

DATE: February 1, 2001

Mental Health Recovery: What Helps and What Hinders
Materials for the Focus Group Facilitator Training

Thank you for agreeing to serve as a focus group facilitator. As you may already know, the purpose of this multi-state project is to devise a set of items that can be used to collect input from consumers regarding the extent to which mental health systems promote mental health recovery. Your involvement as a focus group facilitator will play a key role in the success of this effort. We have created this packet of materials to serve as guides in your preparation and work.

The materials in this packet include:

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Handout 1: Project Background

Many mental health systems are interested in measuring recovery among people with psychiatric disabilities. The purposes of this project, *Mental Health Recovery: What Helps and What Hinders*, are:

- To increase knowledge about what facilitates or hinders recovery from psychiatric disabilities;
- To devise a core set of indicators that measure elements of a recovery-facilitating environment; and
- To integrate the items into a multi-state "report card" study of mental health system performance in order to generate comparable data across state and local mental health systems.

The Technical Support Group (Ruth Ralph, Jeanne Dumont, Doug Dornan, Priscilla Ridgway and Steve Onken) to this project believe that recovery has its basis in individual self-agency. Services, settings and staff-consumer interactions, however, can facilitate or impede the individual's process of recovery. Our undertaking is one of identifying general indicators of the recovery process itself and general indicators of recovery-facilitating relationships and service environments.

A grounded theory, qualitative approach for generating the data from which to develop recovery-facilitating system performance indicators maintains this focus on self-agency. This approach incorporates grassroots consumer input concerning what they have found that hinders and helps them achieve recovery, along with information on what mental health staff, systems and services do that tends to promote or hold back recovery. This data will be collected using the focus group protocol.

The facilitators of the focus groups will be asking set of open-ended standardized questions to generate the data. The broad domains of recovery that have been identified in the development of this project are serving as the foci for these questions. These domains include resources & basic needs, control & self-determination, independence, relationship or connection to others, and hope.

The importance of this undertaking demands scientific rigor in each phase of developing these recovery-facilitating system performance indicators. The performance indicators resulting from this project will only be as defensive as are the underlying process followed in the development of these indicators. As a first step in establishing scientific rigor, it is critical that facilitators follow the protocol as specified in these materials.

This project has substantial implications in terms of recovery-based quality improvement within the mental health service sector. As such, it will be an invaluable step in the evolution of understanding and advancement of mental health recovery. In addition, the involvement of nine states in this effort provides an unique and invaluable opportunity to gain understanding of regional and cultural variations about what facilitates or hinders recovery from psychiatric disabilities. We are aware of no other work that is advancing these important areas of inquiry.

Focus Group Facilitators

Focus group facilitators will play a key role in the success of this project. States have been encouraged to select co-facilitators to lead focus groups. At least one co-facilitator should be a consumer. At least one facilitator should be experienced in focus group methodology.

Focus groups will basically follow a brainstorming approach, with all comments accepted and respected. The focus groups will be taped, and transcriptions of these tapes will be used for coding and abstracting.

Focus Group Recruitment

Each focus group should have 10-15 mental health service recipients, who will be paid an honorarium for participating in the focus group. The state director of mental health consumer affairs (or equivalent position) should be actively involved in the recruitment and selection of the focus group participants.

Recruitment should be done in such a fashion as to strive for diversity in participants regarding geographic characteristics (urban, rural, suburban), ethnicity/race, sex, level of “recovery understanding” (some who view themselves as in recovery/are familiar with the notion of recovery, some who are not), as well as users and non-users of public mental health services (outside of MH system as system not providing what is needed/desired).

Handout 2: Sequential Activities of the Facilitator and Focus Group

Advance Activities

It is important that facilitators work closely with the organizers of the focus group. Many arrangements and activities can be handled prior to the day of the focus group that will help the process go smoothly.

Facilitators need to familiarize themselves with the focus group logistics and review these logistics with the organizers in advance of the meeting and shortly before the meeting. It can serve as a checklist to help with preparations.

Facilitators should work out an agreed upon agenda with their respective states in advance of the actual focus group meeting. The agenda will determine the length of time of the focus group meeting, information needed to plan for the meeting.

Some states are sending an advanced packet of information to the participants that they are recruiting. Facilitators may find it useful to help to review the materials in the packet. The packet may include such items as an introductory letter, the consent form and the focus group agenda. Familiarizing oneself with the packet may provide such useful information as the contact person for assistance with travel, etc. Such information may come in handy the day of the focus group.

If facilitators do not have an opportunity to participate in a teleconference with the Technical Support Group to help prepare for the focus group, they should carefully review all the written material provided. They can note questions they have and arrange through their state organizer to have a telephone call with Doug Dornan, Jeanne Dumont or Steve Onken. More specific content is covered in the teleconference, such as anticipating the unanticipated, that is not covered in these written materials.

The co-facilitators should talk with each other in advance, reviewing the materials and walking through the process together. Several things can be accomplished, specifically:

- Use this time to plan tasks to assist each other in the actual facilitation of the group. For example, the facilitator who is not the lead on a specific agenda item can be observant as to who is participating and who is not. They can look for opportunities to engage those not participating.
- Agree to review during the breaks how the group process seems to be unfolding - leaders emerging, body language, comfort level, etc.
- Plan together as to how to handle crises that may occur. (For example, track down the telephone numbers for local medical emergencies and the local crisis hotline. Bring these to the focus group meeting.)

Prior to the actual focus group, the facilitators should be able to articulate their roles (the core of which is to guide the group to accomplish the agenda) and the approaches they plan to use to accomplish these roles.

The Day of the Focus Group

Facilitators should arrive at the site at least 60 minutes ahead of time to ensure that everything is in place.

The tape recording equipment should be tested before the start of the focus group to ensure that it is recording. It should also be checked periodically throughout the day during the breaks to ensure that it is capturing the discussion. (In the event of equipment failure, one facilitator should be prepared to take verbatim notes of the discussion. The other facilitator should help pace the discussion to allow this verbatim note recording.)

Please greet participants as they arrive, give them a nametag with only their first names and then offer refreshments. Facilitators can provide copies of the consent form, information sheet, and the agenda to the participants as they arrive.

The facilitators begin by introducing themselves and reviewing the purpose of the meeting. These materials include a suggested opening script that can provide guidance.

The first major task is completing the consent forms (if not already done) and the information sheets. The opening script provides guidance. The main points to keep in mind include reading the consent form, asking for questions, answering any questions and asking several questions about participation to insure understanding (e.g., What are the risks to you in participating in this project?).

Collect the completed consent forms and information sheets. Use the first break to check to ensure that they are fully completed.

The second major task is creating a comfort zone for participation. The opening script provides some guidance. The main points to cover include:

- Have participants do quick introductions.
- Review guidelines for participation including submission of written comments.
- Let participants know that if they decide after hearing a question that they would not like to respond, they are free not to do so.
- Let participants know that there will be frequent breaks, but they are free to take a break at any time if they need to.
- Ask the participants directly as to what makes them feel comfortable and work to accommodate these requests. (Give them some of the responsibility in creating the comfort zone.)
- Acknowledge that most all at the table share the experience of having received mental health services some time in the past.
- Generate interest and enthusiasm for the task at hand.

Once the introduction tasks are completed the facilitators begin the focus group discussion. Facilitators need to write each lead question on the board or newsprint when it is the focus of the

discussion. (Facilitators may want to have these written out ahead of time such that they just flip to that particular page.)

There are several things to attend to in facilitating the discussion and managing the group dynamics. The teleconference will cover these in more detail, including:

- In general it is important to stick to the questions as written. We need consistency in questioning across groups.
- Pace comment generation to ensure that there is time to cover all questions - approximately 15-30 minutes per question area.
- Guide the discussion in such a way as to be sure that each participant has a “roughly equal chance” to answer questions; written submission of comments should help here.
- Ask participants to be specific about their experiences. If someone is generalizing, you may want to ask them to give an example
- If only some participants have spoken ask, “Would anyone who hasn’t said something about this question like to say something before we move on?”
- Before moving on to the next question set ask, “Does anyone have something to add that hasn’t already been said?”

For the first question set, the one concerning resources, do a “round the table” if not everyone has spoken. (Basically just go around the table and ask each participant to name a resource that is important to them to have in their life that gives them control. What you are doing is breaking the ice for anyone who hasn’t spoken up.)

If the group seems to have completed work on one set of questions early, facilitators can move one. The new agenda item may trigger more input regarding an agenda item already completed.

Once each set of questions has been covered, the facilitators move into the wrap-up part of the meeting. The wrap-up includes a brief explanation of the next phases of this project, a sign-up for future participation, distribution of the honorarium, and a review of the items on the “Parking Lot.” The materials in this packet include a suggested script for the wrap-up section that can serve as a guide.

After the focus group is over, take time to sit down and write out your observations of the event. Note what things about the physical environment helped or hindered the process. Note how the group dynamics unfolded – did leaders emerge, how was the flow, what did the comfort level appear to be, describe the interpersonal dynamics, etc. Note what things seemed to work and what things seem to have gone in the way of the process.

Handout 3: Focus Group Logistics

The setting should be familiar and comfortable for most participants and provide a space where people can go out easily to smoke.

The tape recorder should be set up in advance, and there should be someone available that understands its operation. The recorder used should be designed to capture group discussion, having two external mikes. There should be several blank tapes available with the first few already unwrapped.

The facilitators will need to have someone available to help handle meeting logistics at the site (such as payment of the honorarium).

Some refreshments should be available.

Nametag materials and printed copies of the consent form, agenda and information sheet need to be on hand.

There should be index cards and pens available at each seat to provide an opportunity for written input.

There should be a flip chart and markers.

The following focus group guidelines should be written on flip chart paper and taped on the wall:

1. Say what ever you think is true for you, there are no right or wrong answers.
2. Make as many comments as you want to.
3. Respect the person who is speaking, do not interrupt him or her and do not criticize anyone else's ideas.
4. Give everyone a chance to share his or her own ideas, by speaking briefly and being to the point.
5. Speak from your own experiences.
6. Personal information that is shared here, stays here.

We have found it useful to also create a “Parking Space” for things that focus group participants want to talk about, but that may not be advancing the task at hand. A “Parking Space” consists to a blank piece of flip chart paper taped to the wall. It is usually titled as such and decorated around the edges. The facilitator can write down the issue/topic that is raised as a means to table it in a respectful way. The facilitator revisits these items during wrap-up.

It is also useful to create a “PASS” index card, one per participant that is left at each seat. If some one is called upon during the focus group, but feels put on the spot, he or she can hold up or point to the “PASS” card as a means to pass for the time being. (Participants have a right to participate at the level that is comfortable, including being quiet.)

Handout 4: Sample Introduction Letter

[Date]

[Participant Address]

[Participant Address]

[Participant Address]

Dear Mr./Ms. [Participant's Last Name],

Thank you for agreeing to participate in our focus group exploring how people getting mental health services grow, change and claim productive lives in their communities. Many people use the term "recovery" to describe this process.

This focus group is part of a federally funded research project called the 16 State Pilot Indicator Grant. The information you provide will help us develop a survey that asks consumers how the mental health system is or is not helping them in their recovery process.

The focus group to be held at [location, date, time].

Enclosed are a consent form, directions to the location, and an agenda for the meeting. Please read the information carefully. If you wish and you have no questions, you may sign the consent form and send it back in the self-addressed envelope. You will also have the opportunity to review and ask questions about the consent form at the focus group meeting. You may want to wait to sign it until then.

The agenda should give you an idea of the topics we will cover at the meeting. As you will see, we will begin the group at 10:00 and break for lunch at 12:30. Lunch will be provided, then we will resume our meeting from 1:00. There will be short breaks in both the morning and afternoon. The focus group will be completed by 3:00 pm.

If you need help with transportation to the meeting, please call [name and phone number] as soon as possible.

If you have any questions about the focus group, consent form, or anything else, please call [names and phone numbers].

We look forward to seeing you on the [date].

Sincerely,

[names and organizations]

enclosures (#)

Handout 5: Sample Consent To Participate Form

You are invited to participate in a research project that is funded by the federal government and mental health officials within several states that will help us better understand how people getting mental health services grow, change and claim productive lives in their communities. We are asking you to be a participant in this study because of your experience with mental health services. You will be one of approximately 80-100 people participating in small groups across several different states. Once the opinions of people from across the country have been gathered and summarized, a report will be written and a group of national experts will turn the information into a questionnaire that will be used to gain opinions from other mental health consumers about the help they are receiving.

If you decide to participate, we will arrange a time and place to meet together in a group of about 12 to 15 people. In the group, everyone will be describing their experiences regarding topics such as resources, choices, independence, connecting with others, and hope. The group meeting will last about 2 and 1/2 hours, including short breaks. **In the group meetings, we will be audiotape recording and taking notes to make an accurate record of what is said including your comments.** There are no right or wrong answers to the questions that will be raised in the group; the important thing is for you to share your experience and opinions. For attending the meeting, you will receive \$20. We will also help arrange for your transportation to and from the meeting site if you need such assistance.

After the group meeting, we would like to stay in touch with you for two additional activities. We will want you to review our work identifying the major themes of the focus group to make sure that we have correctly captured your comments. We will also want your comments regarding the draft questionnaire items that we develop from this work. On each occasion, you will be paid \$20 for your effort.

Our notes and the information you provide us in this project will be kept confidential. Only the staff involved in this project will have access to the information we collect. This information will be kept in a locked place. No one else will see your responses. We will only report summarized results, so your identity will be unknown. We will not disclose any information that can be identified with you, nor connect your name to any information we present.

Your decision whether or not to participate will not affect any services you now receive or will receive from your local mental health center or any other mental health service provider. If you decide to participate, you are free to discontinue participation at any time. We do not feel that there is any risk to you in participating. Talking about your experience both inside and outside the mental health system may make you feel somewhat uncomfortable. We want you to feel comfortable while participating, you can let us know if you are uncomfortable and you don't have to answer any question that feels uncomfortable, and you can leave the group if you need a break at any time. We think you will probably benefit by participating, because many people find it helps them to talk about their experiences, and because the information you provide may help other people going through experiences similar to yours.

If you have any questions, please ask me. If you have any questions later, I will be happy to answer them. You can reach me at _____. [We will need the name, telephone number and address of the Principal Investigator and a local contact (the facilitator too). We need the statement that if they have any questions or concerns in the future whom to contact as well.]

Your signature indicates that you have read the information provided above and have decided to participate. **Your signature also indicates that you have given permission to be audiotape recorded during the focus group.** You can keep a copy of this form.

Signature of Participant

Date

Signature of Explainer

Date

Handout 6: Sample Focus Group Agenda (with suggested time allocations – see note)

Location:

Date:

Time: 10:00 AM to 3:00 PM

WHAT WE ARE DOING:	TIME:	CLOCK:
1. Welcome Arriving participants greeted Receive name tag for first name Get a copy of consent, information sheet & agenda	As arrive	
2. Introduction by the Facilitators Review the purpose of the focus group Review and complete the consent Review and complete the information sheet Review the agenda and guidelines for participating	30 min.	10:00 to 10:30
3. Exploring Resources	25 min.	10:30 to 10:55
<i>Break</i>	<i>10 min.</i>	<i>10:55 – 11:05</i>
4. Exploring Choices	25 min.	11:05 – 11:30
5. Exploring Independence	25 min.	11:30 – 11:55
<i>Break</i>	<i>10 min.</i>	<i>11:55 – 12:05</i>
6. Exploring Connections with Others	25 min.	12:05 – 12:30
<i>Lunch</i>	<i>30 min.</i>	<i>12:30 – 1:00</i>
7. Exploring Hope	25 min.	1:00 – 1:25
8. Further Discussion	35 min.	1:25 – 2:00
<i>Break</i>	<i>10 min.</i>	<i>2:00 – 2:10</i>
9. Decision-Makers	25 min.	2:10 – 2:35
10. Wrap Up	25 min.	2:35 – 3:00

Note: We suggest that between 15 and 30 minutes are allocated for the core question sets (in this sample, items 3 through 9). We also suggest not starting before 10:00 AM to allow time for participants to arrive and to take into account that some medications affect early morning alertness.

Handout 7: Background Information of the Recovery Focus Group Participants

We are asking you to provide the following information in order for us to be able to have a general description of participants of the focus groups. You are free to skip any question you prefer not to answer. Please do not write your name or address on this background sheet. This helps us keep your identity strictly confidential. The information you do provide will not be linked to any of your comments during the focus group.

Directions: Please circle the answer that best fits your response to the question or write in the answer in the line provided. Only answer those items you wish to answer.

1. What is your sex?

1 = Female

2 = Male

2. What is your age? _____ years

3. What is your race, ethnic or national background? _____

4. What language do you mostly speak at home? _____

5. The town, city or community you live in is:

1 = Urban

3 = Rural

2 = Suburban

6. What is your martial status?

1 = Married

4 = Never Married

2 = Separated

5 = Widow/Widower

3 = Divorced

6 = Living Together/Not Married

7 = Other _____

7. Do you have children?

1 = Yes

2 = No

8. Your level of education is: (Circle all that apply)

1 = Some High School

5 = Some Graduate School

2 = High School Graduate/GED

6 = Graduate School Degree

3 = Some College/Technical Training

7 = Self-Directed Study

4 = Completed College/Technical Training

8 = Other: _____

(Please continue on the backside.)

Handout 8: Suggested Script for Starting the Focus Group

Hello, our names are _____ and we have been asked by the _____ to conduct this focus group session. [Like many of you, I have also received mental health services.]

You have been asked to participate in the development of a measure that captures the things we need to be doing to create environments where people getting mental health services can grow, change and claim productive lives in their communities. Many people use the term “recovery” to describe this process of growing, changing and claiming our place back in our communities.

We are asking for your input on several occasions as we develop this measure: (1) today in person during the group discussion and then by mail or phone (2) when we have organized the information you shared with us today and (3) when we create the items for the measure. You are free to choose how much you would like to participate. Your level of involvement is up to you.

Today we will conduct a discussion about what helps and gets in the way of your living your life - surviving and thriving.

First we need to review the consent form. I will read aloud the form.

[Note: Facilitators read form, ask if there are any questions, respond to the questions and ask participants to sign the form. Participants are free not to sign the form; they are thanked and asked to leave at this time.]

Now I would like you each to take a few minutes to complete the Information Sheet. This information is being collected at all of the focus groups. We will summarize the information in order to provide a general description of all of the focus group participants. Let me know if you have any questions.

[Note: Facilitators answer any questions and assist as needed. They collect the forms once the forms are completed. During the first break, the facilitators should review the Information Sheets to ensure that they were completed.]

Now that those tasks are over, let’s take a few minutes and have each of you introduce yourselves. Please just use your first names.

[Note: Use this time to create a comfort zone for participation.]

Before we begin the focus group, there are a few guidelines we’d like you to follow. The guidelines are 1. Say what ever you think is true for you, there are no right or wrong answers. 2. Make as many comments as you want to (we are trying to generate as many responses as possible). 3. Respect the person who is speaking, do not interrupt him or her and do not criticize anyone else's ideas. (We can ask each other for clarification though, if we need to). 4. Give everyone a chance to share his or her own ideas, by speaking briefly and being to the point. 6. Speak from your own experiences. 7. Personal information that is shared here, stays here.

Does anyone want to add any rules that will make them feel comfortable participating?

[Note: Often people will say they want what is said in the room to stay in the room. This gives people ownership over the rules. Posting the rules is good because if someone is monopolizing or criticizing another person's input then the facilitator can point to the rules and remind him or her gently-- "this is what we all agreed to."]

[Facilitators can cover any other tools that they have posted or distributed, such as the "Parking Lot" and/or the "PASS" card.]

Let's go over the agenda at this time.

[Note: Briefly review the agenda. If other topics or issues come up, use the Parking Lot as needed. Participants will be more willing to attend to the task at hand if they know that time will be taken to address some of the things that are immediately on their minds.]

Now we can begin the focus group discussion.

Handout 9: Agenda Question Sets

Question Set #1:

What resources are important to you to have control in your life?

What helps you get these resources?

What gets in the way of getting these resources?

Question Set #2:

What choices are important to you to have control in your life?

What helps expands your choices?

What stands in the way of having choices?

Question Set #3:

How do you or what helps you gain independence in your life?

What gets in the way of gaining independence in your life?

Question Set #4:

How do you or what helps you get connected and stay connected to other people?

What gets in the way of getting and staying connected to others?

Question Set #5:

How do you or what helps you gain hope in your life?

What gets in the way of gaining hope?

Question Set #6:

How have mental health staff and mental health services helped or hindered you in your life with gaining resources, choices, independence, connections with others, and hope?

Question set #7 (final question):

If you were giving advice to the mental health decision-makers in your state, what things would you tell them that they *or staff* could do to make your life better?

Probes and Prompts:

Be sure to let a participant complete his or her thought before you probe.

If someone asks what is meant by “control” “choices” “hope” etc., say, “Whatever it means to you.”

Specific probes and prompts include the following:

“That’s something we’re definitely interested in hearing more about. What can any of you tell us about that?”

“How has this played out in your life?”

“Tell me more.”

“I am not quite following you, could you provide me with an example?”

“Does anyone have a similar (or different) perspective?”

“Tell me what it was like.”

“You look puzzled.”

“You look like _____.” (you have something to say, you have a different point of view, etc.)

“Could you tell me a short story about that?”

Handout 10: Suggested Closing Script

We have now completed the focus group discussion. I want to thank each of you for your participation. I do want to take some time to explain what happens next, and then review what we have listed on the “Parking Lot.”

While I am talking, a piece of paper is being passed around so you can indicate a way you can be reached for follow-up commenting. Please provide your name, address, phone number and an email address if you have one. As we said before, you may choose whether or not to participate when the time comes.

What happens next?

The tape of this meeting will be transcribed. The transcriptions will then be coded to as key statements, items and themes. We will be sharing this work with you to check whether the things we have identified give the information that you feel is important. This may be done by telephone or by mail. You will receive an honorarium for helping.

After this step is completed, we integrate the work being done by the focus group across nine states. We will then generate the items from this work for the actual instrument. We will want to have at least five consumers in each state review the items and talk to us about what the items mean to them, and if each item does measure what it looks like it should measure. Again, you will receive an honorarium for helping.

Any questions?

All we have left to do is cover the topics listed on the “Parking Lot.” For those of you who are done, you are free to go. Be sure to pick up your honorarium from [name] before you go. Again we want to thank you for your help!

[Note: The facilitators then cover the topics/issues/items that are listed in the “Parking Lot.”]