

# Shared Decision Making

## Making Recovery Real in Mental Health

### Exploring Shared Decision Making

Whether you have heard about shared decision making or the term is new to you, you probably have some specific questions about it.

*This issue brief addresses these common questions about shared decision making:*

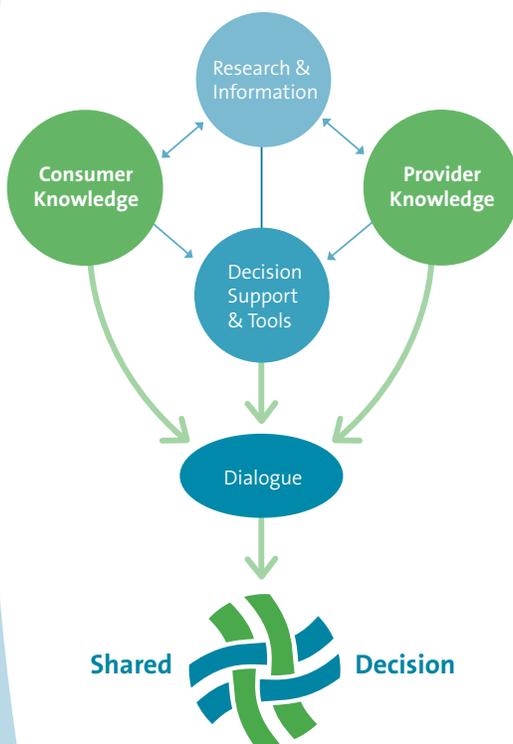
- What is shared decision making?
- When is shared decision making used?
- What kinds of tools are used in shared decision making?
- What does the research say about shared decision making?
- Where can I learn more about shared decision making?

People make decisions every day about their lives, relationships, health care, and services. For people who use mental health services, decisions often are made for them by physicians and other health care providers. Some providers may believe that people who use mental health services are not capable of making decisions on their own or are not interested in doing so. This is not true.

Shared decision making is a way for people who use mental health services and their providers to improve communication about mental health treatment and service options. Integrating full information and decision making tools with respectful two-way dialogue, it helps balance information about mental health conditions and treatment options with an individual's preferences, goals, and cultural values and beliefs. Used effectively, shared decision making can make communication more productive, efficient, and empowering for both the person using services and those providing them. It helps put the person back at the center of person-centered health care.

Shared decision making is an emerging best practice in health care and has been specifically recommended by the Institute of Medicine (IOM) (2005). Though formal shared decision making is new to the mental health field, it is entirely consistent with empowerment, self-determination, and recovery. The Federal Substance Abuse and Mental Health Services Administration (SAMHSA) supports the use of shared decision making as a routine part of mental health care. This issue brief is part of a set of materials designed to help make this possible.

*Creating Dialogue  
Promoting Choice  
Supporting Recovery*





## What Is Shared Decision Making?

Shared decision making is more than a conversation between people who use mental health services and their health care providers.

*Rather, it offers a systematic process and specific tools to help them:*

- Get, understand, and exchange complex information;
- Consider and discuss options together; and
- Make a health care decision.

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Shared decision making can enhance recovery by helping people become more active in their mental health care and personal recovery decisions. It also engages practitioners by providing them with a way to communicate with people that recognizes the values of the service user.

*There are four basic elements to the shared decision making process:*

- **Establish a partnership.** Individuals have the right to make choices about their treatment and services. But people make their best decisions when they have good information, consider the input of others, and take time to think through what is most important to them. Providers can provide crucial information and support throughout the process.
- **Exchange information.** People using services discuss their experiences, history, preferences, values, cultural beliefs, and what has worked or not worked in the past. Providers describe treatment and service options and the possible benefits and risks of each. Shared decision making tools, described in more detail in this issue brief, can support this process of collaborative communication.
- **Weigh options.** Together, the service user and the provider weigh the pros and cons of each option in the context of the individual's preferences, values, and cultural beliefs. Watchful waiting—a proactive decision to take no further action while closely observing the situation—may be a viable choice.
- **Make a decision.** The process of decision making is shared, but the final decision rests with the person using services, who determines what is best for him or her. Both parties agree to review and revise the decision, if need be.

*Shared decision making allows the person to be in the driver's seat—to have an active role, to bring to the table their thoughts, their ideas, what they know about themselves and to be able to have that shared and accepted by their treatment team.*

— Marguerite, a mental health service provider

*It's important to have conversations about treatment and medications with your providers because you know what your illness is. Your provider can only help you manage your illness. So the more information you share with your provider, the better your provider will be able to help you reach a point of wellness.*

— Denise, a person who uses mental health services

# When Is Shared Decision Making Used?

Shared decision making is particularly useful for preference-sensitive decisions.

*These are decisions in which:*

- There is no conclusive standard of care; or
- There are several treatment options, each with pros and cons; and
- Individuals must make tradeoffs based on what they feel will work best for them.

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Most mental health decisions are preference-sensitive. For example, a provider may describe two medications that could be helpful to treat a given condition. However, one has significant weight gain as a potential side effect and the other has sexual impotence as a possible side effect.

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*The person using services—not the provider—must weigh the side effects against the benefits the medication may have for him or her and decide to:*

- Use one or the other medication;
- Use one of the medications together with another therapy (e.g., peer support, diet and exercise, massage, acupuncture);
- Use another therapy instead of medication; or
- Choose watchful waiting.

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Choices about medication are not the only ones that can benefit from a shared decision making process. Many everyday decisions can be framed as opportunities for individuals to talk through options and clarify what is most important to them. These include decisions about everything from where to live to whether or not to work.

Shared decision making also helps people who use mental health services talk about what they do that supports their recovery. For example, they might listen to music, practice yoga, spend time with children, or read a book. Providers can help them balance the need to alleviate unpleasant symptoms with the desire to maintain these important aspects of their lives. Treatment that seriously disrupts what is important to a person is less likely to be followed.

**Q**

**Is shared decision making the same as informed consent?**

**A**

They are complementary but not the same. Informed consent is a communication process and legal document giving permission to provide treatment or services, after risks have been disclosed. It typically gives a health care provider permission to carry out a treatment he or she has recommended. Shared decision making is a process that can lead to and strengthen informed consent but it has broader application. Shared decision making can be used any time an individual faces a choice of health care options.





## What Kinds of Tools Are Used for Shared Decision Making?

Shared decision making is distinguished from other best practices in person-centered planning by the use of two types of tools—decision aids and decision support resources. These tools can help focus the conversation and frame the decision making process.

**Decision aids** are structured tools that help people become involved in health care decision making. They provide information about a specific health condition and associated treatment options and outcomes. They also help clarify personal values related to the decision. Decision aids come in a variety of formats, from simple paper and pencil instruments to audio-guided workbooks, interactive videos and CD-ROMs, and computer-assisted and Web-based tools. A decision aid supplements rather than replaces services offered by health care providers.

There are literally hundreds of decision aids in general health, but few are available to date for use in mental health. Fewer still deal with serious psychiatric conditions. To fill this gap, SAMHSA has created an interactive decision aid that allows users to compare antipsychotic medications used to treat mental health conditions. It also lets them consider the use of alternative therapies and wellness activities as part of an overall recovery plan. The decision aid is accompanied by a series of “cool tools” that include conversation starters for providers and consumers. It features videos of people talking about their experiences with shared decision making. These materials can be found at <http://store.samhsa.gov>.

*We're the best advocates for our own treatment and we know what works and what doesn't. The provider needs to listen to us. You give me information, I give you information, and we come to a mutual agreement.*

— Renee, a person who uses mental health services

### A Tool for Shared Decision Making →

The tool on the facing page is an example of one that can be used for shared decision making. It can help a person talk about how a medication is affecting him or her. A person who uses mental health services can fill this out in preparation for a visit with a service provider. A family member, friend, or peer supporter can help. More tools like this are available at <http://store.samhsa.gov>.

**Decision support resources** are less formal tools to help individuals and providers learn more about various treatment options and to foster communication skills. SAMSHA has developed two general decision support resources that may be useful when no topic-specific decision aid exists. These workbooks are titled *What Is Right for Me? How to Make Important Decisions in Everyday Life* and *Supporting Choice: Helping Someone Make an Important Decision*. They can be found at the web site listed above.



## Medication Effects | *A Watch List*

Put an X in the box at the left of medication effect you are experiencing. Use the blank spaces to add something that is not on the list. Use the “Comments or Questions” boxes to write down things you want to discuss. Use the back of the page if you need more space. Share this chart with your provider.

For more information about medications, see Medline Plus: <http://medlineplus.gov>.

Name: \_\_\_\_\_ Date: \_\_\_\_\_

Mood			Comment or Question			
<input type="checkbox"/>	Anxious	<input type="checkbox"/>	Angry	<input type="checkbox"/>	Happy	
<input type="checkbox"/>	Dull/flat/“whatever”	<input type="checkbox"/>	Irritable/easily upset	<input type="checkbox"/>	Calm	
<input type="checkbox"/>	Depressed	<input type="checkbox"/>	Worried/anxious	<input type="checkbox"/>	Content	
<input type="checkbox"/>	“Up and down”	<input type="checkbox"/>	Worried/suspicious	<input type="checkbox"/>	Other	
Sleep			Comment or Question			
<input type="checkbox"/>	Often very sleepy during the day	<input type="checkbox"/>	Distressing nightmares			
<input type="checkbox"/>	Hard to fall asleep or stay asleep	<input type="checkbox"/>	Sleeping just right			
<input type="checkbox"/>	Hard to get out of bed in the morning	<input type="checkbox"/>	Other			
Energy and Motivation			Comment or Question			
<input type="checkbox"/>	No desire to move or do things	<input type="checkbox"/>	Lots of energy/too much energy			
<input type="checkbox"/>	Feeling numb or “zombie-like”	<input type="checkbox"/>	Just the right amount of energy			
<input type="checkbox"/>	Restless, pacing, hard to sit still	<input type="checkbox"/>	Other			
Memory and Concentration			Comment or Question			
<input type="checkbox"/>	Feeling fuzzy or confused in my thinking	<input type="checkbox"/>	Hard to concentrate or stay focused			
<input type="checkbox"/>	Hard to organize my thoughts	<input type="checkbox"/>	Feeling sharp and clear in my thinking			
<input type="checkbox"/>	Often forgetting important things	<input type="checkbox"/>	Other			
Food and Diet			Comment or Question			
<input type="checkbox"/>	Not interested in food	<input type="checkbox"/>	Frequent gas or heartburn			
<input type="checkbox"/>	Eating more than usual	<input type="checkbox"/>	Change in weight			
<input type="checkbox"/>	Good appetite	<input type="checkbox"/>	Other			
Sex			Comment or Question			
<input type="checkbox"/>	Change in interest in sex	<input type="checkbox"/>	Loss of pleasurable feelings during sex			
<input type="checkbox"/>	Change in ability to perform sexually	<input type="checkbox"/>	Other			
Body			Comment or Question			
<input type="checkbox"/>	Blurry vision: difficult to read things	<input type="checkbox"/>	Sweating often or a lot			
<input type="checkbox"/>	Dizziness	<input type="checkbox"/>	Constipation			
<input type="checkbox"/>	Drooling: wet pillow, too much saliva	<input type="checkbox"/>	Diarrhea			
<input type="checkbox"/>	Dry mouth	<input type="checkbox"/>	Problems urinating			
<input type="checkbox"/>	Headaches	<input type="checkbox"/>	Changes in menstrual cycles (women only)			
<input type="checkbox"/>	Nausea	<input type="checkbox"/>	Other			
Muscles			Comment or Question			
<input type="checkbox"/>	Muscles feel tense or stiff	<input type="checkbox"/>	Cannot sit still – “jump out of skin” feelings			
<input type="checkbox"/>	Muscles shake or tremble	<input type="checkbox"/>	Frequent muscle cramps			
<input type="checkbox"/>	Restless or jittery	<input type="checkbox"/>	Other			





## What Does the Research Say About Shared Decision Making?

Much of the research on shared decision making to date has been done in general health care. Some of these studies show that shared decision making may be effective in producing better health care decisions. A study in the United Kingdom found that people's desire to be involved in making health care decisions varies with age, educational status, severity of disorder, and ethnic or cultural differences. It may also fluctuate over time or depending on circumstances (Coulter & Ellins, 2007).

Only a few studies to date have looked at shared decision making with people who have mental health diagnoses. One of these studies found that people who use mental health services generally prefer more active and collaborative roles in decision making than they currently experience (Adams, Drake, & Wolford, 2007). They were especially interested in collaborating in decisions about their medications. Another study found that individuals diagnosed with schizophrenia who participated in shared decision making had better knowledge about the disorder. They also felt more involved in decisions about treatment and services (Hamann et al., 2006).

Common challenges to establishing shared decision making as standard practice include providers' concerns about the validity or objectivity of information presented in decision aids and their feeling that "we already do that" (O'Cathain & Thomas, 2004). In mental health, one of the most significant barriers is the belief that people who use mental health services are not able to participate in critical decisions concerning their treatment and services.

Decision aids are the most researched aspect of shared decision making. The use of decision aids has been found to improve health care decision making by increasing knowledge of options and their pros and cons. Decision aids also help create realistic expectations of outcomes and increase participation in decision making without increasing anxiety (O'Connor et al., 2004).

There has been less study about decision support resources. The most extensive research in this area has been conducted by Patricia Deegan. She developed a model in which people who use mental health services complete a specialized computer program with the aid of peer supporters. The program helps them clarify values and preferences that may affect their decisions about the use of medications or other treatment and service options. It helps them prepare to have a discussion with a provider about what is important in their lives. Dr. Deegan's research has found that this type of decision support is effective in engaging people in medication decisions (Deegan, 2007).

*One thing that we are beginning to see is that people involved in using the shared decision making process tend to use fewer high cost, intensive services. The other thing that we've clearly seen is very high satisfaction on the part of the consumers who are using the tools, as well as the physicians and the other clinicians who are using them.*

*— James, a mental health program administrator*

## Where Can I Learn More About Shared Decision Making?

The Substance Abuse and Mental Health Services Administration (SAMHSA), <http://store.samhsa.gov>, has information about mental health promotion and mental health and substance abuse treatment and prevention.

An interactive decision aid and set of “cool tools” can be found at <http://store.samhsa.gov>. This site also includes links to video clips, as well as issue briefs and tips for specific groups of people who may be involved in shared decision making.

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*Shared decision making materials are available for:*

- Service users, to help them participate fully in decisions concerning their life;
- Mental health providers, to help them use shared decision making in day-to-day practice;
- Physicians and other prescribers, to help them employ shared decision making for medication management; and
- Program administrators, to help them implement shared decision making as an agency-wide standard of care.

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Ottawa Health Research Institute, <http://decisionaid.ohri.ca>, features links to decision aids on particular health topics and to toolkits for developing decision aids and using them in clinical practice.

Dartmouth-Hitchcock Medical Center’s Center for Shared Decision Making, [http://www.dhmc.org/shared\\_decision\\_making.cfm](http://www.dhmc.org/shared_decision_making.cfm), includes a decision aid library, health care decision guide, and links to information for evaluating decision aids.

**Q**

**Do people who use mental health services have the capacity or legal status to make decisions?**

**A**

Yes. People with mental health diagnoses have a legal right to make their own decisions, unless deemed otherwise by a court. A psychiatric advance directive empowers people to make their treatment preferences known during a mental health crisis. Discussions about whether to prepare a psychiatric advance directive and what it should contain lend themselves well to a shared decision making process. For more information on psychiatric advance directives, see <http://www.nrc-pad.org>



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This publication may be downloaded or ordered at <http://store.samhsa.gov>. Or, please call SAMHSA at 1-877-SAMHSA-7 (1-877-726-4727) (English and Español).

This document was developed by Advocates for Human Potential, Inc. under contract number HHSS 2832007000381 for the Substance Abuse and Mental Health Services Administration (SAMHSA), U.S. Department of Health and Human Services (HHS).

The views, policies, and opinions expressed are those of the authors and do not necessarily reflect those of SAMHSA or HHS.

