

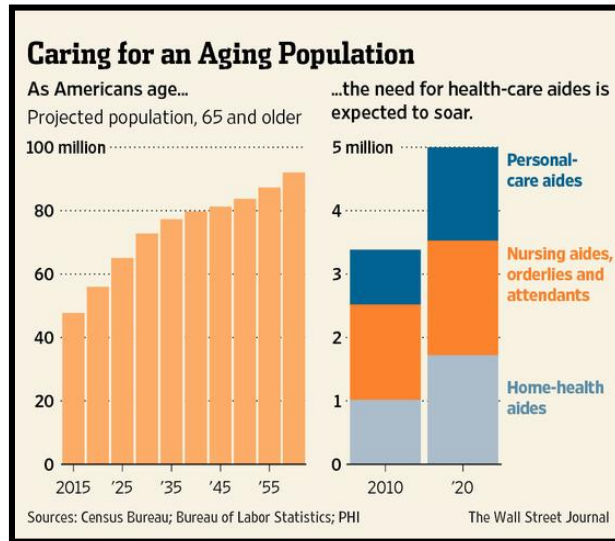
Trends in State I/DD Infrastructure

Mary Lee Fay
Executive Director
NASDDDS

Pressures for System Change!



Shortages of Care Givers as America Ages

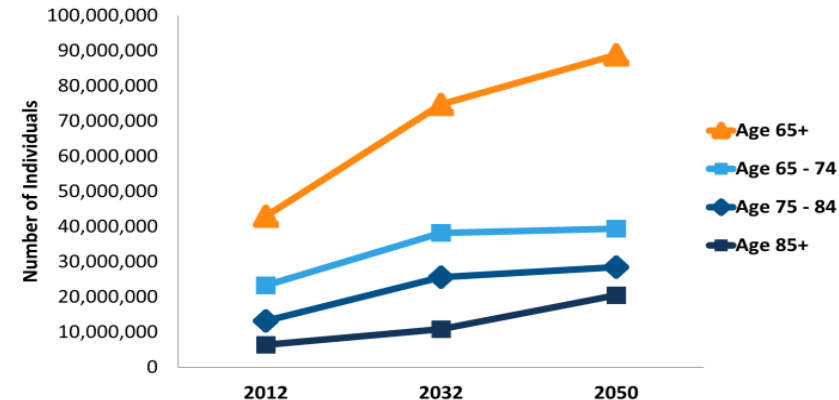


A labor shortage is worsening in one of the nation's fastest-growing occupations—taking care of the elderly and disabled—just as baby boomers head into old age.

Wall Street Journal
April 15, 2013

Figure 1

The 65 and Over Population Will More Than Double and the 85 and Over Population Will More Than Triple by 2050

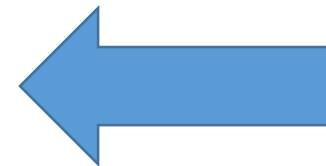


SOURCE: A. Houser, W. Fox-Grage, and K. Ujvari. *Across the States 2013: Profiles of Long-Term Services and Supports* (Washington, DC: AARP Public Policy Institute, September 2012), http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltr/2012/across-the-states-2012-full-report-AARP-ppi-ltr.pdf.



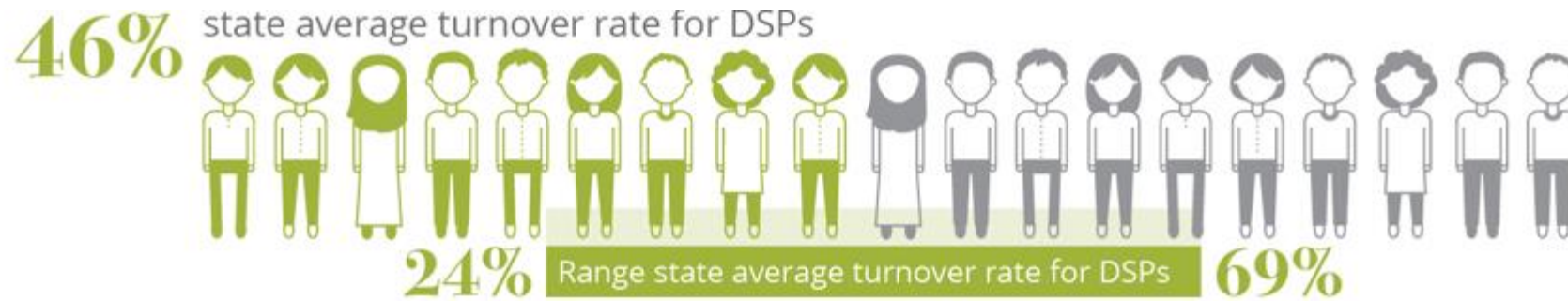
Demographics: Supply

Quick Facts: Personal Care Aides	
2015 Median Pay	\$20,980 per year \$10.09 per hour
Typical Entry-Level Education	No formal educational credential
Work Experience in a Related Occupation	None
On-the-job Training	Short-term on-the-job training
Number of Jobs, 2014	1,768,400
Job Outlook, 2014-24	26% (Much faster than average)
Employment Change, 2014-24	458,100



The projected percent change in employment from 2014 to 2024. The average growth rate for all occupations is 7 percent.

National Core Indicators - Staff Stability Survey Turnover Rates

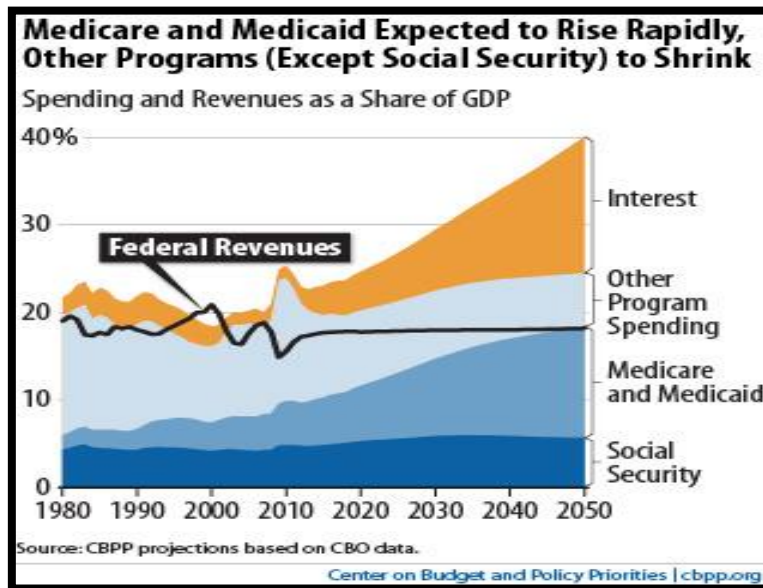


Of DSPs who left positions in calendar year 2016:

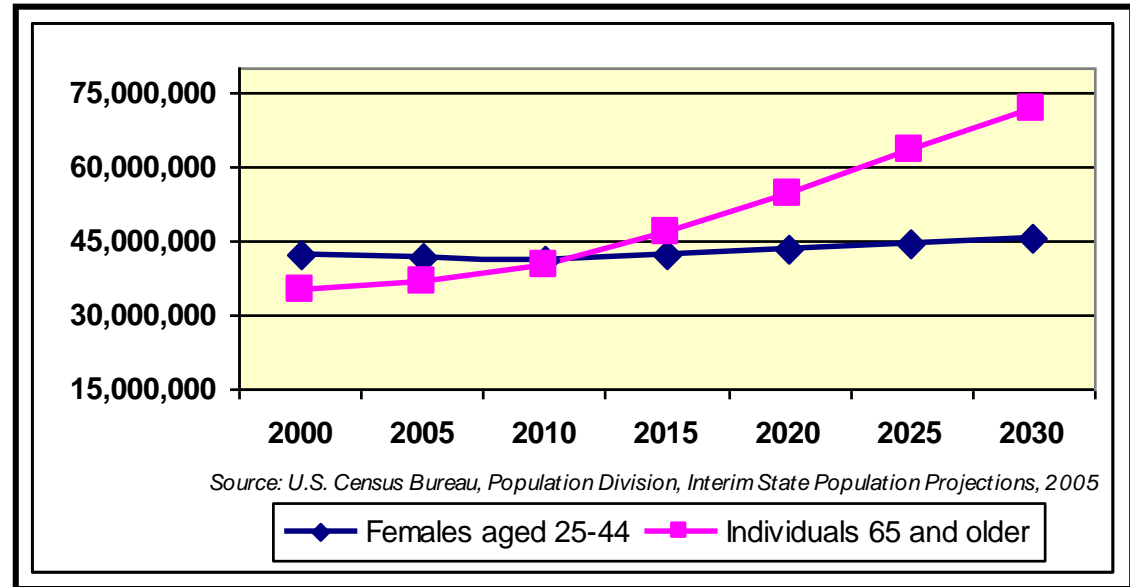


We are Confronted with Reality

Growth in public funding will slow



Workforce will not keep pace with demand



46% state average turnover rate for DSPs



24%

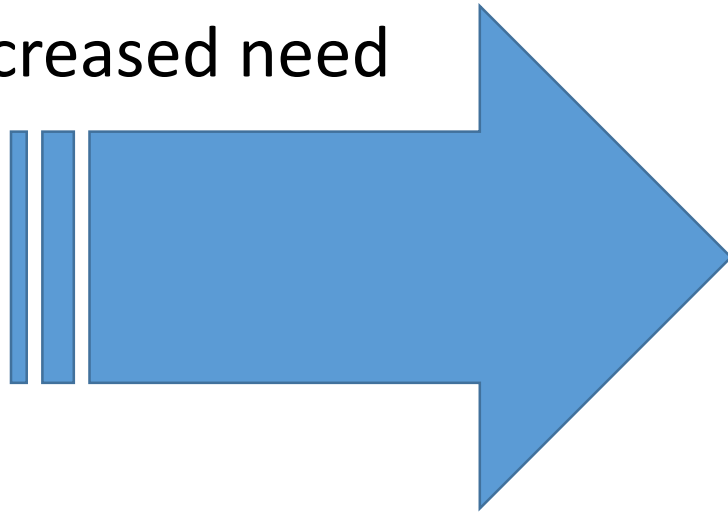
Range state average turnover rate for DSPs

69%

The Conclusion

- Decades of:

- Tight funding
- Workforce shortages
- Increased need



- Service systems must be:

- Affordable
- Sustainable
- Capable of handling the load

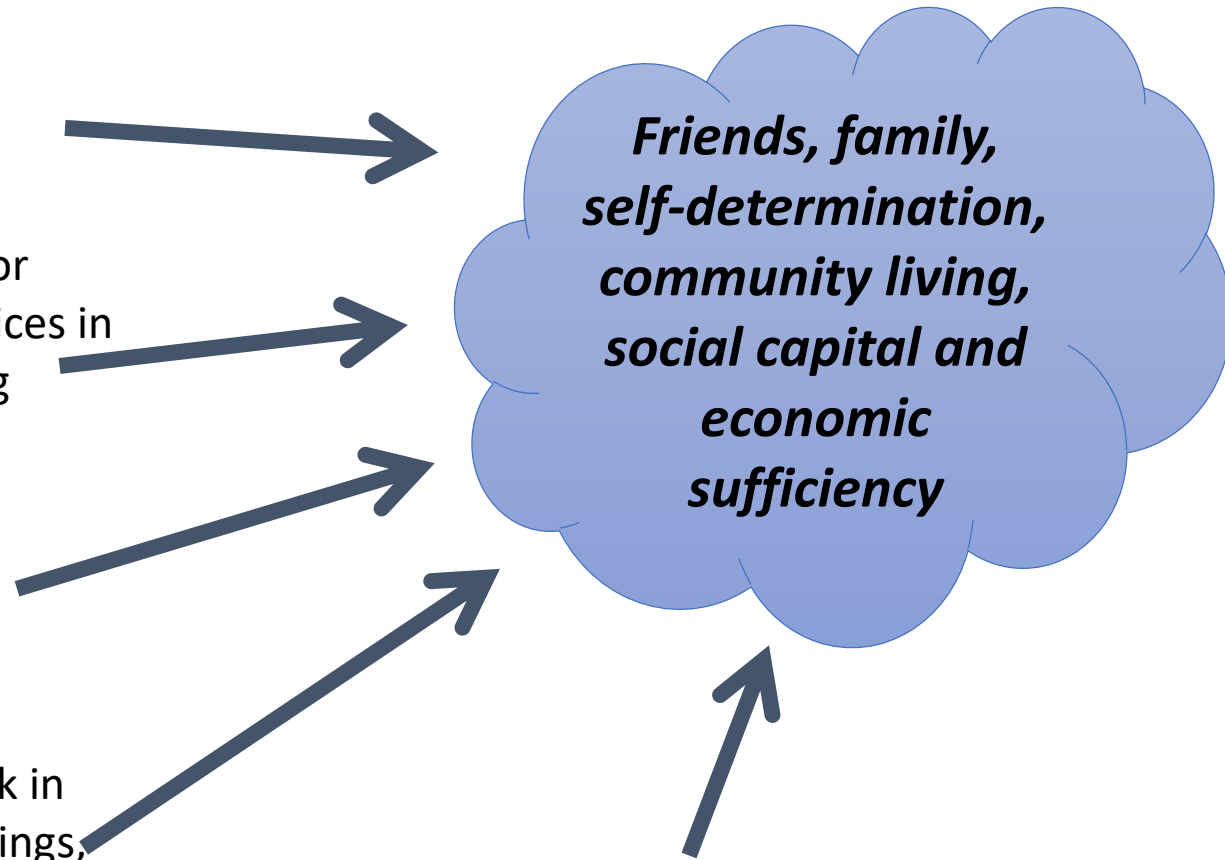
What Does This Mean For States?

- All states are facing the same pressures (budget/demand/workforce)
- Strategies for long term results
 - ❖ Defining Community
 - ❖ Value Based Payment
 - ❖ Workforce
 - ❖ Technology
 - ❖ Supporting families – What does it mean?
 - Self direction and supports waivers



Changes in Home and Community Based Services Regulations

- Focuses on the quality of person's experiences
- Maximizes opportunities for community living and services in the most integrated setting
- **"Qualities"** of the setting - integrated in and supports access to, the greater community
- Seek **employment** and work in competitive integrated settings, **engage in community life**, and control personal resources



- Receive services in the community to the **same degree of access** as people not receiving HCBS

Status of State Transition Plans



As of November 13, 2018:

- 42 States have initial STP approval: AL, AK, AR, AZ, CA, CO, CT, DC, DE, GA, HI, ID, IN, IA, KY, LA, MD, MI, MN, MS, MO, MT, NE, NH, NM, NC, ND, OH, OK, OR, PA, RI, SC, SD, TN, UT, VT, VA, WA, WV, WI, WY
- 10 States have final STP approval: AL, AK, DC, DE, ID, KY, OK, TN, WA, WY
- Rhode Island???

Defining Community and the HCBS Regulations: Heightened Scrutiny



- CMS/State Working Group on Heightened Scrutiny
- States may request “heightened scrutiny” for settings presumed institutional *if they believe the setting can meet the standards in the rule*
- Must submit an evidence package
- Can include programming changes
- **IMPORTANT:** The opportunity for heightened scrutiny does not supersede state authority to set the direction of the system

Tiered Standards: CMS Guidance Excerpt

Tiered Standards are a unique tool made available by the compliance timeline set forth in the regulations

Allows a state to continue certain settings in HCBS (such as facility based day program or 8 person group home) as long as they meet minimum HCBS standards but may suspend admission to that setting or suspend a new provider approval for those settings for future use.

How States are Using Tiered Standards

- Maryland – no new group homes of four or more; exploring strategies to grow more person-centered models of support for day services
- Minnesota – using tiered standards to foster growth of more individualized day and residential supports while “shutting front door of certain services/provider types”
- Pennsylvania – developed new models of day services with graduated standards
- Many other states are exploring options to sunset older, less effective service models while growing more person-centered approaches to supports

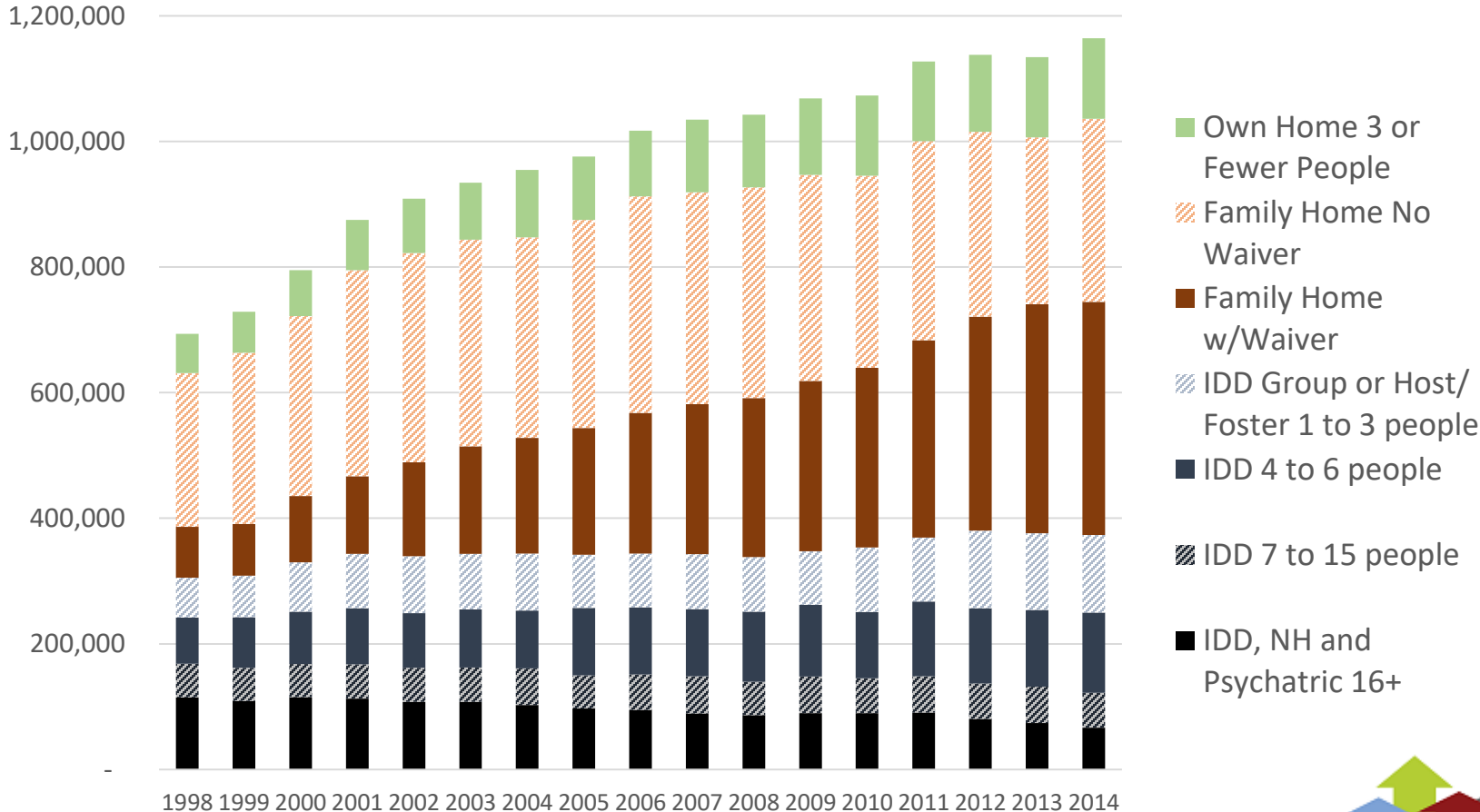
Efforts to Build a Sustainable Future

- Supporting Families AND
- Developing Innovative Supports – Relationship based
- Expecting Employment outcomes
- Building on Technology
- Focusing on Person Centered Planning –
- Investing in Peer Networks

How have Community Settings Changed over Time



Change in Residence Type for People Served by State IDD Agencies 1998 to 2014

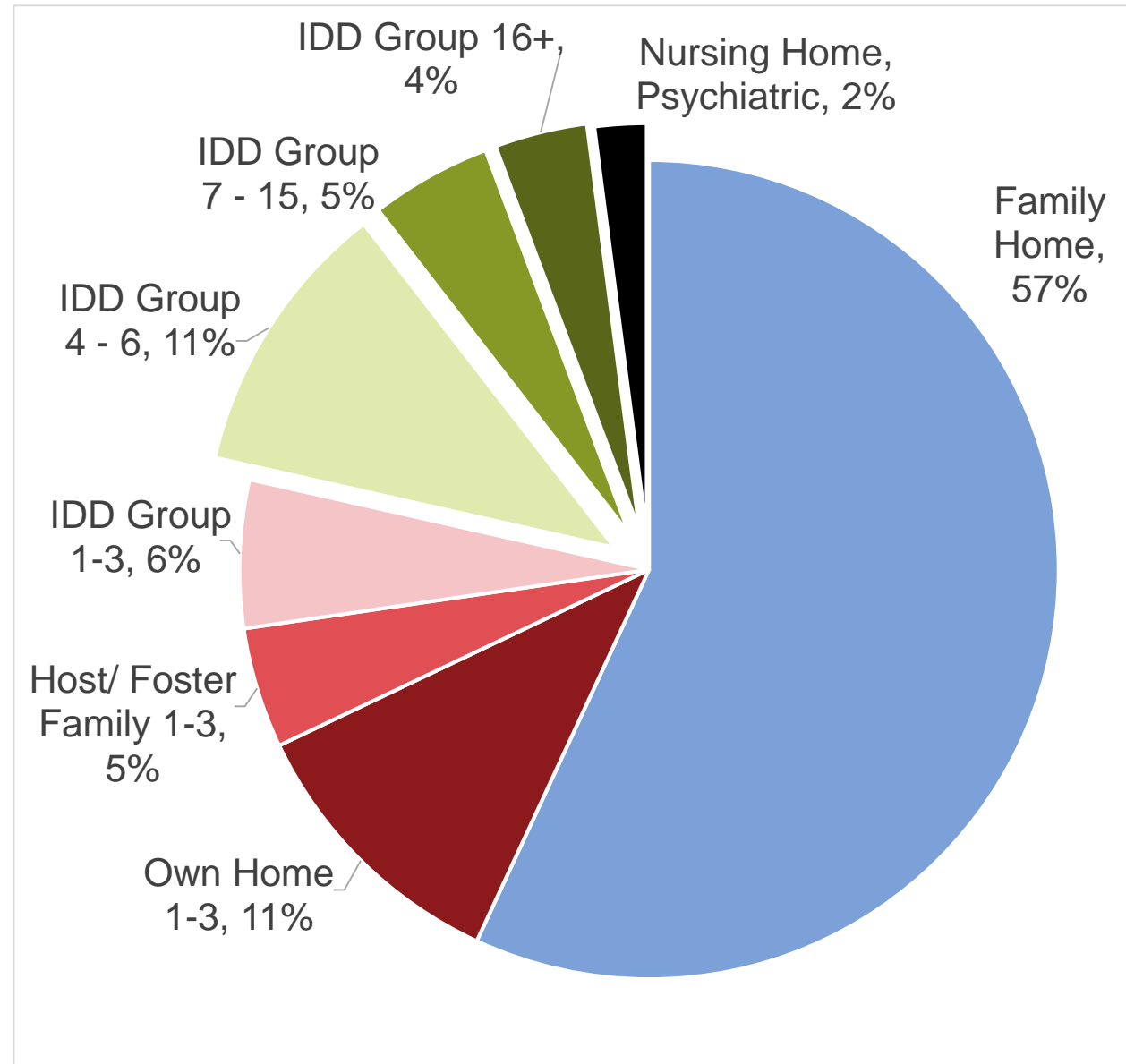


Larson, S.A., Eschenbacher, H.J., Anderson, L.L., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Fay, M.L. (2017). In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2014. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

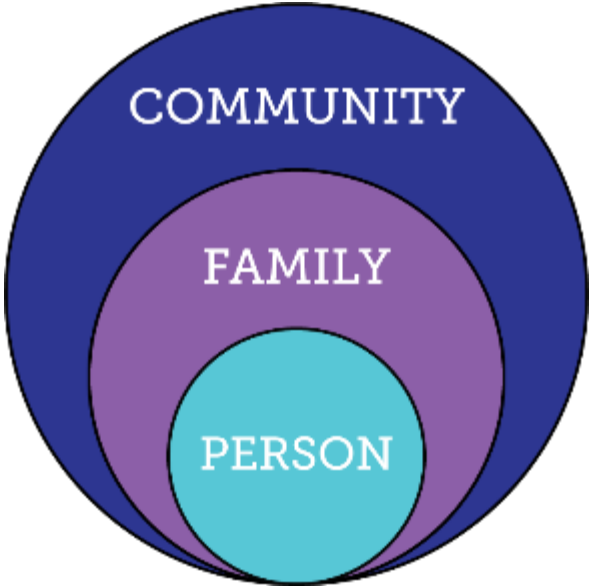


Residence Type and Size for People Receiving Long-Term Supports or Services from State IDD Agencies in 2014

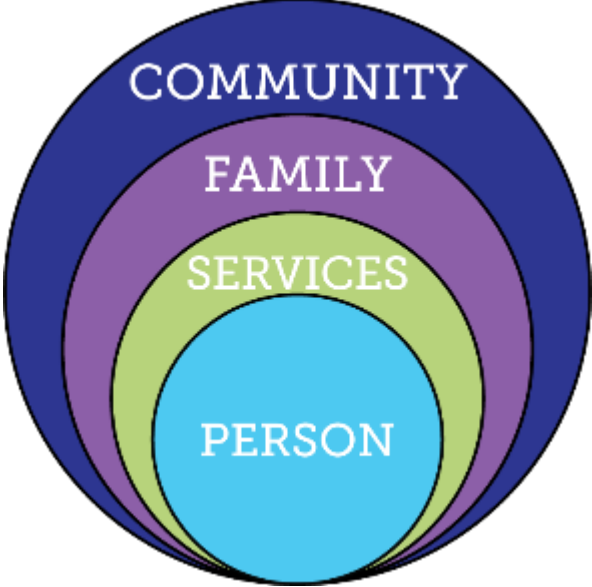
Larson et al (2017). RISP FY 2014



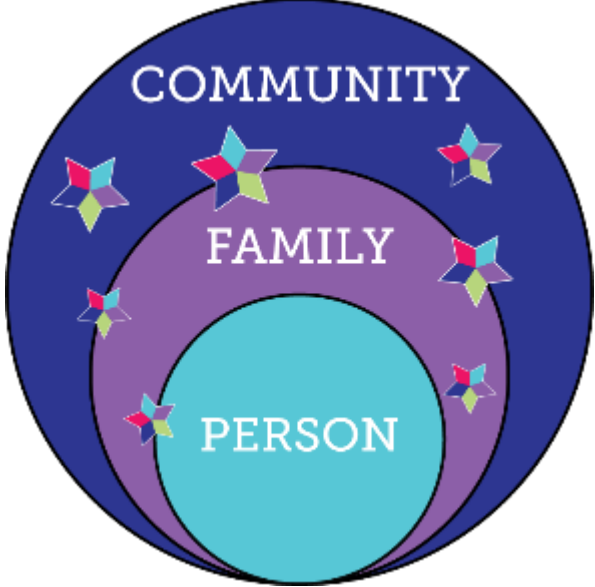
Integrating Services and Supports



75%
People with I/DD not
receiving formal
DD services



25%
People with I/DD
receiving formal
DD services
NASDDDS



100%
People with I/DD
receiving integrated
services and supports

Focusing on Relationship Based Living Options or Shared Living

- ✓ Living with Mom and Dad
- ✓ Paying family care givers
- ✓ Living with siblings or other relatives
- ✓ Living with Friends
- ✓ Living with a partner
- ✓ Supported Living – supports provided in the person's own home
- ✓ Roommate/companion
- ✓ Shared Living – one person matched to live with another



What are Models of Shared Living

- Shared Living
- Supported Living
- Supports in the family home



What is Shared Living



- An individual lives in the home of a provider (typically licensed as foster care).
- Only one individual lives in the home – an exception may be made for 2 people if they are known to each other (couple/friends).
- The provider and the individual come together because of a “match” or shared interest in living together.
- Typically an **umbrella agency** provides the match and ongoing support of the relationship (arranges for respite, provides additional staffing if needed)

What Shared Living is *NOT*

- Shared Living is not place or a “placement” that is based on a vacancy
- It is not traditional foster care
- Shared living is not a “setting” serving three or four individuals
- It is not dependent on other people living in the same home getting a service payment



What is Supported Living



- Person lives in their own home (rented or owned).
- Can contract with provider to manage all supports or hire staff directly.
- Apartment or home is not a part of other agency managed homes (one of four apartments in a four-plex unit)
- Provider agency may support more than one person in a dispersed apartment complex (4 people live in apartments spread throughout a 40 unit complex)
- May have two people sharing their home if they are known to each other or created arrangement for financial (housing) reasons.
- If one person moves out, another is not required to move in.

Supports in the Family home



- Person lives with family
- Supports provided take into consideration some natural supports.
- Family members may be paid as formal care givers.
- Person may self direct all support or may contract with agency to provide supports or a combination of both (person and family direct in-home staff and contract with agency for employment)



ALL Individuals Exist Within the Context of Family

- Family is defined by the individual
- Individuals and their family may need supports that adjust as roles and needs of all members change
- Not dependent upon where the person lives



Lifelong Impact of Family on Individual

Biologically: Likes, dislikes,
skills, abilities

Socially: Family and friend
network, connection with
community members





Environmentally: Neighborhood,
socio-economic, education

Policy:
Dreams, Aspirations,
House rules, cultural rules,
expectations



Reciprocal Roles of ALL Family Members

 Caring About	Affection & Self-Esteem
	Repository of knowledge
	Lifetime commitment
 Caring For	Provider of day-to-day care
	Material/Financial
	Facilitator of inclusion and membership
	Advocate for support

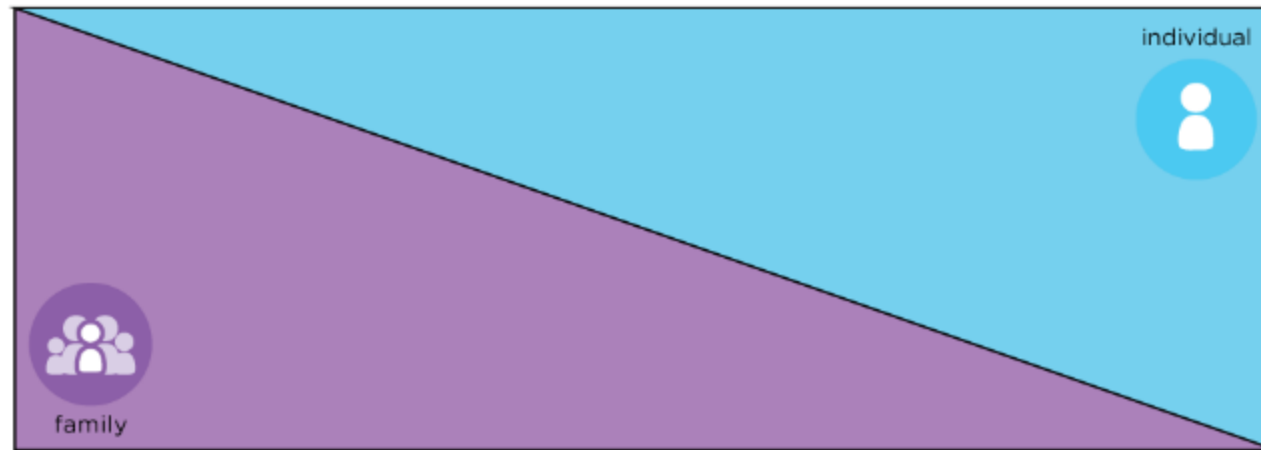
**Adapted from Bigby & Fyffe (2012), Dally (1988), Turnbull et al (2011)*

Types of Supports

Discovery & Navigation Knowledge and Skills	Connecting & Networking Mental Health and Self-efficacy	Day-to-Day Services Instrumental Supports
<ul style="list-style-type: none">• Information on disability• Knowledge about best practices and values• Skills to navigate and access services• Ability to advocate for services and policy change	<ul style="list-style-type: none">• Parent-to-Parent Support• Self-Advocacy Organizations• Family Organizations• Sib-shops• Support Groups• Professional Counseling• Non-disability community support	<ul style="list-style-type: none">• Self/Family-Directed services• Transportation• Respite/Childcare• Adaptive equipment• Home modifications• Financial assistance• Cash Subsidies• Short/Long term planning• Caregiver supports and training

Life Stages and Individual and Family Cycles

Individual Life Stages



Family Life Cycle

Service Examples

One state building a supports program is incorporating the following types of services:

- Family Caregiving Supports –
 - Respite
 - Family Caregiver Stipend
 - Community Support, and Navigation
 - Family-to-Family Support
 - Self-Advocacy Supports
 - Peer-to-Peer Support
 - Supportive Home Care
 - Family Empowerment Supports
 - Family Caregiver Training
 - Health Insurance Assistance
 - Individual Education and Training

Paying Family Care Givers

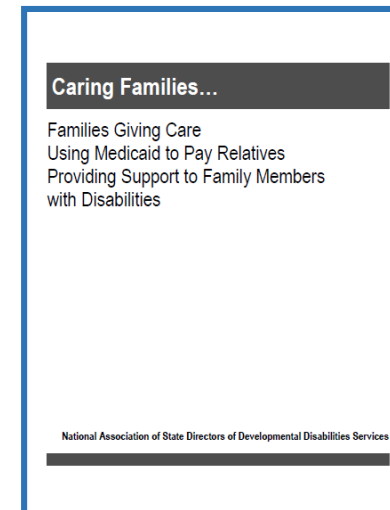
Things can be great and things can go wrong.....It's Life !

Have expectations for outcomes for the person - everything starts with the individual plan

Provide support/supervision that honors the plan and supports the care givers

Establish rules about which and how many family members can be paid

“Prenuptial agreement” ...decide what reasons would result in termination of the arrangement



And What Do People Do During the Day?...

New Possibilities and the Road Ahead-
Employment and Community Life Engagement



States Continue to Emphasize Employment as an Important Key to Community Integration

- Employment First – not Employment only
- States are continuing work to develop an array of services that wrap around employment supports while supporting and enabling meaningful community integration

Employment First Policies: A Closer Look

- **33 states with official policy**
- **17 states passed legislation**
- Remainder have policies issued by state agencies, Executive Orders, etc.
- **21 state polices cross-disability; remainder intellectual/developmental disability specific**



Does Everyone Have to Work?

- What is true in our society?
- Work is an expectation
- If you want things, you have to have an income
- Work brings economic independence
- Work makes you a valued citizen
- Work makes you proud
- We learn from the work we do and the people we work with
- We make friends

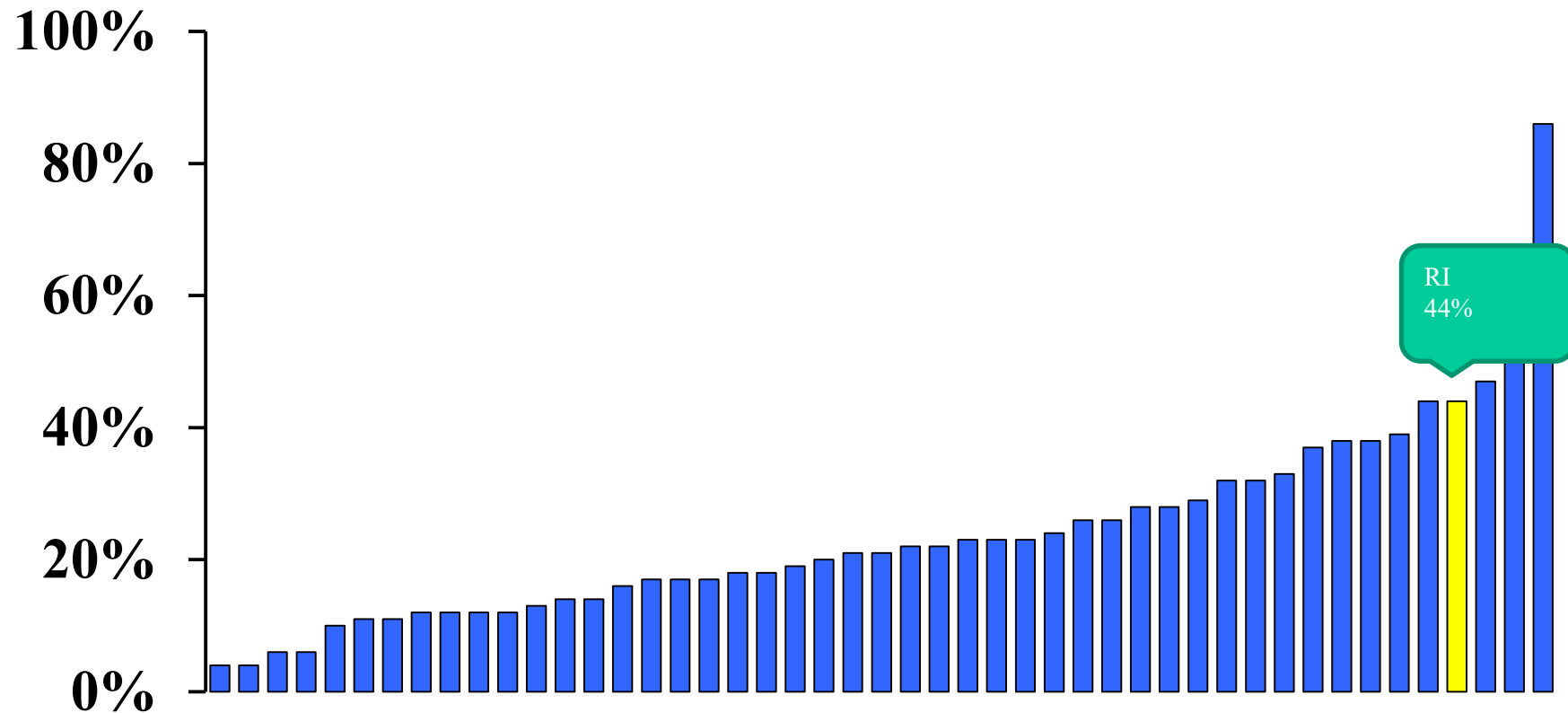


Can Everyone Work?



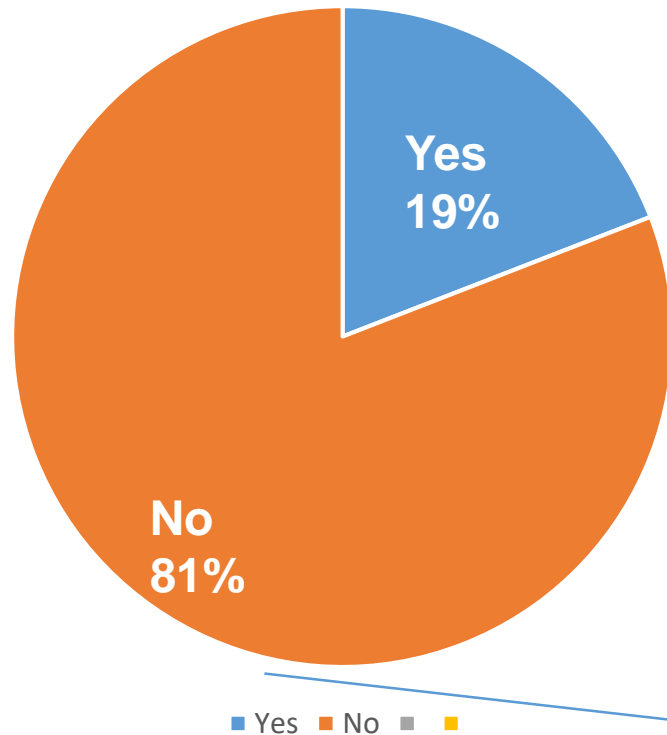
- **FACT:** Among all non-disabled, working-age adults 70% are employed and not all full-time.
- *The question is not “can everyone work?” rather:*
 1. How close can we get to the rate of non-disabled working adults?
 2. If some states have good outcomes, how can we get there too?
 3. Why wouldn't we try to get more people working?

Participation in integrated employment services varies widely

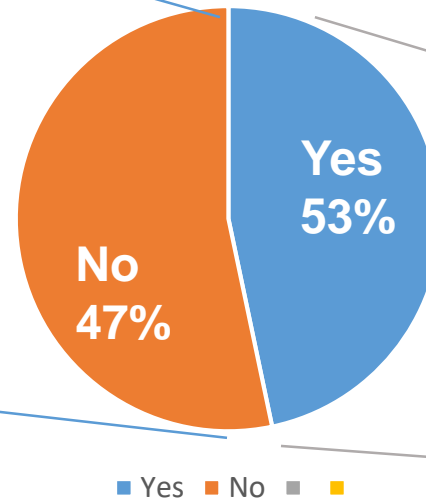


2015-2016 NCI Adult Survey

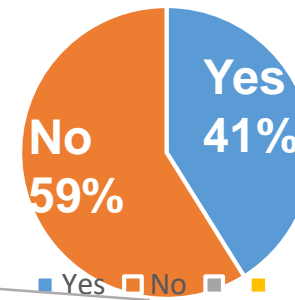
Has a Job (n=16,375)



Would like a Job (n=6,550)



Employment goal in Plan (n=2,808)



24% took classes, training, or did something to get a job or get a better job

New Definitions/Flexibilities for Employment/Pre Voc

Employment:

- Employer check-in
- Benefits analysis
- Transportation
- Asset building
- Self-employment training, planning and start up
- Peer support and mentoring
- Career advancement services

And Prevocational?

- General career exploration, including self-employment
- Informational interviewing
- Soft skills training
- Job search training
- Skill building
- Job shadowing



What Will People Do When They are Not Working?

Good Question

- We have to make sure that people have something to do that gets some of the same benefits or work
- We have to make sure people are busy everyday or as many days as they and their families want to be
- Work, whether part time or full time, should not create hardship for families

Employment and Community Life Engagement



Many Definitions of Community Life Engagement-(CLE) A Practical One

- People with intellectual and developmental disabilities (IDD) accessing and participating in their communities outside of employment as part of a meaningful day
- CLE is an outcome, not a service
- The *supports* given to achieve CLE may be referred to as Community Life Engagement, Integrated Day, Community Integration, Community Based Day or Community Based Non Work

States are Changing to Support Bridges & Pathways to Employment

- Includes volunteer work; postsecondary, adult, or continuing education; accessing community facilities such as the library, gym, or recreation center; any activities that people with and without disabilities do in their spare time
- Sometimes referred to as Community Based Day or Community-Based Nonwork
- May support career exploration, wrap around work time, or serve as a retirement option.

**Many see this related to employment-a path to employment through career exploration & networking. Wraps around job to fill gaps in time, new experiences, social connections, support people in retirement in integrated ways*

“Technology shapes society and society shapes technology”

-Robert Winthrop White

Technology

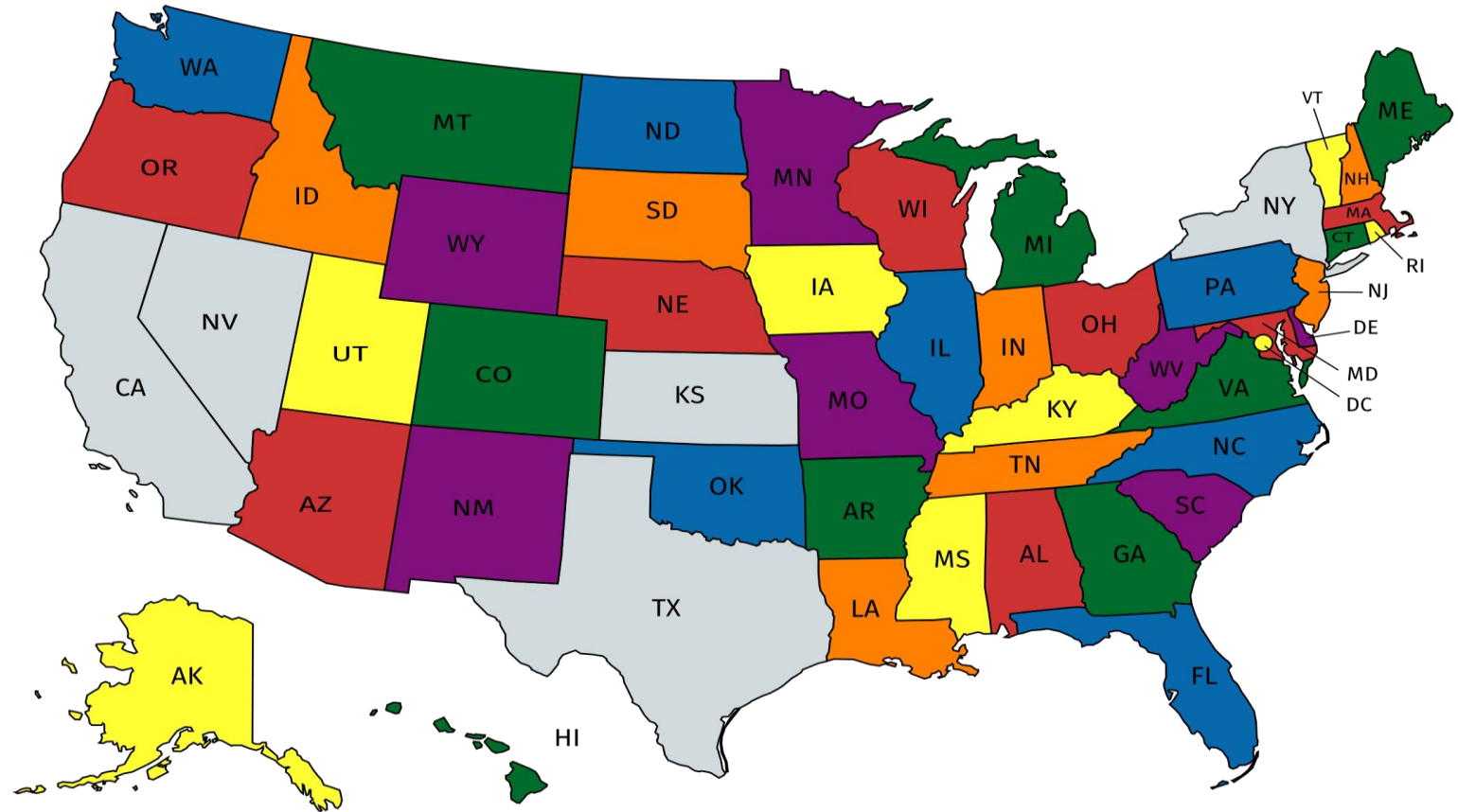


State of the States in I/DD Project of National Significance

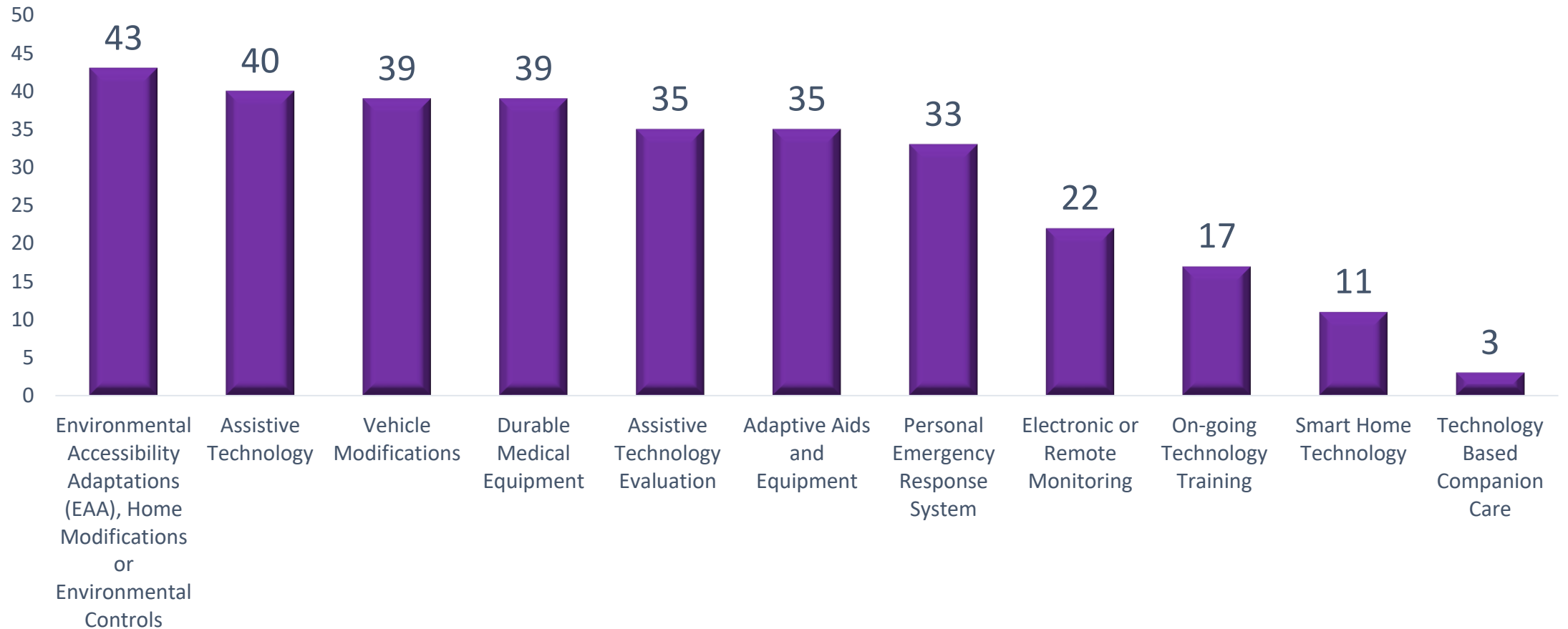
Coleman Institute for Cognitive Disabilities

Data on technology since 2007

- Purpose: Deeper dive 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



What Technology Services and Supports do States Currently Fund?



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)

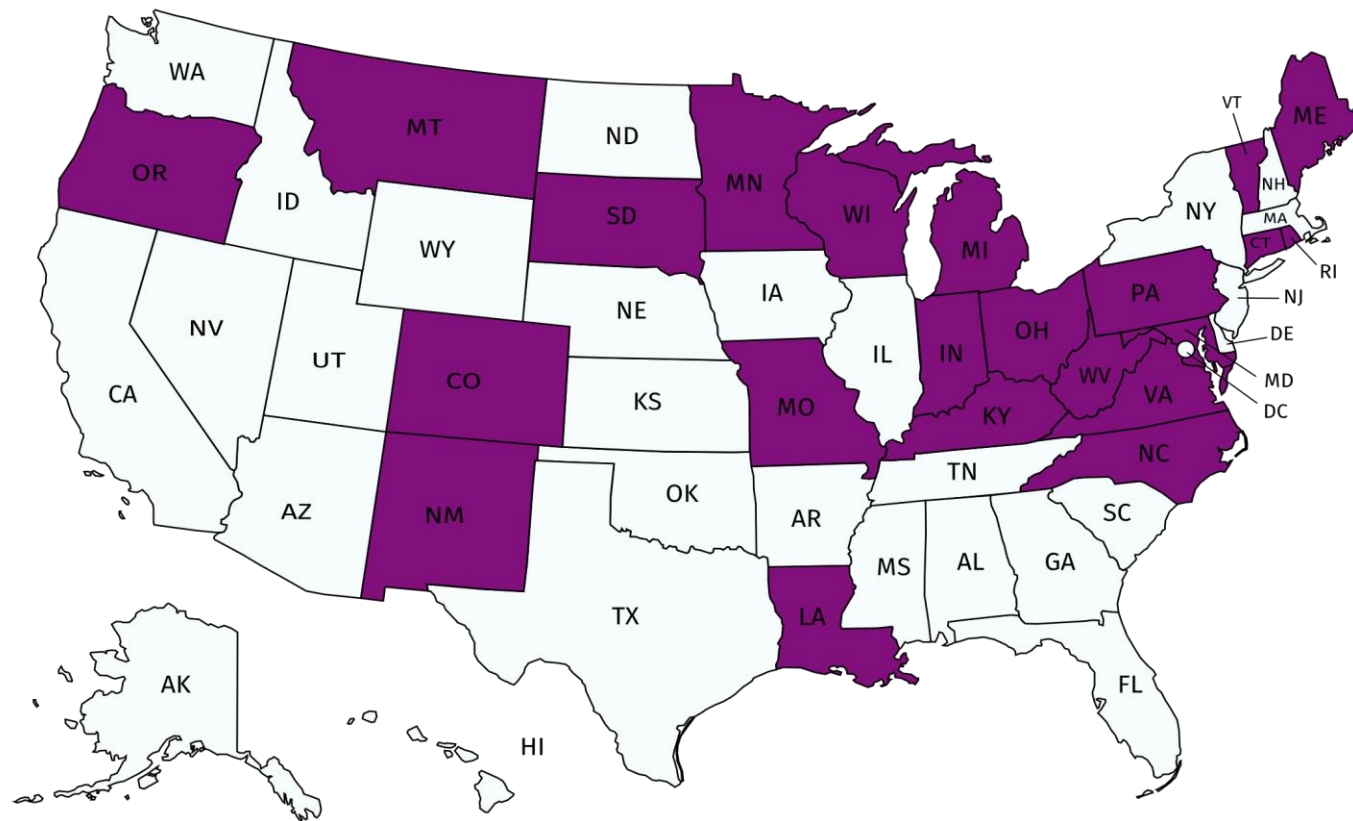
Technology Supports and Services

- 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

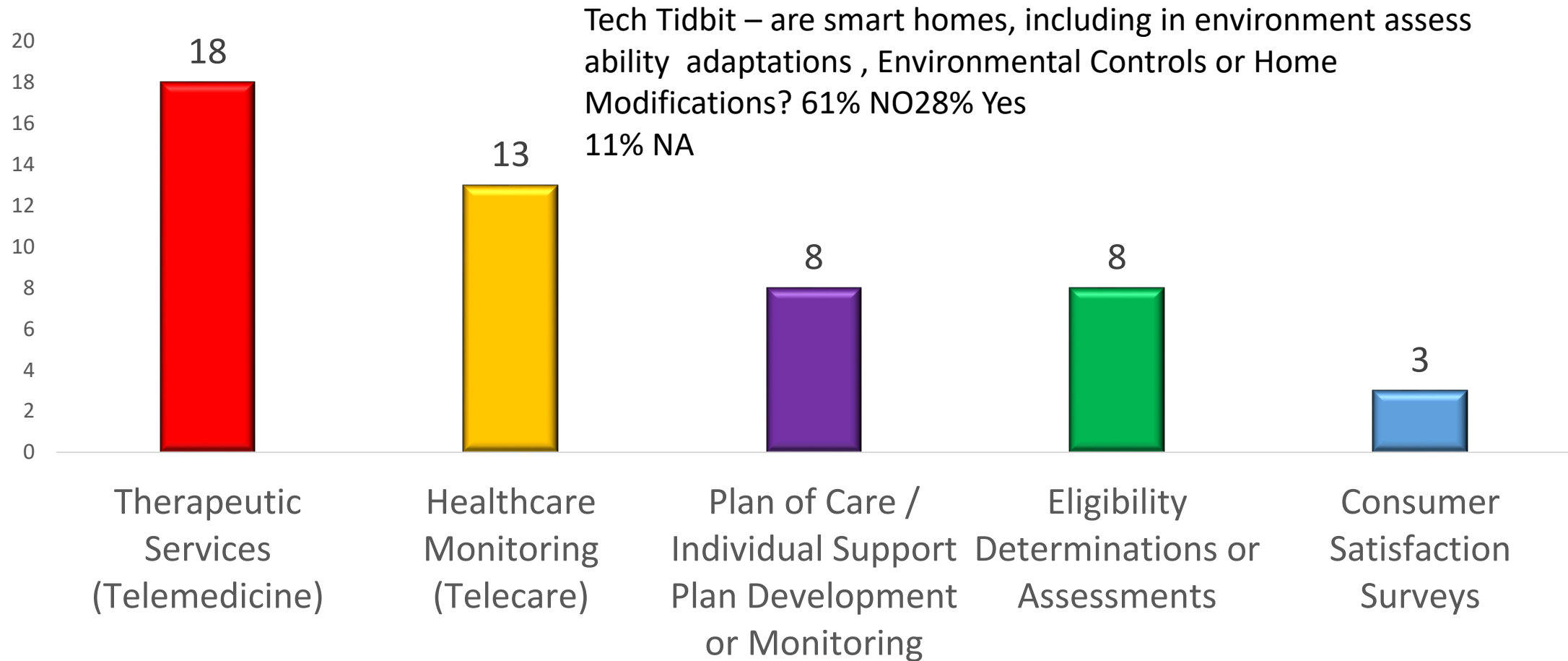
States Funding Electronic or Remote Technologies

22 states report funding for electronic or remote technologies

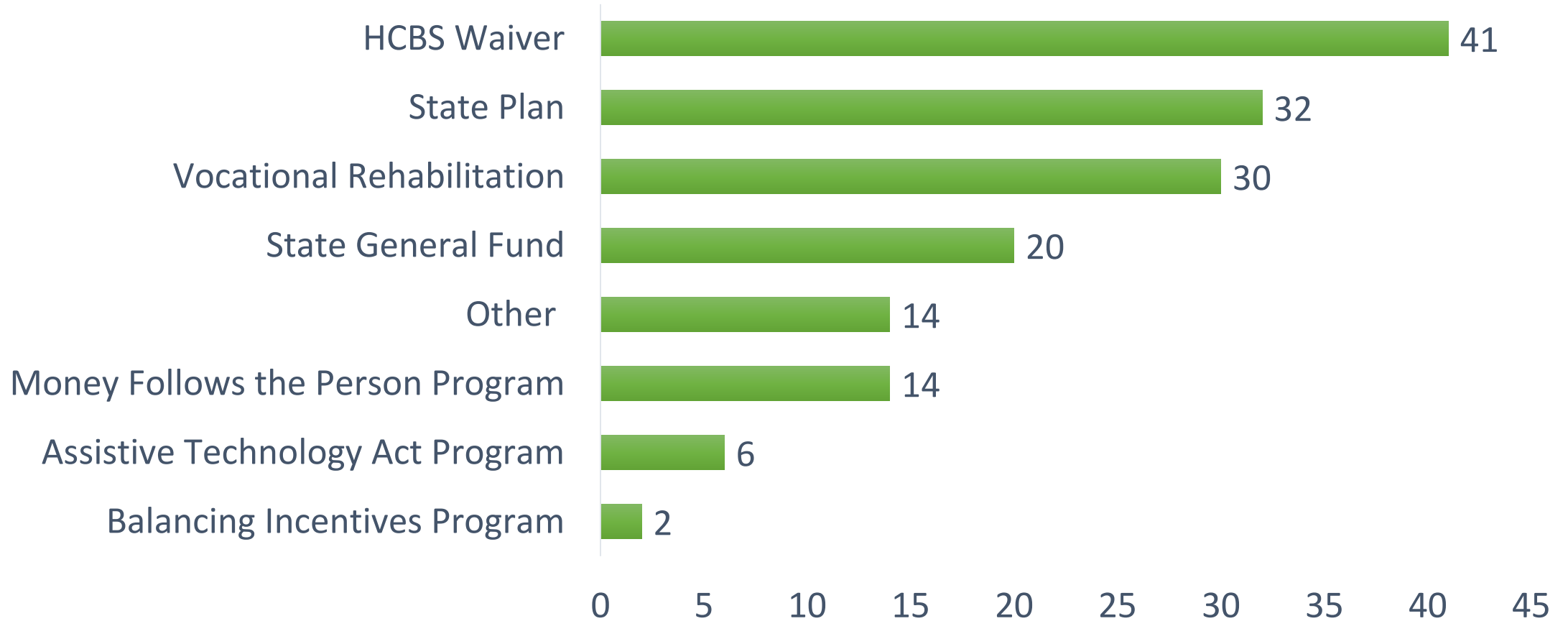
Technology-based companion care is gaining in popularity for aging adults in rural areas. 3 states funding this service in IDD: NM, RI, SD



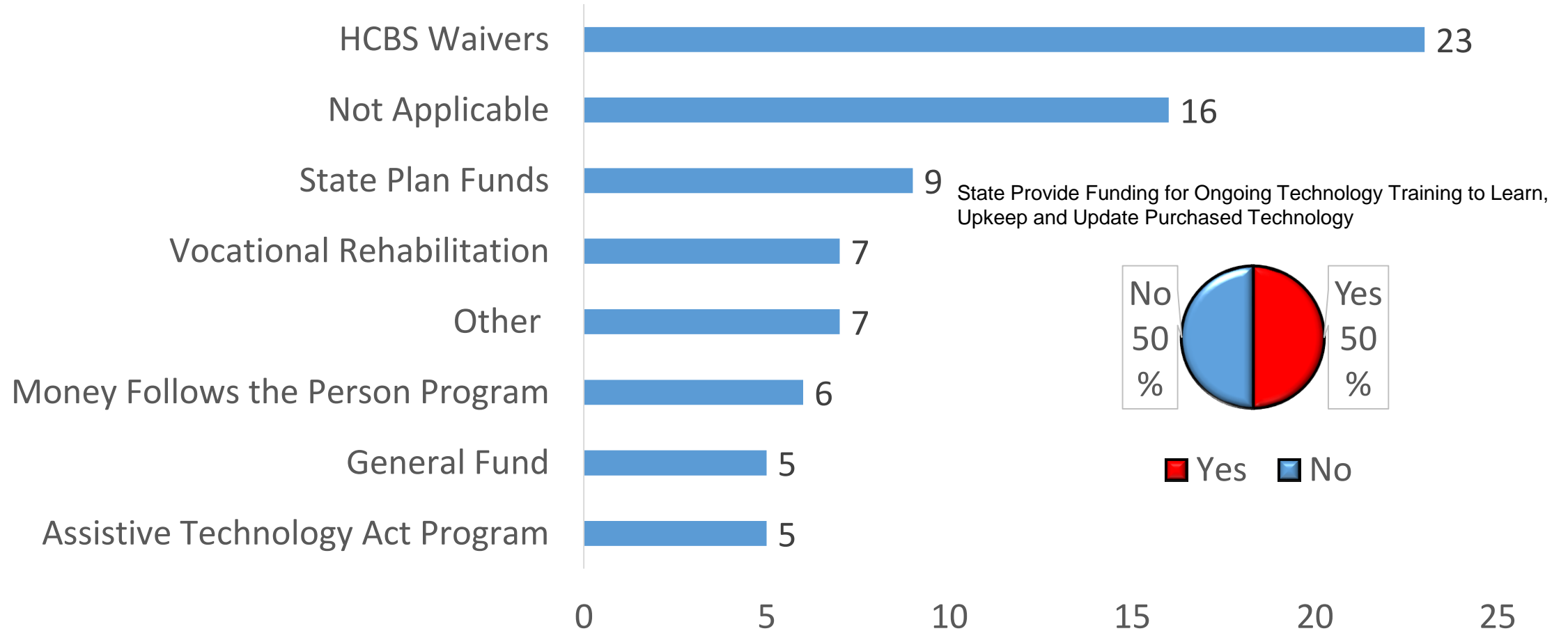
States Report Funding of Remote Teleservices



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



Number of States that Utilize Federal Funds to Provide Ongoing Technology Training to Learn, Upkeep, and Update Purchased Technology

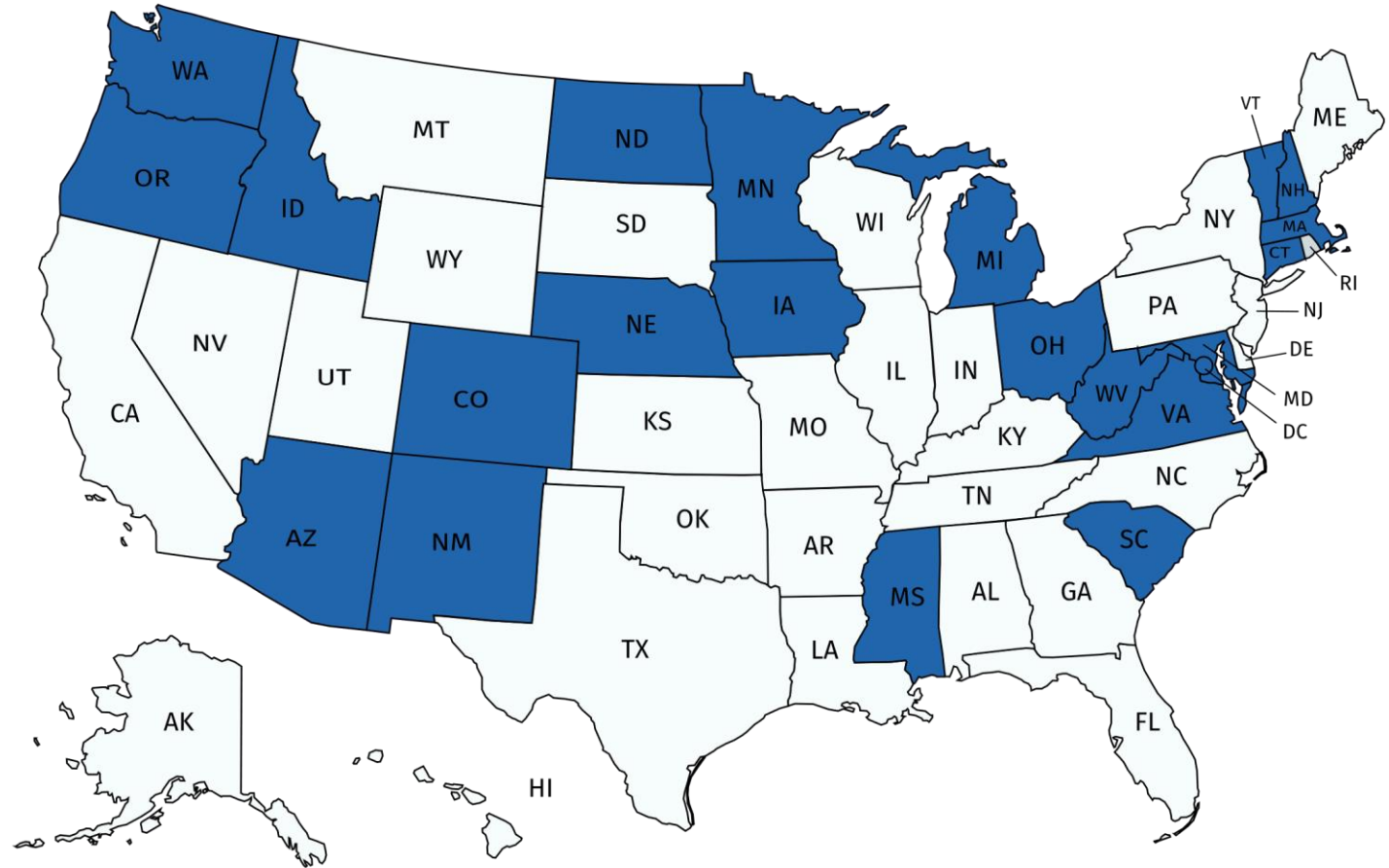


Eight States Funded Six or More Technology Solutions Not Traditionally Covered By Medicaid

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



The Bottom Line

- To prepare for the future, states and Medicaid must work together and will be well positioned if they:
 - Keep the individuals they serve at the center of the decision-making
 - Are open to growing new and innovative approaches to meeting people's needs, in the context of their families, friends and communities
 - Develop necessary acumen to meet the data, reporting and quality requirements that are emerging

What needs to happen

- Administrative rules
- Budget
- Education
- Service coordination
- Provider capacity
- It doesn't happen overnight



***The most
dangerous phrase
in our language
is,
"We've always
done it this way."
- Grace Hopper***

Questions

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