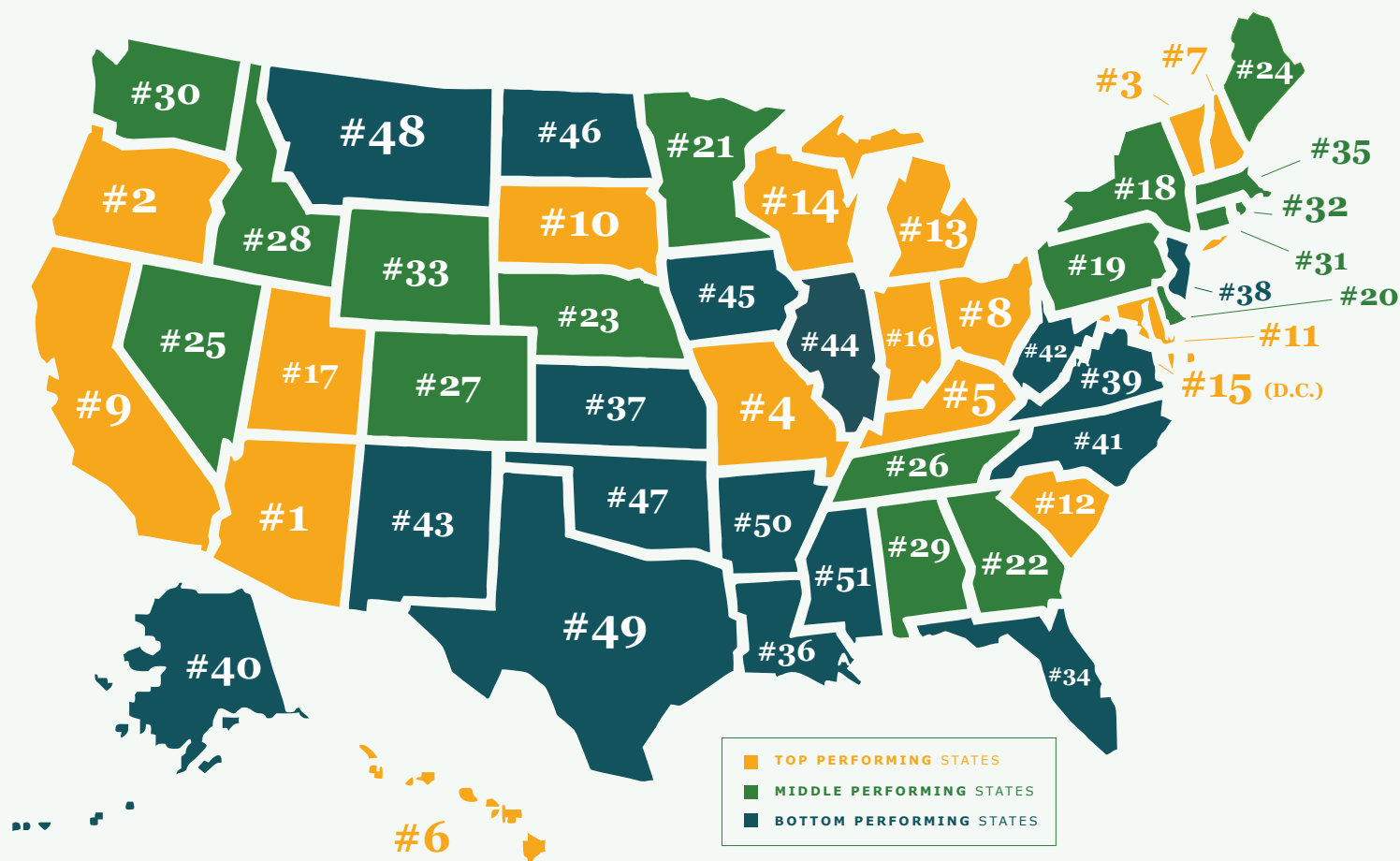
OREGON
UP 19 PLACES

Dramatically increased the share of individuals in home-like settings (from 72 percent to 88 percent) and started participating in and reporting outcomes for the NCI.

2019 INCLUSION REPORT
SUB-RANKING BY CATEGORY

	PROMOTING INDEPENDENCE		TRACKING HEALTH, SAFETY + QUALITY OF LIFE		KEEPING FAMILIES TOGETHER		PROMOTING PRODUCTIVITY		REACHING THOSE IN NEED		OVERALL SCORE + RANKING	
	50% of total ranking		15% of total ranking		8% of total ranking		12% of total ranking		15% of total ranking			
Alabama	39.3	33	14.0	3	1.6	46	4.5	50	13.7	31	73.0	29
Alaska	42.8	12	0.0	46	1.6	45	7.0	16	14.4	19	65.9	40
Arizona	44.4	6	12.7	22	7.6	1	6.4	29	15.0	12	86.0	1
Arkansas	26.1	50	8.5	29	1.3	48	6.1	37	13.3	36	55.3	50
California	42.7	13	7.7	42	6.7	3	6.9	17	15.0	1	79.1	9
Colorado	43.1	10	7.9	40	1.2	50	7.9	4	14.4	21	74.4	27
Connecticut	36.6	43	13.5	12	3.5	23	7.1	11	11.7	46	72.5	31
Delaware	41.1	21	8.4	31	4.6	11	7.6	7	15.0	1	76.8	20
Dist. of Columbia	39.7	30	13.6	10	2.2	37	7.4	9	15.0	1	77.9	15
Florida	40.9	23	8.8	26	3.0	30	3.2	51	13.6	34	69.5	34
Georgia	41.5	16	14.0	2	2.0	39	5.5	48	12.8	37	75.7	22
Hawaii	43.6	8	12.5	24	5.1	8	4.8	49	15.0	1	81.0	6
Idaho	41.2	19	8.4	32	3.3	26	6.2	33	15.0	1	74.2	28
Illinois	28.5	49	13.5	14	1.8	44	5.7	45	14.1	25	63.6	44
Indiana	39.2	34	13.7	8	3.2	27	6.5	25	14.8	16	77.5	16
Iowa	38.2	37	0.0	46	1.5	47	6.3	30	14.6	17	60.7	45
Kansas	37.4	39	8.5	30	1.9	40	6.4	27	14.1	26	68.4	37
Kentucky	43.8	7	13.9	5	3.7	18	5.6	46	14.2	23	81.2	5
Louisiana	35.4	45	8.4	33	6.4	4	6.2	36	12.1	39	68.5	36
Maine	41.1	20	13.2	15	0.4	51	6.2	34	14.5	18	75.5	24
Maryland	43.0	11	12.6	23	1.2	49	7.9	3	14.0	29	78.7	11
Massachusetts	39.4	32	7.8	41	2.5	33	7.3	10	12.0	41	69.0	35
Michigan	44.7	4	7.9	38	3.6	20	7.0	15	15.0	1	78.3	13
Minnesota	39.6	31	13.6	11	5.0	9	6.5	26	11.8	45	76.4	21
Mississippi	21.9	51	7.9	39	2.9	31	5.7	44	13.7	32	52.1	51
Missouri	41.3	18	13.9	4	4.6	10	6.9	20	15.0	13	81.7	4
Montana	35.3	46	0.0	46	3.5	21	6.2	32	14.0	30	59.1	48
Nebraska	39.8	29	12.9	21	1.8	42	7.1	14	14.0	27	75.5	23
Nevada	43.3	9	7.6	44	3.0	29	7.1	12	14.2	24	75.2	25
New Hampshire	46.1	2	8.2	36	3.7	17	7.1	13	15.0	14	80.0	7
New Jersey	36.9	42	8.8	25	2.4	35	5.8	43	14.3	22	68.3	38
New Mexico	40.5	26	1.6	45	2.7	32	6.7	23	12.7	38	64.2	43
New York	38.5	36	13.2	17	4.2	14	6.4	28	15.0	1	77.3	18
North Carolina	33.5	48	8.6	28	3.7	19	6.3	31	13.6	33	65.8	41
North Dakota	37.2	40	0.0	46	2.0	38	5.9	40	15.0	1	60.2	46
Ohio	40.8	25	13.5	13	6.8	2	6.2	35	12.1	40	79.4	8
Oklahoma	34.0	47	8.3	35	1.8	43	6.1	38	9.1	50	59.3	47
Oregon	44.7	5	13.1	19	4.5	12	7.8	6	15.0	1	85.1	2
Pennsylvania	41.8	15	13.8	6	3.7	16	6.1	39	11.4	47	76.9	19
Rhode Island	40.4	27	8.7	27	2.4	34	5.5	47	15.0	1	72.0	32
South Carolina	38.9	35	13.2	18	6.3	5	6.8	22	13.3	35	78.5	12
South Dakota	37.0	41	13.7	7	5.4	6	7.8	5	15.0	1	79.0	10
Tennessee	41.5	17	14.2	1	2.3	36	6.5	24	10.4	48	74.9	26
Texas	36.0	44	13.6	9	3.5	24	5.9	41	0.0	51	59.0	49
Utah	40.0	28	13.0	20	3.4	25	6.9	19	14.0	28	77.3	17
Vermont	45.3	3	13.2	16	4.1	15	8.6	2	12.0	41	83.3	3
Virginia	38.2	38	7.7	43	3.1	28	6.9	18	10.2	49	66.1	39
Washington	42.4	14	0.0	46	5.4	7	10.1	1	14.9	15	72.7	30
West Virginia	41.0	22	0.0	46	1.9	41	7.5	8	14.4	20	64.9	42
Wisconsin	47.8	1	8.2	37	4.4	13	5.8	42	11.9	43	78.2	14
Wyoming	40.8	24	8.3	34	3.5	22	6.8	21	11.8	44	71.3	33

2 0 1 9 **S T A T E   R A N K I N G S**

Legend:
- TOP PERFORMING STATES
- MIDDLE PERFORMING STATES
- BOTTOM PERFORMING STATES

HIGHEST PERFORMING STATES

1. Arizona
2. Oregon
3. Vermont
4. Missouri
5. Kentucky
6. Hawaii
7. New Hampshire
8. Ohio
9. California
10. South Dakota

LOWEST PERFORMING STATES

42. West Virginia
43. New Mexico
44. Illinois
45. Iowa
46. North Dakota
47. Oklahoma
48. Montana
49. Texas
50. Arkansas
51. Mississippi

FACTS ABOUT **TOP-PERFORMING** STATES

Top performers have populations of all sizes

Top-performing states include those with large populations, such as California, Arizona and Maryland, as well as those with much smaller populations, such as Hawaii, New Hampshire, South Dakota and Vermont. This suggests that the size of a state's population doesn't necessarily correlate with its performance.

Top performers' median household incomes range from very high to very low

States with high median household incomes, such as New Hampshire, Maryland and Hawaii, perform well. But so too do states with low median household incomes, such as Arizona, Missouri, South Dakota and Kentucky. This suggests that a state doesn't have to be wealthy in order to perform well, and states with less affluence have a range of opportunities to improve.

Top performers have a range of tax burdens

Top-performing states include Blue states with high tax burdens (e.g., California, Maryland, Oregon, Vermont) and Red states with low tax burdens (e.g., Arizona, New Hampshire and South Dakota), suggesting that states can perform well irrespective of tax revenues or political majorities.

Top performing states aren't necessarily those that spend the most

States that spend lower amounts on HCBS services, such as California, Oregon and South Dakota, find themselves atop the rankings alongside states that spend more, such as Maryland, Missouri and Vermont. This suggests that how resources are spent is as important or more important than how much is spent.

Population and Median Family Income data are from the Kaiser Family Foundation using U.S. Census Bureau data. Tax burden data is from the Tax Foundation. Spending data is from Research and Training Center's RISP 2016 Report.

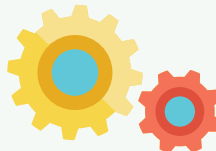# HOW TO USE THE CASE FOR INCLUSION REPORT

This report puts each state's progress in serving individuals with intellectual and developmental disabilities into a national context. It is intended to help advocates and policymakers understand:
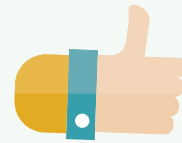
PERFORMANCE

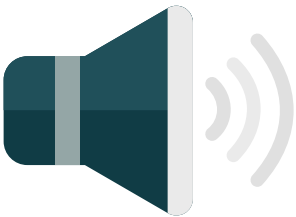How states perform overall in serving people with I/DD.

IMPROVEMENT

Which of a state's services demand improvement.

EVALUATION

How states compare to one another, thereby offering context for opportunities to improve.

STATE ADVOCATES

Advocates should use this information to educate other advocates, providers, families and individuals, policymakers and state administrations on key achievements and areas needing improvement within each state. The facts and figures can support policy reforms and frame debates about resource allocation for the I/DD population. Advocates can also use the information to prioritize those areas that need the most immediate attention and use the facts to support adequate and ongoing funding to maintain high-quality outcomes, eliminate waiting lists and close large institutions.

FEDERAL & STATE ADMINISTRATIONS

Those within federal and state administrations should use this report to put their work and accomplishments in context and to chart a course for the next focus area in the quest for continuous improvement in the quality of life of people with I/DD. States should replicate this data reporting in more detail at the state and county levels to identify areas of excellence and to target critical issues needing attention.

ELECTED OFFICIALS

Elected officials should use this report as a guiding document on which issues and states need time and attention and, possibly, additional resources or more inclusive state policies to improve outcomes for individuals with intellectual and developmental disabilities.

4 KEY ASPECTS OF AN OUTCOME-FOCUSED MEDICAID PROGRAM FOR AMERICANS WITH I/DD

The University of Minnesota's Research and Training Center on Community Living identifies the four key aspects of a high-functioning and effective Medicaid program, which have also been articulated in a number of legislative, administrative and judicial statements describing national policy.
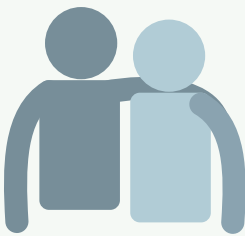
The Case for Inclusion's major outcome areas align, as indicated, with the following four-part holistic approach:

People with disabilities will live in and participate in their communities.

PROMOTING **INDEPENDENCE**

50% of the scoring

People with disabilities will have satisfying lives and valued social roles.
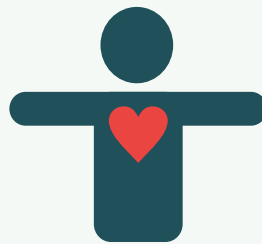
PROMOTING **PRODUCTIVITY**

12% of the scoring

People with disabilities will have sufficient access to needed support and control over that support so the assistance they receive contributes to lifestyles they desire.

KEEPING FAMILIES TOGETHER & REACHING THOSE IN NEED

23% of the scoring - combined

People with disabilities will be safe and healthy in the environments in which they live.

TRACKING HEALTH, **SAFETY, AND QUALITY OF LIFE**

15% of the scoring

A NOTE ABOUT THE DATA

The rankings in this report are a snapshot in time using 30 different data measures across all five major categories.

Most data is from 2016, which is the most recent data available from credible, national sources. All data is sourced directly from the states to the federal government and in response to public surveys. Notably, there are weaknesses in some of the data sources. The Case references data from credible recognized sources, but much of the data is self-reported to those sources by the state themselves.

We have experienced inherent definitional and numerical disparities in some data reported. When we discover glaring anomalies in the data, our protocol is to follow up with the data sources to ensure these anomalies were not reported in error.

Nonetheless, we expect that there will be some inherent inconsistencies in data that is self-reported by all 50 states and the District of Columbia.

The Case for Inclusion rankings were developed through a broad, data-driven effort. Demographic, cost, utilization, key data elements and outcomes statistics were assembled for all 50 States and the District of Columbia. Ninety-nine individual data elements from numerous governmental non-profit and advocacy organizations were reviewed. Dozens of Medicaid, disability and I/DD policy experts were consulted, as well as members of national advocacy and research organizations. They were asked to consider the attributes of top-performing Medicaid programs and offer opinions and recommendations on key data measures and outcomes.

To comprehensively determine the top-performing states, a weighted scoring methodology was developed. Thirty key outcome measures and data elements were selected and individually scored in five major categories on a total 100-point scale. If a person is living in the community, it is a key indicator of inclusion, therefore, the "Promoting Independence" category received half of all possible points. The rankings were slightly changed for 2019. Five measures were dropped (to remove a focus on spending and large private institutions), one measure was added (participation in the National Core Indicators Staff Stability Survey), and 12 measures had updated scoring. The 2019 Case for Inclusion has 23 data elements and 100 total points. The table below shows the updated weighting and data sources.

WEIGHTING OF CASE FOR INCLUSION SCORES

100 TOTAL POSSIBLE POINTS

Category	Measure		2014-2016 Scoring	
Promoting Independence	**Community-Based**	% of Recipients with ID/DD on HCBS	9	50
		% of ID/DD Expenditures on HCBS	7	
		% of ID/DD Expenditures on Non-ICF-MR	8	
	Residential Services in the Community (includes all types)	1-3 Residents - %	13	
		1-6 Residents -%	11	
		16+ Residents % (smaller %, higher rank)	-4	
		% in Large State Facilities	-3	
	NCI - % Self-Directed		2	
Tracking Health, Safety & Quality of Life	Quality Assurance - NCI Participation		0	14
	NCI - Recent Dental Visit		2.8	
	NCI - Lonely Less than Half the Time		2.8	
	NCI - Not Scared		2.8	
	NCI - Inclusion (sum of 4 measures)		2.8	
	NCI - Relationships Other than Staff and Family		2.8	
	NCI - Participation in Staff Stability Survey			
Keeping Families Together	Family Support per 100k		3	8
	% in a Family Home		3	
	NCI - Child/Family Survey Participation		2	
Promoting Productivity	Has Medicaid Buy-In Program		2	12
	Competitive Employment - %		4	
	Voc Rehab - Rehab Rate (finding a job)		2	
	Voc Rehab - Number of Hours Worked		2	
	Voc Rehab - Retain Job for One Year		2	
Reaching Those in Need	Waiting List - Average % Growth for Residential and HCBS		9	16
	Individuals with ID/DD Served per 100k of Population		2	
	Ratio of Prevalence to Individuals served		2	
	Uses Federal Functional Definition for Eligibility or Broader		3	
				100

In general, the top-performing state for each measure was assigned the highest possible score in that category. The worst-performing state was assigned a zero score in that category. All other states were apportioned accordingly based on their outcome in comparison to the highest- and lowest-performing states for that measure.

As noted, most data is from 2016, but all data is the most recently available from credible national sources. Much of the data is self-reported by the states. These state rankings are a snapshot in time, and policy changes or reforms enacted or beginning in 2016 or later would not have an impact on the data.

When reviewing an individual state's ranking, it is important to consider action taken since 2015, if any, to accurately understand both where that state was and where it is presently. Also, it is important to note that not all individuals with disabilities were considered, only those with intellectual and developmental disabilities. This limited the scope of the effort, allowing focus on subsequent initiatives of meaningful, achievable improvement.

A note to the reader: Advocates using the Case for Inclusion should be aware that just 40 points separate the highest- and lowest-ranked states, only eight points separate the #1 state from the #10 state, and only 14 points separate the #1 state from the #25 state. Therefore, minor changes in state policy or outcomes could significantly affect how a state ranks on future or past Case for Inclusion reports.

2019 Scoring		2018 Data Source	2016 Table
15		RTC	Calculated from fiscal reporting
0			
0			
15	50	RTC	Table 1.3
15		RTC	Table 1.3
0			
-5		RTC	Table 4.1
5		NCI	Table 53
0			
2		NCI	Table 104
2		NCI	Table 79
2	15	NCI	Table 133
2		NCI	Tables 62-65
2		NCI	Table 72
5		NCI	2014-2017 participating states
3		State of the States	State Profiles
3	8	State of the States	State Profiles
2		NCI	2013-2017 participating states
2		Mathematica	Table B.3, online research
4		ICI	Table 5
2	12	ICI	Table 9
2		ICI	Table 9
2		ICI	Table 9
12		RTC / Kaiser	Table 2.1 / ID/DD Wait List
0	15		
0			
3		NASDDDS	Table 1
	100		

Sometimes states do not consistently provide data in the most recent of release the above-mentioned reports. In those cases, the most recently reported data (often the previous year's report) is used to provide the best picture possible of activity in that state and to ensure that a state doesn't unfairly receive zero points for what could be simply a lack of data reporting for one year.

| SOURCES |

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ICI – University of Massachusetts' Institute for Community Inclusion – *StateData: The National Report on Employment Services and Outcomes 2016.*

Kaiser – Kaiser Family Foundation's State Indicators – *Waiting Lists for HCBS Waivers 2016.*

Mathematica – Mathematica's Enrollment, Employment, and Earnings in the Medicaid Buy-*In Program, 2011*

NASDDDS - National Association of State Directors of Developmental Disabilities Services and Rutgers Center for State Health Policy - *State Strategies for Determining Eligibility and Level of Care for ICF/MR and Waiver Program Participants 2008.*

National Core Indicators™ (NCI), National Association of State Directors of Developmental Disability Services (NASDDDS) and Human Services Research Institute (HSRI) Adult Consumer Survey *for FY 2014-2017 and Child Family Survey for FY2012-2013, FY2013-2014 and FY2014-2015 and 2016 Staff Stability Survey.*

RTC – University of Minnesota's Research and Training Center's - *In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends Through 2016 - Residential Information Systems Project (RISP). The 2016 report is available online.*

TURNOVER RATES AFFECT OUTCOMES **FOR PEOPLE WITH I/DD**

The Direct Support Professional (DSP) workforce specializes in supporting people with intellectual and/or developmental disabilities (I/DD) so they can live in the community with their family and peers, instead of in state institutions. These supports are primarily funded by Medicaid. DSPs perform a wide range of work, from supporting individuals so they can find jobs to assisting individuals with significant disabilities with daily life activities.

DSPs are the backbone of community supports, but in general they are not staying in the field long enough to turn it into a career. This affects the stability and quality of supports to the point of being a crisis, affecting the health and well-being of people with I/DD who rely on supports for the most critical and personal facets of their lives. We explain the situation and its underlying causes below.

» DSP TURNOVER IS **HIGH AND FREQUENT.**

High turnover is often highly disruptive to people with I/DD, a population for which stability is critical.
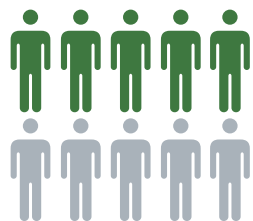
46%
National Average Turnover Rate

24-69% **Range of state turnover rates**

TURNOVER BY **LENGTH OF TENURE**

EMPLOYED LESS THAN 6 MONTHS	**38.2%**
EMPLOYED 6-12 MONTHS	**21%**
EMPLOYED MORE THAN 12 MONTHS	**40.8%**

LOW WAGES ARE A **PRIMARY CAUSE OF TURNOVER.**

» **DSPs operate within a very demanding regulatory framework and have significant responsibilities – including keeping individuals alive – that are not reflected in their wages.**

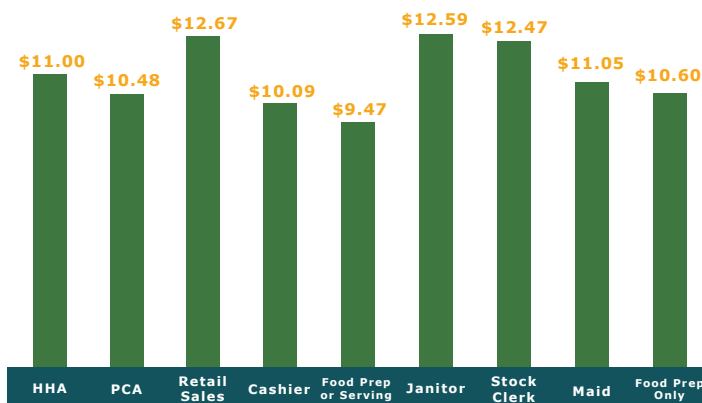| REASON FOR LEAVING	% OF RESPONDENTS
INADEQUATE PAY	**88.54%**
DIFFICULTY LEVEL/STRESS OF WORK PEFORMED	**66.88%**
LACK OF ADVANCEMENT	**49.68%**
LACK OF SUPERVISORY SUPPORT/APPRECIATION	**42.04%**
INSUFFICIENT TRAINING/ GUIDANCE	**28.66%**

Source: Medisked Survey. Multiple choice selection allowed so results add up to more than 100 percent.
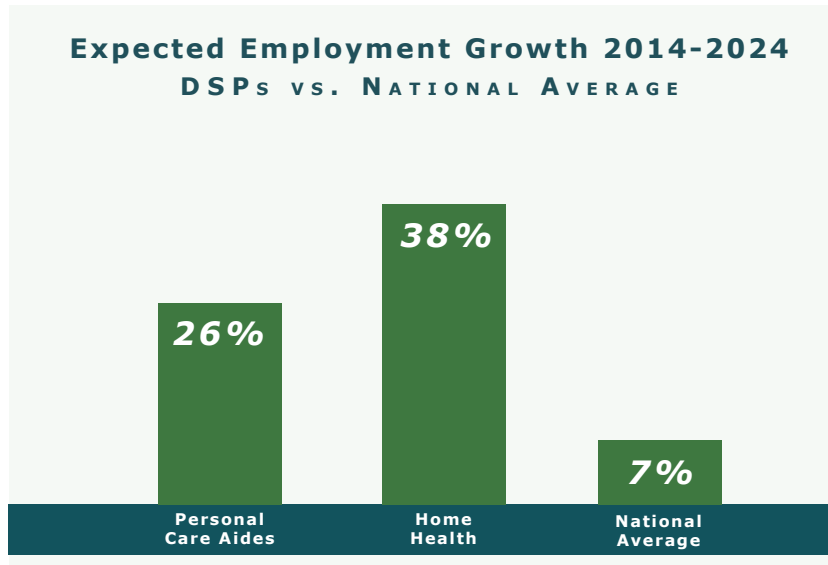
Average Hourly Wages for Direct Care & Alternative Occupations

HHA	PCA	Retail Sales	Cashier	Food Prep or Serving	Janitor	Stock Clerk	Maid	Food Prep Only
$11.00	$10.48	$12.67	$10.09	$9.47	$12.59	$12.47	$11.05	$10.60

Source: ANCOR 2017 workforce report

Expected Employment Growth 2014-2024
DSPs vs. National Average

	38%	
26%		
		7%
Personal Care Aides	Home Health	National Average

Demographic trends increasing demand include the increase in Autism diagnoses, increased longevity of people with I/DD, aging family caregivers needing more assistance to care for their loved ones with I/DD, and demand from baby boomers. Simultaneously, fewer women are being born into the labor pool – and the DSP workforce is predominantly female. This promises unmet demand for support unless we take action soon.

» THE GOOD NEWS? **STATES HAVE FOUND PROVEN SOLUTIONS**

Because DSP wages are set by Medicaid, improving DSP wages requires greater federal and state investments in the Medicaid program. In 2018, several states, including Connecticut, Kentucky, Maine and New York, improved DSP wages by increasing their investments in Medicaid.

Some states have also tackled the DSP workforce crisis by adopting innovative recruitment and retention techniques. Below are three examples of states whose provider agencies found creative ways to improve outcomes.

IOWA

An agency leveraged a federal demonstration project to recruit more specialized DSPs, going beyond the usual recruitment targets.

OHIO

Ohio recruited DSPs to the workforce by partnering with schools to target students on the brink of dropping out. To improve DSP retention, one agency created an Employer Resource Network to offer more flexibility and better benefits.

WISCONSIN

An agency created clear career pathways with built-in wage increases, thus increasing retention.

Having a job is a key part of being connected to the community. For people of all abilities, employment brings a sense of purpose and meaning, a way to support themselves, and the flexibility to pursue one's dream.

Yet, based on 2016-2017 data from the National Core Indicators Project, only about 20 percent of people with intellectual and developmental disabilities who receive services from a state I/DD agency are employed in community jobs, and only 12 to 14 percent of individuals work in individual integrated jobs (competitive integrated employment).[1] That means those without disabilities are employed at three times the rate as those with disabilities, despite people with I/DD demonstrating their strengths as members of the workforce.

» THE CHALLENGE

In 2014, the Special Olympics commissioned a Gallup survey on employment for individuals with intellectual disabilities, although the findings are similar for those with intellectual or developmental disabilities.

Here are the key findings:

» Nationally, **34% of people with intellectual disabilities are employed.**

» Of employed people with intellectual disabilities, **53% are employed competitively** (i.e., they work alongside people without disabilities at a market-driven wage), **38% are employed in a sheltered workshop** (i.e., work centers specifically for people with disabilities), and 9% are employed in other settings (e.g., self-employed).

Of those competitively employed, **28% work in customer service, 17% in retail, 16% in food service, 9% in office settings, 8% in manufacturing, and 22% in other sectors such as childcare and landscaping.**

» Of the adults with intellectual disabilities employed in a competitive setting, **over half (62%) have been at their jobs for three or more years.**

» Only **26% of employed adults with intellectual disabilities have full-time jobs.**

» Only **a third of employed adults with intellectual disabilities were offered health insurance** by their employer.[2]

» THE OPPORTUNITY

There are many positive impacts of competitive employment:

MORE PAY.

Competitive employment saw a **31 percent increase in hourly wages** (in real terms) since the 1980s, while there was a 41 percent decrease in hourly wages for those in sheltered workshops during the same period.[3]

MORE FRIENDS

Work supports socialization that leads to more and longer-lasting interpersonal relationships.

MORE HAPPINESS

Work increases an individual's self-worth and provides them resources that allow them to contribute to and participate in the community.[4]

HIGHER RETURN ON TAXPAYERS' INVESTMENTS

Every dollar spent on supported employment services yields a return of $1.46, based on sales and income taxes alone generated by the individual working. Simply put, **supported employment is good fiscal policy, resulting in a 46 percent return on investment.**[5]

» INSIGHTS FROM **THE FIELD**

In 2006, the state of Washington showed in a big way that policy interventions can ensure that working age adults with I/DD do not have to settle for unemployment. On July 1, 2006, Washington was one of the first states to adopt a policy that set employment as the sole focus of meaningful day services, in what became the Employment First policy.

The most current version of this policy:[6]

- Establishes employment support as the first use of employment and day program funds targeted toward for working-age adults and ensures that after nine months of receiving employment services individuals may choose community access programs.

- Applies to all eligible working-age adults who receive or seek employment and day program services from all state, county and contracted providers.

Linda Rolfe, Washington's Division of Developmental Disabilities director at the time, best summarized the value of Employment First:

"In Washington, we believe that employment is the easiest, most cost-effective strategy available to us to ensure that people have opportunities to experience the benefits we value. We have focused a lot of energy on getting people opportunities to have real jobs with good wages."[7]

The state's approach for individuals with I/DD was to focus on employment first. The focus ultimately was for adults with I/DD entering the system to focus their first nine months on finding a job. Over time and with encouragement from legislative and advocacy groups, the nine-month timeframe was set because it paralleled the employment search of people without disabilities, the vast majority of whom found a job within nine months of leaving school. Leaders and advocates also recognized that employment is a complex and challenging goal to achieve and that the more focused, collaborative and targeted the effort is, the more likely individuals are to achieve their goals of meaningful competitive employment. And, knowing this, they also recognized that employment is a typical part of a full life for any adult in Washington State, including citizens with intellectual and developmental disabilities. Therefore, legislation, policies and practices should be aligned to support the employment goals and outcomes of each individual.

The impact of the Washington's Employment First policy was profound. The number of individuals working for pay rose to 4,200 in May 2018 from 2,322 in 2007, according to state data. This 81 percent increase in just over a decade was particularly impressive given it occurred during the Great Recession (2008 to 2011), which started just after the passage of the Employment First policy. Even more impressive is that in 2015 (the year in which data for this measure is available for all states), Washington had the highest rate in the country of individuals with I/DD participating in competitive employment; at 85 percent, Washington's success rate is more than four times the national average (19 percent).

» HOW OTHER STATES CAN FOLLOW WASHINGTON'S LEAD

Washington and its community-based partners "invested [their] advocacy and development effort into continually building and investing in a community system that can support the needs of everyone, one person at a time," as Cesilee Coulson, executive director of the Washington Initiative for Supported Employment, explained.[8] With all the talk of self-directed services, Ms. Coulson knows, "True choice happens after someone with disabilities gets a paycheck. The government can only provide you limited choices that are part of a service mix; your own paycheck and employment give you independence."

There were five keys to Washington's Employment First success: (1) state and county leadership, (2) training and innovation, (3) quality employment agencies, (4) organized and informed families, and (5) clearly defined goals. In addition, training and development efforts focused on building a "community of practice" based on best practices from throughout the state and the rest of the country. As Mike Hatzenbeler, CEO of Seattle-based UCP affiliate PROVAIL, notes, "The Community of Practice is critical as there are many hard and big barriers to get to full inclusion. It is vital that everyone have a strong belief that this is not just a pipe dream but a real possibility." Hatzenbeler credits strong, focused leadership over the long term within the Administration for the successful achievement of the Employment First goals.

To help achieve competitive employment for very complex clients, agencies established the Cross County Collaboration. Each participating agency, including PROVAIL, identifies their five most challenging clients struggling to achieve the employment goal. All three agencies focused on these 15 individuals, providing intensive support and creating a broader network of employers and community partners. On average, 265 hours of service from intake through job stabilization are devoted to each individual. Over 18 months, 14 of the 15 clients (93 percent) found jobs and retained them.[9]

Several innovative strategies were used to focus legislators on the power of Employment First:

CELEBRATE

Establish employment for
All Day, organized by the
Community Employment Alliance.

ARTICULATE

Develop a winning slogan, such as
"Everyone Deserves a Payday."

ADVOCATE

Urge your governor to issue
a proclamation establishing
"Employment for All" Day.

EDUCATE

Distribute Payday candy bars
to legislators with key facts
and talking points.

With all the competing policy priorities facing legislators, advocates' savvy strategies and inspiring outcomes are keys to sustaining and expanding Employment First success.

Today, 32 states have adopted Employment First policy in legislation or by executive action, with almost all states having Employment First initiatives.[11]

In May 2018, just 58 percent of individuals with intellectual disablities were working for pay in integrated jobs and individual competitive integrated employment. If every state matched Washington State's success of 85 percent of individuals with I/DD receiving services that support integrated employment, there would be 250,000 more individuals with I/DD (up from just 124,000 today) working today.

Despite the fact that Employment First policies exist in 32 states, competitive unemployment rates remain low across the board, suggesting that policy on its own is not enough. In addition, states need to ensure that innovative practices and investments in I/DD supports are coupled with public policy to ensure that people of all abilities have the opportunity to engage in meaningful employment opportunities.

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4. "Unfinished Business: Making Employment of People with Disabilities a National Priority." U.S. Senate Committee on Health, Education, Labor and Pension. July 2012. Page 5.

5.Cimera, Robert Evert. Page 114.

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7. Rolfe, Linda. "Voices from the Field: Employment in Washington State." Alliance for Full Participation. March 8, 2010.

8. "Employment in Washington State – 2010 Report." Washington Initiative for Supported Employment. Page 16.

9. Learn more by reading the case study: "Cross County Collaboration C3 Pilot Project – Final Project Report." PROVAIL, Highline Community College, and Service Alternatives. October 30, 2009.

10. See example from 2013 at: http://www.communityemploymentalliance.org/images/Governor_Employment_For_All_Proclamation_021313.pdf

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WAIT NO MORE

Since the 2006 Case for Inclusion, the number of Americans served by Home and Community-Based Services (HCBS) waivers has increased by 79 percent, from 433,000 in 2005 to 775,000 today.

Yet the need for services is still greater, demonstrated by the fact that the number of people on the HCBS waiting list has tripled in that same time period—from 138,000 in 2005 to 424,000 today. States like Alaska are showing how investments in DSPs are directly related to expanding community capacity to meet the needs of the people on the waiting list. The section that follows shares lessons from Alaska that can be insightful for advocates in other states.

» THE CHALLENGE

Waiting lists are one indicator of how effectively a state is connecting people with quality, inclusive HCBS services. In the past decade, states' progress in moving people off HCBS waiting lists has varied wildly.

According to data from the Kaiser Family Foundation, from 2005 to 2016, six states (Alaska, Indiana, Montana, Oklahoma, Pennsylvania and Wisconsin) saw a significant decline in the number of individuals on their waiting lists. Another 13 states (Arizona, California, Delaware, Hawaii, Iowa, Idaho, Massachusetts, Michigan, North Dakota, New Hampshire, New York, Oregon and South Dakota) and the District of Columbia reported having no waiting list or only a small waiting list in 2016. But on the other end of the spectrum, 31 states have significant waiting lists, suggesting that most of the country has much room for improvement.

Regardless of the size of a state's waiting list, waiting indefinitely for critical services is an intensely frustrating experience for individuals with intellectual and developmental disabilities (I/DD) and their families. Meanwhile, battles for additional funding to reduce waiting lists are a common feature of states' legislative sessions, leaving advocates to constantly fight the same fights with victories few and far between.

» INSIGHTS FROM THE FIELD

Despite these frustrations, a handful of states are making leeway in terms of how waiting lists are publicly maintained and what information is made available.

This matters because information and personalization of the waiting list empowers advocates to successfully make the case for funding and for policymakers to know the waiting list is real, current, and urgent.

Alaska is a good example of this approach. **By cutting its waiting list in half over the past decade, Alaska has doubled the number of people served via HCBS waivers.**

In part, Alaska's success can be attributed to its laws governing data collection and reporting about individuals on the state's HCBS waiting list.

The Alaska statute covering I/DD services explicitly dictates seven sets of data on those waiting for HCBS services that must be reported each year:

- **Purpose of waiting list (including individual's rights)**

- **Process, ranking criteria and management of waiting list**

- **Basic demographic information, such as age, sex, and racial and ethnic background by region**

- **Level of need and services and supports required**

- **Individuals removed from the waiting list during the past year by number, along with reason for removal and length of wait**

- **Number of individuals waiting more than 90 days**

- **Number of people with I/DD graduating from, dropping out of and/or turning 22 years old without graduating from K-12 education**

The Alaska waiting list, which is now called the Registry, is a strong example of how transparency in data reporting can yield significant results. Alaska's 2017 report on these data reveals a series of improved outcomes from stronger and more transparent reporting practices:

» **The number of people on the waiting list dropped 37 percent**—from 1,006 in 2006 to 629 in 2017.

» **The number of individuals under 22 years old on the waiting list dropped 50 percent,** from 818 in 2006 to 409 in 2017.

» **Nearly two-thirds (65 percent) of those on the waiting list are under 22.**

» **The average wait time for someone on the waiting list is less than 30 months** (compared to 38 months in 2006).

» **41 percent of those on the waiting list** in 2017 were already receiving at least some level of state-funded supports.

» In 2017, **183 people (29 percent of all those waiting) moved off the waiting list,** including 45 who were moved off the waiting list because they received services.

» HOW OTHER STATES **CAN FOLLOW ALASKA'S LEAD**

Alaska proves that states can improve outcomes related to their HCBS waiting lists, even without spending their limited financial resources. Advocates should consider Alaska's waiting list transparency laws as a promising option as they seek alternatives to perennial fights with state legislatures over funding hikes. Sample legislation modeled off Alaska's success is provided at the end of this section for advocates considering such an approach in their own states.

Public policy change is always accomplished by a small but vocal group of tireless advocates. By borrowing plays from Alaska's playbook and adapting some of the strategies above in your own state, you have an opportunity to advance major change in your state through a series of manageable, meaningful and moveable strategic steps.

A DETAILED STRATEGY TO EXPAND SERVICES & REDUCE YOUR STATE'S WAITING LIST

31

There are several complimentary public policy approaches to reducing waiting lists that advocates can use. Below are six strategies for advocates to consider.
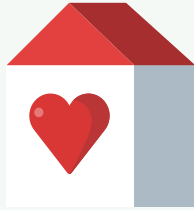
Partner with the state developmental disabilities department on a de-institutionalization initiative and use fiscal savings created by the closure of institutions to reduce the waiting lists.

Build long-term relationships with legislators in both chambers and from both parties to champion and publicize a multi-year campaign to reduce waiting lists. Indeed, many policymakers are looking for a cause, and such a campaign would represent a noble, non-partisan cause that could serve your purposes and theirs.

Pass a law—either on its own or through your state's budget appropriations process—requiring that any surplus funds or balance lapses in the developmental disabilities department at the end of the fiscal year be automatically redirected to waiting list reductions in the subsequent year.

Host a "Wait No More" Day at the legislature or during off-session legislative visits with waiting list families to personify those waiting for services.

Share your successful strategies and tactics with the ANCOR Foundation and UCP so that we can partner with your counterparts in other states to replicate your success.

Celebrate small victories and incremental progress. Rarely in policymaking does big change happen quickly; it is often the sum of several incremental steps, often taken over the course of many years, that together amount to monumental and transformative change.

An Act to Create a Transparent Waiting List for Those with Intellectual and Developmental Disabilities in Need

[To amend State statute delineating the duties of the Department serving those with intellectual and developmental disabilities]

When State funding is not adequate to meet service needs, the department shall establish a waiting list, to be called the registry, for persons with developmental disabilities who would be eligible to receive State-funded services under [reference relevant statute] if adequate State funding were available. The department shall, on an annual basis, review the waiting list and submit a report to the governor containing the information required under this subsection. The department shall send a copy of the report to the persons chairing the House and Senate finance committees and the persons chairing the House and Senate health, education and social services committees and shall notify the full legislature that the report is available to all legislators.

The report must:

1. Describe the purpose for the waiting list and the strategies used to notify persons about the waiting list and must include a copy of the information used by the department to inform individuals and families about their rights and responsibilities under [relevant section of State law].
2. Explain how an individual is placed on the waiting list, what criteria determine rank on the list, with at least quarterly updates to such assessments, and how the waiting list is used to select individuals equitably and fairly across the State.
3. Give the basic demographic information across all regions about the age (under 22 years old, from 23 to 39 years old, from 40 to 59 years old and more than 59 years old), gender, and racial and ethnic background of the individuals on the waiting list.
4. Identify the level of need and preferences of the individuals and families on the waiting list for the services and the supports that may be necessary to meet their needs and project an annual cost to meet this need and show these costs by age and length of time the individual has remained on the waiting list.
5. Identify how many individuals were removed from the waiting list during the 12 months covered by the report, why they were removed from the list, and how long the individuals had been waiting for services or supports before they were removed from the list, shown by age.
6. List the number of individuals who have been on the waiting list for 6 months, 12 months, 24 months, 36 months, 48 months, or more by age and with an account of the department's steps to regularly review each individual's status while waiting for services or supports.
7. Report annual data from the [education department] about the number of students in special education with developmental disabilities graduating from high school, dropping out of high school before reaching age 22, or reaching age 22 without graduating from high school.

THE CASE **FOR INCLUSION**

The Case for Inclusion is an annual review of how well state Medicaid programs serve individuals with intellectual and developmental disabilities (I/DD) and their families. This report ranks each individual state's performance with inclusion, support and empowerment for people with I/DD in the United States. Providing lawmakers and advocates with yearly recommendations for federal and state legislative opportunities, The Case for Inclusion continues to shed light on opportunities to increase quality of life and bring more people with intellectual and developmental disabilities out of the shadows.

The Case does this by holistically ranking the states, showing the sub-rankings of each state in 5 key outcome areas (to showcase the best in class and those states needing improvement) and by highlighting key policy reforms or narrative case studies to point the way to further state-level progress. UCP and its state affiliates, along with ANCOR Foundation and its Included. Supported. Empowered. campaign, are your partners in that advocacy journey.

THE CASE **FOR ACTION**

The tireless work of advocates locking arms with principled elected officials or, when advocacy failed, seeking justice through the nation's judicial system, has achieved unprecedented progress. In a few decades, thousands of Americans moved from isolation in large state institutions to living in the community. In the process, individuals have been supported to experience, often for the first time, a life full of richness and participation in work, friendships, and all aspects of the community.