Participant-Directed Services: Why They Matter

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It’s my own budget, 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
Why Offer the Option for Participants to Manage Their own Supports & Services?

- Control
- Flexibility
- Community
- Worker Shortage
Factors that Will Affect Growth in Participant Direction

- Increasing diversity of America’s elderly
- Baby-boomers desire for choice (AARP survey)
- Section 2402(a) of the Affordable Care Act
- One of the few evidence-based steps states can take to rebalance their funding for LTSS (Mathematica Policy Research 2009, 2013)
Prevalence Of PD

- Currently, 277 programs in the US
  - Ninety-five Intellectual/Developmental Disabilities
  - 53 new programs since 2010
- Serving 840,000 individuals
- Represents a 9% increase from 2010 to 2013
- Two hundred and twenty-three programs funded by Medicaid (1915(c), (i), (k), (j), (b) (b/c), state plan personal care and 1115(a) Demonstration
- Over 63% of the 277 have employer and budget authority
What is the Evidence-Base for Participant Direction?

- Participants
- Families
- Workers
- Costs
Participant Direction Enrollment and Program Size

- Total enrollment is approximately 815,000
- Number of programs is 266
Participant Direction & MLTSS

- Majority of states are delivering, 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.
Centers for Medicare & Medicaid Services Position

- CMS supports self-direction (SD) in both fee-for-service and managed care settings
- Most recently published in May, 2013
  - Applies to Sections 1115 and 1915(b)

*States that offer SD ... are expected to continue....

*States that do not currently offer SD...should consider providing the opportunity...within MLTSS program*
Contractual language for participant direction services in managed and integrated health care settings varies substantially among states.

There are very few requirements specific to monitoring of participant direction services.

Guidance from MCEs regarding training for service coordinators in participant direction is inconsistent.
The Centers for Medicare & Medicaid Services (CMS) and states should identify best practices in participant direction program design, operation, and evaluation to guide further 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 quality measures and a standardized way to collect program information.
Myths of Participant-Direction

- Only for younger persons with disabilities
- Difficult to administer
- Perception of fraud & abuse
- Impossible to monitor
- Challenging to use existing quality assurance & improvement strategies
- Expenditures will sky-rocket
The Cost of Participant Direction

- Acute care and high costs services are lower for those managing their own services and supports
- Basic non-medical services increase
- Per capita Medicaid costs are less for those managing their own services and supports than traditionally served participants
- Costs per hour are lower for those using participant direction than for agency services
- Participant-directed programs can be designed using a cost neutral approach
“I sleep much better. I feel much better. You know, my biggest fear is to be stuck in my bed and waste my life away ... I want to get out and ... get back into society and do lots of things.”
Resources

- Published Report in July, 2013 *An Investigation of Interstate Variation in Medicaid LTC Use & Expenditures Across 40 States in 2006*
  - [http://aspe.hhs.gov/daltcp/reports/2014/ProgBal.pdf](http://aspe.hhs.gov/daltcp/reports/2014/ProgBal.pdf)
Thank you!

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