



NATIONAL RESOURCE CENTER *for*
PARTICIPANT-DIRECTED SERVICES

Participant Direction: Past, Present, & Future

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Living a Self-Determined Life 2015:

A Conference on Empowerment for Older Adults

What is Participant Direction?

- ❑ Person-Centered Planning
- ❑ Ability to hire and manage your own Personal Assistance Worker
- ❑ Ability to manage your own budget



Why Offer the Option for Participants to Manage Their Own Supports & Services?

- ❑ Control
- ❑ Flexibility
- ❑ Community
- ❑ Worker Shortage

Basic Model for Cash & Counseling

- ❑ **Step 1:** Consumers receive traditional assessment and care plan
- ❑ **Step 2:** A dollar value is assigned to that care plan
- ❑ **Step 3:** Consumers receive enough information to make unbiased personal choice between managing individualized budget or receiving traditional agency-delivered services

Basic Model for Cash & Counseling

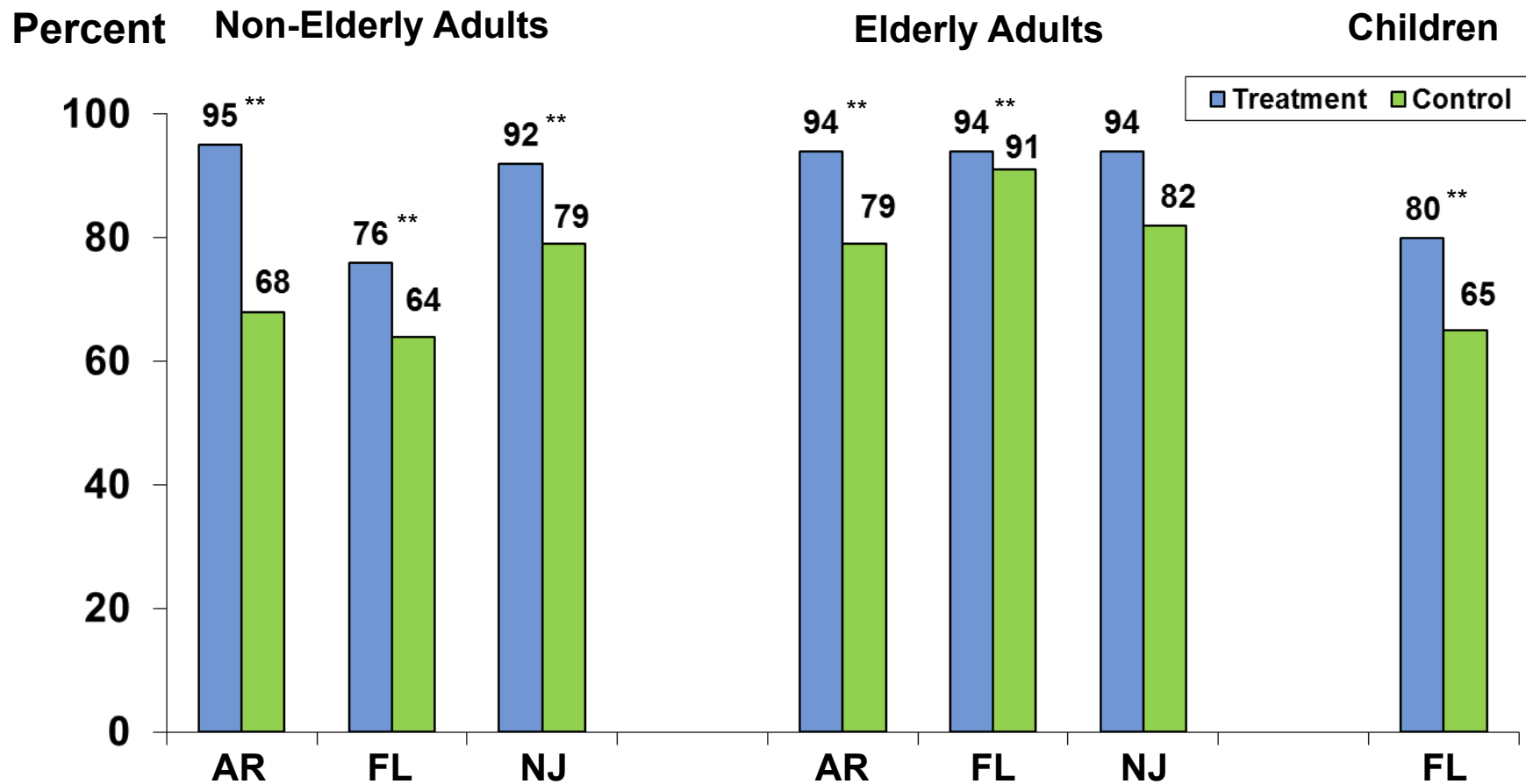
- ❑ **Step 4:** Consumer and counselor develop spending plan to meet consumer's personal assistance needs
- ❑ **Step 5:** Cash allowance group provided with financial management and counseling services (supports brokerage)

What is the Evidence-Base for Participant Direction?

- ❑ Participants
- ❑ Families
- ❑ Workers
- ❑ Costs



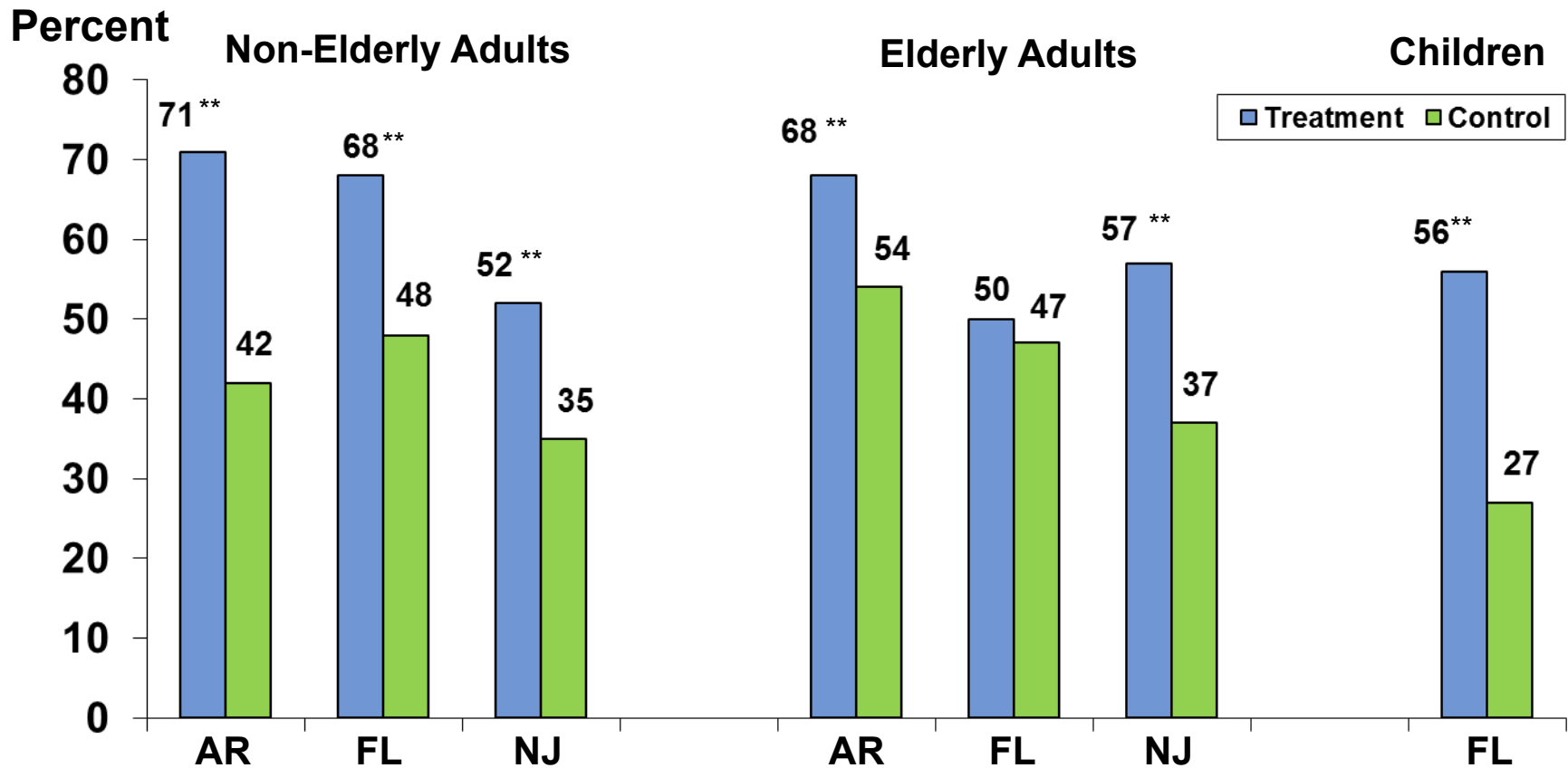
Receiving Paid Assistance at 9 Months



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

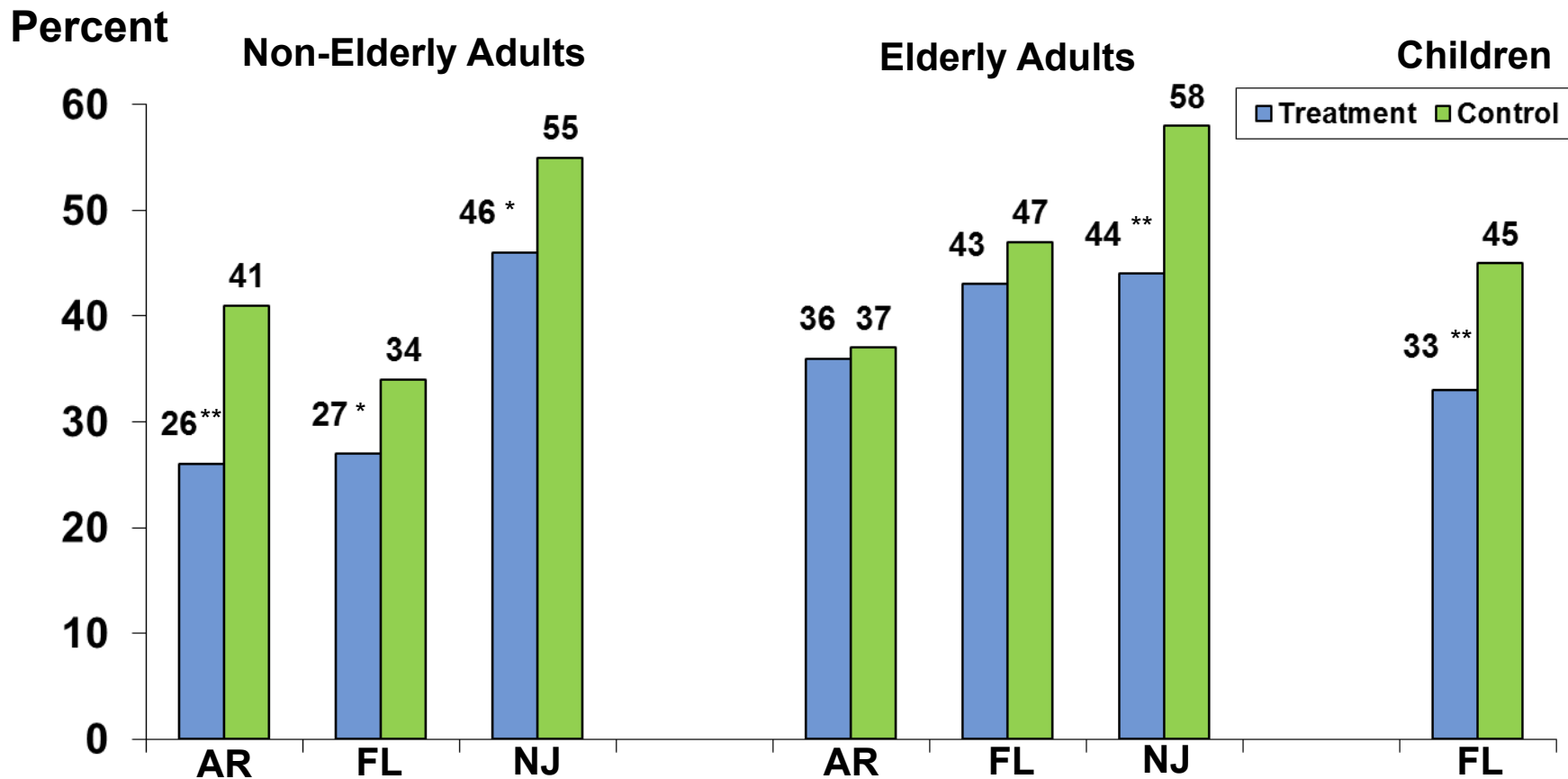
T= Treatment Group
C= Control Group

Very Satisfied with Overall Care Arrangements



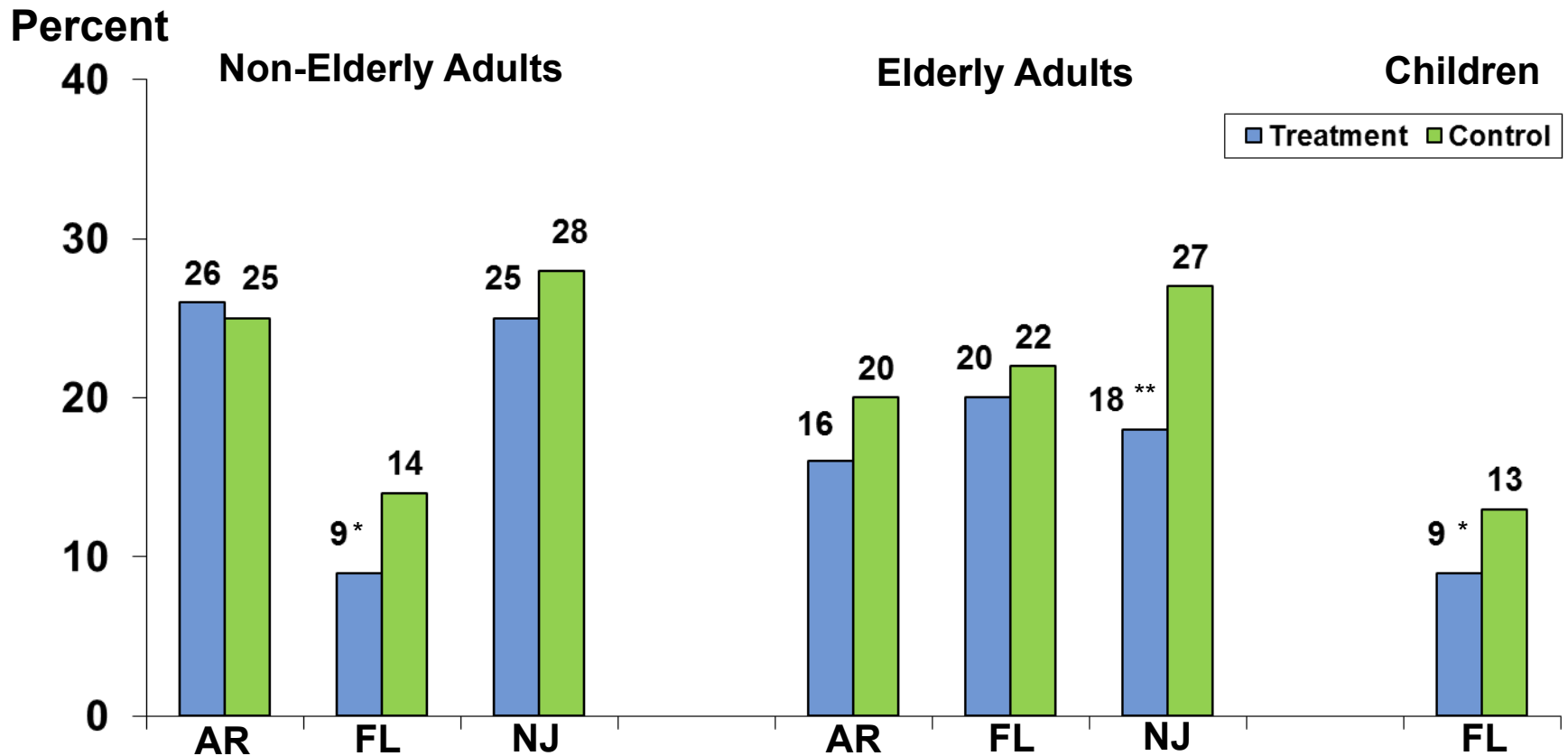
*, ** Significantly different from control group at .05, .01 level, respectively.

Had an Unmet Need for Help with Personal Care



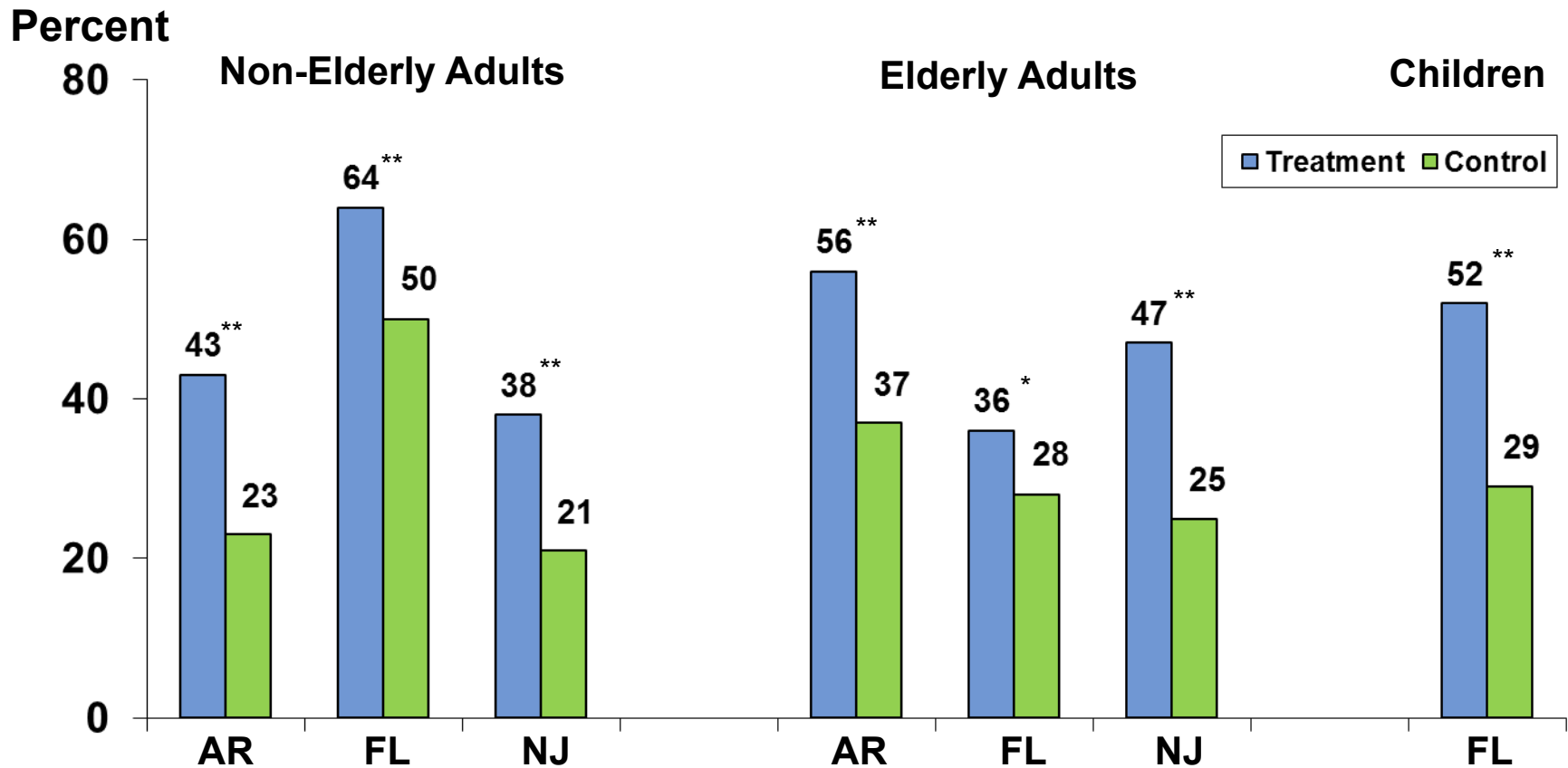
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Contractures Developed or Worsened



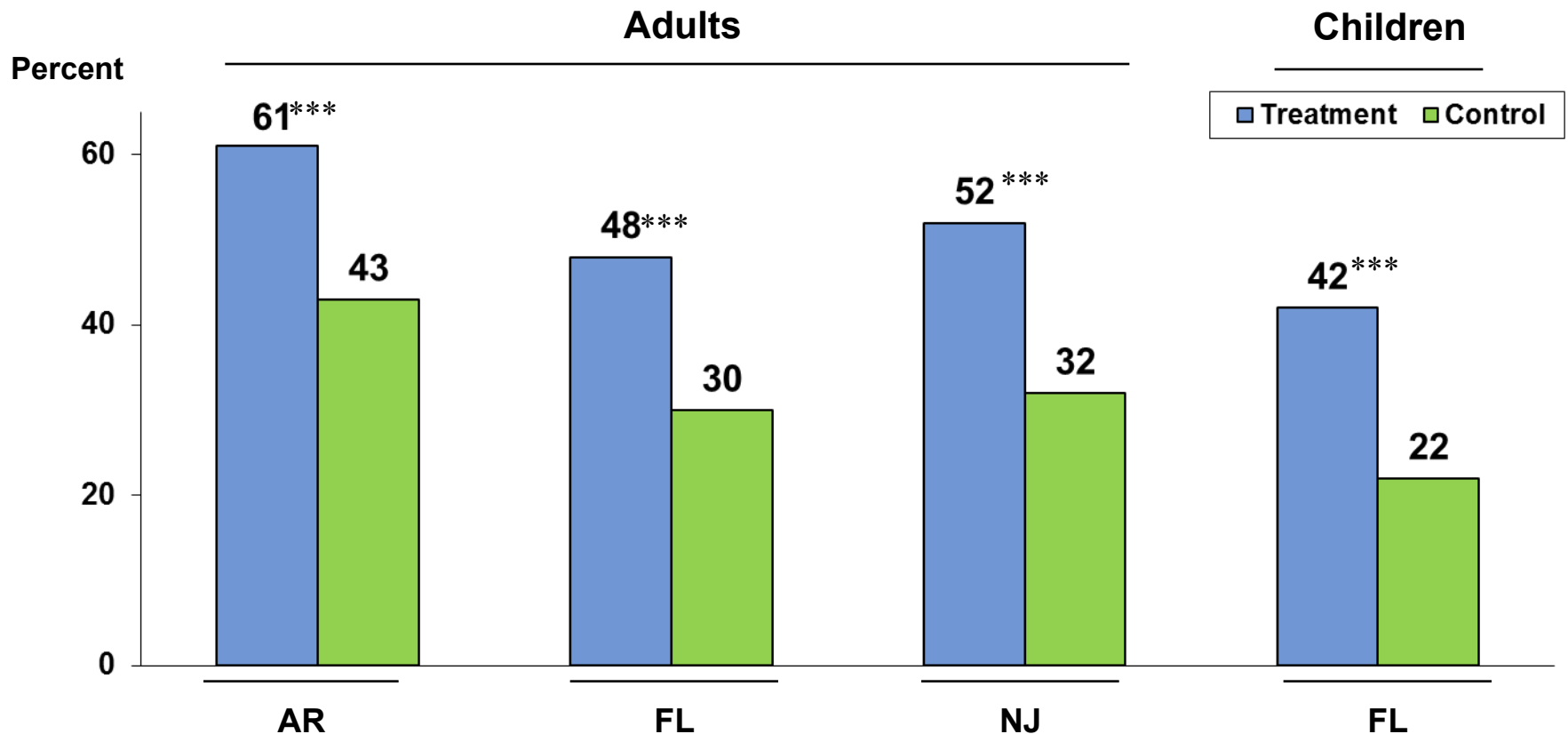
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Very Satisfied with Way Spending Life These Days



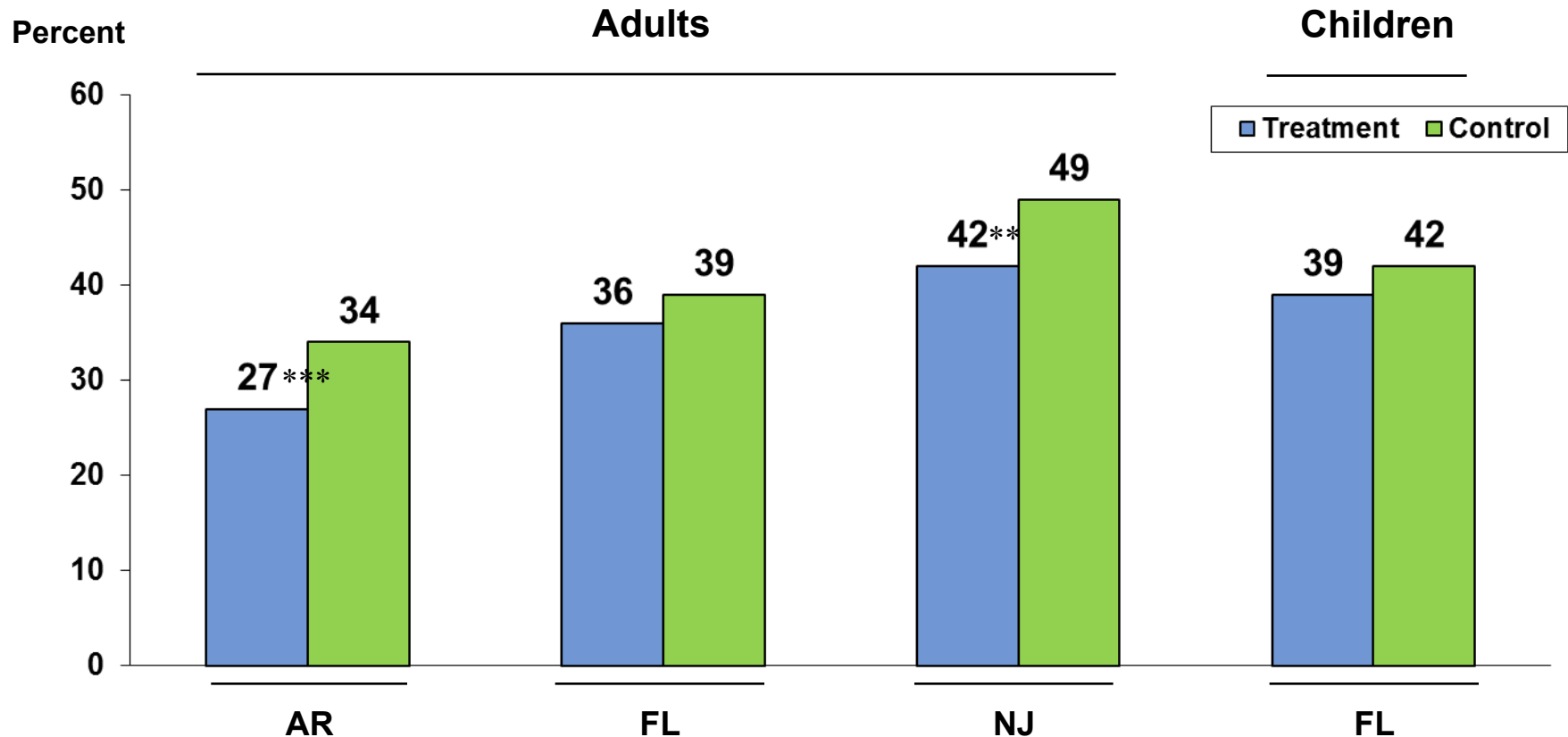
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Informal Caregivers Very Satisfied with Overall Care



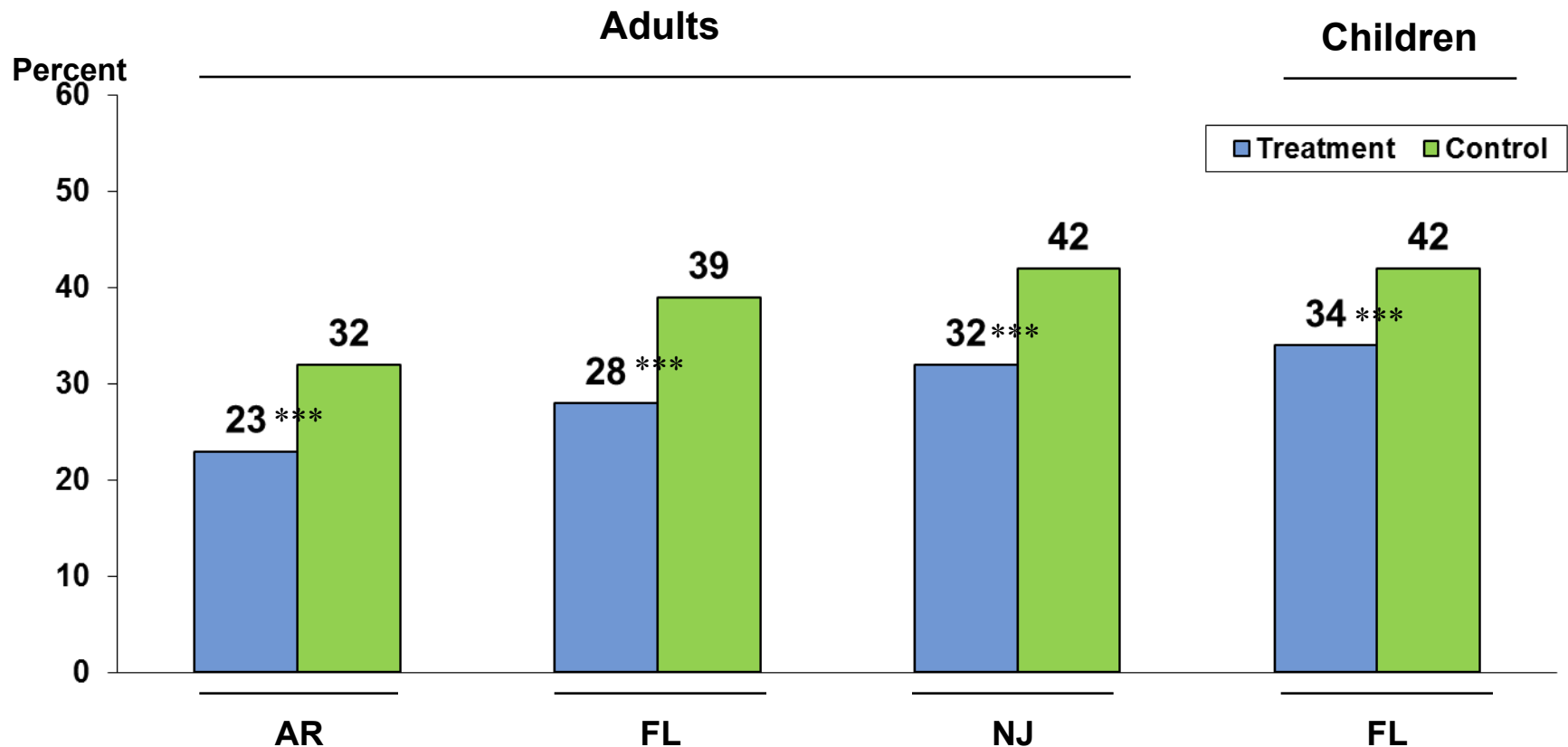
, Significantly different from control group at .10 (*), .05 (**), or .01 (***) level.

Informal Caregivers Experienced Less Emotional Strain



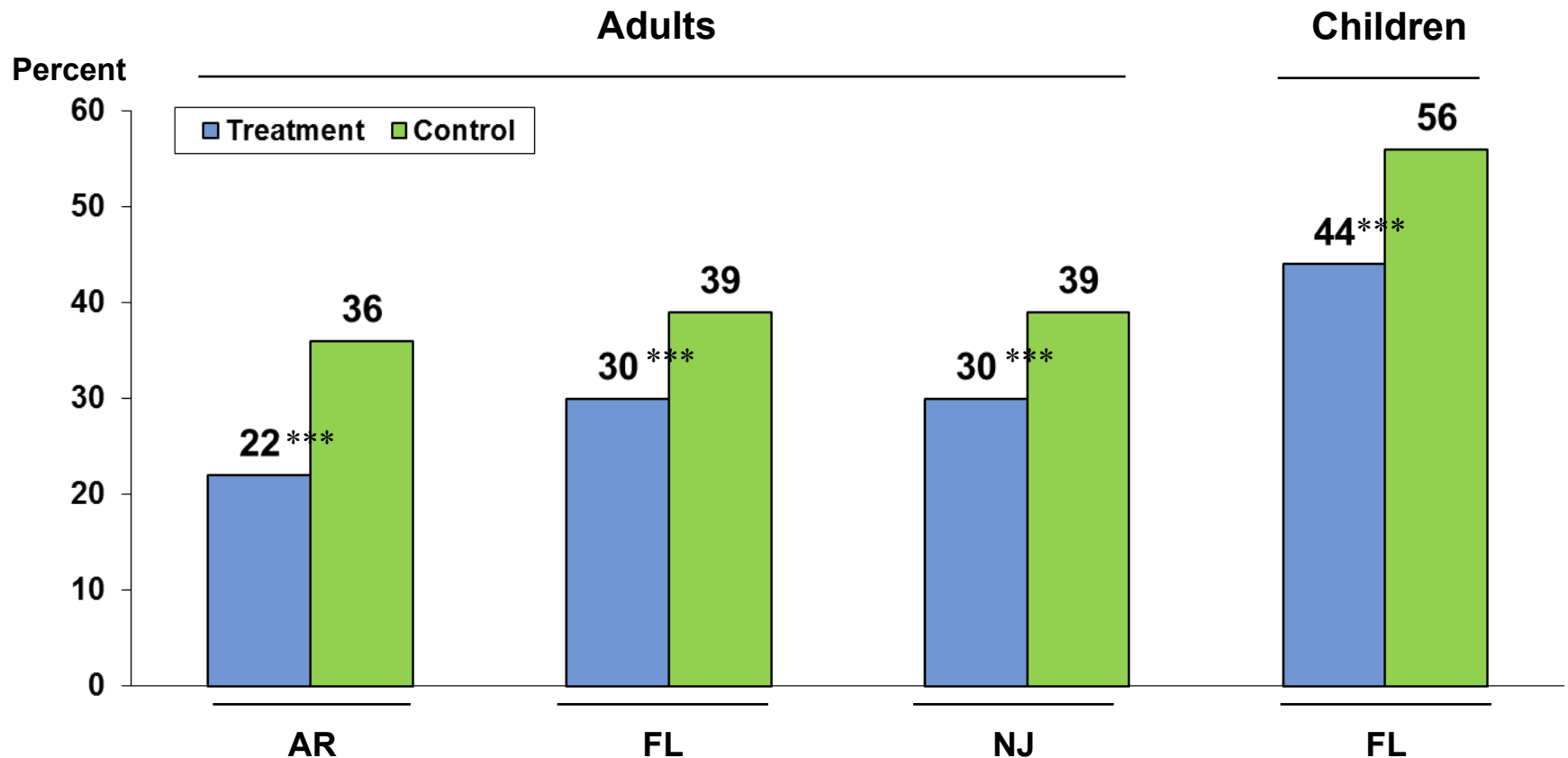
*, **, *** Significantly different from control group at .10 (*), .05 (**), or .01 (***) level.

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

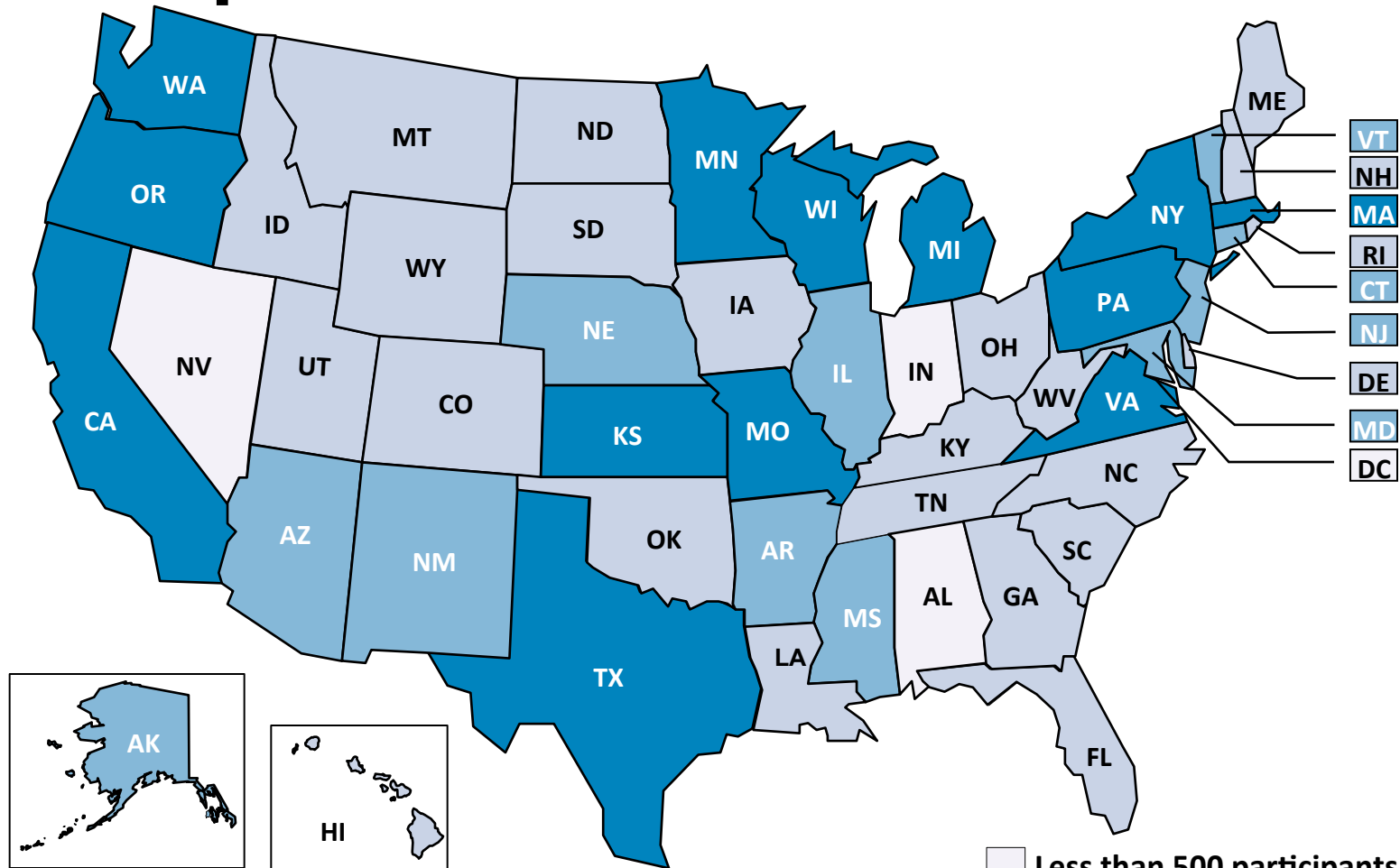
Nursing facility use was 18% lower for the treatment group than for the control group during the 3-year follow-up period. Among those who had received personal care services before the demonstration, nursing facility savings, together with savings in other long-term care costs, fully offset the higher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

-Dale & Brown, 2006

Participant Direction Enrollment and Program Size

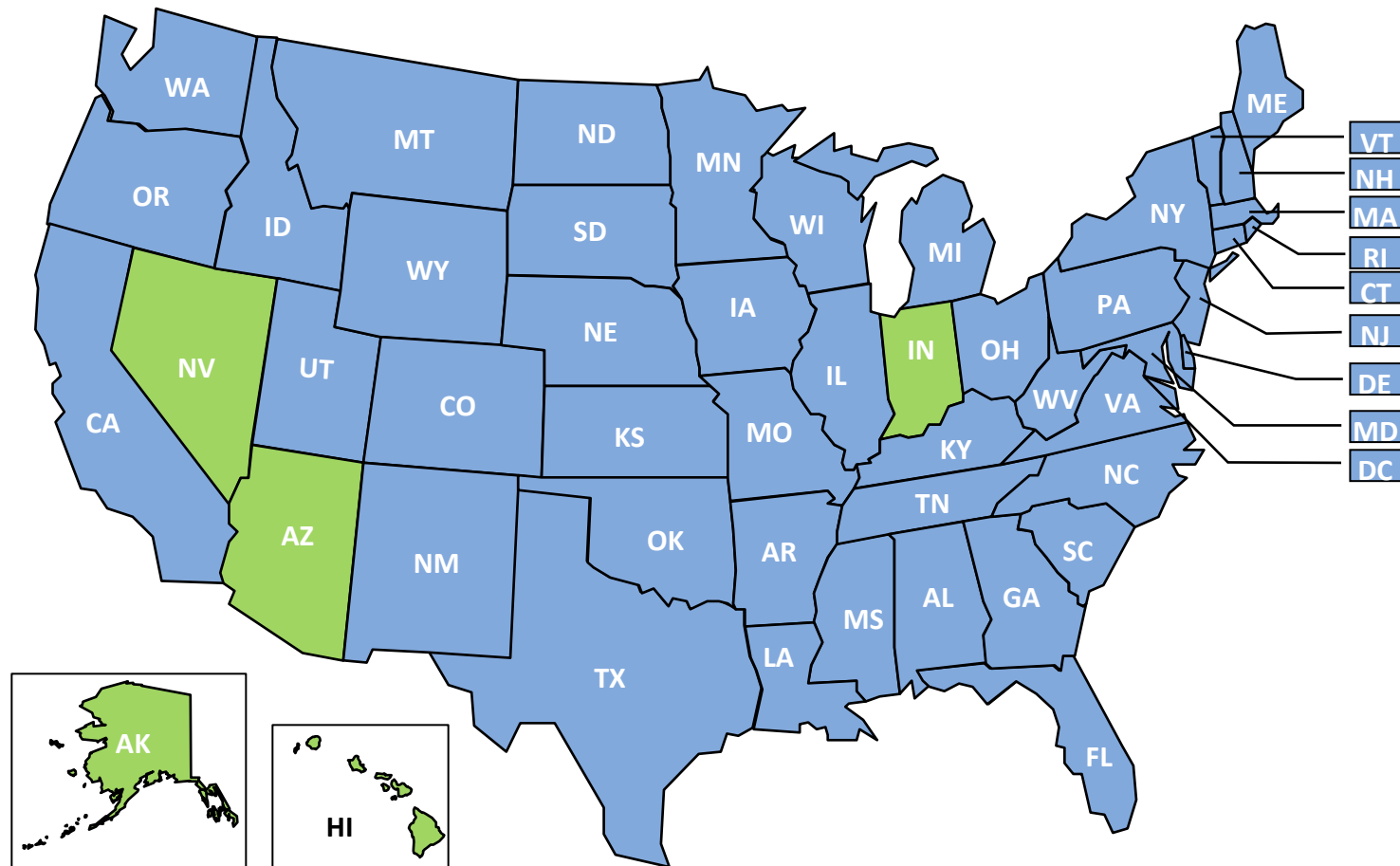
- ❑ Total enrollment is approximately 815,000
 - ❑ Number of programs is 266
 - ❑ California accounts for 54% of enrollment
 - ❑ Average program size is 3,381 participants
 - ❑ The majority (64%) of programs have 500 or fewer participants

Majority of States have 1000 – 5000 Participants



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Employer and Budget Authority Programs



-  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

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.
 - *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))

Factors that Will Affect Growth of Interest in Participant Direction

- ❑ Increasing diversity of America's elderly
- ❑ Baby-boomers desire for choice (AARP survey)
- ❑ Section 2402(a) of the Affordable Care Act

Reasons for Pessimism

- ❑ My son's story
- ❑ A growing “medical” and “professional” emphasis under “integration of care” approaches
- ❑ Possible impacts of the Department of Labor's Companionship Exemption regulations
- ❑ Lack of clear standards, policies and training for participant direction
- ❑ Need for data

Reasons for Hope

- ❑ Students' Interest
 - ❑ New York Community Trust
 - ❑ CSWE



Recommendations

- ❑ Involve participants and seek out their opinions in design, implementation, and evaluation
- ❑ Assemble promising practices tried and tested by others
- ❑ Develop and take part in ongoing training
- ❑ Make sure your agency has policies and procedures to guide each step of the process
- ❑ Develop a continuous quality improvement approach, quality standards as needed



“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.”

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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