

Consumer Control and Choice: An Overview of Self-Determination Initiatives for Persons with Psychiatric Disabilities

NMHA Issue Brief





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Executive Overview

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

New Freedom Commission on Mental Health. Report of the Subcommittee on Consumer Issues, March 2003

For many persons with mental illnesses receiving services through the public mental health system, the concept of self-determination bears little relevance to their daily existence. However, as states are implementing recovery-oriented services, self-determination or self-directed care is becoming a vital component to recovery. The President’s New Freedom Commission’s Final Report (2003) recognizes the need for a change towards more self-determined care programs in the mental health system. This issue brief outlines the origins of the self-determination movement, discusses the major components of the self-determination movement, and makes suggestions for the implementation and funding of self-determined programs.

The Self-Determination Movement has four overarching principles: (Nerney, T. and Shumway, D., 1996):

- **Freedom:** Choosing where and with whom to live, how to make a living, and with whom to develop relationships.
- **Authority:** Being in control of how one’s long-term care dollars are spent.
- **Support:** Arranging public resources in a way that meet the individual needs of a person with a disability.
- **Responsibility:** Using public resource cost-effectively.
- **Confirmation:** Recognizing that individuals with disabilities must play a major role in the development and implementation of self-determination policies.

Self-determination is a growing force for persons with psychiatric disabilities. Advances in technology and services, the recognition that recovery is a reality, combined with the consumer movement motto, “nothing about us without us” all pave the way for persons

with psychiatric disabilities to live self-determined lives. The Final Report of the President's New Freedom Commission on Mental Health (2003) validates the message that persons with psychiatric disabilities have been promoting for years...that consumers and families must be fully involved in the process of transforming the mental health system to one that embodies recovery and is consistent with the cultural, ethnic and linguistic needs of an individual.

Barriers to Self-Determination for Persons with Psychiatric Disabilities

Unfortunately, there are barriers unique to persons with psychiatric disabilities, which have been preventing the self-determination movement from taking hold in the public mental health system. These include:

- **Negative stereotypes**
- **Public mental health systems are designed to manage instead of support**
- **Unemployment**
- **Separate Service System**
- **Lack of outcomes for self-directed care**

Structure of Self-Directed/Self-Determined Programs

Self-directed care can be implemented with varying levels of control. The three of the most common forms of self-directed care are (Powers, 2004):

- **Personal Assistance:** Provides assistance to persons with disabilities with tasks they would be able to do themselves if they did not have a disability, such as personal care and communication supports.
- **Cash and Counseling Programs:** Offer financial allowances to customers to choose the services they want within their spending plan. This form of person-directed service offers the most flexibility and autonomy and makes it possible for customers to compensate their family and/or friends that contribute to their care.
- **Brokered Support** – Is delivered by independent agents who function as an “ally” to customers, supporting in fulfilling their life goals by determining and directing the supports needed.

There are several types of service models of self-directed care that demonstrate a range of fiscal control (Powers, 2004).

- **Direct cash payments:** Customers are responsible for all facets of funding and service management, for example, “cash and counseling” programs.
- **Fiscal intermediary:** Allows consumers to manage the services provided and take control of administrative employment functions such as payroll, taxes and paperwork.
- **Supportive intermediary programs:** Assist consumers with activities such as service coordination and training of providers.

- **Self-Directed case management programs:** Actively involve customers in decisions regarding their services but retain control over the management of funds and services.

Financing and Advancing for Self-Determined Services

If self-determination for persons with mental illness is to become a reality, flexible and targeting funding must be available. Self-directed care can be funded through a variety of governmental agencies such as:

- Center for Medicare and Medicaid Services Waiver programs
- Social Security Administrations
- HUD
- Vocational Rehabilitation system

However, it is imperative that *adequate* funding is made available for such services. With rampant budget cuts in state mental health systems self-determination initiatives might be seen as a way to cut costs. NMHA opposes any initiative aimed at reducing governmental mental health resources and/or accountability for providing quality health care and would contest any effort to market such a proposal as a “self-determination” initiatives. NMHA encourages consumers and advocates to carefully inspect any proposed self-determination initiatives for adequate funding.

Recommendations/Next Steps

Research: National demonstrations and evaluation programs should be implemented and rigorously evaluated to establish emerging best practice. These evaluations should include the exploration of funding options and multi-agency waivers (Cook et al., 2004). State revenue should be re-directed to self-directed care programs in order for pilot programs to be evaluated (Cook et al., 2004).

Collaboration: Consumer/survivor advocacy organizations, mental health professionals, researchers and other stakeholders must convene to make these promises a reality for persons with mental illness (Powers, 2004). Furthermore, the inter-agency collaboration of federal agencies such as SAMHSA/CMHS, CMS, HUD, SSA etc. is necessary to develop leadership for the creation of self-directed programs.

Education: A great deal of education at all levels is required to inform consumers, service providers, policymakers, system administrators and the general public about self-directed care approaches. The use of peer-to-peer education and training should be utilized and certification made possible for those individuals who seek employment at all levels of self-directed programs (Cook et al., 2004). A re-orientation of the public, providers and professionals about the viability of self-directed care for persons with mental illness is also a must, including continuing to combat stigma.

Defining Self-Determination, Person-Centered Care and Self-Directed Care

While the concepts of self-determination, self-directed care and person directed care are by no means synonymous, they are closely related. For the purpose of this paper all three terms shall be used under the broader theoretical construct of self-determination.

Cook and Jonikas (2002) define self-determination as “the rights of individuals to have full power over their own lives, encompassing concepts that are central to existence in a democratic society, including freedom of choice, civil rights, independence, and self-direction”. Nerney (2004 A) describes the goal of a self-determination movement as one that assists persons with disabilities to obtain a meaningful life in their own communities with strong, positive relationships and a presence in the business and commerce arenas.

The Self-Determination movement has four overarching principles: (Nerney, T. and Shumway, D., 1996):

- **Freedom:** Choosing where and with whom to live, how to make a living, and with whom to develop relationships.
- **Authority:** Being in control of how one’s long-term care dollars are spent.
- **Support:** Arranging public resources in a way that meet the individual needs of a person with a disability.
- **Responsibility:** Using public resource cost-effectively.
- **Confirmation:** Recognizing that individuals with disabilities must play a major role in the development and implementation of self-determination policies.

Person directed care refers to a subset of the broader construct of self-determination. It is “the capacity of individuals to assess their own needs, determine how and by whom these needs should be met, and monitor the quality of services they receive” (National Institute on Consumer-Directed Long-Term Services, 1996). Another related term is self-directed care, which is when funds that are ordinarily allocated to service providers are instead directed to individuals with psychiatric disabilities (Cook, Terrell and Jonikas, 2004).

The History of Self-Determination Movement

The Self-Determination movement has its roots in the physical and developmental disability arenas. Many of the self-determination initiatives that are described later were first developed for persons with either developmental or physical disabilities. The notion of person-directed services has been around for decades, as evidenced in the independent living movement, which has long promoted the use of personal assistance services for

persons with physical disabilities (Powers, 2004). Several key factors played a major role in paving the way for the Self-Determination movement:

Americans with Disabilities Act: The Americans with Disabilities Act was enacted in 1990 and prohibited discrimination against persons with disabilities. Such legislation sought to end the treatment of persons with disabilities as second-class citizens.

Self-Determination Initiatives of Robert Wood Johnson Foundation: In the 1990s the Robert Wood Johnson Foundation funded several projects whose purpose was to give individuals with developmental disabilities the opportunities to control the money for their own care. (Nerney and Shumway, 1996). The implementation of these projects allowed participants to demonstrate the five principles of self-directed care; freedom, authority, support, responsibility and confirmation (Nerney, 2001). More information on these projects can be found on page 11.

Olmstead Decision: Expanded access to person-directed, community-based services for individuals with disabilities was facilitated by the Supreme Court ruling on *L.C. v Olmstead*, 1999. The Court ruled that states must develop adequate community services to move people with disabilities out of institutions. This has resulted in a variety of activity in different states. California, Delaware, New York, Oklahoma, Vermont and Virginia have passed legislation to convene Olmstead-related commissions. Litigation has also been brought forth in several states. For example, in New York a lawsuit has been brought forth on behalf of approximately 4,000 individuals who have serious mental illness and who reside in large adult homes in New York City. The lawsuit alleges that New York State is violating federal laws by segregating individuals in these homes. (Bianco, 2004).

Centers for Medicare and Medicaid Services (CMS), Real Choice Initiative: This initiative is supporting many state activities to expand home and community-based long-term services for people with diverse disabilities. In 2002, under the New Freedom Initiative, the Independence Plus program was established. Independence Plus is a waiver program allows states to offer families and individuals greater opportunity to take control of their health care services. (Centers for Medicaid and Medicare Services, 2004 B). Most recently, the Final Report of The President's New Freedom Commission on Mental Health (July, 2003) has called for a recovery-oriented mental health system to embrace self-determination, empowering relationships, meaningful roles in society and the elimination of stigma and discrimination. The report emphasizes the development of highly individualized health management programs that will help lead the way to recovery and resiliency oriented treatment and supports.

Self-Determination for Persons with Psychiatric Disabilities

For persons with psychiatric disabilities, self-determination is a growing force. Advances in technology and services, the recognition that recovery is a reality, combined with the consumer movement motto, "nothing about us without us" all pave the way for mental

health services to become self-directed and for persons with psychiatric disabilities to live self-determined lives.

The Final Report of the President's New Freedom Commission on Mental Health (2003) validates the message that persons with psychiatric disabilities have been promoting for years...that consumers and families must be fully involved in the process of transforming the mental health system to one that embodies recovery. Such a recommendation will pave the way for persons with mental illnesses to experience self-determination. Examples of support for self-determination include leaders in the mental health consumer/survivor movement calling for an end to forced institutionalization and medication as well as the growing support for consumer/peer run programs. (Powers, 2004)

The Substance Abuse and Mental Health Services Administration (SAMHSA) has convened two meetings to discuss a Consumer Direction Initiative that would allow persons with mental and/or substance use disorders to directly control and manage the services they receive. Specific recommendations to SAMHSA for such an initiative include (Self-Determination Initiative Planning Meeting Report, 2003):

- SAMHSA articulation of the importance of a self-determination paradigm shift at systemic and individual levels.
- SAMHSA support for development of a set of services that rely on peer-based approaches.
- A Self-Determination Initiative must be tailored to meeting the need of diverse populations and the differences in mental health and substance abuse systems.
- A Self-Determination Initiative should actively engage consumers and their families, including persons of color in policy development, research and program design, service delivery and evaluation. In other words, a Self-Determination Initiative must incorporate cultural competence.

Barriers to Self-Determination for Persons with Psychiatric Disabilities

Unfortunately, there are barriers unique to persons with psychiatric disabilities, which have been preventing the self-determination movement from taking hold in the public mental health system. These include:

- **Negative stereotypes:** For years, persons with psychiatric disabilities have been combating the centuries old stereotype that they are not competent enough to make their own decisions, or to be in charge of their own mental health care. In contrast, the philosophy of self-determination asserts that individuals are capable to assess their own needs, determine how and by whom their needs are met and evaluate the quality of services they receive. (National Institute on Consumer-Directed Long-Term Services, 1996). Other stereotypes conflicting with self-determined care include the belief that people with mental illness are dangerous,

manipulative and, therefore, are not deserving of self-determined care (Powers, 2004). However, self-determination encompasses concepts central to democracy itself, including freedom of choice, independence, civil rights and self-direction (Cook & Jonikas, 2002).

- **Public mental health systems are designed to manage instead of support:** Mental health services have, for many years, been viewed as a way to “control” or “manage” individuals with mental illnesses. Self-directed care assumes the opposite, that persons with mental illness can manage their own care. This belief is underpinned in the President’s New Freedom Commission on Mental Health. In its final report (2003), the Commission recommended that mental health services be consumer and family driven, and that “the hope and the opportunity to regain control of their lives...will become real for consumers” (p.9).

Overcoming Barriers to Self-Determination:

The Village ISA is a program in Long Beach California which serves individuals with serious mental illness. The Village has a “high risk, high support” philosophy wherein individuals are encouraged to take risks and staff are available to provide support the individual so that they will successfully negotiate the consequences of the risk. Such an approach is consistent with a self-determination approach to mental health services.

- **Unemployment:** The unemployment rate for persons with psychiatric disabilities hovers at 85-90% (USDHHS, 1999) and persons with psychiatric disabilities are the largest category of disability benefits (Social Security Advisory Board, 1998). Persons with a psychiatric disability who are unemployed most likely will receive their mental health services from the public mental health system which as mentioned previously, is designed to manage, not to empower.
- **Separate Service System:** Although self-determined services have been a relative success for those with physical disabilities, the public mental health system has separate rules, regulations and funding streams.
- **Lack of outcomes for self-directed care:** A growing number of states have placed an emphasis on funding evidence-based practices, i.e., those services that have a significant amount of research documenting their effectiveness. Some of the services that persons with psychiatric disabilities might choose under a self-directed care model (where the money follows the individual) may be newer programs that have not had adequate time to document their successes. Therefore, states might be reluctant to fund such programs.

Key Elements of Self-Determination

There is a general structure that is fundamentally important for the success of self-determined programs. Nerney and Shumway(1996) articulate that there are, in essence, three key elements to self-determination; these ideal tools are:

- **Individual Budgets:** The creation of highly personalized and unique budgets for persons is critical to the implementation of self-determination. An ideal standard of individual budgeting should include the budget being created by the individual and his/her freely chosen allies; the individual retaining authority over personnel hired to work for him/her, and flexibility in how and where dollars are spent.
- **Support Coordination** (or independent brokering): This refers to “conflict of interest free” assistance that is provided to individuals, families, and allies in order for them to successfully negotiate the planning, organizing and developing of supports unique to the needs of the individual. This assistance may come from an independent contractor, or an independent agent, (either of which is chosen by and is under the employment of the individual) and must carry sanctioned authority to represent the care of the individual with a psychiatric disability.
- **Fiscal Intermediaries:** These are organizations where an individual budget is banked. The functions carried out by such fiscal intermediaries include writing checks for personnel costs and bills, and dealing with taxes and benefits appropriate to the individual’s budget. The fiscal intermediary is accountable for complying with state and federal laws and ensuring, among other things, separation and accounting for an individual’s budget and no conflict of interests. Wherever possible, these intermediaries should be local, generic, community organizations that create relationships between the individual the community.

Person-Centered Planning:

The Centers for Medicaid and Medicare Services (CMS) have identified person centered planning as a critical component to self-determination. Person-centered planning is a comprehensive strategy for putting necessary services and supports in place to help people achieve their goals. Person centered planning is driven by the individual who is receiving services, but works best when it includes other people who can contribute valuable information to the process. During person-centered planning, an individual identified his or her strengths, capacities, preferences, needs and desired outcomes (Cook et al., 2004).

Types of Self-Directed/Self-Determined Programs

There are a spectrum of programs and services emerging within the theoretical framework of self-determination, each demonstrating varying levels of control. Three of the most common forms of self-directed care are as follows (Powers, 2004):

- **Personal Assistance:** This involves providing assistance to persons with disabilities with tasks they would be able to do themselves if they did not have a disability, such as personal care and communication supports. In-home delivery of services is emphasized, allowing the individual control over the selection and direction of his/her personal assistant.
- **Cash and Counseling:** This form of person-directed service offers the most flexibility and autonomy and also makes it possible for customers to compensate their family and/or friends that contribute to their care. These programs offer financial allowances to customers so that they can choose the services they want within their spending plan. Case managers, provider agencies or independent support coordination organizations frequently offer employment and fiscal intermediary assistance.
- **Brokered Support** – This type of self-directed care is delivered by independent agents who function as an “ally” to customers. The agents support customers in defining and fulfilling their life goals by assisting the customer with determining and directing the needed services. The customer selects these brokers whose functions include accessing providers, resources, information, education and supports in topics such as housing, employment and recreation.

Importance of Adaptation:

Models of self-directed care have traditionally been geared towards persons with physical and developmental disabilities. As with any idea which has been borrowed from another field, the models of self-directed care may need to be adapted to meet the needs of persons

What types and payment structures of person-directed care do consumers prefer? Both the types and payment structure of self-directed care offer a range of choice regarding fiscal control. However, most individuals choose programs which either a) provide cash payments and leave the customer in charge of the management of services or b) programs that allow customers to designate all the service management to an agency.

Payment Structure of Person-Directed Models

A critical component of self-determination for individuals with psychiatric disabilities is the ability to have control over the money used to pay for the services they want and need. There are several types of service models of self-directed care that demonstrate a range of fiscal control (Powers, 2004).

- **Direct cash payments:** Customers are responsible for all facets of funding and service management, for example, “cash and counseling” programs.

- **Fiscal intermediary:** Allow consumers to manage the services provided and takes control of administrative employment functions such as payroll, taxes and paperwork.
- **Supportive intermediary programs:** These programs assist consumers with activities such as service coordination and training of providers.
- **Self-Directed case management programs:** These programs actively involve customers in decisions regarding their services but retain control over the management of funds and services.

NMHA recognizes that self-directed care programs for persons with mental illness are in the early stages of development and are being closely scrutinized. Therefore, in order to insure that such programs remain a viable means to recovery-oriented services, it is important that self-directed care programs receive adequate training in fiscal management procedures.

Current Examples of Self-Determination/Self-Directed Care

Florida: The Florida Self-Directed Care program is one of the few operational examples of a self-direction program for persons with mental illness. The concept was developed by a team of individuals from NAMI's Nassau County Florida office and took about three years to be authorized and implemented (Consumer Direction Initiative Summit, 2004). The program currently has 100 participants and will be expanding. Participants must be eligible for some form of disability income (such as SSI or SSDI) due to their psychiatric disability (Consumer Direction Initiative Summit, 2004).

The Florida SDC program provides independent brokerage and coaching services to adults with psychiatric disabilities who depend on public funding to access mental health care. The Florida SDC program provides fiscal intermediary services so that participants can manage the state funds allocated for their mental health care services. This gives consumers the freedom to choose providers and services that help them achieve a state of mental wellness and recovery. The providers may or may not already be a part of the current community mental health system (FloridaSDC, 2003).

Program outcomes are measured by counting productive days in the community (as defined by each individual), structured self-reports of satisfaction with the program's delivery approach from participants, and structured self-reports about achievement of personal recovery goals and objectives (FloridaSDC, 2003). For more information on Florida SDC, visit: www.Floridasdc.org.

Michigan: Through the creation of Community Mental Health Services Programs (CMHSP's) in 1998, the state of Michigan began a major shift in financing mental health, substance abuse and developmental disability services. Similar to California, Florida and Colorado, Michigan bundled county money into one managed care contract under 1915(b) and 1915(c) waivers (Consumer Direction Initiative Summit, 2004). However, Michigan went beyond the traditional managed care approach by passing legislation requiring person-centered planning to be implemented in all specialty services. This

makes Michigan one of the few states to have implemented self-determination efforts through person-centered planning (Consumer Direction Initiative Summit, 2004).

To increase service options, CMHSPs' managed care contracts include a minimum set of services that must be available, including newly developed services (Centers for Medicare and Medicaid Services, 2004 A). The state expected that cost savings from implementing the managed care model would enable CMHSP's to afford the development of new services (Centers for Medicare and Medicaid Services, 2004 A). Michigan pays the CMHSPs a set amount for each person per month (a capitated payment based on historical costs for services), instead of paying the specialty service providers directly for a service (Centers for Medicare and Medicaid Services, 2004 A).

Evaluations of Michigan's plan report that the wait between an assessment for non-emergency services and receipt of services decreased. Also, the proportion of people with serious mental illness using services increased (Centers for Medicare and Medicaid Services, 2004 A).

Georgia: The State of Georgia has developed a way for self-directed care such as peer support to be funded using the Medicaid Rehabilitation Option (Cook et al., 2004). The Medicaid Rehabilitation Option allows agencies to bill Medicaid for services that promote recovery and are offered outside of traditional clinics. It also allows for self-directed care such as peer services to be provided either through traditional provider settings or in consumer operated settings (Georgia Division of Mental Health, Developmental Disabilities and Addictive Diseases, 2003).

The Georgia Peer Specialist Project is a statewide program that trains and certifies 52 Peer Specialist a year to work in the Georgia mental health system. Peer specialist are recruited, trained and certified in accordance with the requirements of the Georgia State Mental Health Plan. Certified Peer Specialist (CPS) receives extensive training in the delivery of supportive services to assist individuals with their recovery. Examples of supportive services include: goal setting, developing mutual self-help groups, providing vocational assistance (Cook et al., 2004). At the present time, over 191 CPS's have provided Medicaid reimbursable services and over 2500 individuals have been served (Cook et al., 2004).

Cash and Counseling Programs: The Cash and Counseling initiative (www.cashandcounseling.org) is a national program sponsored by the Robert Wood Johnson Foundation (RWJF) and the Department of Health and Human Service (Consumer Direction Initiative Summit, 2004). The vision guiding this program is the promise of a "nation where every state will allow and even promote a participant directed-individualized budget option for Medicaid-funded personal assistance services" (Centers for Medicare and Medicaid, 2004 A).

The programs were implemented in three states- Arkansas, New Jersey and Florida. To date, these programs have been directed at those with developmental and physical disabilities and older adults, although some persons with mental illness have participated in the program (Consumer Direction Initiative Summit, 2004).

The Cash and Counseling approach provides consumers with a flexible monthly allowance that is based on an individualized budget, allowing them to direct and manage their own services and address their own specific needs (Centers for Medicare and Medicaid Services, 2004A). In addition, this innovative program offers financial assistance to help consumers manage their allowances and responsibilities. (Consumer Direction Initiative Summit, 2004). These program characteristics are adaptable to consumers of all ages with various types of disabilities and illnesses.

Cash and Counseling intends to increase consumer satisfaction, quality, and efficiency in the provision of personal assistance services. The results of the program have been impressive and are discussed in detail in the next section.

Due to these successes, the interest in this project, and a suitable political environment, grants and technical assistance will be offered to states wishing to replicate or expand on the Cash and Counseling model (Cash and Counseling, 2004 A).

Evaluation and Research of Self-Determined Care Programs

While research into the impact of self-determination is in its infancy, early findings suggest a range of benefits these programs may have over traditional services. Quantitative analysis of the original demonstrations of the Cash and Counseling program, for example, examined the differences in consumer satisfaction, quality of life, the amount and types of obtained personal assistance services, and the cost between participants in the states' Cash and Counseling programs and those receiving traditional agency-directed care (Powers, 2004). Results from Arkansas found that Cash and Counseling participants were more satisfied with the quality of their services, had increased access to paid care, had fewer unmet service needs, and experience an improved quality of life (Powers, 2004). This research also suggested that the novel approach was budget neutral.

A qualitative study of the same program also revealed consumers' improved quality of life and satisfaction with their care, flexibility offered by the program to meet consumers' changing needs, the important role of families in meeting the complex needs of consumers with multiple disabilities, and creative uses of the cash benefit to meet consumers' needs.

Over 85% of the recipients of cash payments in the Arkansas initiative would recommend the program to others. In Florida, 97% recommended their program. In Michigan, the number of persons with serious mental illness increased, while the average wait times between initial assessment and receipt of services decreased. There were also small cost savings in each of the target populations. For a detailed look at these evaluations please see <http://www.hhp.umd.edu/AGING/CCDemo/index.html>.

While the results of these studies are extremely promising, it should be noted that the majority of participants in the Cash and Counseling Programs are those individuals with

developmental and physical disabilities. Therefore, it is conceivable that the evaluation result cannot be generalized to persons with psychiatric disabilities.

Recognizing the lack of research on self-determination in persons with psychiatric disabilities, The University of Illinois at Chicago developed a National Research and Training Center on Psychiatric Disability devoted specifically to self-determination. Activities of this Center include: a national conference on Self-Determination for mental health consumers/survivors, a self-determination workshop series and a research project on advancing knowledge and training on self-determination disabilities (UIC NRTC Center Abstract, 2004). Judith Cook, the Center Director has written several articles on how mental health systems can promote self-determination.

Leff, Conley, Phil, Campbell-Orde and Bradley (2003) make the following recommendations for developing a self-determination research agenda for persons with psychiatric disabilities:

- The development of an operational definition and measures of self-determination for persons with mental illnesses.
- The identification, development and dissemination of services and practices that directly contribute to self-determination in systems
- The monitoring of self-determination in systems as a component of quality assurance and consumer satisfaction.

Financing and Advocating for Self –Determined Services

If persons with mental illness are to see self-determination as a reality, flexible and targeting funding must be available. Listed below are current and future ways in which self-directed care can be funded.

CMS Waivers

The federal Centers for Medicaid and Medicare Services (CMS) promotes the implementation of self-directed care through person-centered planning, individual budgeting, financial management systems and support brokerage. States can apply these elements of self-directed care by applying for federal Medicaid funding through certain waivers that allow for more effective and efficient use of Medicaid. CMS has developed templates for two of the three waivers (1915(c) and 1115), under the rubric '*Independence Plus*' (<http://www.cms.hhs.gov/independenceplus/>). (Cook et al., 2004)

1915(c) Waivers: This waiver is typically the vehicle for self-direction among those who do not have mental illness. The waiver lists a set of Home and Community Based Services that are optional, such as case management and home health aide services (Cook et al, 2004). This waiver is designed to provide home and community based services for those who would otherwise be placed (or are already placed) in nursing homes, hospitals, or Intermediate Care Facilities for Mentally Retarded Individuals. The 1915(c) waiver cannot be used for adults between 22 and 64 who would be served in an institution for mental diseases, as indicated in the IMD exclusion (Cook et al, 2004). Additional

services supporting self-direction under a 1915(c) Independence Plus Waiver include support brokerage and financial management services.

1915(b) Waivers: 1915(b) waivers allow states to waive freedom of choice of providers, making them ideal for implementing Medicaid managed care programs. They also allow states to use a central broker and, most importantly for self-direction, allow states to use any cost savings to fund additional services (Cook et al., 2004). These new services can be highly flexible, enabling states to create services and supports such as consumer-run drop-in centers or peer support group programs.

1115 Waivers: Section 1115 of the Social Security Act allows States to develop experimental, demonstration or pilot projects by waiving requirements that restrict services and eligibility. CMS has final approval authority, but the waiver process is structured to encourage collaboration between states and the CMS (Cook et al, 2004). The waiver process is multi-step and includes a proposal, site visit and evaluation components, and this process can take up to two to three years – a significant drawback of 1115 waivers (Cook et al., 2004). The CMS has developed a template for States seeking such a waiver to develop self-directed care programs (<http://www.cms.hhs.gov/independenceplus/1115temp.pdf>). This waiver allows services with a great deal of flexibility and the closest resemblance to a recovery model of service (Cook et al., 2004).

Social Security Administration (SSA)

Ticket to Work and Work Incentives Improvement Act (TWWIIA): A program of the Social Security Administration, TWWIIA was signed into law 1999, and targeted individuals receiving SSI or SSDI. The Act aimed to counter some of the work disincentives that are inherent in SSA regulations. TWWIIA offers benefits planning and assistance (BPA) to inform participants about the effects of employment on their disability cash and non-cash income, providing health care to beneficiaries who may otherwise lose eligibility for cover under Medicaid and Medicare by losing eligibility for cash payments, and providing vouchers (referred to as Tickets) directly to participants which can then be “redeemed” for vocational services from local employment providers (Cook et al., 2004). These vouchers cannot, unfortunately, be used entirely at the discretion of the participant, as the choice of vocational service providers is limited to those certified as employment networks (EN’s) by SSA (Cook et al., 2004).

The success of these tickets has been limited, especially among populations with developmental and psychiatric disabilities. Given that the SSA is willing to provide someone with 40% of the average value of an individual’s SSDI or SSI payment, it may be a more reasonable approach to provide direct cash payments to the individual themselves to purchase VR services from EN’s (Cook et al., 2004). This way, individuals could choose services such as assessment, job skills training, job coaching, job placement, and post-secondary education for career advancement, and the SSA could cut out the “middle man.” The EN could cash out ticket monies directly to SSDI/SSI beneficiaries, simply by re-writing its rules and regulations (Cook et al., 2004).

Income Support System: There are two major constraints on self-determination within the SSA that have a significant impact on people with mental illnesses: lack of access to health care coverage and barriers to economic security (Cook et al., 2004). Many people rely on their SSA benefit (either Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI)) to qualify for health care under Medicaid or Medicare, thus trapping them, although unintentionally, in poverty. Additionally, public disability cash payments are set below the poverty line, making persons with psychiatric disability among the poorest in the nation and often unable to meet their basic needs.

As the largest provider of cash benefits for people with mental illnesses, SSA has enormous potential for enhancing self-determination (Cook et al., 2004). The impoverishment built into the system would be greatly reduced by removing economic disincentives (such as the mandated review of disability status upon return to work) and by adjusting policies to allow for the provision of continuous health care coverage to all persons with severe disabilities regardless of employment or earnings status (Cook, 2004). SSA has tried to address these problems by raising the Substantial Gainful Activity (SGA) level (i.e., the amount of money a person is allowed to earn before a reduction in benefits occurs), extending Medicaid eligibility after payments cease, and allowing people to put aside a portion of their earnings for employment-related expenses through a plan written in conjunction with SSA (Cook et al., 2004). Unfortunately, there is a widespread agreement that these changes have been predominantly ineffective (New Freedom Commission on Mental Health, 2003).

The public disability income support system, if reformed, could be one of the most promising major systems in which the economic self-sufficiency of individuals with psychiatric disabilities could be improved and could have a major impact on the possibility of self-determination (Cook et al., 2004).

Housing and Urban Development (HUD) Agency

Section 8 vouchers: The federal Housing and Urban Development (HUD) agency is facing significant problems with its housing voucher program (Section 8) that provides low-income families the choice to rent or buy affordable housing with these vouchers.

Within a self-determination framework the goals of housing assistance are for people to have the choice of where to live, and who to live with, or as Nerney (2004 A) puts it, to have a place where people have “authority over who comes in the front door.”

The agency’s website notes that “...the housing voucher program has grown into a complex, overly prescriptive program that is increasingly difficult to administer” (<http://www.hud.gov/offices/pih/programs/hcv/index.cfm>).

These problems may work to the advantage of those advocating for self-determination for persons with mental illness in the housing sector, as the environment may be more conducive to change given these general problems.

The primary shortcomings of the current Section 8 vouchers are a) the complicated application process, and b) the required documentation that must be assembled

(Nerney, 2004 A). To address these obstacles, non-profit housing corporations can work with local HUD authorities to develop programs, such as the Creative Housing program in Ohio (Nerney, 2004A). This program allows Section 8 vouchers to become portable, so that individuals can take them with them as they move. This system enables people to rent from any landlord who will accept the vouchers. This program also maintains the Section 8 subsidy to the property after tenants leave. The result is that a non-profit housing corporation is able to “maintain subsidies to units that have waiting lists while also providing existing tenants with opportunities to move without losing their vouchers” (Cook, 2004:17).

The Vocational Rehabilitation (VR) system: When structuring their VR systems, states are given a fairly long rein. Thus there are no federally “mandated” services that a person must receive from the VR system. Given this flexibility, self-determination is possible with minimal system changes. Nerney (2004 A) states that one way of doing so would be to “cash out” some of the money spent by the state-federal VR for service delivery. Similar to Medicaid waivers, funds could be funneled through fiscal intermediaries and used to fund small businesses, pursue vocational training, hire job coaches, or higher education.

Another idea proposed by Nerney is to pay employers directly to provide job coaches or employment support specialists or other workplace-based supports. This money could come from VR, SSA, or other sources. This would also give employers assurance that job support personnel would have the company’s best interests at heart while enabling persons with disabilities to choose an employer that has those sorts of supports in place.

Cautionary Note Regarding Funding for Self-Determination Initiatives: It is imperative that *adequate* funding is made available for such services. In this current climate of rampant budget cuts in state mental health systems self-determination initiatives might be seen as a way to cut costs by shifting the financial risks directly to program participants. In a review of the Independence Plus program, Jeffrey Crowley suggests that federal requirements and guidance for states may not be sufficient enough to guarantee the individual budgets are adequately funded. NMHA opposes any initiative aimed at reducing governmental mental health resources and/or accountability for providing quality health care and would contest any effort to market such a proposal as a “self-determination”. NMHA encourages consumers and advocates to carefully inspect any proposed self-initiatives for adequate funding.

Recommendations/Next Steps

A strong consensus is shared by advocates in the self-determination movement that there are certain steps that must take place for self-determined care to become rooted in our mental health system. Increasing the number of available programs will require further investigation into their benefits, ongoing consumer/survivor advocacy, strengthening political will to divert funds to person-directed services, and policy and system

improvements to address the barriers to self-directed care for persons with psychiatric disability (Powers, 2004). The main areas in which recommendations for moving forward in this arena are:

Research: National demonstration and evaluation programs should be implemented and rigorously evaluated to establish emerging best practices. These evaluations should include the exploration of funding options and multi-agency waivers (Cook et al, 2004). State revenue should be re-directed to self-directed care programs in order for pilot programs to be evaluated (Cook et al, 2004). Research and thoughtful planning will have to take place to further evaluate and promote the effectiveness of self-determined programs (Powers, 2004).

Collaboration: Collaboration between the major players in mental health is essential to increasing access to self-determined care. Consumer/survivor advocacy organizations, mental health professionals, researchers and other stakeholders must convene to make these promises a reality for persons with mental illness (Powers, 2004). The inter-agency collaboration of federal agencies such as SAMHSA/CMHS, CMS, HUD, SSA etc. is necessary to develop leadership for the creation of self-directed programs. In addition, federal agencies should collaborate with consumer organizations.

On the collective level, consumers need to be employed in leadership roles in the development of such an initiative, to be involved in research promoting recovery and in campaigns to increase awareness of recovery and to reduce stigma (New Freedom Commission on Mental Health, March, 2003). To achieve the latter, the Subcommittee (New Freedom Commission on Mental Health, March, 2003) urges a shift from traditional services to recovery planning services, such as peer support services and those services provided by independent living centers. Through the integration of peer supported services into the continuum of community care, both public and private funding mechanisms could create enough flexibility to allow access to these effective support services. Furthermore, collaboration among federal agencies (namely between CMS, SAMHSA and RSA) is urged to enable individuals with psychiatric disabilities to manage their Medicaid benefits and to obtain the services, both public and private, that they need (New Freedom Commission on Mental Health, March 2003).

As part of the President's New Freedom Commission on Mental Health, there is a call for federal, state and local governments together to develop a National Recovery Initiative to promote consumers' self-determination both at the collective and individual levels of recovery (New Freedom Commission on Mental Health, July 2003).

Education: A great deal of education at all levels is required to inform consumers, service providers, policymakers, system administrators and the general public about self-directed care approaches. The use of peer-to-peer education and training should be utilized and certification made possible for those individuals who seek employment at all levels of self-directed programs (Cook et al, 2004). A re-orientation of the public, providers and professionals about the viability of self-directed care for persons with mental illness is also a must, including continuing to combat stigma. If self-determination is to succeed, technical assistance will need to be provided at various different levels.

There is also a need for the development of new technologies and materials to support self-directed care programs to allow individuals to seek out the available treatments and information about their illnesses. If the money is to follow the person, individuals with psychiatric disabilities must be well equipped to manage their financial resources (Cook et al., 2004).

REFERENCES

Bianco, Carol (2004). Legal advocacy as a means to systems transformation. Presentation for Recovery In Action: Identifying Factors and Trends of Transformational Systems meeting. Advocates for Human Potential, Inc. Delmar, NY.

Centers for Medicare and Medicaid Services (CMS) (2004 A) Promising practices in home and community-based services. Retrieved from: www.cms.hhs.gov/promisingpractices/mipcp.html.

Centers for Medicare and Medicaid Services (CMS) (2004 B) Accomplishments under the New Freedom Initiative. Retrieved from: www.cms.hhs.gov/accomplish.pdf

Cook, J.A., and Jonikas, J.A., (2002) Self-Determination among mental health consumers/survivors: Using lessons from the past to guide the future. Journal of Disability Policy Studies, 13(2), 87-95

Cook, J.A., Terrell, S., and Jonikas, J.A., (2004) 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, Center for Self-Determination Publication Draft. Chicago, IL: University of Illinois at Chicago National Research and Training Center on Psychiatric Disability. (Draft)

Consumer Direction Initiative Summit: Final Report Draft, (2004). Substance Abuse and Mental Health Services Administration Department of Health and Human Services. Rockville, MD

Crowley, Jeffrey. The Independence Plus Initiative to Promote Consumer Direction of Services. Undated presentation. Health Policy Institute. Georgetown University.

Florida SDC (2003). Booklet Form #4007.

Georgia Division of Mental Health, Developmental Disabilities and Addictive Diseases (2003). Georgia's Consumer-Driven Road to Recovery: A Mental Health Consumer's Guide for Participation In And Development of Medicaid Reimbursable Peer Support Services. Office of Consumer Affairs.

Leff, H.S., Conley, J., Phil, B., Campbell-Orde, T., Bradley, V, (2003). Getting to systems that promote self-determination through research and evaluation. Chicago, IL: University of Illinois at Chicago National Research and Training Center on Psychiatric Disability. Retrieved from: <http://www.psych.uic.edu/uicnrtc.sdconference.html>

Nerney, T., (2001) Filthy Lucre: Creating better value in long term supports. Ann Arbor, MI: Center for Self-Determination

Nerney, T., (2004) The promise of self-determination for persons with psychiatric disabilities. In Jonikas, J.A., and Cook, J.A., (Eds.) The UIC NRTC's National Self-Determination and Psychiatric Disability Invitational Conference "We Make the Road by Traveling On It" Conference Papers (pp.129-175) Chicago, IL: University of Illinois at Chicago National Research and Training Center on Psychiatric Disability

Nerney, T., (2004) Communication, Self-Determination: Freedom, Authority, Support and Responsibility: The Tools of Self-Determination. Retrieved from: <http://www.self-determination.com/publications/toolsprint.html>

Nerney, T., and Shumway, D., (1996) Beyond managed care: Self-Determination for people with disabilities. Retrieved from: <http://www.unh.edu/rwj/library/bmcpage1.html>

New Freedom Commission on Mental Health Achieving the Promise: Transforming Mental Health Care in America Final Report. DHHS Pub. No. SMA-03-3832. Rockville, MD: July, 2003.

New Freedom Commission on Mental Health (March, 2003) Report of the subcommittee on consumer issues: Shifting to a recovery-based continuum of care, Retrieved from: http://www.mentalhealthcommission.gov/subcommittee/consumer_022803.doc

Powers, L.E., (2004) Self-Determination and person-directed support, In Jonikas, J.A., and Cook, J.A., (Eds.) The UIC NRTC's National Self-Determination and Psychiatric Disability Invitational Conference "We Make the Road by Traveling On It" Conference Papers. Chicago, IL: University of Illinois at Chicago National Research and Training Center on Psychiatric Disability

Self-Determination Initiative Planning Meeting Report (2003). Substance Abuse and Mental Health Services Administration Department of Health and Human Services. Rockville, MD

Social Security Advisory Board (1998) How SSA's Disability Programs Can Be Improved. Washington, D.C.

University of Illinois at Chicago National Research and Training Center (2004). Center Abstract. Retrieved from: <http://www.psych.uic.edu/uicnrtc/default>.

U.S. Department of Health and Human Services. Mental Health: A Report of the Surgeon General. Rockville, MD. US Department of Health and Human Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute for Mental Health, 1999.