

## SPECIAL SECTION

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



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*Objective:* This article describes a public-academic collaboration between a university research center and the Texas state mental health authority to design and evaluate a unique “money follows the person” model called self-directed care (SDC). SDC programs give participants control over public funds to purchase services and supports for their own recovery. *Methods:* Through a participatory action research process, the project combined use of evidence-based practice and community consensus as a tool for system change. *Results:* The story of this effort and the program that resulted are described, along with quantitative and qualitative data from the project’s start-up phase. *Conclusions:* Lessons learned about the importance of community collaboration are discussed in light of the current emphasis on public mental health system transformation through alternative financing mechanisms.

**Keywords:** recovery, system transformation, change process, community mental health

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### Introduction

This article describes how the Texas Self-Directed Care (SDC) program was created by a public-academic partnership between a university research center and a state mental health authority, in collaboration with community stakeholders in the north central region of Texas. After presenting the fundamentals of the SDC model and how it operates, participatory action research activities involved in designing and implementing the program will be discussed, followed by a look at the characteristics of initial program participants and their expenditures. Finally, lessons learned thus far will be de-

scribed, along with next steps in the process of program development.

#### Review of the Literature

##### *Fundamentals of Self-Directed Care.*

The SDC model has four core values: 1) participant control; 2) participant responsibility; 3) participant choice; and 4) avoidance of conflict of interest. In an SDC model, service recipients directly control monies that would ordinarily be paid to service provider agencies. This occurs through the basic features of the SDC model (Cook, Russell et al., 2008). First, participants develop a person-centered recovery plan. This plan lays out future goals based on how the individual wants to live along with supports and services

that can facilitate success. Also specified are an action plan and timeline related to the person's goals. The recovery plan epitomizes the first SDC core value — the idea that participants can take control of their own lives and recovery.

Next, participants create individual budgets allocating dollar amounts to achieve the recovery plan's goals. The amount of money they have to spend is arrived at through various formulas that are based on the average yearly cost of providing outpatient services per client which, in mental health, typically ranges from \$3,000-\$4,000 per year (Cook, Russell et al., 2008). Participants' budgets correspond directly with their person-centered plans, with line items that relate specifically to goals specified in their plans. Thus, there is a direct connection between achievement of recovery goals and budgeted goods and services. Participants make purchases and monitor budgets on an ongoing basis, thus realizing the second core value of the SDC model — taking personal responsibility for one's actions.

SDC program staff called "support brokers" are available to help participants purchase services and supports as well as material goods specified in their line item budgets. Support brokers may help participants develop their person-centered plans and budgets, and then advise participants as they explore available community resources and make purchases. Brokers may help recruit, hire, and negotiate rates with providers, and assist participants in developing crisis plans. Brokers may also assist with billing through the program's fiscal intermediary, a component of the SDC model that is described below (Idaho Dept. of Health and Welfare, 2003). Whatever services they provide, brokers always act at the behest of the participant; in other

words, they are always a co-pilot and never the pilot. Thus they help participants realize the third core value of SDC — maximization of participant choice.

An organization called a fiscal intermediary provides financial management services such as provider billing and withholding of money for payroll taxes. It is important that this organization not be a provider of services, so that program participants feel free to choose services from wherever they wish without undue influence. In a federally-funded SDC demonstration called Cash and Counseling, two of the three pilot programs used fiscal agents that were separate entities from the program host (Phillips & Schneider, 2007). This organization may be a college or university, a not-for-profit agency, a managed care organization, an insurance group, or a disability co-operative. Intermediaries act as independent, third party administrators by paying provider claims and processing vouchers for goods and services. The "firewall" between the fiscal intermediary and service providers illustrates the fourth core value of SDC — avoidance of conflict of interest between all parties collaborating to operate the program.

Another unique feature of the SDC model is that participants can choose "service substitutions" in order to pursue their recovery goals. One example is when participants choose to replace a clinical service such as case management with a non-clinical service such as working with a certified peer specialist. Another type of service substitution involves replacing a formal service such as participating in a weight loss skills training group at their mental health center with "normal" community activities such as a health club membership and work with a personal fitness trainer. Yet another

example involves replacing public services with private services, as when a participant chooses to hire a psychiatrist from the private sector in order to receive a type of therapy that is not readily available from public sector clinicians. Finally, service substitution can involve replacing services with goods, as when an individual purchases a cell phone and calling plan rather than using the pay phone at a mental health center. In this way, the SDC model helps maximize choice in people's recovery journey.

#### *Research on SDC Effectiveness.*

Although SDC is infrequently available to people with psychiatric disabilities, the model has been more widely used by elderly individuals and people with physical and developmental disabilities in programs funded by the Centers for Medicare and Medicaid Services (CMS) (Benjamin & Fennell, 2007). In 1997, CMS's Cash and Counseling demonstration funded SDC programs in 3 states that made cash benefits available to individuals with disabilities, the elderly, and children with special needs. Participants could use their funds to hire providers of personal assistance and other household services, buy household appliances, modify homes or cars, and pay for incidental expenses. These demonstrations were the first time that the Medicaid program authorized cash allowances directly to beneficiaries rather than providers. The program has now been expanded to an additional 12 states.

In a randomized evaluation of the Arkansas Cash and Counseling program which focused on people with disabilities and elders, the health and well-being outcomes of SDC participants were found to be as good or better than regular fee-for-service (FFS) clients (Foster, Brown et al., 2003). Moreover, SDC participants received more services than their FFS counter-

parts, and budget neutrality prevailed by end of the program's second year of operation, meaning that SDC was not more expensive than FFS. Consumer satisfaction was significantly higher among those served in SDC than in FFS, and incidents of fraudulent behavior were low. These results were echoed in randomized evaluations of Cash and Counseling programs in New Jersey and Florida serving elders and adults with disabilities (children with development disabilities were also served in Florida), which found that compared with participants in traditional agency-based services, those in the SDC programs were more satisfied with their care, had fewer unmet needs, and experienced equal or better health outcomes (Carlson et al., 2007). Other studies have also shown that consumer-directed care enhances life satisfaction, reduces unaddressed problems, and enhances technical quality of care (Benjamin, Mathias & Franke, 2000). Thus, SDC has been established as an evidence-based practice (EBP) given demonstration of its efficacy in multiple RCT studies (Drake et al., 2001).

There is also evidence to suggest that the SDC model produces positive results for people with psychiatric disabilities. One evaluation examined the outcomes of 106 participants with a mental illness in an SDC program in Northeast Florida, called Florida Self-Directed Care (Cook, Russell, Grey et al., 2008). Compared with the year before entering the program, in the year after enrollment, participants spent significantly less time in psychiatric inpatient and criminal justice settings, and showed significantly higher levels of functioning in social, work, and family roles. Of approximately \$58,000 in direct expenditures by participants over 19 months of operation, 47% was spent on traditional psychiatric services, 13% on service substitutions for tra-

ditional care, 29% on tangible goods, 8% on uncovered medical care, and 3% on transportation. Participant satisfaction with the program was also uniformly high.

Given these promising results, the question arises of whether this model might be introduced for use by people with psychiatric disabilities in other areas of the country using participatory action research (PAR) (Whyte, 1989). In this project, PAR was conceptualized as a type of action research involving academic researchers as full collaborators with members of organizations and their surrounding communities to study and transform systems (Greenwood et al., 1993). It was conceived of as an ongoing organizational learning and transformation process, as well as a research approach emphasizing co-learning and participation, with an aim of improving the mental health system by changing it (McIntyre, 2008).

#### **Genesis of the Texas SDC Program**

*Collaborating Partners.* Staff at the University of Illinois at Chicago (UIC) and the Texas Department of State Health Services (DSHS) have a history of working together to bring recovery-oriented, evidence-based practice via community consensus to the public mental health system in Texas (Cook, Toprac & Shore, 2004; Cook, Ruggiero, Shore, Daggett & Butler, 2007). This public-academic partnership was re-activated as the foundation of PAR in the Texas SDC project. In 2005, the state of Texas was awarded a Substance Abuse and Mental Health Services Administration Mental Health Transformation State Incentive Grant (Center for Mental Health Services, 2005). Also in 2005, the UIC Center received funding to study self-determination financing mechanisms through the National Institute on Disability and Rehabilitation Research of the U.S.

Department of Education and CMHS/SAMHSA. In both instances, the focus on SDC arose from calls for enhanced system accountability and consumer self-determination articulated by Texas mental health advocates, service recipients, providers, and system administrators.

*Program Location.* One of the first decisions was where to locate the PAR project, given that it needed to be a community in which the SDC model would be an option. One attractive region of the state was the seven-county area surrounding Dallas/Ft. Worth in which a program called NorthSTAR was operating. Launched in 1999, NorthSTAR is the first program in Texas to combine service programs and financial assets into an integrated single system of care overseen by the managed care company Value Options. It serves the medically indigent and most Medicaid recipients who reside in Dallas, Collin, Ellis, Hunt, Kaufman, Navarro, and Rockwall counties. This area was chosen for a number of reasons. First, the existence of a managed care waiver meant that the SDC program could be offered to service recipients selectively as a pilot program. Second, the waiver allowed for use of a braided funding system that was already in place for Medicaid, Community Mental Health Block Grant, and state general revenue funds. Third, Value Options was already administering a network of diverse mental health service providers in the NorthSTAR area and was thus a good choice for the role of fiscal intermediary. Finally, the local mental health authority for this area, called the North Texas Behavioral Health Authority (NTBHA), was a willing host for the program. Since NTBHA was not a service provider, it could host the program without presenting a conflict of interest.

*Creating a Climate of Change Through PAR.* Staff from UIC and DSHS began by convening a series of public community meetings that brought together people in mental health recovery, advocates, providers, academics, family members, and policy makers. At these meetings, participants discussed problems with the current system including lack of access to certain resources, the need for greater choice in services and providers, and fiscal constraints due to organizational structure and financing. At the same time, meeting participants learned about the SDC model, its application to different populations, and the research evidence for its effectiveness, as well as knowledge gaps that would require bridging through consensus-building. Discussions ensued about the model's advantages and disadvantages for different stakeholders, and ways in which an SDC program could potentially be organized in the NorthSTAR area. This involved examining data from the state's Management Information System (MIS) Data Warehouse (Cook et al., 2007) to estimate the number of eligible participants, average per capita outpatient service costs, and utilization rates for different services. At the same time, a series of in-person meetings and teleconferences was held to educate DSHS staff about the model and its potential role in service system transformation.

As a result of these information-gathering and consensus-building activities, the decision was made to create an SDC pilot program, and to evaluate the program rigorously to determine whether it should be replicated elsewhere in the state. To ensure the program's responsiveness to the needs of the local community, multi-stakeholder subcommittees were formed, made up of consumers, providers, researchers, DSHS staff, family members and other mental health advocates, to work collaboratively in using EBP and consen-

sus to design the program. These committees addressed the following SDC program areas: 1) personnel; 2) program operations; 3) provider network; 4) purchasing; and 5) information technology (IT). In addition to including service users, the subcommittees included providers to address their concerns and enhance their buy-in for the program, given evidence of provider resistance to SDC in prior studies (Cook et al., 2008; Velgouse & Dize, 2000).

Subcommittees met weekly via teleconference and in-person over a 3-month period to hammer out the program's policies and procedures, determine staffing and organization, create a purchasing policy, design the provider network, and discuss use of IT to enhance program operation. Deliberations were informed by EBP as well as knowledge provided by project consultants who included participants and state administrators from the SDC programs in Florida and Oregon. For example, in designing the purchasing policy, committee members reviewed evidence from the Cash and Counseling demonstration supporting the need for wide leeway in what goods could be purchased and in who could be hired to provide services (Schore, Foster & Phillips, 2007; Simon-Rusinowitz, Mahoney, Loughlin & Sadler, 2005). Similarly, the program operations committee used research evidence regarding the relative effectiveness of different recruitment strategies in designing the program's recruitment procedures to include current providers, family members, and a special website (Mahoney, Fishman, Doty & Squillace, 2005). Where no evidence was available or was inconclusive, the committee used consultant input, discussion, and consensus-building to arrive at decisions.

#### **How Texas SDC Operates**

Participants in Texas SDC have \$4,000 per year to purchase services, supports

and material goods to achieve recovery goals, with up to \$7,000 per year available for individuals who need high levels of service. This latter group includes individuals whose outpatient service expenditures in the year prior to program entry exceeded the average of \$4,000 due to mental health or related life crises. Participants must be willing to leave their current services in order to begin SDC, but can choose to "re-hire" these providers as long as the latter are willing to enroll in the SDC provider network. Participants must purchase services from those enrolled in the SDC provider network; however, any provider can enroll as long as he or she agrees to abide by its philosophy and policies. Support brokers are called SDC Advisors and are available to assist participants with all components of the SDC program, from initial orientation through creation and management of plans and budgets. The SDC program is available to participants for two years as a pilot program, provided they also agree to enroll in the program evaluation.

*How Texas SDC is Funded.* The SDC program uses a "braided" funding approach in which a number of different funding streams are combined in order to adhere to the administrative requirements of each source of payment. The notion of "braiding" refers to combining funds in a manner that appears seamless to the program participant but in which amounts from different funding sources can be separated out at the program's "back-end" for monitoring and reporting purposes. The sources that are combined include Medicaid dollars, state general revenue, federal mental health block grant dollars, and local funds.

*Involvement of Peers and Peer Support Services.* People in mental health recovery were involved in all aspects of planning the project, recruiting and hir-

ing the program's director and SDC advisors, serving on the community advisory board, and working in the research. From its inception, there has been an emphasis on including consumer-operated programs and certified peer specialists in the provider network, and employment of peers as SDC program staff. Currently, 50% of the SDC Advisors are people in recovery from mental health difficulties.

#### *Use of Information Technology.*

Throughout the planning, design, and implementation phases, the SDC program has made frequent use of IT. The community advisory subcommittees met via teleconferencing and communicated through an Internet listserv created for the project by UIC staff. Purchases are made with pre-paid debit cards (The Allow Card of America™ Prepaid MasterCard) that enable participants to spend funds without the stigma of using vouchers or pre-assigned checks that might identify them as receiving services and therefore "different" from other customers. SDC Advisors travel in the community to provide brokerage services with laptops and portable printers, using wireless technology to help participants create recovery plans and budgets. Early on, the decision was made to create an SDC program website (<http://www.texasddc.org/>) that would be the "public face" of the program, and also serve as a communication "hub" around which program activities would flow. Participants also communicate with each other via a chat room that is closed to outsiders, which they access through a secure link from the website.

#### **Program Evaluation**

The use of EBP in the design and implementation of SDC informed the stakeholders' desire to conduct a rigorous evaluation of the pilot program. The fact that a randomized controlled trial

(RCT) design was used in the Cash and Counseling demonstration, and the tremendous impact the findings of that study have had on national public policy have not gone unnoticed by those wishing to replicate the model elsewhere in the state. Thus an RCT study is underway, in which consenting adults in the NorthSTAR public mental health system are randomly assigned to enter the SDC program or to continue receiving "services as usual." One focus of this research is on outcomes that were also studied in the Cash and Counseling and Florida Self-Directed Care evaluations, including changes in both health (e.g., symptoms) and well-being (e.g., quality of life) (Foster et al., 2003). But another important focus is on outcomes that matter to the various stakeholders involved, such as hopefulness and empowerment, participant satisfaction, service use, service costs, and individual economic indicators. Use of PAR has involved stakeholders in the research process from start to finish, including formulation of research questions, design of recruitment and interview protocols, hiring people in mental health recovery as part of the research staff, and ongoing examination and interpretation of program data.

*Preliminary Results.* Preliminary data are available on the first 75 individuals enrolled in the SDC research study. As shown in Table 1, the majority of SDC participants are female, and the predominant racial/ethnic representation is Caucasian and African American. On average, participants are 40 years of age, just under half live in their own home or apartment, and their average household size is 3 co-residents, including participants themselves. Most have a high school education or General Equivalency Diploma, are currently unmarried, and also have children. Many are poor, with a sizeable proportion having household incomes

below \$10,000 per year. When asked to name their primary mental health diagnosis, the large majority report having a bipolar disorder. Almost two-thirds report having been hospitalized for psychiatric reasons, just over half have been treated for substance use disorders, and close to half report a physical condition or impairment such as diabetes or heart disease. The large majority are not employed but around a third report currently seeking employment, and almost two-thirds see themselves as holding a paid job in the next year. There were no significant differences on these and other characteristics between study participants assigned to the SDC program versus services as usual.

At this point in the project a total of 54 participants are enrolled in the SDC program. Of those, 52 have had their first in-person meeting with an SDC Advisor, 27 have completed their recovery plans and had their individual budgets approved by the Program Director and 18 have begun making purchases. Five participants have also completed their first quarterly review.

Data are available on the purchases made by the first 20 SDC participants, which total \$17,187. Of these purchases, 31% has been spent on non-traditional goods and services and 69% has been spent on traditional mental health services. Table 2 presents the purchases made by one individual over four months of program participation totaling \$2,425. Her recovery goals included finding a prescribing psychiatrist within the SDC Provider Network with whom she felt comfortable, participating in supportive psychotherapy to enhance her coping ability, improving her physical fitness and managing her depression through exercise, lowering her stress level through massage therapy, and preparing herself for a job via further schooling. The total amount

**TABLE 1—CHARACTERISTICS OF TEXAS SELF-DIRECTED CARE STUDY PARTICIPANTS BY STUDY CONDITION<sup>a</sup>**

	<b>SDC Program 59% (n=44)</b>	<b>Control 41% (n=31)</b>	<b>Total 100% (N=75)</b>
<b>Demographic Characteristics</b>	Mean (s.d.)	Mean (s.d.)	Mean (s.d.)
Age, in years	40 (10.0)	39 (9.6)	40 (9.8)
Average household size (including self)	3 (2)	3 (2)	3 (2)
	% (n)	% (n)	% (n)
Female	70 (31)	64 (20)	68 (51)
Hispanic/Latino	9 (4)	10 (3)	9 (7)
African American	29 (13)	19 (6)	25 (19)
Caucasian	57 (25)	61 (19)	59 (44)
High school graduate/GED	68 (30)	64 (20)	67 (50)
Married or living as married	20 (9)	6 (2)	15 (11)
One or more children	68 (30)	68 (21)	68 (51)
Live in own house/apartment	46 (20)	55 (17)	49 (37)
Household income <\$10k/year <sup>1</sup>	40 (17)	50 (13)	44 (30)
<b>Clinical Characteristics</b>			
Prior inpatient psychiatric treatment <sup>1</sup>	57 (25)	67 (20)	61 (45)
Substance abuse treatment	48 (21)	58 (18)	52 (39)
Any physical impairment	50 (22)	45 (14)	48 (36)
Schizophrenia spectrum diagnosis	7 (3)	16 (5)	11 (8)
Bipolar diagnosis	71 (31)	68 (21)	69 (52)
Depression diagnosis	9 (4)	10 (3)	9 (7)
<b>Vocational Characteristics</b>			
Currently working for pay	9 (4)	23 (7)	15 (11)
Ever held a paying job <sup>1</sup>	97 (37)	92 (22)	95 (59)
Looked for work past 4 weeks	36 (16)	42 (13)	39 (29)
Foresee paid job in next year <sup>1</sup>	61 (27)	57 (17)	60 (44)

<sup>1</sup>Some responses missing; percent is of total valid responses.  
<sup>a</sup>No statistically significant ( $p < .05$ ) differences between conditions.

spent on traditional services was \$1,332, and this included purchasing medication management services from a psychiatrist, individual therapy from a clinical psychologist, and obtaining a clinical assessment. The total amount spent on non-traditional goods and

services was \$1,093, and this included debit card service charges and fees, school tuition and books, massage therapy, and fitness-related expenses. This participant spent 55% of her total purchases on traditional services, and 45% on non-traditional goods and

services during the 4-month time period. At her quarterly review, she reported that she was pleased with her progress since joining the program, and was looking forward to applying what she was learning in her therapy sessions as well as in the classes she was taking.

### Summary and Conclusion

The hallmark of PAR is its cyclical nature, in which researchers and community members begin by identifying major problems and concerns, initiate research simultaneously with action, learn about this action, and move on to a new research and action cycle in a process that is continuous (Kindon, Pain & Kesby, 2007). This process is evident in the accomplishments of the SDC project thus far, along with the many lessons learned. The project’s most notable action has been implementing a fully functional SDC program in less than 12 months, using a PAR process that involved researchers and community stakeholders in applying EBP through consensus. Another accomplishment has been the recruitment, hiring, and training of a competent and caring SDC program staff that is culturally diverse and highly inclusive of the community of individuals in mental health recovery. A third accomplishment is the development of the project’s website, with its SDC Advisor profiles, provider network listing services and costs, and its chat room for participants to share ideas and provide each other with virtual support. Finally, the research recruitment process has screened over 300 individuals, qualified over 180 potential participants for research enrollment, and interviewed and randomly assigned 122 individuals, with the intention of assigning another 178 to reach the desired sample size of 300.

**TABLE 2—PURCHASES MADE BY ONE TEXAS SDC PROGRAM PARTICIPANT**

Service or Good Purchased	Traditional or Non-Traditional	Duration of Expense	Cost per Unit	Total # of Units	Total Cost of Purchase
Individual Therapy	T	7/15/09 - 10/15/09	\$70.00	3	\$210.00
Psychiatrist	T	7/15/09 - 10/15/09	\$47.50	4	\$190.00
Psychiatrist	T	10/16/09-1/15/09	\$47.50	3	\$142.50
Individual Therapy	T	10/15/09 - 1/14/09	\$70.00	10	\$700.00
Initial Assessment	T	10/15/2009	\$90.00	1	\$90.00
Fitness Expenses	NT	8/09 - 9/09	\$68.34	4	\$273.36
Massage Therapy	NT	8/09 - 2/09	\$50.00	6	\$300.00
Tuition (12 hours)	NT	8/09 - one time	\$250.00	1	\$250.00
Books for School	NT	8/25 - 8/27/09	\$250.38	1	\$250.38
Debit Card Fees	NT	09/09 - one time	\$18.95	1	\$18.95
Total Non-Traditional Goods & Services		\$1,092.69	45.0%		
Total Traditional Services		\$1,332.50	55.0%		
Grand Total Purchases		\$2,425.17	100.0%		

Perhaps the most important lesson learned thus far involves the value of PAR processes in fully involving the local community in decision-making about whether to start an SDC program, how to design it, and how to operate it. Another important lesson is that programs such as this one can encourage the growth of provider networks beyond those that make up the current public system. A number of private clinicians have been willing to become SDC providers due, in part, to the streamlined payment mechanism as well as the high motivation of program clients who have “chosen” to work with the providers they hire. Yet another lesson is that participants’ purchases show a balance between their choices of traditional and non-traditional services, with no one completely eschewing the more standard services such as psychiatric or other clinical mental health services. Instead, participants have used the opportunities presented by expanded choices to purchase goods and services that move them closer to their recovery goals, such as a forklift operator certificate for one indi-

vidual’s job, tuition and books for another person’s schooling, and a medication co-pay for a third participant who prefers an alternative prescription that is not in the state’s formulary.

Future goals for the SDC program include completing research study enrollment, involving more program participants on the Texas SDC Community Advisory Board, monitoring program fidelity, and beginning the initial one-year follow-up interviews. The program has begun bringing its members together in “learning community” sessions for peer support and socialization, orientation of new members, and opportunities to acquire new skills and information on topics of interest to the membership. These voluntary gatherings enable participants to share with each other their progress toward recovery goals, and plans are to continue these sessions throughout the program’s second year. Another goal is to help participants acquire a free personal computer and Internet access so that they can more easily use the SDC website and other resources available on-

line. Still other activities will no doubt arise out of discussion by participants of their needs and interests at in-person gatherings and through the program’s chat room.

As the program nears the end of its first year of operation, there is much to reflect upon and still more to accomplish. There is also a sense of pride in what has been created through a participatory process involving community consensus, incorporation of EBP, and a focus on system transformation through enhancing choice and personal responsibility. By applying economic principles such as free-market competition, fiscal responsibility, budget neutrality, and cost efficiency, this model can help to realize a recommendation made by the New Freedom Commission on Mental Health, that “by allowing funding to follow consumers, incentives will shift toward a system of learning, self-monitoring and accountability” (New Freedom Commission, 2003).

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