



NATIONAL RESOURCE CENTER *for*
PARTICIPANT-DIRECTED SERVICES

Exploring the Future of Participant Direction: Benefits and Challenges from the Perspectives of Program Administrators

Home & Community-Based Services National Conference
Crystal City, VA
September 17, 2014

Workshop Agenda

- I. Summary of the *National Inventory**
- II. Inventory Highlights
- III. Implications
- IV. Recommendations
- V. Panel Discussion

*National Resource Center for Participant-Directed Services (2013). *National Inventory for Participant Direction Programs* [Data file]. Boston College Graduate School of Social Work: Chestnut Hill, MA.

Workshop Aims

- ❑ Identify the benefits and challenges of developing and implementing participant direction programs from the perspectives of program administrators.
- ❑ Explain how the challenges identified are being addressed in different environments.
- ❑ **Discuss strategies to ameliorate these challenges so to better inform policy aimed at “best practices”.**

*National Resource Center for Participant-Directed Services (2013). *National Inventory for Participant Direction Programs* [Data file]. Boston College Graduate School of Social Work: Chestnut Hill, MA.

National Inventory Background

Colleen Bouzan, MS

National Resource Center for Participant-Directed Services (NRCPPDS)

Summary of the National Inventory

- ❑ Provides a better understanding of participant direction programs nationwide.
- ❑ **Identifies best practices, challenges, and future directions.**
- ❑ Stands as only one of its kind.

National Inventory Objectives

- ❑ To identify the number of publicly funded (e.g., Medicaid, Veterans Administration) participant direction programs in the 50 states and the District of Columbia.
- ❑ To delineate the scope of these programs (e.g., number of participant-directing individuals, populations served).
- ❑ To compare and contrast program structure (e.g., eligibility requirements, staffing roles and responsibilities).
- ❑ **To gain insight on the benefits and challenges of developing and implementing participant direction (PD) through the voices of program administrators.**

Data Collection Methodology

- ❑ Sources of data included:
 - ❑ **Surveys from state administrators of PD programs;**
 - ❑ The Medicaid waiver database;
 - ❑ Program websites including online manuals, pamphlets, and fact sheets;
 - ❑ A program's Financial management services (FMS) provider; and
 - ❑ Data requests to state agencies

National Inventory: General Descriptive Findings

Kevin J. Mahoney, PhD

Director, NRCPPDS

Professor, Older Adults & Families and Global Practice,
Boston College Graduate School of Social Work

Emerging Trends

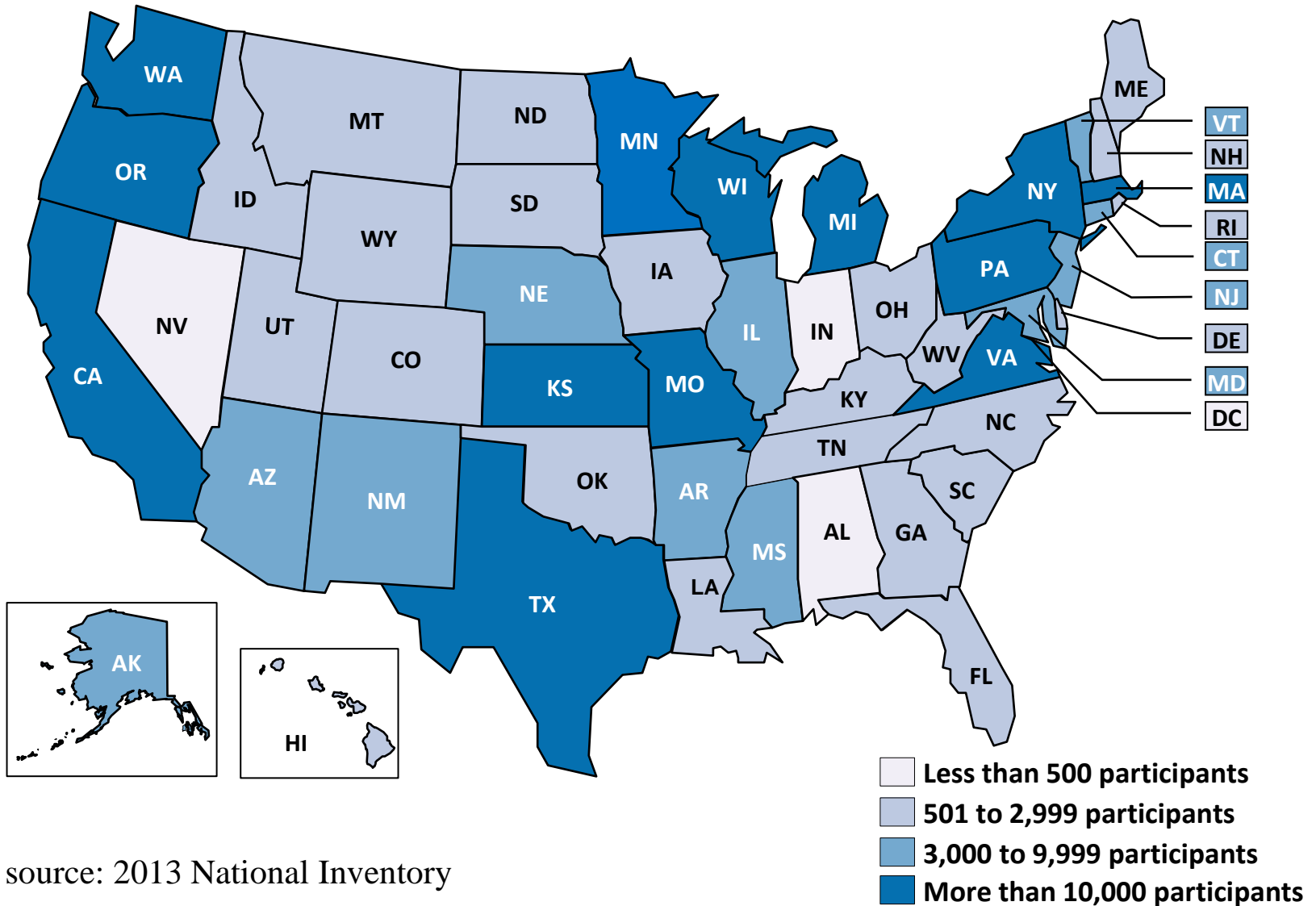
- ❑ Moderate growth in enrollment
- ❑ Transition to managed care entities (MCE)
- ❑ Program expansion/development



Enrollment and Program Size

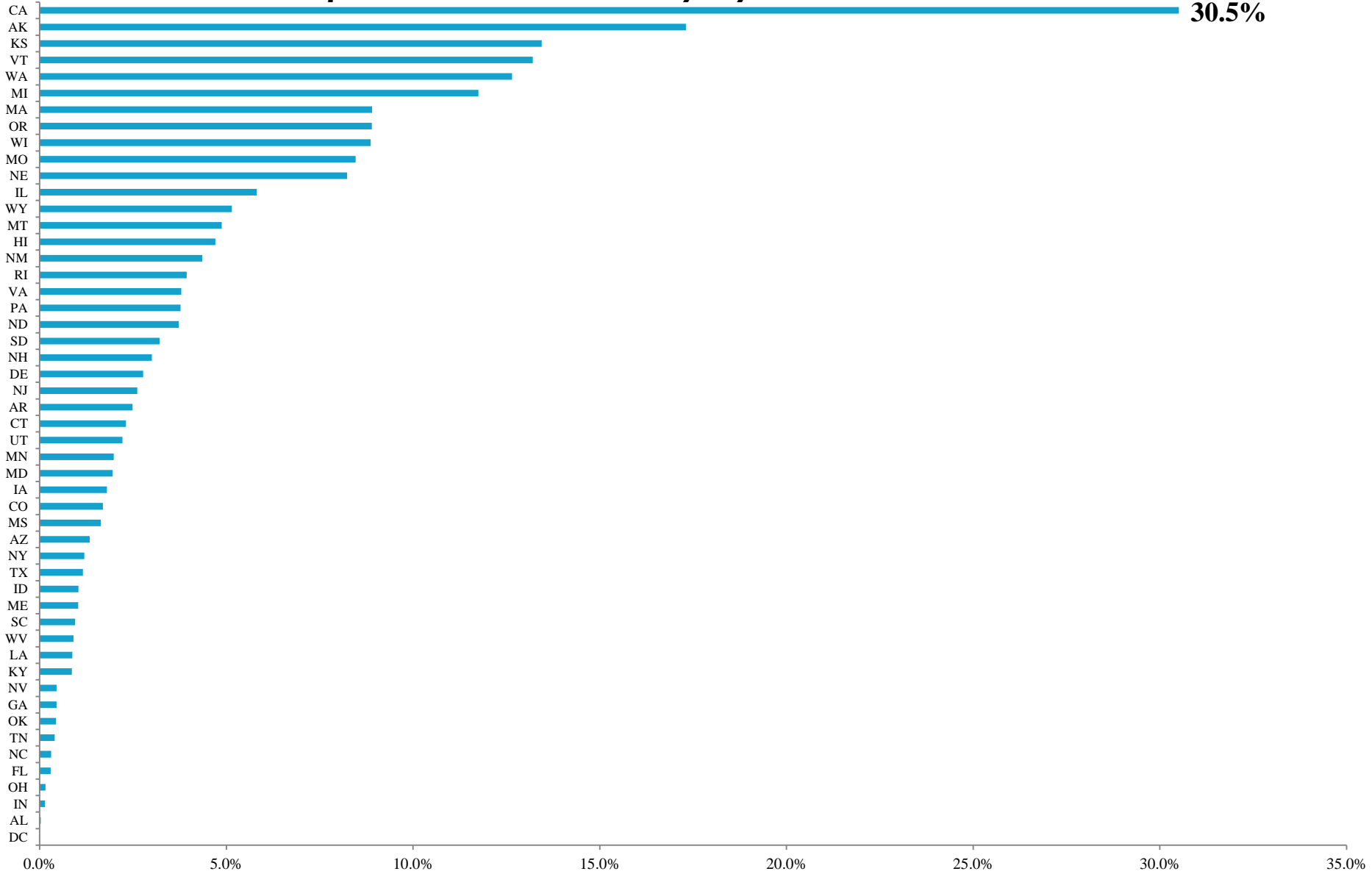
- ❑ Total enrollment is approximately 840,000
- ❑ Number of programs is 277
- ❑ Average program size is about 3,500 participants
 - ❑ Range = 1 – 440,000
- ❑ The majority (64%) of programs have 500 or fewer participants
- ❑ California accounts for 54% of enrollment

Majority of States have 1000 – 5000 Participants



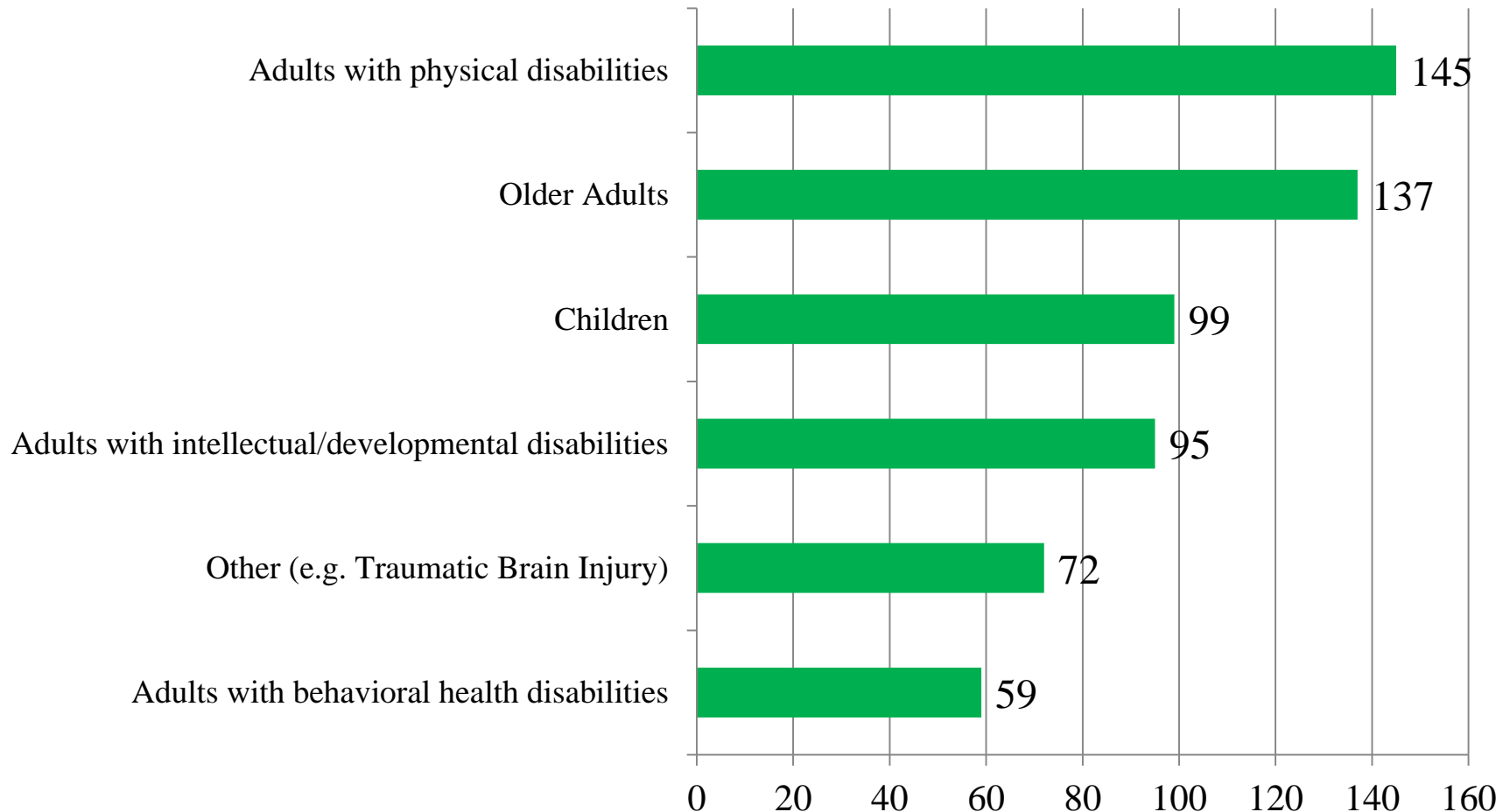
Data source: 2013 National Inventory

Ratio of Participant Direction Enrollment to Income-Based Government Assistance Recipients with a Disability by State*



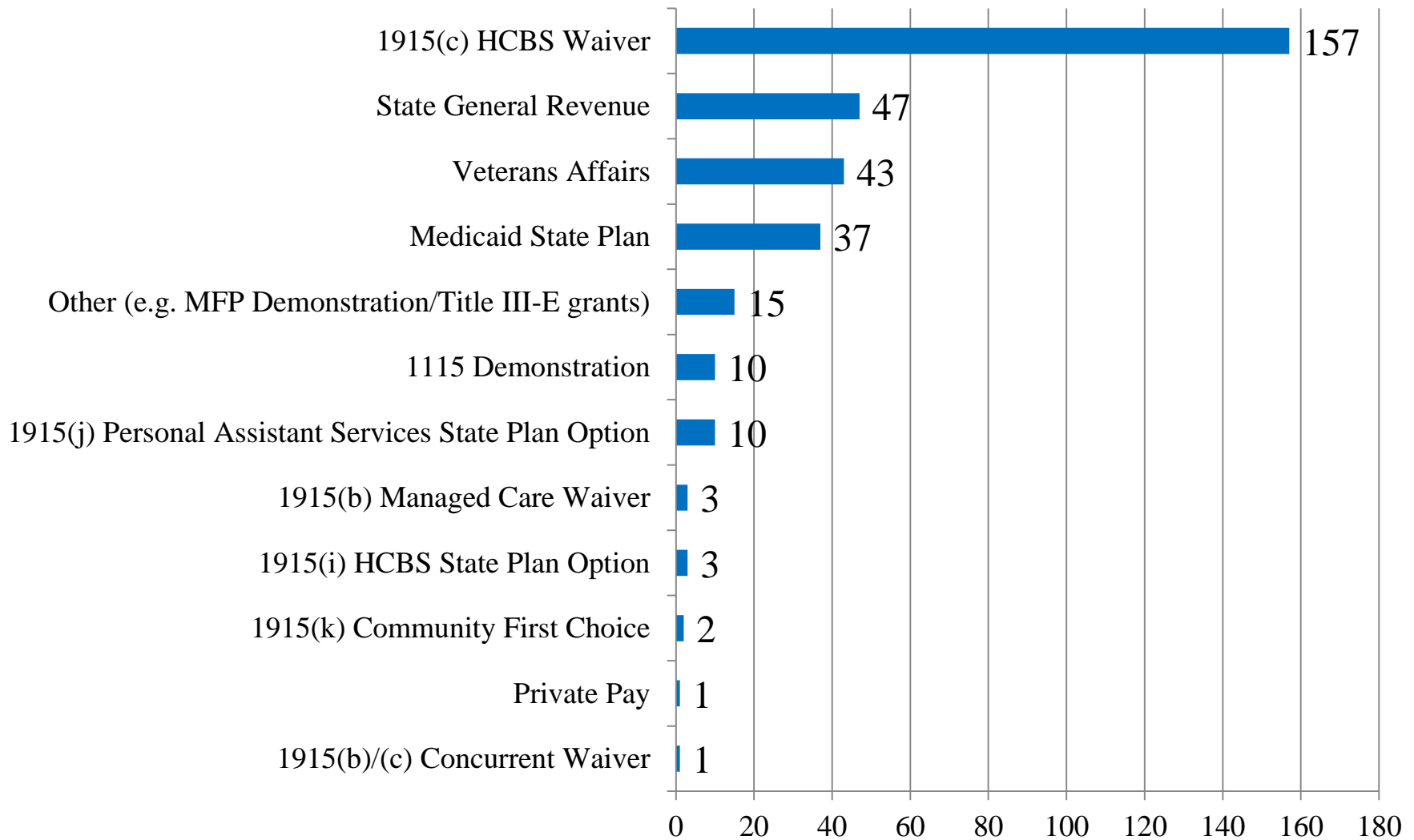
Numerator data source: 2013 National Inventory

Number of PD-LTSS Program Populations Programs (n=276) that Serve Each Population



Data source: 2013 National Inventory

Number of PD-LTSS Programs (n=272) Funded Through Each Source



Data source: 2013 National Inventory

Qualitative Content Analysis

Colleen Bouzan, MS
NRC PDS

Program Administrator Perspectives

- ❑ Emphasize the voices of PD administrators
 - ❑ Explored data from open-ended survey questions
 - ❑ Identified common themes and grouped them into categories
 - ❑ Discovered a synergy between the benefits and challenges and quality



"MY OPINION? ARE YOU SURE I'M SUPPOSED TO HAVE ONE?"

Program Benefits: Development and Implementation

- ❑ Benefits closely aligned with previous research on PD.
 - ❑ Themes/subthemes
 - Participant outcomes
 - Better health outcomes
 - Participant empowerment
 - Increased satisfaction
 - Improvements in patterns of care delivery
 - Expanded and more stable staffing
 - Family more involved in care
 - Needs met
 - More effective use of service dollars
 - Impact on service coordinators
 - Expanding perspectives
 - Consistent with program values

Impact on Service Coordinators

❑ Expanding perspectives

“The [Name of Program] is entirely a participant direction program. Its existence offers an option to those who would otherwise be channeled into the traditional agency-based program for HCBS. A benefit of [Name of Program] is it’s encouraging care coordinators to think more holistically about all of the seniors with whom they work, including those in the traditional program...”

❑ Consistent with program values

“This program demonstrates the Departments’ principles of choice, independence and recognizing the value of person-centered supports and services.”



Service Dollars Used More Effectively

“Participants are able to reduce costs of their care by using services that are less expensive. For example, one participant with severe scoliosis benefits from regular swim lessons that are less expensive than physical therapy.”

“Costs are less, freeing up more money for other program members.”



Improvements in Patterns of Care Delivery

- ❑ Expanded and more stable staffing
“Expands choice of providers and expands the available network of providers of services and supports.”

- ❑ Family more involved in care
“Allowing the empowerment of the parent or responsible party to take ownership of the totality of the services and quality of the services. I think it is more involvement for the family when they self-direct.”

- ❑ Needs met
“Needs of complex and diverse populations are being met with non-traditional approaches.”

Participant Outcomes

❑ Better health outcomes

“Better health outcomes because participants hire and train their PA's.”

“Agencies are able to support extraordinary outcomes and accomplishments for people who have control and flexibility over their supports and services”

❑ Participant empowerment

“It allows the participant to have a voice in services without an agency directing who they hire and what services they receive. This provides more buy-in from the participant.”

❑ Increased satisfaction

“Participant choice and self-advocacy leads to increase in consumer satisfaction and to better outcomes.”



**Yet administrators of participant
direction programs voiced a
number of challenges...**

Program Challenges: Development and Implementation

□ Themes

- Overcoming biases
- Keeping abreast of training
- Quality-cost outcomes
- Preservation of philosophical premise of PD in changing landscape

Overcoming Biases

“The biggest challenge is overcoming the biases of administrators and care coordinators against participant direction - - biases based on their concerns regarding fraud and inadequate supervision, lack of capacity in seniors being able to direct their own services and a belief system which opposes family members being paid to care for family members.”

Overcoming Biases

“mitigating the notion that the professional, not the participant, is the expert about needs, services and supports.”

Keeping Abreast of Training

“Keeping abreast of Dept. of Labor regulations, best practices available, innovative approaches to handling situations, innovative programs for keeping persons from being isolated.”

“I believe having more communication with the other participant-directed programs across the country would help to provide ideas of what works...in the participant-directed care model.”

Quality-Cost Outcomes

“Participants awareness of their spending patterns to make better use of their allocations.”

“Overcoming the perception [...] of higher cost model.”

Preservation of PD Philosophy in Changing Landscape

“How to best write policy and guidelines that can preserve the unique gifts and situations of each individual and how to best allow persons to manage individual risk and understanding and embracing concepts such as dignity of risk. For example, crafting and applying policy and guidelines that are responsive to the great variety of individuals in the program...”

Preservation of PD Philosophy in Changing Landscape

“helping providers understand the principles of self-determination and self-direction (true employer and budget authority) and how to best support these options”

Implications:

“What does quality mean in a participant direction program?”



Implications

- ❑ Standardization of service coordinator training.
- ❑ Development of participant direction standards and requirements which impact the design, operation, and evaluation of these programs.
- ❑ Development of participant-directed quality measures which prevent most states from evaluating program performance and distinguishing high-quality programs from low-quality ones.
- ❑ Great hope in the commitment of many to proactively address challenges

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 and federal agencies to develop participant-directed specific quality measures and a standardized way to collect program information.
 - ❑ National Committee on Quality Assurance (NCQA)
 - ❑ National Core Indicators (collaboration of NASD DDS & HSRI)
 - ❑ Agency for Healthcare Research and Quality (AHRQ)

Acknowledgements

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- ❑ Kaipeng Wang, MSW
- ❑ NRCPDS staff

Panel Discussion

Suzanne Crisp
Director of Program Design & Implementation, NRCPS

From the Field

- ❑ How do you define quality of services/care for your program?
- ❑ How do you *maintain* quality of services/care for your program?
- ❑ What have been some of your greatest *benefits/challenges* in implementing a PD program of quality?
- ❑ How can we take the challenges and transform them into strategies for improving quality of services/care?
- ❑ What type of trainings do you think would help lessen the burden of your role or alleviate any challenges?