



the case for

Inclusion

2016

2 0 1 6 R E P O R T

INTRODUCTION

At no other time in history than now, and in no other place in the world than America, does a person born with intellectual and developmental disabilities (ID/DD) have the best opportunity for a long, healthy, full and meaningful life.

That did not happen by accident.

It happened over decades as a direct result of advocacy and successful policy reforms at the federal and state level, as a result of the work of United Cerebral Palsy and our colleagues in the community.

It continues to be true due to three things: vigilance, cooperation, and progress.

Vigilance to protect the gains that have been achieved in the states and at the federal level with policy and funding to effectively support individuals with intellectual and developmental disabilities.

Progress to show the areas that need attention, reform and improvement to provide further opportunity and inclusion for all Americans with intellectual and developmental disabilities.

And, cooperation to provide this resource and others to advocates and partners throughout the country.

And so it is, that every year since 2006, United Cerebral Palsy (UCP) releases *The Case for Inclusion*, the preeminent annual ranking of how well state Medicaid programs serve Americans with intellectual and developmental disabilities (ID/DD) and their families.

While all states have room for improvement, some states do much better than others in demonstrating the needed political will and sound policies—as well as focused funding—necessary to achieve this ideal.

The Case for Inclusion ranks all 50 States and the District of Columbia (DC) not on their spending but on their outcomes for Americans with ID/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; the policies and practices of top performing states that may be considered as best practices; and, most importantly, the trends and trajectory of how states are—or are not—improving.

ABOUT UNITED CEREBRAL PALSY

UCP educates, advocates, and provides support services through an affiliate network to ensure a life without limits for people with a broad range of disabilities and their families. Together with nearly 70 affiliates, UCP has a mission to advance the independence, productivity and full citizenship of people with disabilities by supporting more than 176,000 children and adults every day—one person at a time, one family at a time. UCP works to enact real change—to revolutionize care, raise standards of living, and create opportunities—impacting the lives of millions living with disabilities. For more than 60 years, UCP has worked to ensure the inclusion of individuals with disabilities in every facet of society. Together, with 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 60 years, and beyond.



THE CASE FOR ACTION

The tireless work of advocates locking arms with principled elected officials achieved the unprecedented progress of moving thousands of Americans from isolation in large state institutions to living in the community in home-like settings, and to having a life full of richness through participation in work, friendships, and all aspects of the community.

What the Report Does

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

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.

Why *Case* Matters

It is hard to find facts about how Medicaid services impact the lives of Americans with ID/DD. *Case* pulls several forms of data together in one place, provides clear links and references to more extensive reports, and combines multiple measures to paint a more complete picture of what the state is: 1) doing, 2) not doing, 3) doing well, or 4) not doing well.

It is important because data matters, and elected officials respond to rankings and comparisons. This gets their attention and focuses them on what outcomes matter the most. But, also, this data is not just numbers. This data represents real people, with real needs, and they have real stories. *Case* tells that story in a way that policymakers and government agencies can use.

How You Can Use It

Facts matter. Context matters. Comparisons matter. *Case for Inclusion* gives all three to advocates so that they can be fact-based in their work and not allow the defenders of the status quo to pretend that a better way is not possible. This is your tool to facilitate the conversation on what is working, and where more resources are needed. There are always states doing a better job. *Case* shows which states are outstanding, and showcases that improvement is possible and easily attainable with focused attention, the necessary resources, and sound public policy.

Getting Results in Your State with the *Case for Inclusion* Report

Advocates and families have tremendous power to be a force for good in their state or to resist a rolling back of progress that has been achieved. Here are three ways to use this report in your advocacy work in your state:

- **Waiting list (s)** - while so much progress has been made to better serve individuals in the community, for 208,000 individuals nationally, residential services are still out of reach because of a lack of funding and prioritization at the state level. UCP suggests that:
 - First, policymakers pass transparency legislation to ensure an accurate and transparent waiting list is maintained.
 - Second, that any remaining Medicaid funds at the end of the fiscal year, or from departmental budget saving initiatives, be directed to fund those highest priority individuals on the waiting list (often adults with aging parent caregivers).
 - Third, that annual legislation or budget amendments are considered to further reduce the waiting list.
- **Competitive employment** - Living in the community is vital, but work is also key to a full and meaningful life. While 46 states have Employment First policies, nationally there are states falling behind when it comes to the proportion of individuals with ID/DD actually in competitive employment. In fact, there are fewer people in competitive employment than a decade ago: despite 325,000 more people being served by HCBS waivers. While Washington State showcased the initial Employment First policy to get almost all (86%) individuals with ID/DD served working, it also showed that it is not just about a policy change but also a priority. Advocates should push for specific strategies and reporting to actually achieve increased competitive employment. A recent UCP case study highlights such approaches.
- **State Institutions** - During the Great Recession and after, tight state budgets forced policymakers to take a hard look at closing expensive (and isolating) state institutions. While the economy has improved, Medicaid budgets are still tight. Advocates in the 36 states with at least one state institution should leverage this fiscal environment and continue to push to close these facilities, transition individuals to the community, and to use any savings to reduce their state's waiting list.

How It Makes a Difference

UCP has seen numerous states adopt policy reforms directly related to measures that we track, score and rank states on—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 Americans. These changes are literally life changing for individuals with ID/DD living in those states.

FOUR KEY ASPECTS OF A HIGH FUNCTIONING MEDICAID PROGRAM FOR AMERICANS WITH ID/DD

The University of Minnesota’s Research and Training Center on Community Living concisely 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.¹ *The Case for Inclusion’s* five major outcome areas align, as indicated, with the following four-part holistic approach:

- 1 Promoting Independence:**
People with disabilities will live in and participate in their communities.
- 2 Promoting Productivity:**
People with disabilities will have satisfying lives and valued social roles.
- 3 Keeping Families Together and Reaching Those In Need:**
People with disabilities will have sufficient access to needed support, and control over that support so that the assistance they receive contributes to lifestyles they desire.
- 4 Tracking Health, Safety, and Quality of Life:**
People will be safe and healthy in the environments in which they live.

One note on 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 2014, 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. UCP references data from credible recognized sources, but much of the data is self-reported to those sources by the state themselves.

UCP has experienced inherent definitional and numerical disparities in some data reported. Where UCP discovers glaring anomalies in the data, our protocol is to follow up with the data sources and provide them an opportunity to correct the data. Nonetheless, UCP expects that there will be some inherent inconsistencies in data that is self-reported by all fifty states and the District of Columbia.

1. The University of Minnesota Research and Training Center on Community Living. “Medicaid Home and Community Based Services for Persons with Intellectual and Developmental Disabilities – Interim Report.” September 26, 2005. Page 3.

CFI DATA MEASURES

Category	Measure	2007-2013	2016	
Promoting Independence	Community-Based	% of Recipients with ID/DD on HCBS	9	9
		% of ID/DD Expenditures on HCBS	7	7
		% of ID/DD Expenditures on Non-ICF-MR	8	8
	Residential Services in the Community (includes all types)	1-3 Residents - %	13	13
		1-6 Residents - %	11	11
		16+ Residents % (smaller %, higher rank)	-4	-4
		% in Large State Facilities	-3	-3
	Waivers Promoting Self-Determination		2	
NCI - % Self-Directed			2	
Tracking Health, Safety & Quality of Life	Quality Assurance - NCI Participation		6	0
	NCI - Recent Dental Visit			2.8
	NCI - Lonely Less than Half the Time			2.8
	NCI - Not Scared in Own Home		12	2.8
	NCI - Inclusion (sum of 4 measures)			2.8
	NCI - Relationships Other than Staff and Family			2.8
	Abuse		6	
Keeping Families Together	Family Support per 100k	6	3	
	% in a Family Home	6	3	
	NCI - Child/Family Survey Participation		2	
Promoting Productivity	Has Medicaid Buy-In Program	2	2	
	Competitive Employment - %	6.5	4.0	
	Voc Rehab - per 100k	1.5		
	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	9	
	Individuals with ID/DD Served per 100k of Population	3	2	
	Ratio of Prevalence to Individuals served	4	2	
	Uses Federal Functional Definition for Eligibility or Broader		3	
			100	100

Eliminated - regularly updated data no longer consistently available

New - new measure added in 2014

SIGNIFICANT TAKEAWAYS FROM THE 2016 RANKINGS

PROMOTING INDEPENDENCE

- 1 All states still have room for improvement, but some states have consistently remained at the bottom of the ranking since 2007**, including Arkansas (#49), Illinois (#47), Mississippi (#51) and Texas (#50) primarily due to the small portion of people and resources dedicated to those in small or home-like settings in these four states.
- 2 32 states, same as last year, meet the 80/80 Home and Community Standard**, which means that at least 80 percent of all individuals with ID/DD are served in the community and 80 percent of all resources spent on those with ID/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, Kentucky, Louisiana, Mississippi, New Jersey, North Carolina, North Dakota, Ohio, Oklahoma, South Carolina, South Dakota, Texas, Utah and Virginia. Connecticut is very close (with 79% spent on HCBS).
- 3 As of 2014, 15 states report having no state institutions to seclude those with ID/DD**, including: Alabama, Alaska, Colorado, Hawaii, Indiana, Maine, Michigan, Minnesota, New Hampshire, New Mexico, Oregon, Rhode Island, Vermont, West Virginia and Washington, D.C. Another 9 states have only one institution each (Arizona, Delaware, Idaho, Montana, Nevada, North Dakota, South Dakota, Utah and Wyoming). Since 1960, 205 of 354 state institutions have been closed, according to the University of Minnesota's Research and Training Center on Community Living.

Case Success Story – Near National Adoption of National Core Indicators

Since this report was first introduced in 2006, UCP has made it a priority for states to utilize a significant quality assurance program. The National Core Indicators (NCI) from the Human Services Research Institute has been that gold standard.

Appreciating this, the Obama administration has provided even more funding and incentives for states to participate. UCP's decade-plus focus, combined with these federal incentives, have had a profound impact.

In 2006 just 24 states participated in NCI. Today, 46 states and DC do (all of the states other than Iowa, Montana, North Dakota, and West Virginia, although WV has participated in the past).

Why is this important? While other reports can give broad stats on where people are living, whether they are working and if they receive family support, NCI gives us person-level information on safety, participation in the community, and a detailed life experience. Think of it like the difference between a restaurant inspection score and Yelp or Google reviews. The former tells one basic information. The latter gives on insight into the **actual** experience of people dining there.

SERVING THOSE IN NEED

- 4** **27 states, up from 26, now report meeting the 80 percent Home-Like Setting standard,** which means that at least 80 percent of all individuals with ID/DD are served in settings such as their own home, a family home, family foster care or small group settings like shared apartments with fewer than four residents. The U.S. average for this standard is 80 percent. Just eleven (up from 8) states meet a top-performing 90 percent Home-like Setting standard: Alaska, Arizona, California, Colorado, D.C., Michigan, Nevada, New Hampshire, Vermont, Washington, and Wisconsin.
- 5** **Fifteen states, up from ten last year, report at least 10 percent of individuals using self-directed services,** according to the National Core Indicators survey in 36 States. Five states report at least 20 percent being self-directed. These states include: Florida, Illinois, New Hampshire, Utah and Vermont.

TRACKING HEALTH, SAFETY AND QUALITY OF LIFE

- 6** **47 states, up from 42 last year, 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 36 states, up from 29 last year, reported data outcomes in 2015.

KEEPING FAMILIES TOGETHER

- 7** **Only 15 states, up from 14 last year, 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 provide assistance to 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, Louisiana, Minnesota, Montana, New Hampshire, New Mexico, New York, Pennsylvania, South Carolina, South Dakota, Vermont, Wisconsin, and Wyoming.

PROMOTING PRODUCTIVITY

- 8** **10 states, up from 8 last year, report having at least 33 percent of individuals with ID/DD working in competitive employment.** These states include: Connecticut, Maryland, New Hampshire, New Mexico, Oklahoma, Oregon, Rhode Island, Vermont, Washington, and West Virginia.

- 9** **15 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.

PROMOTING PRODUCTIVITY

- 10** **Waiting lists for residential and community services are high and show the unmet need.** Almost 350,000 people, 28,000 more than last year, are on a waiting list for Home and Community-Based Services. This requires a daunting 46 percent increase in states' HCBS programs. 18 states, an increase from 16 last year, report no waiting list or a small waiting list (requiring less than 10 percent program growth).

2016 THE CASE FOR INCLUSION RANKINGS

By Ranking

State	2016 Ranking	2015 Ranking
Arizona	1	1
Vermont	2	21
New Hampshire	3	25
Michigan	4	29
Hawaii	5	5
California	6	16
District of Columbia	7	8
Missouri	8	3
South Dakota	9	38
Maryland	10	2
Colorado	11	6
Minnesota	12	7
New York	13	4
South Carolina	14	9
Delaware	15	35
Ohio	16	10
Maine	17	12
Oregon	18	18
Kentucky	19	19
Indiana	20	23
Pennsylvania	21	22
Alabama	22	13
Georgia	23	11
Utah	24	15
Kansas	25	20
Massachusetts	26	14
Connecticut	27	17

State	2016 Ranking	2015 Ranking
Washington	28	26
Florida	29	27
Alaska	30	40
Wisconsin	31	33
Louisiana	32	24
West Virginia	33	30
New Jersey	34	28
Tennessee	35	32
Rhode Island	36	39
Nevada	37	31
North Carolina	38	34
Virginia	39	41
New Mexico	40	36
Nebraska	41	37
Idaho	42	46
Wyoming	43	45
Oklahoma	44	43
Iowa	45	44
North Dakota	46	42
Illinois	47	47
Montana	48	48
Arkansas	49	49
Texas	50	50
Mississippi	51	51

2016 THE CASE FOR INCLUSION RANKINGS

Alphabetical

State	2016 Ranking	2015 Ranking
Alabama	22	13
Alaska	30	40
Arizona	1	1
Arkansas	49	49
California	6	16
Colorado	11	6
Connecticut	27	17
Delaware	15	35
Dist. of Columbia	7	8
Florida	29	27
Georgia	23	11
Hawaii	5	5
Idaho	42	46
Illinois	47	47
Indiana	20	23
Iowa	45	44
Kansas	25	20
Kentucky	19	19
Louisiana	32	24
Maine	17	12
Maryland	10	2
Massachusetts	26	14
Michigan	4	29
Minnesota	12	7
Mississippi	51	51
Missouri	8	3
Montana	48	48

State	2016 Ranking	2015 Ranking
Nebraska	41	37
Nevada	37	31
New Hampshire	3	25
New Jersey	34	28
New Mexico	40	36
New York	13	4
North Carolina	38	34
North Dakota	46	42
Ohio	16	10
Oklahoma	44	43
Oregon	18	18
Pennsylvania	21	22
Rhode Island	36	39
South Carolina	14	9
South Dakota	9	38
Tennessee	35	32
Texas	50	50
Utah	24	15
Vermont	2	21
Virginia	39	41
Washington	28	26
West Virginia	33	30
Wisconsin	31	33
Wyoming	43	45

A Resource for Media

Frequently throughout the year, UCP receives media inquiries about the *Case for Inclusion* report, its data, and what it means.

Reporters want facts and also context. This report provides both.

Often times, these reporters may call to better understand the ranking or what it means. By the time the interview is done, these reporters have a better sense of what is working and what needs improvement in a state. This perspective often leads to positive stories on what's working (which helps to protect those gains) and exposes what needs improvement (which focuses policymakers on fixing it).

A great recent example of this comes from Washington, D.C. Martin Austermuhle of WAMU 88.5 FM (Public Radio) produced a four-part radio and video series called "From Institution to Inclusion: For D.C. residents with developmental disabilities, it's been a decades-long fight to be treated like everyone else."

The series began highlighting the stark reality of institutionalization and ended with a call to action to focus on competitive employment as the next "inclusion" advancement.

This series shows the power of the *Case for Inclusion*. With context, facts, and in-depth case studies, the reporter had the information to do his own investigative series to really dig into the reality of services and outcomes-- both past and present-- in the nation's capital.

Without the *Case for Inclusion*, this report could have been a one-and-done story. With the rankings and data, it was a multi-part exposé ending with a forward-looking, positive call to action. As a result, policymakers, members of the public, and advocates have a new resource and greater awareness about the importance of inclusion and how to advance inclusion even more.

SUB-RANKING BY MAJOR CATEGORY

Although the overall ranking presents a comprehensive view of each state and the District of Columbia, it is also important to consider the top-performing states in each of the five major categories in addition to how improvement in any category would have the biggest impact on better state performance and subsequent ranking. For example, Arizona ranks #1 overall, but ranks low (sub-ranking #41) for promoting productivity. Arizona could potentially learn from Washington State (sub-ranking #1) how it can improve in this area.

	Promoting Independence		Tracking Health, Safety & Quality of Life		Keeping Families Together		Promoting Productivity		Reaching Those in Need		Overall	
	Score	Rank	Score	Rank	Score	Rank	Score	Rank	Score	Rank	Score	Rank
	50% of total		14% of total		8% of total		12% of total		16% of total		100%	
Alabama	43.9	13	11.5	3	1.7	41	4.5	50	10.0	40	71.6	22
Alaska	46.7	6	0.0	39	2.3	34	7.1	12	12.2	22	68.2	30
Arizona	46.9	4	10.7	25	7.1	1	6.4	27	14.3	5	85.5	1
Arkansas	26.4	50	10.9	19	1.3	46	6.1	36	10.8	35	55.6	49
California	43.8	14	10.8	22	4.5	10	6.9	16	14.9	2	81.0	6
Colorado	44.9	9	10.7	26	1.2	48	7.8	6	11.8	26	76.4	11
Connecticut	37.4	39	11.4	6	3.3	22	7.3	9	9.8	41	69.2	27
Delaware	40.1	29	10.9	20	4.0	15	5.6	47	13.5	8	74.1	15
District of Columbia	42.9	17	11.7	2	2.4	33	7.5	8	13.4	10	77.8	7

SUB-RANKING BY MAJOR CATEGORY (CONTD.)

	Promoting Independence		Tracking Health, Safety & Quality of Life		Keeping Families Together		Promoting Productivity		Reaching Those in Need		Overall	
	50% of total		14% of total		8% of total		12% of total		16% of total		100%	
	Score	Rank	Score	Rank	Score	Rank	Score	Rank	Score	Rank	Score	Rank
Florida	40.8	27	11.0	12	3.0	27	3.3	51	10.3	38	68.3	29
Georgia	43.9	12	11.3	9	1.5	44	5.5	48	8.8	46	71.0	23
Hawaii	46.8	5	11.1	11	5.3	7	4.8	49	13.2	12	81.2	5
Idaho	39.2	35	0.0	39	1.1	51	6.0	38	13.1	14	59.4	42
Illinois	26.8	49	11.0	15	1.6	42	5.6	46	10.7	36	55.8	47
Indiana	39.4	33	11.4	7	2.6	31	6.7	23	12.2	20	72.2	20
Iowa	36.8	40	0.0	39	1.5	45	6.2	30	14.2	6	58.8	45
Kansas	40.0	30	10.3	32	2.0	37	6.4	28	12.1	23	70.9	25
Kentucky	42.1	22	11.3	10	1.2	50	6.0	40	11.8	27	72.3	19
Louisiana	35.0	43	10.7	28	6.3	4	6.2	32	9.3	45	67.5	32
Maine	42.7	18	10.6	30	1.3	47	6.0	39	12.4	18	73.0	17
Maryland	44.6	10	10.7	27	1.2	49	8.1	4	12.0	24	76.6	10
Massachusetts	41.0	25	10.9	21	1.9	40	6.9	18	10.8	39	70.9	26
Michigan	47.3	3	10.1	36	3.7	17	7.0	15	13.2	13	81.3	4
Minnesota	42.4	21	11.0	16	5.3	6	6.7	22	11.0	33	76.3	12
Mississippi	9.3	51	2.5	37	2.1	35	5.7	45	10.7	37	30.2	51
Missouri	42.5	19	10.6	29	4.5	11	7.0	14	12.8	16	77.5	8
Montana	34.4	45	0.0	39	3.2	24	6.1	35	11.9	25	55.7	48
Nebraska	40.6	28	0.0	39	1.9	39	7.2	11	12.3	19	62.0	41
Nevada	45.2	8	0.0	39	3.0	26	7.2	10	9.5	44	65.0	37
New Hampshire	48.4	2	10.7	24	2.8	28	7.1	13	13.0	15	82.1	3
New Jersey	33.2	47	11.0	16	2.4	32	5.8	44	13.3	11	65.8	34
New Mexico	44.1	11	2.2	38	2.8	29	6.8	19	7.0	48	63.0	40
New York	39.4	36	10.5	31	4.2	14	6.4	29	15.5	1	76.0	13
North Carolina	31.5	48	10.9	18	4.4	13	6.6	24	10.8	34	64.3	38
North Dakota	35.7	41	0.0	39	1.9	38	5.9	42	14.3	4	57.9	46
Ohio	39.7	32	10.3	35	5.9	5	6.1	37	11.5	30	73.4	16
Oklahoma	34.5	44	10.9	17	2.1	36	6.2	31	5.5	49	59.2	44
Oregon	46.1	7	0.0	39	4.5	12	7.8	5	14.0	7	72.4	18
Pennsylvania	41.1	24	11.3	8	3.4	19	6.1	34	9.8	42	71.8	21

SUB-RANKING BY MAJOR CATEGORY (CONTD.)

	Promoting Independence		Tracking Health, Safety & Quality of Life		Keeping Families Together		Promoting Productivity		Reaching Those in Need		Overall	
	<i>50% of total</i>		<i>14% of total</i>		<i>8% of total</i>		<i>12% of total</i>		<i>16% of total</i>		<i>100%</i>	
	Score	Rank	Score	Rank	Score	Rank	Score	Rank	Score	Rank	Score	Rank
Rhode Island	43.0	16	0.0	39	2.6	30	6.2	33	16.5	9	65.2	36
South Carolina	38.5	36	11.5	4	6.4	3	6.8	21	11.4	31	74.5	14
South Dakota	38.0	38	11.4	5	5.1	8	7.7	7	14.5	3	76.7	9
Tennessee	40.8	26	12.2	1	1.6	43	6.6	25	4.6	50	65.8	35
Texas	33.3	46	10.8	23	3.4	21	5.9	43	0.9	51	54.2	50
Utah	38.4	37	10.3	33	3.6	18	6.9	17	11.8	28	71.0	24
Vermont	49.1	1	10.3	33	3.9	16	8.6	2	11.0	32	83.0	2
Virginia	35.2	42	11.0	14	3.2	25	6.8	20	7.2	47	63.3	39
Washington	41.5	23	0.0	39	4.8	9	10.1	1	12.8	17	69.1	28
West Virginia	42.5	20	0.0	39	3.3	23	8.1	3	12.2	21	66.1	33
Wisconsin	43.4	15	0.0	39	7.1	2	5.9	41	11.7	29	68.1	31
Wyoming	39.7	32	0.0	39	3.4	20	6.5	26	9.7	43	59.3	43

MOST IMPROVED, AND BIGGEST DROPS, SINCE 2007

Over the last decade much has changed in the states. To highlight these changes—both good and bad—below is a table showing those states with the biggest improvement since 2007 as well as those states with the greatest drop in their ranking. A brief explanation as to what caused these changes in each state follows the table.

	2016	2007	Difference 07-16	
IMPROVED	Dist. of Columbia	7	49	42
	Missouri	8	41	33
	Ohio	16	48	32
	Maryland	10	33	23
	Kentucky	19	40	21
	Indiana	20	37	17
	South Dakota	9	26	17
DROPPED	Idaho	16	29	-17
	West Virginia	39	25	-17
	Connecticut	37	22	-21
	Massachusetts	22	6	-22
	Wyoming	36	19	-26
	New Mexico	38	18	-27
	Alaska	23	2	-28
	Montana	29	8	-29

MOST IMPROVED STATES



↑42
PLACES

District of Columbia

Reports a significant increase in the share of individuals (from 44 percent to 82 percent) and resources (from 10 percent to 64 percent) dedicated to those receiving home and community-based services. Now reports 93% of those served are in home-like settings.



↑33
PLACES

Missouri

Substantially increased the portion of resources dedicated to people in the community (from 50 percent to 88 percent), dramatically increased the portion of people served in home-like settings (from 75 percent to 84 percent), closed the last two state institutions, started participating and reporting outcomes for the NCI.



↑32
PLACES

Ohio

Dramatically increased the portion of resources dedicated to people in the community (from 50 percent to 65 percent) as well as the share of individuals served in the community (from 63 percent to 84 percent), closed a state institution (reducing by more than half the portion of individuals served in large institutions from 18 percent to 6 percent), started participating in and reporting outcomes for the NCI.



↑23
PLACES

Maryland

Substantially increased the portion of resources dedicated to people in the community (from 86 percent to 99 percent), dramatically increased the portion of people served in home-like settings (from 74 percent to 82 percent), closed the last two state institutions, started participating and reporting outcomes for the NCI.



↑21
PLACES

Kentucky

Reports an increase in the share of individuals (from 79 percent to 97 percent) and resources (from 63 percent to 79 percent) dedicated to the community, and reduced the population at state institutions by 39 percent. In 2008, Kentucky also added a Medicaid Buy In program to support coverage when individuals work and increase their income.



↑17
PLACES

Indiana

Reports an increase in the share of individuals (from 70 percent to 89 percent) and resources (from 54 percent to 67 percent) dedicated to the community and also closed 5 state institutions. In addition, Indiana receives high marks on the National Core Indicators quality outcomes, which were added to the ranking beginning in 2014.



↑17
PLACES

South Dakota

Primarily improved its ranking as a direct result of its high marks on the National Core Indicators quality outcomes, which were added to the ranking beginning in 2014.

STATES WITH THE BIGGEST DROPS



↓29
PLACES

Montana

Reported a significant (38 percentage point) reduction in the portion of individuals served in home-like settings (from 80 percent to 42 percent) and does not participate in the NCI.



↓29
PLACES

Alaska

Fell dramatically because the number of people being served in a family home was previously estimated (by the state) at 3,700 for the 2007 ranking. Beginning with the 2010 ranking, it was reported accurately and is now at around 332 people served in a family home. Alaska now participates in NCI, but outcomes will not be available until next year.



↓27
PLACES

New Mexico

Primarily dropped due to not reporting on all outcomes measures on the NCI.



↓26
PLACES

Wyoming

Primarily dropped in the ranking because the state just started participating in the NCI, but data will only become available for scoring in next year's ranking. Also, the state had a drop in competitive employment (from 25 percent to 18 percent) and remained stagnant while most other states improved overall causing the state to fall in comparison to others.



↓22
PLACES

Massachusetts

Primarily dropped in the rankings as direct result in the drop in the portion of people served in home-like settings (from 76 percent to 65 percent) and a drop in competitive employment (from 43 percent to 29 percent).



↓21
PLACES

Connecticut

Primarily dropped in the rankings due to a decline in the portion served in home-like settings (from 71 percent to 58 percent) and a drop of 65 percent in number of families served by Family Support. While CT remained flat in competitive employment at about 50 percent, the top scoring state (now Washington State) dramatically improved to 86 percent, meaning Connecticut lost ground (and points) to the top performers.

STATES WITH THE BIGGEST DROPS



↓17
PLACES

West Virginia

Primarily dropped in the rankings due to the fact that it does not participate in NCI.



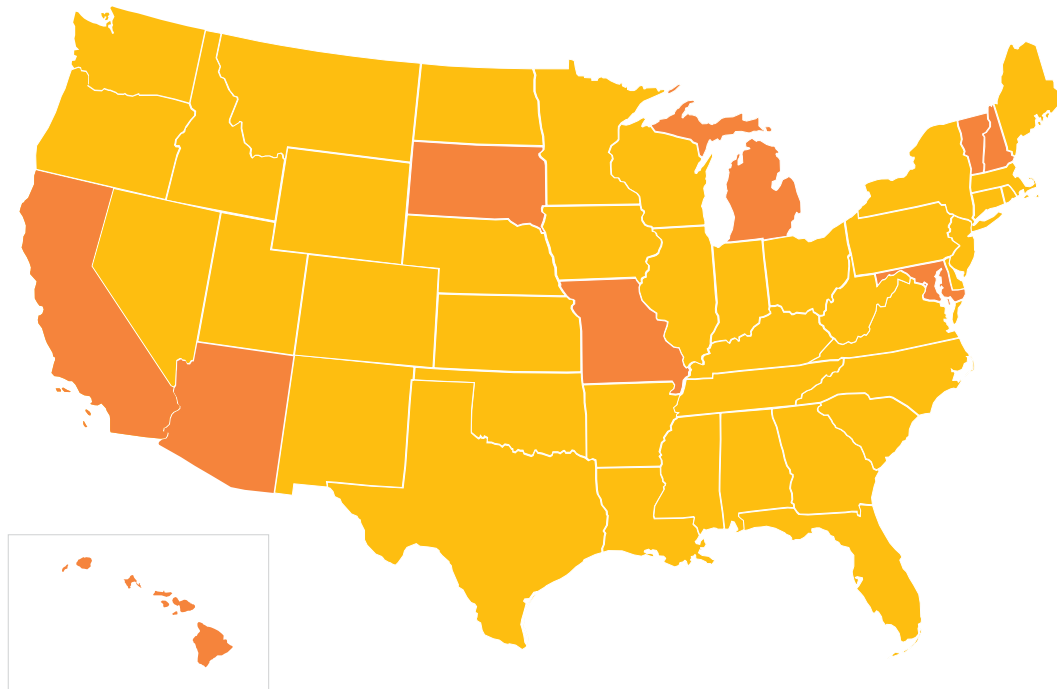
↓17
PLACES

Idaho

Increased the share of individuals (from 75 percent to 93 percent) but only slightly increased the share of resources (from 51 percent to 68 percent) dedicated to community based services. Significantly reduced the portion of individuals served in home-like settings (from 92 percent to 81 percent), and now participates in the NCI but data on outcomes will not be reported until the 2017 ranking.

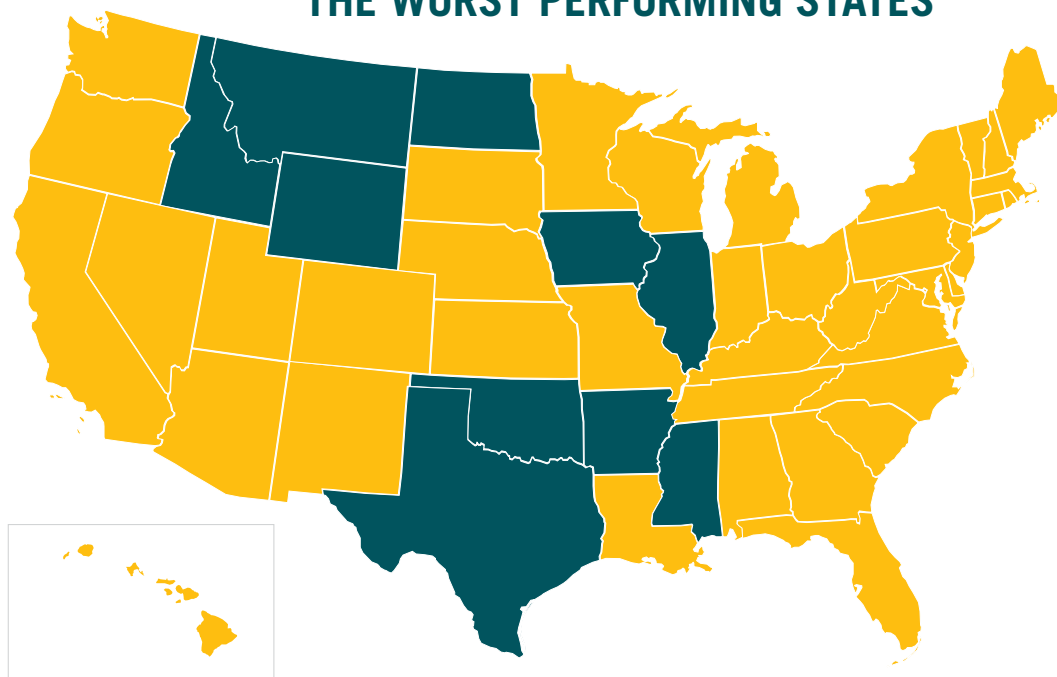
THE BEST, THE BOTTOM, AND FACTS ABOUT THE TOP 10 PERFORMING STATES

THE BEST PERFORMING STATES



- 1 Arizona
- 2 Vermont
- 3 New Hampshire
- 4 Michigan
- 5 Hawaii
- 6 California
- 7 Dist. of Columbia
- 8 Missouri
- 9 South Dakota
- 10 Maryland

THE WORST PERFORMING STATES



- 42 Idaho
- 43 Wyoming
- 44 Oklahoma
- 45 Iowa
- 46 North Dakota
- 47 Illinois
- 48 Montana
- 49 Arkansas
- 50 Texas
- 51 Mississippi

FACTS ABOUT THE BEST PERFORMING STATES

- 1 Top Performers are both big and small states in population**—“big” population states include California (biggest) and Michigan (#9) as well as “small” population states such as South Dakota (#46), Vermont (#50) and the District of Columbia (#49).
- 2 Top Performers are both rich and poor states in terms of median family income**—“rich” states include Maryland (richest), New Hampshire (2nd richest), Hawaii (3rd richest), and D.C. (5th richest) and less affluent states such as Arizona (#38), South Dakota (#31) and Michigan (#32).
- 3 Top Performers are high tax and low tax burden states**—“high tax burden” states include California (#6, tied), D.C. (#10) and Maryland (#6, tied) and “low tax burden” states include Arizona (#37), New Hampshire (#45), and South Dakota (#49).
- 4 Top Performers are big and low spenders per person served through Home and Community-Based Services**—“big spender” states are Vermont (#16) and D.C. (#2) and “low spender” states include Arizona (#49), California (#48), Michigan (#42), and South Dakota (#45).
- 5** While Top Performers tended to trend more politically Democratic, with seven of the top ten being Blue states (according to their 2012 Presidential Election results), three Red states were in the top ten showing some political diversity.

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

HOW TO USE THIS *THE CASE FOR INCLUSION* & HOW THE RANKINGS WERE DEVELOPED

USING *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:

- 1 How their state performs overall in serving individuals with intellectual and developmental disabilities;**
- 2 What services and outcomes need attention and improvement in their state; and**
- 3 Which states are top performers in key areas, so advocates and officials in those top-performing states can act as a resource for those states desiring to improve in key areas.**

Advocates should use this information to educate other advocates, care and service 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 ID/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.


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

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 and improved quality of life. UCP also advocates that government agencies should replicate this data reporting in more detail at the state and county level to identify areas of excellence and to target critical issues needing attention.

HOW THE RANKINGS WERE DEVELOPED:

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 ID/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 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.

WEIGHTING OF *CASE FOR INCLUSION* SCORES— 100 TOTAL POSSIBLE POINTS

Category	Measure	Points Assigned		
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 in Own Home		2.8	
	NCI - Inclusion (sum of 4 measures)		2.8	
	NCI - Relationships Other than Staff and Family		2.8	
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 - %		4.0	
	Voc Rehab - Rehab Rate (finding a job)		2	
	Voc Rehab - Number of Hours Worked		2	
Reaching Those in Need	Voc Rehab - Retain Job for One Year		2	16
	Waiting List - Average % Growth for Residential and HCBS		9	
	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	

WEIGHTING OF *CASE FOR INCLUSION* SCORES— 100 TOTAL POSSIBLE POINTS (CONTD.)

2016 Data Source	2016 Table
RTC	Calculated from fiscal reporting
RTC	Calculated from fiscal reporting
Coleman	State Profiles
RTC	Table 1.1
RTC	Table 1.3
RTC	Table 1.4
RTC	Table 1.5
NCI	Table 43
NCI	Table 86
NCI	Table 63
NCI	Table 106
NCI	Table B2, B30, B32, B34
NCI	Table 58
Coleman	State Profiles
Coleman	State Profiles
NCI	2012, 2013 Participating Stores
Mathematica	Table B.3
ICI	Table 5
ICI	Table 8
ICI	Table 8
ICI	Table 8
RTC	Table 1.6
Kaiser	ID/DD Wait List
RTC	Calculated
Census	Table 1810
NASDDS	Table 1

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

As noted, most data is from 2014, 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 2015 or later would not yet have an impact on the data.

When reviewing an individual state's ranking, it is important to consider action taken since 2014, if any, to accurately understand both where that state was and where it is presently. Especially given the implementation of Home and Community Based Waivers. 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 of caution: although more than 55 points separate the top performing state from the poorest performing state, 9 points separate the top 10 states, 15 points separate the top 25 states and only 11 points separate the middle 25 states. Therefore, minor changes in state policy or outcomes could significantly affect how a state ranks on future or past *Case for Inclusion* reports. This fact alone should also further incentivize state advocates and policy makers into action, as small and incremental changes continue to have a lasting impact on quality of life for individuals with disabilities in communities across the country.

Data Sources

Census – U.S. Census Bureau's Annual Community Survey 2014.

Coleman - The Coleman Institute for Cognitive Disabilities, University of Colorado - The State of the States in Developmental Disabilities' state profiles (through fiscal year 2013).

ICI – University of Massachusetts' Institute for Community Inclusion – StateData: The National Report on Employment Services and Outcomes 2015.

Kaiser – Kaiser Family Foundation's State Indicators – Waiting Lists for HCBS Waivers 2014.

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.

NCI – Human Services Research Institute's National Core Indicators Adult Consumer Survey for FY 2014-2015 and Child Family Survey for FY 2012-2013, FY 2013-2014 and FY 2014-2015.

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 2012 - Residential Information Systems Project (RISP) – advance copies of the 2016 report provided to UCP. The 2015 report is available online.

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A special thank you to Sheryl A. Larson, Senior Research Associate at the University of Minnesota's Research and Training Center on Community Living, who again provided an advance copy of data tables for their 2016 report. It should be noted that the Research and Training Center's data is drawn from their own surveys of state developmental disability directors but, when these directors do not or are not able to respond with the requested information, then data is drawn from Coleman Institute, Kaiser Family Foundation and American Health Care Association reports as well.

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1. The University of Minnesota Research and Training Center on Community Living. "Medicaid Home and Community Based Services for Persons with Intellectual and Developmental Disabilities – Interim Report." September 26, 2005. Page 3.

ABOUT THE AUTHOR:

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Tarren Bragdon has been involved in healthcare policy research and analysis for more than a decade. His work has been featured in newspapers and media outlets nationwide including *The Wall Street Journal*, *New York Post*, *New York Sun* and PBS. He served two terms in the Maine House of Representatives on the Health and Human Services Committee and served as chair of the board of directors of Spurwink Services, one of the largest social service providers in Maine.



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 a spectrum of disabilities. Together with nearly 70 affiliates, UCP has a mission to advance the independence, productivity and full citizenship of people with disabilities by supporting more than 176,000 children and adults every day—one person at a time, one family at a time. UCP works to enact real change—to revolutionize care, raise standards of living and create opportunities—impacting the lives of millions living with disabilities. For more than 60 years, UCP has worked to ensure the inclusion of individuals with disabilities in every facet of society. Together, with 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 60 years, and beyond.

Please visit our website, www.ucp.org for additional resources in your area, or contact us (800) 872-5827 to learn more about UCP.



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