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

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FEBRUARY 27, 2013
AAIDD WEBINAR
I. Current U.S. Trends in I/DD Services, Supports and Spending

II. Factors Influencing Service Demand

III. HCBS Waiver Analysis

IV. State of the States in Developmental Disabilities Interactive Charts
U.S. Demand for New I/DD Residential Services is Growing: 1980-2020

2020 projected based on data from 1990-2011

I. Total IDD Spending Declines in 2011

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.
## Most Recent I/DD Institutional Closures: 2009-13

<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>
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<td>ALABAMA</td>
<td>Partlow</td>
<td>1993</td>
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<td>ARKANSAS</td>
<td>Alexander Human Development Ctr.</td>
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<td>TB Sanatarium</td>
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<td>CALIFORNIA</td>
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<td>GEORGIA</td>
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<td>Battey Veteran’s Hospital</td>
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<td>MICHIGAN</td>
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<td>88</td>
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<td>Nevada Hab. Ctr.</td>
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<td>NEW JERSEY</td>
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<td>OREGON</td>
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<td>Corrections/Community I/DD Pgm.</td>
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<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.

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

United States

- Public-Private 16+ Institutions (84,432)
- 7-15 Persons (56,418)
- 6/Fewer Persons (77%)
- Group, foster, host homes, apartments (200,048 Persons)
- Supported Living (272,286 Persons)

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

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

![Graph showing Federal HCBS Waiver Spending Surpassed ICF/ID Spending in 2001]

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

UNITED STATES

Fiscal Year

Number of Participants

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.
Number of I/DD Caregiving Families Far Exceeds 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.
Measuring States’ Commitments to I/DD Services

**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.
<table>
<thead>
<tr>
<th></th>
<th>I/DD Community Services Fiscal Effort: FY 2011</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>I/DD Spending Per $1,000 of state aggregate personal income</td>
</tr>
<tr>
<td>----</td>
<td>-------------------------------------------------------------</td>
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<tr>
<td>1</td>
<td>New York $9.51</td>
</tr>
<tr>
<td>2</td>
<td>Maine $7.63</td>
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<td>3</td>
<td>North Dakota $6.87</td>
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<td>Connecticut $6.42</td>
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<td>Vermont $6.39</td>
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<td>Ohio $6.09</td>
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<td>9</td>
<td>West Virginia $5.77</td>
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<td>Rhode Island $5.72</td>
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<td>Massachusetts $4.75</td>
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<td>Georgia $1.90</td>
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<td>Florida $1.77</td>
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<td>49</td>
<td>Texas $1.59</td>
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<tr>
<td>50</td>
<td>Mississippi $1.57</td>
</tr>
<tr>
<td>51</td>
<td>Nevada $1.45</td>
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</tbody>
</table>

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.
1. Most People with I/DD Live with Family Caregivers

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

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

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 (35%)
- Caregivers Aged 41-59: 1,232,439 (41%)
- Caregivers Aged 60+: 852,923 (24%)

Total: 3.51 Million Persons

Braddock et al., 2013, based on Fujiura 2008, 2012
2. 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.”

3. 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).
4. 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>
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<tbody>
<tr>
<td>Kentucky</td>
<td>9%</td>
<td>Ohio</td>
<td>1%</td>
<td>District of Columbia</td>
<td>-2%</td>
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<tr>
<td>Texas</td>
<td>6%</td>
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<td>1%</td>
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<td>Alabama</td>
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<td>Rhode Island</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>UNITED STATES</td>
<td>-0.2%</td>
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</tbody>
</table>

Source: Braddock, D., Coleman Institute and Department of Psychiatry, University of Colorado, 2013.
III. Analysis of the HCBS Waiver

Medicaid comprised 77% of total I/DD spending in 2011

Home and Community Based Services (HCBS) Waiver:

- Authorized in 1981 to keep people out of institutions and lower costs
- Supported 627,000: 2011
- Reimburses states for community-based services and supports
- States determine services and number of projected people served

Total I/DD Spending: $56.60 Billion

Status of Waivers in 2010

- 88 HCBS Waiver Applications:
  - types of services (service definitions n=1,329)
  - # of “users”
  - average units per user
  - average cost per unit

- 93 HCBS Waiver Amendments
  - reasons for filing amendments

Source: Rizzolo, et al. (Feb 2013).
What Waiver Services Do States Offer?

Source: Rizzolo, et al. (Feb 2013).
Where Did States Propose to Spend Their Money?

- Residential Habilitation: 53%
- Homemaker/Chore/PA/SL: 11%
- Day Habilitation: 19%
- Supported Employment: 3%
- Remainder: 15%

- Prevocational Services (3%)
- Family Training and Counseling (2%)
- Transportation (2%)
- Care Coordination (2%)
- Health and Professional Services (2%)
- Respite (1%)
- Assistive and Medical Technologies (1%)
  - AT and Environmental Mods (0.5%)
  - Med Equip and PERS (0.7%)
- Community Transition Supports (<1%)
- Financial Support Services (<1%)
- Adult Day Health (<1%)
- Individual Goods and Services (<1%)
- Self Advocacy Training (<1%)
- Education (<1%)
- Recreation and Leisure (<1%)

Source: Rizzolo, et al. (Feb 2013).
What is the Average Cost of Traditional Waivers vs. “Support Waivers”?

- **Traditional Waivers**
  - Range of supports including residential habilitation (e.g. group home, apartment owned or leased by provider agency, licensed foster care)

- **Support Waiver**
  - Typically covers the same supports as traditional waiver with the exception of residential habilitation
  - Relies on unpaid natural supports

**Average Annual Cost 2010**
(n = 16 states)

Source: Rizzolo, et al. (Feb 2013).
Why Do States File Amendments?

1. To revise procedures to
   – …determine who enters the Waiver first
   – …change QA procedures
   – …change rate structures

2. To rebalance the system
   – Reserve “slots” or capacity for
     • people moving out of state institutions or nursing homes
     • children transitioning out of foster care

3. To contain costs
   – …by reducing caps per person
   – …by limiting or eliminating services (e.g. dental and respite)

4. To expand service capacity
   – …by increasing # of participants
   – …by adding services

Source: Rizzolo, et al. (Feb 2013).
How can these HCBS data be used?

- Proposed taxonomy is a tool for describing the array of HCBS Waiver services
- Illustrate how states are investing their limited resources
- Demonstrate creative and flexible supports
  - hippotherapy
  - Native American healers
  - rent and food for live-in caregiver
  - electronic monitoring
  - prescriptions
  - guide dogs, hearing dogs, service dogs and simian aids under “assistive technology – adaptive devices”
- Allow comparisons across waivers
  - Used by dual diagnosis task force (behavioral supports)
  - Used by rate setting task force (to compare residential habilitation per diems)
IV. Personalize Charts for your State or Region
http://www.StateoftheStates.org

The State of the States in Developmental Disabilities
University of Colorado
BOULDER | COLORADO SPRINGS | DENVER | ANSCHUTZ MEDICAL CAMPUS

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.
4. Community spending as a percent of total I/DD spending: 2011

Spending for community services in the states is provided by the Home and Community Based Services (HCBS) Waiver in addition to other state and local government funding. Community services consists of a wide range of residential supports, supported living, supported employment, family supports, case management, service coordination, transportation, and other supports. Total I/DD spending also includes public and private residential facilities serving 16 or more persons per setting, including ICF/ID spending (but excluding nursing facility spending).

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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
Personalize a Chart for your State or Region

Compare as many states or regions as you would like. A longer chart, however, may print on two pages.

Select All States | De-Select All States
Select All Regions | De-Select All Regions

- Alabama
- Alaska
- Arizona
- Arkansas
- California
- Colorado
- Connecticut
- Delaware
- District of Columbia
- Florida
- Georgia
- Hawaii
- Idaho
- Illinois
- Indiana
- Iowa
- Kansas
- Kentucky
- Louisiana
- Maine
- Maryland
- Massachusetts
- Michigan
- Minnesota
- Mississippi
- Missouri
- Montana
- Nebraska
- Nevada
- New Hampshire
- New Jersey
- New Mexico
- New York
- North Carolina
- North Dakota
- Ohio
- Oklahoma
- Oregon
- Pennsylvania
- Rhode Island
- South Carolina
- South Dakota
- Tennessee
- Texas
- Utah
- Vermont
- Virginia
- Washington
- West Virginia
- Wisconsin
- Wyoming
- UNITED STATES

NEW ENGLAND (CT, ME, MA, NH, RI, VT)
NORTHEAST (NJ, NY)
MID-ATLANTIC (DE, DC, MD, PA, VA, WV)
SOUTHEAST (AL, FL, GA, KY, MS, NC, SC, TN)
GREAT LAKES (IL, IN, MI, MN, OH, WI)
SOUTHWEST (AR, LA, NM, OK, TX)
GREAT PLAINS (IA, KS, MO, NE)
ROCKY MOUNTAIN (CO, MT, ND, SD, UT, WY)
PACIFIC (AZ, CA, HI, NV)
NORTHWEST (AK, ID, OR, WA)
Personalize a Chart for your State or Region

Presentation Options

- Alphabetical
- Ascending
- Descending

1. Total Fiscal Effort for I/DD Services: 2011

<table>
<thead>
<tr>
<th>State/Region</th>
<th>$s per $1,000 of personal income</th>
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</thead>
<tbody>
<tr>
<td>Connecticut</td>
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<td>Maine</td>
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<td>Rhode Island</td>
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<tr>
<td>Vermont</td>
<td>$6.39</td>
</tr>
</tbody>
</table>

- Chart

- Table
Contact Information

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@SOS_in_DD
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Final copies of the 2013 SOS Monograph can be obtained in March/April through
The American Association on Intellectual and Developmental Disabilities
and
The Coleman Institute for Cognitive Disabilities
Save the Date

The Thirteenth Annual Coleman Institute Conference on Cognitive Disability and Technology

WEDNESDAY, OCTOBER 2, 2013

Omni Interlocken Hotel, Broomfield, Colorado
• We are happy to respond to questions you submit online.