Free To Choose

Transforming Behavioral Health Care to Self-Direction

Report of the 2004 Consumer Direction Initiative Summit

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Substance Abuse and Mental Health Services Administration
Center for Mental Health Services
www.samhsa.gov

Free To Choose

Transforming Behavioral Health Care to Self-Direction

Report of the 2004 Consumer Direction Initiative Summit

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Substance Abuse and Mental Health Services Administration
Center for Mental Health Services
www.samhsa.gov

ACKNOWLEDGMENTS

Numerous people contributed to the development of this document (see Appendix A). The document was written by Richard H. Dougherty of Dougherty Management Associates, Inc., under contract number 03M000259 with the Substance Abuse and Mental Health Services Administration (SAMHSA), U.S. Department of Health and Human Services (DHHS). Carole Schauer, Ruby Neville, and Cathy Nugent served as the Government Project Officers.

DISCLAIMER

PUBLIC DOMAIN NOTICE

ELECTRONIC ACCESS AND COPIES OF PUBLICATION

This publication may be accessed electronically through the following Internet World Wide Web connection: www.samhsa.gov. For additional copies of this document, please call SAMHSA's National Mental Health Information Center at 1-800-789-2647 or 1-866-889-2647 (TDD).

RECOMMENDED CITATION

Free To Choose: Transforming Behavioral Health Care to Self-Direction. DHHS Publication No. SMA-05-3982. Rockville, MD: Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, 2005.

ORIGINATING OFFICE

Office of Consumer Affairs, Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, 1 Choke Cherry Road, Rockville, MD 20857.

DHHS Publication No. SMA-05-3982
Printed 2005

CONTENTS

OVERVIEW

Self-directed health care is emerging as a critical element in the transformation of America's health care system. Two of the factors that are driving this trend are the recent increases in the cost of health insurance and health services and the inconsistent quality of health care. Both private and public health care delivery systems are responding by developing new consumer-directed products. The President's New Freedom Commission on Mental Health has called for the development of consumer-driven models of care and system changes to support community-based services in behavioral health care. All components of the health care system urgently need to become more consumer-centered; behavioral health services are no exception.

Consumer involvement in behavioral health care systems and programs is a primary value of the Substance Abuse and Mental Health Services Administration (SAMHSA) within the U.S. Department of Health and Human Services (DHHS). For many years SAMHSA has supported consumer advocacy, consumer-operated services, and peer recovery programs. In April 2003, SAMHSA held a self-determination planning meeting that recommended that the agency design a consumer-directed health care initiative for persons with mental illnesses and/or substance use disorders. Accordingly, SAMHSA hosted a Consumer Direction Initiative Summit on March 22-23, 2004, in Washington, DC.

The Consumer Direction Initiative Summit convened recipients of mental health and addiction services and family members, policymakers, providers, and State and Federal representatives. In total, 79 people attended, participated in an in-depth discussion of the issues, and worked to develop recommendations for SAMHSA's next steps towards fostering a more consumer-directed approach in behavioral health care services for people with substance use disorders and mental illnesses and children with serious emotional disturbances. Through a combination of papers, presentations, and discussions, workgroups at the Summit identified specific needs of consumers and potential barriers to self-directed behavioral health care. They developed their visions for a self-directed care service system and formulated recommendations for SAMHSA that seek to transform the delivery of behavioral health services. At the end of the meeting, the recommendations were presented to the directors of the Center for Substance Abuse Treatment (CSAT), the Center for Mental Health Services (CMHS), and the Center for Substance Abuse Prevention (CSAP) within SAMHSA. The directors then presented their perspectives on the work that had been accomplished.

The term "consumer direction" was used in planning the SAMHSA Summit because it has been widely accepted in the general health care field to refer to health care organization and delivery that encourages consumerism among people receiving services. However, in the mental health and substance abuse fields, this term sometimes has a negative connotation. For this reason, the term "self-direction" is used in this report. When the term "consumer" is used, it is intended to refer to recipients of mental health and substance abuse services.

This summary of the Summit is intended to provide an overview of the many issues raised in the working papers prepared for the Summit and during the meeting itself. The working papers are listed in the references and are available on the Web at **www.mentalhealth.samhsa.gov/consumersurvivor** under “Featured Publications.” Some of the topics and many of the themes from the papers have been summarized. In addition, a summary of the workgroup discussions and their specific recommendations have been provided. Taken together, these present the thoughts and perspectives of the participants and provide a basis for those working to develop consumer direction initiatives at any level—local, State, and Federal.

I. WHAT IS SELF-DIRECTED CARE?

The term "self-directed care" has been defined as a system that is "intended to allow informed consumers to assess their own needs . . . determine how and by whom these needs should be met, and monitor the quality of services they receive" (Dougherty, 2003). As defined by one of the papers prepared for the Summit, it refers to a system "in which funds that would ordinarily be paid to service provider agencies are transferred to consumers, using various formulas to account for direct, administrative, and other costs" (Cook et al., 2004).

The Federal Centers for Medicare and Medicaid Services (CMS) identify four essential elements of self-directed care (Cook et al., 2004):

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

Each of these elements must be addressed in implementing self-directed care.

"We have to begin to view parents as a real and aggressive resource in solving problems in children's lives and not be thinking of them as part of the problem as well."

State Official

There are differences in the operation of self-directed care for various groups of service participants, however. For example, young children are likely to depend on their families or caregivers to direct their care. When they reach adolescence, or for some children perhaps earlier, they may become capable of participating in decisions more directly. Even if families are able to direct some of the care for their children, however, there are special challenges associated with the children's system of care. As professionals and advocates noted at the conference, children's mental health services are often funded by other agencies such as education, child welfare, and juvenile justice. Thus, without a concurrent transformation in these other sectors, self-directed care for children and their families may be difficult to realize.

Self-directed care is closely related, although not identical, to both a recovery orientation and self-determination. In its vision statement, the President's New Freedom Commission on Mental Health "envisions a future when everyone with a mental illness will recover" (NFC, 2003). The Commission went on to define recovery as "the process in which people are able to live, work, learn, and participate fully in their communities . . . Science has shown that having hope plays an integral role in an individual's recovery" (NFC, 2003). Self-directed care can help individuals with mental illness and substance use disorders achieve recovery, in part because it empowers these individuals and makes the service delivery system more "consumer" oriented.

Self-determination is a philosophy designed to help persons "build [meaningful lives] with effective opportunities to develop and reach valued life goals" (Cook et al., 2004). It "focuses on the degree to which human behaviors are volitional . . . that is, the extent to which people . . . engage in [their] actions with a full sense of choice" (Cook et al., 2004). As Nerney (2001) states, self-determination is based on five principles:

- *Freedom* to live in the community;
- *Authority* over the funds needed for one's own care;
- *Support* for participants' efforts to make the choices that are best for them;
- *Responsibility* for managing finances, choosing services, and handling the tasks of daily living, and for the appropriate use of public funds; and
- *Confirmation* or *Participation*, that is, the opportunity for service recipients to participate in decision making about the care delivery system.

Self-directed care is . . .
"A process to help you discover who you are, your needs, your dreams, the future of your choosing."

Participant in FloridaSDC

Self-directed care represents one method for achieving the goals of self-determination and ultimately of a recovery-oriented system through changes in financing and the elimination of third parties in the health care system.

Self-directed care also should be distinguished from consumer-operated services or peer support services. "Consumer-operated" services are operated and administratively controlled by consumers and generally emphasize self-help. "Peer support" services are delivered by consumers and/or family members, but they may or may not be consumer operated. Because these kinds of services expand the options available to service recipients, and because they maximize opportunities for recipients to participate in the system, both should be included in a full array of services in a self-directed system of care.

The substance abuse field pioneered the concept of peer support services with the development of Alcoholics Anonymous 70 years ago. But both the nature of alcohol and drug disorders and the system that treats them can present constraints to self-directed care. As Edwards and McCarty (2004) point out, "substance use disorders are not recognized and people do not seek care until they are on a downhill course, compromising their ability to make choices." Moreover, like the need for mental illness services, the need for substance abuse services significantly exceeds the capacity of the system, thus reducing the ability of individuals needing services to freely choose them.

"Nothing about me without me."

Advocate

As conceptualized here, self-directed care in publicly funded services is not identical to "consumer-driven health care" as that concept is defined by some in the private sector, although there are many similarities between the two. Both concepts promote greater choice and decision making by individuals receiving services. Publicly funded, self-directed care does not, however, refer to medical savings accounts, health reimbursement arrangements, or unified health accounts, all of which attempt to compensate for inadequacies in employer-sponsored health insurance systems through tax savings from contributions to these accounts (Scandlen, 2003, April 7). Nevertheless, in publicly funded self-directed care, individual accounts may also be used to pay for certain services as a part of the benefit package.

Participants in the April 2003 conference on the development of a SAMHSA Self-Determination Initiative recommended that SAMHSA "should articulate a set of bedrock principles . . . completely changing the way consumers and their families are thought about and how they think about themselves" (SAMHSA, 2003). These principles should, they said, include peer support as an integral aspect of recovery (i.e., involve consumers and their families from research design to service delivery); real choice and control over services; and a recognition of the importance of the central role of consumers and their families in policy and service delivery.

It is important to acknowledge that, as with any new concept, there is some uncertainty about the specific operational details of self-direction. Questions remain, for example, about

- What services are needed and wanted by individuals;
- How self-direction applies to and should be implemented for various groups of services/supports participants;
- Who provides what type of education about self-direction to participants;
- How a fiscal intermediary should function with multiple sources of funding;
- How the pricing of services is determined; and, perhaps most important,
- Which services of those wanted by individuals meet the requirements for Medicaid reimbursement.

However, much can be learned from the significant work that has been done with the implementation of self-directed services for older adults and people with disabilities and from the growing number of programs and services that seek to achieve self-direction in behavioral health.

II. SELF-DIRECTED CARE VALUES

The concept of self-directed care is based on sets of values and principles at the individual, the behavioral health care system, and the larger society levels. The values and principles that were identified by Summit participants and in the papers presented at the Summit are described here.

INDIVIDUAL LEVEL VALUES

At the individual level, the principles and values include

- **Freedom of choice**
- **Control over one's own life**
- **Personal responsibility**
- **Access to services and support**

Freedom of Choice in a Context of Recovery and Hope

In the vision of the President's New Freedom Commission on Mental Health, consumers will have a personalized health management program that they will design and develop.

> *In a transformed mental health system, a diagnosis of a serious mental illness or a serious emotional disturbance will set in motion a well-planned, coordinated array of services and treatments defined in a single plan of care. This detailed roadmap—a personalized, highly individualized health management program—will help lead the way to appropriate treatment and supports that are oriented toward recovery and resilience. Consumers, along with service providers, will actively participate in designing and developing the systems of care in which they are involved.* (NFC, 2003)

That is, each participant's "roadmap," intended to move him or her toward recovery, will include an array of services that he or she has helped to choose. Self-directed care is vital to a recovery-oriented system.

In March 2003, SAMHSA announced the Access to Recovery (ATR) Program, a new, $100 million initiative that allows people seeking drug and alcohol treatment to use vouchers to pay for a range of appropriate community-based services. Consumer choice is one of the core principles on which ATR is founded. This is in recognition of the fact that the process of recovery is a personal one. Achieving recovery from substance use disorders can take many pathways: physical, mental, emotional, or spiritual. With a voucher, people in need of treatment and recovery support will be able to choose the programs and providers that will help them the most. Increased choice encourages quality.

Access to Recovery and other new initiatives (including the Community Support Program, the Recovery Community Services Program, and technical assistance centers run by consumers) come after years of work by SAMHSA to lay the groundwork for self-direction and develop the role of "consumers" in the field.

"Consumer direction for me. . . made substance abuse treatment successful. It made all the difference in my treatment and recovery—my quality of life."

Advocate

Control Over One's Own Life: A Shift in Power

The most fundamental change that a self-directed care program makes is a shift in power within the treatment system, from a system that is dominated by the needs, concerns, and interests of payers and providers to one that focuses explicitly on the needs of individuals with behavioral disorders. This shift in power requires reeducating mental health and addictions professionals and consumers in how control will be exercised in a recovery-based culture. Instead of the old concept of control as control of one person over another, which relies on compliance, self-directed care necessitates shared control based on a partnership between provider and consumer.

"To choose a path of recovery specific to my needs; to reclaim and restore my life."

Participant in FloridaSDC

For example, in the Florida Self-Directed Care (FloridaSDC) program, the participant may choose a life coach and plan for recovery through an "array of services, service frequency and duration, personal goals, benchmarks for measuring progress, and other factors which are necessary to achieve self-defined recovery within an established budget." Having developed a plan, the FloridaSDC participant selects providers of the services that will be purchased (from among providers in the network). Although services that are purchased on a capacity basis, such as residential and emergency programs, are excluded, FloridaSDC participants nevertheless exercise substantial control over the services and supports that they receive. Similarly, in children's services, families must be part of the solution at every level of care. (Read more about FloridaSDC on page 23.)

Personal Responsibility: A Reframing of Competence Issues

In self-directed care programs, individuals are expected to accept personal responsibility. Thus, self-directed care programs are likely to provide the impetus for reconceptualizing "competence" issues that arise regarding participants. This entails an important paradigm shift for providers and managers and for individuals with mental illnesses themselves. For example, policymakers might ask, "Should there be any prerequisites to participation in a self-directed care program?" and "What limitations on choice should be imposed?" rather than asking "What is the standard of competence, if any, for participation in self-directed care programs for people with psychiatric disabilities?" (Stefan, 2004). If we ask not about limitations, but instead "How will the program help individuals succeed in self-direction," then we can develop the needed supports for true self-direction.

"A few years ago we argued about whether people could live outside the institutions, then we were arguing about whether they could work, have a social life, and now we are arguing about whether people can make decisions about their own care."

Advocate and Professional

Shifting the paradigm suggests solutions to potential problems. As Stefan (2004) says,

> *In order to succeed, programs of self-directed care must include contingency and crisis planning, including the use of advance directives, health care and other forms of proxies, use of fiscal intermediaries, and other ways to ensure that a person's choices are understood and respected. With proper planning, competence should rarely, if ever, be a concern in self-directed care for people with psychiatric disabilities.*

Access to Services and Support

In the commercial marketplace for goods and services, it is assumed that consumers will have access to what they want to purchase, or the marketplace will evolve to create these goods or services. In the world of publicly funded human services, however, this assumption is not always viable. Some programs may have waiting lists, and other services may not exist in close enough proximity to the individual who needs them. Thus, one value underlying the development of self-directed services in behavioral health is that current and new providers will develop new services so that participants will have access to the services and supports they want and need, including services that are culturally and ethnically appropriate.

BEHAVIORAL HEALTH CARE SYSTEM LEVEL VALUES

Self-directed care also solidifies a set of values at the level of the health care system. These values include

- **Consumer satisfaction and service quality**
- **Efficiency and effectiveness**
- **Cost effectiveness**

> ". . . self-direction measures the adequacy of the services, the person's control of these services, and the person's satisfaction with them."
>
> *Technical Assistance Provider*

Consumer Satisfaction and Service Quality

When individuals with behavioral health problems participate in directing their own care and in making the decision to continue purchasing these services, they implicitly evaluate their quality. At the Summit, Cook stated that studies of self-directed care nearly all find that consumer satisfaction with self-directed services is significantly higher than with traditionally delivered services. Nerney (2004) argues that the professional standards of quality embodied in accreditation and quality assurance systems tend to incorporate measures of satisfaction with services without establishing an expectation that "individuals with disabilities will achieve a life considered meaningful by other, non-disabled individuals." "The end result of this approach," he says, "is to measure satisfaction with human service environments and human service interventions, no matter their relevance to what constitutes quality for every American." He therefore proposes that we "look at outcomes for people with disabilities in the context of the expectations and aspirations shared by all humans, not just standards specific to the human service system."

Efficiency and Effectiveness

A rational service delivery system is one that delivers care that is timely, effective, and efficient—that is, care that achieves what it intends with the use of the fewest resources. Self-directed care can contribute toward both efficiency and effectiveness by empowering individuals to evaluate their own needs and to select services that meet them. Furthermore, individuals who are responsible for managing their own "accounts" begin to treat the funding as an asset rather than an entitlement. This change in thinking is crucial to achieving efficiency in public behavioral health care and to fostering self-determination.

Cost Effectiveness

Given the financial and regulatory constraints in public behavioral health, relative cost is an important factor in developing any new program. In home and community (1915c) and freedom of choice (1915b) waiver programs funded by CMS and States, budget neutrality is a basic criterion for approval of the waiver. That is, the new program should not increase net costs to the existing system. Self-directed care programs have been found to be cost-effective alternatives and meet the budget neutrality criterion. Cash and Counseling programs were developed in three States and funded by the Robert Wood Johnson Foundation and DHHS to provide self-directed personal care services for people with developmental and physical disabilities and older adults. The evaluation of these programs conducted by Mathematica (Phillips et al., 2003) found that outcomes of participants in Cash and Carry Counseling were as good as or even better than outcomes of participants in usual fee-for-service (FFS) programs, and the cost was the same or less. Cash and Counseling participants received more services than their FFS counterparts, but by the end of the second year of the program, budget neutrality prevailed (i.e., Cash and Counseling did not cost more than FFS). A number of other States and localities have replicated these programs with similar findings.

SOCIETAL LEVEL VALUES

“Even within the paradigm of self-directed services, it is entirely possible for an individual to . . . freely choose individual providers of service, be ‘satisfied’ . . . and yet, live a life of continued poverty, without love, romance, or deep relationships.”

Technical Assistance Provider

In addition to the individual and systemic values that underlie self-directed care, there is a set of important societal principles and values. These include

- **Protection of civil liberties**
- **Fairness**
- **Freedom from coercion**
- **Use of free market forces**

Protection of Civil Liberties

Civil liberties, the rights and freedoms that citizens enjoy in a democratic society, are often abridged among individuals with disabilities, including those with mental health and substance use problems. By giving individuals the right to make purchasing decisions on their own behalf, self-directed care programs enhance participants’ civil rights, including freedom from discrimination, the right to due process, and the right of personal autonomy.

Fairness

One of the most important values in the United States is that of fairness—the right of every individual to receive equal or comparable treatment. Enabling individuals with behavioral disorders to manage their own lives in ways that are more similar to the ways in which nondisabled individuals do represents a significant step toward achieving fairness.

Freedom From Coercion

Coercion, implicit or explicit, is a frequent component of human service and health care systems, particularly behavioral health care systems. Implicit coercion occurs when people are presented with little or no choice of services and are therefore coerced into accepting what is available. Explicit coercion arises when people are mandated to receive treatments/services they do not desire or are treated against their will. Self-directed care programs can help to reduce this type of coercion by helping people design their own crisis management plans and define actions to be taken when they are unable to act on their own behalf.

Use of Free Market Forces

Nearly all sectors of U.S. society are subject to market forces. Often, however, human services providers and those who receive care from them function outside the normal market structure, with limits on the ability to negotiate with recipients, third party purchasers, and government intermediaries. Enabling individuals with disabilities to become active in the marketplace by encouraging them to choose and pay for their care represents another means of integrating them into the larger society. Specifically, with funds, and therefore power, shifted away from providers to individuals with behavioral health care needs, these individuals become true "consumers." Providers will need to sell themselves and their services to these consumers.

▼

"We, the people who use the services, have to be involved at every level."

Advocate

III. SELF-DIRECTION—ESSENTIAL FOR SYSTEM TRANSFORMATION

Self-directed care is of particular importance to the behavioral health care system because it represents one tool that can help transform the system to achieve the intent of the Olmstead decision and the President's New Freedom Commission on Mental Health. Summit participants discussed these as well as the Institute of Medicine (IOM) *Crossing the Quality Chasm* report (IOM, 2001), trends in the commercial health insurance sector, and new SAMHSA programs that may contribute to advancing the concept of self-directed care.

ACHIEVING THE INTENT OF OLMSTEAD

The U.S. Supreme Court, in its 1999 *Olmstead* v. *L.C.* decision, determined that the unnecessary segregation of individuals with disabilities in institutions may constitute discrimination based on disability. The Court ruled that the Americans with Disabilities Act may require States to provide community-based services rather than institutional placements for individuals with disabilities. States, however, face many challenges as they attempt to bring themselves into compliance with this decision. Integrating individuals with serious mental health and substance use disorders into communities requires that housing and services be accessible. Self-directed care, implemented on a large scale, offers the potential of helping the system move in this direction.

ACHIEVING THE VISION OF THE NEW FREEDOM COMMISSION

The New Freedom Commission on Mental Health's Goal 2, "Mental Health Care Is Consumer and Family Driven" incorporates a series of recommendations, several of which relate to self-directed care:

- **Develop an individualized plan of care for every adult with a serious mental illness and child with a serious emotional disturbance.**
- **Involve consumers and families fully in orienting the mental health system toward recovery.**
- **Align relevant Federal programs to improve access and accountability for mental health services.**
- **Protect and enhance the rights of people with mental illnesses.**

Develop an Individualized Plan of Care for Every Adult with a Serious Mental Illness and Child with a Serious Emotional Disturbance

In the Commission's vision, these plans "should form the basis for care that is both consumer centered and coordinated across different programs and agencies . . . The funding for the plan would then follow the consumer, based on their individualized care plan" (NFC, 2003, p. 35). Although the Commission indicates that "Providers should develop these customized plans in full partnership with consumers," the Commission also cites the Cash and Counseling Demonstration waiver program as a model and says that "Each consumer or child's family should receive the technical assistance necessary to develop the individual plan of care" (NFC, 2003, p. 36). Self-directed care programs offer the potential to achieve this recommendation.

Involve Consumers and Families Fully in Orienting the Mental Health System Toward Recovery

Although the Commission's focus in this recommendation is on the need for expansion of consumer-run organizations and an increase in the number of consumers who work as providers, another interpretation is that individuals can be "involved" in the mental health system by directing their own care. As Fisher and Chamberlin (2004) suggest, a recovery-based mental health system would embrace the value of self-determination, among other values, and would therefore incorporate new models of care such as self-directed care. The Commission also highlighted the importance of consumer involvement in policy and planning at the organizational levels. Since the shift to self-directed care is a large policy transformation, consumers need to play a central role in policy change at managed care organizations as well as at State and Federal government levels.

"Unlike physical disabilities, invisible disabilities make it impossible for people to see the success stories unless people intentionally disclose that they have a mental illness, have recovered, and are living their lives."

Advocate

Align Relevant Federal Programs to Improve Access and Accountability for Mental Health Services

The comments of many participants at the Summit echoed the Commission recommendations to clarify and coordinate the Federal funding guidelines and regulations relevant to people with mental illnesses. These guidelines often result in significant barriers to the integration of funds and the provision of self-directed services. Specifically, the Commission recommended that CMS and SAMHSA collaborate to develop self-directed services and supports for people with mental illnesses (NFC, 2003, p. 40).

Protect and Enhance the Rights of People with Mental Illnesses

The Commission, in making this recommendation, notes the importance of "fully integrating consumers into their communities under the *Olmstead* decision" (NFC, 2003). Clearly, self-directed care represents one means not just of protecting and enhancing rights, but also of extending rights in new ways.

"To live with, not suffer from, mental illness"

Advocate

INSTITUTE OF MEDICINE—*CROSSING THE QUALITY CHASM*

In its already classic 2001 report, *Crossing the Quality Chasm*, the Committee on Quality of Health Care in America of the Institute of Medicine (IOM) proposed six major aims for the health care system. It should, they said, be "safe, effective, patient-centered, timely, efficient, and equitable." The report, focused primarily on the physical health care system, discusses six dimensions of patient-centered care (IOM, 2001, pp. 49-50):

- Respect for patients' values, preferences, and expressed needs
- Coordination and integration of care
- Information, communication, and education
- Physical comfort

- Emotional support—relieving fear and anxiety
- Involvement of family and friends

Self-directed care programs clearly respond to most of these dimensions, and therefore represent an important means of working toward the patient-centered care envisioned by the IOM report.

TRENDS IN THE COMMERCIAL HEALTH INSURANCE SECTOR

Although they were not extensively discussed during the Summit, several new health reimbursement arrangements in the private sector are similar in their broad outlines to existing models of publicly funded self-directed care. For example, medical savings accounts, flexible spending accounts, and unified health accounts all offer participants more choice and flexibility than does ordinary health insurance. Greg Scandlen of the Galen Institute, a research organization that has explored these concepts, notes that "Ultimately, there is only one way to put patients back in the driver's seat. Give them control over the resources, so they can make their own value judgments and trade-offs about their own health care priorities." He continues, "In both financing and service delivery, we are entering the Information Age and leaving behind Industrial Age ideas of centralization, standardization, and paternalism. The new age implies the exact opposite—decentralization, customization, and empowerment" (Scandlen, 2003, April 9).

SAMHSA PROGRAMS

SAMHSA already is applying many of the principles of self-directed care in some programs. These programs include

- **Access to Recovery (ATR)**: This $100 million program provides new funds and an opportunity for States, Territories, and tribal governments to redesign their substance abuse treatment programs to provide more choice of treatment and recovery supports and an expanded group of providers for these services, including nontraditional and faith-based provider organizations.
- **Comprehensive Community Mental Health Services Program for Children and Their Families (Systems of Care)**: The system of care philosophy includes involving families of children, and children themselves when feasible, in making decisions about services.
- **Recovery Community Services Program**: This SAMHSA program, which complements the Access to Recovery program, emphasizes peer-to-peer recovery support services that help prevent relapse and promote sustained recovery from alcohol and drug use disorders.
- **Consumer-Operated Services Program**: SAMHSA funded seven consumer/peer-operated programs and a coordinating center in order to evaluate whether they are effective at improving outcomes and quality of life for people with mental illnesses.
- **2002 Survey of Organized Consumer Self-Help Entities**: SAMHSA funded this survey in order to provide the first national estimates of the number, use, and characteristics of consumer-operated services and mutual support groups and self-help organizations run by and for mental health consumers and/or families.

IV. HOW SELF-DIRECTED CARE OPERATES

Papers prepared for the discussions at the Summit and the resulting discussions identified eight operational elements of a consumer-directed service system. These include

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

PERSON-CENTERED PLANNING

At the heart of self-directed care are individualized service plans that are truly driven by the needs and desires of the individuals served. Michigan has mandated statewide implementation of person-centered planning. The core values and principles of person-centered planning are stated in the Michigan Mental Health Code as follows:

Person-centered planning is a highly individualized process designed to respond to the expressed needs/desires of the individual.

- Each individual has strengths and the ability to express preferences and to make choices.
- The individual's choices and preferences shall always be considered, if not always granted.
- Professionally trained staff will play a role in the planning and delivery of treatment and may play a role in the planning and delivery of supports. Their involvement occurs if the individual has expressed or demonstrated a need that could be met by professional intervention.
- Treatment and supports identified through the process shall be provided in environments that promote maximum independence, community connections, and quality of life.
- A person's cultural background shall be recognized and valued in the decision-making process. (Michigan Mental Health Code, 1995)

Behavioral health systems have used individual service plans for years. Unfortunately, these plans often are driven by professionals and are used just to meet a requirement and/or justify Federal and State funding for services. Rarely are they thought of as a meaningful component of the actual treatment and recovery process. Person-centered planning turns the professional planning model on its head and suggests an entirely new approach to the planning process.

Person-centered planning is essential to the success of any self-direction initiative. It forms the basis for at least one of the major recommendations from the workgroups and is discussed at greater length in the Fisher and Chamberlin paper prepared for the Summit (Fisher & Chamberlin, 2004). Demonstrating that this is not a problem unique to behavioral health, the Institute of Medicine similarly made person-centered medicine one of its major aims for restructuring the health care system (IOM, 2001).

The difficulties involved in transforming a service system that is currently dominated by case management and professionalized services cannot be overstated. Imagine the changes needed in States and localities to shift from a situation in which physician sign-off is required on all care plans to one in which only consumer sign-off is required. Regulatory change, and perhaps even legislative change, as well as a significant change in culture, are likely to be necessary to overcome some of the barriers. For more on barriers, see Appendix C.

INDIVIDUAL BUDGETING

A fundamental understanding and belief among many of the participants in the Summit was that changing the authority and power structure within the behavioral health service system must involve a concomitant change in financing to a system of individual budgeting. Individual budgets involve radically new ways to deliver and finance services. They have been implemented in many programs for people with mental retardation or developmental disabilities and in programs such as the FloridaSDC program that serves adults with mental illnesses.

“Changing the authority and power structure within the behavioral health service system must involve a concomitant change in financing.”

Individual budgeting is a significant challenge to States and others because it involves an entirely different set of financial management skills from those required for the grant-based and fee-for-services approaches currently in use. Individual budgets must be approved for a specific amount in advance of the actual use of services. The initial tendency is to use average costs and the same amount for all participants. Ideally, however, the amounts included in one’s budget are based on one’s specific needs and other resources available to one. Although FloridaSDC uses average cost to serve for cash-out purposes and cost neutrality, each person has an individualized costed-out budget amount, and if psychiatric needs exceed a person’s budget, the budget is increased to accommodate need.

CONSUMER AND PROVIDER EDUCATION

Enabling individuals to make informed decisions and purchasing choices will require new attention to consumer education. Individuals and the families of children being served will need to understand better the nature of their conditions and the range of appropriate options that are available to them.

Similarly, existing providers will need training and education on how to adapt to a more market-based self-directed services system. Funding levels will be much less secure and will change in different directions for different providers. Unless providers can effectively document outcomes, provide a positive experience for the individual receiving services, and market their services, they may experience a decline in funding. States adopting self-direction need to be acutely aware of the challenges their providers will face. At the same time, State officials should not needlessly support providers who have lost business because their consumers are "voting with their feet" and choosing other services.

Provider and consumer education is vital not only on a logistical level, but especially on the level of changing the culture and attitudes of the mental health system. The emergence of self-directed care will require a shift from provider control to control shared with the consumer. Consumers must be trained to be active architects of their recovery, and providers must learn to be coaches instead of directors. People who themselves have recovered from mental illnesses or substance use can best provide this training.

ADVOCACY AND COACHING

One way to provide the education, guidance, and training necessary in self-directed initiatives is through advocacy and coaching by peers and staff. Summit participants strongly supported this new role for peers and paradigm shift for case managers in the existing system. The concept of advocates and coaches is consistent with several current efforts.

- It is very similar to the recovery support roles identified in the Recovery Community Services Programs funded by CSAT. (See **http://rcsp.samhsa.gov.**)
- William White wrote extensively of recovery coaching in his paper on peer-based addiction recovery support services prepared for the Summit (White, 2004).
- Life coaches are a central element of the FloridaSDC program. (See **http://www.floridasdc.info.**)

Although many of the models of coaching and advocacy can and should involve the use of peers in facilitating recovery, this role need not be restricted to peers. It can effectively include family members and many who are currently case managers and care coordinators, provided they can sufficiently adapt their approach and style. They must shift their paradigm from "managing" to "facilitation" and decision support.

The changes required to implement peer advocacy and coaching will be challenging and will require leadership and extensive training of staff and peers in their new roles.

EXPANDED PROVIDER NETWORK

Central to all examples of self-direction in services for people with disabilities is the increased use of nontraditional providers of services. Cash and Counseling demonstrations expanded the range of individuals who were eligible to become providers and changed the credentialing and approval required for these providers. Recovery-based programs for the treatment of substance use disorders are firmly committed to the use of peers and others for recovery coaching, but the use of traditional financing vehicles (e.g., Medicaid) poses many obstacles to these nontraditional services. Access to Recovery explicitly seeks to expand services to include support providers and faith-based organizations. Although theirs is not a true self-direction initiative, Georgia has been very successful in the implementation of peer support and recovery services using the Medicaid Rehabilitation Option to expand their network in support of recovery. (For more information, see **http://www.gacps.org.**) All these services should be included in self-direction initiatives. They will serve to expand the available pool of providers, provide more cost-effective care and support, and maintain recovery. Workforce development, training, and the development of a career ladder are also essential.

FINANCIAL MANAGEMENT

Individual budgeting and self-direction require a new set of financial management tools for the administration of self-direction funds. Cook, Terrell, and Jonikas (2004) described the need for financial management services and support brokerages. Cavanaugh (2004) raised many questions and issues regarding the administration of these programs. Many of these questions have been addressed successfully for people with mental retardation and developmental disabilities across the country. The behavioral health field can benefit from their experience and from the growth of firms that are working in this area, including banks, accounting firms, and other specialized firms.

Financial management includes several distinct activities: determination and approval of the funding amount for individual accounts; administration of spending activity within these accounts, including authorization by consumers, receipt of invoices, monitoring expenses, management of cash balances, and budget revisions; and fiscal intermediary services. Consumers who want to employ an individual for support services can rely on fiscal intermediaries to take care of paying the bills and basic payroll and tax reporting requirements. The fiscal intermediary becomes the fiscal conduit and the employer of record on behalf of the consumer.

▼

"Clearly, recipients' satisfaction with services will be a foundation for their purchasing decisions."

OVERSIGHT AND QUALITY IMPROVEMENT

Self-directed services require a new paradigm for public oversight and quality improvement. The most significant shift involves the basic change in financial arrangements. No longer is a third party purchasing services on behalf of the individual receiving those services. Now the consumer is both receiving and paying for the services. If the changes in financing have been successful and there is true choice among providers, then individuals who receive poor quality services have the freedom not to purchase those services. Consumer protection, oversight, and quality improvement efforts are needed, however, to monitor marketing efforts by providers and to offer information to individuals receiving services so that they can make informed choices among providers. Clearly, recipients' satisfaction with services will be a foundation for their purchasing decisions and should receive equal attention from State officials.

Quality improvement in the context of self-direction and self-determination can achieve a more radical and far-reaching goal, however. As Nerney (2004) points out, quality ultimately should be defined by "quality of life." He notes that "The quality of life of individuals receiving supports should be measured against the quality of life of individuals in the general public, as opposed to comparing them only to other individuals receiving services."

FUNDING SOURCES

Cook, Terrell, and Jonikas (2004) provide a comprehensive review of the various financing streams that are options for self-directed services. As has been seen in many managed care and children's system of care efforts, the choices that are made by each State and program to blend or braid funding will be unique to the circumstances and structure of the local system. The major funding sources will be State funds, SAMHSA block grants, special grants, and the various Medicaid options, including State plan services, rehab options, system change grants, and waivers. Cook et al. also identify a range of other funding sources that impact self-determination and could be part of a self-direction effort. These sources include housing, vocational rehabilitation, public disability income support programs (SSI and SSDI), and the Ticket to Work and Work Incentives Improvement Act, among others.

States planning self-direction initiatives must address unique reporting and regulatory issues within each funding source. This gives rise to the term "braided funding," because the administering entity (State Mental Health Authority or Fiscal Intermediary) is responsible for identifying the sources and uses of funds and separately reporting to each of these sources. Traditional methods of funding discrete programs from each funding source make accounting and reporting easier, but make it much more challenging to create "person-centered" rather than "program-centered" services. The funding paradigm changes significantly with the adoption of self-direction and individual service accounts. Many of the participants at the Summit from both the mental health and substance use disorders treatment and recovery communities identified the Medicaid IMD (Institutions for Mental Disease) exclusion as a major obstacle to providing services.

New funds provided through the President's Access to Recovery (ATR) initiative can be used to provide and expand recovery support services within the community, as well as to develop experience with self-directed care and recovery support in the treatment of substance use disorders.

The major challenge faced by many efforts to implement self-direction involves "cash-outs" of funding from existing provider contracts to finance individual budgets for self-directed accounts. Not surprisingly, existing providers may resist efforts to reduce their own contracts and to expand the pool of available providers by recognizing alternative providers. At the same time, consumer-directed services should meet the same standards for effectiveness as other publicly funded services.

V. SOME EXAMPLES OF SELF-DIRECTED CARE PROGRAMS

Although the Florida Self-Directed Care Program is the only known completely operational self-directed care program in behavioral health, the number of efforts to expand self-direction in behavioral health is increasing. In this section, several self-directed programs, their key features, and some of the lessons that these efforts can provide for the behavioral health field are discussed. Appendix B lists the Internet sites referenced here for those seeking more information about the programs.

FloridaSDC

The Florida Self-Directed Care (FloridaSDC) program is a completely operational self-direction program for adults with mental illnesses. It took approximately 3 years of community grassroots planning and a single legislative session to be authorized. After it was authorized, it took another year to be implemented. The program can accommodate 106 participants. It has gained national attention, and the 2004 Florida Legislature authorized expansion of the program based on its initial success.

▼

"FloridaSDC is driven by individual freedom of choice in setting self-determined goals and selecting one's own services and providers during the journey to recovery from a mental illness."

www.FloridaSDC.info

Eligibility criteria include eligibility for SSI, SSDI, Disabled Veterans income, or some other form of disability income due to a psychiatric disability; residency requirements; and voluntary consent to enter the program. Applicants must terminate case management services and be willing and ready to accept responsibility for setting their personal recovery goals.

The program provides Life Coaches who help participants determine their eligibility and readiness to participate in the program. Life Coaches also provide support and guidance as requested with the development of the Recovery Plan, the completion of other documentation by the participant, and the completion of certain State reporting.

A large amount of very useful information on FloridaSDC is available on its Web site (**www.floridasdc.info**). The site includes participant and provider information, all of the forms and documents used by the program, service directions, and other information. An evaluation of the program is being completed by the Center on Mental Health Services Research and Policy in the Department of Psychiatry at the University of Illinois at Chicago.

Cash and Counseling

The Cash and Counseling demonstrations were funded by The Robert Wood Johnson Foundation (RWJF) and the U.S. Department of Health and Human Services. They began enrolling individuals in 1998 in Arkansas, and subsequently in New Jersey and Florida. The programs sought to demonstrate that consumer-directed support services for community living could be provided to individuals with disabilities on Medicaid through the use of a flexible monthly allowance and, in many cases, with the use of fiscal intermediaries. The results of the program have been positive. Arkansas' experience demonstrates that States can implement the program at a cost no greater than that of agency-based models of care and with generally higher levels of satisfaction (Dale et al., 2003).

> "Consumer satisfaction is significantly higher under [Cash and Counseling] than any other traditional service delivery model."
>
> *Researcher*

Cash and Counseling programs have all concentrated on Medicaid personal care services for persons with disabilities, primarily those with developmental and physical disabilities, and older adults. However, individuals with mental health diagnoses have been served, and data on this subset of the participants are currently being studied. Services are generally limited to personal care, and in some cases, supplies and equipment, that will allow individuals to remain in the community. Most individuals and States found it advantageous to use fiscal intermediaries for the management of funds and to act as the employer of record for participants in the program. More information about the program is available at **http://www.cashandcounseling.org/index.html.**

Michigan's Person-Centered Planning Initiative

In 1998, Michigan began a major shift in the financing of its mental health, substance abuse, and developmental disability services through the creation of Community Mental Health Services Programs. The State has bundled money for one or a group of counties into one managed care contract under 1915(b) and 1915(c) waiver authority. This financing innovation is similar in many ways to the steps taken by several other States—California, Florida, and Colorado, for example—to implement managed care in behavioral health services. However, Michigan's legislation goes beyond a traditional managed care approach in that it requires the implementation of a person-centered plan for all specialty services. This plan is fully incorporated into the managed care plan for behavioral health services. Michigan is one of the first States working to implement self-determination through person-centered planning. Evaluation results have documented the effectiveness of the new financing approaches, but there is little information in the literature or available from the State on the effectiveness of the person-centered planning requirements and progress in reaching the goals of more self-directed care. More information is available on the CMS Promising Practices Web site: **http://www.cms.hhs.gov/promisingpractices/mipcp.pdf.**

Programs for People with Mental Retardation and Developmental Disabilities

Early work in self-determination focused on consumer choice in daily activities and in individual service planning for people with mental retardation and developmental disabilities. Much of this work centered on values training and efforts to train staff and administrators in the new philosophy of choice and freedom. Progress was made, but it became clear to many that until the economic balance of power between consumers and providers was modified, any change would be temporary and limited.

Self-determination "views human services as a means to an end and not an end in itself."

Technical Assistance Provider

In response to this situation, a number of efforts were developed to demonstrate the impact of changes in funding in the service system. Most of this work was sparked by 1993 funding of the Monadnock Self-Determination for People with Disabilities Project in New Hampshire by The Robert Wood Johnson Foundation (RWJF). RWJF convened a group to plan for the expansion of this program in 1995 and issued a call for proposals in 1996. This led to 1997 funding for the RWJF Self-Determination Initiative. This initiative funded planning efforts in Arizona, Connecticut, Florida, Hawaii, Iowa, Kansas, Maryland, Massachusetts, Michigan, Minnesota, Ohio, Oregon, Pennsylvania, Texas, Utah, Vermont, Washington, and Wisconsin. The National Program Office was located at the University of New Hampshire. Ten other States received smaller technical assistance grants. Two follow-on RWJF grants provided up to 5 years of grant support to two projects in self-determination for people with developmental disabilities in Florida and Massachusetts to more specifically replicate the Monadnock Project. See **http://rwjf.org/reports/grr/PC379.htm.**

Since that time, numerous programs have implemented self-direction and individual budgeting in Medicaid through Home and Community Based, or 1915(c), waivers. However, since almost all these States have used 1915(c) waivers to fund deinstitutionalization efforts for people with mental retardation and developmental disabilities, self-direction and self-determination efforts have generally been limited to these populations.

Oregon Plans

The Oregon Technical Assistance Corporation (OTAC) runs a self-determination program for individuals with developmental disabilities. Working with the Oregon Health Science University Center for Self-Determination, OTAC is seeking to expand to a small program in Multnomah County for individuals with mental illnesses. See **http://selfdeterminationohsu.org** for more information as it becomes available.

Centers for Medicare and Medicaid Services Waiver Models

Among the President's New Freedom Initiative activities within DHHS, the Centers for Medicare and Medicaid Services (CMS) have developed templates and guidelines for States that seek to implement self-direction initiatives. These include instructions for modifying 1915(c) Home and Community Based Waivers and also include a new class of section 1115 Research and Demonstration Waivers known as Independence Plus: A Demonstration Program for Family or Individual Directed Community Services. One core element of the Independence Plus Waiver is that the program is voluntary. Voluntary participation is fundamental for self-direction. Self-direction programs might not be right for everyone. Other elements of the Independence Plus Waiver are that a fiscal employer/agent will be used and that the State will conduct an evaluation of the program. In addition, CMS has developed Special Terms and Conditions for all Independence Plus Waivers that include a required submission and approval of an Operational Protocol (OP). This OP must include the organization and structure of the program; benefits; reporting requirements; a description of outreach and marketing; eligibility and enrollment, quality assurance, and monitoring procedures; education, counseling, and fiscal agent services; participant protection; and a description of the evaluation design.

The template for Home and Community Based Waivers addresses a range of issues associated with the plan of care: use of individual budgets; provider selection; plan of care management; participant protections; and quality assurance. It is less comprehensive and detailed than the Independence Plus Waiver application, but touches on many of the same issues. More details can be found on the CMS Web site: **http://www.cms.hhs.gov/independenceplus.**

Other Options That Embody Self-Determination in the Behavioral Health System

Many mental health services programs incorporate some of the elements of self-direction. These include many consumer-operated services, local efforts to implement person-centered planning, program or agency level flexible spending accounts for a range of community support services, and others. One of the more notable efforts is the development in Georgia of the Peer Specialists program that is funded by Medicaid. These Peer Specialists provide services, advocacy, and recovery-based coaching for consumers within Georgia. This program is an example of the creative ways that States are using Medicaid financing for recovery-based services. (See **http://www.gacps.org.**)

TREATMENT OF SUBSTANCE USE DISORDERS

Until recent initiatives such as Access to Recovery and the Recovery Community Services Program, there were no federally funded self-directed treatment and recovery programs for people with a primary diagnosis of substance use disorders. Federal and State funds were directed primarily toward research and the support of professional inpatient and outpatient treatment programs.

The substance use disorders field has a long history of mutual support and self-help groups, such as Alcoholics Anonymous (AA), Narcotics Anonymous (NA), and Alanon, that operate on principles of peer support outside of the health care financing system. Oxford Houses are a model for recovery homes, peer-operated alcohol- and drug-free residences. Today more than 100,000 AA groups meet in more than 150 countries around the world, and more than 800 recovery homes operate in the United States. Some of the people who participate in mutual support groups and/or live in recovery homes have achieved recovery this way. Others have achieved recovery through professional inpatient or outpatient treatment, and others through medication-assisted treatment or one of the many other pathways to recovery.

Recovery Community Services Program (RCSP)

Through the Recovery Community Services Program (RCSP), CSAT supports the development of models of peer-to-peer recovery support services. The RCSP grantees are pioneering peer services to help prevent relapse and promote long-term recovery. Currently, 30 RCSP grantees are at various stages of design and implementation. Their service models run the gamut of social support modalities, including peer mentoring and coaching, the creation of learning circles and other peer-directed adult learning environments, concrete peer assistance with the challenges of early recovery such as housing, employment, and parenting, and safe alcohol and drug-free opportunities to share community and celebrate recovery.

Many of these projects are targeted at special populations whose self-identified recovery support needs vary in some respects from so-called standard models. These groups include, for example, women; groups that self-define by reference to culture or ethnicity (including recent immigrants); people with coexisting disorders; individuals attempting to sustain recovery as they reenter the community from a correctional environment; people in recovery in the lesbian, gay, bisexual, and transgendered community; people with physical disabilities in recovery; and men and women for whom trauma and often homelessness has been a part of their substance use history. Many grantees also work with families.

RCSP has been enthusiastically received by people in recovery and those seeking recovery, as well as their families. Collaborators in the community—such as faith-based groups, community-based groups dealing with issues often associated with substance use problems (such as homelessness and HIV), as well as treatment professionals and State systems—are becoming increasingly supportive as well. Expanding RCSP and the formal roles of people in recovery within the continuum of services will help to develop the consumer movement within the treatment system for people with substance use disorders. It will provide important supports for individuals seeking to maintain their recovery and will advance the goals of self-directed care in the field. See **http://www.rcsp.samhsa.gov** for more information.

Access to Recovery (ATR)

A new Presidential initiative, Access to Recovery (ATR), provides people seeking drug and alcohol treatment with vouchers to pay for a range of appropriate community-based services. The vouchers promote individual choice for substance use clinical treatment and recovery support services by expanding access to care, including access to faith- and community-based programs, and increasing substance use treatment capacity. Programs are required to monitor outcomes, track costs, and prevent waste, fraud, and abuse. Thus, the ATR initiative offers the promise of the development of self-directed programs for individuals with substance use disorders. Besides increasing individual choice and expanding the use of nontraditional services, vouchers will prompt existing providers to be more market oriented and consumer centered.

This major national initiative funds up to $100 million in services in approximately 14 States, tribal governments, and Territories. Implementation of the ATR projects began in Fall 2004. See **http://www.atr.samhsa.gov** for more information on these grants.

VI. VISIONS OF A FUTURE SELF-DIRECTED SERVICE SYSTEM

The ultimate goal of the Summit was to recommend to SAMHSA specific action steps for the expansion and development of consumer/self-direction initiatives at the State and local levels. Four breakout workgroups (Children and Families, Adults with Mental Illnesses, Adults with Substance Use Disorders, and Infrastructure) developed these recommendations. The workgroups encouraged all attendees to contribute action items from their perspectives.

COMMON THEMES

Each workgroup clearly laid out its own vision, and themes that were common across all groups were subsequently identified. In this section, the common themes are summarized.

Person-Centered Planning

All the participants' visions of a consumer-directed service system included person-centered service planning. Every consumer needs to be actively involved in his or her treatment plan and informed about directing his or her own recovery, with professional support if and as needed. Fundamentally, person-centered care will ensure that consumers have the ownership and freedom to choose services that satisfy their wants and needs, by putting the control of resources in their hands. The slogan adopted by the disability community, "Nothing about us without us," captures this sentiment and applies to every organizational level of the behavioral health system: individual, the local provider, the managed care organization, the State agencies, and the Federal administration. Implementing person-centered planning in behavioral health systems involves a major shift in the culture, training, and activities of the professionals in the system. The scope of this kind of change as well as its importance should not be underestimated.

> "... each adult with a serious mental illness and each child with a serious emotional disturbance [shall] have an individualized plan of care [and] consumer needs and preferences should drive the type and mix of services provided."
>
> *New Freedom Commission on Mental Health: Final Report, p. 35*

Integrated System of Care

Workgroups underlined the importance of creating an accessible, integrated system of care to help realize the goal of a self-directed service system. Such a system offers a full array of services that are linked to community and natural supports. Services and the overarching program should seek to facilitate community integration and promote resilience. In this vision, individuals are free to choose from an array of services that are most appropriate for their stage of recovery. A person's recovery will be based on a lifetime recovery plan that makes appropriate use of the continuum of care. States and public behavioral health systems differ dramatically in the degree to which they currently provide a full continuum of services; however, self-directed services can help to significantly speed up the changes that are needed in these systems of care.

Quality and Outcomes

Participants agreed that, rather than focusing exclusively on outcomes that are important to other stakeholders, any measurement system must include outcomes that are significant to service recipients and are desired by any person, regardless of any disability. The groups emphasized the need for individuals to evaluate the quality of their own care and lives. Quality improvement efforts must be driven by the participant's perspective—the "voice of the consumer." Similarly, outcome measures should include broad recovery indicators, such as housing, employment, health care, education, and transportation, and other quality of life measures, not just measures of symptoms.

Access and Cultural Competence

There was also a consensus that individuals should have access to services that are culturally competent. Using peer leaders from the indigenous community as service providers and implementing systems with expanded choice of providers and services will help to improve the cultural relevance of services and the appropriateness of these services to the members of diverse racial and ethnic communities. In a self-directed system, services will evolve to be more responsive and culturally relevant. In this manner, a self-directed care system will embrace diversity and include all populations.

Transformation of Providers' Roles

Another theme that surfaced in all workgroups was the need for a transformation of the current roles and functions of professionals. In a self-directed system, providers will be educated and trained to offer requested information and provide decision support services. Case *managers* will become *advocates* and *coaches* for the individuals they serve. This shift requires changes in training and leadership, and also may require regulatory changes.

INDIVIDUAL WORKGROUPS' VISIONS

The four workgroups also highlighted different themes in their visions of a consumer-directed service system. The visions of the individual workgroups—(1) Children and Families, (2) Adults with Mental Illnesses, (3) Adults with Substance Use Disorders, and (4) Infrastructure (including Oversight, Financing, and Systems)—are summarized here.

> "We have taken the people out of institutions but we have not taken institutional thinking out of the people."
>
> *Advocate*

Children and Families

The Children and Families workgroup's vision focuses on access to information, skill-building, a comprehensive system of supports, and an array of treatment services. These services and supports are fully funded and seamlessly incorporate privately insured and publicly funded components. In addition, children with serious emotional disturbances are universally eligible for Medicaid services. Family organizations have sufficient funds, training, and staff to operate in a meaningful way. Communities offer a range of supports that are culturally competent. Youth and families oversee outcome-based funding. Finally, the vision includes a person-centered, lifelong recovery plan for every child.

Adults with Mental Illnesses

This group emphasized that self-direction is not a single program but rather a foundational value; individual wants and needs direct all service delivery. A self-directed system is totally person-centered, with individuals involved at every stage of their care. In this vision, participants are provided with the tools they need; they have access to information about benefits, financial and educational planning, outreach assistance, peer support, and peer-operated services to facilitate recovery. In this vision, the roles and functions of professionals change. Providers are educated to respond to individuals' requests with respect, and they are able to provide their clients with the information they want regarding their treatment.

The group highlighted the importance of redesigning the public mental health system to support the following outcomes, using the performance of existing systems as a baseline measure:

- Individuals feel that they are moving forward with their lives and are able to make progress toward economic self-sufficiency.
- Individuals have the opportunity to do things that are productive and personally meaningful.
- Individuals live where they want to and have access to available resources. This standard assumes that there are decent choices and the person is aware of them.

"Nothing about us without us" is the guiding principle that is to include the meaningful participation of people with psychiatric disabilities at every level and activity of self-directed care (development, implementation, and evaluation).

Adults with Substance Use Disorders

The shared vision of this workgroup stressed the importance of a network of support, including friends, family, and community. They emphasized a greater role for peer advisors. The concept of "no wrong door to recovery" provides the foundation for this system. Consequently, a service system incorporating housing, employment, health care, education, and transportation is available. Participants have access to services that are person-centered, user-friendly, diverse, and based in the community or neighborhood. Education regarding treatment options is also available, so that individuals are prepared to make choices and direct their own care.

Infrastructure (Oversight, Financing, Systems)

This workgroup summarized their collective vision concerning a self-directed system of care with the following statement:

> *"We envision a future where everyone impacted by a mental illness and/or substance use disorder across their lifespan achieves recovery built upon a self-directed life in the community and centered on freedom and resilience."*

▼

"We envision a future where everyone impacted by a mental illness and/or substance use disorder across their lifespan achieves recovery built upon a self-directed life in the community and centered on freedom and resilience."

Infrastructure Vision

VII. RECOMMENDATIONS OF THE SUMMIT WORKGROUPS

The overarching and unanimous message from the recommendations of the Summit workgroups is that SAMHSA, in partnership with other Federal agencies, should provide strong leadership and resources to States in the implementation of self-directed care for consumers with mental illnesses and substance use disorders. In addition, participants recommended that SAMHSA challenge the present barriers in Federal funding and statutes that limit choice, freedom, and self-direction for people with mental illnesses and substance use disorders. A number of the recommendations were aimed at re-educating and reorienting the public, providers, and professionals about self-directed care as a viable option for individuals with mental illnesses and substance use disorders. Although specific recommendations differ somewhat across population groups, virtually all of the participants and workgroup recommendations sought ways to enhance many of the values and principles of self-determination: freedom, authority, support, responsibility, and participation. (For the workgroups' lists of specific recommendations, please see Appendix D.)

SAMHSA should challenge the present barriers in Federal funding and statute that limit choice, freedom, and self-direction for people with mental illnesses and substance use disorders.

RECOMMENDATIONS COMMON ACROSS TWO OR MORE GROUPS

When the workgroups' lists of recommendations were compared, the following were found to be suggested more than once.

- Develop a national leadership team to champion a self-direction effort, act as a resource for information, and facilitate policy development. This could be an external group such as the National Recovery Initiative Steering Committee proposed by Fisher and Chamberlin in their paper, or an executive leadership team as proposed by the Infrastructure Group. It is clear that interagency cooperation is necessary and consumer input is essential. Consider developing more than one group —one for coordinating self-direction policy for SAMHSA across the Centers and with sister agencies, and other groups for each of the Centers and different populations.
- As funds permit, facilitate the development of self-direction programs through demonstrations and other sources of support to complement and expand upon existing efforts and the Access to Recovery initiative.
- Provide technical assistance and training where needed on all aspects of self-direction, including, but not limited to, State technical assistance and workforce training for providers and self-advocates.
- Evaluate existing programs and barriers to self-direction, then disseminate the information and the findings. Where possible, work with the National Institute of Mental Health, the National Institute on Drug Abuse, and the National Institute on Alcohol Abuse and Alcoholism to develop evidence-based practices.
- Facilitate person-centered planning as one critical piece of self-direction and an element of all treatment services.

- Develop a more formal process to share promising and evidence-based practices in self-direction.
- Review and disseminate information on different financing options for self-direction, including Medicaid and other Federal funding, block grants, State options, and private sources of support.
- Actively promote collaboration among agencies involved with the behavioral health field, including Federal and State agencies.
- Facilitate and seek additional sources of financial support for self-direction from existing and new sources, including CMS, Ticket to Work, Social Security, and IDAs.
- Integrate self-direction into existing State planning mechanisms, e.g., incorporate consumer health education requirements into all State planning grant applications.
- Develop and enhance existing self-education technologies and materials to provide individuals with access to information about their condition and the treatments of choice for that condition.
- Develop media and public relations campaigns to combat stigma and discriminatory barriers to recovery, promote society-wide policies that promote and support recovery and full integration into society, and expand support for consumer direction.
- Facilitate the involvement of consumers and families in all aspects of this effort, particularly the development of local and State initiatives.

INFRASTRUCTURE GROUP RECOMMENDATIONS

The Infrastructure workgroup developed recommendations for SAMHSA on oversight, financing, and the administration of consumer or self-directed services. The group had a broad representation of Federal officials, representatives of provider groups, advocates, and consumer representatives from both mental health and addiction recovery fields.

"... facilitate local community involvement at all levels in advancing self-direction."

Infrastructure Recommendation

Group members reached a consensus that self-direction required a holistic focus, involving representation and perhaps funding from many government agencies, including education, housing, health care, vocational rehabilitation, and other entities. It was particularly clear to this group that the concept of self-direction fits well with the many other efforts that are currently underway in the Federal government, including housing subsidy and support, health savings accounts, individual development accounts, and the recommendations from the Institute of Medicine *Crossing the Quality Chasm* report. One suggestion from the group was that information on the sources and levels of behavioral health funding in each of the various Federal agencies should be identified by SAMHSA and broadly disseminated to provide a clear understanding of the scope of services and the potential gaps in Federal funding.

The Infrastructure workgroup also clearly recognized the importance of finding ways to facilitate local community involvement in advancing self-direction. At the same time, they recognized the need to give incentives to self-directed care initiatives in the form of grants, technical assistance, and new pilot programs. One way to advance self-direction is through policy academies that disseminate knowledge about self-directed care to States. Finally, self-direction efforts should cut across all the Centers and be included as a cross-cutting principle for the SAMHSA Matrix. The specific recommendations from the Infrastructure workgroup are listed in Appendix D.

CHILDREN AND FAMILIES GROUP RECOMMENDATIONS

The Children and Families workgroup discussed the needs and goals of children and their families in both the mental health and substance use treatment service systems, although the majority of the group's attention was given to mental health and co-occurring conditions. In general, participants in the group felt that the role of families in service planning had improved, but lack of choice was an overarching concern. Other issues cited by the workgroup were the need to plan for minority populations and families living in rural and urban areas; the need for family education and training for all populations and racial/ethnic groups; and the relevance and importance of incorporating many of the values, tools, and practices from Children's System of Care grants for children with serious emotional disturbances into programs for substance use disorders.

> "We have given families voice, but we haven't given families choice."
>
> *Advocate*

The workgroup's specific recommendations are listed in Appendix D. They focus on changes in Medicaid financing, developing a public health model, establishing a clearinghouse, and using existing waivers to develop consumer direction efforts. A theme, echoed through all the workgroups, was the importance of having families and youth involved in planning, evaluation design, and ongoing advocacy efforts.

ADULTS WITH MENTAL ILLNESSES GROUP RECOMMENDATIONS

After developing a shared vision of self-directed services, the Adults with Mental Illnesses workgroup spent some time highlighting many of the areas of the current service system that can provide a foundation for self-direction. Several participants commented on the long list of positive accomplishments in many (but certainly not all) mental health systems. Selected examples include peer provided and designed services; the use of advance directives; beginning efforts to implement person-centered planning; the use of informed consent; strengths-based approaches to service planning; human rights and grievance processes that work; Protection and Advocacy programs and other legal supports; increasing Offices of Consumer Affairs and consumer presence on planning boards; the development of some self-management tools; removal of work disincentives; the increase in the number of cross-disability coalitions; the recognition of trauma and trauma services; voluntary access to an array of psychiatric medications; and supported employment, housing, and education.

The group recognized that self-determination was the goal of a transformed mental health system, and self-directed care is one methodology to achieve that. "Money follows the person" is too narrow a focus when talking about self-determination.

The group felt that the public mental health system should be designed to achieve the following individual outcomes:

- People living where they want to live given available resources;
- A broad and diverse social support system of their own choosing;
- Opportunity to be productive and do things that are personally meaningful; and
- A feeling of progress and recovery in life, including progress towards or achievement of economic self-sufficiency.

For the workgroup's list of specific recommendations, see Appendix D.

ADULTS WITH SUBSTANCE USE DISORDERS GROUP RECOMMENDATIONS

This workgroup developed an extensive vision of a self-directed and person-centered service system for those with substance use disorders. They identified strengths of the current system, as well as future needs, and made recommendations.

Selected current strengths of the services system and key issues in the discussion included

- Peer recovery-based services funded through the Recovery Community Services Program;
- The body of knowledge and research for self-support and how to create person-centered services;
- The promise of the Access to Recovery initiative to expand the scope and continuum of services for many States and to educate and involve community-based organizations and peer and faith-based organizations;
- Awareness of screening and brief interventions;
- The strong role of the recovery movement;
- New pharmacological tools; and
- Increasing acceptance of recovery among national leaders.

Participants acknowledged the need for continuing efforts to reduce stigma and discrimination and educate the public on recovery through the media and public relations. SAMHSA should provide leadership for interagency initiatives at Federal, State, and local levels, and should increase support for consumer education and consumer empowerment. Finally, SAMHSA needs to develop recovery-based performance measures and build on the success of Access to Recovery. For the workgroup's list of specific recommendations, see Appendix D.

> "We have to integrate people into the community and give them the opportunity to do things that other people do that are age-appropriate and appropriate to their interests and levels of achievement."
>
> *Advocate*

VIII. CONCLUSION AND NEXT STEPS

The 2004 Consumer Direction Initiative Summit provided an opportunity to chart one of the roadmaps for transformation of the behavioral health system for people with substance use disorders and mental illnesses. Its goal was to establish a foundation and a framework to support self-directed care initiatives at State and local levels. With the foundation provided primarily by eight different papers prepared for the Summit, participants in workgroups were asked to prepare recommendations to SAMHSA.

The recommendations developed by each of the workgroups were presented to the Directors of the three SAMHSA Centers at the end of the Summit. Each Director provided his or her perspective on the workgroup recommendations and noted the critical importance of self-direction to the underlying SAMHSA mission—"Building resilience and facilitating recovery." All agreed that self-direction underlies the priorities and principles of the SAMHSA Matrix.

Self-direction has its roots in the somewhat broader "self-determination" movement for disability rights. Mental health and addiction recovery advocacy groups can learn much about the needed change process from that movement. The goal of the self-determination movement for people with disabilities has always been to help individuals "craft a meaningful life in their communities, rich in relationships and deeply connected" (Nerney, 2004). In fact, that is also the heart of the SAMHSA vision—"A life in the community for everyone."

The recommendations from the Summit are consistent with and significantly advance the recommendations from the President's New Freedom Commission and the Institute of Medicine *Crossing the Quality Chasm* reports. These reports provide an extraordinary opportunity for the field to advance self-direction efforts. In calling for transformation of mental health care, the New Freedom Commission recommended that relevant Federal agencies propose demonstration programs for self-directed services and supports for people with mental illnesses (NFC, p. 40). Bringing to scale the significant efforts in Florida, Michigan, Oregon, and other areas and developing a self-direction action plan within SAMHSA will advance the goals set by the Commission and IOM reports.

The implementation of ATR will provide important lessons on how States seek to take advantage of this opportunity to increase choice and expand the range of treatment and recovery options available to individuals in need of services for substance use disorders. The degrees of transformation proposed by States are likely to differ significantly, but ATR is likely to have a significant impact on the consumer movement in the treatment of and recovery from substance use disorders.

It will be much more difficult to implement self-direction in existing programs. Cashing out funds from provider contracts to create individual service accounts will be resisted by many, if not all, providers unless it is done slowly and very carefully. It will require leadership at the Federal level, support and technical assistance from those States with innovative models that have demonstrated success, and grassroots advocacy. Legislation is likely to be needed in many States to push the system forward; in others, executive branch and advocate leadership may be sufficient. Advocates and professionals at State and local levels are encouraged to work with local policymakers to develop these initiatives. The barriers to self-directed care are discussed in more detail in Appendix C.

Self-direction promises to provide individuals who are receiving publicly funded services the freedom, authority, responsibility, and support that everyone expects for themselves and for their families.

REFERENCES

References marked with asterisks are the working papers that were prepared especially for the Consumer Direction Summit. They may be found on the Web at **www.mentalhealth.samhsa.gov/consumersurvivor** under "Featured Publications."

* Armstrong, M. I. (2004). *The Consumer-Directed Health Care: Challenges and Opportunities for Families with Youth with Serious Emotional Disturbance*. Paper prepared for the SAMHSA Consumer Direction Summit, March 2004.

* Cavanaugh, D. A. (2004). *Consumer-Directed Services: Opportunities and Challenges for Applying the Concepts to Adolescents with Substance Use Disorders*. Paper prepared for the SAMHSA Consumer Direction Summit, March 2004.

* Cook, J. A., Terrell, S., & Jonikas, J. A. (2004). *Promoting Self-Determination for Individuals with Psychiatric Disabilities through Self-Directed Services: A Look at Federal, State and Public Systems as Sources of Cash-Outs and Other Fiscal Expansion Opportunities*. Paper prepared for the SAMHSA Consumer Direction Summit, March 2004.

Dale, S., Brown, R., Phillips, B., Schore, J., & Carlson, B. L. (2003, November 19). The effects of Cash and Counseling on personal care services and Medicaid costs in Arkansas. *Health Affairs* Web Exclusive. Online at **http://content.healthaffairs.org/webexclusives.**

Dougherty, R. H. (2003, June). Consumer-directed healthcare: The next trend? *Behavioral Healthcare Tomorrow, 12,* 21.

* Edwards, E. M., & McCarty, D. (2004). *Systemic Challenges, Barriers, and Opportunities in the Funding and Adoption of Consumer-Directed Initiatives for Substance Use Disorders*. Paper prepared for the SAMHSA Consumer Direction Summit, March 2004.

* Fisher, D. B., & Chamberlin, J. (2004). *Consumer-Directed Transformation to a Recovery-Based Mental Health System*. Paper prepared for the SAMHSA Consumer Direction Summit, March 2004.

Institute of Medicine, Committee on Quality of Health Care in America. (2001). *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: National Academy Press.

Michigan Mental Health Code, Act No. 290, Public Acts of 1995.

* Nerney, T. *Quality Issues in Consumer/Family Direction*. (2004). Paper prepared for the SAMHSA Consumer Direction Summit, March 2004.

Nerney, T. (2001). *Filthy Lucre: Creating Better Value in Long Term Supports*. Ann Arbor, MI: Center for Self-Determination.

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

Phillips, B., Mahoney, K., Simon-Rusinowitz, L., Schore, J., Barrett, S., Ditto, W., Reimers, T., & Doty, P. (2003, June). *Lessons from the Implementation of Cash and Counseling in Arkansas, Florida, and New Jersey*. Prepared for Center on Aging, University of Maryland, and submitted by Mathematica Policy Research, Inc.

Scandlen, G. (2003, April 7). *Time for a Unified Health Account*. Alexandria, VA: Galen Institute. Online at **http://www.galen.org/fileuploads/Unified_Health_Account.pdf.**

Scandlen, G. (2003, April 9). *Consumer Driven Health Care: New Tools for a New Paradigm*. Alexandria, VA: Galen Institute. Online at **http://www.galen.org/fileuploads/New_Tools.pdf.**

* Stefan, S. *Competence Issues in Self-Directed Care*. (2004). Paper prepared for the SAMHSA Consumer Direction Summit, March 2004.

U.S. Department of Health and Human Services. (2003, April 14). Self-Determination Initiative Planning Meeting Report. Rockville, MD: Substance Abuse and Mental Health Services Administration (SAMHSA).

* White, W. L. (2004). *The History and Future of Peer-Based Addiction Recovery Support Services.* Paper prepared for the SAMHSA Consumer Direction Summit, March 2004.

APPENDIX A: LIST OF PARTICIPANTS

Facilitators

RICHARD H. DOUGHERTY
President
Dougherty Management Associates, Inc.

LAURA VAN TOSH
Consultant
Van Tosh Consulting

Authors of Summit Working Papers

MARY I. ARMSTRONG
Director of Child and Family Studies
Department of Children and Family Studies
Louis de la Parte Florida Mental Health Institute
University of South Florida

DOREEN CAVANAUGH
Assistant Professor
Institute for Health Care Research and Policy
Georgetown University

JUDI CHAMBERLIN
Advocate

JUDITH COOK
Professor of Sociology in Psychiatry
University of Illinois at Chicago

ERIKA MILES EDWARDS
Demand Treatment Editorial Coordinator
Join Together

DANIEL B. FISHER
Executive Director
National Empowerment Center, Inc.

JESSICA A. JONIKAS
Managing Director
Center on Mental Health Services Research and Policy
University of Illinois at Chicago

DENNIS MCCARTY
Professor
Department of Public Health and Preventive Medicine
Oregon Health Sciences University

THOMAS NERNEY
Director
Center for Self-Determination

SUSAN STEFAN
Senior Staff Attorney
Center for Public Representation

SHAWN C. TERRELL
Health Insurance Specialist
Disabled and Elderly Health Programs Group
Centers for Medicare and Medicaid Services
U.S. Department of Health and Human Services

WILLIAM L. WHITE
Senior Research Consultant
Chestnut Health Systems

Contributors

JANE ADAMS
Executive Director
Keys for Networking, Inc., and
Board President
Federation of Families

PAM ALGER
Team Leader for Children's Mental Health
Social and Rehabilitation Services
Division of Health Care Policy
Kansas Dept. of Mental Health, Substance Abuse Treatment and Recovery

William A. Anthony
Executive Director
Boston University Center for Psychiatric Rehabilitation

Sonya Baker
Director
Santa Barbara Community Recovery Network
Santa Barbara Council on Alcoholism and Drug Abuse

Robert Bernstein
Executive Director
Bazelon Center for Mental Health Law

Anita Bertrand
Executive Director
Compass Ventures

Jon Brock
Advocate

Julie Caliwan
Project Manager
New Jersey Partnership for Children
New Jersey Department of Human Services

Jenny Collier
Director
National Policy and State Strategy
Legal Action Center

Linda Hay Crawford
Executive Director
Therapeutic Communities of America

Shannon CrossBear
Project Director
Federation of Families for Children's Mental Health

Patricia Deegan
Senior Program Associate
Advocates for Human Potential

John deMiranda
Executive Director
National Association on Alcohol, Drugs and Disability, Inc.
Peninsula Health Concepts

Susannah Dudley
Research Assistant
Dougherty Management Associates, Inc.

Christina Dye
Program Manager
Bureau of Substance Abuse Treatment and Prevention
Division of Behavioral Health Services
Arizona Department of Health Services

Donna Folkemer
Program Director
National Conference of State Legislatures

Nancy Fudge
Member
FloridaSDC Program Advisory Board
Florida Institute of Health and Human Services School of Social Work
Florida State University

Lewis E. Gallant
Executive Director
National Association of State Alcohol and Drug Abuse Directors

June M. Gertig
Director
Recovery Community Services Program
Technical Assistance Project
Health Systems Research, Inc.

Robert Glover
Executive Director
National Association of State Mental Health Program Directors

Patricia M. Greer
Mid-South Regional Vice President
NAADAC--The Association for Addiction Professionals

JOHNETTE T. HARTNETT
Vice President
NCB Development Corporation
National Disability Institute

STEEN HUDSON
President
Santa Barbara Rescue Mission

BARBARA HUFF
Executive Director
Federation of Families for Children's Mental Health

J. ROCK JOHNSON
Advocate

CARYN J.
Al Anon Family Groups Headquarters

KAREN KANGAS
Director
Office of Customer Relations
Connecticut Department of Mental Health and Addiction Services

HARRY KRESSLER
Executive Director
Pima Prevention Partnership

TOM LANE
Director
Office of Consumer Affairs
National Alliance for the Mentally Ill

SAUL LEVIN
President
Access Consulting International, Inc.

KEVIN MAHONEY
Director
Center for the Study of Home and Community Life
Boston College Graduate School of Social Work

PAUL MALLOY
Chief Executive Officer
Oxford House, Inc.

STACIA MURPHY
President
National Council on Alcoholism and Drug Dependence

LINDA PAQUETTE
Deputy Director
New Hampshire Department of Behavioral Health

JOSEPH ROGERS
President and CEO
Mental Health Association of Southeastern Pennsylvania

CAROLYN RUSSELL
FloridaSDC Project Director
Florida Institute of Health and Human Services School of Social Work
Florida State University

KRISTIN SCHUBERT
Program Associate
The Robert Wood Johnson Foundation

FLO STEIN
Chief of Community Policy Management
North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services
North Carolina Department of Health and Human Services

PAT TAYLOR
Executive Director and Campaign Coordinator
Faces and Voices of Recovery

SARA THOMPSON
Senior Director
Adult Mental Health Services
National Mental Health Association

LISA MOJER TORRES
Advocate

BARBARA WARREN
Director
Planning and Research
SpeakOUT!: LGBT Voices for Recovery
Lesbian, Gay, Bisexual, and Transgender Community Center

MARIA YELLOW HORSE BRAVE HEART
Consultant and Research Professor
University of Denver

MICHAEL ZUBER
Associate Director
Bureau of Children and Families
New York Office of Mental Health

Federal Representatives from the U.S. Department of Health and Human Services

CARY APPOLD
Technical Director
Employment Programs
Centers for Medicare and Medicaid Sevices

MADY CHALK
Director
Division of Services Improvement
Center for Substance Abuse Treatment
SAMHSA

PEGGY CLARK
Technical Director
Division of Integrated Health Systems
Centers for Medicare and Medicaid Sevices

H. WESTLEY CLARK
Director
Center for Substance Abuse Treatment
SAMHSA

STEPHANIE COLSTON
Special Assistant to the Administrator
SAMHSA

STANLEY EICHENAUER
Senior Advisor to the Administrator for Mental Health Transformation
SAMHSA

EILEEN ELIAS
Deputy Director
Office on Disability
U.S. Department of Health and Human Services

SYBIL GOLDMAN
Senior Advisor on Children
SAMHSA

MELVYN HAAS
Associate Director for Medical Affairs
Center for Mental Health Services
SAMHSA

RONALD HESTER
Program Analyst
Center for Substance Abuse Prevention
SAMHSA

ED HUTTON
Technical Director
Division of Integrated Health Systems
Centers for Medicare and Medicaid Sevices

CILLE KENNEDY
Operations Research Analyst
Office of the Secretary
U.S. Department of Health and Human Services

NANCY KENNEDY
Special Assistant
Center for Substance Abuse Prevention
SAMHSA

ANDREA KOPSTEIN
Chief
Practice Improvement Branch
Center for Substance Abuse Treatment
SAMHSA

RONALD MANDERSCHEID
Chief
Survey and Analysis Branch
Center for Mental Health Services
SAMHSA

CHRIS MARSHALL
Consumer Affairs Specialist
Center for Mental Health Services
SAMHSA

RUBY NEVILLE
Public Health Advisor
Center for Substance Abuse Treatment
SAMHSA

CATHERINE NUGENT
Public Health Advisor
Center for Substance Abuse Treatment
SAMHSA

A. KATHRYN POWER
Director
Center for Mental Health Services
SAMHSA

CAROLE SCHAUER
Senior Consumer Affairs Specialist
Center for Mental Health Services
SAMHSA

GLENN STANTON
Deputy Director
Disabled and Elderly Health Programs
Centers for Medicare and Medicaid Sevices

MIKIKO D. STEBBING
Public Health Advisor
Center for Mental Health Services
SAMHSA

JAMES L. STONE
Deputy Administrator
SAMHSA

IVETTE TORRES
Associate Director for Consumer Affairs
Center for Substance Abuse Treatment
SAMHSA

RITA VANDIVORT
Public Health Advisor
Center for Substance Abuse Treatment
SAMHSA

BEVERLY WATTS DAVIS
Director
Center for Substance Abuse Prevention
SAMHSA

APPENDIX B: SELECTED INTERNET RESOURCES

This list of selected Internet sites includes a variety of consumer direction and related efforts for people who want more information on consumer direction initiatives. The sites that are directly relevant for behavioral health are few at this time. Many of the sites are from programs or grants that serve people with disabilities and older adults. Other sites provide policy and research articles that may be relevant. ***This list is provided as a resource. It is not exhaustive, nor does the content necessarily reflect the views, opinions, or policies of SAMHSA or DHHS.***

GENERAL INFORMATION

The Center for Self-Determination

The Center homepage includes news, State-by-State summaries, newsletters, events, publications, membership, and other resources.
http://www.self-determination.com

University of Illinois at Chicago National Research and Training Center on Psychiatric Disability

Information on their 5-year agenda of self-determination projects includes these topics: increasing consumer choice in treatment and services through advance directives, peer-to-peer services, and other mechanisms; enhancing economic self-sufficiency through real jobs for real wages; promoting consumer participation in mental health financing strategies; strengthening consumer self-determination skills through self-advocacy; and advancing promising practices in self-determination services to the level of evidence-based practices. This involves exploring the effects of self-determination initiatives such as cash and counseling, fiscal intermediaries, brokered service models, Medicaid Home and Community Based waivers, Medicaid buy-in and rehab options, and TANF return-to-work programs for people with psychiatric disabilities.
http://www.psych.uic.edu/UICNRTC

A collection of papers devoted exclusively to self-determination and mental health:
http://www.psych.uic.edu/UICNRTC/sdconfpapers.htm

FEDERAL SITES

CMS Real Choice Systems Change Grants

http://www.cms.hhs.gov/realchoice
http://www.cms.hhs.gov/systemschange

SAMHSA CSAT Access to Recovery Grants

The Access to Recovery Web site has the Request for Applications, news releases, and frequently asked questions. "The key to implementing the grant program is the States'

ability to ensure genuine, free, and independent client choice of eligible providers. States are encouraged to support any mixture of clinical treatment and recovery support services that can be expected to achieve the program's goal of cost-effective, successful outcomes for the largest number of people."
http://www.atr.samhsa.gov

SAMHSA CSAT Peer-to-Peer Recovery (Recovery Community Services Program)
http://www.rcsp.samhsa.gov

SAMHSA CMHS Consumer Affairs Program
http://www.mentalhealth.samhsa.gov/consumersurvivor/about.asp

Consumer-Directed Models of Personal Care: Lessons from Medicaid
http://aspe.hhs.gov/daltcp/reports/lessons.htm

Independent Choices: A National Symposium on Consumer Direction and Self-Determination for the Elderly and Persons with Disabilities
http://aspe.hhs.gov/daltcp/reports/01cfpack.htm

BEHAVIORAL HEALTH CONSUMER DIRECTION PROGRAMS

Florida Self-Directed Care Program
This site includes a detailed and extensive description of the Florida Adult Mental Health Self-Directed Care Program and all the documents available for eligibility, enrollment, recovery planning, approving services, participant education, etc. It is a rich resource developed to provide information, education, forms, and documentation for program participants, other Florida residents and researchers, and advocates from other States.
http://www.floridasdc.info

NAMI in North Florida provided the initial advocacy, coordination with legislators, and impetus to develop the FloridaSDC program.
http://nassau.nami.org/sdc.htm

Oregon Health Sciences Center on Self-Determination
http://selfdeterminationohsu.org

New Hampshire Self-Direction Model
http://nhdds.org/programs

Minnesota's Consumer-Direction Initiative
http://www.dhs.state.mn.us/main/groups/disabilities/documents/pub/dhs_id_004644.hcsp

Example of Rules Governing Consumer-Directed Personal Care Assistance Services
http://www.state.me.us/rehab/cdpas/cdpas_rules.htm

Texas Health and Human Services Commission: ***Effectiveness of Consumer-Directed Services – First Annual Update***
http://www.hhsc.state.tx.us/pubs/020104_CDS_Update1.html

RELATED SITES—CONSUMER/FAMILY OPERATED PROGRAMS

Recovery Homes
This site contains a description of the Oxford House Model for Recovery Homes.
It includes links to a variety of resources.
http://www.oxfordhouse.org

SAMHSA Mental Health Information Center: ***Consumer/Survivor-Operated Self-Help Programs: A Technical Report***
A review of the findings and recommendations of mental health consumer/survivor self-help programs.
http://www.mentalhealth.org/publications/allpubs/SMA01-3510

Children's Mental Health
Children's systems of care involve many family-directed services, flexible wraparound funding, and a set of values and philosophy that are consumer and family directed.
http://www.mentalhealth.samhsa.gov/cmhs/ChildrensCampaign

Promising Practices in Children's Mental Health
http://cecp.air.org/promisingpractices/#2001

Research and Training Center for Children's Mental Health – Links to related Internet sites
http://rtckids.fmhi.usf.edu/links.html

RELATED SITES—ELDERLY AND DISABLED

Aging Services: Consumer Direction
This Web site is part of a national initiative funded by The Robert Wood Johnson Foundation to increase opportunities for older consumers to direct their own care. Links to other sites are provided.
http://www.consumerdirection.org

National Association of State Units on Aging (NASUA)
NASUA has provided extensive leadership to States and others seeking to develop consumer direction initiatives for personal care services and other alternatives to nursing homes and institutions.
http://www.nasua.org

Robert Wood Johnson Foundation (RWJF): Cash and Counseling Demonstration
This site is the home for the Cash and Counseling demonstrations that RWJF has funded. It provides links to Calls for Proposals, the National Program Office, and the Cash and Counseling site.
http://www.rwjf.org/programs/npoDetail.jsp?id=CAS

RWJF News Release: ***Foundation Aims at Taking Consumer-Directed Service Model for Medicaid to National Level***
http://www.rwjf.org/news/releaseDetail.jsp?id=1073479314892

Cash and Counseling
National program office site for RWJF grantees
http://www.cashandcounseling.org/index.html

Survey of State Administrators: Consumer-Directed Home and Community-Based Services (1996). State Administrators' perceptions of consumer-directed services in long-term care with concerns centered around quality assurance, fraud and abuse, and difficulties in implementation of self-directed programs.
http://www.freedomclearinghouse.org/documents/finalreport96.htm

Improving the Quality of Medicaid Personal Assistance Through Consumer Direction by Leslie Foster et al.
http://content.healthaffairs.org/cgi/reprint/hlthaff.w3.162v1.pdf

The Cash and Counseling Demonstration: An Experiment in Consumer-Directed Personal Assistance Services by Pamela J. Doty
http://www.independentliving.org/docs4/ar398.html

ADVOCACY AND EDUCATION

Current Legislation

MiCASSA, S. 971, cosponsored by Senators Harkin and Specter, would require States to provide community-based attendant services to individuals with disabilities and older Americans.
http://www.adapt.org/casaintr.htm

Money Follows the Person Act, S. 1394, cosponsored by Senators Harkin, Smith, and Specter, gives States additional resources to provide home and community-based services to individuals choosing to leave a nursing home or institution. With the new emphasis on the role of State governments, some ADAPT groups have urged that CASAs be passed by their State legislatures. Vermont (Personal Assistance Services Act - PASA), Ohio (Community Assistance Services Act - CASA), Texas, and Georgia (Long Term Care Choice Act) are four examples. New Mexico and Wisconsin have also been working on bills. For the latest information on efforts at the State level, get in touch with a local ADAPT contact.

Self Advocates Becoming Empowered
http://www.sabeusa.org

Center for an Accessible Society
Funded by the National Institute on Disability and Rehabilitation Research.
This is the Center's page of consumer direction in personal assistance services:
http://www.accessiblesociety.org/topics/persasst/consumerdir.htm
This extensive site functions as a communications clearinghouse for journalists:
http://www.accessiblesociety.org/index.shtml

POLICY ISSUES

***Consumer-Directed Home and Community Services: Policy Issues* —Urban Institute Report**
http://www.urban.org/Template.cfm?NavMenuID=24&template=/TaggedContent/ViewPublication.cfm&PublicationID=7379

Heritage Foundation—*The Future of Medicaid: Consumer-Directed Care*
by James Frogue
http://www.heritage.org/Research/HealthCare/BG1618.cfm

Consumer-Directed Health Care: Will This Growing Trend Affect the Long Term Care Delivery System?
American Medical Directors Association – Caring for the Ages
http://www.amda.com/caring/december2003/consumer.htm

Galen Institute: Center for Consumer-Driven Health Care
Links and information about the commercial sector and Medicare reforms in Health Savings Accounts.
http://www.galen.org/ccdhc.asp?1

***Toward a Consumer-Directed National Mental Health Policy* –** by Andrew Imparato
http://cdrc.ohsu.edu/selfdetermination/leadership/alliance/documents/Toward Consumer-Directed_National_Mental_Health_Policy.pdf

The Federal Role in the Move Toward Consumer Direction
http://www.hhp.umd.edu/AGING/CCDemo/Publications/dotyFederal.html

Annotated Bibliography on Consumer-Operated Services
http://mimh200.mimh.edu/PieDb/01599.htm

OLMSTEAD

Health Care Financing Administration (CMS)—Americans with Disabilities Act/Olmstead Decision
http://www.hcfa.gov/medicaid/olmstead/olmshome.htm

Bazelon Center for Mental Health Law
This Web site includes a 2001 review of the status of States' planning for the development of community-based children's services entitled *Merging System of Care Principles with Civil Rights Law: Olmstead Planning for Children with Serious Emotional Disturbance.*
http://www.bazelon.org/olmstead.html

White House Executive Order—"Community-Based Alternatives for Individuals with Disabilities"
http://www.whitehouse.gov/news/releases/2001/06/20010619.html

The New Freedom Initiative
http://www.hhs.gov/newfreedom

Delivering on the Promise
Preliminary Report of Federal Agencies' Actions to Eliminate Barriers and Promote Community Integration Presented to the President of the United States, December 21, 2001
http://www.hhs.gov/newfreedom/prelim

National Association of Protection and Advocacy Systems, Inc.
Information about State-advocacy efforts to develop comprehensive, effectively working State plans for moving unnecessarily institutionalized persons into the community with support.
http://www.napas.org/I-3/I-3-D/Plan%20template%20oct%2012.htm

National and Statewide Coalitions to Promote Community-Based Care
Targeted financial assistance, technical assistance, and training to States.
http://www.olmsteadcommunity.org

APPENDIX C: BARRIERS TO SELF-DIRECTED CARE

Self-direction initiatives involve a major transformation of the service system and require a significant rethinking of virtually every aspect of the current system—from financing and network development through case management and education. As a result, existing programs have received significant resistance from many people and organizations in the system. In this section, many of these barriers, which were discussed at the Summit, are highlighted under the headings Popular and Political Culture; Providers and Professional Groups; Legislation and Regulation; and Resources.

POPULAR AND POLITICAL CULTURE

Popular opinion and the media that stigmatize mental illnesses, definitions that influence social perceptions, and competency issues that arise from fear of liability all pose barriers to self-direction. These issues of popular and political culture raised by the Summit participants are explained below.

Stigma and Discrimination

The stigma and discrimination attached to psychiatric disabilities and substance use disorders represent a major obstacle to self-directed care initiatives. Participants, professionals, advocates, and individuals in recovery echoed these concerns throughout the Summit.

Popular culture is a powerful influence and is often a source of stigmatization. An example of this is the reporting about mental illnesses and substance use in the media. Medically oriented definitions have fueled the public's notion that individuals with mental illnesses may be too irrational and irresponsible to direct their own care. Many persons continue to view addiction as a moral and/or personal weakness that in some way lessens the responsibility of society to treat the condition. Some who hold this view believe that one's fear of incarceration should be sufficient to reduce one's addictive behaviors. These misconceptions have the potential to severely limit the achievement of self-directed care initiatives.

Common perceptions of people with mental illnesses are "dirty, homeless, incurable, dangerous, and a blight on our neighborhood."

Advocate

Unlike physical disabilities, behavioral health outcomes are often "invisible," making it difficult for people to see the success stories of recovery. Without this visibility, it will be hard to sustain the changes necessary for self-direction.

Definitions of Mental Illnesses and Substance Use Disorders

Discussions about how people with mental illnesses and substance use disorders are perceived focused on current definitions of mental illnesses and substance use disorders, as well as the language used in referring to these conditions. Participants from the mental health community highlighted issues such as the way in which current medical models and definitions have led to political inertia, influenced social perceptions, and inhibited recovery. Participants involved in recovery from substance use disorders, on the other hand, emphasized problems with language and attitudes that fail to recognize that substance use disorders are a disease.

"Unless people with mental illnesses and substance use disorders intentionally disclose that they have a disability, have recovered and are living their lives, the public and decision-makers will continue to focus on their deficits rather than capabilities and abilities."

Advocate

The current definitions of mental illnesses are based on medical models that contradict the foundations of the self-directed care movement. For instance, one existing definition of mental illness states that "mental illness is a brain disease that impairs judgment" (Chamberlin, Panel Discussion on Adults with Mental Illnesses, March 2004). Despite the fact that an institutionally based psychiatric system has been largely transformed into a community-based one, people with mental illnesses continue to have their recovery impeded due to stakeholders' persistent institutional thinking (Fisher & Chamberlin, 2004). The "outdated, classical medical model that describes serious mental illnesses as permanent, biological diseases" (Fisher & Chamberlin, 2004) considers mental illnesses incurable and recovery unlikely. As a result, services remain provider-oriented and based on control and exclusion, rather than being centered on consumer/survivor recovery, self-determination, and community participation.

The concept of a "substance use disorder" indicates a belief in a medical and biological basis for addiction, but it is sometimes accompanied by the mistaken belief that the disorder is permanently disabling and that no one ever gets better. The concept of "recovery," however, also has a long history in the addiction field. Far more problematic for the addiction field are definitions and concepts that imply that people "choose" to have substance use disorders and could simply "choose" to get better. For this reason, for some people the principle of choice that is embedded within the self-directed care movement can seem to conflict with the addiction and recovery field's traditional emphasis on the disease model.

"The only people who are going to qualify for self-directed care or individual accounts are people who are no longer labeled mentally ill, because the definition of mental illness, as it presently exists, says that a person (with mental illness) cannot make decisions for themselves."

Advocate

Competency

Competency issues stemming from a culture of expertise and fear of liability also were highlighted as potential barriers to self-directed care. It was argued that treatment is currently based on compliance and focused around competency scales with supervision and control. Moreover, the underlying assumptions about people with mental illnesses and substance use disorders continue to equate disability with lack of capacity. Therefore, challenges may arise if and when competence inquiries are used in evaluating self-directed care (Stefan, 2004).

PROVIDERS AND PROFESSIONAL GROUPS

One major issue that resonated throughout the Summit was that there is a "culture" within some professions that will resist many of the changes of self-direction and self-determination. Medical models and the culture of professionals may not support self-direction for people with psychiatric disabilities and substance use disorders. Moreover, formal treatment systems often do not recognize the degree to which nontraditional supports assist people with their recovery, thus presenting a further obstacle to successful implementation of self-directed care.

One participant emphasized the need to modify the way professionals are taught about mental illnesses because "everything in their training has led them to believe that self-direction (for those with mental illnesses) is impossible."

Provider resistance is likely to be strong for several other reasons, the most significant being fears about the loss of funding. One outcome of the cashing-out of funds for services is likely to be loss of provider revenue from current sources due to program cuts. Therefore, the redistribution of funds is likely to be highly controversial and to engender considerable political opposition from powerful trade and lobbying groups (Cook et al., 2004). Armstrong (2004) referenced previous studies of consumer-directed models of personal care that indicated that the level of choice and satisfaction are improved when individuals can hire whomever they wish. Moreover, when given the choice, many consumers tend to hire persons with whom they are familiar, such as family members, friends, and neighbors. She highlighted the threatening nature of this type of change to providers.

Although some providers are likely to experience reductions in total revenue through the implementation of consumer choice and self-direction, others will respond with more innovative services that are responsive to the needs of consumers. The challenge for public purchasers is in maintaining the safety net of services while transitioning to self-direction. Substantial consumer advocacy will be needed to realize self-directed care.

> "People often form their views about addiction from media coverage about celebrities going into rehabilitation. . . Treatment is more than just detox and Betty Ford."
>
> *Advocate*

LEGISLATION AND REGULATION

Current policies deny people with psychiatric disabilities and substance use disorders the kinds of opportunities for self-directed care that people with other disabilities have. Therefore legislation and regulations as well as eligibility criteria, many of which represent barriers to the provision and financing of self-directed care initiatives, need to be addressed. Although significant steps have been made to demonstrate successes in self-directed care, some of the benefits and eligibility criteria are not appropriate for all populations.

Medicaid Waivers

The services CMS finances are based on the medical model, though in recent years that has been changing to include a more rehabilitative approach. As a result, CMS has not recognized lay practitioners as qualified to provide medical or remedial treatments. This limits the use of peers as service providers unless they are "certified" or "licensed" as practitioners by the State. "States using the rehabilitation option for Medicaid-funded peer supports must demonstrate that practitioners are recognized by the State as professionals, through certification or licensure. States must also ensure adequate training, care coordination, supervision, and ongoing support of peer service providers" (Cook et al., 2004). Georgia's and South Carolina's recent success in seeking approval for and implementing peer support programs is an example of how States might overcome some of these barriers.

The approval process for Medicaid 1115 waivers (which include the New Independence Plus waivers) is cumbersome; it may take 2 to 3 years to complete because the State's application must be approved by the Federal Office of Management and Budget in addition to CMS (Cook et al., 2004). This limits most States to the use and modification of Home and Community Based Waivers (HCBW). As a result of limitations on Medicaid funding for State hospitals, only three States use HCBW for mental health conditions, and all three focus on the needs of children.

As noted earlier, many participants were concerned about the IMD exclusion and the resulting limits on Federal funding for residential services that individuals often need.

> "Many mainstream social welfare programs are not designed to serve people with serious mental illnesses, even though this group has become one of the largest and most severely disabled groups of beneficiaries."
>
> *New Freedom Commission on Mental Health: Final Report, p. 28*

"Before we make any of these changes, first we have to change some of the laws that institutionalize this discrimination and continue to perpetuate it."

Professional

Eligibility

Eligibility issues related to both functional and income status can create challenges for self-directed care.

- CMS Waivers are available for States to use for self-directed programs, yet some specifically exclude people who reside in "institutions for mental disease" (IMD).
  - The 1915(c) waiver cannot be used to provide home and community-based services to adults between the ages of 22 through 64 who would otherwise be served in IMDs. This was primarily due to the Federal government's desire in Medicaid enabling legislation not to supplant existing State expenditures when Medicaid was created.
  - Medicaid 1915(c) waivers often use measures of Activities of Daily Living as eligibility criteria, yet these do not apply to adolescents with substance use disorders. "Moreover, those adolescents termed experimenters in the substance use community cannot use Medicaid money for treatment, as they do not meet the diagnostic threshold of abuse" (Cavanaugh, Panel Discussion on Population Groups, March 2004).
- Social Security Income is not available to people with substance use disorders as their primary diagnosis, yet it is available to people with those as secondary diagnoses.

RESOURCES

The public behavioral health system is resource poor in most States, and there is a large range in per capita expenditures for public behavioral health services across States. The current fiscal crisis, which is exacerbating an already chronic problem, may be used to justify the reduction of services currently provided by States and to prevent the development of new service delivery models (Cook, Summit Presentation, March 2004).

Infrastructure and Interagency Constraints

Infrastructure Constraints. Participants suggested that one of the main barriers to the implementation of self-directed care initiatives was the existing infrastructure of the behavioral health service system. The current system focuses on treatment of acute illness and disability, rather than on prevention, early interventions, and ongoing recovery. This system perpetuates reliance on professional advice and/or institutional care.

Substance use disorder treatment systems for adolescents are less developed than the children's mental health system and lack a developed clinical core. It was pointed out that although "wraparound" services are highly desirable, a core system is needed first.

Currently, many States' mental illness and substance use disorder treatment systems have significant service gaps and lack any real choice in services. Consumers/survivors and recovering people sounded a cautionary note about trying to create "choice" where there are few services to choose from. Many participants cited the IMD exclusion by Medicaid as a significant barrier for services in both the recovery fields. However, the use of "nontraditional" providers can increase the choice and scope of services available to individuals.

Interagency Constraints. Concerns were raised about how individuals can access and integrate care, support services, and benefits that will facilitate their recovery across an already fragmented and overly complex system. All population groups emphasized the difficulties of collaboration and coordination within the current public system.

Representatives of children and families underlined the difficulties associated with intersystem involvement. The efforts of child welfare agencies, juvenile justice agencies, treatment providers, and schools, as well as mental health agencies, can have a significant impact on the outcomes of services provided to children and their families. Because so many agencies often finance portions of mental treatment services for children, "cashing-out" services (as is appropriate for adult groups) may not be appropriate for children/youth and family groups.

One participant pointed out that although child welfare agencies have a best practice model called family group conferencing, in which families have considerable choice in supports and care, such services, in practice, are very limited.

In addition, a large number of youth with substance use disorders are already in the juvenile justice system, and their treatment is frequently prescribed as a condition of probation and parole. Thus, their freedom of choice is severely circumscribed.

APPENDIX D: SPECIFIC RECOMMENDATIONS OF THE SUMMIT WORKGROUPS

INFRASTRUCTURE GROUP RECOMMENDATIONS

1. SAMHSA and CMS should provide clear leadership in ensuring the implementation of self-direction. In particular, they should

- Establish a SAMHSA executive-level workgroup to support and expand the focus on self-direction throughout all SAMHSA initiatives.
- Ensure the inclusion of the values and principles of self-direction (freedom and quality) throughout the SAMHSA Priorities: Programs and Principles Matrix.
- Foster a strategic collaboration with each other to ensure that Medicaid system supports and evidence-based and promising practices for mental illness and substance use disorder treatments, including the scope, intensity, and duration of services, are paid for by Medicaid.
- Establish a workforce initiative to support the cultural changes that are necessary to recognize peer, consumer, and family involvement in care. This initiative would include families and local systems of care, peers, and professionals.
- Provide highly focused technical assistance and training for States, providers, consumers, and other system stakeholders.
- Develop guidance for model legislation and regulations and assist States where needed with legislative and regulatory issues.
- Provide incentives for procurements involving self-directed care programs.

2. Develop and ensure person-centered recovery planning including the essentials for living, working, learning, and participating fully in the community.

- Assist States and professional groups with training in the significant changes involved in implementing person-centered planning.
- Develop guidelines for professionals regarding self-determination in specific areas such as seclusion, restraint, involuntary medication, and commitment processes.

3. Learn from and leverage existing State/local self-determination models to build other State/local initiatives.

- Identify new and emerging partnerships to build State and local initiatives. In particular, relationships should be established with the following: the Departments of Health and Human Services, Labor, Justice, Housing and Urban Development, the Social Security Administration, other Federal departments, and their State and local counterparts to maximize the momentum for self-directed life in the community.

- Share and study the implementation of practices and models across disability systems that use self-direction tools, i.e., Wellness Recovery Action Planning, psychiatric advance directives, fiscal intermediaries, individual budgets, asset building, and financial strategies.

4. Analyze barriers and opportunities and identify the needed changes in Federal funding and regulatory and statutory mechanisms to support self-determination.

- Investigate and work to promote the reform of liability laws.
- Review all financing supports across the Federal government in support of self-direction.
- Maximize flexibility within Medicaid to cover nontraditional services, such as family and peer-support services.
- Ensure that family members can receive Medicaid services to support the recipient's plan of care.
- Identify and share with other States the various financing options needed for consumer-directed treatment and support.

5. Identify a phase-in process, including benchmarks and timetables that support a national self-determination initiative.

- Delegate planning of self-directed care programs to a representative body of "consumer" leaders who would work in collaboration with designated SAMHSA staff.
- Utilize State planning mechanisms, such as Olmstead and Community Mental Health and Substance Abuse Prevention and Treatment Block Grant plans and other State planning mechanisms, including those in criminal justice, to support and expand self-direction.
- Update the Partners for Recovery Initiative to include self-directed care.
- Develop educational tools and programs to empower consumers and their families to lead self-directed plans.
- Launch a public media campaign to promote self-direction and address stigma and discrimination for persons with psychiatric disabilities and/or substance use disorders.

CHILDREN AND FAMILIES GROUP RECOMMENDATIONS

SAMHSA should

1. Involve CMS in discussions with the Federation of Families and representatives of families with youth in the substance use disorders treatment system to develop a plan to help families in States, tribes, and Territories to receive services that families and youth value. This should include (but not be limited to) respite and family support services.

2. Establish a national recovery resource center as a national clearinghouse for recovery research and service models for adolescents and adults in the areas of mental health, substance use disorders, trauma, etc.

3. Convene consumers, families, and youth in States, tribes, and Territories to operationally define "self-direction" for families and youth with specific elements to be evaluated.

4. Provide planning funds and support for technical assistance to convene States with existing Home and Community Based Waivers to guide other States with the implementation of self-directed care pilots.

5. Use lessons learned from experienced States and State leadership to help other States apply for waivers.

6. Fund statewide family advocacy organizations beyond the current competitive grant program.

The three States (Kansas, Vermont, and New York) that have Home and Community Based Waivers for behavioral health for children's mental health services have a strategic advantage in the implementation of self-direction in mental health services funded by Medicaid. SAMHSA should consider how they could support the implementation of self-direction in these States through technical assistance, pilot funds, and other consultation with family organizations, advocates, and State staff.

ADULTS WITH MENTAL ILLNESSES GROUP RECOMMENDATIONS

1. Promote and foster self-directed care programs in every State in the United States.

- Fund a national demonstration program.
- Include a majority, or significant representation, of consumers at every stage of the process at both Federal and local levels. These stages include planning, implementation (initial and ongoing), evaluation, and dissemination. Supports should be available to ensure this level of consumer representation.
- Demonstration initiatives of self-directed care should include evaluations of every program according to the following outcomes:
  - Participants are living where they want to and have access to available resources. This standard assumes that there are decent choices and the person is aware of them given available resources.
  - Participants have a broad and diverse social/support system of their own choosing.
  - Participants have opportunities to do things that are productive and personally meaningful.
  - Participants are moving toward increasing economic security.
- Solicit interagency agreements or other collaborative agreements with other Federal agencies such as CMS, the Rehabilitation Services Administration (RSA), the Departments of Labor and Housing and Urban Development, the

Social Security Administration, and others to co-fund this self-directed care demonstration.

- Seek collaborative funding for self-directed demonstrations from private sources (e.g., foundations, faith-based initiatives, banking institutions).
- Actively encourage States to use mental health block grant monies to help fund self-directed care demonstration programs and provide technical assistance to States for this purpose.
- Request additional funding from Congress to fund this initiative.
- Ensure that all proposals for self-directed care programs are guided by the principles of self-determination: freedom, participation, authority, responsibility, and support.
- Actively encourage the development of new peer-run programs and their adequate funding.

2. Address regulatory barriers to self-directed care for people with mental illnesses.

- Work with CMS to ensure that 1115 waivers are available to populations that include people with mental illnesses and that waiver proposals are reviewed in 60 to 90 days. Legislation should be passed to mandate this.
- People with mental illnesses should be able to benefit from funding streams available to people with other disabilities (e.g., Personal Assistance Services).
  - Collaborate with CMS to rewrite the regulatory language so that people with mental illnesses can qualify for personal assistance services.
- Work with the Social Security Administration to fund a demonstration program in which Ticket to Work funds are cashed-out and banked to be used by people with psychiatric disabilities in self-directed return-to-work plans.
- Work with the Rehabilitation Services Administration to develop waivers or other mechanisms whereby State-Federal Vocational Rehabilitation (VR) funds are cashed-out and banked in order to be under the control of people with mental illnesses who wish to return to work.
- Remove barriers to Medicaid funding of peer-run services.

3. "Nothing about us without us."

- Include the meaningful participation of people with mental illnesses at every level and activity of self-directed care, in recognition of their full humanity. This must be a guiding principle.
- Provide technical assistance, training, and support to ensure peer leadership development at local, State, and national levels.
- Provide people who are participants in self-directed care with resources, training, and compensation to become leaders and mentors of self-directed care.
- Fund a project to initiate a peer-developed and controlled curriculum on the history of self-directed recovery.

- Implement workforce development to train people with mental illnesses to deliver self-directed services in a wide range of programs, including peer-run programs.

4. Import person-centered medicine and the shared decision-making model as recommended in the Institute of Medicine's *Bridging the Quality Chasm* report into psychiatry. Fund a demonstration initiative to

- Study and create decision-making aids and values clarification tools to ensure that people direct their mental health care.
- Train psychiatrists and other clinicians in the shared decision-making model (including making this training a requirement of American Psychiatric Association psychiatry residency training).
- Train people in mental health recovery in the skills necessary to engage in shared decision making and self-directed mental health care.

5. To address the enforced impoverishment of people with mental illnesses, encourage asset development among people with mental illnesses.

- Fund a demonstration program or other initiatives to enable consumers to establish Individual Development Accounts (IDAs).
  - Allowable funds in IDAs should include both earned and unearned income—for example, contributions from family.
  - IDA funds should not be counted in Supplemental Security Income asset calculation.
  - Purposes for which IDAs are intended should be expanded to include purchasing transportation, needed technology, child or elder care, retirement, and other impairment-related expenses.
- Provide financial education, planning, and counseling to people with mental illnesses.

ADULTS WITH SUBSTANCE USE DISORDERS GROUP RECOMMENDATIONS

1. Increase financial support and technical assistance for CSAT's Recovery Community Services Program (RCSP) in addition to providing additional technical assistance and resources for non-RCSP recovery and consumer-support organizations.

2. Create and establish an intra-agency council consisting of consumers and their families to address research, advocacy, and best practices for self-directed care.

3. Take a leadership role in developing an interagency initiative to address consumer-directed care and self-determination in recovery communities.

4. Fund and establish a national media campaign to reduce stigma and educate the public on substance use disorders and recovery.

5. Fund a consumer education initiative organized and operated by consumers.

6. Design a consumer direction initiative that delivers an appropriate level of support to engender safety for the consumer and ensure that services are provided in an atmosphere of respect and accountability.