Shared Decision-Making
in Mental Health Care

Practice, Research, and Future Directions

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
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Introduction

Shared decision-making (SDM) is a practice and concept with the potential to advance wellness and recovery in mental health care. By making the consumer an indispensable partner in the process of recovery, SDM advances many of the goals of mental health care transformation, previously identified by the President's New Freedom Commission on Mental Health, the Institute of Medicine, and others. As A. Kathryn Power, Director of the Center for Mental Health Services (CMHS), Substance Abuse and Mental Health Services Administration (SAMHSA), said: "SDM is an opportunity to make recovery real. By developing and promoting SDM in mental health care, we can advance consumer-centered care and recovery" (Power, 2007).

In July 2007, a meeting of approximately 50 experts and stakeholders in SDM and mental health was convened in Washington, DC by CMHS. Participants included researchers and SDM providers in general and mental health care, policymakers, and mental health consumers. The meeting provided an opportunity for participants to exchange perspectives on SDM, inform one another of the state of the science and practice of SDM in general and mental health care, and develop recommendations for advancing SDM within the U.S. mental health care field. Participants shared their experiences as consumers and providers of mental health care and offered insights and perspectives on a variety of aspects of SDM.

This report is intended to provide a general overview of SDM and the available research on its effects in both general and mental health care. It includes recommendations from the participants of the SDM meeting. Participant perspectives are included throughout the report, as well as in a section specifically devoted to learnings from the meeting. A resource list, to assist those seeking further information about the concept and practice of SDM, is included in Appendix A.

This report also includes three manuscripts prepared as premeeting papers; these background materials were distributed to meeting participants in advance, and are included here to further the readers' understanding of the topic. Supplement 1, Shared Decision-Making in Mental Health Care: Overview and Current Status, reviews SDM definitions, research, and practices in relation to mental health care and the recovery process. Supplement 2, Shared Decision-Making in Mental Health Care: Overcoming Barriers to Changing Embedded Norms, reviews the implementation barriers to SDM and describes promising service delivery models and programs that may incrementally overcome impediments to routine use of SDM. Supplement 3, Aids to Assist Shared Decision-Making in Mental Health Care, presents information on decision aids (DAs) that are available to mental health consumers and professionals; the paper also lists resources for professionals and consumers.

Section 1
Overview of Shared Decision-Making

SDM provides an approach through which providers and consumers of health care come together as collaborators in determining the course of care. Research has shown that SDM, when practiced in general health care, increases consumers' knowledge about and comfort with the health care decisions they make. These alone are worthy goals—but the promise of SDM in mental health care is truly transformative.

By placing mental health consumers at the center of the decision-making process, SDM provides a model through which multiple calls for transformation of the mental health field might be answered.

- The report of the President's New Freedom Commission on Mental Health (2003) calls for mental health care to be consumer and family driven.
- The Institute of Medicine's (IOM) 2006 report, Improving the Quality of Health Care for Mental and Substance-Use Conditions, asserts that the individuals receiving care should be at the center of that care at all times, and that mental health care should be respectful of and responsive to individual needs and preferences. In addition, the report called for "providing decision-making support to all M/SU [mental and/or substance-use] health care consumers" (p. 105).
- Among the 10 fundamental aspects of mental health care identified in SAMHSA's National Consensus Statement on Mental Health Recovery (2006a) are self-direction; individualized care; person-centered care; and care that supports empowerment, individual responsibility, and recovery.
- The 2007 Action Plan of the Annapolis Coalition on the Behavioral Health Workforce includes as its first goal "Significantly expand the role of individuals in recovery. . . to participate in, ultimately direct, or accept responsibility for their own care" (Annapolis Coalition, 2007, p. 15).
- Recent documents from SAMHSA (Consumer-Driven Care, 2006b; Family-Driven Care, 2006c) support consumers and families in having the primary decision-making role regarding mental health and related care offered and received.

Despite its promise, several barriers to widespread implementation of SDM in mental health care exist. Among these are some unfounded concerns about the capacity of persons with mental illnesses to make informed decisions, discomfort on the part of some mental health care providers at the shift in roles required by SDM, unease on the part of some mental health consumers regarding their ability to take the

responsibilities offered through SDM, and lingering public fear and prejudice around mental illness and persons with mental illnesses.

Defining SDM: Concepts, Components, and Goals

A precise definition of SDM has yet to be established. However, key characteristics have been identified:

- At least two people, acting as partners, are involved. Generally, these are the health care provider and consumer.
- Both partners take steps in sharing a treatment decision.
- The two partners share information about treatment options.
- The partners arrive at consensus regarding the preferred treatment options (Charles, Gafni, & Whelan, 1997; Schauer, Everett, del Vecchio, & Anderson, 2007).

Schauer et al. (2007, p. 56) further detailed the role of each partner in the information exchange: "The practitioner brings information related to the illness, treatment options, risks, benefits, and evidence base. The patient is considered an expert in his or her own values, treatment preferences, and treatment goals." According to Deegan (2007, p. 64), "SDM is founded on the premise that two experts are in the consultation room. . . neither. . . should be silenced, and both must share information in order to arrive at the best treatment decisions possible."

The objectives of SDM are improved communication, understanding, and decision-making, or in Deegan's words, "SDM is predicated on breaking silence and enhancing dialogue" (Deegan, 2007, p. 64). When consumers and providers engage in SDM, more information about consumer preferences, practices, and values can emerge and be taken into consideration. It is expected that this process will result in decisions that are more appropriate for individual consumers, and that these characteristics will lead to increased satisfaction and perhaps to better health outcomes.

Related Concepts

Any discussion of SDM must necessarily touch upon the concept of decisional conflict; when the focus is the mental health field, considerations of adherence and coercion are also integral to the discussion. Person-centered care, self-directed care, and personal medicine are important concepts in mental health transformation that are related to, but different from SDM.

Decisional Conflict

Decisional conflict or decisional uncertainties are terms describing a person's difficulty in coming to a decision, in this case, about treatment. Decisional conflict can delay a person from making a decision, can create regret and uncertainty about a decision that is made, and can precipitate a lack of follow-through on a decision that appears to have been made.

In her presentation at the SDM meeting, Patricia Deegan, Ph.D. noted that decisional conflict is often related to the level of certainty that is available regarding treatment options. Treatment options that have a strong evidence base and have risen to the level of a standard of care—such as antibiotics in the case of bacterial infection—rarely cause decisional conflict. However, when the benefits of treatment are not so well known, or when treatment carries a risk of significant side effects—such as the risk of metabolic dysregulation following the use of psychiatric medication—decisional conflict is more common.

Adherence and Coercion

Adherence or compliance, in this context, refers to the extent to which a consumer follows a treatment plan. In the context of mental health treatment, the "compliance versus noncompliance dichotomy can serve to reinforce the power of the physician and silence people with psychiatric disabilities" (Deegan, 2007, p. 63). Because noncompliance is often perceived to be symptomatic of the illness, rather than indicative of consumer preferences or decisional conflict (Deegan, 2007; Perlman et al., Supplement 3 to this report), the concept of compliance is related to the concept of coercion within the mental health system.

In Supplement 2 to this report, Holmes-Rovner, Adams, and Ashenden describe coercive treatment as a barrier to SDM in mental health care. Consumers and providers alike are aware of the presence of coercive treatment in both inpatient and outpatient settings. While regulations vary from State to State, involuntary outpatient commitment typically requires patients to take medication and comply with other elements of treatment or risk being placed in an inpatient psychiatric hospital. Coercive treatment at inpatient facilities can include seclusion, restraint, and forced medication. Participants at the SDM meeting pointed out that mere knowledge that coercive treatment exists may impact consumers' sense of their ability to truly participate in treatment decisions.

> *"Even in a coercive environment, decisions [appropriate for SDM] are made every day." —State hospital worker; SDM meeting participant*

The perception that people with serious mental illnesses are not capable of participating in decisions about their own treatment is the basis of ethical arguments against SDM (Dudzinski & Sullivan, 2004), is activated in orders of involuntary

outpatient commitment (Holmes-Rovner et al., Supplement 3), and was reported by focus groups of mental health consumers convened through SAMHSA's Elimination of Barriers Initiative (Schauer et al., 2007). In its report, Improving the Quality of Health Care for Mental and Substance-Use Conditions, the IOM strongly rebutted this belief, stating that "many people with mental illness, indeed, many with severe mental illnesses, are not incompetent on most measures of competency" (IOM, 2006, p. 112).

> *"A clear majority of mental health consumers are fully capable of making decisions about their care." —A. Kathryn Power, CMHS Director*

Person-centered Care

Person-centered care describes the effort to ensure that mental health care is centered on the needs and desires of the consumer. It means that consumers set their own recovery goals and have choices in the services they receive, and they can select their own recovery support team. For mental health providers, person-centered care means assisting consumers in achieving goals that are personally meaningful.

Self-directed Care and Personal Medicine

Self-directed care, on the other hand, focuses primarily on the rights and responsibilities of the consumer to "assess their needs, establish an individual plan of care, budget funds to meet their needs, choose how and by whom these needs will be met, and monitor the quality of services they receive" (SAMHSA, 2005, p. 5). In this case, collaboration by the provider is not explicitly required, although providers are identified as sources of information and services.

Deegan (2007) coined the term "personal medicine" to describe self-taught, non-pharmaceutical strategies that persons with mental illnesses use, often in combination with psychiatric medication, to advance their recovery and improve their lives. As an example, Deegan shared the story of a man with bipolar disorder who used math problems to help himself get to sleep and thus avoid a manic episode. She notes, "there seem to be as many types of personal medicine as there are individuals: fishing, parenting, repairing airplanes, walking, diet, caring for pets, friendship, driving. . ." (Deegan, 2007, p. 65).

The concepts of self-directed care and personal medicine are important to a consideration of shared decision-making because, in Deegan's words, "Personal medicine reminds us that there are many ways to change our body's biochemistry and that, within the task of recovery, pill medicine must complement and support personal medicine, or the things that give one's life purpose and meaning" (Deegan, 2007, p. 65).

Values and SDM

SDM holds the promise of transforming the relationship between providers and consumers of health care into a relationship of equals with diverse expertise. As it advances mental health recovery, SDM may also change the understanding and perception of mental illness in our Nation.

> *"SDM is a basic human right." —SDM meeting participant*

SDM promotes what Schauer et al. (2007, p. 55) identify as ". . . psychiatric rehabilitation's fundamental belief that rehabilitation is done with people and not to people." SDM attempts to change the traditional power imbalance between provider and consumer present in general health care and perhaps amplified in mental health care, given concerns about the capacity of persons with mental illnesses and the presence of legal coercive power within the mental health care system. Deegan (2007) defines the traditional psychiatric goal of consumer "compliance" with a treatment plan as constituting oppression at its core.

SDM goes beyond the traditional model of health care and informed consent. In the traditional model (also sometimes called a "paternalistic" model), the provider makes all the decisions and is responsible to educate the consumer only to the extent required to attain treatment compliance. Informed consent ensures that the consumer understands the planned treatment, but does not ensure that the consumer had any role in developing the treatment plan. The SDM approach shifts responsibility for understanding and making decisions to the consumer who is working in collaboration with his or her provider.

SDM upholds the autonomy of health care consumers by engaging them in shaping the course of treatment. SDM assumes that consumers have chosen to participate in the process and recognizes that some level of information is necessary for consumers to make the choice in an informed manner (Schauer et al., 2007). The health care provider plays a crucial role as a consultant to decisions, providing information and supporting consumers in the consideration of treatment options and their individual values. Some consumers do not prefer an SDM approach to health care. Choosing to have one's provider make the health care decision may be related to other issues, such as the values and preferences of one's cultural background. In honoring consumers' autonomy, proponents of SDM must honor the choice of not engaging in SDM as well.

Advantages and Disadvantages of SDM

A number of researchers have identified advantages of SDM; disadvantages have also emerged. Schauer et al. (2007, p. 57) provide a succinct synopsis.

Advantages

- Practitioners can best obtain relevant information on illnesses and intervention (Charles & Demaio, 1993).
- Clients can best make decisions because of the unique values they place on outcomes and the necessary tradeoffs based on preferences and needs (Charles & Demaio, 1993).
- SDM is a self-evident right because each person should determine what happens to his or her body (Nelson, Lord, & Ochocka, 2001).
- Surveys demonstrate near universal client desire to receive health care information and to participate in treatment decision-making (Benbassat, Pilpel, & Tidhar, 1998).
- SDM leads to improvements in the provider-client relationship and health outcomes, such as treatment adherence, treatment satisfaction, and biomedical outcomes (Stewart, 1995).
- An SDM orientation can be very effective in promoting consumer engagement in and responsibility for his or her care. They may generalize to other facets in an individual's recovery plan (Schauer et al., 2007).
- An interaction of mutual respect is fostered and modeled. This can be a confidence builder for consumers (Schauer et al., 2007).
- SDM can be empowering to individuals (Schauer et al., 2007).

Disadvantages

The plethora of choices could be overwhelming to those who have difficulty with decisions; this can result in a sense of lost opportunities (Kahneman & Tversky, 1979).

- Clients may experience regret, or may reject options to spare themselves the possibility of regret (Loomes & Sugden, 1982).
- There is difficulty in valuing options because clients cannot foresee how they will adapt to illness (Jansen, Kievit, Nooij, & Stiggelbout, 2001).
- The anticipation of choice and control may lead to disappointment when expectations meet clinical realities (Adams & Drake, 2006).
- Consumers may be concerned about making a physician or provider angry if they do not choose the recommended course of treatment (Schauer et al., 2007).
- Consumers who have the expectation that professionals will tell them what to do may become frustrated with the latitude in choosing a course of treatment (Schauer et al., 2007).

Outcomes of SDM

There is limited research on SDM in mental health care, but evidence does exist that components of SDM result in positive outcomes for health care consumers. Schauer et al. (2007) summarized the evidence of the value of SDM in general health care.

- The use of client-centered communication reduces consumer stress and improves functional status.
- Consumers who report fully expressing themselves and receiving all the requested information had better functional outcomes than those who did not.
- The provider's ability to "display concern, warmth, and interest" was the most powerful predictor of consumer satisfaction (Adams & Drake, 2006, p. 94).
- "Clients who believe they are actively involved in treatment decisions generally have better outcomes, whereas having a low sense of control over decisions is associated with less behavioral involvement in care, poorer self-rated health, and increased illness burden" (Adams & Drake, 2006, p. 94).
- The use of decision aids appears to increase the utilization of underused services, and decrease the utilization of overused services (O'Connor et al., 2007).

Section 2
The Practice of Shared Decision-Making

The process of SDM, as identified by Simon et al. (2006), includes several steps:

- Recognition that a decision needs to be made;
- Identification of partners in the process as equals;
- Statement of the options as equal;
- Exploration of understanding and expectations;
- Identifying preferences;
- Negotiating options/concordance;
- Sharing the decision; and
- Arranging followup to evaluate decision-making outcomes.

These steps do not all have to be taken at one time, and may not all be conducted in the presence of both parties. Decision aids (DAs), for example, can be utilized by consumers on their own or with the assistance of peers. These tools can help a consumer identify the treatment options and explore their preferences prior to meeting with their provider.

Decision Aids

DAs are tools used to help consumers understand and clarify their choices and preferences in regard to a discrete decision within SDM. DAs are offered in a variety of forms, from printed brochures to interactive electronic tools. Some are designed to be completed by a health care consumer in advance of a professional consultation; others are designed for completion during the clinical encounter. DAs are often utilized in the context of SDM.

> *"When people have the opportunity to carefully consider their care, they tend to have less decisional conflict." —Patricia Deegan, Ph.D.*

DAs have been shown to improve consumer knowledge of treatment options, support more realistic expectations of treatment outcomes, increase consumer comfort with choices, decrease the number of consumers with decisional uncertainty, increase consumer participation in decision-making without increasing consumer anxiety,

and increase the agreement between consumers' values and choices. Consumer satisfaction with the decision-making process or the final decision has not been shown to be affected by the use of DAs (O'Connor et al., 1999; O'Connor, 2001; Molenaar et al., 2000).

The International Patient Decision Aids Standards (IPDAS) Collaboration has developed a set of standards for health care DAs. These standards include the following.

- The DA must provide information about options and the probable effects of taking each option. The options should include the natural course of the disease or condition if no action is taken.
- Information presented should be based on the latest scientific evidence.
- Options must be presented in a balanced way.
- DAs should use plain language.
- A DA must provide support for a consumer to clarify and express his or her values as they relate to the decision.
- Personal stories should be utilized to communicate options and model values clarification.
- Consumers should receive guidance or coaching in their deliberation and communication of concerns or decisions.
- Any conflicts of interest should be disclosed.

In addition, IPDAS recommends that DAs be available via the Internet in order to promote wide access to them and to ensure they may be easily updated if the evidence base changes. For more information, see the IPDAS Web site at http://ipdas.ohri.ca.

During the CMHS-sponsored meeting on SDM, participants reviewed a variety of decision aids. Their observations included the following.

- Preference for those DAs that expressed probabilities in both positive (X of 10 will experience this side effect) and negative (X of 10 will not experience this side effect) terms.
- Recognition that the values clarification portion of the DAs that were reviewed functioned as a bridge between the consumer's life and clinical information about the illness and treatment option.
- Support for DAs that, rather than asking consumers to commit to a course of action prior to speaking with their providers, instead asked them to record their current leanings toward or away from specific treatment options.

In mental health care, there is "less evidence, less certainty of a particular outcome, and less clarity as to which outcome is best" when weighing treatment options (Perlman et al., Supplement 3, p. 107). Because of the risk of significant side effects as well as individual variations in response and tolerance, the benefit-to-harm ratios of many psychiatric medications are uncertain (Holmes-Rovner et al., Supplement 2 to this report). Deegan (2007) provides examples of the ways in which psychiatric medication may interfere with personal medicine, as in the case of a woman who risked losing custody of her children because the medication she took made it difficult to wake up and get them to school on time. In another case, a man who found great joy in restoring engines was unable to do so because of tremors caused by his medication.

> *"Consumers make decisions about their treatment every day—decision aids can help make these decisions more collaborative."—SDM meeting participant*

Due to these complications, Holmes-Rovner et al. (Supplement 2, p. 75) identify many mental health treatment decisions as "preference-sensitive." Preference-sensitive treatments tend to create substantial decisional conflict and uncertainty among consumers seeking to develop mental health treatment plans. Unfortunately, there are relatively few DAs available to help consumers make mental health decisions.

SDM in General Health Care

A wide variety of DAs have been developed for general health care. They are often used when a standard of care has not yet been developed (the most common use), when evidence for a particular treatment plan has not been developed, or when treatments carry significant side effects and risks. In these situations, health care consumers are likely to feel great uncertainty about their choices. DAs have been shown to decrease this decisional conflict or uncertainty, which can in turn reduce treatment delays. Consumers who use DAs have demonstrated greater knowledge about their treatment options and more realistic expectations of their treatment. They are also less likely to regret their decisions.

A number of decision aids are available to general health care consumers, although not all of them meet IPDAS standards. Examples include the following; see Supplement 3 for more information.

- Healthwise DAs are available through WebMD and other Internet sites.
- NexCura® creates DAs that are embedded into the programming of other Internet sites, such as the American Cancer Society and American Heart Association.
- WebMD provides lists of "Questions to Ask Your Doctor," which can provide a step toward informal shared decision-making.

- The Ottawa Health Research Institute maintains a Web-based library of decision aids that meet IPDAS criteria. The Web site also includes the Ottawa Personal Decision Guide, which is designed to assist individuals in making any health care or social decision.
- Individual institutions and organizations, such as the Mayo Clinic, also provide decision aids for their patients or the public at large.

While a variety of surveys demonstrate varying degrees of interest in SDM, a substantial portion of health care consumers consistently express an interest in receiving additional information about their care. Increased age, poorer health, lower education and literacy levels, and greater consequences of a decision tend to decrease an individual's interest in participating in SDM—although these variables do not decrease interest in receiving additional information or negotiating decision-making (Levinson, Kao, & Kuby, 2005; Robinson & Thomson, 2001; Shalowitz & Wolf, 2004; Thompson, 2007).

SDM in Mental Health Care

During the SDM meeting, Dr. Deegan provided an overview of the CommonGround program, a comprehensive, U.S.-based SDM program in mental health. The program is described in detail in print (Deegan, 2007) and serves to highlight many aspects of SDM in mental health that can be advanced within the mental health care system.

The CommonGround program, currently being piloted at several U.S. urban community support programs, is informed by three principles:

- The goal of psychiatric medication is recovery;
- Psychiatric medication must serve personal medicine and recovery; and
- The role of the treatment team is to support clients through decisional conflict to achieve optimal use of personal medicine and psychiatric medicine in the recovery process.

The three components to the program are designed to work together to provide multiple points and modes of support:

Peer-to-peer workshop

A peer-to-peer workshop is offered, and can be used by the client alone, in a peer group, or in a group facilitated by peer specialists or other staff. The curriculum provides opportunities for consumers to learn about the lived experience of others using psychiatric medication in their recovery process and is designed to ready consumers to participate in SDM.

Peer-run Decision Support Center

A typical medication clinic waiting area is transformed into a Decision Support Center providing peer support, food and beverages, and information on client rights. Medication appointments are scheduled to include 20–30 minutes of work time in the Decision Support Center prior to meeting with the provider.

During their time in the Decision Support Center, consumers use specialized software on computers to respond to 33 questions which promote information about personal medicine, overall mental health status, concerns and decisional conflict about using medication, and primary goals for the visit. Also a series of short videos is available, each consisting of peers sharing their experiences of recovery and the use of personal medicine. A one-page report is generated from these responses; one copy is printed out for the consumer, the other is transmitted to the provider electronically. This report then serves as the basis for the consultation with the provider.

Training for Case Management Staff

Case management staff, already trained in a strengths-based approach to case management, receive additional skills training focused on implementing the decisions arrived at by the consumer and provider. Staff are trained to assist consumers in identifying personal medicine and to use decision-making tools such as decisional balance sheets, tradeoff worksheets, and health care journals. Also, a series are trained to train consumers in a variety of coping skills during their time in the peer-run decision support center.

Dr. Deegan reported that consumers tended to be quite forthcoming in the process of completing their report during their time in the peer-run decision support center. Providers received more accurate information about consumers' use of medication, alcohol, and other drugs, and consumers felt that their concerns were addressed more directly. In some cases, consumers appeared to be empowered simply by the organization of their concerns onto a printed page, and to be more assertive that their concerns be addressed. Dr. Deegan reported that providers at the center required some time to adjust to consumers' increased assertiveness.

Psychiatric advance directives, supported by the IOM (2006), can be seen as another method for supporting SDM, even in circumstances such as psychiatric emergencies, when consumers may not be able to participate in SDM. Advance directives are statements of an individual's treatment and services preferences during times of incapacitation, and can assign decision-making authority to another person during these times. Participants at the SDM meeting stressed that, even in the case of involuntary commitment, opportunities for SDM exist and should be utilized.

> "*We don't have to rule out SDM in emergency or crisis situations.*"
> —*SDM meeting participant*

Training Providers and Consumers to Use SDM

A national survey of U.S. physicians showed a 75 percent endorsement of SDM, but it is still not widely implemented in practice. Training is needed to better communicate the components of SDM, and to assist providers in assessing their need for such training. Decision aids, by including all treatment options, might help to reduce the variability of care and serve as reminders and training aids for health care providers.

Research studies have demonstrated that skills critical to SDM—such as agenda setting, reflective listening, presenting the advantages and disadvantages of various treatment options, and collaborative decision-making—can be taught to and learned by health care providers, including doctors, nurses, and pharmacists (Stevenson, Cox, Britten, & Dundar, 2004; Edwards et al., 2004; Fellowes, Wilkinson, & Moore, 2003; Lewin, Skea, Entwistle, Zwarenstein, & Dick, 2001). Some studies suggest the use of the skills results in improved health status and decreased anxiety on the part of consumers (van Dam, van Der, van Den, Ryckman, & Crebolder, 2003).

Despite their endorsement of the concept of SDM, health care providers also report holding several beliefs that serve as barriers to its implementation. In addition to misperceptions about the competence of mental health consumers to make treatment decisions, physicians and nurses expressed concerns about:

- Limitations of the research evidence regarding SDM;
- Their own lack of skills in risk communication;
- Consumer reluctance to take decision-making responsibility, and consumers' abilities to cope with the stress of decision-making;
- Consumers' choosing the most expensive treatment options, or options they could not afford;
- Lack of technical support (e.g., risk communication tools, decision aids) for SDM;
- Time limitations of consultations; and
- Undermining the doctor-patient relationship (Ford, Schofield, & Hope, 2002).

Providers expressed reluctance to change or challenge their perceived role responsibilities to demonstrate authority and provide advice and cure (Holmes-Rovner et al., 2007; Hammond, Bandak, & Williams, 1999).
Consumers need support and training to understand their right to SDM, and to understand its benefits. In addition, consumers may need to develop specific skills, including the ability to explain themselves within the time constraints of a consultation; organizing and prioritizing their concerns and thoughts; and clear communication (Holmes-Rovner et al., 2007).

Peer support specialists may be uniquely qualified and positioned to provide this training and support. Peer support specialists are trained mental health care consumers who meet one-on-one with other consumers to listen, discuss concerns, and provide support. Because they have lived experiences with mental illnesses and making treatment decisions as well as experience in navigating the mental health system as consumers, peer support specialists are able to engage in a nonhierarchical, reciprocal relationship. Peer support specialists may also be more likely than health care providers to share and reflect a consumer's culture and language (Perlman et al., Supplement 3).

> *"Hiring consumers as staff changes the attitudes of providers and models recovery to other consumers." —SDM meeting participant*

Barriers to consumer use of SDM include "learned helplessness" (where a person has learned to behave in a helpless manner because of lack of control of their situation) on the part of consumers whose experience has been limited to a paternalistic mental health system focused on ensuring their compliance to treatment (Holmes-Rovner et al., Supplement 2). Participants at the SDM meeting identified additional barriers.

- A culture of silence among consumers surrounding the use of psychiatric medication.
- "Caretaking" of providers by consumers. Consumers may hesitate to share information about medication's side effects, to ask questions, or to seek change in treatment for fear of inconveniencing or distressing their care providers and risking a loss of services.
- Lack of consumer knowledge about medication options—including the option to have treatment without medication—and consumer acceptance of side effects as unavoidable.

> *"There's an enormous taboo against those of us using psychiatric medications discussing them with one another. Many patients don't believe they have a right to mention side effects to their providers; they think they just have to live with them." —Patricia Deegan, Ph.D.*

Section 3
SDM Research

Current research on SDM has focused primarily on Western Europe and the United States, and on the use of SDM in general health care. Additional research is needed to increase understanding of the use or perceptions of SDM in other cultures and in mental health care.

SDM in General Health Care

As discussed previously, research has demonstrated a strong interest in SDM among both consumers and providers. Additional research is needed to explore the reasons SDM is not more widely used by health care providers. In addition, the reluctance of some consumers to utilize SDM could be further explored, to determine if such reluctance can—or should be—ameliorated.

Other outcomes of interest, such as a greater sense of involvement in decision-making, are difficult to quantify. Research on health outcomes is ongoing; to date, few effects on health outcomes have been demonstrated (O'Connor et al., 2002).

SDM in Mental Health Care

Celia Wills, R.N., Ph.D. provided an overview of the research on SDM in mental health care at the SDM meeting. Both the practice of and research on SDM in mental health are still in the early stages, and newer research is primarily concentrated in the countries of Western Europe and the United States. More studies in populations of greater cultural diversity are needed to strengthen the evidence base and understanding of SDM in mental health care.

A number of studies have been conducted, primarily with consumers with depression or schizophrenia, over the last 5 years. General findings regarding patients with depression include the necessity for more information, decision support, and involvement. Patients with depression generally expressed a strong interest in information and involvement. Interventional studies demonstrated improvements in knowledge, decision stage, and involvement, and a reduction in depression and stress. Lower preferences for SDM were found among consumers with severe depression or consumers who reported a lack of agreement with their medical diagnosis. These consumer groups also demonstrated a lower capability for digesting information or becoming involved in decision-making (Simon et al., 2007).

A strong interest in information and involvement was also documented among consumers with schizophrenia. Positive outcomes were demonstrated, including improved knowledge, higher involvement, and improved social function and

satisfaction. Physicians in these studies expressed concern about the decision-making capability of consumers with schizophrenia.

Specific studies highlighted by Dr. Wills include:

- A survey of 96 consumers with schizophrenia found most were interested in SDM especially in regard to medication (Bunn, O'Connor, Tansey, Jones, & Stinson, 1997);
- A randomized control trial of SDM among consumers with schizophrenia in Berlin found that those involved in SDM were more knowledgeable than those in usual care (Hamann, Cohen, Leucht, Busch, & Kissling, 2005; Hamann et al., 2006);
- SDM was associated with improved social interaction and satisfaction in a 2-year randomized control trial of two Swedish community-based treatment programs for people with schizophrenia (Malm, Ivarsson, Allebeck, & Falloon, 2003); and
- An intervention study at Michigan State University of persons with diabetes who also have depression found improved knowledge, improvement in decision stage, greater satisfaction with decision-making, improved involvement, and decreased depression and stress with SDM (Wills, 2006).

Dr. Wills reported that the Michigan State University study included an analysis of the feasibility of the intervention—a depression decision support booklet. The booklet was evaluated as easy to read, and more than 80 percent of participants reported that the time required to complete the materials, the amount of information, and the balance of information provided were appropriate. The decision-making exercises were found to be helpful in activating or clarifying consumers' thinking about decisions, and case illustrations of others' decisions were reported to be very helpful. Consumers with more severe depression or lower education levels reported that the materials required effort, but were still helpful. Project partners perceived the intervention to be a value-added aspect of diabetes self-management education and described it as a feasible intervention.

Liability Concerns

The doctor-patient relationship is defined to include legal and financial responsibilities and rights. The effect of employing SDM within a mental health care setting must be explored in light of these existing rights and responsibilities. Participants at the SDM meeting suggested that other models might inform new understandings of responsibilities and liability in the context of SDM. For example, a tax accountant is a professional with particular expertise hired to provide particular services. The honest input of the consumer, however, is understood to be critical to the accountant's ability to provide those services.

Mental health care providers are assigned some responsibility for protecting the safety of consumers and the public. However, the threat of involuntary treatment—whether real or perceived—colors the relationships and operations of the mental health care field and must be minimized if consumers are to be fully engaged in SDM. Public perceptions of persons with mental illness as dangerous, and policy support for some degree of coercion, will influence efforts to minimize involuntary treatment.

> *"We need to educate the public that mental illness is not a crime, and people with mental illness are more likely to be victims than perpetrators of crime."*
> *—SDM meeting participant*

Section 4
Learnings from the SDM Meeting

Participants at the SDM meeting were strongly supportive of further efforts to understand, promote, and implement SDM in mental health care. In addition to sharing their knowledge and experience, participants crafted consensus recommendations to guide the field in its efforts to advance wellness and recovery, and to support the autonomy and dignity of mental health consumers. Recommendations for advancing SDM were developed in the areas of policy, practice, research, and training. These recommendations follow a summary of the discussions held during the SDM meeting.

> *"All people have the potential and expectation of healing." —SDM meeting participant*

Engaging Providers in SDM

Meeting participants recognized that mental health care providers must invest in SDM if it is to take hold in the mental health care system. A participant noted that most consumers do not have access to peer support networks, and thus receive most of their information and guidance from clinicians.

To engage clinicians in promoting SDM, meeting participants suggested that the benefits to providers be well articulated in educational literature. These benefits, they suggested, could include time savings, better decision outcomes, increased satisfaction on the part of consumers, and better support for consumers' recovery. One participant suggested that the role of provider be specifically defined as "supporting the lives of consumers as they want to live them."

Meeting participants spoke to the variety of professionals at work in the health care field and asserted the need that all be involved in SDM. Some suggested that SDM be promoted as the strategy for decision-making in all aspects and among all participants in mental health care, so that everyone would experience SDM and become fluent in its use and support.

Participants spoke to their interest in identifying and engaging the spectrum of mental health care providers—from clergy to social workers and case managers to psychologists and psychiatrists—in learning about and promoting SDM. They also recognized that a provider's training might predispose him or her to a particular approach to mental health care, and asserted that education around SDM must focus on ensuring that all treatment options are discussed with consumers.

"We can't promote cutting-edge practices with old training models."
—SDM meeting participant

The variety of care settings was also discussed as a dimension to consider in promoting SDM. One meeting participant pointed out that SDM could be utilized in even the most coercive settings and suggested that special efforts be made to promote SDM at facilities where consumers are involuntarily committed. These consumers, she suggested, are among the most vulnerable and might receive the greatest benefit from SDM. She also noted that staff at State mental hospitals are not often provided with opportunities to engage in new mental health initiatives.

Engaging Consumers in SDM

Meeting participants acknowledged that SDM would not be appealing to all consumers; they suggested, however, that the reasons for avoiding SDM should be explored. Meeting participants suggested that some reasons—lack of understanding, fear of coercion, fear of irritating the provider—should be overcome. Culturally competent models of SDM also need to be developed.

"When we are labeled with mental illness, we can lose friends, families, jobs, housing, possessions. . . our confidence in our ability to manage our lives."
—SDM meeting participant

Participants also suggested that SDM should be incorporated in all stages of care; this includes goal setting in treatment planning as well as decisions about specific interventions. This strategy, they suggested, could build confidence and competence in communicating and making decisions. In addition, using SDM throughout the care process may improve the provider-consumer relationship.

As consumers are supported in taking on a larger role in their own recovery, however, one participant cautioned that the responsibility for the success or failure of an encounter or treatment plan should not be placed solely on consumers' shoulders.

"We must do more than plant the seeds. We must nurture their growth."
—SDM meeting participant

Issues of Competence and Coercion in Mental Health Care

Meeting participants identified provider and community concerns about competence—and consumer concerns about coercion—as barriers to the promotion of SDM in mental health. If a provider considers a consumer not competent to make decisions, then SDM may not occur. A clear majority of consumers are able to make health care decisions (IOM, 2006). For those who may have difficulty with decision-making and wish to engage in SDM, it should be recognized that making one small decision may be the first step to making other decisions. For those who do not

want mental health treatment or do not acknowledge the presence of a mental illness, the first step may be to engage these persons to accept negotiations (Adams & Drake, 2006).

Participants noted that the 2007 shooting of students and faculty by a student with mental illness who attended Virginia Tech would strongly color public perception of persons with mental illness, and spoke to the need to educate the community at large that consumers of mental health services are much more likely to be victims than perpetrators of violent crime.

Participants also spoke about the presence of coercion in the mental health care system, and the effect of that threat upon consumers. A consumer participant at the meeting suggested that involuntary commitments should always be considered treatment failures. Participants strongly supported efforts to eliminate coercion from mental health care.

Meeting participants expressed a deep desire to reduce or eliminate coercion within the mental health care field and spoke of the need to support consumers in trusting the system and developing their own capacity to make decisions. Learned helplessness, prejudice, and fear of coercive consequences may result in consumers' reluctance to embrace shared decision-making.

A participant pointed out that consumers who have difficulty in communicating may be more likely to be judged incompetent to make decisions, and suggested that special efforts be taken to reduce this risk.

Complexities of Medication Use in Mental Health Care

Participants discussed a recent report by the National Association of State Mental Health Program Directors (NASMHPD, 2006), which acknowledged that "persons with serious mental illness are now dying 25 years younger than the general population" (p. 4). The NASMHPD report called for state mental health directors to embrace the principles of wellness in mental health recovery and overall health as an essential element of mental health. In addition to the concerns about issues of general health raised by the NASMHPD report, meeting participants discussed the side effects of some psychiatric medications, particularly atypical and first-generation antipsychotics.

> *"Overall health and mental health are intertwined and cannot be separated. [SDM] must promote and address overall health and wellness."*
> *—SDM meeting participant*

In light of these health concerns, SDM meeting participants promoted a complex view of decision-making around the use of medication. Decisions to use or not to

use medication may change over time in light of life circumstances, the presence or absence of symptoms of mental illness, and the presence or absence of side effects. Meeting participants pointed out, for example, that sexual side effects might be tolerated by a consumer who is in crisis and isolated, but may be less well accepted as that consumer recovers and begins to form relationships with others.

Dr. Deegan shared the understandings she developed through conducting interviews with people with psychiatric disabilities who use medication in their efforts to recover from major mental disorders (Deegan, 2007). She shared a conversation she had with a man who described his marriage as one of the strongest supports for his recovery. He recognized that the paranoia he sometimes felt threatened his marriage, and so he would agree to take medication at those times. The medication, however, precluded sexual intimacy with his wife—another threat to his marriage. Dr. Deegan referred to this type of situation as a "medication trap," in which psychiatric medication works against other strategies or tools that consumers use to address their illnesses.

In the case she shared, the consumer's marriage was an important support for his recovery. Dr. Deegan suggested that psychiatric medication be viewed within the context of such supports and strategies—what she termed "personal medicine." She suggested that consumers should be taught to identify their personal medicine and encouraged to bring it into discussions of care and treatment with mental health providers. Personal medicine can include a job, a marriage, children, or friendships. It also includes strategies consumers employ to manage symptoms in conjunction with, or in place of, medication.

Maintaining the Consumer's Voice

Participants expressed concern that the consumer's voice could be "drowned out" in situations in which treatment decisions are made by a team of providers, or in conjunction with family members. A participant noted that, in some cases, decisions made within a clinical setting could be undone by a skeptical community or family. Meeting participants shared concerns that provider, community, and/or family preferences often have more weight in treatment decisions than the preference of the consumer. They expressed hope that SDM could provide tools to ensure that the consumer's voice is heard and honored, and that consumers could be strengthened in supporting their decisions beyond the clinical encounter.

> *"The individual receiving care should have the loudest voice in planning that care." —SDM meeting participant*

Some participants raised concerns about the need for cultural competence in ensuring that SDM is hospitable to all consumers. They stated that, in many cultures, family and/or community members were expected to participate in important decision-making processes and cautioned against promoting models of SDM that were not inclusive of a variety of perspectives, expectations, and values regarding decision-making.

The Role of Peer Specialists

Peer specialists emerged as a central strategy for promoting SDM among meeting participants. Participants felt that peers would be best able to support mental health consumers in trusting the process of SDM. In addition, a participant spoke to the way provider perceptions of mental health consumers can be changed when consumers join the staff. Greater support for peer specialists within the mental health system was identified as a significant step forward in improving care in general and in promoting SDM.

Communication and SDM

Meeting participants discussed the relationship between communication and SDM. Some felt that SDM was simply a type of respectful communication, while others spoke to the need to promote better communication skills among providers as necessary precursors to SDM. Some participants expressed concern that many providers feel they are "already doing" SDM; they pointed to the need to develop measures by which providers could assess their practice.

Financial Considerations

The decisions available to consumers of mental health care are often determined by the payer system that supports their care. Consumers may choose not to use medication because of its cost—or to use medication because it is the only reimbursed option. Also, there is the issue of whether payers are willing to reimburse providers for their time in the use of SDM and decision aids. Payers must be educated and involved in the promotion of SDM and associated practices, if SDM is to be viable.

Section 5
Future Directions and Recommendations

Participants at the SDM meeting discussed strategies and recommendations for advancing the understanding and practice of SDM among all stakeholders in the mental health care system. Specific recommendations for policy, practice, training, and research are provided below. Participants also engaged in a general discussion of two primary strategies for promoting SDM on a policy level: accreditation and legislation.

Accreditation

Accreditation policies in the United States and abroad are beginning to embrace SDM. The U.S. Agency for Healthcare Research and Quality funds and administers the Consumer Assessment of Healthcare Providers and Systems (CAHPS). (See Web site https://www.cahps.ahrq.gov/default.asp) Through standardized consumer surveys that are administered in every State through the Medicare program, consumer evaluations of the care received have begun to be included in the overall CAHPS assessment of health care quality. These surveys include questions related to decision-making in its survey of consumer satisfaction. In the United Kingdom and the Netherlands, physicians must demonstrate communication skills in order to be certified and recertified. The American Board of Internal Medicine has a similar requirement, and other U.S. medical boards are moving in that direction.

Legislation

The State of Washington recently passed legislation that supports the use of SDM in general and mental health care. SB 5930 recognizes and defines a method of demonstrating informed consent that includes the essential components of SDM: the health care consumer signs a form certifying that he or she has discussed the planned treatment with the provider, understands the disease, understands the risk of treatment, understands the risk of no treatment, and has had the opportunity to ask questions. The form further certifies that the consumer has shared relevant personal information with the provider, and agrees to the treatment plan. For further information, see the Web site http://apps.leg.wa.gov/billinfo/summary.aspx?bill=5930&year=2007.

The legislation does not define a process through which these understandings and consents are to be achieved. However, funding is provided for the implementation and evaluation of a demonstration project in which a variety of decision aids will be utilized.

Participants supported these efforts to institutionalize SDM in health care systems and discussed other policy recommendations for disseminating knowledge and practice of SDM. Participants also identified areas where greater understanding is needed regarding the practice of SDM and its legal and financial implications, the effectiveness of SDM for various consumer populations, gaps and opportunities in SDM training, and systems development to sustain all components of a robust SDM system. Recommendations to address these concerns follow.

Policy Recommendations

Promoting SDM

- Promote SDM through accreditation processes and organizations such as the Commission on Accreditation of Rehabilitation Facilities (CARF) and the Joint Commission. For example, CARF already requires rehabilitation facilities to provide consumer orientation. This requirement could be further defined to ensure that consumers receive information about SDM and their rights as consumers.
- National thought leaders should be recruited and educated to promote SDM as an essential human right and an expression of American democracy.
- Promote SDM to the National Conference of State Legislatures and the National Association of Counties.
- Utilize electronic medical health record systems as pathways to promote SDM in primary care.
- Embed the use of SDM among all players throughout the mental health care system so that everyone is trained in the practice of SDM and SDM becomes the norm by which decisions are made.
- Promote partnerships among mental and general health care organizations to promote SDM among their members.

Financing for SDM

- Review insurance models to ensure the most appropriate match for recovery services. A disability insurance model, rather than a health insurance model, may be most appropriate to support the recovery of mental health consumers.
- Promote the development of a Centers for Medicare and Medicaid Services waiver that would allow documented use of SDM in place of a traditional treatment plan.

- Ensure that SDM is incorporated into and promoted through funding mechanisms that support mental health initiatives such as person-centered care, the elimination of seclusion and restraint, and transformation of the mental health care system.
- Develop a viable network of financial support for peer-run agencies by developing the capacity of peer-run agencies to provide decision-support services and promoting the practice of outsourcing these services to peer-run agencies.

Strengthening Cconsumer Voices in Health Care

- Require health care delivery systems to demonstrate that their consumers have the knowledge and support to effectively access and navigate the systems of care provided.
- Develop and promote health literacy education for all secondary school students; such education should address patient/consumer rights, strategies for the best utilization of health care encounters, preparing questions to ask of a provider, and related issues.
- Recognize the vital role of peer specialists in promoting and supporting SDM. Develop a career ladder for peer specialists, to provide an avenue for growth and recognition. Develop additional training and support for peer specialists.

Related Topics of Concern

- Develop protocols and policy statements that clarify the understanding of issues regarding competency.
- Explore and elucidate the legal and financial implications to the provider-consumer relationship.

Practice Recommendations

Building a Constituency

- Promote the inclusion and employment of peers to advance and support SDM among consumers.
- Involve families and advocacy groups in education about and promotion of SDM.
- Work with student groups to establish networks of knowledge on college campuses throughout the Nation.
- Promote SDM within the children's mental health system. Develop models and guidelines for implementing SDM in children's mental health care.

- Promote SDM through professional associations and guilds so that providers, like consumers, can be educated and supported by their peers.
- Educate consumers about their rights and support their refusal to sign treatment plans in which they feel they did not have significant input.
- Develop user-friendly, clear, and concise educational materials for State commissioners of mental health and other State policy personnel.
- Develop SDM support and tools that address decisions and transitions (e.g., from jail or hospital to community, from homelessness to care, from treatment to self-help).

Promoting SDM Among Providers

- Develop models for and materials about SDM in mental health care that are targeted to social workers, nurses, case managers, and other mental health providers, in addition to psychologists and psychiatrists.
- Develop models and materials to support the use of SDM in mental health care in primary care settings.
- In educational materials, place SDM in familiar contexts, such as self-management and decision support.
- Emphasize to providers that SDM can help to ensure that a better decision will be made—more information about the consumer surfaces in the process, and the consumer is more likely to feel comfortable with the decision.
- Advance SDM as an instrument of recovery and the demonstration of a consumer's ability to manage his or her own life interdependently with others.
- Promote models of SDM that relieve providers of other responsibilities. For example, the CommonGround model provided a history of medication usage and symptoms as well as other feedback about consumer concerns.
- Develop a fidelity scale for SDM that providers can use to assess their own practices and processes.
- Distinguish between a consumer's difficulty in communicating a decision and a lack of capacity to make the decision.

Decision Aids: Characteristics

- Develop DAs that focus on bilateral communication and collaboration between consumers and providers.
- Train peer specialists to support the use of decision aids.

- Ensure that decision aids are relevant and appropriate for all targeted groups.
- Ensure that DAs are inexpensive to duplicate and distribute, and focus on issues of importance to the providers who will duplicate and distribute them.
- Develop DAs that are appropriate for repeated or ongoing use, in order to promote reassessment of consumer circumstances and values over time.
- Develop a DA classification system to assist providers and consumers in choosing the best DA. Consider characteristics such as whether the DA is intended for use with a provider or for consumer completion before a consultation, and whether a DA is better suited for use when a consumer is at a high or low level of readiness to make a decision.

Decision Aids: Topics

- Develop DAs that address nonmedication issues in mental health, including housing, transitions, and noncrisis and preventive care.
- Develop DAs to address the use of atypical and neuroleptic medications in light of the age-adjusted risk of tardive dyskinesia and other side effects.
- Develop DAs to support treatment planning and help consumers and clinicians identify and articulate life goals.
- Develop DAs to address the use of electroconvulsive therapy.

Training Recommendations

Audiences

- Develop training for consumers on the use of DAs and the practice and philosophy of SDM. Support and training in the general concept of making choices may be needed, as will emphasis on nonmedical decisions and transitions to and within the mental health system of care.
- Develop a peer-to-peer curriculum on SDM.
- Develop training materials for clergy, family members, and community leaders. Cultural competence will demand the inclusion of these persons in the promotion and practice of SDM.
- Develop training and educational materials for all levels of care and the variety of institutions within the mental health system of care.
- Develop training and educational materials for medical schools, nursing schools, and schools of social work and psychology.

Other Characteristics of Training

- Ensure that training in the use of computer technology and Internet access is available to link consumers to Web-based and electronic materials.
- Develop educational materials that clearly distinguish SDM from person-centered planning, Wellness Recovery Action Planning (WRAP), and other mental health initiatives, while also linking SDM as a strategy to employ in pursuit of other goals.
- Develop nondidactic training models (e.g., in vivo training in which participants put SDM quickly into use and receive continued supervision and feedback about SDM).

Research Recommendations

Topics

- Conduct research on the use and acceptance of SDM in a variety of cultures and contexts.
- Conduct research on the influence of payers on consumer options and the availability of SDM.
- Conduct research on potential funding mechanisms for SDM and on real or potential savings resulting from SDM.
- Conduct a trial in which staff at one facility receive communication training in addition to training in SDM, while staff at another facility receive only SDM training.
- Establish multiple SDM sites using promising models such as CommonGround and conduct real-time research to document its use and effects. This strategy would educate consumers and providers about SDM while developing knowledge about the model(s).
- Address outcomes including: decreased symptomology; increased function in a number of areas; decreased incarceration, homelessness, and hospitalization; decreased clinic no-shows; cost savings; and consumer empowerment.
- Promote naturally occurring experiments in practices and localities that are eager to try SDM.
- Conduct research to determine the amount of time and effort needed for clinicians and consumers to develop comfort with SDM.
- Develop taxonomy for decision-making that addresses decision characteristics such as high-stakes/low-stakes decisions and one-time/recurrent decisions.

- Explore and identify reasons for consumer disinterest in SDM and consumer preferences and beliefs about decision-making, SDM, and health care.
- Conduct research on the linkages between communication skills and SDM.
- Conduct research to determine whether consumer preference for SDM varies with illness, symptom type, and severity.
- Conduct research on the use and acceptance of advance directives in mental health care.

Other Recommendations for Research

- Ensure that the research agenda recognizes SDM as a human right and seeks to determine the best strategies for promoting SDM.
- Promote and utilize a variety of research methods: case studies and both quantitative and qualitative research.
- Develop clear outcome measures that will then promote comparable research and generalizable conclusions.

Section 6
Conclusions

Shared decision-making holds substantial promise to advance the goals of many initiatives focused on improving care and promoting recovery for persons with mental illnesses. Because it supports consumers' self-determination and their involvement in decisions about their care and aids consumers in identifying and advancing their values and preferences, SDM can also be viewed as a basic human right. In that light, the question is not whether to advance SDM, but how best to do so.

There is much still to learn regarding SDM, including the roots of reluctance to implement SDM—among providers, consumers, and the public. Realistic expectations about the results of broader implementation will be developed only through such implementation. Strategies for implementing SDM within the mental health field and implications for its use in diverse cultural settings need further exploration.

The promise of shared decision-making and increasing recognition of the cost of the current system of care—in both mortality and vitality—underscore the urgent needs for better understanding and wider implementation of SDM.

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Appendix A
Resources

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 HHS. This list is not intended to endorse any view expressed, or products or services offered.

Agency for Healthcare Research and Quality. This agency is committed to helping the Nation improve our health care system through conducting and supporting a wide range of health services research. http://www.ahrq.gov.

Cochrane Collaboration. This is an international not-for-profit and independent organization, dedicated to making up-to-date, accurate information about the effects of health care readily available worldwide. It produces and disseminates systematic reviews of health care interventions and promotes the search for evidence in the form of clinical trials and other studies of interventions. http://www.cochrane.org/index.htm.

Commission on Accreditation of Rehabilitation Facilities (CARF). An independent, nonprofit accreditor of human service providers in the areas of aging services, behavioral health, child and youth services, Durable Medical Equipment, Prosthetics, Orthotics, and Supplies (DMEPOS), employment and community services, medical rehabilitation, and opioid treatment programs. http://www.carf.org.

Consumer Assessment of Healthcare Providers and Systems (CAHPS). A public- private initiative to develop standardized surveys of patients' experiences with ambulatory and facility-level care. https://www.cahps.ahrq.gov/default.asp.

Center for Shared Decision-Making at Dartmouth-Hitchcock Medical Center. The Web site includes information about shared decision-making, a library of decision aids, and a health care decision aid worksheet. http://www.dhmc.org/webpage.cfm?site_id=2&org_id=108&gsec_id=0&sec_id=0&item_id=2486.

Infusing Recovery Based Principles into Mental Health Services. The Web site describes this resource as "A White Paper by People who are New York State Consumers, Survivors, Patients, and Ex-Patients." September 2004. http://www.omh.state.ny.us/omhweb/statewideplan/2005/appendix4.htm.

International Patient Decision Aids Standards (IPDAS) Collaboration. A body that developed consensus standards for decision aids and now offers a variety of materials, including guides to help organizations or individuals grade decision aids against these standards. http://www.ipdas.ohri.ca.

Mayo Clinic. The Mayo Clinic offers an extensive library of DAs, including a "Depression Guide." This guide includes an explanation of the various forms of depression, information on medications and their side effects, and personal stories of two women with depression. It also includes links to further information. http://www.mayoclinic.com.

Mental Health Matters. This site provides extensive information about mental health issues. http://www.mental-health-matters.com.

Ottawa Health Research Institute, A-Z Inventory of Patient Decision Aids. An inventory of more than 100 decision aids that meet IPDAS criteria. Also includes the Ottawa Personal Decision Guide, designed to assist individuals in making any health care or social decision. http://decisionaid.ohri.ca/AZinvent.php.

Society for Medical Decision Making. Its mission is to improve health outcomes through the advancement of proactive systematic approaches to clinical decision- making and policy formation in health care by providing a scholarly forum that connects and educates researchers, providers, policymakers, and the public. http://www.smdm.org.

WebMD. WebMD provides extensive free information on health care. A "Depression Center" includes information on medications, psychotherapy, "living and managing," consulting a doctor about depression, and links to other resources. http://www.webmd.com.

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Shared Decision-Making Meeting Participants

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Supplement 1
Shared Decision-Making in Mental Health Care: Overview and Current Status

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Abstract

The consumer-driven recovery movement and informed shared decision-making (SDM) are of central contemporary interest for quality improvement in mental health interventions and services. SDM is being advocated as a promising health care reform paradigm for the improvement of mental health services via recognition and provision of support for consumers to be equal partners with their health care providers in health-related decision-making. This paper reviews SDM definitions, research, and practice in relation to SDM in the mental health care and recovery process. A small but increasing number of studies provide evidence of consumer interest in and favorable outcomes of SDM in the mental health care context, but SDM is not widely and fully implemented in practice. There is an urgency that exists in implementing practices that are consistent with and supportive of consumer recovery, within additional research to describe and test the effects of SDM in mental health contexts, including that of diverse populations.

Introduction

The consumer-driven recovery movement and informed shared decision-making (SDM) are of central contemporary interest for quality improvement in mental health interventions and services. It is increasingly recognized that the active engagement of consumers in the treatment and the recovery process is essential to achieving high-quality outcomes. This interest has led to a number of key national reports in recent years emphasizing the essential role of consumers in achieving positive outcomes. For example, the final report of the President's New Freedom Commission on Mental Health (2003) and two Institute of Medicine (IOM) reports, *Crossing the Quality Chasm* (2001) and *Improving the Quality of Health Care for Mental and Substance-Use Conditions* (2006), emphasize a goal of understanding and honoring consumers' preferences and supporting fully shared decision-making with service providers to develop person-centered plans of care to foster improved satisfaction, better meeting of needs, and meaningful recovery. Federal agencies that support research on health clinical interventions have also highlighted the importance of a person-centered approach and shared decision-making to achieve high-level recovery (Schauer, Everett, del Vecchio, & Anderson, 2007). For example, patient-provider decision-making is identified as a key research priority for the Primary Care Research Program by the National Institute of Mental Health (National Institute of Mental Health, 1999). The Substance Abuse and Mental Health Services Administration (SAMHSA) convened a National Consensus Conference on Mental Health Recovery and Mental Health Systems Transformation in 2004, in which 10 fundamental components of recovery highlighted the role of individual preferences and active participation in decision-making (SAMHSA, 2004). Three of the ten identified fundamental components of recovery—self-direction, individualized and person-centered, and empowerment—describe the importance of consumer choice, control, preferences, and active participation in decision-making. SAMHSA has set forth principles and characteristics of consumer- and family-driven care that emphasize the control of decision-making by families and individuals (SAMHSA, 2006).

In the mental health interventions and services literature, consumers also are increasingly acknowledged as full partners in SDM with their health care providers as social perspectives evolve regarding mental illness treatment and meaningful recovery (Deegan & Drake, 2006; Wills & Holmes-Rovner, 2006). SDM is being advocated as a promising health care reform paradigm for the improvement of mental health services via recognition and provision of support for consumers to be equal partners with their health care providers in health-related decision-making. This shift in perspective to support and better appreciate the consumer's role comes from the recognition that well-achieved SDM can avoid some significant limitations of the traditional medical (paternalistic) model and the unsupported informed choice model of care that have often resulted in suboptimal care processes and outcomes (Deegan & Drake, 2006; Hamann, Leucht, & Kissling, 2003). Effective approaches for

supporting SDM in general health care include communication skills training for health consumers and care providers, and decision aids to support information and values clarification needs (Adams & Drake, 2006; Lewin, Skea, Entwistle, Zwarenstein, & Dick, 2001; O'Connor et al., 2003). These approaches are now beginning to be tested in mental health contexts (Adams & Drake, 2006; Wills & Holmes-Rovner, 2006). Current mental health intervention approaches often do—to some extent—support choice and engagement in care without necessarily using the terminology of SDM (Adams & Drake, 2006). There is currently a dearth of research on SDM interventions for mental health treatment contexts, interventions and services models that are consistent with the vision of National health care policy reform to yield high-quality mental health services for all.

Purpose. The purpose of this paper is to provide an overview of SDM in health and mental health care and to offer recommendations for application of SDM within mental health care. Within the broader purpose, the specific aims of this paper are to: (1) provide an overview of SDM definitions, the practice of SDM, and the purported benefits of SDM; (2) describe the current status of SDM, including its implementation in mental health care and the recovery process; and (3) describe emerging areas and controversies in SDM, including research and policy agendas.

Background: Definitions of SDM and Related Terms

Multiple SDM Definitions

There is no single agreed-upon definition of shared decision-making (SDM). A variety of decision-making terms are used in the literature to refer to similar concepts, yet they also lack consistent definitions. Examples include: empowerment, patient participation and involvement, person- and patient-centered, self-directed care, self-care management, and patient activation (Elwyn, Edwards, Kinnersley, & Grol, 2000; Makoul & Clayman, 2006; Trevena & Barratt, 2003). "Empowerment" essentially refers to consumer[1] activation via the acquisition of specific knowledge and skills needed by a person to enact health behaviors. "Person-centered" interventions focus on the actions of the service provider (instead of the consumer) to achieve outcomes. "Self-directed care" or "self-care management" focuses on what an individual does to manage their own health condition but without necessary reference to the service provider role.

By contrast, SDM can be defined as an interactive, collaborative process between providers and consumers that is used to make health care decisions, in which at least two individuals work together as partners with mutual expertise (professional and experiential) to exchange information and clarify values in relation to options and thereby arrive at a discrete decision (Adams & Drake, 2006; Deegan & Drake, 2006; Hook, 2006; Simon, Loh, Wills, & Harter, 2007). SDM process steps include: (1) recognition that a decision needs to be made; (2) identification of the partners in the process as equals; (3) statement of options as equal; (4) exchange of information on pros and cons of options; (5) exploration of understanding and expectations; (6) identifying preferences; (7) negotiating options and concordance; (8) sharing the decision; and, (9) arranging followup to evaluate decision-making outcomes (Simon et al., 2006).

Decision-making itself is a process of making a choice (decision) from among two or more discrete options (Wills & Holmes-Rovner, 2006). Adams and Drake (2006) characterize the provider role in SDM as, "the practitioner becomes a consultant to the consumer, helping to provide information, to discuss options, to clarify values and preferences, and to support the consumer's autonomy" (Adams & Drake, 2006, p. 90). SDM can decrease the informational and power imbalance between the practitioner and the consumer by increasing the consumer's information, autonomy, or control over health care decision-making (Charles, Gafni, & Whelan, 1997, 1999). SDM ideally provides a supportive encounter in which the partners clarify their values and preferences in relation to the information and options (Wills & Holmes-

[1] Editorial notation will be used throughout this paper to show adherence to recommended language styles reflective and supportive of People First Language. See http://www2.ku.edu/~lsi/news/featured/guidelines.shtml for further discussion.

Rovner, 2006). SDM is explicitly person-centered within a goal of promoting the ideal conditions for effective decision-making to occur.[2] This is consistent with national policy objectives to incorporate preferences in individualizing person-centered care. The values aspect of decisions, including identifying preferences, is especially relevant in decisions for which preferences do (or should) significantly guide decision-making and for situations in which an equal balance of pros and cons exists for at least two different alternative choices (i.e., in which there is more than one reasonable option as defined by the key partners in the decision-making process) (Elwyn et al., 2000; Whitney, McGuire, & McCullough, 2004; Wills & Holmes-Rovner, 2006). These types of preference decisions constitute the large majority of mental health treatment decision-making.

Self-directed Care, Self-determination, and Person-centered Planning

One of the more challenging aspects of mental health recovery-oriented services and the adoption of innovative practices is the establishment of working definitions for an evolving language. This is even more the case when one is attempting to refine policy-provoking nuances and societal implications. Within the context of SDM, particularly as it relates to mental health, there are specific terms and jargon that should be considered. A few of these are: self-directed care, self-determination, and person-centered planning. It is important to note that each of these terms originated outside the context of mental health, but are deeply rooted in the larger cross-disability movement. A linguistic task that is before the stakeholders is to flesh out the nuance of yet another "foreign language" in order to adequately assess both the adaptability of the language and the application of the practice of SDM.

Free To Choose: Transforming Behavioral Health Care to Self-Direction, a 2005 publication of the Center for Mental Health Services (SAMHSA, 2005), identified the following definitions for self-directed care and self-determination.

> Self-directed care is closely related, although not identical, to both a recovery orientation and self-determination. 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). **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:

[2] Effective decisions are informed, consistent with personal values, implemented, and associated with an increased likelihood of positive outcomes (O'Connor, 1995).

- 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** 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 (pp. 3-4).

Neal Adams, M.D., M.P.H., and Diane Grieder, M.Ed., who authored the text, *Treatment Planning for Person-Centered Care: The Road to Mental Health and Addiction Recovery,* state that person-centered care is characterized as a partnership between the provider and consumer that establishes meaningful recovery and wellness goals for consumers and a therapeutic relationship that is collaborative, consultative, and mentoring (Adams & Grieder, 2004). The person-centered approach helps the provider recognize consumers' strengths and unique cultural backgrounds, and helps consumers to become good problem-solvers on the road to recovery. This process can also help providers to better communicate with payers, document medical necessity, and coordinate services. A thorough discussion of the origins of person-centered planning by C. O'Brien and J. O'Brien can be found at http://thechp.syr.edu/PCP_History.pdf.

Models of Decision-Making in Health Care

Shared decision-making as a model of care falls between the traditional (paternalistic) medical model and the informed choice model (Charles et al., 1997; Hamann et al., 2003). In the traditional model, the care provider controls information exchange and decision-making. Consumer values, expertise, and preferences are not necessarily considered, and are not weighed equally with those of the care provider if considered. The main (passive) consumer role is to be a "good patient" in complying with the prescribed treatment (Emanuel & Emanuel, 1992). In the informed choice model, the care recipient actively controls the information exchange and decision-making about the options (Hamann et al., 2003), but without necessarily taking the provider's perspective into account or weighing it equally in decision-making.

Both extremes of these models can have significant limitations for people obtaining adequate information, clarifying personal values and preferences, and making effective decisions that are more likely to be associated with favorable outcomes. In an SDM process, the exchange of information is bidirectional, a supportive context exists for the clarification and sharing of values and preferences, and responsibility for decision-making about the options is equally shared between the consumer and care provider as appropriate and determined by both partners (Charles et al., 1999; Edwards & Elwyn, 2006).

Autonomy and SDM. An SDM approach includes an emphasis on respect for the autonomy of an individual, a value that is deeply embedded in traditional American culture and many other Western societies.[3] In Western health care, a person's participation in decision-making occurs on a spectrum of traditional to informed choice models. Research has shown that most people who use Western health care services prefer the SDM model in which partners engage in a dialog and come to a consensual decision (Benbassat, Pilpel, & Tidhar, 1998; Elwyn & Edwards, 2001; Murray, Pollack, White, & Lo, 2007a).[4] A representative sample of U.S. physicians also showed that 75 percent preferred SDM (Murray, Pollack, White, & Lo, 2007b), although current evidence indicates that SDM has not been widely implemented in practice (Gravel, Legare, & Graham, 2006). Exceptions in which the traditional medical (nonautonomous) model can be appropriate are true emergency situations (e.g., severe life-threatening traumatic injury) or instances when a person is totally unable to interact or process information (e.g., coma, severe cognitive impairment). Models in which only the consumer or the provider makes a decision may be most appropriate for situations in which there is low uncertainty or conflict in decision-making (Frosch & Kaplan, 1999; Whitney, 2003).

Research on SDM in Mental Health

Overview

In mental health care, the practice and study of SDM is just beginning to be addressed and the actual evidence base is currently insufficient to provide strong empirical support for the use of SDM as an evidence-based practice in mental health care (Fenton, 2003; Fischer, 2006; Hamann et al., 2003). Much of the newer research is international and largely concentrated in Western European countries. Decision-making in theory has been applied in health care practice and research since the 1960s, but until the 1980s was largely focused on the decision-making of health care

[3] The value on individualism is not universal and may be viewed as irrelevant or represent a counter-cultural value in some societies.

[4] Certain other exceptions and debates about the use of SDM are discussed later in this paper.

providers only (Wills & Homes-Rovner, 2006). In general health care, SDM (including in the use of decision aids to support SDM) has been shown to be associated with favorable outcomes, including reduced decisional conflict, greater knowledge, improved satisfaction with the decision-making process, improved ability to make choices (fewer people undecided), improved concordance of decisions with personal values, more active involvement of consumers in decision-making, and improved communication between consumers and providers (O'Connor et al., 2003; Thistlethwaite, Evans, Tie, & Heal, 2006). However, limited research has been done in the mental health field on understanding how decision-making preferences and processes impact the choices that are made by consumers, including service engagement and intervention outcomes (Cooper, 2006). A small but increasing number of studies published within the past five years have focused on SDM in people experiencing depression and schizophrenia. These studies demonstrate some favorable outcomes of SDM (see later in this report for review of relevant mental health studies). Ethical arguments have also been proposed for SDM as a self-evident right based on individual autonomy and respect for persons (Duggan, Geller, Cooper, & Beach, 2006; Nelson, Lord, & Ochocka, 2001).

While a majority of people are interested in being informed about their treatment options, potential disadvantages of universal application of SDM are also beginning to be identified and critiqued. Almost no empirical information is available on the views of diverse cultural groups about SDM and interventions to support involvement in decision-making. These issues include the preference of some individuals for the traditional medical model for decision-making (e.g., older, less well-educated, lower literacy people who are in poorer health and who are making high-stakes decisions) (Levinson, Kao, & Kuby, 2005; Robinson & Thomson, 2001; Shalowitz & Wolf, 2004; Thompson, 2007; also see de Haes 2006 for a critique of vulnerability issues in relation to SDM). These critiques highlight needed areas of research, as well as the need to better specify key concepts such as participation, concordance, and SDM (Charavel, Bremond, Moumjid-Ferdjaoui, Mignotte, & Carrere, 2001). Legal and ethical issues with concordance are also being highlighted, such as people's preferences to sometimes reject guidelines-based care (Penston, 2007).

SDM for Depression Treatment

A limited but rapidly expanding body of research literature exists on SDM for depression treatment. Garfield et al., in a qualitative descriptive study of 51 people beginning antidepressant medication, found that many individuals had unmet information needs and that involvement in decision-making varied between individuals and at different periods in treatment (Garfield, Francis, & Smith, 2004). Loh et al., in a survey of 30 general practitioners and 207 persons with depression at initial consultation and 6–8 weeks later, found that depression severity predicted clinical outcome but not consumer participation in a structural equation model. The effect

of participation on clinical outcome was indirect, in that adherence mediated the relationship between participation and clinical outcome (Loh, Leonhart, Wills, Simon, & Harter, 2007). At baseline, there were very low levels of consumer involvement in decision-making, based on a sample of 20 audiotaped primary care consultations for depression treatment (Loh et al., 2006).

Other research has also shown that people who experience depression have generally strong interest in information and participation in decision-making with their health care providers, as well as needs for formal decision support for complex depression treatment decisions involving substantial tradeoffs between pros and cons of the options (Simon et al., 2007; Wills, 2003; Wills, Franklin, & Holmes-Rovner, 2007; Wills & Holmes-Rovner, 2003, 2006). Simon et al. (2007), in a qualitative descriptive study of 40 persons with depression, found that individuals identified a need for additional information about depression and its treatment. Wills, in a representative sample of 133 people with depression receiving services from a U.S. health maintenance organization, found that these individuals had a variety of needs and preferences for decision support around depression treatment decision-making, including a preference for SDM (Wills, 2003). Stacey et al., in a study of the decision-making needs of people considering depression treatment options, found that relatively few people wished to abdicate decision-making to their health care provider or a family member (Stacey et al., under review). In Michigan, in an intervention study of 32 people with co-occurring depression and diabetes, it was found that exposure to a decision support intervention for depression (support booklet in print or on Internet) was associated with a significant increase in knowledge, decision stage, reduced numbers of depressive symptoms, and lowered stress levels (Wills et al., 2007). However, some research has also documented that people with more severe forms of depression or psychological distress (including lack of insight into illness and severity) may have lower preferences and capability for digesting information and for involvement in decision-making (Schneider et al., 2006; Simon et al., 2007; Wills, 2003).

Taken together, these studies provide some initial evidence for the interest of persons with depression in information and supportive interventions to aid depression treatment decision-making. However, consistent with the conclusion of Levinson et al. based on a national U.S. survey, not all people are equally interested in full partnership in decision-making, especially those with more severe distress at the time of decision-making (Levinson et al., 2005). Almost no information is available on the preferences of diverse cultural groups that represent views other than mainstream white Western culture. Decision support interventions to promote effective SDM must be designed and implemented in ways that can back a range of preferences for involvement in the informing and deciding process. This type of matching of needs and preferences with interventions does not negate the spirit or intent of fully shared decision-making and maintains respect for persons in the design and delivery of interventions and services.

SDM for Schizophrenia Treatment

Bunn et al., in an exploratory descriptive study with 96 people receiving outpatient services for schizophrenia, found that these individuals were interested in and able to participate in their health care decision-making (Bunn, O'Connor, Tansey, Jones, & Stinson, 1997). O'Neal et al., in a study of role preference for SDM among older adults with severe mental illnesses, found that these individuals were interested in information, preferred SDM with their psychiatrists, and were more interested in decision-making involvement compared to younger adults (O'Neal, Adams, Drake, & Bartels, 2007). Similarly, Adams et al. found that approximately three in four people with severe mental illness preferred a shared role in decision-making about new psychiatric medications (Adams, Wolford, & Drake, 2007). Seale et al., in a qualitative study of 21 general adult psychiatrists in the United Kingdom, found that there was a general commitment to achieving concordant relationships with consumers around antipsychotic medication decision-making, but that concerns about consumer competence for decision-making were a key concern for fully shared decision-making (Seale, Chaplin, Lelliott, & Quirk, 2006).

Some interventions are beginning to be developed and tested. For example, Deegan has recently developed and is testing an innovative three-tiered approach to assist mental health consumers to participate in SDM related to use of psychiatric medication. This pilot program includes a peer-to-peer workshop, a specialized software program to support SDM that can be effectively used by all service recipients (including those with active symptoms), and a training program for case managers and therapists to help consumers navigate decisional conflict related to medication (Deegan, 2007). Hamann et al., in a randomized controlled trial of an SDM program compared to usual care with 107 people receiving inpatient care for schizophrenia, found that the intervention was feasible for most individuals without exceeding the available time of physicians. Individuals in the SDM group had better knowledge and higher perceived involvement in decision-making compared to the usual care group (Hamann et al., 2006). Hamann et al., in a survey study of 122 people receiving inpatient care for schizophrenia, also found that there was a somewhat stronger preference among the individuals for SDM compared to primary care consumers, and that younger people with a negative attitude toward medical treatment were relatively more interested in participation (Hamann, Cohen, Leucht, Busch, & Kissling, 2005). Malm et al., in a 2-year randomized controlled trial of two community-based treatment programs with 84 people with schizophrenia in Sweden, found that there was significantly improved social function and consumer satisfaction for an integrated care model incorporating SDM and consumer empowerment content (Malm, Ivarsson, Allebeck, & Falloon, 2003). These studies show that there is the potential for SDM interventions, including structured decision support interventions, to be of interest and feasible for use among people with serious mental health conditions. Testing of interventions is in the very initial stages, how-

ever, and much additional research needs to be done to identify the optimal design and implementation formats for supporting SDM in the context of serious mental illnesses. As with SDM research on depression treatment, almost no information is available about the views of people from other than mainstream white Western culture.

SDM Controversies and Emerging Areas

Capacity for SDM in the Mental Health Treatment Context

When SDM is considered for its application to mental health decision-making, concerns about autonomy are often noted insofar as there are some contexts in which a person with a mental illness may not be capable of making fully autonomous choices (Appelbaum, Grisso, Frank, O'Donell, & Kupfer, 1999; Appelbaum & Redlich, 2006; Pescosolido, Brooks-Gardner, & Lubell, 1998; Wills & Holmes-Rovner, 2006). Beauchamp and Childress (2001) assert that virtually all definitions of autonomy include liberty and agency. Liberty implies independence from controlling influence, and agency includes themes of capacity for intentional action. In psychiatry, it is this element of agency or capacity that is often cited as a reason that the autonomy of mental health consumers is necessarily different from that of other people who are seeking health care advice and treatment. For example, it has been argued that treating people who are decisionally impaired as autonomous decision-makers is ethically not justified on the basis of a lack of respect for vulnerable persons (Dudzinski & Sullivan, 2004). Prejudice in mental health care on the part of providers is of strong concern among mental health consumers, and can severely impact the promotion and use of SDM by mental health care providers. The Situational Analysis prepared for SAMHSA's Elimination of Barriers Initiative, an eight-State pilot to test public education approaches to reducing prejudice and discrimination, found through focus groups of mental health consumers that providers of mental health care were among those who most stigmatized mental health consumers (Schauer et al., 2007). Consumers often report feeling disempowered and having little input into treatment choices and care plans because they are thought not able to make decisions in their own best interests. (Schauer et al., 2007)

Decision Aids and Support Interventions for SDM

Shared decision-making assumes that the consumer and care practitioner first must choose to participate in such a process. To make this model work, certain prerequisites need to be satisfied. The consumer must be adequately informed of the risks and benefits of the treatment choices, and the practitioner must be aware of the consumer's values and preferences. Person-centered decision aids (DA) or decision support interventions (DSI) are intervention approaches that have been shown to be effective in helping people make complex decisions about health treatments (O'Connor et al., 2003). Use of DAs is associated with favorable outcomes, including increased knowledge; lower decisional conflict; improved satisfaction; more realistic expec-

tations; improved ability to formulate decisions; improved congruence between preferences and choices; more active involvement; and improved communication between consumers, providers, and significant others (O'Connor et al., 2003; Thistlewaite et al., 2006). The overall intent of DAs is to aid in the task of helping health consumers make evidence-based decisions (O'Connor, 2001) as an enhancement of usual care approaches. DAs also include values clarification exercises to help individuals consider what is important to them in evaluating the pros and cons of various options. DAs have been developed and tested for a number of health conditions in which complex choices are made (O'Connor et al., 2003), but have mostly focused on discrete, one-time choices as opposed to "continuance" and everyday decisions made by people who are living with long-lasting or ongoing health conditions (Wills & Holmes-Rovner, 2006). DAs have been developed in many formats, including decision boards, interactive computer-based support guides and DVDs, booklets, interactive group discussions, and individualized person-to-person coaching (Wills & Holmes-Rovner, 2006). An international consensus panel recently developed and published criteria for evaluating the quality of decision aids (see http://ipdas.ohri.ca for additional information and criteria) (Elwyn et al., 2006).

The Recovery Movement and SDM

Despite the limited and early stage of research on SDM in the mental health context, there is good reason to explore the implications of adopting SDM practices within mental health care. As previously noted, social advocacy and public policy advances have called for increased participation by consumers of mental health services. One example can be found in goal 2 of the *New Freedom Commission Report on Mental Health* (2003, p. 5): "in a transformed mental health system mental health care is consumer and family driven." Other examples are found in the 10 fundamental components of recovery as identified in the National Consensus Statement on Mental Health Recovery released by the Center for Mental Health Services in 2006—self-direction, individualized and person centered, empowerment, strengths-based, respect, and responsibility (CMHS, 2006). The elemental recognition "that both members [of the shared decision-making process] have important information to contribute" (Adams & Drake, 2006, p. 87) is consistent with a recovery orientation.

There is an urgency to implement practices that are consistent with and supportive of recovery. Overwhelming evidence continues to build that mental illness is a holistic disease that must be treated with holistic interventions. The mortality rates associated with mental illness are becoming more clearly defined. It is known that there is a significantly higher frequency of deaths from accidental and intentional injuries, particularly poisoning by psychotropic medications, in people who experience psychiatric symptoms (Dembling, Chen, & Vachon, 1999), but what is most alarming is the evidence around medical comorbidities. Heart disease, obesity, and

hypertension are among the most prevalent medical comorbidities in people who live with psychiatric symptoms (Miller, Paschall, & Svendsen, 2006). There is evidence that individuals diagnosed with both a serious mental illness and diabetes are "less likely to receive the full complement of recommended services and care support" than their counterparts who do not have a diagnosis of severe mental illness (Goldberg et al., 2007, p. 536). In October 2006, the National Association of State Mental Health Program Directors (NASMHPD) released a report that stated individuals diagnosed with mental illness die, on average, 25 years earlier than individuals without mental illness (see report at http://www.nasmhpd.org/general_files/publications/med_directors_pubs/Technical%Report%20on%20Morbidity%20and%Mortality%20%-%20Final%2011-06.pdf). Within this context, two guiding principles are suggested: Overall health is essential to mental health, and recovery [as an orientation for service provision] must include wellness. It follows, then, that the adoption of emerging best practices in general health care can positively influence the outcomes of mental health care.

The recovery process is acknowledged to be a unique and personal process that relies on the intrinsic strengths of an individual to leverage the development of illness management skills. Additionally, recovery from mental illness may be inclusive of, but is not limited by, a legalistic definition of being "cured"—that is, being asymptomatic—but embraces the concept of healing, which allows for the adaptation of the person, within the context of their illness, living a life without limits. . . living a life with meaning and purpose (Deegan, 1996).

The self-agency and autonomy inherent in a recovery orientation are supported in the practice of shared decision-making. SDM relies on the participant acting on health care decisions after being informed, supported by best available evidence, compatible with personal values, practical, considerate of preferences, and measured—weighing pros and cons. Other characteristics of SDM that are consistent with a recovery orientation include: the key participants of the SDM process are the provider and the recipient of services, transparency is achieved through the sharing of information, steps are taken to build consensus about the preferred treatment or care, and agreement is reached on the decision to be implemented.

Early examples of SDM within mental health practice are demonstrating positive outcomes. For example, in addition to published research documenting favorable outcomes, an in-process pilot project in the Midwest is achieving results that support the continuation of SDM research.[5] Staff members from a community mental health center have related anecdotal comments such as, "The SDM approach changes how

[5] All quotes are based on structured and unstructured conversations held between October 2006 and May 2007 with participants within the pilot setting by the project manager of the University of Kansas, School of Social Welfare Shared Decision Making Project.

I interact with my consumers; I find I listen more closely," and, "Shared decision-making helps me acknowledge the expertise and role of the consumer." Likewise, consumers report feeling "heard, acknowledged, listened to."

The motivation for adopting SDM processes within the context of mental health services does need to be closely examined. There are many common attributes between mental illnesses and the illnesses in general health care to which shared decision processes are applicable. However, there are also some key differences. The impact of stages and lengths of acuity of health conditions need to be examined in SDM research. Social and environmental factors differ dramatically, encompassing everything from social and legal discrimination to lack of parity in insurance. Historical implications and assumptions must be overcome. Too often, a paternalistic and authoritarian approach of compliance and coercion in mental health treatment may affect both the willingness of the care provider and the adaptability of the recipient. Moving from a passive patient role to an expert partner in the decision-making process will take some time. Also, identification of effective decision aids that are feasible and acceptable for people who vary in symptoms, and in cultural and social backgrounds, will take time.

Challenges exist in attempts to change systems as well. Appropriate funding and billing codes that allow for increased technology and information exchange are few and far between. Treatment planning and documentation that focus on lack of progress as a condition for continued access to services disempower both the consumer and provider of services. Overreliance on judicial or criminal interventions affects efficacy of self-agency.

Overcoming these and other yet-to-be-identified challenges will require a firm commitment to educational exploration that must include all the experts. The principles of a good decision aid can be used to provide a solid evaluation guide for the process. The overall aim is to improve decision quality and to reduce undesirable practice variations by: (1) providing facts about the condition, options, outcomes and probabilities; (2) clarifying patients' evaluations of the outcomes that matter most to them; and (3) guiding patients in the steps of deliberation and communication so that a choice can be made that matches their informed values (O'Connor et al., 2007).

Conclusions and Recommendations

Schauer et al. have provided a comprehensive set of recommendations to promote SDM via research, practice, and policy initiatives (Schauer et al., 2007). The research and practice of SDM in mental health care are in the early stages. SDM is consistent with the goals of the recovery movement and national initiatives to improve the quality and outcomes of mental health care. A small but increasing number of studies provide evidence of consumer interest in and favorable outcomes of SDM in the mental health care context. Further research and development of innovative practice models are needed. There is urgency to implementing practices that are consistent with and supportive of consumer recovery, with additional research to describe and test the effects of SDM in diverse mental health contexts.

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Supplement 2
Shared Decision-Making in Mental Health Care: Overcoming Barriers to Changing Embedded Norms

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Abstract

Shared decision-making is increasingly being seen as a way to implement person-centered care in both general and mental health care. It proposes that people learn how to be active participants in driving their own recovery, with the support of providers and others while working within the limitations and constraints of the delivery system. To date, this fundamental change in the historical relationships between providers and mental heath consumers has been demonstrated in research studies to improve knowledge and self-efficacy among consumers. Implementation in routine care, however, remains challenging. This paper reviews the implementation barriers documented to date, and describes promising service delivery models and model programs that may incrementally overcome barriers to routine use.

Introduction

Shared decision-making (SDM) is a potentially radical change in current mental health practice. It proposes that people learn how to be active participants in driving their own recovery, with the support of providers and others while working within the limitations and constraints of the delivery system. Accomplishing this requires a fundamental change in historical relationships between providers and mental heath consumers. It requires that providers and consumers learn different ways to talk to each other in clinical encounters, to engage in making decisions, and ensure their follow through. SDM's goal is to engage people in decision-making and recovery. SDM embodies the recovery values of empowerment, choice, and self-determination, and promises to "make recovery real" and facilitate individuals' recovery as well as optimize the use of resources.

To accomplish the move to SDM, a number of strategies have been developed and tested that address the needs and concerns of providers and consumers, as well as the changes required in the process of providing care. Interventions to train health professionals have focused on interviewing skills and patient-centered care. Interventions focused on consumers have included chronic disease self-management, question-asking skills (with and without prompt sheets), decision aids, peer counseling, and other educational interventions. The assumption has been that if providers listen better, and consumers learn more about their choices and become more assertive, both providers and consumers will come together prepared to make encounters more productive and the health care system will work better.

In order to successfully implement SDM within mental health care, it is necessary to identify barriers that may originate with providers, consumers, and the mental health care system. This paper examines traditional provider and client perspectives about decision-making, the legacy of judgments of competency (and the coercion solution), as well system-level barriers to implementation. We describe an adaptation of the chronic care model (Bodenheimer, Wagner, & Grumbach, 2002) to mental health, and describe promising approaches that help support consumers and providers in their efforts to achieve SDM. Our analysis reflects the current literature, our perspectives as consumers and providers of mental health services, and our experiences as developers of interventions.

Confronting Critical Challenges: The IOM Report

Historically, the mere diagnosis of a psychiatric disorder has been viewed as a barrier to the ability of the individual to successfully participate in making shared decisions about treatment and recovery. However, this perception was significantly challenged in the Institute of Medicine's (IOM) (2006) report on *Improving the Quality of Care for Mental and Substance-Use Conditions*. Following a careful review of the literature, the IOM study committee concluded that the evidence shows:

> It is inappropriate to draw conclusions about individuals' capacity for decision making solely on the basis of whether they are mentally ill, or even whether they have a particular mental illness, such as schizophrenia. Many people with mental illnesses, indeed, many with severe mental illnesses are not incompetent on most measures of competency. Even among patients hospitalized with schizophrenia, the MacArthur researchers found only 25 percent incompetent on any given measure, and only 50 percent if the measures were aggregated (Applebaum, Applebaum, & Grisso, 1998). Other studies have found a higher proportion of individuals with schizophrenia to be competent in decision making (Saks, Jeste, Granholm, Palmer, & Schneiderman, 2002). The evidence shows that poor decision making has a stronger relationship to cognitive problems (e.g., problems with memory, attention, learning, and thought) and deficiencies in higher-level executive functions than to the symptoms of mental illness, such as psychosis. The minority who experience a decline in such cognitive abilities because of their mental illness may not be very different from individuals who have general medical conditions such as cerebrovascular disease, are under the effects of serious emotional stress or in pain, or generally have lower abilities to understand and analyze information (p. 98).

Involuntary or coercive treatment is viewed by many as a potential barrier to SDM. The need to resort to coerced or forced treatment is increasingly viewed as a failure of the service system and a result of inadequate public funding of the services and supports needed to promote consumers' voluntary participation. Such interventions reflect the inability of mental health systems to equitably provide the best evidence-based practices and person-centered approaches. Involuntary treatment can occur in an inpatient or outpatient setting. Coercive treatments, such as seclusion and restraint and forced medications, are more typically seen in the inpatient setting. Involuntary outpatient commitment (IOC) most typically involves issues related to adherence to treatment and taking medications. Involuntary inpatient treatment most typically involves issues of the immediate safety and well-being of the individual and others, and is seen to require confinement or containment in a locked setting. Given the alienation, distrust, and disempowerment caused by involuntary and coercive treatment, it is a potential (but not an absolute) barrier to SDM.

Although IOC laws vary from State to State, they generally require individuals to take medication and comply with other outpatient treatment recommendations or risk being placed in inpatient psychiatric hospitals. Currently, the requirements for IOC may be defined very loosely (e.g., diagnosis of a major mental disorder and a history of treatment noncompliance) or very tightly (e.g., imminent risk of danger to self or others). Overall there is little standardization, and few specific guidelines, for recommending IOC. Laws and procedures typically rely on past behavior as a predictor of future behavior, or on a subjective assessment of current community functioning (Bazelon, 2007). IOC is a legal definition and may constrain decision-making and self-care.

However, the Institute of Medicine (2006) did not view involuntary or coerced treatment as an absolute barrier to SDM, and concluded:

> The phenomenon of coercion, like the consequences of stigma and discrimination, has implications for the implementation of the Quality Chasm rule of patients being able to exercise the degree of control they choose over health care decisions that affect them. Despite these difficulties, however, the committee finds that the aim of patient-centered care applies equally to individuals with and without mental and substance use (M/SU) illnesses. To compensate for the obstacles presented by coercion, as well as those posed by stigma and discrimination the committee finds that health care clinicians, organizations, insurance plans, and Federal and State Governments will need to undertake specific actions to actively support all M/SU patients' decision-making abilities and preferences, including those of individuals who are coerced into treatment (p. 112).

The IOM went on to recommend:

> [T]he ways in which individuals perceive coercion vary and are influenced by the nature of the coercive process and the extent to which patients perceive those who are coercive as acting out of concern for them; treating them fairly, with respect, and without deception; giving them a chance to tell their side of the story and considering what they have to say about treatment decisions (Morley, Finney, Monahan, & Floyd, 1996). In all circumstances, then, but especially when negative pressures are being used, patients need to be afforded as much process as possible. Further, individuals who are coerced

> into treatment should still be involved in decision making about the types of treatment to be used for their illness and in the choice of provider (p. 112).

The IOM strongly recommended the provision of decision support to all individuals—regardless of legal or commitment status—by providing them with information, avoiding undermining their decision-making abilities, and appreciating the changing nature of consumer decision-making preferences. The IOM also recommended the use of peer support services, especially for those individuals with impaired cognition or diminished self-efficacy, as well as the use of advance directives.

If involuntary or coercive treatment does occur, understanding and addressing this treatment failure is essential. In the process, every effort at optimizing SDM should be made. Accomplishing this vision will require changes in provider attitudes and behavior as well as systems processes, and the active provision of decision supports regardless of diagnosis and/or legal status. Significant redesign of current systems, and the adoption of practices and processes consistent with these values and rules, will be needed to remove system-level barriers to SDM. This redesign is intended to clearly identify the steps and processes necessary to provide services that meet the Institute of Medicine's six quality goals of being person-centered, safe, timely, efficient, effective, and equitable, and to engage and support service users in making shared decisions about their recovery goals, objectives, and preferences for services and supports.

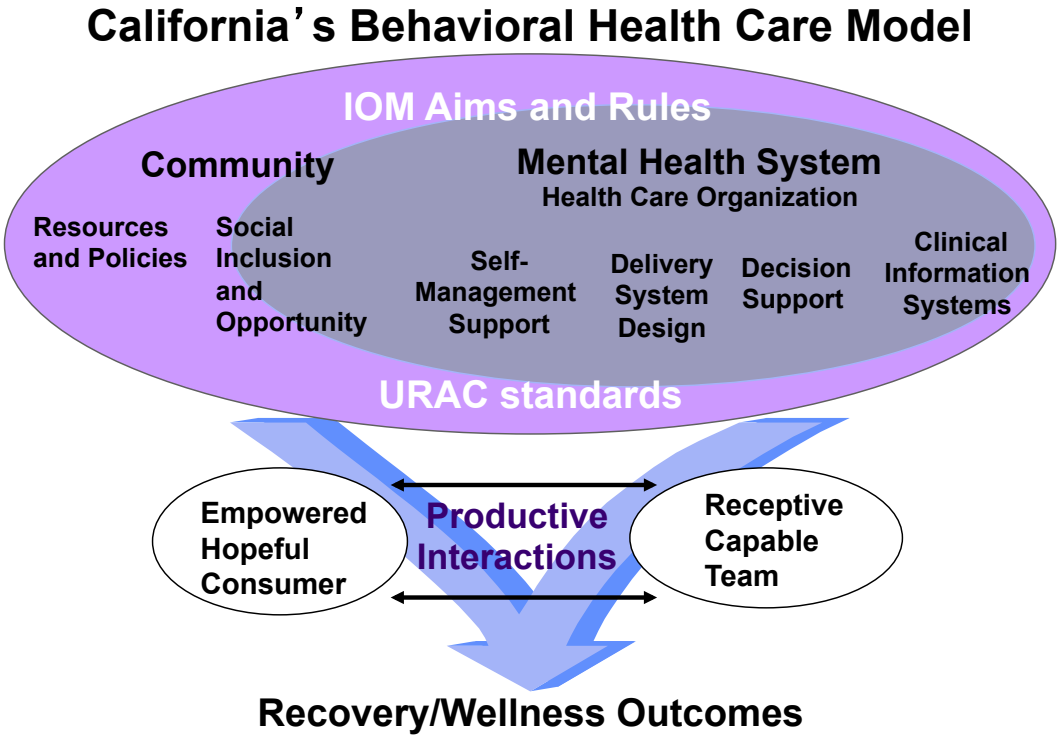
System Redesign

Historically, service delivery has largely been organized around provider and/or system concerns. Administrative, regulatory, and payer demands, as well as professional priorities and traditions, have driven system design. Much of the organization of care has been based on traditional hierarchical relationships and provider authority. The result has often been far from person-centered care, or from supporting and promoting SDM.

The service delivery system's values, priorities, organization, and functions may all be barriers to SDM. Significant redesign is required to create and sustain the resources and supports necessary for SDM. Wagner's chronic care model (Bodenheimer et al., 2002) has become a well-accepted framework to guide system redesign in the general health care sector, and proposes community roles as well as those of providers and consumers required to support SDM. Figure 1 illustrates how the model can be adapted to mental health care. The CalMEND framework was developed by the California Institute for Mental Health (www.CalMEND.org) to promote person-centered approaches and SDM. The diagram depicts the centrality of productive interactions—in essence, shared decisions—between consumers and providers as a key to realizing individuals' recovery and wellness outcomes. The model also

identifies a number of critical components in the community and in the health care system that support and promote that shared decisional process. These include self-management, decision support, clinical information systems, and delivery system design.

FIGURE 1



Unpacking Shared Decision Barriers to Identify Solutions

Providers and Consumers

The primary approach to changing providers' and consumers' behaviors focuses on the decision support element of the framework. Clinical information systems are also critical in delivering decision support in forms and at times that serve to facilitate productive interactions. We include information tools in our definition of decision support, as well as training in communication skills to teach providers and consumers how to exchange information, use the information tools, and negotiate a treatment plan.

Patient-centered care, in the context of clinician training, has largely focused on interviewing skills (Lewin, Skea, Entwistle, Zwarenstein, & Dick, 2001). Rigorous research studies have shown that doctors, nurses, and pharmacists can learn new skills of agenda setting, reflective listening, presenting pros and cons of treatment, and collaborative decision-making and planning. When health professionals adopt

these approaches, people are more satisfied with their care, and more likely to follow through with therapy (Stevenson, Cox, Britten, & Dundar, 2004; Edwards et al., 2004; Fellowes, Wilkinson, & Moore, 2004). Some studies show improved health status and lowered anxiety (van Dam, van Der, van Den, Ryckman, & Crebolder, 2003). A Cochrane Collaboration review (Lewin et al., 2001) indicates that physicians in structured training programs learn communication skills quickly and retain them, especially when offered the opportunity for practice with observational evaluation and feedback. Other systematic reviews show similar results (Coulter & Ellins, 2006).

However, the results of both inpatient and outpatient surveys show that one-third to one-half of patients indicate they would have liked more involvement in decisions about their treatment and care (Coulter, 2006). This apparent gap between expectations and experience is beginning to be investigated. Clinician barriers to fully embracing the collaborative approach include both role concerns and skill concerns. Physicians' and nurses' perceived barriers to providing evidence-based information to patients and involving them in decisions, as identified by Ford, Schofield, and Hope (2002), include:

- Concern about knowledge gaps and limitations of the research evidence;
- Concern about their own lack of skills in risk communication;
- Belief that many patients could not cope with the information and/or would not want to take responsibility for decision-making;
- Fear that patients would tend to choose the most expensive or unaffordable options;
- Concern about lack of technical support for shared decision-making, e.g., non-availability of risk communication tools or decision aids;
- Concern about time constraints within the consultation; and
- Concern about disrupting or undermining the doctor-patient relationship (p. 181).

To overcome resistance by physicians and other providers, examination and licensure requirements have become a leverage point to require providers to learn communication skills. Passing competency examinations in communication skills is now part of step three of the examination of the National Board of Medical Examiners. The American Board of Internal Medicine requires demonstration of competency in communication skills, and other members of the American Board of Medical Specialists are in the process of adding communication as a basic skill in their specialty. However, even in countries that have widely adopted this approach, there are continuing concerns expressed by providers. A recent study of clinicians in the

Netherlands found that while doctors accept the general idea, they feel that their capacity to structure and manage the clinical encounter is somewhat compromised by communication skills guidelines they are required to follow. Veldhuijzen et al. (2007) found that while physicians accepted a positive effect on the quality of medical care, and were aware that communication guidelines define best practices, actual adherence to communication guidelines remains low despite participation in intensive communication skill training. Barriers most frequently cited by general practitioners focused on lack of fit with the workflow in their day-to-day practice. They also felt the guidelines were rigid and inefficient, and misconstrued the basic reasons patients consult a doctor. Here, as elsewhere, the proposition that patients come to doctors for advice and cure was felt to be violated by the drive to SDM.

While SDM continues to grow in use, it remains difficult for clinicians, trained to give advice, to embrace shared decision-making in a way they feel is appropriate and responsible. Many feel that there is a basic conflict between their duties of beneficence and of supporting patient autonomy. Hammond, Bandak, and Williams (1999), in studying perceptions of unilateral versus equalitarian role functions for nurses, physicians, and consumers in a psychiatric facility, found concern about retaining authority also contributed to the lack of implementation of collaborative decision-making, even though clinicians supported the general idea.

Interventions that teach communication skills to consumers have also been tested. Results show that people taught to ask questions (with and without prompt sheets) and to share in decisions, show improved knowledge and recall of what was said during the visit, usually with no increase in time spent in the encounter. However, the results with regard to patient satisfaction, medication adherence, and treatment outcomes are mixed in these interventions (Stevenson et al., 2004; Gaston & Mitchell, 2005; Harrington, Noble, & Newman, 2004; Griffin et al., 2004; Scott et al., 2003). The most effective interventions have directed intervention simultaneously to both parties in the encounter, and provided external reminders (Kennedy, Robinson, Hann, Thompson, & Wilkin, 2003).

Patient Decision Aids

Patient decision aids (DAs), also called decision support tools, are evidence-based information tools designed to assist consumers and providers to discuss the pros and cons of treatment or screening. This includes consumers' own personal priorities and values for both the amount of gain that can be obtained from treatment and the cost in terms of side effects as well as money. This background information is designed to encourage a deliberative process in the clinical encounter in arriving at a decision about intervention. DAs are focused on specific clinical problems, synthesizing the best available evidence on treatment or screening options in ways that encourage

consumers to engage with their providers in making a choice that is consistent with the evidence and with their personal values. DAs are used most often for what have been called preference-sensitive health decisions—decisions for which the benefit-harm ratio is uncertain. These so-called "gray-zone" decisions involve more than one alternative that is reasonable from the standpoint of efficacy, yet the outcomes may be valued differently by different people. This definition has been used most for situations where surgical and medical options, as well as wait-and-see options, are all reasonable. In mental health, DAs are useful for problems such as depression, where medical therapy, talk therapy, and a wait-and-see approach may all be reasonable. DAs are particularly helpful in clinical problems for which there is a small risk of a grave outcome, or when people attach very different levels of importance to a certain outcome. Some DAs include an explicit strategy to clarify values for outcomes or elicit preliminary treatment preferences prior to talking with a clinician. Many DAs also provide structured guides for decision-making, as well as examples of other people's decisions, opinions, and experiences.

Role of DAs in Health Service Reform

DAs are designed to improve clinical decision-making, which has frequently been shown to be suboptimal (Braddock, Fihn, Levinson, Jonsen, & Pearlman, 1997). In particular, consumers are often not well informed about treatment options and the benefits and downsides of each option. Providers rarely assess patient values explicitly, and infrequently involve patients in SDM. The focus on patients, rather than providers, emerged from at least two sources. The health services argument made by Wennberg, Barnes, and Zubkoff (1982) was that patient self-interest would balance provider self-interest, expressed as supplier-induced demand. This argument was the logical extension of Wennberg's work documenting practice variation that clearly was not a function of patient or disease characteristics. At the same time, an ethical argument was made by many, proposing that SDM was a higher ethical standard than simple informed consent (President's Commission, 1981; Siegler, 1981). Taken together, these two parallel threads of inquiry, combined with a deep interest in supporting patient choice, led researchers and developers to create tools to support patient participation in treatment decision-making. From the health services perspective, it was hoped that patient participation would improve the quality of decisions, and thereby improve care, cost, and satisfaction. It was anticipated that patient self-interest in avoiding unnecessary intervention would eliminate unwarranted variation. The ethical rationale focused on SDM as the appropriate moral principle. The goal of DAs is not to suggest "mandatory autonomy," but rather to encourage informed patients to share in decision-making as they like, or to defer to their providers (Schneider, 1998). A systematic review of DAs assessed the efficacy of 55 clinical trials for a variety of clinical conditions. Results show that when they are used, DAs appear to modestly increase the utilization of services in situations of underuse of services and decrease utilization in cases of overuse (O'Connor et al., 2007).

Barriers to Routine Use of DAs

While DAs appear to function well in experimental settings, getting them routinely used in everyday practice is challenging. An early observational study of DA adoption by enthusiastic providers found that they were rarely used (Holmes-Rovner et al., 2000). SDM multimedia videos for prostate cancer, breast cancer, and ischemic heart disease were judged by physicians and nurses to be clear and accurate, and to present about the right amount of information in an appropriate amount of time. Programs were judged to be informative and appropriate for patients to see before making a decision. However, the study revealed that clinicians were unconvinced about patients' desire to participate in treatment decision-making, and referral volume to the programs was lower than expected. In seven months across three medium-sized hospitals, 34 physicians and nurses referred a total of 24 patients to the programs.

A more recent pilot study conducted in the United Kingdom in outpatient settings found similar difficulties. In 2004, four National Health Services Hospital Trusts implemented two SDM videos (benign prostatic hypertrophy [BPH] and early stage prostate cancer) in outpatient urology practices. The intervention consisted of nurse training for counseling about SDM and decision support, the videos, and decision quality assessment (DQA) (Wirrmann & Askham, 2006). However, during 12 months in four trusts, only 86 patients answered questions on the DQA, indicating use of either video. Interviews with patients and health professionals showed that health professionals felt a need to carefully screen the patients for whom the information was considered appropriate, reflecting a somewhat narrow vision of when patient choice might be appropriate. In addition, finding a mechanism for reliably getting the videos to patients before the consultation was problematic, as was the case in the prior study. In this particular approach to implementation, specialist nurses were the main counselors and DA implementation staff had an information and support role. The administrative burden on an already overworked staff was a serious threat to program sustainability.

As in the U.S. study, not all patients accepted the decision support program. Ironically, in the U.S. program, when physicians were especially thorough and supportive in their discussions with patients, patients were not interested in spending an hour getting further education. Only the physician who did not provide extensive information, and who required the patients to view the video before their visits to receive biopsy results, was able to get consistent patient participation in seeing the video. These studies suggest that physician referral is unlikely to be a reliable mechanism for patient access to DAs. Better information systems may help with timely and helpful delivery of information to both consumers and providers. However, finding the right triggers to such timely support has been elusive to date. In addition, the United Kingdom study found what has been found previously in guidelines studies, that most providers want a say in designing materials for their local settings. Materials

that were produced in the U.S., with video clips of people speaking with Boston accents, were found to be off-putting in London.

The United Kingdom results, like those reported by Légaré et al. (2006), suggest that accessibility needs to be smooth, automatic, and timely, and that DAs need to be compatible with practitioners' practices and personal beliefs, up-to-date, attractive, easy to use, and not require additional cost, time, or equipment. Findings also suggest that providers need to feel motivated to use DAs by factors such as time saving, avoidance of repetition, the potential to decrease liability, and improved decision quality. In the example of prostate cancer, it became difficult to make the DAs an integral part of the communication and support process between the time of biopsy and the consultation to make a treatment choice. In BPH, where treatment was felt to be more truly elective, it seemed more possible to deliver the DA outside of the context of the medical encounter. Given that the innovation literature in general suggests only a 10 to 12 percent adoption rate in early stages, adoption of SDM can be expected to be slow, and in need of substantial institutional support and incentives.

Barriers to SDM from Consumers

It is well established that individuals living with mental health problems need more than medical treatment from their health care providers. Individuals pursuing recovery often need a range of services and supports to manage their own lives and be as healthy as possible. Although now in the midst of multiple reform efforts, the mental health system has historically been built on the model that the consumer was "broken" and needed to be "fixed." Some mental health service models are steeped in the medical tradition of diagnosis, focus on symptoms, and physician-directed prescription of medications for amelioration if not cure.

While there may be instances where the medical management model is appropriate and effective, for many it has not worked. Using this approach, the experience of the consumer has often been characterized as "learned helplessness," though it has been argued that it can more accurately be described as a realistic defensiveness born of past experience with mental health services. Similarly, experience with provider prejudice in mental health care creates an expectation that can set up barriers to SDM implementation. The situational analysis prepared for SAMHSA's Elimination of Barriers Initiative, an eight-State pilot to test public education approaches to reduce prejudice and discrimination, found through focus groups of mental health consumers that mental health care providers were among those who most stigmatized mental health consumers (Schauer, Everett, del Vecchio, & Anderson, 2007).

Mental health consumers often report feeling disempowered and having little input into treatment choices and care plans because of provider assumptions that they are not able to make decisions in their best interests. Experienced mental health service users often feel that programs to improve adherence can quickly translate into

coercion. Thus, they may well feel that SDM programs are unlikely to really mean participation in decision-making on their terms.

Observations from within a peer-operated agency yield a number of insights from the perspectives of service users that provide context for designing approaches to SDM. Users of mental health services, who are seeking wellness and a lifestyle that they have selected (not one mandated by a health care professional), often find it difficult to follow the provider-recommended or -directed treatment plans. It is not simply a lack of motivation that can cause these failures. Although lack of motivation can play a part, more typically a host of other factors can contribute. For example, consumers may find that they:

- Do not have sufficient knowledge of the condition or its treatment;
- Have not had an opportunity for reflection to determine if this is the desired course of action;
- Lack the self-confidence or skills to manage the condition well;
- Do not have adequate support from friends or family members;
- Lack financial resources to buy items necessary to maintain and sustain a wellness-focused lifestyle;
- Are not be able to reach out to others to have any successful social interaction or relationship as a result of their symptoms; and
- Have lost hope that things can change and recovery is possible (Wills 2005).

These concerns often create a level of what appears to be defensiveness and disinterest in "going along with providers" that can derail a clinical encounter long before it ever gets to collaborative decision-making about treatment. Wills (2005) found that depressed patients may be more receptive to information about treatment options, possible outcomes, and the chances of those outcomes when they access the materials first from the Internet. With this information, consumers and their families are better able to judge the value of benefits versus risks associated with any treatment decision—including the option to forgo treatment. Accurate and usable information can be critical to engaging consumers in SDM.

Studies have shown that if consumers use DAs and are able to engage in SDM, the result is reduced uncertainty, improved knowledge, and more realistic expectations about treatment outcomes (O'Connor et al., 2003). Although the decision-making partnership may never be fully equal, it proceeds based on mutual respect for the professional's expertise along with the consumer's preferences, values, and lived experience. Having shared access to the same information to guide decisions ultimately empowers both professionals and consumers, and supports their efforts in sustaining

a healing partnership and developing a mutually agreeable plan. Recording decisions in a document most commonly referred to as a "treatment plan" may extend the collaborative relationship and serve as an ongoing and shared reference or recovery guide.

Barriers to SDM from the mental health care system

Historically, the service delivery system has been organized around the provider's preference to control decision-making about pharmacotherapy and psychosocial interventions and supports. The role of the helping professional was defined by his or her ability to provide guidance and sound advice to consumers who did not have the same level of knowledge, training, and experience. Treatment plans were developed with the expectation that the consumer would be compliant with prescribed treatment. However, unless deemed otherwise by a court, consumers make their own independent decisions on a daily basis to accept or reject the professional's plan with each dose of a medication or participation in a prescribed activity.

SDM can only proceed from a shared understanding of the consumer's recovery hopes and dreams as well as the barriers that lie in the way of success. However, neither the infrastructure nor the encounter-level practice of mental health has put shared understanding at the center of the process. This omission is critical because shared understanding is the first—and in many respects, the most critical—of all the decision points in creating an effective and acceptable recovery and services plan. Understanding is based on the ability of the provider and consumer to weave all the threads of information gathered in an assessment into at least partial (if not whole) cloth. Compassionate and empathic understanding is often the key that unlocks the door of possibility for individuals feeling overwhelmed and unable to proceed in their own recovery. It must be shared and mutual if it is to serve and support the overall process, beginning with setting goals, then developing a plan, and providing services. Without this understanding, there cannot be the productive interactions that are identified in the Wagner care model. Without this understanding, there is no real basis for SDM even if the best DAs are available. In most service delivery systems today, this essential step is all too often overlooked. Even when such understanding is considered, disagreements that become barriers to true mutuality in decision-making are avoided and may go unrecognized rather than being acknowledged and resolved.

Promising Approaches to System Redesign

CalMEND is a joint quality improvement initiative between the California Department of Mental Health (DMH), the State's Medicaid agency (Medi-Cal), and the California Institute for Mental Health (CiMH). The work of CalMEND draws heavily on not only the participation and input of paid staff, but also on committee and task group volunteers who represent all stakeholders and in particular providers (including physicians and pharmacists), consumers and recovery specialists, and family members. Initiated as a disease-management project to address quality of care

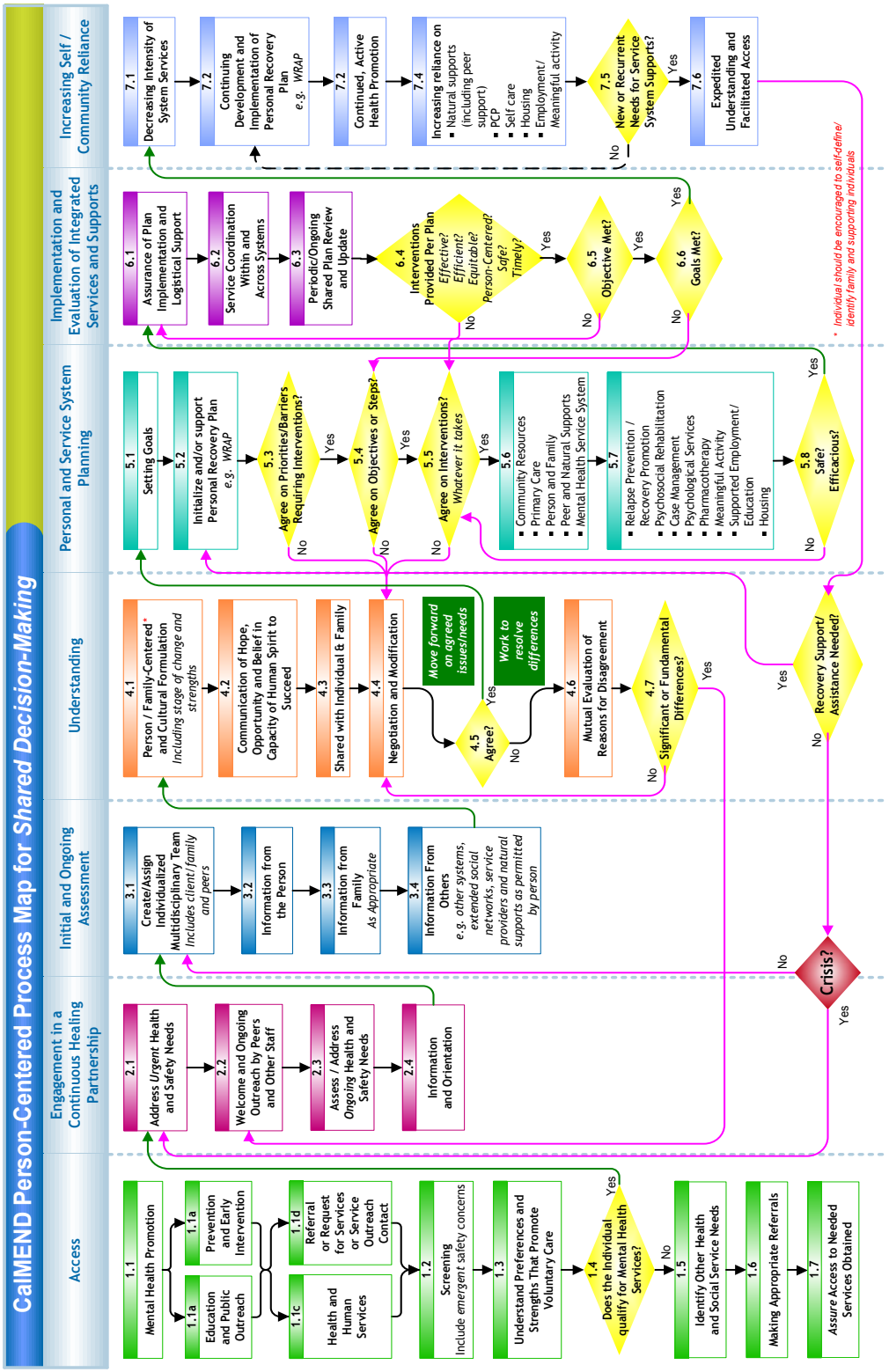
and cost concerns associated with the use of atypical antipsychotics, CalMEND has become a comprehensive effort to redesign the service delivery system and process across all sites and settings that deliver mental health services.

CalMEND has developed a process map (see Figure 2) that has become central to communicating its work as well as organizing the project's structure and further work. Inspired by Gustafson's (2007) work with addiction treatment and the value of understanding existing processes to drive systems improvement, CalMEND at first tried to capture and map the service user's experience of the existing system. This effort quickly collapsed in frustration with the recognition that there was more variance and perhaps even chaos than a consistent person-centered approach to consumers.

In place of a map of the existing system, a framework was developed; that framework is shown in the visual diagram (Figure 2) of how a service delivery system should be organized and function in order to promote the IOM goals, honor recovery values, ensure person-centered approaches, promote cultural competence, and support SDM. While the many lanes of the diagram are complex, a virtual walkthrough of the service-seeking experience can identify both barriers and opportunities that must be addressed. Barriers may include a lack of resources; issues related to financing a truly person-centered system; regulatory requirements; the knowledge, skills, and abilities of providers; and the needs and skill levels of consumers and family members for information, preparation, and support. At the same time, the process map helps to focus on those innovations, interventions, resources, training, policy changes, and other factors that can be made to support implementation of the model.

The process map shown in Figure 2 is organized into seven phases (also called swim lanes), each representing a cluster of associated activities that moves from left to right, from access to community integration and self and/or community reliance. The companion narrative for the flowchart that explains and describes the values, intent, and concerns embedded in each lane, and the accompanying performance goals and measures to support their implementation, are being vetted and pilot tested in several California counties. The arrows in the figure depict the transition from one phase to the next and reflect a logic model in which each step builds on the completion of the preceding activity and becomes a virtual condition for moving forward. Activities and tasks are depicted by rectangles in the figure, and the diamonds symbolize decision points that, with the possible exception of access and/or eligibility, should be consensus-based shared decisions. Backflow, or the need to repeat steps in the process, is identified by lines and arrows.

FIGURE 2


CalMEND Person-Centered Process Map for Shared Decision-Making
Access
Engagement in a Continuous Healing Partnership
Initial and Ongoing Assessment
Understanding
Personal and Service System Planning
Implementation and Evaluation of Integrated Services and Supports
Increasing Self / Community Reliance
1.1 Mental Health Promotion
1.1a Education and Public Outreach
1.1a Prevention and Early Intervention
1.1c Health and Human Services
1.1d Referral or Request for Services or Service Outreach Contact
1.2 Screening Include emergent safety concerns
1.3 Understand Preferences and Strengths That Promote Voluntary Care
1.4 Does the individual qualify for Mental Health Services?
1.5 Identify Other Health and Social Service Needs
1.6 Making Appropriate Referrals
1.7 Assure Access to Needed Services Obtained
2.1 Address Urgent Health and Safety Needs
2.2 Welcome and Ongoing Outreach by Peers and Other Staff
2.3 Assess / Address Ongoing Health and Safety Needs
2.4 Information and Orientation
3.1 Create/Assign Individualized Multidisciplinary Team Includes client/family and peers
3.2 Information from the Person
3.3 Information from Family As Appropriate
3.4 Information From Others e.g. other systems, extended social networks, service providers and natural supports as permitted by person
4.1 Person / Family-Centered* and Cultural Formulation Including stage of change and strengths
4.2 Communication of Hope, Opportunity and Belief in Capacity of Human Spirit to Succeed
4.3 Shared with Individual & Family
4.4 Negotiation and Modification
4.5 Agree?
Move forward on agreed issues/needs
Work to resolve differences
4.6 Mutual Evaluation of Reasons for Disagreement
4.7 Significant or Fundamental Differences?
Crisis?
Recovery Support/ Assistance Needed?
5.1 Setting Goals
5.2 Initialize and/or support Personal Recovery Plan e.g. WRAP
5.3 Agree on Priorities/Barriers Requiring Interventions?
5.4 Agree on Objectives or Steps?
5.5 Agree on Interventions? Whatever it takes
5.6 Community Resources
Primary Care
Person and Family
Peer and Natural Supports
Mental Health Service System
5.7 Relapse Prevention / Recovery Promotion
Psychosocial Rehabilitation
Case Management
Psychological Services
Pharmacotherapy
Meaningful Activity
Supported Employment / Education
Housing
5.8 Safe? Efficacious?
6.1 Assurance of Plan Implementation and Logistical Support
6.2 Service Coordination Within and Across Systems
6.3 Periodic/Ongoing Shared Plan Review and Update
6.4 Interventions Provided Per Plan Effective? Efficient? Equitable? Person-Centered? Safe? Timely?
6.5 Objective Met?
6.6 Goals Met?
7.1 Decreasing Intensity of System Services
7.2 Continuing Development and Implementation of Personal Recovery Plan e.g. WRAP
7.2 Continued, Active Health Promotion
7.4 Increasing reliance on
Natural supports (including peer support)
PCP
Self care
Housing
Employment / Meaningful activity
7.5 New or Recurrent Needs for Service System Supports?
7.6 Expedited Understanding and Facilitated Access
Yes
No
* Individual should be encouraged to self-define/identify family and supporting individuals

The process map is intended to articulate and reveal insights about how system design can either promote and support or thwart SDM. In particular, the CalMEND map identifies important early steps that may be essential preconditions to SDM. The process really begins in the first and second lanes with outreach, welcoming, and engagement. The focus is on creating a healing partnership between the consumer and provider that is hopeful and strengths-based, honors the dignity of the individual, and is guided by respect. While most relationships improve and mature with experience over time, the basic foundations of trust and collaboration are prerequisites.

Promising Peer Support Approaches: Preparing Consumers for New Roles

To resolve the challenges and barriers to SDM in routine practice, it is essential that we develop interventions that can sustain SDM and decision support in the context of a service delivery system designed to promote person-centered approaches (for example, as envisioned by CalMEND). Linking practice change with systems design is critical. Successful peer-support programs that help promote effective self-management, and that ultimately support shared decision-making, may be a key ingredient for success. This approach combines traditional peer support (from someone who has the same condition or comes from similar circumstances) with a more structured program of education and assistance (Dennis, 2003).

Peer-support interventions have been found to reduce problematic health behaviors and depression (Malchodi et al., 2003; Winzelberg et al., 2003; Joseph, Griffin, Hall, & Sullivan, 2001) as well as other mental and physical health issues. In the face of these challenges, interventions that mobilize and build on peer support are an especially promising way to prepare consumers for SDM. To date, peer support has been used largely to improve self-management of symptoms. However, effective self-management support is a key element of the model that ultimately supports SDM. Peer-support interventions combine traditional peer support—meaning support from someone who has the same condition or comes from similar circumstances—with a more structured program of education and assistance (Dennis, 2003). Additionally, peer-support interventions have been found to reduce problematic health behaviors and depression (Malchodi et al., 2003; Winzelberg et al., 2003; Joseph et al., 2001) as well as other mental and physical health issues.

Peer support is effective in part because of the nonhierarchical, reciprocal relationship created through the sharing of experiences and knowledge with others who have faced or are facing similar challenges. This exchange promotes mastery of self-care behaviors and improves wellness and recovery outcomes (Broadhead et al., 2002; Wilson & Pratt, 1987). In addition to improving the recipient's learning, peer support provides a reciprocal (or even larger) benefit for the peer provider. Individuals who provide social support through volunteering experience less depression (Krause, Herzog, & Baker, 1992), heightened self-esteem and self-efficacy, and improved quality of life, even after adjusting for baseline health status and socioeconomic status (Perry et al., 2005; Riegel & Carlson, 2004; IOM, 2002).

However, peer support requires structure and training. Mentorship is often critical to maintaining a wellness-focused lifestyle, a successful career, success in completion of personal goals such as education, and reconciliation with family. Peer coaches or mentors meet one-on-one with other patients to listen, discuss concerns, and provide support. Peers have been effective with patients suffering from such chronic conditions as HIV, cancer, stroke, and chronic kidney disease, and with patients who are facing organ transplants (Perry et al., 2005).

Peer coaches are usually individuals who have successfully coped with the same condition or surgical procedure and can serve as positive role models. They provide hope and understanding that could not be provided as powerfully by someone lacking their personal experience. Candidates to be peer mentors are often referred by clinicians or social workers who recognize their successful coping and/or recovery. Qualities that should be considered when selecting and developing mentors who are peers include whether they represent the individuals they are serving, are part of the community's culture, are conversant in the language of the individuals being served, are respectful of others and respected by those they serve, have good judgment, and demonstrate listening skills and empathy.

It is also critical that individuals who serve as peer mentors have the opportunity to share with other mentors in a supportive and structured way. All teaching is improved by sharing experience and techniques; care must be taken to avoid mentor burnout. Additionally, it is critical that training for peer mentors address:

- Role expectations;
- Mentoring examples;
- Relationship building;
- Self care;
- Barriers;
- Confidentiality;
- Avoidance of personal relationships;
- Identification of community resources; and
- Successful networking strategies.

Peer mentoring is especially effective with people of color who have a historic and cultural mistrust of predominantly white health care systems (Perry et al., 2005). For all races and cultures, peer mentors foster trust of the health care staff and enhance coping and health outcomes among patients. In New York City, it has been demonstrated that individuals of African American and Hispanic heritage have been

disproportionately subjected to involuntary outpatient commitment (U.S. Psychiatric Rehabilitation Association, 2007). The results of such treatment have often been to alienate individuals from the alleged services designed to help them. Homelessness can be preferable to being in a system viewed as controlling, unhelpful, and not respectful of individuals' culture and ethnicity. Value and social class differences between providers and consumers may interfere with establishing the engagement that is desired by the health care professional. The experience of peer mentors can contribute to provider training as well as peer training.

One peer-decision support model (Deegan & Drake, 2006) attempts to build and support consumer decision skills immediately before the clinical encounter. The decision support center is a place where consumers can go to work with a peer and decide what they want from their next appointment with their health care professional. The systematic approach examines goals, helps the person focus and state the goal, examines desired outcomes, and supports the individual during the health care appointment if desired. These centers are staffed by trained peer mentors, offer light snacks and beverages, and are inviting and flexible, often replacing the usual waiting room. The center becomes an inviting and stimulating place where social connections and coaching for the clinical encounter can occur.

Conclusions

Implementation of SDM requires important changes in the values and principles that guide interactions between consumers and providers. SDM builds on recovery-oriented services and goes further. It invites candid disclosure of consumers' personal values about what is important to them, and it invites providers to clearly present all the treatment choices that may be effective, along with discussion of which options work best and what side-effects may occur. The mental health field provides special challenges to implementation of SDM because of the history of interventions that assume limitations in mental health consumers' capacity to make decisions in their own best interests.

By itself, supplying decision support tools cannot be expected to accomplish major reforms. In order to make SDM a vehicle for true person-centered care in mental health, these promising interventions must be sustained, strengthened, and repeated. Provider training in SDM and the use of decision support tools must become a part of training in many preclinical, clinical, and postgraduate education settings. Consumers also require training and practice in how to accept the challenge and responsibility for making choices and following through. SDM requires new skills for effective self-advocacy for individuals with mental illnesses. Service delivery systems must assist in delivering treatment choice information to both consumers and providers. It must also develop quality measures that establish reward systems for SDM, and the ability to document negotiated treatment decisions, including those that may be somewhat novel in matching treatment with consumers' priorities and provider expectations. Where such treatment decisions include specific followup expectations, these must also be documented. Episodes of treatment have to give way to trajectories of treatment that allow for trial and error and new strategies for reaching recovery goals.

Mental health research is far from devoid of participation in research on SDM interventions and services. There is an active field of research, with some of the most positive results in the whole health field being found in studies of depression. Building on these successes requires concerted effort at all levels of the service delivery system, including the community and formal health care systems. Training and educating both providers and consumers, structuring the service delivery system and/or process, and ensuring access to decision support may all contribute incrementally to bringing SDM into routine practice as the standard of care.

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Supplement 3
Aids to Assist Shared Decision-Making in Mental Health Care

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Abstract

This paper presents information on decision aids (DAs) that mental health consumers can use to support their participation in shared decision-making. DAs are far more readily available, and have been studied in more detail, in physical health than in mental health. The recent Institute of Medicine and Annapolis Coalition reports, however, point to the importance of developing more and better DAs in mental health. DAs may be distinguished from other informational materials because they present objective evidence and explicit alternatives, and also offer guidance in clarifying personal values. DAs may be used passively, actively, or with assistance. They may be accessed over the Internet (increasingly common), on paper, with a CD-ROM, and/or through audio or video formats. They may focus on a specific treatment decision or on decision-making in general, and they may be related to one-time decisions or to ongoing decision-making. The paper lists sources of DAs that are available to the public, including some in the mental health arena, and notes the dearth of evidence regarding the results of their use, especially in mental health. It concludes by presenting a number of questions regarding implementation of DAs in mental health care, and recommendations for consideration by the Substance Abuse and Mental Health Services Administration (SAMHSA).

Introduction

Significance of Shared Decision-making (SDM) in Mental Health Care

The concept of shared decision-making (SDM) has been discussed for nearly 30 years (Adams & Drake, 2006), but its significance has been highlighted by the recent efforts of several bodies working in both physical and mental health care. The Institute of Medicine's (IOM's) groundbreaking volume, *Crossing the Quality Chasm* (2001), included among the "rules for patient-centered care" the notion that the patient should be the "source of control," and, "The health system should be able to accommodate differences in patient preferences and encourage shared decision making" (p. 61). The President's New Freedom Commission on Mental Health (2003) emphasized the need (within goal 2) for an individualized plan of care for each consumer. It noted that "Consumer needs and preferences should drive the type and mix of services provided. . . . Providers should develop these customized plans in full partnership with consumers" (p. 35). Thus, implicitly if not explicitly, the commission suggested the value of what this paper refers to as SDM.

Improving the Quality of Health Care for Mental and Substance-Use Conditions (2006), the report produced by the IOM Committee on Crossing the Quality Chasm: Adaptation to Mental Health and Addictive Disorders, focused on the 10 rules laid out in *Crossing the Quality Chasm*. Key among the steps this committee discussed was "providing decision-making support to all M/SU [mental and/or substance-use] health care consumers" (p. 105). SDM has thus been seen over several years as representing one potentially important means to achieve a mental health system that is strength based and recovery oriented.

New confirmation of the importance of involving mental health consumers in their own care also comes from the Annapolis Coalition on the Behavioral Health Workforce. Its Action Plan (2007) lists seven goals that are intended to provide a "framework for discussion" of ways to relieve the crisis in the behavioral health care workforce. It notes that, "Perhaps no change has as much impact on the workforce as the emerging redefinition of the role of the consumer in making health care decisions" (p. 10). First among their seven goals, which were developed through a multiyear collaborative process, is "Significantly expand the role of individuals in recovery, and their families when appropriate, to participate in, ultimately direct, or accept responsibility for their own care; provide care and supports to others; and educate the workforce" (p. 15). The coalition's initial statement therefore relates to broadening the concept of "workforce" to include consumers and their families.

Definition

"Shared decision-making (SDM)," according to Adams and Drake, "denotes an interactive process in which clients and practitioners collaborate to make health care decisions. It assumes that both members have important information to contribute

to the process" (2006, pp. 87-88). Providers have information about diagnosis, illness, treatments and their likely side effects and outcomes; consumers bring knowledge about their own goals, values, and preferences. This paper focuses on the actual aids that are provided to consumers to assist them in the decision-making process.

The move toward a system that encourages mental health consumers and their families to take responsibility for their own care, and to educate the workforce, stands in stark contrast with the more traditional, paternalistic approach to the delivery of medical care, including mental health care. The latter approach has typically begun with the assumption that the clinician made decisions and expected compliance from the patient. Deegan (2007b), writing from the perspective of the mental health consumer, described her reaction to experiencing this model of care: she threw her medication away at the earliest opportunity. This anecdote points to several issues that are important to SDM in mental health care. One is that many professionals, like much of the public, may believe that people with serious mental illnesses have such impaired judgment or delusional beliefs that they cannot participate in decisions about their own treatment (Hamann et. al., 2006). Another issue is that an action like Deegan's may be seen as deriving from pathology, rather than as an effort to take more control over her own life, and/or a refusal to listen to professionals who do not listen to her. Some professionals may see consumers' decisions not to take prescribed medications (even when those decisions relate to realistic issues in their lives) as part of their illness, rather than part of a rational decision-making process. Deegan's anecdote is by no means intended to imply that her reaction was typical of all consumers for whom medication is prescribed. It does suggest, and a number of studies have demonstrated, that many, and perhaps most, individuals with mental illnesses and their families can and want to participate in making the decisions that affect their lives (Hamann et al., 2005, National Council on Disability, 2000). For these consumers, more collaborative approaches to care are preferable.

Decision-making as a Process

Welcoming consumers of physical or mental health care and including them in decision-making constitutes a process that can be implemented in a variety of ways. For example, consumers can be encouraged to prepare for their appointments by writing and prioritizing lists of questions, role playing, bringing a support person, requesting copies of the clinician's notes, or even recording their sessions with professionals. These options suggest another fact that may be critical to SDM: mental health consumers may need to develop new skills. They need skills to be able to explain themselves in a brief period of time, to organize and prioritize their thoughts, and to communicate clearly. In other words, information is necessary but not sufficient. Offering consumers materials that both inform them and help them better under-stand their own priorities can be seen in this context as one important step, but not the only step, in the SDM process.

In recent years, a variety of techniques for incorporating the needs and wishes of mental health consumers into their care have been developed and implemented. Peer support, achieved through a variety of mechanisms (including peer coaching or mentoring), is one such technique; another is creation of wellness recovery action plans (WRAPs) (Copeland, 1997). These methods, and others, help large numbers of consumers. Many, if not most, mental health consumers also use what Deegan calls "personal medicine," defined as "self-initiated, non-pharmaceutical self-care activities that served to decrease symptoms, avoid undesirable outcomes such as hospitalization, and improve mood, thoughts, behaviors, and overall sense of wellbeing" (Deegan, 2005, p. 3).

In the SDM process, the consumer receives information that objectively assesses the advantages and disadvantages, or risks and benefits, of a specific treatment or activity, as well as guidance in assessing personal preferences and values. All of the information is specifically geared to assist in the decision-making process. SDM is different from the process of gaining informed consent; in the latter case, consumers who are receiving certain forms of treatment or are being asked to participate in research programs are presented with documents requesting their signatures. Such materials may offer information on the possible risks and benefits of the treatment or of involvement in the research, but are not intended to, and should not necessarily, guide the individual's decision-making process.

SDM assumes not only that consumers can and should participate actively in their own care, but also that they need and want access to information and that their values should be identified and accommodated to the extent possible. By incorporating consumers' preferences in decisions about their care, SDM offers the prospect that they will be more likely to engage in treatment. However, research has yet to determine whether this prospect will be realized (O'Connor, Légaré, & Stacey, 2003). But, as two distinguished researchers in the field have said, "Most patients ultimately decide for themselves what they will or will not do in regard to treatment" (Wills & Holmes-Rovner, 2006, p. 9); care must therefore be oriented toward facilitating patient decision-making.

SDM also requires that providers perceive its value and have access to any training they need in order to implement it. Since SDM is a two-way process, all participants must have equivalent assistance in encouraging it to happen. In addition, it is vital that the organizational context within which the provider works supports whatever extra time is required to achieve SDM, especially early in its adoption.

The immediate goal of SDM is to align care as closely as possible to the consumer's wishes and thus to improve satisfaction with care. In the longer term, SDM offers the possibility that individual outcomes, as well as the efficiency and effectiveness of the system of care, will be improved. Consumer satisfaction and outcomes, as well as system efficiency and effectiveness, are measurable constructs; research has only

begun to measure the impact of SDM and to determine whether it can achieve these goals. Some recent studies have found use of DAs to have a positive effect on consumer satisfaction (O'Connor et al., 2004; Thistlethwaite, Evans, Tie, & Heal, 2006).

Definition of Decision Aid (DA)

Decision aids (DAs), according to Adams and Drake, "are information interventions that help clients to understand the pros and cons of a medical decision and may also include exercises to help clients clarify their own values and preferences. They can be self-administered or used with a practitioner" (2006, p. 96). DAs are not the same as health education materials; they focus explicitly on alternatives in order to prepare consumers to make important decisions (O'Connor et al., 2003). Nor are DAs simply brochures or booklets developed by pharmaceutical companies or other entities whose ostensible purpose may be to educate, but whose actual intent is to validate and encourage the use of a specific therapeutic intervention.

However, information is never value neutral. If a consumer received every bit of information available on a particular topic, the resulting document would be several inches thick and serve no purpose. There are always values behind decisions about what to include and what to omit from patient information, especially what type and level of risk is meaningful for the consumer. If the writer of an informational document really feels medication is valuable in most cases, this belief will be evident in the material; if the writer feels that medication is overused and should be avoided unless it is absolutely essential, then this notion will be part of the fabric of the presentation, even if he or she is trying to be neutral. Furthermore, the format in which the information is presented may also influence the reader (Wills & Holmes-Rovner, 2003). Indeed, it is worth noting that research has demonstrated the effect of the use of positive or negative frames in describing the advantages and risks associated with medical interventions (O'Connor, Pennie, & Dales, 1996).

DAs have been developed and used far more widely for physical health care than for mental health care. The International Patient Decision Aid Standards (IPDAS) Collaboration, a group of researchers, practitioners, and stakeholders, used a two-stage consensus process to develop criteria by which DAs can be evaluated. According to IPDAS (2005), each DA should:

- Include information about the available options;
- Describe what happens in the natural course of the condition if no action is taken;
- Present the probabilities of various outcomes;

- Provide balanced information, i.e., information about both the positive and the negative features of the options;
- Use plain language;
- Use current scientific information;
- Use consumer stories and/or testimonials;
- Offer guidance or coaching;
- Help the consumer to clarify his or her values; and
- Disclose conflicts of interest.

For the development of a comprehensive inventory of DAs, O'Connor et al. (2005) searched widely through the medical and social science literatures and databases, and contacted developers and evaluators known to them. Through this process they identified 221 DAs, of which 131 were currently available and had been developed within the preceding 5 years. The most frequent types of decisions covered by the aids were related to breast cancer, prostate cancer, menopause options, cardiovascular disease, colon cancer screening and prenatal diagnostic testing. If any DAs addressed decisions related to mental health, the article does not mention them.

The same article describes a systematic review of randomized trials of DAs. The researchers identified 636 citations that focused on decision-making, only 34 of which ultimately met the criteria for inclusion in their study. These studies evaluated 31 different DAs which focused on 16 screening or treatment decisions in areas similar to those listed above; none addressed mental health. The lack of randomized trials examining mental health DAs does not indicate that no DAs exist for mental health conditions. It does suggest, however, that mental health DAs are in an earlier stage of development than are DAs for physical health.

Situations in Which DAs are Useful

DAs are appropriate to situations in which several treatment options are available to the health care consumer and the individual needs to weigh their advantages and disadvantages in the context of his or her own life circumstances. The available options may be likely to impose very different outcomes or complications; they may entail tradeoffs between more immediate outcomes and longer term ones; their likely outcomes may be only slightly different; or one of the choices may possibly result in a serious negative outcome (O'Connor, 2001). In addition (although the authors did not find this issue mentioned in the literature), the options may have different financial implications. Moreover, each individual has unique characteristics and a

particular context for decision-making. The consumer may, for example, have other physical ailments or be in a living situation that constrains choice. The challenge entailed in making a satisfactory decision in the face of complex alternatives may be considerable, and using a DA may be helpful.

Use of DAs is intended to result in more informed, and therefore improved, decision-making and/or an improved outcome. The two phenomena are different, and not necessarily related. O'Connor et al. (2003) found that DAs increased knowledge of options and outcomes, provided more realistic expectations of potential benefits and risks, helped people feel more comfortable with their decisions, and improved their involvement in decision-making. But few effects were found on the actual health outcomes individuals experienced. The very goal of behavioral health treatment and recovery—changing thinking and behavior—would seem to suggest that improving consumers' decision-making should be a focus, regardless of whether actual improvement in health outcomes is measurable. Furthermore, SDM can be seen as a basic human right, because every person should be able to determine what happens to his or her own body (Nelson, Lord, & Ochocka, 2001).

Types of Decision Aids

While the IPDAS Collaboration has identified the necessary elements of a DA, as previously noted, DAs nevertheless come in many different forms and vary along several dimensions. This section of the paper categorizes DAs according to some of those factors. Different individuals have different learning styles and levels of education and literacy; what is effective in helping one person may be less so for another. As a result, DAs have been developed in a variety of formats. When DAs on any given topic are available in several different formats, each individual can select the ones he or she finds most valuable. The following scheme may be useful in categorizing the various types of DAs.

Passive, Active, or Assisted

One of the most important distinctions among DAs is whether the individual uses them passively, actively, or with assistance. Passive DAs (i.e., those that entail no involvement on the part of the consumer other than reading, watching or listening) may include educational groups, booklets, brochures, audiotapes, or videos. DAs that have an active component (i.e., those that enables the consumer to enter personal information, respond to questions and/or indicate decisions that then lead to variable options) include computer-based support guides, interactive DVDs, decision boards, and audio-guided workbooks. Yet other DAs may be used by the consumer with guidance or assistance from a professional or paraprofessional.

Form of Access or Administration

Consumers may access a DA in a variety of ways. O'Connor et al. (2003) found that of the 131 DAs they inventoried that were "up-to-date, completed and available," 94 were Web-based, 14 paper-based, 12 were videos with print resources, 8 were audio-guided print resources, 2 were CD-ROMs, and 1 was Web-based with a workbook. Most of these formats, including the Web-based resources, the videos, the audio-guided print resources, and the CD-ROMs may be intended for the consumer to use on a personal computer, presumably in the privacy of his or her home. (The authors did not delve into this level of detail on use of the DAs.) If so, access might be problematic for mental health consumers, many of whom have low incomes and lack home computers, although consumer-run organizations often make computers available to those who need them. DAs can also be administered in group settings with facilitators or individually with case managers, nurses, or other staff.

Focus on a Specific Diagnosis and/or Treatment, or on Decision-making in General

As previously noted, DAs often focus on one decision related to a specific treatment for a particular diagnosis. These aids present, in simple language, the known benefits of the treatment as well as its known risks or disadvantages. They may include dimensions other than the strictly medical, such as social or emotional implications (O'Connor et al., 1999).

There are also decision frameworks derived from psychological and economic models that focus on helping people optimize their decisions on any issue. One example is the Ottawa Personal Decision Guide, subtitled "For People Facing Tough Health or Social Decisions" (Ottawa Health Research Institute, 2005). This guide suggests a series of four steps:

- Clarify the decision;
- Identify your decision-making needs: support, knowledge, values, and certainty;
- Explore your needs (including a chart that helps in balancing benefits and risks); and
- Plan the next steps based on your needs.

These generic frameworks do not meet the criteria for formal DAs because they do not contain actual information on pros and cons, or probabilities of various outcomes. They may, however, prove useful in situations for which no DAs exist, but a difficult decision must be made.

Related to One-time Decisions or to Ongoing Decision-making

The typical DA, focused as it is on a specific diagnosis and potential treatments, is intended to be used once by any given individual. However, some types of chronic conditions, mental illnesses among them, require not just one discrete decision but ongoing or continuous decision-making in response to changing symptoms, abilities, needs, and wants. Indeed, most physician contacts, health care decisions, and expenditures support the management of chronic illnesses, including mental illnesses (Agency for Healthcare Research and Quality, 2007). Thus, while one decision may need to be made today, it is predictable that other related or similar decisions will need to be made in the future.

The process of using DAs can therefore be extended over a longer period of time. Web technologies are constantly evolving and improving to enable consumers to maintain their own health records securely online and DAs can also be used in conjunction with disease management technologies. The Web site at http://www.myself-help.com is one example of such a technology; for a flat monthly fee, it offers consumers self-help programs and discussion boards to assist in recovery. It also offers providers tips for working with individuals who are using the Web site's resources. Another example is the Network of Care Web sites supported by Trilogy Integrated Resources. These sites can incorporate a wide variety of materials to aid in consumer decision-making over any length of time.

Formal DAs and other Informational Materials

In addition to the formal DAs that are intended to serve as such, and that have been evaluated in the research literature, there are innumerable sources of information intended to help health care consumers make decisions. For example, many disease-specific organizations, such as the American Heart Association and the American Cancer Society and insurers offer help to patients facing important decisions, sometimes using materials from Healthwise or other sources discussed in the following pages. These materials may well be thorough and scientifically rigorous. Similarly, the National Alliance on Mental Illness (NAMI, www.nami.org) offers extensive information for consumers about medications, both generally and specifically, stating that "Knowledge is power." Mental Health America (mentalhealthamerica.net) also offers detailed information at its Web site, and the Depression and Bipolar Support Alliance's Web site provides a Wellness Toolbox, replete with information and suggestions (http://www.dbsalliance.org/site/PageServer?pagename=empower_toolbox). Thus the distinction is unclear between a real DA and a body of information available—usually on a Web site—that is intended to achieve the goal of helping an anonymous patient understand and make a decision about an available medical treatment. Many publicly available Web offerings meet the definition of a DA offered earlier (i.e., they help clients understand the benefits and costs of a medical decision and include materials that can help individuals clarify their own values and prefer-

ences). Some of these Web-based materials probably also meet the more rigorous criteria established by the Cochrane Collaboration, explained in the following pages.

Geared to Professionals or to Consumers

This paper focuses primarily on DAs intended for use by health care consumers. There are also different kinds of DAs that are intended for use by health care clinicians. These tools are necessarily of a very different nature, and are not in fact decision aids as defined here. Yet they are important because they are likely to shape the thinking and practice of providers. However, such tools may weigh options and expected outcomes in a very different manner than consumer DAs (Hunink, 2001).

Sources of DAs for Physical Health Issues

As suggested in the preceding discussion, there are numerous approaches to the development of DAs using a variety of technologies. Given the goals of the Institute of Medicine, the Annapolis Coalition, and many individuals in recovery from mental illnesses, it seems likely that more DAs intended for mental health consumers will be developed. At present, DAs are used primarily in physical health care. This section identifies some of the key sources of these aids and describes the kinds of materials they offer. However, evaluating the quality of the information they present is beyond the scope of this paper.

Lists of DAs

Several organizations maintain lists of DAs developed elsewhere. At least one of these organizations offers assistance in determining the quality of the aids themselves by evaluating whether they meet the standards established by the International Patient Decision Aids Standards (IPDAS) Collaboration, previously discussed. Note that this list is not exhaustive, nor is it intended to endorse any of the organizations involved.

Ottawa Health Research Institute (OHRI). The Ottawa Health Research Institute (OHRI), the research arm of the Ottawa Hospital and affiliated with the University of Ottawa, houses the Patient Decision Aids research group. The group and its director, Annette M. O'Connor, R.N., Ph.D., are international leaders in the design, evaluation, and dissemination of DAs. They have written numerous papers about the use of DAs, and have prepared a Decision Aid Toolkit that guides others who want to create DAs. In addition, they develop and test training programs for patients and health practitioners (O'Connor & Jacobsen, 2003). The Web site can be accessed at http://decisionaid.ohri.ca.

The Patient Decision Aids research group maintains an "A to Z Inventory" of available decision aids that have been developed by other organizations. DAs may be included in the inventory if they satisfy the Cochrane Collaboration definition of a

patient decision aid (i.e., are designed to help people make specific choices by providing information about the relevant options and outcomes and by clarifying personal values); have a development process that includes expert review; have an update policy; use scientific evidence; and disclose their funding sources and/or conflicts of interest (Ottawa Health Research Institute, 2008). The inventory assesses the extent to which each aid meets IPDAS criteria.

The Cochrane Collaboration. The Cochrane Collaboration, founded in 1993, is an independent, international, not-for-profit organization that makes information available about the effects of health care interventions. It produces and disseminates systematic reviews of interventions and promotes study of them (Cochrane Collaboration, 2007). The Cochrane Inventory, which lists all identified DAs (including those that are still under development and some that are no longer available) currently includes 343 DAs. The Web address is http://www.cochrane.org.

Foundation for Informed Medical Decision Making. This foundation is a not-for-profit organization that creates SDM programs in videotape and other forms to bring medical evidence together with an "appreciation of patients' attitudes and preferences regarding treatment alternatives." It works in partnership with Health Dialog (see below) to distribute its materials, and does not make those materials available directly to the public. The foundation also sponsors research into decision-making in health care. At the time of this writing, the 2006 recipient of their dissertation fellowship was studying "shared decision making for patients with severe and persistent mental illness." The foundation's Web address is http://www.fimdm.org.

Health Dialog, Inc. Health Dialog is a for-profit company that offers a program to help health plans, employers, government entities, and providers support individuals in their health care. Health Dialog's program provides individuals served by its client organizations with round-the-clock access to health coaches (specially trained health care professionals) who offer help by supporting decisions as well as in a variety of other ways. They also provide educational tools and resources online, in print, on audiotapes, and in videos. Health Dialog produces its videos in collaboration with the Foundation for Informed Medical Decision Making (see above), and does not make them available to the general public. The Web site is located at http://www.healthdialog.com.

Sources of DAs available to the public

Center for Shared Decision Making, Dartmouth-Hitchcock Medical Center. The Foundation for Informed Medical Decision Making and Health Dialog, Inc. helps to support this center, which is the first in the United States focused on helping patients make all kinds of medical decisions, and offers its services free of charge. Individuals can call to make an appointment, send questions via e-mail, visit the office (in Lebanon, NH), and/or borrow materials. The center's decision aid library offers a

video about shared decision-making, *The Informed Health Care Consumer,* which introduces evidence-based medicine and shared decision-making. The library makes available materials on a variety of diagnoses; different topics naturally have different numbers of items associated with them. Among the center's online resources, the topic of mental health lists only a 35-minute video titled *Coping with Symptoms of Depression* (for more information on this video, see under Health Dialog). Other materials and forms of assistance are available at the center's Web site, http://www.fimdm.org.

Healthwise®. Healthwise is a not-for-profit organization founded in 1975 whose mission is to help consumers make better health care decisions. One of the principal sources of DAs, Healthwise has developed 107 "Knowledgebase Decision Points." They report that nearly 30 million of their health care guides have been distributed, and that people use their DAs nearly 90 million times a year. Numerous organizations, including health plans, providers, and government agencies, work with Healthwise and distribute their materials. Healthwise makes its DAs available to the public, but through others' Web sites rather than their own. OHRI, for example, offers access to many Healthwise DAs through links; OHRI's site also assesses the extent to which DAs meet IPDAS criteria. The organization's Web address is http://www.healthwise.org.

NexCura®. NexCura, part of Thomson Scientific & Healthcare, offers a system that allows each individual to complete an online profile. This information is then matched with the organization's database of relevant scientific information to provide an individualized DA. NexCura works with not-for-profit organizations (such as the American Cancer Society and the American Heart Association), medical centers, health plans, major corporations, and commercial Web sites, each of which embeds the NexCura tools within its own Web site. NexCura markets its methodology to pharmaceutical companies, suggesting that it can serve purposes other than those of just the consumer. The Web address is http://www.nexcura.com.

WebMD. Although WebMD does not offer DAs per se, it does provide extensive free information and constitutes a vast and significant Web presence in the health arena. Its Web site (http://www.webmd.com) includes information organized by symptom and by disease; drug information; information specifically geared to women, men, and children; and guidance about virtually every aspect of health, wellness, and fitness. It has a huge "Depression Health Center" that includes information on specific drugs, psychotherapy, and on "living and managing," as well as offering blogs, advice, and a long list of links to other resources. It also suggests "questions to ask your doctor about depression." WebMD has its own staff of experts and writers who write and review what appears on the site; it also has links with MedicineNet.com. As all-encompassing as it is, WebMD's vast site could be somewhat confusing to a consumer who lacks familiarity with the cyberworld. For example, it incorporates a great deal of "sponsored information." This material is clearly labeled as such, but

the naïve user might still not recognize the distinction between WebMD's own offerings and those of its sponsors.

Evidence Supporting Specific DAs

O'Connor et al. (2003), who examined more than 100 DAs for people facing health treatment or screening decisions, concluded that:

> Those that have been evaluated in randomized controlled trials have had positive effects on the decision making process with improved knowledge and realistic expectations, enhanced participation in decision making, lowered decisional conflict, reduced proportion remaining undecided, and improved agreement between values and choice. . . . Patients, practitioners, insurers, and health policy makers may need more empirical evidence about the effectiveness of decision aids before their wide-scale implementation can occur (p. 16).

They point out that few of the DAs available on the Internet have been evaluated, and that little is known about practitioners' attitudes toward DAs or about the impact DAs have on communication between consumers and their clinicians. All of these are issues that are especially critical to the development and use of DAs in mental health care.

Most of the DAs to which the public currently has access have not been developed in research settings, and have not been subjected to thorough study in terms of their impact on either decision-making or clinical outcomes. As mentioned earlier, the boundary between the kinds of DAs that are developed for research purposes, and formally tested, and those that are available to the public on the Web, usually for free, is not a firm or clear one.

DAs in Mental Health Care

As this paper has indicated, there are relatively few aids available to guide decision-making in mental health care. The majority of those that exist relate to depression and seem geared to individuals with mild or moderate depressions. This section presents information the authors have been able to gather on existing mental health DAs and on the apparent barriers to creating more of them.

Availability of DAs for Mental Health

While most of the resources listed on the following pages do not explicitly call themselves "decision aids," they do fulfill that function: in line with the definition used in this paper, they help individuals understand the positive and negative implications of a medical decision. Many include information if not exercises that can help one

clarify one's own values and preferences. Note, again, that this list is not necessarily exhaustive, nor is it intended to endorse any of the organizations named.

Health Dialog. Health Dialog, as previously described, offers a library of several dozen videos, including one titled *Coping with Symptoms of Depression*. The authors have not viewed this video, but OHRI reports on its Web site that this DA meets 11 of 14 content criteria, 8 of 9 development process criteria, and 1 of 2 effectiveness criteria.

The Cochrane Collaboration. OHRI, as previously noted, the Cochrane Inventory lists 343 identified DAs. Only three of these deal with any mental health issue, and all of those address depression. Two relate to decisions about taking medications for adults and children, respectively, and both were developed by Healthwise. They are available online. The third depression DA is a proprietary one developed in the United Kingdom.

Healthwise via OHRI. OHRI, as previously discussed, offers a list of DAs and indicates the extent to which each of them meets IPDAS criteria. It reveals, for example, that the Healthwise DA titled, "Should I take medications to treat depression?" meets 8 out of 13 of the content criteria, 4 of 9 development process criteria, and neither of 2 effectiveness criteria (i.e., no research has been conducted on this DA).

Mayo Clinic. The Mayo Clinic offers extensive information online about a wide variety of conditions, including an explanation of various forms of depression and information on medications and their side effects. It offers many links to further information about medications, their side effects, and other forms of treatment.

Mental Health Matters. Mental Health Matters, owned by Get Mental Help, Inc., is a source of extensive information on mental health issues. Its goal is to "provide a structured source of information about mental health issues." However, it includes a significant amount of advertising, which consumers might find confusing.

Trilogy Integrated Resources. Trilogy has developed Network of Care for Mental Health Web sites for hundreds of counties in 12 States. The sites offer, among other things, access to a large set of resources developed and maintained by Healthwise; links to other mental health Web sites, support groups, and advocacy resources in the community; and information about best practices. They also offer individuals the opportunity to maintain their own personal records, including advance directives and WRAPs on a secure site. These tools offer valuable guidance to professionals and others during times of crisis and transition. The Network of Care for Mental Health Web sites were identified as model programs in the final report of the President's New Freedom Commission on Mental Health. The sites could readily incorporate DAs as they become available.

CommonGround. CommonGround (CG) is a program that supports shared decision-making and offers electronic decision support in psychiatry (Deegan, 2007a). Developed by Patricia Deegan, Ph.D., it does not meet formal criteria as a decision aid, but does fulfill several of the related functions noted earlier. CG entails transforming a waiting room in a mental health clinic into a "peer-run Decision Support Center." Individuals who are in recovery from psychiatric disorders staff the center and invite arriving consumers to use a Web-based software program that helps organize the concerns the consumer wants to raise with his or her clinician. The consumer chooses whether to read or listen to the program, which can be completed in about 20 minutes or less. The software generates a one-page report for the consumer to bring to the appointment. The program also includes brief vignettes of people telling their recovery stories.

Each consumer may use an electronic version of his or her report as a portal for connecting to a variety of information including DAs and factsheets. Through a simple interface, a consumer can graph recovery and access decision support worksheets and peer support to help resolve decisional uncertainty about medication.

Evidence Regarding Effectiveness of DAs in Mental Health Care

Very few studies have been done to assess the use of DAs in mental health care (Hamman, Leucht, & Kissling, 2003). Indeed, Adams and Drake point out, "In the mental health field. . . shared decision-making is a relatively novel and somewhat controversial concept" (2006, p. 88). One possible reason for the paucity of DAs in mental health care, and for the lack of research on them, may be the presence of more significant barriers to the creation of DAs in mental health than in physical health. The IOM (2006) focuses on prejudice, discrimination, and coercion as the principal reasons why mental health consumers may not always "receive care that is respectful of and responsive to their individual preferences, needs, and values" (p. 77), and why there is less support available for mental health consumers' decision-making. Prejudice and the resulting discrimination lead to questions about mental health consumers' decision-making capacity, which is irrelevant for most of them. Mental health consumers have been shown to be competent to make decisions regarding their own care (Hamann et al., 2006). According to the IOM (2006, p. 97), "research has shown that although patients' decision-making performance is correlated modestly with psychotic symptoms, it is correlated more strongly with cognitive dysfunction." Adams and Drake concluded their recent paper by saying, "Research on shared decision-making in mental health lags considerably behind work in general medicine and urgently needs attention" (2006, p. 100).

Types of DAs That Might be Adapted for Use in Mental Health Care

Because definitive outcome data are relatively lacking in the field, DAs for mental health might need to focus more on the options that consumers face, and some of the

potential results, than on quantitative data. Moreover, DAs for mental health might be thought of broadly, and encompass decisions regarding issues such as housing, education, and employment as well as the medical aspects of care (e.g., medication and various forms of psychotherapy). Web-based aids could be developed to help mental health consumers make decisions about their treatment. Brief video clips showing individuals who have confronted various decisions, and how they thought them through, might help consumers by demonstrating that others have faced similar concerns and have made decisions that were appropriate for them. Also, as noted earlier, some DAs for individuals with mental illnesses might be thought of as tools not to be used once, but to be returned to over time.

Aids such as the Decision Board might be adapted for mental health care. The Decision Board was devised by Canadian physicians to help women with breast cancer decide on a course of treatment. The board consists of a set of panels, each covered by a sliding door. During an appointment, the patient and her physician open the panels in succession and read the information, stopping to discuss the patient's specific situation. The patient also receives a copy of the Decision Board on paper to help her recall the information (Supportive Cancer Care Research Unit, 2008; ACS News Center, 2003). Research has demonstrated that the Decision Board helped women feel more knowledgeable about their chances of recurrence and better satisfied with their decision-making.

Issues Related to Implementation in Mental Health Care

The use of DAs in mental health care can empower the consumer to be a genuine decision-making partner and can help foster mutual respect among consumers, doctors, nurses, case managers, and others as they all seek to support the recovery process. The word "empower" is especially meaningful in this context, because the power disparity between providers and consumers can impose a particular burden on the latter, as observed in the discussion below.

How is the Use of DAs in Mental Health Care Different From Their Use in Physical Health Care?

In physical health care, at least for certain forms of treatment, there may be more objective criteria according to which decisions can be made. The relative likelihood of one outcome or another resulting from a course of action can be estimated reasonably well for many physical conditions, and the outcomes themselves are perhaps more quantifiable. For mental health conditions, there is often less evidence, less certainty of a particular outcome, and less clarity as to which outcome is best. Thus, DAs in mental health might be usefully seen as helping the consumer evaluate tradeoffs, for example, thinking about the side effects and effects of beginning or ending use of medications, and of other potential steps that might enhance recovery.

For mental health consumers it would also be appropriate to develop DAs focused on broader life decisions related to housing, employment, and budgeting, for example. These are crucial issues for many, and formal decision-making guidance is currently minimal. Given the stigmatized and often isolating nature of mental illness, it might be especially useful for mental health consumers to have the opportunity to learn about the recovery experiences of others as they are trying to make their own decisions. Videos of consumers describing their decision-making processes, and individual or group sessions with peer specialists or coaches, might offer this opportunity.

Questions About Implementation of DAs in Mental Health Care

Given the minimal use of DAs in mental health care thus far, there are many questions about how they might be implemented in practice.

What triggers consumer access/use? All consumers might be offered DAs when they are about to make specific decisions, or DAs might be offered only to individuals who seem uncertain about their decisions. One approach might be to offer all consumers general information about the availability of DAs, and information about DAs relevant to their specific illnesses, just as they receive information about WRAP and other recovery tools. All mental health consumers could receive such information independent of the role their individual providers play in the process. Then, at a point of decision, they might be reminded that a DA is there if it is wanted. In settings where strong consumer movements and trained peer specialists are present, it may be relatively straightforward to institutionalize use of DAs. In other areas, the attitude of the professionals is likely to be a primary determinant of whether consumers are offered DAs. Clinicians and case managers need information and training if they are to support more consumer-centered decision-making. Moreover, reimbursement and other resource issues must be acknowledged and resolved.

Does initial refusal lead to attempt at persuasion? If a mental health consumer declines the opportunity to use a DA, should a case manager or clinician attempt to persuade the individual to try using it, or make the offer again at a later date? Given that consumers may see doctors and nurses as the exclusive keepers of medical expertise, and given the power disparities inherent in these relationships, they may find it difficult to engage in direct dialogue. Some consumers may fear disappointing or angering their doctor or nurse, or upsetting valued relationships with them. Refusal to consider using a DA may suggest that the consumer does not feel safe enough to share feelings openly, or feels unable to communicate in a manner which they think their doctor would understand. A case manager or clinician might try to use a consumer's refusal as an opportunity to open a conversation, discussing the professional's role as advisor or consultant to the recovery process. Once this kind of engagement becomes natural and routine, consumers may participate more fully in the SDM process and develop a sense of control over their mental health recovery.

Once again, however, it is worth noting that SDM does take additional time for clinicians and prescribers; resource issues confronting these professional staff must be recognized.

What if a consumer needs help in using a DA? Many if not most individuals need help using DAs for both physical and mental health care, especially when DAs are still new to consumers. Each individual who visits the Center for Shared Decision Making, for example, receives assistance from staff. Training peer specialists in the use of DAs, and offering peer support groups, perhaps with case managers and peer specialists as co-facilitators, might prove helpful. Some consumers do not have computers at home. Their needs may best be accommodated by consumer-run organizations or services, which usually have computers available for consumers to use at no cost.

How and when are consumers' decisions incorporated into care? Clinicians need training in how best to work with individuals who are using DAs, incorporating their goals and values into their treatment plans. For example, if a consumer is struggling to decide whether to use medication, he or she may be trying to balance its positive effects against its potentially significant side effects; the more of these concerns that can be identified and discussed with the professional, the more the treatment plan can reflect his or her specific needs. For example, the consumer may need to wake early and get to the job on time, focus on required tasks at work (not fall asleep), communicate clearly with people (not have involuntary tics or movements), keep a calm and clear head (not have racing thoughts), go home, do household tasks, and still have energy to engage with his or her family (not feel drained of energy and fall asleep before being ready). Discussion with the doctor might also include the information that the individual is diabetic and doesn't want his or her psychiatric medications to counteract physical health needs. Using DAs could help give mental health consumers a way of sharing this kind of information more clearly and feeling understood. Indeed, it might be helpful if both providers and consumers saw medication as one of a number of tools that can help individuals achieve their life goals. Some consumer groups host annual summits, at which information is exchanged between consumers and providers. This kind of process might facilitate dialog on the use of DAs.

What are the differences between use of DAs in primary care and specialty care offices? Many consumers receive mental health care from their primary care clinicians. It is important to consider how best to prepare those professionals as well as specialists to treat consumers who use DAs. Both patients in general and mental health consumers in particular traditionally depend on their doctors' professional expertise. If primary care doctors are to modify their usual practices, they may need guidance in understanding the recovery process and in using a strength-based approach.

What is the role of the professional? If the goal of SDM is to help enable mental health consumers to be true collaborators in decisions about their own lives, the professional's role is to offer support to that end by:

- Welcoming and inviting participation. Consumers need to feel empowered to be part of the decision-making process; professionals can help them build confidence as they take on new roles.
- Providing information. Mental health consumers often lack adequate information about potential benefits, risks, side effects, and alternatives to make fully informed decisions. DAs can clearly offer such information. The professional can offer DAs at the appropriate time, help interpret them, and ensure that the consumer understands their relevance to his or her life.
- Offering suggestions about both the process itself and the decision. Professionals can guide consumers through the collaborative process. It is important for case managers and clinicians to provide neutral information, both in the form of DAs and in face-to-face interaction with consumers. These individuals can also present their own opinions and values, based on their professional knowledge and experience, within the context of a process that is structured to provide balanced information and that fully supports the consumer as a peer to the professional.

What might encourage professionals to offer DAs to consumers? The effort to train consumers needs to be balanced by an effort to train providers. Providers may be expected to need help in developing collaborative approaches to care and in understanding that DAs have potential value not only for consumers but also for themselves. Although not confirmed by data in this writing, providers who encourage SDM believe that a consumer who is actively involved in decision-making is more likely to follow through with treatment, especially over the period of time needed for recovery from mental illnesses. An informed consumer, these providers believe, is more likely to recognize the benefits of a potential intervention, more alert to side effects, and more inclined to perceive what a particular treatment can and cannot accomplish. Providers may need help understanding how best to work with consumers on SDM.

What are some of the special considerations that must be taken into account for poor and minority group consumers? Seeking mental health treatment itself is a taboo in some minority cultures and in some communities mental illness may be equated with a character flaw or weakness. In addition, mistrust of the public mental health system, experiences of discrimination, and discouragement by family and community members (possibly including faith-based organizations) may deter some from seeking mental health care. When minorities do seek treatment, some report discriminatory behaviors or a lack of genuine concern on the part of the staff, thus validating their earlier mistrust. Mental health centers may have few staff members

who belong to minority groups or live within the community. Doctors and nurses may know relatively little about the cultural experiences of minority mental health consumers, their recovery values, and how they view mental health treatment. They may be challenged to understand different styles of communication. In sum, some minorities may feel they are looked upon with caution. The impact of social class should also be considered; consumers who are less educated or have less money may feel uncomfortable trying to make their wishes known to middle-class professionals. The development of culturally sensitive DAs, and of DAs that focus specifically on mental health issues that impact minorities, use the most appropriate language, and are geared to individuals with low literacy (including health literacy) might help to mitigate some of these factors.

Recommendations

In guiding the development of DAs for mental health consumers, SAMHSA might do well to begin with the assumption that individuals will need DAs in different forms, and consider the scheme laid out in this paper suggesting the variety of formats and technologies available—for example, active and passive DAs. DAs with similar content might be developed in numerous formats: on paper, on the Web, on videotape, on CD-ROM, and for use by the individual alone or with assistance. Some DAs might be developed explicitly for peer specialists to use with individuals or groups.

In the absence of many DAs for mental health conditions, the type of generic framework that offers guidance to individuals faced with any difficult decision might help meet the needs of mental health consumers. This type of paradigm might be especially useful in providing consumers with a way to think about the decisions they confront, and with a tool they can use more than once.

Developing DAs for mental health consumers will be challenging and costly. SAMHSA can serve as a valuable resource to guide and support the process. In order for DAs to be effectively implemented, however, the provider community must be trained both to accept the general concept of SDM and to know how to make the best use of DAs with consumers. Trained peer specialists or mentors can play a valuable role in the implementation process, helping providers understand the value of DAs and guiding consumers in their use. Ensuring the relevance and utility of DAs for linguistic, racial, and cultural minorities will also be critical.

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