
SELF-DETERMINATION INITIATIVES

Mental Health America Policy Statement

Mental Health America (MHA) envisions a just, humane and healthy society in which all people are accorded respect, dignity and the opportunity to achieve their full potential free from stigma, discrimination and prejudice, and supports recovery as the guiding principle for treatment of mental illness and addiction.^[1] Consistent with this philosophy, MHA promotes individualized planning and self-determination^[2] initiatives for individuals with mental health and substance use^[3] conditions as important tools in the development of recovery-oriented systems of care.

Along with peer services, self-directed care (SDC) is the leading self-determination initiative, and it is proving very successful. MHA supports self-directed care for two reasons:

- **It furthers important consumer rights to autonomy and choice, and**
- **It has been shown to be an effective model to assure quality of health care and promote recovery.**

The overarching principles of self-directed care are:

- **Freedom to decide how a person wants to live his or her life.**
- **Authority over a targeted amount of dollars.**
- **Support to organize resources in ways that are life enhancing and meaningful to the individual.**
- **Responsibility for the wise use of public dollars and recognition of the contribution that individuals with disabilities can make in their communities.**
- **Confirmation of the important role that individuals with disabilities must play in a redesigned system.^[4]**

Background

Since the inception of the first asylums, mental health services have been viewed as a way to “control” or “manage” individuals with mental health conditions who are presumed not to have the competency and skills required to live “normal” lives. Self-directed care, which began with systems serving people

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with developmental disabilities, assumes the opposite, that people with disabilities can manage their own care, and, in a recovery-oriented system, should be encouraged to do so. In the process, individual autonomy and satisfaction can be increased, and the use of public resources may be reduced.

In the 1990s, the Robert Wood Johnson Foundation (RWJF) funded projects whose purpose was to give individuals with developmental disabilities the opportunity to control the money available for their own care. The mental health recovery movement has advocated giving the same autonomy to people with mental health conditions.

The Medicaid.gov website offers a comprehensive history:

Beginning in the 1990s, many states began to offer "consumer-directed" personal care services pursuant to section 1905(a)(24) of the [Social Security] Act, the optional state plan personal care services benefit. During the mid-1990s, the Robert Wood Johnson Foundation awarded grants to develop "Self-Determination" programs in 19 States, with self-direction of Medicaid services being a crucial aspect of self-determination. These projects primarily evolved into Medicaid-funded programs under section 1915(c) of the Act, the home and community-based services waiver program.

In the late 1990s, the Robert Wood Johnson Foundation again awarded grants to develop the "Cash and Counseling" (C&C) national demonstration and evaluation project in three states. These projects evolved into demonstration programs under the section 1115 authority of the Act. The Deficit Reduction Act (DRA) in 2005 authorized two more avenues for states to offer the self-direction option, i.e., [section 1915\(i\)](#) and [section 1915\(j\)](#) of the Act. In 2010, the Affordable Care Act, passed by Congress and signed by the President on March 23, 2010, authorized section [1915\(k\)](#) of the Act to offer self-directed services.^[5]

Thus, over 30 years of federal and state policy have established that Americans with cognitive and behavioral disabilities should be trusted to manage their own lives like other people with chronic health conditions, and be empowered to live close to their families and friends, to live independently, to engage in productive employment, and to participate in all aspects of community life. There is now a growing recognition that people who require support from the public mental health and substance abuse systems should have the freedom to define the life they seek to live, and to direct the assistance they require.^[6] As stated by the New Freedom Commission on Mental Health:

...The culture of mental health care must shift to a culture that is based on self-determination, relationships, and full participation of mental health consumers in the work and community life of society.^[7]

In partnership with their health care providers, consumers and families will play a larger role in managing the funding for their services, treatments, and supports. Placing financial support increasingly under the management of consumers and families will enhance their choices. By allowing funding to follow consumers, incentives will shift toward a system of learning, self-monitoring, and accountability. This program design will give people a vested economic interest in using resources wisely to obtain and sustain recovery.^[8]

Self-determination relies on a shift from dependency to choice in service delivery and emphasizes peer-based, family-based and community-based approaches to services. MHA encourages affiliates, consumers, and other advocates to support the development of self-determination initiatives that are culturally and linguistically competent and consumer- and family-driven and to ensure that these programs do not simply shift financial risk to participants. MHA supports programs that assure that individuals receive appropriate coaching and planning assistance to ensure that their choices will likely promote their recovery, supporting people with an integrated care team, not leaving them alone to seek out their own care.

MHA opposes initiatives aimed at reducing government resources or accountability for providing quality care, and will contest any effort to market such a proposal as a self-determination initiative. Self-determination programs should begin with personal care and respite and expand to include a range of self-directed services as policy and funding evolve.

HHS. After the success experienced in granting consumers with developmental disabilities spending autonomy, a follow-up RWJF program focused on aged and disabled populations was extended to portions of 12 states starting in 2004. Simultaneously, using state and Medicaid resources, Florida, Iowa, Michigan, Southeast Pennsylvania, Texas and Oregon initiated demonstration programs that were more focused on consumers with lived experience of mental illness. Four of these programs were evaluated in 2007 by The Office of Planning and Evaluation of HHS.^[9] Although preliminary, the findings were encouraging:

[Self-directed care programs] for adults with SMI is at a very early stage in its development. Initial findings are positive and indicate that self-direction could play an important part in creating a higher performing public mental health system that responds more effectively to consumer needs.

There are two aspects ...that appear to be critical to its success. The first is that self-direction shifts control over the different dimensions of service delivery -- the who, where, when and what -- to service users. Much attention in health care focuses on being able to choose who provides a service but this has its limits. Experience of mental illness is highly individualized and recovery is a very personal issue. Self-direction gives individuals the opportunity to choose between different types of treatment and develop packages of care that respond to their specific needs. For many people, a personalized package of care involves addressing wider aspects of health such as wellbeing, self-esteem, employment and family life. The second critical feature of self-direction is that it provides consumers with support from the outset rather than leaving them to navigate the complex public system alone. In the rest of the health care system, individuals have to seek out their own sources of information and advice, whether that is their doctor, friends or family.

There is a clear need for more rigorous research before firm conclusions can be drawn about the effectiveness of self-direction. This will be greatly aided by the proposed randomized control trial of Texas' ... pilot. In the meantime, while giving consumers control of financial resources through an individual budget has attracted attention and controversy, the value of supporting consumers to articulate goals and develop plans to achieve them should not be overlooked as an extremely important component States that

are hesitant about implementing individual budgets can start to improve existing services by providing peer support to enable consumers to play a more active part in service planning and become more self-determined. In this way, states can begin to reshape mental health services around the needs and preferences of consumers. (Emphasis supplied)

TEXAS. The Texas study was conducted by Dr. Judith Cook of the University of Illinois at Chicago, focused on people with severe mental illness in Dallas and surrounding counties receiving “package 3” services (just short of assertive community treatment). According to the unpublished analysis, the project has been very successful, but the study has not yet been peer-reviewed and published. The primary questions to be addressed by the study are whether the program improves participants' mental health and enhances their quality of life, and whether it is cost-effective.

Consumers who consent to join the study are randomly assigned to self-directed care (SDC) or a “services-as-usual” condition. Those in the services as usual condition continue to receive services through the area’s managed care network. Those assigned to self-directed care are provided with tools for person-centered planning and creation of an individual budget tied to specific recovery goals. Participants have \$4,000 (and in special cases up to \$7,000) per year to spend on traditional and non-traditional services, as well as material goods tied directly to recovery goals. Medications, crisis services, and inpatient care remain available through the current service system.

Dr. Cook’s unpublished summary concluded that:

In a randomized controlled trial, the SDC model achieved superior client outcomes for no greater service delivery expenditures than those resulting from the traditional service delivery system. Giving clients control over their service delivery dollars did not cause them to eschew traditional services such as psychiatric medication or psychotherapy, and did not lead to fraud or misuse of funds. With support from program staff, individuals with serious mental illnesses were able to develop recovery plans, formulate individual budgets with line items corresponding to goals in their recovery plans, and spend money responsibly and effectively on both traditional and non-traditional services.

Self-directed care participants:

- had significantly *lower somatic symptoms* (i.e., physical manifestations of physiological distress such as dizziness, pain, nausea, shortness of breath) than controls, and this difference persisted across the 2-year study period,
- had significantly *higher levels of coping mastery* than controls throughout the 24-month follow-up period,
- had *higher self-esteem* than controls throughout the follow-up period,
- had significantly *higher levels of self-perceived recovery* from serious mental illness than controls over time,
- reported *greater ability to ask for help, to rely on social support from others, and willingness to pursue recovery goals* than controls over time, and

- were more likely to perceive their *service delivery system as client-driven* than controls throughout the follow-up period. (Emphasis in original)[[10](#)]

FLORIDA. Patrick Hendry, MHA's Director of Consumer Affairs, was the state coordinator for the Florida Self-Directed Care Program in SW Florida for five years and was the Chair of the statewide FLSDC program for four years. The Florida program is the largest in the US and the oldest pure self-directed care model. As described by Hendry, the Florida program provided for a robust array of alternatives:

- **Psychological Assessment**
- **Medical Services (i.e., Psychiatric Evaluation, Medication Management)**
- **Individual and Group Therapy provided by a licensed mental health professional**
- **Supported Employment**
- **Co-pays for Clinical Recovery Services purchased with Medicaid or Medicare funds**
- **Transportation**
- **Massage Therapy as a form of touch therapy to assist an individual overcome issues documented by a licensed mental health professional**
- **Forms of Art Therapy**
- **Occupational, speech, and physical therapy when recommended by a licensed mental health professional**
- **Services related to developing employability and/or productivity that will lead to employability**
- **Smoking cessation activities under the supervision of a medical doctor**
- **Non-cosmetic dental work**
- **Hearing aids**
- **Non-cosmetic eye glasses and non-disposable contacts once per year, unless otherwise noted by a licensed eye care professional**
- **Haircuts from a professional not to exceed once every 3 months**
- **Make-up lessons**
- **Facial cosmetic and make-up products for the purposes of camouflaging medical conditions, such as facial scars, burns, etc. and for the purposes of seeking or participating in employment and/or other productive activities**
- **Tutoring**
- **Face-to-face and distance learning educational classes**
- **Pet ownership, initial costs only (a maintenance plan must be submitted with action plan that details the ability to have the pet in the current place of residence, food and health upkeep, and care for the animal in the event of the individual's absence)**
- **Time-limited assistance to secure or maintain a more independent living arrangement (a maintenance plan must be submitted with action plan that details long-term financial ability to maintain the living arrangement, i.e., rent, utilities, living needs, groceries). It is the participant's responsibility to ensure that payments are made on time.**
- **Time-limited assistance with vehicle repair for purposes of employment and/or transportation to access Clinical Recovery Services**
- **Entertainment items (i.e., movie tickets) and restaurant dinners if recommended by a licensed mental health professional.**

Hendry concludes that:

The evaluation revealed positive outcomes for self-directed care participants in terms of community integration and residential stability, both strong indicators of recovery and community functioning. Compared to non-participants, self-directed care participants also used significantly less crisis stabilization unit and other crisis support services. Self-directed care participants had significantly higher numbers of assessments, medical services including psychiatry, outpatient psychotherapy services, and supported employment.

Survey data collected from self-directed care consumers by personnel certified to administer the Personal Outcome Measures questionnaire, developed by The Council of Quality and Leadership, on participants assessed presence or absence of conditions conducive to positive outcomes in 25 quality of life domains. Overall, 75 percent of the ratings indicated the presence of these conditions, with relative strengths in areas such as working toward personal goals, satisfied expectations, daily routine, interaction in the community, choice of service options, and exercising rights.[\[11\]](#)

A 2010 report to the Florida state legislature specific supplied data on actual usage:

[M]ost (81%) purchases were for non-traditional services, which included both recovery supports and recovery enhancements. However, the types of services purchased by participants varied between the two circuits. In Circuit 4, participants directed a little more than half (54%) of their budgets to pay for living expenses (food, housing, and utilities) and transportation. In contrast, a much smaller proportion (25%) of Circuit 20 participants' expenditures was spent on these types of services. In addition, Circuit 20 directed a higher proportion of their budgets to traditional mental health services than did Circuit 4 participants (24% compared to 16%) and participants in both circuits used their budgets to purchase computers and computer accessories.[\[12\]](#)

Dr. Cook, who is publishing the Texas study, also studied consumer self-determination in Florida. In an article published in a peer-reviewed journal in 2008, she and her colleagues concluded:

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.[\[13\]](#)

Mental Health America encourages public dialogue to support meaningful self-direction and consumer choice. The 2004 Mental Health America issue brief, *Consumer Control and Choice: An Overview of Self-Determination Initiatives for People with Psychiatric Disabilities*,[\[14\]](#) provides greater detail on the history, elements and funding mechanisms for person-centered planning and self-determination initiatives. Development of consumer-centered systems will require education on mental health and

substance abuse treatment and services for consumers and their families and the development of policy, financing and planning efforts that support this new paradigm of service delivery.

Call To Action

Mental Health America calls on the public and private systems to provide meaningful autonomy to individuals in treatment for mental health and substance use issues. Advocates should:

- **Encourage states to use the 1915(j) waiver to allow for state and county self-determination programs, such as Self-Directed Care, and use their 1115 waiver for other innovative programs.**
- **Encourage public and private health plans to pursue funding mechanisms and quality improvement strategies that support self-directed care.**
- **Encourage states and counties to incorporate self-determination into their existing benefit offering or invest in self-determination programs, such as Self-Directed Care.**
- **Encouraging private plans and provider groups to incorporate self-determination into their existing benefit offerings, which could include using case management to assist with personal budgeting, or to invest in training and materials for a self-determination program.**

Recovery requires that people with lived experience of a mental health or substance use condition have the freedom to try alternative approaches to determine what works best for them and exert direct control over how, by whom, and to what ends they are served and supported. MHA affiliates and other advocates should support self-directed care initiatives, especially in substance abuse programs where control has been the paramount value.

References

[1] See MHA Position Statement 11, In Support of Recovery-based Systems Transformation, <http://www.mentalhealthamerica.net/positions/recovery-systems>

[2] Self-determination encompasses concepts intrinsic to self-actualization such as free will, civil and human rights, freedom of choice, independence, personal agency, and individual responsibility.

[3] Substance use is different in that money can be used to buy substances, but other approaches are being studied. Thus, SAMHSA/CSAT's national Access to Recovery Demo explored SDC for people with SA disorders using vouchers. The ATR Toolkit describes the model in greater detail.
<http://store.samhsa.gov/shin/content//SMA10-ATRKIT/SMA10-ATRKIT-01.pdf>

[4] Center for Self-Determination, (2005), <http://www.centerforself-determination.com/> Crafting the Instruments of Freedom: Tools of Self-Determination.

[5] <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Self-Directed-Services.html>

The 15j waiver description is found at <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/self-directed-personal-assistant-services-1915-j.html>

[6] See Cook, J.A. et al., Promoting Self-Determination for Individuals with Psychiatric Disabilities Through Self-Directed Services: A Look at Federal, State, and Public Systems as Sources of Cash-Outs and Other Fiscal Expansion Opportunities, SAMHSA, March 2004, <http://mentalhealth.samhsa.gov/publications/allpubs/NMH05-0192/default.asp> and 2014 power point by Dr. Cook – “Self-Directed Financing of Services for People with Serious Mental Illnesses.”

[7] New Freedom Commission on Mental Health. Report of the Subcommittee on Consumer Issues, March 2003, <http://www.mentalhealthcommission.gov/>[link doesn't work]

[8] Id., Executive Summary at 6, <http://www.mentalhealthcommission.gov/reports/Finalreport/FullReport.htm>[link doesn't work]

[9] Vidhya Alakeson. U.S. Department of Health and Human Services “The Contribution of Self-Direction to Improving the Quality of Mental Health Services,” (November 2007), <http://aspe.hhs.gov/daltcp/reports/2007/mhslfdir.htm>

[10] See Cook, Judith A., “Randomized, Controlled Trial of Self-Directed Care in Texas.”

[11] See Hendry, P., “The Florida Self-Directed Care Program: A Practical Path to Self-Determination.”

[12] See office of Program Policy Analysis & Government Accountability Report No. 10-40. “Insufficient Information Available to Fully Assess the Success of the Self-Directed Care Program.”

[13] [Cook, J.A., Russell, C., Grey, D.D. & Jonikas, J.A.](#), "Economic Grand Rounds: a Self-directed Care Model for Mental Health Recovery," [Psychiatr Serv.](#)59(6):600-2. doi: 10.1176/appi.ps.59.6.600 (2008).

[14] http://www.mentalhealthamerica.net/sites/default/files/Consumer_Control_IssueBrief.pdf