Research In Focus: A Weekly Digest of New Research from the NIDILRR Community

Self-directed care may help people with serious mental illness take an active role in their recovery

Serious mental illnesses (SMI) are conditions like schizophrenia, bipolar disorder, or depression. People with serious mental illness often receive traditional mental health services funded by Medicaid, such as medications or psychotherapy. These services may help reduce SMI symptoms, but they may not be effective enough to help people with SMI participate fully in their communities. Self-directed care (SDC) is a new and alternative approach to traditional care for people with SMI. In one version of SDC, people with SMI can request funding through their provider for nontraditional goods or services that they need to achieve their wellness goals. For example, someone in an SDC program could request funding for a gym membership, a bus pass, or clothes for a job interview. In a recent NIDILRR-funded study, researchers looked at the types of SDC requests people with SMI made while participating in such a program and their reasons for making the requests. The researchers also wanted to find out how often people with SMI requested nontraditional items through SDC, and the most common wellness goals that people with SMI hoped to meet by making those SDC requests.

Researchers at the Rehabilitation Research and Training Center on Community Integration and Participation for Individuals with Psychiatric Disabilities (TU Collaborative) looked at data from 120 participants enrolled in a larger study about SDC. The participants were adults with a SMI (schizophrenia, bipolar disorder, or depression) who were receiving Medicaid-funded mental health services in Delaware County, Pennsylvania. Half of the participants took part in an SDC program and half received usual care. For this study, the researchers focused on the 60 participants who were offered the SDC program. The SDC program participants were paired with a recovery coach who explained the program and helped them set personalized wellness goals. The coach also reviewed the participants' current mental health services with them and encouraged them to decide whether or not they were satisfied with their current services and whether or not they wanted to request any nontraditional goods or services. The participants who decided to request a nontraditional item submitted a written justification explaining how the requested item would help them achieve specific wellness goals. The participants also submitted the estimated costs to the behavioral health managed care agency for approval. All of the SDC requests were approved. After approval, the participants were given debit cards to purchase their requested items.

The researchers looked at how many participants requested nontraditional items, how many requests they made, how long it took to make their first request, and what types of items were most often requested and the wellness goals those items addressed. The researchers found that:

- Almost all SDC participants (87%) requested at least one item, with an average of about 10 items requested per person.
- On average, it took the participants about 3 months to make their first request after they joined the SDC program.
- Participants made requests to improve broad wellness goals in diverse areas including: Self-Care; Domestic Life; Mobility; and Community, Civic, and Social Life.
- The most common specific wellness goals that SDC requests addressed were: managing diet and fitness, using public transportation, and handling stress. Most of the participants made requests related to more than one wellness goal.
- The participants with schizophrenia requested more items related to managing their health and fitness, such as gym memberships. The participants with bipolar disorder and depression made more requests related to reducing stress, such as paying the electric bill or legal fees related to a divorce.

The authors noted that traditional, medically-oriented mental health services may not fully meet the individual needs of people with SMI. Traditional care may also put people with SMI in a passive role regarding their care. This approach to SDC can give people with SMI a more active role in their recovery by letting them identify and request the goods and services that they feel would be most relevant to their personal wellness. SDC may also help people with SMI overcome financial barriers, such as the inability to pay for a bus pass, which might prevent them from fully participating in valued activities like employment and social gatherings. The ability to participate in meaningful activities, in the long run, may beneficially impact overall health and wellbeing. It may be beneficial for behavioral health agencies and policymakers to broaden the definition of "medical necessity" to include nonmedical goods and services that individuals with SMI feel are important for achieving wellness goals. This study did not test the effectiveness of SDC; it just looked at the types and number of requests that people made. Also, the SDC program was new, and the types and number of requests could change as the program matures. More research is needed to evaluate the long-term impact of an SDC approach to mental health services.

To Learn More

The TU Collaborative website features several resources on self-directed care including factsheet, a guide to creating self-directed care programming, and a self-advocacy planning tools.

The NIDILRR/SAMHSA-funded Center on Integrated Health Care and Self-Directed Recovery is dedicated to advancing knowledge and utilization of innovative models to promote health, recovery, and employment among people with mental health

conditions. The Center's website features resources for practitioners, policymakers, and self-advocates interested in SDC.

To Learn More About this Study

Snethen, G., Bilger, A, Maula, E.C., Salzer, M.S. (2016) Exploring personal medicine as part of self-directed care: Expanding perspectives on medical necessity. Psychiatric Services In Advance, 2016, 1-7. This document is available from the NARIC Collection under Accession Number J74076.

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