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

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Transformation Initiative

What is Self-Directed Care?

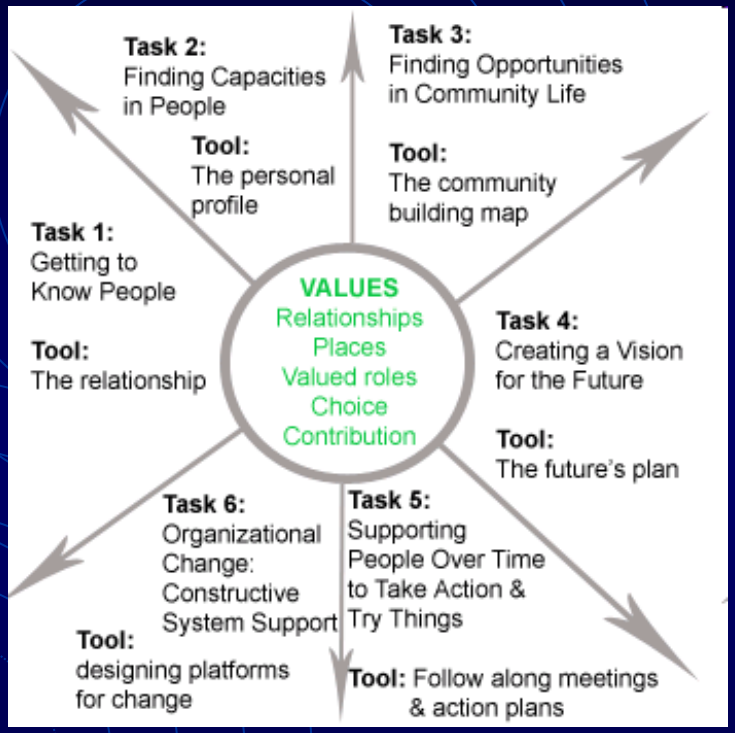
Funds ordinarily paid to service provider agencies are controlled by service recipients

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

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)

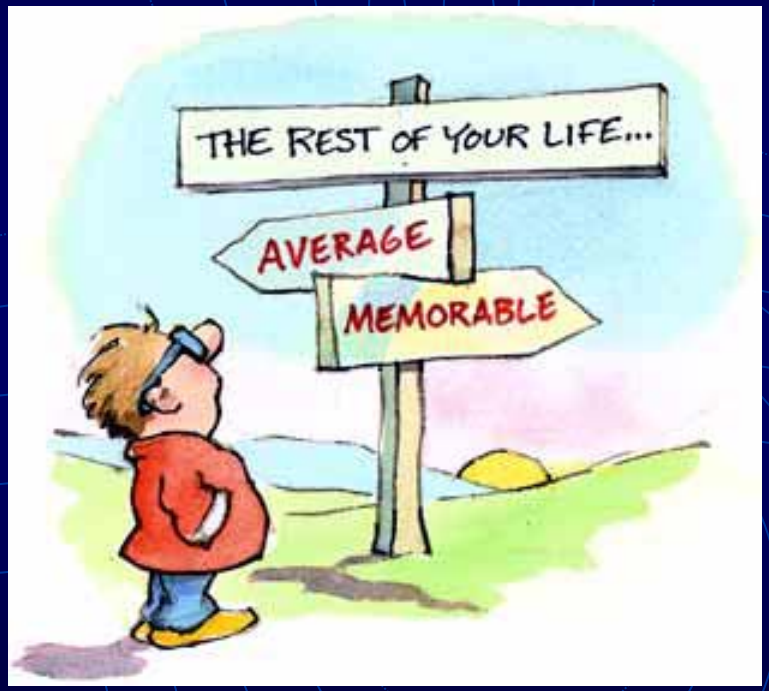
SDC Core Value: Absence of Conflict of Interest

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 2nd 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

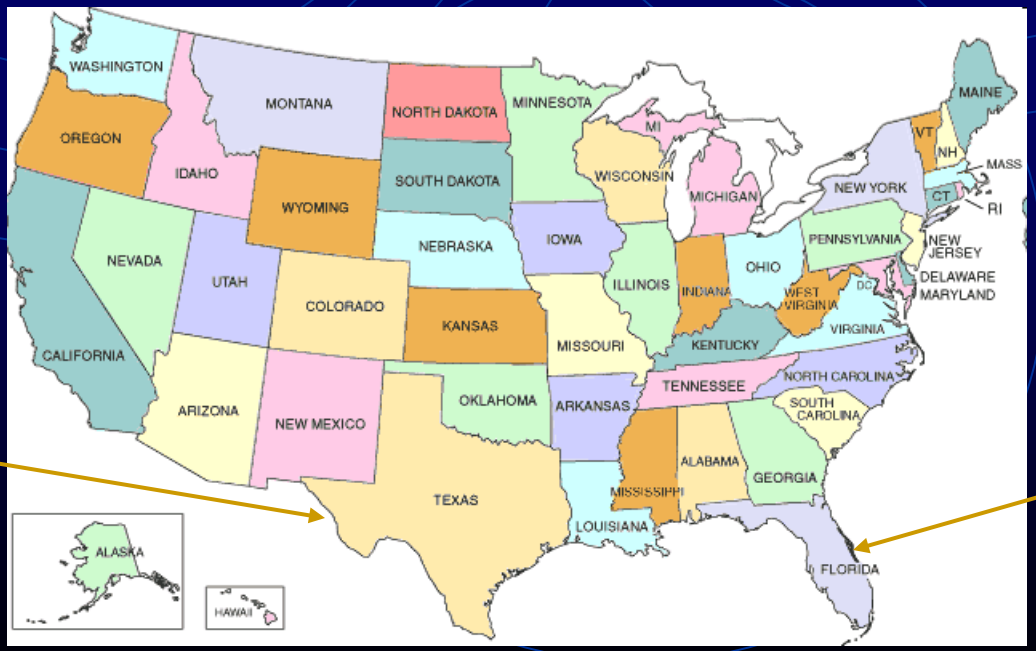
(http://www.cmhsrp.uic.edu/download/sdsamhsaconfsentver3.pdf)

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



Texas

Florida

FloridaSDC's 2 Locations & Host Organizations

Circuit 3

Nassau, Duval, Clay counties

Mental Health Resource Center

Circuit 20

Charlotte, Glades, Hendry, Lee, Collier counties

NAMI of Collier County

How FloridaSDC 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 good & 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.
Dennis D. Grey, B.A.
Jessica A. Jonikas, M.A.

This column describes a mental health program in which participants were given control over public funds to purchase services and supports for their own recovery. Data were examined for 106 individuals and showed that compared with the year before enrollment, in the year after enrollment, participants spent significantly less time in psychiatric inpatient and criminal justice settings and showed significantly better functioning. Of approximately $858,000 in direct expenditures by participants over 19 months of operation, 47% was spent on traditional psychiatric services, 13% on service substitutions for traditional care, 29% on tangible goods, 8% on uncovered medical care, and 3% on transportation. Early positive results of this pilot program support replication and evaluation elsewhere. (*Psychiatric Services* 59: XXXXXXXX, 2008)

Models of self-determination in which the "money follows the person" are the focus of increasing attention in health and behavioral health care financing (1). One approach, called self-directed or consumer-directed care, gives individuals with disabilities direct control over their service delivery dollars and was used by the Centers for Medicare and Medicaid Services (CMS) in its Cash and Counseling demonstration program (2). Use of this model for people with serious mental illnesses is rare. This analysis describes one such program in Northeast Florida, called Florida Self-Directed Care (FloridaSDC), presenting its structure, operation, and initial evaluation results.

In 1997 CMS's Cash and Counseling programs made cash allowances directly available to individuals with disabilities, the elderly, and children with special needs to hire caregivers for personal assistance and other household services, purchase household appliances, modify homes or cars, and cover incidental expenses (3). A randomized evaluation of the cash and counseling programs in Arkansas, New Jersey, and Florida found that, compared with participants in traditional agency-based services, nine months after program entry, those in the cash and counseling program were more satisfied with their care, had fewer unmet needs, and experienced equal or better health outcomes (4). These results confirmed those of prior research showing that consumer-directed care enhances life satisfaction, reduces unaddressed problems, and enhances technical quality of care (5–7).

More recently, in response to the Supreme Court's *Olmstead* decision affirming the right of individuals to live in integrated environments rather than institutions, CMS established the Independence Plus Initiative (8). This 1115 waiver program provides a cash allowance to elders and people with disabilities who are vulnerable to institutionalization to purchase services enabling them to remain in the community. *Olmstead's* affirmation of the state's responsibility for ensuring its citizens' right to reside in the community has implications for the 2.1 million individuals with severe and persistent mental illness who are at risk of institutionalization (9). The *Olmstead* ruling and Independence Plus Initiative have created an impetus to apply the CMS 1115 waiver program to people with psychiatric disabilities. Moreover, policy recommendations in the President's New Freedom Commission report specifically call for "self-directed services and supports for people with mental illnesses" (10).

Program genesis and financing

In January 2000 a Self-Directed Care Bill created through consumer and family advocacy established the FloridaSDC Program under Chapter 2001-152, Laws of Florida. Annual funding of $170,000 for program administration was allocated from the Alcohol, Drug Abuse and Mental Health (ADM) Trust Fund in the Department of Children and Families. Funding for the purchase of services came from the local District 4 ADM office's budget for community mental health services. A purchasing arrangement was established with the Florida State University as fiscal intermediary and administrative service organization.

Program structure and fiscal management

Eligibility criteria included an axis I or II diagnosis of mental disorder, age 18 years or older, legal competence, current or former disability income beneficiary status, and permanent

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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 CommunityConsensus & 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

http://www.bazelon.org/issues/mentalhealth/publications/DriversSeat.pdf

Managed Care & SDC

http://www.magellanprovider.com/MHS/MGL/about/whats_new/providerfocus/new/archives/fall06/clinical/article1.asp

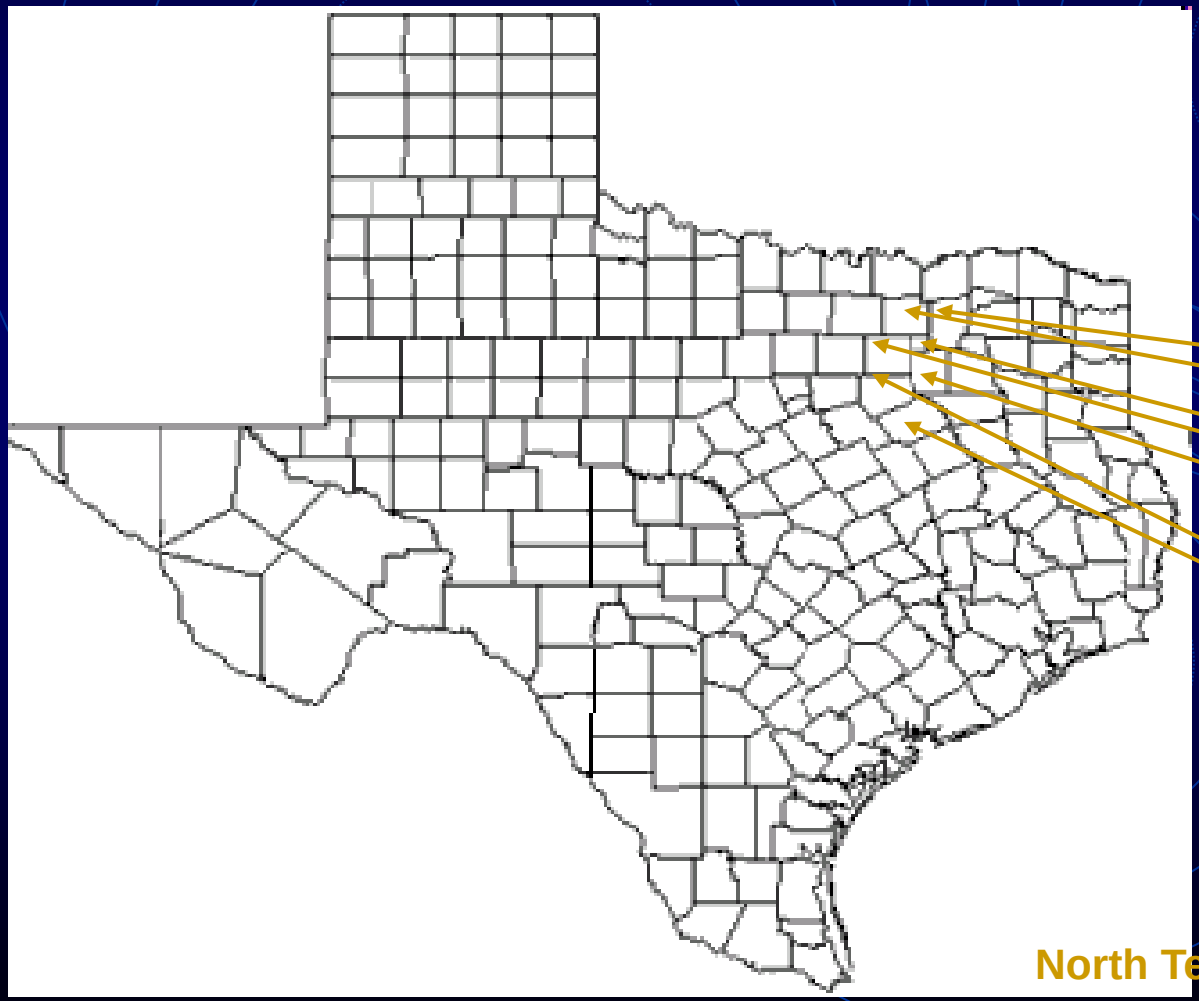
For more information, see your web links for this webinar

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

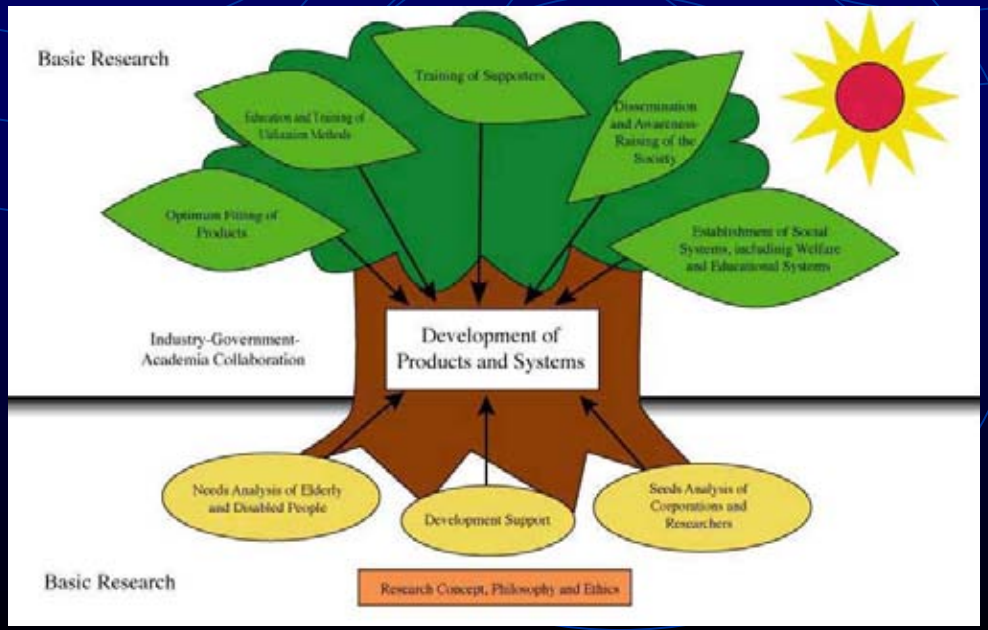
- Regardless of Medicaid eligibility, participants have $4,000/year to purchase goods & services, with up to $7,000/year available for individuals who need high levels of service
- People must be willing to leave their current services in order to begin SDC
- Life coaches (called SDC Advisors) are available 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?

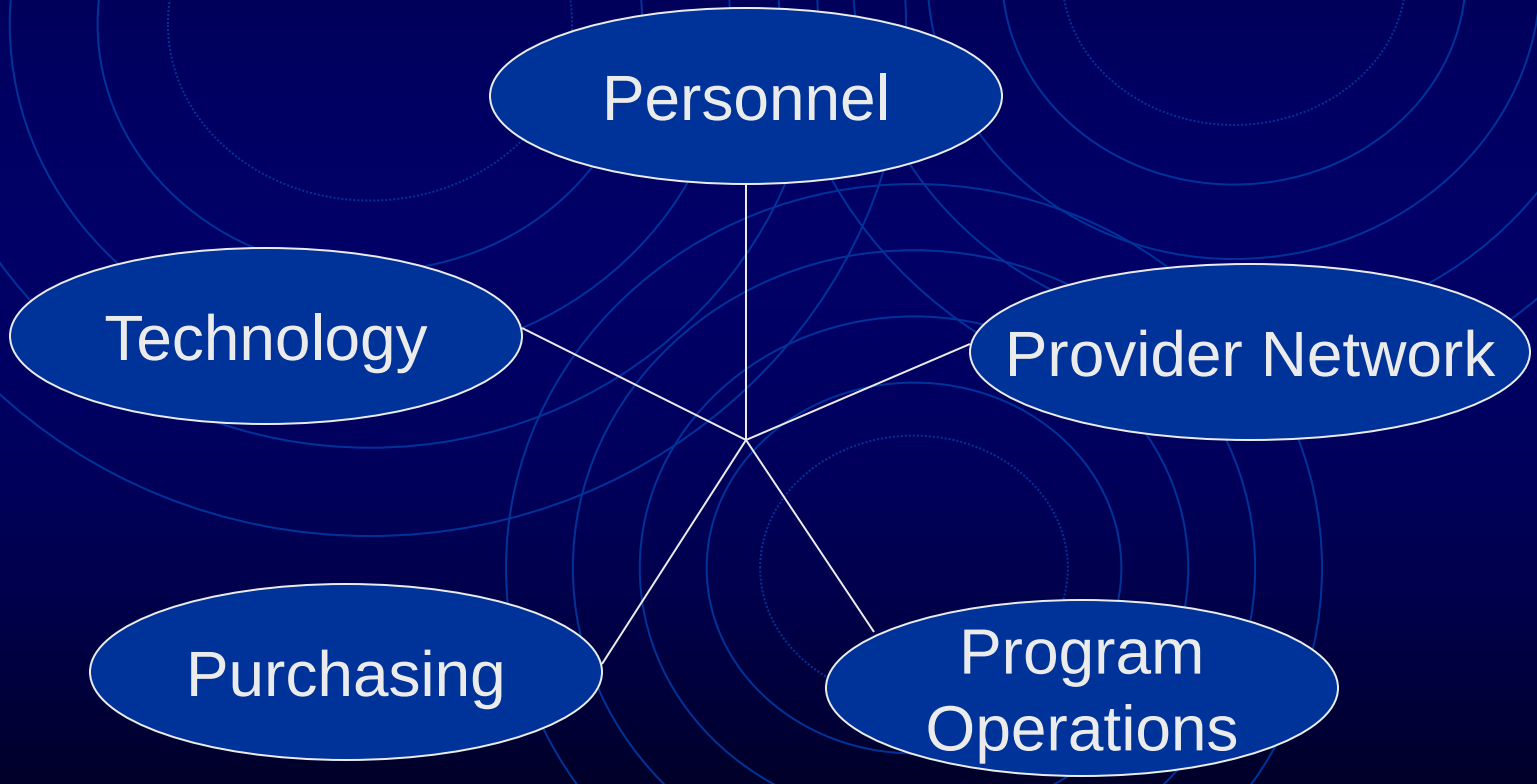
- Managed care waiver already in place in the 7-county NorthSTAR area
- Braided funding system in place for Medicaid and State general revenue funds
- ValueOptions managed care company already administering a network of diverse MH providers
- Local mental health authority is a conflict of interest-free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



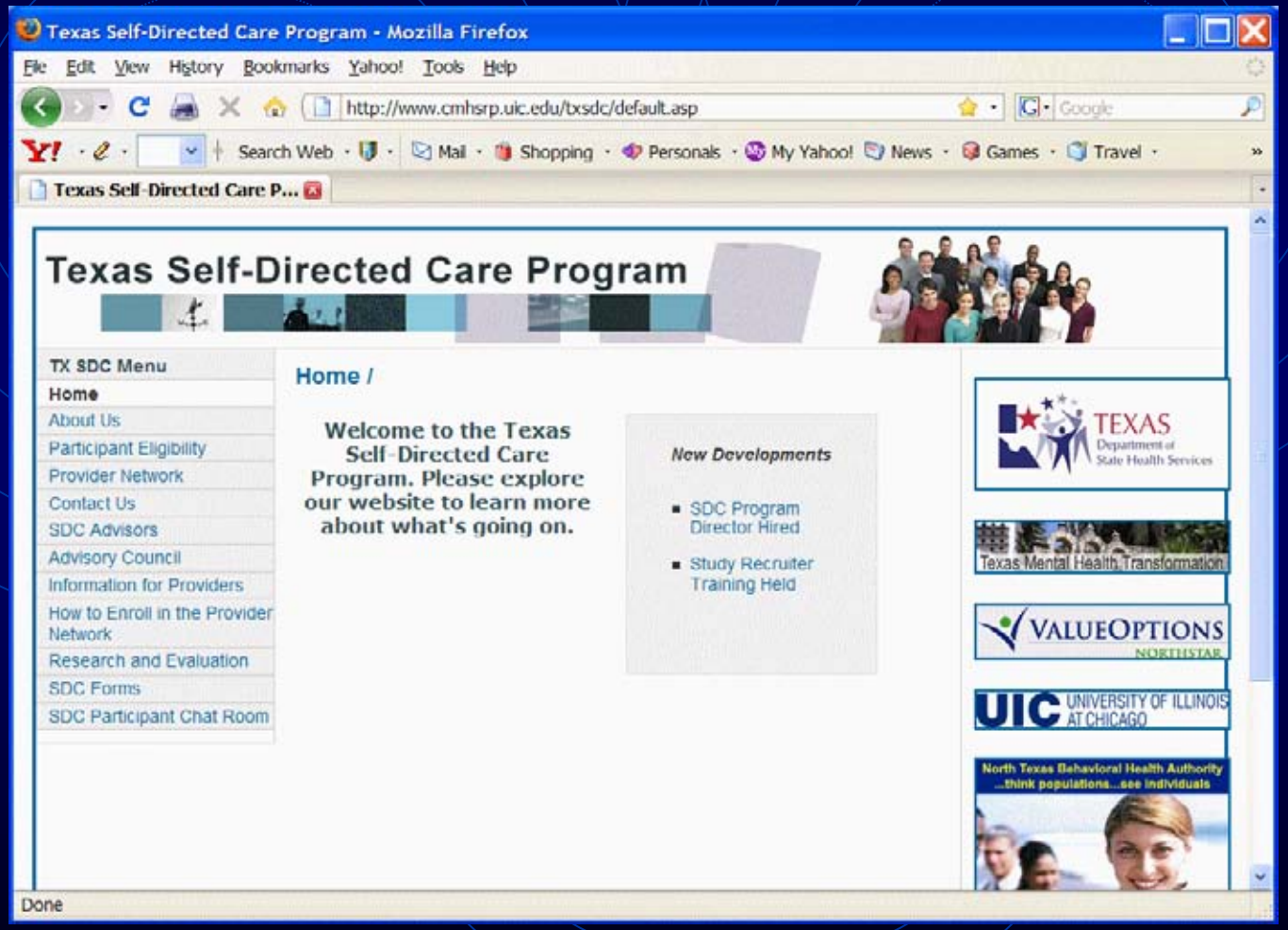
Convened collaboratively via teleconference by UIC & DSHS

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