State of the States in Intellectual and Developmental Disabilities: Project Update

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The Arc of Indiana and INARF
Critical Issues Forum
January 10, 2019
Indianapolis, IN

Overview

I. Financial and Programmatic Trends in the U.S. an Indiana

II. Using Data for Advocacy, Research, and Practice

III. Advancing Technology Use and Adoption

State of the States in Intellectual and Developmental Disabilities

Longitudinal investigation of the determinants of public spending for intellectual and developmental disabilities (IDD) services and supports in the United States

Dr. David Braddock

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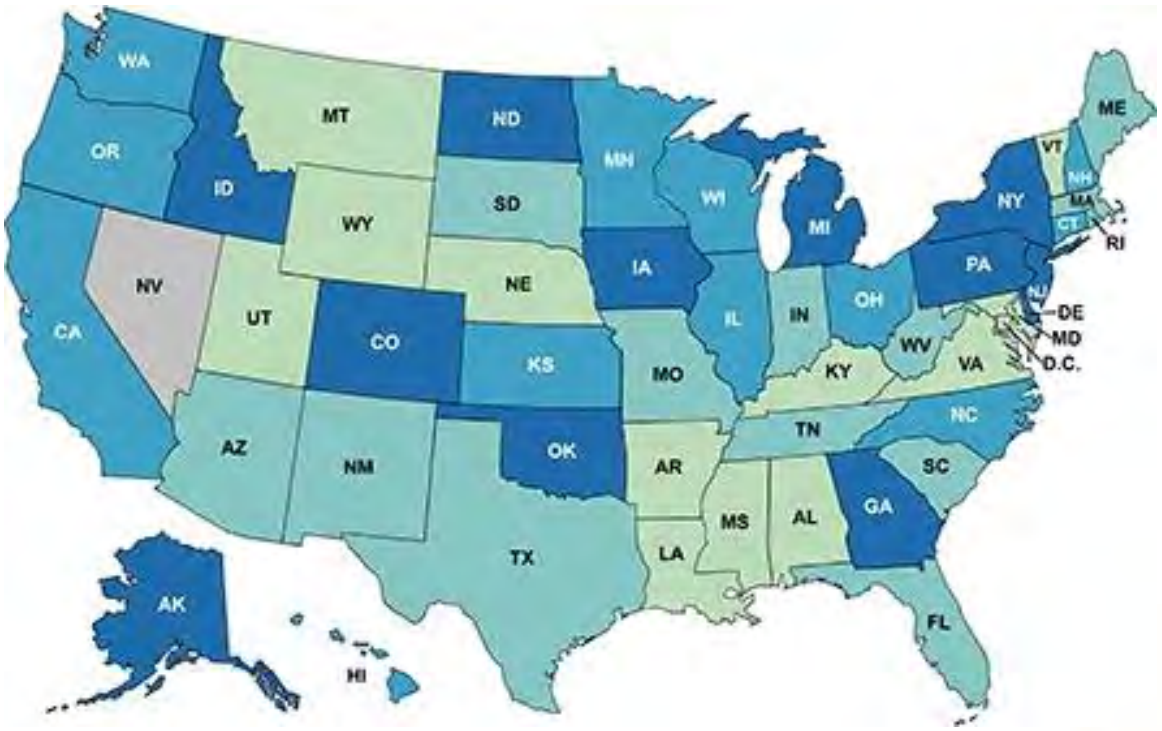
Data Sources



SOCIAL SECURITY ADMINISTRATION USA

United States™ Census Bureau

CMS
CENTERS for MEDICARE & MEDICAID SERVICES

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Key Federal and State Financial Supports Utilized in Data Collection

IINSTITUTIONAL SERVICES FINANCIAL DATA
(16 or more persons)

A. Public 16+ Institutional Services Funds
1. State Funds
    a. ICF/ID Medicaid Match
    b. General Funds (not including state ICF/MR match)
    c. Other State Funds (not including state ICF/MR match)
    d. Local Funds in Excess of Match
2. Federal Funds
    a. Federal ICF/ID
    b. Title XX/Social Services Block Grant
    c. Other Federal Funds

B. Private 16+ Institutional Services Funds
1. State Funds
    a. ICF/ID Medicaid Match
    b. General Funds (not including state ICF/ID match)
    c. Other State Funds (not including state ICF/ID match)
    d. Local Funds in Excess of Match
2. Federal Funds
    a. Federal ICF/ID
    b. Other Federal Funds

Sources: Braddock (1981, 2002a); Braddock, Hemp, & Fujiura (1987).

Key Federal and State Financial Supports Utilized in Data Collection

COMMUNITY SERVICES FINANCIAL DATA
(15 or fewer persons)

A. Community Services Funds for 15 or Fewer Persons
1. State Funds
   a. ICF/ID Medicaid Match
   b. General Funds (not including state ICF/ID match)
   c. Other State Funds (not including state ICF/ID match)
   d. Local/County Funds in Excess of Match
   e. SSI State Supplement Funds

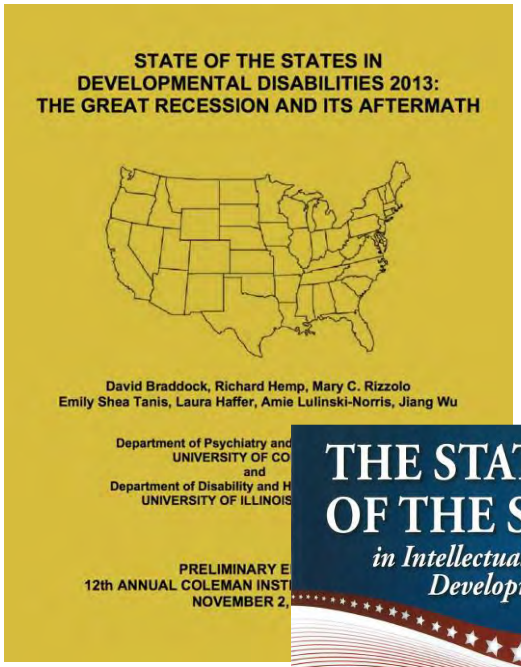
2. Federal Funds
   a. Public ICF/ID (<16)
   b. Private ICF/ID (<16)
   c. HCBS Waiver
   d. Other Medicaid Services
      1. Rehabilitation Services
      2. Clinic Services
      3. Targeted Case Management
      4. Personal Care Services
      5. Other Medicaid Services
   e. Title XX/Social Services Block Grant
   f. Other Federal Funds
   g. SSI and Adults Disabled in Childhood (ADC) benefits – HCBS Waiver participants

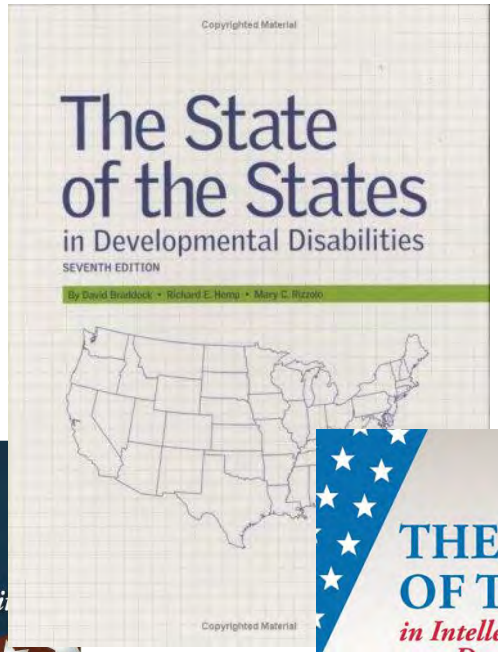
Sources: Braddock (1981, 2002a); Braddock, Hemp, & Fujiura (1987).

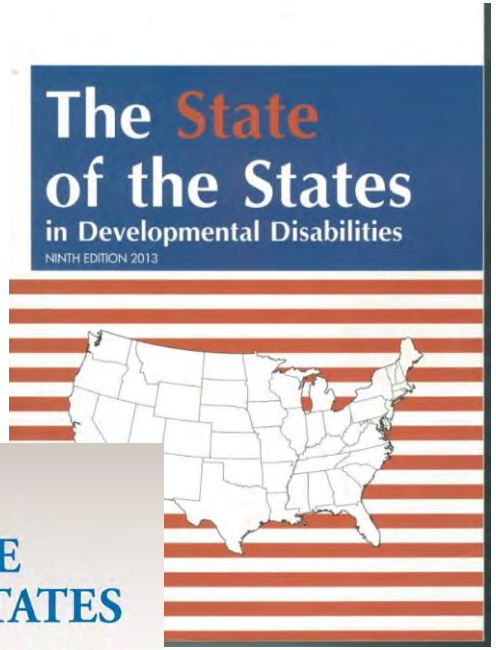
Key Program and Participant Categories

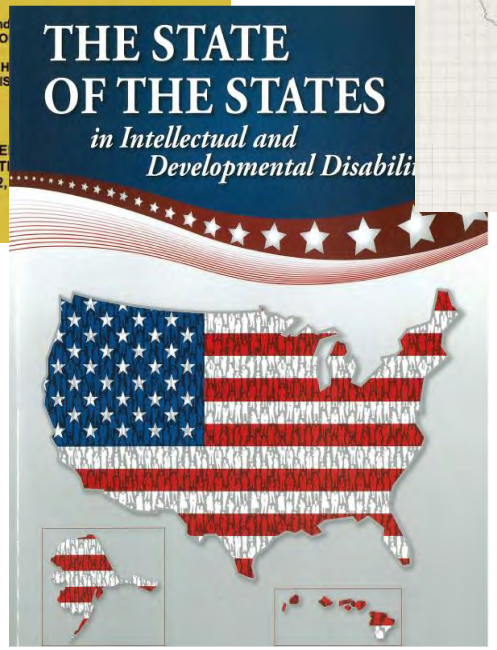
Community and Residential Settings (1-6)	Community and Residential Settings (7-15)	Institutional Settings (16+)	Day/Work Program	**Technology**
• Public/Private ICF/ID • Supported Living • Personal Assistance • Family Support • Other Residential	• Public/Private ICF/ID • Other Residential	• Public/Private ICF/ID • Nursing Facilities • Other	• Sheltered Employment/Work Activity • Day Habitation • Supported Employment	• Smart Homes • Individual Support Technology • Remote Monitoring

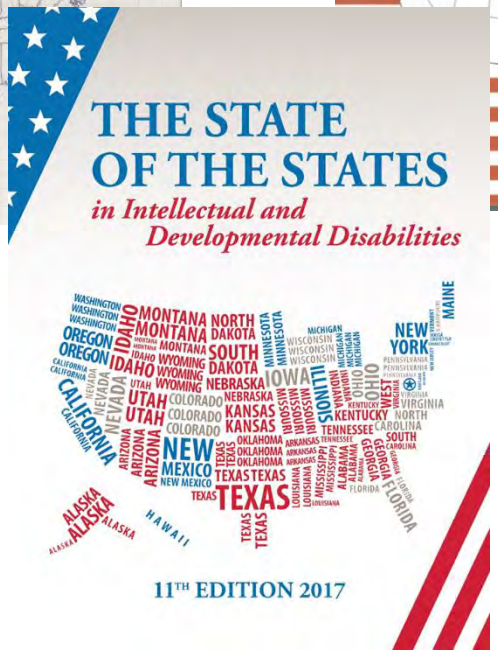
National Publications











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State of the States in IDD in the Future

State of the States in IDD Project

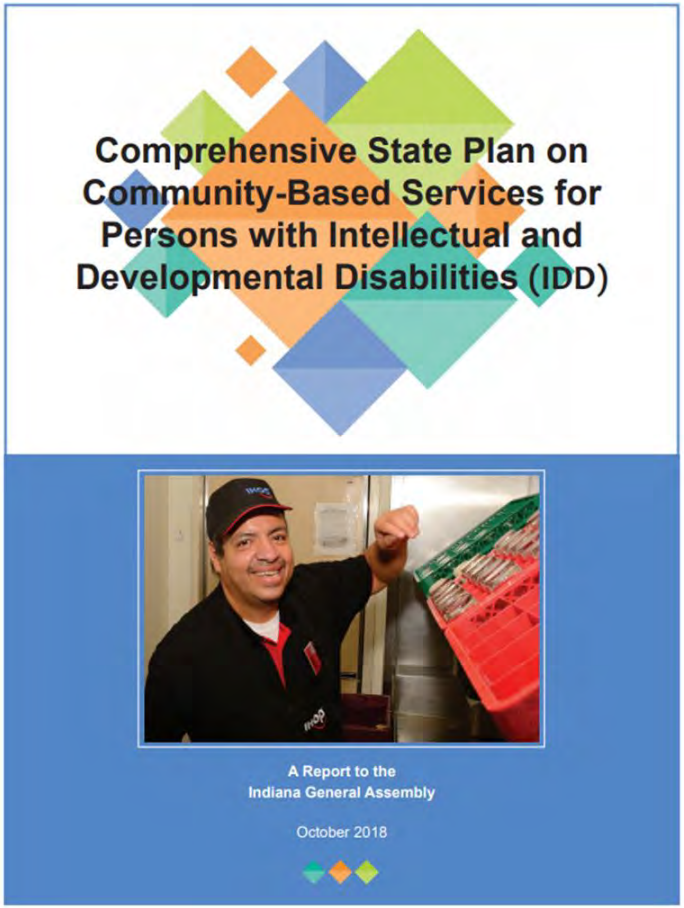
Preserve

- Investigation of key financial determinants of public spending for IDD services and supports
- Purpose to provide advocates, families, policymakers, researchers, and practitioners with the necessary data to drive decision-making and advocacy for local, state, and federal services and supports available to people with IDD and their families

Change

- Impact through diverse project partners
- Dissemination strategies and formats
- Data collection strategies for greater efficacy
- Special studies to address contemporary data needs and investigate new variables for inclusion in project

Indiana's Comprehensive State Plan (2018)



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Indiana Areas of Investigation

- Declining use of institutions
- Growth of:
  - 6 person/fewer settings
  - Nursing homes
  - HCBS waiver
  - Fiscal effort
  - Individual and family support

Preliminary Data

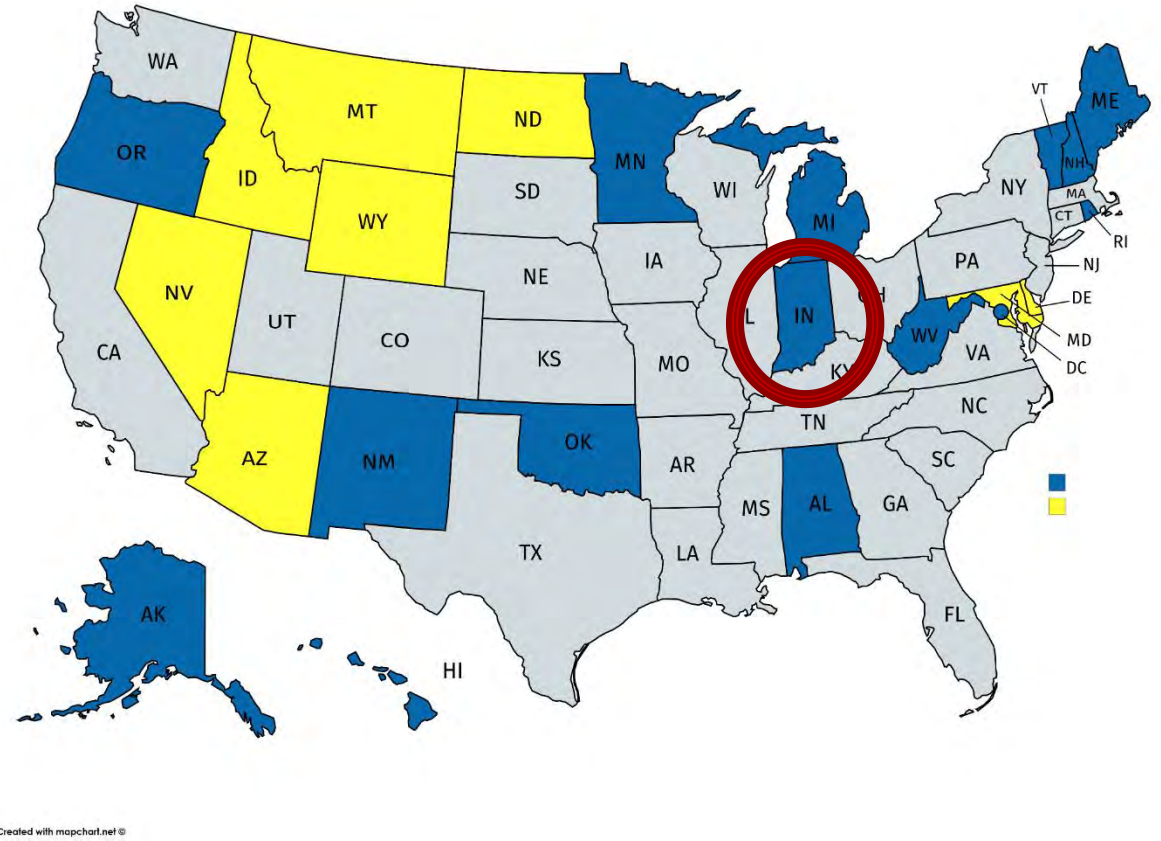
Institutionalization

D. Braddock, University of Colorado, 2007.

SABE, in their 1995 statement about institutions, said “We believe that all institutions, both private and public should be closed. All people regardless of severity of their disabilities should live in the community with the support they need.”

15 States Without State-Operated IDD Facilities in 2017

- Alabama
- Alaska
- District of Columbia
- Hawaii
- Indiana (2013)
- Maine
- Michigan
- Minnesota
- New Hampshire
- New Mexico
- Oklahoma
- Oregon
- Rhode Island
- Vermont
- West Virginia



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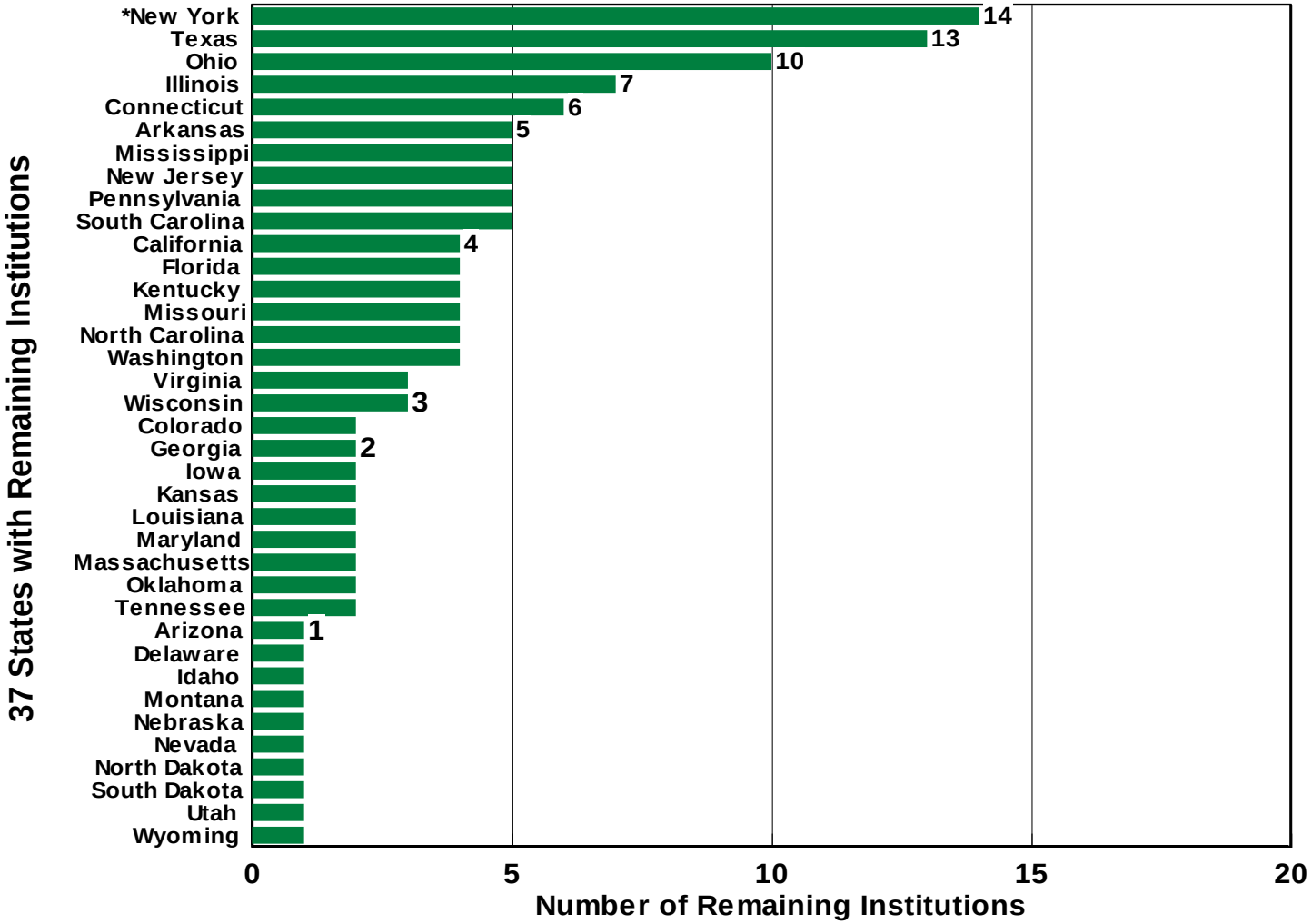
133 State-Operated Remain in 2015



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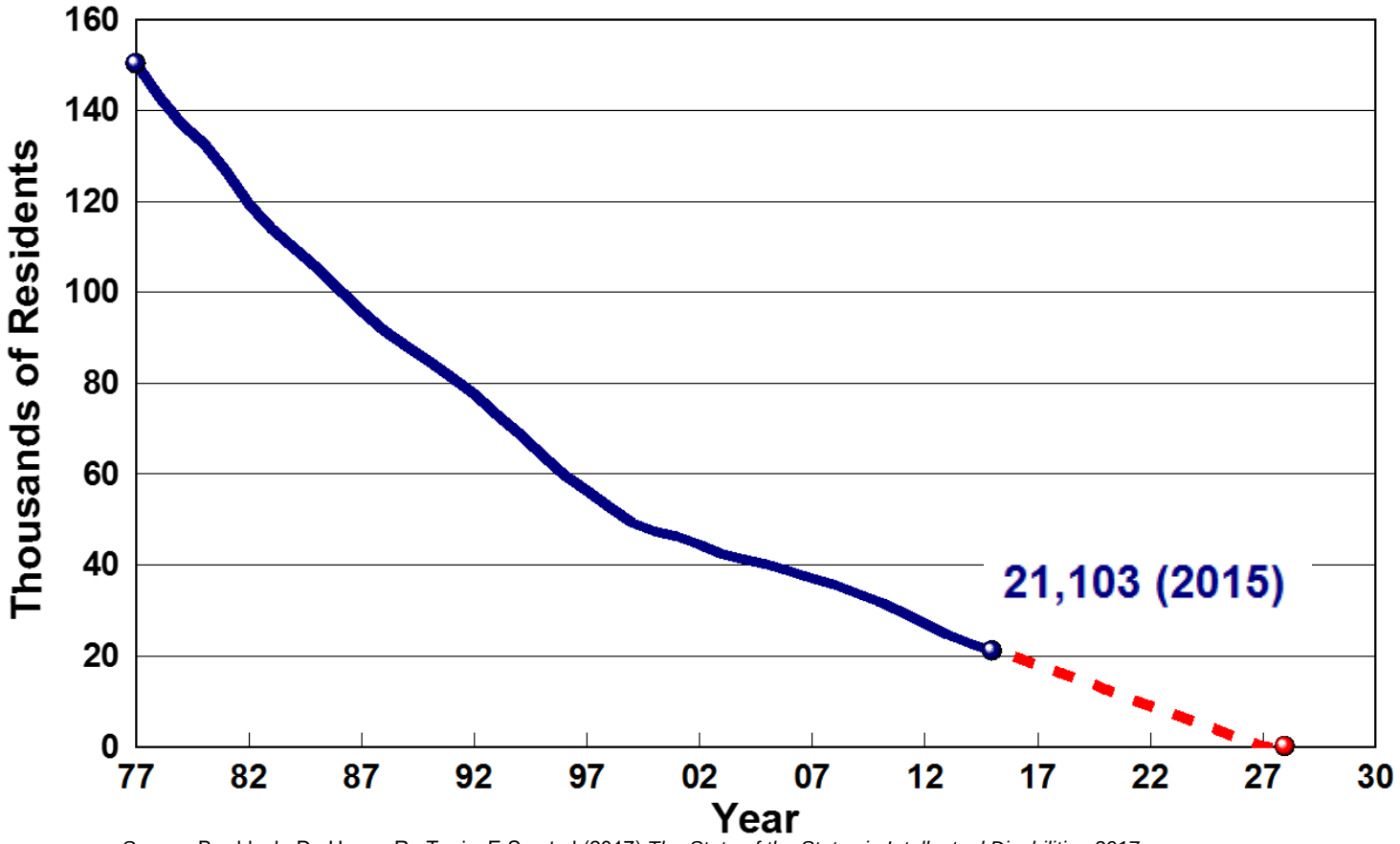
*New York's 14 remaining institutions included two large facilities--Brooklyn and Broome--and12 special units where large institutions had closed.

Source: Braddock, D., Hemp, R., Tanis, E.S., et al.(2017).*The State of the States in Intellectual Disabilities:2017*

Projected Closure of State-Operated Institutions



Source: Braddock, D., Hemp, R., Tanis, E.S., et al.(2017).*The State of the States in Intellectual Disabilities:2017*

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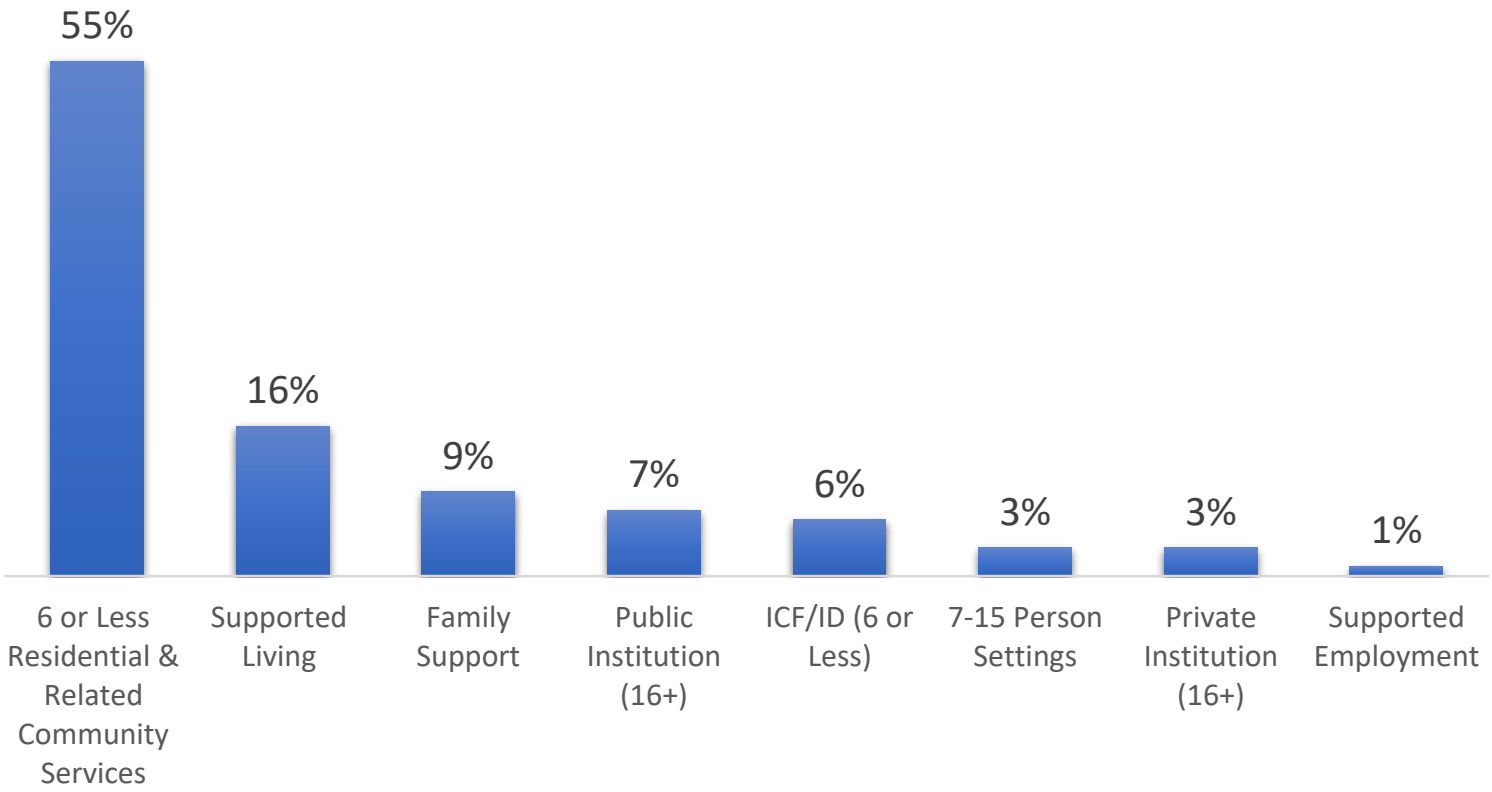
Total IDD Spending by Category in U.S. FY 2017



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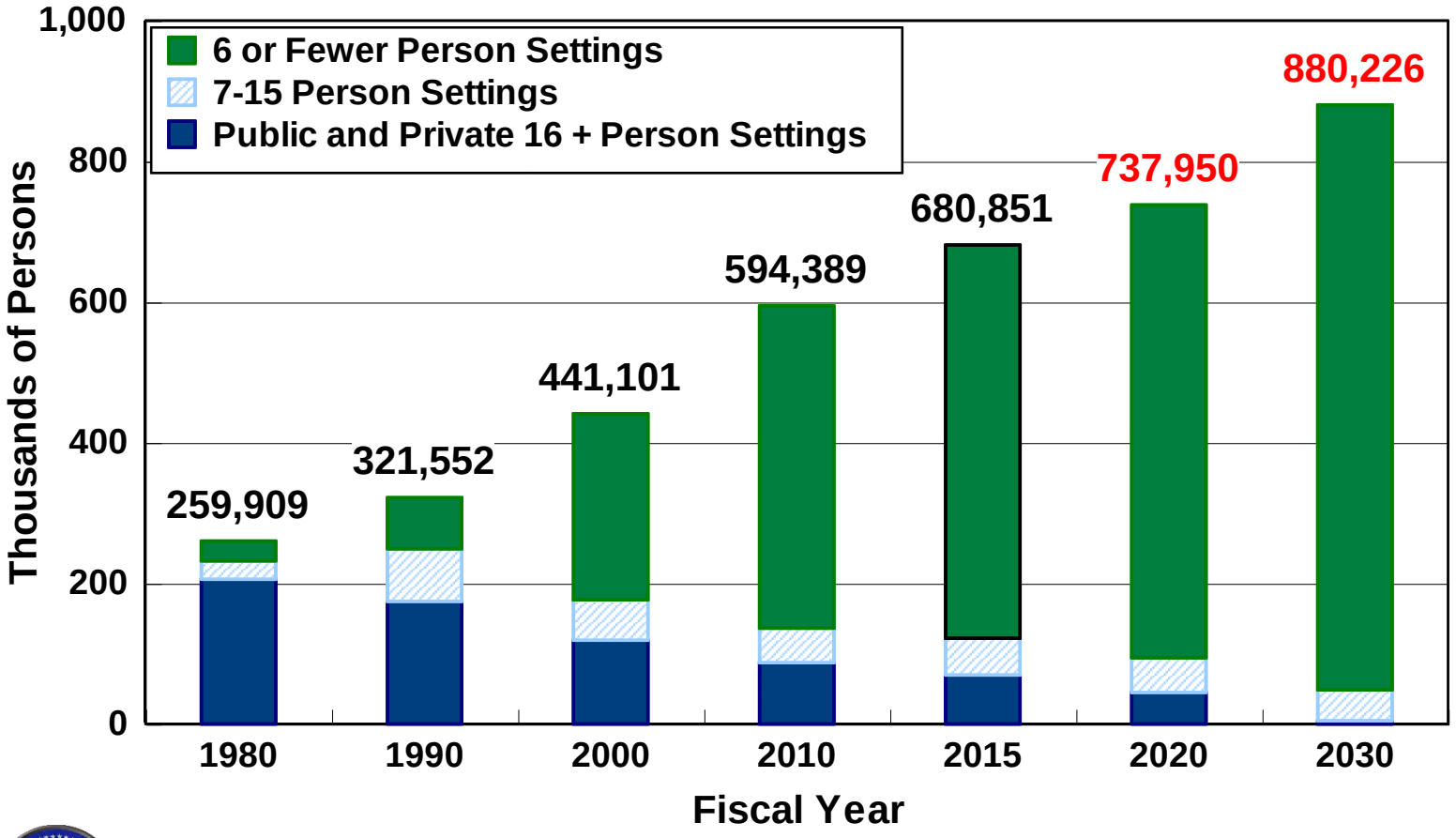
Increased Demand for Six or Fewer Residential Services in the U.S.



Source: Braddock, D., Hemp, R., Tanis, E.S., et al.(2017).*The State of the States in Intellectual Disabilities:2017*

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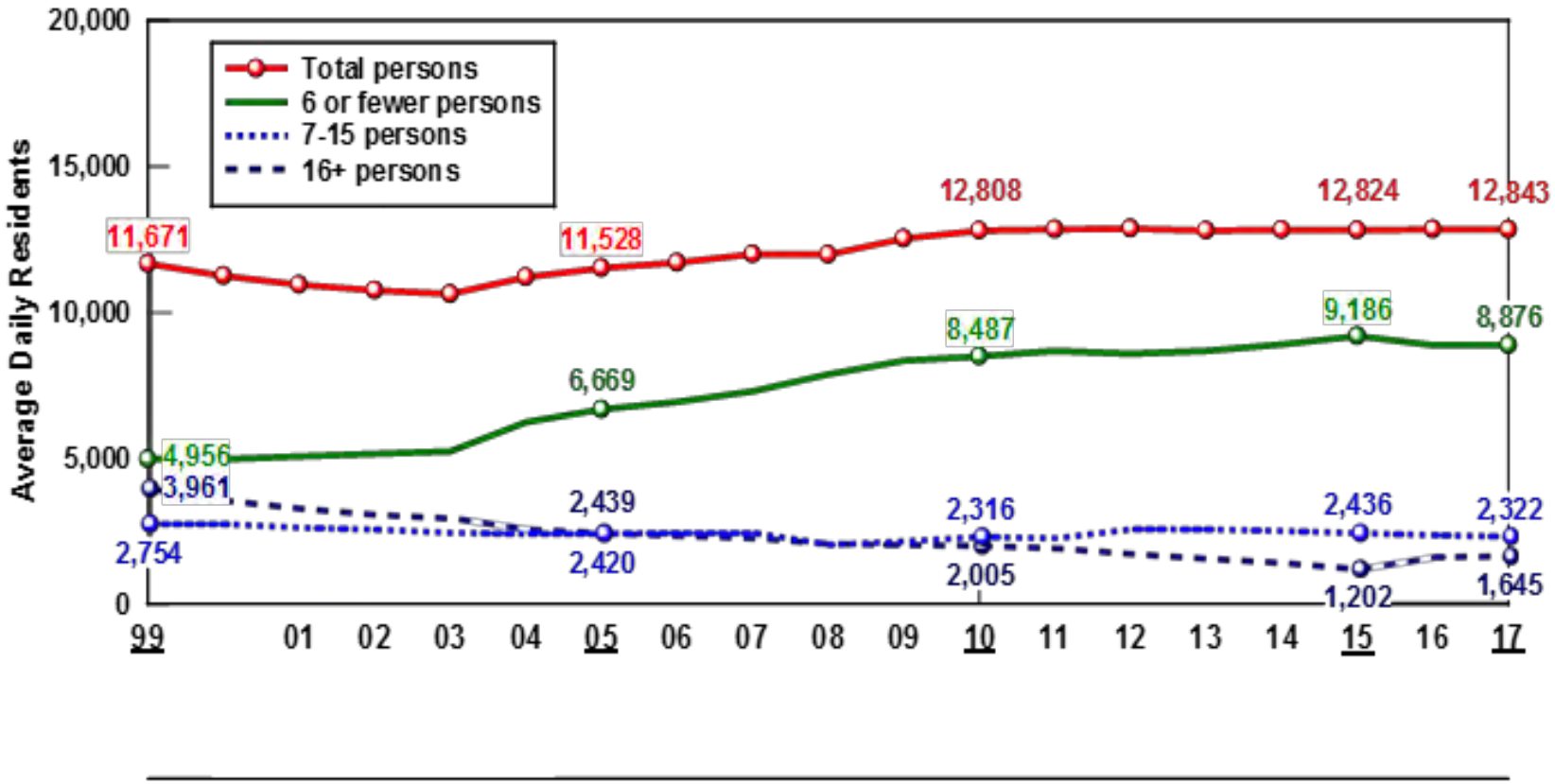
Persons with IDD By Size of Setting: FYs 1999-2017 in Indiana



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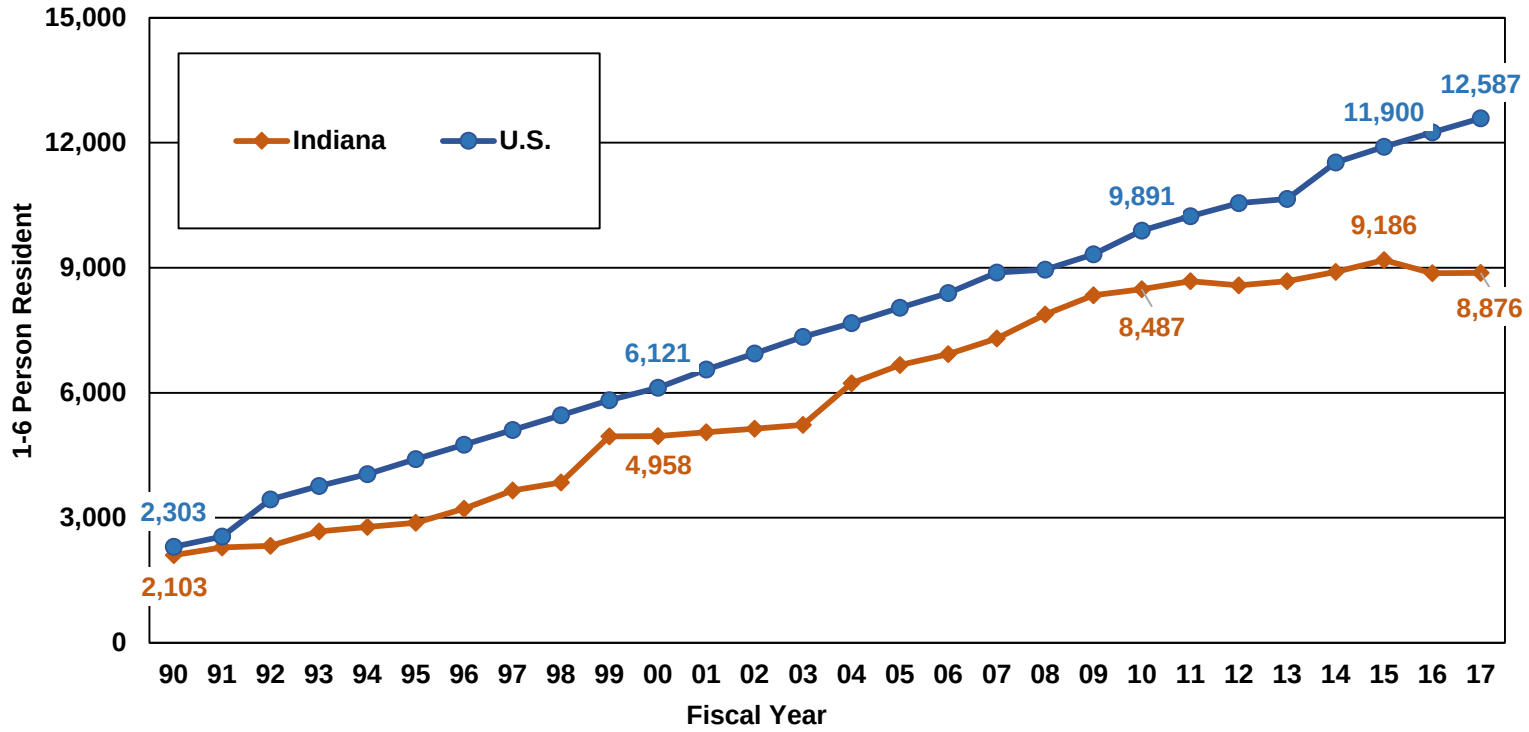
Utilization of Six or Fewer Persons Settings in Indiana is Below U.S.



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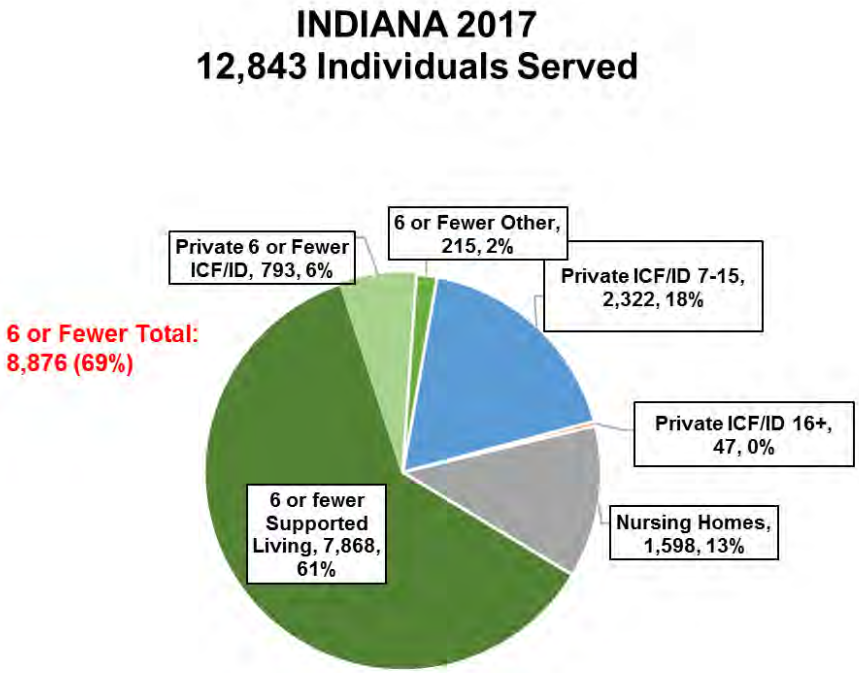
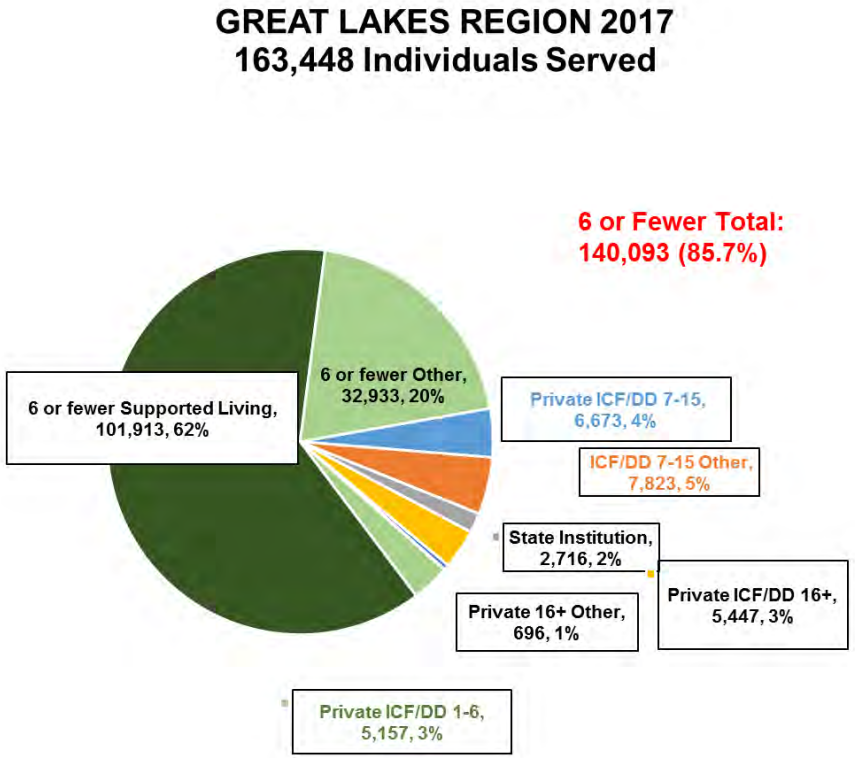
Comparison of Persons with IDD in Out-of-Home Placements: FY 2017





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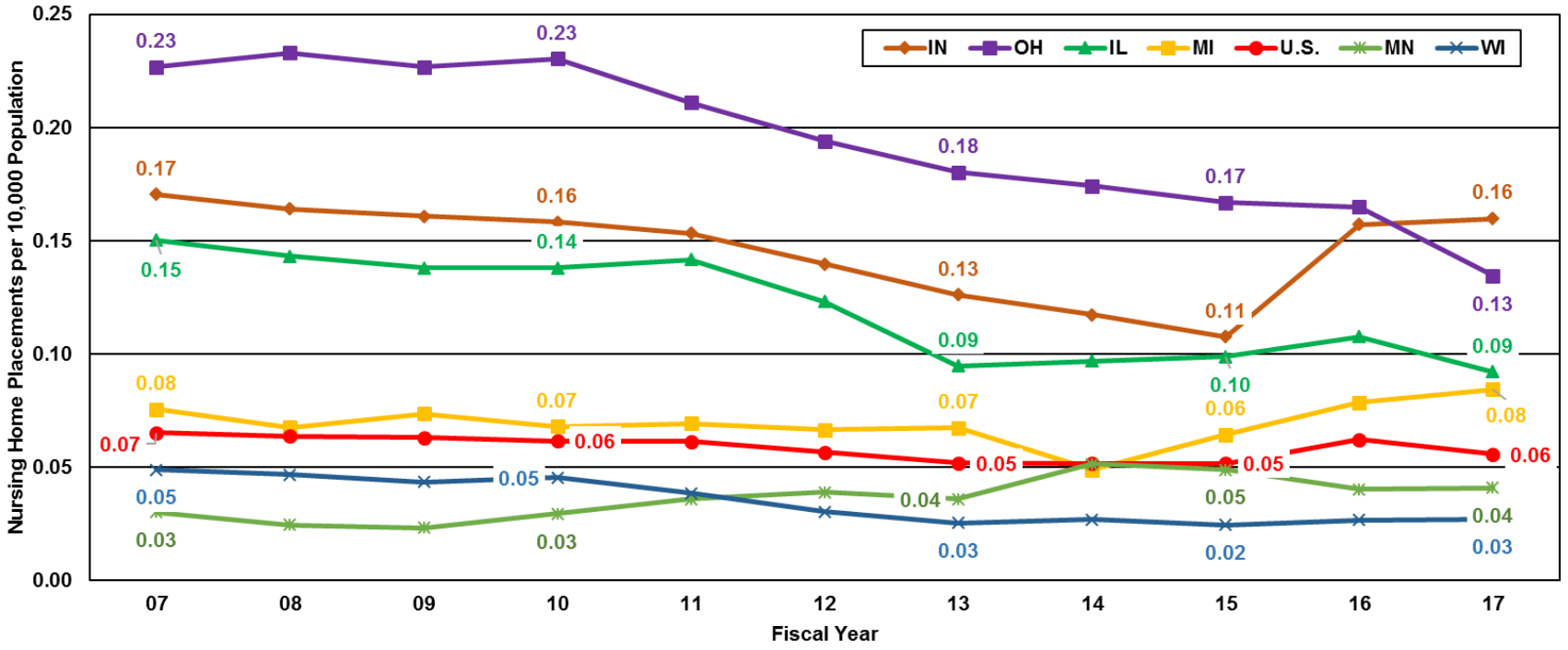
Nursing Home Placement per 10,000 in Great Lakes States



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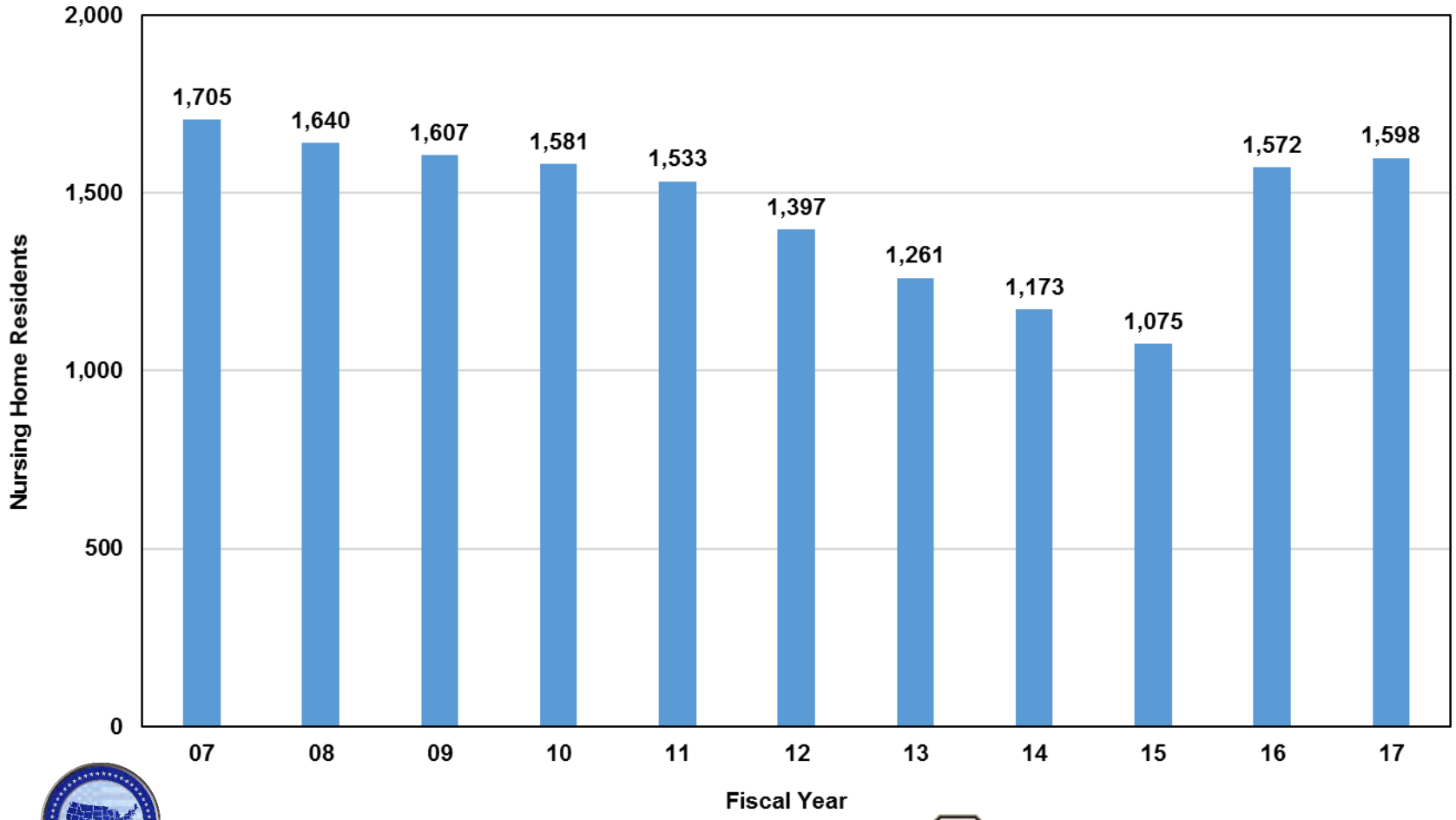
Nursing Home Utilization in Indiana



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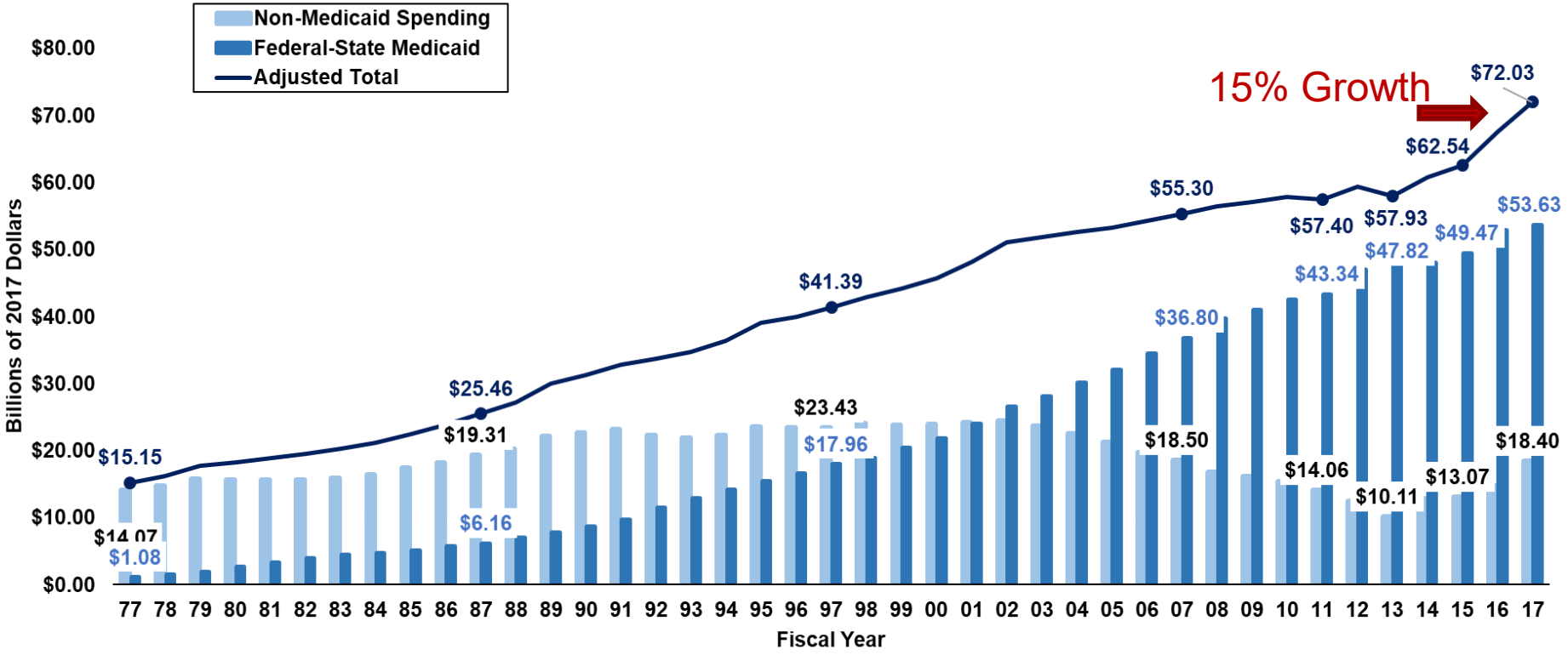
Growth of the Home and Community-Based Services Waiver

HCBS waivers "waive" certain Medicaid requirements applied to Medicaid nursing or other facilities, thereby making Medicaid funding eligible to those living in home-like and family settings.

Sustained Growth of IDD Services Spending in the U.S.: FYs 1977-2017



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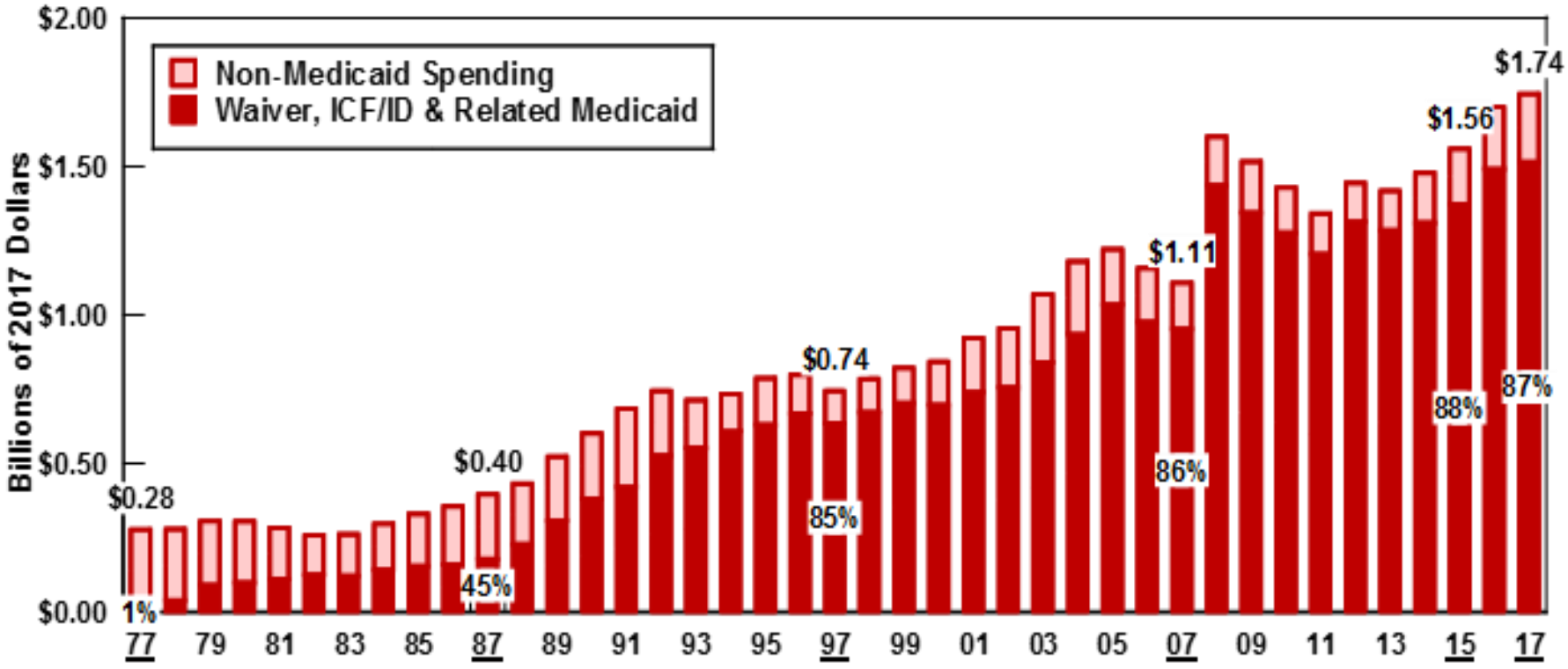
Indiana Total Public IDD Spending for Services: FY 1977-2017



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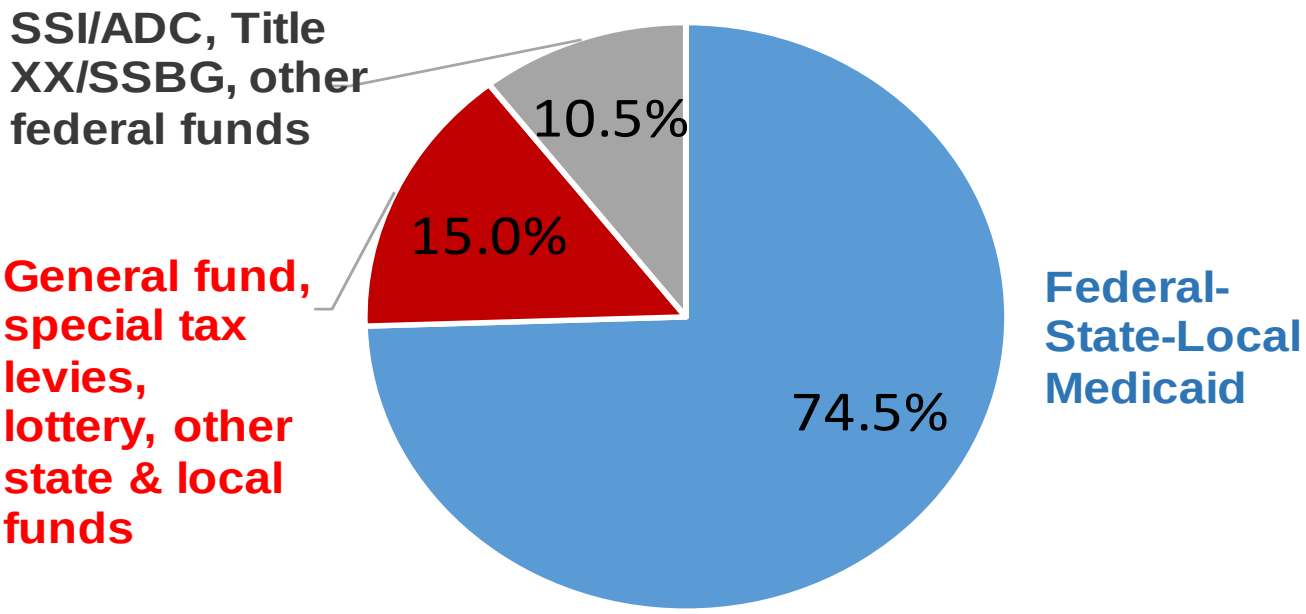
Federal, State, and Local Medicaid Spending in the U.S.: FY 2017



Total Spending $72.03 Billion

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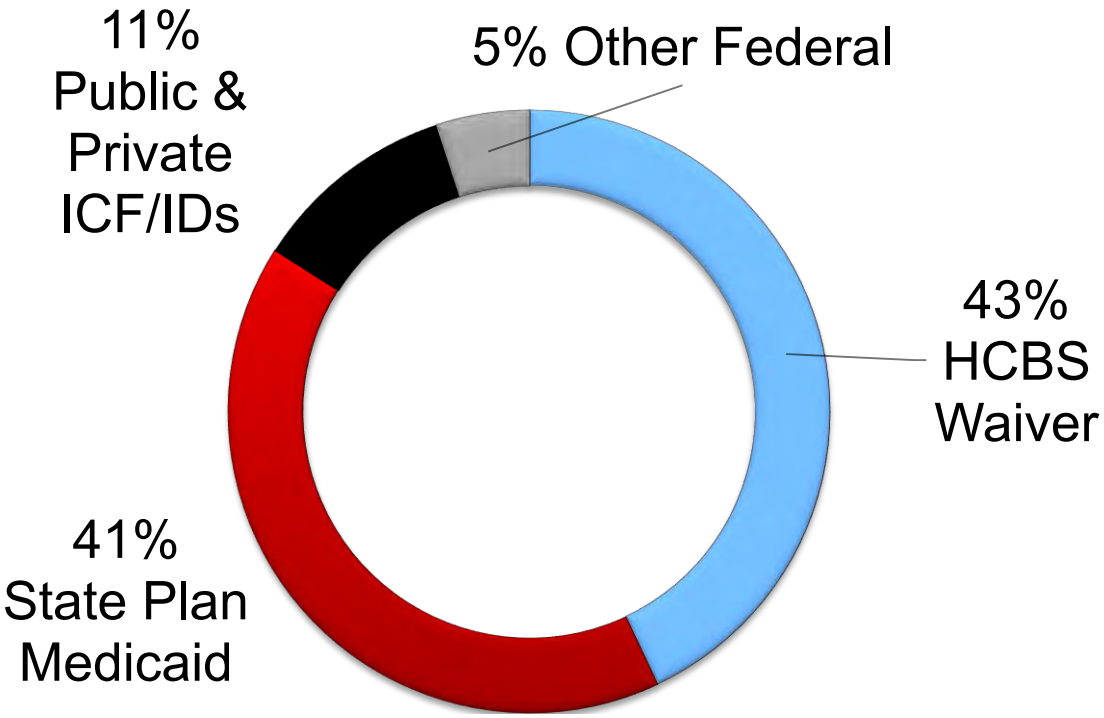
Breakdown of Medicaid Spending U.S.: FY 2017



Total Medicaid Spending $53.6 Billion

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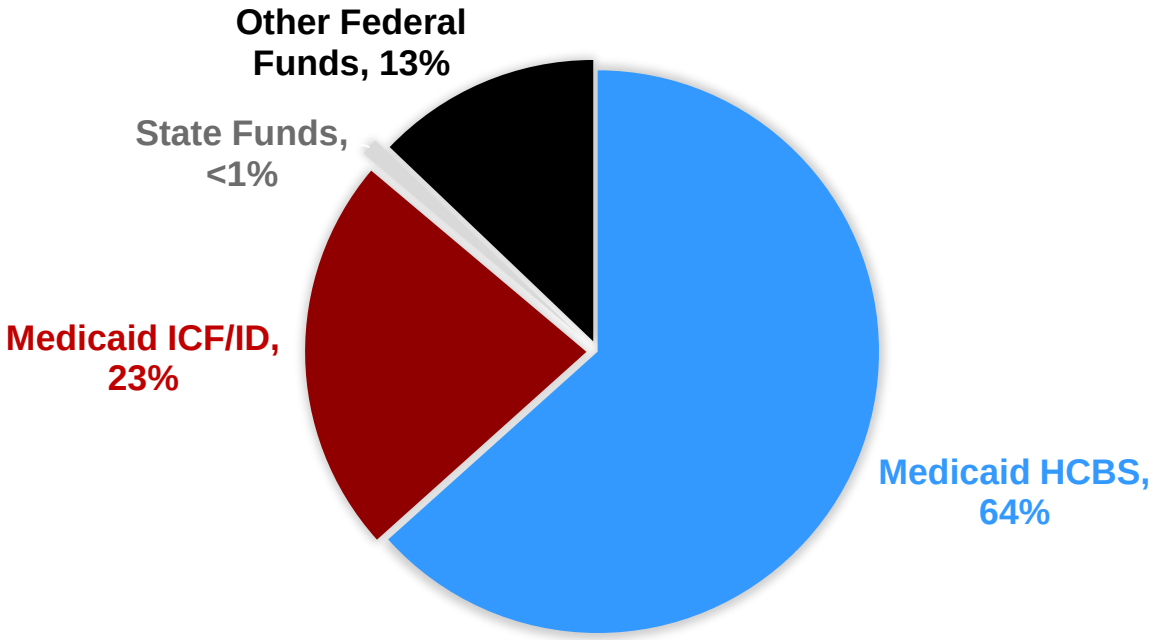
Indiana Federal-State Medicaid As a Percentage of Total IDD Spending in FY 2017



Total IDD Spending: $1.74 Billion
Total Federal-State Medicaid: $1.51 Billion (87%)

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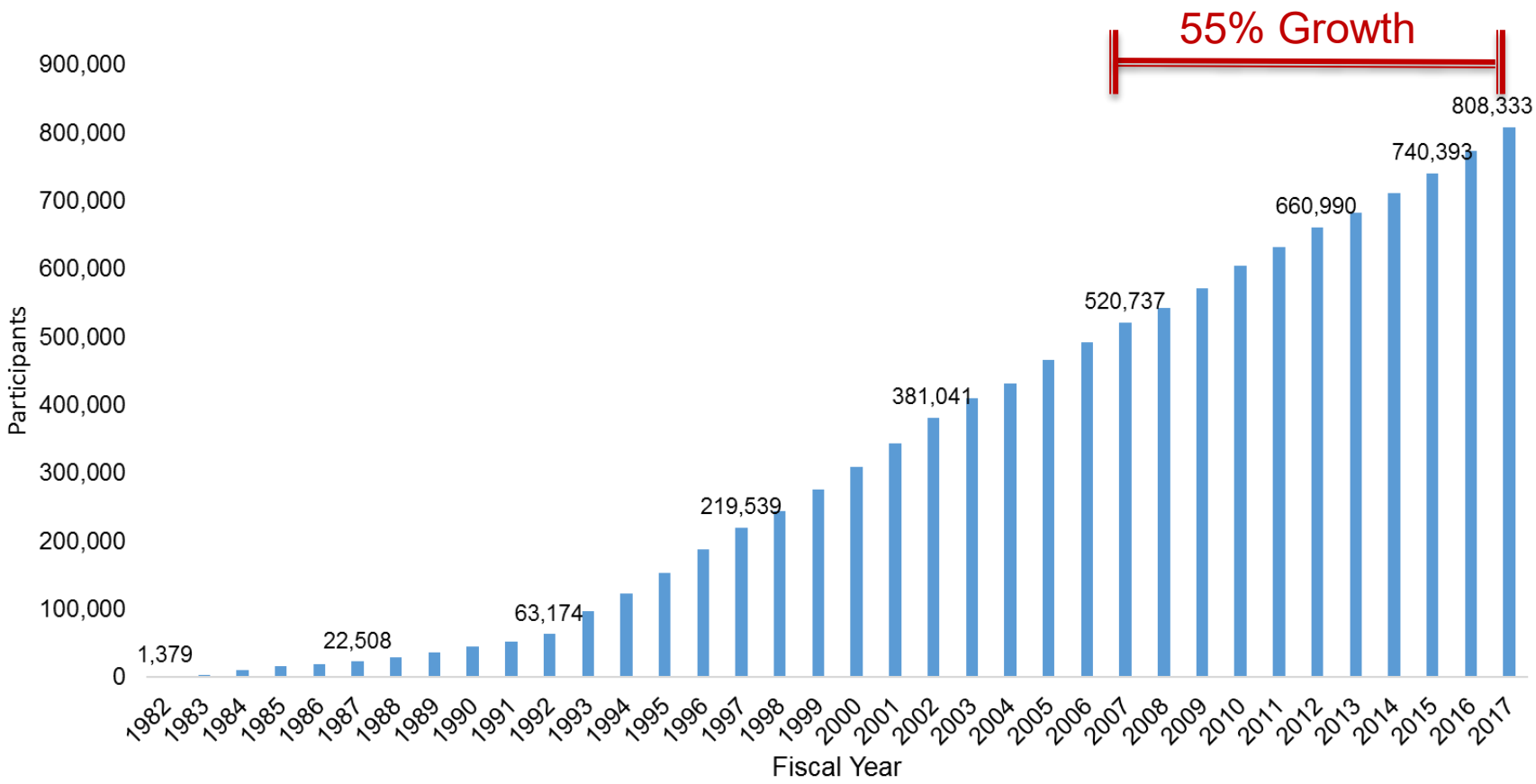
HCBS Waiver Participants with IDD in the U.S.



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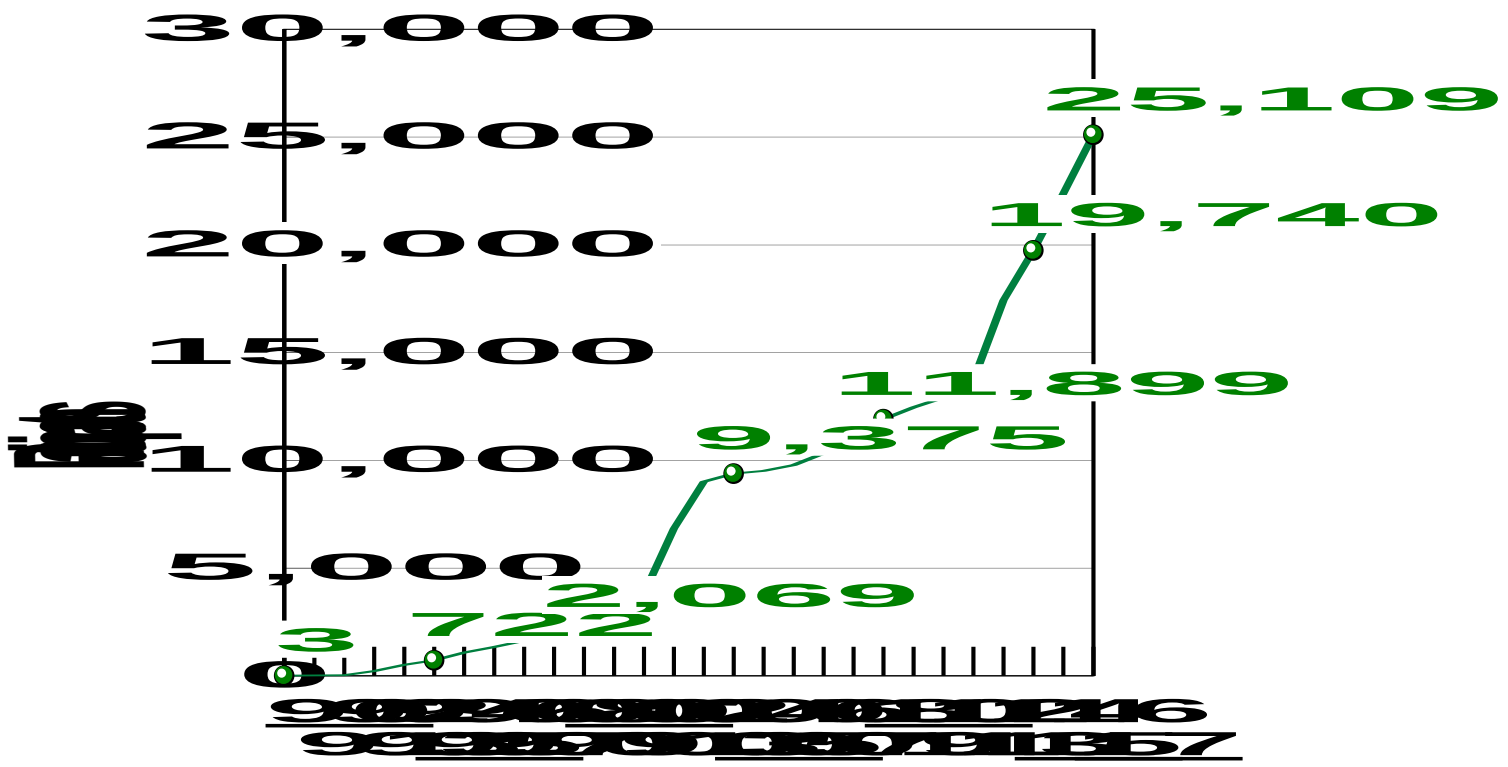
Indiana Waiver Participants



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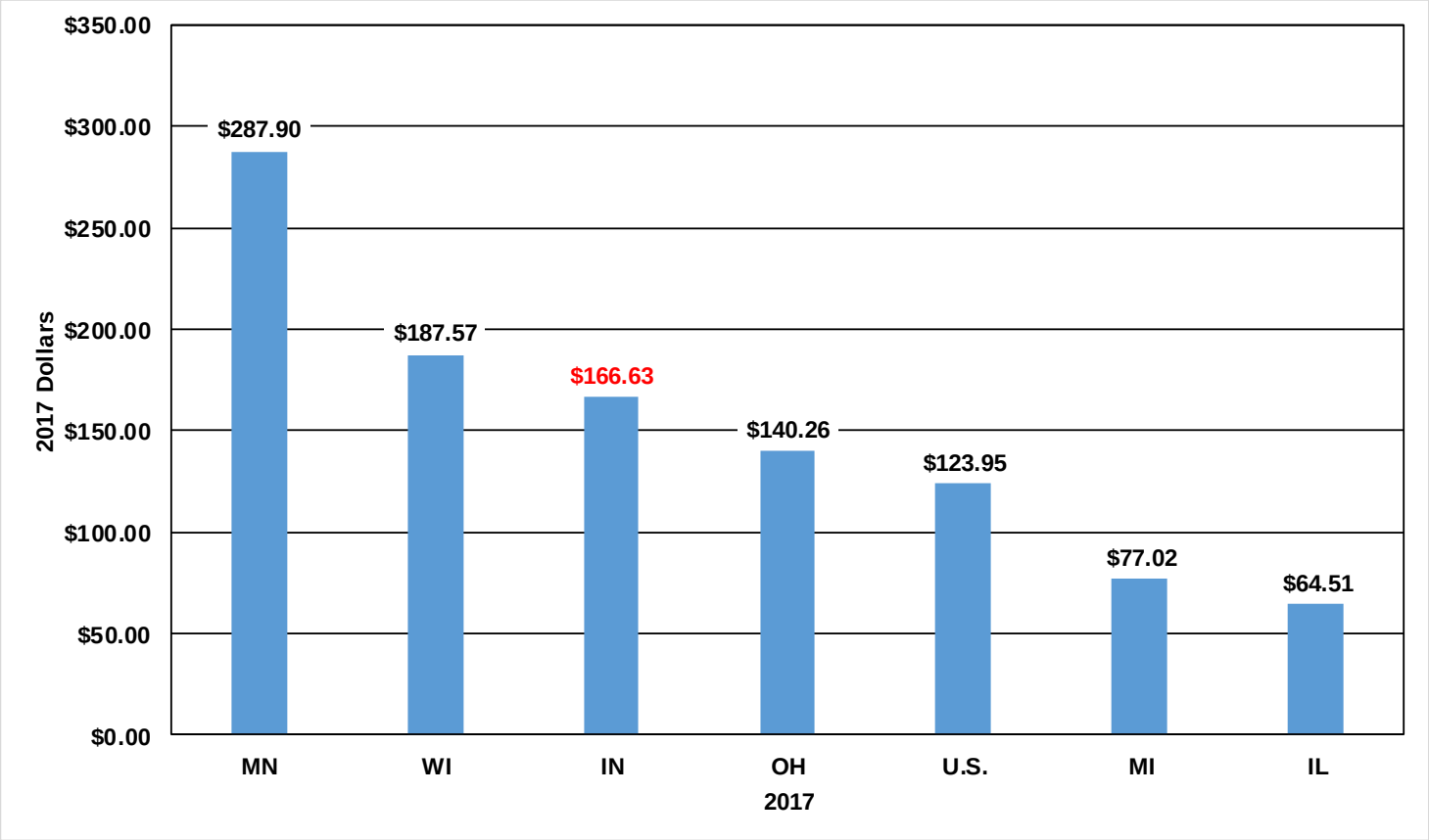
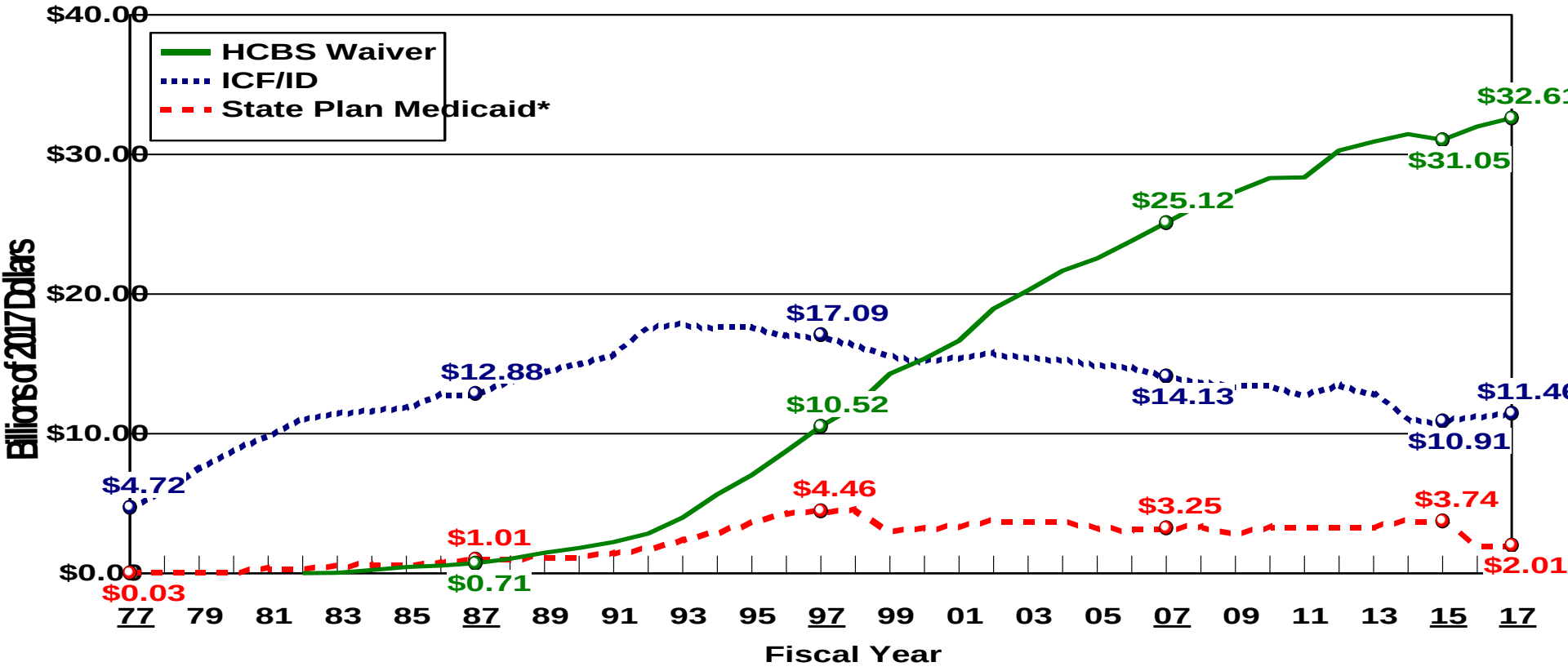
Federal-State Waiver Dollars Per Capita in Great Lakes States



Federal IDD Medicaid Spending By Revenue Source in the U.S.



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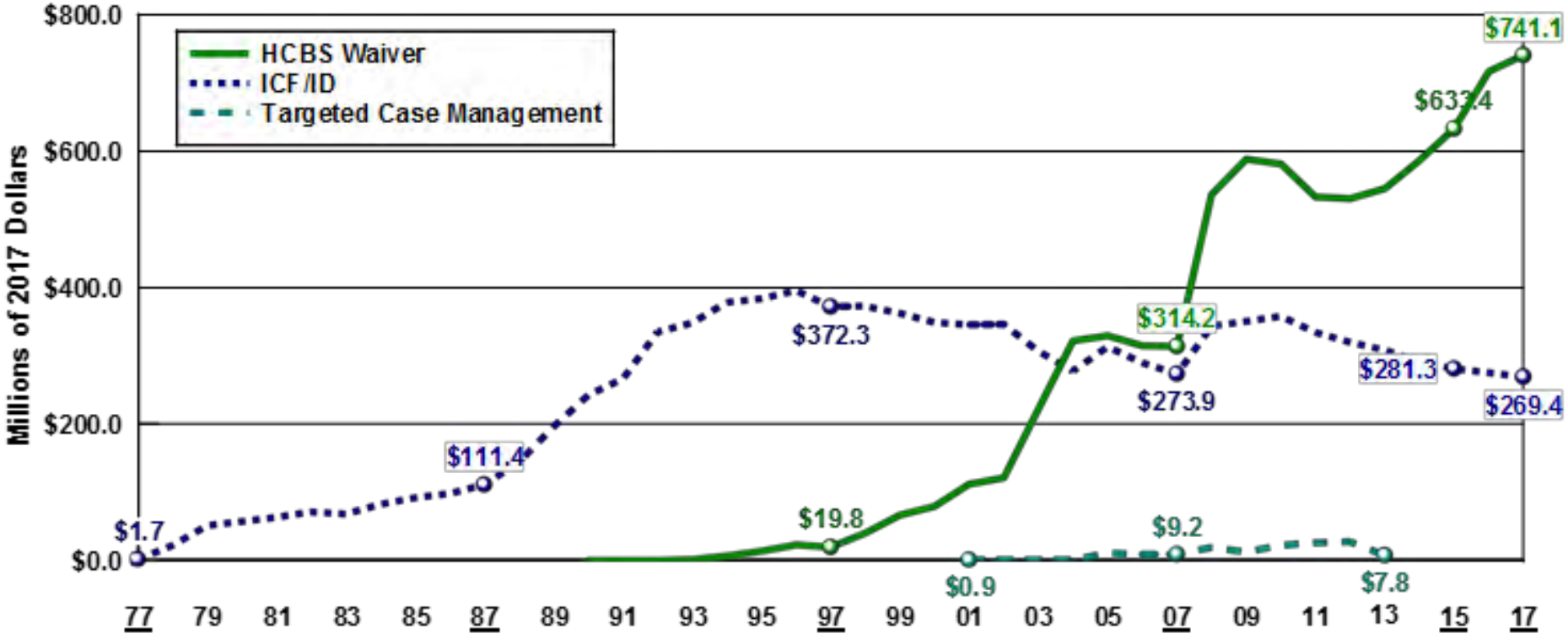
Federal IDD Medicaid Spending by Revenue Source in Indiana



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Waiver Services Provided in Indiana

- Adult Day Services
- Case Management
- Residential-Based Habilitation
- Respite
- Supported Employment
- Behavior Management/Behavior Program and Counseling
- Community Transition
- Environmental Modifications
- PERS
- Specialized Medical Equipment
- Transportation
- Prevocational
- Rent and Food for Live-in Caregiver
- Family Caregiving Training
- Intensive Behavior Intervention
- Residential Habilitation and Support
- Supported Employment Follow-Along
- OT/PT/Speech/Music/Recreation/ Psychological Therapy
- Community-Based Habilitation Group
- Community-Based Habilitation Individual
- Electronic Monitoring
- Extended Services
- Facility-Based Habilitation Group
- Facility-Based Habilitation Individual
- Wellness Coordinator
- Workplace Assistance
- Facility-Based Support Services
- Participant Assistance and Care

Waiver Services To Include

- Crisis services
- Employment discovery
- Self-advocacy training
- Recreation and leisure
- Personal technology supports
- Ride share as transportation

Fiscal Effort

- **Fiscal Effort** is a measure of how much a state spends on IDD LTSS per $1,000 of statewide personal income.
- …in other words, **how much does your state spend after you control for state wealth** – this allows you to compare your state to any other state regardless of state wealth.

U.S. Total Fiscal Effort: $4.41
Indiana Total Fiscal Effort $5.94

U.S. Community Fiscal Effort: $3.89
Indiana Community Fiscal Effort: $5.89

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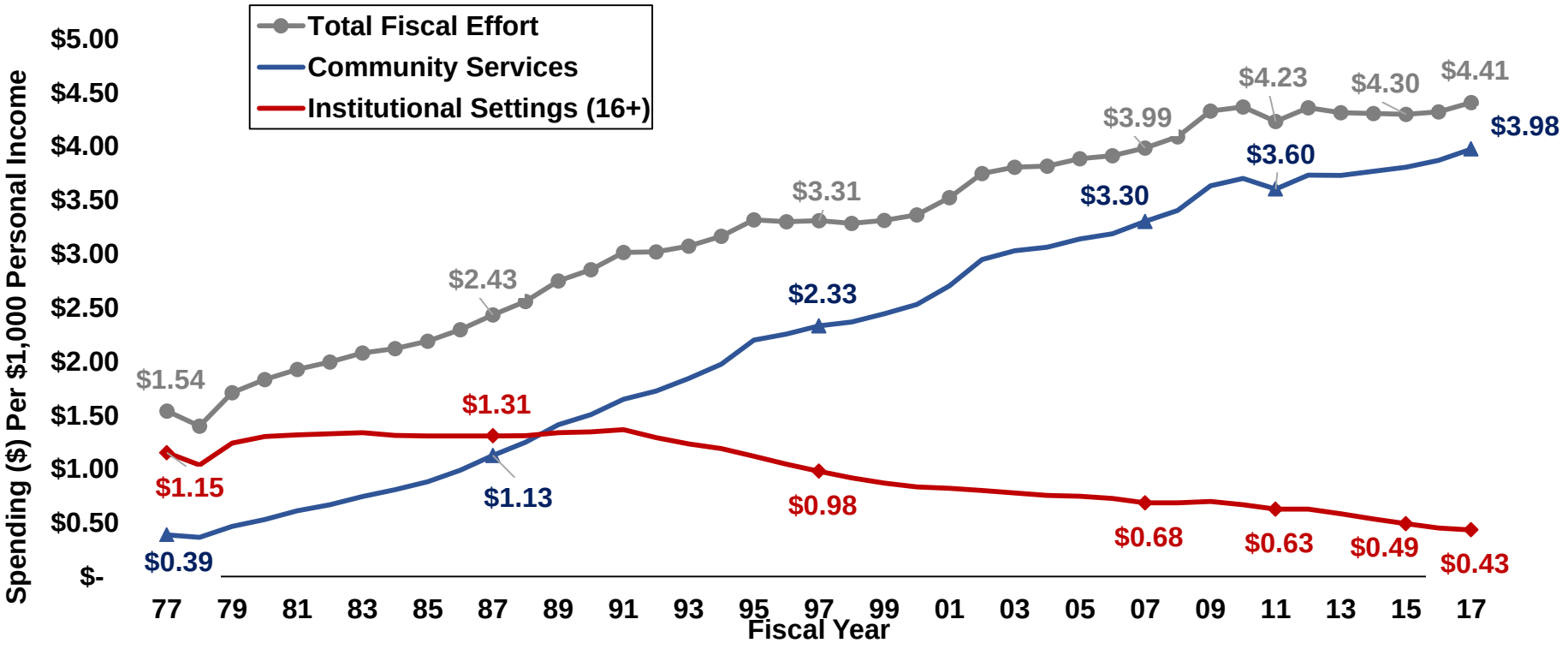
Fiscal Effort for IDD Services in the U.S.: FYs 1977 - 2017



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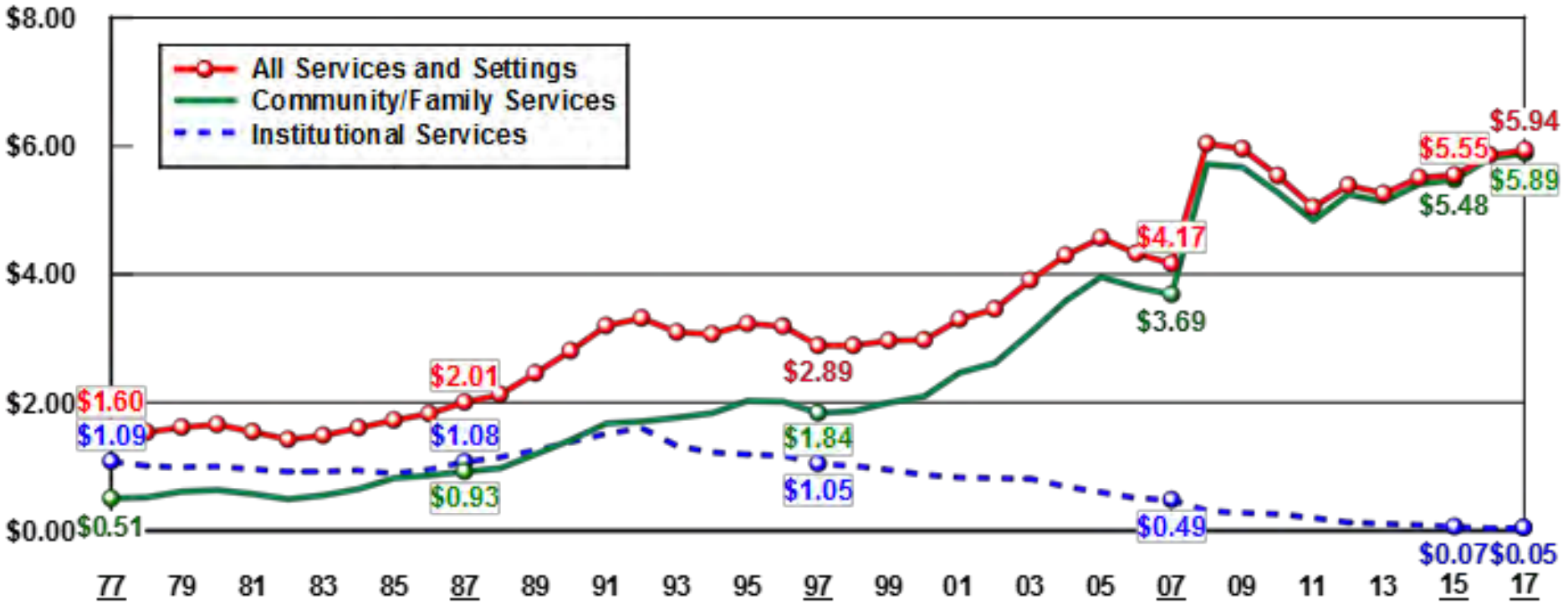
Fiscal Effort for IDD Services in Indiana: FYs 1977-2017



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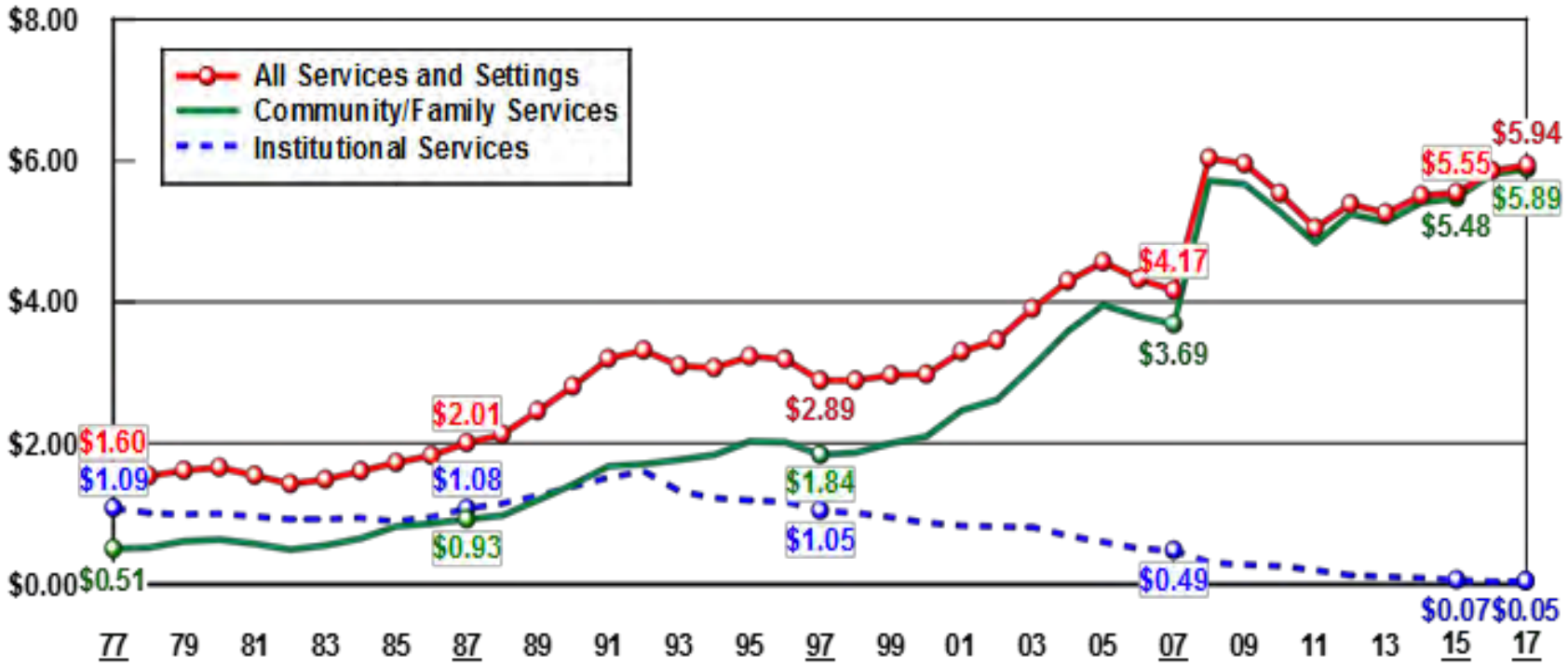
Percent Change in Spending For Community Services in Great Lakes States

State	Percent Change 2015-2017
Indiana	7.50%
Ohio	5.20%
Minnesota	4.30%
Wisconsin	3.90%
Illinois	-1.50%
Michigan	-8.80%
United States	4.50%

Indiana Fiscal Effort for IDD Services: FY 1977-2017



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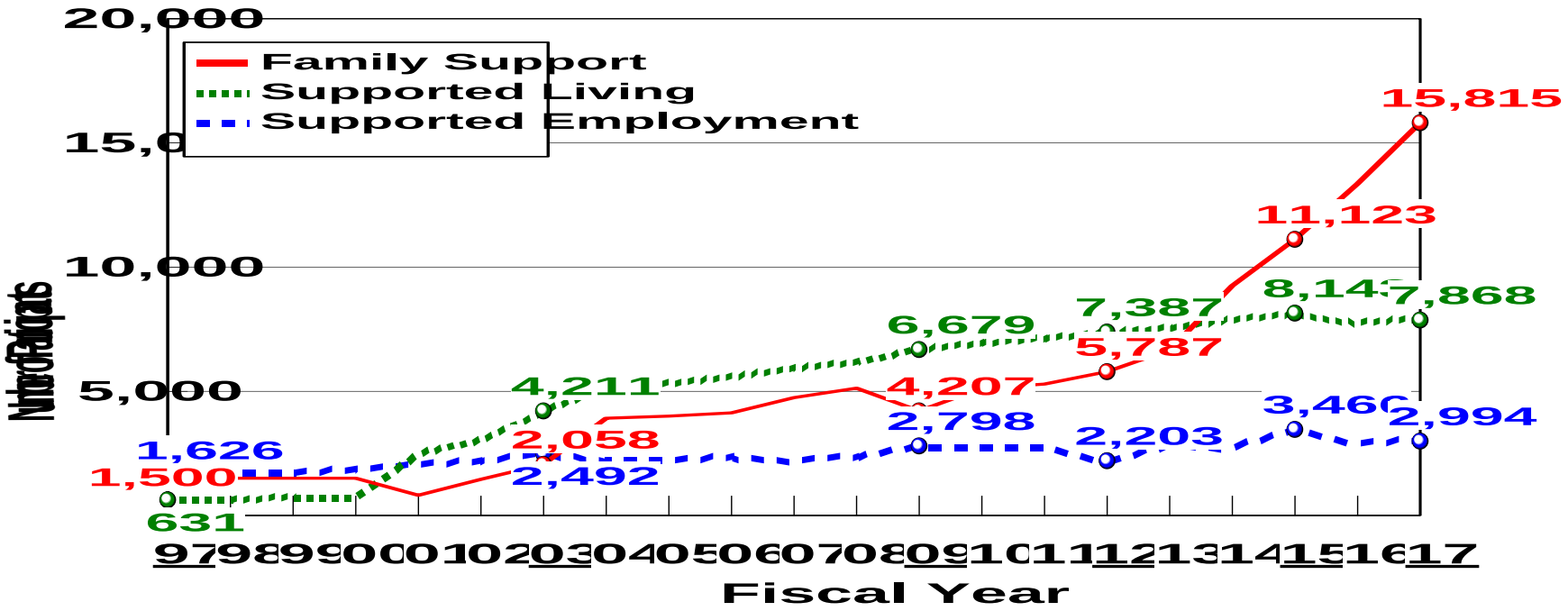
Individual and Family Supports

- Supported Living – choice, independent ownership of one's home, and individualized support are the three principles of supported living and personal assistance
- 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; recreation and leisure; other family support and cash subsidy
- Supported Employment - support of individuals in integrated work settings, work stations in industry, enclaves, or work crews. Broke down employment data in 2016 to align with WIOA

Participants in Individual and Family Support in Indiana



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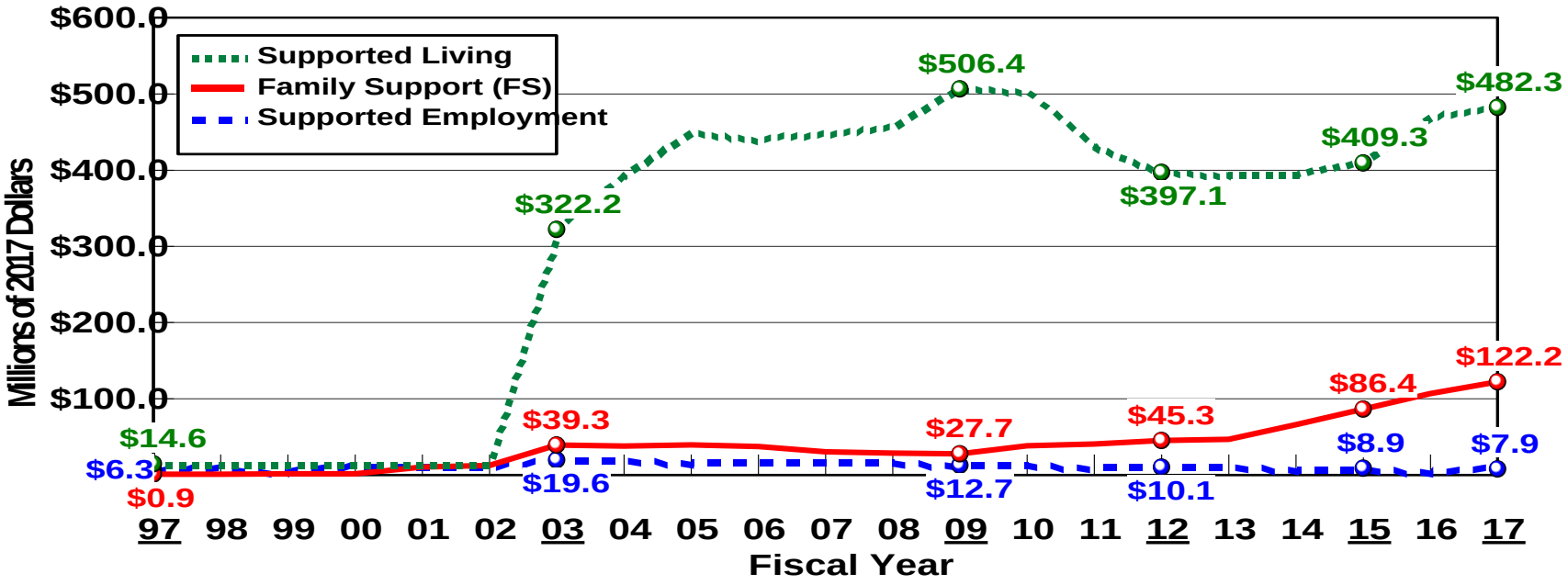
Spending for Individual and Family Support in Indiana



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Supported Employment

- In 2016, 10% of individuals (1,714) in Indiana participating in integrated employment services as compared to 19% nationally

  – StateData, UMASS Boston
- 40% of individuals do not have a paid job and would like a job in the community in Indiana

  – National Core Indicators
- 21% of people have community employment as a goal in their service plan as opposed to 20% nationally

  – National Core Indicators

Systems of Support for Every Stage of Employment Lifecycle

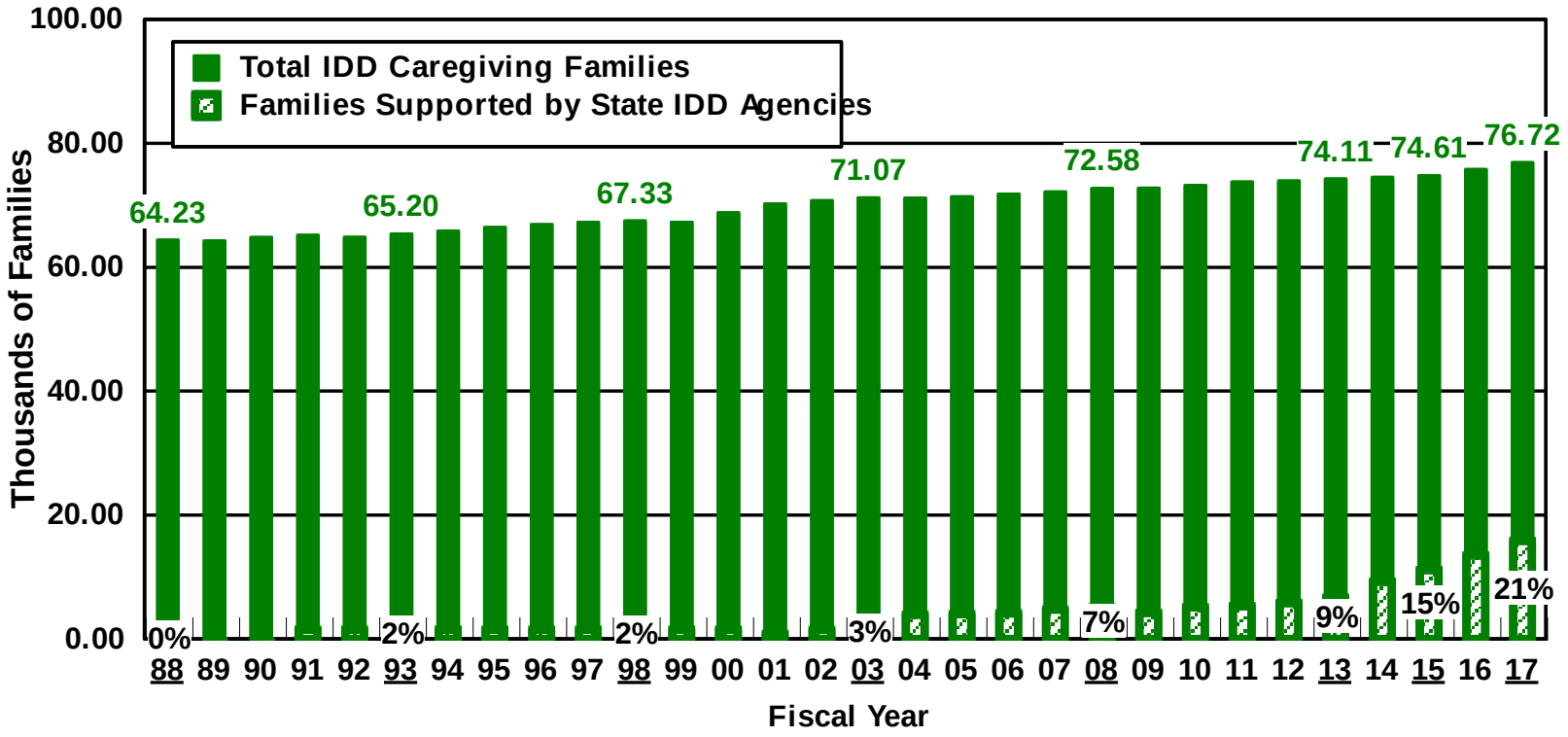
Family Support

Caregiving Statistics in The U.S.

- About 34.2 million Americans have provided unpaid care to an adult age 50 or older in the last 12 months
  - National Alliance for Caregiving and AARP, 2015

- At $470 billion in 2013, the value of unpaid caregiving exceeded the value of paid home care and total Medicaid spending in the same year, and nearly matched the value of the sales of the world's largest company Wal-Mart ($477 billion)
  - AARP Public Policy Institute, 2015

Estimated Number of IDD Caregiving Families and Families Supported by IDD Agencies in Indiana: FY 1988-2017



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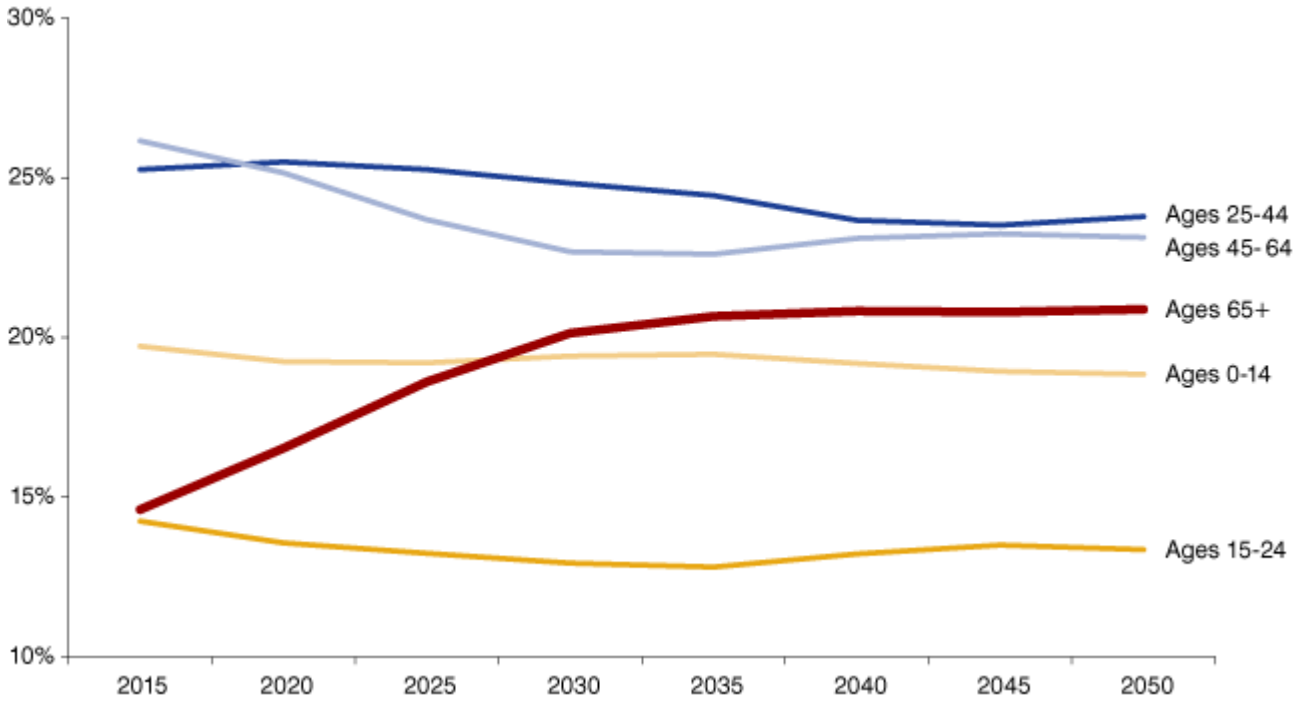
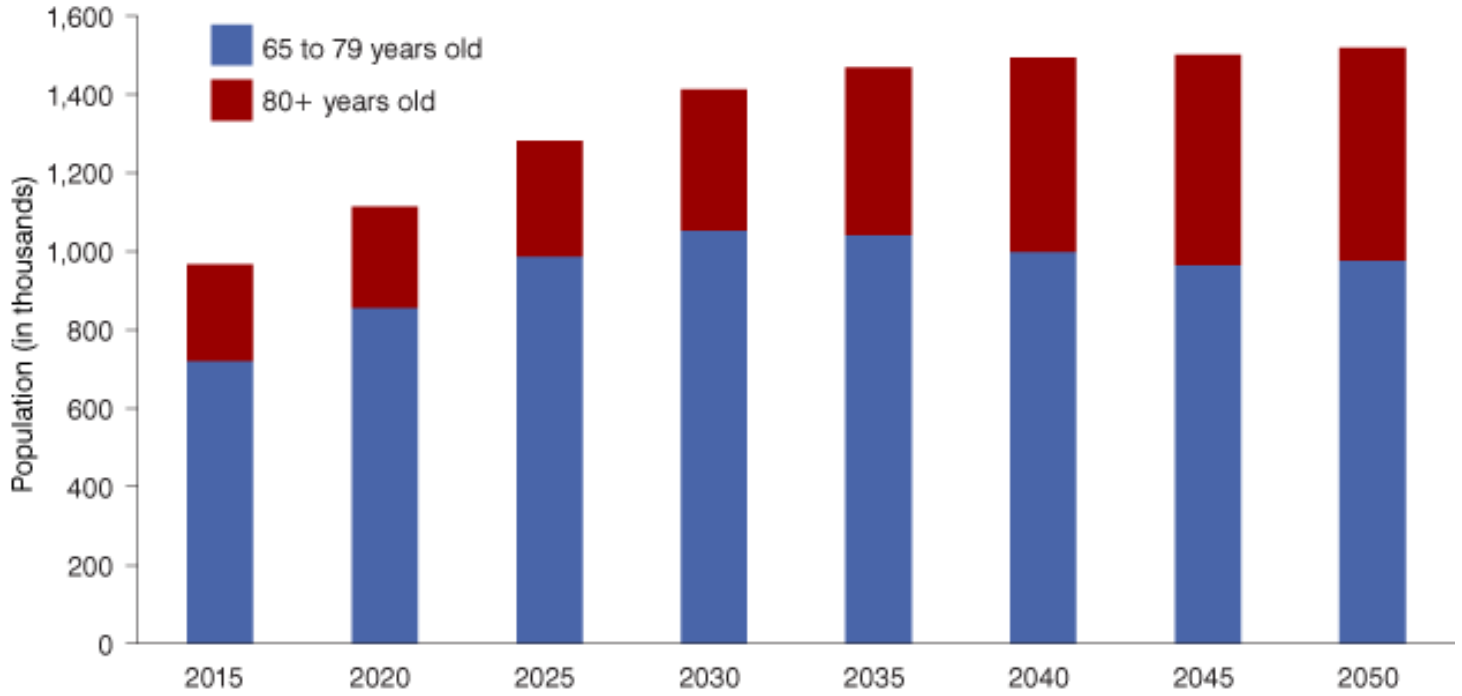
Indiana's Aging Population: Projected Share of Total Population by Age Group, 2015 -2050



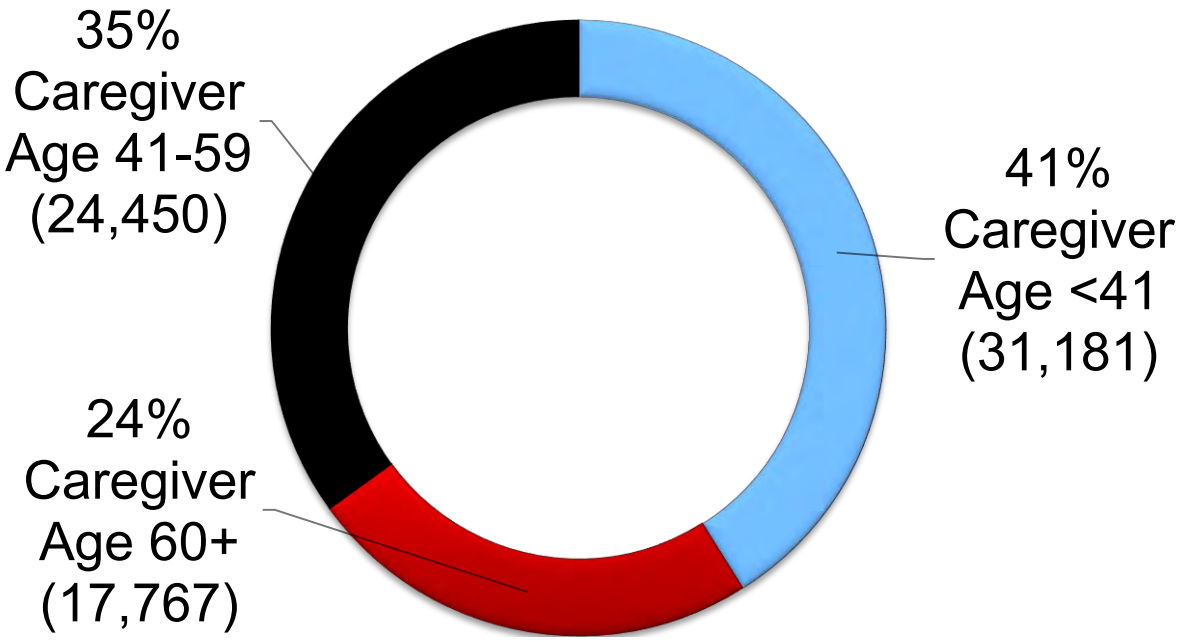
Kinghorn, M. (2016). Indiana population projections to 2050. *InContext,* Indiana Business Research Center, Indiana University Kelley School of Business.

Indiana's Projected Senior Citizen Population



Strange, R., (2018). Indiana's elderly population projected to climb sharply. *InContext* Indiana Business Research Center, Indiana University Kelley School of Business.

Estimated Number of Individuals with IDD Living with Family Caregivers in Indiana: FY 2017



Total: 75,398 Persons

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Summary of Findings

- Indiana is one of 15 states without state operated IDD facilities and 47 individuals utilize private 16+ residential facilities
- Number of individuals served in 6 or fewer or 7-15 person settings has plateaued
- Utilization of 6 or fewer settings is below the national average
- Indiana has a higher utilization rate of nursing homes than the U.S. and any surrounding states

Summary of Findings (Continued)

- Total spending for IDD services has increased (but only slightly)
- Percent change in community fiscal effort is above the national average
- Waiver spending and participants have increased
- Decrease in supported employment participants and spending
- Family support participants and spending increased
- Only 21% of families are supported by IDD agencies

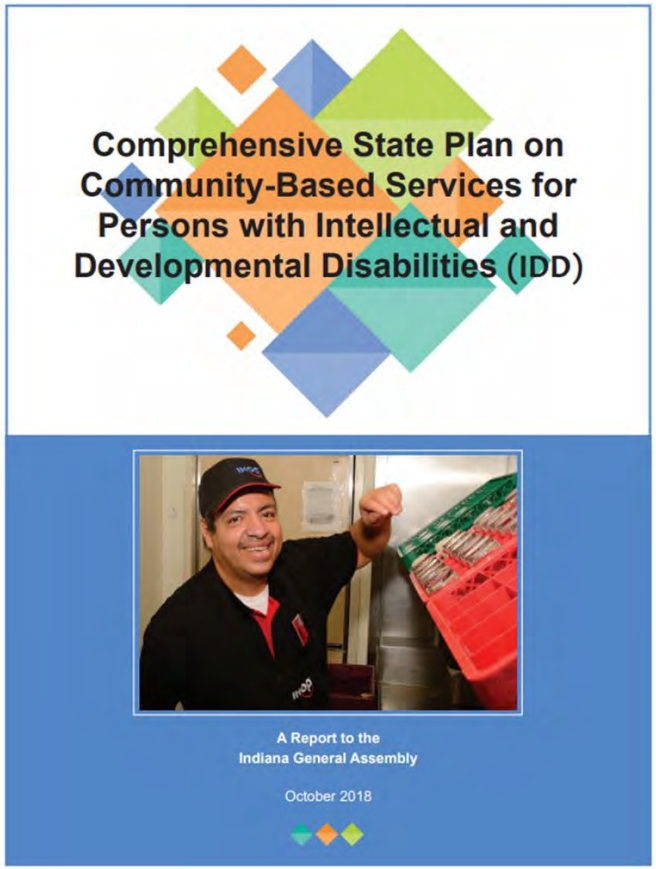
Indiana Progress

- Closure of state-operated institutions 16+
- HCBS waiver growth spending and participants
- Growth of six or fewer settings options
- Investment in family support
- Introduction of wellness coordination

2019 Recommendations

- Invest in self-directed service delivery
- Investigate shared living options
- Expand waiver services (including, crisis services, self-advocacy, technology, and transportation options, etc.)
- Expand family supports
- Reduce the use of nursing facilities
- Increase inclusive competitive employment supports and options looking at the employment lifecycle
- Utilize technology solutions to support systems of service delivery that promote self-determination

II. Using Data for Advocacy, Research, and Practice



Task Force Recommendations

- "The design and implementation of a self-directed care model in Medicaid HCBS waivers …for individuals to convert their shift model to a version that allows them to hire people they choose via a fiscal intermediary."
- "The DDRS convene a group of diverse stakeholders to assist with waiver redesign."
- "DDRS to develop and adopt a Shared Living model as a residential service option"
- "Reduce the use of settings with institutional funding (i.e. ICF/IDD and nursing facilities"

Task Force Recommendations

- "The creation of services and support system that supports and promotes self-advocacy…"
- "The establishment of a statewide IDD crisis response program."

Task Force Employment Recommendations

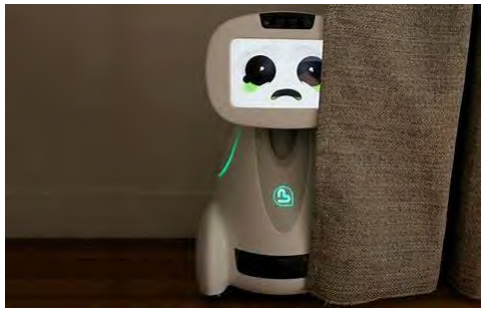
- "…implement Employment First in Indiana"
- "Create more school-to-work transition opportunities that foster individualized exploration of and experiences with community-based employment options that enable youth to make informed choices"
- "Explore, expand, and promote workforce initiatives to help employers in hiring individuals with disabilities."

Indiana Technology Recommendations

- "Maximize the incorporation of technology in the delivery of services to people with disabilities to increase individuals' access to community services, natural supports, and assist in addressing the direct support professional workforce shortage."
- "DDRS encourage the use of emerging technology in Medicaid HCBS waiver service delivery."
- "…include in state's initiatives…the development and use of driverless vehicle technology."
- "Telehealth be approved as a viable and approved service delivery method for services, for example Behavior Management and Wellness Care."

III. Advancing Technology Adoption and Use

AputTime

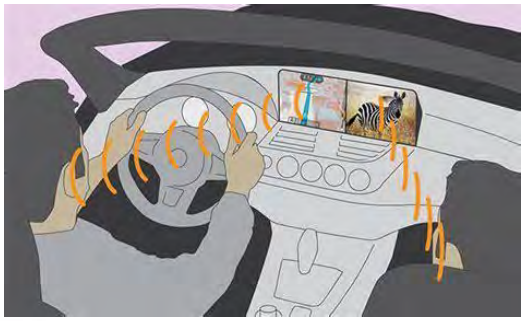


Buddy Robot

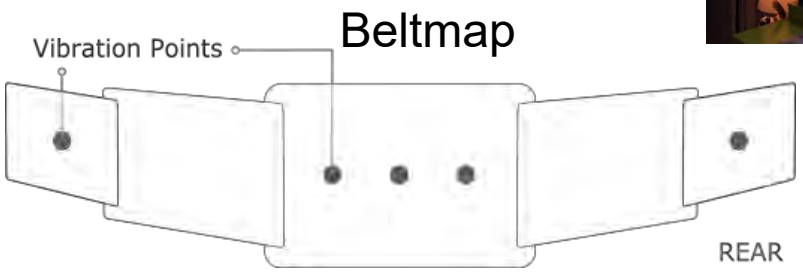
HabitAware

SMARTEAR

Nanoleaf



Metasonics



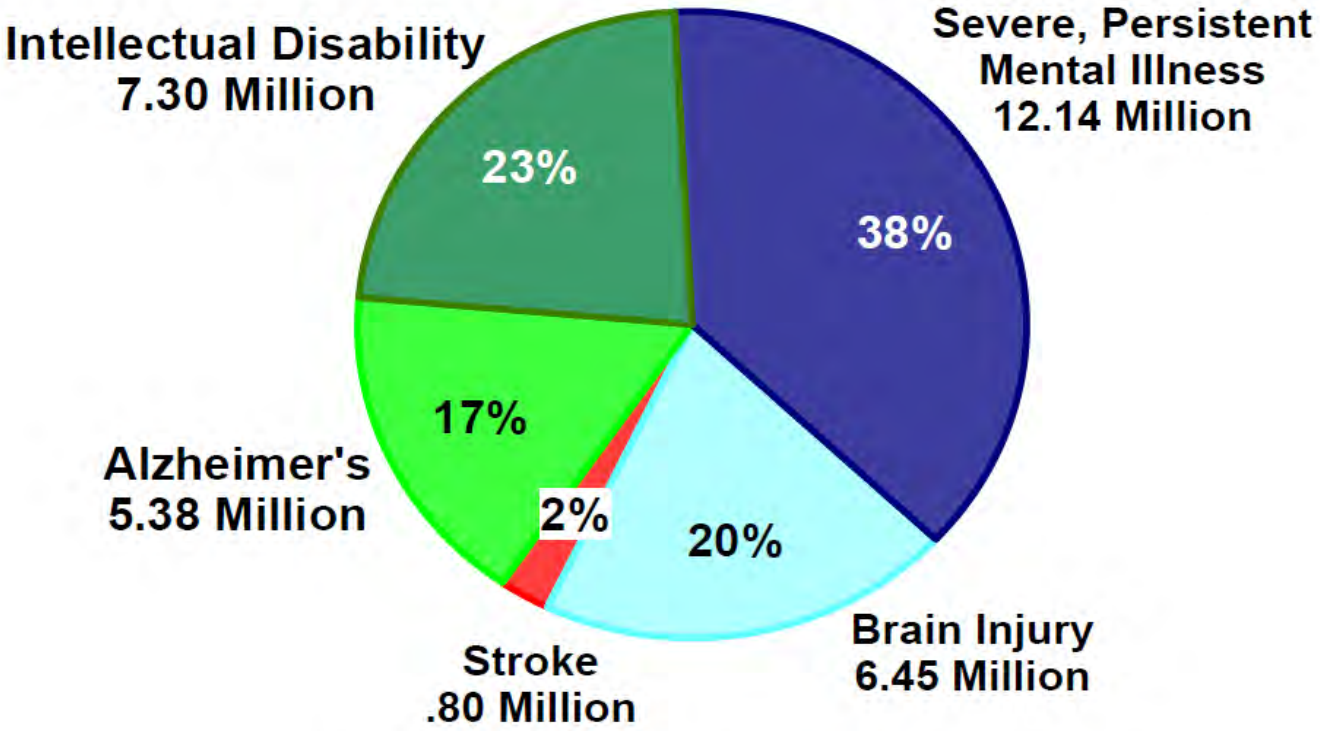
Beltmap

BeBop Sensors

The mission of the Coleman Institute for Cognitive Disabilities is to catalyze and integrate advances in technology to promote a meaningful quality of life for people with cognitive disabilities and their families.

Source: Ablelink Technologies, Colorado Springs (Terry & Jonathan).

Prevalence of Cognitive Disability in The U.S. 2016



Total: 32.07 Million Persons

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Adapting to the Digital Ubiquity

"Soon everyone on earth will be connected. With five billion more people set to join the virtual world, the boom in digital connectivity will bring gains in productivity, health, education, quality of life and myriad other avenues in the physical world- and this will be true for everyone, from the most elite users to those at the base of the economic pyramid" (p.13).

- Eric Schmidt & Jared Cohen
The New Digital Age

Applied Cognitive Technology

Building cognitive supports into technology used by all.

"As a field, Applied Cognitive Technology would constitute research and development to provide technology supports that enable people with cognitive disabilities to successfully function in inclusive environments, to increase participation in tasks and activities in inclusive environments, and to promote social inclusion, self-determination and quality of life.

(Wehmeyer & Shogren, 2013)

Accessibility

- Accessibility is about giving equal access to everyone. Without being able to access the facilities and services found in the community, persons with disabilities will never be fully included. In most societies, however, there are innumerable obstacles and barriers that hinder persons with disabilities. These include such things as stairs, lack of information in accessible formats such as Braille and sign language, and community services provided in a form which persons with disabilities are not able to understand. – United Nations

- Accessibility refers to the design of products, devices, services, or environments for people who experience disabilities.

- Accessibility is not to be confused with usability. Usability or user experience which is the extent to which a product (such as a device, service, or environment) can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use.

- Accessibility is strongly related to universal design which is the process of creating products that are usable by people with the widest possible range of abilities, operating within the widest possible range of situations. This is about making things accessible to all people (whether they have a disability or not).

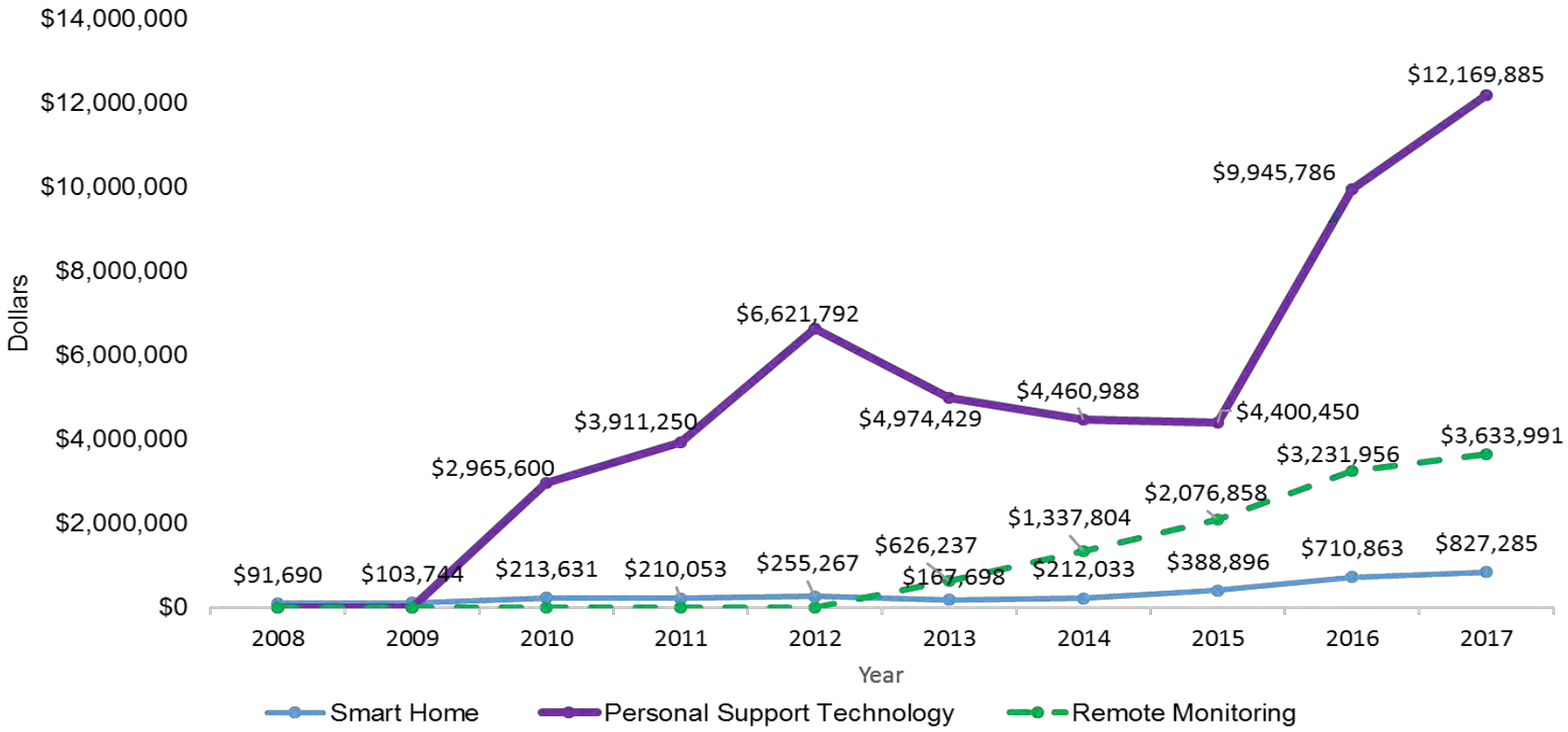
Technology Use By People with Disabilities

- Technology is appreciably underutilized by people with disabilities particularly those with intellectual and developmental disabilities (I/DD) (Tanis, Palmer, Wehmeyer, Davies et al., 2012)
  - The number of people with (I/DD) who need a device outnumber those identified as already using a device/technology in 4/5 life domains
  - Contributing factors to underutilization:
    - Cost of device
    - Lack of information about a device/technology
    - Inadequate training to use the device
- Technological Divide
- Mobile Devices
  - Popularity of smart phones and tablets
  - Physical, sensory, and cognitive accessibility issues
  - Need for personalization and compatibility across platforms

State Expenditures for Technology Solutions

State of the States in Intellectual and Developmental Disabilities Project of National Significance housed at the Coleman Institute for Cognitive Disabilities has been collecting data on technology since 2007. However, the project was interested in doing a deeper investigation on technology funding and interests and thus partnered with NASDDDS on the 2018 Technology Solutions State Survey.

Technology Spending by IDD Agencies: FYs 2008 - 2017



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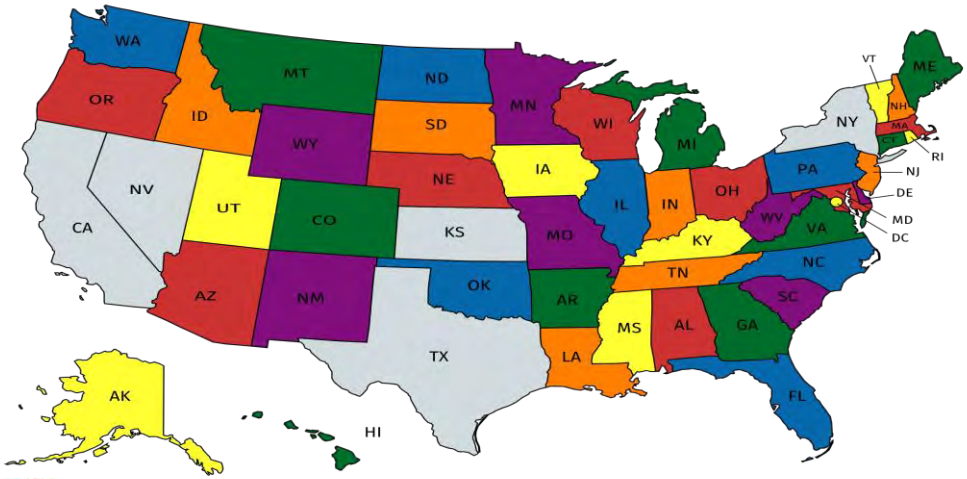
Technology Solutions State Survey

- Purpose: To investigate creative funding mechanisms and interest in technology solutions for people with IDD across the U.S.
- 45 States and District of Columbia responded to the survey



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NASDDDS
National Association of State Directors of Developmental Disabilities Services

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Top Ranking States for Technology Services and Supports Funding

States were ranked on the number of technology solutions supported and the variety of funding sources utilized.

#1 Minnesota
#2 Colorado
#3 & #4 Connecticut and North Carolina
#4 - #8 Alaska, Iowa, New Mexico and Washington

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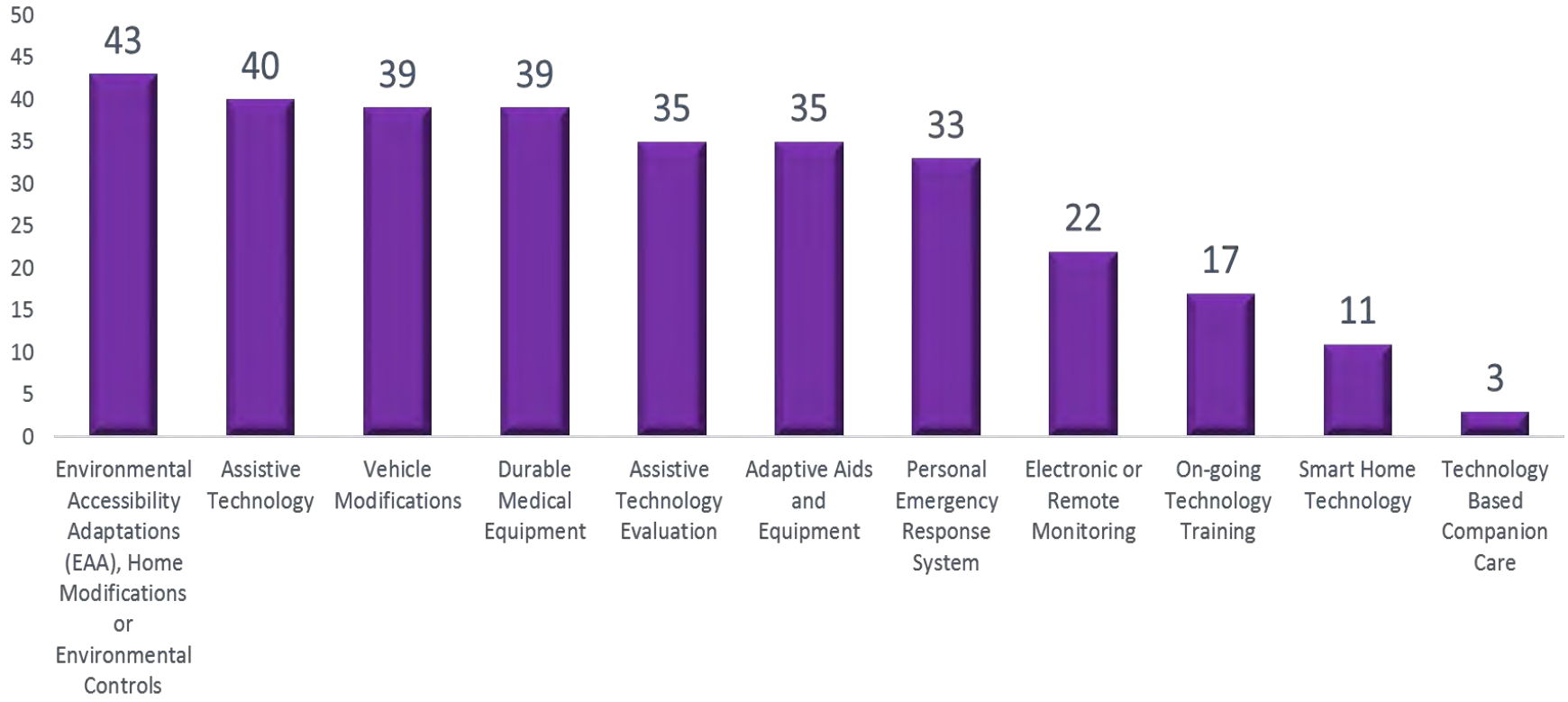
What Technology Services and Supports do the States Currently Fund?



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Six States Identify Funding Ten or More Technology Services and Supports

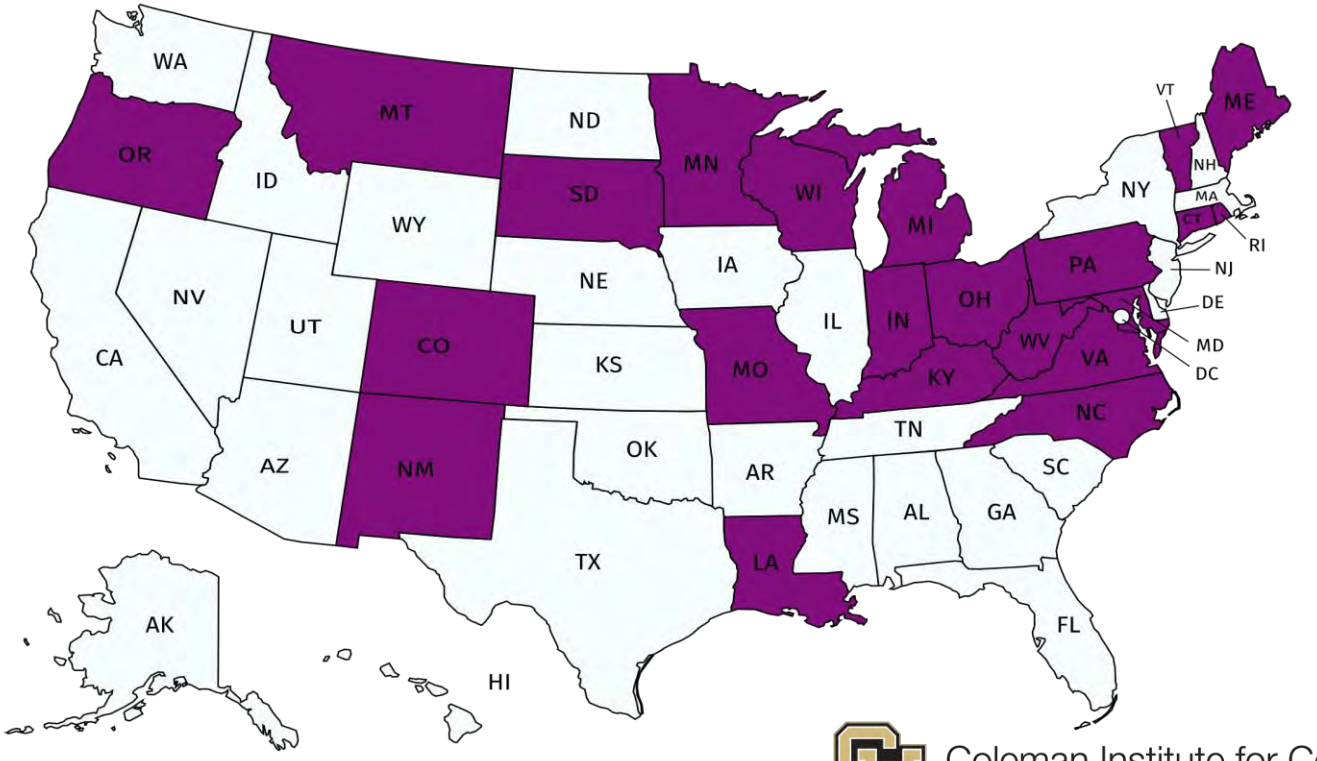
States
Connecticut (10)
Minnesota (10)
North Carolina (10)
New Mexico (10)
Rhode Island (11)
Wisconsin (10)

Technology Supports and Services

- Environmental Accessibility Adaptations
- Assistive Technology
- Durable Medical Equipment
- Vehicle Modifications
- Assistive Technology Evaluation
- Adaptive Aids and Equipment
- Personal Emergency Response Systems
- Electronic or Remote Monitoring
- On-going Technology Training
- Smart Home Technology
- Technology-Based Companion Care

States Funding Electronic or Remote Technologies

- 22 states report funding for electronic or remote technologies



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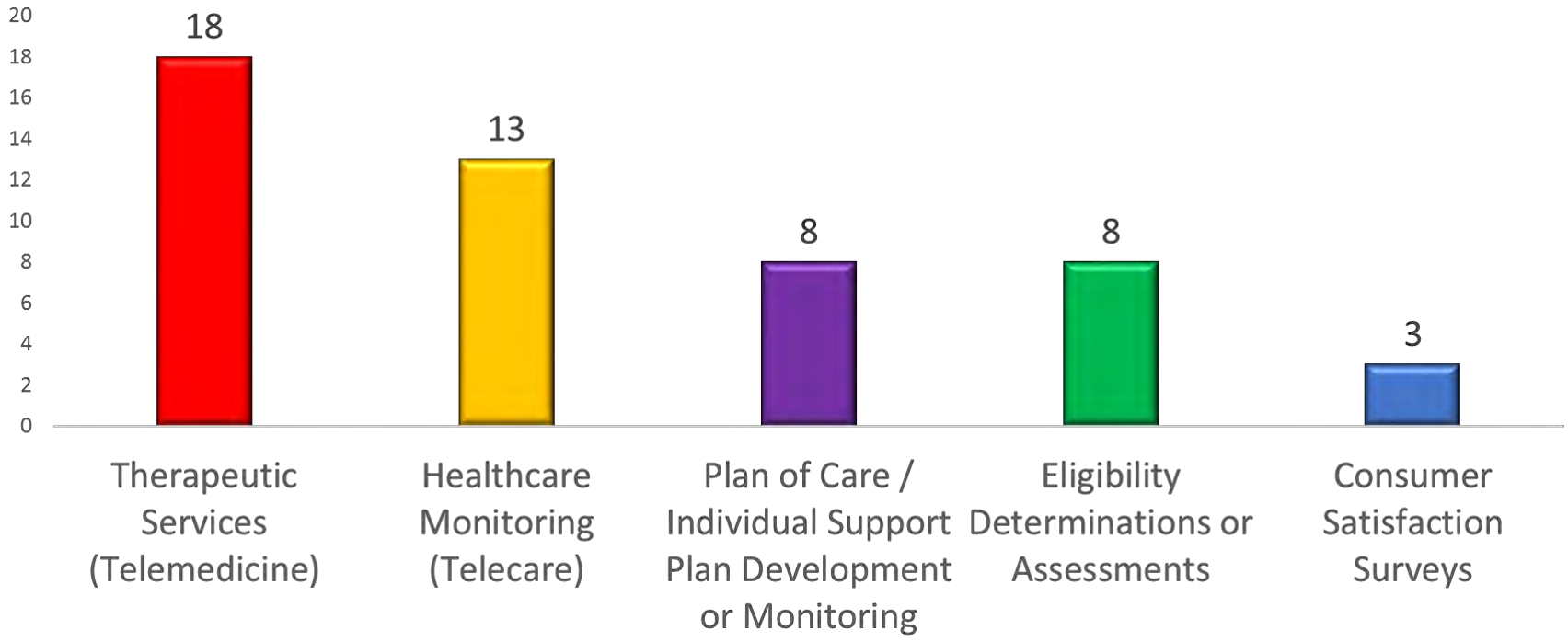
Technology-Based Companion Care

- Technology-based companion care is gaining in popularity to address loneliness for aging adults in rural areas and three states have begun funding this service for people with IDD: New Mexico, Rhode Island and South Dakota

States Report Funding of Remote Teleservices



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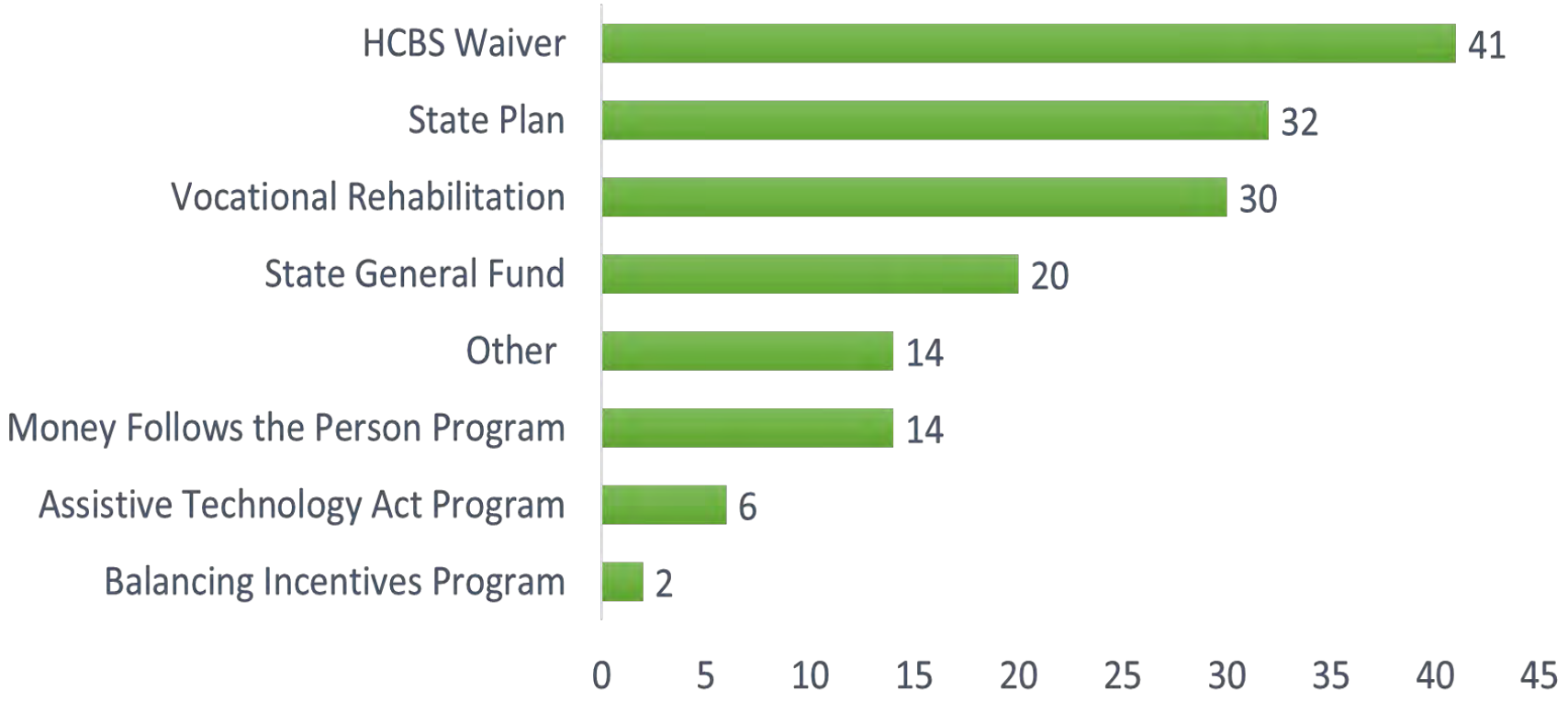
Types of Teleservices States are Funding

- Therapeutic Services – Telemedicine (counseling, speech and language therapy, physical therapy, etc.)
  - AK, AL, CO, DC, IA, ID, IL, ME, MN, MO, MS, MT, NJ, OH, SC, UT, VA, and WY
- Healthcare Monitoring (telecare)
  - AK, CO, CT, IL, MI, MN, MO, MS, NC, NE, UT, VT and WY
- Eligibility Determinations or Assessments
  - AK, GA, IA, ID, MO, NE, OH, and VA
- Plan of Care/Individual Support Plan Development or Monitoring
  - AK, CO, IA, ME, MN, NE, OH, and WY
- Consumer Satisfaction Survey Instruments
  - AK, IA, and NH

Number of States Reporting Specific Federal Funds to Purchase Technology Services, Applications, Devices or Solutions



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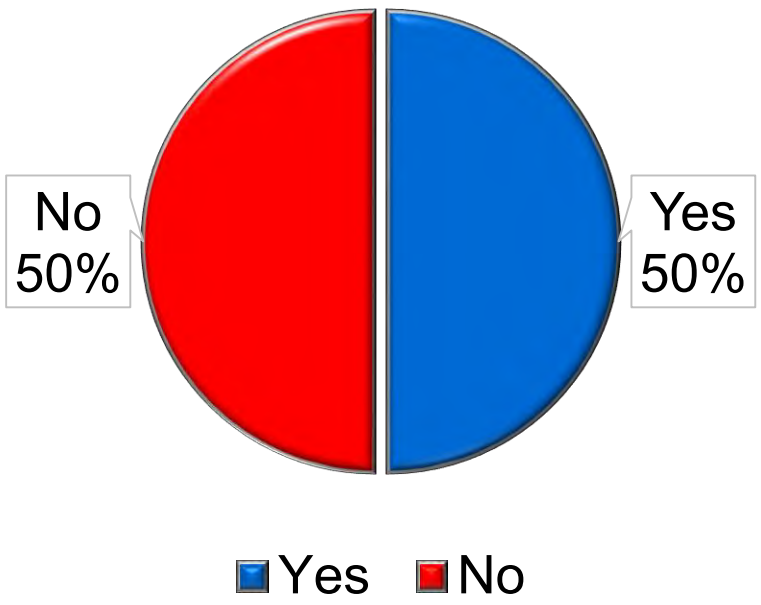
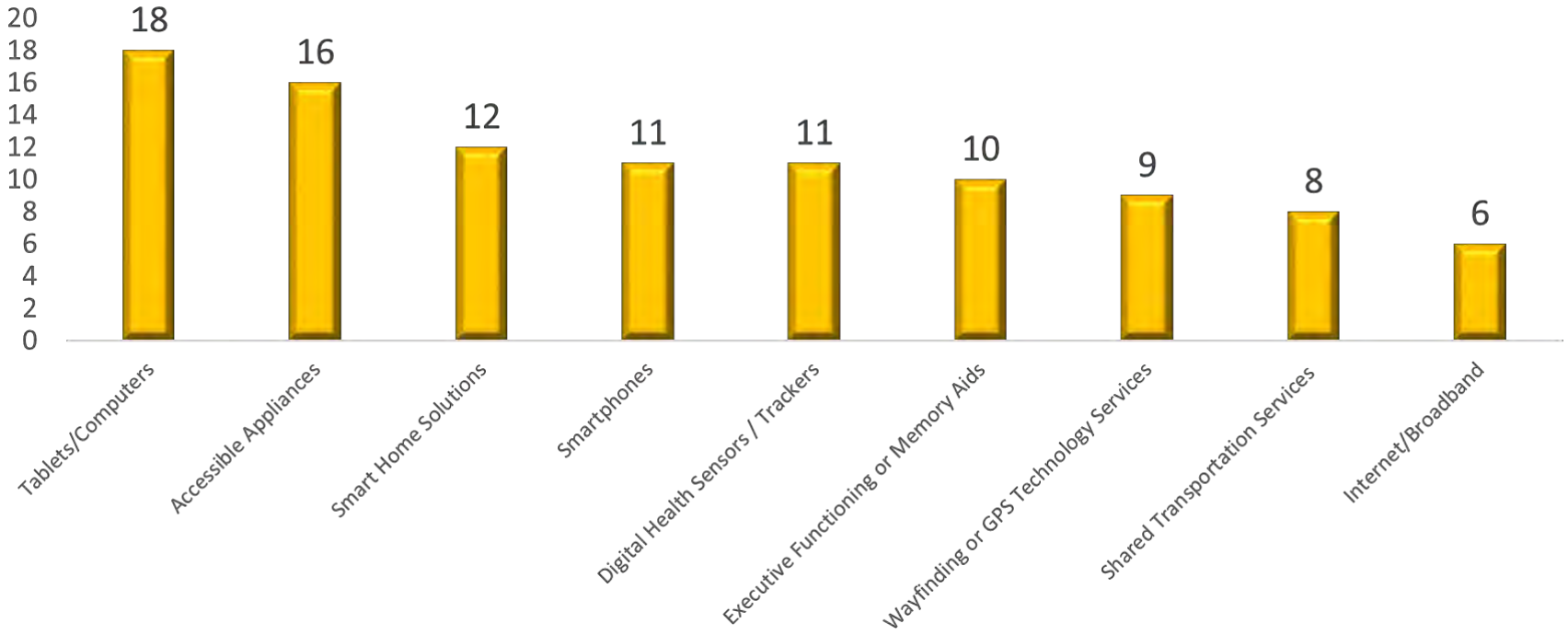
Does Your State Provide Funding for Ongoing Technology Training to Learn, Upkeep and Update Purchased Technology?



When technology users do not have access to reliable technical or professional support to help troubleshoot or update technologies, they are more likely to abandon the technology. Half the states surveyed report funding ongoing technology training to learn, upkeep and update purchased technology.

Number of States that Purchased Technology Solutions with Public Dollars, Pilots or Special Programs



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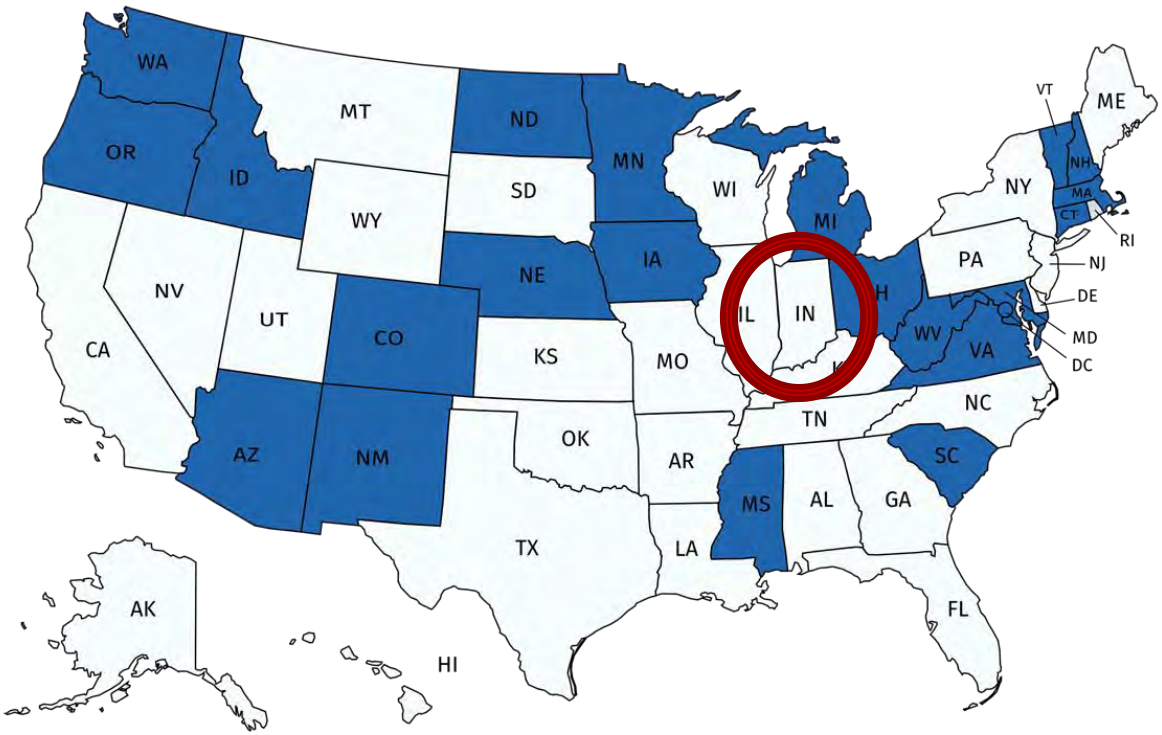
Eight States Funded Six or More Technology Solutions Not Traditionally Covered By Medicaid

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

Is the Consideration of Technology Supports and Services a Requirement Within the ISP or Person-Centered Plan?



- 22 states report consideration of technology supports and services are a requirement within the ISP or person-centered plan

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States Overwhelmingly Utilized Direct Payments to Purchase Technology Services or Solutions Associated with Residential Rates

- Tablets/Computers (CO, HI, MA, MN, OR, PA, WA, and WY)
- Transportation (IA, MA, MN, PA, and WA)
- Smart Homes (CO, MN, NM, PA, and WA)
- Wayfinding/GPS Services (CO, MN, NC, NM, PA, VT, and WA)
- Executive Functioning Aids (CO, HI, IA, MN, NM, and WA)
- Digital Health Sensors (CO, MN, NC, NM, and WA)
- Accessible Appliances (CO, MN, NM, PA, and WA)

Employment Recommendations

1. Assistive Technology Act Programs
2. Case Managers and Providers
3. Vocational Rehabilitation
4. Universities
5. Medical and Educational Professionals
6. Online

What Emerging Technologies Are States Interested In?

1. Smart Homes
2. Health Related Technologies (sensors, telehealth, etc.)
3. Remote Monitoring
4. Transportation Technologies
5. Mainstream Technologies

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Emerging Technologies of Interest to the Cognitive Disability Community

- Promise of 5G
  - Tactile internet
- Artificial intelligence
  - Machine learning
    - Conversational assistants
    - Text simplification
    - Decision-making supports
- Augmented reality
- Smart communities
  - Context aware systems
- Autonomous vehicles

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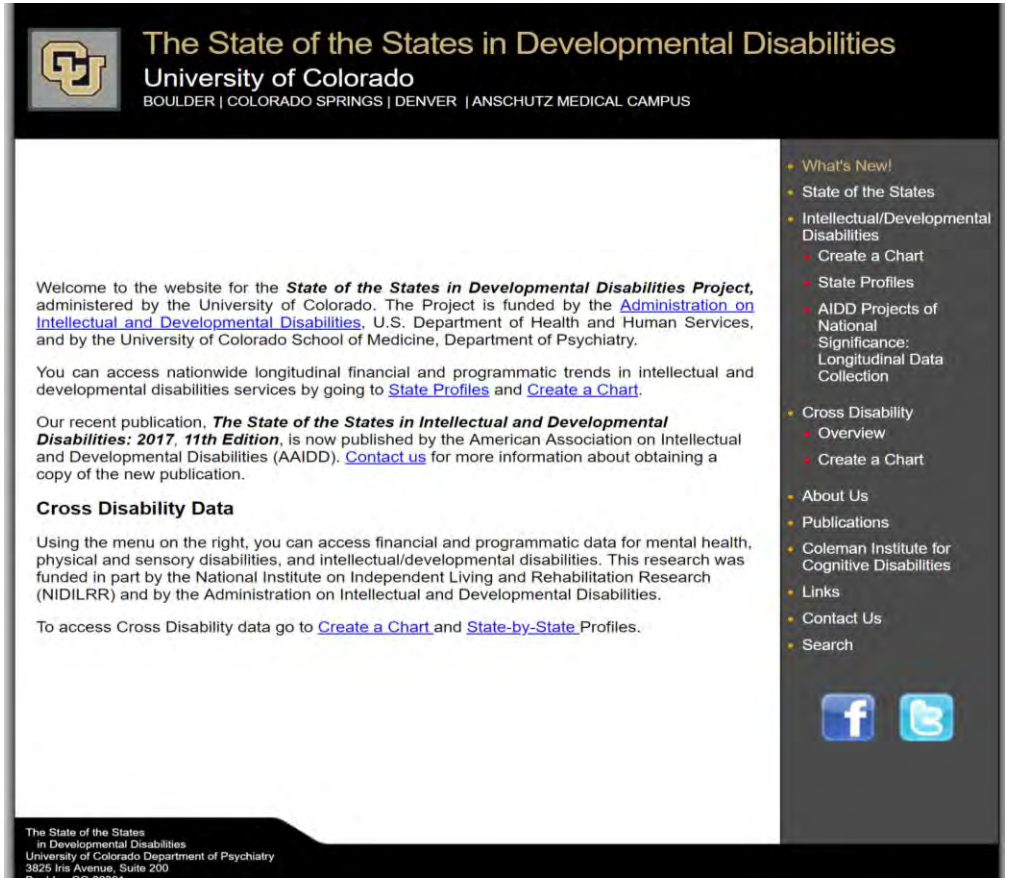

- Review State Profiles
- Create-a-Chart
- View Presentations and Publications
- Contact us

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1. Total Fiscal Effort for I/DD Services
2. Community Fiscal Effort for I/DD Services
3. Institutional (16+) Fiscal Effort for I/DD Services
4. Community Spending as a Percent of Total I/DD Services
5. Percent of Total Out-of-Home Placements in Settings for 6 or Fewer Persons
6. Percent of Total Statewide 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. Home and Community Based Services (HCBS) Waiver Federal-State 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 Additional Federal Medicaid Funding
15. Medicaid Percent of Total I/DD Spending
16. Public Spending for Family Support and Supported Living as a % of Total I/DD Spending

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