

3 *Shared Decision Making*

Your Wellness Counts



Your Wellness Counts: *Shared Decision Making* – May 2017

New Jersey Division of Mental Health and Addiction Services
Rutgers UBHC Technical Assistance Center

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What's Shared Decision Making?

Welcome to **Your Wellness Counts**, the **Shared Decision Making** Module. This module is entitled “**Shared Decision Making**” because it offers a collaborative way for you to work with your doctor, nurse, and other healthcare providers. With Shared Decision Making, you and your healthcare providers are viewed as having *important yet different* expertise that can actively contribute to mutually agreed upon decisions in treatment.

So, how am I an “expert”?

You know your needs, strengths, and life goals. You also know how well your treatment is currently addressing what's most important to you.

“I'm my own best doctor.”

How can “Shared Decision Making” make a difference in my life?

Shared Decision Making (SDM) means that you can be a more active participant in all areas of your treatment, including identifying meaningful life goals, choosing your medication, and improving your physical wellness. It can help you to discover other treatment options that may work better for you. SDM also means that you can encourage people who support you, like peers, friends, family, and professionals, to help you in shared decision making.

How can this module, *Shared Decision Making*, help me?

If you're not sure where to start or how to become a more active participant in your treatment, this module can help. You will learn how to share your wishes about your care, as well as some ideas on how you can be more involved in your treatment to support your recovery.



What areas of your current treatment would you would like to change or improve? This might include your treatment plan, your medication, or how you are managing your physical health.



Resource: <http://store.samhsa.gov/home> (search for “shared decision making”)



Self-direction and Responsibility Drive Shared Decision Making



In developing this module, people in recovery were asked what they thought about the idea of shared decision making. Here are some things they said:

- *“It’s my recovery, not theirs.”*
- *“They don’t (understand) what we’ve done to survive.”*
- *“The psychiatrist I see definitely listens to my concerns about medication side effects.”*
- *“The doctors don’t tell you everything they know.”*
- *“I wonder how many doctors know about (shared decision making).”*
- *“It revolves around education. Theirs and ours.”*

People reported different experiences around shared decision making. Some were good; some not so good. Whatever your experience, remember that you have the right and responsibility to be an active member in your recovery. You are the person in charge of your health and wellness.

Self-direction and individual responsibility are two of the fundamental components of recovery.* Both are vital to the shared decision making process. Self-direction means that you are the person who makes choices and takes control of your recovery goals. Individual responsibility means you set and pursue habits and routines to achieve a satisfying lifestyle.



How active are you in directing your current treatment? Think of an example of something you did or something you do now.



Resource: <http://store.samhsa.gov/home> (search for “10 fundamental”)



What Gets in the Way of Shared Decision Making?

For many years, being in treatment for mental health and/or substance use disorders meant that you were expected to follow your doctor's or clinician's directions. If you didn't follow directions about your treatment completely, you might have been characterized as "resistant" or "noncompliant."



People with mental health or substance use conditions have stated that they often felt labeled or negatively (e.g., lazy, unmotivated, less intelligent, irrational, incurable). This type of **stigma** can be a huge barrier to shared decision making as it devalues the person in recovery. Even for the many practitioners who are open to hearing your experiences, fears, doubts, hopes, and dreams, listening takes time that they may not think they have.

You may feel that it seems easier to give in and blindly agree to decisions about your treatment and recovery. When you feel hopeless due to bad experiences, and just can't see a way out, this is called **learned helplessness**.

"My psychiatrist made the decision.
I just let it go."

There is always hope. Shared Decision Making primarily aims to switch the experience of persons in recovery *from* stigma and learned helplessness *to* full and active participation in treatment decisions. This module includes information on your rights, expressing yourself, and respecting others' rights.



What would help you feel more confident talking with healthcare professionals about your treatment?



Your Basic Personal Rights



In order to direct your own care, it is critical to know your rights and responsibilities. A critical part of shared decision making is to believe that *you are absolutely worthy of dignity and respect.*

You have the right to*:

- Be safe.
- Follow your own values, standards and spiritual beliefs.
- Ask for what you want, say yes or no, and *change your mind.*
- Make mistakes.
- Be afraid and uncertain.
- Express your feelings, both positive and negative, *in a responsible way.*
- Have the friends and interests of your choice.
- Know the side effects of recommended medications and treatments.
- Refuse medications and treatments that are unacceptable to you.

This list is a brief sketch of your rights. Some circumstances may change how they are applied, such as if you are in a psychiatric hospital.** *Ask for a copy of your “bill of rights” and discuss your questions or concerns.*



How do you feel these rights could be better honored in your current treatment?



References and Resources:

* <http://store.samhsa.gov/home> (search for “recovering your mental health”)

** <http://www.state.nj.us/> (search for DMHAS rights of patients)



You Can Express Yourself and Respect the Rights of Others



Many people in recovery have found that **assertiveness** is an essential skill in shared decision making. So before launching into specific steps of how you make shared decisions about your treatment, let's take a brief look at this skill and ways to develop it.

*You can be assertive by expressing yourself clearly and firmly while also respecting the other person's beliefs. **Assertiveness** is the midpoint between being too passive (like a doormat) and being too aggressive (like a bully). You're simply advocating for yourself so your voice can be integrated into your treatment decisions.*

If communicating assertively doesn't come naturally to you, there are some ways that you can try being assertive. Here are some ideas:

- ☞ Use “I” statements. Mention your goals, acknowledge the other person's situation, and express what you would like the other person to do. For example, *“I don't like how my medication is making me feel. I know you think it will help me. Is there another one that won't make me feel so tired?”*
- ☞ Be comfortable saying “no.” This can be difficult at first. It can help to offer a brief, specific reason.
- ☞ Practice what you're going to say aloud. You can role play with someone you trust, like a peer. You also can practice by talking in front of a mirror.
- ☞ Take small steps. You can choose to use the assertive skills first with a trusted friend or family member.



Which of the above steps are you most confident in trying? Who can support you in being more assertive?



Are There Benefits to Shared Decision Making?

At this point, you may be thinking “Why do I need to change the way I’m participating in my treatment?” That’s a very fair and practical question. In order to invest the time and effort it takes to change, you need to believe the change has value and that it is something that you are empowered to do. So, how important is making shared decisions to you?

This module on **Shared Decision Making** (SDM) isn’t recommending that you simply accept and believe that SDM is the best approach for you. By considering benefits that you & others have identified, you can decide what’s best for you.

Here are some statements about what people have liked and seen about shared decision making:

- *“I feel like a partner in the decision making process.”*
- *“An educated consumer is the best consumer.”*
- *“He didn’t scare me but I wasn’t a nervous wreck.”*
- *“When it’s pretty much my decision, it gives me motivation to do better.”*

By learning to speak assertively within the shared decision making process, you can gain some benefits:

- 🗨️ Build your self-confidence
- 🗨️ Understand and express your ideas and feelings
- 🗨️ Share honest, accurate information
- 🗨️ Earn respect by preparing questions
- 🗨️ Increase the chance you and your practitioner will agree on treatment decisions
- 🗨️ Increase the chance you will follow through with your decisions



What’s the best thing that can happen for you when you voice your needs and concerns about your treatment?





Overcoming Fears about Shared Decision Making

Naturally, trying something new can contribute to a person feeling anxious, uncertain, and even afraid. It's important to be aware of negative thoughts and feelings so we can manage them.

Barriers to shared decision making can be your own feelings of doubt, anger and anxiety. Negative thoughts can get in your way. Below are some other ways to challenge negative thinking:

| Example of negative thinking | Another way to think about it |
|---|---|
| <i>"I don't know what to say."</i> | <i>"I can learn how to express myself."</i> |
| <i>"They don't believe me."</i> | <i>"I can firmly express my beliefs."</i> |
| <i>"I'm afraid I'm going to be yelled at."</i> | <i>"I'll manage my own emotions."</i> |
| <i>"Nothing really gets resolved."</i> | <i>"I want to improve my part in resolving things."</i> |
| <i>What is an example of your negative thinking and another way?</i> | |
|  |  |



How can Shared Decision Making help you despite fears, doubts and frustrations? How can your recovery team and other supports help you?

[My son] refused to take medication and talk therapy doesn't work... When I mentioned how getting a dog had helped him to his psychiatrist at the time, *she dismissed the benefit saying it was just a crutch*. We became involved in volunteer work through the organization that assisted with us rescuing his dog from a shelter. We attend community events and promote how "dogs are good for our mental health." - Family member



Wellness Strategies to Show You're an Expert

On the last page, we identified some of the potential fears involved with shared decision making. Another possible challenge is believing that you don't have any expertise to offer. One way to start addressing this belief is to recall the 8 dimensions of wellness.

Here are some of the wellness strategies many people have identified as important for personal recovery and achieving their Overall Wellness Goal:

- Emotional: laugh often, be grateful, set time with friend each week
- Spiritual: yoga, prayer, read, meditate
- Social: share a meal, dance, play games with friends
- Financial: bargain shop, set time each week to review budget
- Intellectual: read, visit a library or museum, research a new idea
- Environmental: do yard work with friends, decorate, sit outdoors
- Physical: walk, dance, lift weights, ride bike, set sleep-wake time
- Occupational: take a class, volunteer, find a job I love



You may not realize it, but you do things every day that contribute to your wellness. You're an expert at knowing what strategies work and those that don't.

On the next page, list some things you do every day or every week. These are positive things that help you get well and stay well in each of the eight dimensions on the list. Small things are fine—these are just some habits and routines that you build into your life.

Sometimes, people find it hard to list their strengths on their own. If this is true for you, ask a trusted support person to help.



Who might help you identify and discuss your strengths? What might/did they say?



Your Current Wellness Strategies

Write down things you do each **day or week** for each of the wellness dimensions.

Emotional

Environmental

Financial

Intellectual

Occupational

Physical

Social

Spiritual

Other things you do:



How Does Your Treatment Affect Your Wellness Strategies?

Behavioral health professionals often explain how a treatment, such as attending individual or group therapy sessions, can improve your mental and emotional health. *Even though treatment can be helpful, professionals may forget to talk with you about how such treatments could get in the way of your efforts to engage in activities that help your wellness.*

So, it is important for you to discuss **how your treatment affects your wellness strategies**. This is part of shared decision making with your recovery team.

Think about things that *you believe* improve your quality of life, even if others don't know about them or agree with you. For example, you may find you are helped by praying, having sex, listening to your music, drinking coffee, having a job, reading, or being with certain friends and family.

“Taking medication makes me feel like a zombie. It’s hard to find the energy to do the things that help me, like yoga and being in nature... There are many ways for people to heal. Whether it be medicine, vitamins, exercise, or therapy, if, in the end, the person heals, then mission accomplished. This should be the focus of recovery.”



What parts of your current treatment recommendations are a good fit with your wellness strategies [p.9]? What parts of treatment can get in the way of your wellness strategies?



You can share decisions about your recovery plan



Behavioral health professionals typically recommend some type of treatment that they believe will help with your recovery. This may include attending program, taking medication, or starting an exercise program. After an initial assessment, a treatment plan is created to outline what will be done by you and your team to help with your recovery. This treatment plan can also be referred to as a “recovery plan,” “service plan,” or just simply “plan.” From this point on, this module will use the term “recovery plan” to emphasize the person-centered nature of planning.

Being active in your recovery planning is an excellent way to learn and practice shared decision making. You can voice what is most important in your life, how you can take steps toward your goals, and how services & personal supports can aid in your recovery. Professionals can offer a range of service options for you and provide any needed information or resources. Your personal supports, such as a close friend or relative, can provide encouragement and help you celebrate your success.

On the next page is a worksheet entitled “Shared decision making about your recovery plan” which can help you prepare for meetings about your plan. Here are some other things to keep in mind:

- Before the meeting, prepare by writing about or discussing the things you value, including cultural beliefs. Invite supporters such as family.
- During the meeting, be direct & respectful in voicing what is important to you. Be free to ask questions if you’re worried, upset, or confused.
- After the meeting, review the written plan and talk about any questions or concerns. Ask for a copy of the plan for yourself. Think about other ways you could be more involved in the planning process.*



What part of the planning process (before, during or after) are you most confident about?



* Resource: <http://portal.ct.gov/> (search for “PCCQ”)



Shared Decision Making & Your Recovery Plan

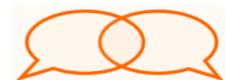
1. Identify your wellness strategies (see page 9 of *this module*). Think of how you promote recovery in each wellness domain.

2. Think about how your current treatment recommendations (see page 10) might help or hinder how you currently try to be well. Consider how treatment can integrate one or two of your best wellness strategies.



3. Prioritize what to discuss with each health care professional. Include how your wellness strategies can be included as a strength and a way to improve or promote your overall health (for example, emotional, social, or spiritual wellness).

4. Discuss your thoughts on how you would like to proceed. Include areas where you are willing to hear other options and when you'd like to evaluate how it's working for you.





You Can Share Decision Making About Your Medication

Talking about medication is a crucial part of shared decision making. However, you may find it hard to think about what to ask your doctor or nurse. Maybe you feel intimidated. Maybe there are too many questions and issues that you want to discuss, especially if you haven't spoken much about these things before.

"As long as we're getting 15 minutes, questions aren't really in depth. It's like a conveyor belt."

Limited appointment times are a challenging barrier. Since there is often a time crunch for appointments with health professionals, it's important that you *prepare for your visit by organizing your thoughts ahead of time*. List the top 3-4 questions you wish to discuss. Mark which ones to ask first and which ones can wait for next time.

"Sharing Decisions about Medication" is a valuable tool (see the next page). It has many helpful ideas to guide your thinking about what to do before, during, and after your appointment. For example, **you can ask about how your medication affects what's important to you** (question #4). Asking this question directly shows you're taking responsibility and willing to collaborate in shared decision making.

"I brought in a list of my current meds and past meds to make their job easier. I said, 'This med works, this one didn't.' They saw I had my education. You want to be book smart *and* street smart."

Other ways to be more educated and involved in shared decision making about medication include:

- Read information about your specific medication
- Think about starting or updating your psychiatric advance directive, that is, a guide you write to direct your care when your symptoms are severe



Resource: <http://www.state.nj.us/> (search for "Sharing Decisions")



You Can Share Decision Making About Your Physical Health



Another area of your treatment where you can be more actively involved is your physical health. You may feel that speaking to health care professionals such as doctors and nurses can be challenging. This may seem especially true concerning your physical health because many of the medical terms can be confusing, hard to remember, and difficult to understand.

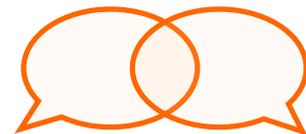
You can work with your health professionals and social supports to better understand your physical health and make more informed decisions.

I want my psychiatrist to talk to my medical doctor. - Consumer

Your Wellness Counts contains a number of helpful resources to help you make informed choices about your health, such as the modules ***Eating Better, Moving More*** and ***Deciding about Smoking***. After completing ***Shared Decision Making***, you may choose to explore these other modules to find out how to adopt new physical wellness habits.

Decision aids are on-line, interactive tools to help people participate in making informed health decisions. “Questions are the Answer” is a very helpful decision aid* designed to help identify questions you can ask your doctor. This website has tools to help you build your own list of questions about your medical concerns, including:

- Talking about a health condition
- Getting, changing or stopping a medicine
- Having medical tests
- Talking about surgery



In the meantime, on the next page is a worksheet entitled “Shared decision making about your physical health” that can address some of the key physical health issues that are not directly covered in the rest of **Your Wellness Counts**.



* Resource: <http://www.ahrq.gov/> (search for “Questions are the Answer”)



Shared Decision Making about Physical Health

1. Identify your Overall Wellness Goal (see p. 6 of *Wellness Any Way – module 2*).

2. Identify issues related to your physical health. *Include common physical health concerns such as weight, vision, dental hygiene, diabetes, high blood pressure, etc. You can also discuss topics which may be impacted by medical conditions such as your energy, sleep, and mood.*

3. Think about how addressing your physical health needs will help you attain your Overall Wellness Goal. *Be prepared to share your interests and concerns with your health professional.*

4. Discuss your thoughts on how you would like to proceed. *Include areas where you are willing to hear other options (including choosing to do nothing), your understanding of the benefits and harms, and how/when you'd like to evaluate how it's working for you.*



5. Ask to schedule a time when you can discuss other issues related to your physical health. *Possibilities may include: change in medications, side effects or symptoms, costs of options, getting or understanding test results, getting a second opinion.*



What's Next?



You may be thinking, “Why do I need *another* goal?” You may have a Wellness and Recovery Action Plan (WRAP) or you may have participated in Illness Management and Recovery* (IMR) groups at a program that you attend. You might have discussed your life goals in an Individualized Recovery Plan (IRP), service plan, or treatment plan. It can be a lot to keep track of all your goals.

To make it simpler for you, we encourage you to connect **Your Wellness Counts** to other plans that you may have. One way to make this connection is to complete the “Connecting with Your Recovery Team” page near the end of each of the modules on eating, moving and smoking.

To come up with a good plan, it’s helpful to identify which of the healthy habits (for example, eating better, moving more, or stopping smoking) is one you’d prefer to work on first. By addressing your physical wellness you can improve wellness in the other 7 dimensions, build momentum for your recovery journey, and reach your Overall Wellness Goal.

After completing the “Physical Wellness Self-Assessment” tool on the next page, you’ll have the chance to identify the health behavior you’d like to start with. Then, you can write down your decision and share this decision with your health care professional or your supporter.

You can start by asking yourself questions like these:

- “Am I satisfied in how I am doing with this health habit?”
- “How do I feel about making a change in this area?”



What are your initial thoughts and ideas on which healthy habit (eating, moving more, smoking) you’d like to try working on first?

* Resource: <http://store.samhsa.gov/> (search for “IMR handouts”)





Physical Wellness Self-Assessment

For each of the health behaviors below, circle the number or response that applies to you.

| Health Behavior | How <u>important</u> is this to you now? | How <u>confident</u> are you that you can do this now? | Next step? |
|---|--|---|------------|
| Eating Better  |  1 2 3 4 5 6 7 8 9 10 Not important Most important |  1 2 3 4 5 6 7 8 9 10 Not confident Most confident | Yes No |
| Moving More  |  1 2 3 4 5 6 7 8 9 10 Not important Most important |  1 2 3 4 5 6 7 8 9 10 Not confident Most confident | Yes No |
| Deciding about Smoking  |  1 2 3 4 5 6 7 8 9 10 Not important Most important |  1 2 3 4 5 6 7 8 9 10 Not confident Most confident | Yes No |



What's Most Important Now?

To start to change a long-standing behavior, most people need to believe that they can do it and that it's meaningful to them. After completing the "Physical Wellness Self-Assessment," you probably have a better idea concerning how you'd like to proceed now.

To help you determine which way you'd like to go in **Your Wellness Counts**, here are some clarifying questions:



Which of the three areas (eating, moving, and smoking) do you think is most important for you to change right now? What are some of the best things that can happen for you if you make this change?



In which of these three areas do you feel most confident in starting to make a change? What strengths, skills and resources do you have now that can help you succeed?

Looking at how you rated each of the health behaviors in terms of importance and confidence, which area do you think you're ready to work on first?

- Eating better
- Moving more
- Deciding about smoking
- Not sure

If you'd like to explore one of these health habits, you can start discussing how to include it in your current recovery/treatment plan.

If you're not sure, you can re-read this module, try one of the other ones, or simply *take a break* and return to **Your Wellness Counts** when you can.





Congratulations!

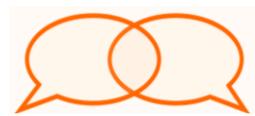
You have completed the *Shared Decision Making* module.

What's the best thing you've learned so far about *Shared Decision Making* that will help your recovery?



From here, move around in *any way* that supports your recovery:

- If you decide to continue working on shared decision making, go ahead and revisit this module, ***Shared Decision Making***. You can also get some more information on the next few pages, "***Shared Decision Making – Resources and References***".
- If you decide that the way you eat is a thing you want to change, go ahead and move on to the module on ***Eating Better***.
- If you decide that getting more physical activity is most important, take a look at the module on ***Moving More***.
- If you're most concerned about your smoking, see the module on ***Deciding about Smoking***.
- If you want to learn how to maintain and track your wellness, you can go directly to ***Wellness Every Day***.



Go to the module that you think is right for you.



Shared Decision Making – Resources and References



- Listed in order of topics mentioned in this module
- Reference or resource with asterisk*= mentioned previously on page

For “Shared Decision Making in Mental Health Care”:

1. *<http://store.samhsa.gov/shin/content/SMA09-4371/SMA09-4371.pdf>

For the “10 Fundamental Components of Recovery”:

2. *<http://store.samhsa.gov/shin/content/SMA05-4129/SMA05-4129.pdf>

For more on self-directed care in behavioral health:

3. <http://store.samhsa.gov/shin/content/SMA05-3982/SMA05-3982.pdf>

For more on your rights:

- 4.* <http://store.samhsa.gov/product/Recovering-Your-Mental-Health-A-Self-Help-Guide/SMA-3504>
- 5.*http://www.state.nj.us/humanservices/dmhas/publications/misc/Patients_Rights.pdf
6. <http://www.drnj.org/> (For assistance in obtaining & protecting your rights)

For more on being assertive:

- 7.<http://www.mayoclinic.com/health/assertive/SR00042>

“Well done is better
than well said.”
- Benjamin Franklin

To assess how person-centered treatment planning is:

8. *<http://www.ct.gov/dmhas/lib/dmhas/publications/PCCQperson.pdf>

How to prepare for your recovery plan:

9. <http://www.yale.edu/PRCH/documents/toolkit.draft.3.5.11.pdf>

On integrating cultural values into behavioral health:

10. <http://www.ct.gov/dmhas/lib/dmhas/publications/Disparitiesreport.pdf>

To help involve two people in making a choice:

11. <http://decisionaid.ohri.ca/decguide.html>



For an on-line version of the “Sharing decisions about medication” brochure:

12.*http://www.state.nj.us/humanservices/dmhs/news/publications/Sharing_Decisions_re_Meds_revised_2012.pdf

For a summary of medication information:

13.http://www.state.nj.us/humanservices/dmhas/publications/misc/Medication_Manual_English.pdf (English)

14.http://www.state.nj.us/humanservices/dmhas/publications/misc/Medication_Manual_2012/Med_Info_Manual_July_2012_Spanish.pdf (Spanish)

For more on advance directives:

15. <http://www.state.nj.us/humanservices/dmhas/resources/mental/pad/>

For questions to ask your health care team:

16.*<http://www.ahrq.gov/patients-consumers/patient-involvement/ask-your-doctor/index.html>

For “I wish I had asked that” worksheet:

17. http://www.informedmedicaldecisions.org/wp-content/uploads/2011/09/Patient_Visit_Guide.pdf

18. For info on Illness Management and Recovery:

<http://store.samhsa.gov/product/Illness-Management-and-Recovery-Evidence-Based-Practices-EBP-KIT/SMA09-4463>

Additional Resources

- **Ottawa Personal Decision Guide** offers a 2 page guide for “any health related and/or social decisions” in 7 languages: English, Spanish, French, German, Japanese, Dutch and Swedish:
<http://decisionaid.ohri.ca/decguide.html>
- **Effective Health Care Program** “creates free research summaries about the benefits and risks of different treatments for different health conditions” including diabetes, heart and blood vessel conditions, mental health and obesity:
<http://www.effectivehealthcare.ahrq.gov/index.cfm/research-summaries-for-consumers-clinicians-and-policy-makers/>



- **Mayo Clinic Shared Decision Making National Resource Center** “advances patient-centered medical care by promoting shared decision making through... decision aids” including diabetes medication management and depression medication management:
<http://shareddecisions.mayoclinic.org/decision-aids-for-chronic-disease/>
- **Informed Medical Decisions Foundation** “dedicated to helping people make better health decisions”: <http://www.informedmedicaldecisions.org>
- **How services need to be integrated** for persons with chronic health conditions in a person-centered way, see “Behavioral health homes for people with mental health and substance use conditions”:
http://www.integration.samhsa.gov/clinical-practice/CIHS_Health_Homes_Core_Clinical_Features.pdf
- **Assessing the level of customer service** in a behavioral health care organization, see “Customer Service Action Plan”:
http://www.thenationalcouncil.org/expert-buzz/wp-content/blogs.dir/3/files/2013/10/Customer-Service-Action-Plan-HEALTHCARE-4-2006_new2.pdf
- **Principles for partnership** of both “patient” and “health care partner”, see “The Universal Patient Compact”: For principles of health care partnership:
<http://c.ymcdn.com/sites/www.npsf.org/resource/resmgr/PDF/UniversalPatientCompact.pdf>

