



NATIONAL RESOURCE CENTER *for*
PARTICIPANT-DIRECTED SERVICES

Participant Direction Long- Term Services And Supports for People with Disabilities: Past, Present, and Future

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Presentation at the Silberman School of Social Work

March 17, 2014

Today's Agenda

- ❑ Cash & Counseling: The Budget Authority Model
 - ❑ **Past:** Early design development and key decisions
 - ❑ **Current:** Trends and challenges
 - ❑ **Future:** Opportunities for growth
- ❑ Participant Direction in Managed Long-Term Services and Supports: 12-State Review
- ❑ Participant Direction in the Dually Eligible Demonstration: 8 State Review
- ❑ Study Implications
- ❑ NRCPDS Recommendations

Budget Authority Model: Past

Original Cash & Counseling (C&C) Demonstration Overview

- ❑ Demonstration States
 - ❑ Arkansas, Florida, New Jersey
- ❑ Study Populations
 - ❑ Adults with disabilities (Ages 18-64)
 - ❑ Elders (Ages 65+)
 - ❑ Florida only: Children with developmental disabilities
- ❑ Feeder Programs
 - ❑ Arkansas and New Jersey: Medicaid personal care option programs
 - ❑ Florida: Medicaid 1915(c) Home and Community-Based long-term care waiver programs

Basic Model for Cash & Counseling

Step 1: Participant receives traditional assessment and service plan.

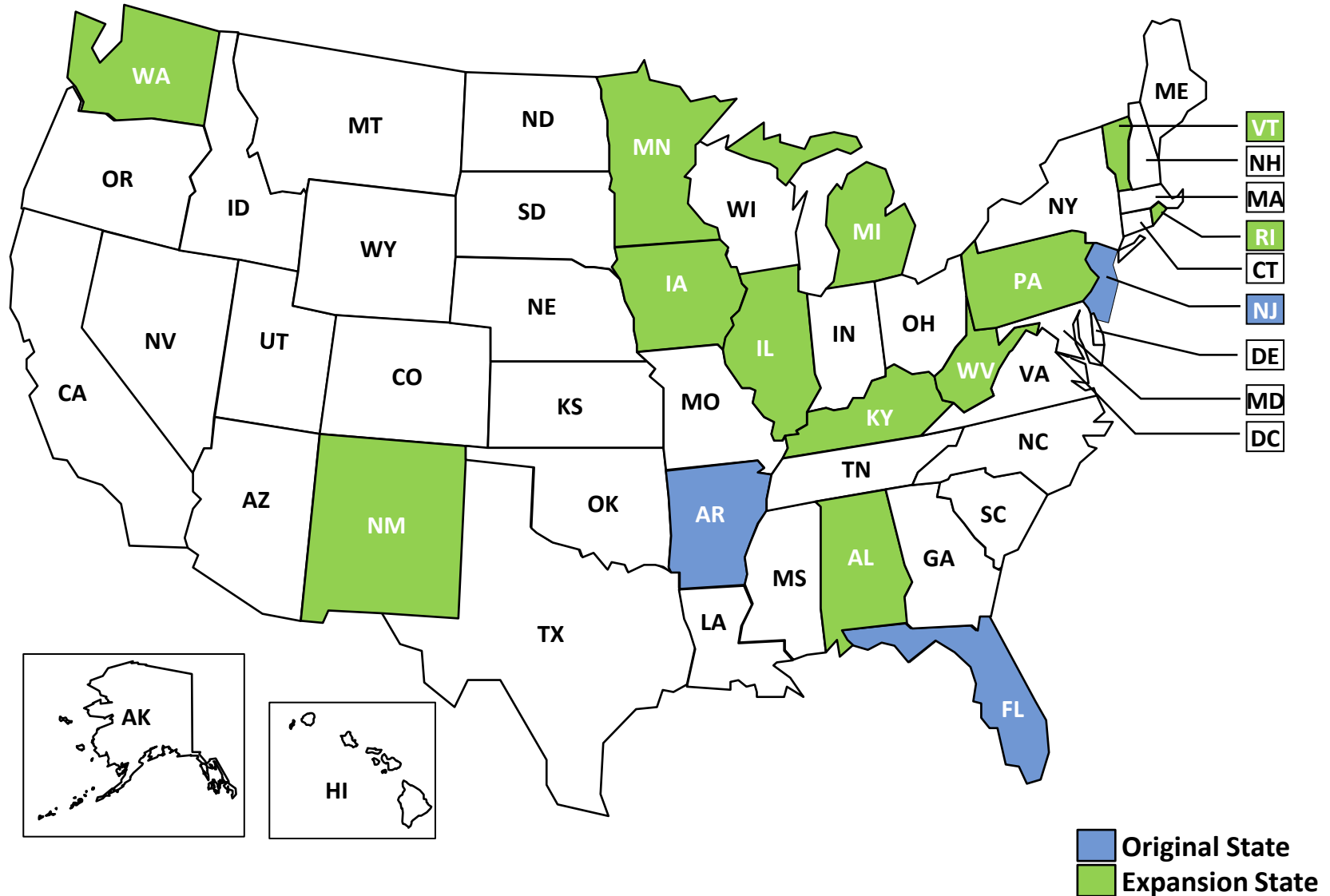
Step 2: A dollar value is assigned to that service plan.

Step 3: Participant receives enough information to make unbiased personal choice between managing individualized budget or receiving traditional agency-delivered services.

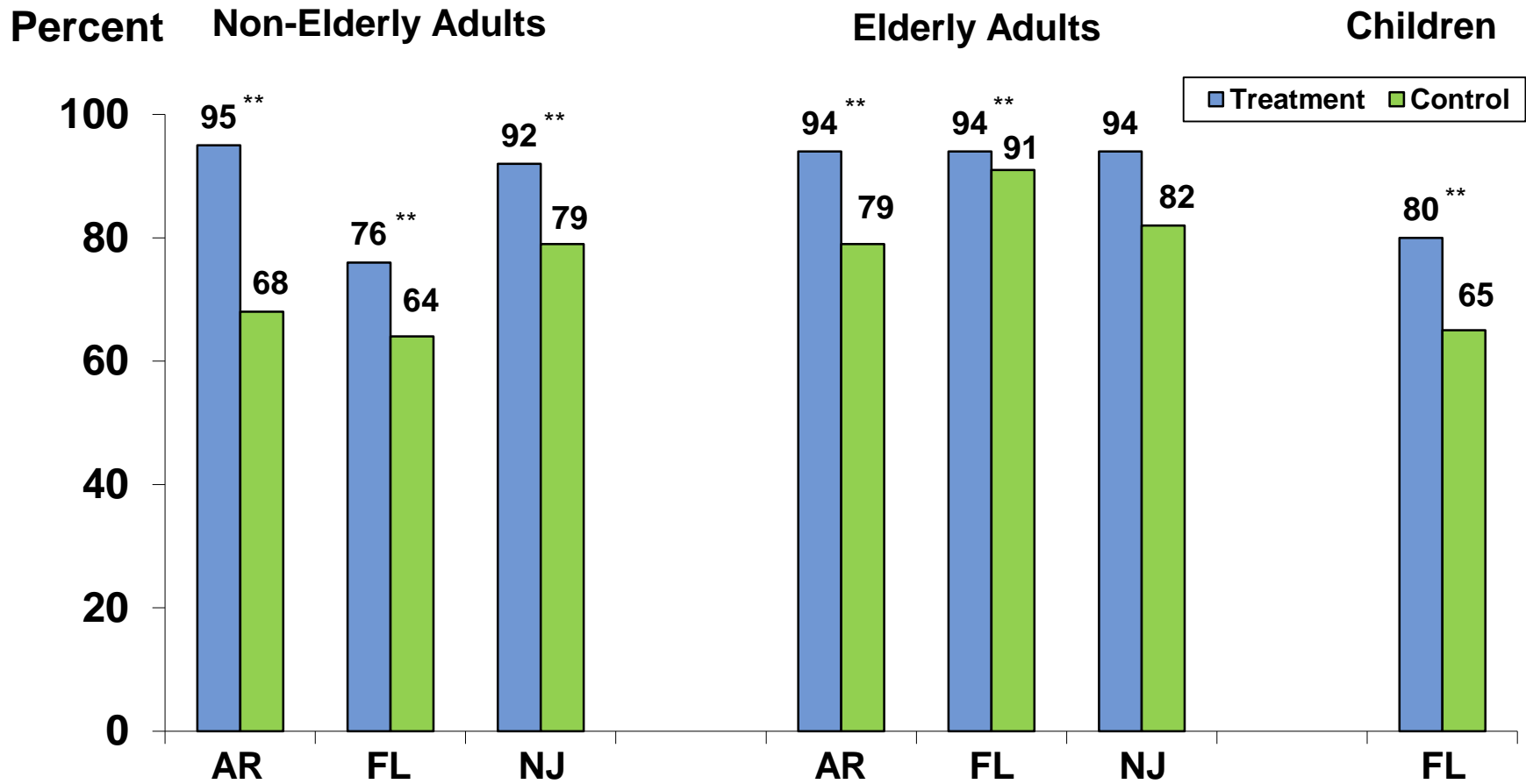
Step 4: Participant and counselor develop spending plan to meet participant's personal assistance needs.

Step 5: Cash allowance group is provided with financial management and counseling services (supports brokerage).

Original and Expansion C&C States



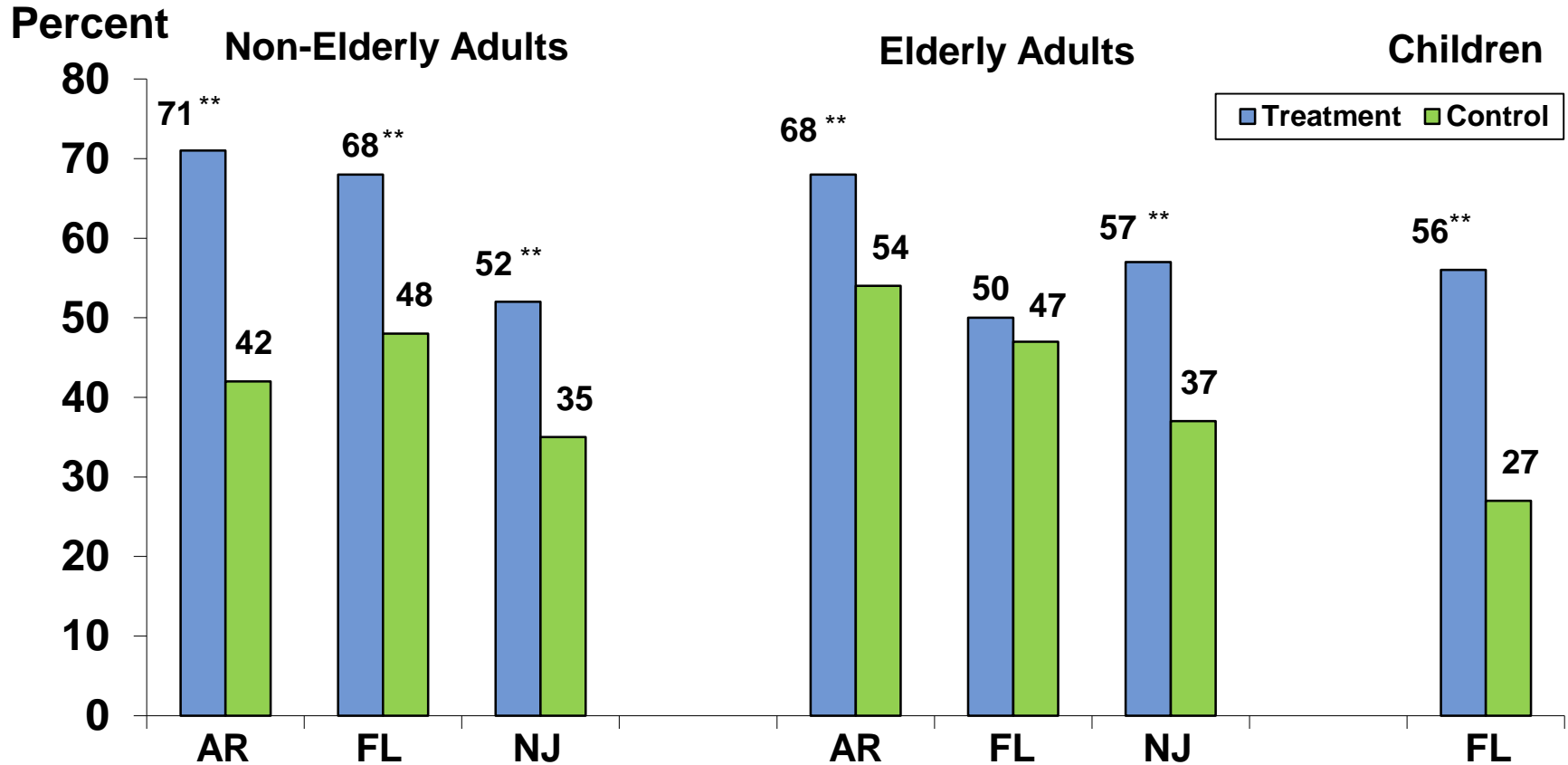
Receiving Paid Assistance at 9 Months



*, ** Significantly different from control group at .05, .01 level, respectively.

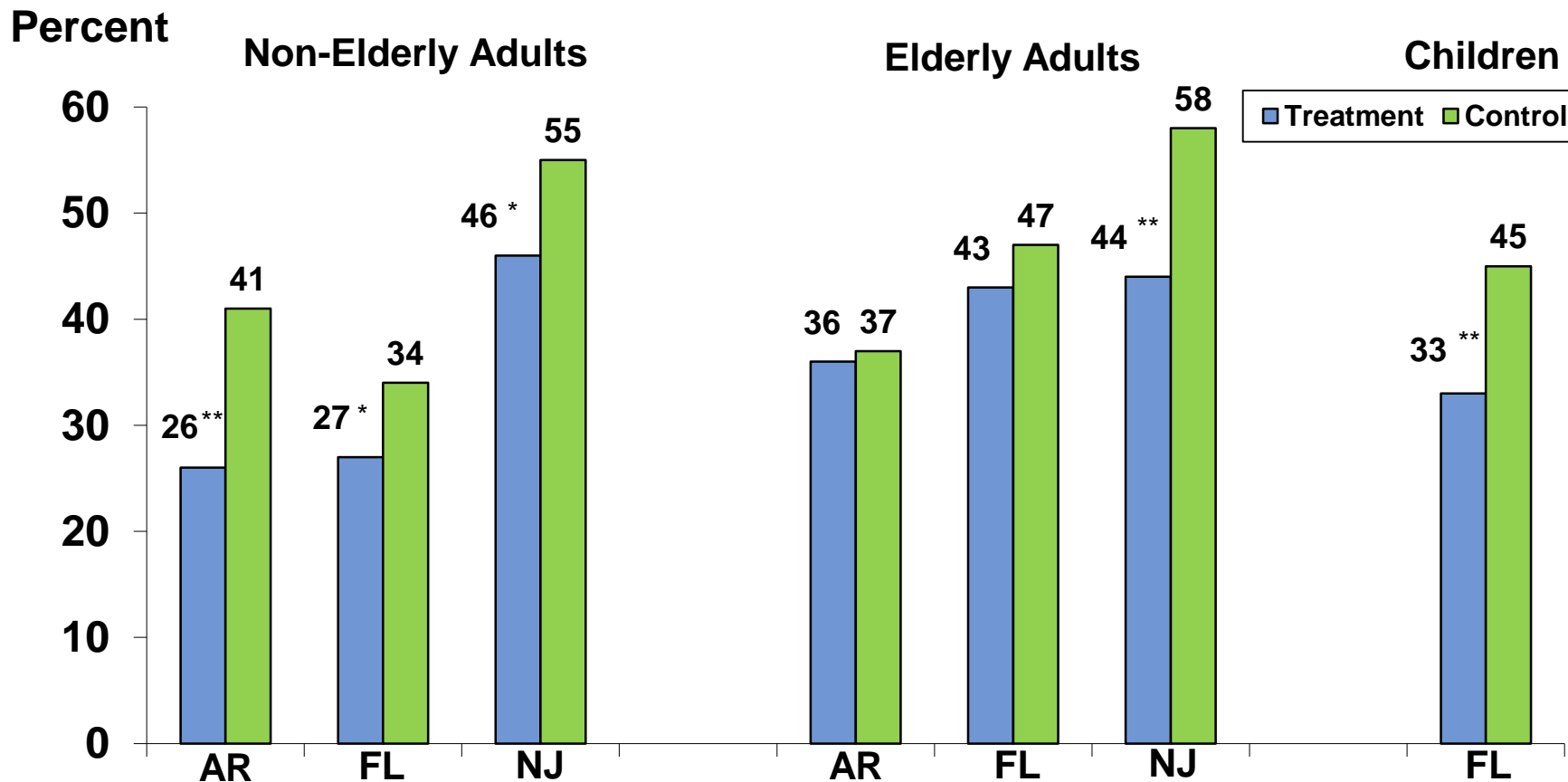
T= Treatment Group
C= Control Group

Very Satisfied with Overall Care Arrangements



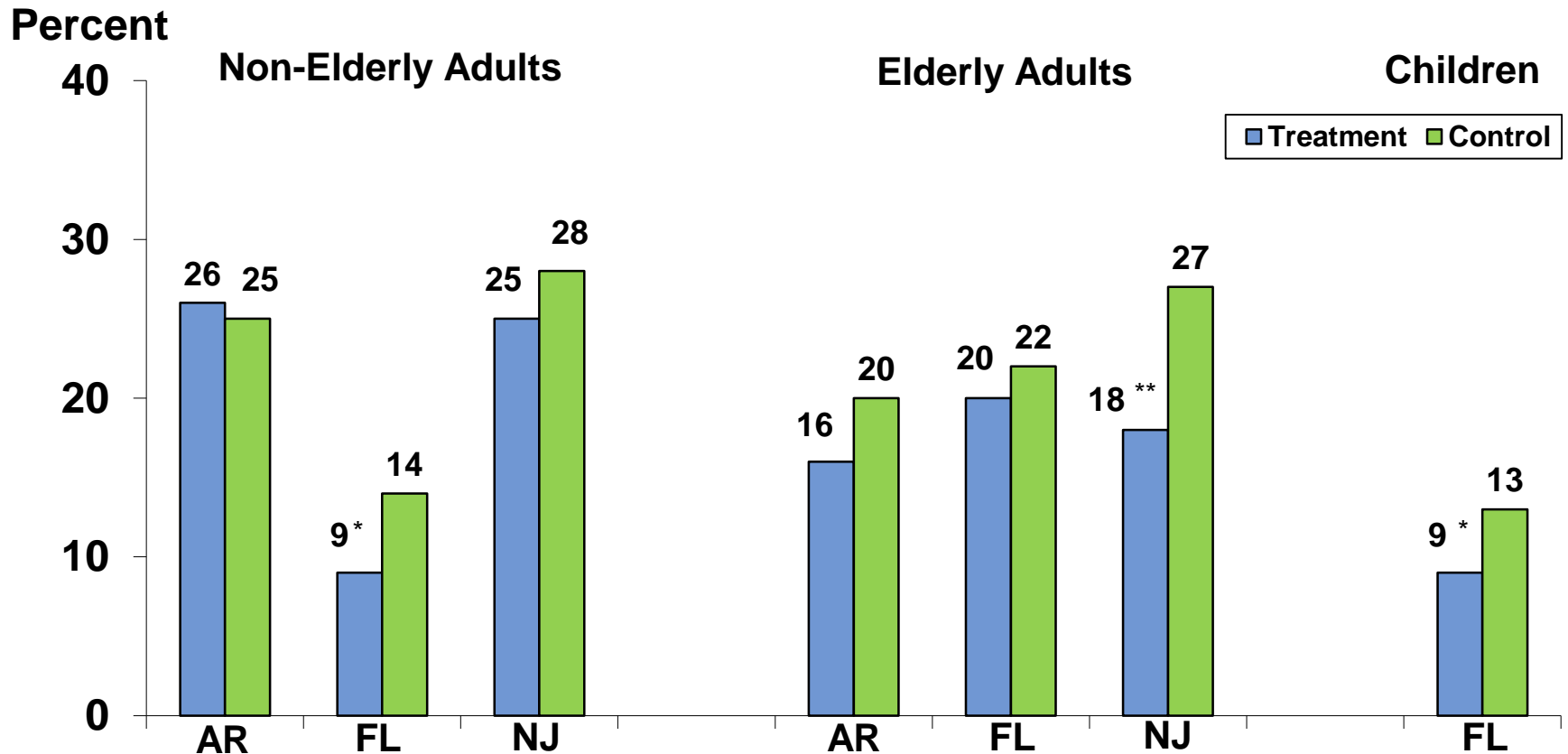
*,** Significantly different from control group at .05, .01 level, respectively.

Had an Unmet Need for Help with Personal Care



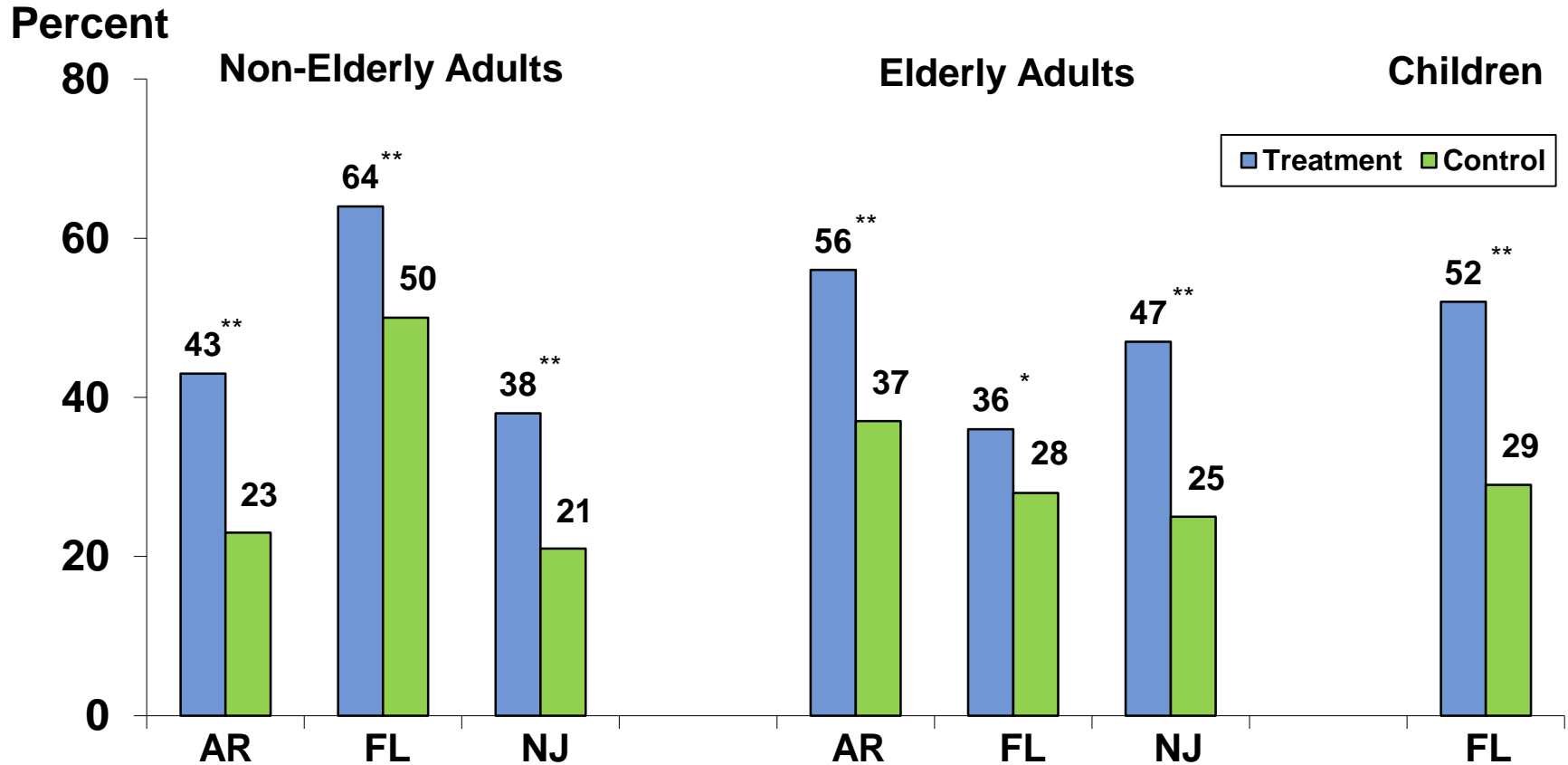
*, ** Significantly different from control group at .05, .01 level, respectively.

Contractures Developed or Worsened



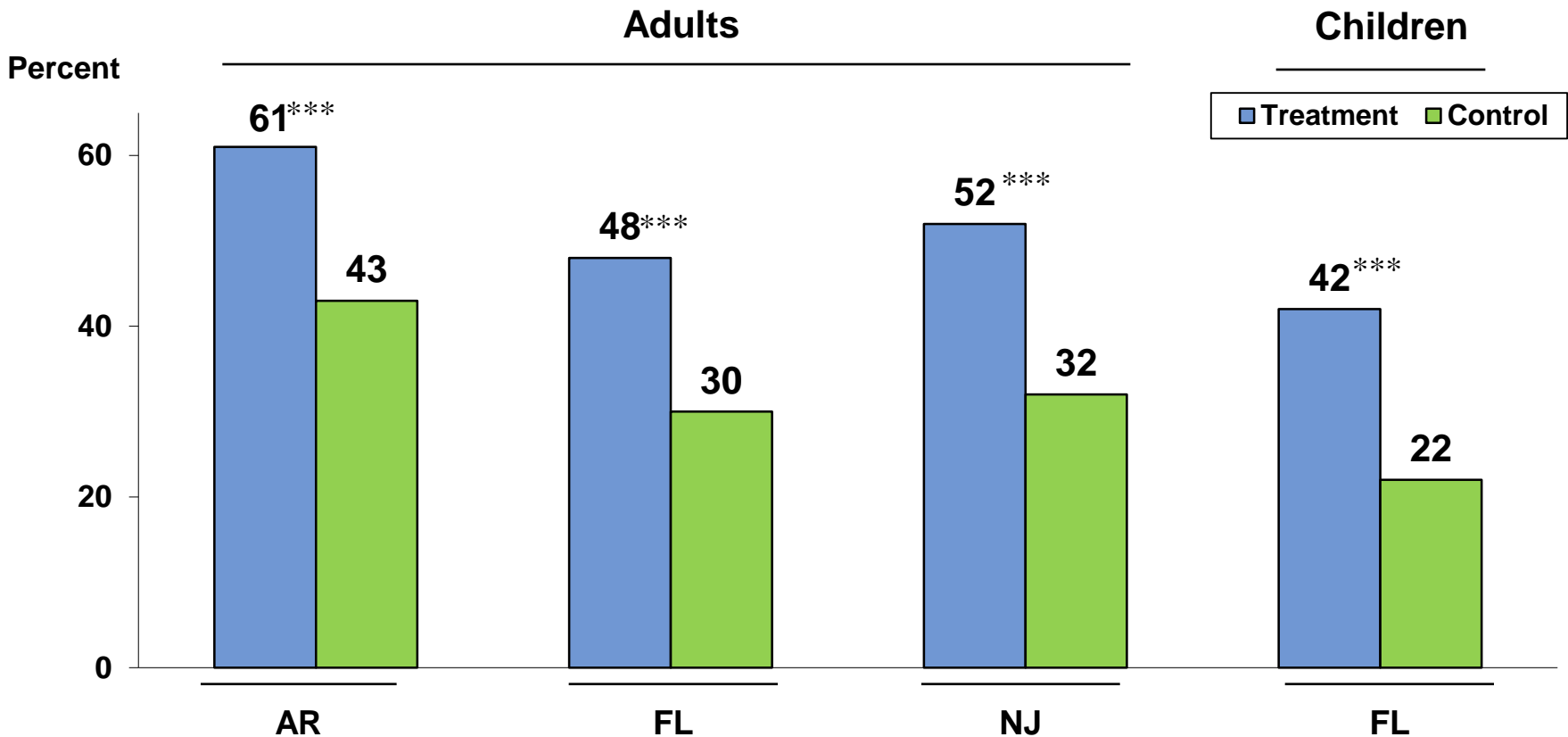
*, ** Significantly different from control group at .05, .01 level, respectively.

Very Satisfied with Way Spending Life These Days



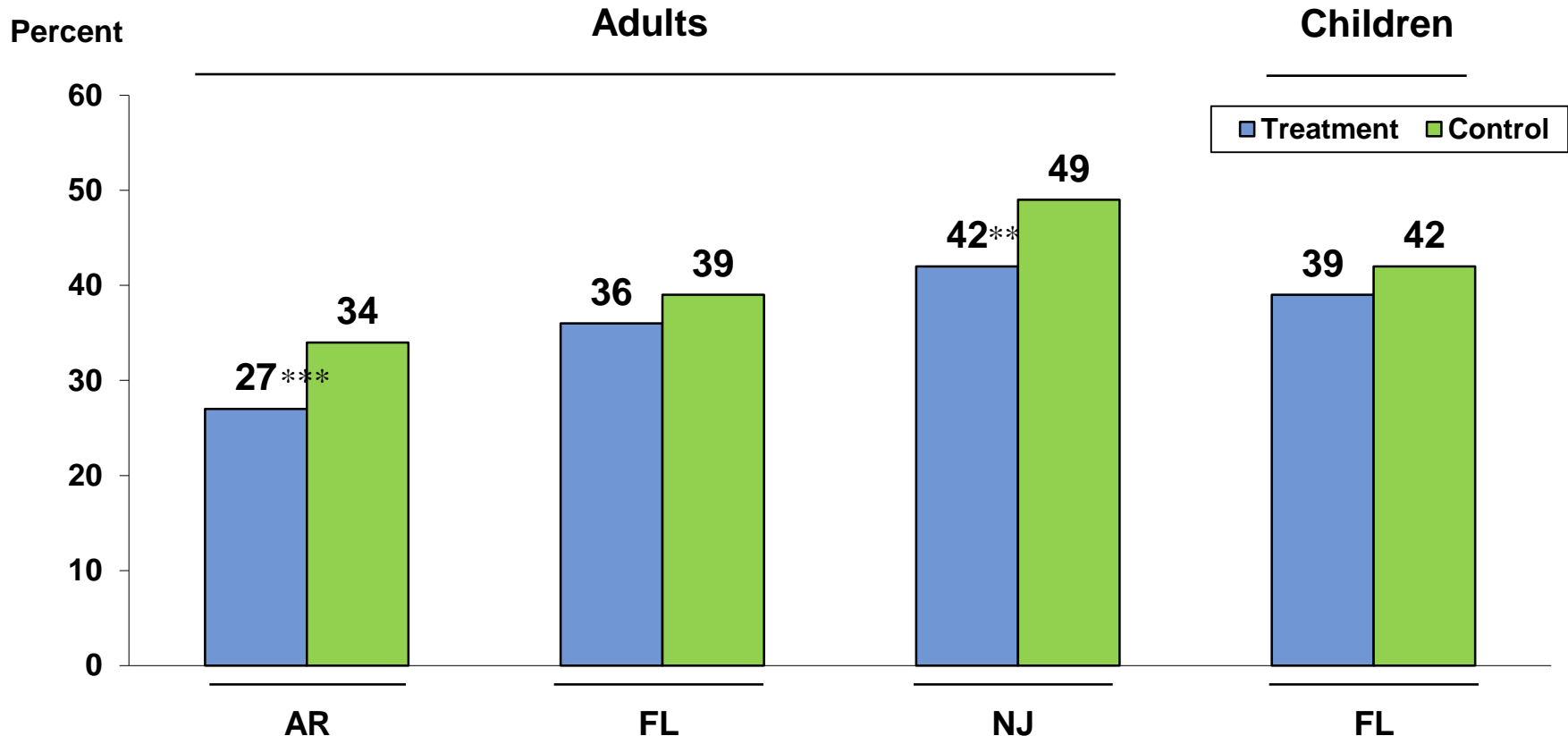
*, ** Significantly different from control group at .05, .01 level, respectively.

Informal Caregivers Very Satisfied with Overall Care



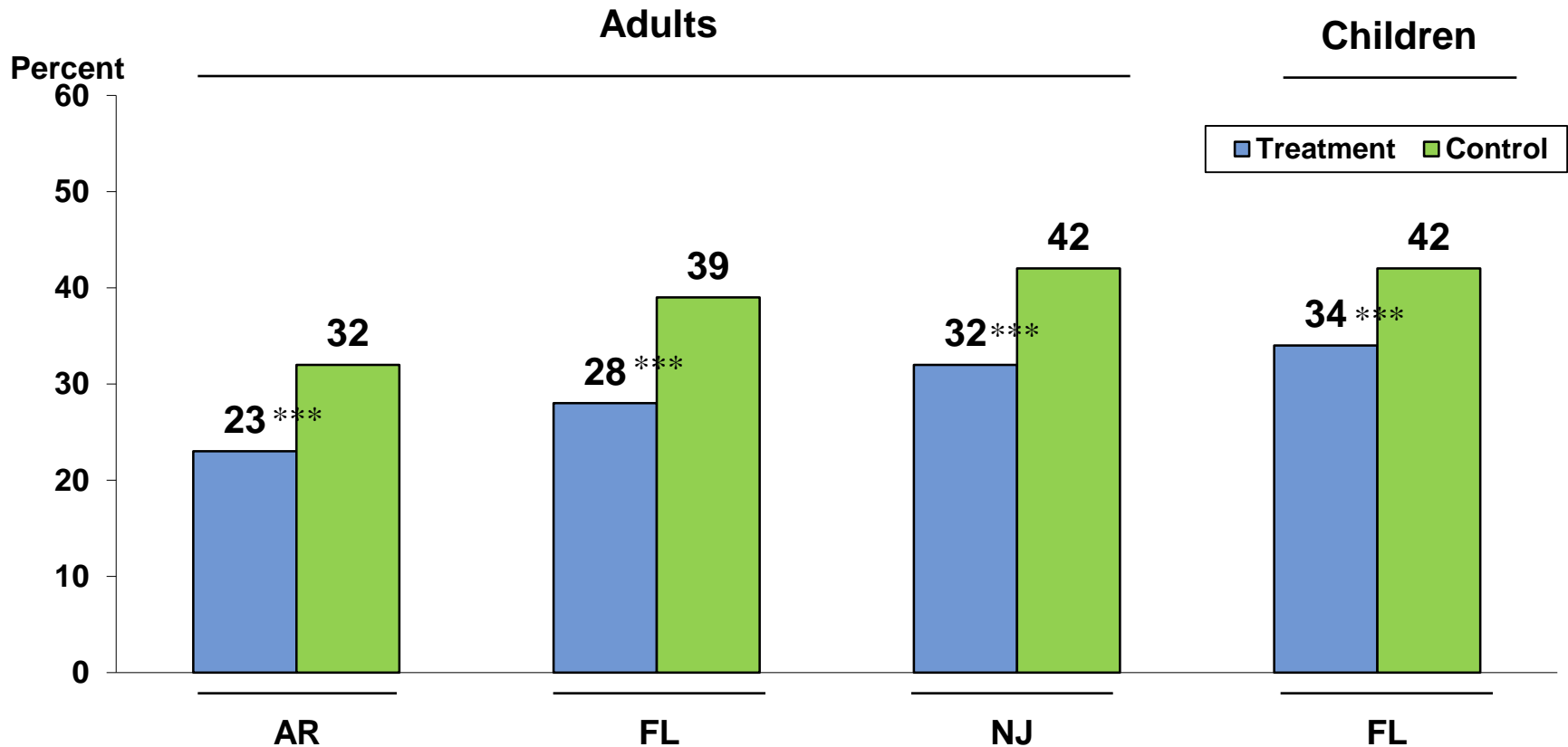
*,**,*** Significantly different from control group at .10 (*), .05 (**), or .01 (***) level.

Informal Caregivers Experienced Less Emotional Strain



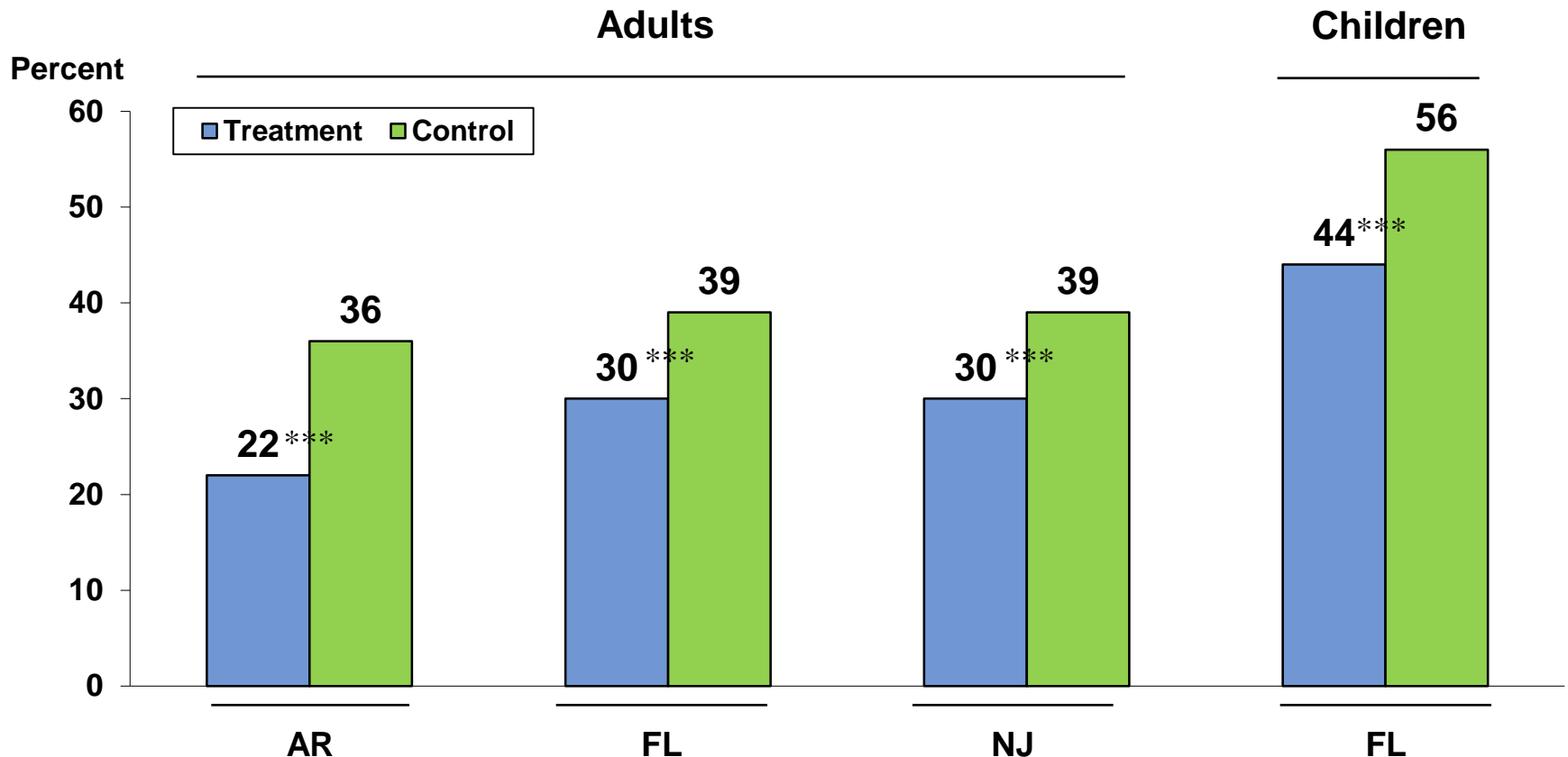
*,**,*** Significantly different from control group at .10 (*), .05 (**), or .01 (***) level.

Informal Caregivers Experienced Less Physical Strain



*,**,*** Significantly different from control group at .10 (*), .05 (**), or .01 (***) level.

Informal Caregivers Experienced Less Financial Strain



*,**,*** Significantly different from control group at .10 (*), .05 (**), or .01 (***) level.

Working Conditions

| | Directly Hired | Agency |
|--|----------------|-----------|
| Hourly Wage | | |
| AR | \$6.00 | \$6.30 |
| FL and NJ | \$10.00 | \$9.00 |
| Receives Fringe Benefits | 2 to 5% | 17 to 24% |
| Very Satisfied with Wages and Benefits | 41 to 50% | 19 to 23% |
| Very Satisfied Overall | 79 to 85% | 69 to 83% |

Effect on Total Medicaid Costs

- ❑ In AR, no significant difference by end of year 2
 - ❑ Reductions in nursing facility and other waiver costs off-set increase in personal care costs
- ❑ In NJ and FL, costs up 8-12%, but states learned how to control costs
- ❑ Higher costs in AR and NJ due to failure of traditional system

Cash & Counseling: Costs

Nursing facility use was 18% lower for the treatment group than for the control group during the 3-year follow-up period. Among those who had received personal care services before the demonstration, nursing facility savings, together with savings in other long-term care costs, fully offset the higher personal care services costs.

-Dale & Brown, 2006

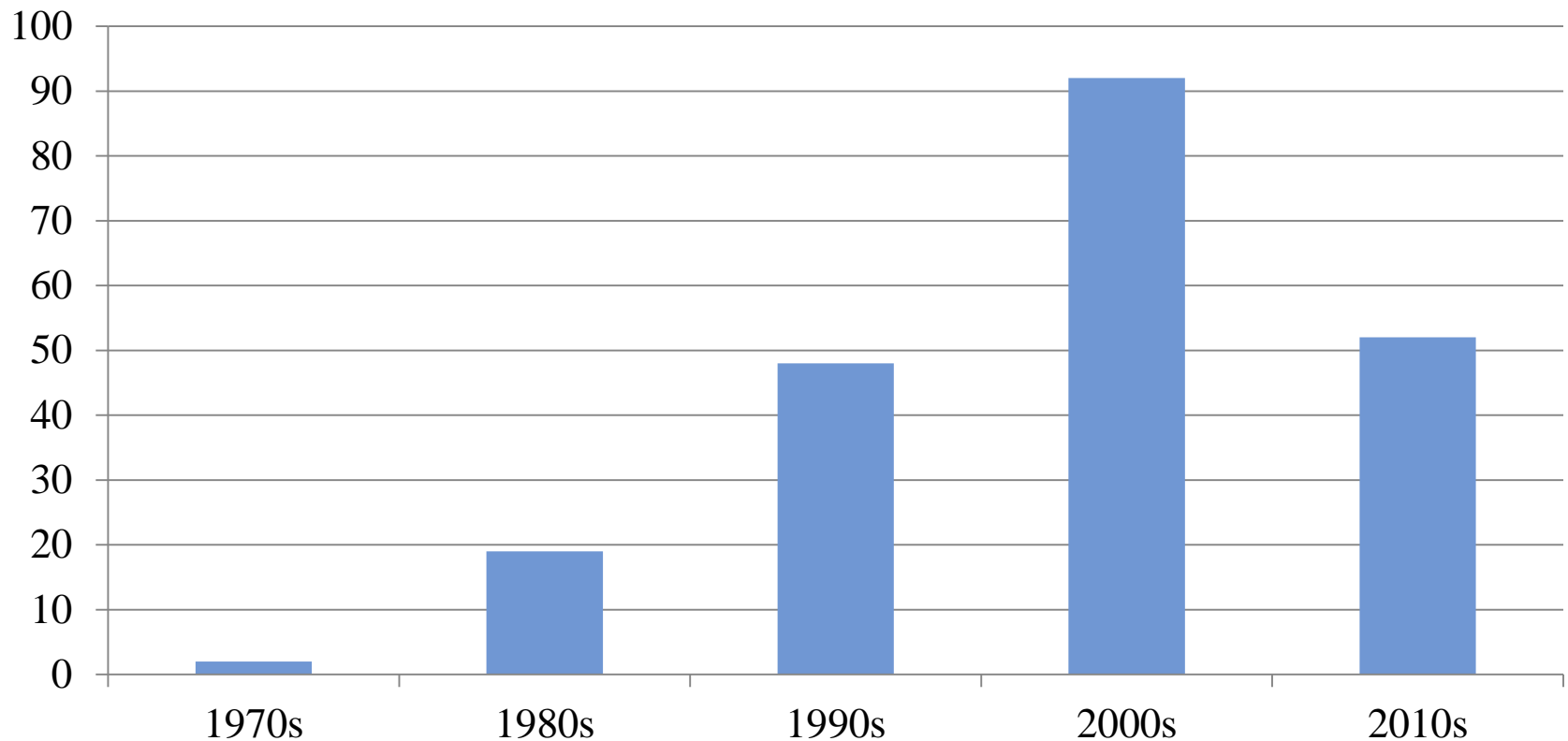
Budget Authority Model: Present

How widespread is participant direction today as compared to ten years ago?



Program Growth

Number of New Participant Direction Long-Term Service and Supports (PD-LTSS) Programs by Decade

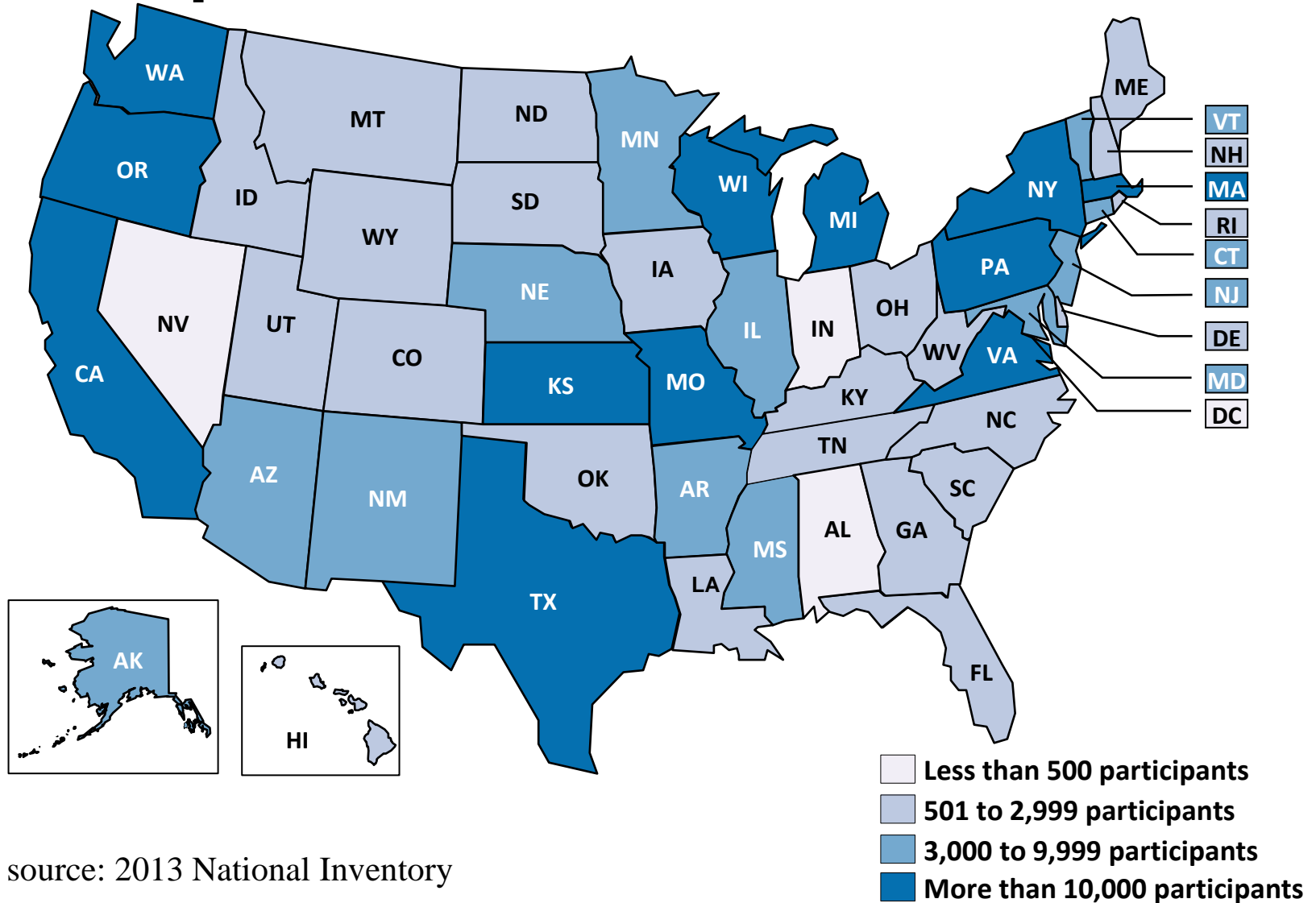


Data source: 2013 National Inventory

Participant Direction Enrollment and Program Size

- ❑ Total enrollment is approximately 815,000
 - ❑ Number of programs is 271
 - ❑ California accounts for 54% of enrollment
 - ❑ Average program size is 3,381 participants
 - ❑ The majority (64%) of programs have 500 or fewer participants

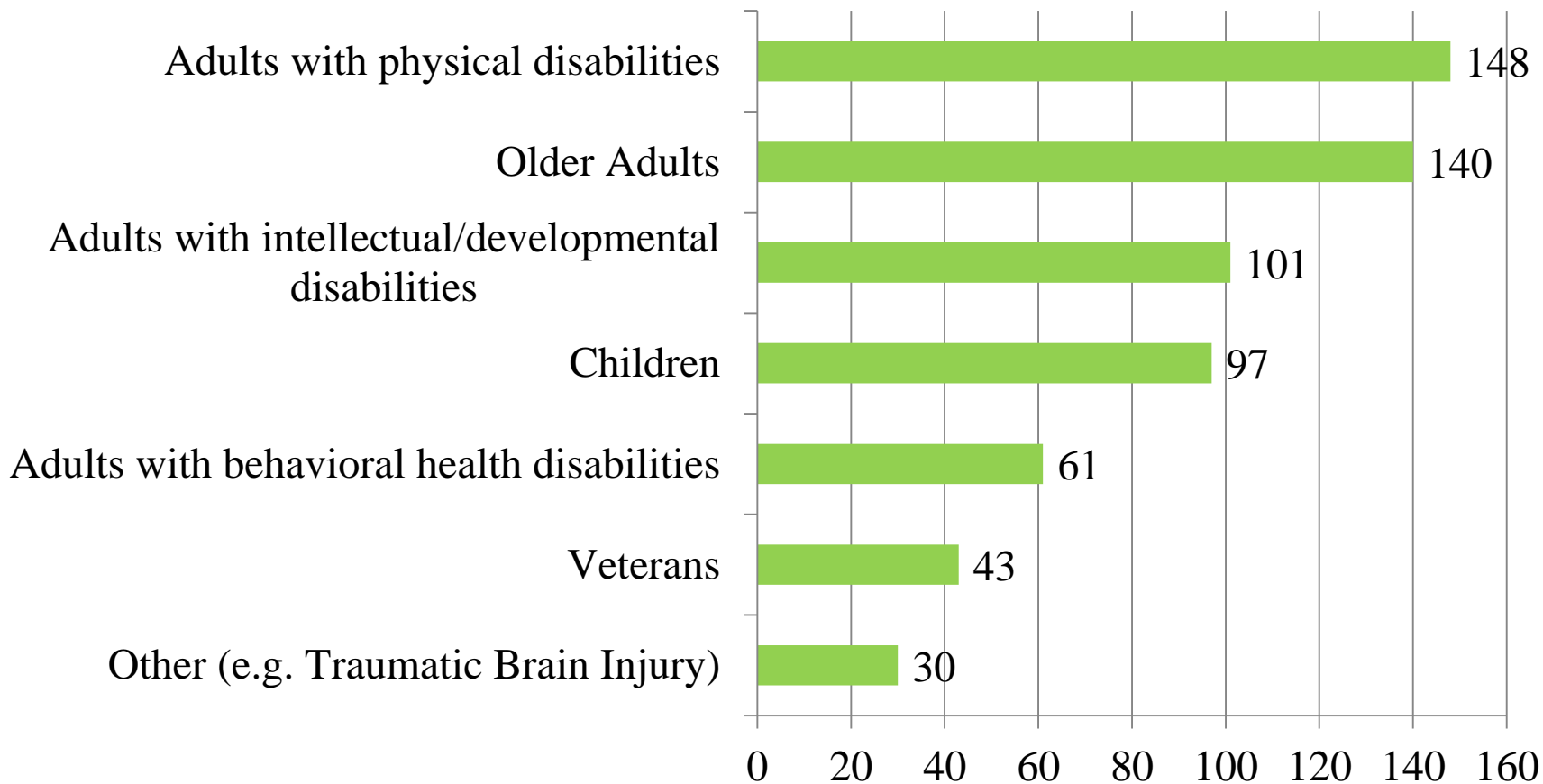
Majority of States have 1000 – 5000 Participants



Data source: 2013 National Inventory

Program Populations

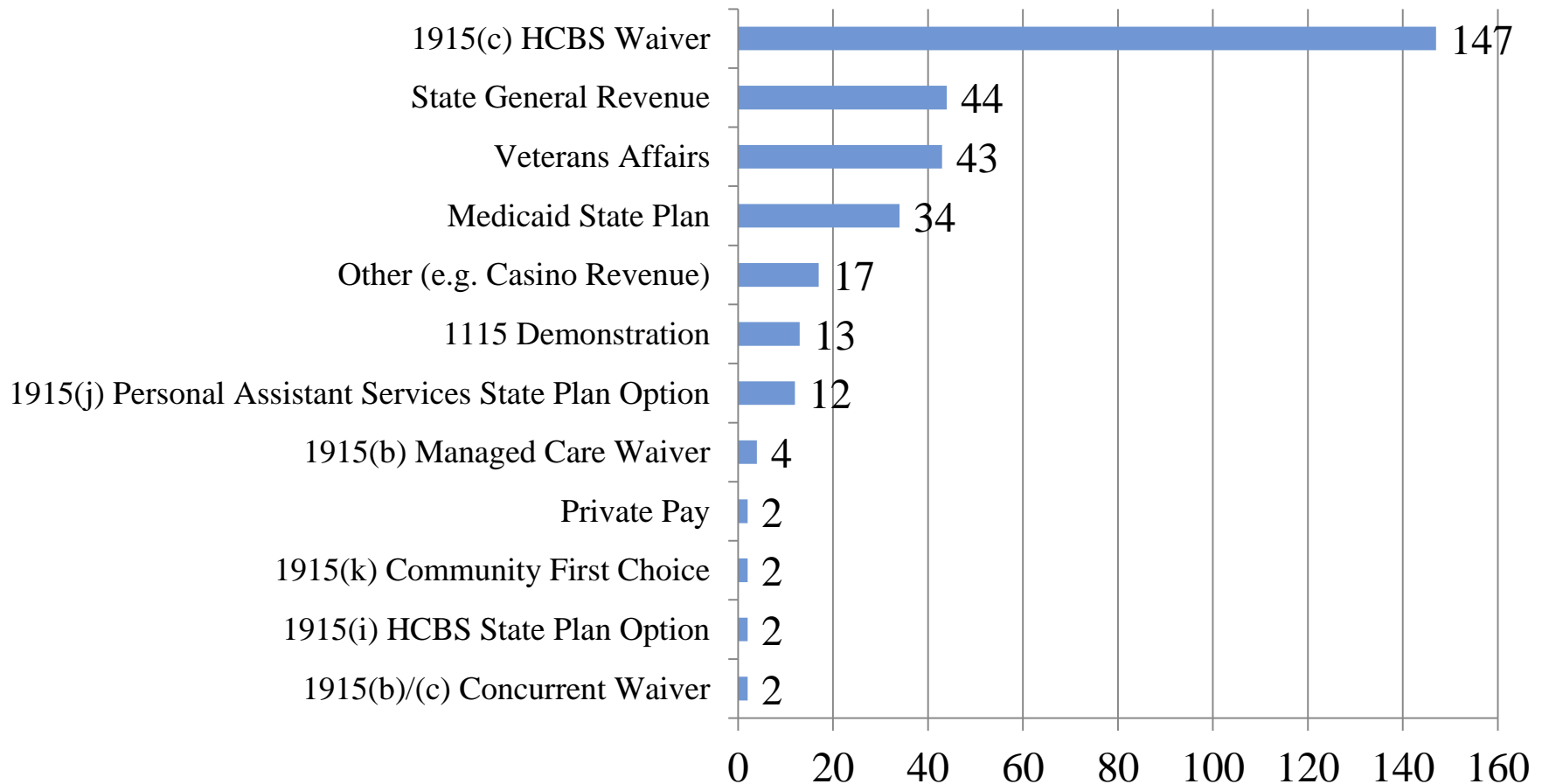
Number of PD-LTSS Programs that Serve Each Population



Data source: 2013 National Inventory

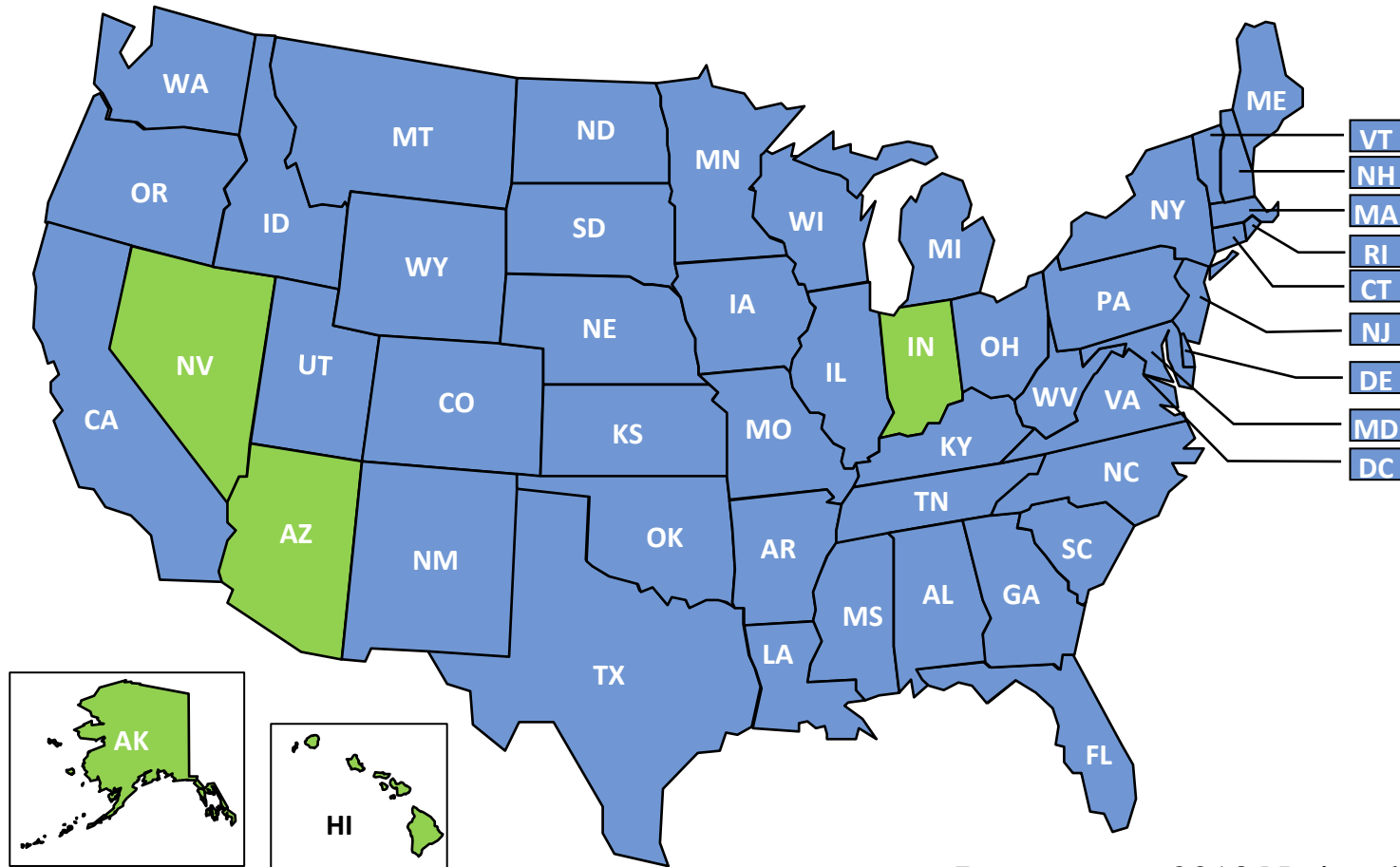
Funding Sources

Number of PD-LTSS Programs Funded Through Each Source





Data source: 2013 National Inventory

Employer and Budget Authority Programs in 2014



Data source: 2013 National Inventory

-  State has at least 1 program with Employer Authority, but no Budget authority programs
-  State has at least 1 program with both Employer and Budget Authority

Budget Authority Model: Future

*“Among a representative group of AARP members over the age of 50, **75% preferred managing services for themselves** over receiving care from an agency.”*

-AARP Public Policy Institute

Opportunities/Barriers to Participant Direction

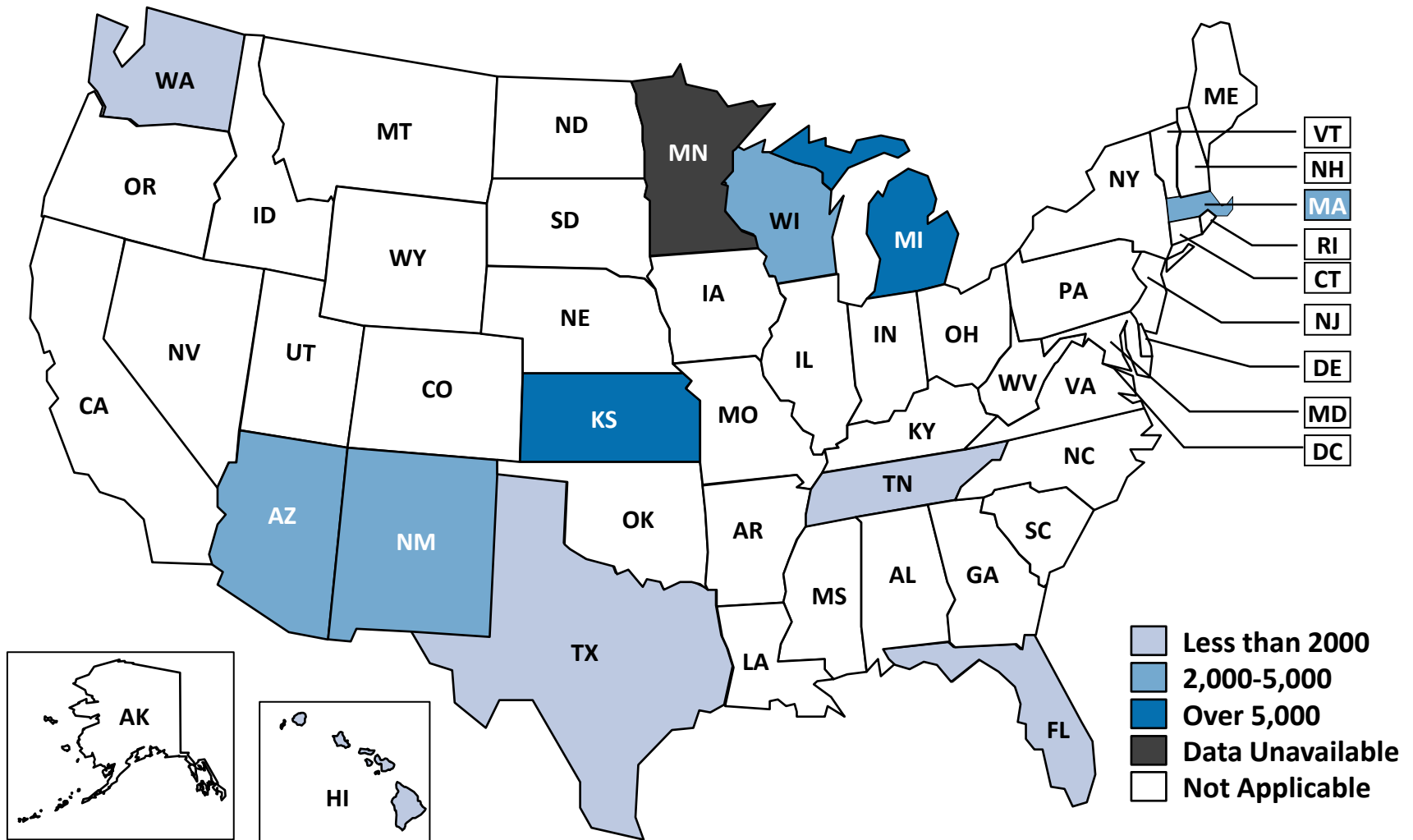
- ❑ Managed Long-Term Services and Supports (MLTSS)
- ❑ Integrated Care
- ❑ Training needs, especially for support brokers
- ❑ Opportunities with new populations and service arenas

Participant Direction & MLTSS

- ❑ Within the next two years, 26 states will, or intend to, deliver Home and Community-Based Services through managed care.
- ❑ The NRCPDS has recently completed research to better understand the role of participant direction in MLTSS.
 - ❑ Upcoming papers include:
 - *Selected Provisions from Integrated Care RFPs and Contracts: Participant Direction in Home and Community-Based Services* (via contract with Mathematica Policy Research for the CMS Medicare-Medicaid Coordination Office)
 - *Participant-Directed Services in Managed Long-Term Services and Supports Program: A Five State Comparison* (via contract with Truven Health Analytics for the DHHS Office of the Assistant Secretary for Planning and Evaluation (ASPE))

**Participant Direction in
MLTSS:
12 State Review**

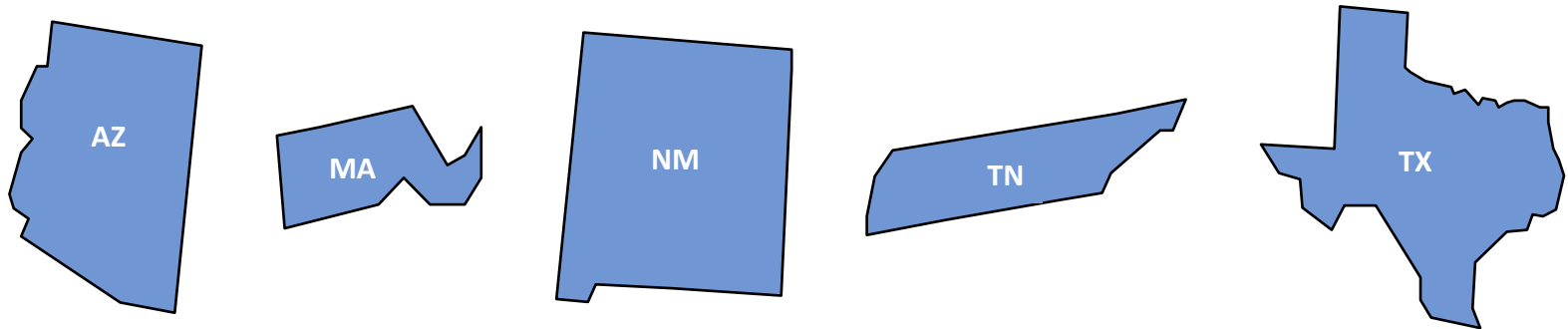
12 State Document Review: Individuals Self-Directing MLTSS



12 State Document Review: Data Highlights

- ❑ Participant direction authorities
 - ❑ 7 states offer Employer Authority
 - ❑ 5 states offer Employer and Budget Authority
- ❑ Populations served
 - ❑ 11 states serve the Disabled/Elderly population (ID/DD carved out)
 - ❑ MI serves persons with developmental & mental health disabilities
- ❑ MCO staff are responsible for introducing participant direction
- ❑ No standardization of participant-directed services or requirements across states
 - ❑ Participant-directed contract language varies extensively by state
 - ❑ Very few monitoring requirements
 - ❑ No standardization in the collection of data

A Closer Look at 5 of the 12 States



This examination revealed wide variation in:

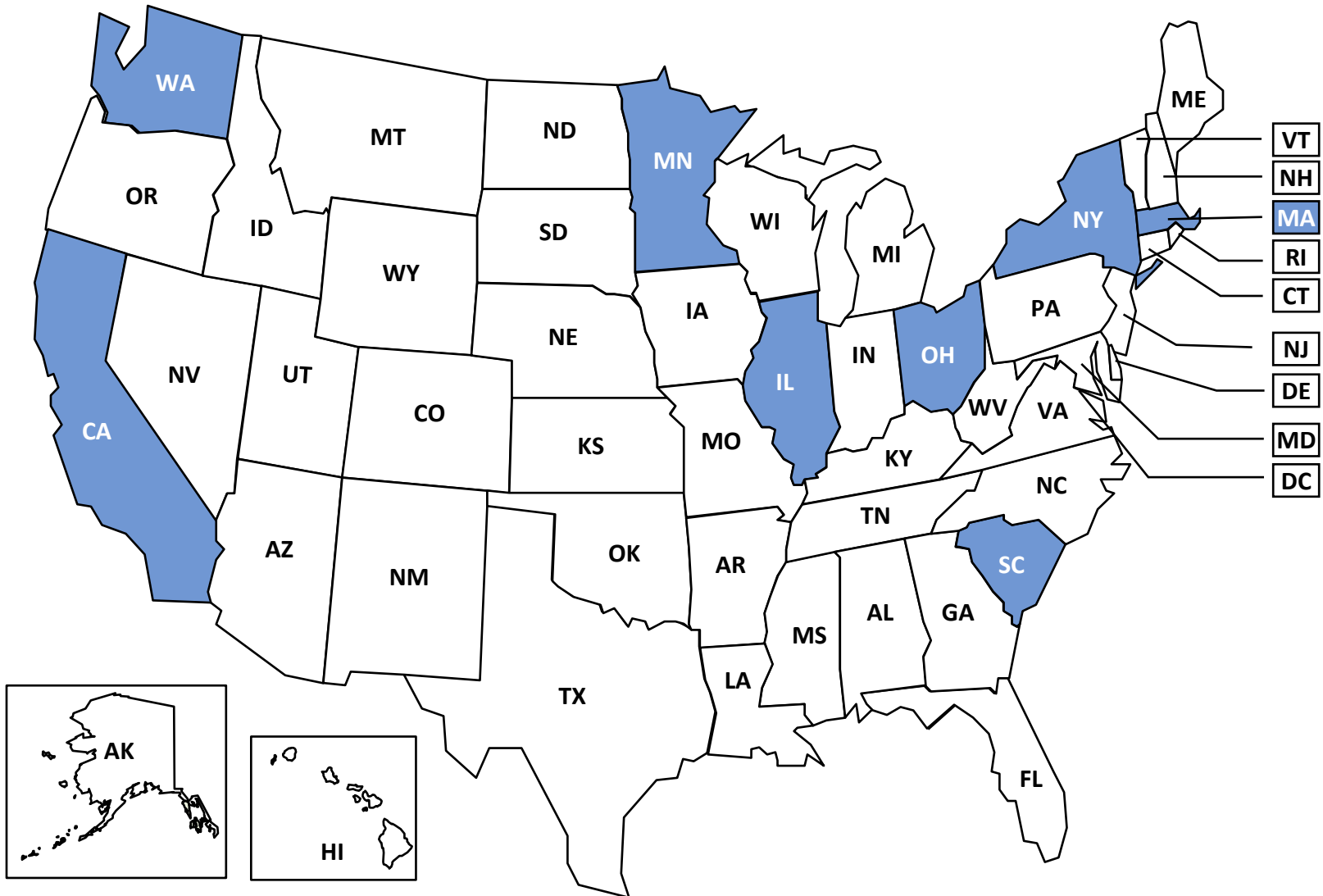
- ❑ The numbers of participants enrolled in participant-directed MLTSS
- ❑ Training for the Managed Care Organization's service coordinators
- ❑ Quality assurance, oversight, and improvement

**Participant Direction
in the Dually Eligible
Demonstration:
8 State Review**

Overview of Dually Eligible Demonstration Project

- ❑ Affordable Care Act of 2010
 - ❑ CMS created Medicare-Medicaid Coordination Office
 - ❑ Funding for demonstration grants to integrate Medicaid and Medicare services and their financial alignment
- ❑ All 8 states have completed Memorandum of Understanding agreements to implement the demonstration
- ❑ All 8 states have adopted the managed care capitated model
 - ❑ Washington also has a managed fee-for-service model
- ❑ All 8 states will have Employer Authority
 - ❑ At least 3 states will have Budget Authority

8 State Document Review: Data Highlights



8 State Document Review: Data Highlights

- ❑ Care coordination is a major component of the demonstration implementation
- ❑ All 8 states have chosen to require health plans to offer participant direction as an option
 - ❑ Only 3 have clearly included the budget option
- ❑ All 8 states require health plans to operate using a person-centered approach
- ❑ Quality indicators and data reporting on participant direction are not completely reflective of the quality of the program
 - ❑ Half of the states only collect data on the number of care coordinators trained on participant direction but they have no other quality measures specific to participant direction

Study Implications

Study Implications

- ❑ Lack of participant direction standards and requirements impacts the design, operation, and evaluation of these programs.
- ❑ The implementation of participant direction is delegated to health plans that may or may not understand the philosophy or roles and responsibilities of participant direction.
- ❑ Lack of standardized service coordinator training results in widely varying participant experiences within and across states.
- ❑ Lack of participant-directed quality measures prevents most states from evaluating program performance and distinguishing high-quality programs from low-quality ones.

NRC PDS Recommendations

NRCPPDS Recommendations

- ❑ CMS and states should identify best practices in participant direction program design, operation, and evaluation to guide the development of these programs.
- ❑ CMS, states, and health plans should identify standardized participant-directed training curricula and techniques for training health plan staff.
- ❑ The health plan industry should work with national consumer groups to develop participant-directed specific quality measures and a standardized way to collect program information.
 - ❑ Similar to the National Committee on Quality Assurance (NCQA)

How Will We Collect Data in the Future?

Bank of America 

Online Banking

BofA Premium -Checking - 3716: Account Activity Transaction Details

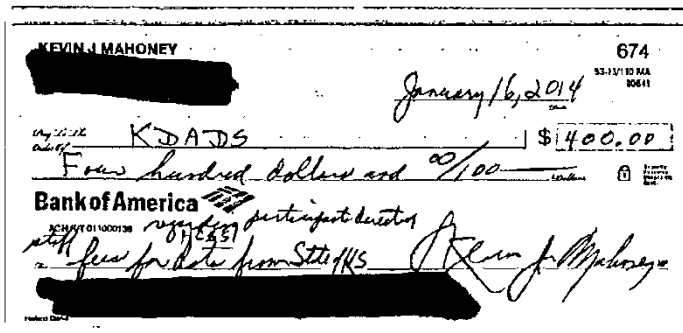
Check number: 00000000674

Post date: 01/23/2014

Amount: -400.00

Type: Check

Description: Check



KEVIN J. MAHONEY 674
[Redacted] 53-1271 00 00A
00611
January 16, 2014
pay to the order of KDADS \$400.00
Four hundred dollars and 00/100
Bank of America
participating institution
[Redacted] Kevin J. Mahoney
[Redacted] still free for the from Stt/HS



“I sleep much better. I feel much better. You know, my biggest fear is to be stuck in the damn bed and waste my life away ... I want to get out and ... get back into society and do lots of things.”

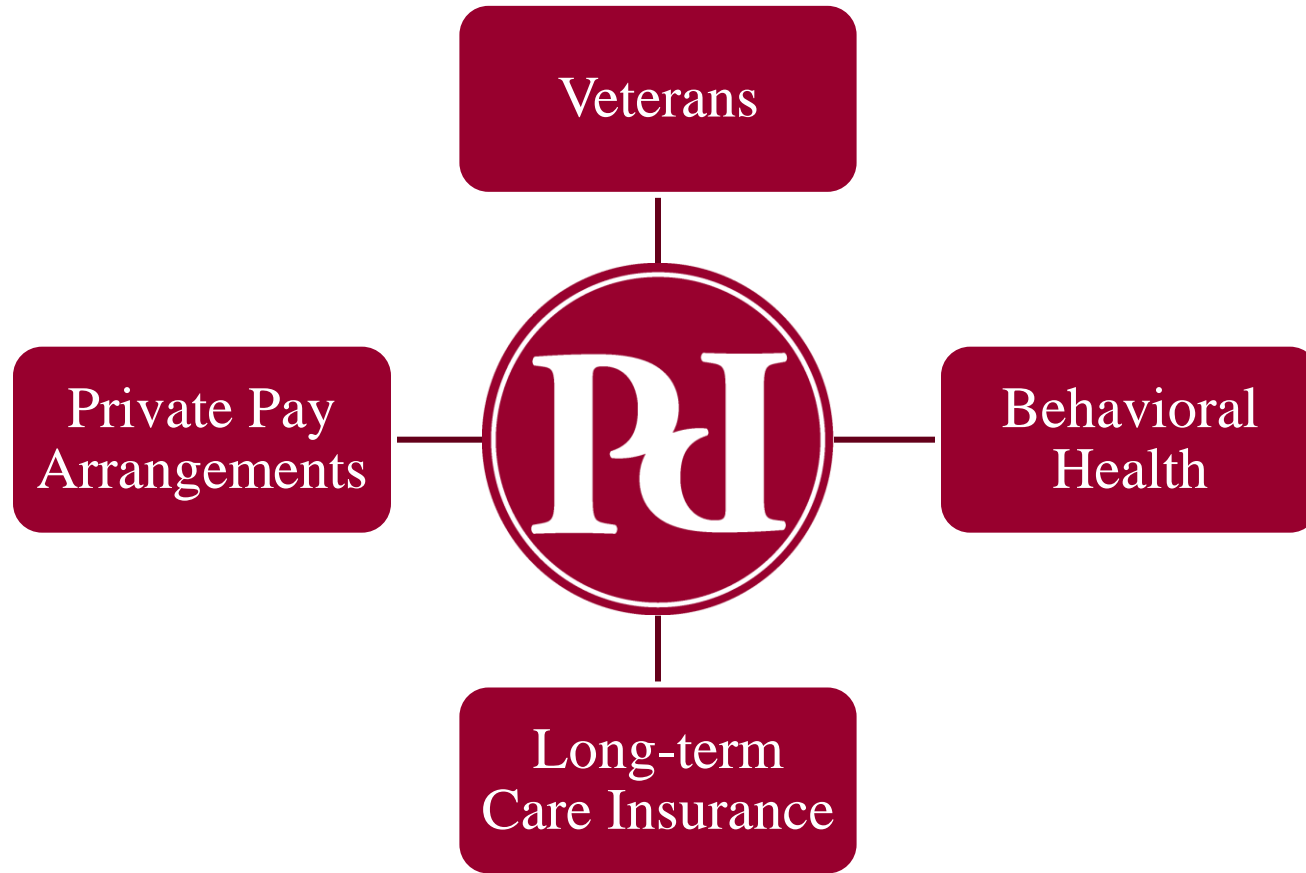
Participant Direction & Integrated Care

- ❑ As efforts unfold to integrate acute care, long-term services and supports, and behavioral health care, current ways of delivering participant direction will need to morph and adapt.

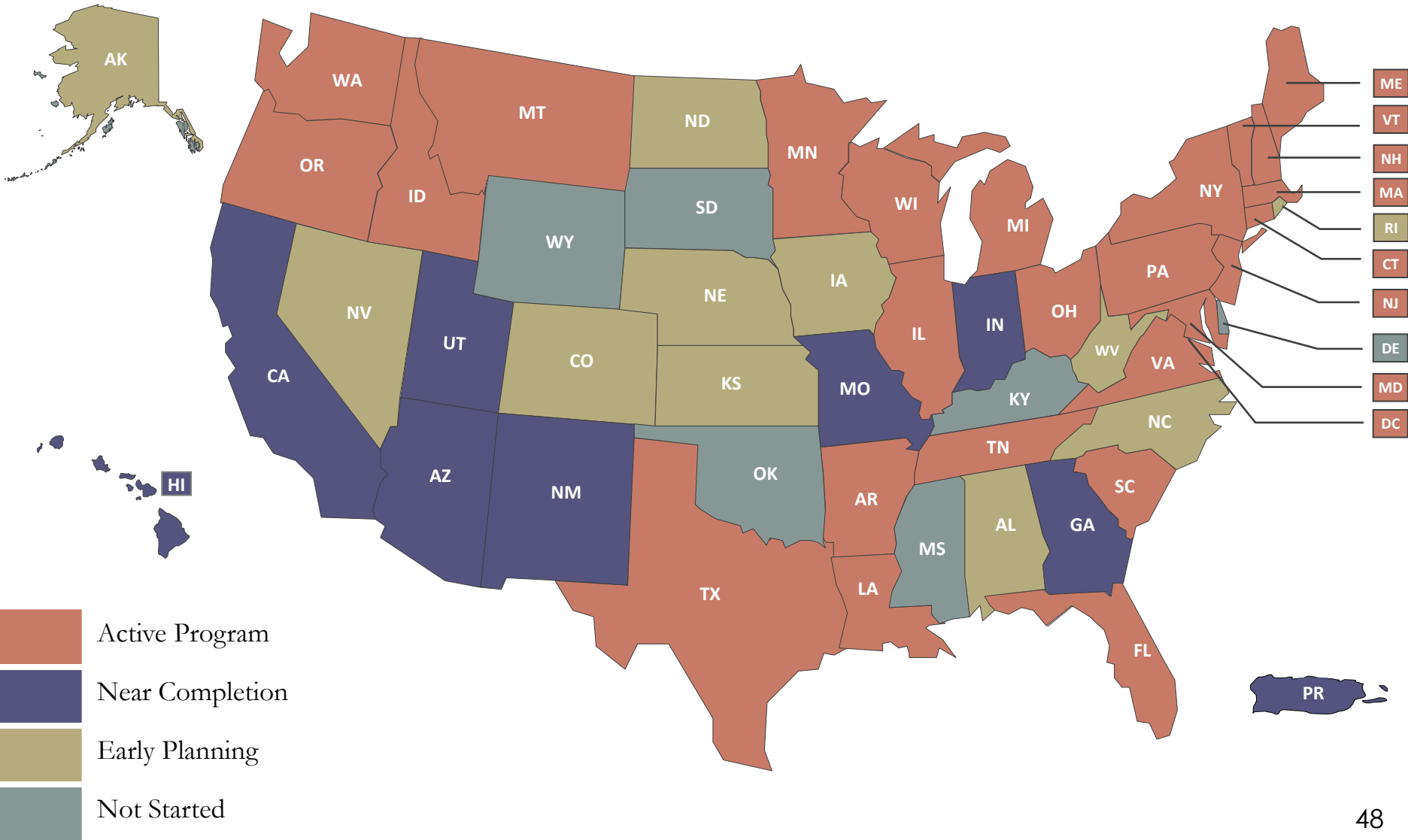
Participant Direction Training Needs

- ❑ The need for a paradigm shift to help present and future support brokers and their supervisors move from a “professional knows best” to an empowerment framework is critical for the growth of participant direction.
- ❑ The NRCPDS & the Council of Social Work Education have received a grant from the New York Community Trust to work with 9 schools of social work to infuse person-centered planning and participant direction competencies in their curriculum.

Recent Opportunities for the Spread of Participant Direction



Veteran-Directed Home and Community-Based Services (VD-HCBS)



At-A-Glance: VD-HCBS Program

- ❑ Collaboration between the Administration for Community Living (ACL), the Veterans Health Administration (VHA), & the NRCPDS
- ❑ Rebalance home and community-based options with institutionalization
- ❑ Quick Facts
 - ❑ Over 1,400 Veterans served
 - ❑ 26 States
 - ❑ 43 VA Medical Centers
 - ❑ 101 Aging and Disability Resource Centers/Area Agencies on Aging
- ❑ Sustainability Study:
 - ❑ 94% Very or Highly Effective
 - ❑ 52% Exceeded or met expectations

Participant Direction & Behavioral Health

- ❑ **Life:** There is substantial evidence that participant direction increases confidence and has positive outcomes regarding quality of life, independence, empowerment, choice, and access.
- ❑ **Costs:** There is evidence that, with participant direction, hospitalizations and emergency room visits trend downward.



Increases participation in employment and education



Decreases social isolation



Demonstrates potential for cost-saving or cost neutrality

Concluding Thoughts

It's my own money, I'm more careful with it ... I'm building skills and have to do research to see how much things cost ... I try to do as much as I can myself.

-Self-Directing Participant



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-THANK YOU-

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www.participantdirection.org