

**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***

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“... 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” (Final Report of the President’s New Freedom Commission on Mental Health, 2003).

INTRODUCTION

Self-determination refers to the right 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 (Cook & Jonikas, 2000). In the United States today, individuals with serious mental health problems experience minimal self-determination given society's failure to provide them with adequate, recovery-oriented services or choices in how to use available services (Fisher & Ahern, 1999; Lamb, 1994; Manderscheid, Henderson, et al., 1998). For those who do seek help, services often fall far short of those considered minimally adequate for clinical care, rehabilitation, and recovery (Lehman, Steinwachs, et al., 1998; Wang, Demler & Kessler, 2000). This has created a need for new models such as self-directed care, in which funds that would ordinarily be paid to service provider agencies are transferred directly to people with psychiatric disabilities, using various formulas to account for direct, administrative, and other costs. By giving financial control to service users -- via fiscal intermediaries who handle billing, payroll, taxes, and other administrative functions -- people with mental illnesses can better coordinate their own services and service providers and can, presumably, better direct their own recovery.

Self-directed care is not the only route to enhancing self-determination among people with mental illnesses. Other strategies include consumer-operated services (Campbell & Salzer, 2002), illness self-management (Copeland, 2004), advance directives for mental health care (Sherman, 1998), advance crisis planning to reduce seclusion and restraint in inpatient settings (Jonikas, Cook, et al., in press), leadership training (Belcher & Muscari, 2004), peer-to-peer services (L. Fricks, personal communication, February 20, 2004), political activism and non-violent civil disobedience (Oaks, 2004), service provision by consumers working in traditional programs (Jonikas, Solomon, et al., 1997), and improving the degree of choice available to individuals in the already-existing public mental health system through methods such as consumer advocacy (Cook,

Toprac & Shore, in press). In fact, self-directed care may not be more highly preferred than any of these other approaches, and it can certainly co-exist with all of them.

Self-direction is built on a system of values that operate at individual, societal, and systemic levels. Some *individual* values of self-direction include freedom of choice, control over one's own life, access to support and assistance, and personal responsibility. *Societal* values inherent in self-direction include promotion of civil liberties, fairness, freedom from coercion, nondiscrimination, and reliance on free market forces. *Systemic* values underlying self-direction include efficiency, effectiveness, budget neutrality, quality, and consumer satisfaction.

In this paper we begin by examining promising interconnections between the concepts of recovery, self-determination, and self-directed care. We then review five principles of self-direction, noting how freedom, authority, support, responsibility, and confirmation operate to enhance individual choice and enable people with psychiatric disabilities to build meaningful lives. Next, we explore the major systems in the U.S. that can serve as sources of cash-out funding as well as those that would be most affected by widespread adoption of self-directed care, along with some of the barriers to change that are present in these systems. The systems we discuss include Medicaid, Community Mental Health Block Grants, State general revenue and legislative systems, public housing, fiscal agents and intermediaries, federal-State vocational rehabilitation, workforce development, public disability income support, the Ticket to Work, the banking system and Individual Development Accounts, and the system of technology. The paper concludes with a series of recommendations for next steps in adopting this mental health care financing mechanism for self-determination, including the important role of peer-to-peer services in operating these programs.

RECOVERY, SELF-DETERMINATION, AND THE STAGES-OF-CHANGE MODEL

While the concepts of recovery and self-determination are fundamental to self-directed care for individuals with psychiatric disabilities, these constructs have different historical origins and trajectories. The notion of recovery from mental illness originates from the psychiatric survivor movement in mental health and refers to a process by which persons create a meaningful, productive life despite the challenges faced by the illness (Anthony, Cohen, Farkas & Gagne, 2002; Deegan, 1988). Self-determination theory grows out of 30 years of psychological research on human motivation concerned with the development and functioning of personality within social contexts (Deci & Ryan, 1985). It focuses on the degree to which human behaviors are volitional or self-determined; that is, the extent to which people endorse their actions at the highest level of reflection and engage in these actions with a full sense of choice (Deci & Ryan, 2000).

In the 1990s, the Robert Wood Johnson Foundation funded a series of successful self-determination projects focused on individuals with developmental disabilities (Nerney & Shumway, 1996). In these projects, participants were given the opportunity to control financial resources in order to direct their own care. As embodied by these projects, self-determination rests on five interrelated principles: freedom, authority, support, responsibility, and confirmation (Nerney, 2001). The following discussion

outlines the two related concepts of recovery and self-direction and suggests a framework that connects the two in a manner that mutually reinforces each construct.

Recovery from Mental Illness. The Final Report of President Bush's New Freedom Commission, "Achieving the Promise: Transforming Mental Health Care in America," supports the philosophy of recovery through its Recommendation # 2.2 to "Involve consumers and families fully in orienting the mental health system toward recovery."

Recovery from serious mental illness involves regaining a sense of purpose and control over one's life that overcomes, to the extent possible, limitations imposed by the illness. Research in this field has identified a set of outcomes that result from the recovery process. A recent literature review (Lieberman, Kopelowicz, Ventura & Gutkind, 2002) suggests that these outcomes are both subjective and objective. Subjective outcomes include the establishment of meaningful relationships and social roles, and the development of a sense of hopefulness and purpose in life. Objective outcomes of recovery from mental disorders include symptom remission, improved or restored vocational functioning, independent living, and economic security.

Stages-of-Change Model. The adoption of Recovery as a goal of treatment for mental illness involves acknowledgement that such personal changes are possible for individuals, as well awareness that changes must occur in the service delivery system in order to facilitate and support the recovery process. Part of this "systems change" effort involves the recognition that people with mental illnesses are at various stages in the recovery process. The Transtheoretical Model developed by Prochaska and DiClemente (1983) provides a useful heuristic device for conceptualizing recovery on an individual level. This model was developed through research in health psychology and addiction treatment as a way to create more effective program models. The stages of change model views the change process as incorporating five stages: precontemplation (not yet thinking seriously about changing), contemplation (beginning to desire to change), preparation (taking small steps toward change), action (taking necessary steps to realize change), and maintenance (sustaining change over time). This model also takes into account relapse and recycling through stages.

When applying the model in work with an individual, it is important to be aware of the person's current stage in the recovery process, and to provide the services and supports that are needed to move to the next stage in the sequence. For example, individuals typically do not move directly from precontemplation to action, but instead from precontemplation to contemplation, or from action to maintenance. This model has proven effective in substance abuse treatment and other types of health related behavior such as smoking cessation and compliance with automobile seatbelt laws. It has now begun to generate positive results for persons with serious mental illnesses (Hilburger & Lam, 1999).

In applying the model to the recovery process of people with mental illnesses, it is important that a wide range of service options be available, in accordance with the individual's stage in the change process, as well as their values, preferences, and stated

goals. Historically, most treatment programs are designed for persons who are at the later stages of the model (Hilburger & Lam, 1999). Instead, systems can be designed to provide supports for individuals along the entire spectrum of the change process, ultimately challenging the system to create self-directed opportunities for all persons needing assistance at all points in their recovery process and across the entire range of symptoms and experiences of psychiatric disability. The following discussion posits that the principles of self-direction provide an ideal context to support the recovery process.

Self-Direction. Self-direction is a philosophy designed to help persons with special needs build a meaningful life with effective opportunities to develop and reach valued life goals. Self-direction provides a framework for the organization of service delivery systems to support the recovery of people with mental illnesses, at any stage in the process of change by accommodating a wide range of goals and preferences. Self-direction is built on the five principles of freedom, authority, support, responsibility, and confirmation mentioned earlier and discussed in detail below.

Freedom. A fundamental aspect of freedom is the ability to choose how to live and the capacity to obtain the means to develop and achieve our goals. “Effective freedom,” first conceived by Nobel Prize Laureate Amartya Sen (1999), is the notion that freedom, even when legally codified, is effectively restrained when there is a lack of psychological, social, and monetary resources available to achieve goals and live a meaningful life. Effective freedom is predicated on individual values and preferences, and in this regard it is mediated by the capacity a person has to develop and act on meaningful choices.

Using this framework, the role of a service delivery system for persons with mental illnesses is to maximize the potential for equality of capability by ensuring that services and supports are geared toward harnessing the motivation inherent in idiosyncratic as well as shared values. Effective freedom is increased by creating a support system that is as flexible as possible in helping people with psychiatric disabilities develop a sense of the possible while providing the assistance necessary for them to obtain resources, including social and psychological as well as financial and other materials resources. Traditional systems of care offer people few choices and little individual control over their mental health services or caregivers. Paradoxically, this kind of system increases dependency in the name of “treatment” rather than fostering independence. For instance, the dire poverty experienced by many persons with serious mental illnesses restrains their ability to participate in desired activities that lead to meaningful social relationships, such as going out with a friend to dinner or a movie. Instead, they are forced to rely on providers for social contacts such as “leisure and recreation activities,” which can be an unnecessary “service” provided at potentially high cost to the system.

One of the major controversies in the field of psychiatry today is a debate about the competency of individuals with serious mental illnesses. On one side of the debate is the argument that significant numbers of people with mental illnesses lack the insight to make rational decisions (likened to the neurological disorder anosognosia, see

Amador & Paul-Oudouard, 2000). Some proponents of this argument support legal reforms that require persons deemed incompetent to receive outpatient services and unwanted medications against their will, thereby encroaching on their personal freedom. The argument for these legal reforms is based on assertions that persons with serious mental illnesses are or may become dangerous, and therefore need to be protected from causing harm to self or others. On the other side of the argument is the assertion that freedom from coercion is a basic societal value in a democracy, as well as a human right, regardless of one's level of competency. Advocates of this perspective believe that forced treatment will only worsen the fundamental problem of an already overly coercive mental health service delivery system. Proponents of this approach to dealing with problems of competency assert that a well-designed system of care based on principles of recovery and self-direction that is also integrated at the community level will largely negate the need for coercive treatment.

Regardless of the outcome of this debate, in the daily lives of many public mental health service recipients, the very fact of their illness means that their competency and credibility are called into question on a regular basis. This misperception is a formidable barrier to effective freedom for many persons with mental illnesses who are deemed incompetent by the lay public in a variety of settings, including discrimination in housing, employment, education, transportation, and community integration.

Furthermore, it is during the most acute phases of the illness (the so-called "psychiatric crisis") where competency is legally called into question and basic freedoms are restricted. People who are hearing voices suggesting harm to self or others are often presumed to be at a point where all of their preferences can be disregarded in order to assure health and safety. While health and welfare are essential prerequisites for self-determination, the challenge is for their assurance without crossing the line to abuse and coercion. For instance, the use of physical and psychopharmacologic restraints is one such practice that can be easily misused.

One alternative to complete loss of personal freedom in times of crisis is use of a psychiatric advance directive (AD) (Sherman, 1998). Like medical ADs, ADs for psychiatric care document a person's treatment preferences during a period of inability to make decisions by applying a self-determination framework (i.e., the promotion of choice) along with person-centeredness (i.e., an individually tailored plan often including the designation of an "agent" or a person empowered by the individual to make choices on his or her behalf if necessary). This can serve as a mechanism for legally ensuring that emergency workers and inpatient staff honor a person's preferences when he or she is unable to communicate these choices during periods of illness exacerbation.

Authority. Authority in self-determination refers to the fact that persons have control over the dollars spent on their care. This concept is important for people with mental illnesses both on an individual and a collective level. A fundamental assertion of self-determination is that giving people purchasing power promotes a wider range of service choices and enhances both consumer outcomes and satisfaction. The challenge is to develop a system that allows persons with mental illnesses to exercise this authority

over who controls and provides services and supports, as well as what services and supports are needed to meet their recovery goals.

For instance, it may well be that, when given authority, many people will choose alternative services such as peer supports or relaxation therapies in addition to or in place of traditional psychiatric treatment and case management services. Authority to manage a budget allows people to make such decisions, thereby combining the benefits of traditional and alternative therapies. Authority also has the intrinsic value of increasing one's sense of responsibility and self-efficacy, consistent with the recovery model. This is accomplished in an atmosphere of partnership and negotiated risk. Consumer operated services (organizations run by persons with mental illnesses) can greatly enhance the ability of people to exercise their authority in a supportive atmosphere that has been too often absent from the traditional mental health system.

Support. As discussed above, adoption of a self-directed care model requires that a range of service options be available to people in a public mental health system. It is very difficult for people who have long been dependent on public systems to suddenly assert themselves as fully independent agents, capable of making well-informed choices. The reality is that many people receiving services and supports in the mental health system have experienced the same type of demoralizing treatment that politically oppressed groups have faced throughout history. Too often, when people enter the public mental health system they are told that their illnesses will be life-long, precluding recovery. This attitude of low expectations can create a type of psychological "imprisonment" that is antithetical to freedom of choice. The walls of such prisons are reinforced by a system of treatment where responsibility and authority are withheld from individuals, creating unnecessary dependency. Persons with mental illnesses often come to believe that the current system and its imposed reality are all that exist for them. Belief in the likelihood of a more independent, self-actualized future quickly fades from their realm of possibility. They forget how to dream, and hope dies. The role of services in a self-determined, recovery-oriented system is to re-establish hope and to support participants' efforts to make the choices that are best for them. Taking into account both readiness to change and the concept of effective freedom means that some form of self directed care is available to individuals who want it, no matter what stage of change they are in, and that their personal preferences and values are respected. The notion of personal responsibility inherent in providing people with opportunities to control their own dollars, requires that there be sufficient support for decision-making when symptoms of the illness are overwhelming, in order to ensure health and safety.

Responsibility. Often people in the public mental health system lose skills related to taking responsibility for their lives. Abilities to manage finances, choose services, and handle the tasks of daily living are easily lost in a system that fosters dependency. Part of the process of recovery is the reclaiming of personal responsibility for control over one's life. For people with mental illnesses, opportunities for risk-taking are often viewed as being at odds with their ability to act responsibly. For instance, people with mental illnesses are often discouraged from returning to work or pursuing intimate relationships because of the unpredictable nature of their illnesses. This presumed inability to deal responsibly with relapses and set-backs can thus create an

oppressive mental health system that unintentionally promotes dependency and isolation.

Responsibility in self-determination is a “two way street.” Professionals working in the system have responsibility for fostering the recovery of people with whom they work, in ways that promote personal dignity while also allowing for risk taking and learning from mistakes. Participants in the system have the responsibility for setting goals and deciding how to achieve those goals, even in the face of set-backs, as well as developing and adhering to a budget to purchase services and supports for goal attainment. In a self-determining system, service professionals participate in an “equal partnership” with the participant. When responsibility is shared in this way, risk-taking can occur in an atmosphere of safety and supportiveness. In programs where individual budgets are used, the challenge of responsibility is to find the optimal balance between respecting a participant’s unique values and goals and the provider’s responsibility to ensure the health and welfare of the individual as well as society at large.

Confirmation (Participation). The Final Report of the President’s New Freedom Commission on Mental Health recommended that people with psychiatric disabilities and their families be fully included in planning and evaluating treatment and support services. States committed to developing a self-determining mental health system will foster consumer participation at all levels of the system. For this to be meaningful, there must be more than tokenism, where one or two persons with mental illnesses are placed on State and local councils, advisory boards, and steering committees. If systems of care are to be truly self-directed there must be opportunities for service recipients to decide, within a given legal framework, what services and support should be part of the system, who should deliver them, how to develop flexible reimbursement policies, ways to obtain ongoing feedback from the recipients of care, and methods for incorporating participant feedback to improve the existing system. Ultimately, persons with mental illnesses must have formal, sanctioned authority at both the system-wide as well as individual levels, and ideally they will share control over system-wide allocation of dollars as well.

THE MEDICAID FUNDING SYSTEM

Overview of the Medicaid System

In order for self-determination for persons with mental illness to become a reality, there must be sources of flexible, targeted funding available. The federal Centers for Medicare and Medicaid Services (CMS) has developed a set of services and supports that can be used in conjunction with Medicaid programs in a variety of ways, to support self-directed care options. The following sections provide an overview of the federal Medicaid program and discuss State plan options, waivers, and grant opportunities that are available to assist States in developing consumer directed care for persons with mental illnesses.

Medicaid was created as a medical assistance program in 1965 with Title XIX of the Social Security Act. Medicaid is the single largest payer of mental health services in the country, funding almost 20% of all mental health services delivered in the United States (GAO, 2000). Medicaid is funded through combined State and federal dollars using a formula based primarily on the relative income levels of people residing in each State. The minimum share of federal Medicaid funding that States receive is 50% and the maximum is 83% [1905(b)(1)].

The design of Medicaid programs is based on a partnership between States and the federal government, with States taking the lead in developing programs within a legislative and regulatory framework devised by the federal government and administered at the local level by State agencies. While the primary emphasis of the Medicaid program is placed on the delivery of medical services and supports, several amendments over the past decade have created options for States to expand services, supports, and eligibility groups, creating highly variable programs across the country. In part, this is due to the structure of the Medicaid program, in which States set their own rates and administer their own programs.

Currently, self-direction is being promoted among a wide variety of populations at CMS. However the most significant progress with this approach has occurred for persons with developmental disabilities and those who are elderly. The availability of self-direction for people with mental illnesses is fairly limited at this point in the Medicaid program's history, yet, there are several States exploring this option using a variety of funding and delivery mechanisms.

Self-Direction at CMS

CMS has adopted the assumption that self-direction is a prerequisite to a meaningful life and that all participants in Medicaid programs should have effective opportunities to self-direct their services. CMS promotes four essential elements necessary to assist people in implementing self-direction while minimizing undue risk. The essential elements are:

- Person-centered planning;
- Individual budgeting;
- Financial management systems; and
- Supports brokerage.

The following describes current CMS best practices for each of these essential elements.

Person-Centered Planning. One of the most important first-steps in any helping process is to determine what goals a person has and then to devise a plan for achieving these goals. Person-centered planning is a comprehensive strategy for putting necessary services and supports in place to help people achieve their goals.

True to the principles of self-direction, person-centered planning is conducted by individuals who identify their own strengths, capacities, preferences, needs, and desired outcomes. The process works best when it includes other knowledgeable people who can serve as important contributors to the process. However, the individual creating the plan must freely choose any additional participants.

Individual Budgeting. Individual budgets allow people needing assistance to have a detailed say about how the dollars used for their care should be spent. Budgets provide a mechanism for people to have control over their service delivery monies along with who will provide the services and supports named in their individual plan.

There are two aspects to developing an effective budget. First is the determination of the total amount of money to be allocated to different line items in the budget. This is typically based on the individual's needs as identified in the person-centered planning process along with the allowable types of services and supports on which funds may be spent. Second, is the process of monitoring expenditures and adjusting budgeted dollars, as necessary, in order to achieve recovery goals as determined in person-centered plans. This should be a creative and flexible process that allows for modifications to occur, as goals and their associated expenses change across the budgeting time period.

Financial Management Services. There are many functions and responsibilities that must be fulfilled when public dollars come under the control of private citizens. CMS uses the term financial management services (FMS) to refer to activities such as tracking individual expenditures and monitoring overall budgets, performing payroll services, and handling billing and documentation responsibilities. The types of services performed by FMS providers depend to a large extent on the participants' personal preferences, the designs of States' plans, and the regulations of specific CMS programs. These financial management services are described in greater detail in a later section of the paper on fiscal agents and intermediaries

Supports brokerage Activities. Supports brokerage consists of a set of individual support services intended to assist participants in the overall design and management of their self-directed care plan. Supports brokerage activities include both education and operational assistance with critical aspects of self-direction, such as the development of individual plans and creation of budgets that correspond with these plans, as well as assisting with the management of all other aspects of self-directed services. One of the fundamental activities in supports brokerage involves helping the person understand the many responsibilities of being an employer, along with establishing a risk management process that protects participants who take on employer responsibilities. Another common activity is assisting participants in locating and purchasing needed services and supports.

CMS Tools for Self-Direction

There are several ways that States can apply these essential elements of self-directed care using State and federal Medicaid funding. In order to qualify for federal

funding for Medicaid programs and receive the Federal Medical Assistance Percentage (FMAP), States must provide a core set of services to all eligible persons under the State plan. States also have the option of providing additional services and supports using the *rehabilitation services option* under the State plan [42 CFR 440.130(d)], and *waiver programs* under 1115 and 1915 authority. CMS also administers *Real Choice Systems Change Grants for Community Living* (<http://www.cms.hhs.gov/systemschange/default.asp>), which may be used by States to increase opportunities for people with disabilities who live in the community. Each of these funding options is described below.

Medicaid State Plan Services. In order for a State to claim FMAP from CMS, it must provide the following core set of services.

- Inpatient hospital services (other than services in an institution for mental diseases)
- Outpatient hospital including Federally Qualified Health Centers and if permitted under State law, rural health clinic and other ambulatory services provided by a rural health clinic which are otherwise included under States' plans
- Other laboratory and X-ray services
- Services provided by certified pediatric and family nurse practitioners (when licensed to practice under State law)
- Nursing facility services for individuals age 21 or older (other than services in an institution for mental diseases)
- Early periodic diagnosis and screening for children under age 21
- Physicians' services
- Medical and surgical services of a dentist
- Family planning services and supplies
- Medical supplies and surgical services of a dentist
- Home health services for beneficiaries who are entitled to nursing facility services under the State's Medicaid plan
 - Intermittent or part-time nursing services provided by a home health agency or by a registered nurse when there is no home health agency in the area
 - Home health aides
 - Medical supplies and appliances for use in the home
- Nurse midwife services
- Pregnancy related services and service for other conditions that might complicate pregnancy
- 60 day postpartum pregnancy related services

The required State plan services listed above are primarily medical in nature (including primary prevention), a circumstance that poses both opportunities and limitations for States. Opportunities include the possibility of combining required services and specialty services under the rehabilitation option (discussed below), with the intent of creating an integrated service delivery system. Adding an option for self-

direction allows full consumer control over the entire health care package, setting the stage for further integration of additional systems discussed later in this paper.

Limitations of the medical nature of required State plan services include the fact that they do not cover the specialty services that are of primary importance to persons with serious mental illness living in the community. Examples of specialty services include case management, psychosocial rehabilitation, Assertive Community Treatment, peer support, and outpatient therapy, among others.

Such specialty services can be offered under the rehabilitation services option mentioned earlier. The rehabilitation option is very broad in scope and allows for the creative development of services and supports. The entire regulation as written in the Code of Federal Regulations is reproduced here:

“Rehabilitative services,” except as otherwise provided under this subpart, includes any medical or remedial services recommended by a physician or other licensed practitioner of the healing arts, within the scope of his practice under State law, for maximum reduction of physical or mental disability and restoration of a recipient to his best possible functional level [42 CFR 440.130(d)].

These services must be rehabilitative in nature, meaning they must be primarily geared toward restoring *lost* functioning for individuals, rather than helping to develop *new* skills. This distinction however, is not absolute. For instance, while a service that assists a person to better manage auditory hallucinations results in a new skill, it also helps him or her restore prior functioning in a variety of settings, and is therefore a service that could be covered under the rehabilitation option.

One of the most difficult aspects of the process of obtaining CMS approval for rehabilitative services for persons with mental illnesses is the fact that the Medicaid statute is based on a medical model of assistance. Narrow application of a medical model can result in a highly circumscribed approach to assisting participants. Treatment implies the *application of a procedure to a patient* that heals disease or treats illness. The patient is primarily a passive recipient of the treatment. However, much of contemporary mental health services and supports are based on a more loosely defined and open-ended *therapeutic model, which requires the active participation of the person in his or her recovery process*. Under the therapeutic model, a service or support is provided to assist a person to reach a goal.

The therapeutic model greatly expands on the notion of treatment and challenges the medical approach that forms the historical basis of federal Medicaid policy. For instance, expressive therapies such as art or music therapy require the active participation of the participant, but do not conform to medical models of treatment. Given the emphasis on participant control over services and supports in self-direction, answers to the question of what is therapeutic are highly individualized. One person may find that (in addition to medication and case management) engaging in physical exercise by joining a health club is a therapeutic endeavor, while another may find that engaging in productive activity such as starting a micro-enterprise is therapeutic.

The larger question from the perspective of rehabilitation is how do these sorts of endeavors provide for “maximum reduction of physical or mental disability and restoration of a recipient to his best possible functional level” [42 CFR 440.130(d)]? The example of engaging in physical exercise may help to reduce stress and thus reduce the possibility of relapse, thereby contributing to a reduced likelihood of inpatient treatment. However, such arguments are still filtered through the lens of the medical model by CMS. While reasonable and scientifically defensible arguments are made for Medicaid supporting non-medical services under the State rehabilitation option, it is important to remember that any non-required service is approved for federal funding at the discretion of the Secretary of Health and Human Services [1905(a)(27)].

Several States are using the rehabilitation option to develop alternative services and supports. One example is the State of Georgia that has developed a Certified Peer Specialist (CPS) service under the rehabilitation option of its Medicaid State plan (L. Fricks, personal communication, February 20, 2004). CPSs are current or former recipients of mental health services who deliver a range of services designed to assist individuals in their recovery process. Certified Peer Specialists receive extensive training in the delivery of supportive services that assist individuals in the recovery process, including goal setting, developing mutual self-help groups, teaching problem solving skills, providing vocational assistance, and developing plans for symptom management using the Wellness Recovery Action Plan (WRAP) model (<http://www.mentalhealthrecovery.com/>). Agencies that are providing CPS services must have a board of directors in which at least 75% of the members are persons with mental illnesses. To date, over 191 CPSs have provided services in Georgia that are funded by Medicaid, and over 2,500 individuals have been served (<http://www.gacps.org/Home.html>). Peer support is considered essential for an optimized recovery model (Lieberman, Kopelowicz, Ventura & Gutkind, 2002).

Because of CMS’s reliance on the medical model, it does not recognize lay practitioners as qualified to provide medical or remedial treatments, which may limit the use of peers as service providers if they lack professional qualifications. Therefore, States using the rehabilitation option for Medicaid-funded peer supports must demonstrate that practitioners are recognized by the State as professionals, through certification or licensure. States must also ensure adequate training, care coordination, supervision, and ongoing support of peer service providers.

Under the Rehabilitation Option, self-directed care for people with mental illnesses can be funded with Medicaid monies. In such an arrangement, person-centered planning and individual budgeting would be part of the overall treatment planning process and could be conducted by qualified peer providers. However, supports brokerage and financial management would need to be approved for Medicaid funding as administrative expenses and not as services. Otherwise, the costs of brokerage and financial management would need to be covered by the State through other, non-Medicaid funding sources.

An additional way to fund self-directed care would be through the targeted case management option (Social Security Act 1915 [g]). Targeted case management allows states to provide case management services to a defined (targeted) group of recipients as well as limiting the geographic area of the service. In this instance a State could use the option to fund persons (including qualified peer providers) to do person-centered planning and individual budgeting. Once again, however, supports brokerage and financial management would need to be approved for Medicaid funding as administrative expenses or these costs would need to be covered by the State through other, non-Medicaid funding sources.

Medicaid Waivers. At times the Social Security Act has been amended to accommodate changes that allow for more effective and efficient operations of Medicaid programs. These changes have included modifications to eligibility criteria, financial structure, geographic variability and others. Many of these amendments have been formalized as waiver program templates that are designed to provide States with an efficient means of requesting federal matching funds under FMAP (see U.S. Department of Health and Human Services, 2000).

There are three types of waivers that may be applicable to persons with mental illnesses. These are the 1915(b), 1915(c), and 1115 waivers. CMS has developed templates for two of these waivers, (1915(c) and 1115), under the rubric *Independence Plus*, as a way for States to use waivers to draw on FMAP to create self-direction programs (<http://www.cms.hhs.gov/independenceplus/>).

1915(c) waivers. The 1915(c) waiver is the primary vehicle for self-direction for persons who do not have mental illnesses. The waiver lists a set of Home and Community-Based Services that are optional, and also allows for additional services defined by the State, but which must be approved by CMS to be eligible for coverage under FMAP. The Home and Community Based Services include: case management, homemaker services, home health aide services, personal care services, adult day health services, habilitation services, respite services, and other services defined by the State and approved by CMS. Additional services supporting self-direction under a 1915(c) Independence Plus Waiver include supports brokerage services and financial management services.

The 1915(c) waiver is intended to provide home and community based services to individuals who would otherwise be placed (or are currently placed) in one of three types of institutions: nursing home facilities, hospitals, or Intermediate Care Facilities for Mentally Retarded individuals (ICF/MR). The 1915(c) waiver cannot be used to provide home and community based services to adults between the ages of 22 through 64 who would be served in an institution for mental diseases (IMD) [42 CFR 440.180 (d)(2)(i), who are explicitly excluded in federal law [1905(a)(27)(b)]. This is primarily a result of the historical responsibilities of States to provide institutional care to persons with mental illnesses.

1115 waivers. Section 1115 of the Social Security Act allows States to develop experimental, pilot, or demonstration projects by waiving requirements that restrict

services and eligibility, as well as other requirements in the State plan and other waivers. While CMS has final approval authority, the waiver process is structured to encourage collaboration between the States and CMS. The multi-step 1115 waiver process includes: a proposal from the State outlining the project; a site visit to the State by CMS staff; and a comprehensive evaluation component. A significant drawback of 1115 waivers is a cumbersome approval process that commonly takes two to three years to complete because the State's application must also be approved by the federal Office of Management and Budget in addition to CMS.

CMS has developed a template for States that are seeking 1115 waivers to develop self-directed care programs (<http://www.cms.hhs.gov/independenceplus/1115temp.pdf>). Services allowable under these waivers bear the closest resemblance to those of the therapeutic model. A great deal of flexibility is permitted in defining and delivering services and supports under these waivers. For instance, 1115 waivers were used to fund the successful Cash and Counseling projects that provided individual budgets and cash to persons with developmental disabilities and those who are elderly to hire personal care service providers (Dale, Brown, Phillips, Schore & Carlson, 2003; Foster, Brown, Phillips, Schore & Carlson, 2003). This model can be modified for persons with mental illnesses as well. The Florida Self-Directed Care model, described elsewhere in this paper is ideally suited for an 1115 approach.

1915(b) waivers. In addition to allowing States to waive "Statewideness" and comparability requirements, 1915(b) waivers allow States to waive freedom of choice of providers, making these waivers ideal for implementing Medicaid managed care programs. 1915(b) waivers are limited in that they apply to existing Medicaid eligible beneficiaries, and authority under this waiver cannot be used for eligibility expansion. 1915(b) waivers also allow States to use a central broker and, *importantly for self-direction*, allow States to use any cost savings to fund additional services. The new services can be highly flexible, enabling States to create services and supports that are owned and operated by persons with mental illnesses such as consumer-run drop-in centers and peer support programs such as the Georgia Certified Peer Specialist Program described above. All of these services can be used by States with 1915(b) waivers as options for people to implement self-directed care.

1915(b) waivers also allow States to develop specialized systems of care for different populations through the carve-out option. For instance, a specialty system for persons with serious mental illness could be established, including a variety of evidence based practices such as supported employment, Assertive Community Treatment, illness self-management, integrated dual-diagnosis treatment, and family psycho-education, as well as other innovative services and supports.

Michigan is an example of a State that uses 1915(b) waivers coupled with State policy and Substance Abuse and Mental Health Services (SAMHSA) block grants (described below) to promote self-directed care models throughout their regional and county-based managed care system. The State has developed a policy requiring that self-determination (including individual budgeting, financial management services, and

person centered planning) be offered to all Medicaid eligible individuals, including persons with mental illnesses
(http://www.michigan.gov/documents/SelfDeterminationPolicy_70262_7.pdf).

The 1915(b) waiver in Michigan is divided between primary health care providers and specialty services. Eligible persons with serious mental illnesses may receive a variety of specialty care services with some variation across regional and county systems. Most systems in Michigan have consumer owned and operated drop-in centers funded through savings from the Medicaid prepaid health plans. These drop-in centers provide a varied mix of services, including peer support services, warm lines, person-centered planning facilitation, and micro-enterprise development, funded through a variety of sources. The goal of the Michigan Statewide policy is to ensure that participants have access to individual budgets to purchase a full range of services and supports needed to meet their goals as defined in the person-centered planning process.

Michigan (among other states) uses a combined 1915(b/c) waiver to provide mental health and substance abuse services to persons with developmental disabilities. Combined 1915(b/c) waivers require that States meet the requirements of both waivers, including reporting requirements, making these waivers administratively costly to implement.

Systems Change grants. Systems Change Grants were created in 2001 as a way for States to develop the systems necessary to allow persons with disabilities to reside in the community. States were awarded a total of \$64.4 million in 2001, \$55 million in 2002, and \$40 million in 2003. While a small portion of systems change dollars may be used for direct services, the primary purpose of the grants is for States to create the necessary infrastructure that will allow persons with disabilities and the elderly to successfully live in the community.

A specific category for Independence Plus programs was added to the 2003 Systems Change Grant Solicitation. While none of the Independence Plus grants was specific to mental illness, several States are including this population in their activities. For instance, the State of Oregon is developing a consumer-directed program for persons with mental illnesses using its systems change grants. Oregon is using funding to promote self-directed, person-centered planning, to fund drop-in centers, and to deliver consumer self-advocacy training.

Taken together, these Medicaid waivers and special programs present a wealth of opportunities for States that are interested in mounting demonstrations of self-directed care for people with psychiatric disabilities. It remains to be seen, however, whether States preoccupied with their own fiscal crises (described in a later section) will explore these options without considerable prodding from advocates and other mental health stakeholder groups.

COMMUNITY MENTAL HEALTH SERVICES BLOCK GRANT SYSTEM

First established in 1981, the Community Mental Health Services Block Grant (also referred to as the MHBG) was amended in 1986 to require States to provide adults and children with serious mental disorders with a comprehensive service system. The overarching goal of the MHBG is to help fund services that will reduce reliance on psychiatric hospitalization and enable people with serious mental illnesses to lead independent and productive lives in the community. The MHBG is a flexible source of funding that States use to support new community-based services and programs, expand or enhance existing programs, and leverage additional State and community funding (National Association of State Mental Health Program Directors [NASMHPD], July, 2003).

At one time administered by the National Institute of Mental Health, in 1992 the MHBG became the responsibility of the then newly-formed Center for Mental Health Services of the Substance Abuse and Mental Health Services Administration (CMHS Block Grant, FY2005-07, p. 7). Legislation enacted by Congress in the year 2000 (P.L. 106-310) converted the Block Grant into a Community Mental Health Services Performance Partnership, with new performance and reporting requirements that are briefly described in a later section.

In this Program, grants are awarded to States based on an allotment calculated for each fiscal year by a legislative formula, one component of which is the Cost of Services Index that takes into account variation between States in the costs of labor and rent paid by facilities. Awards are made in response to States' applications (also called State Plans) and to each State's implementation report submitted for the previous fiscal year. State Plans are required to be developed in conjunction with a State Mental Health Planning and Advisory Council comprised of at least 51% of people with mental illnesses, family members (including parents of children with serious emotional disturbance), and non-treating professional citizens.

States have the option of submitting one, two, or three-year Plans. States are required to use five criteria to structure their planning efforts and application (four apply to adults, and a fifth is specific to children). These are: 1) Comprehensive Community-Based Mental Health Service Systems; 2) Mental Health System Data Epidemiology; 3) Children's Services; 4) Targeted Services To Rural And Homeless Populations; and 5) Management Systems (CMHS Block Grant, FY2005-07, p. 124). Under Criterion 1 in particular, States must describe in their Plans available services and supports in their comprehensive system of care (with combined Federal, State, and other funding) to include: health, mental health, and rehabilitation services; employment services; housing services; educational services; substance abuse services; medical and dental services; support services; school-based services provided under the Individuals with Disabilities Education Act (IDEA) legislation; case management services; services for people with co-occurring mental health and substance abuse disorders; and other activities leading to the reduction of psychiatric hospitalization.

As of Fiscal Year 2001 (Lutterman, 2003), the MHBG represented an average of 2% of the total resources controlled by State mental health authorities to provide institutional and community-based care. In addition, Medicaid funding (federal and State) comprised 36% of all State mental health authority revenues, and State general revenue funds comprised another 45%. The remainder consisted of Medicare (2%), other federal (2%), State (8%), local (0.4%), and other sources (5%).

In spite of the relatively low funding it provides, because it is a block grant rather than categorical funding, the MHBG does provide the States with flexibility to: 1) fund services that meet the unique needs and priorities of stakeholders in each State; 2) hold providers accountable for access and quality of services provided; and 3) coordinate services and blend funding streams to finance a broad range of medical, social, and rehabilitative services to effectively support community living for individuals with serious mental illnesses (NASMHPD, July, 2003).

In the past two years, much effort has been directed to the transition of the MHBG to a performance partnership. This federal-State partnership shifts emphasis from system accountability based on expenditures to system flexibility in exchange for accountability based on State performance, as measured by appropriateness and outcomes of services (NAMHSPD, February, 2003). Under the new system, there continues to be an emphasis on States structuring their planning efforts based on the previously described five criteria; however, there is a greater focus on the use of performance indicators that are both State-specific and national in scope using the 2002 Uniform Reporting System (URS). Due to concerns about the added cost of the new performance requirements, States' efforts in this area have been supported by a Data Infrastructure Grant Program (DIG). CMHS considers the transition to a performance partnership to be a gradual and developmental process, and they continue to gather feedback from States about their experiences with the new system and its accompanying application. Nonetheless, it is expected that all measures should be collected by each State beginning in 2005 (SAMHSA, CMHS, Director's Report, September 2003).

There is great potential for using the MHBG to support cash-outs for self-directed care. One of the broad goals recommended in the 2003 Report of the President's New Freedom Commission on Mental Health is that mental health care be consumer- and family-driven, a concept that is considered formative to the planning and development of future expectations for the MHBG and for a comprehensive and recovery-oriented public mental health care system in each State (CMHS Block Grant, FY2005-07, p. 9).

Under this new program, individuals with serious mental illnesses would have the option of cashing out some or all of the MHBG designated funds that would typically be awarded to their outpatient, behavioral healthcare providers. In most States, it is likely that psychiatric inpatient treatment, emergency services, and residential care would be excluded from such cash-out arrangements. Individual cash-out amounts would be determined by the local, district, or State office of mental health, based on the average cost to the State (or county or district) of serving each person from the previous fiscal year. Set amounts would likely be somewhat different for Medicaid

and non-Medicaid eligible individuals, and cash-outs would not typically be available to people who receive health care coverage through a managed care arrangement, to ensure that their care would not be “double funded” by public monies.

Program participants would use cashed-out funds to choose from a variety of community-based provider organizations or individuals that may or may not already be part of the currently contracted system. These providers, along with a Fiscal Intermediary (the functions of fiscal intermediaries are discussed in detail in a later section), would join the self-directed care network through memoranda of understanding. For the providers (peer and non-peer), these agreements would ensure their adherence to the State’s services vision, to fiscal cost ceiling rates commensurate with contracted rates set by the district or State, to providing immediate access to requested services/supports, and so forth. States would work with a Fiscal Intermediary to determine how budget allowances would be made to each participant, how unspent funds (if any) would be handled at the end of a fiscal year, how to address over-spending (if any), how accounts would be adjusted based on the previous year’s spending, and so forth.

Program participants would work with supporters of choice to develop a person-centered service plan against which their choices for using cash-out funds would be monitored by the Fiscal Intermediary. Participants would be responsible for determining which community-based services/supports they want, from whom, and for how long, in order to achieve personal recovery goals outlined in their plans. Enrollment in the new program would be strictly voluntary (for providers and participants), and participants could choose to return to traditionally contracted community services at any time. In its Plan submitted to CMHS, each State is required to describe its current State service system (Section I), to provide identification and analysis of the system’s strengths, needs, and priorities (Section II), and to include performance goals and action plans to improve the service system (Section III). For adults, these three Sections must address each element of the previously described four criteria for adults with mental illnesses. Depending on how a State prepares its application, implementation of self-directed care services might be included in Section II, when describing plans to address identified unmet needs in the system, or in Section III, under planned enhancements to the comprehensive service system and related performance goals.

Assuming that a State decides to implement a self-directed care pilot project or to focus on one region for the initial program, it would describe in its Plan the rationale for implementing the new self-directed care project, the locale chosen for the project, how many people it would serve, the new program’s relationship to the current community-based system (i.e., that clients would disengage from traditional community-based psychiatric treatment, but would continue to have access to State inpatient, emergency, or residential care), performance indicators for the new program, and so forth. The entity(ies) chosen to act as Fiscal Intermediary(ies) also would be named in the State Plan, since intended service recipients are not authorized to receive direct cash payments via the MHBG. If community-based providers (peer and non-peer) that

would be in the network of those accepting self-directed care payments are known, they also would be named in the State Plan.

Because the MHBG is unlikely to be the sole source of cash-out for a self-directed care program (particularly as it goes “State-wide”), plans for supplementing funding via the General Revenue Fund, other State-specific funds (such as a Trust Fund), and/or a CMS 1115 Medicaid waiver also would be provided in the State application. As described in more detail below, in one State’s experience (Florida), after the initial self-directed care program had been described in the State Plan, it was not subsequently included as a special project, since it falls directly under the MHBG’s general goals and is considered part of the State’s comprehensive service system.

There are several benefits and challenges inherent in using Block Grant funds to support self-directed care models. The main advantages are the flexibility of the MHBG, its focus on helping States to expand community-based service options, CMHS’ clear priority on the development of recovery-oriented service systems, and the speed with which a self-directed care program could be implemented under the MHBG (as compared to relying solely on a Medicaid waiver, which is negotiated with several federal agencies, often for as many as one to three years). Some of the barriers include: the need for education at the State and federal levels regarding the promise of self-directed care models (the national and regional technical assistance meetings that CMHS hosts regarding the MHBG could be a good forum for widespread education); the need for education about these models among clients, families, providers, and others (especially because providers may initially resist the loss of direct program funding and having to compete for clients); the push to fund only “evidence-based” practices which could thwart use of this new model (unless it can be promoted as “illness self-management”); the lack of community-based options (particularly peer-run) in many communities across the country; and the relatively small amount of money provided to the States via the MHBG (which has been addressed in one State by combining funding streams to support the program).

Thus far, only one State in the U.S. has had direct, multi-year experience with a cash-out program designed specifically for people with psychiatric disabilities. This is the Florida Self-Directed Care Program (FloridaSDC), a behavioral health care program in which participants with serious mental illnesses control the funds necessary to purchase services and supports from providers of their choice to achieve the goals of their self-designed recovery plans. The program currently serves individuals living in Northeast Florida (District 4), although plans are underway for service expansion throughout the State, including a proposed pilot program to include children with serious emotional disturbances and their families.

FloridaSDC was conceived by a task force of individuals receiving public mental health services, family members, and other advocates interested in ensuring more client choice and a recovery orientation in community-based mental health services. Program design was based on the Florida Developmental Disabilities Choice program, a Medicaid 1115 waiver program serving individuals with developmental disabilities. Initially, the pilot program was funded by the Florida State legislature, which allocated

\$470,000 in annual funding from the Alcohol, Drug Abuse and Mental Health Trust Fund in the Department of Children and Families, with the remainder of costs being absorbed by the local district's Alcohol, Drug Abuse and Mental Health office. Another \$400,000 allocated only for direct participant services came from State General Revenue funds. In its second year of operation, program funding came from Florida's MHBG, and the program has been included in Florida's current State Plan, although it is no longer described as a "special" project, but is considered part of the State's comprehensive system of care (C. Russell, personal communication, February 18, 2004).

The premise of FloridaSDC is that access to mental health treatment and supportive services should occur by providing individuals with the opportunity to design their own recovery plans and then implement these plans directly through purchasing services from vendors of their choice. A purchasing arrangement using a Fiscal Intermediary is used to broaden the network of available community providers to include private and public professional and peer supports. Program participants in Northeast Florida have the option of cashing out the State designated monies that would typically be awarded to their behavioral healthcare providers (excluding inpatient treatment, emergency services, and residential care). Once they join the program, participants disengage from traditionally contracted community-based services, although they are free to reenroll in such services at any time. Providers join the FloridaSDC network through an Agreement of Understanding, which delineates service mission, cost rates, service access expectations, and the like.

Based on average costs of service, Medicaid eligible participants receive \$1,449 annually and non-Medicaid eligible individuals are allotted \$2,776 annually for community-based services and supports (the latter are required to set aside 48% of their budgets to purchase behavioral health services). The Fiscal Intermediary is Florida State University (FSU), which receives from the State quarterly budgetary allowances for each participant on an annual prepaid case rate basis. All accounts carry forward through the fiscal year and are zeroed-out at the end of the year, per State budgeting requirements. Adjustments are made annually based on the previous year's expenditures and average cost to serve each person. Thus, the program remains budget neutral, unless there are significant cuts in spending for the eligible population in the prior year. FSU fulfills the standard functions of a Fiscal Intermediary, which are described in a later section of this paper.

As described in detail elsewhere (Russell et al., 2004), once individuals join the program, they work with program staff to create an individualized, person-centered Recovery Plan, which includes a description of services/supports they would like to purchase. They are encouraged at this time to employ a Recovery (non-peer) or Recovering (peer) Coach. Recovery Plans are reviewed by program staff and the Fiscal Intermediary to ensure that each proposed purchase is clearly linked to an identified need in the initial comprehensive assessment and a recovery goal. Upon approval of the Plan, pre-authorizations are sent to the participant and chosen service providers for purchases that are to be directly billed to FSU. All behavioral health, medical, and other professional services are billed directly to FSU; all other purchases are made via cash reimbursement or money orders given directly to program participants. Post-

authorizations are only allowable for access to behavioral healthcare providers in an emergency, and must be reported to FSU within 24 hours. A progress report is prepared every three months detailing what purchases have been made, how they relate to the Recovery Plan, and the individual's progress towards goals. New expenditures to fulfill Plan goals are pre-authorized at that time as well. Russell and colleagues (2004) further detail how Recovery Plans and expenditures are monitored, as well as preliminary evaluation results, in a descriptive paper regarding this program.

The Community Mental Health Services Block Grant Program is an important and highly flexible source of funding for self-directed care cash-outs directed to people with mental illnesses. However, its comparatively small size means that its power comes primarily from blending its fiscal resources with either Medicaid dollars, as described above, or with State general revenue funds, as discussed in the following section.

THE STATE GENERAL REVENUE AND LEGISLATIVE SYSTEMS

As in the case of the FloridaSDC program described above, State general revenue is a significant potential source of funding for self-directed care programs targeted to people with psychiatric disabilities. In FY 2001, State general funds constituted a full 45% of State mental health authority expenditures. Thus, close to half of all funding available for mental health services is under the direct control of the State itself. States are largely free to spend their general revenue funds as they see fit, within State (and sometimes federal) legislative guidelines. Thus, through the "will of the people" residing in a State, portions of tax-generated revenue currently directed to the purchase of services from professional agencies can be "cashed out" and directed to service recipients through Fiscal Intermediaries using models of self-directed care.

One potential obstacle to the use of State general revenue funding to support self-directed care for people with mental illnesses is the current State fiscal crisis in the United States. According to the National Governor's Association, 45 of 50 States experienced budget reductions in FY 03, and 38 State mental health authorities reported FY 2003 mental health budget reductions (Lutterman, n.d.). However, this unfortunate situation can present opportunities as well as obstacles to the development of self-directed care. On the one hand, States' fiscal crises can be used to justify a reduction of services provided by the current provider-funded system and a moratorium on development of new service delivery models. On the other hand, fiscal constraint can be used to argue for the promulgation of self-directed care programs, if it can be shown that this approach for people with mental illnesses reduces costs while also increasing consumer outcomes and satisfaction, as it did for people with developmental disabilities and the elderly in Arkansas' Cash and Counseling program (Dale, Brown et al., 2003).

It is no simple matter to direct State general revenue dollars to self-directed care programs. In the case of Florida, a State law was required to re-direct funding so that the "money follows the person." Russell and her colleagues (2004) describe the nature of this legislation (Self-Directed Care Bill, Chapter 2001-152, Laws of Florida) and the events surrounding its bi-partisan support and passage in the Florida legislature. This

effort can serve as a model for other States, local communities, and advocates seeking similar redirection of State general revenue to support mental health system change.

THE PUBLIC HOUSING SYSTEM

The U.S. Housing, Act of 1937 created the Public and Indian Housing Program, which now provides affordable housing to over 1.3 million households nationwide. Under this program, housing choice vouchers (known as Section 8 vouchers) allow low-income families to choose and lease or purchase safe, decent, and affordable privately-owned rental housing. Currently, however, the federal Housing and Urban Development (HUD) agency faces significant problems in its voucher program. The agency's website notes that "...the housing voucher program has grown into a complex, overly prescriptive program that is increasingly difficult to administer. The present program has separate rules for more than a dozen different types of vouchers, along with 120 pages of regulations to navigate. In addition, the absence of positive incentives to help more families afford housing within the funds available has limited the numbers who are helped. In recent years, costs have escalated without a corresponding gain in benefits." (<http://www.hud.gov/offices/pih/programs/hcv/index.cfm>).

It appears that a number of structural changes are needed in order to promote self-determination in publicly funded housing. The major goals of housing assistance in a self-determination framework are to enable individuals to: 1) choose typical housing arrangements; 2) reside with another person only by mutual consent; and 3) live where they would have "authority over who comes in the front door" (Nerney, 2004). As Nerney (*ibid*) points out, a national and State-level cross departmental agenda is needed to build such a system.

Rafter (2003) notes that rent subsidies are a key ingredient to avoid relegating individuals with disabilities to living in congregate facilities. A Statewide commitment is required to enable individuals to live in existing market rate rental units, something that typically calls for a Medicaid waiver to accomplish. However, non-profit housing corporations offer another alternative that can provide housing at below market rates.

Since the HUD Section 8 program has been drastically reduced in recent years and requires substantial initial investment, it has proven difficult to use the Section 8 program to develop low-density housing that is truly integrated. Since existing HUD programs offer only partial solutions, supplemental approaches are necessary. Two ways to accomplish this are by: 1) expanding rent subsidy programs to stimulate landlord participation and increase access to market rate rental properties (Nerney, 2004); and 2) developing non-profit housing corporation infrastructures sensitive to the needs of individuals with psychiatric disabilities (Rafter, 2003).

One need is for special accommodations that enable individuals to deal with two typical impediments for Section 8 housing voucher users: 1) the complicated application process; and 2) the need to assemble required documentation. To address these barriers, not-for-profit housing corporations can work with local HUD authorities to develop special programs, such as the one described by Nerney (2004) run by Creative Housing

Inc. in Columbus, Ohio. In this program, Creative Housing is directly assigned housing choice vouchers for use with individuals with significant disabilities. After one year, individuals' Section 8 vouchers become portable and individuals are able to take their vouchers with them when they move. This enables individuals to rent from any landlord who will accept the voucher. But, in addition, when tenants do leave, under this program the Section 8 subsidy to the property also is maintained. Thus, a not-for-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.

Other examples include Associations for Retarded Citizens (ARCs) in Arundel County, Maryland and Hennepin County, Minnesota aided by a grant from the Joseph P. Kennedy Foundation (Rafter, 2003). These ARCs have partnered with their local public housing authorities (PHAs) to pair Section 8 vouchers with individuals receiving HCMS waivers. Unfortunately, however, these collaborations tend to be the exception rather than the rule. As noted in the congressional testimony of two groups interested in housing and disability issues – the Technical Assistance Collaborative and the Consortium for Citizens with Disabilities – “most public housing authorities do not see people with disabilities as an important constituency.” This highlights the importance of non-profit housing corporations as a catalyst for change. One such housing corporation, *Preferred Properties* in Toledo, Ohio has been extremely successfully in developing HUD Section 8 projects through the use of low income tax credits available through the Ohio Housing Finance Agency. Another, *Northcoast Community Homes* in Cleveland, provides housing to over 800 individuals in 200 locations spread over a four county area.

This kind of partnership enables PHAs to target especially needy individuals while, at the same time, reducing administrative expenses (Rafter, 2003). For disability organizations, ongoing Section 8 revenues represent a solid funding stream to develop the kind of housing required by “deep” subsidies. For example, *Creative Housing* in Columbus, Ohio, mentioned above, provides housing to over 900 individuals in 450 locations including extensive renovation activities.

Nerney (2004) and Rafter (2003) present a series of additional suggestions for establishing greater self-determination in housing. First, there is a need for all States to take steps to develop their own rent subsidy programs. For example, in the Ohio program, bond dollars are available to non-profit housing corporations to purchase and renovate properties to make affordable housing available for people on SSI. Second, there is a need to use regional or State subsidy funds on a short-term basis until an individual can apply for and be granted a Section 8 voucher. Third and fourth, a financial fund is needed for individuals to pay security deposits and a fund is also needed to cover extraordinary property damages. Fifth, a special fund is needed to cover gaps that occur in paying rent so that people do not get evicted when they miss a rent payment. Sixth, the ability of not-for-profit disability organizations to develop affordable housing must be strengthened.

THE SYSTEM OF FISCAL AGENTS AND INTERMEDIARIES

Despite what is implied by the title, in most “money follows the person” type programs, participants seldom directly receive and administer funds. Instead, an individual or organization commonly referred to as a Fiscal Intermediary (FI) is used to perform some of the functions necessary for participants to choose their own services and providers. FIs provide the “financial management services” described in an earlier section of this paper regarding the CMS system.

There are four basic types of individuals, organizations, and agencies comprising the “system” providing FI services (or financial management services in CMS parlance) in the United States (Flanagan, 2004). Some FIs are *State or local government entities* that are approved by the IRS to be employer agents on behalf of self-directed care participants (known as Government Fiscal/Employer Agents). Other FIs are *individuals or organizations* (either public or private) that are approved by the IRS to act as employer agents (known as Vendor Fiscal/Employer Agents). A third group of FIs includes a variety of different agencies (e.g., Centers for Independent Living, social service agencies, Area Agencies on Aging) that provide support services but do not typically act as the managing employer (known as an Agency of Choice). The final group consists of *government entities or vendors* that disburse public funds directly to individuals or their representatives but do not engage in employer or payroll functions (known as Fiscal Conduits). As reported by Flanagan (ibid.), an August 2001 survey of 121 Consumer-Directed Support Service Program FIs conducted by the U.S. Department of Health and Human Services/Office of the Assistant Secretary for Program Evaluation found that 4% (n=5) were Government Fiscal/Employer Agents, 43% (n=52) were Vendor Fiscal/Employer Agents, 23% (n=28) were operating as an Agency of Choice, and 12% (n=15) as Fiscal Conduits.

This diverse group of entities provides an equally diverse array of services, including: handling payroll for those individuals employed by self-directed care participants, handling labor tax withholding and paperwork for these workers, interfacing with government sources by handling billing and reporting to State and federal agencies, and providing reports to self-directed care participants about the status of their accounts.

One example of a national organization capable of performing all of these services is Acumen, a for-profit company that currently operates in 13 States, serving over ten thousand individuals who participate in some form of self-directed care (G. Nebeker, personal communication, February 19, 2004). Headquartered in Mesa, AZ, Acumen contracts primarily with States (also occasionally with individuals) to provide some or all of the following services: medical billing, payroll services, filing and depositing federal and State income taxes, statistical reporting, invoicing and receiving support funds, and conducting employee background checks (*What is Acumen?* Acumen, 2004). For example, the company provides participants enrolled in self-directed care programs with forms and paperwork needed to recruit, screen, and hire service providers such as personal care attendants (e.g., W-4, I-9, employment applications, time cards, descriptions of labor laws). Acumen then handles the associated payroll

functions such as cutting and sending the employee's paycheck, and withholding funds for paying employee labor taxes to the federal and State government (FICA FUDA, SUDA). In addition, Acumen interfaces with government agencies on behalf of the participant, by billing State agencies such as Medicaid intermediaries or State departments of aging or developmental disability, to cover the costs of employing the provider. In some cases, Acumen pays the provider and then bills the State and in other cases the organization receives funds on a quarterly basis and then draws monies from these funds to pay providers and withhold taxes. Acumen's services are largely determined by the contracts they have with individual States for individual programs.

Acumen's experience with thousands of participants in multiple States is instructive and, while not necessarily representative, offers a picture of how self-directed care operates (G. Nebeker, personal communication, February 19, 2004). The company reports a relatively low turnover in the positions they oversee, and notes that most participants (estimated at around 70%) initially choose relatives as providers, moving after one to two years to non-relatives with whom they often are already familiar, such as a neighbor or someone from their religious or ethnic community or other social contacts. In Acumen's experience, many providers only work for the individual who initially hires them and do not re-enter the labor force in a similar position if the job ends. On the other hand, some attendant care providers do go on to work for other individuals or agencies that provide this service. In the State of Florida, a company specializes in connecting self-directed care participants with difficult-to-find professionals such as RNs, but this kind of organization is reported to be relatively rare (G. Nebeker, personal communication, February 19, 2004).

According to Acumen representatives (G. Nebeker, personal communication, February 19, 2004), most participants sign off on their own paperwork, although many individuals designate someone who can sign time cards and authorize expenditures in addition to themselves. Some participants and their families show a high level of creativity in how funds are utilized, for example by pooling their funds to hire a provider or obtain a service they could not obtain within the scope of their individual budgets. Acumen estimates that their services save States 25-50% of administrative costs, since the company handles the administrative "back-end accounting" functions of self-directed care (G. Nebeker, personal communication, February 19, 2004).

Acumen has had experience with a variety of types of self-directed care programs, including ones that combine self-directed and agency care. For example, in the State of Connecticut, the State provides participants with dollars that can be used to purchase services from an agency, to hire an individual directly, or some combination, according to the participants' needs and preferences. In the opinion of some, States tend to accumulate knowledge over time, which often results in operating programs more efficiently, offering more choices of service options, and extending eligibility to larger and more diverse groups of participants.

Other providers of FI services include Certified Public Accountants, banks (which typically limit their services to budgetary planning and fiscal holding), universities, community agencies, and other private entities. The reality is that anyone

can act as a FI under Revenue Procedure 70-6 (1970) of the Internal Revenue Service, with a new modification in 2003 that authorizes an organization to do payroll-reporting functions on behalf of an individual. In some cases, other organizations perform budgetary planning and fiscal holding services and “contract out” the payroll functions to Acumen or some other organization.

A new organization called the National Association of Fiscal Agents and Intermediaries (NAFAI) has recently been formed (G. Nebeker, personal communication, February 19, 2004). The mission of NAFAI is to establish cohesiveness and engage in training and education of FIs and their clients, such as through the *NAFAI Educator*, a series of informational pamphlets describing new IRS regulations and forms relevant to providers of financial management services.

The newly emerging system of financial management service providers is a key part of self-directed care initiatives. These organizations will no doubt play a pivotal role in the further development of these programs as they respond to the needs of CMS and the States, as well as individual self-directed care participants and their families.

THE FEDERAL-STATE VOCATIONAL REHABILITATION SYSTEM

The passage of the Social Security Act in 1935 established a permanent federal-State vocational rehabilitation (VR) system. In 1943, the Barden-LaFollette Act eliminated the requirement that a person be employed prior to receiving services, and extended VR services to people with blindness, mental illness, and mental retardation, as well as providing a new State-federal matching formula and money for States' administrative costs. The Rehabilitation Act, passed in 1973, became the legislation governing federal-State VR and requiring that services be delivered first to individuals with severe (vs. mild) disabilities, with Amendments to the Act in 1998 mandating: eligibility determination within 90 days, emphasis on employment as the desired service outcome, informed consumer choice of services and providers, the right of individuals to develop their own service plans, and an appeals process to resolve disputes. The most recent Amendments to the Act in 2000 instituted new regulations for measuring VR program effectiveness.

Three-fifths (60%) of working age adults with mental illnesses are out of the labor force (defined as not having a job and not having looked for work or been on layoff in the past two weeks), compared to less than one-fifth (18%) of their counterparts in the general population without psychiatric disabilities (Kaye, 2002a, based on data from the National Health Interview Survey-Disability Supplement or NHIS-D, 1994-5). Underemployment is also a serious problem for people with psychiatric disabilities. In the NHIS-D (Kaye, 2002b), nearly two-fifths (38%) of workers with mental health disabilities had near minimum wage jobs, compared with only one-fifth (20%) of people without disabilities. People with mental health disabilities earned a median hourly wage of only \$6.33 in 1994-95, versus \$9.23 for those without disabilities; and more than one-third (36%) of all workers with mental health disabilities were employed in part-time jobs, compared to only 16% of people without disabilities

By federal legislative mandate, the Rehabilitation Services Administration (RSA), an agency of the Department of Education, funds vocational rehabilitation (VR) programs in each State to provide vocational assessment, training, job placement, and ongoing support services to eligible persons with disabilities. In fiscal year 1995 (the latest year for which data are available), 1.3 million adults were clients of State-run VR programs, accounting for 12% of all Americans estimated to have health conditions or impairments that limited their ability to work (Bureau of the Census, 1995). The State-federal VR program uses a formula grant structure in which approximately 78% is provided by the federal government and no less than 22% must be matched by the State. Some \$2 billion in federal dollars matched by \$645 million in State and local programs are allocated annually to State VR programs (Kaye, 1997). Unfortunately, some States decide not to match all of the federal monies available to them and, thus, do not draw down the full amount of federal funding that could be used for the rehabilitation of the State's citizens with disabilities.

States are given fairly wide latitude in structuring their own VR programs. Section 103(a) of the Rehabilitation Act, amended in 1998, permits "...any services described in an individualized plan for employment necessary to assist an individual with a disability in preparing for, securing, retaining, or regaining an employment outcome..." Thus, there are no federally "mandated" services that a person must receive from its federal-State VR. Every State VR client must have an "Individualized Plan for Employment" (IPE) that specifies that client's employment goal and the services he or she will receive in order to reach that goal. There appears to be no prohibition in federal regulations against provision of direct cash assistance to clients. In fact, as part of an IPE, States can and do provide direct financial assistance to clients. One example is the State of Virginia, which provides direct cash payments to clients in emergency situations to purchase necessities such as shelter and clothing (M. Morris, personal communication, February 19, 2004). In some States, direct cash grants are made to clients to provide the start-up capital for micro-enterprises or businesses owned and operated by the client. Cash grants also are permitted for employment-related expenses such as vehicle maintenance or repair, housing assistance, and the purchase of tools, uniforms, or equipment (Hayward & Schmidt-Davis, 2003).

Given this flexibility, one system change to promote self-determination would be to "cash out" a portion of monies currently spent by the State-federal VR for service delivery (Nerney, 2004). As with Medicaid waivers, funds would be funneled through a fiscal intermediary and used to capitalize micro-enterprises, hire job coaches, and pursue vocational training or higher education required for career building. Some have suggested (M. Morris, personal communication, February 19, 2004) that direct cash assistance could also take the form of incentive payments to those clients that achieve their employment goal before the average time that most clients become employed, or for clients who exceed job tenure of a certain length.

Another potential plan suggested by Nerney (2004) is to pay employers directly to provide workplace-based supports such as job coaches and employment support specialists. These monies could come from VR, SSA, or other sources. This would enable employers to have some assurances that job support personnel would have their

company's best interests in mind while also enabling those with disabilities to choose companies with these kinds of available supports.

THE WORKFORCE DEVELOPMENT SYSTEM

The Workforce Investment Act (WIA) of 1998 (Public Law 105-220) establishes a framework for a national workforce preparation and employment system that addresses the needs of both employers and those seeking employment. Title 1 of WIA is designed to provide workforce investment activities that enhance employment, job retention, earnings, and occupational skill levels of program participants, thereby improving the quality of the U.S. workforce, reducing welfare dependency, and increasing the productivity of the nation's economy. This is accomplished through a One-Stop delivery system, comprised of separate organizations (referred to as One-Stop partners) responsible for workforce development, education, and human services that collaborate in the creation of a seamless service delivery system.

States and local areas are mandated to establish workforce investment boards (WIBs) that oversee the operation of One-Stop employment centers where individuals can go to receive assistance in becoming job ready and finding employment. The major intent of these centers is to "co-locate" a number of services critical to labor force re-entry together in one building in local neighborhoods so that services are accessible to those who are unemployed. These One-Stop centers must include "mandated" partners such as programs authorized under State unemployment compensation laws, programs for dislocated workers, State VR, veteran's workforce programs, welfare-to-work programs (Temporary Assistance to Needy Families), Native American programs, adult education and literacy activities, and State services to return unemployed individuals to work. One-Stop centers are required by the WIA to serve individuals with disabilities and to be fully accessible to those with disabilities.

Under Title 1 of WIA, participants may receive: 1) core services (consisting of outreach, establishment of eligibility, vocational assessment, career counseling, and provision of employment-related information such as job vacancy listings and job skills required of particular positions); 2) intensive services (such as development of an individual employment plan [IEP], job search assistance, job placement, paid or unpaid work experience, and job coaching); and 3) training services. At this third and most intensive level, training services include Individual Training Accounts (ITAs). ITAs provide vouchers for services designed to return individuals to employment, such as post-secondary education and training. Among all available One-Stop services, ITAs are the most difficult to obtain because they represent such a substantial financial contribution. It is possible, although rare, for individual One-Stop centers to petition their local WIBs to "reserve" ITAs for persons with disabilities (M. Morris, personal communication, February 19, 2004). Thus, direct payments, in the form of vouchers, could be made available to individuals with mental illnesses to purchase employment-related goods and services. In addition, Title 1 of WIA also authorizes direct cash payments to individuals. One of the set of supportive services to participants includes "needs related payments," which are defined as "financial assistance...for the purpose of enabling individuals to participate in training..." (20 CFR 663.815). To qualify for this

financial assistance, participants must be unemployed, not qualified to receive unemployment compensation, and be enrolled in a training program under an ITA. Needs-related payments may also be paid while a participant is waiting to start training classes, in cases where training is to begin within a 30-day period.

Thus, within WIA there currently exists a mechanism whereby people with disabilities could receive “cashed-out” funds through intermediaries or through other mechanisms. The challenge here is to make more people with psychiatric disabilities eligible for ITAs so that they can qualify for both vouchers and cash payments, making them candidates for potential cash-outs of WIA funds for self-directed care related to return-to-work.

THE PUBLIC DISABILITY INCOME SUPPORT SYSTEM

Two primary federal programs of benefits and entitlements, including cash payments and vouchers, currently assist disabled individuals who are unable to work. Supplemental Security Income (SSI) enacted by Congress in 1975 is a means-tested income assistance program aimed at aged, blind, or disabled individuals, while Social Security Disability Income (SSDI) legislatively established in 1956, is a social insurance program to which all employed citizens contribute via payroll taxes, with benefits based on prior earnings. Both programs include large overrepresentations of people with mental illnesses who enter the rolls early in life and (as is the case for virtually all citizens with disabilities who enroll) never exit the rolls (LaPlante, Kennedy & Trupin, 1997). According to the Social Security Administration (SSA), people with psychiatric disabilities constitute the largest working age disability group receiving public income supports: in 2001, individuals with mental disorders comprised 36% of all working age SSI recipients, and 22.1% of all SSDI recipients (33.3% of those under age 50).

There are two major constraints on self-determination within the SSA system that have a significant impact on people with mental illnesses: barriers to economic security, and lack of access to health care coverage. First, public disability cash payments are set below the poverty level and people with disabilities are among the poorest in the nation. As a national average, year 2000 SSI benefits were equal to around \$3.43/hour, equivalent to only two-thirds of the current minimum wage of \$5.15/hour (O’Hara & Cooper, 2002). In 2002, for the first time ever, the average national rent was *greater than the total amount of income on SSI*. On average, rental of a modest, one bedroom apartment was equal to 105% of year 2002 SSI benefits (ibid). Annual year 2002 SSI benefits were only 18.8% of the one-person median household income (ibid). Thus, public disability income support for people with mental illnesses is largely inadequate to help them meet basic needs.

Just as troubling, many people with mental illnesses have severely limited access to health care coverage, due to their low employment rates (with employers being the major suppliers of health care coverage in the U.S.), as well as the lack of parity in health and mental health care coverage in the U.S. (Sing & Hill, 2001). Since many people rely on their SSA beneficiary status to qualify for health care coverage under Medicaid or Medicare, disability income support and health care coverage are inter-twined to the

detriment of many recipients, especially those attempting to establish economic security. This is because SSI and SSDI program rules and regulations constitute a considerable disincentive to work that prevents people with mental illness from realizing their full career potential, thereby unintentionally trapping them in poverty. For example, federal regulations mandate an administrative review of disability status upon return to work, effectively “punishing” those who obtain employment. Unlike SSI, which allows recipients to retain part of their income supports after substantial gainful employment, SSDI recipients encounter an allowable income “cash cliff,” whereby their cash payments cease entirely once they exceed the SGA level (\$810 per month in 2004) for a specified number of months. Individuals who lose disability income status because of their return to work also experience an “implicit tax” because they risk losing other unearned income such as housing subsidies, utility supplements, transportation subsidies, and food stamps (Polack & Warner, 1996). SSDI beneficiaries must undergo a two-year waiting period before becoming eligible for health coverage under Medicare, while most SSI recipients become eligible for Medicaid immediately upon receiving SSI.

Clearly, removal of these disincentives is key to enhancing the self-determination of people with mental illnesses. As the largest cash benefit program for people with mental illnesses, putting millions of dollars directly into the hands of consumers, SSA has a tremendous potential to enhance self-directed care by removing economic disincentives and by adjusting its policies and procedures (in concert with CMS) to provide continuous health care coverage to all people with severe disabilities regardless of their employment or earnings. Measures such as these are needed to avoid the enforced impoverishment built into the current system.

A number of proposals have been put forth to tackle different aspects of these interrelated problems. For example, Nerney (2004), suggests that the SSDI “income cliff” (in which cash payments cease abruptly after certain earnings levels are reached) be replaced by a system in which employed individuals on SSDI could keep one out of every four to seven dollars earned once reductions in cash benefits begin. He also suggests that SSI and SSDI income be eligible for being deposited in Individual Development Accounts (another money-follows-the-person program described in a later section). Over the past several decades, SSA itself has tried to address these problems by raising the SGA level (i.e., the amount of money an individual can earn before reductions in cash benefits begin), extending Medicaid eligibility for a significant period of time after cash payments cease, and allowing people who work to set aside part of their earnings for employment-related expenses, such as through PASS plans and IRWEs. A number of new proposals to eliminate work disincentives are described in the following section on the Ticket to Work. However, there is widespread agreement that these incremental changes have been largely ineffective (President’s New Freedom Commission on Mental Health, 2003), and the public disability income support system remains one of the major systems in which reforms could enhance the economic self-sufficiency of individuals with psychiatric disabilities, and have a major impact on possibilities for self-directed care.

TICKET TO WORK AND WORK INCENTIVES IMPROVEMENT ACT

The Ticket to Work and Work Incentives Improvement Act (TWWIIA , P.L. 106-170) was signed into law in 1999. A program of SSA, TWWIIA targets those receiving SSI or SSDI, rather than the general workforce and, thus, has particular relevance to people with disabilities. The Act is aimed at removing a number of work disincentives inherent in SSA regulations, providing health care to beneficiaries who might otherwise lose eligibility for coverage under Medicaid and Medicare by losing eligibility for cash payments, offering benefits planning and assistance (BPA) to inform participants about the effects of employment on their disability cash and noncash income, and providing vouchers (referred to as Tickets) directly to participants which can be “redeemed” for vocational services from local employment providers. Unfortunately, these vouchers may not be used completely at participants’ discretion, since choice of vocational service providers is limited to those individuals or organizations that have been certified as employment networks (ENs) by SSA.

There are two payment systems by which ENs are reimbursed under TWWIIA (Adequacy of Incentives Advisory Group, 2003). The first, known as the outcome payment system, pays an EN forty percent of the national average monthly benefit that clients receive under SSDI/SSI for every month that the individual does not receive a cash benefit for a period of up to five years. The second, known as the milestone-outcome payment system, offers payments to the EN at the time of the first, third, seventh and twelfth months that the employed worker’s monthly income is above substantial gainful activity SGA (currently \$810/month), and then for every month thereafter that the worker does not receive a cash payment, also for a period of up to five years. Neither of these payment systems offers sufficient payments to EN providers, especially those who work with individuals unlikely to achieve earnings above SGA and to exit and remain off of the SSI/SSDI rolls (Cook, 2003). Research has shown that two groups for which this is often the case are those with developmental disabilities (Wehman & Revell, 2003) and those with psychiatric disabilities (Salkever, 2003). Thus, the EN incentive payment system appears highly unlikely to stimulate employment services to individuals with these disabilities.

Thus far, the Ticket’s success has been disappointing. As of February 2004, in the third and final year of the Ticket’s roll-out, close to seven million (6,946,302) Tickets have been issued, yet less than one percent (.0055) or 38,279 Tickets have been assigned to EN providers (3,796 to State VR and 1,112 to other ENs). As of September 2003, only 95 individuals were returning any money to providers whose clients had achieved one or more outcomes due to work or earnings (Adequacy of Incentives Advisory Group, 2003).

This has led many individuals to wonder why this legislation’s “cash-out” has been targeted to providers rather than those in need, that is, individuals with disabilities who are attempting to re-enter the labor force. Clearly, SSA is willing to provide *someone* with 40% of the average value of an individual’s SSDI or SSI payment. Given the success of self-directed care programs, a more reasonable approach might be to provide direct cash payments to the individual him or herself, through FIs, which could

then be used to purchase VR services from ENs or (in keeping with the philosophy of self-directed care) from *anyone of the individual's choosing* for services such as assessment, job skills training, job placement, job coaching, and post-secondary education for career advancement. In fact, there appears to be "...nothing in the existing legislation [that] precludes persons from being their own providers or at least coming close to it" (Berkowitz, 2003, p. 25). In a history of the Ticket's genesis as the brainchild of the Disability Policy Panel of the National Academy of Social Insurance, Berkowitz notes that "...some panel members thought that beneficiaries should be allowed to be their own providers" (2003, p. 25). In fact, one EN operating entirely on the Internet (AAATake Charge) directly offers its "clients" a cash stipend of 75% of all payments it receives from SSA. Thus, SSA could accomplish removal of the "middle man," in other words the EN, by re-writing its rules and regulations so that ticket monies could be "cashed out" directly to SSI/SSDI beneficiaries.

One current proposal for reforming TWWIIA (Adequacy of Incentives Advisory Group, 2003) is that Individual Development Accounts (IDAs) be created for SSI/SSDI beneficiaries who work and meet financial eligibility criteria. (IDAs are described in detail in the following section). Under this plan, SSA would not count as income deposits to these accounts; amounts held in IDAs would not count toward the SSI resource limit of \$2,000; matches could come from AFIA grant funds (also described in the following section), TANF funds, State funds or private entity contributions; and amounts up to \$10,000 could be saved. Both SSI and SSDI beneficiaries could theoretically receive the same matched income in IDAs. However, the question remains, why not cash out the amounts provided to ENs and make *these directly available* to Ticket participants to use *as they see fit*? Some reform proposals (Adequacy of Incentives Advisory Group, 2003; Otto & Coburn, 2004) suggest a more generous front-loaded payment system for ENs to stimulate their willingness to serve individuals who take longer to reach SGA. Yet, one wonders why reforms would be limited to increased cash payments to ENs when people with disabilities themselves might more efficiently and effectively spend this money. The Ticket represents a significant step by SSA toward addressing barriers to return to work among those disabilities. But its major deficiency, as well as that of the current reforms being proposed, may lie in its failure to direct cash resources to the real agent of change in the vocational rehabilitation process – the individual worker.

THE BANKING SYSTEM: INDIVIDUAL DEVELOPMENT ACCOUNTS

The Assets for Independence Act (AFIA) was signed into law on October 27, 1998. The purpose of the Act is to provide for the establishment of demonstration projects designed to determine: 1) socio-psychological, economic, and civic effects of providing low-income individuals with opportunities to accumulate assets by saving a portion of their earned income; 2) the degree to which asset development can increase economic self-sufficiency among those with limited means; and 3) the extent to which an asset based policy stabilizes and enriches the lives of families and their communities (Boshara, 1998).

One of the Act's provisions was the establishment of individual development accounts (IDAs) which are administered by the HHS Office of Community Services (OCS) under the Administration for Children and Families. Eligibility for IDAs is based upon income: individuals eligible for TANF are automatically eligible for IDAs, others must qualify for the earned income tax credit and meet a net worth test, and individuals' household net worth cannot exceed the value of the primary dwelling unit plus one motor vehicle owned by a household member (Cinurea, Blain, et al., 2002).

Individuals with AFIA-funded IDAs must choose from one of three goals: the purchase of a first home, small business capitalization, or post-secondary education. Another requirement for some types of IDAs is that individuals must receive a certain number of hours of financial education and counseling in order to qualify for IDAs.

AFIA IDAs must be set up as a separate "lock box" account at a federally insured institution, to which the individual has limited access. For example, monies may not be withdrawn from IDAs for the first six months, except for emergency situations such as medical expenses, forestalling eviction, or meeting expenses following loss of a job. IDA accounts are controlled by banks, credit unions, or in some cases by community based agencies. The individual's contributions to the IDA must come from earned income; and contributions are prohibited from family or use of other forms of unearned income such as SSI/SSDI. The individual's contribution to an AFIA account is matched by a non-federal source as well as a federal source. At least once every three months, this matching deposit is made by the State, private foundations, or banking institutions responding to Community Reinvestment Act requirements. A federal deposit then equals the non-federal one. The non-federal matching source sets the match rate, and has the option of using different rates for different accounts (e.g., setting a higher match for families with lower incomes). For example, if a non-federal source adopts a 2-to-1 match rate and a participant deposits a total of \$100 to their IDA over three months, then the non-federal match is \$200 and the federal match is \$200, totaling \$500 plus accrued interest. Federal funds may not exceed \$2000 per individual (\$4000 per household) (Boshara, 1998).

As of 2002, at least 23 States had passed IDA legislation and were operating a State supported program; 16 additional States/territories passed legislation but failed to develop a program (n=4), were in the process of program development (n=5), or had allowed the legislation to expire without re-authorization (n=7) (Center for Social Development, 2002). At this point in time, over 500 IDA programs exist in the U.S. and approximately 25,000 individuals have participated in IDAs (M. Morris, personal communication, February 19, 2004).

A new proposal by Nerney (2004) is the establishment of Freedom Accounts, which are a potential type of IDA in which participants could save up to \$10,000 per year of both earned *and* unearned income. In this scenario, savers could use the accounts for personal goals such as building or expanding a micro-enterprise, saving the down payment for a home or automobile, purchasing needed technology, and paying for training or education to advance careers. These accounts could be checking accounts, savings accounts, certificates of deposit, and money market or mutual funds.

At the same time, new regulations would need to be put in place exempting non-federally funded (i.e., non-AFIA) IDAs from being counted as assets in figuring SSI/SSDI eligibility and cash payments. Also to be excluded from being counted as assets would be employee retirement plans, unearned income (from workers compensation, unemployment insurance, private disability insurance, State disability payments, and private gifts and donations), income from PASS plans, and other benefits such as food stamps and Section 8 housing vouchers (Nerney, personal communication, February 6, 2004).

THE TECHNOLOGY SYSTEM

In society in general, and in the field of rehabilitation in particular, new information is being distributed at an unprecedented rate (Barrett, 1994), which is increasing exponentially due to advances in information technology (IT). This has led to concerns about maximizing access to IT by a wide variety of stakeholders, especially people with disabilities (Fullmer & Mujumder, 1991). Many people lack access to these new technologies, leading to the much-discussed “digital divide.” According to the U.S. Department of Commerce, households with incomes above \$75,000 are 20 times more likely to have access to the Internet than lower-income households (Foxhall, 2000).

One concern about the digital divide is that it limits the access of people with disabilities to knowledge and information directly related to self-directed care and money-follows-the-person initiatives. There is growing recognition in disability disciplines that the gap between the development of knowledge and knowledge application can impede both consumers’ personal progress as well as innovation in service settings and systems (Zeren et al., 1999). Differences in literacy rates, inadequate computer education, lack of high-speed equipment, and scarcity of culturally relevant information on the World Wide Web also impede the appeal and utility of technology for many communities.

Another potential application of Web technology in self-directed care is an initiative in the private health care sector called Consumer Directed Health Care (CDHC) (Dougherty, 2003). In CDHC, Web-based spending accounts called health reimbursement arrangements (HRAs) are established from which people directly purchase a portion of their health care services via the Web. In addition to promoting choice, CDHC incentivizes cost reduction in health care expenditures by enabling “customers” to control the costs of their own health care using Web technology. These plans, currently being used by about 1 million people, can serve as a model for privately-insured individuals with mental illnesses, and has the potential for replication in the public system as well. For example, electronic banking systems could be of use in managing cashed out and pooled funds.

Another use of IT is the marketing of professional associations and providers as well as peer providers who can advertise their services and supports on the Web. The FloridaSDC program described earlier operates as a “virtual” program, with much of the paperwork and interactions occurring via electronic and telecommunications channels.

In short, the possibilities are endless, but the digital divide remains an obstacle that must be overcome in order for this form of self-determination to be available to everyone.

In addition to IT, computer technology has vast implications for self-directed care involving a large group of low-income individuals, many of whom have disabilities, known as the “unbanked.” These are people with no savings or checking accounts, who are forced to use the services of check-cashing companies that charge steep fees for their services, creating barriers for people living on low levels of income. This has led to the use of “Smart Cards” or debit cards for accounts into which monies can be deposited and used by people without bank accounts via ATM banking machines, thereby avoiding check-cashing fees.

SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

This paper has explored the concepts, values, and principles of self-determination among people with psychiatric disabilities, with an emphasis on their role in building systems of self-directed care involving individualized planning, budgeting, and financial management services. It has reviewed key principles inherent in self-direction and illustrated how these principles can be activated by placing control of financial resources and the authority to purchase one’s own services directly into the hands of people with psychiatric disabilities.

By examining the inter-workings of multiple public systems in the U.S. that are designed to promote the welfare and well-being of individuals with mental illnesses, we have shown how current policies of incremental reform have led to unintended consequences that inhibit rather than promote self-direction. We also have found many instances in which monies that are now poorly spent could *theoretically* be re-directed through cash-outs to the control of individuals with mental illnesses and their agents. The purpose of such efforts would be to develop and implement the services and supports that lead to recovery from a diagnosis of mental disorder, and return people with mental illnesses to full, productive lives with meaning and purpose. We are not sanguine about the ease or likelihood of cashing-out funds that are currently directed to other entities and stakeholders. There would, no doubt, be considerable political opposition from powerful mental health trade and lobbying groups whose members currently receive these funds. Moreover, the fact that the legislation we have reviewed does not *expressly prohibit* direct cash payments to service recipients does not mean these laws *actively promote* such cash-outs. In all likelihood, money will not follow the person without substantial mental health consumer advocacy and political activity designed to actively encourage the growth of self-directed care.

While research in the area is in its infancy, randomized evaluations of self-directed care funded as part of the CMS “cash and counseling program” demonstrations has shown that other groups of disadvantaged individuals (those with developmental and physical disabilities as well as the elderly) benefit from opportunities to develop individualized recovery plans and purchase services and supports. This research has found that the outcomes of clients in self-directed care programs are equivalent to or better than those achieved by clients served in fee-for-

service programs, and that more services are received by those who direct their own care (Dale, et al., 2003; Fisher, et al., 2003). This research also indicates that self-directed care approaches are budget neutral. However, the most common finding in these studies, and thus the greatest argument for promoting self-direction, is the high degree of consumer satisfaction among those who participate in programs where “the money follows the person.”

Recommendations

Given the foregoing, we conclude with a series of recommendations that we believe will further the development and widespread availability of self-directed care for individuals with psychiatric disabilities.

First, each of the federal agencies described in this paper (CMHS/SAMHSA, CMS, HUD, RSA, DOL, SSA, HHS) should collaborate with the States in a series of national demonstration and evaluation projects designed to explore multi-agency waivers that include cash-out options for funding voluntary, self-directed care programs for people with mental illnesses.

Second, States should establish pilot programs, including rigorous evaluation components and aggressive quality assurance activities, in which a portion of State general revenue dollars is re-directed to self-directed care programs using person-centered planning and budgeting along with fiscal intermediaries.

Third, a national education campaign should be conducted to inform mental health service consumers, providers, system administrators, and the general public about the success of self-directed care approaches with other target populations, as well as the current state of the public mental health system and the need for alternative approaches to systems that foster dependency, poverty, hopelessness, coercion, substandard housing, and community isolation.

Fourth, peer-to-peer education, training, and certification should be provided to individuals who seek employment at all levels of self-directed care programs. The potential roles of peers in recovery from mental illnesses are diverse and include all four functions of self-directed care such as person-centered planning, individual budgeting, financial management, and supports brokerage, as well as the provision of more traditional services such as job coaching, supported housing, personal care assistance, and case management.

Fifth, a national demonstration program should be conducted to evaluate the establishment of Freedom Accounts, or IDAs in which participants could save up to \$10,000 per year of both earned *and* unearned income for personal goals such as developing or expanding a micro-enterprise, saving the down payment for a home or automobile, purchasing needed technology, and paying for training or education to advance careers.

Sixth, efforts to close the “digital divide” that exists between many people with mental illnesses and the rest of society should include improved Internet access as well as education in computer literacy. This could lay the foundation for enhanced use of information technology in implementing self-directed care programs.

Seventh, financial education and benefits planning and assistance should be provided to all individuals with psychiatric disabilities and should become one of the key services offered in publicly funded mental health programs. If money is to follow the person, individuals should be well equipped to participate fully in the management of their own financial resources.

This list of recommendations is necessarily partial, given the wide range and types of activities with the potential to expand self-direction in the United States today. However, it is a beginning, and one that takes into account the power of effective freedom, full recovery, personal responsibility, and fiscal control. Most importantly, it takes seriously the objective of establishing a society that promotes self-determination for a group of people who aspire to and deserve a chance to be part of the American Dream.

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