Self-Directed Care for Adults With Serious Mental Illness: The Barriers to Progress

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The President's New Freedom Commission on Mental Health identified self-directed care as one service innovation that could create a more consumer- and family oriented mental health system. Four years later, there are still fewer than 400 consumers in five states accessing self-directed care in the public mental health system. This Open Forum identifies three main barriers to explain this lack of progress: the absence of a strong evidence base to support the effectiveness of self-directed care for serious mental illness, uncertainty over the appropriate scope of self-directed care, and the absence of a sustainable source of funding. The introduction of the 1915(i) provision of the Social Security Act in 2007 appears to partly address the funding barrier to self-directed care. There is also a strong case for a large-scale evaluation of self-directed care for persons with serious mental illness to address the two remaining barriers to progress. (*Psychiatric Services* 59: 792–794, 2008)

It has been over four years since the final report of the President's New Freedom Commission on Mental Health called for the creation of a more consumer- and family oriented mental health system that would give a greater number of individuals with serious mental illness the chance of regaining a meaningful life in the community (1). The report identified self-directed care as one service innovation that could create this kind of transformation. After the Commission dispersed when the report was completed, the Substance Abuse and Mental Health Services Agency picked up the baton and has held several meetings and produced publications promoting the approach (2). But there are currently fewer than 400 consumers in the public mental health system across the country accessing self-directed care. This Open Forum identifies three barriers to explain the lack of progress: the absence of a strong evidence base, uncertainty over the appropriate scope of self-directed care, and the absence of a sustainable source of funding.

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Self-directed care: the evidence

Self-direction is a broad term that is used to describe a range of service delivery models that place greater emphasis on consumer involvement, including peer support services and consumer-run services. This Open Forum does not deal with all aspects of self-direction but focuses on one particular service model: self-directed care. Self-directed care is based on giving each consumer control of an individual budget with which to purchase goods and services to meet his or her needs in place of or in addition to receiving directly provided services. The rationale is that greater consumer choice over treatment and services can allow care to be better tailored to individual recovery.

An individual budget differs from Social Security cash benefits because the money in an individual budget can be spent only on goods and services that meet needs defined in a person-centered plan, and certain items, including alcohol, cigarettes, and illegal substances, are entirely prohibited. Individuals who choose to direct their own care have access to support services that provide information and advice on available choices and that help manage the associated financial transactions (3).

There are currently five states with programs and pilot programs in self-directed care for adults with serious mental illness: Florida, Maryland, Michigan, Oregon, and Tennessee. Iowa recently completed a pilot program with 25 adults, and Texas and Pennsylvania are in the process of developing a pilot program. The oldest and largest program is in Florida and serves approximately 200 consumers across two districts. Programs in other states serve 50 or fewer consumers each.

The programs differ in the degree of control that they provide consumers. In Oregon and Iowa, consumers receive a budget in addition to the services provided by the traditional mental health system. This budget can be used to purchase recovery supports that are not provided by the traditional system, but participating in self-directed care does not give consumers additional opportunities to change the traditional services they receive. However, in Florida, Maryland, and Michigan, consumers do have the option to use money from their budgets to visit alternative providers of traditional services and, in some cases, to substitute services provided by the traditional mental health system for nontraditional alternatives.

Initial findings from self-directed care for adults with serious mental illness are promising. Surveys of consumers in Florida and Oregon who use self-directed care have shown

significant increases in satisfaction, compared with users of traditional services (4,5). These findings are supported by analysis comparing the experiences of older adults with and those without a mental health condition in the experimental Cash and Counseling demonstration in Arkansas (6). The authors conclude emphatically that "if a client is mentally ill, it is better for him or her to be in Cash and Counseling than in traditional treatment" (6). There is little evidence about longer-term impacts, but recent analysis of the program in Florida highlights a promising development: consumers who use self-directed care are more likely to make use of routine and early intervention services and to have less use of crisis units, compared with a matched sample of consumers who do not use self-directed care (7).

The barriers to progress

Self-directed care extends consumer involvement beyond the well-established principle of choice of provider to give consumers control over what treatments and services are provided. Although self-directed care is becoming well-established in home- and community-based long-term care services for older adults and persons with disabilities, it is not well established in health care. Self-directed care is often associated with health savings accounts (HSAs), but although both approaches are intended to extend consumer control, self-directed care provides consumers with greater control over the use of public resources, while HSAs rely heavily on private savings. The introduction of self-directed care for the management of chronic diseases such as diabetes is currently under serious discussion in the National Health Service in the United Kingdom, but the approach is in its infancy in the health care arena internationally. As a result, existing evidence, although promising, remains inadequate to convince more states and third-party payers to pilot the approach for adults with serious mental illness.

In developing a stronger evidence base for self-directed care as an effective approach, an important dimension to clarify would be the appropriate scope for consumer control. Existing programs differ significantly in the extent to which they do or do not give consumers control over traditional mental health services. Proponents of self-directed care argue that the current system is overly reliant on clinical treatment and that consumers should be given greater control to rebalance the system in favor of services that better address individual recovery. At the same time, there are understandably concerns about consumers' capacity to make effective decisions beyond the realm of personal care and other supportive services. More evidence of the impact on service utilization and health outcomes of giving consumers control over different types of services would help clarify the appropriate scope for self-directed care.

The appropriate scope for self-directed care is closely linked to the third, and perhaps most significant, barrier to progress: the absence of a sustainable funding source. The Medicaid program is the single largest source of funding for public mental health services and is expected to account for an increasing share of the resources that underwrite state-administered mental health services over time (8). But self-directed care pushes at the limits of what Medicaid will support.

Medicaid was designed to pay for health care services based on medical necessity criteria. Several of the items that consumers choose to purchase in programs that are not reliant on Medicaid dollars, such as the program in Oregon, would not be permissible under Medicaid regulations—for example, room and board, as well as education and job-related services. Neither does Medicaid pay for goods. It funds services. But many consumers want and need goods to help them rebuild a life in the community—for example, a computer to support education, an exercise bike to improve physical health, or a new set of pots and pans to support independent living.

The consequence of the existing Medicaid rules is that states that are experimenting with self-directed care are doing so by using state general revenue funds or grant funds that impose fewer restrictions and can support far greater flexibility than Medicaid. The current exception to this pattern is Michigan, which supports self-directed care under a concurrent section 1915(b)/(c) waiver. But flexibility in this context comes at the expense of sustainability. There are many competing claims on general revenue funding, not least of which is the need to match increasing federal expenditures under Medicaid, and grant funding is by its very nature time limited. Self-directed care cannot flourish if it cannot be supported by Medicaid dollars.

Future prospects

The introduction of new waiver provisions under the Deficit Reduction Act of 2005 created new options for states interested in pursuing self-directed care for adults with a primary diagnosis of serious mental illness. Although the provision codified as section 1915(i) of the Social Security Act restricts self-directed care to defined categories, such as day treatment and psychosocial rehabilitation, rather than providing a broad scope, within these categories states should be able to apply significant flexibility. It remains to be seen how many states take up the option, but it appears to partly address the funding barrier to self-directed care posed by existing Medicaid regulations.

Going beyond the new possibilities created by the Deficit Reduction Act will require a more robust evidence base. There is a strong case for a large-scale evaluation of self-directed care for adults with serious mental illness similar to the Cash and Counseling demonstration. In 1998 Medicaid approved three Cash and Counseling programs in Arkansas, Florida, and New Jersey under the section 1115 Medicaid authority. These programs conducted an experimental trial of self-directed services for adults with disabilities, for elderly persons, and for children with developmental disabilities. The scale and rigor of this evaluation have been instrumental in making the case for self-directed care in home- and community-based servic-

es. Positive findings from a large-scale evaluation of self-directed care for adults with a primary diagnosis of mental illness could provide a strong platform to begin discussions about further reforming the Medicaid system to better support self-directed care and could convince other third-party payers to experiment with the approach.

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