UCP United Cerebral Palsy™

the case for Inclusion 2014

2014 Report

INTRODUCTION

Every year since 2006, United Cerebral Palsy (UCP); an international advocate, educating and providing support services for children and adults with a spectrum of disabilities through an affiliate network; produces The *Case for Inclusion*, an annual ranking of how well state Medicaid programs serve Americans with intellectual and developmental disabilities (ID/DD). Individuals with ID/DD, including the aging, want and deserve the same freedoms and quality of life as all Americans.

Medicaid affects so many—children and adults with disabilities, the elderly and folks living in poverty. It is the critical safety net that provides financial and health care security and community support to Americans, including those with ID/DD, so their desired freedom, quality of life and community participation can be fully realized.

It is the duty of a civil society such as ours to aid these individuals, who are often the most vulnerable among us.

Yet some states do much better than others in demonstrating the needed political will and sound Medicaid policies 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* shows how well each individual state is performing overall; how each state matches up against other states regarding key data measures; and, most importantly, the top performing states with policies and practices that should be replicated.

MEDICAID FACT-FISCAL YEAR 2011

TOTAL SPENDING (STATE AND FEDERAL)– $432 BILLION

Individuals with ID/DD -$40.5 billion (9.3%)

TOTAL ENROLLMENT – 55.7 MILLION PEOPLE

Individuals with ID/DD –767,000 (1.4%)

Source: Medicaid 2012 Actuarial Report & the Research and Training Center on Community Living

FOUR KEY ASPECTS OF A HIGH FUNCTIONING MEDICAID PROGRAM

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. The *Case for Inclusion*'s five major outcome areas align, as indicated, with the following four-part holistic approach:

1. **People with disabilities will live in and participate in their communities [Promoting Independence]**
2. **People with disabilities will have satisfying lives and valued social roles [Promoting Productivity]**
3. **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 [Keeping Families Together and Reaching Those in Need]**
4. **People will be safe and healthy in the environments in which they live [Tracking Health, Safety, and Quality of Life]:**

The Case for Inclusion's five major outcome areas align, as indicated, with the four-part holistic approach

MAJOR ENHANCEMENTS IN 2014

Since 2006, UCP's *Case for Inclusion* rankings have revealed how state's Medicaid programs measure up in areas including how many individuals are supported in the community, how many participate in competitive employment and family support services and how states are doing helping those in need, including serving those languishing on waiting lists.

Responding to feedback from UCP affiliates, policymakers and advocates asking for more person-centered measures to showcase if and how individuals are faring as an active part of their community, UCP has made several major enhancements to this year's *Case for Inclusion* rankings to take a closer look at how Americans with intellectual and developmental disabilities are faring throughout the states. The issue of inclusion remains UCP's primary focus, but a more person-centered approach creates a better understanding of how it is defined. While it is positive to close large state institutions

that isolate individuals from the rest of their community and have individuals live more independently in their own home or apartment or in small home-like settings, true inclusion means so much more:

- **Are individuals still isolated at their non-institutional home?**
- **Are they lonely? Do they have meaningful relationships and friends?**
- **Are individuals stuck in their residence, or do they regularly go out into the community and have an active and social presence in their neighborhoods?**
- **Are individuals getting healthier since good health is key to a high quality of life?**

To answer these questions about the true quality of life for Americans with intellectual and developmental disabilities, substantial revisions were made to the *Case for Inclusion* index. A critical part of these changes was to emphasize the importance of the National Core Indicators (NCI), a survey that uses in-person interviews and extensive questioning to better reflect the true health, safety and quality of life of individuals, with 39 states participating and 19 states publicly reporting their survey results. In the past, UCP's *Case for Inclusion* simply scored states on whether or not they participated in the NCI survey. Beginning in 2014, UCP uses nine different NCI data measures from the survey, to paint a more complete picture of the quality of life and inclusion for individuals. In addition, UCP begins ranking states on whether or not they participate in the NCI's child survey, as part of the Keeping Families Together section of the *Case for Inclusion* ranking. In total, NCI-related data measures now make up 18 points of the 100-point *Case for Inclusion* scale, up from six points in prior rankings. States not participating and tracking outcomes through NCI see a loss of up to 20 points.

Beginning in 2014, UCP uses nine different NCI data measures from the survey, to paint a more complete picture of the quality of life and inclusion for individuals.

In addition, this year UCP enhanced the Promoting Productivity section of the ranking by including measures on how successful states are in placing individuals in work through vocational rehab, the average number of hours worked and the retention rate of individuals staying on the job after one year.

In summary, UCP added 14 new data measures (25 points out of 100), eliminated four measures that were no longer regularly updated or were not changing (15.5 points out of 100) and re-weighted another six measures to keep the full scale consistent at 100 points.

As always, the rankings in this report are a snapshot in time. Most data is from 2012, 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.

Category	Measure		2007-2013		2014	
Promoting Independence	Community-Based	% of Recipients with ID/DD on HCBS	9	50	9	50
		% 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	12	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	
	Abuse		6			
Keeping Families Together	Family Support per 100k		6	12	3	8
	% in a Family Home		6		3	
	NCI - Child/Family Survey Participation				2	
Promoting Productivity	Has Medicaid Buy-In Program		2	10	2	12
	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	16	9	16
	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	

Eliminated - regularly updated data no longer consistently available
New - new measure added in 2014

SIGNIFICANT TAKEAWAYS FROM THE 2014 RANKING

PROMOTING INDEPENDENCE

1 **All states still have room for improvement,** but some states have consistently remained at the bottom since 2007, including Arkansas (#47), Illinois (#46), Mississippi (#51) and Texas (#50).

2 **38 states now meet the 80/80 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 community support. Those that do not meet the 80/80 standard are Arkansas, Illinois, Iowa, Kentucky, Louisiana, Mississippi, Nebraska, New Jersey, North Carolina, Oklahoma, Texas, Utah and Virginia, although Nebraska, North Carolina, Oklahoma, Utah and Virginia are very close.

3 **As of 2012, 14 states have no state institutions to seclude those with ID/DD,** including Alabama, Alaska, Hawaii, Indiana (new this year), Maine, Michigan, Minnesota, New Hampshire, New Mexico, Oregon, Rhode Island, Vermont, West Virginia and Washington, D.C. Another 11 states have only one institution each. Since 1960, 219 of 354 state institutions have been closed (10 more in the past year alone), according to the University of Minnesota's Research and Training Center on Community Living. Another 16 more are projected to close by 2016.

4 **18 states now meet 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 three residents. The U.S. average for this standard is 77 percent. Just eight states meet a top-performing 90 percent Home-like Setting Standard: Alaska, Arizona, California, Kentucky, Nevada, New Hampshire, New Mexico and Vermont.

5 **Seven states report at least 10 percent of individuals using self-directed services,** according to the National Core Indicators survey in 19 states. These states include Connecticut, Georgia, Hawaii, Illinois, Kentucky, Michigan and Ohio.

TRACKING HEALTH, SAFETY AND QUALITY OF LIFE

6 **39 states participate in the National Core Indicators (NCI) model,** a comprehensive quality-assurance program that includes standard measures to assess outcomes of services, but only 19 states reported data outcomes in 2012.

(nationalcoreindicators.org). In January 2012, the Obama Administration made available grant funding so that even more states could participate and ensure their quality assurance efforts were benchmarked and comprehensive. (NCI has more than 100 measures; see Endnote #3 for more details).

KEEPING FAMILIES TOGETHER

7 **Only 15 states were 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 Alabama, Arizona, California, Delaware, Louisiana, Minnesota, Montana, New Hampshire, New Mexico, New York, Pennsylvania, South Carolina, South Dakota, Vermont and Wisconsin.

PROMOTING PRODUCTIVITY

8 **Just 10 states have at least one-third (33 percent) of individuals with ID/DD working in competitive employment.** These states include Connecticut, Louisiana, Maryland, Nebraska, New Mexico, Oklahoma, Oregon, Vermont, Virginia and Washington State. Washington, D.C. and Pennsylvania are very close.

9 **13 states report successfully placing at least 60 percent of individuals in vocational rehabilitation in jobs,** with six states reporting the average number of hours worked for those individuals placed being at least 25 hours and five states reporting at least half of those placed remaining in their job for at least one year. Only Nebraska and South Dakota meet the standard on all three success measures.

SERVING THOSE IN NEED

10 **Waiting lists for residential and community services are high and show the unmet need.** Almost 317,000 people are on a waiting list for Home and Community-Based Services. This requires a daunting 46 percent increase in states' HCBS programs. However, 22 states report no waiting list or a small waiting list (requiring less than 10 percent program growth).

2014 THE CASE FOR INCLUSION RANKINGS

By Rank in 2014

States	2014 Ranking
Arizona	1
Michigan	2
Hawaii	3
Georgia	4
New York	5
South Carolina	6
Maine	7
Massachusetts	8
Ohio	9
Missouri	10
Oregon	11
Louisiana	12
California	13
Vermont	14
New Jersey	15
Pennsylvania	16
New Hampshire	17
Kentucky	18
Alabama	19
Washington	20
Nevada	21
Connecticut	22
Alaska	23
North Carolina	24
Delaware	25
New Mexico	26
Maryland	27
West Virginia	28
Colorado	29
Wisconsin	30
Minnesota	31

States	2014 Ranking
Dist. of Columbia	32
Rhode Island	33
South Dakota	34
North Dakota	35
Montana	36
Kansas	37
Florida	38
Idaho	39
Nebraska	40
Wyoming	41
Iowa	42
Utah	43
Illinois	44
Arkansas	45
Indiana	46
Tennessee	47
Oklahoma	48
Virginia	49
Texas	50
Mississippi	51

2014 THE CASE FOR INCLUSION RANKINGS

Alphabetical

States	2014 Ranking
Alabama	19
Alaska	23
Arizona	1
Arkansas	45
California	13
Colorado	29
Connecticut	22
Delaware	25
Dist. of Columbia	32
Florida	38
Georgia	4
Hawaii	3
Idaho	39
Illinois	44
Indiana	46
Iowa	42
Kansas	37
Kentucky	18
Louisiana	12
Maine	7
Maryland	27
Massachusetts	8
Michigan	2
Minnesota	31
Mississippi	51
Missouri	10
Montana	36
Nebraska	40
Nevada	21
New Hampshire	17
New Jersey	15
New Mexico	26
New York	5
North Carolina	24
North Dakota	35
Ohio	9
Oklahoma	48
Oregon	11
Pennsylvania	16
Rhode Island	33
South Carolina	6
South Dakota	34
Tennessee	47
Texas	50
Utah	43
Vermont	14
Virginia	49
Washington	20
West Virginia	28
Wisconsin	30
Wyoming	41

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
Alabama	38.9	27	11.6	2	4.0	11	4.4	48	10.8	38	69.7	19
Alaska	46.5	4	0.0	20	1.8	39	7.8	5	11.6	31	67.7	23
Arizona	47.3	1	10.4	18	7.4	1	5.9	41	14.5	6	85.5	1
Arkansas	24.8	50	11.1	13	1.2	48	5.8	42	11.4	34	54.4	45
California	44.3	10	0.0	20	4.4	7	7.5	11	15.0	3	71.2	13
Colorado	44.5	9	0.0	20	2.1	34	5.2	46	12.3	23	64.2	29
Connecticut	35.9	40	11.5	4	3.2	20	7.4	12	10.0	45	68.1	22
Delaware	41.9	18	0.0	20	4.2	9	5.4	45	13.9	10	65.4	25
Dist. of Columbia	41.0	23	0.0	20	1.7	41	5.2	47	13.7	11	61.6	32
Florida	39.8	25	0.0	20	3.0	26	3.9	49	12.3	24	59.0	38
Georgia	44.2	11	11.5	8	2.2	32	8.9	2	10.7	39	77.4	4
Hawaii	47.0	3	10.7	15	3.3	18	3.5	51	13.5	12	77.9	3
Idaho	37.9	34	0.0	20	0.9	51	6.3	33	13.4	14	58.5	39
Illinois	25.9	49	11.2	11	1.3	47	6.1	36	10.3	43	54.7	44
Indiana	37.5	37	0.0	20	1.9	38	6.6	26	6.9	49	52.8	46
Iowa	34.6	43	0.0	20	1.4	45	6.3	32	14.5	5	56.9	42
Kansas	38.3	30	0.0	20	1.9	37	6.5	27	12.4	22	59.2	37
Kentucky	41.1	22	9.2	19	1.2	49	6.1	37	12.2	25	69.8	18
Louisiana	35.3	41	11.5	7	6.4	2	6.6	24	11.9	28	71.7	12
Maine	43.5	14	11.5	6	1.3	46	5.6	44	13.3	16	75.3	7
Maryland	43.5	13	0.0	20	1.6	43	7.6	7	11.9	29	64.7	27
Massachusetts	42.0	17	11.3	10	3.3	17	6.2	35	11.6	32	74.4	8
Michigan	46.4	5	10.4	17	3.1	22	7.1	16	14.3	8	81.2	2
Minnesota	41.6	19	0.0	20	3.4	15	6.8	20	11.0	35	62.9	31

SUB-RANKING BY MAJOR CATEGORY (CONTD.)

	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
Mississippi	8.6	51	0.0	20	1.8	40	6.0	39	9.5	46	25.9	51
Missouri	38.7	28	11.6	3	2.7	29	6.6	23	13.2	17	72.9	10
Montana	37.9	35	0.0	20	3.1	23	6.4	30	12.5	21	59.9	36
Nebraska	37.8	36	0.0	20	1.1	50	7.5	10	12.2	26	58.5	40
Nevada	44.1	12	0.0	20	3.0	25	8.0	4	13.0	19	68.1	21
New Hampshire	46.0	6	0.0	20	3.6	14	7.5	9	13.1	18	70.2	17
New Jersey	34.0	44	11.7	1	3.2	21	6.5	28	15.0	2	70.3	15
New Mexico	45.0	8	0.0	20	2.4	30	7.0	18	10.5	42	65.0	26
New York	38.2	31	11.5	5	4.1	10	6.2	34	15.5	1	75.6	5
North Carolina	31.4	46	11.2	12	4.4	8	6.8	21	12.0	27	65.6	24
North Dakota	35.9	39	0.0	20	2.0	36	7.4	14	14.8	4	60.2	35
Ohio	40.1	24	11.0	14	5.6	4	6.6	25	11.0	36	74.4	9
Oklahoma	32.9	45	0.0	20	2.1	35	6.0	40	6.0	50	47.0	48
Oregon	45.8	7	0.0	20	4.5	6	7.4	13	14.1	9	71.8	11
Pennsylvania	39.1	26	11.4	9	3.2	19	6.4	31	10.1	44	70.2	16
Rhode Island	42.1	16	0.0	20	2.2	33	6.7	22	10.6	40	61.5	33
South Carolina	38.1	33	10.5	16	6.2	3	7.3	15	13.5	13	75.6	6
South Dakota	36.4	38	0.0	20	2.7	28	7.7	6	14.4	7	61.3	34
Tennessee	38.2	32	0.0	20	1.6	42	3.9	50	8.8	47	52.5	47
Texas	30.9	47	0.0	20	3.4	16	5.8	43	0.8	51	40.9	50
Utah	34.9	42	0.0	20	1.6	44	6.9	19	11.7	30	55.0	43
Vermont	47.3	2	0.0	20	3.7	13	8.6	3	11.5	33	71.1	14
Virginia	27.0	48	0.0	20	2.8	27	7.0	17	8.0	48	44.7	49
Washington	41.2	21	0.0	20	4.6	5	10.2	1	13.3	15	69.3	20
West Virginia	41.3	20	0.0	20	3.0	24	7.5	8	12.6	20	64.5	28
Wisconsin	42.4	15	0.0	20	3.9	12	6.1	38	10.8	37	63.2	30
Wyoming	38.5	29	0.0	20	2.3	31	6.5	29	10.6	41	57.8	41

MOST IMPROVED AND BIGGEST DROPS

(Since 2007)

***Case for Inclusion* Ranking: Most Improved and Biggest Drops**

		2014	2007	Difference 07-14
IMPROVED	Ohio	9	48	39
	Louisiana	12	44	32
	Missouri	10	41	31
	Georgia	4	30	26
	Kentucky	18	40	22
	Dist. of Columbia	32	49	17
	Maine	7	24	17
	Alabama	19	32	13
	Pennsylvania	16	29	13
DROPPED	Idaho	39	25	-14
	Kansas	37	22	-15
	Connecticut	22	6	-16
	Montana	36	19	-17
	Florida	38	18	-20
	Alaska	23	2	-21
	Colorado	29	8	-21
	Minnesota	31	7	-24
	Wyoming	41	17	-24

Alabama

Up 13 places: Closed its only large state institution.

Washington D.C.

Up 17 places: Dramatically increased the share of individuals (from 44 percent to 80 percent) and resources (from 10 percent to 70 percent) dedicated to those receiving home and community-based services.

Georgia

Up 26 places Significantly increased the share of individuals (from 88 percent to 97 percent) and resources (from 73 percent to 89 percent) dedicated to the community, closed three large state institutions and reduced the population at state institutions by 75 percent. It increased the portion of people in competitive employment (from 38 percent to 52 percent).

Kentucky

Up 22 places: Increased the share of individuals (from 79 percent to 97 percent) and resources (from 63 percent to 73 percent) dedicated to the community, closed one large state institution and reduced the population at state institutions by 71 percent. It also added a Medicaid Buy In program to support coverage when individuals work and increase their income.

Louisiana

Up 32 places: Had a huge improvement in the portion of individuals (from 49 percent to 68 percent) and resources (from 41 percent to 79 percent) dedicated to community services over institutions, closed seven large state institutions and had a large drop in the portion of individuals served in large institutions (from 18 percent to 8 percent).

Maine

Up 17 places: Increased the share of individuals (from 92 percent to 96 percent) and resources (from 78 percent to 98 percent) dedicated to the community and supported a greater share of individuals in home-like settings (from 66 percent to 80 percent).

Missouri

Up 31 places: Dramatically increased the portion of resources dedicated to people in the community (from 59 percent to 85 percent), reduced by half the number of individuals isolated in large state institutions (500 individuals moved into the community) and started participating in and reporting outcomes from NCI.

Ohio

Up 39 places: Dramatically increased the share of individuals (to 82 percent from 63 percent) and resources (from 50 percent to 83 percent) dedicated to the community, closed a state institution, reduced by more than half the portion of individuals served in large institutions (from 18 percent to 7 percent), started participating in and reporting on NCI quality measures.

Pennsylvania

Up 13 placess: Substantially increased the portion of resources dedicated to people in the community (from 70 percent to 81 percent), dramatically increased the portion of people served in home-like settings (from 58 percent to 76 percent), closed a state institution, and reduced by 24 percent the total population isolated at state institutions.

Alaska

Down 21 places: Fell so 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 at around 200 people served. It is also important to note that Alaska does not participate in NCI and therefore loses out gaining a better understanding of individuals' true quality of life and inclusion and the related points participating in that survey provides.

Colorado

Down 21 places: Fell so dramatically because of a significant decline in competitive employment participation, (from 53 percent to 21 percent) and, although the state does participate in NCI, it did not publicly report outcomes for NCI in 2012.

Connecticut

Down 16 places: Dramatically reduced portion of individuals served in home-like settings (from 71 percent to 54 percent) and remained stagnant while most other states improved overall, which caused the state to fall in comparison to others.
increased the portion of individuals living in home-like settings (from 48 percent to 76 percent) and dramatically increased participation in competitive employment (from 6 percent to 21 percent).

Florida

Down 20 places: No major changes or decline in performance over the past seven years but most other states improved, causing Florida to drop in comparison.

Idaho

Down 14 places: : On the positive side, Idaho significantly increased the share of individuals (from 75 percent to 86 percent) and resources (from 51 percent to 94 percent) dedicated to the community but also dramatically reduced the portion of individuals served in home-like settings (from 92 percent to 58 percent).

Kansas

Down 15 places: On the positive side, Kansas significantly increased the share of resources (from 78 percent to 90 percent) dedicated to the community but also dramatically reduced the portion of individuals served in home-like settings (from 73 percent to 60 percent).

Minnesota

Down 24 places: Remained stagnant while most other states improved overall which caused the state to fall in comparison to others. Although the state does participate in NCI but it did not publicly report outcomes for NCI in 2012.

Montana

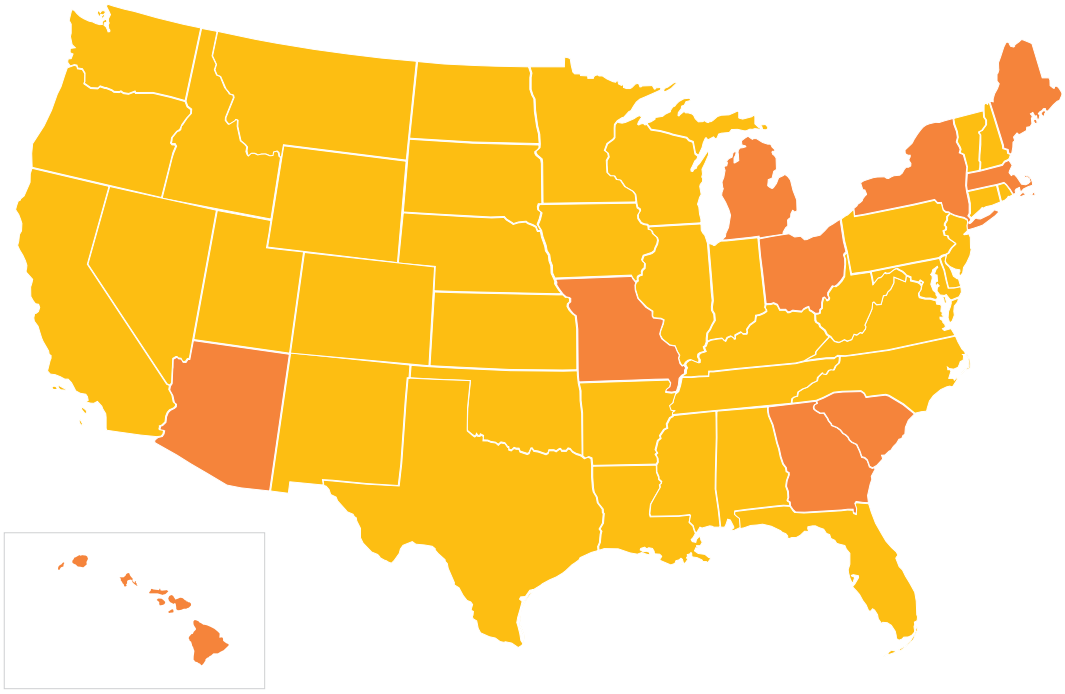
Down 17 places: Dramatically reduced portion of individuals served in home-like settings (from 80 percent to 57 percent).

Wyoming

Down 24 places: Primarily due to the fact that it does not participate in NCI, remained stagnant while most other states improved overall causing the state to fall in comparison to others, and had a drop in competitive employment (from 25 percent to 17 percent).

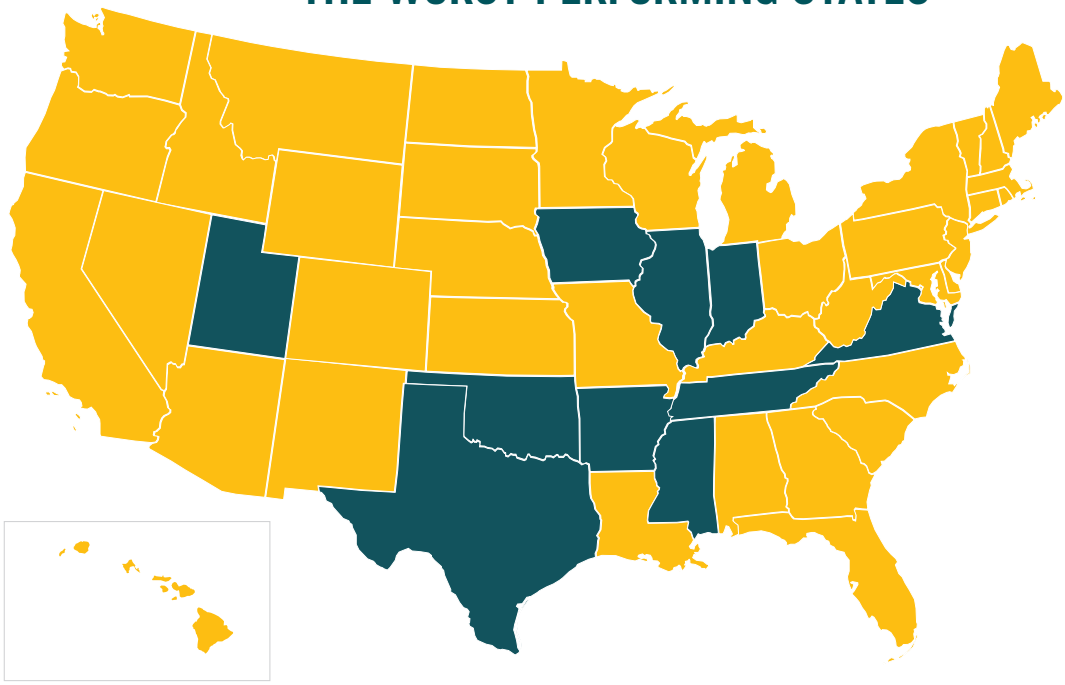
THE BEST, THE WORST AND FACTS ABOUT THE TOP 10

THE BEST PERFORMING STATES



1 Arizona
2 Michigan
3 Hawaii
4 Georgia
5 New York
6 South Carolina
7 Maine
8 Massachusetts
9 Ohio
10 Missouri

THE WORST PERFORMING STATES



42. Iowa
43. Utah
44. Illinois
45. Arkansas
46. Indiana
47. Tennessee
48. Oklahoma
49. Virginia
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 New York (3rd biggest), Ohio (#7), Michigan (#8) and Georgia (#9) as well as "small" population states such as Hawaii (#41) and Maine (#40).
2. **Top Performers are both rich and poorer states in terms of median** family income – "rich" states include Hawaii (9th richest) and Massachusetts (#5) and less affluent states include Arizona (#31), Georgia (#40), Michigan (#32) and South Carolina (#47).
3. **Top Performers are high tax and low tax burden states** – "high tax burden" states include Massachusetts (#10) and New York (#1) as well as "low tax burden" states include Arizona (#35), South Carolina (#42) and Georgia (#36).
4. **Top Performers are big and low spending per person, served through the Home and Community-Based Services** – "big spender" states are New York (#7) and Maine (#6) and "low spender" states are Arizona (#49), Georgia (#40) and South Carolina (#48).

CASE STUDY: KANSAS

KanCare: Integrating Care and Community with Private Medicaid Plans for Kansas Individuals with ID/DD

States are struggling with limited revenues, climbing Medicaid costs and the need for better individual outcomes. Given this, many state leaders are turning to managed care to have private companies help them better coordinate care for Medicaid beneficiaries at lower costs.

Lieutenant Governor Jeff Colyer, M.D., on behalf of Governor Sam Brownback, led the Kansas Medicaid transformation that transitions almost all Medicaid populations (about 380,000 people in this state of 2.76 million) and all Medicaid services into comprehensive managed care plans. The reform is called KanCare. KanCare began on January 1, 2013. Unlike other states which exclude individuals with ID/DD, Kansas Medicaid integrates all individuals with ID/DD, including those in institutions, and all services, including home and community-based services. More than

just a privatization of Medicaid, KanCare directly integrates work, health and community; broadens the scope of benefits and prioritizes competitive employment and improving health outcomes for those with ID/DD.

Like any substantial Medicaid reform, KanCare is not without controversy. Some legislators in 2013 have sought further delays or carve-outs for those with ID/DD, although these efforts have been unsuccessful to date.

For individuals with ID/DD living in Kansas, the goals of the KanCare reform are explicit: 1) more individuals in competitive employment, 2) fewer individuals isolated in large institutions and 3) more individuals with improved health and longer lives.

According to the UCP *Case for Inclusion* ranking, for many years, Kansas Medicaid had stagnant but average outcomes for its ID/DD population compared to other states. The 2013 ranking (reflecting 2011 data) showed Kansas dropping to 41sth, indicating the status quo was unsuccessful.

What are the basics of KanCare for those with ID/DD?

KanCare provides almost all individuals in Kansas Medicaid with a choice of three different private managed care plans administered by Amerigroup, Sunflower State Health Plan and UnitedHealthcare. On January 1, 2013, individuals with ID/DD could choose from these three private plans, all of which fully integrate medical and behavioral health benefits. Beginning February 1, 2014 (the annual open enrollment period), these same private plans will include all home- and community-based services in their offerings for individuals with ID/DD.

What about those with ID/DD living in institutions?

Unlike other state-managed care efforts that exclude those languishing in institutions, the KanCare reform is integrated with Kansas' ongoing effort to move or divert individuals from isolation in institutions to supportive inclusion in the community. In addition, the state includes these individuals in comprehensive managed care so managed care companies have a financial incentive to be even more creative and committed to moving individuals from institutions and supporting them effectively in the community.

This partnership between private managed care companies and the state to drive further community inclusion makes KanCare unique among state reforms.

What are the projected ID/DD-related Medicaid savings from the KanCare reforms?

KanCare is projected to save about $126 million over five years from its ID/DD-related reforms. A percentage of these savings will be reinvested into new work-related pilot programs designed to assist Kansans with disabilities to become engaged in the community through meaningful employment.

What is "new and improved" under KanCare regarding available benefits and services for individuals with ID/DD?

New services and benefits in KanCare prioritize better health and socialization. Individuals with ID/DD now have available, including: heart and lung transplants, adult dental, gift card incentives for participating in preventive health services, cell phones for health-related texting and calling, weight loss and smoking cessation programs, $120 annually toward over-the-counter medication, free transportation to community events, peer & family support services, pest control, vision, pet therapy, extra respite services, three days of additional in-home tele-monitoring and additional podiatry services, depending on the plan.

In addition, those in the DD Pilot (which tests in 2013 some of the new coordinated community services in private plans that will be made available to everyone beginning February 1, 2014) have access to even more services including: three days of additional personal care, 48 segments of transportation to community events, recreational outings to dinners and movies, hospital companions, additional home modifications, practice visits to physicians and dentists, career development and an additional 40 hours of respite. These extra services do not meet the definition 1915(c) waiver service, but are available to those in the pilot in one of the three private managed care plans.

What is "new and improved" under KanCare regarding employment for individuals with ID/DD?

Integrating work with health outcomes is both unique and core to the KanCare reform. This work-focus builds on previous legislative reforms. Prior to KanCare's implementation, the Kansas Legislature passed an Employment First initiative in 2011 and then, in 2012, passed legislation to give preference in state contracts to companies that employ individuals with disabilities.

KanCare also creates two employment-focused pilot programs serving up to 600 individuals (compared to about 7,800 served on the HCBS waiver in 2010):

1. For up to 400 individuals receiving SSI and on the HCBS waiting list, the first pilot will provide assistance obtaining employment and up to $1,500 per person per month in employment support services. If the individual does not find employment, he or she is restored to the waiting list.
2. For up to 200 individuals, the second pilot will focus on youth and those who would likely meet the criteria for Social Security Disability but are not yet receiving it. These individuals will complete a presumptive eligibility process, receive employment assistance focused on jobs with employer-sponsored health coverage and wrap-around Medicaid services once enrolled in work-related health plan.

How is success defined for those with ID/DD?

Key goals of the KanCare reform are to improve health, work and functional outcomes for those with ID/DD. The 1115 Waiver application specifically cites Kansas Medicaid studies that show those with ID/DD had poor health outcomes in Kansas Medicaid. For example,

those with ID/DD who had diabetes only had the routine HbA1C test (monitoring blood sugar levels) 55 percent of the time compared to 72 percent of the time for national Medicaid managed care population. Similarly, cholesterol checks for those with ID/DD were completed only half the time in the study year, despite the fact that 93 percent of individuals had a primary care visit during that year.

KanCare withholds three percent to five percent of the capitated rate for these private plans and rewards plans based on actual outcomes, including specific outcomes for individuals with intellectual and developmental disabilities.

- **Increased competitive employment: An increased number of people with developmental or physical disabilities, or with significant mental health treatment needs, will gain and maintain competitive employment.**
  - Tracking both those with ID/DD overall being competitively employed and those receiving employment services being employed
- **Improved life expectancy**
- **Integration of physical health, behavioral health, and HCBS: based on case manager evaluation tool.**
- **Improved health: The HEDIS (Healthcare Effectiveness Data and Information Set) health outcomes, standard in Medicaid managed care, will now be specifically tracked for those with ID/DD and can be compared with other states.**

Plans must achieve a five percent improvement in these measures each year to be eligible for the full incentive payment.

Although not explicitly stated, KanCare is also focused on community inclusion, as evidenced by:

- **Decrease of those living in institutions: a drop of those living in ICF-MRs, either state or privately run**

KanCare represents one of the most aggressive and comprehensive Medicaid reforms affecting those with ID/DD. By combining health, community and work, KanCare seeks to improve the overall quality of life for those with ID/DD by improving health outcomes, increasing work participation and providing greater community inclusion. Whether these private managed care companies accomplish these goals will be closely watched and determined by advocates, family members, policymakers and researchers. One thing is clear: the goals, strategies and outcomes of KanCare are explicit and transparent so there will be little debate of its success or failure.

CASE STUDY: MASSACHUSETTS

Massachusetts' One Care Demonstration: Integrating Medicaid and Medicare-Funded Care for Individuals with ID/DD (not on the HCBS waiver)

Medicaid is a partnership between the states and the federal government, whereas Medicare is completely administered and financed by the federal government. Because both programs can serve individuals with intellectual disabilities, the two programs' different rules and structures can result in fractured and inefficient care. This is a disservice to those individuals and their families, as well as providers and taxpayers.

For years, both state and federal leaders have expressed interest in combining Medicare- and Medicaid-funded services for dually-eligible individuals to maximize quality of care and taxpayer savings. President Obama's Affordable Care Act (ACA) advanced the most comprehensive combined state-federal initiative targeting dually-eligible individuals under its newly created Medicare-Medicaid Coordination Office.

Nationally, more than 9 million individuals are dually eligible for both Medicaid and Medicare, with five percent to 18 percent of those (460,000 to 1.7 million) being Americans with intellectual and developmental disabilities. Dually-eligible individuals of all types represent nearly 40 percent of all combined Medicare and Medicaid spending, despite just being 15 percent to 21 percent of total enrollees in each program.

Dually-eligible individuals of all types represent nearly 40 percent of all combined Medicare and Medicaid spending, despite just being 15 percent to 21 percent of total enrollees in each program.

In December 2010, the federal government announced that 15 states would receive grants of up to $1 million each to propose an integrated program that combines Medicare and Medicaid services for dually-eligible individuals. These 15 states are: California, Colorado, Connecticut, Massachusetts, Michigan, Minnesota, New York, North Carolina, Oklahoma, Oregon, South Carolina, Tennessee, Vermont, Washington and Wisconsin.

Reflecting the challenge of integrating the complex Medicare and Medicaid programs, of these 15 states only 10 states moved forward by October 2013: California, Colorado, Illinois, Massachusetts, Minnesota, New York, Ohio, South Carolina, Virginia, and Washington. Of these 10 states, eight are pursuing a solely capitated model (California, Illinois, Massachusetts, New York, Ohio, South Carolina and Virginia). Of these states, only Massachusetts and New York have indicated that they will include those with developmental disabilities in their demonstrations. In Massachusetts, all individuals with intellectual disabilities on the HCBS waiver (about 7,300 individuals) are excluded, but those individuals with intellectual

disabilities not on the waiver but dually eligible are included. MassHealth has indicated an interest in including this waiver population in One Care in the future.

The scope of this demonstration testing both integrating care and a capitated system is substantial, as shown in the table below, reaching up to one in ninedually-eligible Americans.

State with Capitated Demonstration	Population Eligible for the Demonstration (not all may enroll)
California	456,000
Illinois	135,825
Massachusetts	90,240
New York	170,000
Ohio	115,000
South Carolina	53,600
Virginia	78,600
TOTAL	1,099,265

Source: Kaiser Family Foundation

Massachusetts began enrolling dually-eligible individuals into these private plans starting October 1, 2013. Massachusetts estimates that about seven percent of individuals in its demonstration have developmental disabilities and almost all reside in the community.

New York will begin enrollment in July 2014.

Since the UCP began its annual *Case for Inclusion* ranking in 2006, Massachusetts Medicaid, called MassHealth, has been a top performer for its ID/DD population, compared to other states.. The 2014 ranking (reflecting 2012 data) ranked Massachusetts 11th best in the country.

What are the basics of the MassHealth reform One Care for dually-eligible individuals with ID/DD?

The demonstration in Massachusetts was dramatically scaled back from what was originally planned. Rather than six private plans operating statewide, MassHealth's One Care program now only operates in nine of Massachusetts' 14 counties. Rather than six private plans, only three remain and only those in four counties (Hampden, Hampshire, Suffolk, and Worchester) have more than one private plan available. Rather than reaching all 115,000 dually-eligible individuals in Massachusetts, the scaled back demonstration now reaches up to 90,000, of which about 6,300 have developmental disabilities. As noted previously, those with developmental disabilities served on the HCBS waiver are currently excluded from One Care. All plans fully integrate medical, prescription drug

and behavioral health benefits covered by Medicare and Medicaid. For individuals with ID/DD, certain services are carved out of the ICO plans and provided through existing contracts. These carved-out services still operating in a traditional manner include adult day health, adult foster care, day habilitation, day services, group foster care, home care, personal care, respite and targeted case management.

How many people have enrolled in the voluntary One Care reform?

Through February 1, 2014, 9,541 individuals have enrolled in One Care, or about 11.6 percent of the total 82,000 eligible individuals who initially were targeted. Only about 20 percent of individuals have chosen to opt-out of One Care. However, in those counties where there are two or three different plans to choose from, about 13 percent to 19 percent of all eligible individuals are already enrolled. MassHealth plans enrollment to be fully phased in by July 2014. As of February 1, 2014, Commonwealth Care Alliance, the original pilot provider as detailed below, has about two-thirds of all participants.

How does the Massachusetts demonstration build upon past successful pilots for this same population?

The Massachusetts demonstration builds upon a successful pilot administered by the Commonwealth Care Alliance (formerly Boston's Community Medical Group) for 650 dually-eligible non-elderly individuals with physical, developmental and mental illness-related disabilities. That pilot operates an intense care management model with a ratio of 45 patients per full-time equivalent (including both medical and social work professionals).

From 2004 to 2011, individuals in the pilot (which also included 4,400 seniors with almost three-quarters of these seniors needing nursing home level of care) experienced the following impressive outcomes:

- **Half of the rate of hospital admissions compared to those in fee-for-service Medicare (2009 to 2011)**
- **A readmission rate of four percent compared to 13 percent for a similar population in Medicare Advantage (2010)**
- **Two-thirds lower nursing home placement rate (2009 to 2011)**
- **Annual trend cost increases below Medicare for similar populations**
- **60 percent reduction in hospitalization for those under 65 with disabilities**
- **50 percent reduction in surgical flap procedures for those with spinal cord injuries**
- **High degree of consumer satisfaction**

The experience of this pilot greatly shaped the Massachusetts demonstration. Commonwealth Care Alliance is one of the three ICO plans available as part of the demonstration.

What about individuals with ID/DD living in institutions?

Individuals living in state ICF-MR facilities (about 570 dually-eligible individuals out of about 800 total individuals in state institutions) are excluded from the ICO demonstration.

What are the projected savings in both Medicare and Medicaid spending from the ICO-MassHealth reform?

The goal of the MassHealth dual demonstration is to save one percent from baseline spending in the first year, two percent in the second year, and four percent in the third year. In 2008, about $880 million (35 percent) of the $2.5 billion total (Medicare and Medicaid) spent on all dually-eligible individuals in Massachusetts was for individuals with developmental disabilities. Given this, using the savings target of one percent to four percent a year, the annual savings for dually eligible individuals with developmental disabilities range from $9 million in the first year to about $35 million by year three, and roughly $62 million over the entire three years. That figure is significantly less now that the demonstration has been reduced.

What is "new and improved" under MassHealth regarding available benefits and services for dually-eligible individuals with ID/DD as part of the demonstration?

Individuals with ID/DD will have new benefits available through the ICO plans, including: restorative dental services, expanded personal care assistance and greater access to durable medical equipment.

What is "new and improved" under MassHealth regarding employment for individuals with ID/DD?

There are no goals or initiatives specific to employment as part of the demonstration proposal. Unfortunately, Massachusetts has seen participation in competitive employment plummet from 43 percent in 2004 to 14 percent in 2011.

How is success defined for individuals with ID/DD?

MassHealth withholds one percent to three percent of the capitated rate for these private plans and rewards plans based on actual outcomes, including specific outcomes for individuals with intellectual and developmental disabilities. Although the actual outcomes tracked have yet to be determined, below is a sampling of possible measures taken from the demonstration proposal approved by the federal government:

ACCESS:

- Number of preventative health care services received
- Number of enrollees receiving dental services
- Number of enrollees receiving community support

PERSON-CENTERED CARE

- Care Plan development is directed by the enrollee and Care Plan is based on the enrollee's preferences

I

NTEGRATION OF SERVICES

- Changes in patterns of care (facility-based care to community-based care, where appropriate)
- Reduced preventable and acute hospital admissions, readmissions and emergency departments visits

ENROLLEE OUTCOMES

- Pain and fatigue scores for persons with mobility impairments (CAPHS PWMI survey)
- Hospitalization rates for care coordination-sensitive conditions (e.g. bowel impaction, UTI, pressure ulcers).

MassHealth's demonstration represents the first statewide experiment of better coordinating and integrating services for individuals on both Medicaid and Medicare. For dually-eligible individuals with ID/DD, many home and community-based services and case management are carved out of the private ICO plans in the MassHealth reform. However, the Massachusetts reform still represents the first large scale effort to improve coordination of care, improve actual health outcomes and improve overall quality of life for Americans with developmental disabilities with both Medicare and Medicaid. Only Massachusetts and New York are testing integrated care for this population.

CASE STUDY: WASHINGTON STATE

Employment First – Washington State leading the way

In 2011, the National Association of Councils on Developmental Disabilities issued its "The Time Is Now: Embracing Employment First" call to action. The report revealed the alarming fact that 88 percent of working-age adults with developmental disabilities are unemployed.

Given the following, this is particularly tragic:

From an individual's perspective, working in competitive employment means:

- More pay—competitive employment pays better wages, rising 31 percent per hour in real terms since the 1980s compared to dropping 41 percent for those in sheltered workshops during the same period.
- More friends—work supports socialization that leads to more and longer-term relationships and friendships.
- More happiness—work increases an individual's self-worth and provides them resources that allow them to contribute to and participate in their community.

From a taxpayer's perspective, achieving competitive employments means:

- More return on investment—every $1 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 ROI.

Washington State has shown that working-age adults with ID/DD do not have to settle for unemployment. On July 1, 2006, Washington was the first state to adopt what became the Employment First policy, the most current version of which:

- Establishes employment support as the first use of employment and day program funds targeted for working-age adults and ensures that after nine months of 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.

The value of Employment First was best summarized by Linda Rolfe, Washington's long-time Division of Developmental Disabilities director:

"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."

"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."

In 2005, the vast majority of individuals without disabilities took nine months or less to find a job after schooling. Washington State believed individuals with ID/DD shouldn't be left out. The state's approach for individuals with ID/DD was to focus on employment first. The idea was for adults with ID/DD entering the system to focus their first nine months on that same goal—finding a job. 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 developmental disabilities. Therefore, legislation, policies and practices should be aligned to support the employment goals and outcomes of each individual. Simply put, Washington State embraced a strategy of doing the hardest thing first, realizing how important it is to an individual's self-worth and well-being and that it would likely never get done otherwise.

The impact of the Employment First priority was profound. The number of individuals competitively employed rose from 4,440 in 2004 (before the policy) to 5,562 by 2011. This 25 percent increase in just seven years was particularly impressive given it occurred during the Great Recession from 2008-2011.

Overall, Washington State scored 6th best in the country for its Medicaid programs serving individuals with ID/DD, according to UCP's 2013 *Case for Inclusion* ranking (based on 2011 data). This was a significant jump from its 2007 ranking of just 20th. In 2011, Washington State tied with Oklahoma for the highest rate of individuals with ID/DD participating in competitive employment (65 percent)—more than three times the national average of just 20 percent.

ADDITIONAL KEY OUTCOMES OF EMPLOYMENT FIRST IN WASHINGTON STATE

- **$40 million in wages for individuals with developmental disabilities in 2011**
- **40 individuals with developmental disabilities working as entrepreneurs in 2009**
- **5,562 total individuals in competitive employment in 2011**
- **65 percent competitive employment rate in 2011 (tied for best in the**

Not only is the Employment First policy change a positive reform that changes the lives of individuals with ID/DD, it also creates positive outcomes for other areas of support services. Washington State did not significantly cut back on sheltered workshop funding. In fact, the number of participants in sheltered workshops remained unchanged. The state did

not even significantly increase supported employment funding—it was $30.8 million in 2005 and $34 million in 2011, just a 10 percent increase. Instead, 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. 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."

The keys to the Employment First success were state and county leadership, training and innovation, quality employment agencies, organized and informed families and clearly-defined goals. In addition, training and development was focused on building a "Community of Practice" from best practices. Mike Hatzenbeler, CEO of PROVAIL, the Seattle, Washington UCP Affiliate, notes that "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." Mr. Hatzenbeler credits strong long-term focused leadership within the Administration on the Employment First goals, reinforced with robust advocacy before the legislature, as described below.

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.

WASHINGTON STATE EMPLOYMENT FIRST RESULTS

	2004	2012	% Change
Participants - Number	4,778	5,314	11%
Participants - Percent	58%	64%	10%

	2004	2012	% Change
Average Wages per Person	$6,381	$7,065	11%
Cumulative Wages	$30.5 million	$37.5 million	23%

Source: Washington Initiative for Supported Employment

In addition to the above outcomes, Employment First experiences clearly show that more working hours results in fewer service hours. Specifically, the Washington Initiative for Supported Employment's data showed that having a job means:

- "On average, for each person almost five hours worked for every hour of service.
- On average, for each person, almost 419 annual hours of paid service isn't needed because the person is working"

In fact, in 2010 Washington State set the lofty goal of doubling the number of supported employment participants by 2015. The state is well on its way to accomplishing just that.

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

- Celebrate—establishing Employment for All Day, organized by the Community Employment Alliance
- Advocate—an Employment for All Day proclamation issued by the Governor
- Articulate—developing a winning slogan; "Everyone Deserves a Payday."
- Educate—distributing Payday candy bars to legislators with key facts and talking points

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

As of September 2013, 26 states have adopted Employment First-type strategies:

- 12 through legislative changes: California, Delaware, Illinois, Kansas, Maine, North Dakota, Ohio, Pennsylvania, Texas, Virginia, Utah and Washington.
- 14 through departmental policy changes: Arkansas, Colorado, Connecticut, District of Columbia, Louisiana, Maryland, Massachusetts, Missouri, New Jersey, Oklahoma, Oregon, Rhode Island, Tennessee and Vermont.

If every state matched Washington State's successes, there would be 228,000 more individuals with ID/DD working today, as shown in the table below.

Washington has provided a roadmap. Now, policymakers can introduce similar legislation (a model bill is provided on the following pages) and executive branches can adopt similar departmental policies (http://www.dshs.wa.gov/pdf/adsa/ddd/policies/policy4.11.pdf).

WHAT IF EVERY STATE WERE LIKE WASHINGTON STATE?

State	Current Competitive Employment Outcomes			Outcomes if Matched Washington State				
	Participants in 2011	Spending	Spending per Participant	%	# of Participants if Matched WA's Rate	Increase in Participants if Matched WA	Spending if Matched WA's Per Person Costs	Increase in Spending to Match Increase in Participants
Alabama	244	$2,778,981	$11,389	5%	3,172	2,928	$22,472,495	$19,693,514
Alaska	517	$6,024,372	$11,653	29%	1,159	642	$8,211,104	$2,186,732
Arizona	1,209	$12,234,196	$10,119	17%	4,623	3,414	$32,752,316	$20,518,120
Arkansas	74	$490,742	$6,632	7%	687	613	$4,867,151	$4,376,409
California	10,613	$83,596,356	$7,877	14%	49,275	38,662	$349,095,903	$265,499,547
Colorado	1,766	$8,284,357	$4,691	25%	4,592	2,826	$32,532,692	$24,248,335
Connecticut	4,115	$58,069,582	$14,112	49%	5,459	1,344	$38,675,079	$(19,394,503)
Delaware	339	$7,155,678	$21,108	19%	1,160	821	$8,218,189	$1,062,511
Dist. of Columbia	596	$13,694,308	$22,977	31%	1,250	654	$8,855,807	$(4,838,501)
Florida	2,688	$9,750,555	$3,627	25%	6,989	4,301	$49,514,587	$39,764,032
Georgia	2,294	$12,763,901	$5,564	15%	9,941	7,647	$70,428,460	$57,664,559
Hawaii	85	$1,254,440	$14,758	13%	425	340	$3,010,974	$1,756,534
Idaho	812	$3,165,796	$3,899	12%	4,398	3,586	$31,158,271	$27,992,475
Illinois	2,455	$11,600,478	$4,725	12%	13,298	10,843	$94,211,615	$82,611,137
Indiana	2,736	$9,518,228	$3,479	19%	9,360	6,624	$66,312,281	$56,794,053
Iowa	2,169	$7,672,856	$3,538	20%	7,049	4,880	$49,939,666	$42,266,810
Kansas	271	$4,357,063	$16,078	10%	1,762	1,491	$12,483,145	$8,126,082
Kentucky	911	$3,405,742	$3,738	15%	3,948	3,037	$27,970,180	$24,564,438
Louisiana	1,638	$12,085,360	$7,378	33%	3,226	1,588	$22,855,066	$10,769,706
Maine	909	$5,697,193	$6,268	22%	2,686	1,777	$19,029,358	$13,332,165
Maryland	4,693	$68,395,782	$14,574	40%	7,626	2,933	$54,027,506	$(14,368,276)
Massachusetts	2,377	$44,439,129	$18,695	14%	11,036	8,659	$78,186,147	$33,747,018
Michigan	4,930	$26,854,883	$5,447	29%	11,050	6,120	$78,285,332	$51,430,449
Minnesota	2,568	$18,333,912	$7,139	17%	9,819	7,251	$69,564,133	$51,230,221
Mississippi	399	$2,535,500	$6,355	27%	961	562	$6,808,344	$4,272,844
Missouri	307	$1,703,654	$5,549	6%	3,326	3,019	$23,563,531	$21,859,877
Montana	228	$1,638,267	$7,185	14%	1,059	831	$7,502,639	$5,864,372
Nebraska	1,371	$9,575,396	$6,984	34%	2,621	1,250	$18,568,856	$8,993,460
Nevada	502	$3,923,427	$7,816	24%	1,360	858	$9,635,118	$5,711,691
New Hampshire	341	$5,493,695	$16,111	45%	493	152	$3,492,730	$(2,000,965)
New Jersey	908	$8,916,689	$9,820	20%	2,951	2,043	$20,906,789	$11,990,100
New Mexico	1,279	$9,915,607	$7,753	34%	2,445	1,166	$17,321,958	$7,406,351
New York	8,574	$53,339,352	$6,221	12%	46,443	37,869	$329,032,187	$275,692,835

WHAT IF EVERY STATE WERE LIKE WASHINGTON STATE?(CONTD.)

State	Current Competitive Employment Outcomes			Outcomes if Matched Washington State				
	Participants in 2011	Spending	Spending per Participant	%	# of Participants if Matched WA's Rate	Increase in Participants if Matched WA	Spending if Matched WA's Per Person Costs	Increase in Spending to Match Increase in Participants
North Carolina	1,469	$13,071,805	$8,898	17%	5,617	4,148	$39,794,453	$26,722,648
North Dakota	292	$2,798,443	$9,584	17%	1,116	824	$7,906,464	$5,108,021
Ohio	7,046	$88,269,976	$12,528	23%	19,913	12,867	$141,076,544	$52,806,568
Oklahoma	2,419	$24,480,686	$10,120	65%	2,419	0	$17,137,757	$(7,342,929)
Oregon	1,192	$22,875,046	$19,190	42%	1,845	653	$13,071,171	$(9,803,875)
Pennsylvania	4,637	$34,057,394	$7,345	31%	9,723	5,086	$68,884,007	$34,826,613
Rhode Island	603	$451,974	$750	19%	2,063	1,460	$14,615,623	$14,163,649
South Carolina	1,452	$8,573,672	$5,905	21%	4,494	3,042	$31,838,397	$23,264,725
South Dakota	578	$5,799,282	$10,033	26%	1,445	867	$10,237,313	$4,438,031
Tennessee	1,134	$10,496,648	$9,256	24%	3,071	1,937	$21,756,946	$11,260,298
Texas	4,532	$5,062,156	$1,117	16%	18,411	13,879	$130,435,407	$125,373,251
Utah	636	$4,762,184	$7,488	24%	1,723	1,087	$12,206,844	$7,444,660
Vermont	973	$10,408,016	$10,697	43%	1,471	498	$10,421,513	$13,497
Virginia	1,832	$22,195,891	$12,116	35%	3,402	1,570	$24,101,964	$1,906,073
Washington	4,800	$34,006,298	$7,085	65%	4,800	0	$34,006,298	$-
West Virginia	451	$1,663,754	$3,689	9%	3,257	2,806	$23,074,690	$21,410,936
Wisconsin	2,363	$15,519,333	$6,568	14%	10,971	8,608	$77,725,645	$62,206,312
Wyoming	178	$916,614	$5,150	13%	890	712	$6,305,334	$5,388,720
United States	101,505		$8,256	20%	329,891	228,386	$2,337,160,761	

MODEL LEGISLATION FOR EMPLOYMENT FIRST

(based on SB 638 4 of the Washington State Legislature, which passed July 2012)

An act to promote employment first among working-age adults with developmental disabilities

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF [STATE]:

NEW SECTION. Sec. 1. A new section is added to [SECTION OF LAW DEALING WITH SERVICES FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES]

1. Clients age twenty-one and older who are receiving employment services must be offered the choice to transition to a community access program after nine months of enrollment in an employment program, and the option to transition from a community access program to an employment program at any time. Enrollment in an employment program begins at the time the client is authorized to receive employment.

An act relating to ensuring that persons with developmental disabilities be given the opportunity to transition to a community access program after enrollment in an employment program.

2. Prior approval by the department shall not be required to effectuate the client's choice to transition from an employment program to community access services after verifying nine months of participation in employment-related services.
3. The department shall inform clients and their legal representatives of all available options for employment and day services, including the opportunity to request an exception from enrollment in an employment program. Information provided to the client and the client's legal representative must include the types of activities each service option provides, and the amount, scope, and duration of service for which the client would be eligible under each service option. An individual client may be authorized for only one service option, either employment services or community access services. Clients may not participate in more than one of these services at any given time.
4. The department shall work with counties and stakeholders to strengthen and expand the existing community access program, including the consideration of options that allow for alternative service settings outside of the client's residence. The program should emphasize support for the clients so that they are able to participate in activities that integrate them into their community and support independent living and skills.
5. The department shall develop rules to allow for an exception to the requirement that a client participate in an employment program for nine months prior to transitioning to a community access program.

Effective Date:

This bill takes effect upon enactment.

USING THE CASE FOR INCLUSION REPORT

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

- **How their state performs overall in serving individuals with intellectual and developmental disabilities;**
- **What services and outcomes need attention and improvement in their state; and**
- **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, 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 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.

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. The states 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.

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 between the top- and worst-performing.

As noted, most data is from 2012, but all data is the most recent available from credible national sources. Therefore, these state rankings are a snapshot in time. In addition, changes and reforms enacted or beginning in 2013 or later have not been considered.

When reviewing an individual state's ranking, it is important to consider action taken since 2012, 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 of caution: Although nearly 60 points separate the top performing state from the poorest performing state, 12 points separate the top 10 states, 20 points separate the top 25 states and only 12 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.

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	
	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

ACKNOWLEDGEMENTS

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 the 2014 report for The *Case for Inclusion* 2014 ranking to successfully release in a timely manner.

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

[2] Shields, Mike. "House Panel Hears Bill to 'Carve Out' DD Services from KanCare." Kansas Health Institute News. February 20, 2013. http://www.khi.org/news/2013/feb/20/house-panel-hears-bill-carve-out-dd-services-kanca/ (accessed March 12, 2013)

[3] Case for Inclusion 2012. Medicaid.UCP.org (accessed March 12, 2013)

[4] "KanCare Section 1115 Demonstration Waiver." State of Kansas. August 6, 2012. Pages 43-45. http://www.kancare.ks.gov/download/KanCare_Section_1115_Demonstration_August_6_2012.pdf (accessed March 12, 2013)

[5] "DD Community and KanCare Frequently Asked Questions." Kansas Department for Aging and Disability Services. Page 2. E-mailed to Tarren Bragdon on March 13, 2013 by Lea Stueve of the Kansas Department of Aging and Disability Services. Available upon request. And HB 2029 - Vulnerable Kansan Protection Act's Fiscal Note (2013 legislative session). http://www.kslegislature.org/li/b2013_14/measures/documents/fisc_note_hb2029_00_0000.pdf (accessed on March 12, 2013)

[6] "Choosing a KanCare Health Plan." State of Kansas. http://www.kancare.ks.gov/choosing_a_plan.htm (accessed March 12, 2013)

[7] "DD Project Pilot Summary." State of Kansas. http://www.kancare.ks.gov/download/DD_Pilot_Project_Summary.pdf (accessed March 12, 2013)

[8] "KanCare Section 1115 Demonstration Waiver." Page 15.

[9] "KanCare Section 1115 Demonstration Waiver." Page 16.

[10] "KanCare Section 1115 Demonstration Waiver." Page 10.

[11] "KanCare Quality Measurement." State of Kansas. http://www.kancare.ks.gov/quality_measurement.htm (accessed March 12, 2013)

[12] "Overview of Dual Eligibles." The ARC. http://www.thearc.org/page.aspx?pid=3312 (accessed March 20, 2013)

[13] "State Demonstrations to Integrate Care for Dual Eligible Individuals." Centers for Medicare and Medicaid Services. https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/StateDemonstrationstoIntegrateCareforDualEligibleIndividuals.html (accessed March 20, 2013)

[14] "Medicare-Medicaid Coordination Office: Fiscal Year 2013 Report to Congress" U.S. Department of Health and Human Services: Center for Medicare and Medicaid Services. February 2014. Page 11. http://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/Downloads/MMCO_2013_RTC.pdf (accessed March 15, 2014)

[15] "State Demonstration to Integrate Care for Dual Eligible Individuals." Massachusetts Executive Office of Health and Human Services, Office of Medicaid. https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/Downloads/MAAddendum.pdf (access March 15, 2014)

[16] "Financial and Administrative Alignment Demonstrations for Dual Eligible Beneficiaries Compared: States with Memoranda of Understanding Approved by CMS." Kaiser Commission on Medicaid and the Uninsured. Kaiser Family Foundation. November 2013. Page 2. http://kaiserfamilyfoundation.files.wordpress.com/2013/11/8426-05-financial-and-administrative-alignment-demonstrations-for-dual-eligible-beneficiaries-compared1.pdf (accessed on March 15, 2014)

[17] One Care and Providers: What You Need to Know. Massachusetts Executive Office of Health and Human Services. http://www.mass.gov/eohhs/consumer/insurance/one-care/one-care-and-providers.html (accessed March 15, 2014)

[18] "State Demonstration to Integrate Care for Dual Eligible Individuals." State of Massachusetts. February 16, 2012. Appendix C. http://www.mass.gov/eohhs/docs/eohhs/healthcare-reform/prev-meetings/120216-final-proposal.pdf (accessed March 20, 2013)

[19] "EIP Monthly One Care Enrollment Data Report—February 2014" MassHealth. http://www.mass.gov/eohhs/docs/masshealth/onecare/eip-monthly-enrollment-data-report-2014-february.pdf (accessed March 15, 2014)

[20] Master, Robert."Realizing The Promise Of Integrated Care For The 'Dual Eligibles." Health Affairs Blog. October 22, 2012. http://healthaffairs.org/blog/2012/10/22/realizing-the-promise-of-integrated-care-for-the-dual-eligibles/ (accessed April 18, 2013)

[21] "State Demonstration to Integrate Care for Dual Eligible Individuals." State of Massachusetts. February 16, 2012. Page 17. http://www.mass.gov/eohhs/docs/eohhs/healthcare-reform/prev-meetings/120216-final-proposal.pdf (accessed March 20, 2013)

[22] Ellen Breslin Davidson and Tony Dreyfus. Slide 18.

[23] MaryBeth Musumeci. "Massachusetts' Demonstration to Integrate Care

[24] and Align Financing for Dual Eligible Beneficiaries." Kaiser Commission on Medicaid and the Uninsured. Kaiser Family Foundation. October 2012. Page 7 (Text Box 3, Expanded State Plan Services) http://www.kff.org/medicaid/upload/8291-02.pdf (accessed March 20, 2013)

[25] Case for Inclusion. Massachusetts State Scorecard. Medicaid.UCP.org (accessed March 20, 2013)

[26] "State Demonstration to Integrate Care for Dual Eligible Individuals." State of Massachusetts. February 16, 2012. Appendix F. http://www.mass.gov/eohhs/docs/eohhs/healthcare-reform/prev-meetings/120216-final-proposal.pdf (accessed March 20, 2013)

[27] "The Time Is Now: Embracing Employment First." National Association of Councils on Developmental Disabilities. November 2011. http://www.nacdd.org/documents/EmploymentFirstFINALNov132011_PRINT.pdf (access March 31, 2013)

[28] Ibid. page 5.

[29] Cimera, Robert Evert. "The economics of supported employment: What new data tell us." Journal of Vocational Rehabilitation 37. 2012. Page 111. http://www.worksupport.com/documents/economics_jvr.pdf (accessed March 31, 2013)

[30] "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. http://www.harkin.senate.gov/documents/pdf/500469b49b364.pdf (accessed March 31, 2012)

[31] Cimera, Robert Evert. "The economics of supported employment: What new data tell us." Journal of Vocational Rehabilitation 37. 2012. Page 114. http://www.worksupport.com/documents/economics_jvr.pdf (accessed March 31, 2013)

[32] "County Services for Working Age Adults: Policy 4.11." Washington State Department of Social and Health Services' Division of Developmental Disabilities. July 2012. http://www.dshs.wa.gov/pdf/adsa/ddd/policies/policy4.11.pdf (accessed March 31, 2013)

[33] Rolfe, Linda. "Voices from the Field: Employment in Washington State." Alliance for Fulll Participation. March 8, 2010. http://www.allianceforfullparticipation.org/the-news/183-voices-from-the-field-employment-in-

washington-state (accessed March 31, 2013)

[34] Cesilee Coulson interview with Tarren Bragdon on April 12, 2013.

[35] Cesilee Coulson. "Washington State Employment Data Presentation." Slide 7. Available at: INSERTURL1 (access April 15, 2013).United Cerebral Palsy's Case for Inclusion 2012. Available at: Medicaid.UCP.org (accessed March 31, 2013)

[36] "Employment in Washington State – 2010 Report." Washington Initiative for Supported Employment. Page 16. Available at: http://www.dshs.wa.gov/pdf/adsa/ddd/2010%20WA%20Employment%20Report.pdf (accessed April 14, 2013)

[37] 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. Available at: LINKURL2 (accessed April 15, 2013)

[38] "The Community Summit: Employment Meeting Summary 2013." Washington Initiative for Supported Employment. Page 9. http://gowise.blob.core.windows.net/media/Default/Documents/2013%20WA%20State%20Employment%20Report%20final.pdf (accessed March 15, 2014)

[39] See example from 2013 at: http://www.communityemploymentalliance.org/images/Governor_Employment_For_All_Proclamation_021313.pdf

[40] Hoff, David. "Employment First Resource List." State Employment Leadership Network . Revised Septmeber 2013. Pages 1-2. http://www.selnmembers.org/components/com_wordpress/wp-content/uploads/2013/10/seln-ef-2013-09.pdf (accessed on March 15, 2014)

[41] "Senate Bill 6384: Ensuring that persons with developmental disabilities be given the opportunity to transition to a community access program after enrollment in an employment program." Washington State Legislature. 2012 Session. As passed and signed by the Governor on June 7, 2012 becoming Public Law Chapter 49, 2012. http://apps.leg.wa.gov/documents/billdocs/2011-12/Pdf/Bills/Session%20Laws/Senate/6384-S.SL.pdf (accessed March 31, 2013)

ABOUT THE AUTHOR:

Tarren Bragdon

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 100 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.

1825 K Street NW Suite 600 Washington, D.C. 20006
www.ucp.org