The Key ASSISTANCE REPORT

FOCUS ON SELF-DIRECTED CARE

National Mental Health Consumers' Self-Help Clearinghouse

IN THIS ISSUE

- Alternatives and Choice
- New Frontiers
- Who Benefits?
- Facts and Findings
- Advocacy
- The Future

Julie Schnepp, who participates in a self-directed care program in Delaware County, Pa., says it has made "the biggest difference in my life." "Self-directed care has gotten me back out in the world," Schnepp said.

Self-directed care is a way of giving people greater control over the types of services and goods they receive to bolster their individual paths to recovery. According to the Substance Abuse and Mental Health Services Administration (SAMHSA), self-directed care helps individuals "assess their own needs, determine how these can be met and ensure a high quality in those services." Self-directed care promotes recovery, SAMHSA concluded.

Self-directed care began in the 1970s and 1980s when disability rights groups – primarily comprising people with intellectual and developmental disabilities, and older adults – began to question the suitability of the services made available to them by the public systems of care, and to request more personalized options. The systems responded with programs that allowed them to make more of their own decisions.

ALTERNATIVES AND CHOICE

In self-directed care, individuals meet with advisors to reevaluate their services. "Self-directed care participants can typically choose from a wider range of service providers and different types of services," said Judith Cook, Ph.D., director of the Center on Mental Health Services Research and Policy at the University of Illinois in Chicago. "They can also shop around for providers that fit their budget. Another advantage is having the opportunity to exercise personal responsibility for developing your own recovery plan and managing your personal budget."

Participants are given a certain sum of money and are encouraged to use it toward the purchase of alternative resources that they typically might not be able afford within the Medicaid structure. These might include yoga classes, gym memberships, tennis shoes, a security deposit for a new apartment, appliances and technological devices, tuition or educational supplies – anything that could help someone engage in the community. Participation is voluntary and participants can leave the program at any time. Brokers, facilitators or coaches – who are sometimes peers – work with participants to outline recovery plans and assess needs. The money for each individual can range from $1,000 to $5,000 per person per year. Its expenditure is typically flexible, with a few limitations.

NEW FRONTIERS

In recent years, the recovery movement has brought the idea of self-directed care to the forefront of mental health

care delivery, but the process has been slow and painstaking. "Over the past decade, self-directed care has become a widely accepted form of service delivery for the long-term care needs of people with a wide range of disabilities, and the elderly," Dr. Cook said. "But this has been less true for people with psychiatric disabilities. This is so even though the Affordable Care Act [ACA] of 2010 authorized the use of self-directed services in section 1915(k), and specifically included people with serious mental illness in its 'final rule' regarding funding of self-directed care services under the ACA, released May 2012."

Florida Self-Directed Care (SDC) began as a grassroots effort in Jacksonville in 2000; its success led to the creation of a second Florida SDC, around Ft. Myers. Participants use their individual budgets to choose the providers, services and wellness activities that they feel will aid their recovery. They often have match-funding opportunities to purchase items such as clothing and shoes to assist with their integration back into the community, through work or other activities. The effectiveness of these choices is measured through self-reporting about recovery goals, along with reports from family members and recovery coaches.

The self-directed care program operated by the North Texas Behavioral Health Authority in its seven-county area works in tandem with the ValueOptions managed care company as well as the Texas Department of State Health Services. Participants create a person-centered recovery plan and budget for the purchase of goods and services that will further their recovery aims.

In Multnomah County, Ore., Self-Directed Services includes a "wellness brokerage" that allows participants to work with peers to develop a recovery plan and use brokerage funds and other sustainable resources to assist their efforts. A sustainable housing component allows a number of individuals to use resources toward affordable housing. The Michigan Self-Directed Care program similarly trains peer support specialists to work as coaches to facilitate peer-directed planning.

"The hope with all these programs is that when you have the opportunity to manage your own care, you're more empowered and can make choices that are more relevant to you, opening up the limited menu of choices that the normal mental health system offers into hundreds of choices," said Joseph Rogers, chief advocacy officer of the Mental Health Association of Southeastern Pennsylvania (MHASP), and executive director of the National Mental Health Consumers' Self-Help Clearinghouse.

"It's really about allowing people to figure out what's going to work for them. . . . I tell people to dream big."

Rogers was heavily involved in creating Consumer Recovery Investment Funds Self-Directed Care (CRIF SDC), a pilot project that is offered to some people receiving mental health services in Delaware County, Pa. In January 2010, MHASP launched the pilot with the goal of enlisting 150 participants. The main criteria for joining are that the person must be enrolled in HealthChoices (Pennsylvania's mandatory managed care program for Medicaid recipients) in Delaware County; must have been diagnosed with major depression, schizophrenia or bipolar disorder; and must not have been hospitalized in the past six months. Magellan Behavioral Health Services – which is a CRIF partner with MHASP, the Office of Behavioral Health in Delaware County, and the Temple University Collaborative on Community Inclusion – determines whether the individuals' requests can be deemed "medically necessary." CRIF SDC participants meet with a team of recovery coaches who are certified peer specialists and WRAP (Wellness Recovery Action Plan) facilitators. "We wanted people with their own personal experience to help others move forward in recovery. The concept of peer support is very important and as a service, it is Medicaid-reimbursable," said CRIF SDC program manager Erme Maula, RN, MSN, CRRN.

With the recovery coaches, participants start to look at their lives and their vision for the future. "It's really about allowing people to figure out what's going to work for them. We come up with what is called a 'psychosocial assessment,' which is really just a life story, putting someone's experiences into language. We talk about goals and barriers. We do a dream exercise, which we borrowed from the Texas program: it helps people think about where they see themselves down the road. It covers all of the meaningful domains of life: social, physical health, housing, wellness, education, work. I tell people to dream big," Maula said.

WHO BENEFITS?

Self-directed care may not be for everyone. There are those who enjoy the traditional services they are receiving and don't want to complicate matters with more decision making. "Some people are interested in having choice and options and about a third of people we asked said, 'I like the way things are and I don't want to participate in this,' " said Mark Salzer, Ph.D., who has been studying the CRIF program with his research team at the Temple University Collaborative on Community Inclusion in Philadelphia.

By the same token, the people who join in self-directed care programs by default seem to be those who are actively engaged in the recovery process, Dr. Salzer said. "Of the 40 or so involved in CRIF, about two thirds are engaged with recovery coaches and really actively thinking critically about services."

Robert Waters, vice president of account management at Magellan, said that the company is interested in seeing how self-directed care can improve people's

outlooks for their own recovery. "So far it's been very interesting to hear about participants' experiences, the ways in which they feel more in control of their own choices," he said. "You see that it's really opening up whole new set of opportunities for empowerment and helping people reach their goals."

FACTS AND FINDINGS

The jury is still out about self-directed care's efficacy for people in mental health recovery, and researchers like Dr. Salzer and Dr. Cook are looking closely at these programs and their outcomes.

"There's a great deal of interest in it, from counties, from other states," said Dr. Salzer. "But people are waiting to see data from our studies before they implement anything."

So far, the anecdotal evidence seems to support the idea that programs like CRIF can be a boon to the recovery process. "From the interviews we've done with people in Delaware County, [it appears as if] they feel like this opportunity had increased their choice and ability to make decisions about their care and facilitates their mental health and recovery," Dr. Salzer said.

While research is still being gathered about mental health systems, self-directed care shows promise as a model for a reformed general health care system in which dollars follow people – and their needs. A 2007 Health Services Research study showed that older adults, individuals with physical disabilities and children with special needs enrolled in a self-directed Cash and Counseling program reported more satisfaction with their care and they experienced equal or better health outcomes compared to their peers who were not involved in the program.

Meanwhile, a 2008 evaluation of the Florida SDC, conducted by Dr. Cook and her colleagues and published in the journal *Psychiatric Services*, found that, compared to the year before entering SDC, participants spent significantly less time in criminal justice settings and psychiatric inpatient settings and demonstrated improved functioning in the year after entering the program.

ADVOCACY

With so few existing self-directed care programs around the country, one of the most important things interested individuals can do is to get involved in their state, especially in light of recent efforts for health care reform under President Obama's Affordable Care Act, which may be opening new doors for this model.

"One of the things we encourage people to do is get involved in systems planning to help with the mental health plans at the state level," Rogers said. "Each state is required to file a federal plan as part of a block grant program for Medicaid dollars. The best thing people can do now is to inquire about self-directed care, asking where they can access it and start introducing it into the discussion."

System users have been instrumental in planning efforts for self-directed care initiatives in Michigan, Oregon and elsewhere where consumer advisory boards or networks have actively engaged with the governing boards of local community mental health programs.

One of the most exciting aspects of self-directed care is that relatively small amounts of money can have a big impact: if any self-directed care choices can prevent an individual from going to the hospital, it creates a huge savings for the system at large.

THE FUTURE

Proponents of self-directed care envision a world where it is accessible to anyone who wants to participate. "I would like to see self-directed care be as available for people with psychiatric disabilities as it is for people with other types of disabilities," Dr. Cook said. "In most states, at least some people can access a self-directed care program of some type. I would like that to be the same for people who are in the process of recovering their mental wellness."

The momentum toward self-directed care is part of the bigger momentum toward recovery-based systems, said Rogers, which may mean that Cook's vision is inevitable. "When people define 'recovery,' they talk about choice and self-direction. The recovery movement is giving us the opening for more choice and more self-direction in the system. Self-directed care might be presenting a challenge to the traditional mental health system because people might not choose the same old services, but we know that the traditional system is also limited and could benefit from the change," he said. "That's not to say we should throw the baby out with the bath water, but we have a chance to offer something different and really help people move forward with recovery and integrating into the community."

When it comes down to it, the belief in the potential of the self-directed model is simply a belief in human potential. "If you're interested in self-directed care, your attitude is that people can make decisions for themselves," Dr. Salzer said. "And there's good evidence out there that shows that people can." ■

RESOURCE LINKS

University of Illinois Center on Mental Health Services Research and Policy
http://www.cmhsrp.uic.edu/nrtc/sdcwebpage.asp

Texas Self-Directed Care Program
http://www.texassdc.org/

Florida Self-Directed Care Jacksonville
http://www.floridasdc4.com/

Florida Self-Directed Care Ft. Myers
http://www.flsdc.org/

Consumer Recovery Investment Funds Self-Directed Care (Pennsylvania)
http://www.nyaprs.org/e-news-bulletins/2011/2011-04-29-Self-Directed-Care-Pilot-Puts-Consumers-in-Drivers-Seat.cfm and https://www.magellanprovider.com/MHS/MGL/about/whats_new/providerfocus/new/current/winter10/regionnews/pa_healthchoices/article4.asp

Oregon Self-Directed Services
http://www.luke-dorf.org/sds.php

The Clearinghouse welcomes all programs in which consumers play a significant role in leadership and operation to apply for inclusion in its Directory of Consumer-Driven Services. The directory, accessible at www.cdsdirectory.org, is searchable by location, type of organization, and targeted clientele, and serves as a free resource for consumers, program administrators and researchers.

Apply online at www.cdsdirectory.org/contact, via fax at 215-636-6312, or by phone at 800-553-4KEY (4539). To receive an application by mail, write to info@cdsdirectory.org or NMHCSH Clearinghouse, 1211 Chestnut Street, Suite 1100, Philadelphia, PA 19107.

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