ENVIRONMENTAL SCAN OF SELF-DIRECTION IN BEHAVIORAL HEALTH: A REVIEW OF THE LITERATURE

February 2013

Developed by
Human Services Research Institute and
The National Resource Center for Participant-Directed Services

With support from the Robert Wood Johnson Foundation

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Acknowledgements

The project team is extremely grateful to the following individuals, who provided guidance and feedback in the preparation of this literature review:

Vidhya Alakeson, Resolution Foundation (UK)
Shawn Terrell, U.S. Health and Human Services, Office on Disability
Paolo del Vecchio, SAMHSA Center for Mental Health Services
Olga Acosta-Price, George Washington University
Richard Dougherty, DMA Health Strategies
Dan Fisher, National Empowerment Center
Chris Gordon, Advocates, Inc.
Patrick Hendry, Mental Health America
Glenn Stanton, Magellan Health Services
Pam Werner, Michigan Department of Community Health
Susan Bergeson, OptumHealth
Elaine Carroll, On Our Own of Maryland
Robin Cooper, National Association of State Directors of Developmental Disability Services
Jon Delman, Reservoir Consulting Group
Melissa Harris, Centers for Medicare and Medicaid Services
Harvey Rosenthal, New York Association of Psychiatric Rehabilitation Services
Shannon Skowronski, Administration on Aging
Michael Smull, Support Development Associates
Amy Zulich, Mental Health America
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EXECUTIVE SUMMARY

This literature review examines the current knowledge base of self-direction in behavioral health. The review – and the environmental scan of which it is a part – aims to explore making self-direction available to individuals with primary mental health and/or substance use diagnoses who are receiving publicly funded behavioral health services. Chapter One defines self-direction and outlines the need for self-direction in the behavioral health arena. Chapter Two examines the theoretical and value base for self-direction. In Chapter Three, the Cash & Counseling Demonstration and Evaluation is reviewed. Chapter Four provides an overview of the current state of self-direction in a behavioral health context. Chapter Five explores existing and potential financing mechanisms. Some key issues and concerns are explored in Chapter Six.

CHAPTER 1: WHAT IS SELF-DIRECTION?

Self-direction is based on the premise that people with disabilities can and should make their own decisions about the supports and services they receive. Using a budget and/or employer authority model, resources are allocated to meet individual needs and preferences for supports and services. The budget authority allows participants to manage a flexible budget, the employer authority allows participants to recruit and hire workers. A support broker helps the participant develop a budget based on his or her person-centered plan, and a financial management service handles the tax and payment details. Aims of self-directed programs vary, but many work to reduce reliance on inpatient care, promote independence, and reduce fragmentation (Report: Personal Health Budgets Research Scan, 2010).

A heavy reliance on costly inpatient and emergency services, disparities in quality of and access to care, and high rates of untreated behavioral health needs are all too common in the behavioral health arena, leaving participants with an understandable desire for more options. Persons with mental health and substance use diagnoses are represented in some existing programs that offer self-directed arrangements. However, behavioral health-focused self-direction programs are small in number, and self-directed programs that target other populations (for example, persons with physical disabilities) are associated with an array of services and supports that are different than those in behavioral health programs. For example, a self-directed program for physical disabilities may primarily involve personal care and home modifications, whereas a self-directed behavioral health program might be more likely to involve counseling and peer support.

This environmental scan is designed to understand barriers and facilitators to self-direction in behavioral health, ascertain interest among stakeholders, adapt the model and outcome measures to better fit the needs of behavioral health service users, and develop recommendations to inform future efforts, which may include a large-scale demonstration and evaluation. The scan is a joint effort of researchers from the National Resource Center for Participant-Directed Services (NRCPDS), Human Services Research Institute (HSRI), and others, funded by the Robert Wood Johnson Foundation (RWJF).

CHAPTER 2: THE VALUE BASE

The principles of recovery, self-determination, and person-centeredness underpin this discussion of self-direction in behavioral health. These three concepts are distinct yet highly inter-related.

1. Recovery is a self-defined, non-linear journey involving hope, social inclusion, and fostering psychological, physical, emotional, and spiritual wellness (Anthony, 1993; Whitley & Drake, 2010). SAMHSA recently identified a “self-directed life” as a key tenet of recovery in its new “working definition” of mental health and
substance use recovery (SAMHSA, 2011b). A decisive, organized, and evidence-based move towards implementing a budget authority model is an opportunity to put recovery principles into practice.

2. **Self-determination** is the guiding principle in the development and implementation of self-directed programs. Components of self-determination are freedom, authority, support, responsibility, and confirmation (Nerney & Shumway, 1996). Self-determination posits that those receiving publicly funded services and supports have a right to control some portion of public dollars and a responsibility to use those dollars in a manner that best supports both the individual and the community.

3. **Person-centeredness** is “providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions” (Institute of Medicine, 2001, p. 3). Person-centeredness overlaps with several of the key principles of self-direction, including the emphasis on personal preferences and values and a commitment to participant-driven treatment decisions.

In the behavioral health arena, the values outlined above are illustrated by three current practices, each of which is related (and perhaps integral) to self-direction in behavioral health: **Shared decision-making** is a method of dialogue between a clinician and a client that could serve as a viable tool to promote self-determination by increasing feelings of autonomy through a process of exploring the service recipient’s own goals and preferences in the clinical encounter (Deegan & Drake, 2006). **Self-management programs** are peer-led education programs that teach problem-solving skills to enhance self-efficacy and empower people with chronic medical conditions to work towards wellness (Bodenheimer, Lorig, Holman, & Grumbach, 2002). **Peer support** is the provision of behavioral health services and supports by those who have first-hand experience of mental health or substance use issues. In the context of self-direction, peers may function as support brokers, and peer-provided services may serve as cornerstones of the service and support options available to a self-directed program participant.

**Chapter 3: Cash & Counseling**

The Cash & Counseling Demonstration and Evaluation (CCDE) is the largest test of the budget and employer authority models. Beginning in 1995, the RWJF and the U.S. Department of Health and Human Services (DHHS) Office of the Assistant Secretary for Planning and Evaluation (ASPE) partnered to develop the Cash & Counseling Demonstration, a pilot program in which 6,700 older adults and younger people with disability-related needs were randomized to either a self-directed or traditional agency-based program. Medicaid dollars were used to fund self-direction for 3,350 older adults and adults and children with disabilities. The demonstrations were initially conducted in New Jersey, Arkansas, and Florida (Doty, et al., 2007). Evaluators found that Cash & Counseling provided higher levels of participant satisfaction and quality of life while achieving similar or better health outcomes, reducing unmet need, and keeping costs similar to traditional services (Carlson, Foster, Dale, & Brown, 2007; Dale & Brown, 2005). The Cash & Counseling program was designed to include cost-neutral budgets, based on existing costs associated with traditional, agency-based care (Doty et al., in press). After two years, total program costs remained the same for Arkansas and were slightly higher for New Jersey and Florida, although administrators were able to control these costs (Dale & Brown, 2005). In a more recent paper, Doty, Mahoney, and Sciegaj (2010) reported that Arkansas saved $5.6 million after nine years of its Cash & Counseling program.

**Chapter 4: Self-Determination in a Behavioral Health Context**

Currently, self-directed programs are active in Europe, Australia, and Canada and the United States (Report: Personal Health Budgets Research Scan, 2010). A small number of self-directed behavioral health programs are operating throughout the United States. The largest programs are located in Florida, Texas, and Pennsylvania. These programs share the following basic elements:
• **Person-centered planning**, the central driver of the self-direction process, identifies strengths and capabilities and incorporates the use of natural supports along with traditional behavioral health services.

• **Budgeting** involves an allocation of dollar amounts to each of the services and goods outlined in the person-centered plan. Self-direction provides an array of options for individuals to customize their treatment to meet specific needs, including traditional and non-traditional services and supports. The participant has control over how to spend funds with a few restrictions, such as cigarettes, illegal drugs, and alcohol.

• **Support brokers** assist participants with the development, implementation, and monitoring of the person-centered plan throughout the process. Some programs employ peers as support brokers.

• **Financial management services** help the participant with financial management responsibilities such as billing providers, preparing payroll taxes, writing checks, tracking budgets, and handling documentation.

• **Monitoring and implementation** is ongoing. Participants may hire and fire providers as they wish, and can change services and supports as needed within the constraints of their individual budgets.

Outcomes associated with self-direction in behavioral health are promising. Analyses of the CCDE data found that the sub-group of participants with mental health diagnoses fared better than those in the control group on several measures, including participant satisfaction and quality of life (Shen, Smyer, Mahoney, Simon-Rusinowitz, et al., 2008). Preliminary evaluations of the existing programs have found increased satisfaction, higher functioning, and increased use of wellness and preventive services (Alakeson, 2008b; Cook, Russell, Grey, & Jonikas, 2008). Programs using a model similar to Cash & Counseling in England, Germany, Austria, and the Netherlands found improvements in quality of life, access and coordination, participant satisfaction, and cost similar to those found by the CCDE (Alakeson, 2010). While these results are promising, gaps remain in our knowledge about key issues and costs specific to a self-directing behavioral health population. A 2010 scan of existing research concluded that the cost-effectiveness of self-directed models remains somewhat unclear because of a lack of rigorous cost-effectiveness studies accompanying pilots and demonstrations (Report: Personal Health Budgets Research Scan, 2010).

**CHAPTER 5: FINANCING BEHAVIORAL HEALTH SELF-DIRECTION**

Currently, no single funding source is widely used to fund behavioral health self-direction. Funding from multiple sources is often combined or “braided” to work within the regulations and restrictions. A number of federal agencies, including the Administration on Aging (AoA), the Substance Abuse and Mental Health Services Administration (SAMHSA), the Veteran’s Health Administration (VHA), and the Centers for Medicare & Medicaid Services (CMS) offer potential funding mechanisms for self-direction. In the past decade, the AoA has increased their attention and resources to address older adult behavioral health needs. Historically, SAMHSA has funded service innovations including self-direction through mental health block grants and other discretionary grant programs. Additionally, SAMHSA has supported many services and supports that are highly related to self-direction in mental health, including peer-provided services, shared decision-making, and supported employment. The VHA operates the Veteran-Directed Home and Community Based Services program that is active in 20 states.

Several Medicaid waivers and state plan options have the potential to support self-direction in behavioral health. The **1915(i) state option** is the most likely Medicaid funding source to hold promise as sustainable support. The 1915(i) allows states to cover services that are currently available under the 1915(c) waiver plus additional services such as psychiatric rehabilitation and peer-provided services. New language contained in the ACA supports an expansion in the range of covered services and supports, an extension to include individuals with incomes up to 300 percent of the SSI Federal Benefit Rate, and an allowance to target specific populations such as individuals with psychiatric disabilities.
In addition to looking to federal mechanisms, it is possible that local and state funding options may support self-direction. States and local governments often provide or purchase behavioral health services directly, and have been used to fund self-direction in the past, although dependence on state general revenue is unlikely to be stable or sustainable over the long term due to state budget shortfalls (Karakus, et al., 2011). In keeping with the value base of self-direction, individuals should be supported in accessing more mainstream supports and services in the areas of housing, transportation, technology, education, employment, and recreation (Elder-Woodward, et al., 2009). These areas are associated with their own funding streams, which could be integrated into an overall financing package for self-directed behavioral health services.

**CHAPTER 6: KEY ISSUES**

All people, regardless of functional need, are assumed to benefit from self-direction if given proper supports. The shift to self-direction in behavioral health is a significant endeavor and involves a number of fundamental changes to the traditional behavioral health system. This section provides a partial list of issues to consider.

Self-directed programs require careful planning, clarification of new roles and responsibilities for providers, staff training, staff recruitment and retention activities, and evaluation mechanisms that focus on both quality and cost (Report: Personal Health Budgets Research Scan, 2010). As programs are implemented, it is critical to pay attention to the "downgrading" or "watering down" of the program model - through limitations on eligibility, providers influencing selection, and other mechanisms - to keep the program philosophy strong (Spandler & Vick, 2006).

- The success of a self-directed program hinges on the person-centered planning process; if a participant is not fully engaged in the process of setting goals and identifying services and supports, the process is not self-directed.
- The budget development methods must be accurate, consistent, reliable, equitable, flexible, and transparent. Determining the benefit amount and the costs of existing service and support packages were significant challenges for many of the programs included in this review (Alakeson, 2007; Jones, et al., 2010).
- The support broker occupies a critical position in the scheme of self-directed services and supports. Successful self-directed behavioral health programs must have clear procedures in place to hire and train support brokers.
- Financial management services (FMS) are also a critical element in the implementation of the budget and employer authority models. FMS should provide the maximum amount of participant choice and control.
- Most self-directed programs are designed to allow for representatives to manage budgets and make decisions about services and supports on behalf of the participant. For participants who use a representative, it is critical they support maximum choice throughout the process.
- To ensure that the program is meeting its goals and also to maintain sustainability over the long-term, it is critical that eligibility criteria are carefully designed. Too many restrictions on eligibility may undermine the flexibility of a program, whereas too few restrictions may lead to diminished program sustainability.
- The potential for increased administrative complexity is a major concern for providers and policymakers (Teague & Boaz, 2003). Economy of scale is important to consider here; if a self-directed program is implemented on a large scale, a single administrative structure could be used across multiple programs. Newly implemented programs can draw from programs and processes of existing self-directed programs to identify strategies to reduce administrative complexity while preserving the self-directed approach (Alakeson, 2007).
- The monitoring and evaluation of person-centered plans and budgets is critical to the program success, and it also has a bearing on public and political attitudes towards self-direction. Fraud and abuse on the part of both
participants and providers are key concerns, and strong monitoring and evaluation systems must have the capacity to address these issues.

- Whereas traditional quality management approaches focus on provider agencies overseeing and improving the quality their services, quality improvement and assurance activities in self-direction are focused on empowering the participant to determine and improve the quality of his or her services and supports (NRCPDS, 2010). Further, quality improvement activities should involve participants at every stage.

The Cash & Counseling experience highlighted the critical role of communication with stakeholders, including participants, providers, and policymakers, for the success of a self-directed effort. An understanding of the various service user, provider, and policymaker attitudes towards the concept of self-direction informs design and implementation of future efforts in valuable ways.

- In all, it is likely that participants and family members will be in favor of the expansion of self-directed services and supports. Self-directed programs are often associated with high rates of satisfaction, quality of life, empowerment, and self-determination.

- Provider attitudes are key to the success or failure of a self-directed program. If implemented on a large scale, it is possible that some providers would perceive self-direction as a direct threat to their sustainability, given its potential to open the market for behavioral health services and supports to include a range of options outside of the traditional system. On a conceptual level, the self-direction may also be difficult for some providers to accept because it deviates from the medical model of mental illness. Some providers may also be reluctant to acknowledge the legitimacy of non-traditional supports.

- While there is widespread consensus among policymakers that self-direction could help people, there was also widespread concern about how realistic implementation of self-direction would be. Respondents to a 2009 National Health Service Survey reported three primary areas of concern: 1) cost and complexity, 2) organizational culture as a barrier to handing over control, and 3) the risk of compromising safety and quality.

A large body of literature documents the negative effects of stigma on life chances related to employment, housing, legal status, health, and quality of life. The stigma associated with mental health and substance use issues will likely have an impact on how participants experience self-direction as well as the acceptability of such programs for policymakers, administrators, providers, family members, and the general public. Stakeholders in self-directed programs have expressed concern that a lack of adequate support for decision-making for less advantaged individuals could lead to an exacerbation of existing inequalities in health care (Alakeson, 2008a; National Health Service, 2009). Two areas of equity concerns emerge when considering self-direction in behavioral health: Ensuring that individuals with differing levels of need have equal access to self-directed programs, and ensuring that services and supports in a self-directed program meet the needs of certain population groups, including racial and ethnic minorities and those living in rural areas.

The assumption that people diagnosed with mental health and substance use disorders lack the ability to make responsible decisions about treatment is a key barrier to implementation of self-direction on a number of levels. Some behavioral health service users may experience acute, short-term crises during which their decision-making ability may be impaired. In keeping with the principles of self-direction, however, individual choice should be honored even when a person is in crisis. Some concerns regarding competency and decision-making can be addressed through the integration of pro-active crisis planning such as Psychiatric Advance Directives into the support process. Additionally, if individuals are given the opportunity to self-direct, there may be a reduced need for acute care services. Current behavioral health and legal systems are configured to discourage risk-taking. If clients in self-directed programs share a common vision of recovery with their providers, the process should work smoothly. If the person's understanding of recovery is different in ways that the provider sees as dangerous, or if the person refuses certain services the provider deems necessary
and there are no alternative services to choose from, these disagreements could be obstacles to self-direction (Stefan, 2006). Administrators may have liability concerns such as a concern that if self-directed program participants make harmful decisions, provider organizations will be subject to lawsuits or poor evaluations (Stockport Council, nd). However, self-directed programs are likely to be less of a liability than traditional behavioral health systems because of their emphasis on open and positive relationships between the participant and provider and a decreased likelihood of disagreements regarding treatment decisions.

Self-direction requires culture change, shifting the balance of power between professionals and patients; defining the system by the outcomes it results in, not the services it delivers; and a focus on the whole person with one budget covering all behavioral health-related needs (Alakeson, 2011). Cultural change and community acceptance of self-direction takes time and requires a continuous focus on the underlying values and principles of self-direction (Rogers, 2009). Self-direction has the potential to expand the existing range of services and supports to include modalities and goods that support individuals beyond outpatient support, medications, and day treatment. In a self-directed program, individuals may opt for complementary and alternative therapies and non-medication alternatives to treatment. Finally, self-direction holds promise for the expansion of peer-provided services, with peers as support brokers and peer-run services to competing with traditional behavioral health services for participant choice. If implemented broadly, self-direction may lead to increased competition and could serve as impetus for providers to change their practices to support recovery in the long run, working across organizations to provide better services and involving participants every step of the way (Glendinning, et al., 2008; Report: Personal Health Budgets Research Scan, 2010). There are also potential pitfalls in regards to the market forces associated with self-direction. Participants may make choices on price alone rather than quality, and providers may “cherry-pick” participants, leaving those with more complex needs in the traditional service system. An increase in choice without adequate supports and information could lead providers to limit access to people with more serious problems (Smith & Lipsky, 1992). In this context, successful self-direction depends on the availability of recovery-oriented services and supports, and mechanisms for participants to effectively gauge service and support quality.

**CHAPTER 7: CONCLUSIONS**

Introducing self-direction in behavioral health services is a complicated endeavor. Culture change will be needed on multiple fronts. In the behavioral health context, the budget authority model calls for different services and different delivery mechanisms by different people, and it involves a paradigm shift from the medical model of illness and disability to the more holistic recovery model. However, the behavioral health community has already embraced principles of recovery, as evidenced by the emergence of the current demonstrations and the growing interest in self-direction in the behavioral health field. Cash & Counseling and the existing mental health demonstrations have paved the way and opened the door for future efforts. This environmental scan is a next step towards bringing self-direction to behavioral health services.
1. INTRODUCTION – WHAT IS SELF-DIRECTION?

Self-direction is based on the premise that people with disabilities can and should make their own decisions about the supports and services they receive. Currently, self-directed programs help people of all ages and with many types of disabilities maintain independence by enabling them to determine what supports and services work best. Using a budget and/or employer authority model, resources are allocated to meet individual needs and preferences for supports and services. The budget authority model allows people with disabilities the option to manage a flexible budget to support ongoing care, rehabilitation, and recovery. The employer authority model allows individuals to recruit and hire staff to assist with their individual recovery needs. These models can be implemented together or separately in a self-directed program. A support broker helps the participant develop a budget based on his or her individualized recovery plan, and a financial management service handles the tax and payment details. Hallmarks of self-direction include voluntariness, individual articulation of preferences and choices, and participant responsibility (National Resource Center for Participant-Directed Services [NRCPDS], 2010).

Self-directed programs are referred to as personal health budgets, individual budgets, direct payments, consumer-directed care, self-directed support, cash for care, Cash & Counseling, and personalized allocations (Report: Personal Health Budgets Research Scan, 2010). Aims of individual self-directed programs vary, but many aim to reduce reliance on inpatient care, support family caregiving, promote independence, reduce fragmentation, and address long-term care staffing shortages (Report: Personal Health Budgets Research Scan, 2010).

1.1 ORGANIZATION OF THIS REVIEW

This literature review examines the current knowledge base of self-direction in behavioral health. The review – and the environmental scan of which it is a part – aims to explore making self-direction available to individuals with primary mental health and/or substance use diagnoses who are receiving publicly funded behavioral health services. It draws on published and unpublished sources, including articles from scholarly journals, reports and white papers, policy briefs, conference presentations, and informational interviews with experts in the field. The paper explores the mechanics of self-directed behavioral health programs, current self-directed programs and practices in the behavioral health arena, mechanisms for financing self-direction, and key issues related to behavioral health self-direction. Chapter one defines self-direction and outlines the need for self-direction in the behavioral health arena. It also describes the Robert Wood Johnson Foundation-funded Environmental Scan of Self-Direction in Behavioral Health, the larger project for which this literature review was developed. Chapter two examines the theoretical and value base for self-direction, namely self-determination, mental health and substance use recovery, and person-centeredness. In chapter three, the Cash & Counseling Demonstration and Evaluation is reviewed, including key findings relevant to behavioral health self-direction. Chapter four provides an overview of the current state of self-direction in a behavioral

Environmental Scan of Self-Direction in Behavioral Health: A Review of the Literature
health context, including a review of the basic mechanics of a typical self-directed behavioral health program and recent and current self-directed behavioral health programs in the United States and abroad. Chapter five explores existing and potential financing mechanisms for behavioral health self-direction. Some key issues and concerns related to behavioral health self-direction are explored in chapter six.

1.2 A Few Notes About Language

In this review, behavioral health refers to both mental health and substance use. The word “participant” is used to refer to a person receiving services and supports through a self-directed program. The term “peer” is used to refer to individuals with lived experience mental health or substance use issues.

In the United States, self-direction is also commonly referred to as self-directed care, consumer direction, participant direction, or as a particular program name such as “Cash & Counseling”. This review uses the term self-direction, unless referring to a specific program that uses other terminology. Self-direction refers to the use of a budget authority, an employer authority, or both. As such, self-directed programs vary greatly in regards to the amount of choice and flexibility they offer.

1.3 The Need for Self-Direction in Behavioral Health

Leaders in the fields of aging, physical disabilities, and developmental disabilities have increased the amount of self-direction in their services, and behavioral health leadership, including the Substance Abuse and Mental Health Services Administration (SAMHSA), has done the same (Description of a Good and Modern Addictions and Mental Health Service System, 2011). However, behavioral health efforts have mainly focused on peer-provided services and shared decision-making, but not on a budget authority model. In 2004, SAMHSA convened 79 peers, providers, and State and Federal policymakers to participate in the Consumer Direction Initiative Summit, which resulted in a set of recommendations for future self-directed efforts (Free to Choose: Transforming Behavioral Health Care to Self-Direction, 2005). Currently, persons with mental health and substance use diagnoses are represented in some existing programs that offer self-directed arrangements. However, behavioral health-focused self-direction programs are small in number (these programs will be discussed in depth later in this review), and self-directed programs that target other populations (for example, persons with physical disabilities) are associated with an array of services and supports that are different than those in behavioral health programs. For example a self-directed program for physical disabilities may primarily involve personal care and home modifications, whereas a self-directed behavioral health program might be more likely to involve counseling and peer support.

A heavy reliance on costly inpatient and emergency services, a tendency towards institutional treatment, disparities in quality of and access to care, and high rates of untreated behavioral health needs are all too common in the behavioral health arena, leaving participants with an understandable desire for more options. By providing budget and/or employer authority to individuals who wish to self-direct their mental health or substance use recovery, we may begin to address these issues. Individuals can more freely choose to combine appropriate clinical services with community-based supports that promote long-term recovery. For example, individuals may benefit from increased access to supported and customized employment and education as well as other forms of social participation and integration.

The Cash & Counseling Demonstration and Evaluation (CCDE), described in detail in a later section, is the largest test of the budget and employer authority models. Prior to the demonstration, concerns regarding the decision-making competency of the study population of older adults and people with disabilities were similar to some of the existing assumptions about the competency of individuals suffering from mental health or substance use disorders. However, evaluators found that Cash & Counseling provided higher levels of
participant satisfaction and quality of life while achieving similar or better health outcomes, reducing unmet need, and keeping costs similar to traditional services (Carlson, Foster, Dale, & Brown, 2007; Dale & Brown, 2005).

Further analyses of the CCDE data found that the sub-group of participants with mental health diagnoses fared better than those in the control group on several measures, including participant satisfaction and quality of life (Shen, Smyer, Mahoney, Simon-Rusinowitz, et al., 2008). Although these sub-group analyses are illuminating, it is important to note that the CCDE did not focus on participants with mental health diagnoses and services specific to their needs. Preliminary evaluations of small pilot self-directed care programs in behavioral health have found increased satisfaction, higher functioning, and increased use of wellness and preventive services (Alakeson, 2008b; Cook, Russell, Grey, & Jonikas, 2008). While these results are promising, gaps remain in our knowledge about key issues and costs specific to a self-directing behavioral health population. A large-scale demonstration may be needed to fill these gaps in knowledge and address policymakers’ concerns about whether a budget authority model is a cost-effective and viable option for this population.

1.4 DESCRIPTION OF THE ENVIRONMENTAL SCAN

This environmental scan is designed to understand barriers and facilitators to self-direction in behavioral health, ascertain interest among stakeholders, adapt the model and outcome measures to better fit the needs of behavioral health service users, and develop recommendations to inform a potential large-scale demonstration and evaluation. The scan is a joint effort of researchers from the National Resource Center for Participant-Directed Services (NRCPDS), Human Services Research Institute, and others, funded by the Robert Wood Johnson Foundation.

The assembled research project team comprises experts in design, implementation, and evaluation of budget authority programs, as well as behavioral health service users and researchers. The scan will consist of four components:

1. A Literature Review drawing from diverse sources examining current knowledge base (nationally and internationally), key issues and concerns, and potential funding mechanisms.
2. State Behavioral Health Program Director Webinars, Surveys, and Interviews to educate/inform and ascertain views on the budget authority model.
3. Stakeholder Interviews and Focus Groups to understand key stakeholders’ concerns, hopes, and views about self-direction. Stakeholders include behavioral health service users, providers, advocates, and policymakers.
4. Recommendations to guide next steps for promoting self-direction and the use of a budget and/or employer authority model in the behavioral health arena.

The project will be informed by recent behavioral health priorities, including the expansion of peer-provided services, the use of person-centered planning, integration of medical and behavioral health care, and increased access to supported and customized employment and education. The resulting evidence base will hopefully promote rehabilitation and recovery through providing behavioral health service users with increased choice and control.

1.5 POPULATION OF FOCUS

The environmental scan and this literature review will focus primarily on self-directed services and supports for adults who are diagnosed with serious mental illness. Within this larger target population, the scan will
focus on issues particular to transition age youth (individuals aged 18-24 who are in the process of transition from the children’s mental health system to a system that serves adults) and individuals with co-occurring mental health and substance use service needs.

2 THE VALUE BASE: RECOVERY, SELF-DETERMINATION, PERSON-CENTEREDNESS

The principles of recovery, self-determination, and person-centeredness underpin this discussion of self-direction in behavioral health. These three concepts are distinct yet highly inter-related.

2.1 RECOVERY

Major players in the behavioral health arena, including SAMHSA, state and local behavioral health authorities, and advocacy organizations like the National Alliance on Mental Illness (NAMI), have embraced recovery as the primary goal of a transformed system. Mental health recovery is a self-defined, non-linear journey involving hope, social inclusion, and fostering psychological, physical, emotional, and spiritual wellness (Anthony, 1993; Whitley & Drake, 2010). Substance use recovery is defined as “a voluntarily maintained lifestyle comprised of sobriety, personal health and citizenship” (Betty Ford Institute, 2007, p. 222). Substance use recovery relates not just to abstinence but also to quality of life, motivation to change, the development of strategies to cope with triggers, and emotional support from friends and family as well as peers in recovery (Laudet, 2008).

Self-direction and recovery are highly inter-related. SAMHSA has identified self-direction as one of the ten guiding principles of recovery (National Consensus Statement on Mental Health Recovery, 2004). In late 2011, SAMHSA released its new “working definition” of recovery, which is meant to encompass both mental health and substance use recovery: “A process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential” (SAMHSA, 2011b, emphasis added). Further, self-direction and recovery share an explicit focus on wellness rather than illness, whole health rather than individual deficiencies, active rather than passive participation in services, the fostering of relationships both within and outside of services, and the development of new meaning and purpose in one’s life (Alakeson & Duffy, 2011; Spandler & Vick, 2006).

A decisive, organized, and evidence-based move towards implementing a budget authority model is an opportunity to put recovery principles into practice. For example, the budget authority model offers opportunities to assist participants and providers alike to integrate alternative therapies (such as yoga, meditation, and massage) into traditional treatment, creating a balanced approach that supports overall health and wellness. In this and many other ways, the budget authority model is in accordance with the “whole person” orientation of recovery.

2.2 SELF-DETERMINATION

Self-determination is a theory of human motivation that sees competence, autonomy, and relatedness as innate human needs critical for psychological health and lead to enhanced motivation (Ryan & Deci, 2000). A large body of social psychology research examines how environmental contexts promote or hinder motivation, which is defined as the “manifestation of a human tendency toward learning and creativity” (Ryan & Deci, 2000, p. 69). In the self-determination framework, the concepts of autonomy, competence, and relatedness are manifested in a sense that experiences and outcomes are a result of internally motivated behaviors. Although self-determination is an individual process, it is bolstered by relationships with others, and fostered through interpersonal exchanges and engagement with one’s community (Deci & Ryan, 2000).
Environments that foster competence, autonomy, and relatedness contribute to health and wellbeing and allow motivation to flourish. Conversely, environments that prevent the expression of competence, autonomy, and relatedness lead to diminished health and wellbeing and a lack of motivation.

Over the past 30 years, the disability rights community has embraced the concept of self-determination and used it as a guiding principle in the development and implementation of self-directed programs. The principles of self-determination in Figure 1 illustrate the ways in which self-determination theory has been applied in a program/policy context. For users of behavioral health services, self-determination is often not maximized because of inadequate supports, persistent poverty, and a system of care that has not historically respected or responded to needs and preferences (Cook & Jonikas, 2002).

**Figure 1: Five Principles of Self-Determination** (Nerney & Shumway, 1996)

<table>
<thead>
<tr>
<th>Principle</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Freedom</td>
<td>The opportunity to choose where and with whom one lives as well as how one organizes all important aspects of one’s life with freely chosen assistance as needed</td>
</tr>
<tr>
<td>Authority</td>
<td>The ability to control some targeted amount of public dollars</td>
</tr>
<tr>
<td>Support</td>
<td>The ability to organize that support in ways that are unique to the individual</td>
</tr>
<tr>
<td>Responsibility</td>
<td>The obligation to use public dollars wisely and to contribute to one’s community</td>
</tr>
<tr>
<td>Confirmation</td>
<td>The recognition that individuals with disabilities themselves must be a major part of the redesign of the human service system of long term care</td>
</tr>
</tbody>
</table>

The above principles specifically highlight the notion that those receiving publicly funded services and supports have a right to control some portion of public dollars. In addition, it is clear that those receiving publicly funded services have a responsibility to use those dollars in a manner that best supports both the individual and the community. Thus within the self-direction model, autonomy is operationalized as a directive that individuals with disabilities should have financial control over the supports and services that they receive.

The principle “Confirmation” is particularly important in the context of behavioral health. For decades, the mental health advocacy community has asserted that the supports and services necessary for recovery are outside the traditional behavioral health system (Chamberlin, 1978). Currently, many in the mental health advocacy community are pushing for fundamental changes to the system itself, working to ensure that peers have an active voice in all system change efforts (Fisher, Chamberlin, Cummings, O’Donohue, & Cucciare, 2005). Of particular relevance to this review, consumer-owned and operated supports are a critical component of a behavioral health system that supports self-determination (Holter, Mowbray, Bellamy, Dukarski, & MacFarlane, 2004; Chinman, Young, Hassell, & Davidson, 2006). Such services represent a collective approach to self-determination that complements the individual self-determination offered by the self-directed program model.

Self-determination shares two critical aspects – self-agency and choice – with the concept of mental health recovery (Mancini, 2008), a concept widely regarded as an aim of a transformed behavioral health system (New Freedom Commission on Mental Health, 2003; SAMHSA, 2011a). In an eloquent account of their own recovery stories, Rogers and Rogers (2003) elucidate the facilitators and barriers to self-determination:

*In our stories, the personal facilitators and barriers to self-determination are clear: hope versus despair; choice and empowerment versus their absence; effective versus destructive –*
including forced mental health treatment; self-confidence versus self-stigma; support from people who believed in us including peers, mental health professionals and service providers, and employers versus people who didn’t; and meaningful employment versus a life without meaning. Other important personal facilitators are spirituality (however an individual defines it), and education about oneself, and about one’s illness and symptoms, so that one has more control over one’s own life.”

2.3 PERSON-CENTEREDNESS

In their seminal report on the health system in the 21st century, the Institute of Medicine (IOM) named person-centeredness (termed patient-centeredness in the report) as one of the six core aims for improving the American healthcare system. The IOM defines patient-centeredness in this way: “providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions” (IOM, 2001, p. 3). Person-centeredness overlaps with several of the key principles of self-direction, including the emphasis on personal preferences and values and a commitment to participant-driven treatment decisions.

A move towards patient-centeredness and individualization is seen in the growing popularity of the Patient-Centered Health Home model, a comprehensive approach to primary care that has the patient at the center of his or her treatment and focuses on coordination and integration to meet unique patient needs (American Academy of Family Physicians [AAFP], et al., 2007). Although providers continue to manage care in the health home model, the focus on the person receiving services resonates with the values of self-direction and marks a general shift towards patient-centeredness in health care as a whole. Beyond the health system, “patient-centeredness” is referred to as “person-centeredness”.

Characteristics of person-centered systems include (National Health Service, 2010):

- People are treated with respect, as equal partners
- Planning is more than just a document and focuses on what matters to people
- People work in partnership with family, supportive others, and professionals to plan
- There is genuine listening and an appropriate pace for the person
- The system is integrated and doesn’t just focus on the times when people aren’t well
- Culture promotes values of personalization; new staff are indoctrinated into this culture
- Management is committed to personalization
- Clarity of resources, good information systems
- Learning and problem-solving is encouraged
- Local and government support for innovative practices

2.4 THE VALUE BASE IN ACTION: THREE RELEVANT PRACTICES

In the behavioral health arena, the values outlined above are illustrated by three current practices, each of which is related (and perhaps integral) to self-direction in behavioral health.

2.4.1 SHARED DECISION-MAKING

Shared decision-making is a method of dialogue that could serve as a viable tool to promote self-determination by increasing feelings of autonomy through a process of exploring the service recipient’s own goals and preferences for treatment. Shared decision-making occurs between a clinician and a client during
the treatment encounter and assumes that both parties have relevant and information to contribute to the process (Schauer, Everett, del Vecchio, & Anderson, 2007). It has been widely used in the fields of general health as well as behavioral health (Charles, Gafni, & Whelan, 1997; Deegan & Drake, 2006). The approach recognizes that client and provider goals may not be congruent, and introduces a consensus-building process involving a systematic and ongoing co-exploration of treatment goals and expectations (Charles, et al., 1997; Joosten, De Weert-Van Oene, Sensky, Van Der Staak, & De Jong, 2011).

A small body of literature has shown shared decision-making to be effective. In behavioral health, shared decision-making has been associated with increased participant satisfaction with the treatment encounter (Harmon, Hawkins, Lambert, Slade, & Whipple, 2005), participation in treatment, and health status (Joosten et al., 2008). A study examining the use of shared decision-making in substance use services in the Netherlands found that provider and client treatment goals became more closely aligned during the shared decision-making intervention (Joosten, De Weert-Van Oene, et al., 2011). The authors hypothesized that the goal alignment was a result of having a method with which to examine and dialogue about discrepancies between goals. In a separate study, Joosten and colleagues (2011) found that participation in shared decision-making increased feelings of autonomy and control relative to individuals receiving treatment-as-usual.

Traditionally, behavioral health treatment involves a diagnosis and a prescription. The patient is placed in a passive role, and the clinician is an informed authority on mental health or addictions. In the case of mental health and substance use treatment, the clinician may tell the person that he or she has a certain condition and prescribe medications and/or a set of therapies to treat the condition. The patient's role is to take medication or attend treatment sessions. Patients who do not comply with prescribed regimens are labeled as "non-compliant" or perhaps "lacking insight" into their own conditions. Shared decision-making, on the other hand, offers an alternative to this type of clinical interaction through dialoguing with, not explaining to. By promoting reciprocity and not assuming a known and objective reality, the shared decision-making method involves co-learning, in which the clinical encounter involves two individuals negotiating reality with one another to reach agreement for the best way to move forward.

2.4.2 SELF-MANAGEMENT
Self-direction shares some common elements with self-management, particularly a rationale for individual management of long-term health conditions and service delivery by people with lived experience. Self-management programs teach problem-solving skills that enhance self-efficacy and empower people with chronic medical conditions to work towards wellness (Bodenheimer, Lorig, Holman, & Grumbach, 2002). Self-management programs are delivered in a group format by people who have a lived experience of the chronic condition of focus, such as diabetes, asthma, and more recently, serious mental illness (Druss, Zhao, von Esenwein, Bona, Fricks, Jenkins-Tucker, et al., 2010). Elements include action planning and feedback, modeling, reinterpretation of symptoms, and training related to specific techniques (Druss et al., 2010). Druss and colleagues (2010) expanded and adapted the model for promoting wellness among people diagnosed with serious mental illness. This expanded model includes sections on mental health advance directives, coordinating physical and behavioral health care, and the mind body connection.

Self-management programs for a broad range of physical conditions have been associated with improved health outcomes, better communication with physicians, and greater community integration (Lorig, Sobel, Stewart, Brown, Bandura, Ritter, et al., 1999; Lorig, Ritter, Stewart, Sobel, Brown, Bandura, Gonzalez, et al., 2001). Similarly, the randomized evaluation of the mental health self-management program found that participants scored higher on a number of health and wellness behaviors, including participation in primary care and exercise, than a comparison group (Druss et al., 2010).

2.4.3 PEER SUPPORT AND MUTUAL HELP
Peer support is the provision of behavioral health services and supports by those who have first-hand experience of mental health or substance use issues. The focus on peer support emerged from the mental health consumer movement and is based on the “nothing about us without us” mantra of the larger disability rights movement (Chamberlin, 1990). Peer support posits that people with lived experience offer a unique perspective and foster hope that recovery is achievable (Chinman, Young, Hassell, & Davidson, 2006). Mutual help refers to communities of individuals in recovery from alcohol and drug addiction who form support groups such as Alcoholics Anonymous, Narcotics Anonymous, SMART Recovery, and others. Most mutual help groups have an explicit focus on the social nature of recovery and the responsibility of people in recovery to contribute to their community by supporting others who struggle with addiction (Kelly & Yeterian, 2010). A growing body of research demonstrates that peer-provided services result in a wide array of positive outcomes, including improved social functioning, reduced substance abuse, and enhanced quality of life (Chinman, et al., 2006; Min, Whitecraft, Rothbard, & Salzer, 2007; Yanos, Primavera, & Knight, 2001). Similarly, participation in mutual help groups has been associated with better outcomes than traditional addictions treatment alone (Kelly & Yeterian, 2010).

The approach of both peer-provided services and mutual help groups is rooted in shifting the power dynamic in traditional behavioral health services and supports in which patients are assumed to be helpless recipients of care. Rather than the clinician having power over the care recipient, peers share power with one another through engagement in a process of dialogue and reflection. Rather than reverting to the traditional imbalance of power in the treatment relationship in which the clinician delivers a prescription for behavioral health to the participant, the peer relationship involves a leveling of the field and an open discussion, without the presumption that one person has any more expertise than another. In peer support the provider-consumer dyad is also a peer-peer dyad; the treatment encounter can thus be approached with an aim towards mutual understanding.

In the context of self-direction, peers may function as support brokers, and peer-provided services may serve as cornerstones of the service and support options available to a self-directed program participant. The role of peer providers in the self-direction model will be discussed in greater depth later in this review.
3 CASH & COUNSELING

The distinguishing features of the Cash & Counseling program are participant choice and control, use of a monthly budget, and access to counseling and financial services (Doty, Mahoney, & Simon-Rusinowitz, 2007). In Cash & Counseling and the programs that evolved from it, participants have control of budgets and can use the funds to hire caregivers of their choosing and purchase a wide range of goods and services that help them remain independent in the community.

In the early 1990s, a growing curiosity emerged about alternative funding mechanisms and service arrangements to promote self-direction. There had been a number of successful demonstration programs of self-directed services overseas, and the Robert Wood Johnson Foundation (RWJF) was interested in funding a demonstration domestically (Mahoney, personal communication, February 11, 2010). Beginning in 1995, the RWJF and the U.S. Department of Health and Human Services (DHHS) Office of the Assistant Secretary for Planning and Evaluation (ASPE) partnered to develop the Cash & Counseling Demonstration, a pilot program in which 6,700 older adults and younger people with disability-related needs were randomized to either a self-directed or traditional (agency-based) program. Medicaid dollars were used to fund self-direction for 3,350 older adults and adults and children with disabilities. The demonstrations were initially conducted in New Jersey, Arkansas, and Florida (Doty, et al., 2007).

3.1 DEMONSTRATION FINDINGS

The CCDE found significant improvements in the areas of access, quality of care, increased life satisfaction, reduced unmet need, the same or better health outcomes, and caregiver benefits (Carlson, et al., 2007). In follow-up surveys, Cash & Counseling participants in all three states reported significantly higher levels of satisfaction with care arrangements and quality of relationships with care providers than those of the control group (Carlson, et al., 2007). They also reported significantly lower rates of unmet need, cases of neglect, and instances in which caregivers were rude or disrespectful. Both elderly and non-elderly program participants were between 8 and 23 percentage points more likely to report high levels of life satisfaction than the control group (Carlson, et al., 2007). Participants in the Cash & Counseling programs reported similar but not significantly better levels of safety and health status as those in the control group, although some indicators of health status were significantly better in the participant groups (Carlson, et al., 2007).

3.1.1 COST SAVINGS IN CASH & COUNSELING

The Cash & Counseling program was designed to include cost-neutral budgets, based on existing costs associated with traditional, agency-based care (Doty et al., in press). Dale and Brown (2005) examined expenditures for participants and the non-participant control groups in the three original Cash & Counseling states, New Jersey, Arkansas, and Florida. The authors found that spending on in-home personal care was significantly higher in all three states. However, this was due in part to the fact that non-participants in the control group used less care than was authorized while those in the Cash & Counseling group used almost all of their budgets. Most significant to this analysis, it was observed that other Medicaid expenditures for goods and services were moderately lower for the treatment group in all three states. After two years, total costs remained the same for Arkansas and were slightly higher for New Jersey and Florida, although administrators were able to control these costs. An overall reduction in nursing home stays of 40 percent was observed in the treatment group in Arkansas (Dale & Brown, 2005), and these savings fully offset increased spending in Arkansas (Dale & Brown, 2006). In the final analysis, Dale and Brown concluded that costs varied a great deal based on the timeliness and ease of implementation. Ultimately, the higher short-run costs of the Cash & Counseling Demonstration can be attributed to failures of the traditional system rather than flaws with the self-direction model itself. In a more recent paper, Doty, Mahoney, and Sciegaj (2010) reported that Arkansas saved $5.6 million after nine years through their Cash & Counseling program.
3.2 Future Directions for Cash & Counseling

Ten years out, the Cash & Counseling Model is spreading (Mahoney, Fishman, Doty, & Squillace, 2007). Each of the original states in the Cash & Counseling Demonstration have made the model a part of their regular care delivery systems. In 2004, a new initiative was introduced by the RWJF, ASPE, and the Administration on Aging (AoA) to replicate the program in 12 more states. There are over 300 self-directed programs nationwide, enabling over 800,000 people to self-direct (Sciegaj & Selkow, 2011). Every state offers some kind of employer authority, and all but six states authorize a budget authority (Sciegaj & Selkow, 2011). Self-directed programs have been tailored to meet service and support needs of people with developmental disabilities, traumatic brain injury, children with autism, and many other groups. Several initiatives in the 2010 Patient Protection and Affordable Care Act, outlined later in this review, also support self-direction. Programs worldwide in England, Germany, Austria, and the Netherlands have also implemented self-direction for individuals with a broad array of health and disability-related needs (Alakeson, 2010).

In recent years, the NRCPDS has worked with participants in self-directed programs nationwide to form a National Participant Network (NPN). With a current membership of 300, the NPN was designed to give voice to self-directed participants at state and national levels (Doty et al, in press).
4 SELF-DETERMINATION IN A BEHAVIORAL HEALTH CONTEXT

The concept of self-direction emerged out of the disability rights movement in the late 1980s and early 1990s (Doty, Kasper, & Litvak, 1996). This movement espoused the philosophy that given adequate supports, individuals with disabilities are capable of living productive and fulfilling lives in community settings. Members of the disability rights community claimed that if they had the resources of federal programs like Medicaid at their fingertips, they could spend the money in a more cost-effective way that would contribute to a better quality of life. Concurrent with these developments, the mental health consumer movement (also called the ex-patient’s movement) advocated for increased self-direction and self-reliance for individuals receiving mental health services (Chamberlin, 1990).

The landmark 1999 Olmstead v. L.C. ruling of the U.S. Supreme Court determined that holding individuals in institutions is a form of discrimination based on disability. The ruling led to increased emphasis on mental health treatment in the community rather than coercive institutional confinement. This, in turn, has drawn attention to the current inadequacy of many community mental health systems and has served as an impetus to look to models that can promote community integration in a cost-effective and equitable manner (Rosenbaum & Teitelbaum, 2004).

In the years since Olmstead, numerous federal entities and leaders in the health and behavioral health care fields have identified person-driven services as a primary goal (Institute of Medicine, 2001, 2006a; New Freedom Commission on Mental Health, 2003). Federal agencies such as SAMHSA and the Centers for Medicare and Medicaid Services (CMS) have endorsed self-direction as a value and made statements in support of greater service user involvement in the behavioral health system (Free to Choose: Transforming Behavioral Health Care to Self-Direction, 2005). The 2003 report of the New Freedom Commission (NFC), which serves as a blueprint for mental health systems transformation in the 21st century, identified as one of its core goals that mental health care is person-driven. Further, the NFC report specifically called for “a personalized, highly individualized health management program” for each person receiving mental health services. Similarly, the IOM recognized the need for person-driven care by identifying the service recipient as the “locus of control” in their 2006 adaptation of the Crossing the Quality Chasm report for improving care for mental health and substance abuse services.

“Placing financial support increasingly under the management of consumers and families will enhance their choices. By allowing funding to follow consumers, incentives will shift toward a system of learning, self-monitoring, and accountability. This program design will give people a vested economic interest in using resources wisely to obtain and sustain recovery.” (New Freedom Commission on Mental Health, 2003)

4.1 BEHAVIORAL HEALTH SERVICE USERS AND CASH & COUNSELING

In 2008, Shen et al. examined data from Cash & Counseling participants in New Jersey and Arkansas with mental health diagnoses and contrasted the data with other participants without mental health diagnoses. These examinations found no significant differences in the level of unmet needs, satisfaction with care, or safety issues between the CCDE participants with and without mental health diagnoses; further, CCDE participants with mental health diagnoses fared far better on outcomes of interest than those receiving traditional agency-based care (Shen, Smyer, Mahoney, Simon-Rusinowitz, et al., 2008; Shen, Smyer, Mahoney, Loughlin, et al., 2008). These findings indicate that the successes of the Cash & Counseling program may be found in self-directed behavioral health programs.
There are significant differences between the populations served by the Cash & Counseling program and users of publicly funded behavioral health services in terms of preferences, needs, outcomes, and service availability. Thus the significant successes found by the CCDE may not be completely generalizable. Although Shen et al.’s findings regarding the applicability of self-direction to behavioral health are promising, they are too inconclusive to give an adequate picture of the appropriateness of behavioral health self-direction in general.

4.2 Basic Mechanics

The following basic elements of the budget and employer authority models are used in the mental health self-directed care demonstrations in Florida, Texas, and Pennsylvania (In the Driver's Seat: A Guide to Self-Directed Mental Health Care, 2008).

- **Person-Centered Plan**: The highly individualized person-centered plan (also called a recovery plan or a life plan) is the central driver of the self-direction process. Rather than taking a traditional medical approach and focusing on clinical diagnosis and deficits in functioning, the person-centered plan identifies strengths and capabilities and incorporates the use of natural supports such as family and friends along with traditional mental health services. With the help of the person-centered planning team, participants select their own providers and make their own choices about what kinds of services they receive.

- **Budget**: The participant develops a budget that allocates dollar amounts to each of the services and goods outlined in the life plan. This budget amount may be based on previous Medicaid spending, the costs authorized in a previous care plan, or another set amount determined by the program. The participant has control over how to spend funds with a few limitations, such as restrictions on purchasing cigarettes, illegal drugs, and alcohol. In some programs, participants are given a card that functions like a debit card to purchase approved items. The use of a card decreases stigma, increases participant familiarity with debit/credit card use, and promotes participant responsibility. It also allows programs to restrict purchases and monitor expenses (Norris, Warnick, Moreno, Warren, & Razzano, 2010).

- **Support Brokers**: Participants typically create and manage plans with the assistance of a support broker (sometimes referred to as a life coach or a recovery coach) who is specially trained in person-centered planning and recovery-oriented care. Some programs employ peers as support brokers, while others use a mix of peer providers and other mental health professionals. The support broker supports the development, implementation, and monitoring of the person-centered plan. This involves helping the participant to locate services and supports in the community, developing crisis and risk management plans, and monitoring the quality of services. In addition to the support broker, some programs offer resources such as worksheets, websites, and educational materials to support participants in developing and facilitating their plans and budgets.

- **Financial Management**: A financial management service (FMS) helps the participant with financial management responsibilities such as billing providers, preparing payroll taxes, writing checks, tracking budgets, and handling documentation. FMS agencies must establish systems of holding, accounting for, authorizing, and disbursing funds for self-direction. FMS agencies could be built into a program itself or be purchased through a contract.

- **Monitoring and Implementation**: The participant, with the support of the support broker as necessary, monitors the plan, the budget, and their implementation on an ongoing basis. Participants may hire and fire providers as they wish, and can change services and supports as needed within the constraints of their individual budgets. Participants often have key roles in the management, oversight, and administration of programs.
For a more detailed discussion of each of the above program components, please consult the Bazelon Center’s report *In the Driver’s Seat: A Guide to Self-Directed Mental Health Care* (2008), and the NRCPDS’ *Developing and Implementing Self-Direction Programs: A Handbook* (2010).

### 4.3 Covered Goods and Services

Self-direction provides an array of options for individuals to customize their treatment to meet specific needs. Both traditional and non-traditional services are covered. Participants are encouraged to be creative and outcomes-focused in choosing supports and services (Stockport Council, nd). A partial list of such services is included in Figure 2. Individuals can be creative in their life plans and may customize or develop new services provided the rationale for doing so is included in the recovery plan.

#### Figure 2: Some Covered Services and Supports

<table>
<thead>
<tr>
<th>Therapy and counseling</th>
<th>Smoking cessation support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychiatry and medication management</td>
<td>Acupuncture and massage</td>
</tr>
<tr>
<td>Shared decision-making</td>
<td>Dental and eye care, including denture and glasses</td>
</tr>
<tr>
<td>Peer support</td>
<td>Physical or occupational therapy</td>
</tr>
<tr>
<td>Case management</td>
<td>Email and phone connections</td>
</tr>
<tr>
<td>Supportive housing</td>
<td>Computer equipment</td>
</tr>
<tr>
<td>Supported employment</td>
<td>Help with housework or cooking</td>
</tr>
<tr>
<td>Tuition and other educational expenses</td>
<td>Transportation costs such as taxi and bus fares</td>
</tr>
<tr>
<td>Gym memberships</td>
<td></td>
</tr>
</tbody>
</table>

Crisis, inpatient, pharmacy, and residential or room and board services are not typically covered under self-directed programs and are available to participants through traditional funding mechanisms (Alakeson, 2011; *In the Driver’s Seat: A Guide to Self-Directed Mental Health Care*, 2008). Some programs cover substance use services in addition to mental health services, while others, including Texas and Florida, do not (Alakeson, 2010).

In the experiences of programs in Texas and Pennsylvania, participants asked for different types of goods and services depending on how long they had been participating in the program. For example, “first asks” in the Pennsylvania program included services and supports related to physical health such as ear, nose, and throat care not covered by insurance and prescription eyeglasses as well as back rent payments and utility bills (Maula, 2010). This pattern of first attending to physical and housing needs is consistent with Maslow’s (1943) hierarchy of needs, which posits that individuals must first meet basic physiological needs before moving on to achieve stability and growth in roles and relationships.

In the United Kingdom’s Individual Budgets Evaluation Network (IBSEN) pilots, participants with mental health diagnosis were less likely to employ personal assistants than participants in other groups (Spandler & Vick, 2006). Those personal assistants who were hired helped with social, emotional, and practical support both within and outside of the home, housework, and childcare for approximately five to ten hours per week. Participants who hired a personal assistant reported that it was difficult to find individuals who shared common interests and hobbies; however, when participants were able to find suitable personal assistants, they reported significantly less social isolation and a lessening of guilt related to relying on friends and family to provide unpaid assistance (Spandler & Vick, 2006).

### 4.4 Description of United States Pilots and Demonstration Projects
Figure 3 provides an overview of recent and existing pilots and demonstration projects that have used some form of self-direction for behavioral health services and supports.

**Figure 3: Self-Directed Behavioral Health Programs**

<table>
<thead>
<tr>
<th><strong>Florida Self-Directed Care (SDC)</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Start and End Date:</strong> 2002 to present</td>
</tr>
<tr>
<td><strong>Number of Participants:</strong> 330 (Office of Program Policy Analysis and Government Accountability [OPPAGA], 2010)</td>
</tr>
<tr>
<td><strong>Funding Source:</strong> The program uses braided funding, a combination of Medicaid, state, and local dollars. Because of this funding arrangement, participants do not need to be Medicaid recipients, which allows for increased flexibility in eligibility (Cook, Shore, &amp; Fudge, 2009).</td>
</tr>
<tr>
<td><strong>Yearly Budget Amounts:</strong> $1,673 to $3,194 (OPPAGA, 2010)</td>
</tr>
<tr>
<td><strong>Resource Allocation:</strong> Fixed amount, based on eligibility for Medicaid, Medicare, and Veteran’s Administration benefits.</td>
</tr>
<tr>
<td><strong>Program Description:</strong> The largest and longest-standing program of its kind, the Florida SDC pilot was established through the state legislature in January 2000 and is administered through the Florida Department of Children and Families (Cook, et al., 2008). The program has two sites, one in the Jacksonville area, and the other in the Fort Myers area.</td>
</tr>
<tr>
<td><strong>Covered Goods and Services:</strong> Participants receiving the larger budget amount are required to spend 48% of their budgets on traditional services; does not include substance use services.</td>
</tr>
<tr>
<td><strong>Evaluation:</strong> A 2007 evaluation examined service use, satisfaction, residential stability, and community integration outcomes for 131 participants compared with two groups of non-participants, one randomly selected and one matched to participants on the variables of gender, education, and minority status (Hall, 2007). The Florida OPPAGA conducted a second evaluation in 2010, examining aggregate service utilization and cost by program.</td>
</tr>
<tr>
<td><strong>Online Resources:</strong> Program websites for <a href="#">Circuit 4</a> and <a href="#">Circuit 20; OPPAGA Report (pdf)</a></td>
</tr>
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<table>
<thead>
<tr>
<th><strong>Pennsylvania Consumer Recovery Investment Funds Self-Directed Care Program</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Start and End Date:</strong> 2009 to present</td>
</tr>
<tr>
<td><strong>Number of Participants:</strong> 75 participants, 75 in comparison group (Maula, 2010)</td>
</tr>
<tr>
<td><strong>Funding Source:</strong> The Consumer Recovery Investment Funds Self-Directed Care (CRIF-SDC) is funded through a partnership with Magellan Behavioral Health Care, a behavioral health managed care organization. Magellan’s savings from reduced hospitalizations and other managed care strategies are used to fund the project. Magellan also acts as the fiscal intermediary. Medicaid funding covers traditional services, and managed care reinvestment funds covered non-traditional services.</td>
</tr>
<tr>
<td><strong>Yearly Budget Amounts:</strong> $2,000 to $12,000</td>
</tr>
<tr>
<td><strong>Resource Allocation:</strong> Budget based on previous 24 months of Medicaid spending</td>
</tr>
<tr>
<td><strong>Program Description:</strong> CRIF-SDC is a collaboration of the Mental Health Association of Southeastern Pennsylvania, the Office of Behavioral Health of Delaware County, Magellan Health Services, and Temple University. The program is brokered by Recovery Coaches, who are Certified Peer Specialists.</td>
</tr>
<tr>
<td><strong>Covered Goods and Services:</strong> Both traditional and non-traditional goods and services; purchased must be justified in recovery plan; includes substance use services.</td>
</tr>
<tr>
<td><strong>Evaluation:</strong> A two-year randomized controlled evaluation is being conducted by Temple Collaborative on Community Integration of Individuals with Psychiatric Disabilities. The target population is individuals who received Medicaid behavioral health services over eight consecutive quarters in a two-year period with no inpatient episode in the last six months and fewer than five inpatient episodes in the past 24 months (Alakeson, 2010). The program targeted individuals who...</td>
</tr>
</tbody>
</table>
were in the 60th to 90th percentile of behavioral health service use. Participants were randomized into either the CRIF-SDC program or a control condition (Maula, 2010).

**Online Resources:** "[Welcome to the CRIF SDC Program](#)" (pdf)

### Texas Self-Directed Care

| Start and End Date: | 2009 to present |
| Number of Participants: | 75 participants, 75 in control group (OPPAGA, 2010) |
| Funding Source: | The program uses braided funding, a combination of Medicaid, state, and local dollars. |
| Yearly Budget Amounts: | $4,000 fixed; may increase up to $7,000 (OPPAGA, 2010) |
| Resource Allocation: | Fixed amount per participant, with the option to increase based on individual need. |
| **Program Description:** | The Texas SDC is a collaborative of the North Texas Behavioral Health Authority, the Texas Department of State Health Services, the University of Illinois at Chicago, and ValueOptions, a behavioral health managed care organization (Norris, et al., 2010). ValueOptions manages the pilot and serves as the fiscal intermediary. |
| **Covered Goods and Services:** | Traditional and non-traditional goods and services; individuals required to spend 60% of budget on traditional (Medicaid-covered) mental health services. |
| **Evaluation:** | The University of Illinois at Chicago’s National Research and Training Center on Psychiatric Disability is conducting this two-year randomized controlled trial. |
| **Online Resources:** | [Program website] |

### Oregon Empowerment Initiatives, Inc./Luke-Dorf Self-Directed Services

| Start and End Date: | 2004 to present |
| Number of Participants: | 25 (OPPAGA, 2010) |
| Funding Source: | CMS Real Choice Systems Change Grant and state general revenue |
| Yearly Budget Amounts: | $3,000 |
| Resource Allocation: | Set amount for a single year. |
| **Program Description:** | Portland, Oregon’s Empowerment Initiatives program was funded by a CMS Real Choice Systems Change grant. The county mental health agency contracted with a local non-profit peer-run organization to provide support brokerage services. Subsequently, program management was transferred to a local provider and is called Luke-Dorf Self-Directed Services. |
| **Covered Goods and Services:** | Participants received treatment services through the traditional mental health system and were given a separate budget to purchase additional services to support their recovery (Barczyk and Lincove, 2010). |
| **Evaluation:** | Kinetic Flow conducted a participatory evaluation of the program, under contract with the Oregon Technical Assistance Corporation (Sullivan, 2006). |
| **Online Resources:** | [Program website] |

### Maryland Self-Directed Care

| Start and End Date: | 2007 to present |
| Number of Participants: | 50 |
| Funding Source: | SAMHSA CMHS Mental Health Transformation Grant and state general revenue |
| Yearly Budget Amounts: | Approximately $3,000 |
| Resource Allocation: | Budget based on individual participant’s plan |
| **Program Description:** | Maryland’s Self-Directed Care program is administered through a peer-operated program network, On Our Own of Maryland, located within the network’s affiliate in the western part of the state, the Office of Consumer Advocates (Carroll & Hegner, 2011; Task Force on Self-Directed Mental Health Care Final Report, 2005). All program staff, including management, are peers. |

**Online Resources:** [Program website]
**Covered Goods and Services:** Goods and services not available through existing community resources.

**Evaluation:** No formal evaluation was conducted.

**Online Resources:** [On Our Own](#) website (does not contain information specific to the Self-Directed Care program).

### Iowa Self-Directed Care

- **Start and End Date:** 2006 to 2008
- **Number of Participants:** 36
- **Funding Source:** Managed care reinvestment funds (Magellan Behavioral Health)
- **Yearly Budget Amounts:** Up to $2,000 over two years, average amount $1,299 (OPPAGA, 2010)
- **Resource Allocation:** Participants identified one goal and applied a budget to work towards that goal (OPPAGA, 2010).
- **Program Description:** The Iowa Self-Directed care program was a budget enhancement of an existing psychiatric rehabilitation program.

### Covered Goods and Services

- Goods and services not covered by Medicaid or otherwise available.

### Evaluation

- An evaluation compared budget-holders with non-budget-holders in the same program.

### Online Resources

- None available

### Westchester County Department of Community Mental Health (DCMH) Care Coordination

- **Start and End Date:** 2007 to present
- **Number of Participants:** 48
- **Funding Source:** Self-determination component is funded through County general revenue
- **Yearly Budget Amounts:** Up to $1,500 per person (Agency for Healthcare Research and Quality [AHRQ], 2012)
- **Resource Allocation:** Budget based on individual’s plan
- **Program Description:** The program as a whole consists of person-centered case management, peer support (provided in collaboration with the local Empowerment Center), and a discretionary fund (called self-determination funds) to be used to promote the goals outlined in the person-centered plan.

### Covered Goods and Services

- Those not covered by Medicaid and linked to plan. Funds have been used to purchase computers, furniture, job training, and dental services.

### Evaluation

- A pre-post evaluation conducted by the program found enhanced access to treatment, more participation in employment and job training, reduced suicide and self-harm attempts, fewer hospitalizations, ED visits, incarcerations, and homelessness, and lower health care and mental illness-related costs (AHRQ, 2012).

### Online Resources

- [Program description](#) from AHRQ website (pdf)

### Michigan Self-Determination Arrangements

- **Start and End Date:** 2003 to present
- **Number of Participants:** No set cap; anyone receiving mental health services can opt for self-direction; however, few participants are currently self-directing mental health services
- **Funding Source:** Managed care and mental health block grant funds
- **Yearly Budget Amounts:** Varies
- **Resource Allocation:** Based on previous year’s public mental health expenditures
- **Program Description:** Michigan’s Department of Community Health has the infrastructure in place to promote behavioral health self-direction. In Michigan, peer-run drop-in programs are funded using savings from prepaid health plans. County managed care organizations support person-centered planning, warm lines, and micro-enterprise development (Alakeson, 2007).

### Covered Goods and Services

- Services must meet medical necessity criteria (per state Medicaid
Michigan’s behavioral health authority is the only in the country that has a statement of policy on the practice of self-determination in the public mental health system. The core elements of the policy are as follows (Self-determination policy and practice guideline, 2003):

- Participants are provided with information about self-determination and have access to tools that support it.
- Providers ensure that their planning and service delivery activities are designed to support self-determination.
- Participants direct their own services, choosing them based on their person-centered plan.
- Fiscal responsibility and accountability is shared between the provider and the participant.
- Providers and participants are actively committed partners.
- Providers support the participants to be successful in self-determining their care.
- Safety, health, and wellbeing are paramount; issues are addressed through the person-centered planning process and implemented with maximum participant choice and control in mind.
- Providers must minimize conflicts of interest between providers and participants.
- Self-determination arrangements are administrative; they don’t change eligibility.

The Michigan practice guideline also includes detailed policies to support each of the above core elements.

4.5 INTERNATIONAL SELF-DIRECTED BEHAVIORAL HEALTH PROGRAMS

Currently, self-directed programs are active in Austria, Australia, Belgium, Canada, Denmark, Germany, Italy, Finland, France, the Netherlands, Sweden, the United Kingdom, and the United States (Report: Personal Health Budgets Research Scan, 2010). Programs using a model similar to Cash & Counseling in England, Germany, Austria, and the Netherlands found improvements in quality of life, access and coordination, participant satisfaction, and cost similar to those found by the CCDE (Alakeson, 2010).


1. An “open” model in which the participant or caregiver is given a cash allowance and selects goods and services that are not accounted for by the government. In this model, the individual is responsible for obtaining adequate care.
2. A “budget” model, which maintains a direct connection between the person’s needs and the goods and services that are purchased.

The “open” model is currently used in Germany and Austria. The “budget” model is currently being used in England and the Netherlands and most closely resembles the budget authority model used in the CCDE and in the domestic behavioral health self-directed programs. This second model will be the primary focus in this review.

4.5.1 AUSTRALIA

The Direct Consumer Funding program in Australia serves individuals and families with physical and intellectual disabilities. The program uses two kinds of funding: “untied” for one-time purchases and emergency expenses, and “tied” for ongoing expenses associated with a detailed service plan. Planning is conducted with the participant but separate from service providers. An evaluation of this program found that
participants were highly positive about the option. 30 percent of eligible individuals chose the option, with one third requiring minimum support, one third moderate, and one third intensive (Lord & Hutchinson, 2003). In 2006-2007, a total of 1,521 individuals received Direct Consumer Funding (Chenoweth & Clements, 2009). In the area of behavioral health, the Western Australia Mental Health Commission (2011) Independent Community Living Strategy program uses person-centered and individualized approaches to support 100 individuals transitioning from long-term stays in hospitals to the community.

4.5.2 Canada
The Family Services Association in Toronto, Canada administered the Individualized Quality of Life Project, later called Options. The program served individuals with learning difficulties, some of who were also mental health service users. The program focused on network building, strengthening families as primary supports, increasing community integration, and access to providers. Community resource facilitators, distinct from case management, connected participants to networks. Like the Australian Direct Consumer Funding program, services and planning were completely separate (Lord & Hutchinson, 2003). Currently, nearly every province in Canada has some form of budget or employer authority in place, particularly for individuals with intellectual and physical disabilities (Chenoweth & Clements, 2009). As with Australia, this review found no mention of self-directed programs with a specific behavioral health orientation.

4.5.3 The Netherlands
Since 1996, The Netherlands has offered a self-direction option for people with long-term care needs including people with psychiatric disabilities (White, 2011). Popular with both the public and politicians, the program had an estimated monthly net growth of 1,000 individuals in July 2010 (White, 2011). Eligible individuals may opt for a fully self-directed budget or combine a personalized budget with traditional in-kind care. Budgets are calculated based on the care needs required in terms of time, intensity, and the need for residential services (Brewis, 2007).

Evaluations have found that self-directed participants in the Netherlands receive a higher volume of services and supports than in-kind participants; this may occur because self-directed participants are afforded more choice as they personalize services, which may lead to more service and support use overall (Brewis, 2007). Evaluations also found that participants reported better relationships with care providers and more control over the context of care, particularly in terms of flexibility and timing. However, officials in the Netherlands have reported difficulties related to the sustainability of the program in recent years, in part because of the program's broad eligibility. In 2011, the program had to impose waiting lists because of financial difficulties associated with costs and demands for services shifted from other programs (Nadash, Doty, Mahoney, & Von Schwanenflugel, 2012).

The experience in the Netherlands has also been one of new innovations related to self-direction. Self-directed participants have driven the creation of new initiatives such as care farms, independent living initiatives, and the "Thomashuizen," community houses for individuals with intellectual disabilities (Brewis, 2007). Two budget-holder associations have been formed that function in a manner similar to the NPN in the United States. These organizations focus on trainings, publications, online support, and a collective defense of the interests of self-directed program participants (Brewis, 2007). Within the provider community, small innovative businesses have sprouted up targeted to PGB holders (Brewis, 2007).

4.5.4 United Kingdom
As in the United States, the introduction of self-direction in the UK is part of a larger movement towards more personalization and person-centered care. In the UK, pressure for direct payments arose out of the disability movement and was related to the social model of disability, critiques of the medical model, and the
independent living philosophy (Spandler, 2004). The UK government has embraced the self-direction model approach, with approximately 100,000 people participating in this model in the UK's social care system, and a stated government commitment to expand the model (Alakeson, 2011).

The Individual Budgets Evaluation Network (IBSEN) included a randomized controlled trial of nearly 1000 social care service recipients across 13 sites in the United Kingdom between 2005 and 2007. Another pilot program to test self-direction in the National Health Service began in 2009 and focused on individuals with chronic health conditions, including serious mental illness and substance use conditions. 63 sites are taking part in the pilot, which concluded in 2012. Of these sites, 20 are examining issues and outcomes particular to participants with mental health service needs, and two focus specifically on individuals with substance use conditions (Report: Personal Health Budgets Research Scan, 2010). An in-depth evaluation accompanied the pilot program in 20 sites and found significant increases in care-related quality of life and reductions in inpatient and primary care costs, particularly for the mental health sub-group (Forder et al., 2012). The final evaluation report concluded that personal health budgets are a cost-effective and recommended a large-scale rollout by the National Health Service with priority given to mental health populations (Forder et al., 2012).

Despite the promising directions for self-direction, take-up rates for self-direction in mental health in the UK are low. For example, the expenditures on self-directed payments as a percentage of total expenditures for people younger than 65 years of age with a physical or sensory impairment is 9.4%; for individuals with psychiatric disabilities, this figure is 0.3% (Brewis, 2007). To date, there is little quality information regarding the cost-efficiency of self-direction in the UK; although some studies have found reductions in cost, these studies have not fully accounted for costs related to implementation (Report: Personal Health Budgets Research Scan, 2010).

4.6 SELF-DIRECTION FOR PEOPLE WITH SUBSTANCE USE DISORDERS

While self-direction in mental health appears to be a developing area, self-direction in the area of substance use services and supports is nearly non-existent. However, it appears as though existing mental health self-direction pilots serve a population with co-occurring mental health and substance use disorders: The National Health Service pilots of personal health budgets included populations with both mental health and substance use disorders (Alakeson, 2011), and 49 percent of participants in Texas’ self-directed care program reported having ever received treatment for substance use (Norris, et al., 2010). This review of the literature found no information regarding the relative effectiveness for co-occurring populations. This is an area well-worth exploring, given the high prevalence of co-occurring mental health and substance use disorders. According SAMHSA (2007), an estimated 5.6 million adults experience both serious psychological distress and co-occurring substance use disorders. Approximately 15 percent of individuals with a serious mental illness also have a substance use disorder, compared with approximately 4 percent of the general population, and the prevalence of serious mental illness among adults with substance use disorders is approximately three times higher than the general population (Harris & Edlund, 2005).

In her examination of the views of over 70 stakeholders on behavioral health self-direction in the UK, Brewis (2007) identified a commonly held perception that people with substance use issues are not right for self-direction because they will "drink their money away" (p. 14). Brewis counters that such concerns might be addressed through a one of a variety of monitoring mechanisms such as implementing more restrictive rules on purchasing or appointing a trusted representative to hold and disburse funds. Brewis noted that it is essential that such mechanisms be matched to the level of perceived risk and should be continuously reassessed to address issues of risk while supporting maximum self-determination.
In recent years, a number of programs relevant to this review have emerged. Access to Recovery (ATR) is a three-year discretionary grant program that provides funds to states to redesign their substance use treatment systems to promote more choice of treatment and recovery supports, and expand existing provider networks to include nontraditional and faith-based organizations (SAMHSA Access to Recovery Grants, 2011). Program participants are given vouchers to purchase substance use treatment services as well as supports, including childcare, transportation, housing, and goods to help secure employment such as tools and clothing. The ATR initiative was introduced in 2003 and is funded by SAMHSA's Center for Substance Abuse Treatment. The ATR program is administered to an estimated 170,000 individuals each year, and in 2010, SAMHSA awarded $379 million to a second round of grantees (SAMHSA Access to Recovery Grants, 2011). The ATR program does not follow the budget authority model directly because it uses vouchers rather than cash budgets. While both mechanisms afford the participant more choice, vouchers involve arrangements with particular recovery support service providers, whereas case budgets can be spent on any purchase authorized by the person-centered plan. Further, the programs are implemented differently than other self-directed programs in that provider agencies also function as support brokers in some states. Despite these differences, ATR’s continued and widespread adoption marks a shift towards self-direction and choice in the behavioral health arena and has laid the groundwork for self-direction (Free to Choose: Transforming Behavioral Health Care to Self-Direction, 2005).

A small body of research points to potential effectiveness of the ATR model. An evaluation of the ATR program in Washington State found that participation in ATR was associated with increased treatment duration, increased likelihood of treatment completion, and increased likelihood of attaining employment (Krupski, Campbell, Joesch, Lucenko, & Roy-Byrne, 2009). Wickizer, Mancuso, Campbell and Lucenko (2009) examined the cost savings associated with the ATR model. The authors looked at per member per month costs of working-age, disabled ATR clients in the Washington State program with a propensity-score-matched comparison group. The analysis found modest savings from the ATR program; ATR was associated with $66-$136 reductions in per member per month Medicaid costs and a 20 percent reduction in hospital emergency room costs.

Some unique aspects of financing substance use services may be important to consider in the context of funding services through a self-directed program. In substance use services more than in mental health, the government acts as a direct purchaser. A greater proportion of public dollars are spent on substance use services relative to mental health services. Public sources – Medicaid, Medicare, state and local governments, and other federal funding – pay for 79 percent of substance use treatment and only 58 percent of mental health treatment (Mark, Levit, Vandivort-Warren, Buck, & Coffey, 2011). Substance use treatment accounts for only 1.5 percent of total Medicaid spending; in contrast, mental health accounts for 10 percent of total Medicaid spending (Mark, et al., 2011). Further, the sources of these public dollars differ: 54 percent of public spending in mental health is through health insurance, while 68 percent of public spending in substance use is through direct government grants and provider contracting (Institute of Medicine, 2006b).

### 4.7 Self-Direction and Transition-Age Youth

Transition-age youth are adolescents and young adults (generally between the ages of 16 to 25) who have been diagnosed with a behavioral, emotional or substance use issue that has led to impaired functioning (Pottick, Bilder, Vander Stoep, Warner, & Alvarez, 2007). Garland and colleagues (2000) report that youth in public sectors of care, such as alcohol and drug services, child welfare, juvenile justice, mental health, and public school services for youths with serious emotional disturbance have “extremely high” rates of psychiatric disorders. Over the course of one year, over 750,000 transition-age youth were admitted to inpatient, outpatient, and residential facilities for psychiatric problems in the United States (Pottick et al., 2007). Additionally, substance use disorders increase in prevalence during the transition period; the 2004
The National Household Survey on Drug Use and Health showed the 1-year prevalence of illicit drug or alcohol disorders went from 9 percent among 12- to 17-year-olds to 21 percent for 18- to 25-year-olds (SAMHSA, 2005). The population of transition age youth who are involved with public services pose challenges to the existing systems due to their unique behavioral health needs.

The transition to adulthood is particularly difficult for these individuals for several reasons. For some, behavioral health issues can make it challenging for transition-age youth to develop healthy social and problem-solving skills (Davis & Vander Stoep, 1997). Diagnoses of serious mental illnesses become more prevalent during transition age, which may lead to an increased need for targeted, intensified services (Pottick et al., 2007). In addition, weak and fragmented connections between child-serving and adult-serving systems further complicate the transition to adulthood for this population, and create gaps in care that can jeopardize healthy development. Self-direction has the potential to address the needs of this population.

This review was not able to identify any behavioral health self-direction programs that are tailored specifically to meet the needs of transition age youth. However, two approaches to behavioral health services for youth could serve as a basis or starting point for implementing self-direction with younger people: The system of care framework and the Wraparound approach. The family-centered system of care framework involves teams of professionals and natural supporters working together across organizations to address the behavioral health needs of young people and their families (Stroul, 2002). Wraparound is a widely used process for planning and organizing the delivery of services and supports that emphasizes individualization and family-centeredness (Burchard, Bruns, & Burchard, 2002). Such approaches could serve as a platform for implementing an individual budget for younger people with behavioral health issues.

In addition to a scarcity of self-directed program models for transition-age youth, this review found that there was a paucity of research into the potential effectiveness of self-directed behavioral health programming for transition age youth. There is, however, promising research that examines self-direction in the context of academics and education planning. Researchers have found that when youth are able to work towards self-specified goals, identify and articulate strengths, monitor their own progress, and act as self-advocates to specify the mix of services and supports that work best, they are more likely to be engaged and successful in school (Pierson, Carter, Lane, & Galeser, 2008). In addition, Brockelman (2009) found that the perception of independence, personal agency and individual responsibility was predictive of academic success in students diagnosed with mental illness. It is unclear whether these conclusions can be translated into a behavioral health recovery context. More research is needed on self-directed behavioral health programs for the transition aged community.

Transition age youth are going through a developmental stage characterized by increased competence, cognitive, moral and social development and a desire for independence (Davis & Vander Stoep, 1997). Although the development of these domains may be hampered by the presence of behavioral health issues, participation in self-directed programs may encourage a sense of autonomy, choice, and independence in youth, that may encourage stronger engagement in recovery and ultimately, positive outcomes as were seen in the educational context. Self-direction may also provide youth with valuable life experience in decision-making, future planning, and autonomy that can be valuable in the future. In addition, when youth are more engaged in the supports and services they receive, it may ensure more continuity as youth transition from children’s to adult services.

4.8 Outcomes
Evaluations accompanying existing pilot programs in behavioral health have examined a range of outcomes, from cost to quality of life. This section presents some of these findings, as well as a discussion of the variety of outcome measures needed to truly capture the impact of self-direction on recovery.

4.8.1 QUALITY OF LIFE DOMAINS
Most recently, the UK’s personal health budgets pilot found significant increases in care-related quality of life for individuals with self-directed arrangements compared with those receiving traditional services and supports; these findings were particularly strong for individuals with mental health conditions (Forder et al., 2012). These findings add to a growing body of evidence indicates that self-directed programs increase quality of life, in a number of domains.

EMPLOYMENT AND EDUCATION
Employment and education are critical elements of any comprehensive system of care for individuals with behavioral health service needs. Mental health issues are the leading cause of disability in the United States for individuals aged 15 to 44; this is the largest working-age group receiving public income supports (Cook, 2006). Employment rates for individuals who meet disability criteria for mental illness range from 32 to 62%, and employment rates for individuals with diagnoses related to schizophrenia range from 22 to 40% (Cook, 2006). Despite high unemployment rates amongst this population, fewer than 25% of individuals diagnosed with mental illness receive any form of vocational assistance (Bond et al., 2001). Preliminary evidence suggests that self-direction may lead to increased participation in both employment and education. For example, some participants in the Florida SDC program reported that they were able to return to work and school as a result of participating in the program (OPPAGA, 2010).

MEANINGFUL RELATIONSHIPS
People with mental health problems commonly experience social isolation - because of stigma, low expectations, a lack of vocational and social supports, and barriers in accessing basic services like housing and transportation (Brewis, 2007). Self-direction may help to decrease social isolation in profound and individualized ways. There is a need for increased peer support networks and safe places for people to be in the community. Florida SDC participants reported that support brokers provided an “emotional safety net” and that the purchase of computers enabled them to connect electronically with family and friends (OPPAGA, 2010).

COMMUNITY PARTICIPATION
Given the strong emphasis on autonomy, self-directed programs have the potential to support individuals in living their lives in an integrated community setting, rather than institutional or otherwise segregated settings like congregate living. The West Australia Mental Health Commission, for example, is currently using self-directed individualized budgets to support 100 individuals in moving out of extended stay hospitals and into the community (Western Australia Mental Health Commission, 2011). Anecdotally, the Maryland Self-Directed Care program has supported participants to become more integrated into their communities by increasing access to employment, education, transportation, and wellness activities (Carroll & Hegner, 2011).

EMPOWERMENT, AND SELF-ESTEEM
There is substantial evidence that self-directed programs increase confidence and self-efficacy, and outcomes regarding quality of life, independence, empowerment, choice and access (Report: Personal Health Budgets Research Scan, 2010).

In the IBSEN pilots, self-directed participants with mental health service needs reported significantly higher quality of life than a comparison group of mental health service users receiving traditional agency-based care.
Participants in the UK individual budget pilots also reported greater feelings of self-worth and an increased ability to take part in activities that weren’t associated with mental health (Spandler & Vick, 2006). These outcomes were strongest for programs that included a heavier emphasis on supports (through support brokerage and other forms) and involved the participant at every step (Report: Personal Health Budgets Research Scan, 2010). Similarly, participants in the Florida SDC program reported that the program helped them to develop more self-esteem and move toward recovery (OPPAGA, 2010).

Cultural Preferences
There is some evidence that self-direction might promote more culturally competent support. The increased flexibility associated with self-direction can promote cultural competence since individuals have more discretion regarding desired services and supports. They can be tailored to reflect an individual’s preferences regarding involvement of family, level of independence, appropriate settings and contexts for services and supports. In the Cash & Counseling program, services were better tailored to suit individual cultural preferences (San Antonio, Simon-Rusinowitz, Loughlin, Eckert, & Mahoney, 2007) and participants were more likely to hire workers of the same race compared to non-participants (Foster, Brown, Phillips, & Carlson, 2005).

Access to Health Services
Given the high rates of medical co-morbidities and the lower life expectancy associated with behavioral health conditions (Colton & Manderscheid, 2006), health and access to healthcare is a critical outcome for any recovery-oriented behavioral health program.

As noted above, the CCDE found that individuals in a self-directed option experienced lower levels of unmet needs and adverse health events than individuals receiving traditional agency-based services (Carlson et al., 2007). There is some evidence that when self-directed participants are unable to access goods and services related to medical needs, they are able to purchase these things as part of their self-directed budget. For example, participants in the UK pilots purchased things defined as health care, such as injections, foot care, physiotherapy, and pain management, with the goal of integrating health-related services and supports into their regular wellness routines (Alakeson, 2008a). Participants in Florida SDC similarly reported being able to afford needed medical treatments that were not covered by health insurance (OPPAGA, 2010). In both the Texas and Pennsylvania programs, participants used budgets to meet outstanding medical needs early on, indicating previously unmet needs (Maula, 2010).

The self-direction model can also increase participant access through its promotion of transportation to and from medical appointments. Individuals in a participant-directed program can use their funds to purchase bus passes or bicycles, automotive services, or to pay friends or family to drive them to medical appointments (NRCPS, 2010).

There is some evidence that self-direction might promote more culturally competent support. The increased flexibility associated with self-direction can promote cultural competence since individuals have more discretion regarding desired services and supports. They can be tailored to reflect an individual’s preferences regarding involvement of family, level of independence, appropriate settings and contexts for services and supports. In the Cash & Counseling program, services were better tailored to suit individual cultural preferences (San Antonio, Simon-Rusinowitz, Loughlin, Eckert, & Mahoney, 2007) and participants were more likely to hire workers of the same race compared to non-participants (Foster, Brown, Phillips, & Carlson, 2005).

4.8.2 Satisfaction with Services and Supports
Participants in self-directed programs tend to report high levels of satisfaction with services and supports. A recent survey of 1,114 personal budget holders in England found high levels of satisfaction, with the majority of respondents stating that self-direction had made a positive impact on their lives (Hatton & Waters, 2011). Similarly, a report outlining personal budgets in the Netherlands found that overall, the program was very popular and that participants valued the freedom and choice it afforded them (White, 2011). In the United States, reports of satisfaction with pilot programs were significantly higher than with traditional service arrangements (Alakeson, 2007; Cook, et al., 2008; OPPAGA, 2010; Sullivan, 2006).

In regards to relationships with providers, participants in self-directed mental health pilots reported that they had a different relationship with their providers; participants reported being treated with more respect and listened to. Participants also felt that they could take their business elsewhere if they were not satisfied (Alakeson, 2007).

4.8.3 Fraud and Abuse
In any self-directed program, there is the potential for an intentional or unintentional misuse of funds. Additionally, the added responsibility of managing a budget could leave participants vulnerable to fraudulent practices on the part of service and support providers. These concerns are not unique to self-direction; indeed, the potential for fraud and abuse is present in traditional service and support arrangements as well. Despite these concerns, there was minimal evidence of fraud in the CCDE and the preliminary evaluations of the Florida SDC (Schore, Foster, & Phillips, 2007; Stefan, 2006). This could be in part due to effective accountability mechanisms built into self-directed program models. Nonetheless, concerns regarding fraud and abuse are frequently identified by stakeholders of all types, and will need to be continually addressed through training and education (Alakeson, 2007; National Health Service, 2011a).

4.8.4 Cost-Effectiveness
The costs of mental illness were estimated at $79 billion in 2003, and it is likely that they have risen in recent years (New Freedom Commission on Mental Health, 2003). Further, our current mental health system continues to rely on institutional and emergency care and suffers from fragmentation and gaps in care for adults with serious mental illnesses (New Freedom Commission on Mental Health, 2003). Innovative programs – like those that support self-direction – have the potential for creating efficiencies in the current system by supporting self-determination and overall wellness while reducing costs (Alakeson & Duffy, 2011).

In the current economic climate, the need for cost-effective programs is greater than ever. Many states face longstanding budget crises, and taxpayers demand that public dollars be put to their best use. States may be more likely to adopt innovative practices if they are shown to be cost-effective.

As noted in an earlier section, evidence from the CCDE, and ATR suggests that self-directed behavioral health care has the potential for cost-savings or cost-neutrality compared to traditional services (Dale & Brown, 2005; Wickizer et al., 2009). Further, the recent National Health Service pilot evaluation found that self-directed arrangements were associated with significant reductions in inpatient and primary care costs, particularly for individuals with behavioral health conditions (Forder et al., 2012). The extent to which these results are generalizable to the United States behavioral health population is unclear, but the 2008 analyses of Shen et al. demonstrate that self-directed care for those suffering from behavioral health issues may have cost implications similar to the CCDE. Further investigation is needed.

Factors in Determining Cost-Effectiveness
A number of factors make the calculation of cost-effectiveness in behavioral health self-direction an extremely complicated endeavor. Most evaluations compare costs of self-directed programs to those of traditional care. However, costs of traditional care and personal budgets tend to be underestimated due to
unpredicted demands, unmet needs, and the costs of starting up schemes and uncompensated out of pocket expenses in traditional care (Report: Personal Health Budgets Research Scan, 2010).

When calculating program costs, it is critical to factor in costs associated with planning and securing service provision. Additionally, there may be “one-off” costs associated with starting up supports for self-direction that will have an impact on cost-effectiveness calculations during the start-up phases of demonstrations (Alakeson & Duffy, 2011; Elder-Woodward, McColl, & Neil, 2009; White, 2011). Programs that have implemented self-direction in the past have developed strategies to deal with some of these issues, and new programs can better factor these costs into overall program costs at the outset (Doty, et al., 2010).

Any analysis of cost savings is highly influenced by the resource allocation process. The method for determining participant budget amounts can have an impact on costs; if amounts are set too low, participants may appear to overspend their budgets and cost savings will be underestimated, and if amounts are too high, cost-savings may be overestimated.

While calculating costs is difficult, so is calculating savings. Alakeson (2007) writes that calculating the full range of possible savings across multiple funding streams is an extremely complex endeavor. Many savings could accrue to the behavioral health system; on the other hand, cost savings (or increases) could result from a shifting in funding streams from the areas of employment, general healthcare, criminal justice, or other systems. For example, if a person in a self-directed program moves from a group home to independent housing subsidized by HUD, the costs of housing are shifted from the mental health system to the housing system. Additionally, many of the savings may occur in the area of prevention – preventing the need for emergency services or more costly medical services down the line. These savings are also difficult to estimate.

Finally, if implemented properly, self-direction might lead to cost savings to society as a whole through "making better use of the natural energies and skills of people and communities" (Alakeson & Duffy, 2011, p. 12). The cost savings of these long-term results are similarly difficult to quantify.

**Cost-Effectiveness Evidence from Current Pilots and Demonstrations**

A 2010 scan of existing research concluded that the cost-effectiveness of self-directed models remains somewhat unclear because of a lack of rigorous cost-effectiveness studies accompanying pilots and demonstrations (Report: Personal Health Budgets Research Scan, 2010). However, in pilots conducted by the National Health Service, cost-effectiveness tends to be clearer for individuals with mental health issues and younger physically disabled people than older people and people with learning disabilities, particularly when measures of overall wellbeing are used (Forder et al., 2012; Glendinning et al., 2008; Report: Personal Health Budgets Research Scan, 2010).

Additionally, there is some evidence that individuals spend significantly less on goods and services than is allocated in their individual budgets. In demonstrations in Germany and the Netherlands, participants spent 50 percent and 30 percent less, respectively (Report: Personal Health Budgets Research Scan, 2010). In the early years of the Florida SDC demonstration, evaluators found that individuals only spent one third of the funds that had been allocated to them in their budgets (Cook, et al., 2008). However, a later analysis of the Florida SDC costs found that participants spent more, on average, than individuals receiving services in the traditional mental health system (OPPAGA, 2010). It is unclear whether these additional costs were due to previously unmet need, however, and the methodology of the cost-neutrality analysis has been questioned because of its exclusion of those receiving Assertive Community Treatment from the services-as-usual group, which may have lead to an underestimation of the costs of traditional services (Costlow, Heller, & Fudge, 2010).
4.9 A Need for More Research

There remains a scarcity of research into the effectiveness and implementation of self-directed programs in behavioral health. Reviews of the literature have found that people with behavioral health issues are among those least commonly using self-directed models, and that there is no theoretical justification for this disparity (Consumer-Directed Health Care: How Well Does It Work?, 2004; Glendinning, et al., 2008; National Health Service, 2010). Most information from the current evaluations is descriptive, and more information is needed regarding the impact of self-direction on key outcomes including health and wellness, employment, education, and cost. However, the available literature is promising and suggests that more exploration is recommended and needed (Report: Personal Health Budgets Research Scan, 2010).
5 Financing Behavioral Health Self-Direction

Behavioral health in the United States is “organized and financed through a patchwork of insurance and direct provision of services” (Institute of Medicine, 2006b). Services and supports are funded in a range of ways – through state and county dollars, managed behavioral health care, and federal mental health and substance abuse block grants. Currently, no single funding source is widely used to fund behavioral health self-direction. Funding from multiple sources is often combined or “braided” to work within the regulations and restrictions of various funding sources.

Elements of the Patient Protection and Affordable Care Act of 2010 (ACA) such as changes to the 1915(i) state plan option and the development of Accountable Care Organizations may provide opportunities for self-direction in behavioral health. Beyond health funding, there is the potential to braid behavioral health funding with vocational rehabilitation, labor, and education dollars. This section explores the broad range of funding streams that could support behavioral health self-direction on a large scale.

5.1 Federal Funding Sources

A number of federal agencies, including the Centers for Medicare & Medicaid Services (CMS), the Administration on Aging (AoA), the Substance Abuse and Mental Health Services Administration (SAMHSA), and the Veteran’s Administration (VA) offer potential funding mechanisms for self-direction.

5.1.1 Medicaid

Medicaid is the single largest funder of behavioral health services in this country. The Deficit Reduction Act of 2005 and the ACA require that Medicaid increase the amount that Medicaid matches state funds in the future. The new health reform law stipulates that all individuals under the age of 65 with incomes below 133% of the federal poverty level will be eligible for Medicaid by January of 2014. When the Medicaid expansion takes effect, it is expected that Medicaid will be the primary source of coverage for an estimated 32 million newly eligible beneficiaries, 17.5 percent of whom will have a mental health or substance use disorder (Manderscheid, 2010; Garfield, Howard, & Lyons, 2011). However, it is currently unclear whether the benefit packages for these newly eligible beneficiaries will include many optional behavioral services such as peer support, housing and vocational supports, and psychiatric rehabilitation (Garfield, Lave, & Donohue, 2010). If this is the case, it is unclear whether self-direction will be an option for this group.

The self-direction model stretches the bounds of what Medicaid will pay for, which presents a significant barrier to its implementation (Alakeson, 2008b). For example, Medicaid does not typically reimburse for the cost of goods such as a computer to support vocational rehabilitation or exercise equipment to promote wellness. However, a number of Medicaid waivers and state plan options have the potential to support self-direction in behavioral health.

State Plan Options

States can submit state plan amendments to CMS for approval to add self-direction features (budget and employer authority) to the state Medicaid program. Once approved, these features are established as additions to the program. Medicaid state plan options that are relevant to self-direction are outlined below.

Rehabilitation Option

1 Accountable care organizations are groups of health care providers that enter into collaborative agreements to share responsibility to improve quality and control costs.
Mandatory Medicaid state plan services are designed to cover services for medical conditions and often do not include many integral community behavioral health services, including case management, psychiatric rehabilitation, peer support, and outpatient therapy (Cook, et al., 2004). These services can, however, be covered under the Rehabilitation Option (called rehab option). Under rehab option, some states have funded certified peer providers for community-based behavioral health services including Assertive Community Treatment, psychiatric rehabilitation, community support, and crisis support. In 2005, 46 states used the rehab option to fund psychosocial rehabilitation and other mental health services (O’Keeffe et al., 2010).

The rehab option services must be targeted at restoring lost functioning (rehabilitation) rather than developing new skills (habilitation), but such distinctions are often ambiguous. Rehab option is based on the medical model of assistance, which can lead to the person characterized as the passive recipient of a service or procedure. This stands in opposition to many of the values of self-direction (Cook, et al., 2004).

Under the rehab option, person-centered planning and budgeting by certified peer providers could be reimbursed, but the costs of brokerage and financial management would have to be considered administrative expenses, not services. Those services could also be covered as other non-Medicaid expenses (Cook, et al., 2004).

Further, the rehab option typically reimburses services via direct payments to providers, but not goods. Self-direction operates under the premise that the purchase of certain goods can promote recovery. The purchase of a bicycle or business attire would not be reimbursable under the rehab option but would be a covered expense for an individual working towards community integration and employment in a behavioral health self-direction program.

**1915(g) Targeted Case Management Option**

The 1915(g) Targeted Case Management option allows states to provide targeted case management services to a defined group within a limited area. Adults with serious behavioral health conditions are an allowable target population. The option, however, only covers certain allowable services, including assessment, service plan development, referrals and linkages, plan monitoring and follow-up (Karakus, Frey, Goldman, Fields, & Drake, 2011). In a behavioral health self-direction program, the 1915(g) option could be used to pay for person-centered planning activities and budgeting, but like the rehab option, would not cover brokerage and financial management as part of treatment (Cook, et al., 2004).

A behavioral health program might also target the option to individuals receiving peer-provided supports. Historically, however, the 1915(g) option has not been used to fund peer-provided services as some requirements for targeted case management may conflict with the peer-support role (Policy Issue #3: Financing Peer Provided Services, 2008).

**1915(i) Home and Community-Based Services Option**

The 1915(i) state plan option is the most likely Medicaid funding source to hold promise as sustainable support for behavioral health self-direction. The 1915(i) was designed to expand HCBS to individuals who did not require an institutional level of care by allowing states to amend their state Medicaid plans to offer HCBS as a benefit (O’Keeffe, et al., 2010). The 1915(i) allows states to cover services that are currently available under the 1915(c) waiver plus additional services such as psychiatric rehabilitation and peer-provided services. The 1915(i) option is very similar to the 1915(c) waiver, but with a few important exceptions. Section 1915(i) authorizes states to offer home and community-based services to individuals with psychiatric disabilities and not be linked with any type of institutional eligibility. The option uses needs-based rather than institutional level of care eligibility criteria, so the Institutes for Mental Disease (IMD) exclusion does not restrict eligibility in this case (Karakus, et al., 2011).
New language contained in the ACA supports the expansion of 1915(i) state option. The 1915(i) state option has been amended in a number of ways that promote its adoption for the funding of a behavioral health self-direction program, including an expansion in the range of covered services and supports, an extension to include individuals with incomes up to 300 percent of the SSI Federal Benefit Rate, and an allowance to have more than one 1915(i) benefit and to target specific populations such as individuals with psychiatric disabilities. The option must be available statewide, and states cannot set limits on the number of individuals who can receive the benefit. These changes to the 1915(i) state plan option were made effective shortly after reform was passed in April 1, 2010 (Senate Bill HR 3590 - The Patient Protection and Affordable Care Act Home-and Community-Based Services Option Provisions, March 2010).

Despite its promise as a financing strategy for self-direction, states have yet to take advantage of the new option to increase self-direction. Thus far, six states – Iowa, Colorado, Nevada, Washington, Wisconsin, and Idaho - have enacted the 1915(i) state option, and none of them uses the funds for self-direction (Kaiser Family Foundation, 2011a).

It is possible that states are hesitant to adopt the option before final rules are released (the rules were released in the spring of 2012). Additionally, states may be reluctant to adopt the 1915(i) because of the requirement that the option be implemented statewide and limitations on enrollment caps are not allowed. These requirements promote an “all or nothing” approach to self-direction, which is a potential deterrent, particularly in the context of current fiscal environment. Notably, there may be an option for states to phase-in the 1915(i) option over five years, implementing it in certain areas before others. This feature could be useful if states wished to understand the impact of the 1915(i) before going statewide. Additionally, states implementing the 1915(i) may be able to target services to a very specific population, which could assuage cost concerns (Barth, Klebonis, & Archibald, 2011).

1915(j) Self-Directed Personal Assistance Services Option

The 1915(j) authority, part of the Deficit Reduction Act of 2005, was implemented in January 2007. Without this authority, individuals who were directing services under a state plan option could only use employer authority. Further, neither prospective payments nor cash benefits were allowed. With the 1915(j) authority, those individuals can use budgets to purchase non-traditional goods and services used for personal assistance-related issues obtain payment for services prior to their delivery and receive a cash allowance. The 1915(j) was designed to eliminate the need for states to implement 1115 waivers to offer full budget authority to participants using personal care budgets. As of 2010, seven states have obtained CMS approval to use the (j) option (O’Keeffe, et al., 2010 ). Potentially, peer support workers could be hired to support behavioral health service users who have needs related to instrumental activities of daily living (IADLS) under this option.

1915(k) Community First Choice Option

In 2010, the ACA authorized the Community First Choice Option of the 1915(k) authority. The 1915(k) option allows states to provide community-based attendant services and supports with a 6 percent Federal Medical Assistance Percentages (FMAP) increase over the life of the program. To be eligible, an individual must need assistance with activities of daily living (ADLs) or IADLs and health-related tasks. If a person’s income is lower than 150% Federal Poverty Level (FPL), he or she does not need to meet the institutional level-of-care criteria required by the state; if above 150% FPL, the person must meet institutional level-of-care criteria. In order to provide services under the 1915(k) option, states must meet a series of quality assurance and reporting requirements and must work with a Development and Implementation Council with a majority of members being individuals with disabilities and their representatives (O’Keeffe, et al., 2010). For individuals with significant behavioral health service needs, the Community First Choice Option could ensure the
availability of the intensive support needed to remain in the community and avoid institutional placement (Mechanic, 2012).

**Medicaid Waivers**

Medicaid waivers allow states and localities to depart from the traditional Medicaid service delivery structures and financing mechanisms. States may apply for Medicaid waivers to remove or alter federal requirements regarding the provision of services. A number of Medicaid waivers have the potential to support self-direction, although each of them has elements that make it difficult to obtain and sustain a self-directed behavioral health program. The approval process for some waivers can be cumbersome and can take years to put in place, which could make movement towards behavioral health self-direction prohibitive (Free to Choose: Transforming Behavioral Health Care to Self-Direction, 2005). Waivers relevant to self-direction are detailed below.

**1915(b) Managed Care Waivers**

1915(b) Managed Care Waivers are used to support a managed care delivery system for certain specialized populations, including behavioral health populations. States must demonstrate cost-effectiveness when operating under a 1915(b) waiver (Smith, Kennedy, Knipper, & O’Brien, 2005).

Currently, 70 percent of Medicaid enrollees receive some or all of their services through managed care, either capitated or non-capitated (Kaiser Family Foundation, 2011a). Managed care organizations – particularly managed behavioral health care organizations – may have the potential to support future behavioral health self-direction efforts. ValueOptions and Magellan Behavioral Health Care currently fund the demonstration projects in Texas and Pennsylvania, respectively. Managed care organizations may choose to support behavioral health self-direction given the potential cost-savings associated with other demonstration findings and the potential for decreased use of inpatient and emergency services.

Historically, managed behavioral health organizations have designed and procured innovative and recovery-oriented services like peer support, involved service users and families in planning and implementation, and worked to engage individuals in mental health services (Holt & Dougherty, 2011). The 1915(b) waiver is used by several states to fund peer-operated service programs through savings achieved using managed care strategies (Policy Issue #3: Financing Peer Provided Services, 2008). In Washington State, savings are used to fund clubhouse, respite, and supported employment services (Karakus, et al., 2011). Under a managed care system, behavioral health carve-outs can cover fiscal intermediary and support broker services for a self-direction program that would not normally be covered by Medicaid.

The data infrastructure of managed care is potentially a good fit for self-direction as well, in that it would allow for ease in developing budgets, tracking expenditures, etc. It would, however, require that companies develop new systems and codes to ensure that financial management could be conducted in a way that is not onerous to the participant (personal communication, Susan Bergeson, November 11, 2011).

In interviews with stakeholders from managed care companies Magellan Behavioral Health and Wellcare, Alakeson (2007) learned that managed care companies see a potential fit between self-direction and managed care due to possible cost savings in self-direction. In addition, managed care companies see self-direction as an opportunity to express commitment to high-quality and recovery-oriented care. An interview for this review with a representative at large managed care company echoed these sentiments.

In addition to public managed care organizations, it is possible that private managed care companies may have an interest in self-direction for the reasons described above.
**1915(c) Home and Community-Based Services Waivers**

The 1915(c) supports traditional and non-traditional community-based services in a targeted environment and represents the most frequently used Federal authority to promote community living. 1915(c) waivers, created through Federal legislation in 1981, cover a broad range of home and community-based services, including those not traditionally covered by Medicaid such as in-home personal assistance.

When implementing a 1915(c) waiver, states have the option to (O’Keeffe, et al., 2010):

- Limit implementation of participant direction to certain parts of the state or pilot the option in one area before moving statewide
- Limit participation to specific groups, such as individuals who live in their own homes
- Allow services to be directed by a participant-selected representative
- Limit services that can be directed
- Limit the extent of authority participants exercise over employer or budget authorities
- Offer either an “agency with choice” model (the organization employs a set of workers the participant can choose amongst) or a fiscal/employer agent model (the participant is the legal employer)
- Create a budget authority option for individuals to purchase goods and services authorized by the plan
- Cover non-traditional goods and services

States participating in the 1915(c) waiver must demonstrate that the costs associated with the waiver are no more than the costs of institutional care and must renew the waiver every five years (Smith, et al., 2005). All states except Vermont and Arizona operate at least one 1915(c) waiver (O’Keeffe, et al., 2010). Four states (IA, CO, NV, WA) offered home and community-based services targeted to persons with serious mental illness (HCBS) under the state option. 39 states report HCBS waiver waiting lists, total of 365,553 in 2009 (Kaiser Family Foundation, 2011a). Of the 49 states with a HCBS waiver, 37 allow participant direction in at least some of their waivers (Kaiser Family Foundation, 2011a).

The Institutions for Mental Disease (IMD) exclusion complicates funding for behavioral health programs using a 1915(c) waiver. Federal law stipulates that Medicaid dollars will not pay for services and supports for individuals between the ages of 22 and 64 in psychiatric inpatient settings. The IMD exclusion limits states’ ability to use the 1915(c) waiver because states cannot use the waiver to pay for services that would otherwise have been provided to individuals in long-term psychiatric facilities (Smith, et al., 2005). This criterion could be met if states are able to demonstrate the population being served would otherwise need institutional care. For example, a person who has a co-occurring physical and behavioral health issue that required intensive support would qualify for 1915(c) waiver services. Further, many people diagnosed with mental illness reside in nursing facilities; in states where this is the case, the 1915(c) waiver program could apply as a basis for self-direction. However, this restriction severely limits the scope and target population of a self-directed behavioral health program (Alakeson, 2008b).

**Combined 1915(b)/(c) Waivers**

The 1915(b) waiver is often used in conjunction with the 1915(c) Home and Community-Based Services Waiver to fund self-direction for other populations. By applying both authorities, states may operate a managed care type model and restrict the participant’s ability to select the provider of his or her choice.

**Demonstrations and Other Medicaid Funding**

This section explores other Medicaid funding options that have supported self-directed programs in the past and may serve as a funding source for programs in the future.
**1115 Demonstration Waivers**

The original Cash & Counseling programs were funded using the 1115 Demonstration Waivers, which support innovation through funding experimental research and demonstration projects. Originally, the 1115 demonstration was the most effective authority by which to implement employer and budget authority. The use of 1115 Demonstration to promote self-direction has since been replaced by the 1915(j) self-directed personal assistance services state plan option previously discussed.

Demonstrations funded by 1115 waivers are required to maintain budget neutrality, which means that the amount spent under the demonstration waiver is comparable to federal spending in the absence of a demonstration (Smith, et al., 2005). The application process includes a proposal from the state, a site visit to the state by CMS, stringent budget-neutrality thresholds, and a comprehensive evaluation component. This approval process is cumbersome and takes two to three years because both CMS and the Office of Management and Budget (OMB) must approve the application. Forthcoming regulations will address concerns about the transparency of the 1115 waiver approval process, including new requirements regarding the timing of reviews/approvals (Kaiser Family Foundation, 2011a).

**Money Follows the Person**

The Money Follows the Person (MFP) program encourages states to transition individuals from institutions to the community and increase the quality and availability of home and community services for individuals leaving institutions. The DRA created the MFP demonstration program to support states in this transition, and 43 states plus the District of Columbia have received grants as of 2011. The ACA extended the program until 2016, appropriating an additional $2.25 billion in funding (Barth, Klebonis, & Archibald, 2011). Self-direction is an option for states implementing the MFP program, with 33 states offering some form of self-direction and an estimated 12 percent of MFP participants self-directing some part of their services (KFF, 2011c). Additionally, all states implementing the program may have enhanced infrastructure for community-based behavioral health services and supports to support such a program.

**5.1.2 Administration on Aging**

In the past decade, the AoA has increased their attention and resources to address older adult behavioral health needs. This interest was first formed in June 30, 2003 by a collaboration with SAMHSA to create new educational materials to assist providers in the aging services community better cope with medications, alcohol and emotional issues among older people, and learn how best to provide the knowledge and support they need to deal effectively with these issues. Many of these grants were issued to community mental health agencies working with Area Agencies on Aging and other Aging Network service providers. These grants have continued and in June 2011, 18-month grants were issued to the Aging Network including Adult and Disability Resource Centers (ADRCs) by SAMHSA to include a focus on the prevention of suicide and prescription drug misuse among the older adult population. The grants also include funding to conduct webinars on topics covering elder behavioral health issues and convene regional meetings to aid in establishing meaningful relationships between agencies that focus on the behavioral health needs of older adults.

**Aging and Disability Resource Centers**

Aging and Disability Resource Centers, funded by the Administration on Aging and other funding mechanisms within the community, provide assistance to individuals needing long-term care services and supports. They are designed to serve as entry points to publicly provided long-term care. The ACA extended funding for ADRCs (Kaiser Family Foundation, 2011b). With this combined or braided funding, a series of information and assistance activities directly related to behavioral issues and the elderly are funded. These activities include screening for mild to moderate depression.
5.1.3 Chronic Disease Self-Management Programs

Funded by the American Recovery and Reinvestment Act of 2009, the Chronic Disease Self-Management Program is a collaboration between the AoA, Centers for Disease Control and Prevention, and CMS. The program enables older adults with chronic diseases to learn how to manage their conditions and take control of their health. Grants have been offered to 48 states. In the mental health arena, Michigan is working most intensively by creating Certified Peer Specialists to provide intensive support to persons with behavioral health issues.

5.1.4 SAMHSA Mental Health Block Grant

Historically, SAMHSA has funded service innovations, including a self-directed program in Maryland. Additionally, SAMHSA has supported many services and supports that are highly related to self-direction in mental health, including peer-provided services, shared decision-making, and supported employment.

The Mental Health Block Grant (MHBG) administered by SAMHSA’s Center for Mental Health Services (CMHS) provides highly flexible funding that can be used to support cash payments in a behavioral health self-direction program. Currently, states use MHBG funds to support peer-provided services and other self-help supports that are in line with the principles of self-direction (Policy Issue #3: Financing Peer Provided Services, 2008). Although not widely used by states, Michigan has used MHBG funding coupled with a 1915(b) waiver for a small self-direction initiative (In the Driver’s Seat: A Guide to Self-Directed Mental Health Care, 2008; Policy Issue #3: Financing Peer Provided Services, 2008).

CMHS has stated a preference for every state to consider using the MHBG for services like self-direction (Cook, et al., 2009). Such funds are relatively limited, however; in 2001, the MHBG represented approximately two percent of the resources held by state mental health authorities. The MHBG must be combined with other monies such as Medicaid to support a sustained self-direction project (Cook, et al, 2004).

5.1.5 Veteran’s Health Administration

The Veterans Health Administration (VHA) operates the Veteran-Directed Home and Community Based Services program. This initiative, launched in 2008, is the result of a partnership between the AoA and the VHA. The program provides services to Veterans of all ages and across all disabilities including behavioral health. The program provides home and community-based serves in a participant-directed fashion enabling Veterans to avoid nursing home placement and to continue to live in their home and communities. The Veteran, using a flexible, individual budget, decides for himself or herself what mix of services best meet their needs. The program is currently active (as of late 2011) in 20 states. It suggests that self-direction can be compatible with other payment systems, including private sector capitated plans (Alakeson, 2010).

5.1.6 Health Homes

In health homes (also called patient-centered medical homes), the patient and primary care physician work collaboratively with a multi-disciplinary team to deliver comprehensive, individualized care. The ACA includes provisions to support and expand the medical home through pilot programs and creation of a Medicaid state plan option. This state plan option allows states to permit Medicaid beneficiaries with chronic conditions and serious mental health conditions to designate a provider as a health home (Kaiser Family Foundation, 2010). Health homes include the following elements: a personal physician who provides continuous and comprehensive care; a physician-led team practice that provides ongoing care that is coordinated across medical subspecialties, hospitals, and community-based services; the use of health information technology to facilitate follow-up, clinical monitoring, and population-based decision making; expanded access to health practitioners through open scheduling and after-hours availability; and the effective use of financial incentives to reward providers for supporting PCMH features (Fields, Leshen, &
Patel, 2010). Typically, payment structures are designed to promote overall care coordination. This includes reimbursement for care management work that occurs beyond the face-to-face visit such as coordination of care between providers, activities associated with linking the individual to community resources, and time spent monitoring clinical data (American Academy of Family Physicians [AAFP], American Academy of Pediatrics [AAP], American College of Physicians [ACP], & American Osteopathic Association [AOA], 2007).

Recent analyses have found that individuals with serious mental illness may be best served by a behavioral health-focused health home, rather than a primary care-based health home (Alakeson, Frank, & Katz, 2010; Koyanagi, et al., 2011).

It is unclear exactly how health homes fit with self-direction, although there are aspects of the two models that might be seen as complementary. Fundamentally, Health homes are designed to promote wellness. Self-direction could be an engagement tool to get people who are seen as high-cost, high-need, and under-engaged into the system, leading with the tools of peer support and the use of peer wellness coaches who work with the person to navigate the health system (personal communication, Harvey Rosenthal, November 3, 2011).

There are also some tensions between health homes and self-direction, particularly in regards to the heavy emphasis on medical needs in a health home.

5.2 State Funding Options

In addition to looking to federal mechanisms, it is possible that local and state funding options may support self-direction.

5.2.1 State General Revenue

States and local governments often provide or purchase behavioral health services directly, and have been used to fund self-direction in the past. Programs in both Maryland and Florida have used state general revenue funds to support self-direction (Cook, et al., 2004; Lafferty, nd).

General revenue financing relies on state and local tax revenues rather than insurance premiums or federal funding sources. However, states, unlike the federal government, are required to balance budgets, so there tends to be more competition within states and localities for funds to cover services such as education, roads, and prisons (Institute of Medicine, 2006b). Thus dependence on state general revenue to fund behavioral health services and supports is not ultimately stable or sustainable due to state budget shortfalls (Karakus, et al., 2011).

5.3 Pursuing Financing outside the Health and Behavioral Health Systems

In keeping with the value base of self-direction, individuals should be supported in accessing more mainstream supports and services in the areas of housing, transportation, technology, education, employment, and recreation (Elder-Woodward, et al., 2009). These areas are associated with their own funding streams, which could be integrated into an overall financing package for self-directed behavioral health services. For example, a partnership with the Department of Housing and Urban Development (HUD) to expand rent subsidy programs and partner with non-profit housing corporations may support self-direction (Cook, et al., 2004). Additionally, vocational rehabilitation systems might cash out agency monies and use them to pay for micro-enterprises, job coaching, or other training in a self-directed program (Cook, et al., 2004). States or counties interested in implementing self-direction might work with employment and education funders to develop a program that incorporates funding outside of the behavioral health system.
VI. Key Issues

The shift to self-direction in behavioral health is a significant endeavor and involves a number of fundamental changes to the traditional behavioral health system. This section provides a partial list of issues to consider.

6.1 Program Design and Implementation

Self-directed programs require careful planning, clarification of new roles and responsibilities for providers, staff training, staff recruitment and retention activities, and evaluation mechanisms that focus on both quality and cost (Report: Personal Health Budgets Research Scan, 2010). As programs are implemented, it is critical to pay attention to the "downgrading" or "watering down" of the programs - through limitations on eligibility, providers influencing selection, and other mechanisms - to keep the program philosophy strong (Spandler & Vick, 2006). Findings from the recent National Health Service personal budgets program highlight this point: the evaluators observed greater improvements in care-related quality of life for individuals in programs that emphasized flexibility and choice in what can be purchased, informed budget holders of the amount of their budget, and provided maximum choice over how resources are managed (Forder et al., 2012). The authors concluded that self-directed programs should be implemented to provide maximum participant engagement, choice, and flexibility.

For a more detailed discussion of self-directed program design and implementation, please refer to the NRCPDS' Developing and Implementing Self-Direction Programs and Policies: A Handbook and In the Driver's Seat: A Guide to Self-Directed Mental Health Care, produced by the Bazelon Center for Mental Health Law and the UPENN Collaborative on Community Integration.

6.1.1 Person-Centered Planning

Person-centered planning is based on an assumption that participants should be the primary actors in the process of assessing their personal needs, developing individual goals, and identifying appropriate services and supports (NRCPDS, 2010). In a self-directed program, the person-centered plan is a collaboration between the participant and supportive others, including support brokers and providers. Person-centered planning replaces the status quo process in which the provider conducts an assessment, matching services to needs. Participants, family, friends, providers of traditional and also non-traditional services, and community members may contribute to the plan. On an ongoing basis, the plan is tested and evaluated to ensure that it supports independence, health, and wellbeing.

The success of a self-directed program hinges on the person-centered planning process; if a participant is not fully engaged in the process of setting goals and identifying services and supports, the process is not self-directed. This is reflected in current HCBS policy: person-centered planning – including the ability to select individuals involved in plan development – is a requirement for funding of HCBS through the 1915(c) and (j) waivers and will likely be required for states selecting the 1915(i) option (O’Keeffe, et al., 2010).

Research suggests that person-centered planning leads to improved quality of life, but plans can fall short of realizing these gains if not implemented as part of an overall person-centered effort (Smull, Bourne, & Sanderson, 2009). The following list of considerations for implementing person-centered planning in self-directed programs was gleaned from evaluation reports covered in this review:

- Language in the person-centered plan must be concise and written in a way that the participant can best understand (Rogers, 2009).
- Person-centered planning worked best when the participant and support broker focused on how a particular service or support would help the participant achieve goals rather than what the participant...
wished to spend money on; in other words, a goal-focus rather than a need-focus was emphasized (Stockport Council, nd).

- Mechanisms that record the reasoning linking goals to purchased goods and services are critical; these records were important for audit purposes but also facilitated team coordination (Stockport Council, nd).
- Too much focus on the financial aspects of self-direction detracted from the network-building and person-centered planning pieces, and created a false impression that money alone will address disability-related needs (Lord & Hutchinson, 2003).
- Training must be system-wide and must introduce skills and values. Even the most effective training will not be effective if it doesn't impact the underlying culture of the organization (Smull, et al., 2009).

One evaluation report from the UNITED KINGDOM noted that when the participant was truly involved, the person-centered planning process resulted in new and innovative solutions to needs, which helped to challenge clinicians’ notions that individuals shouldn’t be involved in determining what kind of services and supports they should receive (Jones et al., 2010).

6.1.2 Budget Allocation, Scope, and Development

The NRCPDS (2010) emphasizes that the budget development process must be accurate, consistent, reliable, equitable, flexible, and transparent. There are four core components of the budgeting process: 1) identifying needs, 2) creating a person-centered plan to meet those needs, 3) determining a budget amount, and 4) creating a spending plan. Currently, programs vary in the methods for implementing this budgeting process (NRCPDS).

Determining the benefit amount for self-directed program budgets was a significant challenge for many of the programs included in this review (Alakeson, 2007; Jones, et al., 2010). Programs used a variety of methods for determining the amount of resources to allocate to a self-directed budget. These included using the cost of existing service and support packages, developing budgets based on the participant’s previous spending, using mathematical formulas based on participant characteristics, using an assessment of needs and preferences to guide budgeting, and establishing set amounts based on available funds. Some programs may assess participant need and create a person-centered plan and then calculate a budget, while others may develop budgets before the assessment and person-centered planning processes (NRCPDS, 2010).

A primary complicating factor for allocating funds to individual budgets was that many providers are not aware of the cost of existing service and support packages since many services are paid through block contracts and not on a person-by-person or hourly basis. In order to aid in effective budgeting and support participant choice, providers involved in a self-directed program will need to be able to break down costs by assigning individual-level services, even when they are paid for through a bulk contract (Alakeson, 2007). In the IBSEN pilots, project leads noted that a close look at the cost of health services was a difficult but useful endeavor (Jones, et al., 2010).

One key program design decision hinges on whether to create budgets that are based on a flat or set amount versus budgets determined based on individual need, previous spending, or some other measure. An evaluation of a program in the United Kingdom stressed the importance of reviewing and adjusting budget allocations continuously so that budgets can be gradually reduced as participants gain skills and greater independence (Rogers, 2009). Alakeson (2007) notes a need to move towards differentiated (as opposed to flat amount) budgets that reflect individual needs; the real test of cost-effectiveness will come when this occurs because it is easy for those far along in recovery to underspend budgets when they are set at a flat rate.
Another key decision relates to the amount and extensiveness of the budget. Some programs, such as the CRIF-SDC program in Pennsylvania, use high-value budgets designed to include all behavioral health-related services and supports excepting inpatient and medication services and have no requirement that individuals purchase any traditional services. Others, such as the MarylandSDC and Oregon Empowerment Initiatives programs, offer a smaller fixed budget amount designed to supplement traditionally funded services and supports, and participants continue to use their existing health insurance (often Medicaid and/or Medicare) to cover the costs of traditional behavioral health services like psychiatry and outpatient counseling. In the recent National Health Service pilots, total cost reductions were greater and care-related quality of life outcomes were stronger for individuals with higher-value budgets (over 1,000 pounds) compared with those with smaller, more supplemental budgets, leading the authors to conclude that personal health budgets should be offered to individuals with higher levels of need and should act as substitutions, rather than complements, to traditional service deliver methods (Forder, et al., 2012).

The question of what is not covered is also a critical aspect of program design. In programs in the United States and the UK, budgets do not include inpatient, emergency, pharmacy, and medical services. Current self-directed behavioral health programs vary in the extent to which they require participants to spend a portion of their budget on traditional goods and services. For example, participants in the Florida and Texas programs are required to spend 48 and 60 percent respectively on traditional services.

One rationale for restricting the types of services and supports that can be included is that including the above service categories would shift risk entirely onto the individual (Alakeson, 2011). Alakeson (2011) presents a model for analyzing whether interventions should be included in budgets using two criteria:

1. The ideal point of control (for some interventions such as surgery, the individual must give control over to another person)
2. The degree of clinical evidence to support treatment effectiveness

The model creates four quadrants to differentiate between service arrangements that may or may not be included in a self-directed program.

A) Professional Managed Treatment - requires professional control, we can be confident putting ourselves in the hands of others
B) Citizen Managed Treatment - benefits from professional definition, some evidence of effectiveness, but are most effective when we are in direct control
C) Professional Managed Experiment - we put ourselves in the hands of others even when there is little evidence to support it, maybe because there aren’t many options
D) Citizen Directed Solutions - we are in control of both defining and managing solutions to meet our needs; there is weak clinical evidence, but this could be because solutions cannot be found in clinical data (individual budgets most useful here)

6.1.3 Role of the Support Broker

The support broker occupies a critical position in the scheme of self-directed services and supports. The support broker’s primary responsibility is to ensure that the participant has the skills and knowledge necessary for self-direction (NRCPDS, 2010). Research in England found that not connecting participants with support brokerage services to navigate the programs was a barrier to take-up, particularly for vulnerable groups including people with psychiatric disabilities, suggesting that supports brokerage is a requirement for behavioral health self-direction (Alakeson, 2010).
Support brokers assist with the person-centered planning process, educating the participant on his or her rights in the program, existing resources and options for services and supports, the risks and responsibilities associated with self-direction, and limits and restrictions of the program (NRCPDS, 2010). Although the role of the support broker is similar to the role of a case manager, there are key differences worth noting. Whereas traditional case managers oversee service delivery for the individual, support brokers work with the individual to oversee his or her own services and supports (NRCPDS, 2010). Support brokers should ideally function separately from the behavioral health service system (Lord & Hutchinson, 2003). Additionally, case managers’ caseloads are larger, and roles are more limited and more professionalized (Lord & Hutchinson, 2003).

The NRCPDS, in collaboration with the AoA, has developed a set of Core Competencies for staff working as brokers in self-directed programs that fall into four tiers (Sanders & Sceigaj, 2011):

- **Tier 1.** Personal Effectiveness, including interpersonal skills, integrity, decorum/behavior, initiative, dependability/reliability, adaptability/flexibility, willingness to learn, and cultural sensitivity
- **Tier 2.** Basic Education Competencies, including reading, writing, mathematics, science/technology, communication, critical/analytical thinking, basic computer skills, cultural knowledge, human development, and customer service
- **Tier 3.** Workplace Competencies, including teamwork, customer focus, planning and organizing, problem resolution/decision making, working with technology, instructing, scheduling/coordinating, organizational basics, and cultural awareness
- **Tier 4.** Long-Term Services and Supports Technical Competencies, long-term care/supports/services, supporting independence, crisis prevention/conflict resolution, cultural competency, documentation, ethics/laws/regulation, and health/wellbeing

The NPN, an organized group of self-direction participants, has articulated their own set of core competencies. For a support broker to be successful, he or she must fully embrace the principles behind self-direction including the concept that all individuals are capable of self-direction if given adequate supports and have the ability to communicate openly and with empathy (NPN, 2011). The above NRCPDS and NPN competencies were designed to be crosscutting, applicable to a self-directed program that targets any population group, including those with behavioral health service needs.

Support brokers should work with participants to access other funding streams for services and supports whenever possible. For example, if a person can receive a free or discounted bus pass through a transportation program, or through a vocational rehabilitation program, the person should not need to use recovery funds for this purpose (Alakeson, 2007).

Successful self-directed behavioral health programs must have clear procedures in place to hire and train support brokers. In several behavioral health self-direction programs, including Pennsylvania’s CRIF-SDC program, people with lived experience with mental health or substance use issues are trained to act as support brokers.

For some programs, the level of recovery of the population is linked to the ways the programs operate. For example, Oregon’s Empowerment Initiatives program took an intensive approach, with weekly meetings and support brokers on call 24 hours a day. Many individuals in this program are in early stages of recovery, and more intensive brokerage supports were therefore in place to support self-direction (Alakeson, 2007).

### 6.1.4 Role of the Fiscal Intermediary
Fiscal intermediaries, or financial management services (FMS), are also a critical element in the implementation of the budget and employer authority models. FMS functions can be performed by a number of different organizations. The NRCPDS (2010) highlights two FMS models in particular because they provide the maximum amount of choice and control: the Government/Fiscal Employer Agent and the Vendor Fiscal/Employer Agent. These models allow participants to act as common law employers for any workers they may hire, ensure that all tax and Department of Labor requirements are met, and provide greater fiscal accountability for states (NRCPDS, 2010). Such organizations must have clear and efficient processes and infrastructures to provide an array of important functions, including the following (NRCPDS, 2010; SAMHSA, 2011a):

- Paying claims and processing vouchers
- Acting as a third party administrator for bill payment
- Managing provider networks
- Provide training and assistance in the process of hiring, training, managing, evaluating, and dismissing workers if applicable
- Establishing mechanisms to receive, hold, authorize, distribute, and account for self-directed funds
- Communicating and coordinating with participants, providers, and other stakeholders
- Assisting the participant with monitoring expenditures and revising the person-centered budget as needed
- Issuing clear and comprehensive budget information upon request
- Holding and prepare records for audits
- Administering purchasing policies
- Implementing quality assurance and improvement activities

Through the careful design and implementation of the above functions, effective FMS promote equity and accountability, which are key concerns for multiple stakeholders (Lord & Hutchinson, 2003; NRCPDS, 2010).

The 1915(c) and (j) waivers require states to offer FMS and assistance with participant direction and supports brokerage. The 1915(i) state plan option also addresses supports, although final rules have yet to be released (O’Keeffe, et al., 2010).

Although FMS functions are critical, it is important that the management of funds be understood in the context of the goals and values of a self-directed program. In a review of self-directed programs in Canada, U.S., and Australia, Lord and Hutchinson (2003) found that for some projects, too much focus on the financial aspects of self-direction detracted from the network-building and person-centered planning processes, creating a false impression that money alone will address disability-related needs.

### 6.1.5 Role of the Representative

Most self-directed programs are designed to allow for representatives to manage budgets and make decisions about services and supports on behalf of the participant. For minors and people with severe cognitive impairments, the appointed representative often has a primary role, actively working alongside the participant throughout the process to support choice and self-direction. These representatives are tasked with ensuring that the preferences of the participant are articulated throughout the person-centered planning, budgeting, and monitoring and implementation processes (NRCPDS, 2010).

In the context of behavioral health self-direction, representatives may have a different role because of the nature of psychiatric disabilities. In behavioral health, participants may have a need for a representative to step in only during times of acute crisis. When the crisis is resolved, the representative would then work with
the participant to resume his or her place as the primary decision maker. Thus, in the context of behavioral health, it is critical that participants appoint trusted representatives who will support maximum choice throughout the process. As discussed in the next chapter, pro-active planning mechanisms such as psychiatric advance directives will need to be developed to support maximum choice. As in any self-directed program, it is critical that representatives in self-directed behavioral health programs are screened to ensure that they are fully committed to the participant’s wellbeing and that they understand representative roles and responsibilities (NRCPDS, 2010).

6.1.6 ROLE OF THE PARTICIPANT COMMUNITY
As noted throughout this document, a core principle of self-direction is the involvement of participants in all aspects of self-directed program and policy planning, implementation, monitoring, and evaluation. Early and sustained participant buy-in has been associated with greater success of long-term service system change, including the development of self-directed programs (NRCPDS, 2010). Engaging with the community of participants and potential participants is therefore a critical activity for any self-directed program.

In the United States and in Europe, participant networks strengthen the participant voice and inform self-direction efforts at the national, state, and local levels. Activities include providing support, representation, and advice to participants as well as ensuring that participants are represented in all self-direction-related efforts at the policy and program levels (National Participant Network: Who We Are, 2011).

Programs also commonly work with participant advisory committees, composed of program service users and sometimes members of the advocacy community. A behavioral health self-direction program might form its own participant advisory group, or work with existing groups of behavioral health service users already formed in the community. Programs should work with participants in advisory groups to ensure that they have the necessary training to ensure that their voice is represented (NRCPDS, 2010). Additionally, programs will need to ensure that there is adequate funding to support advisory group activities.

Focus groups, interviews, surveys, and informal consultations offer additional, supplementary avenues for garnering participant input, and are key to effective quality monitoring and improvement systems, discussed later in this chapter.

6.1.7 PROGRAM ELIGIBILITY
To ensure that the program is meeting its goals and also to maintain sustainability over the long-term, it is critical that eligibility criteria are carefully designed. Too many restrictions on eligibility may undermine the flexibility of a program, whereas too few restrictions may lead to diminished program sustainability.

SAMHSA’s Financing Center of Excellence identifies the following group as a target population for self-directed services and supports in behavioral health quite broadly:

“Adults with serious mental illness and/or a substance use disorder who are actively in recovery; transitional aged youth with severe emotional disturbance and/or a substance use disorder who are actively in recovery and in need of such services; families of adolescents with serious emotional disturbance and/or a substance use disorder who are actively in recovery.” (SAMHSA, 2011a)

Current self-directed behavioral health programs vary in their eligibility criteria. In the Florida SDC program, eligibility is determined by the following (OPPAGA, 2010):

- A resident of Florida circuits 4 or 20
- 18 or older
• A DSM-IV diagnosis of schizophrenia, bipolar or depressive mood disorder, delusional disorder, psychotic disorder, autism or any other ICD-9 diagnosis
• Be legally competent
• At least one of the following:
  o Current mental health service usage (for at least 12 months and expected to need at least an additional 12 months)
  o Receives disability income for a psychiatric condition
  o Unable to perform day-to-day activities independently

In contrast, Pennsylvania’s CRIF-SDC program eligibility is as follows (Maula, 2010):

• Delaware County resident
• Member of Health Choices of Magellan Behavioral Health, the managed care carve-out for the state’s Medicaid program
• A DSM diagnosis of schizophrenia, bipolar disorder, or a related disorder
• Be within the 60th to 90th percentile of service users
• Have had no hospitalizations within the past six months

One key difference between the two programs is that the CRIF-SDC program targets eligibility to participants who are frequent or heavy users of mental health services. Alakeson (2010) has hypothesized that individuals with lighter mental health service use may have fewer opportunities to make changes to their service packages, and there may be fewer observed differences in outcomes for this population.

6.1.8 RECRUITMENT AND TAKE-UP

Although self-direction has the potential to fundamentally change the behavioral health service system, it is not meant to replace the traditional behavioral health system in its entirety. From its inception, self-direction was designed to serve as an option for individuals and not a requirement (NRCPDS, 2010). As such, self-directed programs are not for everyone. It is likely that many individuals receiving traditional behavioral health services are content with the ways their services and supports are delivered and are not interested in greater personalization. Others may be interested but find the prospect of managing a budget and arranging services and supports in a self-directed way to be daunting. It is critical that outreach efforts focus on providing accurate information about the program to all eligible participants (NRCPDS, 2010).

As noted in an earlier section, take-up rates for self-direction in the United Kingdom have been lower for behavioral health than other groups (Brewis, 2007). Researchers found that not connecting participants to counseling to navigate a self-directed program was a significant barrier to take-up for all groups in general, and more of a barrier for vulnerable groups, including people with mental health issues (Alakeson, 2010).

The NRCPDS (2010) offers the following recruitment strategies to promote enrollment: the use of focus groups with potential participants, providers, and other stakeholders to guide outreach campaigns; the use of peers to educate about self-direction, correct misperceptions, and provide consultation to potential participants. Additionally, it is critical that all promotional materials and efforts are offered in multiple languages to ensure that non-English speakers are aware of the program (NRCPDS, 2010).

One United Kingdom mental health pilot program experienced higher than expected enrollment, perhaps attributable to its recruitment strategies (Stockport Council, nd). To identify potential participants, the program sent leaflets to relevant organizations, worked with individual staff members in provider organizations to act as champions, encouraged service users to be involved, and collaborated with existing
peer networks to promote the program. The pilot also created a separate “recovery budget” for behavioral health service users not involved in the pilot to apply for certain items such as bikes, laptops, walking boots, and transportation fees. This extension of the self-directed program was used as an incentive to familiarize potential participants with the concept of self-direction (Stockport Council, nd).

6.2 INFORMATION TECHNOLOGY

It is a growing imperative that modern health and social service programs use information technology to support access, efficiency, and quality – and self-directed programs are no exception. Because self-directed programs often involve a number of different stakeholders, including the participant, significant others, providers, support brokers, and fiscal intermediaries, it is ever more critical that technology be maximized to facilitate communication and coordination.

Insufficient information technology systems have been cited by a number of programs as a barrier to implementation, monitoring, and evaluation (OPPAGA, 2010; Rogers, 2009). However, programs have also used information technology to increase program functioning. For example, the use of a debit card for purchases allows programs to monitor and restrict purchases when needed, while also promoting increased participant responsibility (Maula, 2010; Norris, et al., 2010). Programs might also use secure web-based applications to document the person-centered planning and budgeting processes so that information is readily available to all stakeholders.

6.3 ADMINISTRATIVE COMPLEXITY

The potential for increased administrative complexity is a major concern for providers and policymakers when implementing a self-directed program (Teague & Boaz, 2003). For both the provider and the participant, moving from one provider to another can result in a disruption in services and supports, which constitutes a transaction cost (Smith & Lipsky, 1992) that must be factored into a decision to participate in a self-directed model.

To reduce administrative complexity, self-directed programs must attempt to integrate the administration of the program into existing processes to minimize duplication and bureaucracy associated with running two separate systems. For example, a program that administers both traditional and self-directed services might merge the person-centered plan and the traditional planning processes into a single process (Stockport Council, nd). However, it is critical that streamlining processes do not distort the original purpose of the self-directed program; otherwise, participants may find that the bureaucratic complications of the program do not square with the underlying empowerment approach of self-direction (Alakeson, 2011).

Economy of scale is also important to consider in regards to administrative complexity; if self-directed programs are implemented on a small-scale level, there is the potential for greater administrative costs because programs will have to establish new administrative structures for each program. On the other hand, if a self-directed program is implemented on a large scale, a single administrative structure could be used across multiple programs.

Newly implemented programs can draw from programs and processes of existing self-directed programs to identify strategies to reduce administrative complexity while preserving the self-directed approach (Alakeson, 2007).

6.4 EVALUATION AND MONITORING
The monitoring and evaluation of person-centered plans and budgets is critical to the program success, and it also has a bearing on public and political attitudes towards self-direction. Fraud and abuse on the part of both participants and providers are key concerns, and strong monitoring and evaluation systems must have the capacity to address these issues. Programs should be equipped to monitor increases in spending, and to review service packages on a continuous basis (Rogers, 2009).

6.4.1 Measuring Quality

Whereas traditional quality management approaches focus on provider agencies overseeing and improving the quality their services, quality improvement and assurance activities in self-direction are focused on empowering the participant to determine and improve the quality of his or her services and supports (NRCPDS, 2010). Applebaum, Schneider, Kunkel, and Davis (2004) at the Scripps Gerontology Center at Miami University developed a guide for the quality of self-directed services that would serve as a useful starting point for self-directed behavioral health programs looking to create a self-directed quality assurance and improvement system. The guide states that a high-quality participant-directed system must reflect needs of participants and be “policy-responsive.” Underlying assumptions of a self-direction quality program are: participants are key actors in quality improvement and assurance, stakeholder (participant, family, provider, regulator, and funder) views should serve as a starting point for all activities, and a quality system satisfies both participants and organizations that oversee and fund self-direction (Applebaum, et al., 2004).

Based on focus groups with participants and workers, the guide outlines four dimensions of quality: 1) independence and choice, 2) relationships, 3) knowledge and support for participants and workers, and 4) health, safety, and accountability. The NRCPDS (2010) offers the following design elements of a quality management strategy that may inform a self-directed behavioral health program:

- An effective person-centered planning process that reflects individual needs
- Clear operational policies, practices, and procedures
- Educating participants, family members, representatives, and providers about their rights and responsibilities
- Managing risk and critical incidents
- A system that is responsive to changing needs
- Effective workforce orientation and training
- Policies and procedures for the participant to return to the traditional agency-based model
- A system for regularly obtaining participant feedback
- Systems for monitoring the degree of person-centeredness and self-direction
- Data that is collected and reviewed regularly and systematically and used to improve quality
- A quality improvement committee
- Targeted quality improvement projects

Ultimately, Applebaum and colleagues assert that greater participant choice is both associated with and defined by higher quality services and supports. Similarly, the CCDE experience found that consumer-directed programs had the same or higher quality than traditional agency-based services (NRCPDS, 2010). Thus it follows that program design should maximize participants’ ability to obtain high-quality services. Monitoring and accountability must function in accord with participant-centered activities, and quality improvement information must be used regularly and consistently.

Further, quality improvement activities should involve participants at every stage. Data collection activities should be easily implemented, user friendly, and responsive to changing needs. Strategies that support this approach include (Applebaum et al., 2004):
Use and development of performance indicators
Complaint hotlines available to participants but also providers and anyone in the community
Personalized outcomes data comparing goals with participant assessments of whether they are meeting those goals and identifying barriers; this approach allows for the fact that quality means different things to different participants
Independent review of participants
Quality improvement committee reviews
Program self-assessments

The above approaches may serve as a starting point for programs looking to improve quality of self-directed programs. The guide referenced above also highlights the fact that quality efforts in a self-directed program must themselves be informed by principles of self-determination and person-centeredness.

6.5 Stakeholder Views and Attitudes

According to a survey of over 1,000 advocates, providers, and policy experts in the field of long-term care, 61 percent favor expansion of self-directed programs like Cash & Counseling (Miller, Mor, & Clark, 2008). Polls like this indicate that the support of self-direction may be part of a larger shift towards empowerment and consumer rights and away from the traditional medical models in which the provider has full authority over an individual's treatment. Yet, while this may be the case in the field of long-term care, stakeholders in behavioral health have had little exposure to self-direction, and may be more hesitant to embrace it. This section explores what is currently known about participant, provider, and policymaker attitudes towards behavioral health self-direction.

The Cash & Counseling experience highlighted the critical role of communication with stakeholders, including participants, providers, and policymakers, for the success of a self-directed effort. One aspect of communication is developing an in-depth knowledge of the nature of the resistance to self-direction (who, why, how to break through it). An understanding of the various service user, provider, and policymaker attitudes towards the concept of self-direction informs design and implementation of future efforts in valuable ways.

6.5.1 Participant Attitudes

As noted above, participants and family members in the Cash & Counseling program had significantly higher rates of satisfaction and quality of life than those in the control group, and early behavioral health self-direction demonstrations domestically and abroad found evidence of increased participant satisfaction with services as well as increases in empowerment and self-determination. Anecdotally, recruitment for the CRIF-SDC project found that service users and their families are typically open to self-direction, particularly when they are assured that the desired existing services would remain available to them (Salzer, personal communication February 17, 2010). In all, it is likely that service users and their family members will be in favor of the expansion of self-directed services and supports. This is particularly likely given that self-direction is by definition an option; individuals who enter into these arrangements are a self-selected group who take initiative to seek out new programs and have a willingness to try something different. Individuals will likely opt for self-directed services and supports because they value individual choice and feel confident that exercising this choice will improve their lives.

A report examining implementation issues with a mental health self-directed program in England identified some concerns voiced by participants, which were primarily related to issues of implementation. These concerns included issues with the complexity of the assessment and support plan process, delays between
plan development and service/support receipt, and not being fully involved in the process. However, once the plans were implemented, participants reported satisfaction with the process overall (Rogers, 2009). The authors concluded that it was critical to use timelines for planning and budgeting processes and to make this information available to participants.

Additional concerns voiced by West Sussex participants (Rogers, 2009):

- Process is not for everyone; may be too distressing for some
- Important that a self-directed program not replace traditional goods and services
- Unclear how participants would know if they were getting good quality services
- Providers “haven’t caught up yet” and embraced the principles of self-direction

A 2011 National Health Service report examined the views of mental health service users and caregivers through a survey (n=104) and focus groups (n=58). Findings were as follows (National Health Service, 2011b):

- Skepticism about changing clinical and organizational culture.
- Uncertainty about taking on autonomy without adequate support.
- Confusion about the model among both service users and providers.
- Important that the self-directed planning and budgeting process be transparent.
- Concern that access to valued services might become more limited in a self-directed scheme because of limited demand, particularly culturally specific services and supports for minority communities.
- The process must be adaptable to changing needs; the option should not be taken away entirely because of a brief crisis such as a manic episode.
- Increased levels of support must accompany increased independence; not doing so could lead to a widening of health inequalities.
- Appropriate levels of support must be available on an ongoing basis.
- System changes must be accompanied by a culture shift in order to be effective.
- Services and supports must be coordinated across systems and grounded in a holistic understanding of behavioral health.

Respondents reported frustrations with traditional services, including poor coordination, an overreliance on pharmacology, and a need for more person-centered services and supports. The overwhelming majority of respondents said that they wanted more choice, freedom, and control, and that providers did not take their views and ideas into account. Respondents felt that their providers were overly risk-averse and that they wished they could take more responsibility (including risk) for themselves. The authors of the report noted that self-direction could address each of these issues (National Health Service, 2011b).

6.5.2 Provider Attitudes

Authors of much of the literature reviewed here noted that provider attitudes are key to the success or failure of a self-directed program. While there are many reasons that providers might support self-direction, there are also many aspects that could be perceived as threatening to the current role of behavioral health providers.

On a conceptual level, the self-direction may be difficult for some providers to accept. Many mental health providers were trained using the medical model of mental illness that posits that mental illness is an often-incurable medical disease, and that sees recovery as an impossibility for many. Perhaps because of this
medical orientation, the IBSEN pilots found that provider resistance was most pronounced in those teams working with mental health service users (Glendinning, et al., 2008).

Some providers may also be reluctant to acknowledge the legitimacy of non-traditional supports (Free to Choose: Transforming Behavioral Health Care to Self-Direction, 2005). Some survey respondents in the National Health Service reported that they had requested personal health budgets of their providers but been refused with little to no explanation. One person reported that a provider refused outright, saying that he or she did not believe in personal health budgets (National Health Service, 2011b).

Provider respondents to a National Health Service survey indicated that they felt that behavioral health service users were already sufficiently involved and that increased choice would lead to unnecessary stress for participants (National Health Service, 2011a). Further, providers were skeptical that their patients were capable of self-direction; 51 percent of providers believed that less than a third of their patients could self-direct, and only 20 percent of providers believed over two thirds of their patients were capable of self-direction. Additionally, 46 percent of providers felt that self-direction is not appropriate for individuals with fluctuating needs (National Health Service, 2011a).

Some providers in the National Health Service survey were concerned that it would be unethical to allow individuals to select interventions that had no evidence-base, such as complementary and alternative medicine (National Health Service, 2011a).

In the early stages of the Florida SDC program, providers expressed some reluctance to participate because they did not think it would be a good business decision, while others were put off by additional paperwork requirements and reimbursement rates. Smaller providers saw participation as a potential to increase business, but this was not the case with larger providers (Teague & Boaz, 2003). These findings were echoed in the National Health Service survey of providers (National Health Service, 2011a). If implemented on a large scale, it is possible that some providers would perceive self-direction as a direct threat to their sustainability, given its potential to open the market for behavioral health services and supports to include a range of options outside of the traditional system. In such a scenario, providers might have a financial stake in current payment arrangements and work to defend the status quo.

Another category of concerns relates to provider apprehension about the administrative burden of self-directed programs. In a number of reports, providers expressed nervousness that the support planning process would increase their workload and detract from one-to-one interactions (National Health Service, 2011a; Rogers, 2009; Teague & Boaz, 2003).

However, there has been an increasing trend towards the recovery model in the mental health professions, and many providers are working with service users to ensure that services are person-driven and support self-sufficiency (Barczyk & Lincove, 2010). Surveys of providers in a number of programs have found that they are supportive of the principles behind self-direction such as choice, empowerment, recovery, and self-determination (National Health Service, 2011a; Rogers, 2009).

Authors identified a number of strategies to address provider attitudes (Alakeson, 2007; National Health Service, 2010, 2011a; Rogers, 2009):

- Promote a clear vision of self-direction, and communicate this regularly to providers.
- Involve providers early on in any self-directed project, and work to obtain provider buy-in as early as possible.
Hold regular staff meetings that serve as shared practice networks as providers value the opportunity to meet and share their learning experiences.

Create job descriptions and performance management activities that reflect the values of personalization.

Involve participants in the design, delivery, and evaluation of all training activities; include personal experiences and stories in all training activities so that providers can see firsthand the benefits of the model.

6.5.3 **Policymaker Attitudes**

A National Health Service report examined the views of 40 senior leaders from health and social care organizations (2009). While there was widespread consensus among respondents that self-direction could help people, there was also widespread concern about how realistic implementation of self-direction would be. Many respondents predicted that self-directed models would never grow beyond a niche model, while others felt that even a small number of self-directed programs could lead to broader system change through opening the market to lower-skilled providers and increasing competition. Respondents also predicted that a small number of self-directed programs could contribute to a culture that better responds to the needs of behavioral health service users.

Respondents to the National Health Service survey reported three primary areas of concern (National Health Service, 2009):

1. Cost and complexity could be prohibitive. Interviewees were particularly concerned about additional administrative costs during start-up, limited administrative capacity, and an increased demand for services resulting from previously unmet needs.
2. Organizational culture could be a barrier for handing control over to participants.
3. Safety and quality could be compromised.

The report authors identified a set of strategies for working with the barriers outlined above (National Health Service, 2009):

- To support culture change, involve clinicians from the beginning and dedicate ample funds to training.
- Use personal stories of the impact of self-direction on individuals’ lives so that providers can see the benefits of firsthand.
- Involve peer providers at the outset.
- Focus on coordination between and among organizations.
- Risks can never eliminated; ultimately, leaders will have to display courage in addressing this issue.

6.6 **Stigma**

A large body of literature documents the negative effects of mental illness stigma on life chances related to employment, housing, legal status, health, and quality of life (Corrigan, Markowitz, & Watson, 2004; Corrigan & Penn, 1999; Feldman & Crandall, 2007; Link & Phelan, 2001; Pescosolido et al., 2010). Although understandings of the causes of mental illness among the general public have shifted over the past ten years, with greater numbers attributing mental illness to neurobiological causes rather than personal or moral failings, this changed understanding has not decreased stigma (Pescosolido, et al., 2010). Among the general public, the need for social distance and perceived dangerousness of people with mental illness has not increased in the past decade. In the 2006 General Social Survey (GSS), 45 percent of respondents indicated that they are unwilling to have a person with schizophrenia as a neighbor; this figure is up 11 percentage points from the 1996 GSS (Pescosolido, et al., 2010). Mental illness stigma is prevalent among the general...
public but also among those who provide services, with mental health service users reporting high levels of stigma from mental health professionals (Corrigan & Penn, 1999; Corrigan & Watson, 2002; Stromwall, Holley, & Bashor, 2011). Finally, the person diagnosed with mental illness commonly internalizes stigma: self-stigmatization is associated with lower self-esteem, lower quality of life, and less life success (Corrigan & Penn, 1998; Corrigan & Watson, 2002).

Corrigan, Markowitz, and Watson (2004) examined stigmatizing policies and processes that restrict the opportunities of persons with mental illness both intentionally and structurally through unintended policy consequences. Approximately one-third of states have laws that restrict the rights of people with mental illness to vote, serve on juries, and hold elective office, and over one-third of states have laws that limit the rights of people with mental illness to be married and have custody of their children (Corrigan, et al., 2004). Stigma is also experienced through policies that create or promote structural discrimination. For example, less money is allocated to research to understand and treat mental health issues relative to other conditions, and mental health professionals leave the public mental health system because of lower salaries, when those served by the public system are among the most vulnerable (Corrigan et al. 2004).

Taken together, ample evidence documents the negative impact of stigma on multiple facets of the lived experience of people diagnosed with mental illness. This impact has not decreased over time.

The stigma associated with mental health and substance use issues will likely have an impact on how participants experience self-direction. For example, participants with low self-efficacy due to stigma may need support and encouragement to develop a sense of hope and engage in the person-centered planning process. Stigma will also impact the acceptability of self-directed programs for stakeholders, including policymakers, program administrators, providers, and family members. Fudge (2005) presents self-direction as a powerful tool to combat stigma and discrimination: “[Self-direction] is an opportunity to dispel the myths that people living with mental illnesses are irresponsible, incapable and unpredictable in directing their own lives. A person becomes responsible through the experiences of both failing and succeeding. A person becomes capable when they are encouraged to believe in their potential and abilities. Concerning unpredictable...life is not predictable and it’s a defeating goal that destroys individuality.”

6.7 Equity Concerns

The target population of behavioral health self-direction is heterogeneous along multiple dimensions, including race, culture, ethnicity, geographical location, skills, experiences, and service needs. The challenge faced by behavioral health leadership is to meet these diverse needs in a manner that is fair and equitable. Equity does not necessarily mean that all individuals receive the same treatment. Rather, equity is a subtler concept that depends on the context of the issue at hand. In other words, “equal treatment may require unequal treatment” (Stone, 2002, p. 42). Thus equity can be defined in the context of the IOM’s definition of health service disparity: “the difference in treatment or access not justified by the differences in health status or preferences of the groups” (McGuire, Alegria, Cook, Wells, & Zaslavsky, 2006). Given the great diversity in this country, it is essential that behavioral health services are flexible enough and culturally competent enough to serve all individuals equally well.

Stakeholders in self-directed programs have expressed concern that a lack of adequate support for decision-making for less advantaged individuals could lead to an exacerbation of existing inequalities in health care (Alakeson, 2008a; National Health Service, 2009). In the National Health Service survey of behavioral health leadership, only 15 percent thought that self-direction would lead to a fairer allocation of resources, and 42 percent thought that it would lead to a less fair allocation (National Health Service, 2009). Such concerns can be addressed through support brokerage systems that are focused on meeting the needs of individuals, and
matching complexity of need to intensity of support. For individuals who do not have the capacity to self-direct without intensive support, representatives may also have a role. Such strategies require that additional resources be available to assist individuals and representatives to navigate the system.

Self-direction is premised on the assumption that all people, regardless of disability, are capable of making choices about the services and supports that they receive. However, the model is also designed to support individuals throughout the process, when such support is wanted and needed. All people, regardless of functional need, are assumed to benefit from self-direction if given proper supports. Two areas of equity concerns emerge when considering self-direction in behavioral health: Ensuring that individuals with differing levels of need have equal access to self-directed programs, and ensuring that services and supports in a self-directed program meet the needs of certain population groups, including racial and ethnic minorities and those living in rural areas.

As noted in the section on attitudes, there is a belief among some providers that only certain individuals are capable of self-direction. These beliefs can translate into unequal opportunities to participate in self-direction when programs are implemented. The inequality in opportunity to access self-directed programs could result in an overall “downgrading” of the self-direction principles. Programs might employ overly restrictive eligibility criteria, or providers may promote the program only with individuals viewed as trustworthy or stable, or who are able to easily articulate their needs and preferences (Spandler & Vick, 2006). Evaluations of pilots in the England and Scotland found that providers were selective of whom they promoted direct payments with and that program take-up was hindered because of narrow perceptions regarding suitability for programs (Report: Personal Health Budgets Research Scan, 2010). In the Cash & Counseling program, all individuals were eligible to apply, although some were required to appoint representatives; this feature prevented the possibility of creating inequities by refusing participation to certain groups.

Even if programs are designed to promote maximum equity, it is possible that protocols that promote equity can be undermined during program implementation. At the level of program management and support brokerage, it is possible that programs may target participants who are able to complete large amounts of paperwork or participate in complicated program processes without assistance. In the early years of the Florida SDC program, for example, participants were more educated and less likely to be from a minority group than the general population of behavioral health service users. Suspecting that this disparity was due to complicated and mail-based enrollment processes, the program took steps to increase face-to-face time with support brokers, devoted more resources to flexible outreach efforts, and allotted more support for person-centered planning (Alakeson, 2007).

As with any other system of services and supports, it is critical that there are opportunities for all to participate without discrimination. This includes individuals from racial and ethnic minority groups, those who are lesbian, gay, bisexual, or transgender, and those living in rural areas. It is critical that culture (broadly speaking) is taken into account and accommodated throughout the self-direction process (National Health Service, 2010).

Racial and ethnic disparities with respect to access and quality of behavioral health services and supports in this country are well documented (Mental Health: Culture, Race, and Ethnicity—A Supplement to Mental Health: A Report of the Surgeon General, 2001). Additionally, the mental health service needs of those living in rural communities are quite different from the needs of individuals in urban communities (New Freedom Commission on Mental Health, 2003). These inequities persist for myriad reasons, but the lack of opportunities to customize services and supports is likely a factor. The design and implementation of a self-directed program must take into account existing systemic inequalities faced by minority groups so that barriers to equity can be anticipated and addressed (National Health Service, 2011b). Further, self-directed
programs should ensure that participants involved in design, implementation, and monitoring are representative of the diversity of the populations served (NRCPDS, 2010).

As noted earlier in this review, evidence from the CCDE suggests that the increased flexibility associated with the self-direction model afforded participants the opportunity to tailor services and supports to individual cultural preferences (Foster, Brown, Phillips, & Carlson, 2005; San Antonio, Simon-Rusinowitz, Loughlin, Eckert, & Mahoney, 2007).

6.8 Competency, Decision-Making, and Risk

"Choice is therapeutic in its own right. (i.e. when three treatments for depression all with the same predicted outcome are offered and one is chosen by the patient, the success rate increases.) We all like choice and feeling in control, including [general practitioners] and mental health staff. For GPs and others a tension exists between having the confidence to 'let go' and the uncomfortable feeling of not being 'in control.'" (Brewis, 2007, p. 22).

The assumption that people diagnosed with mental health and substance use disorders lack the ability to make responsible decisions about treatment is a key barrier to implementation of self-direction on a number of levels. According to Stefan (2006), an attorney at the Center for Public Representation who conducted a survey of legal cases as they pertain to self-direction, this belief is rooted in a culture rife with liability concerns. Stefan concludes that a person's legal status as competent or incompetent does not correlate with his or her ability to articulate preferences about services and supports or to participate in self-direction.

The Florida SDC program found that autonomy was not innate to all participants when they first began the program (Stefan, 2006). In particular, participants who have spent many years living in institutions or group homes may not possess the skills to self-direct without learning and practicing. A Florida SDC administrator interviewed by Stefan reported no problems in regards to competence in decision-making. On the contrary, participants in the Florida SDC program were so unused to being asked to make decisions about services and supports that it took a long period of time until they were able to embrace the self-direction the program offered (Stefan, 2006).

If clients in self-directed programs share a common vision of recovery with their providers, the process should work smoothly. If the person’s understanding of recovery is different in ways that the provider sees as dangerous, or if the person refuses certain services the provider deems necessary and there are no alternative services to choose from, these disagreements could be obstacles to self-direction (Stefan, 2006). For example, an individual may decide that the side effects associated with psychiatric medications are decreasing his or her personal wellness and may seek assistance from a provider to safely taper off the medications. While the person may see this as supporting recovery, a provider may have concerns that such a decision will threaten the person’s mental health and stability. This dynamic is complicated by the fact that providers may interpret disagreement with treatment decisions as incompetence (Stefan, 2006).

Self-direction offers an opportunity to expand the pool of mental health providers, which may refute assumptions about competency that have developed over the years. Individuals can go out into the marketplace and get a second opinion when there is disagreement. Participants can choose professionals who tend towards supporting autonomy. They can be paired with professionals who share their own values and understandings of recovery. Thus, increasing choice of providers increases the likelihood of consensus (Stefan, 2006).

6.8.1 Understanding Risk
Stefan (2006) writes that health and legal systems are configured to discourage risk-taking. Sometimes activities undertaken to obviate risk lead to treatment relationships that are the very antithesis of recovery, and inhibit personal ambitions and aspirations (Elder-Woodward, et al., 2009; Stefan, 2006).

The nature of crises is different for behavioral health participants than for other populations, and it is important to understand these issues in the context of self-direction. Some behavioral health service users may experience acute, short-term crises during which their decision-making ability may be impaired. In keeping with the principles of self-direction, however, individual choice should be honored even when a person is in crisis. Traditional crisis, inpatient, and residential services are not typically covered under behavioral health self-direction programs and are available to participants through traditional funding mechanisms (In the Driver’s Seat: A Guide to Self-Directed Mental Health Care, 2008). Therefore, if an individual is in crisis, he or she will still have access to wanted or needed services while in the pilot programs.

Another consideration in regards to acute crisis is the possibility that if individuals are given the opportunity to self-direct, there may be a reduced need for acute care services. The decreases in inpatient stays amongst Cash & Counseling participants in Arkansas suggest that such reductions may be possible for behavioral health service users as well. Similarly, Florida SDC participants were less likely to use crisis stabilization care and more likely to use outpatient mental health services such as psychiatry, psychotherapy, and supported employment (Hall, 2007; Cook et al., 2008). This evidence suggests that it is possible that increased access and improved quality of home-based rehabilitative services could reduce the need for psychiatric emergency rooms and hospitalizations. More options for crisis services and supports, such as peer-run crisis respite and other crisis alternatives may also decrease the need for emergency services (Brewis, 2007; Greenfield, Stoneking, Humphreys, Sundby, & Bond, 2008).

6.8.2 PROVIDER AND ADMINISTRATION LIABILITY AND INFORMED CONSENT
Administrators may be concerned that if self-directed program participants make harmful decisions, provider organizations will be subject to lawsuits or poor evaluations (Stockport Council, nd). Providers may be worried that allowing behavioral health service users to self-direct could lead to detrimental outcomes. Stefan argues, however, that self-directed programs are likely to be less of a liability than traditional behavioral health systems because of their emphasis on open and positive relationships between the participant and provider and a decreased likelihood of disagreements regarding treatment decisions. In other words, liability is decreased by true informed consent.

Informed consent is the obligation of the provider to adequately disclose all risks, benefits, and alternatives to the individual so that he or she can voluntarily consent (or refuse to give consent) to treatment. In practice, such voluntariness rests on a continuum, and providers are constantly challenged to ensure that individuals are adequately informed (Sabatino, 2007).

6.8.3 PRO-ACTIVE CRISIS PLANNING
All too often, the experience of a behavioral health-related crisis leads to coercive or forced treatment at a time of greatest need (Bonsack & Borgeat, 2005). Some concerns regarding competency and decision-making can be addressed through the integration of pro-active crisis planning into the support process. Laws regarding decision-making in general health care have gradually evolved towards a greater emphasis on ongoing, flexible communication between the patient and the provider (Sabatino, 2007). Advance directives were developed via the concept of informed consent and rest on the premise that no one should be subjected to treatment of any kind without his or her consent. Whereas informed consent occurs at the time of treatment, advance directives are developed before treatment begins.
Similar to the person-centered planning process, the advance directives process involves an ongoing exploration of preferences and goals on the part of the person and his or her representatives and providers. Some tools, such as Wellness Recovery and Action Plans (WRAP) and Psychiatric Advance Directives can be used to manage and avert crises within the self-direction model. Psychiatric Advance Directives have been shown to reduce the number of involuntary hospital admissions and the length of stay during those admissions for individuals with serious mental illness (Henderson et al., 2004).

More research is needed to understand how these tools can best be put to use to maximize self-determination while managing risk. It is critical that such plans be reevaluated on a continuous basis, as individual needs change. When a plan is amended to take control out of the hands of a person who is in crisis, it is critical that that amendment be revisited when the person is no longer experiencing the crisis (Smull, personal communication, October 14, 2011).

6.8.4 Tapered Control Model
To further address issues related to risk and liability, Alakeson (2011) offers a Tapered Control Model in which a budget is handled by a team consisting of the person, a representative when needed, support brokers and service planners, providers, and the organization overseeing the self-direction process. In such a model, however, it is critical that choice be maintained as needs fluctuate. Variability must be acknowledged and built into the support plan pro-actively (Brewis, 2007).

Ultimately, complete acceptance of participant decisions is not a value of self-direction. Rather, self-direction is a process in which participants work with providers and other natural supporters such as family and friends to articulate goals and preferences and determine the best manner to further recovery. Responsible providers and supporters can and should respectfully challenge the person’s ideas about how to reach his or her goals when necessary. There may be scenarios in which unconditional provider support of participant decisions constitutes neglect. Most importantly, participants, providers, and the person-centered planning team must work proactively to understand and address the risks and crises that the individual is likely to experience.

Involuntary commitment will still exist in a self-directed model. Stefan writes, "In this situation, as suggested above, the most ‘patient-centered’ approach may be to acknowledge the truth of the situation, validate the patient’s perception of his or her relative powerlessness, acknowledge how frustrating that must feel, and how difficult it is to participate in treatment under those circumstances" (2006, p. 23). Focus might shift to maximizing autonomy within the context of commitment. Patients can decline some treatments, or express preference for one treatment over another. Ultimately, the goal is to avoid a "vacuum of decision-making and control" which leads to the involvement of people who do not know the person’s preferences and values (Stefan, 2006, p. 40).

6.9 Impact on the Traditional Behavioral Health System
As noted above, many stakeholders feel that even a small shift towards self-direction in behavioral health has the potential to create large culture change. A shift to self-direction requires changing the balance of power between professionals and patients; defining the system by the health outcomes it results in, not the services it delivers; and a focus on the whole person with one budget covering all health and social care needs (Alakeson, 2011). Cultural change and community acceptance of self-direction takes time and requires a continuous focus on the underlying values and principles of self-direction so that it is not seen as just a system change (Rogers, 2009).
"...the challenges that personal health budgets pose to the [National Health Service] are becoming clear. They focus on outcomes not services, eroding established ideas of what is legitimate use of [National Health Service] funding and breaking down the institutional silos of public services. They create a shift in power in favour of patients and necessitate a change in practice from clinical professionals. They challenge the risk-averse culture of the [National Health Service] by supporting individuals to make choices for themselves, recognising that individuals are generally safer if they are involved in their care." (White, 2011, p. 22).

6.9.1 Innovation and Non-Traditional Services

Self-direction has the potential to expand the existing range of services and supports in behavioral health to include modalities and goods that support individuals beyond traditional outpatient support, medications, and day treatment.

Personal Medicine

The theory of personal medicine posits that everyday activities involving work, recreation, and interpersonal relationships have a therapeutic value (Deegan & Drake, 2006). When medical professionals do not take personal medicine into account, traditional treatment can conflict with personal decisions and preferences that underlie personal medicine (Alakeson, 2011). Self-direction provides an opportunity for participants to align their preferences for both personal medicine and professional services in one person-centered plan.

Complementary and Alternative Medicine

In a self-directed program, individuals may opt for complementary and alternative therapies such as yoga, meditation, and tai chi, and in some programs, participants may choose non-medication alternatives to treatment.

In the self-direction model, non-traditional providers can take advantage of opportunities to orient their services towards participants. An example might be a local yoga studio offering discounted classes for self-directed participants. In this way, the introduction of self-direction could be beneficial to small businesses interested in supporting choice and broadening their client base (Salzer, personal communication February 17, 2010).

Peer-Provided Services

Self-direction holds promise for the expansion of peer-provided services, both in terms of the role of peers as support brokers and the opportunities for peer-run services to compete with traditional behavioral health services for participant choice. Peer providers bring different attitudes, perspectives, and insights to behavioral health services and supports, and can encourage engagement and enhance the recovery focus of any mental health service (New Freedom Commission on Mental Health, 2003).

In a demonstration program for young mental health service users in England, a group of ten participants pooled funds to set up a user-led weekly drop-in support program to provide assistance and consultation to other service users (Alakeson, 2011).

6.9.2 Market Forces

If self-direction were to be implemented broadly, it may lead to increased competition for self-directed services and could serve as impetus for larger providers to change their practices to support self-direction in the long run. Similarly, a self-directed model may encourage providers to work with one another across organizations to provide better services (Elder-Woodward, et al., 2009). Self-direction could incent providers to become more participant-oriented and involve participants and families every step of the way (Glendinning, et al., 2008; Report: Personal Health Budgets Research Scan, 2010).
On the other hand, there are potential pitfalls in regards to the market forces associated with self-direction. The National Health Service survey of providers found that many were concerned that participants would make choices on price alone rather than quality, and that providers may “cherry-pick” participants, leaving those with more complex needs in the traditional service system. Similarly, Smith and Lipsky (1992) caution that an increase in choice without adequate supports and information could lead providers to limit access to people with more serious problems, or to make it more difficult for participants to determine the quality of their services.

Smith and Lipsky (1992) argue that empowering participants to choose their own services and supports puts them in a similar role to government contractors. The participant is responsible for evaluating the quality and effectiveness of the health services he or she is choosing. The authors argue that, like government contracting agencies, participants are subject to peer and community pressure, marketing, and desire for good relationships and continuity. In this context, the understanding the quality of available services and supports in a self-directed program is paramount. Participants – and also support brokers, fiscal intermediaries, and representatives – must be fully supported to effectively gauge the quality of services and supports in order for market forces to make a positive impact on the behavioral health system via self-direction.

Additionally, self-direction could potentially lead to insurers – including Medicaid – capping costs for participants, which could in turn lead to reductions in coverage over time.

The extent to which self-directed services and supports introduce incentives for providers and payers to improve or diversify services depends on whether the program is carefully designed and implemented (White, 2011). Additionally, the government must continue to play a role in determining and monitoring quality standards (Brewis, 2007).

### 6.9.3 Availability of Recovery-Oriented and Person-Centered Services

The availability of recovery-oriented services and supports such as peer-operated services and wellness supports is a critical element in the success of a self-directed behavioral health program. Even if individuals are given their own budgets and empowered to choose how to spend their treatment dollars, recovery-oriented services and supports may remain unavailable. Self-directed program planning efforts may need to include efforts to proactively “make the market” and ensure that recovery-oriented services and supports are available.

The viability of a self-directed behavioral health program is likely impacted by the existing behavioral health environment. For example, project leaders of the Texas SDC program noted that the Dallas County area had a strong existing peer advocate network, which paved the way for a self-directed program in that area (Cook, Shore, & Fudge, 2009). Of critical importance is the availability and prominence of peer-provided and mutual help services and supports and the strength of mental health and substance use advocacy community. Without these system-level changes, individual-level options for true self-determination via self-direction will remain limited, and recovery-related needs will continue to be unmet.
7 VII. CONCLUSIONS

Introducing self-direction in behavioral health services is a complicated endeavor. Culture change will be needed on multiple fronts. In the behavioral health context, the budget authority model calls for different services and different delivery mechanisms by different people, and it involves a paradigm shift from the medical model of illness and disability to the more holistic recovery model. However, the behavioral health community has already embraced principles of recovery, as evidenced by the emergence of the current demonstrations and the growing interest in self-direction in the behavioral health field. Cash & Counseling and the existing mental health demonstrations have paved the way and opened the door for future efforts. This environmental scan is a next step towards bringing self-direction to behavioral health services.
8 REFERENCES


*Description of a good and modern addictions and mental health service system.* (2011). Rockville, MD: Substance Abuse and Mental Health Services Administration.


*Free to choose: Transforming behavioral health care to self-direction.* (2005). Rockville, MD: Center for Mental Health Services, Substance Abuse and Mental Health Services Administration.


Phelan, J. C., & Link, B. G. (1998). The growing belief that people with mental illnesses are violent: the role of the dangerousness criterion for civil commitment. *Social Psychiatry and Psychiatric Epidemiology, 33*(0), S7-S12.


