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AN ENVIRONMENTAL SCAN OF SELF-DIRECTION IN BEHAVIORAL HEALTH

Summary of Major Findings

Funded by: The Robert Wood Johnson Foundation

This document summarizes an in-depth report submitted to the Robert Wood Johnson Foundation in April 2013. To request a complete copy of the Environmental Scan Final Report, please e-mail **info@participantdirection.org**.

AN ENVIRONMENTAL SCAN OF SELF-DIRECTION IN BEHAVIORAL HEALTH: SUMMARY OF MAJOR FINDINGS

Prepared by the Boston College National Resource Center for Participant-Directed Services, University of Maryland, and Human Services Research Institute

Released May 2013

This environmental scan was designed to understand facilitators and barriers to self-direction in behavioral health (i.e. mental health and substance use disorders), ascertain interest among stakeholders, adapt the model and outcome measures to better fit the needs of behavioral health consumers, and develop recommendations to inform next steps. The scan was a joint effort conducted over 18 months (September 2011 – February 2013) by researchers from the National Center for Participant-Directed Services, Human Services Research Institute, and the University of Maryland, funded by the Robert Wood Johnson Foundation (RWJF). The research team comprised experts in design, implementation, and evaluation of budget authority programs, as well as behavioral health services consumers and researchers. The research team was advised by an Environmental Scan National Advisory Committee made up of content leaders and experts in self-direction and behavioral health. (See **Appendix I** for a list of key contributors.)

This document begins with an **Executive Summary** which provides a brief overview of the five deliverables developed as part of this environmental scan. The remainder of the document summarizes the five deliverables in detail:

A. A **Literature Review** drawing from diverse sources examining the current knowledge base (nationally and internationally), key issues and concerns, and potential funding mechanisms.
B. A **Survey of State and County Behavioral Health Program Directors** administered following an educational webinar to ascertain state and county leader's views on the self-direction model.
C. A memo summarizing key findings from a series of **State and County Behavioral Health Program Director Interviews**.
D. A memo summarizing key findings from a series of **Stakeholder Interviews and Focus Groups.** Stakeholders include consumers, providers, advocates, and policymakers.
E. **Potential Parameters for a Demonstration and Evaluation** informed by findings summarized in documents A-D.

Based on the extensive findings from this environmental scan, **the research team's final recommendation is for the implementation of a large-scale demonstration and evaluation of self-direction in behavioral health services**. The key findings summarized in this document indicate an identified need, highlight strong interest and support across a diverse set of key stakeholders, and include core questions to consider for successful implementation of a behavioral health self-direction demonstration and evaluation.

EXECUTIVE SUMMARY

LITERATURE REVIEW

The literature review examines the current knowledge base of self-direction in behavioral health. The review explores making self-direction available to individuals with serious mental illness 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 describes the budget authority model and outlines the need for self-direction in the behavioral health arena. Chapter Two examines the theoretical and value base for self-direction, including a discussion of recovery, self-determination, and person-centeredness in behavioral health. In Chapter Three, the Cash & Counseling Demonstration and Evaluation is reviewed. Chapter Four provides an overview of the current state of self-direction in behavioral health, including descriptions of current behavioral health programs and a review of the literature examining the impact of self-direction on behavioral health outcomes. Chapter Five explores existing and potential financing mechanisms, including the Medicaid 1915(i) state plan option and managed behavioral health care. Some key issues and concerns are explored in Chapter Six, outlining program design considerations and roles of key stakeholders including peers, providers, and policymakers. Chapter 7 offers the following conclusions: Introducing self-direction in behavioral health services is a complicated endeavor. 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.

For a more complete summary, see **Section A.**

BEHAVIORAL HEALTH PROGRAM DIRECTOR SURVEY

The Behavioral Health Program Director Survey was administered to participants following the *Self-Direction in Behavioral Health* webinars, designed to educate state and county mental health and substance use program directors about the basic principles of self-direction. Over three dates in February 2012, the webinars were attended by a total of 84 individuals representing the leadership of state and county mental health and substance use programs in 35 states and the District of Columbia. Of these participants, 50 respondents completed the post-webinar survey (a 60 percent completion rate). Respondents were asked about their views

on self-direction, including perceived benefits and challenges, priority of and interest in self-direction, and expectations about self-direction in the future. Survey questions were developed based on the findings of the literature review and were piloted with experts in the behavioral health field, including former behavioral health program directors, prior to survey administration.

Respondents were asked to rate a set of potential benefits and challenges associated with self-direction. Over three-quarters of survey respondents endorsed the following benefits as being strongly associated with self-direction: stronger consumer choice and voice, greater flexibility, enhanced recovery, increased community integration, improved service quality, and better access to services. The most commonly identified challenge associated with self-direction was less control for providers, which was rated as a significant challenge by over half of respondents.

Respondents were also asked to rate a series of potential facilitators and barriers to the adoption of self-direction within their agencies. Nearly all respondents indicated that an increasing emphasis on self-determination and recovery within their systems was an important facilitator for adopting self-direction. In terms of barriers, approximately three-quarters of respondents identified resistance from providers and policy makers as significant barriers. When asked about expected costs of self-direction as compared to the costs of traditional behavioral health services and supports, respondents held mixed views. Approximately half expected costs to be lower, a quarter expected costs to be the same, and only eight percent expected costs to be higher.

Next, respondents were asked a series of questions about their agencies' expectations, priorities, and interest in self-direction. A strong majority of respondents expected that self-direction would have either a high or moderate impact on behavioral health systems in coming years. Half of participants indicated self-direction as a high priority, and another quarter identified self-direction as a moderate priority. A majority of respondents indicated that they were "very interested" in implementing a self-direction program in their agency, and no respondents indicated that they were very disinterested.

For a more complete summary, see **Section B**.

BEHAVIORAL HEALTH PROGRAM DIRECTOR INTERVIEWS

For the most part, program director interviewees were drawn from a larger group of respondents who took the Behavioral Health Program Director Survey following the educational webinar. Project staff completed a total of 17 interviews in the late spring and early summer of 2012. Interviewees represented ten states and four counties. Four of the interviews were conducted with peers holding positions at Offices of Consumer Affairs in state and county behavioral health programs. Interviews were semi-structured using an interview guide developed based on the literature review and survey results.

When asked about the benefits of self-direction, interviewees indicated that self-direction has the potential to enhance recovery, promote engagement and empowerment, increase choices, and lead to greater participant satisfaction. Interviewees also expected that self-direction might help individuals to rebalance their mix of services towards more community-based support and less use of emergency or inpatient services, which could lead to lower system costs overall. Interviewees highlighted full stakeholder participation (particularly grassroots and peer advocacy groups), a need for champions and leaders in state and local government, pro-active education and outreach strategies, and the power of personal stories as key facilitators to promote the adoption and implementation of self-direction. In terms of challenges, provider resistance was the most commonly discussed theme. Interviewees also identified existing challenges with health and behavioral health systems, including a lack of clarity in regards to Medicaid regulations and self-direction, tough economic times, and fragmentation in service systems. Interviewees also discussed a number of program design considerations, including broker training and support, participant education, monitoring and oversight activities, and the role of peers.

A number of local, state, and federal policy issues were identified as important contexts for the discussion of self-direction in behavioral health. These included the implementation of the Affordable Care Act, efforts to integrate physical and behavioral health care, changing county-state relationships, and an increasing role for managed care in behavioral health systems. The states and counties represented by interviewees employed diverse strategies to finance their behavioral health services. All interviewees noted that Medicaid was a critical funder, be it through state plan services or specialty waivers and state plan options, and predicted a growing role for Medicaid in the future. While some interviewees saw the changes as opportunities for enhancing self-direction and spoke of initiatives that promote self-direction in the context of health reform and other major policy changes, others expressed uncertainty. One interviewee aptly noted, "*Some people might say we are in a state of chaos, others a state of opportunity.*"

In regards to next steps, a large-scale demonstration and evaluation was endorsed by a majority of interviewees, and some interviewees offered suggestions for design, including identifying important evaluation outcomes for a behavioral health context such as cost, service utilization, quality, employment and housing retention, and participant satisfaction. Interviewees also noted that technical assistance materials would be useful to them.

For a more complete summary, see **Section C**.

STAKEHOLDER INTERVIEWS AND FOCUS GROUPS

In the winter of 2012 and 2013, the project team conducted five focus groups and seventeen in-depth interviews with a range of stakeholders in behavioral health. The focus groups involved:

- Life coaches/support brokers in Florida
- Peer specialists in Michigan

- Transition-age youth with SMI diagnoses in Maryland
- Adults with SMI diagnoses in Boston
- Adults with co-occurring alcohol and other drug and SMI diagnoses in Boston

The interviewees included:

- Five Florida Self-Directed Care participants and one former participant
- Six providers, including two psychiatrists, a clinician specializing in issues related to older adults with SMI, and three clinicians who work with individuals with self-directed arrangements
- Six individuals who work in self-directed programs in Maryland and Michigan, one of whom works with transition-age youth. Four of these individuals identified as peers, and one previously held a self-directed arrangement before holding employment

Interviewees identified a number of positive outcomes associated with self-direction. These included increased recovery, community engagement, independence, empowerment, motivation and hope, and self-esteem. Several interviewees shared stories about how self-directed programs have led to increased participation in employment and education, improvements in housing arrangements (for example, moving from a group home to one's own apartment), and a decreased need for inpatient and emergency services. A theme of "giving back" emerged, with several participants reporting motivation to work or volunteer in the mental health field to help others achieve the recovery gains realized through participation in self-directed programs.

Interviewees spoke in depth about varying aspects of program design, including participant recruitment and education, broker training and support, outreach and engagement with providers, the use of pro-active crisis planning, planning and budgeting activities, and the role of peer sharing and participant advisory groups.

For a more complete summary, see **Section D**.

POTENTIAL PARAMETERS FOR A DEMONSTRATION AND EVALUATION

Based on the findings from the four environmental scan components, the research team developed potential parameters for a large-scale demonstration and evaluation of self-direction in behavioral health services. Key stakeholders and the Environmental Scan Advisory Committee reviewed and offered comments on the potential parameters that follow.

For a more complete summary, see **Section E**.

The remainder of this document represents a detailed summary of the major findings of the five deliverables from the environmental scan of self-direction in behavioral health.

A. LITERATURE REVIEW

The literature review examines the current knowledge base of self-direction in behavioral health. The review explores efforts to make self-direction available to individuals with serious mental illness 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. **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**. Each of the chapters are summarized briefly below.

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 model allows participants to manage a flexible budget to hire workers and buy goods and services to meet their needs. An employer authority model allows participants to recruit and hire workers without a budget to buy goods and services. 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, increase employment, expand education, and reduce fragmentation.

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.

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. 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. 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. 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. According to the Institute of Medicine, **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." Person-centeredness overlaps with several of the key principles of self-direction, including the emphasis on individual preferences and values and a commitment to participant-driven treatment decisions.

CHAPTER 3: CASH & COUNSELING DEMONSTRATION AND EVALUATION

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 Office of the Assistant Secretary for Planning and Evaluation partnered to develop the CCDE, 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 elders and adults and children with disabilities in New Jersey, Arkansas, and Florida. Evaluators found that the Cash & Counseling model 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. These positive findings led to a twelve-state replication project that was also successfully completed.

CHAPTER 4: SELF-DETERMINATION IN A BEHAVIORAL HEALTH CONTEXT

Currently, self-directed programs are active in Europe, Australia, and Canada and the United States. 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 (persons with lived experience of behavioral health issues) as support brokers.
- **Financial management services** help the participant with financial management responsibilities such as checking expenditures against an approved budget plan, 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. Secondary analyses of the CCDE data indicated that a sub-group of participants with mental health diagnoses fared as well as or better than those in the control group on several measures, including participant satisfaction and quality of life. Preliminary evaluations of the existing self-directed behavioral health programs have found increased satisfaction, higher functioning, and increased use of wellness and preventive services. 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. 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.

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 regulations and restrictions. Although this review identified numerous funding sources for self-direction, two emerged as primary, the 1915(i) state plan option and managed care.

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 Affordable Care Act supports an expansion in the range of covered services and supports and an allowance to target specific populations such as individuals with psychiatric disabilities.

Managed care organizations – particularly managed behavioral health care organizations – may have the potential to support future behavioral health self-direction efforts. 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. 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. 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.

CHAPTER 6: KEY ISSUES

All people, regardless of functional need, are assumed to benefit from self-direction if given proper supports. 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. 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 participant selection, and other mechanisms - to keep the program philosophy strong. 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 summary of the literature on a number of important program design considerations, including:

- Person-centered planning and systems
- Budget development methods
- The role of the support broker
- Financial management services
- The role of representatives
- Eligibility criteria design
- The administrative complexity of self-directed programs
- Monitoring and evaluation strategies
- Quality assurance approaches
- Engaging with stakeholders, including participants and family members, providers, and policymakers
- Ensuring access
- Behavioral health crises and pro-active crisis planning

Self-direction requires culture change, shifting the balance of power between professionals and service users; defining the system by service outcomes, not the services it delivers; and a focus on the whole person with one budget covering all behavioral health-related needs. Cultural change and community acceptance of self-direction takes time and requires a continuous focus on the underlying values and principles of self-direction. 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. 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 for people with more serious problems. In this context, successful self-direction depends on the availability of recovery-oriented services and supports, and mechanisms for participants to effectively gauge the quality of services and supports.

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. The CCDE and the existing mental health demonstrations have opened the door for future efforts. This environmental scan is a next step towards bringing self-direction to behavioral health services.

B. BEHAVIORAL HEALTH PROGRAM DIRECTOR SURVEY

The Behavioral Health Program Director Survey was administered to participants following the *Self-Direction in Behavioral Health* webinars, designed to educate state and county mental health and substance use program directors about the basic principles of self-direction. Over three dates in February 2012, the webinars were attended by a total of 84 individuals representing the leadership of state and county mental health and substance use programs in 35 states and the District of Columbia.

Of these participants, 50 respondents completed the post-webinar survey (a 60 percent completion rate). Respondents were asked about their views on self-direction, including perceived benefits and challenges, priority of and interest in self-direction, and expectations about self-direction in the future. Survey questions were developed based on the findings of the literature review and were piloted with experts in the behavioral health field, including former behavioral health program directors, prior to survey administration.

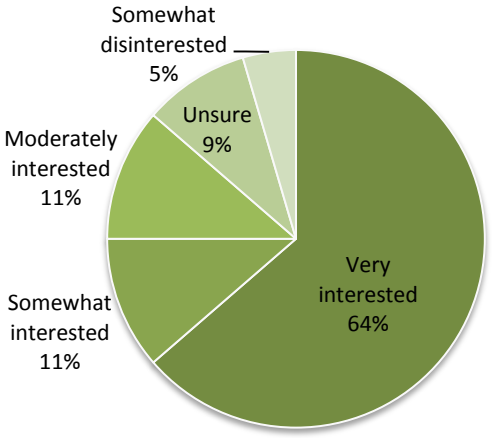
Respondents were asked to rate a set of potential benefits and challenges associated with self-direction. Over three-quarters of survey respondents endorsed the following benefits as being strongly associated with self-direction: stronger consumer choice and voice, greater flexibility,

enhanced recovery, increased community integration, improved service quality, and better access to services. The most commonly identified challenge associated with self-direction was less control for providers, which was rated as a significant challenge by 54 percent of respondents. Other challenges included less control for payers (32 percent rated challenging), safety and risk concerns (28 percent), more complex to manage (24 percent), potential for misuse (23 percent), and higher costs (20 percent).

When asked about expected costs of self-direction as compared to the costs of traditional behavioral health services and supports, respondents held mixed views. Approximately half (48 percent) expected costs to be lower, a quarter (26 percent) expected costs to be the same, and only eight percent expected costs to be higher.

Next, respondents were asked a series of questions about their agencies' expectations, priorities, and interest in self-direction. A strong majority of respondents expected that self-direction would have either a high (42 percent) or moderate (46 percent) impact on behavioral health systems in coming years. Half of participants indicated self-direction as a high priority, and another quarter identified self-direction as a moderate priority. As seen in Figure 1, a majority of respondents indicated that they were "very interested" in implementing a self-direction program in their agency, and no respondents indicated that they were very disinterested.

FIGURE 1: INTEREST IN IMPLEMENTING A SELF-DIRECTED PROGRAM (N=49)



Respondents were also asked to rate a series of potential facilitators and barriers to the adoption of self-direction within their agencies. Nearly all (96 percent) of respondents indicated that an increasing emphasis on self-determination and recovery within their systems was an important facilitator for adopting self-direction. In terms of barriers, 86 percent of respondents identified provider resistance as a significant barrier, and 74 percent indicated that policy maker resistance as a barrier.

C. BEHAVIORAL HEALTH PROGRAM DIRECTOR INTERVIEWS

For the most part, interviewees were drawn from a larger group of respondents who took the Behavioral Health Program Director Survey following the educational webinar. Project staff completed a total of 17 interviews in the late spring and early summer of 2012. Interviewees represented ten states and four counties. Four of the interviews were conducted with peers holding positions at Offices of Consumer Affairs in state and county behavioral health programs. Interviews were semi-structured using an interview guide developed based on the literature review and survey results.

BENEFITS OF SELF-DIRECTION

Several interviewees indicated that self-direction has the potential to have a positive **impact on recovery** for participants. Interviewees noted numerous domains of recovery, including housing retention, education and employment, community engagement, health and wellness, and clinical improvement. Interviewees also expected that self-direction might help individuals to rebalance their mix of services towards more community-based support and less use of emergency or inpatient services.

When identifying how self-direction benefits participants, respondents spoke about how self-directed arrangements promote both **engagement and empowerment** for participants by **increasing choices** and leading to greater overall **satisfaction**. As one respondent noted when asked about the benefits of self-direction, "*Number one is empowerment. That it is not 100% control in the hands of professionals, that empowerment aids them along in their resiliency."*

Increasing choices was endorsed as a key benefit because it allows individuals to create a mix of services that works best for them. This appropriate mix of services leads to greater effectiveness in achieving recovery outcomes as well as system level improvements in quality and accountability. Speaking from the perspective of a peer, one interviewee noted, "*For myself and some people I work with, that further level of control – that somebody actually trusts me to take some control - has been huge in our own lives*."

BARRIERS TO ADOPTION AND IMPLEMENTATION OF SELF-DIRECTION

Several respondents identified the **medical model** of mental illness as something to be "treated" or "cured" as a barrier to adoption. In general, **provider concern** was a common theme in the majority of interviews. For example, when asked about barriers, one respondent replied, "*The first thing that comes to mind would be a provider revolt*." The most commonly endorsed reason for provider concern is that self-direction is a **financial threat to providers**. Providers were described by interviewees as being legitimately concerned that they will lose money under self-directed arrangements, where participants have purchasing power and can take their business elsewhere if they choose. Because it affords participants the power to choose between providers, self-direction is a threat to census preservation and reliance on base budgets. To the contrary, some noted that more competition might provide impetus for providers to improve/expand their services. In addition to the financial threat issue, interviewees noted that

paternalism and doubt that individuals with serious mental illness are capable of self-direction and a **lack of provider education** about self-direction contribute to provider concern. One interviewee noted that there might also be resistance from compliance departments within provider organizations due to a **lack of clarity** about self-direction (see discussion on role of CMS).

Several interviewees identified **participant circumstances** that may be roadblocks to implementing self-direction. These circumstances include churn (individuals with mental health issues come in and out of the system more frequently than those in other population groups), low levels of education (which may lead to an assumption on the part of providers and administrators that a person is not capable of self-direction), poor self-advocacy skills, and general poverty, including a lack of access to basic community resources and transportation. Some interviewees noted that when asked what it is they want to do with their lives, many potential participants have a difficult time responding, perhaps because they have never been given an opportunity to dream about the future and set goals in ways that the general population may take for granted.

Two interviewees noted challenges related to **provider availability**, stating that self-direction will be difficult to implement in communities in which there are no high quality, recovery-oriented providers from which to choose. Such dynamics were thought to lead to stymied competition and fewer incentives to provide services that are attractive to participants.

A handful of interviewees also noted that **fragmentation between service systems** is a barrier to implementing self-direction. Interviewees noted issues with fragmentation between counties, between mental health and substance use systems, and between mental and physical health systems. This fragmentation leads to increased challenges to coordinate services and collaborate across systems. See the section on policy context for more discussion of these issues.

Nearly all interviewees identified the current **tough economic times** as a barrier to self-direction in particular, or systems change in general. Some spoke of how their state had managed to preserve self-direction or person-centered thinking in spite of budgetary constraints, while others indicated that uncertainty about tight budgets poses a barrier to self-direction.

FACILITATORS FOR ADOPTION AND IMPLEMENTATION OF SELF-DIRECTION

Two interviewees spoke of the importance of **exemplary states** that lead the way and pioneer self-directed efforts to facilitate systems change. Other states may build on the successes of those that adopted self-direction early. These states must be willing to bear some degree of political risk in taking on a new and innovative initiative.

Full stakeholder participation is a critical element for success of a self-directed program, involving buy-in from all stakeholders -- including providers. In particular, many interviewees spoke of the importance of **grassroots and peer advocacy** groups in providing impetus for self-direction. Peers with lived experience were seen as having the power and responsibility to advocate to leadership/legislators/administrators, and to demonstrate to providers that self-direction is possible and worthwhile. The **power of personal stories**, particularly stories of

people who have successfully self-directed behavioral health services, was noted as critical for education and promotion of self-directed programs. Several interviewees noted that personal stories must be paired with data on cost and effectiveness.

Leaders and champions at the highest levels (governors, legislators, department directors, Medicaid directors) to champion initiatives were identified as critical. However, interviewees also noted that leaders must find ways to transmit their enthusiasm and support to lower levels of management: "*One of the things that I think happens is sometimes you can get a state director to be invested and excited about something, and then he or she has difficulty getting their managing team staff excited about it. Sometimes it's not only about getting on their level but the next level down, too*." Another interviewee echoed this sentiment, observing that in her/his experience, program leadership were enthusiastic about self-direction, but in order for effective **participant recruitment and education** to take place, **middle management** and direct service staff such as **case managers needed to buy-in, too**.

Pro-active not reactive movements to change systems were endorsed as critical facilitators for self-direction. Not just reacting to what is "burning your fingertips," and instead, thinking in terms of a broader vision for system change. Interviewees noted a need to proactively put services and supports in place for people to have true choice within a system.

Interviewees identified **salience of personal responsibility** among lawmakers, and in political rhetoric, as a potential facilitator for the adoption of self-direction. Interviewees noted that self-direction is of a piece with larger political trends/movements.

COSTS AND COST-EFFECTIVENESS

All respondents discussed the **importance of cost** to any discussion on self-direction, particularly the importance of demonstrating **cost-efficiency**. Respondents spoke of the salience of a "win-win" proposition – that self-direction leads to greater recovery and also lowers costs. Such cost efficiency is particularly critical given the **tough economic times** faced by states and counties. However, a few respondents also added that an over-emphasis on cost could be problematic: "*It is always a problem when a program gets sold on cost benefits as primary. There's always a problem with that*."

Several respondents predicted that when participants are aware of the funds available to them and the costs of their service packages, they are more likely to be more judicious with the use of those funds and the outcomes associated with purchasing services and supports (which some respondents referred to as "taking responsibility"). In addition, some respondents expected that by enhancing recovery, self-directing participants might rely less on high-cost services like inpatient and acute care. This shift could translate to a **potential for lower costs** and cost-effectiveness overall.

SPECIAL POPULATIONS

Some respondents spoke about self-direction from the perspective of certain populations. In regards to **transition-age youth**, several interviewees noted a gap in the continuity of services

between the child and adult behavioral health systems. One interviewee noted that in his/her experience, children receiving more individualized, wrap-around social services early in life are less likely to end up in the mental health system as "professional patients" later on. Conversely, another interviewee expressed concern that the current systems serving children with behavioral health conditions do too little to promote self-determination, which could lead to continued dependence on the adult systems. These observations suggest that introducing increased self-determination early on could have a preventive effect on the need for publicly-funded behavioral health services in adulthood.

Two other interviewees noted their experiences with self-direction for younger persons with developmental disabilities; observing that individuals who are afforded more choice and flexibility in their services early on are more likely to expect more choice and control as they transition to an adult system. They hypothesized an increase in demand for self-direction as a younger population more accustomed to exercising self-determination ages into the adult system. When asked, one interviewee expected that a similar dynamic might be observed on the mental health side if self-determination were to be introduced earlier in the continuum of services.

Four interviewees noted special concerns regarding populations living in **rural areas**. These concerns centered on limited capacity for traditional behavioral health services in rural areas. Two interviewees noted that the shortage of traditional behavioral health services in rural areas could lead to greater interest in more entrepreneurial or less traditional community support services. Two interviewees also expressed some concern that more rural areas tend to be less progressive than those with greater population density, which could lead to inconsistent implementation of innovations like self-direction. Another interviewee, however, noted that in at least one rural area of his/her state, there was movement towards implementing greater self-determination.

PROGRAM DESIGN CONSIDERATIONS

In discussions with interviewees, numerous themes emerged related to features of self-directed programs.

Individuals with direct experience as administrators of self-directed programs spoke of the importance of intensive **broker training and support**. In particular, person-centered planning was emphasized in these trainings as a critical component of self-direction. In one program, brokers were given training in the services and supports available in participants' communities.

Interviewees also spoke about the importance of **education for providers** throughout the behavioral health system. One interviewee in a state that has implemented ongoing training for staff and service users in self-direction noted, "*For us it is how to speed up systems change, the paradigm shift so people believe they can manage their budget and that staff also believe that. To me it's the paradigm shift.*" Another interviewee in a system that has not implemented self-direction noted a lack of education for providers on informed choice and person-centered planning.

Interviewees, including those with direct experience with self-direction programs that employ peers as support brokers, spoke of the **role of peers** in self-direction arrangements. They spoke of their unique position to build relationships with and inspire hope in self-direction participants. One interviewee observed a natural synergy between self-direction and peer-provided services; s/he noted that when holding focus groups with mental health service users about self-direction, "*As people were learning about the project, they were very excited, and one of the things some folks said was 'Hey, I could be a* [support broker]*. If this were my area you could hire me to do this.'"*

Several interviewees noted synergies between self-direction and **employment supports**, suggesting that self-direction program design should incorporate linkages to supports for employment. These linkages could occur through trainings, and ensuring the availability of such services when possible. Given that many state Medicaid programs do not reimburse for employment support services, the introduction of self-direction could increase access to such supports. As one interviewee noted, "*…that's what people figure out they need if they want to move on with their lives. They want to get some education, get some training, a get a better job that gets them out of poverty – get out of benefits.*"

Several interviewees raised issues related to participant **misuse of funds**. One interviewee spoke of concern that self-directed programs require a large amount of administrative oversight in order to ensure that funds are not misused. However, another interviewee offered a differing perspective: the program can put in place basic safeguards, such as the use of a debit card rather than actual cash disbursements, to track the use of funds. This interviewee noted that an overemphasis on misuse could come at the expense of program mission: "*In planning for the worst case scenario, you worry about the wrong detail…You're worried about the one in a hundred thousand people who might be doing the wrong thing.*" Another interviewee observed that individuals in the publicly funded behavioral health system are very likely to be living in poverty. As such, it is a challenge for administrators, brokers, and participants themselves to understand what purchases are related to recovery from behavioral health conditions and which might be more related to providing relief from poverty. This interviewee suggested that recovery goals (developed in the person-centered planning process) are critical tools for determining what constitutes an acceptable purchase.

Given that many mental health service users may be unused to exercising choice in their services or setting recovery goals for the future (see **participant circumstances**), **participant education** and **participant recruitment** are important features of a self-directed program. A first step in recruitment is ensuring that potential participants are aware that a self-directed program exists. This in itself is a challenge that requires some resources. Interviewees from Michigan, where self-determination arrangements are available to mental health service users, noted a considerable challenge working with **case managers** to recruit potential participants (which is how the recruitment process works in Michigan with all disability groups). These challenges were attributed to high case manager caseloads/demands on case manager time and the fact that self-determination is required to be discussed once per year (when it should be an ongoing conversation throughout the year). Some Michigan interviewees noted a new initiative to measure the number of contracted self-determination arrangements for mental health service users. Another interviewee noted that "*the complexity of* [self-direction] *is under-rated*" and

that it takes a great deal of time and initiative to learn about and initiate self-directed arrangements. Up front investments in training and skill building for participants are needed to foster self-direction. Individuals will need assistance building skills to self-advocate, to navigate the system, and to participate fully in the person-centered planning process.

Because many potential participants live in poverty, it is critical to help them understand that a self-directed program is not, in and of itself, a "*relief from poverty*" (although fostering recovery may have a long-term outcome of reducing poverty). Therefore, participants must be educated about purchasing guidelines and the relationship of purchases to recovery. Beyond skill building, education must also serve to foster hope that recovery and self-direction is possible. Several interviewees noted that while some individuals take very easily to the idea of self-direction, others have doubts that self-directing is possible ("*And then there's the other reaction, which is like "This can't be real. Are you people for real? Is this okay?"*). One interviewee noted that intake interviews for a self-directed program often took two hours or more because potential participants were unused to the process of setting goals for themselves.

One interviewee noted success with the creation of a learning community of service users who could come together to share experiences and knowledge about self-directing. **Peer sharing within SD** was endorsed as a useful tool/element of program design. Interviewees familiar with self-directed programs said that peers were able to successfully educate one another about various elements of self-direction, such as available resources, goal setting, and the person-centered planning process.

POLICY CONTEXTS

A number of local, state, and federal policy issues were identified as important contexts for the discussion of self-direction in behavioral health. While some interviewees saw the changes as opportunities for enhancing self-direction and spoke of initiatives that promote self-direction in the context of health reform, others expressed uncertainty and a sense of waiting until health reform is implemented ("*Everything is on hold that's not related to integration and health care reform*."). One interviewee aptly noted, "*Some people might say we are in a state of chaos, others a state of opportunity.*"

Various changes grouped by topic area are discussed in more detail below.

Health Reform. Interviewees varied in their perspective on the implementation of the Affordable Care Act (ACA) and self-direction. The diversity of perspectives may also reflect the diversity of state programs, both behavioral health and Medicaid, as well as the diversity in relationships between Medicaid and state agencies (see **role of Medicaid**). Interviewees from states that have already begun moving on ACA-related activities noted that the ACA has opened up an enhanced role for research and innovation, and has spurred change system-wide. One interviewee pointed out that there are initiatives unrelated to insurance that receive less national attention that are important to self-direction. The expansion of the Money Follows the Person program is one example. Others noted that the implementation of the ACA is leading states to rethink and redesign their managed care arrangements (see **role of managed care**). Interviewees from two states that were challenging the ACA, and considering opting out of the

Medicaid expansion, expressed more apprehensiveness about the role of self-direction. Taking a national perspective, another interviewee hypothesized that states that are most likely to opt out of Medicaid and resist implementing the ACA are also those states that currently offer the least self-direction for service users.

Behavioral and Physical Health Integration. Several interviewees noted that there is a synergy between the integration of physical and behavioral health and the values orientation of self-direction. They noted that there are opportunities to move self-direction forward in an integrated care context. Integration is in keeping with the recovery paradigm's holistic understanding of wellness and **focus on whole health**. Interviewees from three states spoke of initiatives to integrate physical and behavioral health systems, and how those efforts relate to self-direction. On the other hand, some interviewees expressed the feeling that administrators may be overwhelmed with the current system changes, and may have a difficult time prioritizing self-direction among so many other important initiatives. One interviewee expressed that it is important to be **proactive not reactive** in seizing opportunities to incorporate self-direction into existing efforts to integrate care, given the synergies between the two.

Mental Health and Substance Use Integration. Interviewees from two states spoke about plans to merge the state mental health and substance use departments within the year. Similar to responses to other integration and health reform efforts, these interviewees expressed uncertainty about how the changes will play out. "*The fact that we're combining departments and combining cultures is going to make the near future different, and I'm not sure how.*" Interviewees from both states identified the merging of mental health and substance use systems as being part of a larger shift towards the implementation of health reform in their states.

County-State Relationships and Impact on Self-Direction. In states where counties had key roles in the provision of behavioral health services, there were strong opinions about how the state-county organization will impact self-direction and mental health in general. Multiple interviewees noted that there are large discrepancies in service funding and availability between counties or localities. Two states are in the midst of a large-scale reorganization of state and county roles in mental health, elevating the Medicaid program to the state rather than the county level. Both interviewees expressed uncertainty about how this shift will play out in the long term. One interviewee also noted that because of this change, conversations about adopting the 1915(i) have taken a backseat. Another state reported major problems with implementing the 1915(i) in the context of a county-administered system.

Role of Medicaid. Interviewees spoke in depth about the role of Medicaid in self-direction. Interviewees varied in their views because, as one interviewee remarked, Medicaid programs differ a great deal from state to state. Some state mental health and substance use departments work closely with Medicaid (and even share umbrella agencies), whereas others are quite disconnected. Several interviewees also noted that Medicaid is likely to have a more prominent role in financing behavioral health services and supports in the future as health reform is implemented. Those interviewees who endorsed a positive/constructive working relationship with Medicaid agencies noted that there were individuals in leadership positions who acted as bridgers between those agencies (for example, a leader in the mental health agency once worked at Medicaid; see **leaders and champions**).

Views on the **(in)flexibility of Medicaid** differed between interviewees. Some noted that Medicaid's lack of flexibility poses a barrier to creating self-directed programs, and forces states to fit services and supports into an insurance model -- a difficult and labor-intensive task. Interviewees in states with Medicaid waivers (such as Michigan, which has a 1915(b)/(c) combination waiver) noted that their arrangements with Medicaid support flexibility in enhancing self-determination. However, even interviewees in Michigan expressed that the rules can get "fuzzy" at times. Interviewees noted that managed care and health home arrangements are a promising way to increase flexibility within Medicaid. One interviewee expressed faith that Medicaid arrangements are changing to support programs like self-direction (*"a new paradigm in what we fund and how we fund"),* although this change is slow-moving because of the size and scope of Medicaid. Interviewees noted that change of Medicaid policy to increase flexibility is more likely to occur if cost savings are established.

Role of Managed Care. Five interviewees observed that there is a national trend towards moving to managed care in behavioral health. Interviewees identified positives and negatives of managed care as it relates to self-direction. Managed care organizations may be in a position to bear risks associated with self-direction that budget-strapped states are not able to bear, which could facilitate adoption. One interviewee noted that there is "less politics" in a managed care context, which perhaps could lead to fewer barriers to adoption, such as those related to a philosophical opposition to self-direction. Because managed care organizations are interested primarily in the bottom line, they may be more likely to endorse self-direction if there is evidence that it saves money. At the same time, a strong focus on cost only is problematic, given that lower costs are not the sole goal of a mental health and substance use system. One interviewee stated that it will be important to ensure that **grassroots and peer advocacy** communities are strongly engaged in managed care organizations, or transitions to managed care.

Two interviewees voiced concern that managed care leadership may not be familiar with person-centered practices or share a social services vision held by mental health and substance use programs at the state level, which could ultimately be a threat to self-direction. Another interviewee noted that managed care organizations differ in this respect; behavioral health carve-out organizations may be very familiar with person-centered practices (some, such as Magellan and ValueOptions, employ peers and support innovative person-centered programs already). Therefore, in moving towards managed care, behavioral health carve-outs may be more well-equipped than general managed care organizations to support and implement self-direction.

Another interviewee, who had experience implementing self-direction on a small scale in a managed care context, noted that there is still a lot of work to do regarding administering self-directed programs at a managed care level. For example, the accreditation process for managed care organizations, focuses on handling insurance products, not purchasing goods and services. However, this interviewee noted that it is "worth exploring with them" since systems are moving towards managed care, and managed care organizations do have infrastructure to manage costs and improve quality.

FINANCING SELF-DIRECTION

The states and counties represented by interviewees employed diverse strategies to finance their behavioral health services. All interviewees noted that Medicaid was a critical funder, be it through state plan services or specialty waivers and state plan options, and predicted a growing role for Medicaid in the future.

All interviewees were asked whether they had considered the **1915(i) state plan option** for funding behavioral health self-direction. Interviewees from five states reported some tentative discussions about moving to a 1915(i), although no states reported concrete plans. An interviewee from one state with a 1915(i) currently in place (covering psychiatric rehabilitation, supported employment, and peer provided services but not self-direction) indicated that they will be moving out of the 1915(i) because of the new statewideness requirement, citing the fact that counties are refusing to implement the new services despite the promise of federal matching funds. Similarly, interviewees from other states spoke about reservations related to the statewideness requirement and restrictions on capping enrollment. One interviewee said that discussions about the 1915(i) have "taken a back seat" to other systems change initiatives. One interviewee expected that states are cautious to implement the 1915(i) because of confusion about its impact; this person hypothesized that if one or two states did implement the 1915(i), this would open the gates for broader adoption and implementation.

NEXT STEPS

Three respondents commented on the **lack of empirical support** for self-direction. One interviewee stated that it would not be possible to advocate for self-direction in his/her agency without more empirical evidence of self-direction's effectiveness with a population that is representative of the persons served by that agency. Another interviewee noted that more empirical support would lend substance and meaning to SAMHSA's endorsement of self-direction/self-determination in recent statements on recovery and systems transformation.

A **large-scale demonstration and evaluation** was endorsed by ten interviewees. Several interviewees noted that it is difficult to make the case for adopting self-direction on a large scale when it has only been tested with small groups. One interviewee envisioned that self-direction would have the same richness of research and development as a model like Wraparound services for children. Three interviewees spoke about building from the efforts of current small demonstrations and programs, taking data and lessons learned from those programs to advocate for change on a larger scale. Some interviewees offered **suggestions for design** of evaluations in the future. One interviewee, who had participated in a small self-directed program in the past, noted some lessons learned from that effort: an evaluation should involve a clearly defined target population and eligibility criteria, thorough measurement at baseline, replicable program activities and design, and research partnerships at the beginning. Another interviewee remarked that while large numbers are important, it is also important to ensure that different areas of one state are represented, for example including both rural and urban counties in the sample. Similarly, another interviewee noted that it is important that large metropolitan areas are represented, to show that the program can affect broad populations. An interviewee also suggested over-sampling those with high service costs, or those particularly

disgruntled with existing services. Finally, an interviewee suggested that an evaluation might examine whether those who self-direct are making innovative and creative choices about services and supports, or whether they are continuing with arrangements similar to those of people who are not self-directing. Interviewees also endorsed a number of **evaluation outcomes**: cost, service utilization, quality, employment and housing retention, and participant satisfaction.

Nine interviewees noted that **technical assistance** materials would be useful to them. Several interviewees endorsed education for administrators and presentations about self-direction models and financing options. One interviewee noted that this training is particularly important given that some administrators may not understand that self-direction refers to a particular program of budget authority, not just an orientation towards person-centeredness or empowerment. Such presentations could serve as "blueprints", showing what other states have done so that states are better equipped to develop their own self-direction programs. Interviewees also endorsed "nuts and bolts" toolkits on program design and best practices for establishing and implementing self-direction programs. Such toolkits should include information on the involvement of stakeholders, program design, research and evaluation considerations, strategies for creating a paradigm shift and infrastructure change in organizations, cultural competence, quality and fidelity monitoring, training for and about peers. Several interviewees also noted that **guidance from CMS** would be useful. One interviewee suggested that materials could be targeted to financial managers, compliance departments, policy makers, case managers, supervisors, and recipients. One interviewee recommended reaching out to states or regions individually to offer technical assistance. Finally, interviewees endorsed including personal stories alongside technical assistance.

D. STAKEHOLDER INTERVIEWS AND FOCUS GROUPS

This section presents findings from a series of interviews with behavioral health (i.e. mental health and substance use) stakeholders – including peers, providers, program administrators, and advocates – to ascertain their views on the role of self-direction in behavioral health services and supports.

In the winter of 2012-2013, the project team conducted five focus groups and seventeen in-depth interviews with a range of stakeholders in behavioral health. The in-depth interviews and focus groups were structured using a series of guides designed based on the comprehensive review of the literature on self-direction in behavioral health. The focus groups involved:

- Life coaches/support brokers in one self-direction program
- Peer specialists working in self-direction programs
- Transition-age youth with serious mental illness (SMI) diagnoses
- Adults with SMI diagnoses
- Adults with co-occurring alcohol and other drug use and SMI diagnoses

The interviewees included:

- Five self-directing program participants and one former participant

- Six providers, including two psychiatrists, a clinician specializing in issues related to older adults with SMI, and three clinicians who work with individuals with self-direction arrangements
- Six individuals who work in self-direction programs in Maryland and Michigan, one of whom works with transition-age youth. Four of these individuals identified as peers, and one previously held a self-direction arrangement before holding employment[1]

PARTICIPANT EXPERIENCES

High level of satisfaction. When asked if they would recommend the program to a family or friend, participants unanimously said that they would. In particular, participants seemed satisfied with program functions (greater choice and flexibility, the ability to purchase non-traditional services and supports, and increased access to out-of-network providers) as well as interactions with self-direction program staff. *"Being in the system you feel like you can just drop off and you don't matter as a person, you're just a number. With [self-direction] you feel like an individual, you have value, and that gives you hope... [Self-direction] is great; I have nothing but good feelings about it. It's so important to me, that if the government is going to cut spending, I don't want them to cut this, because it's needed. It's a lifesaver – literally."* ***~Self-directing participant***

Broader range of choices. Although technically individuals receiving services in traditional arrangements are able to choose between providers, self-directing participants reported experiencing greater levels of choice than they had in the traditional system. There appeared to be various reasons for this expanded choice. Many participants used self-direction funds to cover additional costs associated with seeing mental health providers not covered by their insurance (often Medicaid or Medicare). In this sense, individuals experienced greater choice and increased access through an expanded array of options for treatment.

Purchases. Types of purchases varied by program, with participants using self-direction funds primarily for goods in one program, a mix of goods and services in another, and primarily using only the employer authority (hiring support staff) in a third. The primary categories of purchases were dental and eye care, physical health support, transportation, social activities, education and employment, housing-related expenses, and traditional mental health services.

Support staff. Support staff were hired in various ways, including through mental health organizations, public advertisements, worker registries, and personal connections like friends or acquaintances.

[1] This memo is organized into sections based on areas of inquiry in the interview and focus group guides. Bolded text and section sub-headings represent themes and categories that emerged in each of the areas of inquiry. Direct quotes from stakeholders and focus group participants are presented in italics. For greater ease of reading, quotes have been edited to exclude the stutters and stops of normal speech (i.e. "um", repeated words at the beginning of sentences). To protect confidentiality, gendered pronouns
are presented as gender-neutral (i.e. "him" changed to "her/him", "she" changed to "s/he"), and all names have been omitted. In quoted text, "self-direction program staff" refers to any position in a self-direction program, including support brokers, peer mentors, managers, or administrators.

BENEFITS OF SELF-DIRECTION

In discussions about the relationship between self-direction and **recovery**, participants stressed that mental health recovery is a critical outcome that is self-defined, non-linear, ongoing, and difficult to measure. One participant drew a distinction between being "stable" and free of mental health symptoms and working actively towards **recovery**, arguing that self-direction can promote working towards the latter because it covers many different domains of wellness, not symptoms alone.

Enhanced Recovery. Self-directing participants and providers shared numerous stories of how self-direction enhanced **recovery**, through the attainment of employment, engagement in education and training, sobriety, and increased community engagement as well as being better able to manage mental health symptoms. One interviewee who had experience working with transition-age youth noted that the program's emphasis on empowerment would be particularly salient for youth just entering into the adult system and experiencing a new level of independence. Interviewees asserted that when participants are able to select the services they receive, they are more invested in the outcome of those services. *"The people [self-directing] are more pro-active. When you give them that power, they use it, trying to arrange their lives and their services specifically how they want them. You can see improvement in general, as people see their own empowerment and care about their lives in a different way." ~Peer provider*

Similarly, several interviewees endorsed enhanced **motivation** as a benefit of self-direction. This motivation may stem from having increased decision-making power, and through setting ones own goals for recovery (rather than having those goals dictated by others). Increased engagement and motivation and support for decision-making appear to be associated with greater **independence** for individuals who self-direct. Stakeholders observed increased independence in the form of participants taking a more active role in their service and support arrangements. *"…They want you to become more independent, and learn to make decisions on your own and to become healthier and not totally dependent on somebody telling you what to do and all of that...." ~Self-directing participant*

Additionally, stakeholders observed more long-term independence among self-directing individuals in the form of increased employment, independent housing arrangements, expanded social networks, a decreased reliance on traditional behavioral health services and supports, and for some, independence from the publicly funded behavioral health system entirely. Stakeholders noted that self-directing participants learn to better take advantage of natural supports rather than relying on behavioral health services.

Many stakeholders recounted stories of self-directing individuals achieving greater levels of engagement in the community and **decreased isolation**. In particular, several participants who had purchased computers as part of self-direction activities endorsed the purchase as helping connect them to the outside world, particularly when they found it challenging to physically leave the house. Other stakeholders related stories of participants who hired support staff to accompany them outside of the house and help them to gain comfort engaging in community activities.

Many stakeholders also endorsed gains in **self-esteem** as a key benefit of self-direction. On a fundamental level, several participants noted that having funds to afford dental care and appropriate clothing directly enhanced self-esteem. *"…if your teeth are falling out or they're all*

black, your self-esteem is going to be lowered. And it's all about being mentally healthy… part of your mental health is your self-esteem and the way you look, and taking care of yourself and being able to eat so you can eat properly." ~Self-directing participant

Several focus group participants also voiced frustration with the separation of physical and behavioral health service systems. *"…I have a physical, developmental, neurological, whatever you want to call it, disability, and mental health stuff. So when I get symptomatic from my anxiety and stuff, it'll make my other disabilities exacerbated, or that disability will impact my mental health disability, and I can't find a psychiatrist that actually can get my medications – like, they don't understand the interaction between both of them." ~Focus group participant*

Several interviewees expected that self-direction could enhance efforts to integrate physical and behavioral health services and supports through shared communication, coordination, and a whole health orientation. Specifically, peer and life coach focus group participants stated that they work with participants on physical health and coordination issues on a regular basis.

Having support from the self-direction program helped one participant to manage her/his serious health problems, including cancer and kidney disease. Another participant lost 70 pounds due to nutritional counseling and increasing exercise and attributed this success to participation in the self-direction program.

Some participants noted that self-direction helped them to meet some **basic needs** such as securing housing and purchasing groceries or household appliances. One participant felt that meeting these more basic goals related to poverty and other life stressors were prerequisites to working on other recovery-related goals. *"I needed to start out with very basic you know things you know before I could get to where I could grow at all. I needed to take care of my basic needs in life you know, just to function… I'm under a lot of stress in life you know because of my finances, but I know that being in the program alleviated some of that stress, I know it did and it has." ~Self-directing participant*

Several participants noted that they have experienced improvements in **community tenure**, not needing to use psychiatric emergency services or go to the hospital since enrolling in the self-direction program. Participants attributed this to more stability and continuity of mental health treatment, better housing situations, and support from self-direction program staff. One provider stated s/he had seen many participants avert hospitalization because of greater access to community-based services. Another provider stated that in her/his experience, self-directing participants did experience psychiatric crises and use inpatient services, but that the services were needed less frequently and for a shorter duration. One participant noted that self-direction programs increase access to mental health services, which keeps people out of hospitals and therefore leads to **cost savings**. Another participant speculated that self-direction has led to cost savings because s/he no longer uses psychiatric emergency services as frequently and lives independently rather than in a supported housing program. *"…in my situation, keeping me out of the crisis stabilization unit is saving a lot of money to tax payers… You know, supportive housing, they were paying my rent; they were paying someone to supervise me…they were paying a nurse to look in on me. It costs a lot of money." ~Self-directing participant*

Several participants and staff noted that the self-direction model requires more **accountability** on the part of the participant than traditional mental health services, and endorsed increases in personal accountability or responsibility as promoting positive growth and change. Interviewees

noted that increased accountability could lead to **costs savings** to the system, particularly if self-direction is an option for all individuals receiving behavioral health services and supports. *"It's my own money, I'm more careful with it. And I think of it as eventually being my own money if I get out of the system. I'm building skills and having to do research to see how much things cost, before you do the budget… I try to do as much as I can myself." ~Self-directing participant*

Several participants and providers noted that when self-directing participants experience recovery gains, they are motivated help others who have experienced similar challenges, **giving back** to the behavioral health community in the form of educating others about self-direction and recovery, volunteering, or working as peer specialists.

BARRIERS AND CHALLENGES OF SELF-DIRECTION

Interviewees identified a number of barriers and challenges related to providers and provider networks in the context of self-direction

Provider Concerns. Consistent with other findings in this environmental scan, numerous program stakeholders indicated that they had heard some concerns because self-direction may pose a **financial threat to providers**. If self-directing participants are unhappy with the services being delivered, they have a choice to take their business elsewhere. *"There was a sense [among providers] of being threatened by the program, that there was going to be a loss of funds, that we were going to steal business, that sort of a thing." ~Self-direction program staff*

For some service types, the financial threat goes beyond market dynamics associated with competition. Some providers noted a need to maintain a census for certain programs, such those where there is **housing tied to services**. If self-direction introduces more flux into the market, this could lead to challenges associated with assuring adequate staffing and resources for such programs. Several stakeholders noted an inherent disconnect between self-direction and residential programs, including one self-direction program administrator who noted that individuals in supported housing programs are not eligible for self-direction arrangements because of contracting issues in her/his state. The interviewee noted that individuals interested in the self-direction program are first supported to transition out of the residential program before initiating self-direction.

Other stakeholders noted that concerns may come from a perception that self-direction represents an increased administrative burden for the provider. This observation was particularly common among stakeholders in one program, where case managers are responsible for participant recruitment and the administrative aspect of self-direction activities.

Stakeholders also speculated that introducing competition into the behavioral health market could lead to more **entrepreneurship and buy-in** from providers interested in improving their services. The benefits of this increased competition – for participants and the behavioral health system as a whole – outweigh the drawbacks for some providers. *"…competition in any business arrangement is what makes businesses better. [Self-direction] is competition, and it's going to make providers provide a better service if they want to stay viable. The good ones will always be good, there will always be room at the table for those folks; the bad ones, they need to go away." ~Self-direction program staff*

Stakeholders asserted that many providers **doubt self-direction is possible** for persons diagnosed with serious mental illness, which leads to a lack of buy-in from many. *"A fear about people not getting the support that they need. Not intensive enough. Kind of like getting involved in a program and then being out on a limb." ~Self-direction program staff*

Some stakeholders asserted they doubt that participants are capable of self-direction is rooted in the **medical model** of mental illness. Specifically, the medical model posits that mental illness is a problem of decision-making, and that providers are responsible for making decisions, not service users. *"I always come back to the fundamental problem of the mental health system and that it's got a very institutional way of thinking, very hierarchical and very individual, very medical. So that means the decision making is with a doctor, usually." ~Provider*

Although many interviewees endorsed the above barriers as significant, many were quick to point out that for many providers, the benefits associated with self-direction outweigh the financial risks and counteract skepticism that self-directing participants can be successful. In general, program stakeholders observed that providers do buy in to the program once they see that self-direction actually benefits the participant. Stakeholders almost unanimously endorsed **provider education** and relationship-building as critical in addressing the challenges and barriers associated with provider resistance.

Public Perceptions. A small number of stakeholders identified **public perceptions** and **stigma** related to mental illness as a barrier to self-direction. Stakeholders noted that newspaper headlines could report purchasing patterns out of context. For example, noting that individuals are buying computers with self-direction funds without mention that the computers are purchased to be used for specific recovery-related goals. These stakeholders noted that public education is critical in addressing issues related to stigma. In particular, stakeholders discussed the importance of individual stories in countering negative public perceptions about self-direction in particular and mental illness in general.

System-Related and Participant-Related Challenges. Stakeholders discussed various challenges related to **a lack of coordination** between different service and support systems in behavioral health. These included separations between physical and behavioral health systems, inpatient or detox and community-based services, and challenges for people dually eligible for Medicaid and Medicare. Stakeholders noted particular challenges transitioning between systems of care for youth transitioning to adulthood as well as individuals transitioning from the general mental health system to a services and supports that are focused on the needs of older adults. A handful of focus group participants stated skepticism that it would be possible to implement self-direction in such a fragmented service environment. Other stakeholders spoke of the potential for self-direction to bridge gaps in services and supports due to its person-centered focus and the flexibility associated with the budget authority.

Stakeholders expressed concern that many individuals with mental illness have limited social support, which could be a barrier to self-direction because supportive others can often aid a participant in navigating self-direction and engaging in the person-centered planning process. One participant spoke of challenges related to not having a support network: *"Again, [support broker] is very good at what [s/he] does, but if you don't have a support group, if you don't have family to back you…The program is the individual. If you don't have the motivation to make your*

appointments and deadlines, you're pretty much on your own. You can easily fall through the cracks…" ~Self-directing participant

Several stakeholders noted that physical health problems make it difficult for some individuals to participate in self-direction programs, which typically require a high degree of engagement on the part of the participant. These challenges can be particularly acute for older adults who may experience higher rates and greater severity of health problems.

One program administrator noted the importance of accounting for challenging life circumstances of participants when examining outcomes associated with self-direction. This individual developed a "life stressor scale", completed quarterly, to document and account for participant-related challenges when examining the effectiveness of a self-direction program.

PROGRAM DESIGN

Stakeholders came from a variety of self-direction programs that differed from one another in regards to program design. Some common program design elements are discussed in this section. These include person-centered planning, crisis planning, and budgeting.

Person Centered Planning. Stakeholders universally referred to person-centered planning as a cornerstone of self-direction programs, and that it is hard to conceptualize one without the other because person-centered planning organizes the self-direction process and helps participants to be successful in the long term.

Some self-direction program staff spoke of the importance of adhering to principles of person-centered planning. Stakeholders observed that in many circumstances, the term "person-centered plan" might be applied to something that is not actually person-centered. According to stakeholders, important principles of person-centered planning were: active and engaged participant involvement; taking natural support networks into account and including friends, family members, and supportive others in the process; incorporating strengths, dreams, and preferences; ensuring that the process is informed by special circumstances the person may be facing, such as external life stressors; and identifying large over-arching goals as well as smaller steps to reach those goals to ensure that they are sustained over time.

Several stakeholders noted the value of having peers facilitate the person-centered planning process. Stakeholders felt that peers were in an ideal position to put the values and principles of person-centered planning to work. One interviewee noted that a peer-facilitated approach is particularly important for younger adults who may have less experience with the person-centered planning process.

Several staff and participant interviewees said that the amount of paperwork required for the person-centered planning and budgeting processes was somewhat overwhelming. However, participants were also quick to assert that they felt supported throughout the process, and that the process was ultimately meaningful for them.

Crisis Planning. All of the participants interviewed for this study reported that they had used **crisis services**, including inpatient care, at some point in their adult lives. Providers working with

participants similarly noted that behavioral health crises are common among the population of individuals eligible for self-direction behavioral health programs. Focus group participants not familiar with self-direction expressed concern about how self-direction might work in the context of a crisis, stressing that because of the fluctuating nature of mental health symptoms, self-direction programs will need to operate with a high level of flexibility.

Focus group participants also expressed concern that if they used detox or inpatient services, those services might use up their entire budget. It was explained to these individuals that in most self-direction programs, inpatient and emergency services are kept separate from the budget for that reason. Focus group participants also said that they would hope that they would be able to exercise choice and self-determination while using inpatient or emergency services.

When self-directing participants experience extended periods in the hospital, most reported that they were able to remain in the self-direction program. Two participants who had spent time in the hospital reported that they did not maintain contact with self-direction program staff while inpatient. One other reported that self-direction program staff visited her/him while s/he was in the hospital. All participants who used crisis services while in the self-direction program reported that they received support from self-direction program staff after returning from the hospital.

In general, participants in self-direction programs reported that they were supported in pro-active **crisis planning** as part of the self-direction program. Two participants reported that they had been offered an opportunity to participate in crisis planning but declined to do so. Four others reported that they had plans in place.

One provider who does not work extensively with self-direction expected that pro-active crisis planning and self-direction are a natural fit. *". To have anticipated it with your self direction – 'if I get in a jam again, I want to hold out a certain amount of money for this purpose, and if I'm in the hospital I would like to have a massage rather than' – just that idea alone would be quite powerful." ~Provider*

Staff from one self-direction program reported using Wellness Recovery Action Planning (WRAP) as a guiding framework for developing crisis plans. A stakeholder with expertise in crisis planning recommended that future programs explore the use of the Open Dialogue approach, and more generally involving all members of participants' network – including providers, family, friends, and supportive others – in the crisis planning process. Such approaches might also inform the **role of representatives** in a self-direction behavioral health context.

Budgeting. Staff from all self-direction programs noted that budgets were integrally tied to person-centered plans. However, programs varied significantly in terms of methods of **determining the budget amount**. One program involved a fixed supplemental budget that was completely separate from other insurance benefits, and program staff did not inform participants of the maximum budget amount. In another program, participants received a fixed budget that was disbursed quarterly, with budget amounts varying based on the person's eligibility for public insurance. A third program operated on a "zero-start budget" based entirely on needs assessment.

There was variation in terms of **determining allowable purchases**, although participants tended to describe prioritizing (or being encouraged to prioritize) traditional mental health services over other goods and services. In one program that uses a small supplemental budget, staff said that purchasing guidelines differ from participant to participant based on past experiences. Staff from this program also stressed the importance of the relationship between the support broker and the participant in determining what purchases are allowable, and establishing a relationship to promote continuing engagement in the program.

In focus groups, self-direction program staff from another program expressed that it was challenging to first set goals and then allocate funds to reach those goals. Although self-direction is designed to function in this manner, staff noted that the tendency is to begin with the purchase and then back into the goal based on the purchase. In this way, staff felt that participants viewed the budget as money to be spent ("use it or lose it") as opposed to funds that should be designated to work towards specific recovery goals. Interviewees were quick to note that it is understandable that participants may feel this way, given the fact that they have incredibly limited incomes.

In another program that primarily uses the employer authority, not a full budget authority, stakeholders expressed challenges associated with understanding what purchases are allowable given Medicaid guidelines and state and county policies. At times, this complexity could translate into a lack of flexibility for participants because support brokers (in this program, case managers), were dissuaded from looking into whether purchases or amendments were allowable and filing the necessary paperwork because of the time and energy involved.

EDUCATION AND OUTREACH

Interviewees universally emphasized the importance of education and outreach for the successful implementation of self-direction. Interviewees discussed education and/or outreach in the context of providers, participants, and support brokers.

Provider Education. Stakeholders asserted that if providers understand the numerous benefits associated with self-direction, they will be more likely to support and promote it. In addition, stakeholders said that correcting misperceptions about the the level of support associated with self-direction could counter provider apprehension that individuals will somehow lose access to services if they participate in self-direction. When asked what would be important information to include for providers, one interviewee offered the following: *"…the coaches, how they work with [participants] on setting up a treatment plan. It is [not] that [participants] are coming in to see you, and you have the total responsibility of setting this up, but it's part of a group. And that they have other aspects that they're spending their money on, not just coming in for counseling…I think knowing that they meet someone on a monthly basis, that they have goals and they are learning to be accountable and it helps them increase their self confidence and self esteem and be more motivated – I think those are all big factors." ~Provider*

Participant Education and Outreach. For the most part, focus group participants who were previously unfamiliar with self-direction stated they could see themselves signing up for a self-direction program as long as their questions or concerns were addressed. They viewed such an

option as giving them a say in their treatment that they currently do not have, and an opportunity to obtain goods and services not routinely available to them.

Several stakeholders used word of mouth (participants sharing their experiences with potential participants) as method of **participant recruitment**. Stakeholders noted that many participants who've benefitted from the program naturally want to spread the word to others and ensure that the program remains sustainable. Other recruitment activities included mailings to all eligible participants, having representatives from the program speak at drop-in centers and other mental health organizations, and working with providers to refer potential participants to the program. Several participants in one program stated that they learned of the program through their local NAMI organization.

Stakeholders observed that it can be challenging to get the word out about self-direction because it is a complicated program that is very different than traditional arrangements. Given this complexity as well as the critical importance of full participant engagement, **participant education** was a commonly discussed topic in interviews.

Two interviewees, one provider and one participant, highlighted the importance of self-advocacy skill development in the context of self-direction. These interviewees felt that self-advocacy skills are needed to exercise full choice in a self-direction arrangement, and that many individuals with mental health issues have had limited opportunities to develop such skills in the traditional system.

Interviewees also emphasized the importance of the support broker in providing the education needed for participants to be successful in a self-direction program. This included assistance with **person-centered planning** and **budgeting** and more generally, support with navigating service systems. All participant interviewees noted that support brokers provided them with such training and support.

Broker Training and Support. Almost without exception, participant interviewees described their support brokers as diligent, respectful, flexible, and generous with their time and support . Interviewees and focus participants identified that support brokers have a challenging role to play in self-direction programs, balancing intensive administrative and paperwork demands with developing positive relationships with participants to support the person-centered planning process. Brokers need to have intensive knowledge of existing community resources and program purchasing rules, which can be challenging if the process for **determining allowable purchases** is unclear. Interviewees in support broker roles emphasized the importance of having support from program management to fulfill their roles and to advocate for the interests of participants.

OTHER PROGRAM DESIGN ELEMENTS

Time Limits. One program set a seven-year time limit for participation due to pressure from the state and contractual obligations to work with only a limited number of participants each year. Because the program opened just over seven years ago, this time limit has only recently been implemented. One interviewee had just left the program, and two others were preparing themselves for transitioning out of the program. All three participants expressed that they felt

good about their recovery gains from participating in the program and expressed hope that they would be able to maintain those gains in the future. Two of the three also expressed that they were nervous about the transition.

Participant Advisory Council. One program convened a Participant Advisory Council to oversee and advise the program and represent the interests of program participants. The group provides input into staffing and hiring decisions and reviews aggregate data on participant progress. The group has its own by-laws, which have been amended over the years. One participant interviewee who also serves on the advisory council stated that s/he enjoys taking a leadership role in the program and that the experience is valuable preparation for re-entering the workforce. *"The Advisory Council is the voice of the people." ~Self-directing program participant*

Misuse of Funds. In general, stakeholders said that misuse of funds was somewhat rare, and all programs had developed formal and informal strategies to address the misuse of funds. One stakeholder noted that in her/his experience, support workers, particularly friends, had taken advantage of participants. This stakeholder was also quick to point out that the program had developed strategies to address these issues. *"It does happen, but we got better about how that happens. We got so that we helped individuals to develop better time logs, better checks and balances, better education for their staff, background checks..'" ~Self-direction program staff*

Stakeholders stressed the importance of the relationship between the support broker and participant as being a key element in reducing instances of fund misuse. In particular, one stakeholder asserted that the peer relationship can strengthen trust and understanding between staff and participants, which leads to increased engagement in the program and a decreased likelihood of "taking advantage" of the program.

ROLES OF KEY STAKEHOLDERS

Interviewees spoke about roles of key stakeholders in the context of self-direction, particularly the role of peers, program leadership, advocacy organizations, and representatives.

Peers. Stakeholders frequently endorsed peers as being in an ideal position to work with participants in many aspects of self-direction, including **participant recruitment and education**, **person-centered planning**, and **budgeting**. Stakeholders felt that because they have experienced mental health and/or substance use issues firsthand, they were in a unique position to work with participants to build decision-making skills, promote recovery and positive growth, and inspire hope that change is possible. In this way, peers help to challenge the **medical model** of mental illness.

One stakeholder referred to this unique position as the "authority of lived experience." Peer providers working in self-direction programs stated that their lived experience helps to build connections with participants. *"For me, for the people that I really connect with, it makes them feel that they can be normal. That – I actually – it's funny because I tell them that my degree is my mental illness. And that seems to really put them at ease." ~Self-direction program staff*

Programs represented in this environmental scan differed in regards to the formal roles for peers. While some self-direction programs are entirely peer-run, others employ a mix of peers

and non-peers, and others have no role for peers. While stakeholders were unanimous in their support for peer involvement in some way, one stakeholder offered a perspective that programs should involve a mix of peers and non-peers to support full participant choice.

Stakeholders from one program noted an extensive grant-funded education program for peer specialists that included modules on self-direction as well as person-centered planning. This initiative has helped to build a workforce of peers knowledgeable about self-direction in behavioral health throughout the state. One peer provider observed that as the number of individuals who have formerly held self-direction arrangements grows, this will serve as a catalyst to promote the growth of self-direction in behavioral health.

Program Leadership. The importance of leadership – within self-direction programs, at provider organizations, and at county and state levels – was a common theme in many stakeholder interviews. Within self-direction programs, stakeholders stressed that program management has a key role in **broker training and support**. A program manager spoke of the importance of engaging with state and local leadership by serving as a liaison and going to planning meetings, and engaging with the provider community by providing education about self-direction. One interviewee noted that making connections with leaders at provider organizations was one way to address **provider concerns** and enhance **entrepreneurship and buy-in**.

Advocacy Organizations. Stakeholders discussed the importance of advocacy organizations in applying pressure on communities to initiate self-direction programs to begin with, and also in promoting program stability. *"I think the other thing is to have an active advocacy organization. When we're really, really tired, in my area, we have an active ARC and they pushed us – you know we might be really tired and say to ourselves, 'Jeez, we can't do this with one more person.' and then the ARC would say, 'I'm sorry, but you do have to.'" ~Self-direction program staff*

One self-direction program is administered by an advocacy organization, the National Alliance on Mental Illness (NAMI). A stakeholder from this program noted that this arrangement is a perfect fit, given NAMI's emphasis on outreach and education, fighting discrimination, and challenging the notion that people with mental illness are not capable of making the best decisions about their treatment.

Representatives. Some stakeholders expressed concern that appointing trusted representatives can be challenging due to a **lack of supportive relationships** for many individuals. Stakeholders also expressed concern that friends or family members may take advantage of participants in some situations . However, stakeholders also offered examples of representatives having a helpful role in a self-direction context**.** *"…they had to take me off some meds, and I had to go to [hospital], [representative] came and got me. S/he told them s/he would take me in her/his car and that s/he knew where I wanted to go. S/he pulled out the Advance Directive and the doctor said, 'Fine.' That was power." ~Self-directing program participant.*

E. POTENTIAL PARAMETERS FOR A DEMONSTRATION AND EVALUATION

Based on the findings from the four environmental scan components, the research team developed potential parameters for a large-scale demonstration and evaluation of self-direction in behavioral health services. The following outline incorporates feedback from key stakeholders and the Environmental Scan Advisory Committee. It is organized into six sections, each based on a core question to consider as plans for a behavioral health self-direction demonstration and evaluation continue to take shape.

WHAT IS THE TARGET POPULATION?

The primary population of focus is **adults diagnosed with serious mental illness (SMI)**. Within this group, there may be particular sub-populations of interest:

1. Transition-age youth (possibly youth with severe emotional disturbance age 16+)
2. Older adults
3. Persons dually eligible for Medicaid and Medicare
4. Persons with co-occurring substance use conditions
5. Individuals using a high level of services
6. Individuals transitioning to the community from state hospitals

SAMHSA defines mental illness based on diagnostic criteria in the 4th edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV).* Any mental illness among adults aged 18 or older is the presence of any mental, behavioral, or emotional disorder in the past year that met DSM-IV criteria. Among adults with a disorder, those adults whose disorder caused substantial functional impairments (i.e., substantially interfered with or limited one or more major life activities) are defined as having serious mental illness (SMI) and the most urgent need for treatment (www.samhsa.gov/data/2k11/WEB_SR_078/SR110StateSMIAMI2012.htm).

Note: A key part of this definition is "substantial functional impairment." Thus, a person with a depression or anxiety diagnosis that substantially interferes with major life activities would be part of the target population of a demo.

Other potential populations of focus include veterans, rural populations, individuals with co-occurring intellectual and developmental disabilities, persons experiencing homelessness, justice-involved, lesbian/gay/bisexual/transgender (LGBT) individuals, Native Americans, and other racially/ethnically/culturally diverse populations.

Although it is expected that the majority of the target population be enrolled in or eligible for public health insurance, stakeholders expressed some interest in exploring self-direction for individuals receiving private health insurance. In particular, many transition-age youth with SMI may remain on their parents' private health insurance until age 26. For this group, self-directed arrangements may contribute to earlier recovery and divert some from enrolling in public benefits.

WHAT ARE THE OUTCOMES OF INTEREST, RESEARCH QUESTIONS AND HYPOTHESES?

Based on the environmental scan activities and conversations with stakeholders, the following outcomes emerged as most important to include in a demonstration and evaluation.

1. **Recovery and quality of life**: Stakeholders unanimously endorsed recovery and quality of life as critical. Recovery includes a number of dimensions that can be explored individually; these include employment and education, housing and community tenure (days spent in the community versus institutional settings, jails/prisons, homeless), interpersonal/social relationships, spirituality, sobriety, and physical wellness (discussed separately below). In addition, some dimensions of recovery such as hope and self-defined wellness are difficult to capture using quantitative means. Qualitative methods will aid in exploring the multiple dimensions of recovery to gain a more complete picture.
2. **Health and wellness**: Self-direction is hypothesized to positively impact health and wellness by affording access to services and supports that promote healthier behaviors such as smoking cessation, exercise, and proper nutrition. Further, self-directed funds may allow individuals to access dental and vision services. Through contributing to greater recovery, participation in self-directed programs may also enable individuals to better manage chronic health conditions and attend preventive care visits. In the long term, health and wellness outcomes could inform programs to support individuals in self-directing their medical care.
3. **Cost and service use**: Previous studies suggest that self-direction could lead to decreases in the use of costly inpatient and emergency services. Many stakeholders expressed interest in exploring transitions of care (i.e. from hospitals to the community, re-hospitalization rates), in regards to behavioral as well as physical health services. Individuals in self-directed arrangements may continue with community-based service arrangements for longer if those service arrangements support self-determination and recovery.
4. **Participant satisfaction and perception of services:** In past evaluations of self-directed programs in behavioral health and for other populations, participant satisfaction has been higher in self-directed arrangements.

Although hypotheses point towards improvements in the outcomes listed above, the demonstration will also incorporate investigation into whether self-direction is associated with **unanticipated and adverse outcomes**.

System-level outcomes may also be an important focus. These include quality of care and access to appropriate services and supports. It is possible that in self-directed arrangements, services may be more tailored to individual needs and preferences, which could enhance person-centeredness.

WHAT IS THE EVALUATION RESEARCH DESIGN?

Based on environmental scan findings and stakeholder input, there is strong consensus on a number of research design issues:

1. The **size and scope** should be large; self-direction should be implemented in multiple states, and numbers should be in the thousands.
2. The evaluation design must incorporate a **control or comparison group**, either through the use of experimental (randomized) or quasi-experimental design.
3. Evaluators should use a **mix of quantitative and qualitative methodologies** such as case studies and ethnography to capture the dynamic and multi-dimensional nature of the impact of self-direction on outcomes of interest.
4. **Implementation analysis** will aid in isolating programmatic and policy factors that influence the effectiveness of self-direction. Process evaluation methods will aid in charting fidelity to the intervention and will help guide future replications.
5. In keeping with the values and ethos of self-direction, all planning and research activities must include **meaningful peer involvement** at all stages. Such involvement has been an important part of the environmental scan work thus far, and should be increased as more concrete plans for a demonstration and evaluation take place.

A number of decision points remain:

1. How much flexibility should sites/states have in designing the intervention?
2. How is fidelity to the intervention measured? What safeguards can be put in place to ensure that services and supports are truly self-directed and that sites do not use self-direction as an opportunity to limit or cap benefits?
3. How often and how long should data be collected? It is important to collect data for a period that is long enough to understand the impact of the intervention over time.
4. How many sites and participants are needed?
5. Should the intervention be phased in gradually or implemented all at once?

In discussions about research design, a number of stakeholders commented on the need to engage potential sites/states and generate interest in participating in a demonstration and evaluation. Without such efforts, states may be reluctant to participate because there are many new initiatives underway with the implementation of health reform, and because state budgets are tight. Some stakeholders suggested a role for peers and advocacy organizations to promote participation. Others discussed the importance of emphasizing that self-direction relates to other health reform initiatives.

Finally, some stakeholders expressed that it may be important to include sites with more recovery-oriented systems, including strong peer networks, in place; some states/sites may not have enough recovery-oriented services in place to support a self-directed program.

Questions related to research design will depend on funder priorities, financing, program design, and policy and environmental contexts.

WHAT ARE THE PRIMARY FUNDING SOURCES FOR SERVICES?

The two primary funding sources involve **Medicaid** and **managed care**. In Medicaid, the most promising funding source appears to be the 1915(i) state plan option. States have yet to opt to use the 1915(i) to implement self-direction in behavioral health, and the statewideness requirement will have implications for research design. Some stakeholders voiced concern about conflicts of interest regarding brokerage, provider networks, and financial management services if self-direction were implemented in a managed care context.

Other potential sources of funding for services and supports include:

1. Other Medicaid funding, including the 1915(c), the 1915(k) Community First Choice Option, and 1115 waivers
2. SAMHSA
3. Veterans Health Administration
4. Administration on Community Living
5. State and local general revenue
6. Private sources such as the United Way, local foundations, and small business associations

WHAT ARE THE ESSENTIAL ELEMENTS OF PROGRAM DESIGN?

Existing self-directed behavioral health programs are incredibly heterogeneous, with great variation in program design. Therefore, it will be key to define the intervention that is being tested in a demonstration and evaluation. Some program elements should be consistent from site to site, although states/sites should also be afforded some level of flexibility in designing or adapting the intervention.

First and foremost, there is strong preference for **full self-direction model**, which includes both a budget authority and employer authority and allows for the purchases of goods as well as services.

In discussions with stakeholders and examining the literature, consensus emerged on some program design elements:

1. The **extensiveness of budgets** varies from program to program, with some budgets including the entire behavioral health benefit and others involving a supplemental budget on top of the existing behavioral health benefit. A majority of stakeholders asserted that for a demonstration and evaluation, a **fully integrated behavioral health budget** is the preferred model. A recent National Health Service finding supports this assertion; greater improvements in cost and quality of life outcomes were associated with larger, more flexible budgets. In this fully integrated model, only inpatient and emergency services and the prescription drug benefit are excluded from the budget.
2. **Resource allocation methods** to determine the size of individual budgets vary. These include flat budget amounts that are the same for all participants; budgets based on individual assessment of needs and preferences, which involves comprehensive planning and clear parameters; and budgets based on previous spending or service use. Consensus emerged that budgets should be based on a **combination of individual assessments and past spending**. Future demonstration planning activities should include identifying assessment tools and developing methods for resource allocation.
3. The resource allocation process should be ongoing, with **frequent re-assessments** to account for fluctuations in level of need and periods of intermittent crisis/relapse associated with behavioral health conditions.
4. **Pro-active crisis planning** such as Wellness Recovery Action Planning (WRAP) and psychiatric advance directives are critical for ensuring ongoing self-determination, even during periods of behavioral health crisis.

5. Individuals should be afforded a **high level of flexibility in purchasing**, with restrictions limited to guns, pornography, gambling, drugs, and alcohol.
6. There should be **no requirement that individuals spend a portion of funds on traditional services**.
7. In general, stakeholders felt that there should be no **time limit** for program participation. The planning process, however, should be designed so that budgets reflect individual progress towards recovery.
8. Participants should be heavily involved in the planning and budgeting process, and should be **informed of their budget amounts**.

As noted above, there is broad consensus that persons with lived experience of behavioral health issues must have a key role in the demonstration and evaluation. This involvement should extend to peer inclusion in the intervention itself. There are a number of models to inform peer involvement in self-directed programs. Some are entirely peer-run, others employ peers in brokerage, coaching, or mentoring roles, and others have no formal roles for peers. However, the extent to which programs should require peer involvement (i.e. programs must be entirely peer-run, all brokers must be peers) will likely vary from site to site. At a minimum, peers should have some involvement in program design, and peer-provided services should be available to purchase using self-direction funds.

Other program design elements will be important to keep in mind moving forward:

1. While **representatives** are widely used in self-directed programs for individuals with intellectual and developmental disabilities, older adults, and other populations, it is clear that the role of representatives will be different in a behavioral health context. Criteria will need to be developed for representative involvement, training, and safeguards to ensure that representatives support self-determination as much as possible. In behavioral health programs, representatives should have an intermittent role in decision-making, stepping in only when an individual clearly wants additional support. Representatives should be chosen by the individual and may be family members or supportive others.
2. **Financial management services** may or may not have a role in the administrative infrastructure of self-directed programs, and some models are available.
3. **Program eligibility** decisions will be important to consider. In general, stakeholders were concerned about the implications of formal or informal "screening" or readiness assessments for equity, access, ethics, and research validity. Program designers will need to consider adaptations of this approach for a behavioral health population. Important decision points remain regarding the inclusion of persons with guardianships and representative payees; currently, some programs restrict eligibility to those deemed legally competent to make financial decisions. In the Cash & Counseling model, the use of representatives has addressed eligibility concerns (i.e. no one is screened out, and if program assessors have concerns about a person's ability to participate, they ask that a representative is involved).
4. The environmental scan has identified a number of **strategies for participant outreach, education, and recruitment** that will be important to explore further as a demonstration takes shape.
5. Similarly, **provider and other stakeholder outreach and education** emerged as critical elements for program success. Program design will need to incorporate strategies to engage with stakeholders.

6. **Quality management and monitoring strategies** will need to be developed and existing strategies tailored to assure fidelity to the intervention, quality of support for self-direction, and person-centeredness in all program activities. Explore the role of establishing minimum provider qualifications to ensure quality.

WHAT POLICY CONTEXTS NEED TO BE TAKEN INTO ACCOUNT?

The environmental scan identified numerous policy and environmental contexts, including major changes in the health care system associated with the implementation of the Affordable Care Act that must be taken into account in the design of a demonstration and evaluation. Such contexts will have a bearing on strategies for engaging with states about self-direction, the selection of potential demonstration sites, and the research approach, including a need to separate the impact of the self-directed intervention from concurrent policy and environmental changes.

Relevant policy and environmental contexts include:

1. An increasing role for managed care in behavioral health
2. The 2014 Medicaid expansion
3. The proliferation and implementation of Health homes and Accountable Care Organizations
4. The integration of physical and behavioral health care systems
5. An increased emphasis on behavioral health populations among physical health care providers, driven by Affordable Care Act provisions such as 30-day readmission penalties
6. The implementation of mental health and addictions parity, particularly parity implications for the Medicaid expansion population, which may have a more limited behavioral health benefit than current Medicaid recipients
7. Enhancements in home and community-based services related to behavioral health, including efforts driven by the impact of the *Olmstead* decision
8. Money Follows the Person expansions and continuations
9. Movements to separate housing and community mental health services such as an increased focus on scattered site housing with flexible supports versus group homes
10. An increased emphasis on behavioral health care as well as self-direction from Veterans Health Administration
11. Other changes associated with the Affordable Care Act
12. Changing state and county behavioral health agency relationships
13. Movements to integrate mental health and substance use systems at the county, state, and federal levels
14. Local, state, and federal budget cuts
15. The strength of the mental health peer community in states and localities as well as their working relationships with key state and local stakeholders
16. Changing perceptions of mental health and mental illness related to gun violence, and the implementation of new mental health initiatives related to gun control efforts

APPENDIX I: ENVIRONMENTAL SCAN OF BEHAVIORAL HEALTH AND SELF-DIRECTION KEY CONTRIBUTORS

ADVISORY COMMITTEE

Vidhya Alakeson, **Advisory Committee Chair**, is the Director of Research and Strategy at the Resolution Foundation, an independent economic and social policy think tank based in London. She also works as a consultant on a range of projects related to the implementation of personal health budgets in England as well as several mental health-related projects. This is the self-direction programme that was started in the National Health Service in 2009 and operates across a range of long term conditions, including behavioural health. Her projects range from training clinical staff involved in the implementation of personal health budgets to assessing the potential efficiency savings from implementing personal health budgets in the NHS. From 2006 to 2010, Vidhya was based at the US Department of Health and Human Services, first as a Harkness Fellow in Healthcare Policy and then as a behavioural health policy analyst in the Office of the Assistant Secretary for Planning and Evaluation. As a Harkness Fellow, she conducted a research project into self-direction in mental health in the Medicaid programme and published a report in 2007, entitled *The Contribution of Self-Direction to Improving the Quality of Mental Health Services*. She also worked as a consultant on the design of the CRIF: Self-directed care demonstration in Delaware County, Pennsylvania.

Dr. Richard Dougherty is the CEO at DMA Health Strategies and a national leader in change management and system redesign strategies for purchasers, payers and providers. Projects include the implementation of managed care, the use of evidence-based practices, quality improvement, reducing disparities and implementing consumer directed care. He currently leads a team in program strategy reviews for SAMHSA including the National Child Traumatic Stress Initiative and the Children's Mental Health Initiative, and is a task leader for an intensive review of the evidence for a broad range of mental health services. Dr. Dougherty and DMA Health staff recently completed reports with major recommendations for restructuring mental health systems in Wake County, NC, Detroit/Wayne County, Washington State, Montana, and New York. In addition to his work at DMA, Dr. Dougherty volunteers his time as a co-founder and President of BasicNeeds US, a non-profit international organization supporting community mental health services in 11 low and middle income countries. Dr. Dougherty has an A.B. with honors from Colgate University, an A.M. in Social Service Administration from the University of Chicago and a Ph.D. in Psychology from Boston University.

Daniel Fisher, PhD, MD is a staff psychiatrist at Riverside Community Mental Health Center in Wakefield, Massachusetts. He has worked as a board-certified psychiatrist for 25 years in a variety of inpatient and community settings such as a state hospital, day treatment center, outpatient clinics, and elderly housing. He was Medical Director for a community mental health center for 12 years. He also is a Co-Director of the National Empowerment Center in Lawrence, Massachusetts, a consumer-run Research, Training, and Information Center, which he helped found in 1992. Based on their research, he and Co-Director Laurie Ahern have developed the Empowerment Model of Recovery. They also have designed a training program based on the

empowerment model, called the Personal Assistance in Community Existence(PACE)/Recovery Program. The purpose of the PACE/Recovery Program is to inspire and educate the mental health system and the public to view mental illness in a positive light, and to help all involved in these crises to understand that through hope, self-determination, and believing in the person, people can recover. Dr. Fisher and Ms. Ahern have brought their message of recovery to the public through print, television and radio news. Dr. Fisher is the co-recipient (along with Ms. Ahern) of the National Mental Health Association's 2002 Clifford Beers Award for Advocacy. He also helped found the Ruby Rogers Center for Advocacy and Peer Support in Cambridge, Massachusetts.

Dr. Fisher spent five years doing neurochemical research at the National Institute of Mental Health from 1968 to 1973. He studied the enzymes which control the synthesis of the neurotransmitters dopamine and serotonin. He published several papers and chapters in books on these topics. During this period, Dr. Fisher was labeled with schizophrenia and hospitalized several times. He is among the few psychiatrists in the country who openly discusses his recovery from mental illness. His involvement in advocacy and peer support have played a vital role in his recovery. Dr. Fisher obtained an M.D. from George Washington University Medical School in 1976 and completed his Residency in Psychiatry at a Harvard teaching program at Cambridge Hospital. He earned a Ph.D. in biochemistry from the University of Wisconsin in 1968 and an A.B. in Biology from Princeton University in 1965.

Chris Gordon is a gray-haired psychiatrist, having worked in the field since 1976. For the past 15 years, I have had the privilege of working as the Medical Director and as a clinical leader of a non-profit provider of services to people with a variety of disabilities and life challenges in Metro-west Boston, called Advocates, Inc, and have maintained a toe-hold in academia, as an Associate Professor of Psychiatry at Harvard Medical School, through my teaching and affiliation at Mass General Hospital in Boston. The main focus of my work over the past few years is in the area of promoting recovery through supporting patient empowerment and self-directedness. I am especially interested in such empowerment and self-direction in the area of psychiatric extreme states, and even more especially in early-episode psychosis, to try to decrease chronicity and the harm done by many treatments. I am currently developing an early-episode program, called the Collaborative Pathway, that is built on some of what I hope are the most important ingredients of a Finnish model called Open Dialogue, and principles of patient-centered care and informed choice. To learn about Open Dialogue, I am currently part of an Advocates team studying under the direction of Mary Olson, PhD, Founder and Director of the Mill River Institute for Dialogical Practice in Haydenville, Massachusetts.

Patrick Hendry is the Senior Director of Consumer Advocacy at Mental Health America and he is the former Director of the National Consumer Supporter Technical Assistance Center. He has worked as a mental health advocate for the past eighteen years. His areas of expertise include organizational development, management and sustainability, self-directed care, recovery based trainings and peer run programs. He has lectured and provided consultation services on self-determination and self-directed care nationally and internationally. Prior to joining MHA, he served on the Boards of Directors of the Florida Psychiatric Rehabilitation Association, Florida Partners in Crisis, NAMI of Collier County, and the Mental Health Association of Collier County and other mental health organizations. He was instrumental in the creation of the Florida Certified Recovery Peer Specialist position and served on the Mental Health Advisory Board of the Florida Certification Board. As a self-disclosed consumer of mental health services, Patrick

has presented at numerous conferences on a wide range of recovery topics. In 1992 he co-founded the first peer-run organization in Florida to contract directly with the State for the provision of services and has, since that time, assisted with the development of numerous peer-run programs. He is a strong supporter of the inclusion of mental health consumers in all aspects of the mental health system.

Olga Acosta Price, Ph.D., is director of the Center for Health and Health Care in Schools at the George Washington University School of Public Health and Health Services, and is associate professor in the Department of Prevention and Community Health. She has recently served as project director of a multi-site national program for the Robert Wood Johnson Foundation, called *Caring Across Communities,* an initiative that addressed the mental health needs of immigrant and refugee students and families through school-connected programs. As founding director of the School Mental Health Program (SMHP), Dr. Acosta Price coordinated, implemented, and evaluated comprehensive school-based mental health programs in more than 30 public schools in Washington, DC. Dr. Acosta Price has numerous publications on children's mental health and the effectiveness of school-based services for addressing the health needs of vulnerable children and their families. She received her Master's and Ph.D. in clinical psychology from the State University of New York at Buffalo and her undergraduate degree from Vassar College.

Glenn Stanton is the Senior Vice President of Business Development, where he develops behavioral health business opportunities with state and local government organizations throughout the nation and has led successful efforts in Arizona, Florida, Pennsylvania, Louisiana and New York. Glenn brings to Magellan 25 + years of experience in the behavioral health, developmental disabilities, addiction, aging and disability fields at the county, state and federal levels. Prior to joining the Magellan team, Glenn served as acting director and deputy director of the Disabled and Elderly Health Programs Group of the Center for Medicare and Medicaid Services (CMS) in Baltimore, where he represented the agency on the President's New Freedom Commission on Mental Health. He led development and implementation of self-directed health care and quality initiatives for home- and community-based services and was responsible for review and approval of state requests for managed mental health carve-out programs — accomplishments which were recognized with an "Excellence in Leadership" award from CMS and three Department of Health & Human Services Honor Awards. Before joining CMS, Glenn worked for six years for the State of Michigan Department of Community Health, where he led the development of quality management and performance measurement systems for public sector behavioral health and developmental disabilities system and the development of the State's 1915b/c combination waiver to CMS. He also served as the executive director for a three-county community mental health program in Michigan with 750 employees and a $40+ million budget. Glenn holds a Bachelor's Degree from the University at Buffalo and a Master's Degree in Psychology from Michigan State University.

Pamela Werner is a Specialist in the Michigan Bureau of Community Mental Health Services. She is responsible for leadership and policy direction for the Certified Peer Support Specialist initiative. In addition, she provides training and technical assistance in person-centered planning and self-determination. She is both a member of the Michigan Recovery Council and Recovery Oriented Systems of Care Transformation Steering Committee. She has received an award from the Governor for accomplishments in developing a peer trained workforce as part of Michigan's systems transformation efforts. Pam was the primary author and responsible for the

implementation of several mental health grant awards centered on systems transformation efforts for recovery. She received the Association of Territorial Health Officials Vision Award in 2010 in the area of Creative and Innovative Approaches in Addressing Public Health Challenges. She has provided national presentations, technical assistance and consultation to a variety of states and organizations including the Pillars of Peer Support Summit. She has over 20 years of clinical and administrative experience in providing services and supports for individuals with a variety of disabilities and has been an author and co-author of a text and several journal articles. She has a Bachelor's of Science degree in Occupational Therapy and Master's degree in Clinical Psychology from Western Michigan University.

RESEARCH TEAM MEMBERS

Suzanne Crisp is the Director of Program Design and Implementation for the National Resource Center for Participant-Directed Services.

Bevin Croft is a Policy Analyst at Human Services Research Institute and Ph.D. candidate.

David Hughes is a Vice President at Human Services Research Institute.

Dawn M. Loughlin, Ph.D., is a Senior Research Associate at the National Resource Center on Participant-Directed Services.

Kevin J. Mahoney, Ph.D., is a faculty member at the Boston College Graduate School of Social Work where he serves as Professor as well as Director of the National Resource Center for Participant-Directed Services.

Lori Simon-Rusinowitz, Ph.D., is an Associate Professor at the University of Maryland in the Center on Aging and the School of Public Health, Department of Health Services Administration.

COLLABORATORS

Jon Delman is a Research Professor at the University of Massachusetts Medical School in the Department of Psychiatry.

Bob Glover is the Executive Director of the National Association of State Mental Health Program Directors.

Lauren Grimes is the TAY Outreach Specialist at On Our Own of Maryland.

David Sarchet is a Licensed Mental Health Counselor at FloridaSDC District 20 and contributed with his staff.

Joan Thurston and is a Licensed Mental Health Counselor at FloridaSDC District 4 and contributed with her staff.

Lee Zacharias is the Principal Consultant with the Zacharias Group.