

## The Case for Inclusion 2012

## 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.

| Medicaid Facts: Fiscal Year 2010 |
| :---: |
| Total Spending (State and Federal) - $\$ 404.9$ billion |
| - Individuals with ID/DD $-\$ 32.9$ billion (8.1\%) |
| Total Enrollment -52.9 million people |
| - Individuals with ID/DD - 666,000 (1.3\%) |
| Source: Medicaid 2010 Actuarial Report \& the Research |
| and Training Center on Community Living |

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.

## Disability and Aging

Over the past decade, there has been increasing attention on the combined community living challenges related to both aging and disability populations. Needed resources to serve these populations are becoming harder to secure at the same time that the population in need is increasing.

While shared budget and workforce challenges will require the aging and disability communities to collaborate in finding solutions to meet the exploding demand for community based programs-including implementing shared supports that maintain family units-there needs to be more planning, outreach and education for families with aging caregivers.

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America is aging. In 2010, the number of Americans 65 or older was 40 million. By 2020, the number of elderly will climb to 55 million. By the time today's infants graduate from high school in 2030, the number of elderly will skyrocket to 72 million. ${ }^{1}$

For Americans with intellectual and developmental disabilities, the impact of America's aging population has huge implications. First, it will spark a tremendous increase in demand for community-based services. Second, as family caregivers age, Americans with disabilities, who are also aging, must look to alternative supports and, possibly new and dramatically different living arrangements to remain an active part of their community.

To ensure that families with aging caregivers can maintain their dignity and independence in community settings, the first step is to understand which states face the biggest, most immediate challenge to aging in place. Some states have a very large share of individuals with disabilities with aging caregivers. This report (p. 6) includes a list of all 50 states and DC, in alphabetical and rank order, with the share of aging caregivers shown. ${ }^{2}$ Future The Case for Inclusion reports will track this demographic data and state responses to this impending need.

## Four Key Aspects of a High Functioning Medicaid Program

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. ${ }^{3}$ 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]:


## 2012 Ranking Enhancements

The 2012 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 new web module and design at ucp.org/public-policy/the-case-

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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 online resources also allow visitors to track how states have improved or declined in The Case for Inclusion rankings since the 2006 report.

Second, the 2012 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. 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. ${ }^{4}$

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. ${ }^{5}$ 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.

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.

Finally, 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 2010, 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.

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## Significant Takeaways from the 2012 Ranking

## Promoting Independence

1. All states still have room for improvement, but some states have consistently remained at the bottom since 2007, including Arkansas (\#49), Illinois (\#48), Mississippi (\#51) and Texas (\#50). Given Illinois Governor Pat Quinn's recent proposal to close four state institutions, Illinois could be the breakaway low performer in 2013, should the Illinois legislature agree. Specifically, Governor Quinn proposed closing four state institutions as part of his latest budget ${ }^{6}$. This includes the Jacksonville Developmental Center, which began operating in 1851. Despite the poor quality of life, institutions are extremely expensive, costing more than \$200,000 per person per year, compared to $\$ 84,000$ per person per year in community settings. 7 If successful in what has become a contentious budget debate, Governor Quinn would close half of Illinois state institutions in one year and become a leader in dramatically advancing the quality of life and community inclusion for Illinois residents.
2. $\mathbf{3 6}$ states now meet the $\mathbf{8 0} / \mathbf{8 o}$ 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 80/8o standard are Arkansas, DC (very close), Illinois, Iowa, Kentucky, Louisiana, Mississippi, Nebraska, New Jersey, North Carolina, Oklahoma (very close), Tennessee (very close), Texas, Utah and Virginia (very close).
3. As of 2010 , 11 states have no state institutions to seclude those with ID/DD, including Alaska, Hawaii, Maine, Michigan, New Hampshire, New Mexico, Oregon (new this year), Rhode Island, Vermont, West Virginia and DC. In addition, Minnesota closed its last remaining institution in June 2011, and another 12 states have only one institution each. Since 1960, 205 of 354 state institutions have been closed, according to the University of Minnesota's Research and Training Center on Community Living.
4. 22 states now meet the 8o\% 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 seven states meet a 90\% Home-like Setting Standard, and these top performers include Arizona, California, Hawaii, Idaho, Nevada, New Hampshire and Vermont.

## Tracking Quality

5. 29 states participate in the National Core Indicators (NCI) model, a comprehensive quality assurance program that includes standard measures to asses outcomes of services (nationalcoreindicators.org). In January 2012, the Obama Administration made available grant funding so that even more states could

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participate and ensure that their quality assurance efforts were benchmarked and comprehensive (NCI has more than 100 measures; see Endnote \#3 for more details).

## Keeping Families Together

6. 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 Alaska, Arizona, California, Connecticut, Delaware, Louisiana, Massachusetts, Montana, New Hampshire, New Mexico, New York, South Carolina, South Dakota, Vermont and Wisconsin. New Jersey and Pennsylvania were very close to meeting this standard.

## Promoting Productivity

7. Just nine 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 Alaska, Connecticut, Delaware, Maryland, Michigan, Oklahoma, Pennsylvania, Vermont, and Washington.

## Serving Those in Need

8. Waiting lists for residential and community services continue to climb 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 $46 \%$ increase in states' HCBS programs. However, 14 states report no waiting list or a small waiting list (requiring less than $10 \%$ program growth).

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## 2012 The Case for Inclusion Rankings

| Alphabetical |  |  | By Rank in 2012 |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: |
|  | 2012 | 2011 |  | 2012 | 2011 |
|  | Ranking | Ranking |  | Ranking | Ranking |
| Alabama | 33 | 32 | Arizona | 1 | 2 |
| Alaska | 30 | 30 | Michigan | 2 | 3 |
| Arizona | 1 | 2 | California | 3 | 5 |
| Arkansas | 49 | 50 | New Hampshire | 4 | 4 |
| California | 3 | 5 | Vermont | 5 | 1 |
| Colorado | 28 | 12 | Massachusetts | 6 | 9 |
| Connecticut | 7 | 10 | Connecticut | 7 | 10 |
| Delaware | 16 | 7 | Washington | 8 | 6 |
| Dist. of Columbia | 40 | 47 | New York | 9 | 17 |
| Florida | 20 | 27 | Pennsylvania | 10 | 15 |
| Georgia | 21 | 22 | Maryland | 11 | 31 |
| Hawaii | 19 | 13 | Idaho | 12 | 18 |
| Idaho | 12 | 18 | South Carolina | 13 | 16 |
| Illinois | 48 | 48 | New Mexico | 14 | 11 |
| Indiana | 46 | 42 | South Dakota | 15 | 23 |
| Iowa | 43 | 35 | Delaware | 16 | 7 |
| Kansas | 36 | 25 | Nevada | 17 | 8 |
| Kentucky | 31 | 33 | Montana | 18 | 24 |
| Louisiana | 25 | 37 | Hawaii | 19 | 13 |
| Maine | 24 | 29 | Florida | 20 | 27 |
| Maryland | 11 | 31 | Georgia | 21 | 22 |
| Massachusetts | 6 | 9 | Oregon | 22 | 26 |
| Michigan | 2 | 3 | Missouri | 23 | 28 |
| Minnesota | 26 | 14 | Maine | 24 | 29 |
| Mississippi | 51 | 51 | Louisiana | 25 | 37 |
| Missouri | 23 | 28 | Minnesota | 26 | 14 |
| Montana | 18 | 24 | Wisconsin | 27 | 20 |
| Nebraska | 41 | 46 | Colorado | 28 | 12 |
| Nevada | 17 | 8 | West Virginia | 29 | 19 |
| New Hampshire | 4 | 4 | Alaska | 30 | 30 |
| New Jersey | 37 | 40 | Kentucky | 31 | 33 |
| New Mexico | 14 | 11 | Rhode Island | 32 | 34 |
| New York | 9 | 17 | Alabama | 33 | 32 |
| North Carolina | 44 | 43 | Ohio | 34 | 39 |
| North Dakota | 39 | 36 | Wyoming | 35 | 21 |
| Ohio | 34 | 39 | Kansas | 36 | 25 |
| Oklahoma | 38 | 45 | New Jersey | 37 | 40 |
| Oregon | 22 | 26 | Oklahoma | 38 | 45 |
| Pennsylvania | 10 | 15 | North Dakota | 39 | 36 |
| Rhode Island | 32 | 34 | Dist. of Columbia | 40 | 47 |
| South Carolina | 13 | 16 | Nebraska | 41 | 46 |
| South Dakota | 15 | 23 | Tennessee | 42 | 41 |
| Tennessee | 42 | 41 | Iowa | 43 | 35 |
| Texas | 50 | 49 | North Carolina | 44 | 43 |
| Utah | 45 | 44 | Utah | 45 | 44 |
| Vermont | 5 | 1 | Indiana | 46 | 42 |
| Virginia | 47 | 38 | Virginia | 47 | 38 |
| Washington | 8 | 6 | Illinois | 48 | 48 |
| West Virginia | 29 | 19 | Arkansas | 49 | 50 |
| Wisconsin | 27 | 20 | Texas | 50 | 49 |
| Wyoming | 35 | 21 | Mississippi | 51 | 51 |

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## 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 among the worst states (sub-ranking \#44) for promoting productivity. Arizona could potentially learn from Connecticut (sub-ranking \#2) or Michigan (sub-ranking \#1) regarding how to improve in this area.

|  | Promoting Independence |  | Tracking Quality and Safety |  | Keeping Families Together |  | Promoting <br> Productivity |  | Reaching Those in Need |  | Overall |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  | Score | Rank | Score | Rank | Score | Rank | Score | Rank | Score | Rank | Score | Rank |
| Alabama | 43.1 | 19 | 11.8 | 13 | 4.0 | 39 | 1.2 | 50 | 8.1 | 41 | 68.2 | 33 |
| Alaska | 48.3 | 4 | 1.3 | 51 | 5.1 | 30 | 5.8 | 9 | 8.3 | 40 | 68.8 | 30 |
| Arizona | 48.6 | 3 | 11.9 | 2 | 12.0 | 1 | 2.7 | 44 | 12.3 | 8 | 87.6 | 1 |
| Arkansas | 26.6 | 50 | 6.0 | 29 | 2.7 | 48 | 2.6 | 45 | 9.2 | 36 | 47.2 | 49 |
| California | 45.2 | 11 | 11.6 | 16 | 9.8 | 2 | 3.4 | 38 | 13.0 | 3 | 83.0 | 3 |
| Colorado | 46.7 | 8 | 5.8 | 34 | 5.5 | 29 | 1.8 | 48 | 9.9 | 30 | 69.8 | 28 |
| Connecticut | 40.4 | 33 | 11.9 | 6 | 7.9 | 13 | 7.3 | 2 | 11.7 | 11 | 79.2 | 7 |
| Delaware | 42.2 | 22 | 5.6 | 38 | 8.8 | 7 | 6.2 | 5 | 11.1 | 14 | 74.0 | 16 |
| Dist. of Columbia | 41.4 | 29 | 4.0 | 48 | 3.2 | 47 | 3.1 | 41 | 11.1 | 16 | 62.7 | 40 |
| Florida | 41.8 | 24 | 11.8 | 8 | 6.6 | 19 | 1.8 | 49 | 9.7 | 32 | 71.8 | 20 |
| Georgia | 43.1 | 18 | 11.6 | 14 | 4.2 | 36 | 4.0 | 29 | 8.4 | 39 | 71.5 | 21 |
| Hawaii | 47.7 | 5 | 8.3 | 28 | 5.9 | 26 | 0.8 | 51 | 10.4 | 23 | 73.2 | 19 |
| Idaho | 43.3 | 17 | 5.8 | 33 | 6.1 | 25 | 5.4 | 10 | 16.0 | 1 | 76.6 | 12 |
| Illinois | 27.1 | 49 | 11.8 | 7 | 3.3 | 46 | 4.0 | 31 | 7.4 | 43 | 53.6 | 48 |
| Indiana | 38.2 | 39 | 5.7 | 35 | 3.8 | 40 | 4.6 | 23 | 4.7 | 47 | 57.0 | 46 |
| Iowa | 35.7 | 45 | 5.6 | 36 | 3.7 | 42 | 4.6 | 26 | 12.5 | 5 | 62.1 | 43 |
| Kansas | 41.7 | 27 | 5.8 | 32 | 4.8 | 35 | 3.6 | 34 | 10.3 | 26 | 66.2 | 36 |
| Kentucky | 39.4 | 37 | 11.4 | 19 | 3.4 | 45 | 4.8 | 17 | 9.6 | 33 | 68.6 | 31 |
| Louisiana | 35.7 | 44 | 11.8 | 12 | 9.1 | 5 | 4.0 | 30 | 10.2 | 28 | 70.7 | 25 |
| Maine | 44.8 | 13 | 9.4 | 26 | 1.6 | 51 | 4.7 | 19 | 10.1 | 29 | 70.7 | 24 |
| Maryland | 45.6 | 10 | 11.6 | 15 | 4.2 | 37 | 5.9 | 8 | 9.5 | 34 | 76.8 | 11 |
| Massachusetts | 41.9 | 23 | 11.8 | 10 | 8.5 | 8 | 4.9 | 16 | 12.4 | 6 | 79.5 | 6 |
| Michigan | 45.1 | 12 | 11.9 | 3 | 6.2 | 24 | 8.9 | 1 | 11.3 | 13 | 83.4 | 2 |
| Minnesota | 43.0 | 20 | 5.4 | 40 | 6.3 | 23 | 2.9 | 42 | 12.4 | 7 | 70.0 | 26 |
| Mississippi | 13.1 | 51 | 4.4 | 47 | 5.0 | 34 | 4.9 | 14 | 0.9 | 50 | 28.2 | 51 |
| Missouri | 40.6 | 31 | 11.5 | 18 | 5.9 | 27 | 2.8 | 43 | 10.2 | 27 | 70.9 | 23 |
| Montana | 44.1 | 15 | 5.6 | 37 | 9.2 | 4 | 3.6 | 33 | 11.0 | 18 | 73.5 | 18 |
| Nebraska | 40.8 | 30 | 5.0 | 43 | 2.1 | 49 | 5.3 | 11 | 9.4 | 35 | 62.7 | 41 |
| Nevada | 46.9 | 6 | 4.9 | 45 | 6.7 | 18 | 4.7 | 18 | 10.4 | 24 | 73.6 | 17 |
| New Hampshire | 48.7 | 2 | 11.1 | 22 | 6.9 | 16 | 4.9 | 15 | 10.3 | 25 | 82.0 | 4 |
| New Jersey | 36.5 | 43 | 11.9 | 5 | 8.4 | 10 | 3.3 | 40 | 4.2 | 48 | 64.2 | 37 |
| New Mexico | 46.9 | 7 | 8.6 | 27 | 8.5 | 9 | 5.3 | 12 | 6.5 | 46 | 75.8 | 14 |
| New York | 39.6 | 36 | 12.0 | 1 | 9.5 | 3 | 3.6 | 35 | 13.9 | 2 | 78.5 | 9 |
| North Carolina | 37.1 | 42 | 11.8 | 9 | 5.9 | 28 | 4.9 | 13 | 1.5 | 49 | 61.2 | 44 |
| North Dakota | 37.3 | 41 | 5.4 | 41 | 3.8 | 41 | 3.7 | 32 | 12.7 | 4 | 62.8 | 39 |
| Ohio | 38.9 | 38 | 11.3 | 20 | 6.4 | 21 | 4.6 | 25 | 6.6 | 45 | 67.8 | 34 |
| Oklahoma | 35.6 | 46 | 9.7 | 25 | 5.0 | 33 | 6.1 | 6 | 6.8 | 44 | 63.1 | 38 |
| Oregon | 46.5 | 9 | 5.8 | 30 | 5.1 | 31 | 3.3 | 39 | 10.7 | 22 | 71.4 | 22 |
| Pennsylvania | 41.8 | 25 | 11.0 | 23 | 7.9 | 14 | 6.0 | 7 | 10.7 | 21 | 77.4 | 10 |
| Rhode Island | 43.8 | 16 | 5.3 | 42 | 4.1 | 38 | 4.4 | 27 | 10.8 | 20 | 68.5 | 32 |
| South Carolina | 39.6 | 35 | 11.8 | 11 | 9.0 | 6 | 4.7 | 20 | 11.0 | 17 | 76.1 | 13 |
| South Dakota | 39.9 | 34 | 11.1 | 21 | 7.1 | 15 | 4.6 | 22 | 11.9 | 10 | 74.7 | 15 |
| Tennessee | 40.5 | 32 | 5.6 | 39 | 5.0 | 32 | 1.9 | 47 | 9.1 | 37 | 62.1 | 42 |
| Texas | 29.2 | 48 | 10.9 | 24 | 3.5 | 44 | 2.6 | 46 | 0.7 | 51 | 46.8 | 50 |
| Utah | 37.5 | 40 | 3.5 | 50 | 3.5 | 43 | 4.6 | 24 | 9.1 | 38 | 58.3 | 45 |
| Vermont | 49.6 | 1 | 5.0 | 44 | 8.2 | 11 | 6.8 | 3 | 12.0 | 9 | 81.7 | 5 |
| Virginia | 29.8 | 47 | 11.5 | 17 | 1.7 | 50 | 4.7 | 21 | 8.0 | 42 | 55.7 | 47 |
| Washington | 42.6 | 21 | 11.9 | 4 | 6.6 | 20 | 6.5 | 4 | 10.9 | 19 | 78.5 | 8 |
| West Virginia | 44.3 | 14 | 4.4 | 46 | 6.9 | 17 | 3.5 | 36 | 9.9 | 31 | 68.9 | 29 |
| Wisconsin | 41.6 | 28 | 5.8 | 31 | 8.0 | 12 | 3.4 | 37 | 11.1 | 15 | 70.0 | 27 |
| Wyoming | 41.7 | 26 | 3.6 | 49 | 6.3 | 22 | 4.1 | 28 | 11.5 | 12 | 67.3 | 35 |

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## Most Improved and Biggest Drops

In the past six years, 17 states have moved at least 10 places in the rankings from 2007 to 2012. Nine states improved dramatically, while eight states dropped significantly. The table below shows these moves.


Alaska - dropped 28 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 20 places since 2007 - fell so dramatically because of a significant decline in competitive employment participation (from $53 \%$ to $17 \%$ ), and the state does not participate in NCI.

Idaho - improved 13 places since 2007 - significantly increased the share of individuals (from $75 \%$ to $85 \%$ ) and resources (from $51 \%$ to $91 \%$ ) dedicated to the community. It also more than doubled the number of people with ID/DD in competitive employment (from $14 \%$ to $30 \%$ ).

Kansas - dropped 14 places since 2007 - does not participate in the NCI.
Louisiana - improved 19 places since 2007 - had huge improvement in the portion of individuals (from $49 \%$ to $63 \%$ ) and resources (from $41 \%$ to $77 \%$ ) dedicated to community services over institutions, and it had large drop in the portion of individuals served in large institutions (from $18 \%$ to $8 \%$ ).

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Maryland - improved 22 places since 2007 - closed a state institution and reduced the population at state institutions by $60 \%$. 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.

Missouri - improved 18 places since 2007 - dramatically increased the portion of resources dedicated to people in the community (from $59 \%$ to $81 \%$ ) and started participating in NCI.

Nevada - improved 10 places since 2007-dramatically increased the portion of resources dedicated to people in the community (from $68 \%$ to $93 \%$ ), closed a state institution and reduced the number of people at state institutions by $47 \%$.

New Jersey - dropped 14 places since 2007 - primarily did poorly because the state did not report whether it has a waiting list and how many people are on it.

North Carolina - dropped 10 places since 2007-primarily did poorly because the state did not report whether it has a waiting list and how many people are on it.

Ohio - improved 14 places since 2007 - dramatically increased the share of individuals (to $82 \%$ from $63 \%$ ) and resources (from $50 \%$ to $82 \%$ ) dedicated to the community, closed a state institution, reduced by half the portion of individuals served in large institutions (from $18 \%$ to $9 \%$ ), started participating in NCI and reported on its waiting list which was of average size.

Pennsylvania - improved 19 places since 2007 - substantially increased the portion of resources dedicated to people in the community (from $70 \%$ to $82 \%$ ), 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.

South Dakota - improved 11 places since 2007 - steadily improved in the share of individuals served in the community and added a Medicaid Buy-in Program.

Washington - improved 12 places since 2007 - mostly a result of the state accurately reporting on its waiting list, which is relatively small.

West Virginia - dropped 13 places since 2007 -dramatically increased the share of resources going to the community (from $77 \%$ to $99 \%$ ) but does not participate in NCI.

Wyoming - dropped 18 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 14\%).

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

## The Best Performing States

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

The Worst Performing States
42. Tennessee
43. Iowa
44. North Carolina
45. Utah
46. Indiana
47. Virginia
48. Illinois
49. Arkansas
50. Texas
51. Mississippi

## Facts about the Best Performing States

1. Top Performers are both big and small states in population - "big" population states include California (\#1 biggest), New York (\#3) and Pennsylvania (\#6), 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 (\#1 richest), Connecticut (\#2) and Massachusetts (\#7), and "poorer" states include Arizona (\#34) and Michigan (\#30).
3. Top Performers are high tax and low tax burden states - "high tax burden" states include California (\#6) and Pennsylvania (\#7), and "low tax burden" states include New Hampshire (\#50), Michigan (\#45) and Washington (\#30).
4. Top Performers are big and low spending per person, served through the Home and Community Based Services - "big spender" states are Connecticut (\#5) and New York (\#7), and "low spender" states are California (\#50), Arizona (\#47) and Washington (\#36).

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## 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 topperforming 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.

## 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,

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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 HCBS |  |
|  |  | $\%$ of ID/DD Expenditures on non-ICF-MR |  |
|  | Residential Services in the Community (includes all types) | 1-3-\% | 24 |
|  |  | 1-6-\% |  |
|  |  | $\begin{gathered} 16+\% \\ \text { (smaller \%, higher rank) } \end{gathered}$ |  |
|  |  | \% 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 Buy-In |  | 10 |
|  | Supported or Competitive Employment |  |  |
|  |  | Voc Rehab |  |
| Reaching 'Those in Need | Waiting List | Average \% Growth for Residential and HCBS | 16 |
|  |  |  |  |
|  | Ratio of Prevalence 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 worstperforming.

As noted, most data is from 2010, 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 2011 or later have not been considered.

When reviewing an individual states ranking, it is important to consider action taken since 2010, 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, eight points separate the top 10 states, 17 points separate the top 25 states, and only 13 points separate the middle 25 states. Therefore, minor changes in state policy

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or outcomes could significantly affect how a state ranks on future or past The Case for Inclusion reports.

## Acknowledgements

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#### Abstract

About the Author

Tarren Bragdon has been involved in healthcare policy research and analysis for over 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.


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| State | Promoting Independence |  |  | Ensuring Community Involvement and Safety |  |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  | Waivers | that Can Promo Determination <br> Other SelfDirected - 1115 or 1915(c) Waiver for ID/DD | $\begin{aligned} & \text { Money Self- } \\ & \text { Money } \\ & \text { Follows the } \\ & \text { Person - } \\ & \text { Award or } \\ & \text { Apply } \end{aligned}$ | Council on Quailty and Leadership | Quality Assuran <br> National Core Indicators (HSRI) | Noteworthy State QA Initiatives | Abuse <br> Protection and Advocacy Clients | $\begin{aligned} & \% \text { of all } \begin{array}{c} \text { those } \\ \text { therved } \end{array} \end{aligned}$ |
| Alabama | Yes | Yes | Yes | Yes | Yes |  | 38 | 1\% |
| Alaska |  | Yes |  |  |  | Yes | 117 | 10\% |
| Arizona |  | Yes |  |  | Yes |  | 34 | 0\% |
| Arkansas | Yes | Yes | Yes |  | Yes |  | 734 | 12\% |
| California | Yes | Yes | Yes |  | Yes | Yes | 1,517 | 1\% |
| Colorado | Yes | Yes | Yes | Yes |  | Yes | 60 | 1\% |
| Connecticut | Yes | Yes | Yes |  | Yes | Yes | 45 | 0\% |
| Delaware | Yes | Yes | Yes |  |  |  | 26 | 1\% |
| Dist. of Columbia |  | Yes | Yes |  |  |  | 78 | 4\% |
| Florida | Yes | Yes | Yes |  | Yes |  | 180 | 0\% |
| Georgia | Yes | Yes | Yes | Yes | Yes |  | 96 | 1\% |
| Hawaii |  | Yes | Yes |  | Yes |  | 183 | 8\% |
| Idaho | Yes | Yes | Yes |  |  |  | 85 | 0\% |
| Illinois |  | Yes | Yes | Yes | Yes |  | 105 | 0\% |
| Indiana |  | Yes | Yes | Yes |  |  | 92 | 1\% |
| Iowa |  | Yes | Yes | Yes |  |  | 114 | 1\% |
| Kansas |  | Yes | Yes | Yes |  |  | 40 | 0\% |
| Kentucky |  | Yes | Yes | Yes | Yes |  | 69 | 1\% |
| Louisiana | Yes | Yes | Yes | Yes | Yes |  | 105 | 0\% |
| Maine | Yes | Yes | Yes |  | Yes |  | 166 | 5\% |
| Maryland | Yes | Yes | Yes | Yes | Yes |  | 75 | 1\% |
| Massachusetts | Yes | Yes | Yes |  | Yes |  | 136 | 0\% |
| Michigan | Yes | Yes | Yes |  | Yes | Yes | 55 | 0\% |
| Minnesota |  | Yes | Yes | Yes |  | Yes | 349 | 1\% |
| Mississippi |  | Yes | Yes |  |  |  | 162 | 3\% |
| Missouri | Yes | Yes | Yes | Yes | Yes |  | 143 | 1\% |
| Montana | Yes | Yes |  |  |  |  | 35 | 1\% |
| Nebraska |  | Yes | Yes |  |  |  | 91 | 2\% |
| Nevada |  | Yes | Yes | Yes |  |  | 117 | 2\% |
| New Hampshire | Yes | Yes | Yes |  | Yes | Yes | 48 | 2\% |
| New Jersey | Yes | Yes | Yes | Yes | Yes |  | 130 | 0\% |
| New Mexico |  | Yes | Yes | Yes | Yes | Yes | 259 | 7\% |
| New York |  | Yes | Yes | Yes | Yes | Yes | 35 | 0\% |
| North Carolina | Yes | Yes | Yes | Yes | Yes |  | 84 | 0\% |
| North Dakota | Yes | Yes | Yes | Yes |  |  | 40 | 1\% |
| Ohio | Yes | Yes | Yes | Yes | Yes |  | 610 | 1\% |
| Oklahoma |  | Yes | Yes |  | Yes |  | 333 | 5\% |
| Oregon | Yes | Yes | Yes |  |  |  | 51 | 0\% |
| Pennsylvania |  | Yes | Yes | Yes | Yes | Yes | 1,137 | 2\% |
| Rhode Island | Yes | Yes | Yes |  |  |  | 43 | 1\% |
| South Carolina | Yes | Yes |  | Yes | Yes |  | 74 | 0\% |
| South Dakota |  | Yes |  | Yes | Yes |  | 63 | 2\% |
| Tennessee |  | Yes | Yes |  |  |  | 76 | 1\% |
| Texas |  | Yes | Yes | Yes | Yes |  | 579 | 2\% |
| Utah |  | Yes | Yes |  |  |  | 270 | 5\% |
| Vermont | Yes |  |  |  |  | Yes | 68 | 2\% |
| Virginia |  | Yes | Yes |  | Yes |  | 86 | 1\% |
| Washington |  | Yes | Yes |  | Yes |  | 46 | 0\% |
| West Virginia |  | Yes | Yes |  |  |  | 156 | 3\% |
| Wisconsin |  | Yes | Yes | Yes |  | Yes | 88 | 0\% |
| Wyoming |  | Yes |  |  |  | Yes | 111 | 5\% |
| United States | 25 | 50 | 44 | 24 | 29 | 13 | 10,386 | 1\% |
| United States - Est. |  |  |  |  |  |  |  |  |
| Source | CMS \& NHPF | PAS Center | $\begin{gathered} \text { CMS \& } \\ \text { Mathematica } \end{gathered}$ | Council on Quality and Leadership | Human Services Research Institute | QualiryMall.org | Administration on <br> Developmental <br> Disabilities |  |
| Table/Page |  |  | MRDD | Orgs in ST |  | QA\& $\mathrm{QI}^{\text {I }}$ | Outcomes |  |
| Year of Data | 2008 | Nov 2006 | 2012 | 2010 | Jan-12 | 2010 | 2008 |  |


| State | Keeping Families Together |  |  |  |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  | Families |  | mily Support Spending |  | $\begin{aligned} & \text { ling per } \\ & \text { mily } \end{aligned}$ | $\begin{aligned} & \text { Families } \\ & \text { Supported per } \\ & \text { 100k of } \\ & \text { Population } \end{aligned}$ | $\begin{aligned} & \text { \% Individuals } \\ & \text { Living in Family } \\ & \text { Home } \end{aligned}$ |
| Alabama | 1,377 | \$ | 700,000 | \$ | 508 | 29 | 50\% |
| Alaska | 1,468 | \$ | 6,180,000 | \$ | 4,210 | 206 | 19\% |
| Arizona | 20,899 | \$ | 352,500,000 | \$ | 16,867 | 326 | 86\% |
| Arkansas | 521 | \$ | 500,000 | \$ | 960 | 18 | 34\% |
| California | 99,244 | \$ | 738,400,000 | \$ | 7,440 | 266 | 71\% |
| Colorado | 3,736 | \$ | 6,800,000 | \$ | 1,820 | 74 | 59\% |
| Connecticut | 8,178 | \$ | 47,700,000 | s | 5,833 | 229 | 53\% |
| Delaware | 1,987 | \$ | 1,410,000 | 5 | 710 | 221 | 68\% |
| Dist. of Columbia | 422 | \$ | 11,000,000 | \$ | 26,066 | 70 | 28\% |
| Florida | 17,537 | \$ | 336,400,000 | \$ | 19,182 | 93 | 70\% |
| Georgia | 7,276 | \$ | 24,000,000 | \$ | 3,299 | 75 | 41\% |
| Hawaii | 921 | \$ | 5,000,000 | 5 | 5,429 | 68 | 67\% |
| Idaho | 751 | \$ | 300,000 | \$ | 399 | 48 | 75\% |
| Illinois | 5,609 | \$ | 35,200,000 | \$ | 6,276 | 44 | 36\% |
| Indiana | 4,207 | \$ | 24,000,000 | s | 5,705 | 65 | 37\% |
| Iowa | 1,977 | \$ | 29,000,000 | \$ | 14,669 | 65 | 36\% |
| Kansas | 4,074 | s | $54,400,000$ | 5 | 13,353 | 142 | 31\% |
| Kentucky | 3,370 | \$ | 23,200,000 | \$ | 6,884 | 78 | 28\% |
| Louisiana | 10,985 | \$ | 366,900,000 | S | 33,400 | 242 | 66\% |
| Maine | 545 | \$ | 1,100,000 | \$ | 2,018 | 41 | 13\% |
| Maryland | 8,194 | \$ | 40,200,000 | 5 | 4,906 | 142 | 23\% |
| Massachusetts | 14,817 | \$ | 46,100,000 | s | 3,111 | 226 | 62\% |
| Michigan | 13,588 | \$ | 55,100,000 | s | 4,055 | 138 | 52\% |
| Minnesota | 8,008 | \$ | 231,200,000 | \$ | 28,871 | 151 | 51\% |
| Mississippi | 4,100 | \$ | 21,900,000 | \$ | 5,341 | 138 | 35\% |
| Missouri | 8,332 | \$ | 23,600,000 | 5 | 2,832 | 139 | 48\% |
| Montana | 2,851 | \$ | 11,000,000 | s | 3,858 | 288 | 55\% |
| Nebraska | 712 | \$ | 7,500,000 | \$ | 10,534 | 39 | 20\% |
| Nevada | 2,603 | \$ | 6,900,000 |  | 2,651 | 96 | 70\% |
| New Hampshire | 3,960 | \$ | 7,690,000 | 5 | 1,942 | 301 | 20\% |
| New Jersey | 17,086 | \$ | 64,400,000 | s | 3,769 | 194 | 69\% |
| New Mexico | 6,199 | \$ | 29,200,000 | \$ | 4,710 | 300 | 43\% |
| New York | 53,908 | \$ | 559,700,000 | \$ | 10,383 | 278 | 62\% |
| North Carolina | 8,471 | s | 35,500,000 | \$ | 4,191 | 89 | 61\% |
| North Dakota | 629 | \$ | 8,000,000 | \$ | 12,719 | 93 | 29\% |
| Ohio | 19,603 | \$ | 76,800,000 | \$ | 3,918 | 170 | 47\% |
| Oklahoma | 4,948 | 5 | 84,500,000 | \$ | 17,078 | 132 | 37\% |
| Oregon | 2,142 | 8 | 3,100,000 | \$ | 1,447 | 56 | 58\% |
| Pennsylvania | 25,001 | \$ | 78,300,000 | s | 3,132 | 197 | 62\% |
| Rhode Island | 1,235 | \$ | 11,700,000 | \$ | 9,474 | 117 | 28\% |
| South Carolina | 10,161 | \$ | 57,100,000 | s | 5,620 | 219 | 72\% |
| South Dakota | 2,191 | 5 | 6,600,000 | \$ | 3,012 | 268 | 31\% |
| Tennessee | 7,727 | \$ | 11,400,000 | 5 | 1,475 | 122 | 40\% |
| Texas | 27,567 | \$ | 75,900,000 | \$ | 2,753 | 109 | 21\% |
| Utah | 1,564 | \$ | 10,100,000 | s | 6,458 | 56 | 36\% |
| Vermont | 1,602 | s | 13,900,000 | \$ | 8,677 | 256 | 50\% |
| Virginia | 3,573 | \$ | 2,900,000 | s | 812 | 45 | 12\% |
| Washington | 7,076 | \$ | 58,300,000 | \$ | 8,239 | 105 | 67\% |
| West Virginia | 2,650 |  | 30,200,000 | \$ | 11,396 | 143 | 61\% |
| Wisconsin | 16,695 | \$ | 41,100,000 | \$ | 2,462 | 293 | 38\% |
| Wyoming | 1,038 | \$ | 8,100,000 | s | 7,803 | 184 | 42\% |
| United States | 487,028 | \$ | 3,780,000,000 | \$ | 7,761 | 157 | 59\% |
| United States - Est. |  |  |  |  |  | ulated |  |
| Source |  |  | Colcman In | issitute |  |  |  |
| Table/Page |  |  | amily Support - from | Sta | Profiles |  | Calculated |
| Year of Data |  |  | 2009 |  |  |  |  |



| State | Reaching Those in Need |  |  |  |  |  |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  | Waiting List for Residential Services | \% Growth in Residential Services Required to Meet Waiting List | ting Lists <br> Waiting List ID/DD HCBS Kaiser | \% Growth in HCBS Services Required to Meet Waiting List | Waiting List Average |  | lence <br> \% Adults with Cognitive Disability | Individuals with ID/DD served per 100k of population | Ratio of Prevalence to Individuals Served |
| Alabama | 2,372 | 64\% | NA | NA | 64\% | 6.0\% | 6.0\% | 154 | 3\% |
| Alaska | 662 | 69\% | 982 | 76\% | 72\% | 3.8\% | 3.8\% | 167 | 4\% |
| Arizona | 29 | 1\% | NA | NA | 1\% | 3.9\% | 3.9\% | 476 | 12\% |
| Arkansas | 1,522 | 40\% | 991 | 26\% | 33\% | 6.1\% | 6.1\% | 201 | 3\% |
| California | 0 | 0\% | - | $0 \%$ | 0\% | 3.3\% | 3.3\% | 507 | 15\% |
| Colorado | 1,562 | 26\% | 3,232 | 40\% | 33\% | 3.3\% | 3.3\% | 235 | 7\% |
| Connecticut | 531 | 8\% | 1,846 | 22\% | 15\% | 3.5\% | 3.5\% | 414 | 12\% |
| Delaware | 174 | 17\% | - | 0\% | 9\% | 4.2\% | 4.2\% | 352 | 8\% |
| Dist. of Columbia | 0 | 0\% | - | 0\% | 0\% | 4.2\% | 4.2\% | 304 | 7\% |
| Florida | 3,835 | 25\% | 18,960 | 63\% | 44\% | 4.0\% | 4.0\% | 275 | 7\% |
| Georgia | 1,640 | 21\% | 10,364 | 90\% | 56\% | 3.9\% | 3.9\% | 134 | 3\% |
| Hawaii | 0 | 0\% | - | 0\% | 0\% | 3.0\% | 3.0\% | 173 | 6\% |
| Idaho | 0 | 0\% | - | 0\% | 0\% | 4.6\% | 4.6\% | 1,092 | 24\% |
| Illinois | 15,042 | 70\% | 33,114 | 205\% | 138\% | 3.2\% | 3.2\% | 261 | 8\% |
| Indiana | 17,142 | 174\% | 29,303 | 264\% | 219\% | 4.5\% | 4.5\% | 242 | 5\% |
| Iowa | 94 | 0\% | 108 | 1\% | 1\% | 3.8\% | 3.8\% | 487 | 13\% |
| Kansas | 1,287 | 22\% | 2,414 | 31\% | 27\% | 4.1\% | 4.1\% | 292 | 7\% |
| Kentucky | 295 | 8\% | - | 0\% | 4\% | 6.5\% | 6.5\% | 123 | 2\% |
| Louisiana | DNF | DNF | 4,572 | 58\% | 58\% | 5.4\% | 5.4\% | 465 | 9\% |
| Maine | 337 | 13\% | 98 | 2\% | 7\% | 5.9\% | 5.9\% | 231 | 4\% |
| Maryland | 2,770 | $37 \%$ | 3,210 | 29\% | 33\% | 3.2\% | 3.2\% | 169 | 5\% |
| Massachusetts | 0 | 0\% | - | $0 \%$ | $0 \%$ | 4.1\% | 4.1\% | 489 | 12\% |
| Michigan | DNF | DNF | - | $0 \%$ | 0\% | 5.0\% | 5.0\% | 380 | 8\% |
| Minnesota | 3,243 | 23\% | NA | NA | 23\% | 3.7\% | 3.7\% | 543 | 15\% |
| Mississippi | DNF | DNF | - | 0\% | DNF | 6.2\% | 6.2\% | 164 | 3\% |
| Missouri | 206 | 3\% | NA | NA | 3\% | 5.2\% | 5.2\% | 215 | 4\% |
| Montana | 691 | 36\% | 810 | 35\% | 36\% | 4.3\% | 4.3\% | 437 | 10\% |
| Nebraska | 1,639 | 46\% | 2,390 | 62\% | 54\% | 3.4\% | 3.4\% | 245 | 7\% |
| Nevada | 109 | 7\% | 126 | 8\% | 7\% | 3.0\% | 3.0\% | 190 | 6\% |
| New Hampshire | 19 | 1\% | NA | NA | 1\% | 3.8\% | 3.8\% | 191 | 5\% |
| New Jersey | DNF | DNF | , | 0\% | DNF | 3.0\% | 3.0\% | 498 | 17\% |
| New Mexico | 4,998 | 237\% | 1,141 | 29\% | 133\% | 4.9\% | 4.9\% | 178 | 4\% |
| New York | 3,864 | 8\% | - | 0\% | 4\% | 3.3\% | 3.3\% | 638 | 19\% |
| North Carolina | 397 | DNF | NA | NA | DNF | 4.4\% | 4.4\% | 231 | 5\% |
| North Dakota | 0 | 0\% | - | 0\% | 0\% | 3.2\% | 3.2\% | 457 | 14\% |
| Ohio | DNF | DNF | 43,793 | 172\% | 172\% | 4.9\% | 4.9\% | 365 | 7\% |
| Oklahoma | 5,737 | 132\% | 5,754 | 111\% | 121\% | 5.8\% | 5.8\% | 183 | 3\% |
| Oregon | 3,219 | 51\% | - | 0\% | 26\% | 5.0\% | 5.0\% | 387 | 8\% |
| Pennsylvania | 1,613 | 7\% | 20,460 | 65\% | $36 \%$ | 4.5\% | 4.5\% | 413 | 9\% |
| Rhode Island | 0 | 0\% | - | 0\% | 0\% | 5.1\% | 5.1\% | 294 | 6\% |
| South Carolina | 335 | 7\% | 1,296 | 19\% | 13\% | 4.8\% | 4.8\% | 368 | 8\% |
| South Dakota | 2 | 0\% | 23 | 1\% | 0\% | 3.8\% | 3.8\% | 412 | 11\% |
| Tennessee | 1,158 | 21\% | 2,316 | 31\% | 26\% | 5.6\% | 5.6\% | 142 | 3\% |
| Texas | DNF | DNF | 70,113 | 334\% | 334\% | 3.8\% | 3.8\% | 97 | 3\% |
| Utah | 1,822 | 55\% | 1,847 | 43\% | 49\% | 3.4\% | 3.4\% | 185 | 5\% |
| Vermont | 0 | 0\% | NA | NA | 0\% | 5.4\% | 5.4\% | 517 | 10\% |
| Virginia | 4,395 | 58\% | 6,798 | 78\% | 68\% | 3.6\% | 3.6\% | 108 | $3 \%$ |
| Washington | DNF | DNF | 829 | 7\% | 7\% | 4.4\% | 4.4\% | 321 | 7\% |
| West Virginia | 409 | 22\% | 409 | 9\% | 16\% | 7.1\% | 7.1\% | 253 | 4\% |
| Wisconsin | 4,783 | 38\% | 675 | 4\% | 21\% | 3.6\% | 3.6\% | 358 | 10\% |
| Wyoming | 120 | 9\% | 246 | 12\% | 11\% | 3.8\% | 3.8\% | 392 | 10\% |
| United States | 88,053 | 25\% | 268,220 | 46\% | $36 \%$ | 4.1\% | 4.1\% | 322 | 8\% |
| United States - Est. | 115,059 | 25\% |  |  |  |  |  |  |  |
| Source | Rescarch and Trainin | ig Center on Community Living | Kaiser Family Foundation |  |  | Us Census | Burca, ACS |  |  |
| Table/Page |  | T. 2.5 | Waiting List |  |  |  | 1810 | Calcu | lated |
| Year of Data |  | 2010 | 2010 |  |  |  | 10 |  |  |




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[^0]:    ${ }_{1}$ "Older Population by Age Group: 1900 to 2050 with Chart of the $65+$ Population." U.S. Agency on Aging. August 14, 2008. Available at: http://www.aoa.gov/aoaroot/aging_statistics/future_growth/docs/By_Age_65_and_over.xls (March 16, 2012)
    ${ }^{2}$ Braddock, David. "Aging I/DD Caregivers as Percent of Total Persons with I/DD." 2011. Caregiving families aged 60 years or more, expressed as a percentage of total persons with I/DD. Estimates for total persons with I/DD and total number of aging I/DD caregiving families with children or adult family members with I/DD were from the Survey of Income and Program Participation (SIPP). Available at: http://www.stateofthestates.org/index.php/interactive-charts\#chartControls (March 12, 2012)
    ${ }_{3}$ 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.
    4 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
    5 "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)
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    7 Brino, Anthony. "Lawmakers still skeptical of Quinn facilities-closure plan." Illinois Statehouse News. February 7, 2012. Available at: http://illinois.statehousenewsonline.com/7603/lawmakers-still-skeptical-of-quinn-facilities-closure-plan/ (February 24, 2012)

