SPECIAL SECTION

Pushing the Envelope: Shared Decision Making in Mental Health

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Topic: This article reviews the literature on shared decision making in health and mental health and discusses tools in general health that are proposed for adaptation and use in mental health. *Purpose*: To offer findings from literature and a product development process to help inform/guide those who wish to create or implement materials for shared decision making in mental health. *Sources used*: Published literature and research on issues related to shared decision making in health and mental health, focus groups, and product testing. *Conclusions*: Structured shared decision making in mental health shows promise in supporting service user involvement in critical decision making and provides a process to open all treatment and service decisions to informed and respectful dialogue.

Keywords: choice, person centered planning, recovery-oriented care, shared decision making

The doctors basically thought they knew what was best for me and I started believing that they did. They kept giving me medicine after medicine and I just wasn't getting any better. My life was falling apart while they tried to find a perfect medicine.

–Barbara, a person who uses mental health services

Background

Sadly, Barbara's story is all too common. Even with longstanding values of self-determination within psychiatric rehabilitation (Cohen, Farkas, Cohen, & Unger, 1991; USPRA, 2009; Deegan, this issue), many people who use mental health services do not see themselves as equal partners or feel empowered to make decisions about their mental health treatment and services. Studies find that people typically want more involvement in their health and mental health treatment decisions than they often experience (Klein, Rosenberg, & Rosenberg, 2007). People using mental health services have a strong desire to be involved in decisions about their medications, an arena often considered the sole purview of the physician (Roe, Goldblatt, Baloush-Klienman, Swarbrick, & Davidson, 2009). The process of mental health recovery hinges on individuals taking personal responsibility for their lives, including making decisions about how medications, treatment, and other services fit into their recovery plan (Schauer,

Everett, del Vecchio, & Anderson, 2007).

Shared decision making features a style of communication and a set of tools that help balance clinical information about mental health conditions and treatment options with an individual's preferences, goals, and cultural values and beliefs. It helps both people who use mental health services and providers have a more useful and satisfying conversation about treatment and service options. Further, shared decision making explicitly promotes active consumer involvement in *all* decisions about personal mental health treatment and services, including medication decisions.

Shared decision making is especially useful when more than one viable option exists, when there is any conflict about which option is "best," or when outcomes are dependent on acceptance and follow-through by the person

using the treatment or services. Three distinct, but related aspects of shared decision making are: (1) information and preparation for making a decision; (2) the interactive process of discussing and generating a shared decision; and (3) systematic opportunities to review and revise decisions after they are made.

Shared decision making "reflects the values and processes of client-centered care, evidence-based medicine, and the recovery movement" (Adams & Drake, 2006). It responds to the Institute of Medicine's call for individuals' preferences, needs, and values to guide all physical and mental health care (IOM, 2005) and it helps "put the person back at the center of person-centered care" (Drake & Deegan, 2009).

This article presents the results of a multistage process used to inform the development of shared decision mak-

ing tools for mental health services. The authors reviewed key literature on shared decision making in general and mental health care and surveyed existing decision making tools in both of these areas. They also consulted with providers and users of mental health services and shared decision making experts. Based on this input, they proposed and have begun to develop and test a set of products designed to introduce shared decision making into public mental health services. This article reviews what they have learned at each of these stages and what these lessons hold for future research and adoption of shared decision making in mental health.


History

Provider-Centric Tradition

Barbara's comments remind us that the tradition of provider-centric decision making continues in many contemporary mental health settings. Knowledge is seen as resident in experts who make assessments and determine what treatments are in the best interest of individuals receiving services. The involvement of individuals is often limited to accepting the expert's opinion, seeking a second expert opinion, or rejecting treatment altogether. This paternalism has been reinforced by legal constraints; use of coercion, including involuntary treatment; and assumptions about the ability or interest of people to engage in decision making about treatment or other important personal concerns. It is further compounded by variability in treatment practices, availability of resources, system barriers, and often by lack of conclusive evidence demonstrating effectiveness of specific treatment approaches.

The provider-centric framework has been challenged by the consumer/ survivor movement and advocates

FIGURE 1: SHARED DECISION MAKING PROCESS

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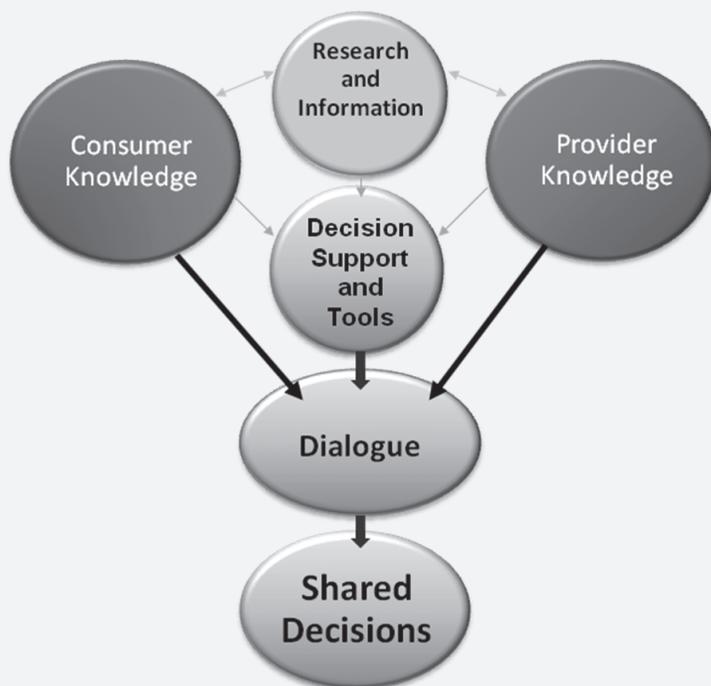
(Deegan, this issue). For example, the field of psychiatric rehabilitation has advanced the principles and values of empowerment and involvement by people using services for over 20 years (Anthony, Cohen, & Farkas, 1990). These efforts have resulted in increased practitioner acceptance, especially in areas such as recovery planning, employment, and housing.

Adams and Drake (2006) note that the mental health field has endorsed the concept of person-centered care and negotiated decision making in some contexts, but it has not explicitly adopted structured "shared decision making" nor prepared consumers and providers for its use. Medication decisions have typically remained exempt from meaningful consumer involvement and self-direction. Current researchers and developers *explicitly include* shared decision making about psychiatric medication as critical to the recovery process in mental health (Deegan & Drake, 2006).

Preference-Sensitive Decisions

Evidence-based practice encourages the use of research and data to inform practitioners' knowledge and guide their judgment in decision making. Often, this information is not available to people using services. Further, when research findings are inconclusive or incomplete, as is common in mental health, preferences and values tend to drive choices (Mahar, 2007). *Whose* preferences and values should guide these decisions can be complex for people who use services and those who provide them.

The outcome of any treatment approach is often as dependent on individuals' active involvement in decision making as it is on the science that may underpin it. For example, studies find that antipsychotic medications have similar efficacy profiles and complex risk-benefit tradeoffs. These medica-

tions can both positively and negatively affect the lives of people who use them and in some cases contribute to shortened life spans (Parks, Svendsen, Singer, & Foti, 2006). Decisions about their use are not just professional decisions; they are also very personal decisions (Drake & Deegan, 2009).

Research

While most mental health treatment or service decisions are preference-sensitive and lend themselves to shared decision making, there has been little research in this area (Schauer, Everett, del Vecchio, & Anderson, 2007).

Outcomes

Research to date reveals that individuals who participate in decision making are more satisfied with their treatment providers and the services they receive (Swanson, Bastani, Rubenstein, Meredith, & Ford, 2007). For example, Mandelblatt and colleagues (2006) found that women who have cancer and their physicians who participate in shared decision making are more satisfied with the decision and the process of making the decision.

Conversely, research indicates that *lack* of informed involvement may contribute to reduced follow-through with treatment decisions such as using psychiatric medication (Roe et al., 2009). Joosten and colleagues (2008) reviewed randomized controlled trials of shared decision making and found that it positively impacted consumer satisfaction and adherence to shared decisions in mental health.

Recent studies suggest that shared decision-making may be effective in producing better health care decisions. A "good" decision, however, is not always based on the outcome of the decision itself. It can be one that is satisfying to those involved; that is

made thoughtfully, with accurate information and deliberation; or that is congruent with important personal values (O'Connor, Jacobsen, & Stacey, 2002).

Preferences for Involvement in Decision Making

A comprehensive review of the evidence base for "patient-focused interventions" in health care found that people's preferences for involvement in medical decision making vary with age, educational status, severity of disorder, and ethnic or cultural differences and may also fluctuate over time or depending on circumstances (Coulter & Ellins, 2006).

Little is known about how people who use public mental health services actually make decisions or what is important to them in the process (Wills & Riefer, 2007). Some researchers have begun to pursue this avenue of study. Adams, Drake, and Wolford (2007) have found that people diagnosed with mental illnesses generally preferred more active involvement than they currently experienced and that they were especially interested in increased collaboration in decisions about psychiatric medications. Likewise, research by Hamann and colleagues (2005, 2007) reveals that people diagnosed with schizophrenia have a greater desire to be involved in decision making about their treatment than people in general health care. Negative attitudes toward treatment and younger age are associated with a *greater* desire for participation in decision making.

Decision Making Tools

Decision Aids (DAs) are structured tools that provide concrete information about health conditions and treatment options and help individuals clarify personal values related to the decision. DAs come in multiple formats, includ-

ing paper and pencil instruments, audio-guided workbooks, videos and CD-ROMs, and computer-assisted and web-based tools. The International Patient Decision Aids Standards Collaboration (http://ipdas.ohri.ca) has prepared a set of standards to assess the quality and effectiveness of DAs (Elwyn et al., 2006).

Research on DAs focuses on their efficacy for decisions about screening and treatment for such medical conditions as cancer, diabetes, and asthma. To date, few DAs focus on mental health issues and very little research is available on their effectiveness. However, O'Connor and colleagues (2006) found that when compared to "usual care," the use of DAs increases involvement in decision making by increasing knowledge of options and their risks and benefits, creating realistic expectations of outcomes, and reducing decisional conflict.

Decision Support

Decision support is broadly defined and includes resources and activities that foster meaningful communication and collaborative decision making between individuals and their service providers. It may include access to information, skill development, assistive tools, and peer support.

In a randomized controlled trial of more than 500 individuals, Priebe and colleagues (2007) looked at the impact of a structured dialogue model designed to help providers elicit and focus on individuals' views. After 12 months, individuals participating in the structured dialogues had a better subjective quality of life, fewer unmet needs, and higher treatment satisfaction.

The most extensive research in this area has been conducted by Deegan (2007 and in this issue), who found that a peer-assisted decision support center is effective in engaging people

who use mental health services in navigating decisional conflict related to medication.

Technology

Technology plays an increasingly important role in health care decision making. In his study of shared decision making in psychiatric medication decisions, Adams (2006) found that while more than 60 percent of participants described themselves as comfortable with computers, their acceptance of computer-assisted DAs was related to the tool's ease of use. Regardless of computer experience, if participants found the paper version easier to use they rated it preferable to the computer version; if they found the computer version easier to use, they rated it as preferable to the paper version. Deegan (2007) has found that the vast majority of people using a mental health decision support center will use computer-aided technology, particularly when assistance from peer supporters is available.

Implementation Challenges

An increasing body of research looks at the implementation and utilization of shared decision making in health care. These studies typically compare use of a specific DA or a proscribed shared decision making process with "routine care."

Even with educated and motivated providers, it is challenging to change long-established patterns of communication (Towle, Godolphin, Grams, & LaMarre, 2006). For example, Karnieli-Miller and Eisikovits (2009) found that while shared decision making may be advocated as a philosophical tenet, treatment decisions continue to be made unilaterally, with a variety of persuasive approaches used to ensure agreement with the provider's recommendation.

Common challenges to establishing and sustaining shared decision making as standard practice in health care include provider perceptions that it is an "add on," not a shift within current practice; disagreements about the validity or objectivity of evidence presented in DAs; concerns about time and funding; and the belief that "we already do it" (O'Cathain & Thomas, 2004).

Decision making in the mental health arena can be more complex than in general health care. Obstacles such as fragmented services, learned helplessness, prejudice and discrimination, and fear of coercive consequences can make it difficult for people with psychiatric diagnoses to actively and fully engage in shared decision making. These barriers are compounded by the perceived inability of people with psychiatric diagnoses to participate in critical decisions concerning their treatment and services.

In addition to psychiatric concerns, individuals may have an array of physical health, addiction, trauma, housing, social, and economic issues that need to be addressed. In 2009, Hamann and colleagues reported that psychiatrists consider psychosocial and lifestyle issues such as work and housing to be more suitable for shared decision making than medical and legal decisions. Moreover, because shared decision making technologies emphasize autonomy and individualism, questions remain regarding their use with people from more collectivistic cultures and for whom decision making involves more social processes (Charles, Gafni, Whelan, & O'Brien, 2006). Whitley (2009) argues that research and development in shared decision making must take serious account of ethnoracial status as a mediating variable. Alegria and colleagues (2008) found that a shared decision making ap-

proach can help increase participation in mental health services by people from non-white cultures.

Shared Decision Making Resources

In the past decade, the availability of tools and resources for decision support in health care has grown exponentially. The bulk of these materials are in general health care, with limited availability of resources for mental health.[1]

Most DAs are diagnosis-specific and relate to one-time or "crossroads" decisions, such as a choice between lumpectomy and mastectomy for breast cancer. Decision support materials are increasingly available for longer-term and complex conditions such as obesity, diabetes, smoking, and insomnia. A number of web-based materials are related to non-medical or "lifestyle" decisions such as making end-of-life choices and developing healthy habits. The Ottawa Health Research Institute (OHRI), a leader in development of health care DAs, has created general decision support guides to help people make personal or health-related decisions when no topic-specific DA exists.

Many health care DAs are available online and some can be downloaded in printable PDF format (often at a cost). Some of these materials hold inspiration for mental health applications. However, it is not always easy to determine the accuracy of information contained in DAs. While much information is sound and comes from objective sources, some is provided by companies that stand to profit from a person's decision. In addition, as Morris and colleagues (2008) discovered, it can be difficult to locate direct links to health care DAs using Internet search engines. Many DAs are proprietary and available only to people who subscribe to a company's services or participate in a network that has purchased licenses for their use.

Most existing DAs relevant to mental health are geared to people with mild to moderate depression who seek care from a personal physician, rather than to people with more severe problems (Perlman, Dougherty, Diamond, & Bledsoe, 2007). Among the mental health resources available online are nine DAs listed in the OHRI *A-to-Z DA Inventory* as of August 2009: five related to depression, one for obsessive-compulsive disorder, one for panic disorder, and two related to children—one for depression and one for attention deficit hyperactivity disorder (http://decisionaid.ohri.ca/AZinvent.php). The treatment choices focus primarily on medication. Further, the medication option is generalized, rather than specific. For example, people are given information about classes of drugs such as selective serotonin reuptake inhibitors (SSRIs) and are prompted to consider taking an SSRI versus other types of medication. They are not given the option to choose a specific type of SSRI, nor typically asked to consider alternatives such as wellness activities or "watchful waiting" (a proactive decision to take no further action while closely observing the situation).

Video and multimedia DAs have been found to successfully engage ethnically diverse patients (Frosch, Légaré, & Mangione, 2008) and those with low health literacy (Volk et al., 2008) in shared decision making around cancer screening. Yet most DAs for both physical and mental health concerns have very limited interactivity. Audio narration and brief video clips accompany some online presentations.

The majority of health care decision making materials are designed for people making their own health care decisions. The mental health DAs listed on the OHRI site are targeted to consumers, without counterpart or instruc-

tions for providers. They do indicate that consumers can take them to providers for discussion, but nothing is available to prepare the provider for this. Further, there is limited technical assistance for using these DAs by either individuals or providers. None of these products was developed by people who use mental health services and there is limited public knowledge of their availability.

Take Away Messages from the Literature Review

This review of shared decision making research and resources reveals some important considerations for developers of materials geared to people who provide and use mental health services.

- Material created for general health does not translate perfectly to mental health. The inherent power differential, coupled with providers' ability to use legal means to override consumer preferences, creates a different practice dynamic in mental health. Decisions in a mental health context are frequently complex, reoccurring, and embedded in day-to-day lifestyle choices rather than one-time crossroads decisions.

- Little is known about how different communication styles affect the process of shared decision making or its acceptance by people who use or provide services. There are no DAs or formal support resources that address different decision making styles. Further, there are few studies about culturally specific approaches to decision making and few materials are available in languages other than English.

- Materials are needed that separately address each of the three aspects of shared decision making, in addition to coordinated systems that integrate them: (1) information and preparation; (2) the interactive process of

discussing and generating a shared decision; and (3) systematic opportunities to review and revise decisions after they are made.

- The linear structure of many DAs may oversimplify the practical reality and multidimensional context in which decisions are actually made. For example, DAs about medications tend to address the question, "medications or something else." But this is not typically an either/or decision. Even DAs that explore the more detailed question, "Which medication is right for me?" are not sufficient to address polypharmacy and its resulting complicated drug interactions and side effect profiles.

- Technology can be both a help and a hindrance. With access and support, people with limited experience with computers can become comfortable with them. Computers offer a sense of anonymity that allows individuals to share information they might find difficult to say in person. But computer technology raises concerns about privacy and dehumanization of services. It also requires availability and maintenance of equipment as well as hands-on support for users.

Developing Resources For Mental Health: Predevelopment Testing

Recognizing the potential of structured shared decision making and the need for resources, the Center for Mental Health Services (CMHS) in the Substance Abuse and Mental Health Services Administration (SAMHSA), U.S. Department of Health and Human Services, funded a project to adapt materials for use in public mental health. Development of these materials is based on the literature and resource review as well as information gathered from three field sources: (1) recommendations from participants at a 2007 meeting on shared decision making in mental health sponsored by CMHS; (2)

regular guidance from a project Planning Team, a panel of 12 people representing national and international experts in shared decision making, mental health consumers, practitioners, and family members; and (3) predevelopment and post-development product testing with people actively using or providing public mental health services.

Predevelopment focus groups and discussions with Planning Team members were used to elicit existing knowledge and attitudes about shared decision making among service users, providers, and administrators. Focus group meetings were held as part of professional and advocacy organization conferences, as well as with people who use mental health services and those who provide them in community-based mental health settings. [2] Participants were presented with general information about the concepts and tools of shared decision making and asked to offer comments and concerns. The specific language, ideas, and approaches that appealed to each group were used to help inform development of shared decision making materials in mental health.

Materials for shared decision making in mental health are now in development by SAMHSA. These materials do not represent the full range of possibilities for shared decision making in mental health but offer a beginning. They are:

- Print and video materials to introduce the concept of shared decision making and encourage learning more about these practices.

- Decision support resources that include a workbook to help individuals make important personal decisions; companion materials for helpers (e.g., family members, friends, peers, providers, etc.) to use when assisting

people who are making difficult decisions; and a set of worksheets and practical communication tips.

- An interactive DA that will allow users to compare different antipsychotic medications and to consider the use of alternative therapies, wellness activities, and watchful waiting as part of an overall recovery plan. It will be available on the Internet and on a CD-ROM.

Take Away Messages from Predevelopment Testing

During the process of predevelopment testing, several overarching themes and concerns emerged.

- Perceptions about the current level of consumer involvement in decision making were dependent on an individual's role in the system. In general, providers tended to believe that consumers already had a good deal of input into decisions affecting their lives. However, discussions with consumers revealed that many felt they currently have little meaningful input into major decisions, especially about medications and finances.

- The concept of shared decision making highlighted existing power issues in the public mental health system. The idea of "sharing" decisions raised objections from some providers and consumers, although for very different reasons. While many providers were open to and even excited about tools that would help support active involvement by people using services, others expressed reservations regarding the advisability of this. For example, some providers worried that shared decision making might "allow" people to make decisions to not use medication, which they saw as unacceptable. People who use services expressed concern that even with the availability of shared decision mak-

ing tools, their input would not be accepted, especially about medication decisions. Some individuals felt that being asked to share decision making with providers seemed like "a step backward" from repeated messages about self-empowerment and taking full responsibility for their lives.

• There was consensus across groups that hands-on tools emphasizing systematic information gathering and a stepped approach to decision making are an important contribution. This was true even among providers who felt that shared decision making was similar to their current practice, whether they called it person-centered planning, psychiatric rehabilitation, or recovery-oriented services.

Developing Resources For Mental Health: Product Testing

All shared decision making materials developed for SAMHSA undergo product testing to ensure that they are relevant, useful, and acceptable to those who will use them. To date, nearly 300 people have reviewed and offered comment on at least one of the products.

Similar to predevelopment testing, materials have been presented to focus groups of staff and service users at community mental health programs and at conferences. During product development, drafts of products were reviewed by representatives of their intended audiences (e.g., people who use services reviewed materials geared toward mental health consumers; providers reviewed materials geared toward case managers, social workers, and so forth.). Structured questions and open-ended discussion were used to gather reactions to the products.

Take Away Messages from Product Testing

The information gathered from product testing has been used to fine-tune suc-

cessive drafts or substantially revise the approach to specific products.

• Generally, people were favorable to the concepts of shared decision making. However, they noted that shared decision making materials need to convey the message that shared decision making builds on and enhances current practice. Many providers believe they are engaging in shared decision making when they include a service user in planning or when they ask, "Is this OK with you?"

• Providers need clarity about how the practices and skills of shared decision making are different from yet support other practices associated with person-centered care. While most current shared decision making materials are designed for people who use services, providers stressed the need for information and support on how to integrate these resources into their practices.

• The use of decision support tools is one factor that differentiates shared decision making from other practices. All groups felt that specific shared decision making tools could enhance collaborative communication between people who use and provide mental health services.

• Audiences noted the importance of preparatory materials. These materials help provide full and accurate information; offer an opportunity to explore and weigh personal concerns; and help people feel they have not only a right, but also the motivation and skills, to have an active and meaningful say in decisions about their treatment and services. Memory aids such as "Questions to Ask the Doctor" are useful preparatory materials.

Discussion

Each stage of this project, from the literature review to product development and audience testing, has revealed some important considerations for future developers of shared decision making tools for mental health. We share a few overall observations here.

In general, there is both interest in and confusion about the concept of shared decision making, which can be viewed as a practice style or a service, as well as a set of structured tools or a specific practice protocol. There is a need to more sharply distinguish shared decision making from informed consent, self-determination, and other person-centered approaches and to demonstrate how it can enhance and strengthen practice in each of these areas. As with any emerging approach, shared decision making must go through a developmental process in which it stimulates dialogue, becomes better defined, undergoes research and evaluation, and ultimately is established as a standard of care in the field.

To clarify the concept and to promote research and adoption within the mental health field, a wide variety of tools and resources specific to shared decision making in mental health must be developed. Along with materials in development by others, the SAMHSA products are a beginning.

Formal DAs are most useful when they provide information tailored to the needs and interests of individuals. They are challenging to create because they should be based on the most current practice literature and research, and consequently must be regularly reviewed and updated to reflect new findings. Though research on mental health issues such as medication, complementary and alternative therapies, and service approaches is often incon-

clusive and incomplete, applying shared decision making approaches to these issues is critical. It is both necessary and difficult to avoid injecting subjective judgment into the preparation of resources. Materials developed by any group with a vested interest in the decision outcome are inherently questionable.

Shared decision making shows promise as an emerging practice in mental health, but it is in its infancy in terms of conceptual understanding and in the availability of tools and resources for practice. There is a desire for practical tools to implement shared decision making within the mental health field and a need for continued development and research. Consumer involvement in decision making has expanded over time, but it is now time to push the envelope by providing impetus and resources to open *all* treatment and service decisions to informed and respectful dialogue.

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[1] For a chart of mental health related decision aids, see http://mentalhealth.samhsa.gov/consumersurvivor.

[2] Readers interested in knowing more about the specific groups and settings for both the predevelopment and product testing are encouraged to contact this article's lead author.