

Position Statement 36: In Support of Self-Determination Initiatives

Statement of Position

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. Consistent with this philosophy, MHA promotes individualized planning, self-directed care and self-determination initiatives for individuals with mental health and substance use conditions of all ages as important tools in the development of recovery-oriented systems of care.

Background

Mental health services have traditionally, since the inception of the first asylums, been viewed as a way to “control” or “manage” individuals with mental health conditions. Self-directed care, which began with systems serving people 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 funded several projects whose purpose was to give individuals with developmental disabilities the opportunity to control the money for their own care. The implementation of these projects allowed participants to demonstrate the five principles of self-directed care: freedom, authority, support, responsibility and confirmation.¹ The history of substance use disorders treatment has a long and valued focus on recovery strategies, which provides further impetus for integrated services and supports.

Over 20 years of federal and state policy have established that Americans with mental health and substance use conditions of all ages are entitled 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, and be supported to direct the assistance they require to live that life.² 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.”³ “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.”⁴

Self determination relies on a paradigm 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 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.

Mental Health America encourages public dialogue in each and every mental health and substance abuse system to support meaningful self-direction and consumer choice. The Mental Health America issue brief, *Consumer Control and Choice: An Overview of Self-Determination Initiatives for People with Psychiatric Disabilities*,⁵ 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.

The University of Illinois at Chicago Department of Psychiatry sponsored a 2009 conference titled: “Self-Determination: The Fierce Urgency of Now, an Invitational State of the Science Summit,” which is a good survey of the success of the self-determination movement in dealing with services to people with mental health conditions. The proceedings of the conference are available on the web.⁶ Because the public substance abuse treatment system remains more coercive, there are few examples to give, but MHA believes that the principles are the same.

Call to Action

Mental Health America calls on the public mental health and substance use disorders systems to provide meaningful self-determined choices to individuals with mental health and substance use conditions. Arrangements that support self-determination should be sponsored by state and county mental health and substance abuse systems, assuring methods for the persons with mental health and substance use conditions to exert direct control over how, by whom, and to what ends they are served and supported. MHA affiliates and other advocates should support self-determination initiatives, especially in substance abuse programs where control has been the paramount value.

Effective Period

The Mental Health America Board of Directors approved this policy on March 5, 2010. It is reviewed as required by the Mental Health America Public Policy Committee.

Expiration: December 31, 2015

1. <http://www.centerforself-determination.com/>

2. See Cook 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>
3. New Freedom Commission on Mental Health. Report of the Subcommittee on Consumer Issues, March 2003, <http://www.mentalhealthcommission.gov/>
4. *Id.*, Executive Summary at 6, <http://www.mentalhealthcommission.gov/reports/Finalreport/FullReport.htm>
5. <https://secured.nmha.org/pbedu/adult/SelfDeterminationInitiativesIssueBrief.pdf>
6. <http://www.cmhsrp.uic.edu/nrtc/summit2009/summit-products.asp>