



Coleman Institute for Cognitive Disabilities
UNIVERSITY OF COLORADO

Boulder | Colorado Springs | Denver | Anschutz Medical Campus

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

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Institute on Disability and Human Development,
University of Illinois at Chicago**

FEBRUARY 27, 2013

AAIDD WEBINAR

State of the States in Developmental Disabilities 2013



Coleman Institute for Cognitive Disabilities

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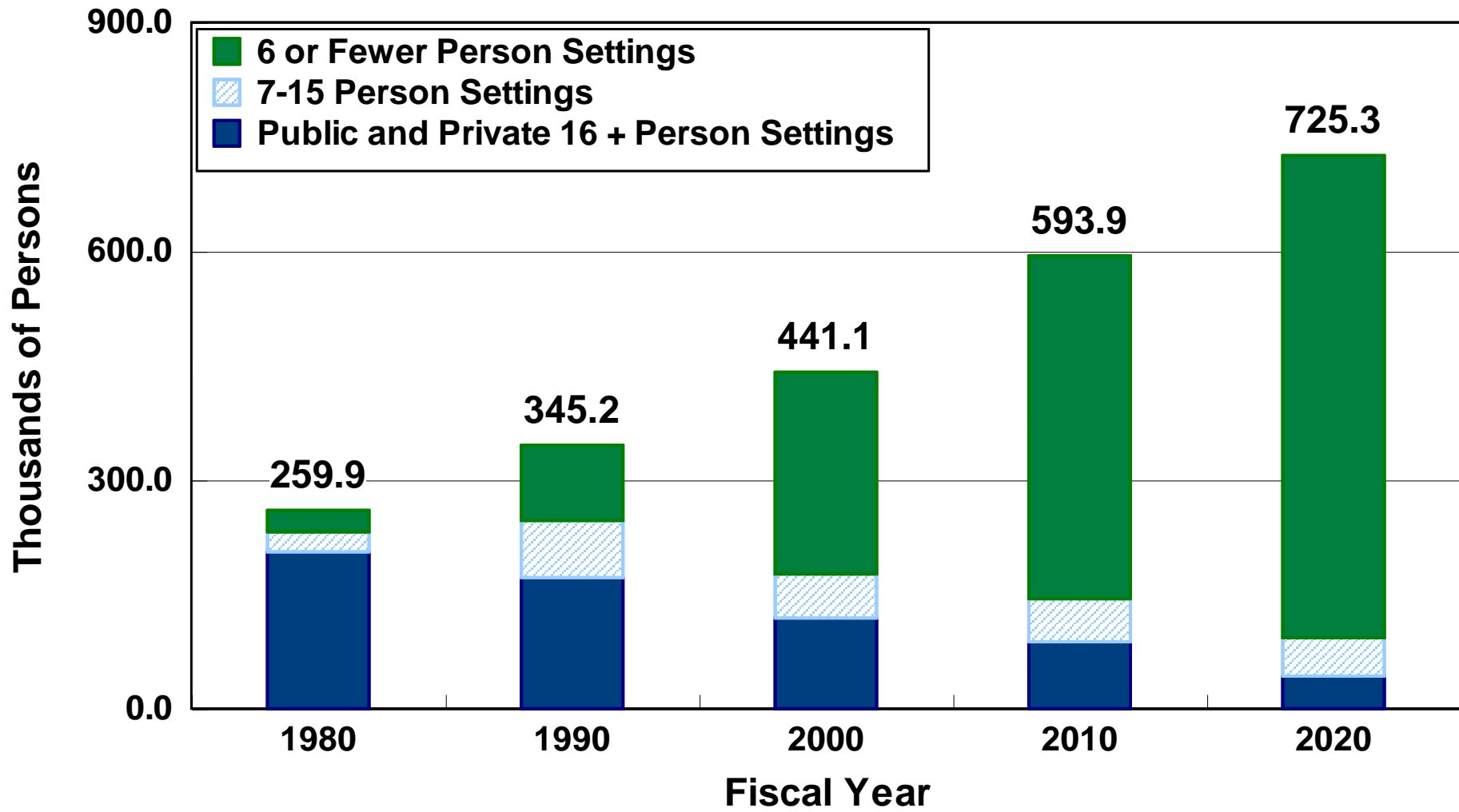
Department of Disability and
Human Development

COLLEGE OF APPLIED HEALTH SCIENCES

Presentation Outline

- 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**

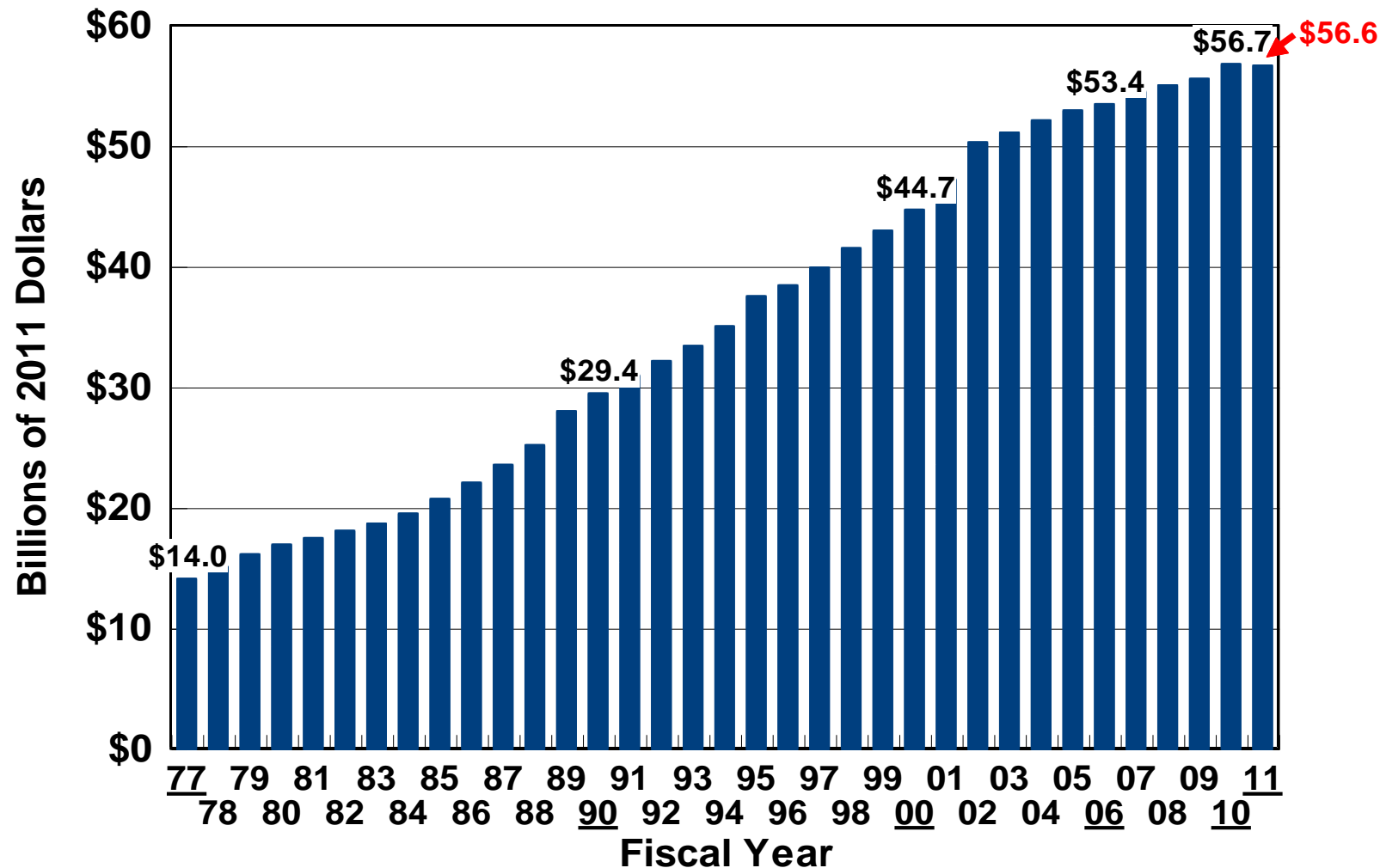
U.S. Demand for New I/DD Residential Services is Growing: 1980-2020



2020 projected based on data from 1990-2011

Source: Braddock, D., State of the States in Developmental Disabilities, 2013.

I. Total IDD Spending Declines in 2011



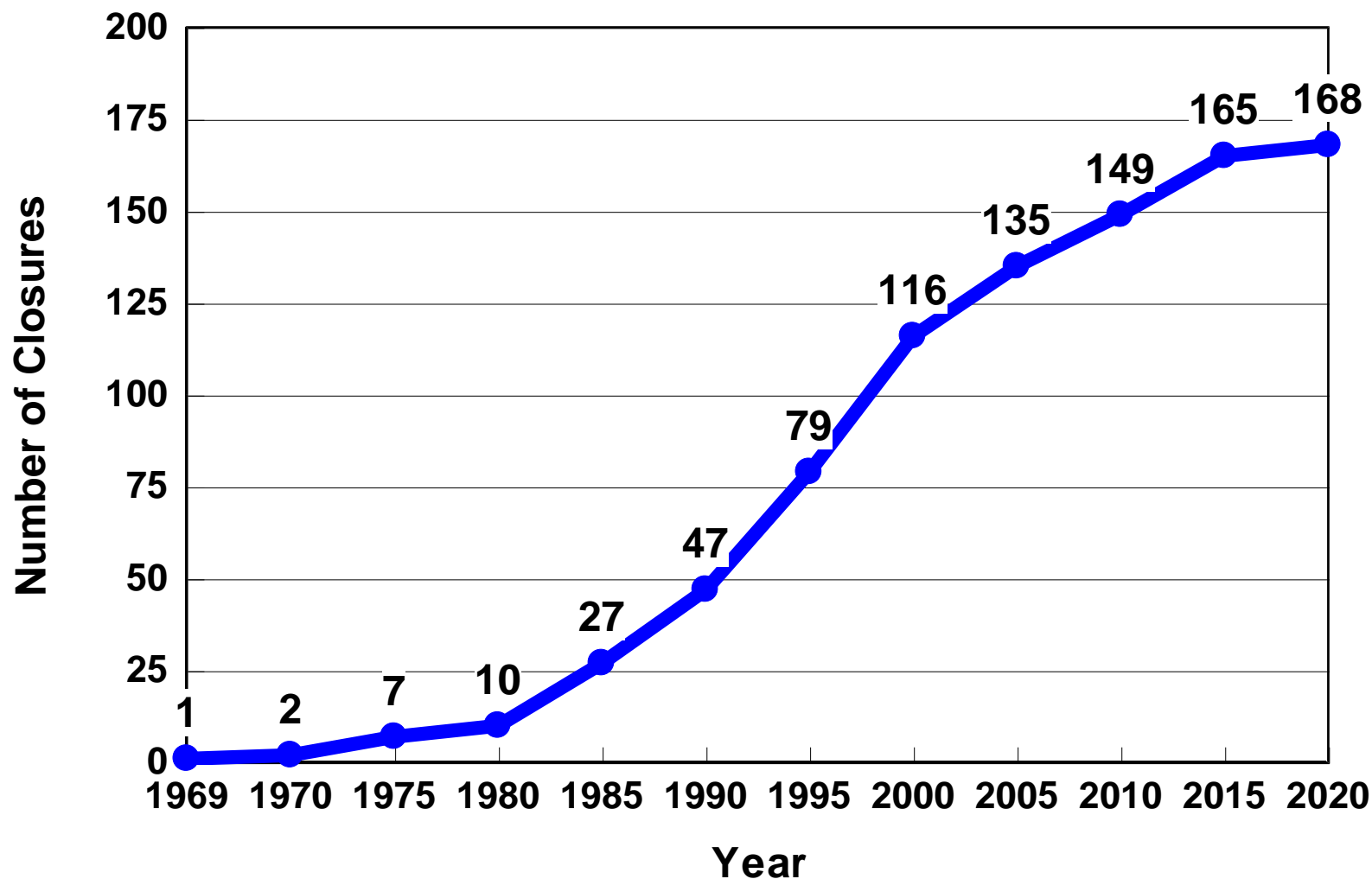
Source: Braddock, D., et al. State of the States in Developmental Disabilities, 2013.

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

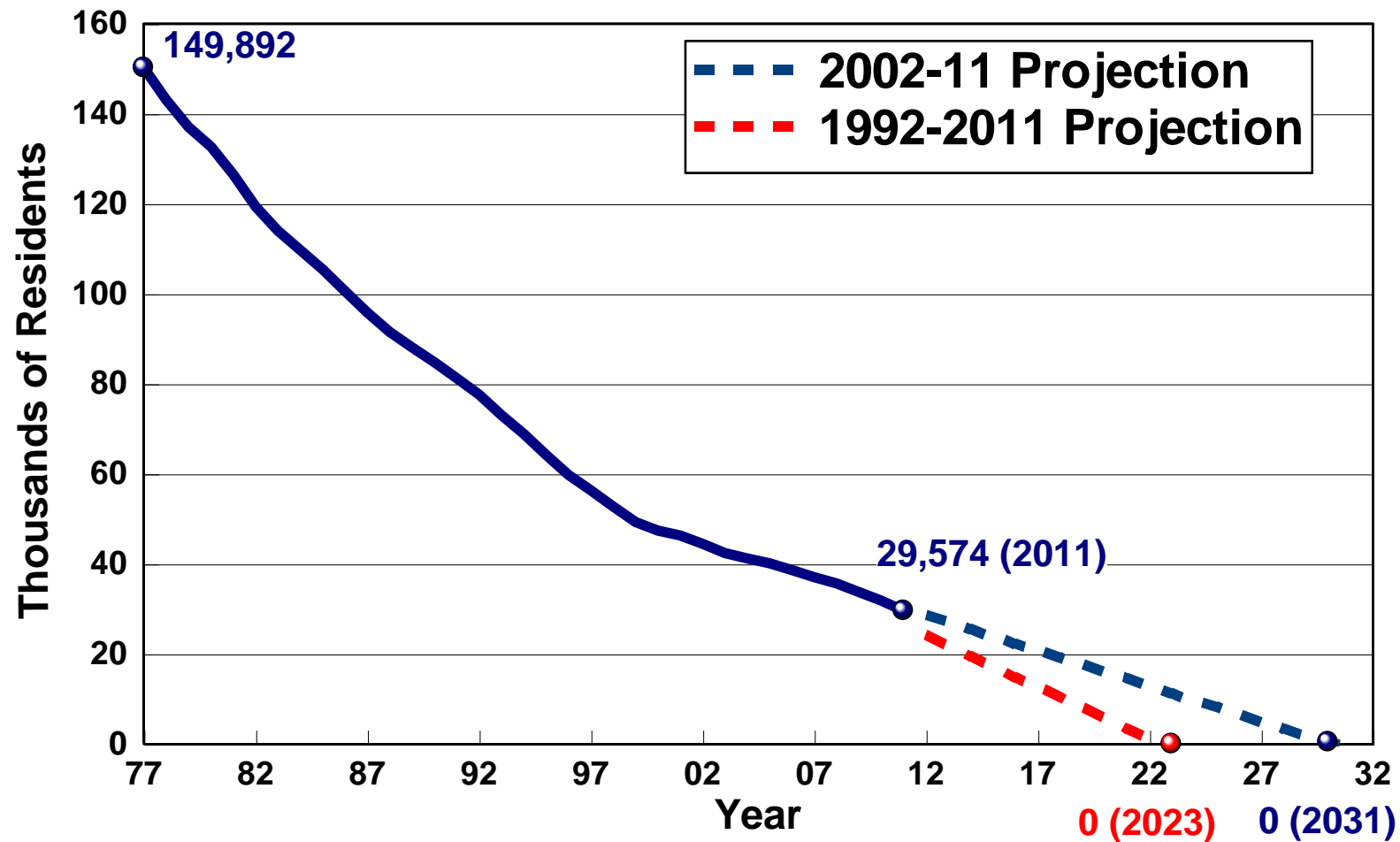
State	Institution	Year Built/ Became MR	Original Use	# Residents*	Year of Closure	Alternate Use
ALABAMA	Partlow	1993	ID Facility	199	2011	Undetermined
ARKANSAS	Alexander Human Development Ctr.	1923/1968	TB Sanatorium	109	2011	Undetermined
CALIFORNIA	Agnews	1855/1966	MH Facility	411	2009	Undetermined
FLORIDA	Gulf Coast Center	1960	ID Facility	312	2010	Florida Gulf Coast University
GEORGIA	NW Georgia Regional Center	1943/1974	Batley Veteran's Hospital	110	2011	Undetermined
ILLINOIS	Howe	1973	ID Facility	251	2010	Undetermined
ILLINOIS	Jacksonville	1851/1970	MH Facility	200	2012	Undetermined
ILLINOIS	Murray		MH Facility	275	2013	Undetermined
KANSAS	Kansas Neurological Inst.	1942/1960	Winter Veteran's Hospital	157	2012	Undetermined
LOUISIANA	Peltier Lawless	1958/1982	Community Hospital	10	2010	Undetermined
LOUISIANA	Ruston	1942/1958	WAC Training/ POW/TB Hosp.	72	2010	Dept./Child Ctr./Sheriff Office
MARYLAND	Rosewood	1888	ID Facility	153	2009	University
MICHIGAN	Mt. Pleasant	1890		88	2009	Undetermined
MISSOURI	Nevada Hab. Ctr.	1885/2000	Mental Hospital	119	2013	Undetermined
MISSOURI	St. Louis DDTC- Northwest Hab. Ctr.	1986	ID Facility	53	2013	Undetermined
NEW JERSEY	Vineland	1888	ID Facility	395	2013	Undetermined, possible sale
OREGON	Eastern Oregon	1929/1963	TB Hospital	50	2009	Corrections/Com- munity I/DD Pgm.
TENNESSEE	Arlington	1969	Psychiatric Hospital	128	2010	Undetermined
WASHINGTON	Francis Haddon Morgan	1973/1988	Military Hospital	52	2012	Office/School/Hsng.

*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.

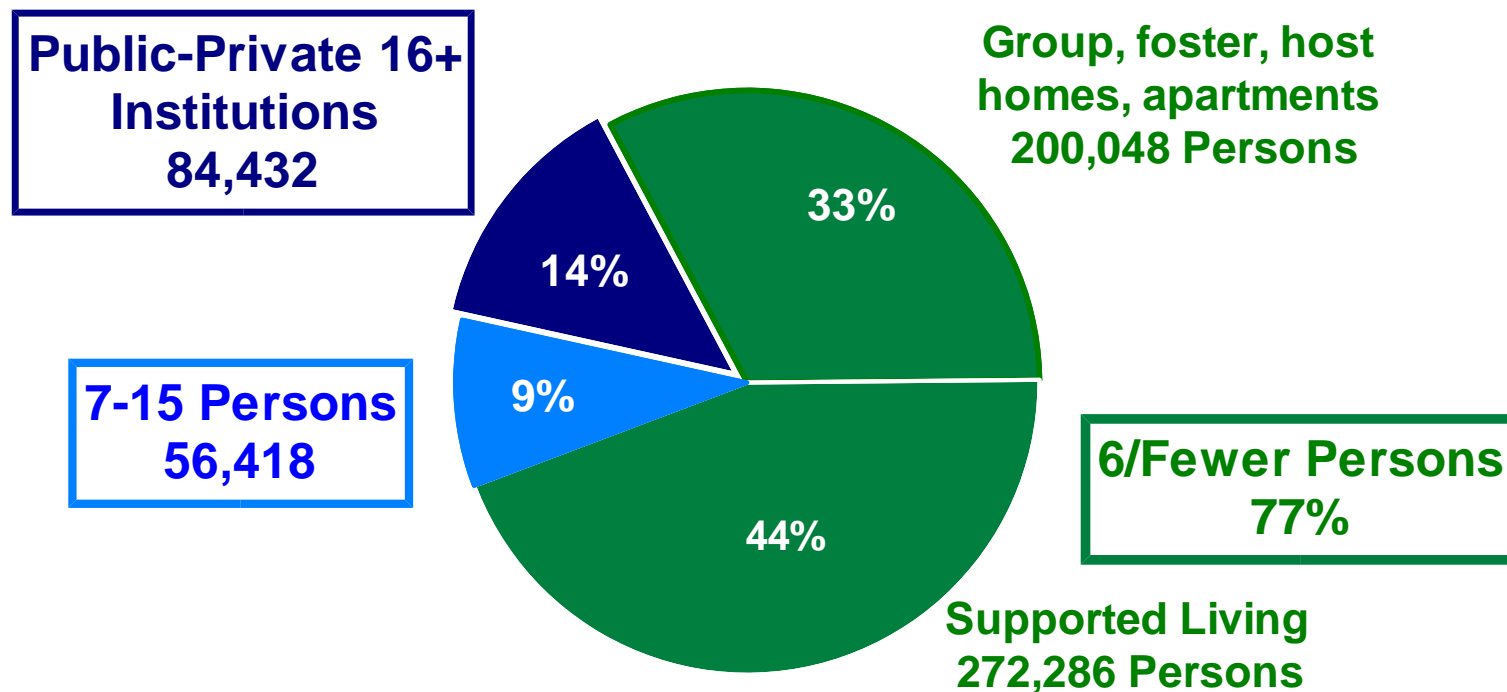
UNITED STATES



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

Out-of-Home Residential Placements for People with I/DD: 2011

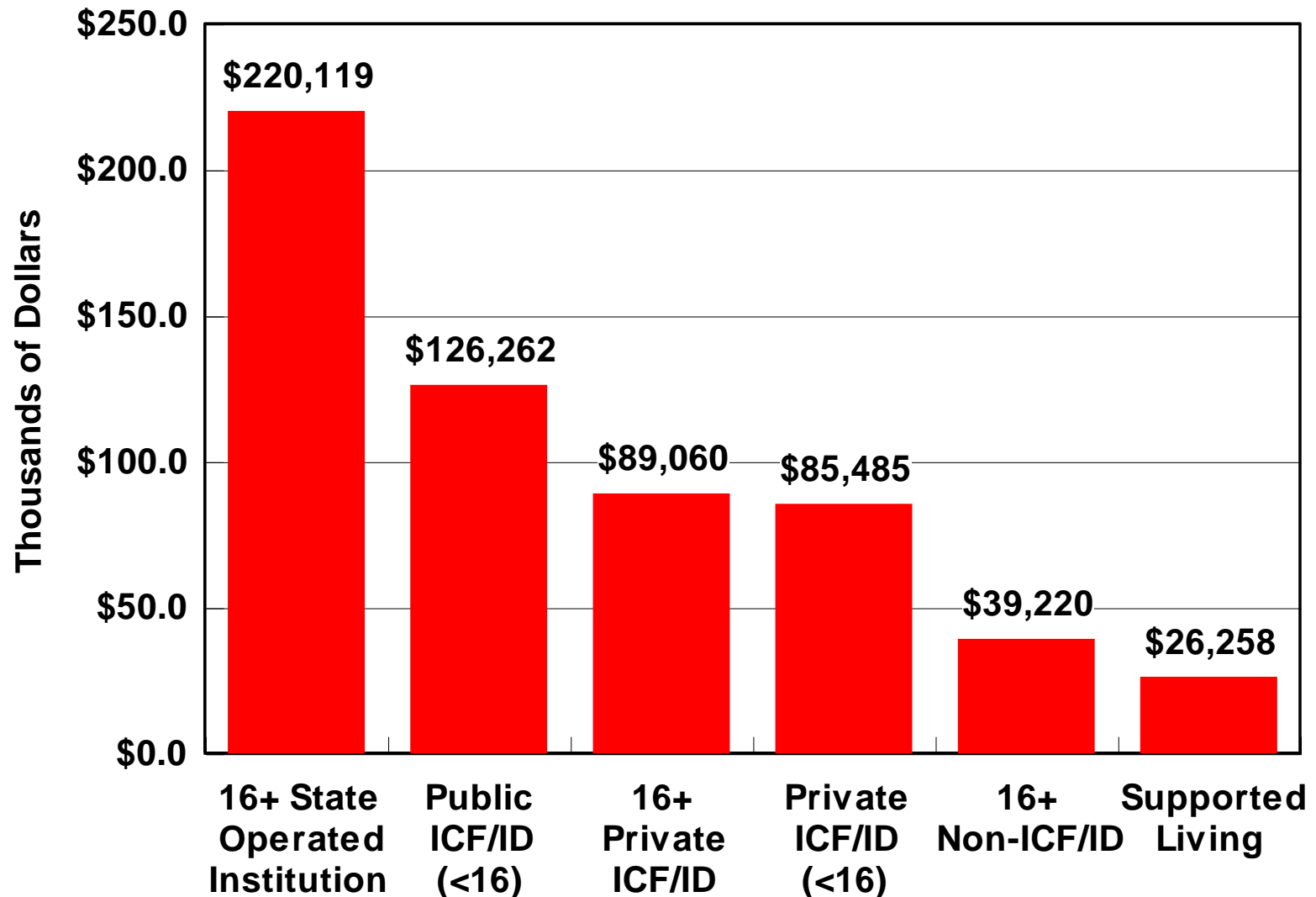
United States



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



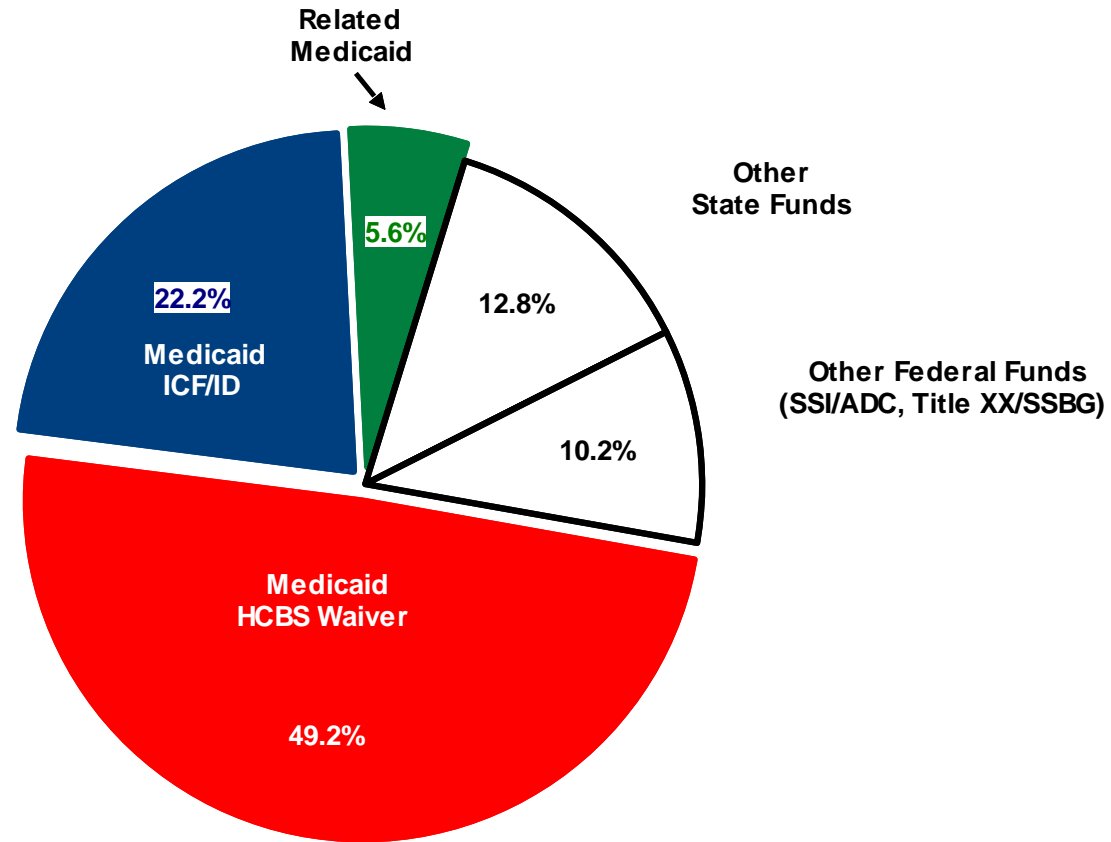
Source: Braddock, D., Coleman Institute and Department of Psychiatry, University of Colorado, 2013.

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

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

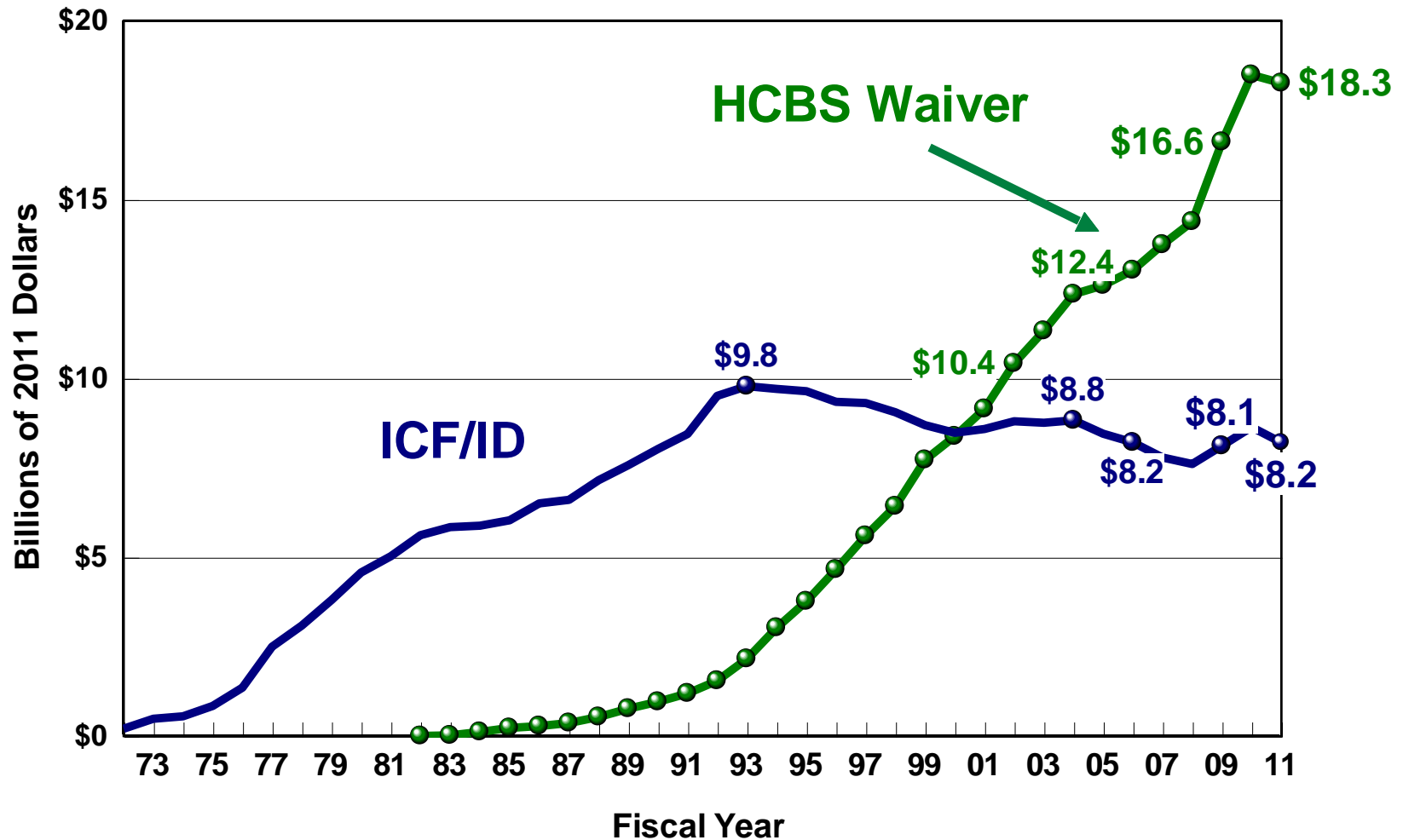


Total I/DD Spending: \$56.65 Billion
Total Federal-State Medicaid: \$43.62 (77%)

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

Federal HCBS Waiver Spending Surpassed ICF/ID Spending in 2001

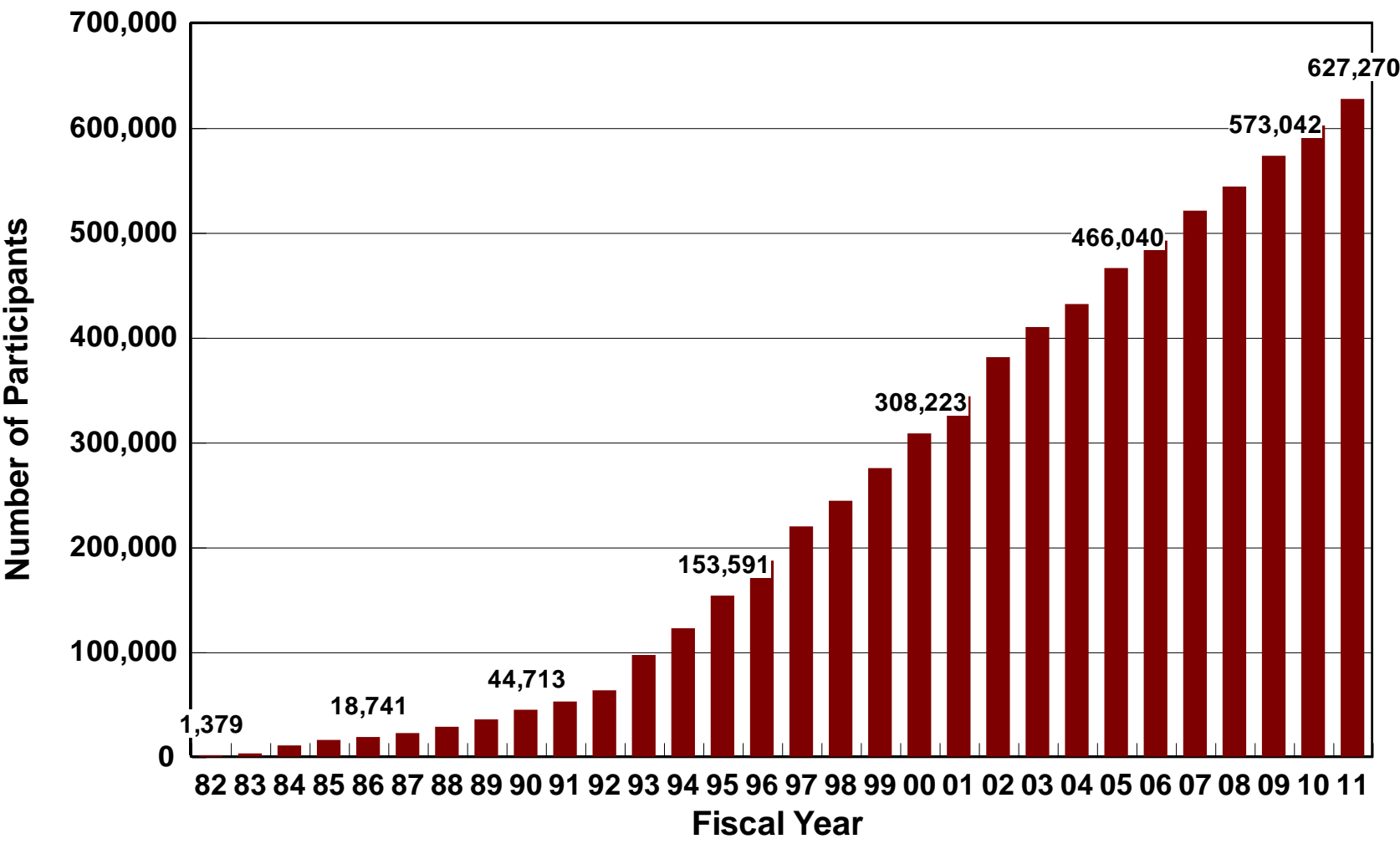
UNITED STATES



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

HCBS Waiver Participant Growth: 1982-2011

UNITED STATES



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](http://www.hcbs.org/Support%20Waivers)

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.

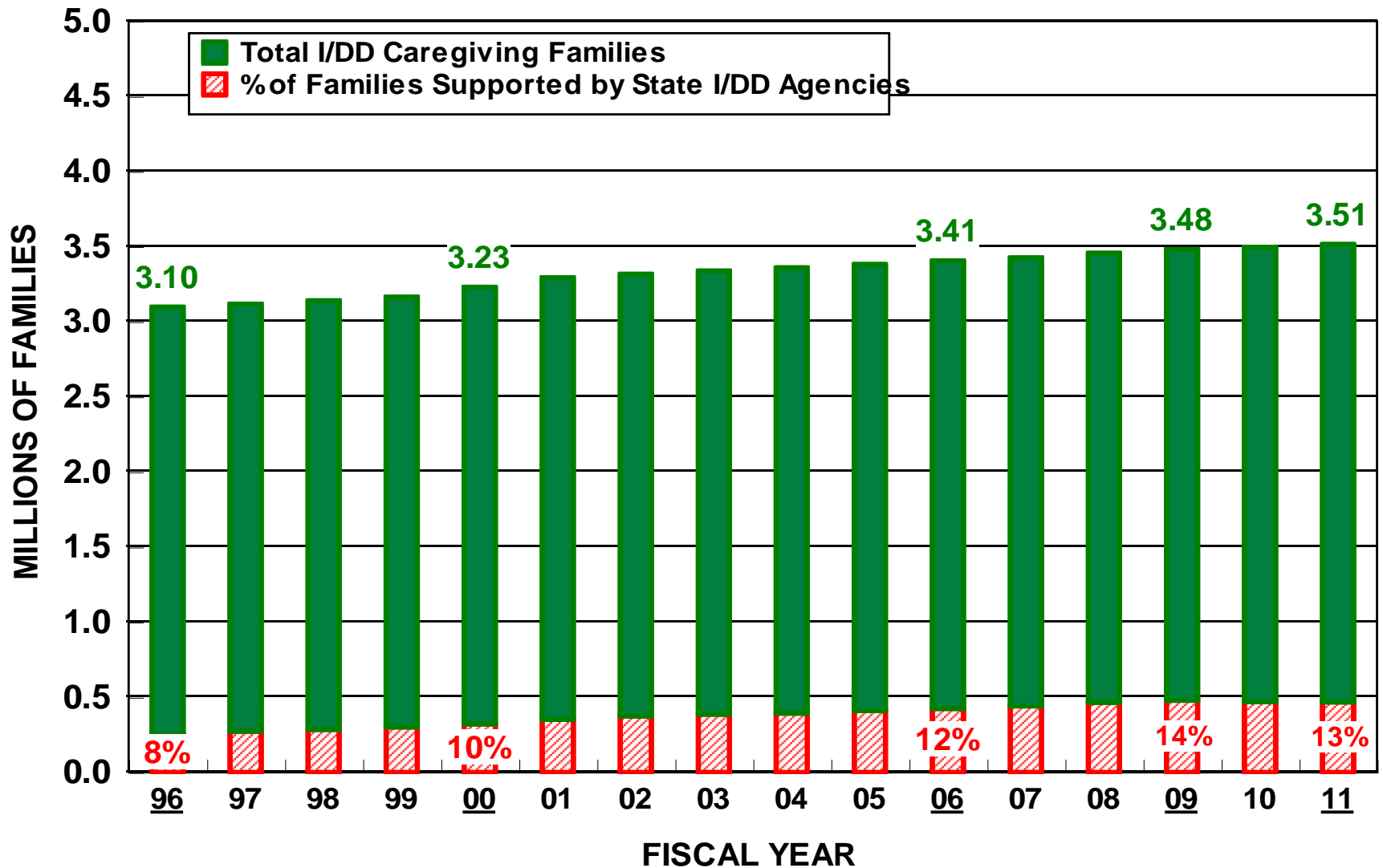
Family Support Defined

- **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

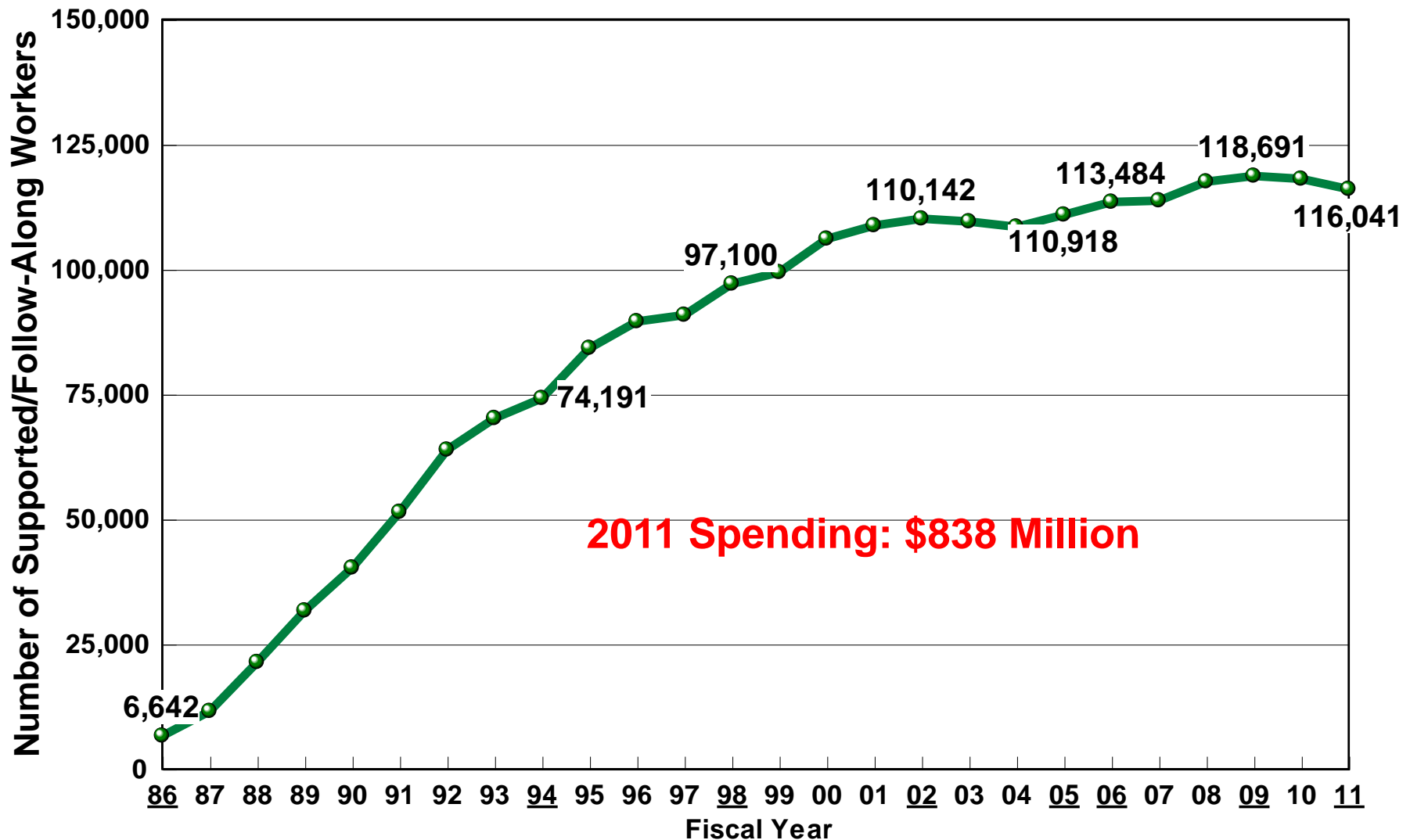
Source: Braddock, D., Coleman Institute and Department of Psychiatry, University of Colorado, 2013.

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

I/DD Community Services Fiscal Effort: FY 2011

1	New York	\$9.51	19	Pennsylvania	\$4.41	37	Maryland	\$2.90
2	Maine	\$7.63	20	Wyoming	\$4.24	38	Washington	\$2.90
3	North Dakota	\$6.87	21	New Hampshire	\$4.19	39	Kentucky	\$2.89
4	District of Columbia	\$6.67	22	Idaho	\$4.17	40	South Carolina	\$2.78
5	Minnesota	\$6.60	23	Delaware	\$3.93	41	New Jersey	\$2.37
6	Connecticut	\$6.42	24	South Dakota	\$3.92	42	Colorado	\$2.19
7	Vermont	\$6.39	25	Arkansas	\$3.78	43	Utah	\$2.08
8	Ohio	\$6.09	26	Michigan	\$3.75	44	Illinois	\$2.05
9	West Virginia	\$5.77	27	Kansas	\$3.68	45	Virginia	\$2.04
10	Rhode Island	\$5.72	28	Montana	\$3.61	46	Alabama	\$1.99
11	Oregon	\$5.49	29	Arizona	\$3.60	47	Georgia	\$1.90
12	Wisconsin	\$5.14	30	Nebraska	\$3.43	48	Florida	\$1.77
13	Louisiana	\$5.13	31	California	\$3.37	49	Texas	\$1.59
14	Indiana	\$5.13	32	Tennessee	\$3.28	50	Mississippi	\$1.57
15	New Mexico	\$5.04	33	North Carolina	\$3.06	51	Nevada	\$1.45
16	Massachusetts	\$4.75	34	Hawaii	\$3.02			
17	Alaska	\$4.68	35	Missouri	\$2.95		United States	\$3.81
18	Iowa	\$4.62	36	Oklahoma	\$2.94			

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

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

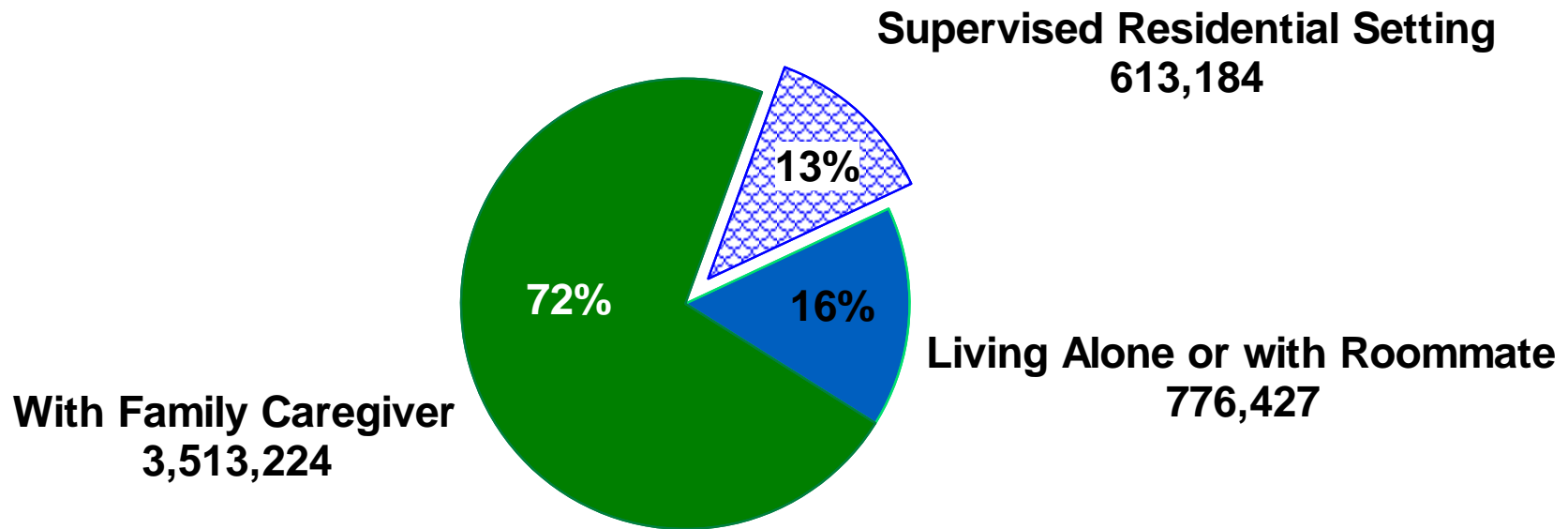
II. Factors Influencing Demand for I/DD Services in the U.S.

- 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.

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

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

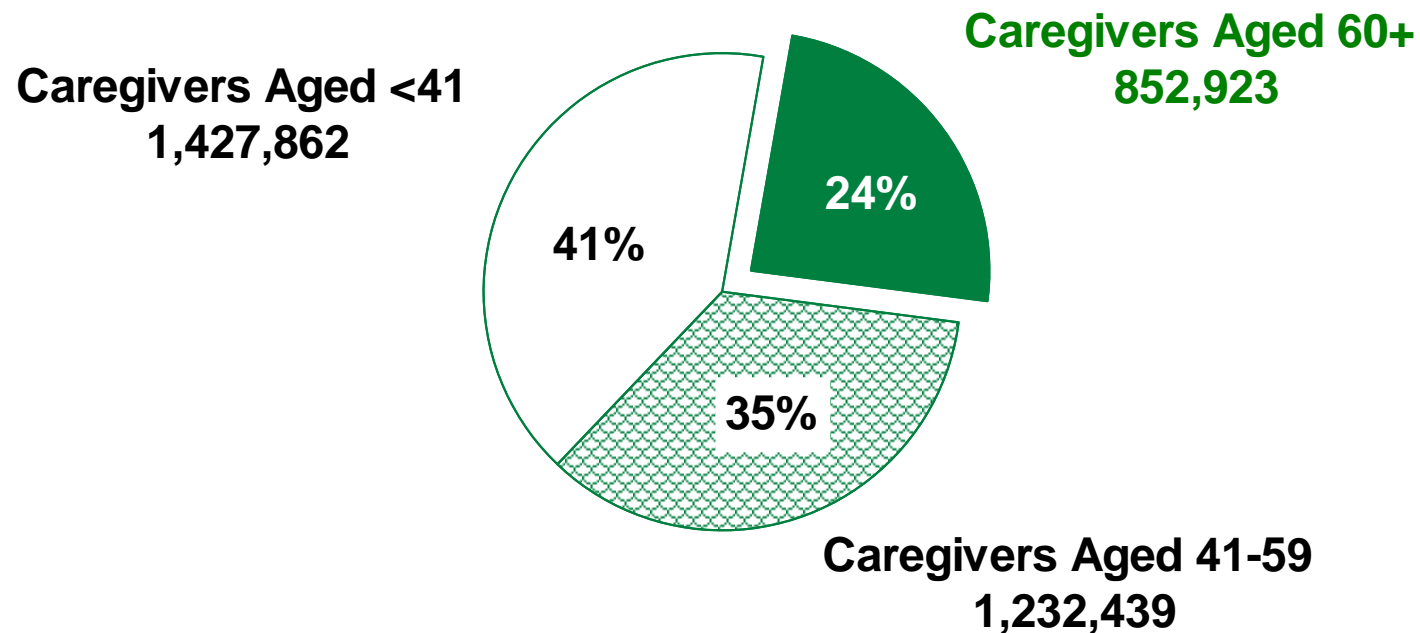


Total: 4.90 Million Persons

Source Braddock et al. 2013, based on Fujiura, 2012.

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

UNITED STATES Family Caregivers by Age: 2011



Total: 3.51 Million Persons

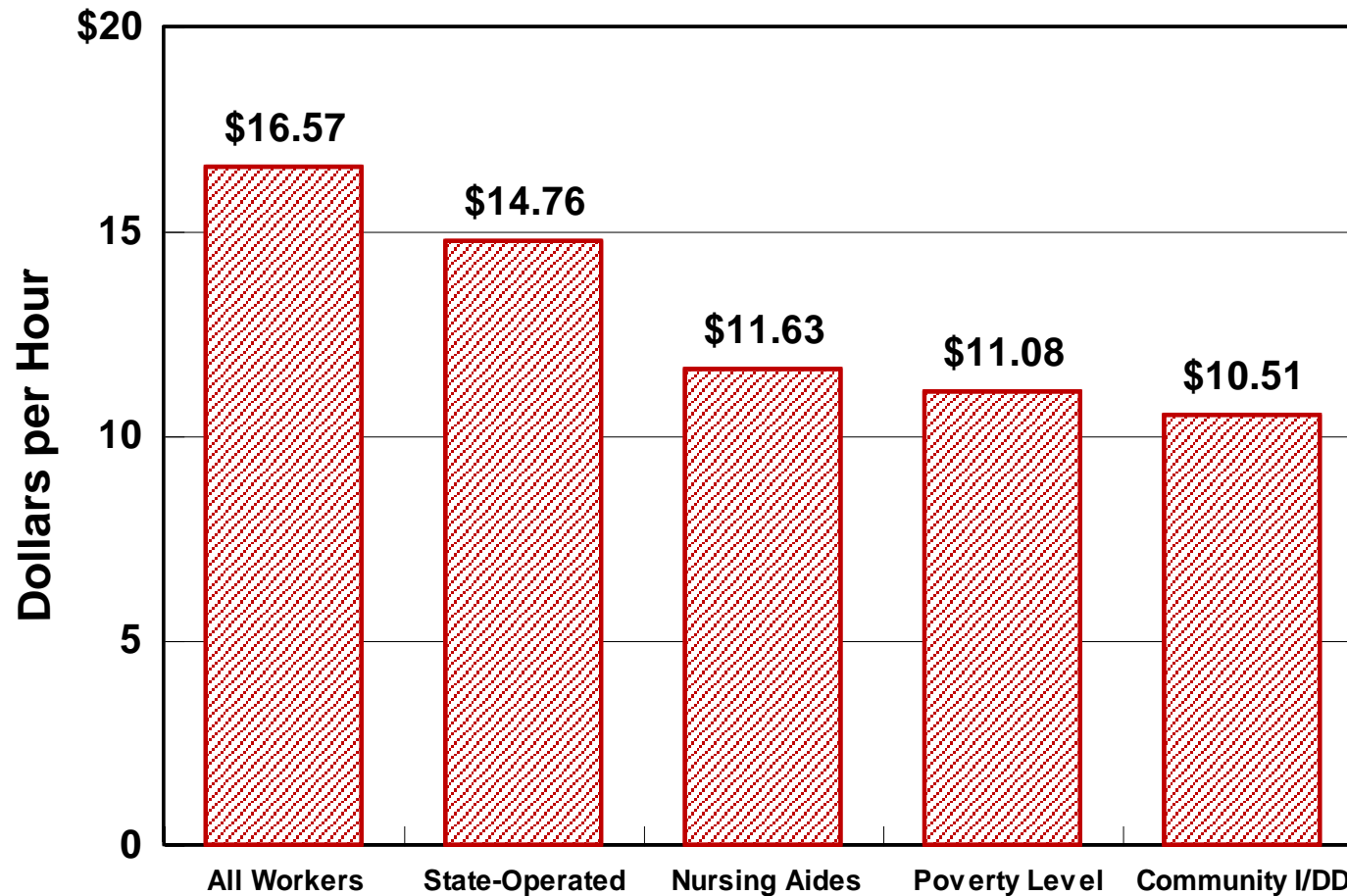
Braddock et al., 2013, based on Fujiura 2008, 2012

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.”**

Sources: M. Janicki. (1999; Janicki, Dalton, Henderson, & Davidson (1999); Rehabilitation Research and Training Center on Aging and Intellectual Disabilities, University of Illinois at Chicago; National Center for Health Statistics (2010); and Bureau of the Census (2012) for U.S. General Population in 2011.

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).

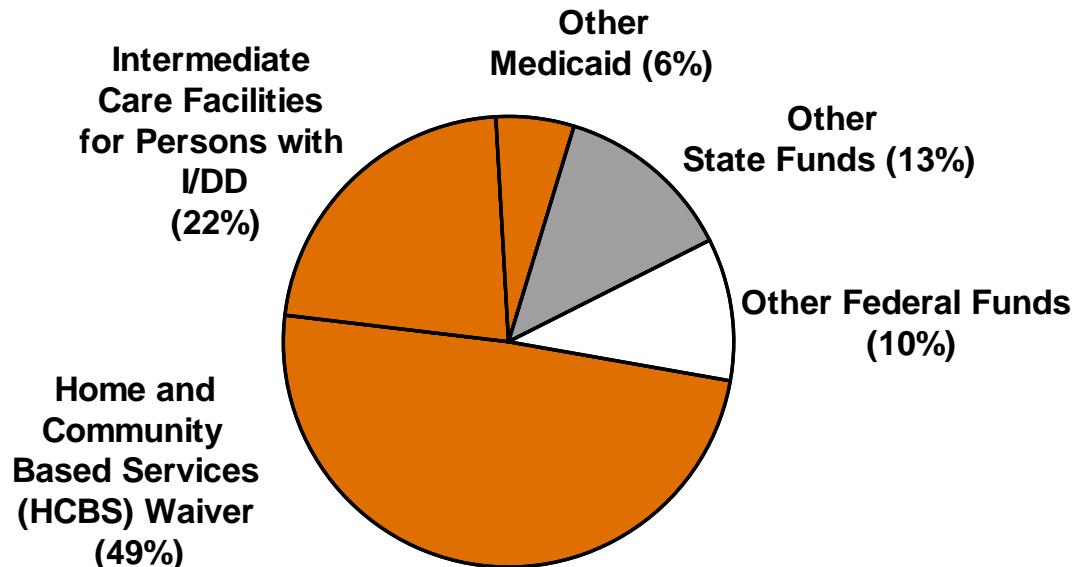
4. About Half the States Reduced I/DD Spending in FY 2011

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

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



Total I/DD Spending: \$56.60 Billion

Home and Community Based Services (HCBS) Waiver:

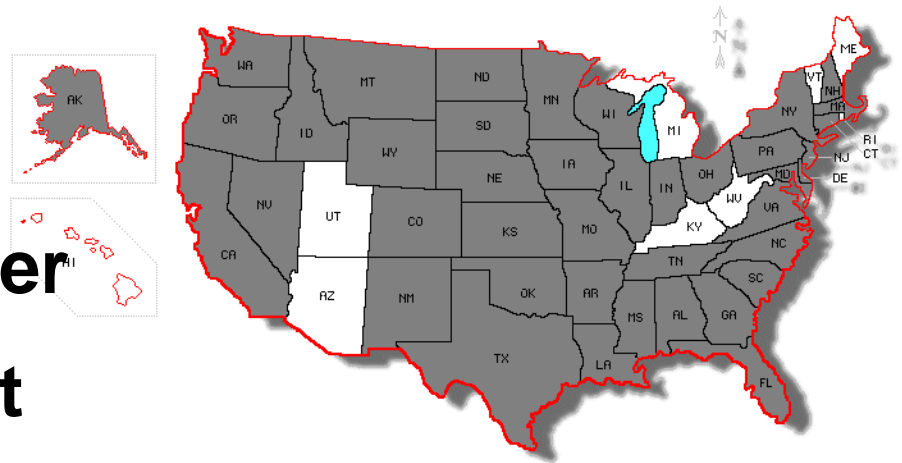
- **Authorized in 1981 to keep people out of institutions and lower costs**
- **Supported 627,000: 2011**
- **Reimburses states for community-based services and supports**
- **States determine services and number of projected people served**

Source: Rizzolo, M. C., Friedman, C., Lulinski-Norris, A., & Braddock, D. (Feb 2013).

Home and Community Based Services (HCBS) Waivers: A nationwide study of the states. Intellectual and Developmental Disabilities, 51(1).

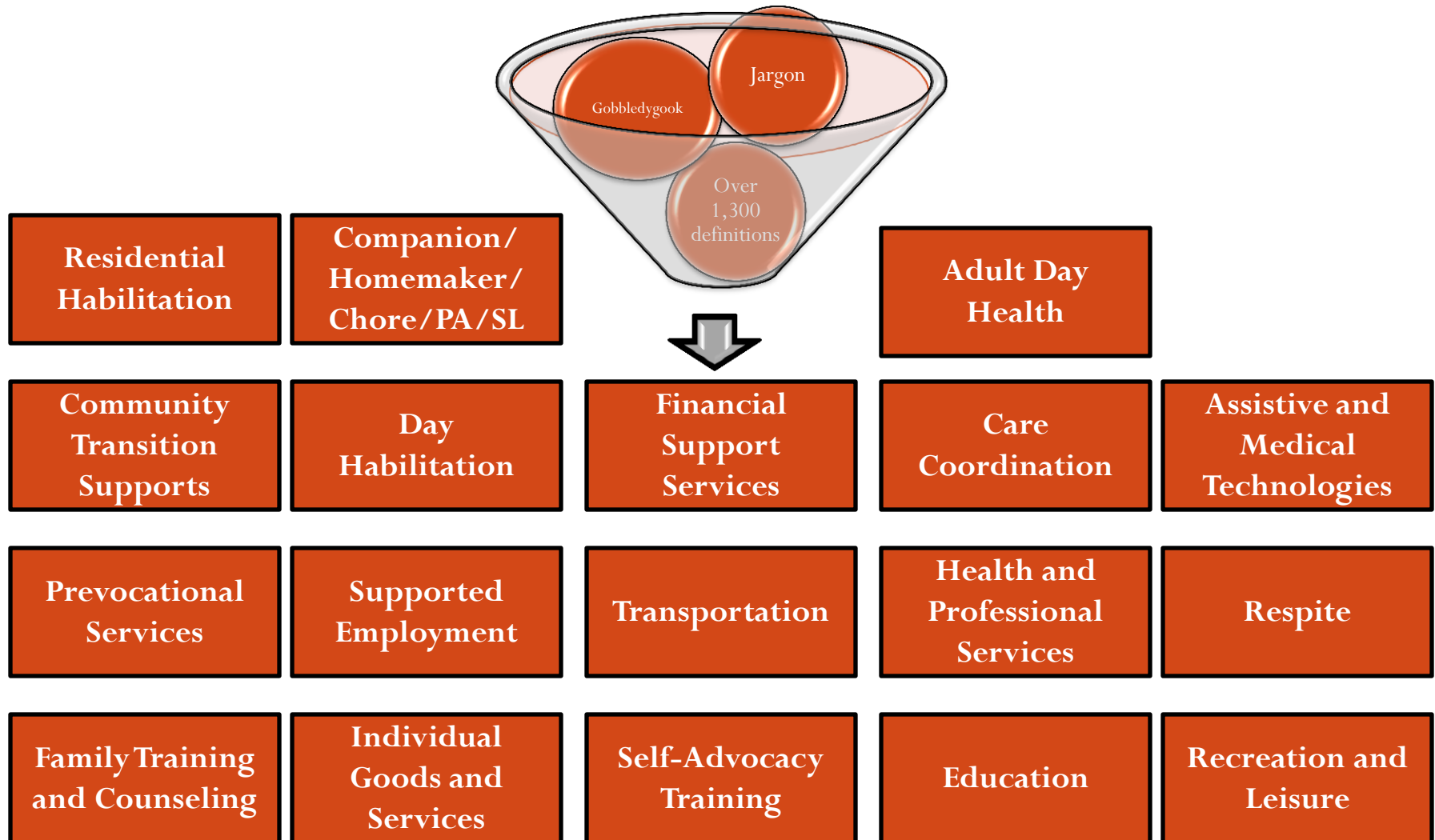
Status of Waivers in 2010

- **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



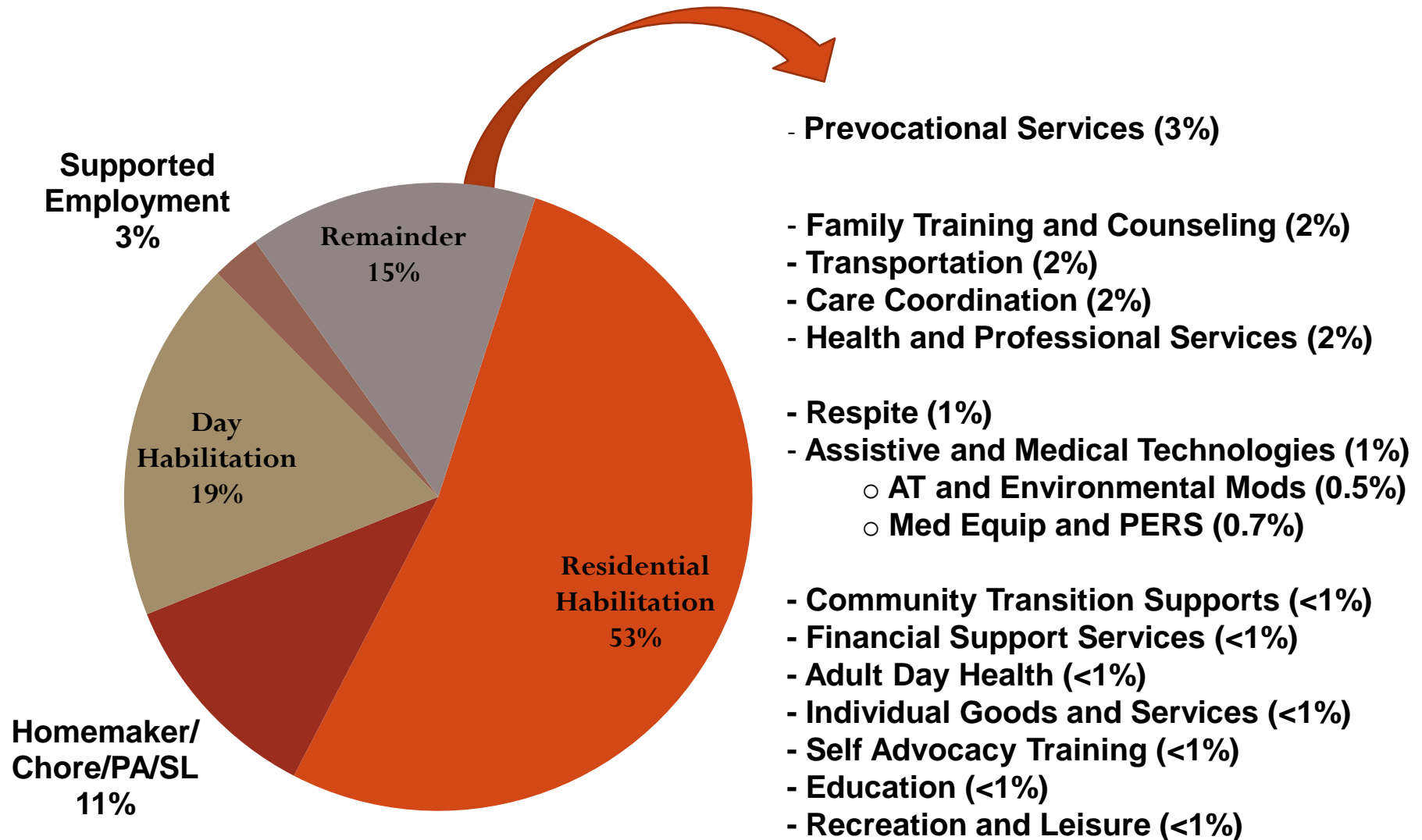
Source: Rizzolo, et al. (Feb 2013).

What Waiver Services Do States Offer?



Source: Rizzolo, et al. (Feb 2013).

Where Did States Propose to Spend Their Money?



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

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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.

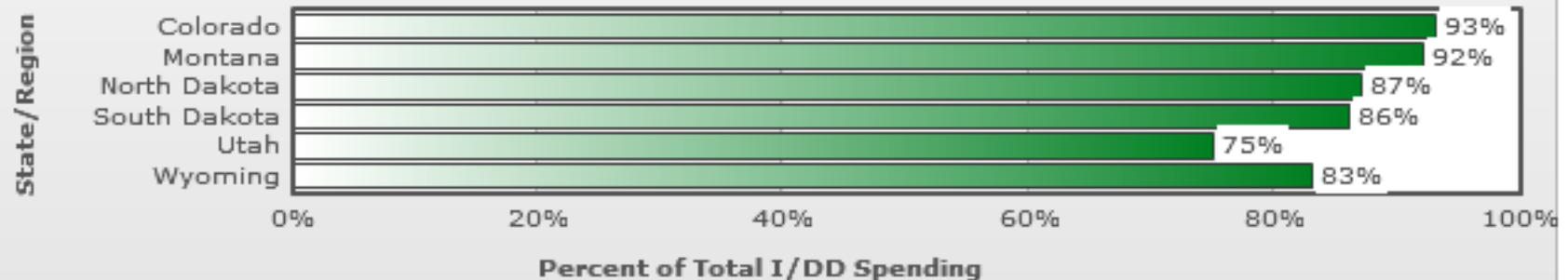
- State of the States
- Intellectual/Developmental Disabilities
 - Overview
 - Create a Chart
 - State Profiles
- All Disabilities
 - Overview
 - Create a Chart
- About Us
- Publications
- Coleman Institute for Cognitive Disabilities
- Links
- Contact Us
- Search

Personalize a Chart for your State or Region: Rocky Mountain States

[\[Close Window\]](#)

To print, [click here](#).

4. Community Spending as a Percent of Total I/DD S...



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

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



- **Chart**

- **Table**

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

State/Region	\$s per \$1,000 of personal income
Connecticut	\$7.76
Maine	\$7.75
Massachusetts	\$5.17
New Hampshire	\$4.24
Rhode Island	\$5.87
Vermont	\$6.39

Contact Information

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Mary Kay Rizzolo, Ph.D., Amie Lulinski, M.S.

Institute on Disability and Human Development

University of Illinois at Chicago

<http://ColemanInstitute.org>

<http://stateofthestates.org>



@SOS_in_DD



THANK YOU!

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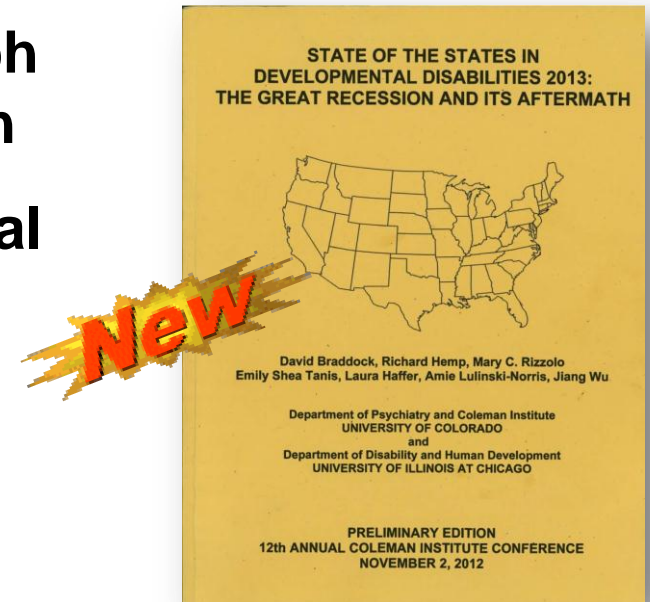
2013 State of the States Monograph

**Final copies of the 2013 SOS Monograph
can be obtained in March/April through**

**The American Association on Intellectual
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The Thirteenth Annual Coleman Institute Conference on Cognitive Disability and Technology

WEDNESDAY, OCTOBER 2, 2013

**Omni Interlocken Hotel,
Broomfield, Colorado**



QUESTIONS?

- We are happy to respond to questions you submit online.

