A Breakthrough Model for Independence and Choice

Self-Direction and Behavioral Health

Welcome and Webinar Overview

Lori Simon-Rusinowitz
Research Director, National Resource Center for Participant-Directed Services
University of Maryland School of Public Health

An Overview of Today's Presentation

- Welcome and Opening Remarks
- What is Self-Direction?
- The Family Perspective
- Self-Direction in Behavioral Health
- Important Elements of Self-Direction (e.g., financing)
- Q&A, Wrap Up and Survey

Opening Remarks

Bob Glover

Executive Director
National Association of
State Mental Health Program Directors

Wendy Yallowitz

Program Officer
Robert Wood Johnson Foundation

"If we can be more flexible and even more innovative in thinking of different ways that people use help and allow them to make those choices about what works for them and what they need, it can start the empowering process of recovery. I'm really glad to have the opportunity to be a part of this project."

Paolo Del Vecchio

Acting Director
Center for Mental Health Services,
Substance Abuse and Mental Health
Services Administration,

"Self-directed care approaches are at the heart of our efforts at promoting recovery from mental and substance use disorders. This is reflected in SAMHSA's new working definition of recovery as 'a process of change through which individuals improve their health and wellness, live a *self-directed* life, and strive to reach their full potential.' We see the promise of self-directed care to increase consumer choice and control over the services they receive as well as their own recovery."

NATIONAL RESOURCE CENTER FOR PARTICIPANT-DIRECTED SERVICES

Ron Manderscheid

Executive Director
National Association of County
Behavioral Health and
Developmental Disability Directors

"We fully support self-direction as a key feature to recovery. Self-direction improves shared decision-making, whole health, and life in the community for everyone including all of our consumers and peers."

Kathy Poisal

Technical Director
Division of Long-Term Services and Supports,
Disabled and Elderly Health Programs Group,
Center for Medicaid & CHIP Services,
Centers for Medicare & Medicaid Services

"CMS recognizes the importance of behavioral health services and the self-directed service delivery method, and encourages states to incorporate this option into their State Medicaid programs."

What is Self-Direction?

Lori Simon-Rusinowitz
Research Director, National Resource Center for Participant-Directed Services
University of Maryland, School of Public Health

What are Self-Directed Services?

- Self-directed services are long-term services that help people of all ages across all types of disabilities maintain their independence and determine for themselves what mix of services and supports work best for them.

- Self-directed services are sometimes referred to as consumer-directed or participant-directed services.

Models of Care

Traditional Model

- Professional decision-making
- Agency oversight
- Rules and restrictions regarding the timing, duration, amount, and scope of services

Self-Directed Model

- Participants have more control over their services

Cash & Counseling Model

✓ One of the most flexible models of self-direction

✓ Allows participants the authority to manage a personal care budget

✓Support Brokers (also called counselors or consultants) provide advice and program information, quality monitoring of services, and informal training in budgeting, planning, and recruiting and hiring workers

✓ Participants hire, supervise, and fire their own personal care workers (including relatives)

✓ Participants may purchase other goods and services.

Important Roles in a Self-Direction Model

- Participant
- Representative
- Support Broker
- Bookkeeper or Fiscal Management
- Paid and Unpaid Workers

Cash & Counseling Demonstration and Evaluation

Funders

- The Robert Wood Johnson Foundation
- US DHHS/ASPE
- Administration on Aging

National Program Office

- University of Maryland (CCDE)
- Boston College Graduate School of Social Work (CCDE Replication)

Waiver and Program Oversight

- Centers for Medicare and Medicaid Services

Evaluators

- Mathematica Policy Research, Inc.
- University of Maryland, Baltimore County

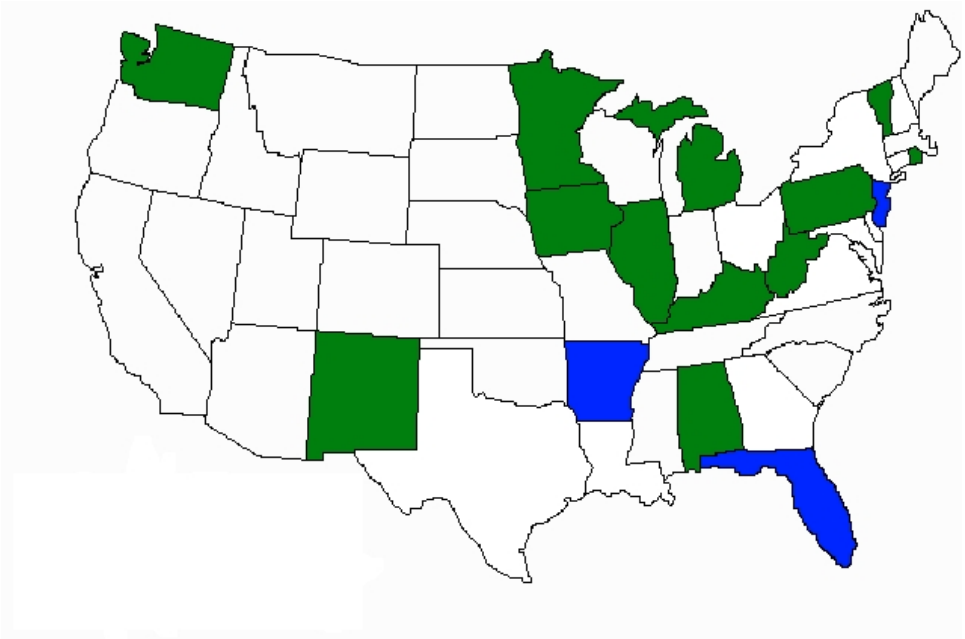
Cash & Counseling Demonstration and Evaluation

- Over 5500 elderly and adult Medicaid consumers in Arkansas, Florida and New Jersey participated in a real world test of this model in which participants manage their own budgets (there were also about 1000 children with developmental disabilities enrolled in Florida's program).
- Half were randomly assigned to manage their own budgets (C&C participants), while the remainder used traditional agency-directed services. Use of representatives by C&C participants ranged from 47 to 70%.
- Almost all participants choose to use agencies to handle financial management and payroll.

Cash & Counseling Demonstration and Evaluation

- C&C participants were highly satisfied, and 85-98% said they would recommend the program to others.
- C&C participants reported more flexibility, control and greater satisfaction with overall quality of life and experienced similar or better health outcomes.
- Over time, the C&C model has been shown to generate program cost savings by reducing institutional care.
- Reports also suggest that this model of service is successful for individuals with diverse disabilities, including those with physical disabilities as well as those with dementia and other mental health diagnoses.

Demonstration and Expansion States



Demonstration

- Arkansas
- Florida
- New Jersey

Expansion

- Alabama
- Illinois
- Iowa
- Kentucky
- Michigan
- Minnesota
- New Mexico
- Pennsylvania
- Rhode Island
- Vermont
- Washington
- West Virginia

National Resource Center for Participant-Directed Services

- Center was launched in April 2009 and funded by:
  - The Robert Wood Johnson Foundation
  - The Atlantic Philanthropies, with additional support from:
    - U.S. Administration on Aging
    - Office for the Assistant Secretary for Planning and Evaluation
    - Veterans Health Administration
- Housed at Boston College Graduate School of Social Work

NRCPDS Mission

To infuse participant-directed options into all home and community-based services by providing national leadership, technical assistance, education, and research, leading to improvement in the lives of individuals of all ages with disabilities.

Self-Direction: Expanding Beyond Medicaid Populations

- NRCPDS Partnership with U.S. Administration on Aging: *Initiative to promote culture change from "professional" to "empowerment" approaches to services and supports*

- NRCPDS Partnership with U.S. Administration on Aging and Veterans Administration: *Initiative to create a network of veterans-directed services programs in every state*

Environmental Scan of Self-Direction and Behavioral Health

- The Robert Wood Johnson Foundation has funded an environmental scan of Self-Direction and Behavioral Health, to ascertain interest in self-direction and behavioral health services.
  - Literature Review
  - State and County Behavioral Health Program Directors – Webinar, Survey and Interviews
  - Other Behavioral Health Key Stakeholders: Focus Groups and Interviews
  - Synthesis of Findings and Recommendations

Participant Direction: A Family Perspective

Pat Wright
Recipient, Participant Directed Services, MN
Core Leader, National Participant Network

Self-Direction in Behavioral Health

Kathryn Poisal
Technical Director,
Division of Long-Term Services and Supports,
Disabled and Elderly Health Programs Group,
Center for Medicaid & CHIP Services,
Centers for Medicare & Medicaid Services

1915(i) State Plan HCBS - Key Features

- Section 1915(i) established by DRA of 2005. Effective January 1, 2007
- State option to amend the state plan to offer HCBS as a state plan benefit
- Unique type of State plan benefit with similarities to HCBS waivers
- Breaks the "eligibility link" between HCBS and institutional care now required under 1915(c) HCBS waivers
- 1915(i) was modified through the Affordable Care Act with changes that became effective October 1, 2010

Who May Receive State plan HCBS?

- Must be eligible for medical assistance under the State plan
- States must provide **needs-based criteria** to establish who can receive the benefit
- Must reside in the community
- Must have income that does not exceed 150% of FPL
- Through changes included under the Affordable Care Act, states also have the option to include individuals with incomes up to 300% of SSI FBR) and who are eligible for a waiver

1915(i) State Options

Under the ACA changes to 1915(i):

- *States may offer HCBS to specific, targeted populations for a 5-year period with option to renew with CMS approval*

- *States can have more than one 1915(i) benefit in their State Plan*

** Note: States may no longer limit the number of participants who may receive the benefit and the benefit must be offered state-wide*

Other Options:

- Option to not apply income and resource rules for the medically needy

- Self-Direction of HCBS: budget and/or employer authority

State plan HCBS: Resources

- Regulation published as NPRM April 4, 2008 (comment period ended June 3, 2008).
  Complete proposed rule (CMS2249P) at

  http://www.cms.hhs.gov/MedicaidGenInfo/08_Medicaidregulations.asp

- State Medicaid Directors Letter released April 4, 2008

- State Medicaid Directors Letter released August 6, 2010 (regarding changes to 1915(i) under the Affordable Care Act)

- CMS Contacts:
  - Regional Office Representative
  - CMS Central Office:
    Kathy Poisal Kathryn.Poisal@cms.hhs.gov

Important Elements of Self-Direction

Suzanne Crisp
Former Director, Arkansas Cash & Counseling Program
Former Director of Program Integration, CMS
Director, Program Design & Implementation
National Resource Center for Participant-Directed Services

Important Elements

- Costs associated with program
- Misuse or misrepresentation of activity
- Balance of autonomy and safety

Challenges in Determining Costs

- Comparative and longitudinal analysis
- Acuity, functional and behavioral cohorts must be comparable
- Need assessments must be standardized
- Service comparison expenditures should be for like services
- Costs of supports and administration vary between models

Available Research

- Program data from Mathematica, State Medicaid Agencies, & FMS provider
- Includes Medicaid programs in AR, NJ, FL, TX, MI, LA, MA, VA, and AZ. Publically funded programs in Great Britain
- Additional research and analysis is needed

Intentional and Unintentional Program Misuse or Misrepresentation

- Intentional:
  - To state as a fact something which is false or untrue
  - Deliberate misrepresentation or omission.
- Unintentional:
  - To misunderstand, not know, become confused
  - An accident or an inadvertent action or lack of action
- Both categories require immediate corrective action
- Evaluation reveals no more likelihood that fraud and abuse exists with self direction

Common Findings – Self-Direction Rebalances Service Dollars

- Acute care and high costs services are lower for those self-directing, however, basic service costs increase
- Per capita Medicaid costs are less for self-directed participants than traditionally served participants
- Costs per hour are lower for those using self-direction than for agency services
- If the cost of counseling and FMS are considered in the design of the program, these are at least neutral

Effective Strategies to Manage

- Fully inform individual and worker of responsibilities to comply with program and state laws about fraud and abuse
- Ensure supports are there if questions or issues arise
- Increase monitoring activities if things appear funny
- Establish strong communication path between SD supports
- Create timesheet reminder on misrepresentation
- Routinely publish newsletters

Balancing Autonomy, Safety, and Acceptability

- Self-direction and autonomy go hand-in-hand
- Goal is not to eliminate but manage
- Depends on the person's state of recovery and ability
- Single most effective step – develop and apply risk assessment and mitigation policy and protocol
- Involves assessing risks, discussing consequences, identifying possible interventions, agreeing to risks, and monitoring outcomes

In Closing

- Collective experience can inform
- Strategies must be stated in a manner compatible with behavioral health community
- An exciting adventure ahead

Self-Direction in Behavioral Health

Patrick Hendry
Senior Director, Consumer Advocacy, Mental Health America
Former Program Coordinator, Florida Self-Directed Care (SDC) Program

Self-Directed Care in Mental Health

- Self-Directed Care (SDC) provides an opportunity for individuals who have been diagnosed with a severe and persistent mental illness to assess their own needs, determine how and by whom those needs should be met, and manage the funds to purchase those services.

- In Self-Directed Care, the funds follow the person.

Self-Directed Care in Mental Health

- The Florida SDC Program hinges on the belief that individuals are capable of choosing services and making purchases that will help them begin or remain on the road to recovery, and to develop or regain a life of meaningful, productive activity.

Life/Recovery Coaches

- Life Coaches orient the individual to the process involved in the program, provide referral information, advocate for the participants and promote self-advocacy, and help them to explore their personal recovery goals and to prioritize and plan for the use of their budgets.

- Life Coaches help broaden a person's world view.

Quotes from Current SDC Participants

"I can honestly say that the SDC program is the biggest incentive for me in the quest for management and attempted recovery from severe, persistent mental illness."

"SDC was a stepping stone to confidence. I now know that I can do things if I want to. I can stand alone. I don't need to surround myself with people just to survive. I am a competent person. I never believed that before. I was only able to dream of it."

"Instead of saying never, I can now say someday."

Q&A

Facilitated by:
Bevin Croft
Policy Analyst, Human Services Research Institute

Please submit your questions in the Q&A box on the bottom left of your screen. There may not be time to address all questions during the Q&A session, but a document will be sent out to all attendees with answers to all questions submitted.

After the webinar ends, you are welcome to submit questions to info@participantdirection.org.

Survey

Please click the link at the end of the meeting to access the survey:

https://www.surveymonkey.com/s/SelfDirection

Thank you!

Advancing choice and control for people living with disabilities

www.participantdirection.org