

Longitudinal Data Projects of National Significance

Data for the DD Council's 5-year plans

State of the States University of Colorado stateofthestates.org



Residential Information Systems Project University of Minnesota risp.umn.edu

Employment
State Data
UMass Boston
statedata.info





Using The State of the States in Intellectual and Developmental Disabilities Data in State Plan Development

Administration for Community Living Webinar for DD Councils August 6, 2019



DEVELOPMENTAL DISABILITIES

Amie Lulinski, PhD, FAAIDD Emily Shea Tanis, PhD, FAAIDD (PI) Joy Wu, PhD



STATE OF THE STATES IN INTELLECTUAL AND DEVELOPMENTAL DISABILITIES



Key Program and Participant Categories

Institutional Settings (16+)

- Public & Private ICF/ID
- Nursing Facilities
- Other

Community and Residential Settings (7-15)

- Public & Private ICF/ID
- Other Residential

Community and Residential Settings (1-6)

- Public & Private ICF/ID
- Supported Living
- Personal Assistance
- Family Support
- Other Residential

Day/Work Program

- Sheltered Employment/Work Activity
- Day Habilitation
- Supported Employment

Technology

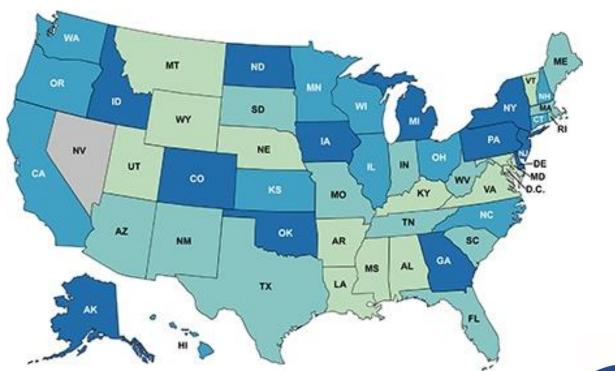
- Smart Homes
- Individual Support Technology
- Remote Monitoring



Follow the money



Data sources



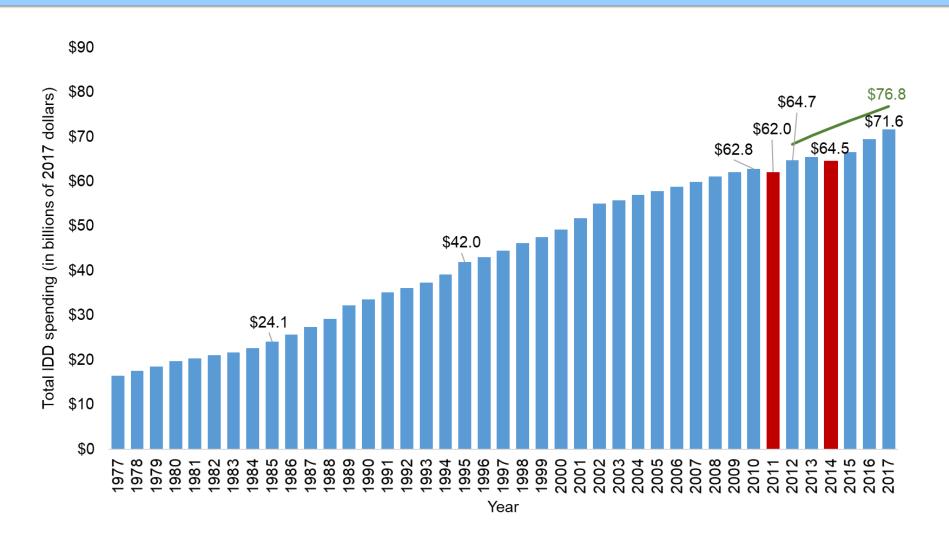




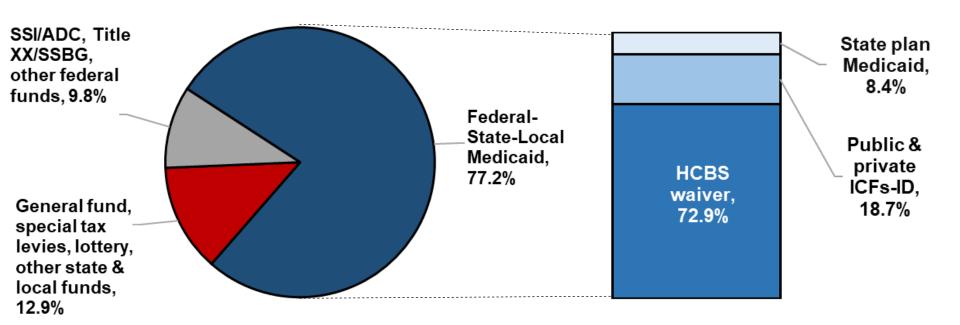




Total public IDD service spending: FYs 1977 – 2017



Federal, State, and Local Medicaid Spending in FY 2017

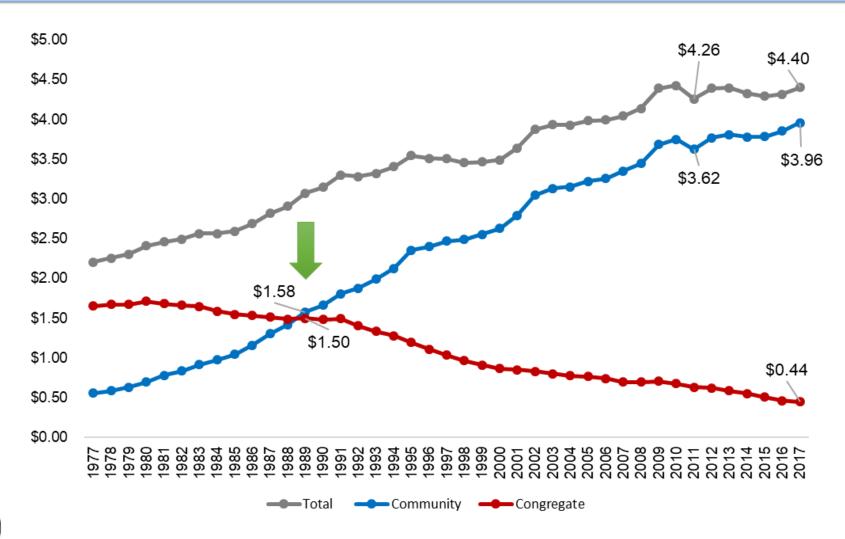


Total IDD spending: \$71.6 billion

Total IDD Medicaid spending: \$55.3 billion

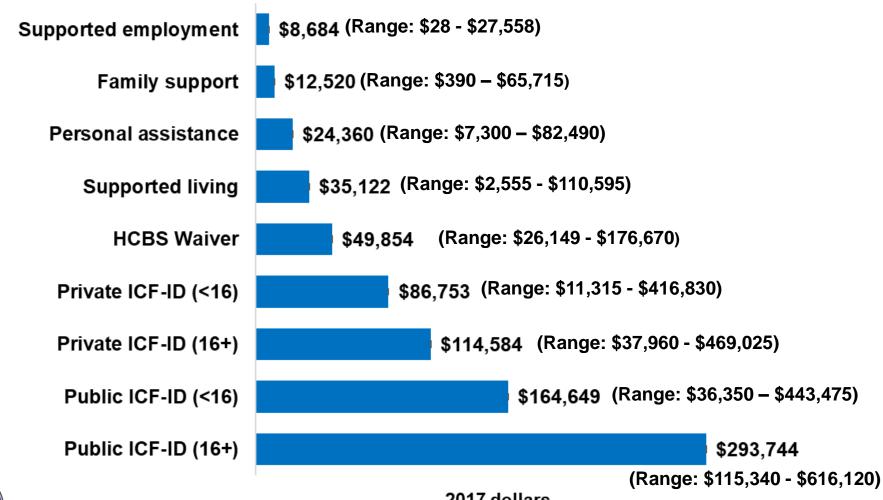


US Fiscal Effort (1977 – 2017)





Average annual costs per person per service category: 2017





2017 dollars

Total Fiscal Effort by State (FY17)





Total IDD spending as a % of total state spending: 2017

State	%	Rank ²
Alabama	1.3%	51
Alaska	2.0%	43
Arizona	2.9%	28
Arkansas	3.2%	23
California	2.4%	34
Colorado	1.9%	45
Connecticut	4.1%	9
Delaware	2.2%	39
District of Columbia ³	5.9%	2
Florida	2.1%	42
Georgia	2.5%	32
Hawaii	1.3%	50
ldaho	3.5%	21
Illinois	2.3%	37
Indiana	4.3%	7
lowa	3.8%	16
Kansas	2.4%	33
Kentucky	3.4%	22
Louisiana	3.8%	15
Maine	6.9%	1
Maryland	2.7%	29
Massachusetts	4.1%	8
Michigan	2.1%	41
Minnesota	4.5%	6
Mississippi	2.2%	38
Missouri	3.8%	14

State	%	Rank ²
Montana	2.4%	35
Nebraska	4.0%	11
Nevada	1.3%	49
New Hampshire	3.7%	17
New Jersey	2.6%	30
New Mexico	2.1%	40
New York	5.1%	4
North Carolina	3.6%	20
North Dakota	5.1%	3
Ohio	4.5%	5
Oklahoma	1.9%	44
Oregon	3.1%	24
Pennsylvania	3.6%	19
Rhode Island	3.0%	27
South Carolina	2.3%	36
South Dakota	3.7%	18
Tennessee	3.1%	25
Texas	1.8%	46
Utah	1.8%	47
Vermont	3.1%	26
Virginia	3.8%	13
Washington	2.6%	31
West Virginia	4.0%	12
Wisconsin	4.1%	10
Wyoming	1.7%	48
United States	3.1%	



Comprehensive Review and Analysis

- Using SOS data can help you complete the following sections:
 - III. B. Employment spending
 - IV. B. Family support, HCBS, LTSS
 - Section V. A & B. Assistive technology
- Data can be found in:
 - State profile
 - Create-a-chart
 - Book
 - Contact us



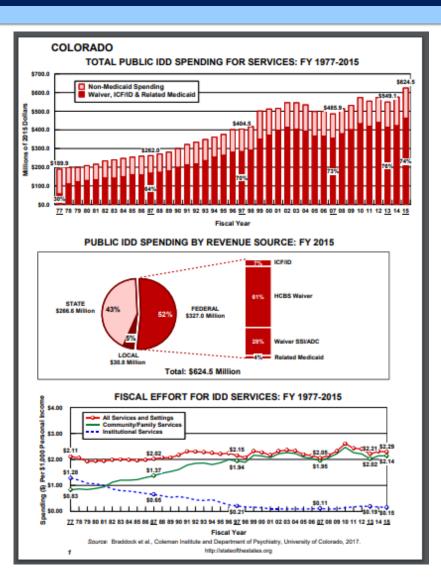
State profile www.stateofthestates.org



Welcome to the website for the **State Disabilities Project**, administered by

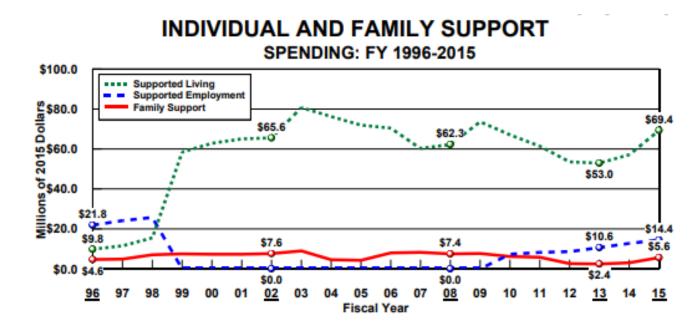
Administration on Intellectual and Deve





CO state profile

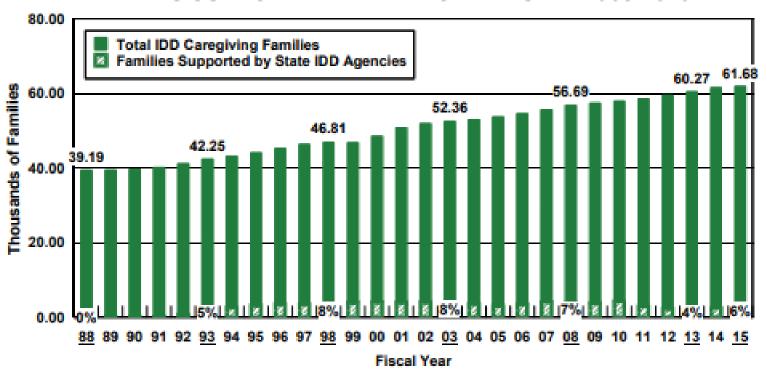
- CRA section III.B.
 - Supported employment spending
- IV.B
 - Family support





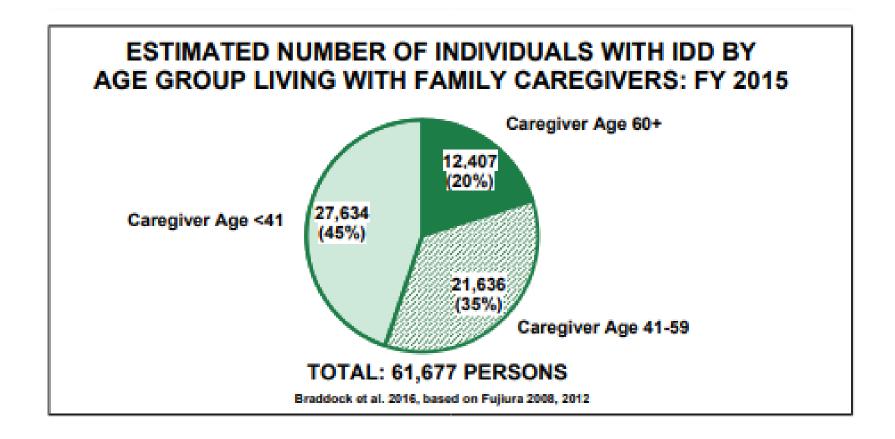
CO state profile – families

ESTIMATED NUMBER OF IDD CAREGIVING FAMILIES AND FAMILIES SUPPORTED BY IDD AGENCIES: FY 1988-2015





CO state profile – with families by age





Create-a-chart

www.StateoftheStates.org





Create-a-chart use

[Close Window]

To print, click here.

18. Public Spending for Family Support and Supported Living as a Percentage of Total I/DD Spending: 2015

State/Region % I/DD spending

Colorado 12.0%

Spending for family support and supported living, as a share of total I/DD spending.

Copyright © 2017, The State of the States in Developmental Disabilities Project



18. Public Spending for Family Support and Supported Living as a Percentage of Total I/DD Spending: 2015 14.6% 4856 64% Salar Chara KT Trial

Spending for family support and supported living, as a share of total I/DD spending.

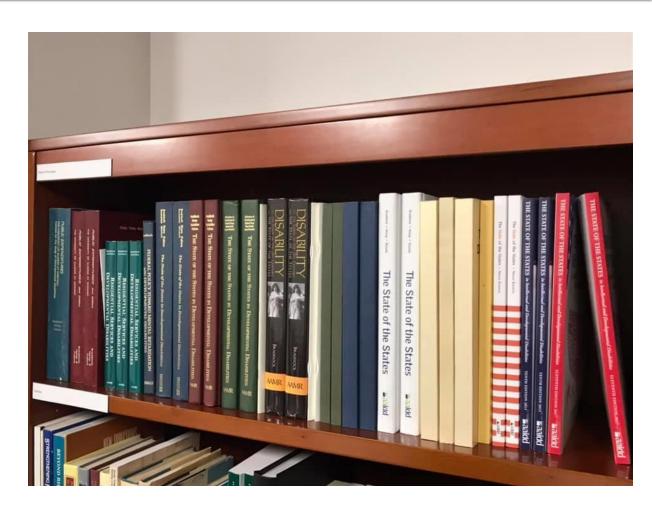
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The Book

Financial and Programmatic Trends

Published by







Family support spending tables

FAMILY SUPPORT IN THE STATES: SPENDING FOR PARTICIPANTS WITH IDD IN FY 2017

	Total Family Support ¹		Spending Per		Families Supported		Cash Subsidy		Other Family Support	
State	Families	Spending	Family	Rank ²	Per 100K	Rank ³	Families	Spending	Families	Spending
Alabama	1,666	\$650,000	\$390	44	34	43	0	\$0	1,666	\$650,000
Alaska	1,162	\$10,618,091	\$9,138	22	155	23	0	\$0	1,162	\$10,618,091
Arizona	28,493	\$539,796,665	\$18,945	11	413	1	0	\$0	28,493	\$539,796,665
Arkansas	374	\$408,070	\$1,091	40	12	49	0	\$0	374	\$408,070
California	128,888	\$973,832,023	\$7,556	24	326	7	0	\$0	128,888	\$973,832,023
Colorado	3,689	\$5,499,039	\$1,491	38	66	37	0	\$0	3,689	\$5,499,039
Connecticut	4,230	\$107,399,167	\$25,390	7	118	26	1,987	\$2,526,255	2,243	\$104,872,912



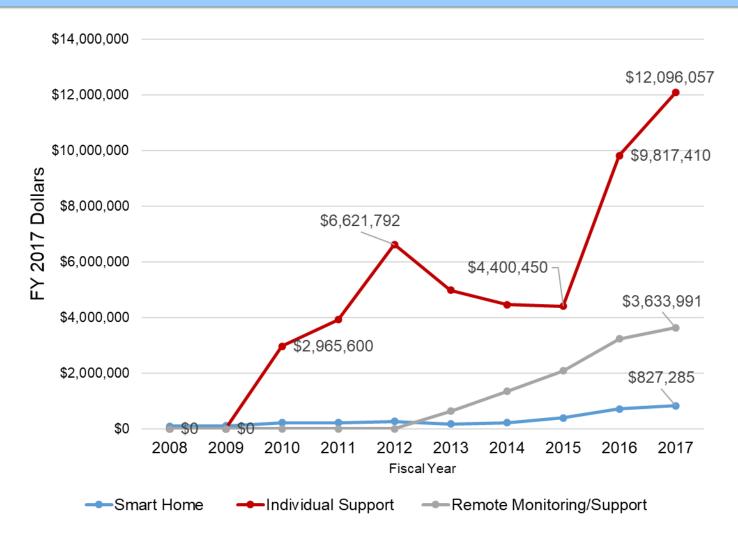
Supported employment spending tables

PROGRAMS IN THE STATES: PARTICIPANTS AND SPENDING IN FY 2017

		% Supported	Spending					
State	Participants ¹	Employment ²	Spending	Per Capita ³	Rank ⁴			
Alabama	186	3%	\$484,923	\$5.46	13			
Alaska	558	23%	\$8,679,739	\$11.56	4			
Arizona	2,555	17%	\$28,700,371	\$4.16	20			
Arkansas	92	9%	\$543,985	\$0.18	49			
California	10,814	12%	\$115,062,703	\$2.91	26			
Colorado	2,602	32%	\$19,925,844	\$3.55	21			
Connecticut	4,799	41%	\$68,470,940	\$19.08	2			

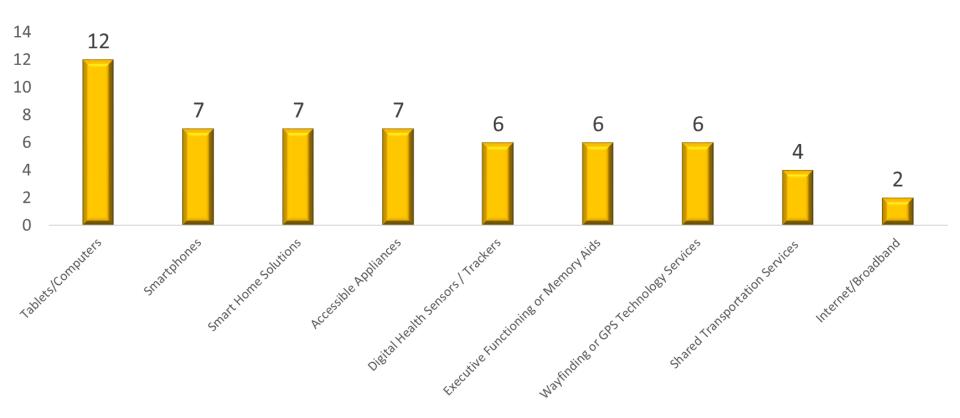


State IDD Agency Technology Spending





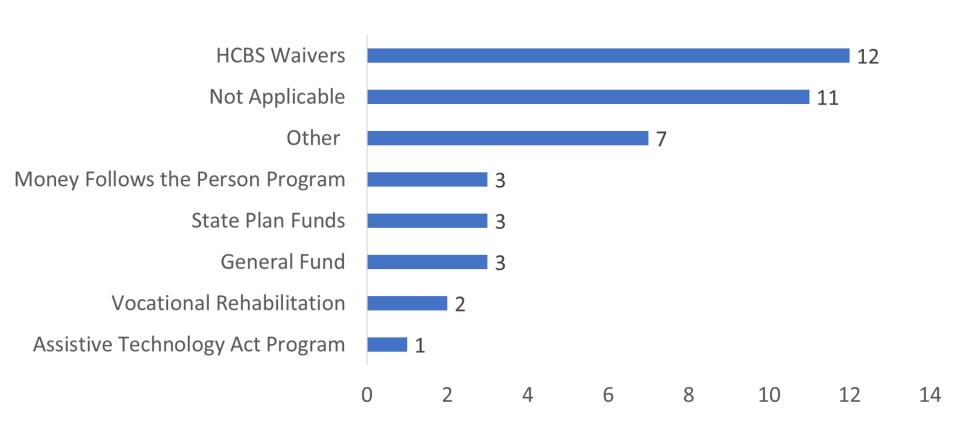
Services Purchased with Public Dollars, Pilots or Special Programs





Source: Tanis, E. S. (2018). State of the States in Technology. University of Colorado Anschutz Medical Campus.

Federal Funds Provide Ongoing Technology Training to Learn, Upkeep, and Update Purchased Technology





Source: Tanis, E. S. (2018). State of the States in Technology. University of Colorado Anschutz Medical Campus.

Eight States Funded Six or More Technology Solutions Not Traditionally Covered By Medicaid

TECHNOLOGY		STATES								
		СО	СТ	MN	NC	NM	RI	WA		
Tablets/Computers	Х	Х	Х	Х	Х	Х	Х	Х		
Accessible Appliances	X	Х	Х	Х	Х	Х	Х	X		
Smart Home Solutions	X	X	Х	Х	Х	Х	Х	X		
Smartphones	X		X	Х	Х	Х		X		
Digital Health Sensors	X	X	X	X	X	X	X	X		
Executive Functioning Aids	X	X	X	X	Х	X	X	X		
Wayfinding or GPS		Χ	Х	Х	Х	Х		X		
Shared Transportation			X	Х	Х		X			
Internet Broadband	X				X					



Source: Tanis, E. S. (2018). State of the States in Technology. University of Colorado Anschutz Medical Campus.

FMI



www.stateofthestates.org



Amie.Lulinski@cu.edu Shea.Tanis@cu.edu

Sources:

Tanis, E. S. (2018). State of the States in Technology. University of Colorado Anschutz Medical Campus.

Tanis, E.S., Lulinski, A., Wu, J., Braddock, D., & Hemp, R. (in preparation). State of the States in Intellectual and Developmental Disabilities: FYs 2016-2017. Aurora, CO: Department of Psychiatry, University of Colorado Anschutz Medical Campus.

Financial support was obtained from the U.S. Administration on Intellectual and Developmental Disabilities and the Coleman Institute for Cognitive Disabilities, University of Colorado.



Residential Information Systems Project (RISP) risp@umn.edu



Principal Investigator: Sheryl Larson larso072@umn.edu

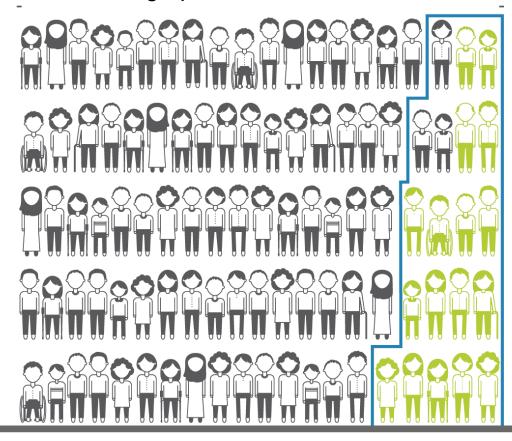
risp@umn.edu

Preparation of this presentation was supported, in part, by cooperative agreement (90DNPA0001-01) from the US Health and Human Services, Administration on Community Living. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore necessarily represent official AIDD policy.

How many people have Intellectual or Developmental Disabilities?

7.37 million people in the United States had IDD in 2016

RISP Infographic





1.49 million people with IDD were known to or served by state IDD agencies



1.23 million people with IDD received long-term supports or services through state IDD agencies



IDD Prevalence Explained

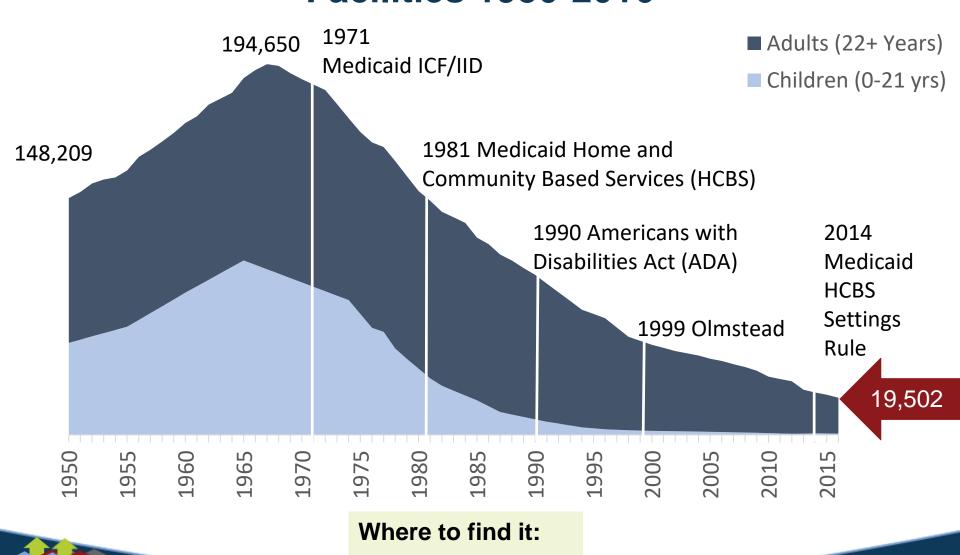
- 5.14 million children (Birth to 17 years)
 - 6.99% of the noninstitutionalized US population had ID, ASD or DD (defined categorically)
 - Parent report from 2016 NHIS (Zablotsky et al, 2017)
- 1.97 million adults (18+ years)
 - 0.79% of the noninstitutionalized US population had ID (defined categorically) or DD (3+ substantial functional limitations from DD Act)
 - Self or proxy report 1995 NHIS-D (Larson et al., 2001)
- 255,873 People in congregate settings (risp.umn.edu)

Where to find it:

Table 1.1 RISP report



Number of Children and Adults in Large State IDD Facilities 1950-2016



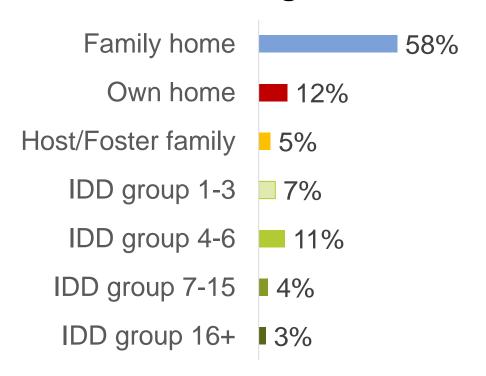
Report Figure 4.6

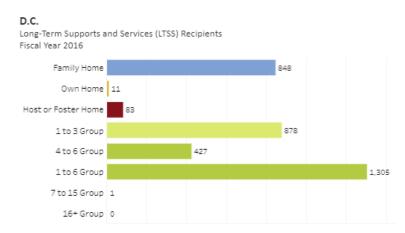
rtc on community living

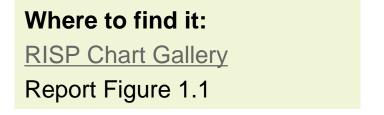
University of Minnesota

National Residential Setting Types 2016

1,228,700 people with IDD received long-term services or supports through state IDD Agencies. Residential settings included:

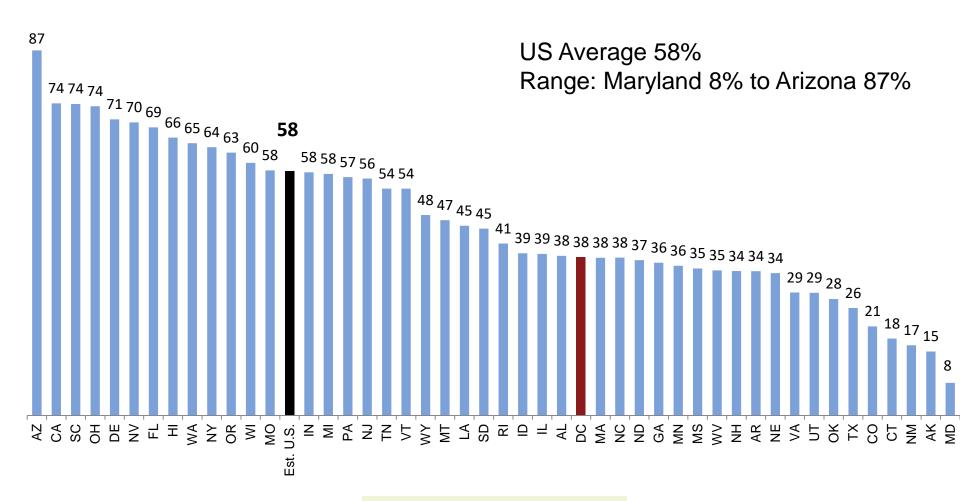








% Living with a Family Member by State

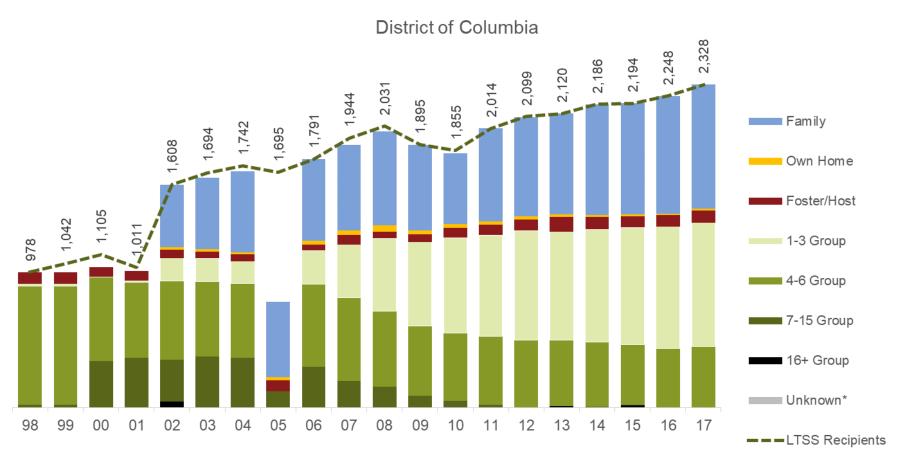


Where to find it:

RISP Chart Gallery
RISP report Figure 1.2



LTSS Recipients with IDD by Residence Type 1998 to 2017



^{*} Unknown setting type or size (2017), otherwise indicated by gaps with LTSS recipients (1998-2016)

Where to find it:

The FY 2017 profile will be available online. There is a similar chart on the chart gallery with FY 2016 data



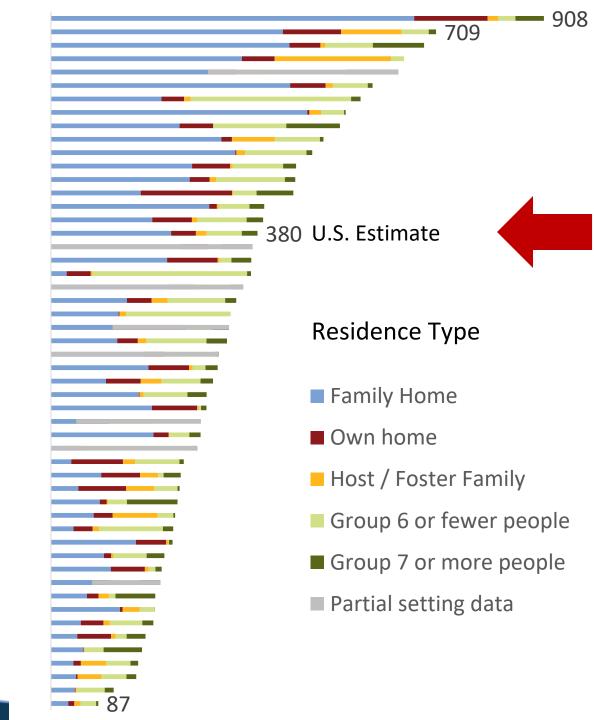
380 people with IDD received LTSS per 100,000 of the population in 2016

Georgia - 87 per 100k Ohio - 908 per 100k

Where to find it:

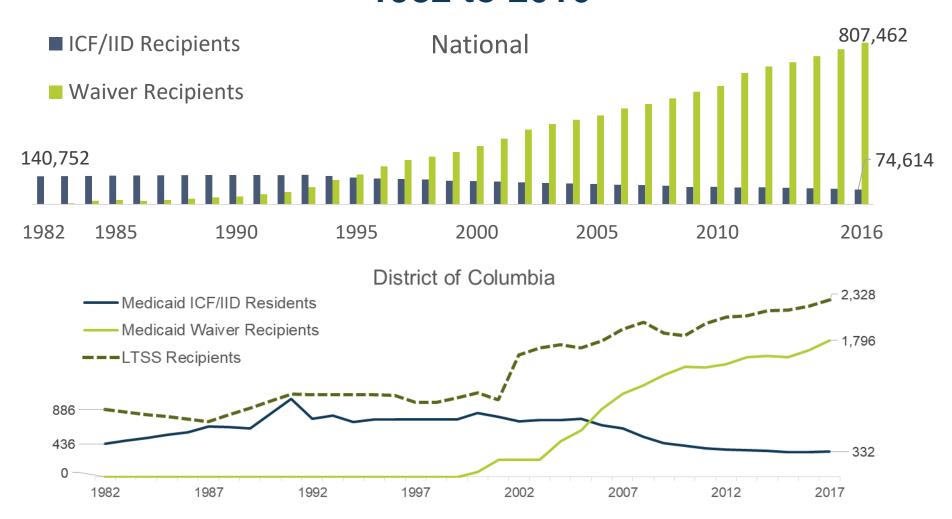
RISP online Chart Gallery

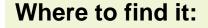
RISP report Figure 1.5





Medicaid ICF/IID and Waiver Recipients with IDD 1982 to 2016

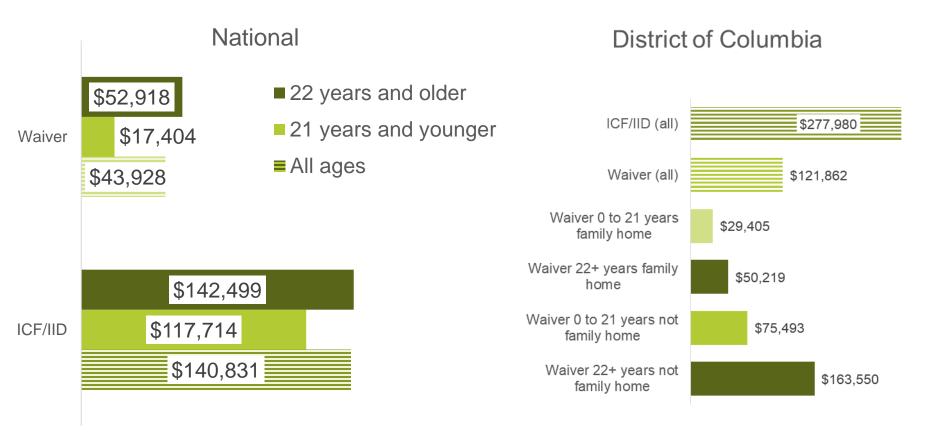




RISP report Figure 1.5
State Profile



Average Per Person Medicaid Expenditures Waiver and ICF/IID by Age FY 2016



Where to find it:

RISP report Figure 2.10 State Profile

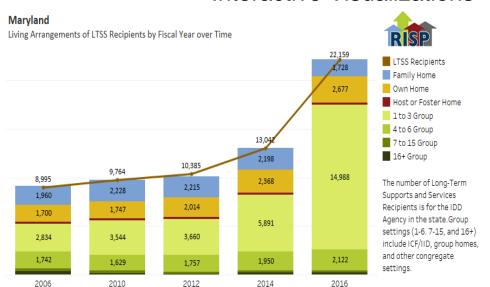


Resources at risp.umn.edu



Project Reports

Interactive Visualizations



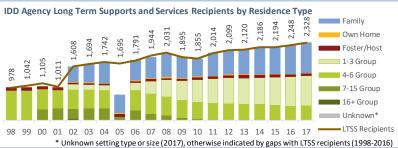
State Profiles



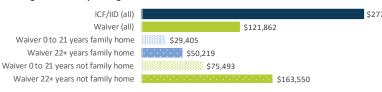
Fiscal Year 2017

Residential Information Systems Project | risp.umn.edu

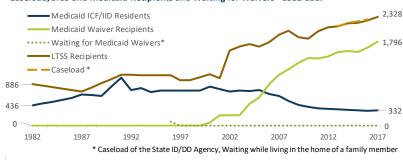




Average Medicaid Spending Per Person in Fiscal Year 2017



Caseload, LTSS and Medicaid Recipients and Waiting for Waivers* 1982-2017



Intellectual or Developmental Disabilities (IDD)	Residential
ICF/IID: Intermediate Care Facilities for Individuals with Intellectual Disabililties;	Information
LTSS: Long-Term Supports and Services;	Systems
See detailed information in the RISP report and interactive charts available on risp.umn.edu	Project (RISP)

Contact: risp@umn.edu References

- Larson, S.A., Eschenbacher, H.J., Anderson, L.L., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Bourne, M.L. (2018). <u>In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends through 2016</u>. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
- Larson, S.A., Lakin, K.C., Anderson, L.L., Kwak, N., Lee, J.H., Anderson, D. (2001). Prevalence of mental retardation and developmental disabilities: Estimates from the 1994/1995 National Health Interview Survey Disability Supplements. *American Journal on Mental Retardation*, 106, 231-252.
- Zablotsky, B., Black, L.I., Maenner, M.J., & Blumberg, S.J. (November 2017).
 <u>Estimated Prevalence of Children with Diagnosed Developmental Disabilities</u>
 <u>in the United States 2014-2016</u>. *National Center for Health Statistics Data Brief, No. 291*. Washington DC: U.S. Department of Health and Human Services.



Access to Integrated Employment

National Data Collection on Day and Employment Services







Core Activities

State Data.info

❖ National Survey on Day and Employment Services
State IDD Agencies

- ❖ VR services and outcomes RSA 911
- National Core Indicators
- American Community Survey
 Employment participation and outcomes
- Social Security Administration
 Work incentive use, work participation
- Workforce development
 Number of customers, entry into employment





STATEDATA: THE NATIONAL REPORT ON EMPLOYMENT SERVICES AND OUTCOMES

2008

Core Activities

- Employment first case studies
 Higher Performing States Model
- Promising Practices
 IDD Agency, Community Providers,
 Community Life Engagement
- Real People Real Jobs www.realworkstories.org
- Special Topic Studies

www.ThinkWork.org





How many people are employed? **POVERTY** WORK



No disability

No disability



Any disability

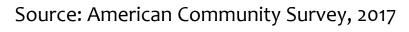




StateData.info

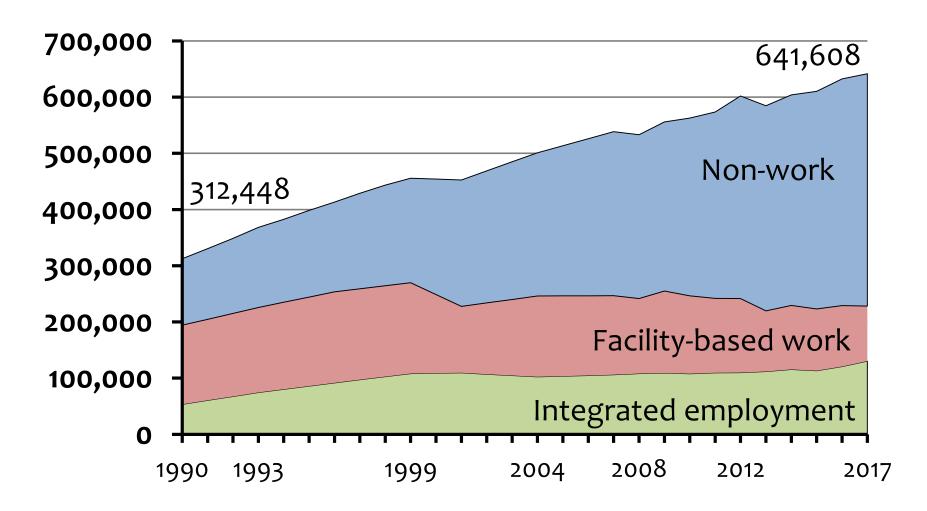
Cognitive disability

Cognitive disability





Number in Employment and Day Services



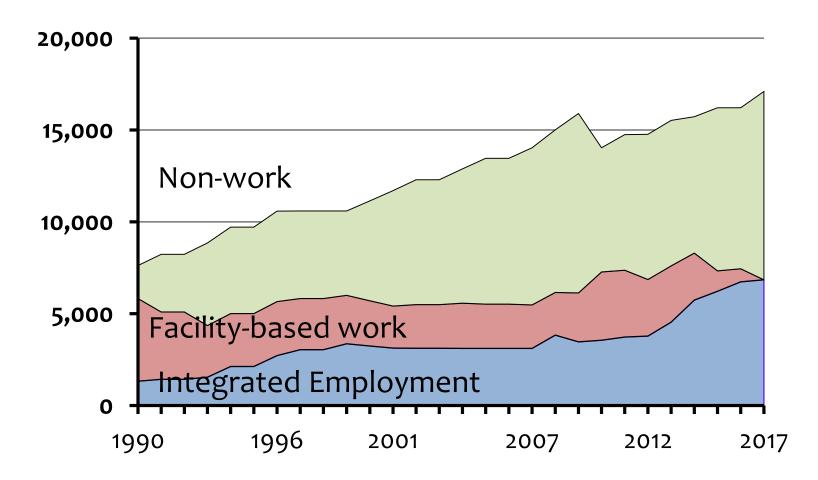


Source: ICI National Survey of

State IDD Agencies



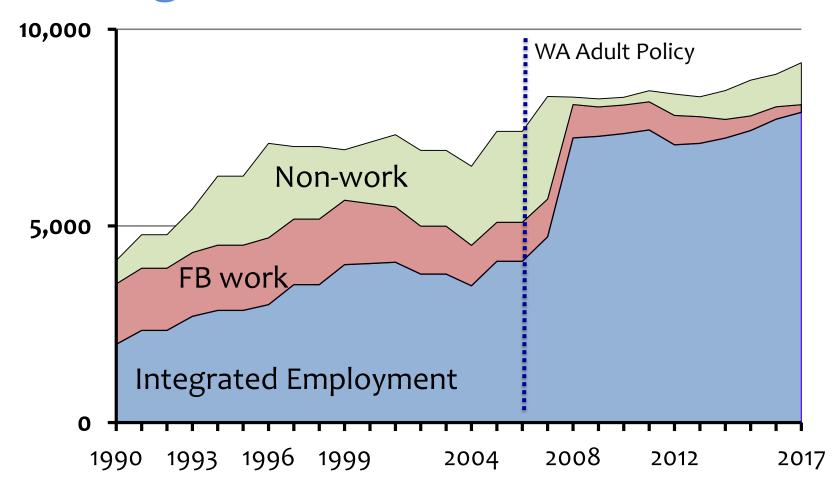
Employment and Day Supports State example







Employment and Day Supports Washington

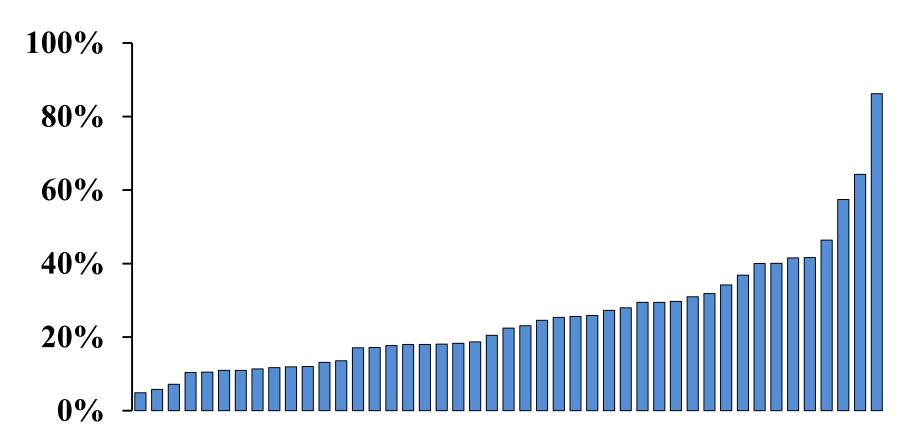




Source: ICI National Survey of State IDD Agencies



Participation in integrated employment services varies widely



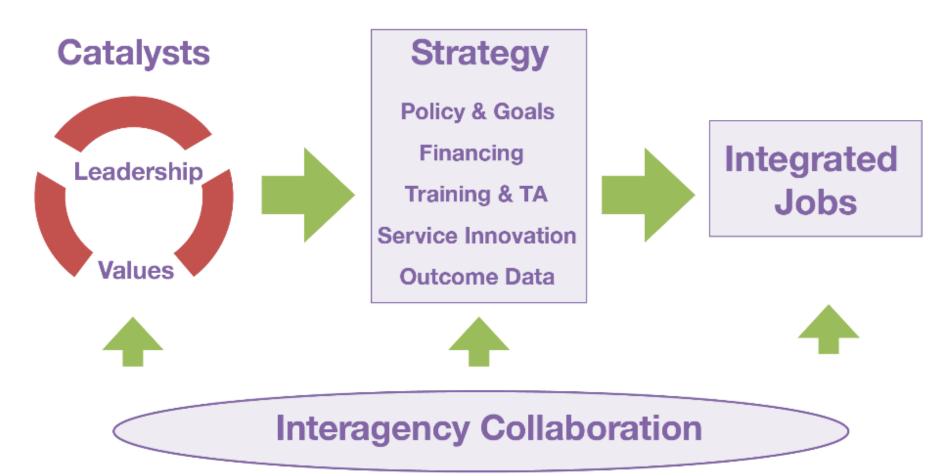
Source: 2017 ICI National Survey of

State IDD Agencies





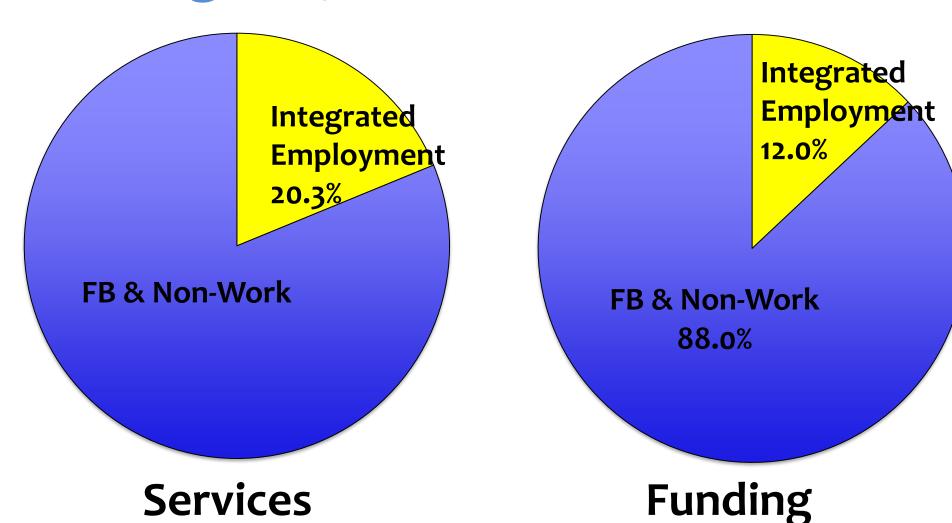
Higher-Performing States Model







IDD agency Investments

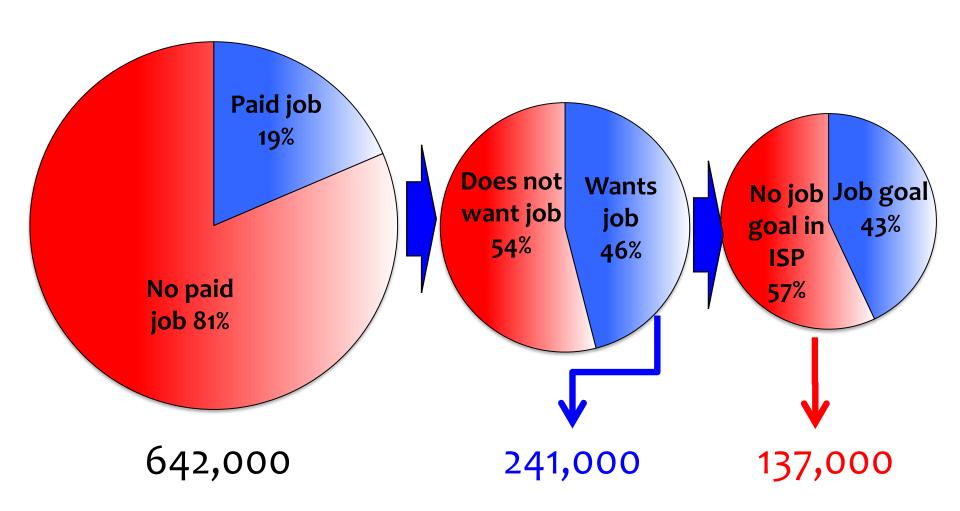




Source: ICI National Survey of State IDD Agencies 2017



Supporting Choice



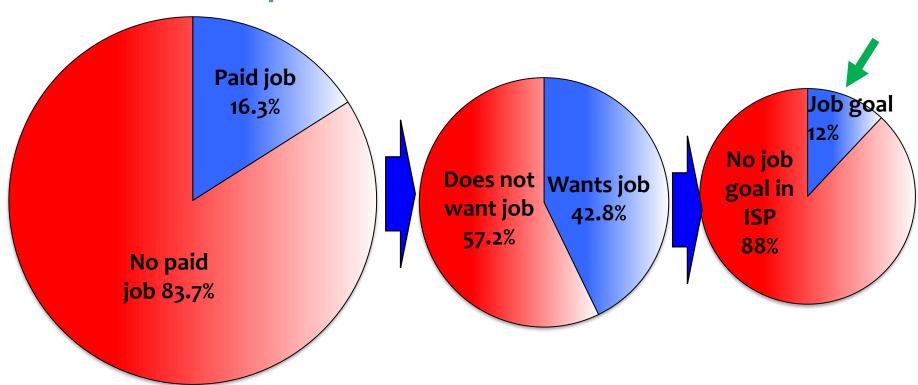


Source: National Core Indicators 2017-2018



Supporting Choice

State example







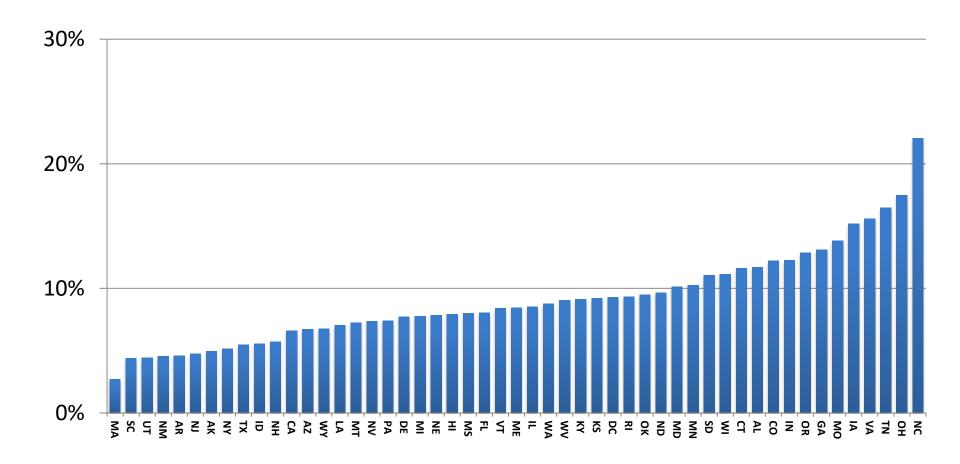
Self Sufficiency & Meaningful Day Mean Hours and Wages per week: Nation

	Hours worked	Gross Wages
Individual job with supports	13.25	\$126
Individual job without supports	15	\$139.80
Group supported job	12.25	\$100.21





Partnerships: Engagement with VR Percent of closures with an ID

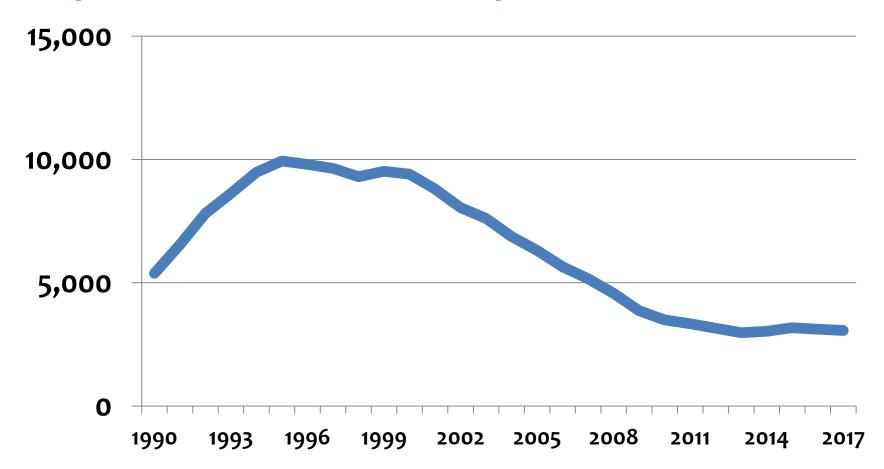




ThinkW@#k!

Use of work incentives: Nation

Impairment Related Work Expenses









State Data info

Sign up for our Email Newsletter

Check the "Employment Data" box on the next page

PUBLICATIONS AND ANALYSIS

2016 Edition is here



StateData: The National Report on Employment Services and Outcomes

StateData: The National Report on Employment Services and Outcomes. 2016 Edition. Access the latest information about employment and economic self-sufficiency for people with intellectual and developmental

disabilities. Both national and state-level statistics are included.

Download the PDF here*

Download the report narrative, no tables (Accessible PDF)

Download Your State:

Alabama 🗘 Go

MAKE OUR DATA WORK FOR YOU

State Snapshots

See the latest trends in state performance in work and participation for people with intellectual and developmental disabilities.

- Choose - 💠

View state summary

Build a Chart

Our chart-building tool offers descriptive information on state characteristics and services drawn from several national databases.

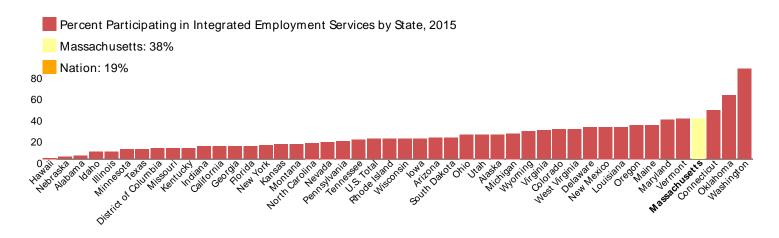
View a single state trend, or compare several states and national data.

Data Updates

According to WIOA data, there has been a

	Massachusetts 2	015	Nation 2015		
	Number	Percent	Number	Percent	
Total in day and employment services	16,217		610,188		
Total in integrated employment services	6,222	38%	113,226	19%	
Total funding for day and employment services	\$125,858,386.00				
Total funding for integrated employment services	\$49,328,917.00	39.2%	*	*	

^{* =} Data not available



How many people are working for pay in an integrated job?

Source: National Core Indicators Project Adult Consumer Survey (http://www.nationalcoreindicators.org)

Who: Individuals who receive any service other than/in addition to case management from the state IDD agency. Inclusion criteria varies by state.

What: Individuals who are reported as working for pay in an integrated job.

	Massachusetts 2015/2016				Nation 2015/2016		
	Percent	Mean wages earned in 2 weeks		Percent	Mean wages earned in 2 weeks	Mean hours worked in 2 weeks	
In an integrated job individual supported job + group supported	30%	*	*	19%	*	*	

Population Data from the American Community Survey (Post 2007)
Social Security Administration
State Demographics

✓ State IDD Agencies
State Vocational Rehabilitation (VR) Agency Data

Reset the form

Select a state



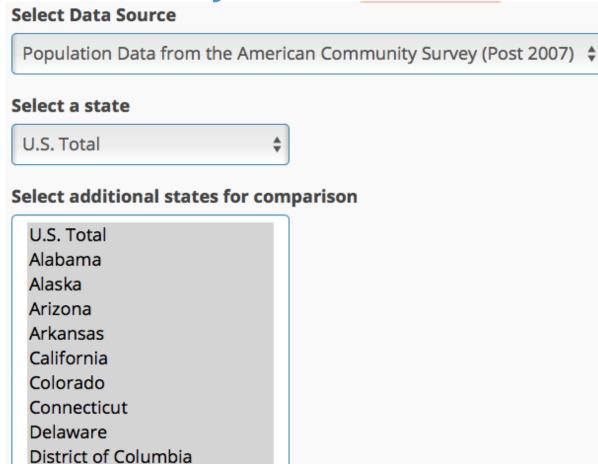
Select additional states for comparison

U.S. Total
Alabama
Alaska
Arizona
Arkansas
California
Colorado
Connecticut
Delaware
District of Columbia

Select a variable *

- Total served
- Integrated employment, number
- Integrated employment percentage

Pro tip #1: Select all states to see a state by state table



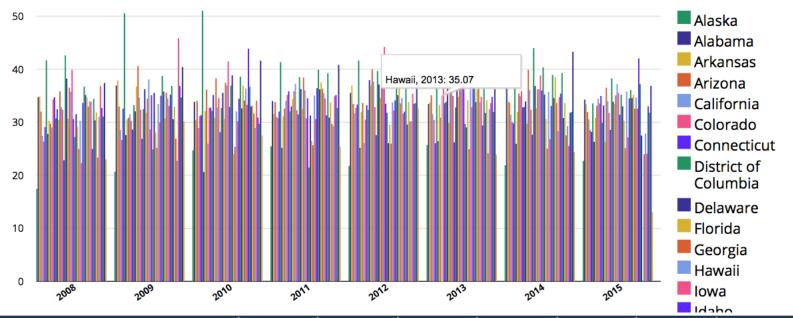
Select a category

Select a variable *

Cognitive Disability \$

ThinkW@rk!

Population Data from the American Community Survey (Post 2007), Cognitive Disability



State	2008	2009	2010	2011	2012	2013	2014	2015
Alaska	17.43	20.68	24.71	25.47	21.75	25.73	21.89	22.71
Alabama	34.76	36.91	33.85	33.98	35.52	33.44	38.78	34.26
Arkansas	34.85	37.88	30.38	31.51	36.95	33.72	33.94	33.36
Arizona	32.01	32.96	34.02	33.81	33.46	35.09	33.73	31.92
California	27.43	28.52	28.91	31.03	31.71	31.56	31.45	30.55
Colorado	26.32	26.65	31.16	30.78	32.73	30.44	30.06	28.51





Pro tip 2:

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West Virginia	37.41	40.40	41.61	40.80	38.53	36.27	43.29	3
Wyoming	22.98	30.15	27.50	25.37	32.62	23.92	24.35	1

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Focus Areas

WIOA Implementation

Pre-employment Transition Services

Section 511: Subminimum wage

Interagency collaboration

Community Life Engagement

Provider capacity

Case Management

Service definition redesign

Funding





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