THE CASE FOR Inclusion 2013

UCP United Cerebral Palsy™
Life without limits for people with disabilities™

2013 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 all of us—children and adults with disabilities, as we are aging, as our family ages, and when the unexpected happens. It is the critical safety net that provides financial and healthcare security, and community supports to Americans with ID/DD, aging, and low-income individuals and families, so that 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 members of society.

Yet some states do much better than others in having 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 Facts - 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 –** 671,000 (1.2%)

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

Trends in the States: Managed Care & Expanded Competitive Employment

This year's Case for Inclusion looks at two key trends affecting those with intellectual and developmental disabilities. As always, states are the laboratories of democracy and state leaders are looking at how they can help those with disabilities improve as well as save tax dollars in the Medicaid program. To that end, states are looking at comprehensive managed care for those with ID/DD and also expanded Employment First initiatives to increase competitive employment for those with ID/DD.

In this report, managed care efforts in Kansas and Massachusetts are highlighted in case studies beginning on page 22. In addition, the nationally inspiring success of Washington State's Employment First initiative is studied with model legislation and state-specific projections of what similar efforts would mean for the other 49 states and Washington, D.C., beginning on page 15.

Significant Takeaways from the 2013 Ranking

There are eight key takeaways from this year's ranking, as noted below. While some states remain as the bottom of the rankings and have for years, those poor performing states can mask the real improvement of many states. This improvement has been achieved despite the significant economic conditions stressing most state budgets over the last several years.

Since the 2007 Case for Inclusion Ranking the following four real improvements have been achieved:

- The number of states serving 80% of individuals and dedicating 80% of spending to the community has gone from a small minority of states (14) to the vast majority (38).
- 27 more state institutions have closed leaving just 149 open
- Now the vast majority of states (34) participate in a uniform, comprehensive quality assurance program called the National Core Indicators (up from less than half)
- 50% more states meet the benchmark for significant family support programs keeping families together (15 up from 10 states)

Yet, the following two troubling trends are also evident:

- The number of states with significant competitive employment accomplishments (one-third of individuals served working competitively) dropped from 17 to just 10.
- The size of the waiting lists has doubled to more than a quarter of million Americans on a waiting list for services.

Promoting Independence

All states still have room for improvement, but some states have consistently remained at the bottom since 2007, including Arkansas (#50), Illinois (#48), Mississippi (#51) and Texas (#49). While these states need real attention, they are not reflective of the real improvement in Inclusion for the vast majority of states, as highlighted below.

38 states now meet the 80/80 Community standard, which means that at least 80% of all individuals with ID/DD are served in the community, and 80% 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 (very close), New Jersey, North Carolina (very close), Oklahoma (very close), Texas, Utah (very close), and Virginia (very close). This measure has improved hugely over the life of the Case for Inclusion. For the 2007 Ranking, only 14 states met this 80/80 Community standard.

As of 2011, 13 states have no state institutions to seclude those with ID/DD, including Alabama (new this year), Alaska, Hawaii, Maine, Michigan, Minnesota (which closed its last remaining institution in June 2011), New Hampshire, New Mexico, Oregon, Rhode Island, Vermont, West Virginia and DC. Another 10 states have only one institution each. Since 1960, 209 of 354 state institutions have been closed leaving just 149 remaining, according to the University of Minnesota's Research and Training Center on Community Living. This measure has improved substantially over the life of the Case for Inclusion. For the 2007 Ranking, only 9 states had no state institution, another 13 states having just one facility, and there were 176 state institutions open.

21 states now meet the 80% Home-like Setting standard, which means that at least 80% 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 US average for this standard is 79%. Just eight states meet a 90% Home-like Setting

Standard, and these top performers include Alaska (new this year), Arizona, California, Kentucky (new this year), Nevada, New Hampshire, New Mexico (new this year) and Vermont. This measure has improved only somewhat over the life of the Case for Inclusion. For the 2007 Ranking, only 17 states met this Home-like Setting standard.

Tracking Quality

34 states participate in the National Core Indicators (NCI) model, a comprehensive quality assurance program that includes standard measures to assess outcomes of services (nationalcoreindicators.org). In January 2012, the Obama Administration made available grant funding so that even more states could participate and ensure that their quality assurance efforts were benchmarked and comprehensive (NCI has more than 100 measures; see Endnote #3 for more details). This measure has improved dramatically over the life of the Case for Inclusion. For the 2007 Ranking, only 24 states were NCI participants.

Keeping Families Together

Only 15 states were supporting a large share of families through family support (at least 200 families per 100,000 of population). This is important, because those 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. This measure has improved dramatically over the life of the Case for Inclusion. For the 2007 Ranking, only 10 states met this benchmark.

Promoting Productivity

Just ten states have at least one-third (33%) of individuals with ID/DD working in competitive employment, which best recognize and support work as key to a meaningful life. These states include Connecticut, Louisiana, Maryland, Nebraska, New Mexico, Oklahoma, Oregon, Vermont, Virginia, and Washington. DC and Pennsylvania were very close. This measure has plummeted over the life of the Case for Inclusion. For the 2007 Ranking, 17 states were meeting this standard.

Serving Those in Need

Waiting lists for residential and community services are high and show the unmet need. More than a quarter of a million people (268,000) are on a waiting list for Home and Community Based Services. This would require a daunting 44% increase in states' HCBS programs! However, 20 states report no waiting list or a small waiting list (requiring less than 10% program growth). This measure has gotten much worse over the life of the Case for Inclusion. Since the 2007 Ranking, the size of the waiting list nationally has almost doubled from 138,000 to 268,000.

2013 The Case for Inclusion Rankings

Alphabetical			By Rank in 2013		
	2013 Ranking	2012 Ranking		2013 Ranking	2012 Ranking
Alabama	20	33	Arizona	1	1
Alaska	31	30	New Hampshire	2	4
Arizona	1	1	Oregon	3	22
Arkansas	50	49	Vermont	4	5
California	5	3	California	5	3
Colorado	32	28	Washington	6	8
Connecticut	9	7	Michigan	7	2
Delaware	28	16	New York	8	9
Dist. of Columbia	36	40	Connecticut	9	7
Florida	27	20	Massachusetts	10	6
Georgia	24	21	Pennsylvania	11	10
Hawaii	13	19	South Carolina	12	13
Idaho	17	12	Hawaii	13	19
Illinois	48	48	Wisconsin	14	27
Indiana	40	46	Maryland	15	11
Iowa	43	43	New Mexico	16	14
Kansas	41	36	Idaho	17	12
Kentucky	30	31	Rhode Island	18	32
Louisiana	21	25	South Dakota	19	15
Maine	38	24	Alabama	20	33
Maryland	15	11	Louisiana	21	25
Massachusetts	10	6	Ohio	22	34
Michigan	7	2	Montana	23	18
Minnesota	25	26	Georgia	24	21
Mississippi	51	51	Minnesota	25	26
Missouri	29	23	Nevada	26	17
Montana	23	18	Florida	27	20
Nebraska	35	41	Delaware	28	16
Nevada	26	17	Missouri	29	23
New Hampshire	2	4	Kentucky	30	31
New Jersey	42	37	Alaska	31	30
New Mexico	16	14	Colorado	32	28
New York	8	9	West Virginia	33	29
North Carolina	45	44	Wyoming	34	35

	Alphabetical			By Rank in 2013	
	2013 Ranking	2012 Ranking		2013 Ranking	2012 Ranking
North Dakota	39	39	Nebraska	35	41
Ohio	22	34	Dist. of Columbia	36	40
Oklahoma	44	38	Utah	37	45
Oregon	3	22	Maine	38	24
Pennsylvania	11	10	North Dakota	39	39
Rhode Island	18	32	Indiana	40	46
South Carolina	12	13	Kansas	41	36
South Dakota	19	15	New Jersey	42	37
Tennessee	46	42	Iowa	43	43
Texas	49	50	Oklahoma	44	38
Utah	37	45	North Carolina	45	44
Vermont	4	5	Tennessee	46	42
Virginia	47	47	Virginia	47	47
Washington	6	8	Illinois	48	48
West Virginia	33	29	Texas	49	50
Wisconsin	14	27	Arkansas	50	49
Wyoming	34	35	Mississippi	51	51

How to Make Medicaid Better for Individuals – 4 Key Outcomes Areas to Focus On and Improve

The ultimate goal of the Case for Inclusion is not just to document how well states' Medicaid programs serve those with ID/DD today. Instead, the ultimate mission of the Case for Inclusion is to create a roadmap for all states n how to improve their Medicaid programs by focusing on those key outcomes that matter the most.

To this end, the University of Minnesota's Research and Training Center on Community Living concisely states the four key aspects of a high functioning and effective Medicaid program, which have 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:

"The promise of access to and support for integrated community lives and roles for persons with [intellectual and developmental disabilities] is clearly expressed in national legislative, judicial, administrative and other sources that make four basic commitments:

- People with disabilities will live in and participate in their communities; [Promoting Independence]
- People with disabilities will have satisfying lives and valued social roles; [Promoting Productivity]
- 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; and [Keeping Families Together and Reaching Those in Need]
- People will be safe and healthy in the environments in which they live. [Tracking Quality and Safety]:

Sub-ranking by Major Category: The Bright Spots and the Areas of Concerns

The Case for Inclusion ranking is a snapshot of how a state is performing overall. Individuals, families, advocates and providers want to look under the hood and see where a state is performing well—the bright spots—and where a state needs improvement —areas of concern.

For policymakers, funding and policy choices should protect the bright spots while focusing attention and new or redirected resources on those areas of concerns.

To that end, the Case for Inclusion shows a state's ranking by major category—aligning with the four key outcomes of a high performing Medicaid program, as noted above.

For example, Arizona ranks #1 overall, but ranks low (sub-ranking #35) for promoting productivity. Arizona could potentially learn from Washington State (sub-ranking #1) regarding how to improve in this area. In fact, later in this Case for Inclusion (beginning on page 2), Washington State's Employment First initiative is highlighted showing Arizona exactly how to improve in this category.

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	Promoting Independence		Tracking Quality and Safety		Keeping Families Together		Promoting Productivity		Reaching Those in Need		Overall	
	Score	Rank	Score	Rank	Score	Rank	Score	Rank	Score	Rank	Score	Rank
Alabama	43.5	19	11.7	15	9.4	2	1.1	51	7.7	43	73.4	20
Alaska	48.7	3	2.5	51	3.9	35	5.4	14	8.8.	38	69.4	31
Arizona	48.6	4	11.9	2	10.9	1	3.8	35	12.4	5	87.5	1
Arkansas	28.2	49	6.0	34	2.7	45	3.2	25	8.9	37	48.9	50
California	45.0	13	11.6	20	8.8	3	3.6	42	13.0	3	82.0	5
Colorado	46.8	8	5.7	36	4.4	33	2.8	47	9.6	31	69.3	32
Connecticut	41.0	33	11.9	5	5.1	28	7.1	3	11.7	11	76.8	9
Delaware	42.2	25	5.6	39	8.1	7	4.5	20	11.3	14	71.8	28
Dist. of Columbia	42.4	23	4.2	48	3.3	40	3.7	40	11.2	15	64.8	36
Florida	42.2	27	11.8	9	6.1	21	2.7	48	9.6	33	72.4	27
Georgia	44.9	14	11.7	18	4.7	31	3.8	36	7.9	42	72.9	24
Hawaii	47.7	6	9.3	32	6.6	15	1.4	50	11.0	18	76.0	13
Idaho	43.1	21	5.8	35	5.2	27	4.0	30	16.0	1	74.0	17
Illinois	26.0	50	11.8	8	2.6	26	3.4	43	7.0	45	50.9	48
Indiana	38.6	39	11.7	16	4.4	32	4.3	26	4.2	47	63.3	41
Iowa	37.1	43	5.6	38	2.9	44	4.4	23	12.3	7	62.4	43
Kansas	40.8	34	5.7	37	3.7	36	3.4	44	9.7	30	63.3	41
Kentucky	43.4	20	11.5	23	2.6	27	4.0	31	9.8	28	71.2	30
Louisiana	36.9	44	11.8	14	8.8.	4	5.6	12	10.2	27	73.3	21
Maine	45.0	12	3.4	50	1.2	51	4.5	21	9.8	29	63.9	38
Maryland	45.6	10	11.6	19	3.3	41	6.2	7	9.2	34	76.0	15
Massachusetts	42.2	25	11.8	11	6.6	16	3.7	39	12.3	6	80.2	7
Michigan	45.5	11	11.9	3	6.2	19	5.4	15	11.2	16	80.2	7
Minnesota	43.5	18	5.4	42	7.5	10	4.0	32	12.3	8	72.7	25
Mississippi	10.9	51	10.2	29	3.5	39	5.6	11	0.8	51	31.0	51
Missouri	41.2	31	11.5	22	5.5	24	3.1	46	10.4	25	71.6	29
Montana	44.7	15	5.6	40	8.0	8	3.9	34	10.9	20	73.1	23
Nebraska	42.3	24	5.2	44	2.4	48	6.0	8	9.6	32	65.4	35
Nevada	46/5	9	5.0	46	5.9	22	4.6	19	10.4	24	72.5	26
New Hampshire	48.8	2	11.1	27	6.7	14	7.0	4	10.3	26	84.0	2
New Jersey	36.6	45	11.9	6	6.4	17	4.3	27	4.0	48	62.8	42
New Mexico	47.8	5	9.0	33	4.9	30	5.8	10	7.6	44	75.2	16
New York	40.0	35	12.0	1	8.2	6	3.6	41	13.8	2	77.6	8

	Promoting Independence		Tracking Quality and Safety		Keeping Families Together		Promoting Productivity		Reaching Those in Need		Overall	
	Score	Rank	Score	Rank	Score	Rank	Score	Rank	Score	Rank	Score	Rank
North Dakota	37.9	41	5.4	43	3.6	38	4.4	24	12.7	4	63.9	39
Ohio	41.1	32	11.7	17	7.3	12	4.5	22	8.7	39	73.3	22
Oklahoma	36.2	46	9.7	30	4.3	34	6.9	5	5.3	46	62.3	44
Oregon	47.5	7	11.9	7	5.0	29	6.5	6	11.6	12	82.4	3
Pennsylvania	41.9	28	11.1	28	6.9	13	5.5	13	10.9	21	76.3	11
Rhode Island	43.8	17	11.3	24	3.7	37	4.3	25	10.8	22	73.9	18
South Carolina	39.9	36	11.8	13	8.5	5	5.0	18	11.0	19	76.1	12
South Dakota	39.5	37	11.2	26	5.5	25	5.1	17	12.2	9	73.5	19
Tennessee	39.4	38	5.6	21	3.3	42	2.6	49	8.9	36	59.7	46
Texas	32.3	47	11.2	25	2.1	49	3.9	33	1.0	50	50.4	49
Utah	37.9	42	9.5	31	3.2	43	5.1	16	8.9	35	64.7	37
Vermont	49.6	1	5.0	45	7.5	11	7.8	22	12.1	10	82.0	4
Virginia	31.4	48	11.6	21	1.9	50	5.8	9	8.0	41	58.7	47
Washington	43.0	22	11.9	4	6.1	20	8.7	1	10.8	23	80.5	6
West Virginia	44.3	16	4.4	47	6.3	18	3.7	37	8.4	40	67.1	33
Wisconsin	41.8	30	11.8	12	7.7	9	3.7	38	11.0	17	76.0	14
Wyoming	41.9	29	3.7	49	5.3	26	4.0	29	11.5	13	66.3	34

Most Improved and Biggest Drops

The performance of individual states is very dynamic over time. Since 2007, 40 percent of the states have had a substantial change in their rankings. In the past seven years, 20 states have moved more than 10 places in the rankings from 2007 to 2012. Ten states improved dramatically, while ten states dropped significantly. The table below shows these moves.

Case for Inclusion Ranking:
Most Improved and Biggest Drops

	2013	2012	2011	2010	2009	2008	2007	Difference 2007 to 2013	
Ohio	22	34	39	43	45	44	48	26	IMPROVED
Louisiana	21	25	37	40	46	45	44	23	
Maryland	15	11	31	18	32	33	33	18	
Oregon	3	22	26	19	21	19	21	18	
Pennsylvania	11	10	15	15	16	15	29	18	
Wisconsin	14	27	20	20	22	23	31	17	
Washington	6	8	6	4	25	20	20	14	
Dist. of Columbia	36	40	47	47	48	48	49	13	
Alabama	20	33	32	32	33	31	32	12	
Missouri	29	23	28	25	29	28	41	12	
North Carolina	45	44	43	34	36	35	34	-11	
Delaware	28	16	7	30	13	14	14	-14	
Maine	38	24	29	28	35	30	24	-14	
West Virginia	33	29	19	22	23	24	16	-17	
Wyoming	34	35	21	29	28	25	17	-17	
Minnesota	25	26	14	12	12	12	7	-18	DROPPED
Kansas	41	36	25	23	24	22	22	-19	
New Jersey	42	37	40	24	20	21	23	-19	
Colorado	32	28	12	9	9	7	8	-24	
Alaska	31	30	30	27	3	3	2	-29	

Alabama – improved 12 places since 2007 – closed a state institution and made modest gains in most measures.

Alaska – dropped 29 places since 2007 – 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.

Colorado – dropped 24 places since 2007 – fell so dramatically because of a significant decline in competitive employment participation, (from 53% to 25%) and the state does not participate in NCI.

Delaware – dropped 14 places since 2007 – dropped out of the National Core Indicators and declined in competitive employment participation from 30% to 19%.

District of Columbia – improved 13 places since 2007 – increased the portion of individuals served in home-like settings (from 48% to 74%)

Kansas – dropped 19 places since 2007 – had a drop in the number of individuals served in their own homes and family homes, has had a drop in families served through family support, does not participate in the NCI and has had their waiting list grow significantly.

Louisiana – improved 23 places since 2007 – had huge improvement in the portion of individuals (from 49% to 65%) and resources (from 41% to 79%) dedicated to community services over institutions, and it had large drop in the portion of individuals served in large institutions (from 18% to 7%).

Maine – dropped 14 places since 2007 – stopped participating in the National Core Indicators and increased the size of their waiting list (from 105 people to 930 waiting for residential services)

Maryland – improved 18 places since 2007 – closed two state institutions and reduced the population at state institutions by 61%. The state also began participating in NCI and added a Medicaid Buy-in Program to support individuals as they go to work, increase their productivity and raise their incomes.

Minnesota – dropped 18 places since 2007 – does not participate in the National Core Indicators and slightly decreased the portion of individuals served in home-like settings (compared to the national trend in the opposite direction)

Missouri – improved 12 places since 2007 – dramatically increased the portion of resources dedicated to people in the community (from 59% to 85%) and started participating in NCI.

New Jersey – dropped 19 places since 2007 – did not change significantly but as the states improved overall, NJ's stagnation meant it fell in the rankings.

North Carolina – dropped 11 places since 2007 – dropped due to decline in the number of individuals served in their own homes or a family home and a drop in competitive employment participation from 22% to 17%.

Ohio – improved 26 places since 2007 – dramatically increased the share of individuals (to 83% from 63%) and resources (to 80% from 50%) dedicated to the community, closed a state institution and decreased number of people there by 24%, reduced by two-thirds the portion of individuals served in large institutions (from 18% to 6%), and started participating in NCI.

Oregon – improved 18 places since 2007 – starting participating in the National Core Indicators, increased portion of individuals served in home-like settings (from 75% to 82%), and increased competitive employment (from 35% to 42%).

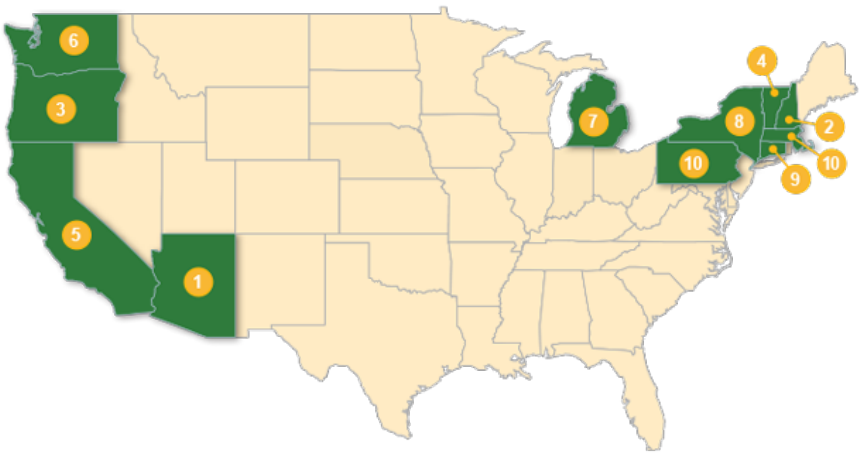
Pennsylvania – improved 18 places since 2007 – substantially increased the portion of resources dedicated to people in the community (from 70% to 81%), dramatically increased the portion of people served in home-like settings (from 58% to 83%), reduced by almost half the portion of people served in large institutions (from 11% to 6%) and closed a state institution.

Washington – improved 14 places since 2007 – closed a state institution and accurately reporting on its waiting list, which is relatively small.

West Virginia – dropped 17 places since 2007 –dramatically increased the share of resources going to the community (from 77% to 99%), does not participate in NCI and had a drop in competitive employment.

Wisconsin – improved 17 places since 2007 – dramatically increased the share of resources (from 72% to 87%) and people (88% to 96%), reduced the number of individuals at large state institutions by 22%, and joined National Core Indicators.

Wyoming – dropped 17 places since 2007 – primarily due to the fact that it does not participate in NCI and resulting from a large drop in competitive employment (from 25% to 13%).



The Best, the Worst and Facts about the Top 10 Performing States

The Best Performing States

1. Arizona
2. New Hampshire
3. Oregon
4. Vermont
5. California
6. Washington
7. Michigan
8. New York
9. Connecticut
10. Massachusetts

The Worst Performing States

42. New Jersey
43. Iowa
44. Oklahoma
45. North Carolina
46. Tennessee
47. Virginia
48. Illinois
49. Texas
50. Arkansas
51. Mississippi

Facts about the Best Performing States

1. Top Performers are both big and small states in population—"big" population states include California (#1 biggest), Michigan (#8), and New York (#3) and "small" population states include New Hampshire (#42) and Vermont (#49).

2. Top Performers are both rich and poorer states in terms of median family income—"rich" states include New Hampshire (#2 richest), Connecticut (#3) and Massachusetts (#5), and less affluent states include Arizona (#31) and Michigan (#32).

3. Top Performers are high tax and low tax burden states—"high tax burden" states include California (#4), Connecticut (#3), Massachusetts (#8), and New York (#1), and "low tax burden" states include Arizona (#40), New Hampshire (#44), and Washington (#28).

4. Top Performers are big and low spending per person, served through the Home and Community Based Services—"big spender" states are Connecticut (#4) and New York (#5), and "low spender" states are California (#50), Arizona (#48) and Washington (#37).

Connecting the Pieces—How the National Core Indicators Focus Attention and Understanding on the Desire for and Positive Impact of Competitive Employment

The National Core Indicators shows how person-level tracking of outcomes is a great tool to overcome myths about Americans with intellectual and developmental disabilities, and underscore the cross benefit of certain key quality of life measures.

For example, the 2013 Case for Inclusion report highlights Washington State's Employment First initiative and the overall portion of individuals served in competitive employment.

> "It is our hope that the Case for Inclusion can be used to strengthen the efforts of states and advocates to advance the independence, productivity and full citizenship of people with disabilities."
>
> *~ Stephen Bennett, President & CEO of UCP*

However, it is the National Core Indicators that shows about half of Americans with ID/DD want to work, whether they are in an institution (43% wanting to work) or living independently (45% wanting to work). But the actual rate of these Americans achieving their dream of an honest day's work is just 2% for those isolated at institutions. By comparison, 33% of independent Americans with ID/DD are realizing this dream (with 23-24% working for those living with parents or in the community in general). Americans with ID/DD want the same things as everyone else—to live a happy, fulfilling life. They realize that meaningful work is a key part of that. Sadly, only those living independently or in the community ever come close to achieving that goal.

And those individuals who work also report being much more social in their community. Compared to individuals with ID/DD who do not work, those who do report a 48% higher rate of going shopping, a 39% higher rate of going out for entertainment, a 41% higher rate of eating out at restaurants, a 22% higher rate of going to church services, and a 42% higher rate of exercising in the last month.

The feeling of independence individuals with ID/DD retain from working increase the self-confidence they exhibit in other parts of their lives. Compared to individuals with ID/DD who don't work, those who do report being almost twice as likely to choose where they live, a 26% higher rate of choosing home staff, twice as likely to choose their roommates, a 40% higher rate of planning their own day's activities, and a 31% higher rate of choosing their case manager.

We all feel that sometimes we work to live and at other times we live to work. While this can be frustrating at times, our work gives us a sense of accomplishment and pride. The same is true for Americans with ID/DD.

These outcomes, as tracked by the National Core Indicators, illustrate why UCP has placed so much emphasis on work as part of the Case for Inclusion.

Washington State Case Study

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 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 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 don't 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 2005, the vast majority of individuals without disabilities took nine months or less to find a job after schooling. Washington'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 obtain their employment goals. 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 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 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[ix]
- 40 individuals with developmental disabilities working as entrepreneurs in 2009[x]
- 5,562 total individuals in competitive employment in 2011[xi]
- 65 percent competitive employment rate in 2011 (tied for best in the nation)

Not only is the Employment First policy change a positive reform that changes the lives of individuals with ID/DD, it is accompanied by good politics as well. Washington State did not significantly cut back on sheltered workshop funding. In fact, the number of participants in sheltered workshops remained unchanged during the Employment First years. 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 realize 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	2011	% Change
Participants – Number	4,694	5,562	18%
Participants – Percent	58%	65%	12%

	2004	2009	% Change
Average Wages per Person	$6,253	$7,245	16%
Cumulative Wages	$29 million	$40 million	37%

Source: Washington Initiative for Supported Employment

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

- "On average, for each person almost eight hours worked for every hour of service.
- On average, for each person, almost 650 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, and 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 April 2013, 22 states have adopted Employment First-type strategies:

- 7 through legislative changes: California, Delaware, Kansas, Pennsylvania, Virginia, Utah, and Washington.
- 15 through departmental policy changes: Arkansas, Colorado, Connecticut, Louisiana, Maine, Maryland, Massachusetts, Michigan, Missouri, New Jersey, Ohio, Oklahoma, Oregon, Rhode Island, and Tennessee.

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, policy-makers 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	%	Number of Participants if Matched Washington State's Rate	Increase in Participants if Matched Washington State	Spending if Matched Washington State'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

State	Current Competitive Employment Outcomes				Outcomes if Matched Washington State			
	Participants in 2011	Spending	Spending per Participant	%	Number of Participants if Matched Washington State's Rate	Increase in Participants if Matched Washington State	Spending if Matched Washington State'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**	**$837,974,646**	**$8,256**	**20%**	**329,891**	**228,386**	**$2,337,160,761**	**$1,499,186,115**

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

Summary

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.

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.
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.

What's New? 2013 Ranking Enhancements

The 2013 report includes several enhancements designed to aid individuals in using its findings as an advocacy tool.

First and foremost, the 2012 report, in addition to data from all previous reports, is published on UCP's website, using a robust and expanded web module and design at **ucp.org/public-policy/the-case-for-inclusion**. This web-based tool enables policymakers, families, advocates, voters and the media to easily track each state's performance over time on key data measures; compare states among one another and to the US average; and export the data, tables and graphs as needed for personal and professional use. The web pages also allow visitors to track how states have improved or declined in The Case for Inclusion rankings since the 2006 report.

Second, as in 2012, the 2013 report has increased focus on quality assurance measures by rewarding states that participate in the **National Core Indicators** (NCI) of the Human Services Research Institute. NCI is a voluntary effort by public developmental disabilities agencies to measure and track their own performance. The *core indicators* are standard measures used across states to assess the outcomes of services provided to individuals and families.

In January 2012, the federal Administration on Developmental Disabilities awarded $1.5 million over five years to the **National Association of State Directors of Developmental Disabilities Services** (NASDDDS) to promote more states using NCI as the uniform data set. It is critical for states to participate in a comprehensive quality assurance effort that can be benchmarked against the national average and to track individual state's progress for critical person-level outcomes. With more than 100 data measures, NCI covers five broad categories including: Individual Outcomes; Health, Welfare and Rights; System Performance; Staff Stability; and Family Indictors.

While many states moved to mandatory managed care for people with ID/DD, participation in NCI and disclosure of patient encounter data (actual services received by individuals) is critical for managed care and provider accountability. Beyond the high-level assessment part of this year's The Case for Inclusion, NCI give states a deeper, more personal look at their Medicaid programs and supports to these individuals.

In addition, this year *The Case for Inclusion* provides sub-rankings for each of the five major categories so that readers have a deeper understanding of each state's performance within each area.

As always, the rankings in this report are a snapshot in time. Most data is from 2011, 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.

Kansas Case Study

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 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 January 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 the managed care companies have a financial incentive to be even more creative and committed to moving individuals from some 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 employment.

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

Individuals with ID/DD have new benefits 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 in 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% of the time compared to 72% 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% of individuals had a primary care visit during that year.

KanCare withholds 3-5% 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.
  - o 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.

Massachusetts Case Study

Integrating Medicaid and Medicare-Funded Care with Private Plans for Individuals with ID/DD

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 these 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 5 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 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.

Massachusetts is the first state to take up this challenge of uncoordinated care. Beginning July 1, 2013, Massachusetts is implementing a statewide pilot program (called a demonstration) for all dually eligible individuals, including those with ID/DD. As of April 2012, five of the original 15 states have received full federal approval to begin similar integrated efforts.

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, since the UCP rankings began in 2006. The 2013 ranking (reflecting 2011 data) ranked Massachusetts 10th best in the country.

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

MassHealth will provide all 115,000 dually eligible individuals in Massachusetts with a choice of six different private Integrated Care Organization (ICO) plans. The plans are administered by Blue Cross and Blue Shield of Massachusetts, Boston Medical Center HealthNet Plan, Commonwealth Care Alliance, Fallon Total Care, Neighborhood Health Plan, and Network Health. On July 1, 2013, dually eligible individuals with ID/DD (14,200 individuals in 2008 or about 13 percent of the 115,000 in the demonstration), can choose one of these six private plans. Individuals who do not pro-actively choose a plan will be auto-enrolled in a plan by January 1, 2014. All ICO plans fully integrate medical, prescription drug, and behavioral health benefits covered by Medicare and Medicaid. For individuals with ID/DD on the HCBS waiver, 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 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 the 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 re-admission rate of 4 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 six 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 1 percent from baseline spending in the first year, 2 percent in the second year, and 4 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 1 to 4 percent a year, the annual savings for dually eligible individuals with developmental disabilities are from $9 million in the first year to about $35 million by year three, and roughly $62 million over the entire three years.

- 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 1 to 3 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

Integration 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 statewide 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. Given that, the rest of the nation will be watching closely to see how the MassHealth reform performs.

How to Use this The Case for Inclusion & How the Rankings Were Developed

Using The Case for Inclusion Report:

This report 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.

This report puts each state's progress in serving individuals with intellectuals and developmental disabilities into a national context.

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. Lastly, advocates can 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.

Advancing public policy change is tough.

Good public policy changes lives. Bad public policy hurts people and keeps them isolated from their families and communities.

UCP recognizes that to many potential advocates the legislative process is mysterious and daunting. To explain that process and learn from the successes of other change agents, UCP has developed a roadmap of how anyone can transform public policy and the lives those policies impact. The Plan for Inclusion (LINK) breaks down the process into four steps (taken from the Massachusetts Institute of Technology-Sloan Leadership Model):

1. Sense-Making – have solid information and facts about what drives the current system. The Case for Inclusion is a key part of this information.
2. Relating – policy change is all about relationships. Advocates have to build those relationships to have the foundation that makes it possible to work together with policymakers toward positive change.
3. Visioning – prioritize the one or two key policy changes and have a laser focus on those areas.
4. Innovating – replicating the proven innovations succeeding in other states is much easier than trying to implement a never-before-tried idea.

The Plan for Inclusion goes in depth into each of these areas with specific action steps about what you can do, how to get it done, and detailed policy reforms that are working. The Plan also includes important lessons learned from change agents in key states who have gone before, learned the tough lessons and share those experiences to make advocacy easier for you. Change is achievable and can make a profound and positive difference in the lives of Americans with intellectual and developmental disabilities. Read the Plan, develop your own action plan, and then make it happen.

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. Twenty 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 a majority of the points.

Weighting of Case for Inclusion Scores – 100 Total Possible Points

Promoting Independence	Community-based	% of Recipients with ID-DD on HCBS	24
		% of ID/DD Expenditures on non-ICP-MR	
		% of ID/DD Expenditures on non-ICP-MR	
	Residential Services in the Community (includes all types)	1-3 %	24
		1-6 %	
		16+ % (smaller %, higher rank)	
		% in Large State Facilities	
	Waivers Promoting Self-Determination		2
Tracking Community Involvement and Safety		Quality Assurance	12
		Abuse	
Keeping Families Together		Family Support per 100k	12
		% in a Family Home	
Promoting Productivity	Medicaid Boy-In		10
	Supported or Cooperative Employment		
	Voc Rehap		
Reaching Those in Need	Waiting List	Average % Growth for Residential and HCBS	16
	Individuals with ID/DD served per 10k of		
	Ratio of Prevelence to Individuals Served		
	Uses Federal Functional Definition for Eligibility		

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 2011, 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 2012 or later have not been considered.

When reviewing an individual states ranking, it is important to consider action taken since 2011, 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, eleven points separate the top 10 states, 15 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 The Case for Inclusion reports.

About the Case for Inclusion's Author:

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.

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 2013 report for The Case for Inclusion 2013 ranking to successfully release in a timely manner.

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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.

[2] "What Work Means: What does NCI tell us about the quality of life of adults with intellectual and Developmental disabilities who are employed in the community?" NCI Data Brief. Human Services Research Institute. December 2011. Figure 2, Page 3. http://www.nationalcoreindicators.org/upload/core-indicators/NCI_Data_Brief-_Employment-_Issue_5_Dec_2011_FINAL_1.pdf (March 20, 2013)

[3] "What Work Means." Figure 8 , Page 7.

[4] "What Work Means." Figure 9, Page 8.

[5] "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)

[6] Ibid. page 5.

[7] 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)

[8] "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)

[9] 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)

[10] "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)

[11] 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)

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

[13] 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)

[14] "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)

[15] Learn more by reading the excellent 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)

[16] "Washington State Employment Data Presentation." Slide 10.

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

[18] Hoff, David. "Employment First Resource List." State Employment Leadership Network . Revised April 2013. http://www.apse.org/docs/Employment%20First%20List%204-13%20%28SELN%29.pdf (accessed on April 14, 2013)

[19] "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)

[20] "Administration on Developmental Disabilities Awards Funding for NCI Expansion." Human Services Research Institute. January 2, 2012. Available at: http://www.nationalcoreindicators.org/news/#new-states-join-nci-with-help-of-add-funding (February 22, 2012)

[21] For more details of these 100 data measures, visit http://www.nationalcoreindicators.org/indicators/ or to ask about how your state can participate contact the Human Services Research Institute at 617.876.0426 or contact Joshua Engler, Project Coordinator for the National Core Indicators, at jengler@hsri.org. To view the latest National Core Indicators report (FY2010) go to: http://www.nationalcoreindicators.org/upload/core-indicators/NCI_Annual_Summary_Report_2009-10_FINAL.pdf

[22] 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)

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

[24] "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)

[25] "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)

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

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

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

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

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

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

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

[33] "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)

[34] "Massachusetts and Ohio: Capitated Financial Alignment Demonstrations for Dual Eligible Beneficiaries Compared." Kaiser Commission on Medicaid and the Uninsured. Kaiser Family Foundation. January 2013. Page 2. http://www.kff.org/medicaid/upload/8407.pdf (accessed on March 20, 2013)

[35] Case for Inclusion 2012. Medicaid.UCP.org (accessed March 20, 2013)

[36] Ellen Breslin Davidson and Tony Dreyfus. "Dual Eligibles in Massachusetts: A Profile of Health Care Services and Spending for Non-Elderly Adults Enrolled in Both Medicare and Medicaid." Massachusetts Medicaid Policy Institute in Collaboration with the Massachusetts

Medicaid Program. September 2011. Slide 17. http://bluecrossmafoundation.org/sites/default/files/MMPI%20Duals%20Chart%20Pack_0.pdf (accessed on March 20, 2013)

[37] "Duals Demonstration Timeline." Massachusetts Department of Health and Human Services. http://www.mass.gov/eohhs/provider/guidelines-resources/services-planning/national-health-care-reform-plan/federal-health-care-reform-initiatives/integrating-medicare-and-medicaid/related-information.html (accessed on March 20, 2013)

[38] "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)

[39] 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)

[40] "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)

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

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

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)

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

[44] "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)