

PARENTS' VOICES: A FEW SPEAK FOR MANY

TRAINERS' GUIDE

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PURPOSE

This guide is designed to assist trainers in presenting the videotape, *Parents' Voices: A Few Speak for Many*. Sections to aid in preparing for the presentation include information regarding possible audiences, a sample goal and objectives of the presentation, and suggestions for conducting the discussion. As in any other training session, planning is essential for an effective presentation. These materials can be used as a guide for developing a presentation format.

ABOUT THE VIDEOTAPE

This videotape was produced by the PACER Center, a parent information and advocacy organization located in Minneapolis, Minnesota. Betty Binkard of the PACER Center staff provided valuable leadership in the conception and production of this videotape.

The PACER Center developed the videotape under an agreement with the Research and Training Center to Improve Services for Seriously Emotionally Handicapped Children and Their Families in Portland, Oregon. The contract was part of an initiative by the Research and Training Center to involve parent organizations in developing training materials that could be used to promote parent-professional collaboration.

The three mothers on the videotape, along with Betty Binkard, have given this panel presentation to a number of professional audiences in Minnesota with the goal of increasing professionals' understanding of the stresses faced by families who have a child with serious emotional problems. When these parents are also present at a training session, they are available to answer questions, or amplify their statements. Since the videotape does not allow for interaction with the presenters, discussion among members of the audience assumes greater importance. This guide is intended to help trainers use the tape effectively.

On this videotape parents of children with emotional handicaps express a number of concerns. These problems relate to effective working relationships between parents and mental health professionals and may make mutual respect difficult. New workers in the mental health professions can gain knowledge of parental concerns by viewing this videotape. Experienced workers can benefit from hearing the expression of parents' concerns, and from consideration and discussion of their own level of collaborative practice with parents.

The content of the videotape includes an overview of the four basic concerns of parents in working effectively with mental health professionals and the illustration of these concerns through personal accounts of three parents. Suggestions for presenting the videotape follow; however, trainers may wish to focus on certain concerns more than others or to add others to the discussion. Flexibility in presenting this video is essential in tailoring it to meet the needs of each particular audience.

POSSIBLE AUDIENCES

This presentation was originally designed for viewing by mental health professionals who work with children with emotional problems and their families. However, the videotape may be used effectively with at least three possible audiences:

- (1) A group composed entirely of professionals;
- (2) An audience consisting solely of parents of children with emotional problems, or;
- (3) A mixed group composed of both parents and professionals.

Professionals only

With a group consisting entirely of professionals, the training objective will probably include increasing the ability of trainees to empathize with parents, understand the stresses faced by families with a child who has serious emotional handicaps, and problem-solve about ways to modify their own practice or to change policies and procedures that make life unnecessarily difficult for parents. The major hazard with this group may be complaints about parents stimulated by the parents' presentation. It may be important for trainers to talk with the professional audience in advance about the video and the fact that some of the parents' comments are critical. Trainers may want to establish the norm of listening to the parents and attempting to put themselves in the parents' place. Once trainers have established an atmosphere of frank, but goal-oriented discussion, groups composed entirely of professionals are usually able to use discussion and problem-solving techniques productively.

Parents Only

The purpose of using this videotape with groups of parents will often be to encourage parents to talk about and analyze their own experiences or to help them understand that their problems are not unique. The video can be used as a tool to stimulate discussion or to encourage ventilation, as with a group of parents meeting for the first or second time. For these objectives, the trainers' main concern may be assuring that all who wish to speak have a chance to do so. When the purpose of the training is to address objectives such as increasing assertiveness, or developing advocacy strategies, the training plan will clearly need to be more structured and goal-oriented.

Parents and Professionals Together

This is probably the most difficult group to manage effectively, although the videotape can be a useful training tool in such mixed groups. The purpose of presenting the videotape to a mixed group might be to encourage frank discussion among parents and professionals about how the concerns identified on the videotape are also problems in a particular community, school, or agency. The videotape, or portions of it, would then be used to begin discussion, and to contrast local problems and solutions with those portrayed on the tape.

There are two major pitfalls with a mixed group. First, parents are often stimulated by the presentation to talk about their own concerns and experiences. If parents have not had past opportunities to talk about their concerns, they may not be ready to engage in more structured training activities. Parents may be angry with the failures of the service system to meet the needs of their child, or they may have had negative experiences with individual professionals.

Second, the content of the videotape may cause some professionals to react defensively. When parents within the audience identify other problems, especially if they are angry, professional defensiveness or negative reactions may be increased. In the presence of parents, however, professionals are often reluctant to speak openly, and may feel constrained in a number of ways. This dynamic, of course, is one of the fundamental impediments to achieving true parent-professional collaboration, and it presents an opportunity for parents and professionals to learn to speak frankly and engage in mutual problem-solving strategies. Working with a mixed group of parents and professionals calls for good planning, conflict management skills, and a very clear idea on the part of trainers about the purpose of the training activity.

These comments are not intended to discourage the use of the videotape with groups of parents and professionals together. Our intent is to alert trainers to possible hazards, and to help them anticipate and prepare for the training session.

Trainers need to know the background of the participants and to plan the presentation around that information. Assessing the background of audience members is usually possible before viewing the tape. Trainers may want to consider:

What are the needs of the members of the audience?
(for example: training, information, taking information back to the organization staff, etc.)

What services do the members of the audience perform (or receive) in relation to mental health, educational, child welfare, or other services for children with emotional handicaps?

What are the possible training problems, such as audience members' experiences in collaboration, their level of defensiveness to the content of the videotape, and their motivation to learn about collaboration?

The videotape is a tool to help trainers discuss the need for parent/professional collaboration. The session can be modified in order to meet the needs of different audiences. Trainers can best determine what adjustments need to be made after determining the composition of each audience.

PREPARING FOR THE PRESENTATION

Previewing the videotape, as well as reviewing and modifying the presentation of the materials to fit the audience will be necessary. Making personal notes about the material at previous presentations to other audiences will help trainers develop a more effective training session from the videotape. Evaluations by the participants can also be used to improve subsequent presentations.

The room selected for the presentation should be large enough for all participants to comfortably view the videotape, but not so large that seeing the screen is difficult. Chairs should be comfortable enough for sitting through a session of an hour or more. A flexible arrangement of chairs is best to facilitate breaking into smaller groups for discussion. The room should be sufficiently light during the screening of the videotape so that participants can take notes if they desire. Newsprint, felt markers, and masking tape should be available for use with small groups and to display the results to the entire audience. Providing writing utensils so that individuals can copy from the brainstorming lists is also a possibility.

Copies of handouts may be provided to participants. Trainers may decide to make copies of the narrator's script available to the audience in order to aid in understanding the introduction. Another option is to use either "Concerns of Parents" or "Things to Think About When Viewing *Parents Voices: A Few Speak for Many*" included in this guide as handouts prior to viewing the tape. The latter handout may also be used for a more general discussion after each parent video or after viewing all three videos instead of the format of parents' quotes and questions for discussion presented on pages 9 to 16 of this guide. Copies of goals and objectives may be presented as a handout, or may be written on newsprint or a blackboard. Evaluation forms for the members of the audience need to be distributed at the end of the presentation. All handouts provided in the trainers' guide are on white paper.

Trainers need to develop an agenda for the presentation, making certain to plan how much time to allot for discussion of each parent presentation on the videotape and to do the related exercises.

A VHS videotape machine and monitor are also necessary. Trainers will want to do a quick check to be sure both are in good operating order before the members of the audience arrive.

SAMPLE GOAL OF THE PRESENTATION

To make mental health professionals aware of the concerns that parents of children with emotional disturbances have that impede parent/professional relationships.

SAMPLE OBJECTIVES OF THE PRESENTATION

After viewing and discussing the parents' videotaped concerns:

- 1) participants will be able to recognize parents' perception that professionals too often assume parents are to blame for their child's emotional handicap;
- 2) participants will understand the necessity for parents and professionals to communicate with each other about particular children with emotional handicaps;
- 3) participants will understand parents' concern that they be told that their child has a problem even if no program exists to handle the problem;
- 4) participants will be able to understand parents' concerns that withdrawn, non-communicative children are served less well than "acting out" children. (Trainers may need to stress this objective beyond what is presented in the video.)
- 5) participants will be able to identify changes in practice and in organization policy that might benefit children with emotional disturbances and their parents.

Trainers can explain to the audience that these objectives are connected to the concerns expressed by the parents in the video. They may also wish to warn the mental health professionals that parents on the video are critical of what they have experienced. The purpose of the video is not to blame the professionals, but to provide them with an opportunity to listen to one set of parents and what they've experienced. Trainers may explain that in previous presentations of the video, professionals have found that it has been important to them in changing the way they looked at parents.

A copy of the goals and objectives developed by trainers for this presentation can be handed out to the audience.

NOTE: This is a sample of a goal and objectives developed for a professional audience. Trainers will want to modify them, or to develop a new goal and set of objectives depending on the purpose of the presentation and the composition of the audience or training group.

SAMPLE PRESENTATION FORMAT

Included in the format are welcome and introductions, explanation to trainers of the video segments, provision for break and closing and instructions for use of the handouts. This material is on pages 6-8 of the guide. The balance of the guide consists of discussion materials for each segment of the video as well as handouts for the audience. All of this material is designed to be copied and used as handouts at trainers' discretion.

Welcome and Introductions

Welcome the participants. If the group is small, participants can introduce themselves. Trainers can explain that the purpose of the videotape is to hear from parents of children who have emotionally disturbances about their concerns regarding their interactions with the professionals who work with their children.

If the audience members are not already acquainted with each other, trainers may want to start the presentation by asking the audience how many of its members are mental health professionals, parents, etc. to get a voluntary sampling of the composition of the audience. They may also want to sample the expectations of the audience by suggesting some purposes for attending the training and asking the audience to raise their hands if they share a particular purpose or several purposes; then members of the audience could be asked if there are other purposes that brought them to this presentation.

At this point, trainers may want to make clear to the audience the objectives of this presentation. Trainers should develop a particular goal or goals and a set of objectives for this group. That information can be shared verbally and in a written handout as well.

Format for Discussion After Viewing Parent's Concern on Video

The video can be divided into four parts: the introduction and three parent presentations. After each parent presentation, opportunity may be provided to consider quotations from each presentation and participate in discussions around questions related to these expressed concerns. If the audience is large, trainers may want to break the group into smaller units for the discussions. The groups will be given a set amount of time to discuss selected comments of the parents. Questions to prompt discussion are given after the quoted comments. Parents' comments from the video are in italics. The last comment and question can be answered using the technique of brainstorming. (Brainstorming refers to the rapid generation of ideas by members of the audience. All ideas are accepted; they are not criticized or questioned at the time they are given. The method is designed to develop a wide variety of options, often very creative options, without limiting their expression by contributors.) Each group can be given newsprint, masking tape or easel, and a felt pen to use to list the generated answers. Each group can then share its answers with the entire audience. Space is provided on the videotape comments and questions sheets for participants to copy the suggestions, if they wish.

Introduction to Parents' Presentations

After playing the introduction, trainers will want to stress to the group that the parents whose presentations will follow are not composites of several parents, but that each is speaking from her own recent experiences.

First Parent: Guilt/Parent Blaming

Before playing the first parent video, trainers may tell the group that this parent will be presenting the first concern of parents--that they are frequently blamed by mental health professionals for their child's emotional handicap.

Research demonstrating that parents are not necessarily the cause of their child's handicap is referred to in E. F. Torrey's *Surviving Schizophrenia. A Family Manual*, New York: Harper and Row (1983) and in *Family Coping and Schizophrenia* by F. H. Jung, L. Spaniol, and W. A. Anthony, Boston: Boston University Center for Rehabilitation Research and Training in Mental Health (1983), and in an article by E. H. Taylor, "The Biological Basis of Schizophrenia," *Social Work*, (32)2, (pp. 115-121), 1987.

At this point, trainers will play the first parent video. The last question on the handout for this segment requires developing a list of resources available to parents. Using newsprint, the group(s) can list some of the ideas that the group members generated. These lists should be reported back to the larger group. Time should be provided to allow participants to copy their list and the lists that other groups generate.

Breaktime

A short ten-minute break could be inserted at this point in the presentation.

Second Parent: Communication

Before playing the second videotape, trainers may tell the group that this parent will be presenting the second concern of parents---the lack of communication between professionals and between professionals and parents.

After playing the videotape, the group members may reassemble in smaller groups for discussion. The last question in the handout for this section requires the groups to brainstorm ways to facilitate cooperative communication between professionals and between professionals and parents. As before, the groups should write their ideas on newsprint and report the ideas back to the larger group providing opportunity for group members to copy ideas from their own and other groups' lists.

Third Parent: No Program, No Problem/Withdrawn Children

Before playing the videotape of the third parent, trainers may tell the group that she will be presenting the third and fourth concerns of parents---the diagnosis of "no problem" when no program exists for that problem, and their perception that withdrawing, non-communicative children are served less well than "acting out" children.

After playing the videotape, the group members may reassemble in smaller groups for discussion. Use newsprint to list programs that are mentioned, and provide paper and pen to those who want to copy the list their group generates and those of other groups, as well.

Other areas trainers may want to address with this group include the following: (1) issues faced by single parents; (2) rural concerns; (3) professional/parent ratios at meetings; and (4) special problems faced by schools and teachers in special education and regular classrooms.

Closing

Trainers may distribute copies of the evaluation form and ask the participants to fill them out if they desire and make comments on the sheet, and thank them for their attendance and for their comments on the evaluation.

The evaluation of learning form may also be used as a pre- and post-test. The evaluation of the presentation can be used to modify future presentations to make them more effective.

Trainers could also distribute the "Concerns of Parents" handout at the end of the presentation.

- c. How do professional services reduce (or increase) the demands placed on families?

3. *"The most [stressful thing] to us was the constant feeling that we were being blamed for a problem . . . that we had not caused."*

- a. How would that feel?

- b. What could a parent do to reduce or relieve these feelings?

- c. How can professionals help with this concern?

4. *"What is the greater good that comes from blaming a parent for their child's problem?"*

- a. Does it serve any good purpose?

- b. Assuming that most professionals do not deliberately or directly "blame" parents, what professional behavior may lead parents to feeling blamed?

c. Why might parents acquire a sense of guilt and feelings of being stigmatized even when the diagnosis of their child's disorder does not suggest that poor parenting has contributed to its origin?

d. How can the professional community help parents avoid the development of unwarranted and nonproductive guilt?

5. *"What does help is to provide parents with suggestions of ways to cope with, understand, and accept their child's disorder."*

a. Discuss the difference between family therapy and helping a family to understand and cope with a child's problem. Are professionals trained for that?

b. What resources are available? Where are they located? What can professionals do to help parents?

SECOND PARENT: COMMUNICATION

1. *"Doctors kept telling me, 'Don't worry, Mom.' And oh, how familiar that phrase has become over the years as we've worked with professionals . . . I knew something wasn't right, and I had reason to worry, in spite of what I was being told."*

- a. Why do you think professionals may minimize emotional disturbance?

- b. What are the dangers in minimizing emotional disturbances to the parents?

2. *"This information [from the neurologist] was shared with his school, but it was as if they never heard me. . . I couldn't follow through with their [the school's] behavior recommendations which contradicted those of the medical and mental health professionals who worked with my son."*

- a. Why might staff members at schools, hospitals, and mental health agencies respond differently to a child's problems?

- b. How would it feel to be in the middle of a disagreement between two important systems like these? What would you do?

- c. What strategies can you suggest to overcome communication barriers between professionals such as those discussed on the videotape?

b. What, if any, is the standard practice regarding consultation at your organization?

c. If consultation is not the norm, what can you do to facilitate cooperative communication between professionals and between professionals and parents?

EVALUATION OF LEARNING

TRUE AND FALSE ANSWERS:

- _____ 1. Parents of children with emotional disturbances are often disturbed themselves.
- _____ 2. Many professionals fail to recognize the demands that are placed on a family with a child with emotional problems.
- _____ 3. The most distressing thing for some parents is the constant feeling of being blamed for their child's problem.
- _____ 4. It's best for professionals to minimize the emotional problems of their children to the parents.
- _____ 5. Mental health professionals' recommendations for parents of children with emotional handicaps are sometimes conflicting.
- _____ 6. Some mental health professionals are so certain of their assessments they do not feel the need for consultation.
- _____ 7. Most parents are not intimidated by the expertise of the mental health professional.
- _____ 8. Schools always pay for the testing children receive to demonstrate their need for special education services.
- _____ 9. Parents believe it is easier to get services for a child who is acting out than for a child who is withdrawn.
10. After checking your answers against the opinions expressed by the parents on the videotape, please choose one answer where you differed from the parents. Explain why you disagree. If you agreed on all, please choose one question to discuss, or talk about another idea that was presented. Please use the back of this sheet for your comments.

EVALUATION OF THE PRESENTATION

A. * Please select the number from the five choices below that best describes the presentation's value for you:

-
1. I fail to see where this will be of any value to me.
 2. I knew this already and didn't gain anything from what was presented.
 3. I have been exposed to this previously, however, this helped me to confirm or to modify some of my opinions.
 4. This was appropriate to my current level of personal or professional development; however, this is just a beginning; I will need more training before applying what I have learned.
 5. This was just what I needed, and I can apply it in my current work.

B. What could be improved to make this training more useful? More comfortable?

C. Please give us your comments on the videotape:

1. Introduction
2. Speaker One: Guilt/Parent Blaming
3. Speaker Two: Communication
4. Speaker Three: No Program, No Problem/Withdrawn Children

D. General Comments on the Presentation

* Thanks to the Oregon Consortium for Continuing Education in Mental Health Content for this evaluation format.

CONCERNS OF PARENTS

The following four concerns of parents with children with emotional handicaps are taken from the videotape produced by PACER Center, Inc., in Minneapolis, Minnesota, titled *Parents' Voices: A Few Speak for Many*. This videotape was developed with grant funds from the Research and Training Center to Improve Services for Emotionally Handicapped Children and Their Families in Portland, Oregon.

1. The first concern is that parents believe professionals too often automatically assume that if a child has an emotional disorder, the parent or family are at fault. PACER recognizes that, in some cases, a parent's or family's malfunctioning may be the root of a disorder. What we question is the automatic or unquestioning assumption on the part of professionals that parents are part of the problem and must be "treated" along with the youngster. This assumption would not be made of parents of children with a hearing impairment; we contend it should not be made of mothers and fathers of a youngster with an emotional impairment.

2. A second concern is expressed by parents who see professionals from different segments of the child's life hesitating or refusing to communicate with each other. One person may have Theory A about the source of the child's problem, a second proposes Theory B, while a third contends there is no problem, and that the child is just going through a "phase." There may be no communication among the three and certainly no consensus about the origin of the child's problem or what program would best meet his/her needs. Yet the parent who reflects understandable confusion about the differing ideas is sometimes viewed with suspicion by each professional when s/he doesn't seem to entirely accept that individual's theory and proposals.

3. A third concern is that felt by parents who believe they have been told that their child has no problem--not because there really is no problem, but because the organization in question has no program to deal with the problem. It is especially exasperating for parents to have their own judgment and instinct denied, to have finally acknowledged that something does seem to be terribly wrong for their child--and then to suspect that professionals are evading an acknowledgement of the problem because a program--not the problem itself--does not exist. The distrust that is bred by this kind of situation is deep and long-lasting and makes future working relationships difficult.

4. Finally, a dilemma faced by many parents who contact PACER is that their child's emotional disorder is characterized by withdrawal and non-communication. Though mental health professionals would rate depressive disorders of this type as among the most serious and threatening to the child, school programs for these children are often hard to obtain. It seems to many parents that their youngster would receive special services much more readily if his/her disorder were characterized by belligerence, hostility, and acting-out behavior.

THINGS TO THINK ABOUT WHEN VIEWING THIS VIDEOTAPE

1. What positive collaborative efforts occurred between parents and professionals?
2. What negative events occurred in relation to parent-professional collaboration?
3. What could have been done sooner to make the experiences of the parents depicted less stressful?
4. If you are a professional, how would you have reacted to the parents?
5. If you are a parent, how much do the parents' experiences reflect your own and how you have dealt with similar concerns?
6. In what ways can parents and professionals work together to improve services for children with emotional problems?
7. How can parents and professionals improve their ability to communicate with each other?

DEFINITIONS OF EMOTIONAL HANDICAP

There is no universally agreed upon definition of emotional handicap. In fact, there is no agreed-upon term to describe the population of children and youth with emotional or behavioral problems. Terms range from seriously emotionally disturbed, to behaviorally disordered, to emotionally handicapped, and so on. When viewing the videotape, *Parents' Voices: A Few Speak for Many*, produced by the PACER Center, Inc., in Minneapolis, Minnesota, the viewer may keep in mind the federal definition of seriously emotionally disturbed from P.L. 94-142 which is as follows:

A condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree, which adversely affects educational performance: (1) an inability to learn which cannot be explained by intellectual, sensory or health factors; (2) an inability to build or maintain satisfactory interpersonal relationships with peers and teachers; (3) inappropriate types of behavior or feelings under normal circumstances; (4) a general pervasive mode of unhappiness or depression; or (5) a tendency to develop physical symptoms or fears associated with personal or school problems. The term includes children who are schizophrenic. The term does not include children who are socially maladjusted, unless it is determined that they are seriously emotionally disturbed.

The PACER video uses a definition of seriously emotionally disturbed that is taken from the Minnesota State guidelines:

disorders characterized by one of the following behavior clusters:

*...severely deviant disruptive, aggressive or impulsive behaviors,
...severely deviant withdrawn or anxious behaviors, general pervasive unhappiness, depression or wide mood swings, or
...severely deviant thought processes manifested by unusual behavior patterns, atypical communication styles, and distorted interpersonal relationships.*

Additionally, existence of the condition must be 'pervasive,' i.e., exist in more than one educational setting, and it must be either chronic or acute in nature. (The Minnesota guidelines define chronic as "ongoing, severe;" and acute as "sudden, severe, serious, an emergency;")

PARENTS' VOICES: A FEW SPEAK FOR MANY

EVALUATION FORM

1. To whom was the *Parents' Voices* videotape shown? (Check all that apply.)

Parents Educators Child Welfare Workers

Juvenile Justice Workers Mental Health Professionals

Others (Please specify) _____

2. Was the videotape shown as part of a training session? Yes No

If yes, type of training? _____

If no, please describe the purpose of showing the videotape:

3. Would you recommend use of the videotape to others? (Circle one)

Definitely Maybe Conditionally Under No Circumstances

Comments: _____

4. Overall, I thought the videotape was: (Circle one)

Excellent Average Poor

Comments: _____

5. Did you use the *Trainers' Guide* in preparation for presenting the *Parents' Voices* videotape to an audience? Yes No

If no, did you use the *Trainers' Guide* for another purpose? Yes No

If used for another purpose, please describe use: _____

6. Would you recommend use of the *Trainers' Guide* to others? (Circle one)

Definitely Maybe Conditionally Under No Circumstances

Comments: _____

7. Overall, I thought the *Trainers' Guide* was: (Circle one)

Excellent Average Poor

Comments: _____

Please return completed form in the enclosed self-addressed, postage paid envelope to:

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