



In the Driver's Seat

A Guide to Self-Directed Mental Health Care

Bazelon Center for Mental Health Law &
UPENN Collaborative on Community Integration

April 2008

Inside cover intentionally blank



In the Driver's Seat

A Guide to Self-Directed Mental Health Care

Bazelon Center for Mental Health Law &
UPENN Collaborative on Community Integration

February 2008

© Judge David L Bazelon Center for Mental Health Law, Washington DC, 2008. Reproduction of any or all sections of this document for noncommercial purposes is hereby granted, with attribution as follows:

Koyanagi C, Alfano E, Carty L: *In the driver's seat: A guide to self-directed mental health care*. Bazelon Center for Mental Health Law & UPENN Collaborative on Community Integration, 2008.

In the Driver's Seat and its accompanying fact sheets were written by Bazelon Center policy director Chris Koyanagi and policy analyst Elaine Alfano, with editing and design by publications director Lee Carty. Development and production were supported in part by funding for the UPENN Collaborative on Community Integration from the National Institute on Disability and Rehabilitation Research (H133B031109).

The guide and fact sheets are available electronically via www.bazelon.org and www.upennrrtc.org. Print copies may be purchased online or by sending \$7.50 plus \$4 postage and handling to Publications Desk, Bazelon Center, 1101 15th Street NW, Suite 1212, Washington DC 20005; pubs@bazelon.org; 202-467-5730 ext 141.



In the Driver's Seat

A Guide to Self-Directed Mental Health Care

Contents

Introduction 1

Part I

Understanding Self-Directed Care

Overview of Self-Directed Care	3
Assistance for Consumers in Self-Directed Initiatives	3
Consumers Have a Budget to Control	3
Consumer-Driven Planning Process	4
Brokers Provide Assistance	4
Not All Services Are Included	5
Consumers' Role in Oversight of Initiatives	5

PART II

Strategies and Tactics for Advocating for Self-Directed Care Policies and Initiatives

Gather Information	6
What Have Other States Done?	7
Content of a Self-Directed Care Initiative	7
Planning the initiative	8
Creating a self-directed care plan	8
Implementation	9
Choice of services	9
Strategy for Promoting a Self-Directed Care Initiative	9
Form partnerships with other advocates	9
Educate policymakers	10
Holding the System Accountable	11
Presenting the Case	11
Challenges and Barriers	12

Part III

An In-Depth Look at Self-Directed Care

Providers Play a Different Role.	15
Operational Elements of Self-Directed Care for	
People with Mental Illnesses	16
Critical Components of a Self-Directed Care Initiative	16
Consumer-Directed Planning Is the First Step	16
Defining goals	17
Getting specific, with concrete steps and a budget	17

Who Helps Consumers Plan and Manage Their Budgets?	18
Peers are often the best brokers	18
Broker training	19
Helping consumers feel ready to self-direct	20
Who Is Eligible for Self-Directed Care?	20
How Are Services and Supports Paid For?	20
What Happens in a Crisis?	20
Can Consumers Play a Leadership Role?	21
Examples of consumer roles in self-directed care policy	21
Benefits that can help consumers achieve life goals	22
How Is Self-Directed Care Financed?	21
States use various funding approaches	22
Federal benefits are useful	23
What Do Consumers Think of Self-Directed Care?	23
Evaluation tools for self-directed care	23
Conclusion	24
Appendix	
Additional Resources	25
Fact Sheets	33-40



In the Driver's Seat

A Guide to Self-Directed Mental Health Care

Introduction

People who rely on public mental health services should be directly involved in designing their own care plan. Even though state and local agencies often include consumers and other advocates in care planning, they often allow them to have only a marginal role and fail to provide important information that could enable them to participate fully and effectively.

Consumer advocates—whether representatives of consumer organizations or individuals sitting on key state or local planning bodies—should have information and tools to press for system change. The Bazelon Center and the University of Pennsylvania Collaborative on Community Integration have prepared this guide to help consumers and other advocates obtain policies that give consumers a primary role in their recovery planning and greater control over how resources are spent to meet their needs.

In what are now described as self-directed care programs, individuals are able to choose from a wider array of services and supports than have traditionally been offered them. Further, they have the flexibility to spend some of the money allocated for their care in new ways, based on an individualized plan and budget. Several federal agencies, including the Substance Abuse and Mental Health Services Administration, the Centers for Medicare and Medicaid Services and the Institute of Medicine, have made recommendations promoting self-directed care and are encouraging its adoption in public mental health systems.

Although there are some self-directed care programs around the country, they are far from universal and generally exist as pilot projects of limited scope. Nevertheless, states that have initiated these programs have learned much from them that can be usefully applied as new programs are designed and implemented.

While public mental health officials still struggle to orient systems to an individual, recovery-based approach, consumer activists have unquestionably been effective in convincing policymakers and other stakeholders about the need for a change in culture and practices in the mental health system. Self-directed care builds on and often incorporates other innovations that have come from the consumer-empowerment movement, including peer support, consumer-operated programs, paid

In self-directed care programs, individuals have the flexibility to spend some of the money allocated for their care in new ways, based on an individualized plan and budget.

peer specialists and consumer leadership in system design and governance. Combining prior innovative features with some new approaches, self-directed care is recognized as an important milestone in the growth and development of consumer self-determination.

Combining prior innovative features with some new approaches, self-directed care is an important milestone in the growth and development of consumer self-determination.

Part I of this guide is a brief description of self-directed care. Part II offers advocacy strategies and tactics, while Part III is a more in-depth look at how self-directed care initiatives work and how they are funded. The appendices include fact sheets with information that would be useful to state policymakers and consumer advocates as well as those who do not have time to read this entire publication. The fact sheets may be copied and distributed as you wish. The appendices also provide a list of further reading and useful information on self-directed care.



Part I

Understanding Self-Directed Care

Below is a short summary of self-directed care and how it works. As you begin your advocacy for this approach, you may need to understand more about how these initiatives function, what other states have done with them and how they can be funded. Part II offers more detailed information on these topics.

Overview of Self-Directed Care

Self-directed care is a new approach to the delivery of community services to people with mental illnesses. It allows consumers to manage their own care and control a budget to pay for their services and supports.

A traditional mental health treatment plan is based on an illness model of care that focuses on eliminating symptoms. Problem-oriented rather than strengths-based, it has little to say about recovery. A self-directed care plan, on the other hand, concentrates on recovery and builds on an individual's strengths and skills. Efforts are directed to helping consumers achieve what they want in terms of their health and mental health, social and family relationships, civic participation, employment and education. A recovery plan emphasizes use of natural supports (e.g., family and friends) and resources in the community along with the services that are available through the mental health system.

Self-directed care starts with the understanding that people with mental illnesses should be free to make choices about important aspects of their lives.

Assistance for Consumers in Self-Directed Initiatives

With the help of facilitators, participants in self-directed care programs develop life/recovery plans that identify goals, the steps to meet these goals and the resources needed. They can select their care providers and may also make choices about clinical care (including medications, therapy, case management) and rehabilitative services, including help with daily-living activities, communication skills and managing chronic illness.

Consumers Have a Budget to Control

Self-directed care programs also give each consumer control of a specific amount of money that can be used for different purposes related to the goals that the individual has identified in the life/recovery plan.

Self-directed care starts with the understanding that people with mental illnesses should be free to make choices about important aspects of their lives, from health and mental health care to housing, family and social relationships, employment and participation in community life.

Participants have used these funds to pay for various things, including wellness activities such as exercise classes or yoga, and for dental services, vision care and glasses, education, job training and transportation costs.

Consumer-Driven Planning Process

Participants begin the process by describing their life goals and how meeting those goals would improve their lives. They will also identify potential barriers. Those seeking jobs, for example, may pinpoint that a lack of eyeglasses, appropriate clothing, bus fare or dental care will hinder their chances of obtaining and maintaining employment. To reach their goals, they will need to include in the plan a strategy for obtaining the needed items or services. If they cannot pay for these and financial assistance is not available from community programs, then they may put these items in their personal budget.

Once participants have explored options, selected goals and decided on strategies for overcoming barriers, they develop a plan with specific steps to meet objectives and a time-line for completing those steps. They also identify needed resources and whether they can obtain those resources through other sources or programs. (Given the limited funds available, it is helpful to make the most of other resources so that participants can use their self-directed care budgets to maximum effect.) Then, with the help of a trained facilitator, participants develop a budget and create a written plan.

In short, a plan identifies steps needed to achieve goals, potential obstacles to success and how to overcome them, resources that will be needed and the amount of money the system should allocate to the individual's budget.

Brokers Provide Assistance

All self-directed care projects offer consumers assistance with the planning process and managing their individual budgets. The individuals who provide this assistance, broadly termed brokers, are specially trained in self-directed planning and facilitation. Brokers are most effective when they can be empathetic, which is why peers are often the best brokers. Some self-directed care programs use only peers as brokers, while others use a mix of peer brokers and retrained mental health case managers or other providers.

Participation in self-directed care is voluntary. Projects operate on the assumption that self-direction should be available to all consumers who wish to engage in it since consumers who are interested and willing to self-direct their care are the ones most likely to succeed.

Typically plans are reviewed and approved in advance of spending. Approval is not contingent upon judgments about a person's choice

Participants begin the process by describing their life goals and how meeting those goals would improve their lives.

of goals but is meant simply to ensure accountability for public funds. Nearly all plans are approved as submitted, since participants are assisted by brokers who understand the program requirements and are able to communicate them successfully.

Not All Services Are Included

Self-directed care programs focus on services in the community, and individual budgets do not include funding for hospital, residential care or crisis services. These types of services are still organized and paid for in the usual way.

However, self-directed care programs generally encourage participants to express their preferences and expectations in the event of a crisis. This can be done in the consumer's self-directed care plan, communicating in advance with providers, family and friends about treatment preferences in the event of a crisis when the consumer can no longer manage his or her own care. A consumer can also express preferences by creating a psychiatric advance directive.

Consumers' Role in Oversight of Initiatives

In keeping with the values and spirit of self-direction, consumers in self-directed care programs have key roles in the management and oversight of state self-directed care policy. Local self-directed care projects generally have advisory boards to work on policy and program issues and to address any consumer complaints or concerns about quality.

Participants are assisted by brokers who understand the program requirements and are able to communicate them successfully.



PART II

Strategies and Tactics for Advocating for Self-Directed Care Policies and Initiatives

In a series of steps, this section lays out a plan for consumer advocates to use or adapt in promoting the adoption of a self-directed care approach to mental health service delivery in their state. Consumer advocates will need to:

- ✓ Gather information so as to understand self-directed care, including its benefits and challenges.
- ✓ Learn what other states have done.
- ✓ Learn what their state is already doing toward self-direction, including whether there are any plans, discussions or pilots on which a statewide initiative can be built.
- ✓ Decide which design and operational features to promote when policymaking bodies are considering a self-directed care approach.
- ✓ Identify and form working alliances with other advocates who hold similar views.
- ✓ Identify the targets for advocacy, such as individuals in the state mental health authority and other state agencies, the Governor's office and the legislature.
- ✓ Undertake an education and advocacy campaign to inform these key decision-makers.
- ✓ Appreciate the challenges and barriers to adoption of self-directed care and devise a strategy to counteract opposition if it arises.

The following sections discuss each of these steps in more detail.

Gather Information

Existing self-directed care initiatives have varying features and you will need to know which are most important or essential for you. You do not need to plan the initiative itself, for that is the responsibility of agency staff, although they certainly should engage consumer advocates as partners in the planning process. To have a real impact on policymaking, you will need a working knowledge of self-directed care so you can talk about it with coalition partners and officials and make informed recommendations.

You can use the information in Part I and the Fact Sheet#1 to learn the basics of self-directed care initiatives. You can learn more by taking a look at other resources that are on the Internet or available free of charge (see appendix).

What Have Other States Done?

Today, a number of states have funded pilot projects of self-directed care for mental health consumers, and several others are engaged in serious planning efforts (see Fact Sheet #3).

These states have launched self-directed care initiatives in various ways. Some, notably Michigan and Florida, have gotten projects off the ground with enactment of legislation that requires the state mental health authority to set in motion a planning and implementation process.

In Iowa, a managed behavioral health care organization (Magellan) involved in the state's Medicaid program worked with the state to move ahead on a pilot plan. Since initiating a pilot in Iowa, Magellan is now funding new self-directed care pilots in Tennessee and Pennsylvania.

Funding opportunities also have stimulated action. Federal grants from the Centers for Medicare and Medicaid Services (CMS) prompted some states to consider self-directed care for various populations of people with disabilities, including, in some cases, people with serious mental illnesses.

In addition to learning about what each state has done or plans to do, consider contacting consumer groups in one or more of these states to find out more about how the initiative works, its successes and challenges, and how it was developed. To start, you could look to a state in your region of the country or one where you already know a consumer leader. You could also consider a state that is similar in some way to yours (e.g., rural, frontier or heavily urban).

When talking to consumer-advocacy groups in these states, ask their views of the project's overall effectiveness and what program features they consider important. Think about whether their model would be a good one to replicate in your state. If not, could it be a good model if just a few things were done differently?

Content of a Self-Directed Care Initiative

Before deciding on the most important aspects of self-direction to promote in your state, you will need to know what the state is doing already that may be related. A good place to start is by examining how the state supports consumer choice for existing services, how much real control consumers feel they have over the service-planning process and whether there are any pilot projects on self-directed care. For example:

- ✓ Is the state committed to a recovery-oriented approach? Can you build on that philosophy to promote self-directed care?
- ✓ Does the state rely on person-centered planning? If so, can you work toward agreement that this means that people in the public mental health system have individualized plans and the choice to direct the planning process and to select from an array of services and supports?

A number of states have launched self-directed care initiatives. Consumer advocates might contact consumer groups in these states to find out more about how the initiative works, successes and challenges of the initiative, and how it was promoted.

- ✓ Does the state offer recovery education, such as training in WRAP (Wellness, Recovery Action Planning; see sidebar on page 20), either directly or through contracts with consumer organizations or providers?
- ✓ Does the state have any self-directed care initiative? If so, is it only a pilot project? Is the pilot an effective model that should be made available statewide, or does it need improvement?

You are not obligated to have all the answers because state planners will be responsible for the full details of a self-directed care initiative. Nonetheless, some aspects are likely to be especially important to consumers. Use the following checklist to consider which policies are most important for the initiative in your state.

Use this checklist to consider which policies are most important for the initiative in your state.

Planning the initiative

- Will consumers be able to apply to participate without having to meet some test of their “readiness”? __YES __NO
- Will consumers be able to leave the project for traditional services any time they wish? __YES __NO
- Will the state devise a plan so consumers can control an individual budget for services, supports or purchases that are not normally available to them through the state system? __YES __NO
- Will all consumers have the option to have an individual budget (within the funds available for the initiative)? __YES __NO
- Will the budget be meaningful—will there be enough money for the types of services and items consumers may need? (Many existing projects have allocated small amounts, such as \$2,000-\$3,000.) __YES __NO
- Can consumers receive these funds for more than one year? (Many projects have allocated funds for only a year, whereas consumers may need more time to reach their goals—for example, two or three years of support might be better.) __YES __NO

Creating a self-directed care plan

- Will consumers have control over the schedule for meetings on their plan? __YES __NO
- Are policies and processes in place to assure that consumers have copies of their plan and budget? __YES __NO
- Will they be able to change the written plan if they believe it no longer reflects their own words and choices? __YES __NO
- Can consumers bring any other person of their choice to planning meetings? __YES __NO

- Will consumers have sufficient training and education to engage effectively in this process? __YES __NO

Implementation

- Will consumers have support to help them manage financial issues, such as payroll for a personal assistant? __YES __NO
- Will trained peers (consumers in recovery) serve as the brokers for consumers who have individual budgets?) __YES __NO

Choice of services

- Does the initiative give consumers an easy way to make meaningful choices among the traditional services? For example, in some projects consumers have been given the choice to opt out of ACT (Assertive Community Treatment) teams, choose their case manager and select among an array of providers. __YES __NO
- Will consumers be assisted in developing crisis plans and a psychiatric advance directive so their wishes are known should they become incapacitated? __YES __NO
- Are there few and reasonable limitations on what consumers may use the funds in their budgets to purchase? __YES __NO

Strategy for Promoting a Self-Directed Care Initiative

Partnerships with other advocates

Early on, consumer advocates will want to identify and begin working with other groups that have similar goals. It is important to present a unified voice to policymakers. This is often best achieved by forming a formal or informal coalition. Other organizations that might join with a consumer organization include the local and state chapters of Mental Health America, the National Alliance on Mental Illness (NAMI) and the Federation of Families for Children’s Mental Health (it will be interested in family-directed care for children’s services). Other allies could be disability and civil rights groups, including the Protection and Advocacy System (P&A) in your state.

You may also want to talk to consumers who sit on mental health planning and advisory committees or who are currently engaged with the mental health authority in some other official capacity. If your state authority has an office of consumer affairs, you should decide how to engage that office in the advocacy campaign.

Coalition-building requires:

- ✓ regular opportunities to meet and exchange views and concerns;

It is important to present a unified voice to policymakers. This is often best achieved by forming a formal or informal coalition.

- ✓ compromise if partners disagree on some aspect of the proposed self-directed care policy or on the tactics to achieve it;
- ✓ time and effort from leaders to organize, initiate contacts, run meetings, etc.; and
- ✓ good will on the part of all participants.

Even though working with a coalition requires time and effort, it is worthwhile to develop these partnerships because they can multiply the impact of any one group's efforts and increase the likelihood that policymakers will seriously consider the request for self-directed care.

Educate policymakers.

An advocacy campaign must identify the key officials who can make the decision to move ahead with the initiative and then organize to educate them. Start by identifying individuals who are important to persuade. These will include:

An advocacy campaign must identify the key officials who can make the decision to move ahead with the initiative and then organize to educate them.

- ✓ individuals in the state mental health authority, particularly the director/commissioner and the director of the consumer affairs office;
- ✓ the Governor's staff, particularly if the Governor has expressed any interest in mental health issues and has a staff member dedicated to mental health;
- ✓ the Medicaid agency, because Medicaid already promotes self-directed care for people with physical or developmental disabilities and these officials already understand and appreciate self-directed care; and
- ✓ key members of the legislature, including those who sit on committees that authorize mental health programs or provide the funding for them, as well as any legislators who have expressed interest in mental health policy in the past.

Additional ways to become involved in policymaking at the state level can be used either by the lead consumer advocacy group or by others in the coalition:

- ✓ Participate on the state's mental health planning council, which is mandated under the federal mental health block grant program.
- ✓ Participate in the state's process for transforming the public mental health system, particularly in states that have received federal "transformation grants."

When meeting with officials, it is advisable to have a specific request. Consider:

- ✓ asking officials in the state mental health authority to create a task force to make recommendations on how to establish and implement self-direction in the state system;
- ✓ asking legislators for a bill that authorizes the state to establish and implement self-direction in the state system;

- ✓ asking the Governor and his staff to issue a directive to the state mental health authority for development of a plan for self-directed care;
- ✓ asking Medicaid officials for information to clarify how and when Medicaid can pay for self-directed care services.

At these meetings, educate critical decision-makers to help them understand the consumer perspective on self-direction and urge the inclusion of consumers in any group that plans such an initiative in your state. Policymakers considering a new approach to service delivery are always interested in what another state has already accomplished. Explain how several other states already have self-directed care programs and that they are successful. If another state has a model of self-directed care that seems well-suited to your state, bring that to the attention of your state officials. They may wish to discuss the project with colleagues in the other state.

As the process moves forward, you will need to be ready and able to explain the type of program you believe is needed in your state and answer questions that may be raised. You may need to prepare materials to leave with the individuals you meet to clarify and remind them about your concerns or ideas (see the sidebar on presenting the case).

To be effective as an advocate you will also need to:

- ✓ Be persistent. Expect a lengthy process with stops and starts, successes and setbacks. Stick with it. You can wear down the opposition, and time is on your side as more and more states come to appreciate the self-direction philosophy.
- ✓ Communicate effectively. For legislators, your message should be simple and presented both orally and in short, easy-to-understand fact sheets and handouts.
- ✓ Learn strategies for negotiation and diplomacy to speak effectively to busy government officials.
- ✓ Reach out beyond the groups who have joined your coalition to providers, family members and others who support the effort.
- ✓ Use every opportunity to become involved in the policymaking process. In most states, legislative committees set the budget amounts for the mental health agency each year. These bills provide an opportunity for the legislature to direct the agency to pursue certain policies, to study an issue and report back to the committee or take other action. These committees can also earmark funds specifically for the self-directed care initiative.
- ✓

Presenting the Case

You can use the accompanying Fact Sheets and other materials you develop yourself to present your case to the decision-makers:

1. Explain what self-directed care is and how it works (use Fact Sheet #1).
2. Since state officials are always interested in what other states have done, use the information in this publication and any additional information you gather from any state you feel is particularly relevant. (Use Fact Sheet #2.)
3. If you are promoting key aspects of self-directed care, write them up on a single piece of paper.
4. How to pay for any new initiative is always a question that policymakers ask. Give thought to how the state might finance the initiative, including using Medicaid funds or special grants (see the Fact Sheet #3).
5. Make clear to decision-makers that some aspects of consumer-directed care do not have significant costs (e.g., giving consumers real choices among services and service providers; helping them make crisis plans or complete psychiatric advance directives) and that such steps can be taken immediately without special appropriations.

Holding the System Accountable

Any self-directed care initiative should create ways for consumers to provide regular feedback and express their wants and needs. A system is needed to allow state and local administrators to take into account consumer input and make modifications as needed.

As the initiative is planned, consumer advocates should ensure that:

- ✓ The need for measuring real outcomes is acknowledged and tools are selected that will assess how consumers are doing once the initiative is in place.
- ✓ Consumer-satisfaction tools are used so that consumers can report in a regular way on:
 - ◆ whether they feel they have real choice among service options;
 - ◆ whether they are satisfied with their broker;
 - ◆ whether they feel their views are truly listened to; and
 - ◆ whether the goals they have for their lives, and the ways in which they would like to reach those goals, are accurately reflected in their plans.

Planning groups can consider some of the existing tools that have been developed to assess outcomes and consumer satisfaction, including the Recovery Assessment Scale or tools used by existing self-directed care projects, such as the Oregon Empowerment Initiative (see Outcomes section in Part I).

Challenges and Barriers

Consumer-advocates can expect opposition to these ideas from various sources. Arguments typically made to discourage self-directed care are listed below, along with some suggested responses.

“Individuals with mental illness lack the capacity to self-direct.”

While mental illness may keep some individuals from participating in self-directed care at a given time, often consumers may only appear unable to self-direct. Anxiety, low self-expectations and a sense of hopelessness can lead consumers to feel inadequate and to appear to providers as unable to self-direct. These problems can be overcome, however, if consumers are amply encouraged and assisted in developing self-management skills. When self-direction is presented as an option, it is likely that individuals who choose it will be those who are motivated and confident that they can do it.

“This is too risky; something will go wrong.”

Providers and policymakers may voice concerns about liability and professional obligations and what will happen if individuals make poor

When self-direction is presented as an option, it is likely that the consumers who choose it will be motivated and confident that they can do it.

choices and are harmed by them. Such paternalism is misplaced. In a comprehensive self-directed care program, consumers have written plans and budgets, the ongoing assistance of a broker and support from professionals and peers. In fact, self-directed care may actually be a way to prevent harm, since it emphasizes consumer education, self-management skills and a shared understanding between consumer and provider. Consumers are encouraged and given tools to help them manage their health and mental health and recognize signs of impending difficulty. Providers who have worked in self-directed care programs, even if they were initially uncertain, now say they feel in a better position to help when the person is actively engaged in his or her own care and that, in these more collaborative interactions, they are better able to discern if psychiatric problems are worsening.

“This will create a major disruption in the system.”

It is important to recognize that those resisting self-directed care may simply feel more comfortable doing things the way they have always been done rather than by trying something different and risking failure. This uneasiness with change is not unique to any group of people. Providers, policymakers, government officials and consumers all may resist change, even when they acknowledge that the status quo is not working. Self-directed care starts with the recognition that learning involves trial and error and that participants will learn, as people generally do, from experiments that fail as well as from those that succeed. In advocating for self-directed care, it will be helpful to ask opponents to make their concerns as explicit as possible and then to listen carefully to what they say. Then, in responding, be as specific as you can in addressing their concerns.

“Agency rules limit the ability to allow self-direction.”

Staff roles, as defined in agency rules, may limit the ability of program staff to support consumers in self-direction. States should review those rules and remove any such barriers.

“The community will not accept the idea of individual budgets and the use of public funds for some of the purchases allowed in self-directed care programs.”

This objection is often cited by those who have other reasons for preferring that the initiative not move forward. The concern expressed is that the general public will not support expenditure of government funds on the types of supports, activities or items that would be permitted in the consumer’s budget. These community concerns may be a real issue once the program is launched, and educating the media and the public about the benefits of self-direction should be a high priority. Concerns can be addressed by documenting beneficial outcomes (e.g., greater consumer satisfaction, increased employment, fewer hospitalizations) as well as explaining mechanisms to ensure accountability.

Community concerns may be a real issue. States, local governments and programs, and consumer-advocacy groups should work to educate the media, and, through them, the public, about the positive benefits of consumer self-direction.

When consumers can achieve stability in their lives, become gainfully employed or develop new skills and the self-confidence to live independently, government costs go down.

“Families are concerned that consumers may be harmed.”

Some families may object to self-direction, citing many of the problems listed above, out of concern that their family member will suffer harm. In time, however, families will come to appreciate the value of self-direction. Educating families on how potential pitfalls can be avoided and on the positive results from these projects in other states can help alleviate their anxiety. It is particularly effective for families to hear from consumers who have benefited from self-directed care.

“There are no resources.”

It may be argued that no resources are available either for the individual budgets or to pay brokers and other managers of such a program. However, the state can look to various funding sources, especially since these programs are generally low in cost. Moreover, there may well be savings in other service costs when consumers can self-direct. When consumers can achieve stability in their lives, become gainfully employed or develop new skills and the self-confidence to live independently, government costs go down.



Part III

An In-Depth Look at Self-Directed Care

Self-directed care is a new approach to the delivery of community services to people with mental illnesses. It allows consumers to manage their own care and control a budget to pay for their services and supports.

A traditional mental health treatment plan is based on an illness model of care that focuses on eliminating symptoms. Problem-oriented rather than strengths-based, it has little to say about recovery. A self-directed care plan, on the other hand, concentrates on recovery and builds on an individual's strengths and skills. Efforts are directed to helping consumers achieve what they want in terms of their health and mental health, social and family relationships, civic participation, employment and education. A recovery plan emphasizes the use of natural supports (e.g., family and friends) and community resources along with the services available through the mental health system.

Self-directed care starts with the understanding that people with mental illnesses should be free to make choices about all important aspects of their lives.

Providers Take on New Roles And Responsibilities.

With self-directed care, clinical professionals assume different roles. Rather than driving the decision-making and service-planning process as traditionally trained to do, providers must function in a more supportive manner, offering information (about mental illness, health and wellness, and options for care), encouragement and decision-making support. When individuals are well informed, encouraged to express their preferences and assisted as needed in making decisions, they are more satisfied with the care they receive.

Underlying self-directed care are the principles that all consumers should have:

- ✓ the freedom to decide how to live their life and to establish life goals;
- ✓ authority to control the funds used to support their life goals;
- ✓ support for a unique personal plan for recovery;
- ✓ responsibility for using the public funds wisely and becoming a contributing member of one's community, and
- ✓ confirmation that they can play an important role in mental health system reform and that their leadership is valuable.

Clinical professionals assume different roles, offering information (about mental illness, health and wellness, and options for care), encouragement and decision-making support.

Operational Elements of Self-Directed Care for People with Mental Illnesses

- ◆ Person-centered planning process
- ◆ Individual budgeting
- ◆ Consumer and provider education
- ◆ Advocacy and coaching
- ◆ Expanded provider network
- ◆ Financial management
- ◆ Oversight/quality improvement
- ◆ Funding

Critical Components of a Self-Directed Care Initiative

With the help of facilitators, participants in self-directed care programs develop life/recovery plans that identify goals, the steps to meet those goals and the resources needed. They can select their care providers and may make choices about clinical care (e.g., medications, therapy, case management) and rehabilitative services, including help with daily-living activities, communication skills and managing chronic illness.

Self-directed care programs also give each consumer control of a specific amount of money that can be used for different purposes related to the goals that were identified in the life/recovery plans. Participants have used these funds to pay for such things as:

- ✓ tuition and supplies for educational classes;
- ✓ training that may lead to a job;
- ✓ a personal assistant or homemaker services;
- ✓ start-up for a micro-business;
- ✓ wellness activities, like exercise classes or yoga;
- ✓ dental services, vision care and glasses;
- ✓ nontraditional services like acupuncture and massage therapy;
- ✓ e-mail and phone connections;
- ✓ interpreter services; and
- ✓ bus passes and other help with transportation costs.

The elements of a self-directed care program for people with mental illnesses have been summarized by SAMHSA (see sidebar). States and localities can use this list to design the details of their programs.

Consumer-Directed Planning Is the First Step

Consumer-directed services begin with a planning process that is driven by the consumer's own goals, meaning that it is not run by the treatment team or the case manager. The planning process is designed to help participants identify their aspirations and goals and develop a plan for achieving them. Facilitators help consumers through this process, and, in many of the existing self-directed care initiatives, these facilitators are peers. Participants may also invite significant others, such as family, friends or mentors, to be involved in the planning if they feel that this would be helpful.

Many mental health systems have adopted the phrase "person-centered planning" to describe the service-planning process they use. Too often, however, consumers have found that the caseworkers assigned to work with them on such plans have been too prescriptive rather than allowing individuals to shape their own plans. Many advocates prefer to

use terms like consumer-directed or self-directed to avoid any confusion about the consumer's primary role. Self-directed care requires a shift in thinking and practice, even among many of the providers who believe they are practicing person-centered planning.

Projects that started using mental health agency case managers to facilitate self-directed planning found that the case managers were apt to impose a system-centric view on the process. This violates a core principle of self-direction. These case managers were accustomed to developing plans that reflected their professional judgments, instead of facilitating self-directed planning by the consumer. When these projects moved to using peer facilitators, they encountered higher levels of consumer satisfaction.

Defining goals

The self-directed planning process helps individuals select and set goals that typically are related to health and wellness, employment, education, social relationships, recreation, participation in civic life, independent living and volunteer activities. The process begins with participants' describing their life goals and how meeting those goals would improve their lives.

For example, one self-directed care participant wanted to *"have a job where I am able to support myself in an apartment and feel positive about my role in society."* She also said she thought she would *"feel better about myself if I am working and see that other people can depend on me. I also think that I will get to know other people at work and that this will make me feel less isolated. I want to work and feel frustrated that I am not working."*

Participants may have a wide range of personal, interpersonal and professional goals. These could be directed toward improving family life, making new friends, obtaining job training or higher education, becoming an entrepreneur or incorporating regular exercise and nutritional meals in daily routines.

Participants also identify potential barriers. Those seeking jobs, for example, may pinpoint that a lack of eyeglasses, appropriate clothing, bus fare or dental care will hinder their chances of obtaining and maintaining employment. To reach their goals, they will need to include in their plan a strategy for obtaining the needed items or services. If they cannot pay for them and financial assistance is not available from community programs, then they may put these items in their personal budget.

Getting specific, with concrete steps and a budget

Once participants have explored options, selected goals and decided on strategies for overcoming barriers, they develop plans with concrete steps to meet objectives, a timeline for completing these steps, the

Participants may have a wide range of personal, interpersonal and professional goals, typically related to health and wellness, employment, education, social relationships, recreation, participation in civic life, independent living and volunteer activities.

A plan identifies the steps needed to achieve goals, the potential obstacles to success and how to overcome them, the resources that will be needed and the amount of money needed for the individual's budget.

resources needed and whether the resources can be obtained through other sources or supplied by other programs. (Given the limited funds available, it is helpful to make the most of other resources so that participants can use their self-directed care budgets to maximum effect.) Then, with the help of a trained facilitator, participants develop a budget and create a written plan. If someone other than the participant is responsible for the written documents, that person is expected to use the same language the participant used in formulating the plan. All items in the budget must be related to the goals set forth in the plan.

Various tools and trainings are available to assist with planning and identifying strategies and practices that will help individuals make progress toward their goals. These include WRAP (Wellness Recovery Action Planning), PATH (Planning Alternative Tomorrows with Hope), Essential Lifestyle Planning, MAPS (Making Action Plans), Personal Futures Planning and Recovery Planning.

In short, a plan identifies the steps needed to achieve goals, the potential obstacles to success and how to overcome them, the resources that will be needed and the amount of money needed for the individual's budget.

Who Helps Consumers Plan and Manage Their Budgets?

All self-directed care projects offer participating individuals assistance in the planning process and in managing their individual budgets. The individuals who provide this assistance are specially trained in self-directed planning and facilitation. They also learn about the values, rules and operational aspects of the program and the community resources that are available and how to access them. Self-directed care projects use different titles for these positions—brokers, coaches, educators, facilitators—but all perform similar tasks. (From this point on, the term “broker” is used.)

Brokers may be specially trained peers or mental health workers who receive new training in how to work in a self-directed, recovery-based system. The broker's role is to be supportive and helpful to the consumer in developing life goals and plans and designing the set of services, supports and purchases that will help the consumer achieve those goals. Brokers provide support throughout the planning process and help the consumer make critical decisions.

Peers are often the best brokers.

Brokers are most effective when they can be empathetic, which is why peers are often the best brokers. Some self-directed care programs use only peers as brokers, while others use a mix of peer brokers and retrained mental health case managers or other providers.

All brokers in all projects receive training for their role. New self-

directed care programs could adapt one of the training models currently used in pilot projects without having to design a training program from scratch (see sidebar below).

Broker Training

In **Oregon**, the self-directed care brokerage offers Service Provider Individualized Recovery Intensive Training (SPIRIT), a 10-week course facilitated by a job developer, a trainer and a peer supporter, who prepare consumers to serve in paid or volunteer peer support positions in the mental health field.

Florida provides a 16-hour training program for peers who already have experience in providing direct services in community-based organizations. At the completion of the training, the peers qualify as life coaches, positions that may also be held by case managers.

Michigan is using trained peer support specialists as coaches to assist those opting for self-directed care. Michigan peers have been trained using the 40-hour curriculum developed by the National Association of Peer Support Specialists (NAPS). This national training is not limited to those working in self-directed programs with individualized budgets, but it is recovery-oriented and trains specialists to facilitate consumer-directed planning. In the states where NAPS conducts training, the trainers work with state and local mental health agencies to ensure that training meets certification requirements and covers material important to peer support specialist work throughout the state.

The Copeland Center offers national training on Wellness Recovery Action Planning (WRAP). Individuals who want to work in the field can become certified as Mental Health Recovery Educators after successfully completing the basic WRAP training and a more advanced 40-hour training course. After completing the training, participants are eligible to receive a Mental Health Recovery Educator Certificate and 40 continuing education credits. There is an additional advanced-level training for advanced-level facilitators. Because this is a national training model, self-directed projects will need to add specific information about how their projects operate and about their state and community programs, services and resources.

See the sidebar on WRAP training on the next page.

Brokers are most effective
when they can be
empathetic, which is why
peers are often the
best brokers.

Helping Consumers Feel Ready to Self- Direct

Recovery-education programs, like WRAP, provide encouragement and skills training to prepare individuals who have lost confidence in their ability to live self-directed lives and manage their own care.

Basic WRAP training helps participants focus on their life goals, identify triggers and warning signs of escalating mental health problems, develop strategies for self-managing symptoms and create a natural support network to cope with problems that arise.

While WRAP can be a basis for helping consumers feel ready to implement a self-directed care plan, it can be widely offered to all consumers, regardless of where they are in their journey to recovery.

Who Is Eligible for Self-Directed Care?

Participation in self-directed care is voluntary. Projects operate on the assumption that self-direction should be available to all consumers who wish to engage in it since consumers who are interested and willing to self-direct their care are the ones most likely to succeed. However, some programs continue to say that consumers need to be “ready” to participate.

In any community, a number of consumers will already have the confidence and interest to sign up for self-directed care, once the voluntary sign-up is in place. However, others may be reluctant to take this step. They can be helped along the road to recovery through encouragement and with programming that fosters skills and attitudes that help them regain control of their lives. WRAP is an example of a systematic consumer-developed training, widely offered nationally and internationally, that has a large base of support among consumers and professionals in the field (see sidebar).

How Are the Services and Supports a Consumer Chooses Paid For?

Self-directed care initiatives must set up a system of oversight regarding how the money in each consumer’s individual budget is spent. Typically plans are reviewed and approved in advance of spending. Approval is not contingent upon judgments about a person’s choice of goals but simply to ensure accountability of public funds. Nearly all plans are approved as submitted, since participants are assisted by brokers who understand the program requirements and are able to communicate them successfully. If a consumer wants to spend a significant amount of money (e.g., more than \$500) for a particular purchase or service, such as rent deposit or purchase of a computer, the program administrator may have to sign off on it.

Self-directed care initiatives develop guidelines for consumers, showing a list of allowable uses for their funds. All self-directed care initiatives have a much shorter list of unallowable spending, generally including alcohol, illegal drugs, tobacco, guns and pornography.

What Happens in a Crisis?

Self-directed care programs focus on services in the community and individual budgets do not include funding for hospital, residential care or crisis services. These types of services are still organized and paid for in the usual way.

However, self-directed care programs generally encourage participants to express their preferences and expectations in the event of a crisis.

This can be done in the consumer's self-directed care plan and by communicating in advance with providers, family and friends about treatment preferences in the event of a crisis when the consumer can no longer manage his or her own care. Creation of a psychiatric advance directive is another option.

Crisis plans and formal psychiatric advance directives allow consumers to have a voice, even if (and in the event that) they are unable to express themselves when their psychiatric crisis occurs. A psychiatric advance directive is a legal document that spells out how an individual wishes to be treated in the event of becoming incapacitated, particularly when involuntarily hospitalized. In these documents, a consumer can give specific instructions for future treatment (for example, asking for specific medications or refusing electro-convulsive shock treatment) and appoint a person (known as a health care agent) to speak for the consumer during times of crisis. All states have laws that permit the use of advance directives and require hospitals to follow them.

More information on psychiatric advance directives is available via a website devoted to that topic, including information on how psychiatric advance directives are governed in each state (www.nrc-pad.org).

Can Consumers Play a Leadership Role?

In keeping with the values and spirit of self-direction, consumers in self-directed care programs have key roles in the management and oversight of state self-directed care policy. Local self-directed care projects generally have advisory boards to work on policy and program issues and to address any consumer complaints or concerns about quality. (Some examples of state policy on consumer roles are summarized in the sidebar.)

Consumer advocates who are already actively engaged in policy and planning positions are ideally placed to raise the question of self-directed care and promote the development and funding of these initiatives.

Other ways to build the infrastructure for increased consumer leadership would be to develop networks of consumers from self-directed care projects, consumer-run programs and peer-support specialists' organizations to advance further innovations and recovery-based programming.

How Is Self-Directed Care Financed?

One aspect of self-directed care requires no additional financing, and that is giving consumers a meaningful choice when it comes to appropriate clinical treatments and standard rehabilitation services. All state systems can readily rearrange their approach to services to give consumers the option to choose their own doctor, therapist or case manager, to choose

Examples of Consumer Roles in Self-Directed Care Policy

The **Oregon** Empowerment Initiative (EI) is entirely operated and staffed by consumers who formed a nonprofit entity with a consumer governing board. The state also has a consumer task force to advise it on mental health policy at the state level, formed as Oregon was applying for a federal Real Choice Systems Change grant.

At the same time that it was developing self-directed care, **Michigan** formed the Michigan Recovery Council, with a majority of consumer members, to inform its mental health policy. Michigan also has requirements for consumers to be included in regional and state-level planning bodies, and each community mental health program must have at least two consumers on the board of directors.

Other states have appointed consumer advisory boards or networks and/or required consumer participation on the governing boards of local community mental health programs. Having consumers meaningfully involved in policy and governance enhances the state's efforts to develop recovery-oriented services.

Benefits that Can Help Consumers Achieve Life Goals

- ◆ Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) benefits
- ◆ Food Stamps
- ◆ TANF services
- ◆ One-Stop Center job search, placement and coaching
- ◆ Individual Training Accounts (through One-Stop Centers)
- ◆ Higher education federal grants and loans
- ◆ Public housing
- ◆ Earned Income Tax credits
- ◆ Section 8 rental vouchers
- ◆ Individual Development Accounts (IDAs) authorized under the Assets for Independence Act. (These are separate accounts set up for qualified low-income individuals, to which the person contributes, and a non-federal source—often the state or a private foundation—provides a match.) TANF recipients are automatically eligible for IDAs, as are recipients of earned-income tax credits if they meet other requirements. IDAs can be used to purchase a home, start a business or pay for post-secondary education.

the medication they wish to take (or choose not to take medication), to opt for supported employment instead of continued therapy, and so on. Choice among standard services is one aspect of self-directed care that should be available in every public mental health system.

While self-directed care initiatives are not expensive compared with many public mental health services, they are not free. Additional funding is needed for consumers to have the opportunity to control an individual budget that they then use for nontraditional services, supports and purchases. Self-directed care projects must also hire brokers to assist consumers with planning and training. Training, supervision and compensation of brokers are among the program's costs.

States use various funding approaches.

Policymakers must determine how to fund a self-directed care initiative. It is therefore important for consumer-advocates to appreciate the different opportunities for financing these initiatives and to know how self-directed projects in various states have been funded.

States have financed these projects primarily through state appropriations and with flexible federal funds, such as the mental health block grant program or other federal discretionary grants. Several states have also used Medicaid to fund self-directed care. This is an especially strong strategy, since Medicaid funds, unlike grants, are not time-limited. States with Medicaid waivers have significant flexibility to use these funds for self-directed care services and supports, but states can also use two basic Medicaid state plan services.

Consumer-advocates do not need to be experts on these funding sources, but they should be prepared to present relevant information to state officials in order to show that self-directed care projects do not call for large, new state spending. Fact Sheet #2 lays out financing options that consumer advocates should urge their state to consider.

The federal grants that states have most often used are Real Choice System Change Grants from the Centers for Medicare and Medicaid Services (CMS). CMS specifically encourages applicants to use these three-year grants for self-directed care. The funds are flexible and can be used for start-up costs, to pay brokers and fiscal agents, for training or retraining staff, to educate consumers, to support quality assurance and for evaluation activities. Oregon used a Real System Change grant to initiate its consumer-run project.

Iowa's pilot initiative was developed by Magellan, the state's behavioral health managed care contractor, in collaboration with Hope Haven, a psychiatric rehabilitation provider. Magellan places 2.5 percent of the money it is paid by the state into a Community Reinvestment Fund that it uses to fund pilot projects. If successful and cost-effective in the first year, pilot projects then may become institutionalized and

efforts are made to expand these initiatives statewide. Since starting a pilot project in Iowa, Magellan has also initiated a new self-directed care pilot in Tennessee for adults with psychiatric disabilities and one in Pennsylvania that allows the family to self-direct care for children with autism spectrum disorders.

Federal benefits are useful.

In addition to the dollars allocated to a specific self-directed care project, there are funds and other supports that may help consumers reach their goals, including federal programs that provide a benefit directly to the consumer. Self-directed care projects can assist consumers in taking advantage of these opportunities (see sidebar).

What Do Consumers Think of Self-Directed Care?

A key component of any self-directed care initiative is evaluation, and a critical piece of that evaluation is feedback from consumers about their satisfaction with the program and whether and how it is contributing to their recovery.

In addition to consumer-satisfaction surveys or interview protocols, several tools have been developed to measure progress on recovery goals. Consumer advocates should be ready to show policymakers that any new self-directed care initiative can readily be evaluated, using tools that have already been developed (see sidebar).

Self-directed care programs should ensure that program beneficiaries are engaged as partners in designing the plan for evaluating the project. Their involvement is important in helping to decide what aspects of self-directed care to assess and which outcomes to measure. Self-directed care initiatives typically use satisfaction surveys to solicit the views of participants, service providers, administrators and other policymakers. Overall, all consumer and other stakeholder groups that have been involved in self-directed care have reported high levels of satisfaction and also expressed general agreement that this approach is of great benefit to consumers moving toward recovery.

Evaluation Tools for Self-Directed Care

The Recovery Assessment Scale is a 41-item survey for consumers that can be used to test a person's empowerment, coping ability and quality of life. The RAS can be used prior to participation in a self-directed care program to establish a baseline, and again during or after participation to determine if these areas have improved. (See Resources list in appendix for more information.)

Oregon uses consumer-satisfaction surveys before and after participation in the state's self-directed care project. The program has developed an assessment tool that brokers administer to measure consumer independence, the capacity to self-define, the ability to work toward life goals, and the capacity to access and manage supports.

Florida has a recovery self-report survey that assesses productive days in the community and achievement of personal goals. A Functional Assessment Rating Scale (FARS) is used to assess outcomes of self-directed care. (The FARS was developed by the Louis de la Parte Florida Mental Health Institute at the University of South Florida and the District 7 Office of the Florida Department of Children and Families.)



Conclusion

States will only adopt policies that promote real self-direction by consumers if consumers themselves speak out for it.

Self-directed care is an approach that is widely acknowledged in the broader disability community as being effective, cost-efficient and popular with people with disabilities. Mental health systems, however, have been slow to adopt it even though it is seen as an essential aspect of recovery.

States will only adopt policies that promote real self-direction by consumers if consumers themselves speak out for it. Other advocates can play a critical role in supporting consumers in this advocacy, but consumers themselves will most fully appreciate the value of self-direction and choice.

The UPENN Collaboration on Community Integration and the Bazelon Center for Mental Health Law hope that this guide will help consumer advocacy groups, family organizations and other advocates, including state and local policymakers, move the mental health field forward, enabling people with mental illnesses to enjoy rewarding lives and full community integration.

Appendix

Additional Resources on Self-Directed Care

There are several useful documents regarding community integration on the website of the **University of Pennsylvania's Collaborative on Community Integration**,

www.upennrrtc.org. In particular:

- ◆ *Promoting Community Integration: Increasing the Presence and Participation of People with Psychiatric and Developmental Disabilities in Community Life*, November 1, 2006:
http://www.upennrrtc.org/resources/view.php?tool_id=32
- ◆ *Natural Supports: Developing a Personal Support System*:
http://www.upennrrtc.org/resources/view.php?tool_id=126
- ◆ *Fact sheet: Self Directed Care in Public Mental Health Systems*:
- ◆ <http://www.upennrrtc.org/var/tool/file/137-CI%20Tool%20-%20Self-Directed%20Care.pdf>

The **Substance Abuse and Mental Health Services Administration (SAMHSA)** has several items on its site. In particular:

- ◆ *Transforming Behavioral Health Care to Self-Direction*: <http://mentalhealth.samhsa.gov/publications/allpubs/SMA05-3982/default.asp>
- ◆ *Promoting Self-Determination for Individuals with Psychiatric Disabilities Through Self-Directed Services: A Look at Federal, State, and Public Systems as Sources of Cash-Outs and Other Fiscal Expansion Opportunities*: <http://mentalhealth.samhsa.gov/publications/allpubs/NMH05-0192/default.asp>
- ◆ *Competence Issues in Self-Directed Care*: <http://mentalhealth.samhsa.gov/publications/allpubs/NMH05-0195/default.asp>

SAMHSA also funds **The National Empowerment Center**: <http://www.power2u.org/>

- ◆ *Personal Care Attendant (PCA) services available to people with psychiatric disabilities*, by Patricia Deegan, Ph.D:
<http://www.power2u.org/articles/selfhelp/pca.html>
- ◆ *Consumer-Directed Transformation to a Recovery-Based Mental Health System*:
<http://www.power2u.org/downloads/SAMHSA.pdf>

The **University of Illinois, National Research and Training Center on Psychiatric Disability** offers information and training on self-determination for individuals with psychiatric disabilities, with a range of written materials and presentations: <http://www.psych.uic.edu/uicnrtc/>

The website for Wellness Recovery Action Planning (WRAP), a nationally acclaimed self-management and recovery program pioneered by Mary Ellen Copeland in collaboration with other individuals, offers tools, strategies, educational materials, and guidance:

<http://www.mentalhealthrecovery.com>

The National Resource Center on Psychiatric Advance Directives (NRC-PAD), a joint project of the Bazelon Center for Mental Health Law and the Department of Psychiatry, Duke University Medical Center, offers timely information on PADs for consumers, family members, clinicians and policy makers. Its website includes forms for creating a PAD and details of state laws governing PADs: <http://www.nrc-pad.org>



In the Driver's Seat: Fact Sheet #1

What Is Self-Directed Mental Health Care?

History of the Self-Directed Care Approach

Self-directed mental health care recognizes the value of helping individuals to identify their goals for recovery and create and implement a plan to meet these goals. Unlike the traditional mental health system, where providers decide what consumers need, self-directed care acknowledges that consumers can manage their own care, choosing services and providers and having available the funds to pay for recovery-oriented services, supports and other necessary purchases.

A self-directed care plan focuses on consumers' lives as a whole, not just their mental health problems. It starts with the assumption that it is possible for them to regain direction and control of their lives. While traditional services may be a component of a recovery plan, self-directed care involves services and supports that are not normally thought of as mental health care.

As states move to transform their mental health systems and to adopt the recommendations of the President's New Freedom Commission on Mental Health, self-directed care should become a core focus. The Commission recognized that critical elements of recovery are being able to make choices and having access to services that increase well-being and support independent living and employment.

Self-directed care has been tested through policies and programs for people with physical and developmental disabilities, with very positive outcomes. For example, under the Cash and Counseling program (a joint initiative of the Robert Wood Johnson Foundation and the federal Centers for Medicare and Medicaid Services), states found that self-direction benefited consumers by "improving their quality of life, increasing their satisfaction, and reducing their unmet care needs—without increasing costs when compared to a well-functioning traditional care system."¹

CMS describes self-directed care approaches as having four essential implementation features:²

- ◆ Person-centered planning, which is a "comprehensive strategy for putting necessary services and supports in place to help people achieve their goals;"
- ◆ Supports brokerage, which includes both education and operational assistance and is intended to help participants design and manage their self-directed care plans;
- ◆ Individual budgeting, which enables people needing assistance to have some control over how the funds used for their care are to be spent; and
- ◆ Financial management, which encompasses such activities as tracking and monitoring budgets, performing payroll services and handling billing and documentation.

Self-Directed Care in Public Mental Health Systems

For populations with other disabilities, self-directed care has most often meant controlling personal-assistance funds and making decisions on hiring and firing of personal assistants and on the purchase of additional services and supports. In public mental health, several pilot projects have tested the approach of an individual budget, allowing consumers to purchase services, supports and items that they believe will help them in their recovery but which would otherwise be unavailable to them. In these pilots,

consumers develop a spending plan, which must be approved before funds are expended, and are offered assistance in managing the resources. While many projects allow spending for a wide range of purposes, there is often an emphasis on supports to help people become employed, improve health habits or further their education.

Consumers in self-directed care projects remain eligible for traditional services, paid in traditional ways, but typically they also have more meaningful choices among these services and providers. Participants may choose their case managers or physicians, for example, or opt out of an assertive community treatment team and access other services instead.

Self-directed care for consumers in the public mental health system has several features:

- ◆ Participation is voluntary and consumers can leave the program at any time.
- ◆ Consumers receive education or training on how to plan and manage their resources.
- ◆ Brokers (sometimes termed coaches or facilitators) are hired to help consumers through the process; often these are trained consumer peers.
- ◆ The overall plan for expenditure is approved in advance, but individual purchases need not be approved unless they are large.
- ◆ There is considerable flexibility in how the money can be spent, although there are generally a few prohibitions.
- ◆ If consumers will be hiring staff, such as personal assistants, a fiscal agent is engaged.
- ◆ Individual budgets are modest— \$2,000-\$5,000 per person—and generally available for a short period of time, typically one year.
- ◆ Crisis services, inpatient care and residential services are not included within the budget; only some projects include the cost of other outpatient clinical services.

Self-directed care projects in public mental health systems have been evaluated and found effective in promoting good outcomes, such as:

- ◆ more consumers living independently;
- ◆ higher rates of employment;
- ◆ greater participation in higher education; and
- ◆ high levels of participant satisfaction.

Financing Self-Directed Care

States that have piloted self-directed care have used various funds to initiate the program and fund individual budgets, including federal discretionary grants, federal block grants and state general funds. Medicaid is also used to fund services and supports through managed care waivers or the personal care option. (See Fact Sheet#2, *Financing Self-Directed Mental Health Care.*)

-
- 1 Cash and Counseling FAQs, Cash & Counseling National Program Office at <http://www.cashandcounseling.org/about/FAQ>
 - 2 Centers for Medicare and Medicaid Services, Department of Health and Human Services at www.cms.hhs.gov/IndependencePlus/



In the Driver's Seat: Fact Sheet #2 Financing Self-Directed Care

This Fact Sheet summarizes how self-directed care initiatives have been financed. This information can be useful to advocates and others considering how to start and sustain new projects.

Flexible Funds

Although in short supply, flexible federal, state and local resources are often the best source for funding consumers' small individual budgets. Monies may be obtained from federal discretionary grants, federal block grants to states and general fund appropriations by state and local governments.

Federal discretionary funds available for self-directed care include Real Choice Systems Change Grants from the Centers for Medicare and Medicaid Services (CMS). These are three year grants focused on various topics, such as person-centered planning and consumer-directed services.

- ◆ Oregon received a Real Choice Systems Change Grant for development of initiatives to promote access to housing, consumer choice, training and personal assistance in the public mental health system. Funding went to pilot demonstrations, including the Empowerment Brokerage Initiative, now an incorporated nonprofit organization directed and run by consumers, and CLASS, an educational initiative to encourage public mental health system beneficiaries to take advantage of self-directed personal care services that had rarely been used by people with psychiatric disabilities.

For the latest information on the priority area for these grants, see

http://www.cms.hhs.gov/RealChoice/01_Overview.asp

The Mental Health Block Grant is another potential source of funds. Block grant money may be used for various purposes and some states have used it to finance self-directed care.

- ◆ Michigan used federal block grant funds to promote and support its self-directed care initiative by funding a consumer cooperative and peer support services around the state.

Other federal funding streams can supply revenue to states that can be used to finance the types of services and supports that help consumers with their recovery; nothing in those programs would prevent the consumer from self-directing those funds. These include the Social Services Block Grant (Title XX of the Social Security Act) and services funding under the Temporary Assistance for Needy Families (TANF) program.

Using Medicaid for Self-Directed Care

The most significant source of funds for self-directed mental health care is Medicaid. Two Medicaid waivers can expand service options to include a range of non-traditional supports and two state plan options can also support self-directed care.

Waivers

Under Section 1915(b) Medicaid waivers, states have the specific option of using funds saved through the use of managed care to finance additional services (as authorized by § 1915(b)(3)). States

have used this flexibility to add services and supports not normally funded by Medicaid, including peer supports and employment or education supports and other aspects of a self-directed care initiative.

- ◆ Michigan has a § 1915(b) Medicaid waiver which allows it to require that consumers sign up for managed care plans (which in Michigan are run by the community mental health centers). Using the authority of § 1915(b)(3), Michigan has received CMS authorization to use Medicaid funds to pay for services and supports that are not normally covered under Medicaid. Using that authority, Michigan is paying for fiscal intermediary services and peer supports with Medicaid funds.
- ◆ Iowa also has a § 1915(b) Medicaid waiver and uses that authority to pay for additional services. Under the authority of § 1915(b)(3), the managed behavioral health care company puts 2.5 percent of its capitation payment into a fund for innovative projects. This money has been used to pilot a self-directed care project and it is expected that the initiative will expand throughout the state over time. Consumers are given individual budgets to spend on a range of services, supports and purchases from this innovation fund.

Under Section 1115 waivers, states have even greater flexibility to reorganize their programs. These are research and demonstration waivers that can be used for a variety of purposes, as long as the overall costs to Medicaid are no more than would have been spent under the traditional program. CMS has made clear that a § 1115 waiver could be used to create a self-directed care program, although the approval process can be lengthy.

State Plan Options: Personal Care Services

States have the option in their state Medicaid plan to offer personal care services, which have been used extensively to give people with physical disabilities and families of individuals with developmental disabilities the ability to self-manage care.

With the self-directed care approach, the hiring and firing as well as the day-to-day supervision of the personal assistant becomes the consumer's responsibility. In addition, states have been able to provide the flexibility for consumers to use the funds allocated to them for purchasing other services and supports and to pay for personal care assistance (allows a family member to be hired to provide specified services). Despite its growing and widespread use among other populations, few states use the personal care services option for mental health consumers.

- ◆ Oregon has a project to allow consumers to self-direct the services of a personal assistant, whose time and costs are paid by Medicaid. Personal assistance services for people with disabilities are covered under the state Medicaid plan. Consumers are responsible for selecting and hiring caregivers and, with the help of a broker, they negotiate contracts, do background checks, file employer forms, and train and supervise the personal assistant.

Federal policy now makes it relatively easy for a state to offer self-directed personal assistance services. The Deficit Reduction Act of 2005 (PL 109-171) created a new section, 1915(j), of the Medicaid law giving states the option of providing self-directed personal assistance services without regard to Medicaid requirements of comparability or statewideness. To help states implement this option, CMS has a state plan amendment pre-print and has explained its policy on self-directed personal care in a letter to state Medicaid directors dated September 13, 2007 (accessible at <http://www.cms.hhs.gov/SMDL/downloads/SMD091307.pdf>).

State Plan Options: Home- and Community-Based Services

Section 1915(i) of the Medicaid law, as amended by the Deficit Reduction Act in 2005, authorizes states to offer home- and community-based services to adults and children without a waiver. The services that can be provided include psychosocial rehabilitation, habilitation and case management. Under this option, there is no requirement for budget neutrality (as there is under the home- and community-based services waiver) and eligibility is based on income and functional need. The income limit requires that individuals have incomes at or below 150% of poverty, although children can become eligible without regard to their parents' income, if the state so chooses.

Section 1915(i) services need not be offered statewide and states are allowed to cap the number of enrollees and create a waiting list for services.

Federal law specifically encourages that services furnished under Section 1915(i) allow consumers to self-direct.

- ◆ Iowa uses § 1915(i) to finance a range of services not normally covered by Medicaid to adults who have significant psychiatric disabilities. Eligibility criteria include diagnosis, functional status, having a history of care and difficulty with daily-living skills and employment. Services covered include pre-vocational services, home-based habilitation, day habilitation and supported employment.

Other states are now considering the § 1915(i) option. They are encouraged to ensure that consumers have greater choice and ability to self-direct their care.

Self-Directed Care Without Additional Funding

Some aspects of self-directed care in public mental health systems may need no special financing. For example, it should not increase public systems' costs, for example, to allow consumers to choose providers and select the type of services they will receive based on the existing array of services, but it will increase the likelihood that consumers will feel satisfied and benefit from the care provided. States with self-directed care projects have given consumers greater choice over existing mental health benefits.

- ◆ Florida uses Medicaid funds to pay for the clinical services over which consumers have been given greater control and choice, including the ability to request that a provider of their choice be added to the list of providers available to self-directed care participants.
- ◆ Michigan amended its mental health code in 1996, requiring community mental health services programs to conduct individualized person-centered planning and provide opportunities for consumers to control and direct their services and supports, including an individual, self-directed budget.

Long-Term Fiscal Benefits of Self-Directed Care

Self-directed care initiatives that provide individual budgets for purchases and other supports to aid consumers in their recovery will require an investment of resources. Given that the number of participants in these pilot initiatives has been quite small, states have found they must come up with additional funding to develop the infrastructure to support the initiative. Any savings that might accrue from reduced use of higher cost, more intensive services will be insufficient to off-set these infrastructure costs initially.

Results from Florida, Oregon and Iowa suggest that self-directed care is a wise investment. As overhead costs are distributed over a larger population, economies of scale may net greater savings. Florida and Oregon, the two projects in existence the longest, are finding self-directed care participants gaining ground in employment and independent living, experiencing fewer crises and avoiding hospitalization. If a substantial number of individuals participate and the results continue to be as favorable, the savings overall could be quite significant.

Thus, while an initial investment in personnel and administrative costs (brokerage costs and training) and for allocation to individual budgets will be necessary, the potential for reducing the total cost due to reduced consumer demand for other services should not be ignored.



In the Driver's Seat: Fact Sheet #3 State Initiatives on Self-Directed Care

States That Have Implemented Self-Directed Care

◆ Oregon: Empowerment Initiatives Brokerage

Empowerment, Inc. is a brokerage run by an independent nonprofit that is operated and governed by consumers. The brokerage operates in two counties and can serve 40-50 people. Each consumer in the program has a budget of up to roughly \$3,000 to spend over a one-year period to help with recovery—for work, home environment, hobbies, education, spirituality, etc. The program was funded initially with a federal Real Systems Change grant and has received high satisfaction ratings from its participating consumers.

◆ Oregon: CLASS Initiative

The Community Living Assistance and Support (CLASS) initiative engages consumers in learning communities to educate and support them in exercising their option under the state's Medicaid program for personal care services. A six-week training helps people develop the knowledge and skills to utilize personal assistance services and supports effectively. The training teaches about application procedures, choosing a provider, all facets of hiring, directing the personal assistant and resolving any conflicts. The project covers four counties. Twenty hours of personal assistant services are available, which can relate to nutrition, medication management, housekeeping, personal hygiene and medical appointments.

◆ Iowa Self-Directed Care

Consumers in Iowa can design and manage a self-directed care plan and a Recovery Purchasing Plan, which allows them to manage a budget of up to \$2,000. Consumers are supported by life coaches (provider-brokers working for a psychiatric rehabilitation agency) and the agency serves as the fiscal intermediary. Proposed expenditures in the consumer's plan must be approved by Magellan, the entity that manages Iowa Medicaid's mental health benefits. Consumers complete a Recovery Assessment Scale once a month. Expenditures can be made for a wide range of services and items that can lead to employment or independent community living.

◆ Florida: Self-Directed Care Projects

Florida's self-directed care initiative operates in two counties and the intent is to make self-directed care an option statewide. Participants have a recovery coach and engage in a process of planning that begins with a Life Analysis to address personal strengths and weaknesses, environmental and community opportunities and supports, health concerns, and education and employment history. A Life Action Plan is then drawn up identifying the services and supports the individual chooses. Each consumer has a one-year budget—up to \$2,000 for Medicaid beneficiaries and up to about \$4,000 for the uninsured, of which 48% must be used for clinical services. (Note: The budget varies, as the uninsured must use their personal budgets to fund clinical services, whereas these services are covered by Medicaid and its beneficiaries do not have to use their individual budgets to obtain this type of care.)

◆ **Michigan: Self-Directed Care Initiative**

Unlike other states, which have policies authorizing pilot projects, Michigan has several statewide policies to support self-directed care. These include a person-centered planning mandate that allows individuals to choose an independent facilitator or case manager for self-directed service planning. The state mental health agency supports training for peer support specialists, who are covered providers under the state Medicaid program, and a network to link peer specialists. Policies are in place allowing consumers to opt for an individual budget, but the option is still in the planning stages in most areas of the state and is not yet available statewide. Consumers with individual budgets can use these funds for various services and supports or for personal assistants. A fiscal agent helps consumers with financial management.

◆ **Maryland**

Maryland developed a Self Directed Care Pilot Project in February 2007 in western Maryland, using the Center for Self-Determination's framework of "tools" for self direction (i.e., independent brokerage, individual budgets and fiscal intermediaries) to support an individual's recovery and autonomy. Brokers, who are called Peer Support Advocates, are on the staff of a mental health consumer-operated wellness and recovery center, the Office of Consumer Advocates. The project is for people in the public mental health system who currently meet, or have met within the past two years, the level of care determination for supported employment, case management, psychiatric rehabilitation program or mobile treatment services.

◆ **Tennessee**

Slated to begin in July 2007, self-directed care projects in Memphis and Chattanooga are being piloted to adults in the state Medicaid program who are identified as severely and persistently mentally ill. Through person-centered planning, more than 65 consumers are expected to have the opportunity to develop a recovery plan that identifies funding needs up to \$2,000 for an individual budget designed to assist participants with recovery goals. The projects have been initiated by a Medicaid managed mental health care company, Magellan.

◆ **Texas**

In addition to the initiatives described above, The National Center on Research and Training at the University of Illinois-Chicago will implement and evaluate a pilot project in the Dallas (TX) area, giving participants control of the funds that are spent for their recovery. Those who consent to be in the project will be randomly assigned to one of two groups: the services-as-usual group or the self-directed group, which will feature person-centered planning and individual budgets that are tied to recovery goals. The project includes fiscal intermediaries to supply vouchers for purchases and services in participants' pre-approved plans and help with payroll services if personal assistants are hired.