INTELLECTUAL AND DEVELOPMENTAL DISABILITIES SERVICES IN THE U.S.: 2013

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Professor of Psychiatry and Executive Director,
Coleman Institute for Cognitive Disabilities

Long Term Care Commission
Washington, DC
July 17, 2013
I. CURRENT U.S. TRENDS IN I/DD SERVICES, SUPPORTS AND SPENDING

II. FACTORS INFLUENCING SERVICE DEMAND

2020 projected based on data from 1990-2011

Total IDD Spending Declines in 2011

Fiscal Year

Billions of 2011 Dollars

States Without State-Operated I/DD Institutions

1. DISTRICT OF COLUMBIA (1991)
2. NEW HAMPSHIRE (1991)
3. VERMONT (1993)
4. RHODE ISLAND (1994)
5. ALASKA (1997)
6. NEW MEXICO (1997)
7. WEST VIRGINIA (1998)
8. HAWAII (1999)
9. MAINE (1999)
10. INDIANA (2007)
11. MICHIGAN (2009)
12. OREGON (2009)
13. MINNESOTA (2011)
14. ALABAMA (2012)

Source: Braddock, D., Coleman Institute and Department of Psychiatry, University of Colorado, 2013.
Cumulative Number of Closures of State-Operated 16+ Institutions in the U.S.: 1960-2020

Source: Braddock, D., Coleman Institute and Department of Psychiatry, University of Colorado, 2013.
<table>
<thead>
<tr>
<th>State</th>
<th>Institution</th>
<th>Year Built/Became MR</th>
<th>Original Use</th>
<th># Residents*</th>
<th>Year of Closure</th>
<th>Alternate Use</th>
</tr>
</thead>
<tbody>
<tr>
<td>ALABAMA</td>
<td>Partlow</td>
<td>1993</td>
<td>ID Facility</td>
<td>199</td>
<td>2011</td>
<td>Undetermined</td>
</tr>
<tr>
<td>ARKANSAS</td>
<td>Alexander Human Development Ctr.</td>
<td>1923/1968</td>
<td>TB Sanatarium</td>
<td>109</td>
<td>2011</td>
<td>Undetermined</td>
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<tr>
<td>CALIFORNIA</td>
<td>Agnews</td>
<td>1855/1966</td>
<td>MH Facility</td>
<td>411</td>
<td>2009</td>
<td>Undetermined</td>
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<tr>
<td>FLORIDA</td>
<td>Gulf Coast Center</td>
<td>1960</td>
<td>ID Facility</td>
<td>312</td>
<td>2010</td>
<td>Florida Gulf Coast University</td>
</tr>
<tr>
<td>GEORGIA</td>
<td>NW Georgia Regional Center</td>
<td>1943/1974</td>
<td>Battey Veteran’s Hospital</td>
<td>110</td>
<td>2011</td>
<td>Undetermined</td>
</tr>
<tr>
<td>ILLINOIS</td>
<td>Howe</td>
<td>1973</td>
<td>ID Facility</td>
<td>251</td>
<td>2010</td>
<td>Undetermined</td>
</tr>
<tr>
<td>ILLINOIS</td>
<td>Jacksonville</td>
<td>1851/1970</td>
<td>MH Facility</td>
<td>200</td>
<td>2012</td>
<td>Undetermined</td>
</tr>
<tr>
<td>ILLINOIS</td>
<td>Murray</td>
<td></td>
<td>MH Facility</td>
<td>275</td>
<td>2013</td>
<td>Undetermined</td>
</tr>
<tr>
<td>KANSAS</td>
<td>Kansas Neurological Inst.</td>
<td>1942/1960</td>
<td>Winter Veteran’s Hospital</td>
<td>157</td>
<td>2012</td>
<td>Undetermined</td>
</tr>
<tr>
<td>LOUISIANA</td>
<td>Peltier Lawless</td>
<td>1958/1982</td>
<td>Community Hospital</td>
<td>10</td>
<td>2010</td>
<td>Undetermined</td>
</tr>
<tr>
<td>MARYLAND</td>
<td>Rosewood</td>
<td>1888</td>
<td>ID Facility</td>
<td>153</td>
<td>2009</td>
<td>University</td>
</tr>
<tr>
<td>MICHIGAN</td>
<td>Mt. Pleasant</td>
<td>1890</td>
<td></td>
<td>88</td>
<td>2009</td>
<td>Undetermined</td>
</tr>
<tr>
<td>MISSOURI</td>
<td>Nevada Hab. Ctr.</td>
<td>1885/2000</td>
<td>Mental Hospital</td>
<td>119</td>
<td>2013</td>
<td>Undetermined</td>
</tr>
<tr>
<td>MISSOURI</td>
<td>St. Louis DDTC-Northwest Hab. Ctr.</td>
<td>1986</td>
<td>ID Facility</td>
<td>53</td>
<td>2013</td>
<td>Undetermined</td>
</tr>
<tr>
<td>NEW JERSEY</td>
<td>Vineland</td>
<td>1888</td>
<td>ID Facility</td>
<td>395</td>
<td>2013</td>
<td>Undetermined, possible sale</td>
</tr>
<tr>
<td>OREGON</td>
<td>Eastern Oregon</td>
<td>1929/1963</td>
<td>TB Hospital</td>
<td>50</td>
<td>2009</td>
<td>Corrections/Community I/DD Pgm.</td>
</tr>
<tr>
<td>TENNESSEE</td>
<td>Arlington</td>
<td>1969</td>
<td>Psychiatric Hospital</td>
<td>128</td>
<td>2010</td>
<td>Undetermined</td>
</tr>
</tbody>
</table>

*When closure announced

**Source:** Braddock, D., Coleman Institute and Department of Psychiatry, University of Colorado, 2013.
Projected Trajectory of the I/DD Institutional Census in the U.S.

UNITED STATES

Source: Braddock, D., Coleman Institute and Department of Psychiatry, University of Colorado, 2013.
Out-of-Home Residential Placements for People with I/DD: 2011

Total: 613,184 Persons

Source: Braddock, D., Coleman Institute and Department of Psychiatry, University of Colorado, 2013.
Annual Cost of Care by Residential Setting: U.S., 2011

Source: Braddock, D., Coleman Institute and Department of Psychiatry, University of Colorado, 2013.
Growth in Community Spending

IMPORTANCE OF THE HOME AND COMMUNITY BASED SERVICES (HCBS) WAIVER
Total I/DD Services and Support Spending in the U.S.: FY 2011--$56.65 Billion

Medicaid Funds Constituted 77% of Total I/DD Services and Support Spending

Total I/DD Spending: $56.65 Billion
Total Federal-State Medicaid: $43.62 (77%)

Source: Braddock, D., Coleman Institute and Department of Psychiatry, University of Colorado, 2013.
Federal HCBS Waiver Spending Surpassed ICF/ID Spending in 2001

UNITED STATES

Source: Braddock, D., Coleman Institute and Department of Psychiatry, University of Colorado, 2013.
HCBS Waiver Participant Growth: 1982-2011

UNITED STATES

<table>
<thead>
<tr>
<th>Fiscal Year</th>
<th>Number of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>1982</td>
<td>1,379</td>
</tr>
<tr>
<td>1983</td>
<td>18,741</td>
</tr>
<tr>
<td>1984</td>
<td>44,713</td>
</tr>
<tr>
<td>1985</td>
<td>153,591</td>
</tr>
<tr>
<td>1986</td>
<td>308,223</td>
</tr>
<tr>
<td>1987</td>
<td>466,040</td>
</tr>
<tr>
<td>1988</td>
<td>573,042</td>
</tr>
<tr>
<td>2010</td>
<td>627,270</td>
</tr>
</tbody>
</table>

Source: Braddock, D., Coleman Institute and Department of Psychiatry, University of Colorado, 2013.
Current Trend: Support Services Waivers

Characterized By:

- A low dollar cap on the total amount of HCBS Waiver services authorized for each beneficiary
- Flexibility in the selection of services within the dollar cap
- Expectation that unpaid family caregivers will provide significant support to Waiver participants

Source: Braddock, D., Coleman Institute and Department of Psychiatry, University of Colorado, 2013.
Innovations in State HCBS Waivers

• Vermont’s Section 1115 Research and Demonstration Waiver builds upon the State’s Comprehensive Waiver and is a model for managing supports for participants
• Connecticut’s HCBS Waiver is flexible in terms of individual budgeting and self-determination
• Washington State’s four Waivers are tailored to individual needs
• Indiana is one of 16 states with Supports Waivers, emphasizing employment, support brokers, financial management services and person-directed goods and services
• Participant States’ information at: http://www.hcbs.org/Support Waivers
Community Supports

- Supported Living
- Family Support
- Supported Employment
Principles of Supported Living/Personal Assistance

1. **Choice**
   - Where to live, with whom and which lifestyle

2. **Ownership by other than the service provider**
   - Individual owns or rents;
   - Family owns or holds lease;
   - Housing cooperative owns

3. **Individual Support**
   - Focus on individual’s changing needs over time;
   - Individualized support plan or support contract

*Source:* Braddock, D., Coleman Institute and Department of Psychiatry, University of Colorado, 2013.
Family Support Defined

- **Family Support Includes:**
  - Respite services
  - Financial support
  - In-home support, education, and training
  - Assistive and medical technology
  - Health and related professional services
  - Family training/counseling
  - Transportation
  - Case management/service coordination
  - Recreation/leisure
  - Other family support

- **Cash Subsidy Family Support Includes:**
  Payments or vouchers directly to families; families determine what is purchased

*Source:* Braddock, D., Coleman Institute and Department of Psychiatry, University of Colorado, 2013.
I/DD Caregiving Families Far Exceed Families Supported by State I/DD Agencies: 1996-2011

Source: Braddock, D., Coleman Institute and Department of Psychiatry, University of Colorado, 2013.
U.S. Supported Employment Workers Plateaus, then Declines 2009-11

Source: Braddock, D., Coleman Institute and Department of Psychiatry, University of Colorado, 2013.

2011 Spending: $838 Million
FISCAL EFFORT is a ratio that can be utilized to rank states according to the proportion of their total statewide personal income devoted to the financing of I/DD services.

FISCAL EFFORT is defined as a state’s spending for I/DD services per $1,000 of total statewide personal income.

There is a 600% variance in the 50 states in I/DD Fiscal Effort.

Source: Braddock, D., Coleman Institute and Department of Psychiatry, University of Colorado, 2013.
## I/DD Community Services Fiscal Effort: FY 2011

<table>
<thead>
<tr>
<th></th>
<th>State</th>
<th>I/DD Spending Per $1,000 of State Aggregate Personal Income</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>New York</td>
<td>$9.51</td>
</tr>
<tr>
<td>2</td>
<td>Maine</td>
<td>$7.63</td>
</tr>
<tr>
<td>3</td>
<td>North Dakota</td>
<td>$6.87</td>
</tr>
<tr>
<td>4</td>
<td>District of Columbia</td>
<td>$6.67</td>
</tr>
<tr>
<td>5</td>
<td>Minnesota</td>
<td>$6.60</td>
</tr>
<tr>
<td>6</td>
<td>Connecticut</td>
<td>$6.42</td>
</tr>
<tr>
<td>7</td>
<td>Vermont</td>
<td>$6.39</td>
</tr>
<tr>
<td>8</td>
<td>Ohio</td>
<td>$6.09</td>
</tr>
<tr>
<td>9</td>
<td>West Virginia</td>
<td>$5.77</td>
</tr>
<tr>
<td>10</td>
<td>Rhode Island</td>
<td>$5.72</td>
</tr>
<tr>
<td>11</td>
<td>Oregon</td>
<td>$5.49</td>
</tr>
<tr>
<td>12</td>
<td>Wisconsin</td>
<td>$5.14</td>
</tr>
<tr>
<td>13</td>
<td>Louisiana</td>
<td>$5.13</td>
</tr>
<tr>
<td>14</td>
<td>Indiana</td>
<td>$5.13</td>
</tr>
<tr>
<td>15</td>
<td>New Mexico</td>
<td>$5.04</td>
</tr>
<tr>
<td>16</td>
<td>Massachusetts</td>
<td>$4.75</td>
</tr>
<tr>
<td>17</td>
<td>Alaska</td>
<td>$4.68</td>
</tr>
<tr>
<td>18</td>
<td>Iowa</td>
<td>$4.62</td>
</tr>
</tbody>
</table>

I/DD Spending Per $1,000 of state aggregate personal income

Source: Braddock, D., Coleman Institute and Department of Psychiatry, University of Colorado, 2013.
II. Factors Influencing Demand for I/DD Services in the U.S.

1. Aging caregivers
2. Increased longevity of people with I/DD
3. Poverty
4. Fiscal conditions in the States

Source: Braddock, D., Coleman Institute and Department of Psychiatry, University of Colorado, 2013.
Most People with I/DD Live with Family Caregivers

UNITED STATES
ESTIMATED DISTRIBUTION OF INDIVIDUALS WITH I/DD BY LIVING ARRANGEMENT, 2011

- With Family Caregiver: 3,513,224 (72%)
- Living Alone or with Roommate: 776,427 (16%)
- Supervised Residential Setting: 613,184 (13%)

Total: 4.90 Million Persons

An Estimated 853 Thousand Persons with I/DD Live at Home with Aging Caregivers

UNITED STATES
Family Caregivers by Age: 2011

Caregivers Aged <41
1,427,862

Caregivers Aged 41-59
1,232,439

Caregivers Aged 60+
852,923

Total: 3.51 Million Persons

Braddock et al., 2013, based on Fujiura 2008, 2012
Longevity is Increasing for People with I/DD

• 1970s:  59.1 years
• 1993:   66.2 years
• U.S. General Population: 78 years (2011)
• In the future “…those without severe impairment can be expected to have a lifespan equal to that of the general population.”

Direct Support Staff Median Wages are Below the Poverty Level

Sources: "All workers" and nursing aides for 2011 (Bureau of Labor Statistics, 2012); "state-operated I/DD" for 2010 (Larson, Ryan, Salmi, Smith & Wuorio, 2012); "community I/DD" 2009 (and inflation-adjusted to estimate 2011 value (ANCOR, 2010), and "poverty level" for 2012 (Assistant Secretary for Planning and Evaluation, 2012).
## About Half the States Reduced I/DD Spending in FY 2011

<table>
<thead>
<tr>
<th>State</th>
<th>% Change</th>
<th>State</th>
<th>% Change</th>
<th>State</th>
<th>% Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kentucky</td>
<td>9%</td>
<td>Ohio</td>
<td>1%</td>
<td>District of Columbia</td>
<td>-2%</td>
</tr>
<tr>
<td>Texas</td>
<td>6%</td>
<td>Vermont</td>
<td>1%</td>
<td>Washington</td>
<td>-2%</td>
</tr>
<tr>
<td>Wisconsin</td>
<td>6%</td>
<td>Montana</td>
<td>0.2%</td>
<td>Louisiana</td>
<td>-2%</td>
</tr>
<tr>
<td>New Jersey</td>
<td>5%</td>
<td>Arizona</td>
<td>-0.02%</td>
<td>Iowa</td>
<td>-2%</td>
</tr>
<tr>
<td>North Dakota</td>
<td>5%</td>
<td>Georgia</td>
<td>-0.1%</td>
<td>Maryland</td>
<td>-2%</td>
</tr>
<tr>
<td>Alaska</td>
<td>5%</td>
<td>Michigan</td>
<td>-0.2%</td>
<td>Colorado</td>
<td>-3%</td>
</tr>
<tr>
<td>Oregon</td>
<td>4%</td>
<td>Connecticut</td>
<td>-0.5%</td>
<td>Massachusetts</td>
<td>-4%</td>
</tr>
<tr>
<td>Arkansas</td>
<td>4%</td>
<td>California</td>
<td>-0.6%</td>
<td>Pennsylvania</td>
<td>-4%</td>
</tr>
<tr>
<td>New Hampshire</td>
<td>3%</td>
<td>Minnesota</td>
<td>-0.7%</td>
<td>Florida</td>
<td>-4%</td>
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<tr>
<td>South Carolina</td>
<td>3%</td>
<td>North Carolina</td>
<td>-0.8%</td>
<td>Tennessee</td>
<td>-5%</td>
</tr>
<tr>
<td>Alabama</td>
<td>3%</td>
<td>Nevada</td>
<td>-1.0%</td>
<td>Maine</td>
<td>-5%</td>
</tr>
<tr>
<td>Wyoming</td>
<td>3%</td>
<td>Delaware</td>
<td>-1%</td>
<td>Indiana</td>
<td>-6%</td>
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<tr>
<td>Virginia</td>
<td>3%</td>
<td>South Dakota</td>
<td>-1%</td>
<td>Utah</td>
<td>-6%</td>
</tr>
<tr>
<td>Kansas</td>
<td>2%</td>
<td>Hawaii</td>
<td>-1%</td>
<td>Mississippi</td>
<td>-7%</td>
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<td>Missouri</td>
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<td>Idaho</td>
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<td>New Mexico</td>
<td>-7%</td>
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<tr>
<td>Nebraska</td>
<td>1%</td>
<td>West Virginia</td>
<td>-1%</td>
<td>Oklahoma</td>
<td>-7%</td>
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<tr>
<td>New York</td>
<td>1%</td>
<td>Illinois</td>
<td>-2%</td>
<td>Rhode Island</td>
<td>-9%</td>
</tr>
</tbody>
</table>

**Source:** Braddock, D., Coleman Institute and Department of Psychiatry, University of Colorado, 2013.
III. Personalize Charts for your State or Region
http://www.StateoftheStates.org

Intellectual and Developmental Disabilities

Welcome to the website for the State of the States in Developmental Disabilities Project, administered by the University of Colorado and funded in part by the Administration on Intellectual and Developmental Disabilities.

On this website you can view longitudinal data for fiscal years 1977-2009 (soon updated to 2011) by going to State Profiles. You can also "Create a Chart" based on state-by-state comparative data for fiscal year 2011 (see Menu to the right).

Data on All Disabilities. On the menu to the right, you can also access data for all disabilities, including a create-a-chart option for data on intellectual/developmental disabilities, mental health and physical and sensory disabilities.

The Publications link provides access to selected books and book chapters, journal articles, technical and brief reports, and testimony from the project. About Us presents a brief history of the study. Links offers access to related websites at the national, state and community level, including our state of Colorado. View Dr. David Braddock's September 17, 2011 presentation to the Arc United States 60th Annual Convention in Denver, Colorado PDF.

We have recently updated our website with "create a chart" comparative data through 2011. We will soon finish updating the 50 state profiles to encompass 1977-2011. Please contact us at stateofthestates@cu.edu with any questions or comments.
List of Data Charting Options for the States

Data Options for Charts:

1. Total Fiscal Effort for I/DD Services
2. Community Fiscal Effort
3. Institutional (16+) Fiscal Effort
4. Community Spending as a Percent of Total I/DD Spending
5. Percent of Total Out-of-Home Placements in Settings for 6 or Fewer Persons
6. Percent of Total I/DD Caregiving Families Supported by State I/DD Agencies
7. Aging I/DD Caregivers as Percent of Total Persons with I/DD
8. Individual and Family Support Spending per Capita
9. Federal-State HCBS Waiver Spending per Capita
10. Average Annual Cost of Care in State-Operated 16+ Person I/DD Institutions
11. Average Daily Cost of Care in State-Operated 16+ Person I/DD Institutions
12. Nursing Facility Residents with I/DD, per 100,000 of the State Population
13. Six-or-fewer Person Community Spending as a Percent of Total I/DD Spending
14. Unmatched State Funds Potentially Available to Match Federal Medicaid Funding
15. Medicaid Percent of Total I/DD Spending
Financial support from the U.S. Administration on Intellectual and Developmental Disabilities and the Coleman Institute for Cognitive Disabilities at the University of Colorado is acknowledged. The participation of State I/DD Agencies in the collection of data for this study is greatly appreciated.
Save the Date

The Thirteenth Annual Coleman Institute Conference on Cognitive Disability and Technology

WEDNESDAY, OCTOBER 2, 2013

Omni Interlocken Hotel, Broomfield, Colorado
CONTACT INFORMATION

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http://ColemanInstitute.org