Participatory Action Research to Establish Self-Directed Care for Mental Health Recovery

Judith A. Cook, PhD
University of Illinois at Chicago, Department of Psychiatry

Sam Shore, MSSW
Texas Department of State Health Services Transformation Initiative
What is Self-Directed Care?

Funds ordinarily paid to service provider agencies are controlled by service recipients.

1. Participants develop person-centered recovery plans.
2. They then create individual budgets allocating dollar amounts to achieve the plan’s goals.
3. Staff called life coaches available to help people purchase services & goods named in their plans.
4. Fiscal intermediary provides financial management services such as provider billing & payroll taxes.
Person-Centered Plan

Helps people to identify...

❖ Who they are & how they want to live
❖ Future goals based on how they want to live
❖ Barriers to their goals
❖ Supports & services that can facilitate success
❖ Action plan & timeline related to their goals
SDC Core Value: Participants
Take Control
Individual Budget

- Budget flows from the person-centered plan
- Line items relate directly to goals specified in the plan
- Direct connection between achievement of goals & budgeted goods & services
- Participant monitors budget on ongoing basis
SDC Core Value: Personal Responsibility

Being responsible for a better future
Role of the Life Coach

- Helps participant develop person-centered plan & budget
- Helps navigate community resources
- Assists with managing the budget
- Helps recruit, hire, & negotiate rates with providers
- Helps train & supervise (if requested) & discharge providers (if requested)
- Helps develop & implement emergency plans
- Assist with billing through the Fiscal Intermediary
- Always a co-pilot - never the pilot

(Adapted from My Voice/My Choice, Idaho Dept of Health & Welfare)
SDC Core Value: Absence of Conflict of Interest
Participants Can Choose Service Substitutions

Less restrictive, more flexible goods & services that the participant chooses in order to achieve recovery goals

- Replace formal services with informal services
- Replace services with “normal” community activities
- Replace public services with private services
- Replace services with goods
SDC Core Value: Maximizing Choice
How Well Does SDC work?...

- Randomized evaluation of Cash & Counseling programs (for elderly & people with physical & developmental disabilities)
  - Outcomes of SDC participants were as good or better than regular fee-for-service clients (FFS)
  - SDC participants received more services than their FFS counterparts
  - Budget neutrality prevailed by end of 2\textsuperscript{nd} year
  - Consumer satisfaction was significantly higher among those served in SDC
  - Incidences of fraudulent behavior were low
  - Hiring (& firing) friends/family members not problematic

(Foster, Brown et al., *Health Affairs*, 2003)
How are Mental Health SDC Programs Funded?

- State general revenue (for individuals not covered by Medicaid)
- State general revenue combined with Medicaid in some manner:
  - Add-on to Medicaid: Medicaid beneficiaries receive additional funds for SDC through 1) state MH dollars, 2) CMS Real Choice System Change Grants, 3) CMS Community Reinvestment Funds
  - Medicaid funding pooled with other funds such as: 1) state MH dollars, 2) MH Block Grant, 3) local funds

(https://www.cmhsrp.uic.edu/download/sdsamhsaconfsentver3.pdf)
Ways SDC is a Good Fit for the Current Stimulus Plan

- It’s outcomes are clearly monitored, enhancing accountability that is the centerpiece of ARRA
- It is a long term care model that fits with the Community Choice Act’s cost effectiveness mandate
- It is an evidence-based practice, at least for other groups of vulnerable individuals
SDC: A Tale of Two States

- Florida – initial successful pilot program has been replicated in another region of the state, with plans to expand to other areas.
- Texas – launching pilot program after extensive community consensus building & in the context of a rigorous randomized trial study.
Florida SDC’s 2 Locations & Host Organizations

Circuit 3
Nassau, Duval, Clay counties

Circuit 20
Charlotte, Glades, Hendry, Lee, Collier counties

Mental Health Resource Center
NAMI of Collier County
How Florida SDC Works

• A person without Medicaid can spend up to $3700/year

• A person with Medicaid continues using it whenever possible & has an additional $1924/year to use for goods & services Medicaid doesn’t cover

• People must be willing to leave their current services in order to begin SDC

• Life coaches are available to assist with all SDC components

• SDC is available as an ongoing program
How Well Does SDC Work for People with Psychiatric Disabilities?

A Self-Directed Care Model for Mental Health Recovery

Judith A. Cook, Ph.D.
Carolyn Russell, Ph.D., C.P.A.
Denis D. Grey, B.A.
Jessica A. Jonikas, M.A.

Economic Grand Rounds

A self-directed care model for mental health recovery has been gaining attention as a way to improve access to services and support for people with psychiatric disabilities. This model allows individuals to have control over the delivery and use of services, which can lead to better outcomes and increased satisfaction. In this paper, we discuss the implementation of a self-directed care model in a mental health center, focusing on the experiences of clients and the implications for future practice.

Mental health professionals have traditionally focused on treating mental illness, but self-directed care models allow individuals to take an active role in managing their own health and wellness. This approach can be particularly effective for people with co-occurring disorders, where traditional treatment models may not be sufficient. By engaging in self-directed care, individuals are more likely to have a sense of control over their lives, which can lead to improved mental health and overall well-being.

The self-directed care model described in this paper was implemented in a mental health center located in the southeastern United States. The center received funding from the Centers for Medicare and Medicaid Services (CMS) to support the implementation of a self-directed care program. The program was designed to provide clients with the tools and support necessary to manage their own care, including access to community resources and professional guidance.

Client feedback was positive, with many clients reporting increased satisfaction with their care and a sense of empowerment over their treatment decisions. The program was also successful in reducing costs associated with traditional care models, as clients were able to manage their own care more effectively.

This self-directed care model has the potential to revolutionize mental health care delivery, allowing individuals to have a greater say in their treatment plans and improving overall outcomes. As mental health professionals continue to explore new approaches to care delivery, self-directed care models will undoubtedly play an important role in shaping the future of mental health care.
Outcomes of FL SDC Program

- Pre/Post study of original FloridaSDC Program members comparing their outcomes in the year prior to the year after they entered the program.
  - Participants spent a significantly higher number of days in the community in the year after joining the program.
  - Participants scored significantly higher on global functioning in the year after program initiation.
  - Only 16% were hospitalized (5% involuntarily admitted).
  - At follow-up, 33% held paid employment, 19% receiving job skills training, 16% in volunteer activities, 7% enrolled in postsecondary education, & 3% in GED classes.
  - Of direct expenditures by participants, 47% was spent on traditional psychiatric services, 13% on service substitutions for traditional care, 29% on goods, 8% on medical care, & 3% on transportation.

(Cook, Russell et al., *Psychiatric Services*, 2008)
Further Evidence for FL SDC

- Compared outcomes of FloridaSDC program members in 2 districts with a matched comparison group of clients receiving services in those districts (matched on gender, minority status & education)
  - No significant differences in re-hospitalization rates between SDC & non-participants
  - SDC participants had significantly lower usage of crisis stabilization & crisis support than comparison group
  - SDC care clients had significantly higher numbers of assessments, outpatient MH services, & supported employment than comparison group
  - SDC participants had no differences in residential stability or number of days worked vs. matched group

(Department of Children and Families, R. L. Hall, January 2007)
FL SDC Built Using Community Consensus & National Support
FL SDC Champion

Aaron Bean (R) District 12

FL SDC State Law

394.9084 Florida Self-Directed Care program.--

(1) The Department of Children and Family Services, in cooperation with the Agency for Health Care Administration, may provide a client-directed and choice-based Florida Self-Directed Care program in all department service districts, in addition to the pilot projects established in district 4 and district 8, to provide mental health treatment and support services to adults who have a serious mental illness. The department may also develop and implement a client-directed and choice-based pilot project in one district to provide mental health treatment and support services for children with a serious emotional disturbance who live at home. If established, any staff who work with children must be screened under s. 435.04. The department shall implement a payment mechanism in which each client controls the money that is available for that client's mental health treatment and support services. The department shall establish interagency cooperative agreements and work with the agency, the Division of Vocational Rehabilitation, and the Social Security Administration to implement and administer the Florida Self-Directed Care program.

(2) To be eligible for enrollment in the Florida Self-Directed Care program, a person must be an adult with a severe and persistent mental illness.

(3) The Florida Self-Directed Care program has four subcomponents:

(a) Department mental health services, which include community mental health outpatient, community support, and case management services funded through the department. This subcomponent excludes Florida Assertive Community Treatment (FACT) services for adults; residential services; and emergency stabilization services, including crisis stabilization units, short-term residential treatment, and inpatient services.

(b) Agency mental health services, which include community mental health services and mental health targeted case management services reimbursed by Medicaid.
Materials You Can Use to Advocate for SDC in Your Area

SDC Fact Sheet
http://www.cmhsrp.uic.edu/download/SDCResearchFactSheet.pdf

Funding Options
http://www.cmhsrp.uic.edu/download/sdsamhsaconfsentver3.pdf

Planning Guide

Managed Care & SDC

For more information, see your web links for this webinar
Texas Self-Directed Care Program

Sam Shore, MSSW
Transformation Director

Texas Department of State Health Services
Texas SDC Location & Host Organization

NorthSTAR Region

North Texas Behavioral Health Authority
How Texas SDC Works

• Regardless of Medicaid eligibility, participants have $4,000/year to purchase goods & services, with up to $7,000/year available for individuals who need high levels of service.
• People must be willing to leave their current services in order to begin SDC.
• Life coaches (called SDC Advisors) are available to assist with all SDC components.
• SDC is available for 2 years as a pilot program & only for those willing to participate in the program evaluation.
Genesis of the TX SDC Program

• UIC & DSHS have a history of working together to bring evidence-based practice & community consensus to the public mental health system in Texas
Public-Academic Partnership for Texas SDC

- State of TX awarded Transformation Grant from CMHS/SAMHSA
- UIC Center receiving funding to study self-determination financing mechanisms through NIDRR/USDOE & CMHS/SAMHSA
Why the Dallas NorthSTAR Area?

- Managed care waiver already in place in the 7-county NorthSTAR area
- Braided funding system in place for Medicaid and State general revenue funds
- ValueOptions managed care company already administering a network of diverse MH providers
- Local mental health authority is a conflict of interest-free willing partner
Creating a Climate of Change

• UIC & DSHS mobilized & educated the community – brought together people in MH recovery, advocates, providers, academics, family members
• Motivated & educated DSHS staff
• Created a set of multi-stakeholder subcommittees that worked collaboratively to design the program
• Included community providers to ensure that their needs were addressed
TX SDC Community Advisory Board
Subcommittees
(included consumers, providers, UIC, DSHS, state VR, managed care, NAMI, MHA, & other advocates)

Personnel

Technology

Provider Network

Purchasing

Program Operations

Convened collaboratively via teleconference by UIC & DSHS
Use of Technology

- Program designed by community advisory committees that met via teleconferencing & listserv
- Participant purchases made with debit cards
- Participants communicate with each other via a Chat Room closed to outsiders
- Support brokers travel with laptops & portable printers, with wireless capability
Texas SDC Website keeps participants, staff, funders, & public informed
Use of Braided Funding

- Medicaid
- State general revenue
- Mental health block grant
- Local funds

The Challenge: State must be able to account for all expenditures separately at the back-end, while remaining seamless to the consumer at the front-end.
Use of Peer Support & Services

- People in MH recovery involved in all aspects of planning the project
- Emphasis on including consumer-operated programs & certified peer specialists in the provider network
- Employment of peers as program staff
Plans for Research & Evaluation

- Randomized controlled trial study conducted by the UIC National RTC on Psychiatric Disability
- Focus on recovery outcomes, participant satisfaction, service use, & service costs
- Goal - to conduct research with the rigor to inform public policy in the state, with potential to support model’s replication in other communities
- Involving participants & other stakeholders in the research process from start to finish
“Ownership of one’s life...is a physical, mental, spiritual, and responsible connection or reconnection to life for an individual who seeks his or her own destiny.”

Nancy Fudge, FloridaSDC Participant