

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.

Self-directed care programs give participants 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 \$58,000 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: 600-602, 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 (Florida-SDC), 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 (2). 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 (3). These results confirmed those of prior research showing that consumer-directed care enhances life satisfaction, reduces unaddressed problems, and enhances technical quality of care (4).

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. 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 (5). 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” (6).

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 \$470,000 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 residency in District 4. The program's

Dr. Cook, Mr. Grey, and Ms. Jonikas are affiliated with the Department of Psychiatry, University of Illinois at Chicago, 1601 W. Taylor St., 4th Floor, M/C 912, Chicago, IL 60612 (e-mail: cook@ripco.com). Dr. Russell is with the National Foundation for Self-Directed Care, Atlantic Beach, Florida. Steven S. Sharfstein, M.D., Haiden A. Huskamp, Ph.D., and Alison Evans Cuelar, Ph.D., are editors of this column.

100 slots were divided between individuals eligible for Medicaid and those who were not eligible to reflect the district's current proportion in each category. Annual funding was determined by the average per capita cost of outpatient ADM-funded services the previous year, to ensure cost neutrality. Excluded from these calculations was the value of inpatient and emergency treatment, guaranteeing the continued availability of these services to participants.

Amounts allocated in fiscal year (FY) 2003 were based on the average cost of services in FY 2002, with Medicaid-eligible participants allotted \$1,449 in FY 2003 and \$1,673 in FY 2004. Those who were not eligible for Medicaid were allotted \$2,766 in FY 2003 and \$3,195 in FY 2004. They also were required to set aside 48% of their budgets for "traditional" behavioral health services (such as medication management or psychotherapy) because of concerns that they might exhaust their budgets by purchasing nontraditional services (such as peer support) or service substitutions (such as Weight Watchers) and then have no coverage for more standard services. This proportion was based on the average percentage of outpatient mental health services billed to Medicaid (versus other sources) per Medicaid beneficiary in District 4. In addition, the budgets of three nonindigent participants were reduced on the basis of a sliding scale, to approximate Florida's mandatory copay fee schedule. A provider network was established for the program through agreements of understanding that included a commitment to recovery and self-determination principles, fiscal cost ceiling rates commensurate with contracted rates set by the district ADM office, and speedy service access.

A senior quality advocate met with each new participant to review and authorize that person's mandatory recovery plan and individual budget. Upon authorization, this staff member assigned each planned purchase to one of the mental health program office's cost centers by using state-selected Health Insurance Portability and Accountability Act (HIPAA) definitions of each cost center and activity code. The program employed consumer and

nonconsumer staff called recovery coaches to offer assistance in identifying and securing goods and services, a process referred to as "brokerage."

A purchasing policy developed by the program's advisory board specified what goods and services were allowable and under what conditions. As managing fiscal intermediary, Florida State University received and disbursed all participant-directed care funds from the state, carrying them forward each quarter and zeroing them out at the end of the fiscal year, per state budgeting requirements. The university also processed enrollment information for the program's provider network, reviewed fiscal records for accuracy, wrote checks to providers, and maintained the program's direct service staff on its payroll. The university ensured that monies spent by participants were excluded from being reported as income for beneficiaries of Supplemental Security Income and Social Security Disability Insurance. University staff also worked with recovery coaches who were consumers to ensure that their earnings did not jeopardize their benefits.

Program managers cited the following advantages to having a state-funded public university act as fiscal intermediary: the university's nonprofit status, the credibility bestowed by a university affiliation, the lower administrative costs because of economies of scale, and the purchasing power of a large organization. Another important advantage was that program staff were based at the university, offering independent brokerage services without the conflict of interest that would have existed had they been located in provider organizations or the state mental health authority.

Program evaluation and outcomes

Yearly program evaluations were mandated by the legislation that created FloridaSDC. The first was conducted in the spring of 2003 by researchers from the Louis de la Parte Florida Mental Health Institute located at University of South Florida (7). Regarding the population served, the evaluation found no statistically significant differences between participants enrolled at that time (N=41) and a comparison sample of 22,222 adults

with severe and persistent mental illness served in District 4 regarding age, gender, ethnicity, primary diagnosis, level of skills, number of days worked, proportion enrolled in Medicaid, and type of services used. Interviews with participants (N=13) revealed high levels of satisfaction with service availability; in contrast, nonparticipants (N=8) (defined as those who had expressed interest in the program but did not enroll) reported dissatisfaction because of their inability to obtain needed services. Examination of FloridaSDC service records showed clear linkages between goals stated in participants' recovery plans and the goods or services purchased to address them. Participants gave more positive responses than nonparticipants about how quickly they were moving toward goal attainment and satisfaction with their rate of progress.

Client-level outcome data, compiled by the state mental health authority for review by state legislators, were examined by researchers at the University of Illinois at Chicago as part of the year 2 evaluation. This evaluation used a pre-post design to follow 106 participants enrolled in the program during its first 19 months of operation (November 2002 through June 2004). Length of program participation ranged from three to 19 months, with a mean±SD of 10.5±3.7 months (median=11 months). A majority were women (N=65, or 61%). Sixty-six (62%) were Caucasian, 34 (32%) were African American, four (4%) were multiracial, one (<1%) was American Indian, and one (<1%) was Asian or Pacific Islander. At intake, participants ranged in age from 21 to 68 years and had a mean age of 42.4±11.0 years (median=41 years). Most (N=96, or 91%) were single, divorced, separated, or widowed, and ten (9%) were married. At program entry, 78 (74%) were living in the community (N=45, or 42%, lived with relatives; N=12, or 11%, lived with nonrelatives; and N=21, or 20%, lived alone), 17 (16%) were living in assisted living facilities, six (6%) were in a hospital, four (4%) lived in group homes, and one (<1%) was homeless. Forty-five (42%) had not graduated from high school, and seven (7%) had a college degree. Forty-seven (44%) had a schizophrenia spectrum disorder, 25 (24%) had de-

pression, 23 (22%) had bipolar disorder, four (4%) had posttraumatic stress disorder, three (3%) had generalized anxiety disorder, two (2%) had panic disorder, two (2%) had psychosis not otherwise specified, and one (<1%) had multiple personality disorder.

Paired t tests were conducted to examine participants' outcomes before and after program entry. Following the state's reporting format, scores were based on the most recently completed quarterly assessment and annualized using a multiplier of 12.1667. On average, participants spent a significantly higher number of days in the community (versus inpatient or forensic settings) after joining the program (mean=354±26 days) than in the year before program enrollment (mean=337±54 days) ($t=3.1$, $df=104$, $p<.01$). Participants also scored significantly higher on the Global Assessment of Functioning Scale (8) in the year following program participation (mean score=58.3±8.3) than in the year before (mean score=50.9±10.2) ($t=6.9$, $df=104$, $p<.001$). At follow-up, one-third ($N=36$, or 34%) held paid employment, 20 (19%) were receiving vocational skills training, 17 (16%) were engaged in volunteer activities, seven (7%) were enrolled in postsecondary education, and three (3%) were enrolled in general equivalency diploma classes. In the first 19 months of the program's operation, 17 (16%) participants were hospitalized for psychiatric reasons, and involuntary commitment was especially rare ($N=5$, or 5%).

Of the \$181,197 in total program costs over 19 months of operation, participants spent a total of \$58,450 in direct purchases of services, supports, and material goods. Of that total, 47% (\$27,517) was spent on "traditional" clinical recovery services, such as psychiatric, therapeutic, and counseling services. Another 13% (\$7,687) was spent on recovery support services that were substitutions for traditional mental health services, such as self-help, wellness, and exercise (for example, Weight Watchers, YMCA memberships, or yoga classes) and alternative medicine. Another 29% (\$16,998) was spent on tangible purchases designed to enhance community integration, such as food and clothing. In addition, 5% (\$2,856) was spent on den-

tal services, and 3% (\$1,751) was spent on ophthalmology or optometry services. Finally, 3% (\$1,641) was spent on transportation. A somewhat surprising finding was that, on average, participants spent only about a third (\$58,450, or 32%) of the funds that had been allocated to them. Overspending, a frequently mentioned concern in early stages of project implementation, was not in evidence.

Summary and conclusions

This pilot program showed that individuals with a mental illness can participate in a service delivery model where they control funds to purchase goods, services, and supports in accordance with individualized recovery plans. Compared with the year before entry in the program, in the year after program intake, FloridaSDC participants spent significantly more days in the community and were rated significantly higher in functioning. Many program members attained important recovery goals, such as furthering their education, living in an apartment, or working at a job.

In April 2004 both houses of the Florida State Legislature enacted legislation extending the original project until June 30, 2008, and expanding it to additional areas of the state so that, currently, two programs are in operation. Also included in this legislation was language authorizing the state mental health authority to operate the program by using a Medicaid 1115 demonstration waiver, along with waivers from the state vocational rehabilitation authority and the Social Security Administration. This demonstration could add vocational rehabilitation funds to the total amount of annual funding available to FloridaSDC participants, expand the number of program slots, enable the program's administrative expenses to be covered by Medicaid, and create the impetus to start up similar programs around the state.

For people with a mental illness, models such as this can allow them to rediscover their talents and rebuild their lives. This alternative uses economic principles such as free-market competition, fiscal responsibility, budget neutrality, and cost efficiency. It also responds to the President's

New Freedom Commission on Mental Health report (6) recommendation that "consumers and their families . . . play a larger role in managing the funding for their services, treatments, and supports" so that "by allowing funding to follow consumers, incentives will shift toward a system of learning, self-monitoring and accountability." The early positive results of this pilot program suggest that replication in other areas of the state and country is called for, along with more rigorous evaluations of participant outcomes, costs, and satisfaction.

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References

1. Cook JA, Jonikas JA: Self-determination among mental health consumers/survivors: using lessons from the past to guide the future. *Journal of Disability Policy Studies* 13:87-95, 2002
2. Benjamin AE, Fennell ML: Putting the consumer first: an introduction and overview. *Health Services Research* 42: 353-361, 2007
3. Carlson BL, Foster L, Dale SB, et al: Effects of Cash and Counseling on personal care and well-being. *Health Services Research* 42:467-487, 2007
4. Benjamin AE, Matthias R, Franke TM: Comparing consumer-directed and agency models for providing supportive services at home. *Health Services Research* 35:351-366, 2000
5. Mental Health: A Report of the Surgeon General. Rockville, Md, Department of Health and Human Services, US Public Health Service, 1999
6. Achieving the Promise: Transforming Mental Health Care in America. Pub no SMA-03-3832. Rockville, Md, Department of Health and Human Services, President's New Freedom Commission on Mental Health, 2003
7. Teague GB, Boaz TL: Evaluation of the Adult Mental Health Self-Directed Care Project. Tampa, University of South Florida, Louis de la Parte Florida Mental Health Institute, 2003
8. Endicott J, Spitzer RL, Fleiss JL, et al: The Global Assessment Scale: a procedure for measuring overall severity of psychiatric disturbance. *Archives of General Psychiatry* 33:766-771, 1976