

National Trends in State I/DD Systems

June 14, 2019

2019 Colorado Alliance Summit /6 State Summit

Jeanine Zlockie

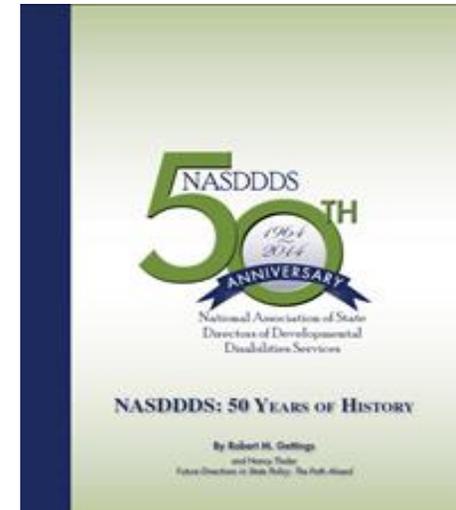
Director of Communications and Educational Programs

NASDDDS

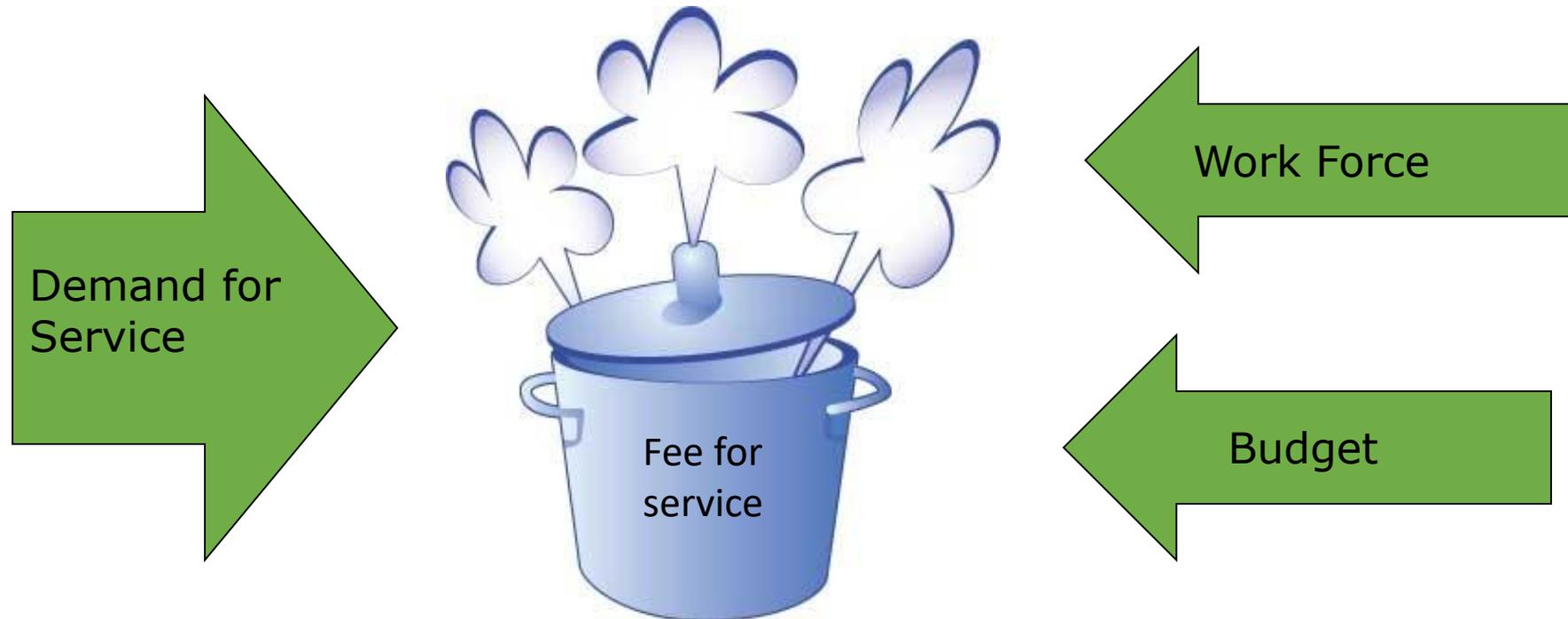
NASDDDS

The National Association of State Directors of Developmental Disabilities Services (NASDDDS)

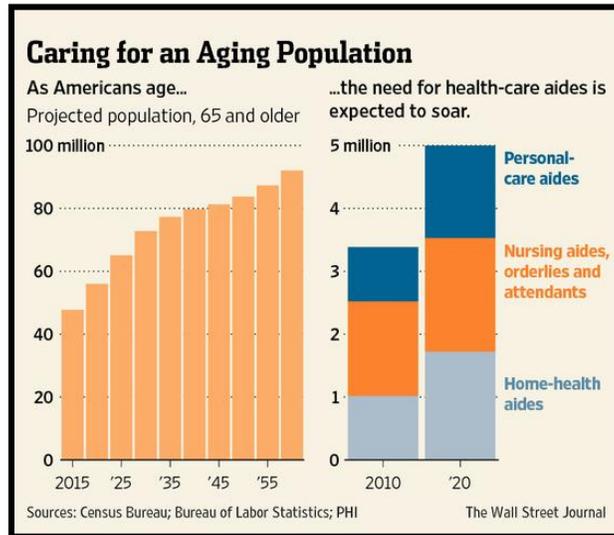
The NASDDDS mission is to assist member state agencies in building person-centered systems of services and supports for people with intellectual and developmental disabilities and their families



What are we Seeing as Pressures for System Change?



Shortages of Care Givers as America Ages



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

Wall Street Journal
April 15, 2013

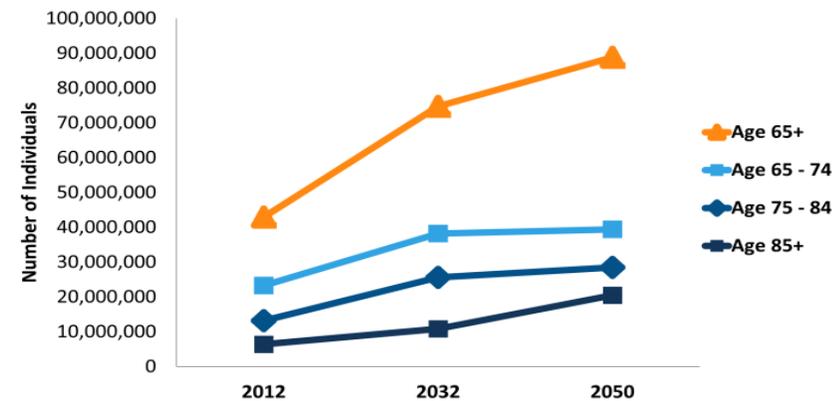


CNBC

The U.S. labor shortage is reaching a critical point

Figure 1

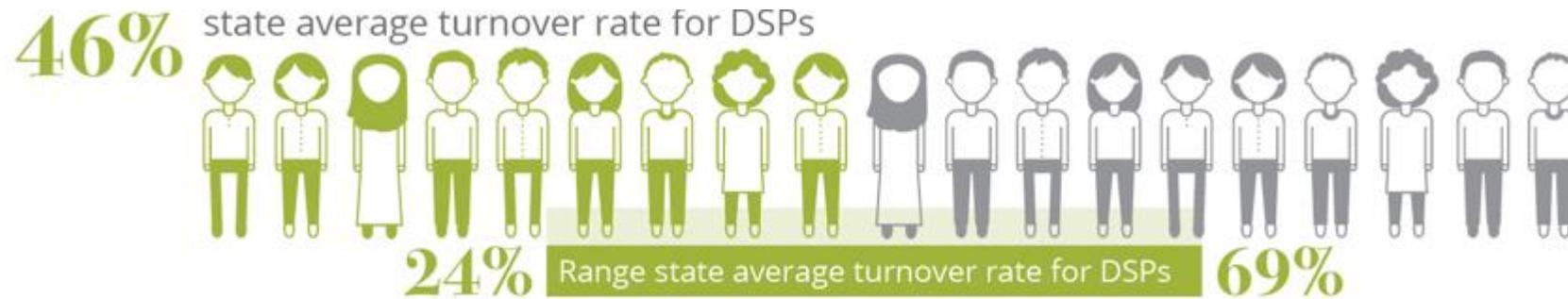
The 65 and Over Population Will More Than Double and the 85 and Over Population Will More Than Triple by 2050



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/ltc/2012/2012-full-report-AARP-ppi-ltc.pdf.



National Core Indicators - Staff Stability Survey Turnover Rates



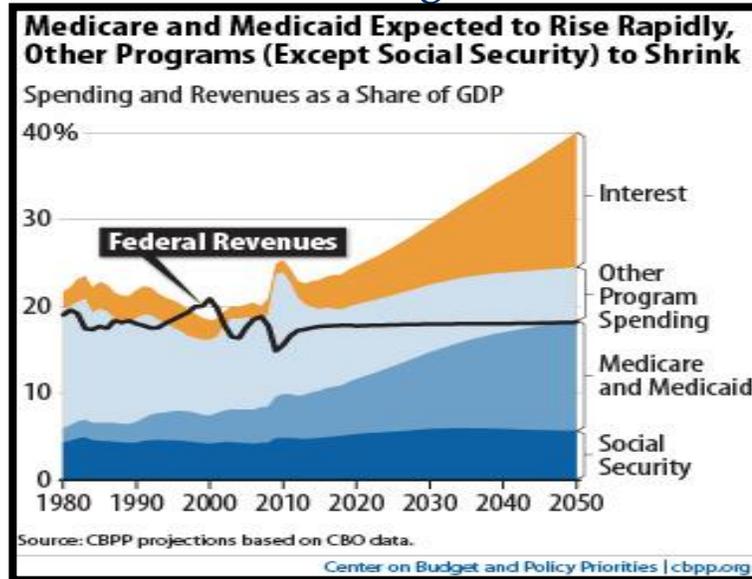
Of DSPs who left positions in calendar year 2016:



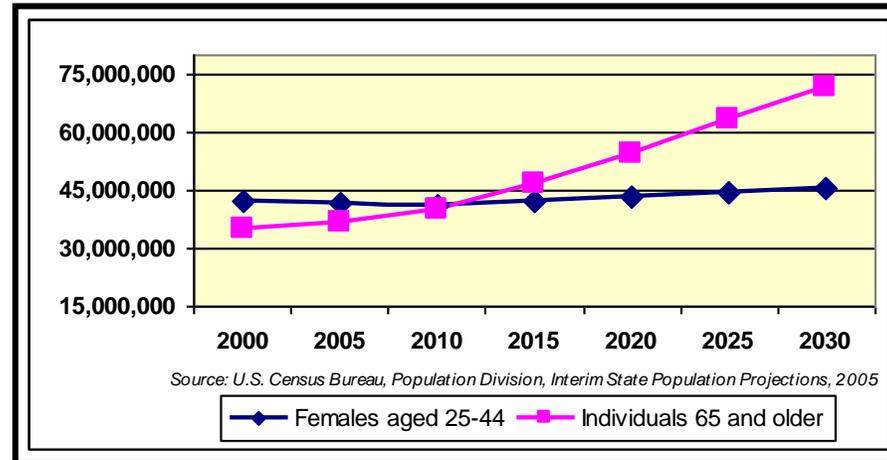
*States: AL, AZ, CT, DC, GA, HI, IL, IN, MD, MO, NE, NY, OH, OR, PA, SC, SD, TN, TX, UT, VT

We are Confronted with Reality

Growth in public funding will slow



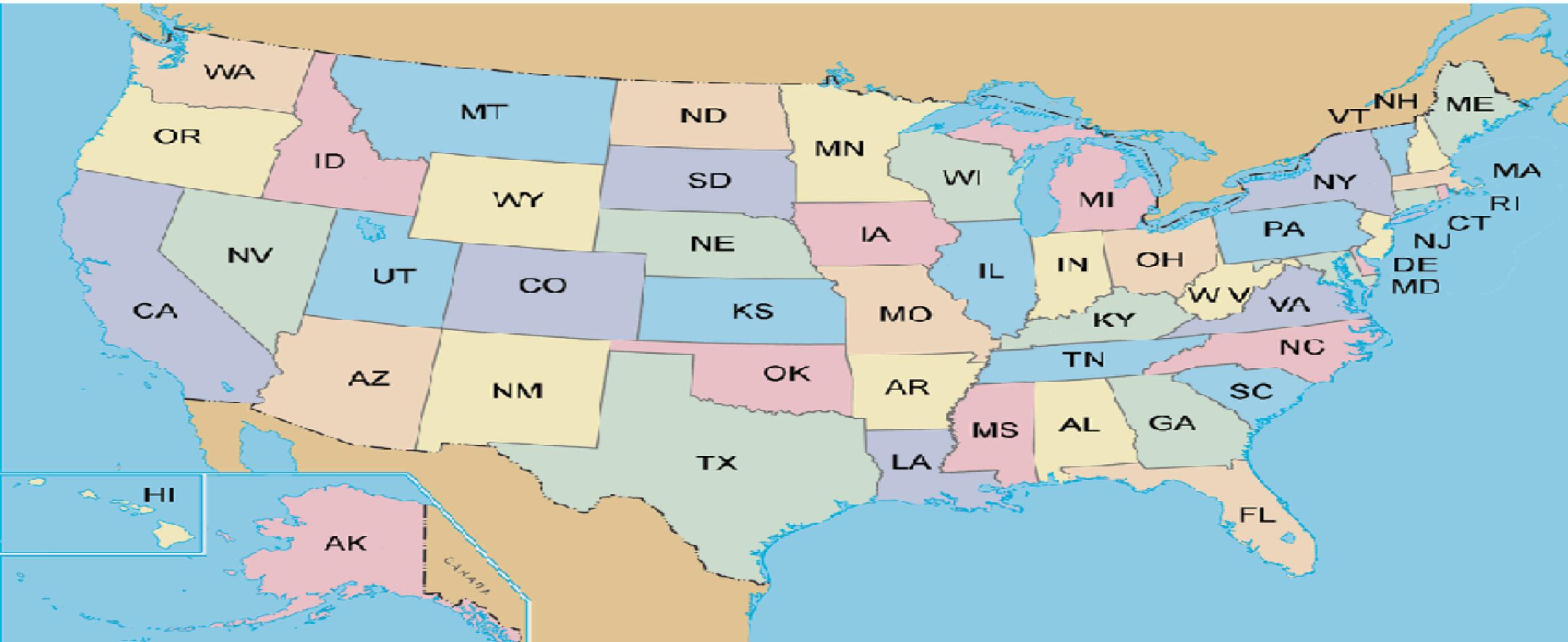
Workforce will not keep pace with demand



The Waiting List

People Waiting For Services	Colorado	Waiver Expenditures
3,199 <i>RISP 2016</i>	10,846 <i>RISP 2016</i>	\$39,484/ Person

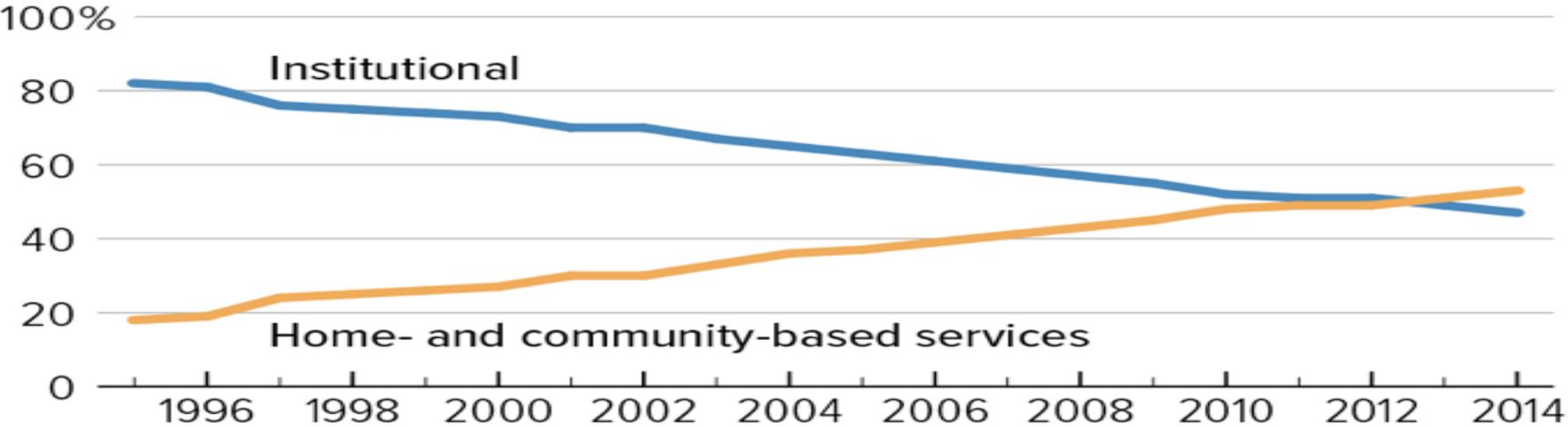
So, How are we doing? National Picture



National Picture

States Have Shifted Spending to Home- and Community-Based Services, and Away From Institution-Based Services

Share of total Medicaid long-term services and supports spending

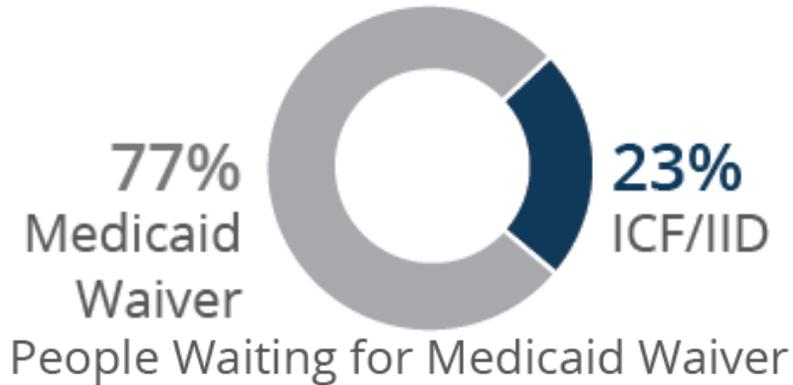


Source: Truven Health Analytics, "Medicaid Expenditures for Long-Term Services and Supports (LTSS) in FY 2014"

National Picture

Medicaid Long-Term Supports and Services

EXPENDITURES



PEOPLE



Medicaid ICF/IID and Waiver recipients

852,408

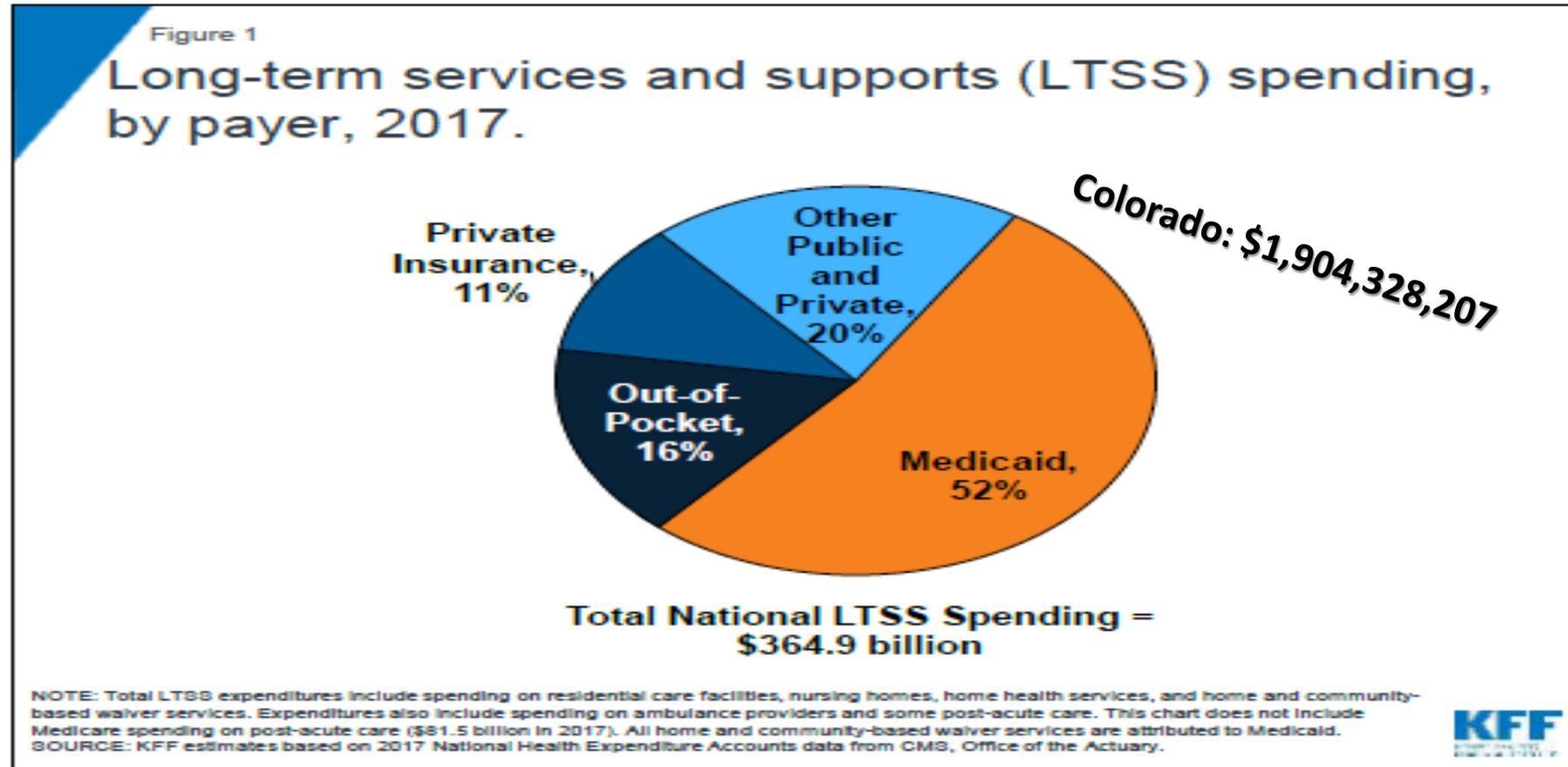
199,641

people waiting for Medicaid Waiver funding living with family members

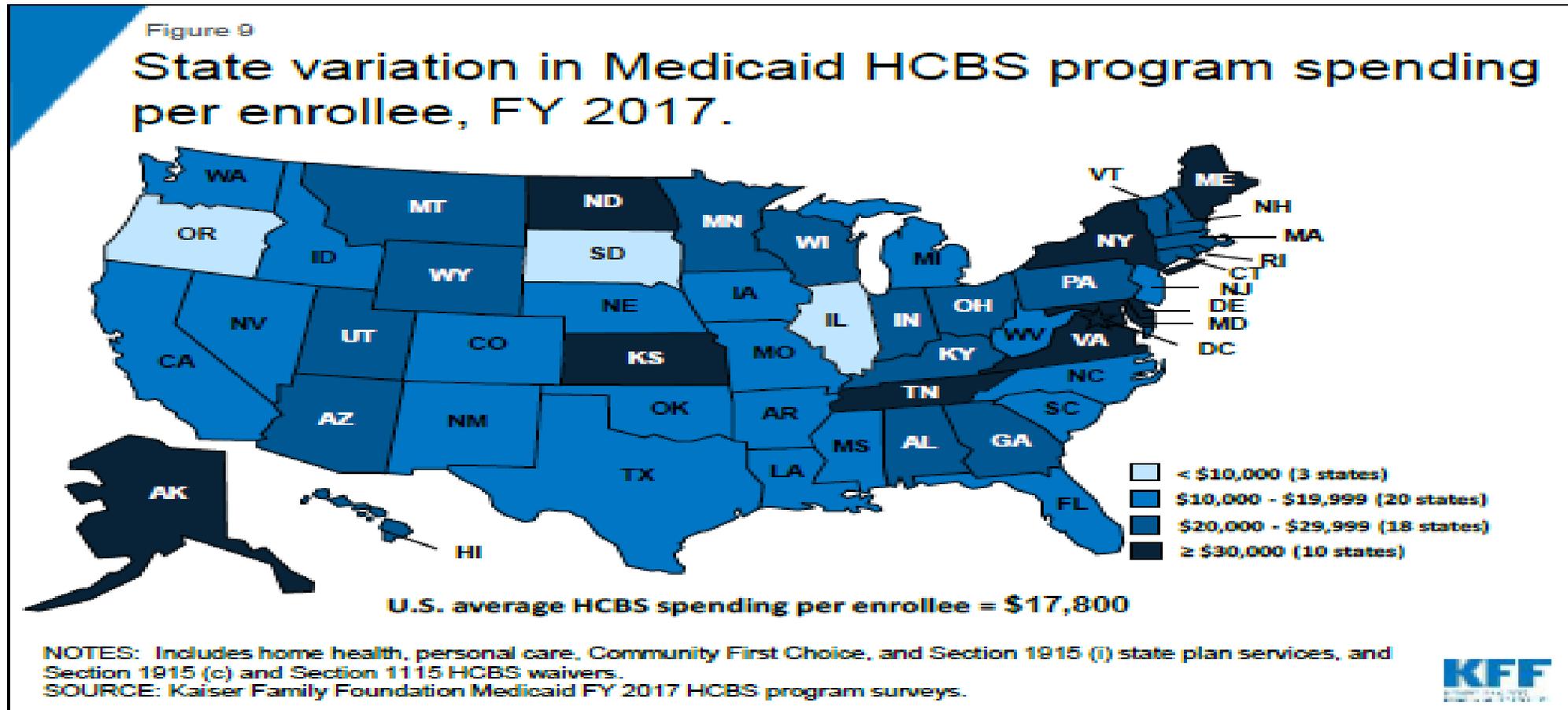


23% increase in Medicaid needed to serve all waiting Medicaid Waivers

National Picture – LTSS Spending

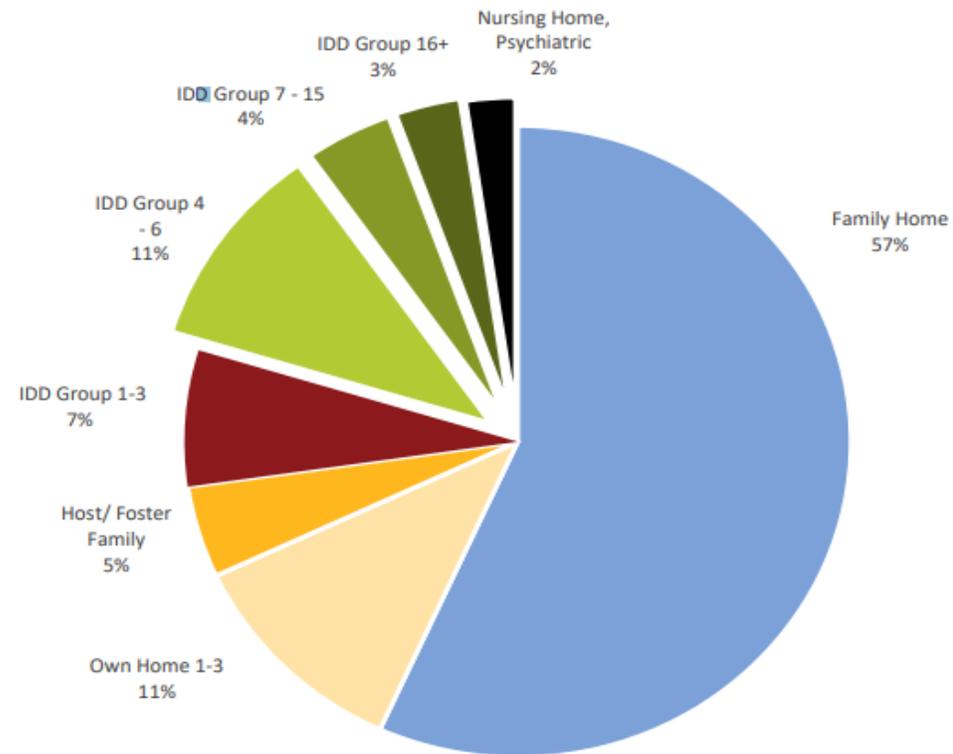


State Medicaid HCBS Program Spending



National Picture

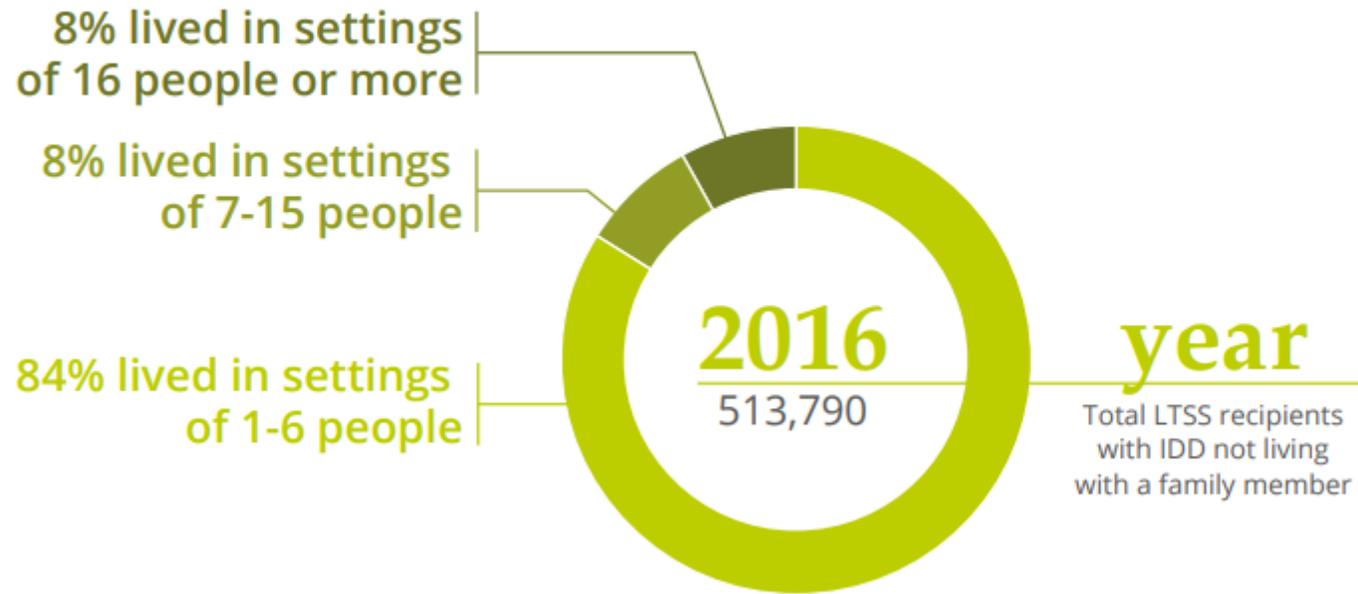
Figure 1.6 Percent of LTSS Recipients with IDD in Family Home, LTSS Settings, Psychiatric Facilities or Nursing Homes by Residence Type and Size on June 30, 2016



Institute on Community Integration (UCEDD), University of Minnesota: National Residential Information Systems Project

National Picture

Proportion of people living in non-family IDD settings



Colorado RISP Profile 2016

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

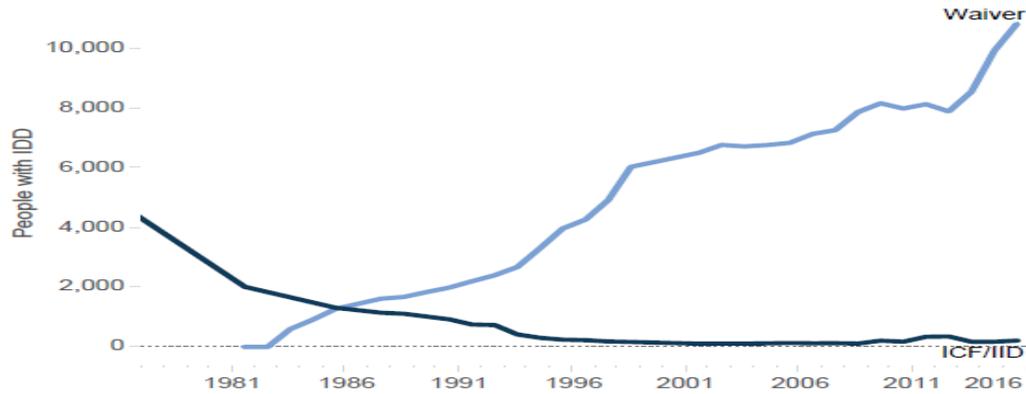


Figure 2: Medicaid Spending Per Person FY 2016

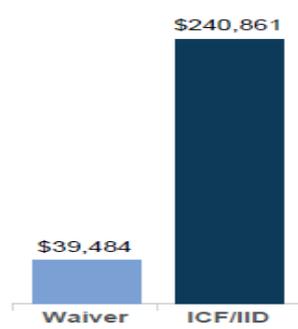


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

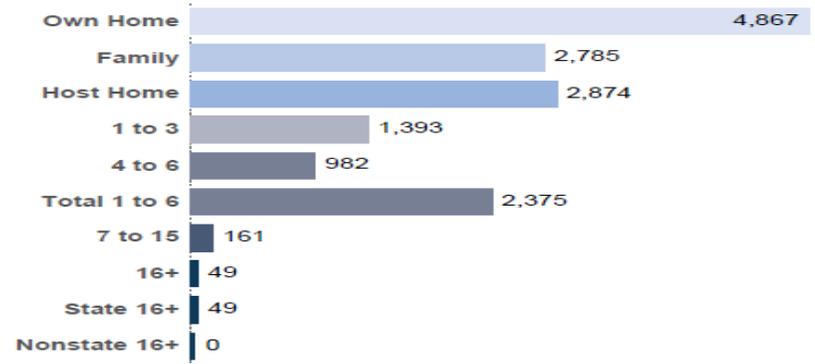


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				865	729	1,020	3,884	3,884	4,799	4,867
	Family				5,628	7,017	5,807	2,580	3,210	4,483	2,785
	Host Home				0	2,492	2,204	2,460	2,605	2,710	2,874
	1 to 3				33	DNF	2,118	937	1,192	1,267	1,393
People in Congregate Settings	4 to 6				646	1,370	110	1,018	998	932	982
	Total 1 to 6	119	670	1,819	679	1,370	2,228	1,955	2,190	2,199	2,375
	7 to 15	421	670	910	499	203	207	166	154	126	161
	16+	2,111	1,960	666	105	67	296	168	PD	29	49
People Served by the DD Agency *	Caseload (known to the DD agency)							21,833	22,085	24,883	19,567
	LTSS Recipients (1)	2,651	3,300	3,395	7,776	11,878	11,857	11,233	12,211	14,346	13,111
	Waiting for Medicaid Waiver				940	1,562	1,794	3,712	3,712	3,314	3,199
People in Non-DD Settings *	Nursing Facility (s)			428	161	97	95	240	160	153	64
	Psychiatric Facility (2)			0	DNF	DNF	0	DNF	0	0	0
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$26,450	\$36,110	\$41,127	\$40,630	\$41,583	\$41,529	\$39,818	\$39,484
	ICF/IID Expenditures per Person			\$60,300	\$481,362	\$134,414	\$115,258	\$123,606	\$253,725	\$233,314	\$240,861
	Waiver Recipients per 100,000			59.0	145.2	162.6	157.0	150.0	160.0	182.0	195.8
	ICF/IID Residents per 100,000			27.5	2.6	4.2	6.6	6.7	3.3	3.2	3.0

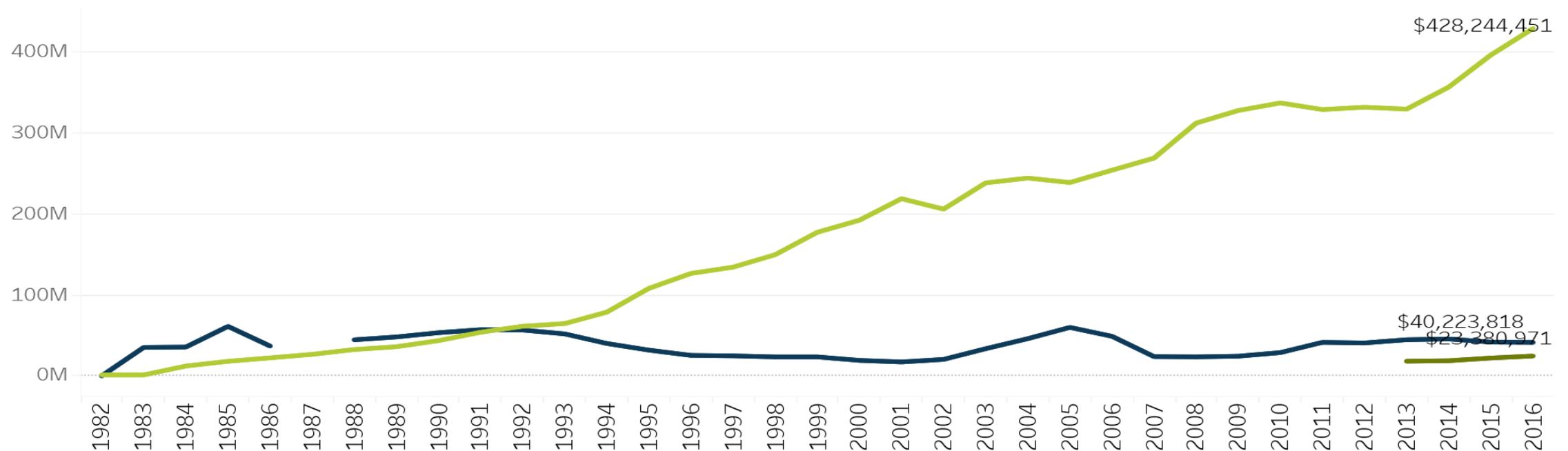
(1) Long Term Supports and Service (LTSS) recipients may include imputed values; Until 2012 LTSS recipients may include people in nursing homes or psychiatric facilities who were not on the IDD agency caseload.
 (2) Includes state operated facilities until 2013.
 (s) Data may be from an outside source.

Settings by size includes ICF/IID, group homes, and nonstate other.
 DNF = Did Not Furnish.
 PD = Partial Data.
 * See state notes and the RISP report for further explanation.

Updated 2/14/2018

Medicaid Expenditures by Funding Authority 1982-2016

Colorado Medicaid Expenditures by Funding Authority 1982-2016



- Waiver Expenditures
- ICF Expenditures
- State Plan Expenditures

From 2013-2016 RISP data for State Plan included Targeted Case Management (TCM), 1915(i) or 1915(k).

HCBS Regulations



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
-
- Friends, family, self-determination, community living, social capital and economic sufficiency*
- Receive services in the community to the **same degree of access** as people not receiving HCBS

Person
Centered
Planning

Conflict of
Interest
Provisions

Status of State Transition Plans



As of March 20, 2019:

- 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

How are State's Responding: Systems Change

New Service Models

- Supporting Families Across the Life Span
- Prioritizing real Employment
- Developing Relationship Based Living Arrangements
- Paying Family Caregivers
- New and innovative approaches to supporting people to engage in their communities
- Technology

New Financing Models

- Managed Care Strategies
- Outcome Based Payment Models
- Explore new federal authorities for HCBS
- Creating Support Waivers
- Implement resource management methodologies

Case Management: What *is* a conflict of Interest?

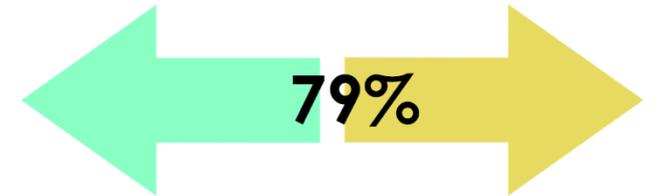
And why does it matter?

Conflict of Interest... State Data

NASDDDS Medicaid and Case Management for People with Developmental Disabilities: Structure, Practice, and Issues – Third Edition, April 2019

Survey responses/majority of states do not identify any conflict of interest.

- Seventy-nine percent of respondents indicated their system offered conflict free case management.
- Twenty-one percent of respondents indicated there were conflicts of interest
 - 11 states out of compliance – many making big steps toward compliance
- Seven states recognized both conflict free case management and situations with remaining conflicts of interest.



Case Management Conflict of Interest

When case management systems have the same entity both assisting an individual to gain access to services and providing services to that individual, there is potential for conflict of interest in:

- **Assuring and honoring free choice**
- **Overseeing quality and outcomes**
- **The “fiduciary” relationship**



Robin E. Cooper, NASDDDS

Quality and Outcomes: “Self-Policing”



- Self-policing occurs when an agency or organization is charged with overseeing its own performance.
- Self-policing puts the case manager in the difficult position of:
 - Assessing the performance of co-workers and colleagues within the same agency
 - Potentially having to report concerns to their mutual supervisor or executive director.

Robin E. Cooper, NASDDDS

State System re-design examples

Wyoming embarked on a path to conflict free case management prior to the promulgation of the CMS rules.

- Redesign permits both individual and agency-based case managers
- Establishes full freedom of choice among any and all of the qualified providers.
- The individual practitioners strategy proved useful in a highly rural state
- Able to develop individual practitioners in the “frontier areas”

South Dakota chose a different route

- procuring agencies with capacity to serve large rural areas.
- There is a least choice between two agencies in their regions
- South Dakota did a particularly robust job of bringing individuals and families into the conversations around system change

System re-design examples



Alaska

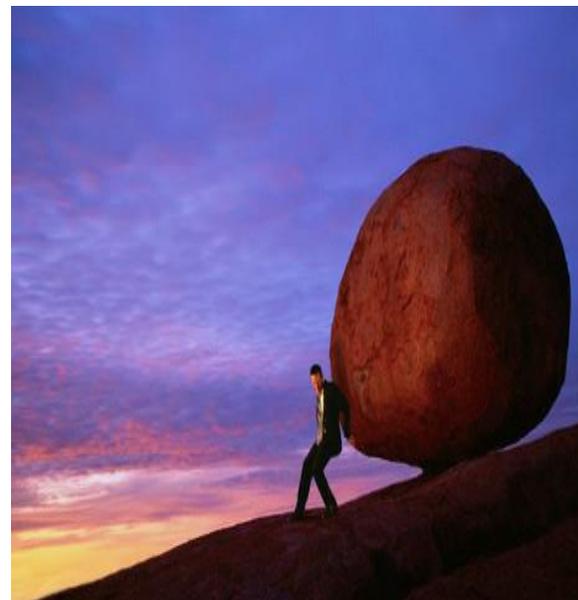
- Did an initial assessment to understand the scope of where conflict of interest occurred in the system across all populations.
- This assessment formed the basis of their comprehensive plan to assure their case management systems meet the COI regulations.

Ohio

- Embarked on a substantial redesign of their county-based system of supports and services serving individuals with I/DD.
- The County Boards provide both case management and direct services as well as significant funding for the services system. Ohio's assessment of conflict of interest discovered more than 14,000 individuals who receive both case management services and direct services (day services mainly) from the County boards.
- In order to redesign their system, Ohio developed multiyear strategy to separate case management and direct services.

What Does This Mean For States?

- All states are facing the same pressures
(New rules and requirements/budget/
demand/workforce)



“The most dangerous phrase in our language is, we've always done it this way.”

- Grace Hopper

Around the Nation



- There is no one “perfect” case management system anywhere, but there are many that are fully independent of services provision, for example:
 - CA, FL, GA, ID, IN, LA, MD, MT *, NJ, NM, have “stand-alone” case management agencies whose mission and function is case management
 - AZ, CT, DC, HI, IA, MA, MN, ND, NE, NJ, OK, OR, PA, RI, WA, use government entities (State , county, community board employees) again whose role is case management

* Adult CM is independent

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Emerging Interest Areas

Direct Support Workforce

Supporting the person in the context of their family

Housing

Employment

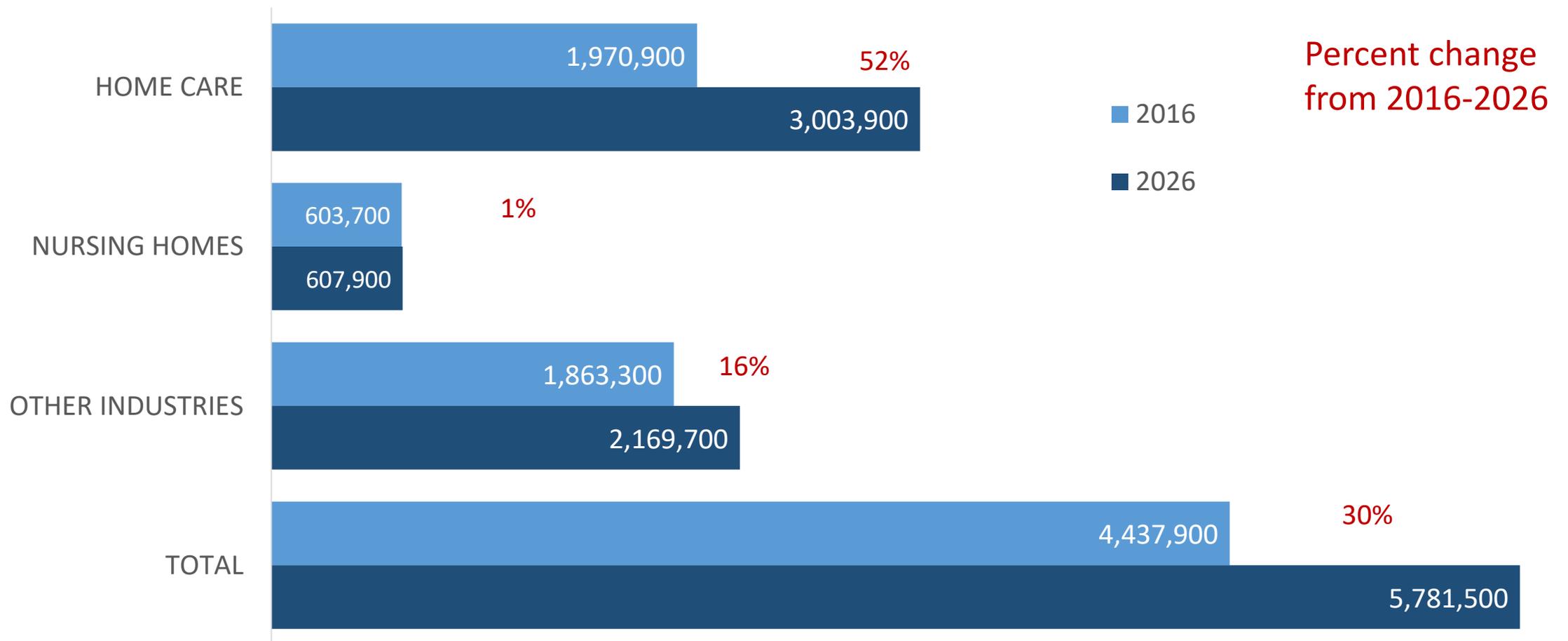
Individual budgets

Technology



Direct Support Workforce Update

Projected growth of workforce 2016-2026 (BLS)



PHI. "Workforce Data Center." Last modified November 10, 2017.
<https://phinational.org/policy-research/workforce-data-center/>.

NCI Staff Stability Survey

	Turnover	Average Starting Wages	Average Overall Wage	Vacancy Rates
Value:	45.5%	\$10.79	\$11.76	9.8% Full Time 15.4% Part Time
Range:	24%-69%	\$8.79-\$13.87	\$9.47- \$14.27	4-28%

Key Data Results

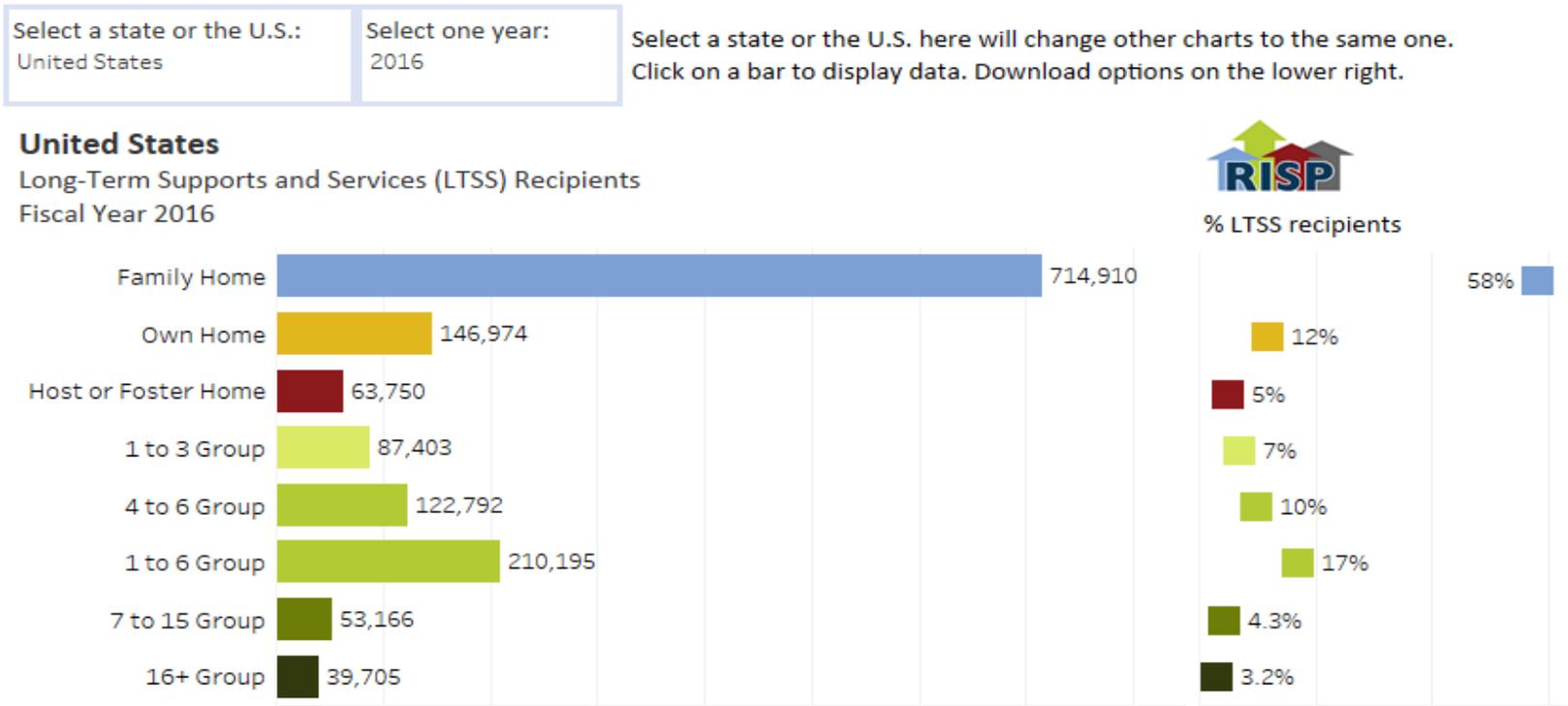
Tenure:

Employed DSP's	<6 months	6-12 Months	> 12 months
Average NCI	19%	16%	65%
Range	12-28%	11-23%	50-74
<u>Separated DSP's</u>	<6 months	6-12 Months	> 12 months
Average NCI	38%	21%	41%
Range	23-50%	17-26%	27-56%

Supporting People in the Context of their Family



People with IDD receiving LTSS Living with Family - 58%



RISP data 2016

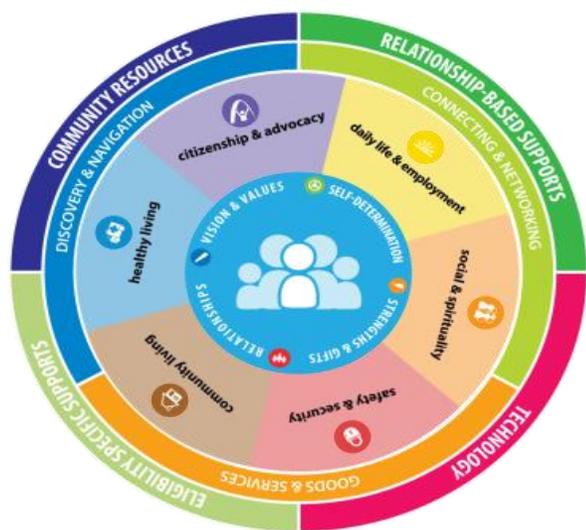
The number of Long-Term Supports and Services Recipients is for the IDD Agency in the state. There may be people with IDD who are served in other state agencies, such as residents of Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID). Group settings (1-6, 7-15, and 16+) include ICF/IID, group homes, and other congregate settings.



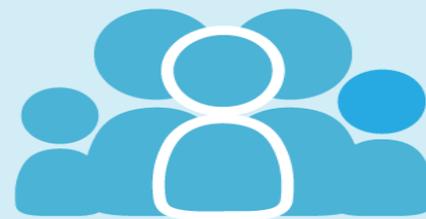
SUPPORTING FAMILIES

of individuals with intellectual & developmental disabilities

THE NATIONAL COMMUNITY OF PRACTICE • FUNDED BY THE ADMINISTRATION ON INTELLECTUAL & DEVELOPMENTAL DISABILITIES



GOAL OF SUPPORTING FAMILIES



Recognizing that individuals exist within a family system, where:



The Individual will achieve self-determination, interdependence, productivity, integration, and inclusion in all facets of community life



Families will be supported in ways that maximize their capacity, strengths, and unique abilities to best nurture, love, and support the individual to achieve their goal

<http://supportstofamilies.org/cop/>

How Are State's Using Supporting Families Tools to Strategize

DDD's overall systems development initiatives to support people with I/DD to have full lives in the community

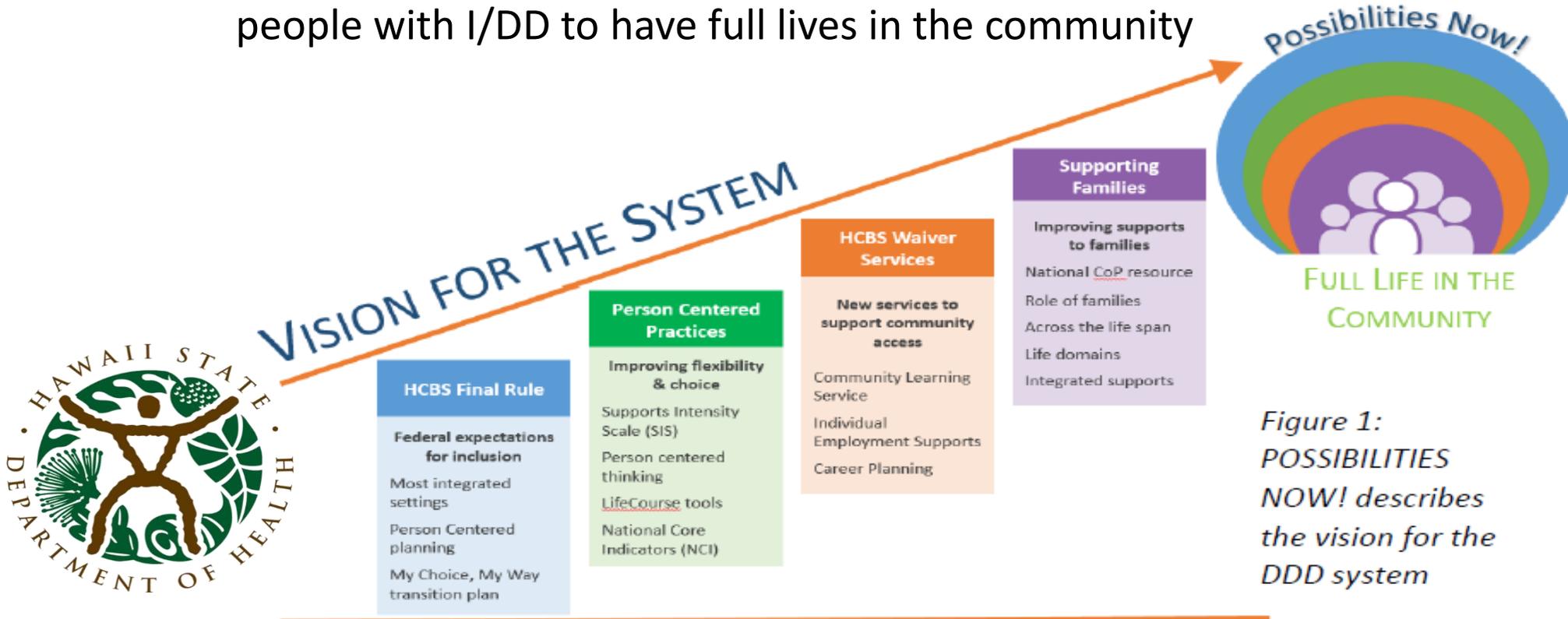


Figure 1: POSSIBILITIES NOW! describes the vision for the DDD system

IN Charting a Trajectory for Case Management



2014

- Changed Practice to Refer Individuals for Intake After Medicaid Eligibility Secured

2015

- Dedicated Liaison with State Agency
- Active Collaboration with CMCOs Resulting in Greater Opportunities for Feedback and Input

2016

- Concerted Focus on Building Case Management as Critical & Valued Role in Supporting DDS Consumers
 - Hired Dedicated Consultant to lead innovations
 - Assembled Innovation Workgroup
- Dedicated Newsletter Focused on Issues Important to Case Managers
- Streamlined the Monitoring Checklist

2017

- Revised CM Certification Exam
- Allow RNs to be employed or contracted
- Retroactive BMR policy and High-Cost policy reduced administrative burden
- Streamlining information technology systems and sunsetting Advocare
- Implementing Workgroup recommendations

Vision for a Good Case Management for Hoosiers with Disabilities

Supports individuals and families of all abilities and all ages to develop a vision for a good life, think about what they need to know and do, identify how to find or develop supports, and discover what it takes to live the lives they want to

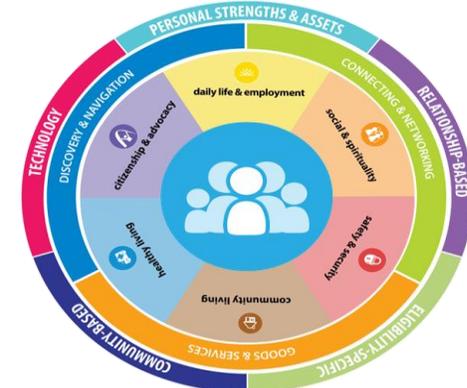
What We Don't Want for Case Management for Hoosiers with Disabilities

- Process over people
- Focused solely on waiver supports
- Focused on skill acquisition



Indiana What the PCISP is Intended to Accomplish

- Infuse the LifeCourse Framework and Values within the individual planning process
- Braid philosophical and technical components so that individuals and their families are supported in identifying their needs and understanding the full array of support options available to address them
- Promote more effective plan implementation through effective linking between the PCP and the ISP
- Address elements of the HCBS settings rule
- Supports Beyond Goods & Services-a colorful life
- Automated system
- See how things are going –re-evaluate soon





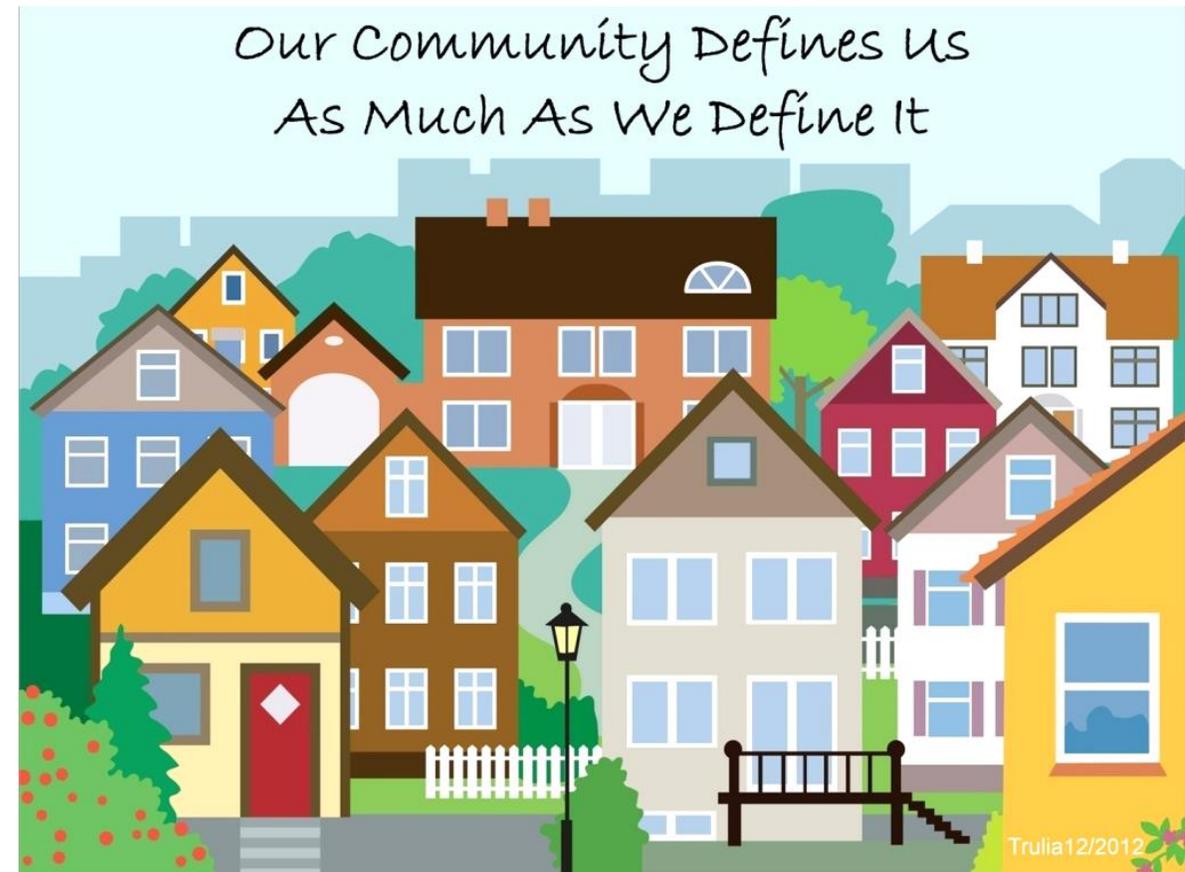
Housing



Community = Better Outcomes

The benefits for individuals with I/DD of living in smaller community settings are well-documented:

- more choices
- control over their lives
- more friendships,
- engaged in their communities,
- safer,
- experience greater life satisfaction.



But, the Facts are.....

The average monthly rent for a basic one-bedroom apartment

is **\$861**

That is 113% of the monthly income of a disabled person in the US, leaving no money for food, transportation, clothing or other necessities.

THIS IS NOT AFFORDABLE.

It's no wonder there are

350,923

homeless individuals living on the streets or in shelters -- and too many people stuck in expensive institutions at a cost of \$187 - \$2,715 per person per day.

In 2016, there was no housing market in the United States where a person with a disability whose sole source of income was SSI could afford a safe, decent rental unit.



Supplemental Security Income (SSI) is only

\$763 per month

What to do? Housing Options

- Community Development Block Grants
- Section 8 rental subsidies
- Non Elderly Disabled rental vouchers –for people with disabilities and “disabled households” (NED vouchers)
- National Housing Trust Fund –subsidies for extremely low income (ELI) individuals
- Section 811



Additional Policy Options

- Case managers explore housing security issues in person centered planning process
- Find ways to expand shared living and other less conventional housing options
- Work with families re: future financial planning
- Take advantage of the ABLE act → tax-free savings accounts to help individuals and families finance disability needs
- Support innovation with greater use of individual budgets and self-direction
- The Arc Center for Future Planning: <https://futureplanning.thearc.org/>

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 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.

What is 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)



New Possibilities and the Road to Employment



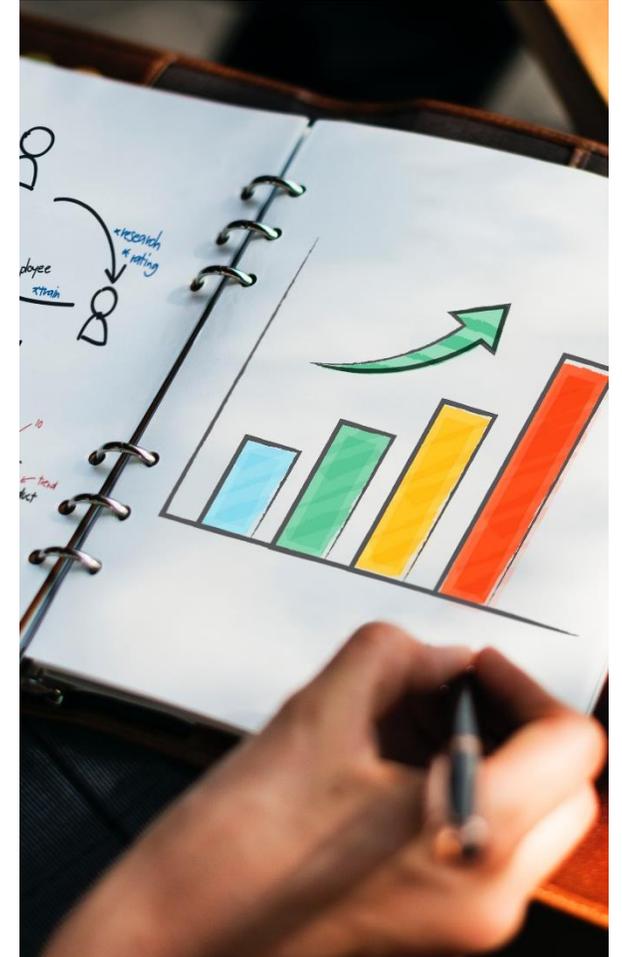
Does Everyone Have to Work?

- 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

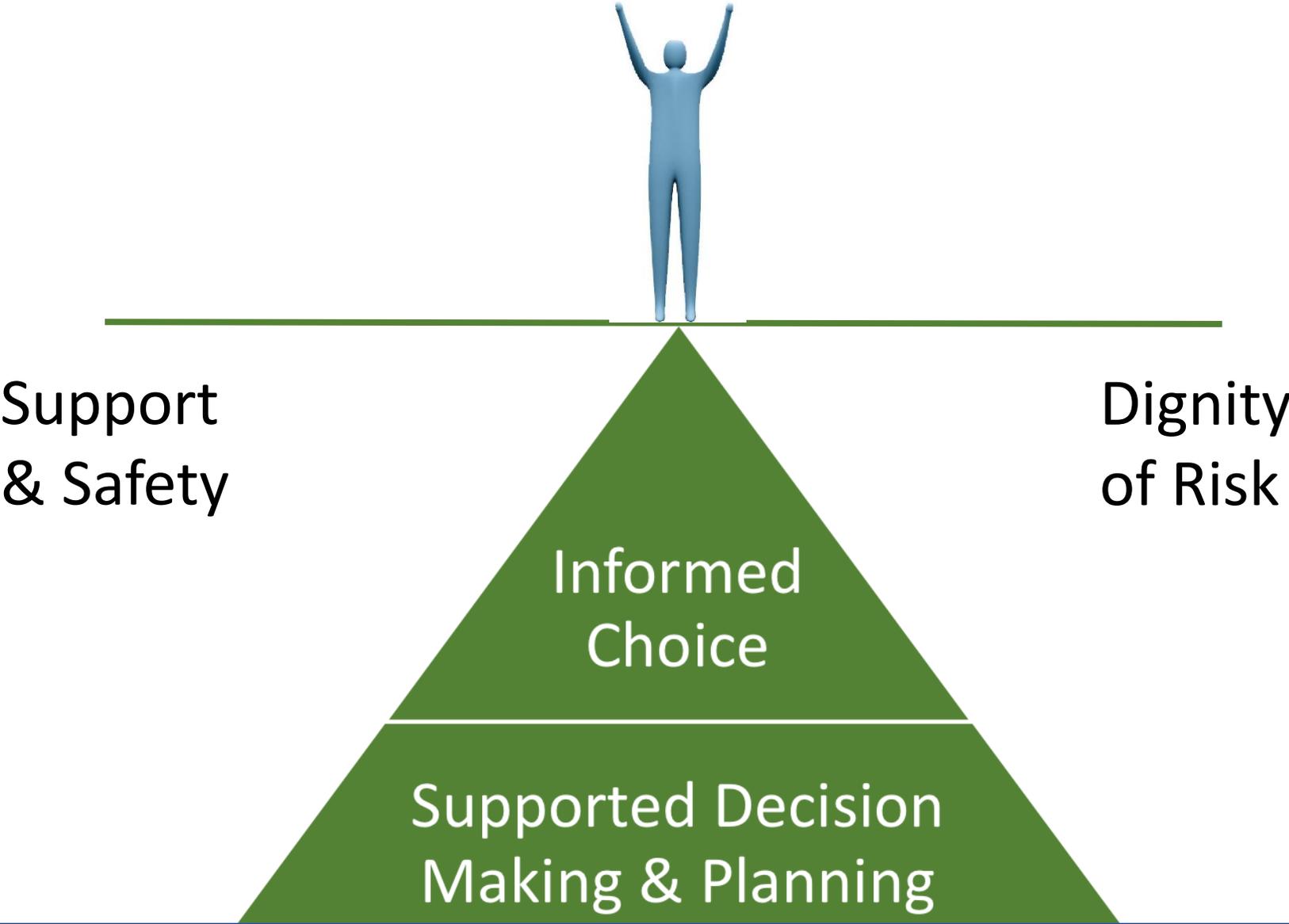


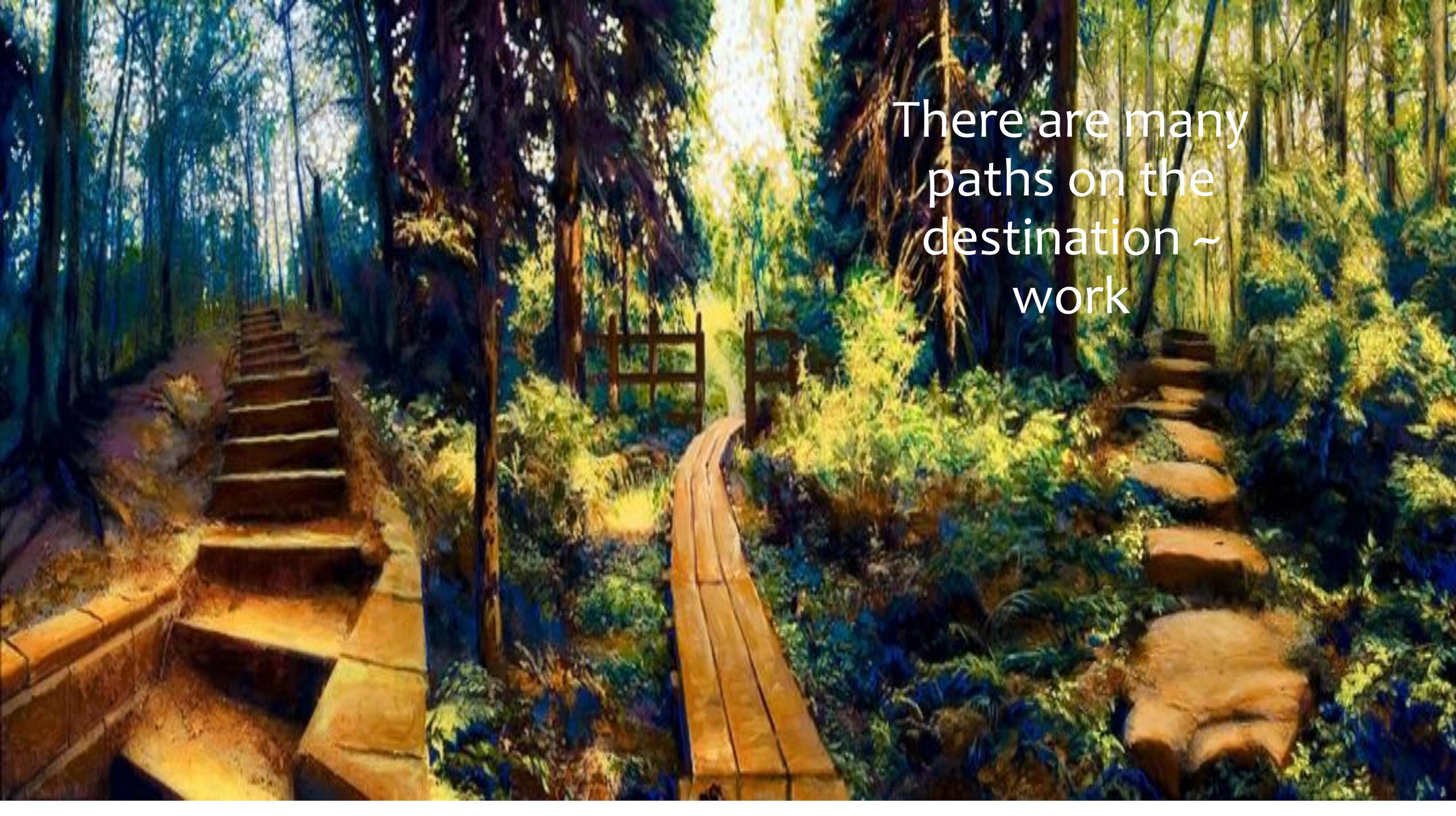
Self-determination and making informed, life choices are a key to:

- ✓ A meaningful, independent life
- ✓ Higher employment at increased wages
- ✓ Increased community belonging
- ✓ Increased health, welfare and safety



Self Determination & Autonomy

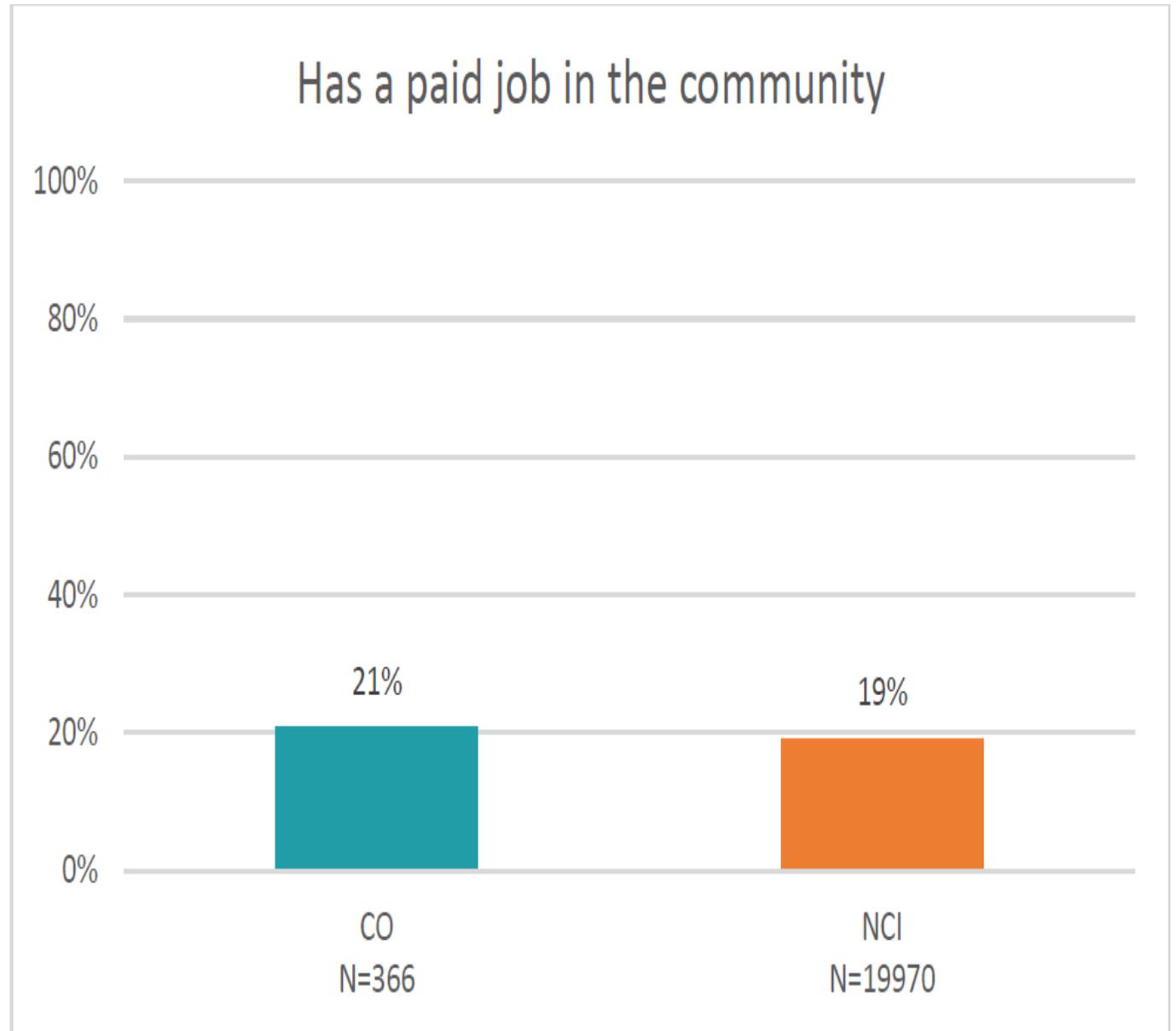




There are many
paths on the
destination ~
work



Range of states
6% to 43%



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?

A low-angle, close-up photograph of a person's legs and feet walking on a wooden boardwalk. The person is wearing blue denim jeans and dark sneakers with white soles. The background is a blurred natural setting with trees and foliage, suggesting a park or outdoor path. The lighting is warm, possibly from late afternoon or early morning.

Person centered planning is about informed choice

Case managers have the responsibility to support informed choice

Medicaid *requires* full freedom of choice of types of supports and services and individual providers

Steps Towards Your Destiny

**If you kept
notes on what
I can do ...**



openfuturelearning.org

Case management and Conversations That Matter

Data in the 2016-2017 National Core Indicators™ Adult Consumer Survey indicate that:

- 47% of those responding didn't have a paid job in the community but wanted one.
- Of those who wanted a job, only 40% had employment as a goal in their individual plan.

We asked if states have:

- Specific monitoring tools regarding employment
- Any specific training for case managers around employment outcomes
- And we also asked about training requirements on person-centered planning

Employment-specific training

- In terms of training specific to promoting employment:
- Sixteen states indicate they provide training to case managers focused on employment outcomes
- Fourteen states report that case managers track employment outcomes using templates.



And 36 states require person-centered planning training

National Landscape of Day and Employment Services

- Facility-based and non-work settings comprise the largest percentage of expenditures
- Participation in integrated employment is limited
- The percentage of individuals served in non-work settings is increasing

Employment First Policies: A Closer Look

- **38 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



Self-direction and Budget Authority

What is Self- Direction

People direct and plan:

- ❖ Their own lives
- ❖ Make their own decisions
- ❖ Choose own supports
- ❖ Determine how resources are spent for their own supports
- ❖ Ultimately be responsible for those discussions

Shift
authority
for decision
making

Control
over
funding

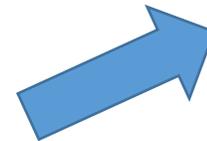
Person is at
center of
relationship
with state and
providers

How is budget authority Determined?

By a budget methodology....

The means by which the amount is calculated that a participant will have available to spend when developing his/her individual Support Plan.

Best practice



Casemanagement have no role in deciding on individual budgets. Having case managers responsible for resource allocation decisions could be construed as a conflict of interest.

Self-Direction and Budget Authority

A component in some Participant Direction programs where the individual is allocated a specific dollar amount from which s/he may purchase goods and services in addition to hiring workers.

Budget authority allows the individual to set worker's wages, purchase non-traditional services, and often save toward large purchases over time.

**National Resource Center for
Participant-Directed Services**

“Technology is not just a tool. It can give learners a voice that they may not have had before.”

George Couros

Technology Landscape and Medicaid



Technology Landscape: Medicaid

- Coverage for Assistive Technology – HCBS and State Plan Benefits (1915(c), 1915(i), Home Health Benefit, others)
- Information Technology Advancements – Business Support (HITECH, MITA)
- Emphasis on Tools for Care Coordination – Improving information-sharing to achieve integration



Coleman Institute for Cognitive Disabilities

UNIVERSITY OF COLORADO

Boulder | Colorado Springs | Denver | Anschutz Medical Campus

NASDDDS

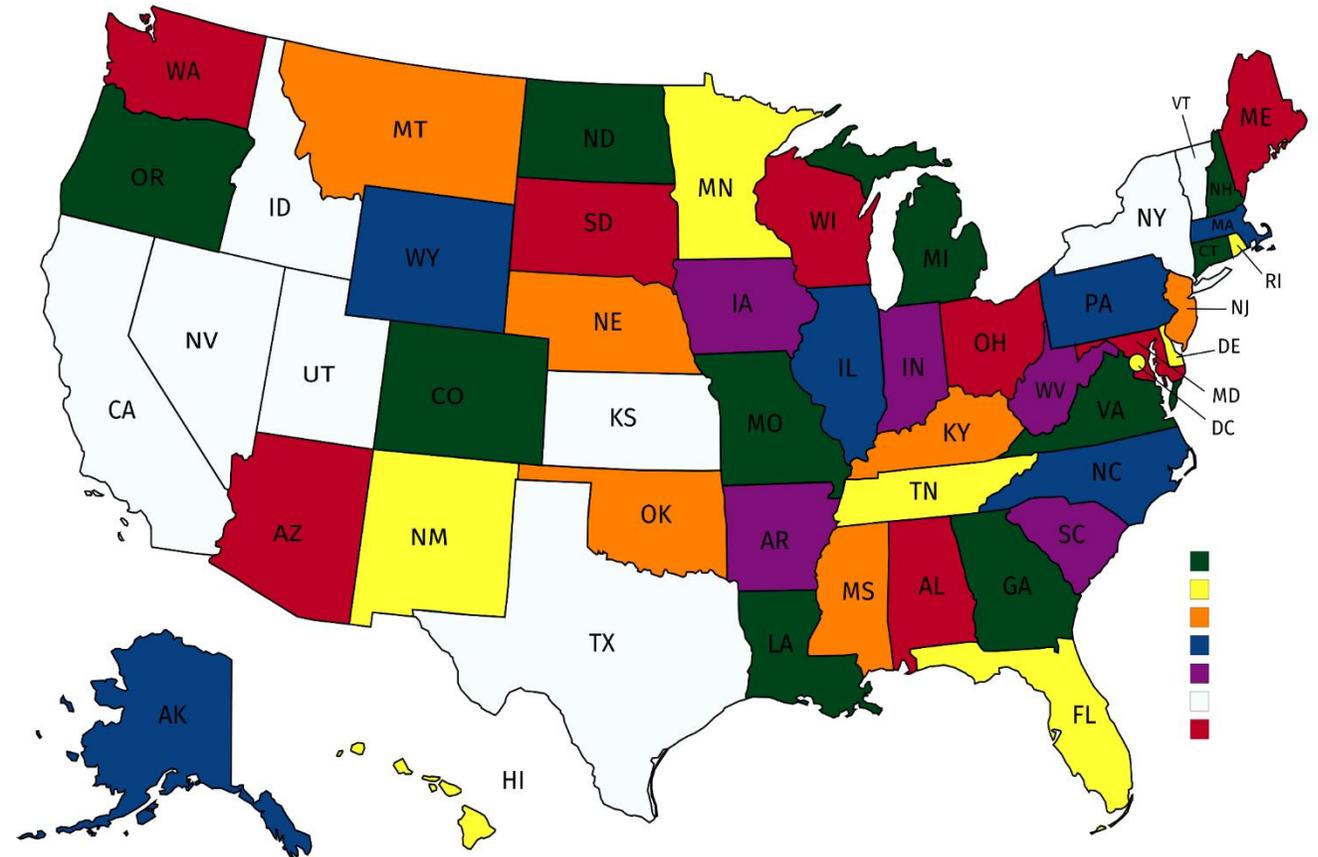
National Association of State Directors of Developmental Disabilities Services



2018 Technology Solutions State Survey

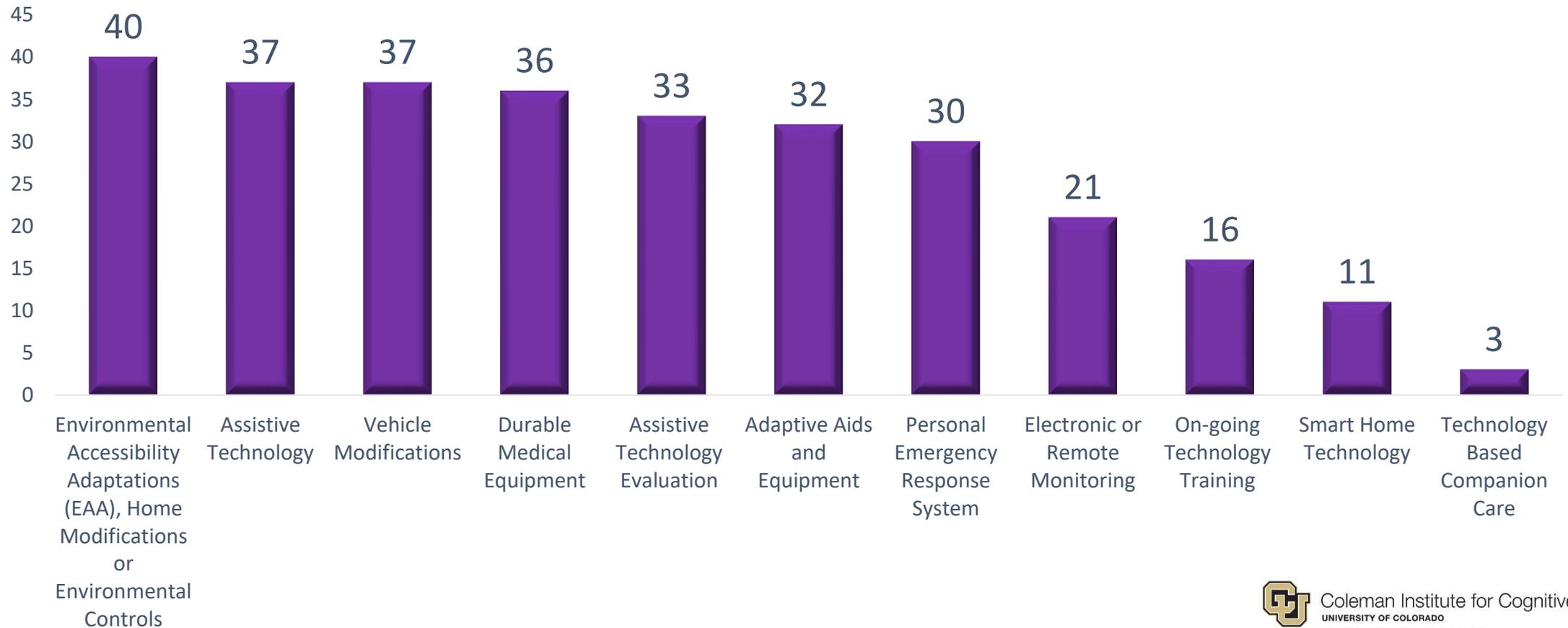
Technology Solutions State Survey

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



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What Technology Services and Supports Does Your State 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

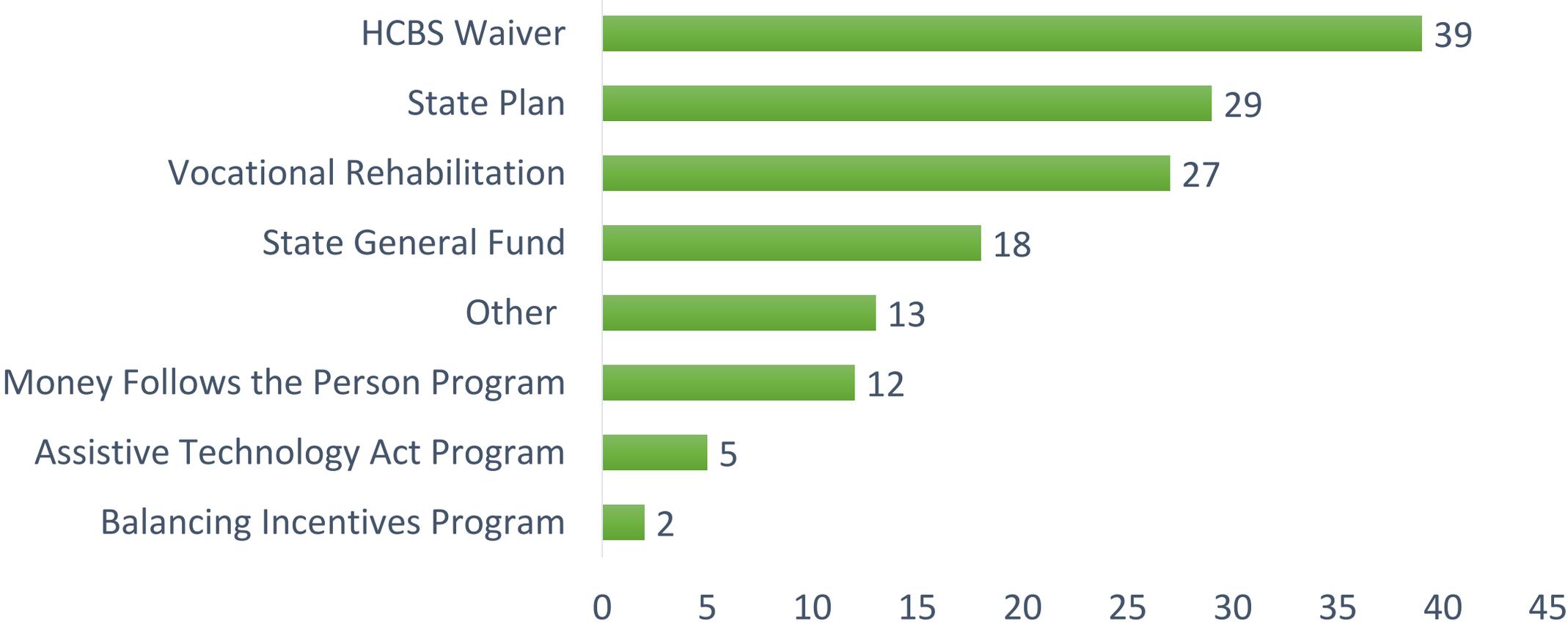
- Environmental Accessibility Adaptations
- Assistive Technology
- Durable Medical Equipment
- Vehicle Modifications
- Assistive Technology Evaluation
- Adaptive Aids and Equipment
- Personal Emergency Response Systems
- Electronic or Remote Monitoring
- On-going Technology Training
- Smart Home Technology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

States Funding Electronic or Remote Technologies

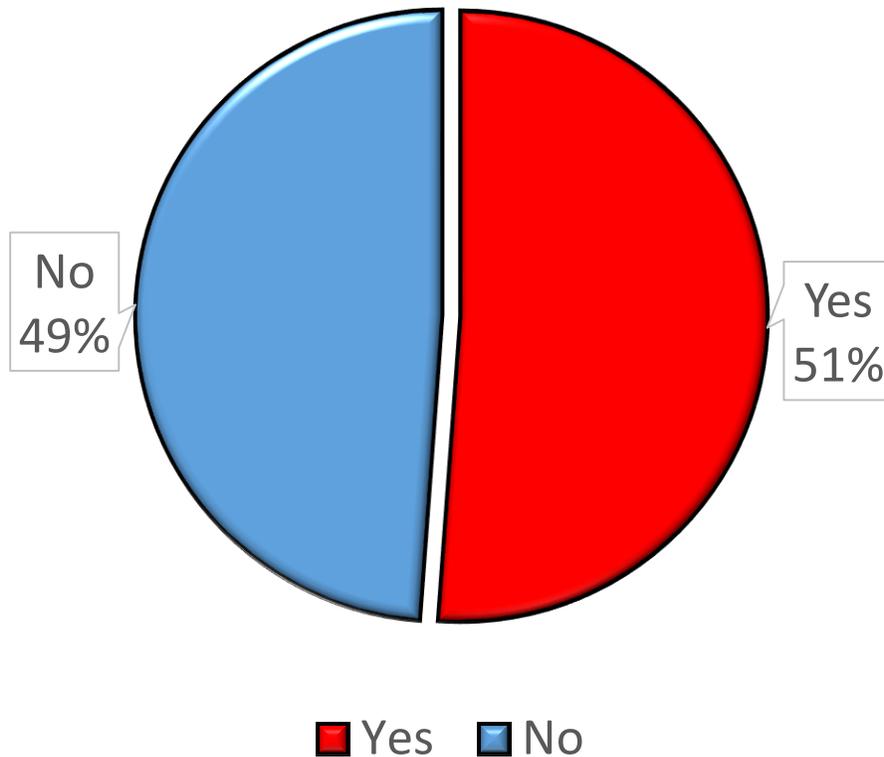
22 states report funding for electronic or remote technologies

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

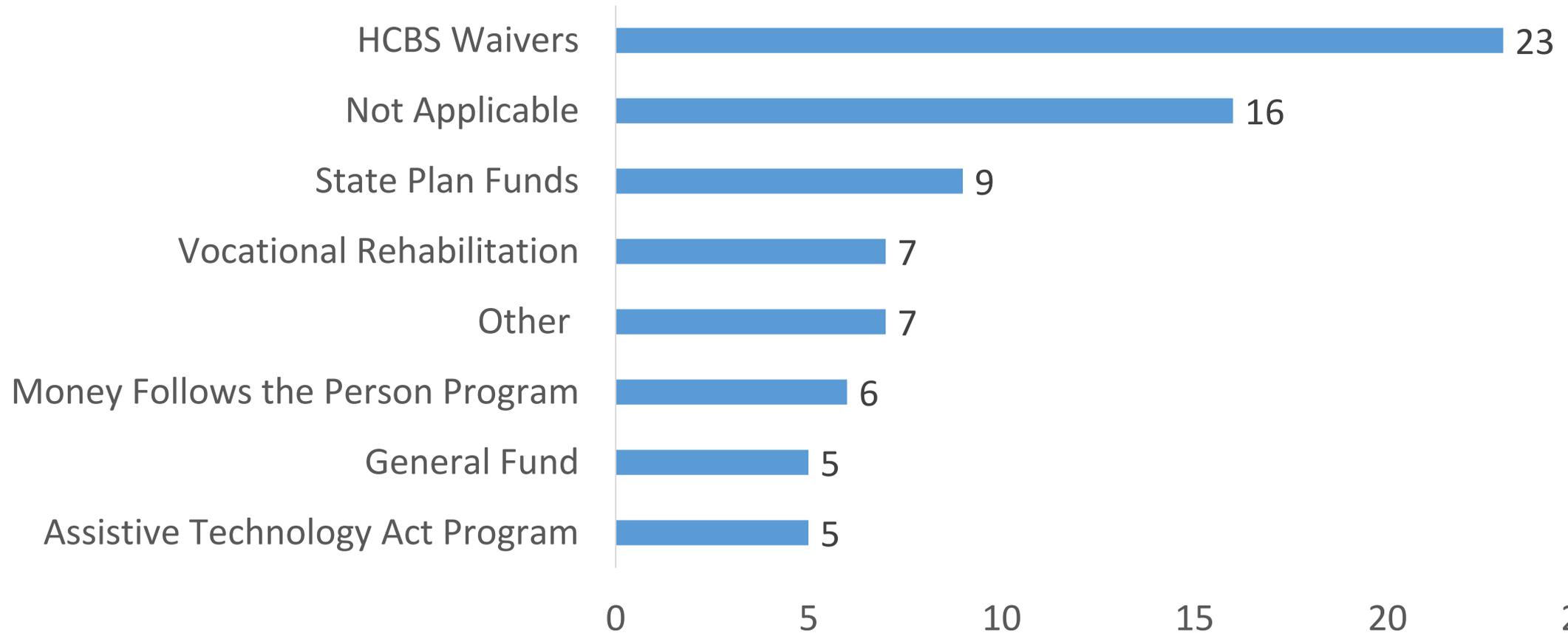
Federal Funds Utilized to Purchase Technology Services, Applications, Devices or Technology Solutions



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



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

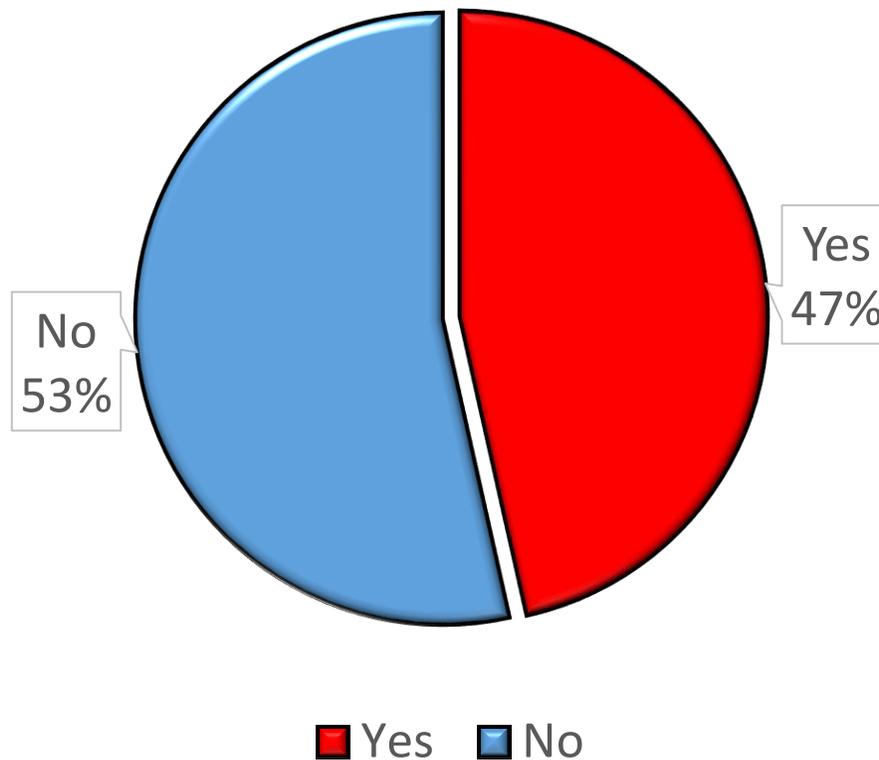


State Adoption of Electronic Documentation Systems

- Billing (23 states)
- Plan of Care / ISP Record (20 states)
- Updating ISP Documentation (18 states)
- Staff Management (5 states)



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

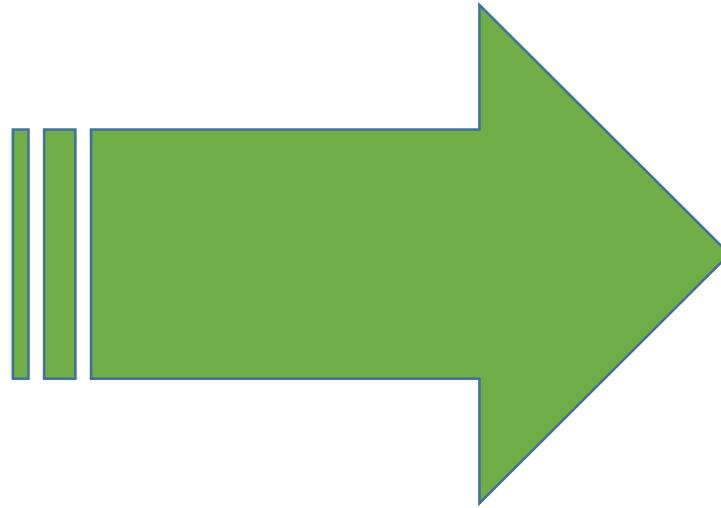


States That Require Technology Supports As Part Of ISP Or Person-centered Plan	
Arizona	Nebraska
Colorado	New Hampshire
Connecticut	New Mexico
District of Columbia	North Dakota
Iowa	Ohio
Maryland	Oregon
Massachusetts	South Carolina
Michigan	Virginia
Minnesota	Washington
Mississippi	West Virginia

The Conclusion

Decades of:

- Tight funding
- Workforce shortages
- Increased need



Service systems must be:

- Affordable
- Sustainable
- Capable of handling the load

Questions



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Thank You