



Participatory Dialogues

A Guide to Organizing Interactive Discussions on Mental Health Issues among Consumers, Providers, and Family Members



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Substance Abuse and Mental Health Services Administration
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— Gayle Bluebird
Author

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Foreword

The Center for Mental Health Services (CMHS), a part of the Substance Abuse and Mental Health Services Administration (SAMHSA) was created in 1992 to meet the need for an entity within the federal government that focuses on real-world experiences, services and evaluation. CMHS works to promote mental health and prevent the development or worsening of mental illnesses when possible. Changes in the public mental health care system are affecting both mental health consumers and practitioners. Mental health care is focusing less on stabilization or custodial care, and more on rehabilitation and recovery; part of this new focus is to involve consumers more than was customary in the past. The widespread adoption of managed care programs and new technologies (particularly changes involved in approaches to medication), along with the continuing problems of discrimination/stigma associated with mental illness, offer tremendous ongoing challenges to the ability to provide high quality mental health care. Current conditions make it important more than ever to establish partnerships — not just building one-to-one relationships, but also creating lasting, productive alliances at both the system and policy level.

Through dialogue people can come together for a mutual exchange of ideas, observations and experiences. Dialogues go beyond the usual interactions between practitioners and recipients of mental health services. They provide a safe environment in which participants may speak freely to create better understanding and mutual trust and respect.

For the first time ever, this participatory dialogue manual, developed by mental health consumers, offers a blueprint for action. It describes the benefits of dialogue meetings and provides easy-to-follow detailed specific action steps on how states, local communities, providers, managed care organizations, advocates, family members and consumers can organize meetings to develop working partnerships to improve mental health service delivery. The goal is to bring all stakeholders together on a level playing field and to develop the kinds of partnerships that are needed to improve mental health services.

CMHS has successfully initiated a number of consumer/provider dialogues using the methods outlined in the manual. After each dialogue, participants remark about the value of the dialogue and the impetus the dialogue has

provided to instill changes, initiate additional programs, and examine the insights offered.

Dialoguing, communicating, and partnering are ongoing processes. These dialogues offer hope for a foundation of sincerity and openness that will lead to significant improvement of mental health services because both providers and mental health consumers are effectively communicating and discovering the importance of such a unique collaboration.

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Introduction

“Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it’s the only thing that ever has.”

— MARGARET MEAD

In July 1997, the Center for Mental Health Services convened a two-day meeting in Arlington, Virginia, *Consumers and Psychiatrists in Dialogue*. The meeting brought together twenty individuals who were equally divided between current and former recipients of services (consumers), and psychiatrists from all over the United States. This historic meeting provided opportunities for people to explore uncharted territory through communication exchange. The meeting was a success, measured by the reported feedback from those who participated.

It was recommended that dialogues be replicated among other constituencies at state and local levels, and for a written report to be distributed to a wide mental health community. Another recommendation was to create a manual for people to learn how to create similar dialogues. This volume is in response to that last recommendation.

Background

Dialogue is not a new concept. Participatory Action Research, twenty years ago, created a new paradigm for the conduct of research using dialogues nationally and internationally.

In the mental health arena, three roundtables were convened in 1989, by the Community Support Program, under the National Institute of Mental Health,

to discuss the issue of involuntary treatment. These three meetings (held first with consumers, then psychiatrists and consumers, lastly with consumers, psychiatrists and family members) were the inspiration for a conference model, *Pioneer Dialogues*, the first of which was held in Broward County, Florida, in 1992. The two-day dialogue conference was held at South Florida State Hospital, bringing consumers and professionals together to discuss basic consumer issues and strategies.

In other parts of the country, similar dialogues were being held. New York State convened a series of *Recovery Dialogues* between psychiatrists and consumers. Darby Penny, New York's Director of Recipient Affairs, describes one of these dialogues in the manual. Dialogues were also organized between state commissioners of mental health and mental health consumers under the direction of Ann Loder, consumer advocate from Florida, while working with the National Consumer Policy and Research Workgroup.

Why are Dialogues Important?

First, there is general agreement that the mental health system needs to change. Consumers have been talking for years about what the problems are, expressing anger about mistreatment in the name of treatment. Consumers have received support for some of these viewpoints. Today, there are innovative programs, many of which are directed by consumers, jobs that have been created, and new policy development that has been influenced by consumer input. Yet, it just isn't enough. The mental health system has had its equal share of failures and advances. The climate of the general community is more volatile than ever; violence on the rise is often attributed to mental patients. Approaches are being considered that may further put consumers at risk for increased involuntary treatment. Consumers need to talk about issues from their different perspectives in order to develop workable solutions that will assure consumer survival.

To Talk About Differences, There Must Be a Partnership

Dialogue can be a first step toward establishing partnerships between people who agree to listen to each other. They offer opportunities for people to exchange their beliefs with others while simultaneously having a deep, private conversation within themselves. A dialogue is a way of healing, opening the possibility for gaining new trust and understanding. When people understand each other, they are able to work together and create partnerships. Ultimately, however, the success of a dialogue rests with the individual whose life has been changed.

Pilot Dialogues

In order to determine whether the steps outlined in this manual were adequate or complete, two pilot dialogues were held in Pittsburgh, Pennsylvania, and in Palm Beach County, Florida, both during the Spring of 1998. Each differed in the dialogue model that was used. Pittsburgh used the roundtable model; Palm Beach County used the conference model.

New approaches that worked in previous dialogues have been added to the “how-to” steps in this manual. Approaches that did not work were considered just as valuable, because they could be used as examples of what not to do. You will find many references to the pilot dialogues throughout the text.

Other dialogues mentioned in the text are: the Pioneer Dialogues held in Broward County, Florida (1992–1995), a dialogue between psychiatrists and consumers held in Arlington, VA (1997), and Recovery Dialogues held in the state of New York. Nebraska is used as an example, several times, to illustrate the difficulties of organizing a dialogue in a rural state.

About the Manual

Although articles and reports have been written describing the benefits of dialogues, writing about them is not the same as organizing them. The goal was to create a practical manual with simple, concise, information that anyone could use. Steps are included that talk about everything from location selection to how to plan meals. Two models of dialogue are presented, the conference model, and the roundtable model. Most of the steps in this manual are applicable to both models, but specific steps for the conference dialogue have been added. Examples in the form of vignettes have been added to most of the steps, as well as tips that can be helpful.

Dialogues are also an art form, a variation on *the art of conversation*, in which listening is as important as talking. A short narrative tells you how to be a good listener. Another form of dialogue is communication on the Internet. A chapter explains how to use it and also lists Web sites for discussion of mental health issues.

The manual is for anyone to use. The main issue presented is mental health, but most of the guidelines will also work for other groups. The population that is the minority, or who has the least power, should take a lead in planning a dialogue as much as possible. In a mental health dialogue, consumers should take the lead. Consumers are the reason for the dialogues because consumers

are the subject of the dialogue. Creating a forum for equal exchange is a goal, but it should not be forgotten that one of the primary reasons for dialogues is for professionals to learn more about consumers from consumers.

The Art of Listening

A good dialogue requires you to be a good listener. Sadly, many people do more talking than listening. Even while listening, we are thinking about what to say, or we are listening to what's going on in our own head rather than what is being said by the other person. Many of us want to talk, but few of us really listen.

The first step in being a good listener is to be truly interested and concerned about the other person. Start listening from the beginning. Clear your mind from other distractions and focus on what the other person is saying.

Listen Objectively

If you listen with the intention of taking issue with what the other person is saying, you will not be able to understand what the person is saying under any circumstances. Good listening requires that you suspend judgment, cut through emotional barriers, and keep an open mind.

Listen for the Main Idea

New information requires that you understand the point the other person is making. However, sometimes the speaker may not be clear enough to be understood. Ask questions for clarification. Make sure you can summarize the gist of the message when the person is finished speaking.

Listen for Details

Specifics of a message are much more difficult when they involve names, dates, places, facts, and figures. Try to remember which details are important, but make sure that you don't pay so much attention to details that you lose the overall concept of what is being said.

Listen to What is Not Being Said

Be aware of body language, tone of voice, eye contact, and gestures. It is often what is *not* said that conveys the true message of what a person is saying. Your own body posture and attentiveness will influence what and how

the person conveys information. Assume a posture of attention. Look at the person while he is talking. It may not improve your ability to listen, but it may have an effect on the other person.

Language Used

The generic term consumer has been used for persons who have or are currently receiving mental health services. It is used only when necessary, because it has been the most accepted term, not because it is the most popular. Other terms such as *consumer/survivor/ex-patient* might have been used, but adding words may be cumbersome. Most often, the words “people” or “persons” are used for description.

Dialogues are being conducted all over the country, in many different ways. They are being used as part of research and evaluation, to evaluate consumer satisfaction, and to train staff in mental health agencies and hospitals. There are many other possible purposes. Let this guide inspire you to create other dialogues. How they take shape is up to you. Last word: *Have fun creating your dialogue! Have fun using the manual!*

What is a Dialogue?

“An ounce of dialogue is worth a pound of monologue.”

— LEONARD RAY FRANK

A dialogue is a forum in which two or more groups of people are brought together as equals to explore their differing views, experiences, and belief systems, in this case, about mental health topics and issues. A dialogue is structured to allow for exploration of one’s own perceptions and attitudes, as well as to listen to other people explore their own.

All dialogues have the following common goals and objectives:

- Create better understanding and mutual respect among consumers, family members and professionals.
- Allow participants to speak from their experiences and belief systems in an atmosphere of safety.
- Create partnership ventures through compromise and consensus.
- Change attitudes and practices in the mental health system.

Dialogues Promote:

- Listening
- Serious inquiry
- Risk taking
- Curiosity
- Healthy conflict
- Openness
- Diversity inclusion
- Consensus building
- Empathy
- Understanding

But Discourage:

- Assumptions
- Being judgmental
- Argumentativeness
- Divisiveness
- Closed-mindedness
- Hidden agendas
- Uniformity

Different Models of Dialogues

Roundtable Dialogue

A Roundtable Dialogue is an open discussion group with 20–25 participants. It brings people together who have different perspectives on mental health topics and issues. The group may consist of two or more specific groups. The Roundtable relies on a respectful facilitator or co-facilitators who treat people as equals and are sensitive to individual needs.

Conference Dialogue

The Conference Dialogue combines speaker presentations with small group dialogues. The audience may include up to 125 people who gather as a group and break up into smaller groups (up to 25) where participants interact as equals. The Conference Dialogue may be used as an annual event to honor our accomplishments, to educate, and to involve a particular aspect of a mental health system.

Both styles of dialogues are intended to help people to understand each other by talking over differences and sharing similarities in life experiences. The results are improved relationships which can help to establish partnerships within the mental health system.

Both Dialogue Models Include:

- Participant guidelines
- Facilitator guidelines
- Goals and objectives
- Participant selection guidelines
- Time for networking
- Conduct guidelines
- Plan for shared meals
- Timekeepers
- Time for strategies
- Evaluation forms
- Participant packets and name tags

Conference Dialogue Model Only:

- Requires more funding
- Planning takes longer
- Agenda more detailed
- Uses speakers/panelists
- Include arts and entertainment
- Small pre-set dialogues
- Uses more volunteers
- Requires brochure
- Location needs differ
- “Open microphone”

Develop the Dialogue

Organize a Committee

- A lead person from an agency will initiate the dialogue. This person may later become the coordinator of the dialogue.
- Keep small, approximately five to six people. Too many people on the committee will be confusing and make it harder to complete tasks on time.
- Include representatives of key constituency groups. Make sure consumers are on the planning committee.
- Always include primary consumers (direct recipients of services), as the dialogue is intentionally established to hear their views; however, a family member may be included, if applicable.
- Select people who have organizing abilities, writing skills, and fundraising experience.
- The sponsoring agency should be represented whenever possible. The agency should be able to provide secretarial support and other technical assistance, including the ability to fax, send mailings, and print copies.

Tip:

The need for a small planning committee cannot be emphasized enough. Sometimes people feel that it is important to be inclusive of more representatives on the planning committee, but it is better to keep it small to ensure that assigned tasks are completed.

Other selection criteria to be considered:

- Enthusiasm about the dialogue.
- Familiarity of members, i.e., do committee members know each other?
- History of working together (because individual strengths and working styles will already be known).
- Commitment to meet the demands of frequent meetings and tasks.

If planning a dialogue from long distance, committee members may meet by conference calls and e-mail. Long-distance planning creates other considerations such as whether a face-to-face meeting is indicated, how to delegate responsibilities, participant selection, etc.

Organizing a dialogue can be a long, tedious process that requires committee members to build trust. The planning process involves ongoing and open communication between the committee members and is often a learning experience as significant as the event itself.

The committee determines:

- The purpose of the dialogue
- Groups to be represented
- Length of dialogue (one or two-day meeting)
- Whom to invite
- Date, location, and time
- Type and model of dialogue (Roundtable or Conference)
- Selection and choice of coordinator and/or co-coordinators (It is helpful to have two coordinators because they can share responsibilities and one can take over for the other if necessary)
- Dialogue agenda

The coordinator(s):

- Demonstrate leadership
- Do the majority of the work
- Bring information to the committee for decisions
- Set agendas and time-lines for completion of tasks
- Keep the committee's work on schedule
- Serve as primary spokespersons for the event
- Make on-the-spot decisions when necessary

It is not so important that everyone on the committee agree on ideologies; however, it is essential that they are able to compromise, build consensus, and work together.

Tip:

The committee may want to add additional people for specific tasks, but the nucleus group should remain intact for consistency, to make major decisions, and to keep things running smoothly.

The committee should allow two to four months to plan a Roundtable Dialogue, and at least four months for a Conference Dialogue.

Choose a Title and Theme

Choose a broad theme or concept for a first dialogue, such as recovery, mental illness, partnerships, or stigma and name accordingly.

Subsequent dialogues are more specific and focus on defined issues such as the criminal justice system, homelessness, state hospital closings, or outpatient commitment.

Keep the title short, concise, and catchy in order to grab attention.

Examples

- The planning group in Pittsburgh, Pa. (March 1998) named their dialogue, “Talking with Each Other: For a Change.” The sub-title was a double entendre. “Finally we are talking together instead of not communicating, AND getting together to talk, pointing out the way to change.”
- “Pioneer Dialogue” was the name given to the first Conference Dialogue held in January, 1992, in Broward County, Florida. The word “Pioneer” was chosen because, as defined in Webster’s Dictionary, pioneer is a “group originating a new idea,” and because of a second Webster’s Dictionary definition, of “a plant capable of establishing itself in barren soil.” “Pioneer Dialogues” has become a common name that other organizations are using in other parts of the country.
- Palm Beach County, Florida (June 1997) used the “Pioneer Dialogue” trade name with the sub-title “The Experience of Recovery.” Their second Pioneer Dialogue in 1998 dealt with more specific issues and was called, “The Health of the Mental Health System and How it Affects You.”

PITTSBURGH, MARCH 1998

***“Talking with Each Other:
For a Change”***

BROWARD COUNTY, FLORIDA, 1992

“Pioneer Discussions”

**PALM BEACH COUNTY, FLORIDA,
1997**

***Pioneer Dialogue
“The Experience of Recovery”***

Focus Questions can be developed to yield information that is desired from the dialogue. The committee should be careful to construct only broad questions, **since the specifics of topic discussion should come directly from the participants in the dialogue.**

Example

- Three roundtable discussions were convened in 1991–1993 by the National Institute of Mental Health’s Community Support Program.

The meetings focused on the subject of involuntary treatment and five basic questions were developed prior to the meetings, as follows:

1. What are the involuntary interventions used by the mental health system?
2. How and why do people get treated against their will?
3. How do involuntary interventions affect people who experience them?
4. What are potential alternatives to involuntary intervention?
5. What are the implications of answers to questions 1–3 for research, training, and program development.

Develop the Budget

A budget must be created with estimated costs for the dialogue.

Find out first if all needed funds are available or if fund-raising will be necessary.

Determine whether a written proposal with narrative and budget is required.

Suggestions for Possible Funding

GOVERNMENT FUNDS

Government agencies are often interested in using funds for dialogues. In fact, many of the dialogues that are discussed in this manual originated at the state or federal government level. There may be discretionary funds at the end of the fiscal year that agencies are eager to use.

PARTICIPATING AGENCIES

Ask participating agencies to contribute funds or in-kind support. Collaboration with participating agencies helps to insure the dialogue's success.

PRIVATE FUNDS

Consider private funds or local foundations. Check the library for foundation listings.

NO FUNDS

It is possible to use an agency conference room requiring no funds at all. Have everyone chip in for a pizza or similar lunch.

Sample Budget Items

- Site location
- Meals/refreshments
- Coordination
- Organizer of dialogue
 - Facilitator fees
 - Travel expenses
- Audiovisual equipment
 - Documentation fees
 - Printing
- Mailing and postage
- Hotel accommodations
 - Recorder fees

Two Dialogue Budgets:

(Note that the two different styles of dialogues vary in expenses.)

Total amount spent on Pittsburgh Pilot Dialogue, March 1998: \$2,200 (Roundtable Dialogue)

This was an all-day dialogue for 25 participants.

Following is a breakdown:

- Room rental at hotel (included breakfast and lunch) \$ 1,000
- Recorder/documenter \$ 500
- Report duplication/mailings/postage \$ 500
- Travel expenses \$ 200

Funds for the above dialogue were raised through the Office of Educational and Regional Programming in the amount of \$1,000 and \$500 each came from the Pennsylvania Providers Association and the State Community Support Program.

Commentary from Pittsburgh organizer/consumer, Linda Morrison: “We probably could have done it cheaper, but we were in the belly of the bureaucracy and we had a good marketer. There were no strings attached to the money.”

Total amount spent on Pioneer Dialogue on Crisis Alternatives, 1995: \$3,000 (Conference Dialogue — Fort Lauderdale)

This was an all-day dialogue for 100 participants. Following is a breakdown:

- Unitarian Church (included six breakout rooms) \$650
- Breakfast (juice, coffee, doughnuts) \$ 375
- Keynote speaker (honorarium and transportation) \$ 600
- Happy hour foods \$ 500
- Lunch (provided by Mental Health Day Treatment Program) \$ 0
- Mailings, postage, brochure development \$250

Funds for Pioneer Dialogue on Crisis Alternatives included approximately \$1,500 allocated by government adult mental health funds. Two local hospitals, the State Protection and Advocacy Center, and a community mental health center provided the balance of the funds. In addition, family member groups volunteered to serve food and provide desserts for lunch.

We have provided you with only two sample budgets; however, there have been many dialogues, each with their own variations.

“Funding has to be in place . . . “

Note

In Nebraska, a planning committee was formed to create a dialogue which never got off the ground because the funding was not in place. In retrospect, one of the planners concluded: *“Funding has to be in place . . . and only when funding is in place can you operate as a planning committee.”*

Set up the Meeting Logistics

Set up:

- Day
- Date
- Hours
- Location
- Meals
- Breaks
- Smoking areas

Day and Date

- Select a day that meets the needs of most participants.
- Consider providers’, administrators’, consumers’ preferences.
- Consult a calendar for already scheduled conferences.
- Note that air fares are cheaper when the weekend is included.
- Decide on a start and finish time (consider traffic patterns during business hours and people’s family needs).

Friday is a good day, since it is easier for provider agencies to give staff leave at the end of the week, and it is the best day to accommodate out-of-town guests. It is also a good day to extend social networking after the dialogue and for out-of-town guests to make plans with friends over the weekend.

Tip:

Select a Location

A **Conference Dialogue** requires a large central meeting room plus break-out rooms with circular seating for small group sessions. This site must be able to support the total number of desired participants. For example, if the total number is 100, at least five break-out rooms are needed. Frequently, locations are considered ideal for the conference in every respect except for adequate

rooms for the dialogue sessions. At some conferences, outdoor space has been used or rooms usually used for other purposes or a large meeting room broken into sections.

A Roundtable Dialogue requires a large meeting room with people seated at a table in a rectangle or square. It is important that all participants can see each other.

An ideal site has:

- Adequate lighting (windows important)
- Adequate rest rooms
- Wheelchair accessibility
- Kitchen space (optional)
- Coffee makers available
- Electric outlets
- Parking
- Transportation to and from airports
- Good acoustics
- Comfortable chairs
- Public transportation accessibility



Hotel Settings

The selection of a site will be dependent on the budget. Select a hotel if there is enough money in the budget. Hotels are desirable because they are convenient. Arrangement of meeting rooms and other details are automatically taken care of, and meals are prepared and served.

Note

Costs vary from city to city depending on the size. Meeting rooms vary greatly in price depending on the facility. Time of year affects rates. (Areas that attract tourists in the summer may lower rates in winter, and vice versa).

CHECK THE FOLLOWING BEFORE SELECTING A HOTEL

- **Parking space and fees** — Check to see whether the hotel offers a discount or free parking for conference participants. Also make sure there are adequate parking spaces.
- **Hidden costs for extras** — It is important to ask whether there are additional costs for microphones or other special equipment.
- **Acoustics** — Make sure the rooms have adequate acoustics so that people can hear each other.

- **Accessibility for disabilities** — Check for accessibility for wheel-chairs, sign language, guides, etc.
- **Food** — Be sure to check menus and costs. Most hotels will let you sample food in advance. Some will even offer a free meal for this purpose if you ask.
- **Staff friendliness and helpfulness** — Does staff take time to answer your questions? Do they return your phone calls in a timely manner? Do they offer suggestions? Does your intuition tell you that they will be friendly and helpful to the participants who attend the dialogue?
- **Centralized location** — Is public transportation accessible, close to participants' homes, and near the airport?
- **Surroundings and furnishings** — Are surroundings pleasing to the eye? Are they comfortable and inviting?
- **Directions to the hotel** — If you choose a hotel make sure you ask for written directions and a map to include with the invitation. Most hotels have these available including directions from the airport, and to restaurants near the hotel. Nothing is more frustrating than to have participants circling streets in a busy commercial area only to arrive at the meeting late, totally exasperated.

Check to see if there are potentially loud conferences scheduled at the same time as yours. There have been problems with concerts, gospel sings, and rallies that can interrupt a dialogue from an adjacent room.

Tip:

LOWER COST ALTERNATIVES

- Agency boardrooms and conference rooms
- Colleges/educational centers
- Training rooms in banks, companies, hospitals
- Public libraries
- City Hall
- Schools (generally available only when school is not in session)
- Churches (not usually advised if religious icons are present)
- Community centers
- Homes are a possibility if nothing else seems workable.

Tip:

Weigh the pros and cons when choosing a location. Make sure you look at several locations and do a comparison on rates and other features. Note that even alternative locations charge a fee, although there are a few exceptions, so don't rule them out. Note also that reservations will be required far in advance for whichever location you choose. Ask around for recommendations. Your best bet is taking the advice of someone who has used a particular hotel or alternative space. They can advise you of any potential problem areas.

Examples of site selections

- In Palm Beach County, Florida, the Mental Health Association held two successive conference dialogues in 1997 and 1998. The first dialogue was held at a United Way office. The second year dialogue was held in a hotel. The conference organizers were all in agreement that the hotel setting was better although more expensive. Tom Menard, one of the planners, stated: *"What we lost in money, we gained in less stress."*
- The Pittsburgh Pilot Roundtable Dialogue planners chose a hotel. Generally speaking, everything was ideal. However, there were two problems. First, the planning group forgot to give instructions on how the room should be set up. As a result, the beginning of the dialogue was delayed. Second, this was one of the meetings during which there was loud noise in the next room.
- The original "Pioneer Dialogue" in Broward County, Florida, would not meet any of the standards for comfort as have been set forth in this manual. The conference site was situated far from where most of the attendees lived. The chairs were straight back and uncomfortable, the acoustics were terrible (an old air conditioner went on and off making it almost impossible to hear) and break out rooms for the dialogue sessions were far away from the general meeting area. Despite these drawbacks, the conference dialogue was a major success! Everyone loved it because it set precedents for involving an entire community to make changes in the mental health system.
- A high school was selected for a "Pioneer Dialogue," for which there was no charge. All criteria were met with only one drawback. The size of the auditorium was too large for the audience, which filled only one fifth of the room. The problem did not become apparent until the day of the dialogue when people spread to all areas of the auditorium, some at the entrance, and some near the stage. The meeting was difficult to hold together, though in many ways the site was ideal.

Sometimes you try an alternative location, the next year a hotel, and compare . . .

Sometimes the site appears perfect, but gaps in planning can disrupt . . .

Sometimes a site appears marginal, and "it works" . . .

Sometimes a site that has no costs, has costs (if it is not working) . . .

And *sometimes* it all comes together.

- One of the best site selections was for the 1996 Pioneer Dialogue, Broward County, that was held at a Unitarian Church which offered pretty grounds with flower gardens and trees and a large patio off the main meeting room. Break-out rooms were adequate. Generally speaking, churches are not recommended they may be offensive to some who are non-religious. Unitarians are a secular congregation, consequently the meeting rooms were acceptable to all participants. The rental cost was also reasonable. All in all, this may have been one of the nicer settings for a conference.

Select Participants

Invite people who will contribute to the dialogue and who will be affected by the outcome. Selected individuals should have good communication and listening skills, and have expressed an interest in participating in the dialogue exchange.

A **Roundtable Dialogue** should be composed of no more than 25 (preferably 20) people. A 20-person dialogue should be equally divided among consumers, providers and/or family members.

A **Conference Dialogue** may not have equal ratios. A 30–40% consumer representation may be adequate if the goal is to educate providers. Make sure that consumers share lead roles.

Note

Consumer and provider definitions may be interchangeable. Some consumers are providers and vice versa. The definition of a consumer used in this manual is a person who has received direct services in the mental health system and who openly defines himself/herself as an advocate for other consumers.

Consider the Following

- Should only those consumers who can articulate an ideology be invited?
- Should non-verbal consumers be invited?
- Should consumers be invited if staff members from their agency are participating, creating possible power imbalances?

These are issues to consider, but generally speaking, we recommend that participants should be verbal and have some opinions on issues. Occasionally someone will make a comment, “*The dialogue doesn’t represent all consumers.*” Usually, when one hears the stories of dialogue participants it becomes evident that they were not as articulate as they are now.

Key Factors in Selecting Participants

- Cultural backgrounds
- Geographic representations
- Background in leadership
- Political perspectives
- Employment-related diversity
- Gender
- Sexual orientation
- Age considerations
- Physical abilities
- Socio-economic backgrounds

In Nebraska, the planners were concerned about whether they had enough consumers who were ready to participate in a Roundtable Dialogue. J. Rock Johnson, a consumer advocate, made the following observation: *“It becomes obvious to me that dialogues are not designed and may not be suitable for ‘bootstrap’ situations such as ours. The expectation is that there is an existing pool of consumers who are self-assured, articulate, and can be at ease with authority figures. My thinking was that we could use this vehicle to help find persons with potential and help develop them. That is still our intention.”*

“. . . dialogues are not designed and may not be suitable for ‘bootstrap’ situations such as ours.”

DIVERSITY

It is important to reach out and include as many people as possible from different racial and cultural backgrounds. Perspectives on mental health differ greatly, and people of color have been discriminated against, not only in society, but in the mental health system as well. Sometimes they are added as an afterthought. Jacki McKinney, consumer advocate (PA) states: *“Most of the time, no matter how large or small the meeting, there’s only one or two people of color present. I am excited, as I see that dialogues can be used as a positive tool to correct this.”*

“. . . no matter how large or small the meeting, there’s only one or two people of color present . . . I see that dialogues can . . . correct this.”

In Arlington, Virginia, a dialogue between psychiatrists and consumers, in 1997, included a diverse group of people who were Asian, Polynesian, African American, as well as people with differing sexual orientations, religious and age backgrounds. Janet Foner, consumer advocate from Pennsylvania, stated: *“The inclusion of persons with so many different backgrounds made it a truly rich experience.”*

“. . . different backgrounds made it a truly rich experience.”

OTHER CONSIDERATIONS

Consider whether to invite an individual who has a history of grandstanding or being hostile or disruptive at meetings. While it is important to be inclusive of all viewpoints, it is also important to ensure as much as possible that participants are not going to be disruptive. Talk to an individual before inviting him/her, define the problem, ask for cooperation, and ask for an agreement to follow guidelines. If the person agrees, fine; if not, reconsider the invitation.

Example

- The planning group from Pittsburgh was worried that a potential invitee might not be able to be objective at the meeting and decided to discuss it with the individual ahead of time to express their concerns. The person agreed to follow the guidelines, was invited, and only had to be reminded once that *“a dialogue is not a debate, and every person’s opinion is valid.”*

PITTSBURGH

“. . . a dialogue is not a debate, and every person’s opinion is valid.”

Finally, the Pittsburgh dialogue raised the question regarding the presence of observers. It was clarified that **all participants should be full participants**, not observers.

The Invitation Letter

Invitation Letter:

- Who
- What
- Where
- When
- Why

An invitation should be sent well in advance of the dialogue.

For a **Roundtable Dialogue**, the letter is sent to individuals who have been pre-selected by the committee. The letter should specify pertinent information.

- **Who** — The name of the sponsoring organization
- **What** — The event (title of the dialogue)
- **Where** — Location of the event, including, address, phone number, fax, and e-mail, if possible
- **When** — Day, date, and time
- **Why** — Objectives, specific goals for the meeting

Make sure to mention if there are any costs involved and whether meals are included. Request that casual clothes be worn. Also, ask if there are any special needs requiring accommodation. After all the pertinent details of the event are given, an RSVP should be requested with an expected date of return.

For a **Conference Dialogue**, an initial notice should be sent to mental health agencies, selected individuals, and other facilities to alert them about the upcoming dialogue. Later correspondence will include a brochure that provides more detailed information (See illustration of a brochure in the conference section).

Plan Meals

Meals are an important part of the dialogue. Plan meals that keep the group together so that people can socialize with each other and network to exchange information. Participants should be told in advance that meals are part of the dialogue.



Selecting Foods

CONTINENTAL BREAKFAST

Coffee, juice, muffins or sweet rolls. Make sure there are selections with little or no sugar such as fresh fruit. Set a cutoff time for coffee in order to minimize distractions during the dialogue.

BUFFET STYLE LUNCH

Simple foods such as sandwich ingredients, cut-up vegetables, finger foods, and salads are good choices. Make sure that vegetarians and people with special diets are accommodated, including persons with religious restrictions. A choice of beverages may include iced tea or lemonade.

Food Preparation

Food can be prepared at the dialogue if the site includes kitchen facilities. However, make sure that participation in the dialogue is not compromised by persons who are involved in food preparation, and that the kitchen is far enough away from the dialogue to avoid distractions. A special committee may be appointed to take care of the food and all of the tasks involved. Another option is to have food prepared in advance and delivered.

Tip:

Serve food attractively. Extras, such as flowers on the table, are nice additions to make the occasion memorable. Have bag lunches made (even a hotel will make them) with a sandwich, potato chips, piece of fruit, and a lollipop. (Lollipops were added to one of the “Pioneer Dialogue” lunches and were a hit!)

Use Volunteers

Recruit volunteers from the invited participants to perform a variety of tasks. This maximizes participation and helps to make participants feel like they are an important part of the planning process. Volunteers can help prepare food, design a brochure, set-up rooms, greet, video or audiotape the conference, keep time, etc.

Note

Use consumers as volunteers whenever possible. Try to pay stipends for performing a variety of tasks. Be creative . . . use volunteers as photographers, “taxi drivers,” ushers, etc. We call stipend volunteers “paid volunteers.”

Technical Considerations

Flip Charts

- Write in bold capital letters
- Use dark colored ink
- Number each page for reference
- Use colors for highlighting
- Keep one idea heading per page
- Post on walls for easy reference
- Pre-cut masking tape and put tape on sides, not top, to remove it easily

Video/Audiotape: “To Tape Or Not To Tape”

ROUNDTABLE DIALOGUE

Videotaping and audio-taping is discouraged in a Roundtable Dialogue because participants may not be as open or honest in their discussions. However, a Roundtable Dialogue may be audio-taped only for the purpose of documenting minutes for a summary report.

CONFERENCE DIALOGUE

Videotapes or audio-tapes may be made of speakers and panelists at a Conference Dialogue, **but the small group dialogues should never be taped.** Assign someone to keep track of when to change the tape and to make sure the tape player is near the microphone. Give the task to someone who has experience with the audiovisual equipment.

Note

Be sure to have signed consent forms for anyone video or audio-taped.

Example

- Dialogues were videotaped in the state of New York between psychiatrists and consumers and they were used as effective training tools. However, a key organizer, Darby Penney, New York State Director of Recipient Affairs, stated: “. . . *the discussion may have been freer and deeper had they not been taped. There was one of our six sessions that was not taped, and my sense is that conversation was much more intense and dealt with more difficult topics than the others.*”



“. . . the discussion may have been freer and deeper had they not been taped.”

Name Tags and Participant Packets

Hand out name tags at the beginning of the dialogue. Name tags can be purchased or made by hand with an artistic design. Cardboard place cards are also important at a Roundtable Dialogue. Place cards can be labeled with names and placed ahead of time in order to diversify seating arrangements. Participant packets can provide all participants with information pertinent to the dialogue, such as dialogue guidelines, agenda and a list of participants.

Participant Packets May Include:

- Dialogue guidelines
- Agenda
- Blank paper
- Pen
- Acknowledgments
- Resource articles
- Brochures of local programs
- Names and addresses of all participants

Tip:

Be sure to include brochures and newsletters of consumer-run services in the packets. Current articles with new approaches to treatment are always enjoyed.

The Evaluation Form . . . *Don't Forget!*

Reasons for evaluating the dialogue:

- To determine whether the dialogue was helpful
- To identify areas of improvement
- To assess the effectiveness and whether to continue

Design a one-page form that is user-friendly and simple with carefully constructed questions for the information needed. (See samples in “Attachments”)

Establish a rating system, with five choices (1–5) that designates excellent to poor.

Include open-ended questions with adequate space for comments and suggestions.

Ask questions like: What did you like best about the dialogue? What did you like least? What suggestions do you have for improvement?

Rate the Following:

- Overall presentation
- Facility/location
- Food and service
- Facilitators and speakers
- Topic relevance
- Pacing
- Start and finish time

Give attendees the option of not revealing their names and addresses. This option encourages candid responses since people write comments more freely if they do so anonymously.

Collect forms at the end of the day.

Note

Do not give people the option of sending forms back since they rarely do. In order to ensure that evaluation forms are completed, announce their importance at opportune times during the day and request that people return them before leaving.

Time Limits and Time Frame



In a **Roundtable Dialogue**, set specific time limits for the introduction and for the closing session.

A **Conference Dialogue** must have carefully planned time frames for each section of the day and for speakers and panelists.

Designate someone to be the timekeeper who will use a stop watch or timer.

The timekeeper will need to present information such as, “*We have about two minutes for each person. When you hear the bell or see the signal that your time is up, please try to finish your thought quickly, so that everyone has a chance to speak.*” If presented correctly, even those people who dislike time limits may like the challenge. Individuals may get a chance to laugh at themselves if they start to go over the time. The group can laugh with them.

Ending Dialogues

Both dialogues should end with spontaneous comments from participants.

In a **Roundtable Dialogue** it is called “Round Robin,” for which an hour is allowed for final comments.

A **Conference Dialogue** ends with “Open Mike” (microphone). Both of these methods are explained in more detail in their respective sections.

Select the Facilitator

Dialogues are interactive and participatory events. They rely on effective facilitation to promote participation, stimulate interaction, and summarize information. A skillful facilitator, therefore, is a major player in the success of a dialogue.

Choose a facilitator with the following qualities:

- Energetic, enthusiastic
- Good active listening skills
- Able to be neutral on sensitive issues
- Previous experience
- Preferably a consumer

Consider the Following

- Whether to use a person on the planning committee or someone outside of the planning process.
- Whether to choose a person not associated with your mental health system to ensure total neutrality.
- Whether or not to select a consumer or professional. One possibility would be to utilize a facilitator and a co-facilitator — one a professional, and the other one a consumer.

Use Co-Facilitators

Two facilitators can share roles and responsibilities. However, one person should take the lead. A co-facilitator can take over if the lead facilitator gets stuck, or if the group becomes stagnant. A co-facilitator can also add information or clarify points being made. Another role may be to record suggestions on a flip chart, serve as timekeeper, and be available for any unanticipated situations that may arise.

The Role of the Facilitator(s)

The facilitator(s) role involves each of the following tasks:

- To create a safe, open, trusting and supportive environment for all group members.
- To guide the group activity and discussion.
- To keep the channels of communication open.
- To sense moods and feelings within the group.
- To keep the group focused.

Directive, Participatory or Non-directive Facilitator(s):

A Directive Facilitator — Asks prepared questions and keeps the discussion focused on those questions.

A Participatory Facilitator — Starts the discussion by reminding the group of the goals and objectives of the dialogue, then invites suggestions on how to proceed as a group, as well as on the specifics of what will be discussed.

A Non-Directive Facilitator — Declares the discussion open, sometimes acting as a “gatekeeper” like the participatory facilitator. He/she will only be involved directly in the discussion when it gets too heated or if there is more than one person talking at the same time.

A good facilitator uses all three styles at different times, and will know when to apply each one. The group that is tightly reined will be less creative, and if too unstructured may lose focus and will not be cohesive. The facilitator who is most effective is eclectic and intuitive to group needs.

A factor in facilitation style may be determined by the particular group and the goals of the dialogue. It may be appropriate for the facilitator to interact as a group member if it is decided the group will benefit.

The facilitator’s primary role, however, is to manage process and time. While doing so, the facilitator should allow the group to direct itself as much as possible, and only introduce new topics to keep the discussion flowing in a positive direction.

Facilitator Top 10 Tips:

1. Greet participants when they enter the room.
2. Acknowledge suggestions.
3. Use names of participants as often as possible.
4. Watch out for your own biases.
5. Avoid interrupting.
6. Allow the group to solve problems.
7. Maintain eye contact.
8. Give positive reinforcement.
9. Recognize sponsors.
10. Remember, this is *their* show, not yours!

Facilitator Pitfalls:

- Not managing monopolizers.
- Talking down to the group.
 - Not finishing on time.
 - Telling a flat joke!
- Using sexist language.

Start the Roundtable Dialogue

Welcome Everyone

- Tell a joke or anecdotal story.
- Brief group members on the purpose and objectives of the dialogue.
- Acknowledge individuals who planned the dialogue.
- Give recognition to sponsors and underwriters.
- Review housekeeping information, including location of rest rooms, smoking areas, time for lunch, and ending time of dialogue.

Introductions

The facilitator should start the introductions so that participants will feel comfortable with him/her and serve as a model for others when it is their turn to introduce themselves.

Information requested may include whether the person is a consumer, family member or provider, job title or employment, advocacy affiliation, whether they are a parent, or grandparent, and where they live, or other pertinent information.

Set time limits for participant introductions (three minutes each for a 20-person dialogue).

Tip:

The facilitator may use an ice breaker such as:
“Please tell us the most embarrassing thing that happened to you this month,” or *“Talk about what you like to do for fun,”* or *“What is your favorite hobby?”*

Present Conduct Guidelines

The following guidelines should be observed:

- Be considerate.
- Be able to consider new ideas.
- Avoid professional jargon.
- Feel free to ask any questions.
- Have fun!

Ask the group if they have any other guidelines to add.

Set Agenda

Pre-selected topics or focus questions should be presented to dialogue participants for their approval or modification. The group should approve the focus questions, make minor changes, but not alter them entirely.

- Allow a limited amount of time for modifications.
- Usually the initial topic is first-person stories and narratives.
- Set approximate time frames for all topics.
- Make sure to allow time for future planning and closing.
- Set times for breaks and lunch, and ending time.

Energy levels are lowest after lunch. Keep lunch light to avoid afternoon drowsiness. Start the afternoon session with something stimulating.

Tip:

Maintain Flow of Conversation

While the dialogue group session is taking place, it is the job of the facilitator to maintain the flow of communication within the group. In order to do this, the facilitator should use the following techniques:

- **Building/Crediting** — Add to others' ideas or suggestions. It can include picking out from what everyone says and adding additional clarification.
- **Encouraging** — The facilitator should be friendly and responsive to members and their contributions and make positive, genuine, reinforcing statements about participants' input.
- **Harmonizing** — Encourage people to explore their differences and appreciate each other's point of view.
- **Clarifying** — Clarify vague statements, as well as offer facts or relevant information about issues being discussed. This technique can include answering questions, interpreting or reflecting ideas and suggestions, or giving and seeking information to clear up confusion. At the same time, the facilitator should avoid interrupting or speaking too long. Interruptions may be necessary only when a person has talked too long or has strayed from the subject.
- **Summarizing** — Summarize statements made by members of the group. These summaries generally recap what has been said or covered; pull together ideas that are related, and identify areas of agree-

ment. A summary can also restate suggestions after the group has discussed them.

- **Motivating** — The facilitator is expected to keep the discussion process flowing. If the group becomes stagnant, he/she can change the direction of the dialogue, suggest a break, or ask the group where it wants to go next. The facilitator can also introduce a new topic. It may be necessary to restate the goal or purpose of the discussion session. If the group reaches a consensus, acknowledge it, and move forward.

Deal with Conflict

As group members interact, it is likely that their perspectives will clash or contradict. This contradiction can create conflict within the group session. It is the job of the facilitator to evaluate this conflict and determine if any intervention is necessary.

When assessing conflict, the facilitator should consider these key points:

- Allow a reasonable amount of subject-related conflict. Such conflict is healthy for the group.
- Encourage the group to thoroughly weigh, explore and examine topics and issues, including conflict.
- Do not retreat from tension-filled situations.
- Minimize conflict among members on unrelated topics.
- Keep the group focused on ideas, not personalities.
- Remain neutral during disagreements. Avoid taking sides.
- Avoid being heavy-handed or too controlling.

Note

Recognize that controversy can spark creativity, promote growth, and build allies. Do not feel compelled to discourage or stop conflict immediately. Remember that feelings, emotions and conflict are legitimate factors in the dialogue process. It is important for the facilitator to recognize this from the start.

Stick to the Agenda

Stick to the planned agenda as much as possible. When you see that participants are ready to move on, go to the next agenda item. Sometimes the dialogue will take on a life of its own, but the facilitator should remind the group that there are topics still to be discussed.

Future Plans and Strategies

The last portion of the dialogue should be used for creating strategies and initiatives and making future plans:

- Take all suggestions and place on the flip charts.
- Allocate at least one hour for strategizing.
- End with a challenge.
- Ask everyone to commit to a task.
- Prioritize suggestions.
- Write participants' suggestions on the flip chart.
- Make plans for reconvening if the group decides to do so.

Record the Dialogue

Designate a person to record minutes of the dialogue which later become the summary report and/or documentation of the meeting. It is important that the draft of the report be read and approved by all of the participants before being put into final form. When recording:

- Respect confidentiality when taking notes.
- Do not tag responses with participants' names.
- Do not feel compelled to note everything.
- Be concise, brief, and summarize.
- If a consensus is reached on a topic or suggestion, record the item.

Conclude the Dialogue

The Round Robin is the final portion of the **Roundtable Dialogue**. Allow an hour at the end of the dialogue for last-minute comments, suggestions and expressions. Instruct each person to take a turn around the group to provide input, but make sure to state that people can pass.

Timekeeping is particularly important during Round Robin. First determine the total amount of time remaining in the dialogue. Then divide that time by the number of participants so that each person receives an equal amount of time. A timekeeper will keep close tabs on each person.

After the Round Robin, show appreciation for everyone's participation. The closing remarks are sometimes very personal and reinforce connections between people, making the day a memorable one.

Conference Dialogue

This section describes the particular steps that need to be added to organize a Conference Dialogue.

Selecting Participants

- Approximately 50–150 people.
- Use the same criteria as for a Roundtable to select participants.
- Ask mental health agencies to select participants after receiving a letter and brochure that includes the number of slots allotted.
- Send individual family members, consumers, and advocates separate invitations.
- Invite public officials and dignitaries.

Note

VIP guests should be full participants but may not be able to stay for the entire conference.

Planning

- Planning takes at least four months.
- The core planning group may add special subcommittees for tasks.
- Early in the planning stages inform mental health constituents about the conference for their information and involvement in planning.

Dialogue as Training Day (Inservice):

Make sure to inform mental health agencies well in advance of the dialogue to ensure their cooperation and participation in giving employees a day for “inservice” training.

Tip:

A Conference Dialogue may be scheduled for two days.

Send Letter and Brochure

Brochure Should Include:

- Title and theme
- Date, time and location
- Purpose/philosophy
- Information about the conference
- Goals and objectives
 - Cost, if any
- Conference coordinators and guest speakers
 - Conference agenda
 - Who will attend
 - Registration form
- Sponsors and funding agents
 - Names of planning committee
 - Phone contact for additional information

Two months before the Conference, send the first letter of invitation to mental health agencies, organizations, and individuals. The letter should be written on agency stationery and signed by the executive director.

The letter assigns a specific number of registration openings for each agency proportionate to its size. Request that mental health consumers be included, as well as persons with different cultural backgrounds and other diversities.

The Brochure

A brochure should be enclosed in a second letter to be sent to all invitees one month before the Conference. The brochure should include all of the factual material. It may include art work and illustrations that are appropriate to the theme of the conference.

Include a registration form in the brochure that will be returned in order to pre-register all participants. For expediency, agencies may fax or e-mail back the names and titles of the participants. Individuals can mail their registration forms or could also fax or e-mail them. When all names are in, compile in categories in order to prepare the dialogue sessions in advance. (Please note that advance preparation of the dialogue sessions is optional).

For an example brochure, see “Attachments.”

Proof the brochure carefully! Don't forget the phone number, e-mail and fax number. Believe it or not, there have been brochures entirely without a phone number, and some with the wrong number, or the date and time have been wrong.

Tip:

Using Speakers

A Conference Dialogue includes a keynote speaker and two sets of panelists (for a one-day conference). A keynote speaker talks for no more than 30 minutes, panelists are given 15 minutes each for a panel of four.

Steer away from long introductions and formal recognitions that distinguish speakers from other participants in the audience. Treat all participants as equals.

Preparing the Small Group Dialogues (Optional)

Allow two hours to organize the small group dialogues. This can be accomplished by a small sub-committee. The committee members must be familiar with the local mental health community professionals and consumers in order to pre-set the small groups.

Assign approximately 20–25 (preferably 20) participants to each group. More than 20 individuals is difficult to manage, however you need to allow for people who leave or do not appear. It is essential to know, in advance, how many breakout rooms are available in order to determine the size of the groups.

Gather all of the names of pre-registered participants. Although there will be people who do not register in advance, it is essential to know most of the attendees' names and affiliations in order to create a balanced group of participants for the dialogue sessions.

Sort participants' names and arrange them according to status, providers, administrators, family members, therapists, psychiatrists, etc. Be sure to include people at all levels of work experience, i.e., front line staff, volunteers, etc. Ideal groups include diverse participants who have different perspectives on mental health issues.

Designate a different color or symbol for each group. A designated symbol or color is attached to the participants' name tag the day of the dialogue. Participants will be given instructions on the location of their group session corresponding to the symbol or color.

Make a plan for the break-out groups. It is recommended that people stay with the same group for each dialogue session.

Tip:

It is important to know the total projected number of participants in order to set up the dialogue sessions. Be sure to calculate extra spaces in each group for persons who register at the door.

Choosing Facilitators

A facilitator and co-facilitator should be selected for each small group dialogue.

Ask the panelists to serve as facilitators of the small group dialogues in order to provide continuity and expansion of ideas that were presented. Panelists generally have the necessary skills, but be sure to offer them the facilitator guidelines.

Persons chosen to be co-facilitators should include a mixture of consumers, professionals, and family members.

Guidelines for facilitators should be developed and enclosed in their packets. It is desirable to offer facilitator training prior to the Conference Dialogue. Skills should include active listening, dealing with conflict, redirecting, and leading the group toward consensus. Role playing situations can be helpful.

The Day of the Conference Dialogue

Documentation

Be sure to make a plan to document the conference with a report, photographs, and/or videotape. When designating the writer, videographer or photographer, it is preferable to use professionals or persons who have skills and experience. Documentations can be circulated to participants and other parties who wish to replicate the effort. Note that release forms are necessary for persons photographed or videotaped. Finally, if you use a professional documenter, he/she will charge a fee, which will need to be included in your budget.

Registration

Registration materials, cash drawer (if applicable), name tags, participant packets, etc. should be assembled, and ready for distribution at the earliest registration time. Allow at least one half hour for registration prior to opening ceremonies.

Registrars should be well informed in order to answer questions.

Assign one registrar for persons who come to the conference without pre-registering.

Serve refreshments during time of registration in an area that will not interfere with the conference. Make sure to establish a cut off time.

Welcoming Remarks

The conference coordinator should welcome all participants, state the theme of the dialogue, review participant guidelines, and set the agenda for the day. The coordinator usually introduces the keynote speaker.

Keynote Speaker

It is desirable that a consumer be the keynote speaker whenever possible, either an out-of-town guest, or a recognized individual from the local community.

Tip:

Get media coverage for the event. Having connections with newspaper writers, television newscasters, or radio announcers helps.

First Panel

The first panel takes place after the keynote speaker.

Typically the first panel includes first person narratives and stories from the perspective of consumers, family members, and providers. All panelists must be given careful time limits (10 to 15 minutes each for a panel of four). It is essential that the panel not exceed an hour in order for the dialogue sessions to have enough time.

First Dialogue Session

All participants go to their assigned room. The facilitators start the group with first name introductions and present the subject matter which relates to what was discussed by the first panel. The small group dialogue is conducted in the same manner as a Roundtable Dialogue. However, discussion will be limited by time constraints, therefore limiting the scope of discussion.

Flip charts should be used to place suggestions and other feedback. At the end of the session, one of the facilitators will be responsible for transcribing flip chart information to a report sheet which is given to the conference coordinator.

Lunch

Time allotted for lunch should be long enough to allow time for networking. An art exhibit and/or book display table would add another dimension to the conference. It may even be desirable to have entertainment presented by local consumers.

Tip:

Pay consumers a stipend for work whenever possible.

Second Panel and Dialogue Session

Timing is important. The conference coordinator should pull everyone together for the second panel discussion. The second panel usually focuses on problems, barriers, and solutions to current mental health issues.

Open Mike

The Open Mike session for a Conference Dialogue is a final feedback session conducted with the entire group.

Involving university mental health research departments can be helpful in providing technical assistance.

Tip:

A pre-appointed emcee moves about the audience with a microphone and encourages people to get involved. A good emcee will know how to encourage people to come up and speak in front of an audience.

Participants should be told they only have one-to-two minutes to speak. The emcee will inspire the audience to express themselves spontaneously with comments ranging from serious to humorous. Subject matter could include thoughts about the conference, suggestions, personal anecdotes, jokes, poetry, songs, etc. It is always nice to end Open Mike with an inspirational thought or song.

Ending the Conference

End the Conference Dialogue with an expression of appreciation and final acknowledgments.

Document the conference. The document can later be circulated to the participants as well as people in other parts of the country who may want to replicate the effort.

Tip:

Collect evaluation forms. In Palm Beach County, Pioneer Dialogue, 1999, the coordinator announced at different times during the day, “*We have certificates of attendance for everyone to receive, but you will only receive one if you fill out the evaluation form.*” Everyone did.


Certificates of attendance are a nice reward and can be given out as participants leave the conference.

Sample Brochure for Conference Dialogue

This sample is of a tri-fold brochure printed on two sides.

Relaying Ideas

Guest Speakers



Stretching for Achievement

Keynote:
Jeanne Dumont, Ph. D., Ithaca, New York: Researcher, consumer/survivor, advocate, educator. Jeanne has a long history with the consumer/survivor movement. In the past five years she has helped to develop a consumer run crisis hospital in New York, a center for Mental Health Services demonstration project now in its third year.

The following speakers will
set the Pace on these different panels:


The ARENA: (The Crisis Experience)
Bill Bowden—Bvd. Alliance for the Mentally Ill
Sandy McCullough—Fl. Lauderdale Police Dept.
Gina Mathers—PEER Center
Alan Nasse—PEER Center
Gayna Dunn, R.N.—Memorial Regional Hospital

The HURDLES: (Barriers to Progress)
Howard Finkelshtein—Bvd. Cty. Public Defender
Steve Fischer—Henderson Walk-In Center
Stephen Ferrante—Bvd. Cty. Elderly Services
Kitty Semerville—HRS, ADAMI
Susan Stefan—Univ. of Miami, School of Law

HIGH JUMPS TO PROGRESS: (Our Successes)
Dianne Côté—PEER Center
Mike Edwell—Broward County
Eric Hadley—Henderson Walk-In
Patty Cooper—Advocacy Center
Russ McLean—Nova Southeastern Univ., CMHC

PIONEER DIALOGUE
1996
**ALTERNATIVES
IN CRISIS CARE**
an
Olympian Event

September 5, 1996
Time: 8:45am to 5:30pm
Happy Hour—5:30 to 6:30pm




**NEVER
STAND
STILL**

Unitarian Universalist Church
3970 N.W. 21st Avenue,
Oakland Park, FL 33309

Conference Coordinators:
Gayle Bluebird
Laurie Weber

Laurie Weber
Center for Psychological Studies
Nova Southeastern University, Mullins Bldg.
3001 College Avenue,
Davie, FL 33314



front side

NAME: (Last) _____ (First) _____ (Middle Initial) _____
 ADDRESS: _____

Are you a consumer? _____ Primary _____ Secondary
 Phone # _____

How are you affiliated with crisis?
 Options: _____ Nurse/Physician
 _____ Clinician
 _____ Case Manager/Social worker
 _____ Administrator
 _____ Crisis worker
 _____ Other (Please specify) _____

Please return this form to:
 Laurie Weber,
 Center for Psychological Studies
 Nova Southeastern University
 3301 College Avenue,
 Davie, FL 33314
 Fax: (954) 476-4863

IMPORTANT: Your registration form must be received by August 30, 1996 in order to guarantee participation.

About This Conference

Welcome to the fourth PIONEER DIALOGUE. The 1996 focus is on Crisis Alternatives. This conference will bring together people who will answer the challenge to change our mental health system. PIONEER DIALOGUES create an atmosphere in which partnerships are created between professionals and consumers. Together we will look at our current crisis system, the advances we have made, and take leaps ahead to set new records.

Who Will Attend

You... have been selected to attend because of your courageous spirit. As a person working in and with the mental health system, you are conscientious and open to new ideas. Space limitations allow for approximately 150-175 people—Participants will include a diverse representation of local service provider employees and administrators, consumers, family members, nurses, and psychiatrists. Representatives will be present from the Advocacy Center for Persons with Disabilities, and Florida Mental Health Institute.

Registration Information

PIONEER DIALOGUE is being presented free of charge with lunch provided. Pre-registration is required as space is limited.

Feel free to wear your Olympic attire.
(Casual dress encouraged.)

For more information call:

Gayle Bluebird,
 Consumers Affairs Coordinator, District 19 HRS
 (954) 797-8411, or
 Laurie Weber
 Mental Health & Training Resource Cooperative
 Nova Southeastern University
 (954) 452-5563,
 or fax: (954) 476-4863

As A Participant You Will:

- Hear from a national guest speaker who will ignite the beginning of our conference with her knowledge of gold medal crisis alternatives.
- Have the opportunity to learn from our community experts actively working in areas of crisis response.
- Have the opportunity to voice your ideas, concerns, and to ask questions in small group dialogues.
- Gain insight and understanding of all participants' perspectives.
- Help to develop a plan for implementation of new approaches and strategies for crisis programs.
- Have time for social interaction.
- Be part of a demonstration conference that will be documented and duplicated in other areas of Florida as well as across the nation.

Funding and other supports provided by:

District Ten, ADAMI, HRS
 Nova Southeastern University, CMHC
 Henderson Mental Health Center
 Memorial Regional Hospital
 Broward General Medical Center
 Advocacy Center for Persons with Disabilities,
 Florida Mental Health Institute



Applause to the Planning Committee:

Pat Kramer, Bill Schaefer, Nichole Winteboom,
 Marti Forman, Stephen Ferrante,
 Arnie Marks, and Steve Fletcher

back side

Sample Evaluation for Conference Dialogue

This sample is of a one-page evaluation, printed on one side.

Second Annual Pioneer Dialogue
"The Health of the Mental Health System and How it Affects You"

Holiday Inn Palm Beach Airport
1501 Belvedere Road, West Palm Beach, Florida 33405

Thursday, May 14, 1998
9:00 a.m. to 4:00 p.m.

PROGRAM EVALUATION

Please respond to the questions below using the following rating scale:

5=Excellent 4=Very Good 3=Good 2=Fair 1=Poor

1. Rate the overall presentation.
5 4 3 2 1
2. Rate the presenters performance.
5 4 3 2 1
3. Rate the relevance of the information given.
5 4 3 2 1
4. Do you have suggestions for future presentations?

5. Please print your name, address and telephone number (optional):
Name: _____
Address: _____
City/State/Zip: _____
Telephone: _____

Mental Health Association
909 Fern Street • West Palm Beach, Florida 33401
(561) 832-3755 • (561) 276-3581

Sample Agenda for Conference Dialogue

This sample is of a one-page agenda, printed on one side.

First Annual Pioneer Dialogue - "The Experience of Recovery"		
United Way Conference Center, Boynton Beach		
Wednesday, June 25, 1997	9:00 a.m. to 4:00 p.m.	
AGENDA		
09:00-09:15 a.m.	Refreshments and Registration	
09:15-09:30 a.m.	Welcome and Introductions	Renee Constantino, Exec. Dir. Mental Health Association
09:30-10:00 a.m.	Keynote Speaker	Dianne Côté, Director Peer Center
10:00-10:40 a.m.	The Experience of Madness - Panel 1	
10:00-10:10 a.m.	David Gross, M.D., FAPA, Palm Beach Evaluation and Treatment Center	
10:10-10:20 a.m.	Sally Clay, Advocate Consultant	
10:20-10:30 a.m.	Mark Mooring, Consumer Consultant	
10:30-10:40 a.m.	Sanjens Clay, Mental Health Administrator, Palm Beach County Sheriff's Ofc.	
10:40-10:50 a.m.	Break	
10:50-11:50 a.m.	The Experience of Madness - Dialogue Group 1	
11:50-01:00 p.m.	Lunch (served on-site)	
01:00-01:50 p.m.	The Experience of Recovery - Panel 2	
01:00-01:10 p.m.	Libby Huey, M.S., LMHC, MAC, SRT Supervisor	
01:10-01:20 p.m.	Diane Benson Harrington, Freelance Writer/Mental Health Advocate	
01:20-01:30 p.m.	Linda G. Kartell, MSW, LCSW, Mental Health Consultant	
01:30-01:40 p.m.	Ellie Siklosy, Vice President of Alliance for the Mentally Ill of PBC	
01:40-01:50 p.m.	Stephen Watts, Advocacy Center	
01:50-02:00 p.m.	Break	
02:00-03:00 p.m.	The Experience of Recovery - Dialogue Group 2	
03:00-04:00 p.m.	Discussion/"Open Mike"	Gayle Bluebird, R.N., Coordinator Office of Consumer Affairs
At conclusion, certificates will be distributed.		

What Happens After the Dialogue?

One way to measure the success of dialogues is to note what happens afterward. A good dialogue is one that results in concrete plans for the future, incorporating the suggestions received from the dialogue participants. All of the suggestions should be reviewed and prioritized in order to develop action plans. Each community's needs are different. Recommendations may include requests for more dialogues on special issues or with different groups, or plans for new program development.

SOME RESULTS FROM PILOT DIALOGUES

In Pittsburgh, participants' suggestions included plans to hold all-day dialogues in ten other counties in Western Pennsylvania, as well as follow-up dialogues on topics such as managed care. Participants at the 1998 Dialogue requested that family members be invited to future dialogues, as well as a broader group of consumers. Other goals focused on the need for consumer sensitivity training in professional educational programs, particularly for medical residents. It was suggested that consumer-run drop-in centers be used for visitation and on-the-job training. It was also recommended that a set of "best practices", describing quality programs and consumer groups be catalogued for professional use. A written report of their first dialogue was sent to major stakeholders in their county system. Proposed plans will be implemented in the next year. In the meantime, people still talk about the dialogue they attended.

Palm Beach County made plans for dialogues and trainings (some of them related to legislative issues) as a result of their conference dialogue. Letter writing campaigns were underway during an election year and a training session was held for consumers to inform them about candidate's issues and ways to respond. It was decided that "Pioneer Dialogue" would become an annu-

al conference each year to focus on a different aspect of their mental health system. Other recommendations included the need for increased consumer involvement in district planning and enhancement of their drop-in center, "Peer Place." Participants who attended Pioneer Dialogue from nearby districts took an interest in the conference, and are making plans to organize their own.

At the national level, dialogues are being held between consumers and different professional groups, i.e., psychologists and nurses. A dialogue with children is being considered, with special regard for confidentiality issues. This Manual is one of the outcomes from a recommendation made at the 1997 dialogue between psychiatrists and consumers. Other recommendations were to establish possibilities for more communication and shared endeavors between psychiatrists and consumers, to replicate dialogues at the state and federal level, and to improve access for consumers in different parts of government and managed care. Some of these issues are being worked on and are at various stages of readiness. As one participant at the national dialogue said: "Success is a journey, not a destination."

WHAT ABOUT PARTNERSHIPS?

One of the goals for dialogues is for partnerships to be created between diverse groups to develop and conduct dialogues. The question is whether partnerships after the dialogue are sustaining.

Depending on what is meant by partnerships, too high expectations may not be realistic. Differences that existed prior to the dialogue do not automatically disappear. People's attitudes will hopefully shift to some degree, but it must be considered that persons with different perspectives usually have different work and life experiences. Consumers who are developing new self-run

programs rely more on life experience than professional degrees. Providers, on the other hand, are required to hold licenses that dictate mode of treatment which limits flexibility. Both groups have certain vulnerabilities. While professional providers are concerned with risk factors and liabilities, consumers worry about being co-opted into adapting to medical model practices.

Positive partnerships then, might be defined as learning partnerships in which both groups agree to continue the dialogue and plan activities that are mutually beneficial.

This may include working on strategies to follow up on recommendations or training on subjects that are helpful to both groups. Informal gatherings that bring people together socially will also help to break down barriers. Full partnerships will occur because people want them to and when they are ready. Full partnerships are like any other relationship. They are chosen. They are trusting. They treat each other as equals. In the mental health arena, this will take time and work. Dialogues are a good way to start the process.

Other Dialogues

INTERNET DIALOGUES

Computer-mediated communication is a new dialogue technology. Electronic mail — e-mail — is less formal than usual written exchanges and less textured than in-person dialogue. E-mail is forgiving of punctuation and spelling errors and typos. E-mail is intolerant of affectation and tends to ignore pedigree. E-mail substitutes for nonverbal communication, not usually with literary expression of mood and affect, but more often with icons: for instance :) for smile, or <grin>. Those who like to use voice and presence and non-verbals to communicate are not always comfortable.

Computer-mediated communication generally takes place on a neutral and level field. Feedback is quick; gratification is frequent. *People Who* have-not can use free e-mail from their public library on equal footing with e-mail from a mental health program director. Rural areas without even cheap local phone service can use wireless, satellite links and Web TV. Third world countries, newly wired, are installing state-of-the-art infrastructures.

People Who experience mood swings, fear, voices and visions (*People Who*) have found each other on the Internet through news groups, Web pages, and mailing lists. They have found support, mutuality, and advocacy for system change. They have found relief from the loneliness associated with seeming different, cutting edge medical information, and quick error correction of bad data. They have found a range of views about psychiatric disabilities, from iatrogenic to disease.

People Who have also found the mental health professionals online. There are a large number of professionally oriented mailing lists — for instance about forensics, psychopharmacology, managed care, outcomes; some

welcome *People Who* as a valued resource, some open the lists only to professionals.

Exchange with a mental health professional by e-mail has a different tone from in-person exchange. The territory is neutral — one's own computer screen rather than a therapist's private office or a mental health director's conference room. The *Person Who* can take whatever space and time is needed to express a point of view, can set the context of the response by excerpting from a previous message, can readily provide supporting ideas and evidence that the professional might not have considered. Those in conversation are not limited by having to share a fixed amount of time, are not limited by having to stay focused on the topic, are not limited by the inherent power imbalance between professional and *Person Who*.

People Who dialogue with peers about work opportunities, and advocacy and rights issues, and about managing the situations that earned them a psychiatric label. *People Who* dialogue with professionals about advocacy and rights issues, especially forced treatment; and about DSM diagnoses, prognoses, and psychotropic medications, and especially new treatments.

People Who read news groups like alt.society.mental-health, sci.med.psychobiology, alt.support.depression, alt.support.anxiety-panic, alt.support.loneliness, and soc.support.depression.family. Moderated news group discussions stay focused. Many unmoderated people like to post to unmoderated news groups, and opinions are apt to be polarized.

People Who visit the many mental health information Web sites. Generally this is a one way exchange — the visitor reads what is provided, perhaps makes a comment to the Web master. Some Web sites provide

chats and have some interaction. Some Web sites are actually run on bulletin board software and have more interactivity.

People Who use Internet Relay Chat and other chat software and situations to join in synchronous exchanges with each other and with professionals.

Managed care companies and public health providers are beginning to use modem technology to provide patient management and support.

And then there are lists. There are lists for moods — Walkers (melancholy), Pendulum (mood swings); for voices and visions — Schizoph; for advocacy — ActMad; for safe support — ClubMad; for spirituality — MadSpirit; for working as a consumer mental health professional — TwoHats; for state-specific issues — MHCONSUMERS-OR. The exchanges are international, asynchronous, and vigorous. Some lists generate upwards of 100 e-mail messages a day. Content varies from humor, to dismay about psychiatric labels and public images, to reviews of newly released DSM's, to newspaper articles. Some participants post a reply to almost every message they read; some only read. Internet lists help to realize the slogan of the South African anti-Apartheid movement: "Nothing about me without me."

The MADNESS list states, "We bear witness each to our own experience with madness, to how we have been treated, and to the social consequences we have felt. We bear witness to the common vision and aspirations of *People Who* experience mood swings, fear, voices and visions."

Lists are effective organizing tools. SAMHSA/Center for Mental Health Service organized a Walk the Walk: With Lives Touched by Mental Illness in May 1998. A hundred Internet users planned ways to participate on a list devoted to the Walk. Australia and Canada planned parallel events, as did some other United States cities. Posters and symbols were devised and posted on the Web, the message *People Who* desired to communicate was hotly debated and finally agreed, and press releases were drafted and distributed. Now it seems there is new momentum among those consumer/survivors wanting to make improvements especially in public mental health systems.

People Who are politically active have found support for resistance to involuntary treatment and resistance to unconsented electro-shock, as well as encouragement for Advance Directives, support for including independent grievance procedures in managed care contracts.

The Recovery Dialogues

A Personal Reflection and a Cautionary Note

In 1992, the New York State Office of Mental Health (OMH) began an innovative project which brought together nine consumers/survivors/ex-patients (c/s/x) with seven psychiatrists for a series of structured dialogues about the concept of recovery. During a two-year period, this group met on five different occasions, four of which were videotaped. Two training videotapes were produced using footage from the first two dialogue meetings.

The goal of the project was to create shared understandings between the two groups about the process of recovery from a diagnosis of "mental illness," resulting in recommendations for the public mental health system on how these understandings could be used to promote recovery. There was a sense that the consumer/survivor/ex-patient movement had valuable experiential knowledge on this issue that wasn't being adequately heard by clinicians and administrators, and the dialogues were seen as a tool to build consensus on the importance of system reform.

On the face of it, the dialogue process seems like an ideal way to bring together two groups of people with disparate positions in order to converse on difficult topics. As envisioned by the project organizers, dialogues bring "groups together as equals and provide a structured opportunity for people to explore and reflect on their own experience and their own belief systems. . . . They allow the integration of diverse perspectives, resulting in a more complex understanding . . . [and] result in a shared vision rather than a vision imposed from the outside."

The dialogue process was painstakingly planned to reduce barriers to communication due to power imbalances between psychiatrists and c/s/x. For example, the

c/s/x outnumbered the psychiatrists, and the particular c/s/x participants were selected because they were seen as strong, articulate individuals who would not be easily intimidated. Skilled, neutral facilitators used a carefully sequenced series of focus questions to guide the discussion. People used first names, not titles; we were seated in the round and the two groups were interspersed; informal time for socializing was built into the schedule.

Over the course of the five meetings, we covered a wide variety of sometimes controversial topics in a fairly collegial manner. After an initial period of polite tenseness, we were able to speak frankly and freely among ourselves. As we got to know the psychiatrists as individuals, some of the distance created by our very different statuses were narrowed. While much of what the c/s/x had to say about our treatment in the system was difficult for the psychiatrists to hear and acknowledge, many of them clearly struggled to understand views that were foreign to them. There was a shared sense that what we were doing was important and valuable. And, yet,

And yet something really didn't feel quite right. While the experience of speaking truth to power was liberating at first, I felt a surprising undercurrent of unease and even resentment associated with the process. Naturally, as a good ex-patient, I blamed myself: somehow, I wasn't feeling the "right" emotions in this process. Here I was with a group of my peers, having the opportunity to explain our views to people who could have an impact, and instead of feeling pleased and excited, I felt very uncomfortable.

During a break, I learned that I wasn't the only c/s/x in the group feeling ill at ease. As we talked among ourselves, several themes emerged that seemed connected to our ambivalent reactions. First, there was a sense that

we were putting out a tremendous amount of emotional energy, talking about difficult personal experiences in the hope of making important points about what was wrong with the mental health system and what would be preferable. Our emotional efforts (and the resulting vulnerability we felt) were not being reciprocated by the psychiatrists. Despite all the steps taken to reduce the power imbalances and to create a level playing field, the process did not feel "equal."

There was a feeling that, while we were finally being listened to, it wasn't really in the spirit of mutuality. Rather, we were being used as teaching tools for the professionals, and in the end, they got much more benefit from the experience than we did. While we spoke from the heart about experiences that had defined our lives and our sense of ourselves, they were still able to listen from their "doctor" roles. They learned some new ideas, rejected others that made them uneasy, and went away with their professional roles intact. We, on the other hand, felt emotionally spent, slightly patronized, and decidedly unfulfilled by the experience.

For me, the emotional strain of the process reached a crescendo at what turned out to be the last structured dialogue between the two groups. During the discussions, it came out that all eight of the c/s/x's around the table that day were trauma survivors. This was a startling revelation to the c/s/x, as we had never discussed this among

ourselves, and we were eager to pursue the subject in the context of discussing recovery. The psychiatrists, to a person, almost immediately shut down, and the discussion was quickly steered to a less threatening topic. At that moment, it finally became crystal clear to me that this was not a process of exploring beliefs and experiences in search of a shared vision. Even in this structured process which worked so hard to be egalitarian, the psychiatrists continued to define reality for us. It brought back all those old feelings of being subordinated, of having one's life discounted, of being seen as "less than." It didn't feel equal, it didn't feel like progress, and it sure as hell didn't feel safe.

In February 1998, more than four years after our last meeting with the psychiatrists, eight of the original nine c/s/x came together again to talk about trauma issues. This time, we did not invite the psychiatrists. We came together to have a dialogue among ourselves, to learn from each other, and to share our experiential knowledge in a safe place. It felt remarkably productive, and we came away with consensus on a number of steps that could be taken to make the mental health system less re-traumatizing for people, as well as hours of videotape with which to make training tapes from our perspectives. If I learned one important thing during this long, multi-stage process called the Recovery Dialogues, it is this: Communication is only possible between equals.

Glossary of Terms

Collaborate — To work with others. In area of mental health, collaboration may refer to interaction between mental health consumers, families and professionals in order to effect change.

Dialogue — A dialogue is a forum in which two or more groups are brought together as equals to explore their differing views, experiences, and belief systems. A dialogue is structured to allow for self exploration of one's own behavior and attitudes as well as to listen to other people explore their own.

Empowerment — "Becoming connected and integrated into a community that is mutually respectful and being able to fully participate in the decisions affecting your life" (Fisher). "When people are transformed from their roles as passive objects to historical self-reflective subjects capable of acting to transform their own conditions" (Rose and Black).

Facilitator — Conductor of a meeting who remains neutral and respectful of all participants. Maintains power balance in the group, ensures that all participants have an equal opportunity to speak and keeps the group focused and within established time frames. Sets guidelines for all participants to follow. Recognizes when the group reaches consensus on issues.

Focus Group — An interview style of collecting data designed for small groups. Researchers strive to learn through discussion about conscious, semiconscious, and unconscious psychological and sociological characteristics and processes among various groups. It is an attempt to learn about the biographies and life structures of group participants. To be more specific, focus group interviews are either guided or unguided discussions addressing a partic-

ular topic of interest or relevance to the group and the researchers.

Moderator — A person who presides over a discussion or meeting differentiated from a facilitator who remains neutral. A moderator may be much more directive and involved in a meeting.

Paradigm — A word used often in current research to define a shift in values, thinking, or ways of conducting treatment. Treatment of mental illness used to be thought of as long-term and non-reversible. People would never get better. Today thinking has changed to include the possibility that full recovery may take place. This is one example of a paradigm shift.

Participatory — Means that all who wish to can make a difference through their participation. The difference can be positive or neutral but not negative. No one need fear that their participation will harm others. Each person's contribution will either contribute to the group's potential for increased learning or it will result in not much difference in whether the group moves forward or stays at the same place.

Participatory Action Research — Defined as a study in which people being studied participate actively with the professional researcher throughout the research process, from the initial design to the final presentation of the results and discussion of their action implications. (E. Sally Rogers)

Recovery — Is best understood as a process, not an outcome. A key element in recovery is the presence of people who offer hope, understanding, and support; who encourage self-determination; and who promote self-actualization. (Frese and Davis)

Self-help — Self-help groups include people who have a common bond, and who voluntarily come together to share experiences, reach out and learn from each other in a trusting, supportive and open environment. The common bond is defined as both a) the collective experience related to being diagnosed as having a mental illness and receiving services from the mental health system and b) the individual experience(s) associated with having survived the process. Self help is based on the prin-

ciple of helping both one's self and others at the same time.

Transformation — A complete change as of appearance or personality.

Working Group — Similar to focus group in regards to size and makeup of group, however, a working group has an action agenda and may include formulation of policies and development of tasks to accomplish.

Literature Summary

At first glance there appeared to be very little literature on the subject of dialogues. Manuals and books are written about focus groups and how to do them. Articles on Participatory Action Research talk about the need for dialogue. There are many articles written about self-help and empowerment, including research studies using focus groups as the means to collect data.

What began as a frustrating task became enjoyable as people around the nation responded to my request on the Internet. Many people shared information with me by e-mail as well as sending me names of individuals to contact. The library also became a great resource when the words "*Communication Building*," "*Community Dialogues*," "*Participatory Action*," and other terms were used to find related materials. Suddenly, a picture began to emerge of what should be read in order to develop and create a dialogue. There were many examples of dialogues. I suspected I only began to scratch the surface. Particularly exciting were examples of dialogues, town meetings, study circles, etc., held not only in this country, but in other countries as well. In many cases, these dialogues served to create better communication between disadvantaged groups and under-served populations.

The Experience of Stigma and Dis-empowerment — It became clear that it is necessary to understand underlying principles and values guiding the consumer/survivor movement. Many articles on self-help, empowerment, and partnerships were reviewed. The ones chosen for this research summary are ones I enjoyed the most, because they are interesting and easy to read. Other articles are cited in a supplementary bibliography for additional insight and reference.

A good place to start is Priscilla Ridgway's, "*The Voice of Consumers in Mental Health Systems: A Call for Change*" (1988). Esso Leete's quote begins the narrative:

"I can talk, but I may not be heard. I can make suggestions, but they may not be taken seriously. I can voice my thoughts, but they may be seen as delusions. I can recite experiences, but they may be interpreted as fantasies. To be a patient or even an ex-client is to be discounted."

Ridgway believes that the most important reason for professionals discounting the consumer voice is the idea, "*that providers know best.*" She explores client self-determination in its raw beginnings, and reports that one of the responses of the consumer movement to this entrenched idea was to develop self-help alternatives, and to focus on the importance of empowerment.

Reidy (1993) did a study on stigma in which 46 people gave personal testimony about their own experiences with stigma, including ones involving employment, including employment in the mental health system.

Empowerment and Self-help Alternatives — Chamberlin (1997) defines empowerment in a research project in which 12 consumers, who are also service providers, agreed on 15 statements, in which they attempted to describe the qualities of empowerment. The statements show that empowerment is a complex process, not an event, in which the power to make decisions, and to have choices from a range of options, are the most important elements. Self-help alternatives and consumer-provided mental health services provide the most favorable situation for these elements to exist. Zinman, Harp, and Budd (1997) describe these in self-help efforts among consumers. Knight and Carpinello (1991) also found these same important elements in a qualitative study of the perceptions of self-help group processes and outcomes.

The Need for Consumer Involvement in Research — Anyone interested in knowing more about consumer

mental health research will want to read the works of Jean Campbell. She has written extensively on the subject and was largely responsible for a Quality of Life Study by The Well Being Project, California (1989). The study was conducted by consumers for consumers and asked questions previously not asked. It was the feeling of 56% of mental health consumers that mental health professionals do not really listen to them, and 47% of the participants stated they avoided mental health services for fear of involuntary commitment. Jonikas and Bamberger (1998) also found important differences in women's perceptions of their own needs, compared to professionals.

Campbell, Ralph, and Glover (1993) presented the subject of consumer/survivor involvement in research at the Fourth Annual National Conference on State Mental Health Agency Services Research and Program Evaluation. Campbell reviewed the history of consumer/survivor involvement in research, and Glover reported that 36 of 50 states fund consumer-operated services, suggesting there is enough consumer leadership to support full integration into research projects. Ralph provides an interesting summary of research models in which consumers are either lab rats (passive objects) at one extreme, or independent researchers at the other end, planning and writing grants, collecting data, and analyzing and interpreting results.

In an article "*Behavioral Healthcare Tomorrow*" (May/June 1995) Campbell and Johnson talk about beliefs and attitudes viewed differently by consumers and professionals. Discussed is the need for research partnerships. The original Pioneer Dialogues is mentioned as having brought consumers and state mental health administrators together to discuss system reform (1994). They state in the conclusion of the article, "*Now is a rare moment, a clearing horizon of historic opportunity for individuals and communities to enter into dialogue about values and goals and to proceed thoughtfully into all areas where health quality and consumer choice are assured and policy decisions are made.*"

Dialogues: Developing the Potential for Partnership between consumers and Professionals — Since about 1990, there has been growing interest in the use of dialogues as a way to bridge the differences between consumers and professionals, or consumers and providers. Also, many writers, including Deegan (1991), Johnson

(1996), Frese (1997), and others have published important work recommending training of professionals to increase sensitivity to, and partnership with, consumers.

Caras (1995) states the potential of the information superhighway in the Internet Report at HSRI. She discusses the Internet as a means for dialogue between people and groups who "experience mood swings, fear, voices, and visions." Caras summarizes the value of Internet discussion groups and dialogues in just 26 words: "*Someone listens. Usually someone replies. I hear. When I'm heard, I feel appreciated. I feel worthy. I feel understood. I feel respected. I feel affirmed.*"

Dialogues: the Practice and the Results — The early Roundtable discussions and dialogues were often on the issue of involuntary treatment. The participants were able to come to surprising levels of consensus, given the initial differences in perspective. Dialogues documented between consumers and providers, state commissioners, and psychiatrists, all seemed to have been quite successful in raising consciousness, influencing some changes in policies, and establishing the value of true collaboration among the participants.

Much of the literature on conducting focus groups is useful to help teach people how to do dialogues. Also, Knight (1998) provides some guidelines for developing dialogues which stress the importance of participant selection, and other specifics of organizing a quality dialogue. Bluebird (1992) outlines steps for replication in the Pioneer Dialogue Recipe.

Bassman (1989) writes an article describing dialogues in which he makes the plea to psychologists and other professionals "*to come forward, to blast open the doors to legitimate inquiry, to separate control and management from treatment services, to question all the so-called truths about mental illness, and to stand up for people's rights.*"

In summary, the published literature is a rich source of materials to enrich planners' understanding of power dynamics and how to overcome them in the conduct of dialogues. Those briefly mentioned above, and others, suggested that all meetings for planning and conducting dialogues must operate in a way that is sensitive to the stigma and dis-empowerment that may be felt by the consumer participants. Care must be taken to ensure an atmosphere of safety to express conflicting perspectives.

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Advisory Group

Advisors to the project participated in a teleconference to review the outline of the dialogue in order to make suggestions and recommendations. In addition, there were numerous phone calls, e-mails, and meetings with individuals in the group.

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List of Resources

Bazelon Center for Mental Health Law
1101 15th Street, NW, Ste. 1212
Washington, D.C. 20005
phone: (202) 467-5730
fax: (202) 223-0409
www.bazelon.org

Carter Center Mental Health Program
One Copenhill
Atlanta, GA 30307
phone: (404) 420-5165
fax: (404) 420-5158

The Center for Community Changer, Institute for
Program Development
Trinity College of Vermont
208 Colchester Avenue
Burlington, VT 054011-1496
phone: (802) 658-0000
fax: (802) 863-6110
e-mail: cc@courage.trinityvt.edu

Consumer Organization and Networking Technical
Assistance Center (CONTAC)
1036 Quarrier Street
Charleston, WV 25301
phone: (888) 825-TECH (8324)
fax: (304) 346-9992
www.contac.org

Substance Abuse and Mental Health Services
Administration
Center for Mental Health Services
Knowledge Exchange Network, National Mental
Health Services
P.O. Box 42490
Washington, D.C. 20015
phone: 1-800-789-CMHS (2647)
fax: (301) 984-8796
tdd: (301) 443-9006
e-mail: ken@mentalhealth.org
www.mentalhealth.org

The Evaluation Center@HSRI
2336 Massachusetts Avenue
Cambridge, MA 02140
phone: (617) 876-0426
fax: (617) 492-7401
e-mail: tecenter@hsri.org
www.hsri.org

National Alliance for the Mentally Ill
2101 Wilson Boulevard, Ste. 302
Arlington, VA 22201
phone: (703) 524-7600 or 1-800-950-NAMI
fax: (703) 524-9094
www.nami.org

National Association of Protection and Advocacy
Systems
900 2nd Street NE, Ste. 211
Washington, D.C. 20002
phone: (202) 408-9514
fax: (202) 408-9520
www.protectionandadvocacy.com

National Depressive and Manic Depressive Association
730 N Franklin, Ste. 501
Chicago, IL 60610
phone: (312) 642-0049 or 1-800-826-3632
fax: (312) 642-7243
www.ndmda.org

National Empowerment Center
599 Canal Street, 5 East
Lawrence, MA 01840
phone: 1-800-POWER2U
tty: (800) TTY-POWER
fax: (978) 681-6426
www.nec.org

National Mental Health Association
1021 Prince Street
Alexandria, VA 22314-2971
phone: (703) 684-7722 or 1-800-969-NMHA
fax: (703) 684-5968
www.nmha.org

National Mental Health Consumers Self-help
Clearinghouse
1211 Chestnut Street, Ste. 1207
Philadelphia, PA 19107
phone: (215) 735-6082 or 1-800-553-4539
fax: (215) 636-6312
tdd: (215) 751-9655
www.mhselfhelp.org

National Research and Training Center on Psychiatric
Disability
104 S Michigan Avenue
Chicago, IL 60603
phone: (312) 422-8180
fax: (312) 422-0706

National Technical Assistance Center for State Mental
Health Planning
66 Canal Center Plaza, Ste. 302
Alexandria, VA 22314
phone: (703) 739-9333
fax: (703) 548-9517
www.nasmhpd.org/ntac

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