This document presents one module in a set of training resources for trainers to use with parents and/or professionals serving children with disabilities; focus is on parent support groups. The modules stress content and activities that build skills and offer resources to promote parent-professional collaboration. Each module takes about 2 hours to deliver. The module guide has eight sections: a publicity flyer, topic narrative, overview, trainer agenda, activities, summary, bibliography, and evaluation. Introductory information explains how to use the modules including conducting a needs assessment, planning the training, selecting the training module, implementation, evaluation, and followup. Objectives of this module are: (1) become familiar with the history and current concepts of parent support groups, (2) recognize the benefits of belonging to a parent support group, (3) identify some functions of a parent support group, (4) identify the elements of successful parent support groups, and (5) develop an initial plan of action to establish and/or maintain a parent support group. A bibliography identifies seven books, magazines, or other resources. (DB)
California State Department of Education
Special Education Division
Program, Curriculum and Training Unit

Presents a Module on:

Parent Support Groups

Prepared by:
Mary Ann Duganne-Glicksman

Revised by:
Lynn Carlisle
Pat Lesniak

1988
This module, as well as thirteen others, were produced under the direction of Karl E. Murray and Susan Westaby of the Program, Curriculum and Training Unit, Special Education Division, CA State Department of Education. The modules are being field-tested throughout 1988. During this field-test stage, they are available by sending $5.00 for each module (includes tax and mailing) to: Parent Training Modules, CA State Department of Education, P.O. Box 944272 - Room 621B, Sacramento, CA, 94244-2720. Make checks payable to Parent Training Modules.
INTRODUCTION

The Parent/Professional Training Modules have been developed to serve as a core set of training resources for trainers to use primarily with groups of parents. Some of the trainings were designed specifically for combined groups of parents and professionals, and all the trainings can be adapted for use with parents or professionals as separate or combined audiences. The training modules in the series focus on content and activities that build skills and offer resources to promote parent-professional collaboration to ensure quality education for all students with disabilities. There are fourteen training modules in this series:

- Parent Professional Collaboration
- Parental Involvement
- Stress and Support in the Family
- Coping with Loss and Change
- Parent Support Groups
- An Effective Community Advisory Committee
- Community Advisory Committee Leadership Training
- Communication Skills
- The Individualized Education Program: Rights and Responsibilities
- Placement in the Least Restrictive Environment
- Training for Professionals Working with Families
- Parent Professional Collaboration in Planning for Employment
- Transition Planning
- Interagency Collaboration: The Parents' Role

Each training module has eight sections:

Flyer
Topic Narrative
Overview
Trainer Agenda
Activities
Summary
Bibliography
Evaluation

Within each of these sections there are these materials:

Flyer - The Flyer highlights what participants can expect to learn by attending the training. It can be personalized for each training by adding date, time, and location in the appropriate spaces.

Topic Narrative -- The Topic Narrative contains content information specifically for the trainer. Trainers use the information to enhance their knowledge and understanding of the subject matter of the training module.
**Overview** -- The Overview contains the goals and objectives for the module; and the content and presentation strategy for each activity contained within the module.

**Trainer Agenda** -- The Trainer Agenda contains details of trainer and participant activities, materials and media. It is a suggested agenda that trainers can personalize to fit their style and the specific needs of the participants. A few modules that deal with sensitive or difficult content have Trainer Tips included in the Agenda section.

**Summary** -- The Summary contains highlights of all the content information presented in activities within the training. The Summary was designed to provide information to prospective participants and to workshop planners.

**Bibliography** -- The Bibliography contains the names of books, magazines and other resources that were used as references in developing the training modules and may serve as a list of suggested reading materials for trainers as well as participants.

**Evaluation** -- The Evaluation contains questions that directly assess the objectives of the module as well as some general questions to evaluate the usefulness of materials and trainer effectiveness.

The Parent/Professional Training Modules have been designed to be a flexible and expandable resource for trainers of parents and professionals. It can be housed in binders or in file folders and rearranged as needed. Trainers are urged to add articles, resources and other materials that will make each training reflect their individual style and meet the needs of the participants.
HOW TO USE THESE TRAINING MODULES

Conduct a Needs Assessment:

Gather as much information as you can about the groups that you will be working with. The following types of questions may help:

Does the group meet regularly or is it assembled specifically for the purpose of this training?

What does the group want to accomplish? Does it have a stated goal? Are there a set of outcomes that the group wants to achieve?

Who is involved in the group (agencies and organizations)?

If the group is an ongoing group, how is the group organized? (officers, executive committee, standing committees, task groups, etc.)

What has the group already done? What training has the group already received?

What is the group working on now?

How does the group get things done?

Has the group conducted a needs assessment to determine the group's need for training and the training topics of interest?

Plan the Training

Typically, this is a dialogue between the trainer and the client. Often, the client will have a specific topic or activity in mind. Sometimes additional topics will be suggested during the needs assessment process when the trainer probes to get more information. The trainer can share a list of module topics and/or several module summaries to aid the client in selection of a topic(s) from the series.

Select the Training Module

The Parent/Professional Training Modules offer a wide selection of topics and activities. The trainer can select the module that deals with the topic chosen by the client.

Review the Training Module

The module provides the core activities and a suggested trainer agenda. The trainer can adjust both to reflect their individual style and the needs of the client.
Identify Additional Resource Materials

The trainer can add articles, resources, and other materials to the core training module. Often a trainer will introduce local resources or pertinent sample materials.

Deliver the Training

The Parent/Professional Training Modules are best delivered by a training team of a parent and a professional. Collaboration is modeled by the team as each member of the team displays unique perspectives, abilities and knowledge as they enhance each others presentation styles.

Evaluate the Training

Evaluation is an essential element of any training. Each module includes an evaluation that assesses the specific objectives of the module and the usefulness of materials. These evaluations can assist the trainer in refining the module content and modifying presentation style, if needed.

"Follow-Up" the Training

It is a good practice to follow-up any training with a personal visit, letter, or a phone call. The trainer may wish to keep a list of names, addresses, and phone numbers of participants to facilitate follow-up. The follow-up usually consists of discussion about how the training may have impacted the client's personal or professional life. Clients may express the desire for further training and/or materials and resources.
Parent Support Groups

(For Parents and Professionals Interested in Establishing a Parent Support Group)

You as a participant will learn about:

- the history and current concepts of parent support groups
- the benefits of belonging to a parent support group
- some functions of a parent support group
- the ingredients of successful parent support groups
- developing an action plan to start or maintain a parent support group

Day and Date:

Time:

Location:

For More Information, Call:

Please Come
Parent Support Groups

Topic Narrative

Parents of children with special needs have long been forming and participating in mutual support groups around disability issues. These groups in the past have been started by, composed of, and governed solely by parents. Historically they were often formed in order to establish a private parent run program to provide services which were denied their children by the existing system. A further reason to draw parents together was to put pressure on the service delivery and school systems and society in general, to accept their children with their differences and to provide public services to them.

With the passage of Public Law 94-142, the Education for all Handicapped Children Act of 1975, rights and safeguards were established for children and their parents. The law called for, and strongly encouraged, parental participation in planning and programming for students with special needs.

Parent pressure had paid off. Together with far thinking supportive professionals, parents had changed the system. There were now public school programs for all children. While parents were not about to relax their vigilance, they realized that there was a new game plan. They and their children were included in the system. In the State of California, Community Advisory Committees were mandated in each special education local planning area (SELPA). Here parents had a mechanism for dialogging, questioning and supporting their school district and SELPA.

In the process of forming groups which had specialized advocacy objectives, parents had found that another major need was fulfilled. They were giving each other emotional support and understanding. Now that there were formalized processes for "taking care of business", parents of children with disabilities in many communities began to take a look at their own needs. They recognized that the emotional support and understanding they received from other parents in a group was very important to them in dealing with the unique stresses and conflicts that arose in parenting their children. Parent groups began to appear whose purpose was not to change the system, but to give and receive mutual peer support. Other existing parent groups added mutual support to their primary goal of advocacy.

This movement toward parent support groups for parents of children with disabilities is part of a national phenomenon. There has been a tremendous increase in the number of self-help groups formed in the past two decades. An estimated 15,000,000 people in this country belong to some 500,000 support groups that deal with virtually every human concern. The U. S. Department of Health and Human Services predicts that the number of people involved will double by 1990. The California Self-Help Center at the University of California at Los Angeles maintains a listing of over 3,000 self-help support groups in their statewide computerized referral service.

Some of the factors contributing to this growth are: the increasing awareness that professional experts don't have all the answers; the civil rights movement where people take control of their own destiny; increased media coverage, and public awareness of problems never before discussed; mounting problems in society, such as crime, drug abuse, youth suicide, and unemployment; and increased research showing that support groups promote mental and physical health.

Surgeon General Everett Koop endorsed America's booming self-help movement. At a conference sponsored by the California Self-Help Center in Los Angeles, September 1987, Koop said, "I believe in self-help as an effective way of dealing with problems, stress, hardship and pain...The self-help support group is one of America's fastest growing methods of coping with personal problems."

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The majority of self-help or support groups are started by people who are experiencing the stress or problem. However, one third of these groups are started with the aid of a professional. Although the professional may continue to be present as a resource, the control of the group remains with the members.

The special education parent support group falls into a category called a "One Step Beyond" group. These are support groups for family and friends of the person with the problem. Some other examples are relatives of mentally ill persons, spouses of head trauma victims, and care giving children of elderly parents.

Support groups for parents of children with disabilities exist in various formats. Some are free standing, such as the Down's Syndrome Parent Group. Others, such as high risk infant support groups and parents of children with cancer, are harbored within hospitals. Some are collaborative efforts with school districts.

Whatever their structure, parent support groups provide parents a safe place to share their struggles and concerns and to acknowledge their victories. It is a place where parents can share emotional support, information and resources.
Overview

The main goal of this module is to provide participants with knowledge of the benefits, elements and functions of a parent support group in to enable them to establish and/or maintain a group that supports their needs as parents of children with disabilities.

Objectives

1. Become familiar with the history and current concepts of parent support groups.
2. Recognize the benefits of belonging to a parent support group.
3. Identify some functions of a parent support group.
4. Identify the elements of successful parent support groups.
5. Develop an initial plan of action to establish and/or maintain a parent support group.

<table>
<thead>
<tr>
<th>Objective Number</th>
<th>Suggested Minutes</th>
<th>Content</th>
<th>Presentation Strategy</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>10</td>
<td>Definition and Concept</td>
<td>Lecturette</td>
</tr>
<tr>
<td>1</td>
<td>10</td>
<td>History</td>
<td>Lecturette</td>
</tr>
<tr>
<td>2</td>
<td>20</td>
<td>Benefits</td>
<td>Large Group Brainstorm and Discussion</td>
</tr>
<tr>
<td>3</td>
<td>20</td>
<td>Functions (What it does.)</td>
<td>Lecturette and Large Group Discussion</td>
</tr>
<tr>
<td></td>
<td>10</td>
<td>Break</td>
<td></td>
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<tr>
<td>4</td>
<td>30</td>
<td>Elements (What you need.)</td>
<td>Lecturette, Individual Activity and Large Group Discussion</td>
</tr>
<tr>
<td>5</td>
<td>30</td>
<td>Action Planning</td>
<td>Individual and Small Group Activity with Large Group Sharing</td>
</tr>
<tr>
<td></td>
<td>10</td>
<td>Conclusion &amp; Evaluation</td>
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</tr>
</tbody>
</table>

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Suggested Trainer Agenda

WORKSHOP TITLE: Parent Support Groups

DATE: __________ PAGE: 1

CLIENT: To provide participants with knowledge of the benefits, elements and functions of a parent support group to enable them to establish and/or maintain a group that supports their needs as parents of children with disabilities.

GOAL: 1. Become familiar with the history and current concept of parent support groups.
2. Recognize the benefits of belonging to a parent support group.
3. Identify some functions of a parent support group.
4. Identify the elements of successful parent support groups.
5. Develop an initial plan of action to establish and/or maintain a parent support group.

<table>
<thead>
<tr>
<th>TIME</th>
<th>WHO</th>
<th>TRAINER ACTIVITIES/CONTENT</th>
<th>PARTICIPANT ACTIVITIES</th>
<th>HANDOUTS MEDIA</th>
</tr>
</thead>
<tbody>
<tr>
<td>10 minutes</td>
<td>Welcome</td>
<td></td>
<td>Listen</td>
<td>Chart Paper</td>
</tr>
<tr>
<td>10 minutes</td>
<td>Introductions</td>
<td></td>
<td></td>
<td>Pens</td>
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<tr>
<td>10 minutes</td>
<td>Objectives and Agenda Review</td>
<td></td>
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<td>Tape</td>
</tr>
<tr>
<td>10 minutes</td>
<td>Display Objectives and Agenda on Chart Paper</td>
<td></td>
<td></td>
<td>Chart of Objectives and Agenda</td>
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<tr>
<td>10 minutes</td>
<td>Warm Up/Inclusion Activity</td>
<td>Ask participants to share what they value most about being part of a support group - any kind of a self-help group. If they are not currently involved in a group, ask them what they would like to get out of a group if they joined.</td>
<td>Share</td>
<td></td>
</tr>
<tr>
<td>10 minutes</td>
<td>Definition and Concept</td>
<td>Activity/Handout 1</td>
<td>Listen</td>
<td>Handout 1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>I lecturette</td>
<td>Discuss</td>
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<td></td>
<td></td>
<td>Distribute Handout 1</td>
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## Suggested Trainer Agenda (continued)

<table>
<thead>
<tr>
<th>TIME</th>
<th>WHO</th>
<th>TRAINER ACTIVITIES/CONTENT</th>
<th>PARTICIPANT ACTIVITIES</th>
<th>HANDOUTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>10 minutes</td>
<td></td>
<td>Using Handout 1, the trainer will define a self-help support group. The trainer may want to use examples of parents of children with disabilities to illustrate how a special education parent support group fits this definition.</td>
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<td></td>
<td><strong>History</strong></td>
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<td></td>
<td></td>
<td>Activity/Handout 2</td>
<td>Listen Discuss</td>
<td>Handout 2</td>
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<td>Lecturette</td>
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<td></td>
<td>Distribute Handout 2</td>
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<td>Using Handout 2, the trainer will discuss the history of special education parent support groups.</td>
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<td>20 minutes</td>
<td></td>
<td><strong>Benefits</strong></td>
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<td></td>
<td></td>
<td>Activity/Handout 3A - nd 3B</td>
<td>Brainstorm</td>
<td>Handout 3A</td>
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<tr>
<td></td>
<td></td>
<td>Large Group Brainstorm and Discussion</td>
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<td>Chart paper</td>
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<td></td>
<td>Distribute Handout 3A</td>
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<td>Use Handout 3A to review the value and rules of brainstorming. Ask participants to brainstorm all the possible benefits they can see for parent support groups for parents of children with disabilities. Trainer will record responses on chart paper. Allow a maximum of 5 minutes for this part of the activity.</td>
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<td>Distribute Handout 3B and compare it with the brainstormed list. Lead participants in a discussion of similarities between the two lists.</td>
<td>Discuss</td>
<td>Handout 3B</td>
</tr>
<tr>
<td>20 minutes</td>
<td></td>
<td><strong>Functions (What it does.)</strong></td>
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<td>Activity/Handout 4</td>
<td>Listen</td>
<td>Handout 4</td>
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<td>Lecturette and Large Group Discussion</td>
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<td></td>
<td>Distribute Handout 4</td>
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</table>

**Handout Notes:**
- Handout 2
- Handout 3A
- Chart paper
- Handout 3B
- Handout 4
### Suggested Trainer Agenda (continued)

<table>
<thead>
<tr>
<th>TIME</th>
<th>WHO</th>
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<th>PARTICIPANT ACTIVITIES</th>
<th>HANDOUTS</th>
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</thead>
<tbody>
<tr>
<td>10 minutes</td>
<td></td>
<td>Using Handout 4, describe the various functions of a parent support group. The Trainer should use examples of parent support groups to illustrate these functions. For example, to illustrate &quot;providing ongoing support&quot; - some groups set aside a portion of each meeting for a rap session. In the case of &quot;help in a time of crisis&quot; - some groups maintain a telephone network so that someone is available to support anyone at any given time. Participants should be encouraged to add examples and ask questions.</td>
<td>Add Examples</td>
<td>Handout 5A</td>
</tr>
<tr>
<td>30 minutes</td>
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<td><strong>Break</strong></td>
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<td></td>
<td><strong>Elements (What you need.)</strong></td>
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<td><strong>Activity/Handout 5A and 5B</strong> Lecturette, Individual Activity and Large Group Discussion.</td>
<td>Discuss Ask Questions</td>
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<td>Using Handout 5A, describe the basic elements necessary to start and maintain a parent support group. Encourage participants to contribute their ideas, concerns and questions.</td>
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<td>Handout 5B</td>
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<td>At the bottom of Handout 5A the participants will find a listing of personal qualities needed to start a group. Instruct participants to examine those qualities and rate themselves using the numbered rating system. Discuss other qualities that could be added to the list.</td>
<td>Complete Self-Assessment</td>
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<td>Distribute Handout 5B. Discuss the roles of professionals in parent support groups - especially those groups started within a school district or agency.</td>
<td>Discuss</td>
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<tr>
<td>30 minutes</td>
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<td><strong>Action Planning</strong></td>
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<td>Handout 6A</td>
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<td></td>
<td><strong>Activity/Handout 6A and 6B</strong> Individual and Small Group Activity with Large Group Sharing</td>
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<td></td>
<td></td>
<td>Distribute Handout 6A</td>
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## Suggested Trainer Agenda (continued)

<table>
<thead>
<tr>
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<th>PARTICIPANT ACTIVITIES</th>
<th>HANDOUTS</th>
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<tbody>
<tr>
<td></td>
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<td><strong>Ask Participants to think about the parent support group that they envision or already belong to. Instruct participants to write a short statement or group of phrases that describes their actual or envisioned group. The statement will form the basis for action planning that will take place in small groups. Allow 5 minutes for this portion of the activity. When participants have completed their statements, ask them to form small groups. If they have come to the workshop session with members of their school district or agency, they should form a group with those people.</strong></td>
<td><strong>Write Statement</strong></td>
<td>Handout 6B</td>
</tr>
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<td>Distribute Handout 6B. Participants will complete an action plan. Based on the information presented and discussed, ask participants to design an action plan that would include the first steps in forming or maintaining a parent support group. Actions should be described in a step-by-step sequence noting the person responsible and the timeline. Allow 15 minutes for this portion of the activity.</td>
<td><strong>Form Small Groups</strong></td>
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<td>The small group should choose one person to share their action plan with the large group.</td>
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<td><strong>Conclusion</strong></td>
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Handout 7
What is a Self-Help Support Group?

Self-Help support groups:

- are made up of people with a common concern who come together in order to help each other cope more effectively by exchanging
  - emotional support
  - information
  - resources.

- are easily accessed,

- are organized and controlled by the members,

- meet regularly, often in homes, in order to provide a warm and private atmosphere,

- have a definite structure even though the structure and form varies among groups. It can range from an informal rap group to a very structured program such as Alcoholics Anonymous,

- can be "primary groups" made up of the people experiencing the problem, such as Alcoholics Anonymous or Amputees in Motion,

- can be "one step beyond" groups made up of family and friends of the person experiencing the problem, such as groups for parents of children with disabilities, care giving children of elderly parents, or spouses of head trauma victims,

- can be started by a professional by networking people with a common concern.
History of Special Education
Parent Support Groups

- **Parent groups formed to provide services and to change the system.**
Parents of children with special needs have long been forming and participating in mutual support groups around disability issues. These groups in the past have been started by, composed of, and governed solely by parents. Historically they were often formed in order to establish a private parent-run program to provide services which were denied their children by the existing system. A further reason to draw parents together was to put pressure on the community service and school systems and society in general, to accept their children with their differences and to provide public services to them.

- **Public Law 94-142 includes parents in the system**
With the passage of Public Law 94-142, the Education for all Handicapped Children Act of 1975, rights and safeguards were established for children and their parents. The law called for, and strongly encouraged, parental participation in planning and programming for students with special needs.

Parent pressure had paid off. Together with far thinking supportive professionals, they had changed the system. There were now public school programs for all children. While parents were not about to relax their vigilance, they realized that there was a new game plan. They and their children were included in the system. In the State of California, Community Advisory Committees are mandated in each special education local planning area (SELPA). Here parents have a mechanism for dialogging, questioning and supporting their school district and SELPA.

- **Parents look at their own needs**
In the process of forming groups which had specialized advocacy objectives, parents found that another major need was fulfilled. They were giving each other emotional support and understanding. Now that there were formalized processes for "taking care of business", parents in many communities began to take a look at their own needs as parents of children with disabilities. They recognized that the emotional support and understanding they received from other parents in a group was very important to them in dealing with the unique stresses and conflicts that arose in parenting their children. Parent groups began to appear whose purpose was not to change the system, but to give and receive mutual peer support, while existing parent groups added mutual support to their primary goal of advocacy.

- **Special education parent support groups are part of a national trend towards self-help.**
This movement toward parent support groups for parents of children with disabilities is part of a national phenomenon. There has been a tremendous increase in the number of self-help groups formed in the past two decades. An estimated 15,000,000 people in this country belong to some 500,000 support groups that deal with virtually every human concern. The U.S. Department of Health and Human Services predicts that the number of people involved will double by 1990. The California Self-Help Center at the University of California at Los Angeles maintains a listing of over 3,000 self-help support groups in their statewide computerized referral system.
Some of the factors contributing to this growth are: the increasing awareness that professional experts don't have all the answers; the civil rights movement where people take control of their own destiny; increased media coverage, and public awareness of problems never before discussed; mounting problems in society, such as crime, drug abuse, youth suicide, and unemployment; and increased research showing that support groups promote mental and physical health.

- **Parent support groups connected with agencies.**
  To further strengthen the movement toward parent self-help support groups, many agencies, such as Regional Centers for the developmentally disabled, hospitals and school districts, are actively promoting parent support groups and providing an agency professional as a liaison or resource person. Parents are finding that support groups which were formerly used to oppose the system now can find a safe harbor within the system. Professionals are finding that active parent support groups can be a source of strength to them and can help in building and maintaining higher quality services. The climate of trust that develops can nourish emotional support for both groups while helping them meet the daily challenges of their roles.

To some, parents and professionals alike, this is a radical concept. To others, it is the result of long years of cultivating nurturing attitudes.

Brainstorming

Brainstorming is one of the most useful and misunderstood of the problem solving methods. It is useful because any group of two to twelve persons can quickly learn to produce scores of ideas for any problem situation in very short periods of time. Fifty ideas in five minutes is not an unusually large number using brainstorming rules.

Idea generating rules of brainstorming

• Make no evaluation, positive or negative, of any idea presented.
• Work for quantity, not quality.
• Expand and elaborate on ideas already recorded.
• Record each idea, even if it is said more than once.
• Set a time limit and hold to it.
• Discuss and prioritize ideas after brainstorming is completed.

The whole idea is to let creative thinking run free. Brainstormed ideas are written on paper, not set in stone.
Benefits of Parent Support Groups

Parents of children with disabilities are under heightened stress in most aspects of family life. They are in a constant process of adjusting to these stresses as well as to the changing needs of their children.

In order to cope and grow during this process, parents may need to share their thoughts and, most importantly, their feelings. This sharing must be done with someone who is a willing and trusted listener. Another parent dealing with a similar problem may be an ideal listener. Often, one of the keys which enables a parent to feel some hope is the "living example" of another parent and child who have come through similar times of crisis and conflict.

Some direct benefits parents might experience:

- Opportunity to express freely their thoughts and feelings in an emotionally supportive atmosphere
- Reduced sense of being all alone
- Development of active coping skills
- Validation and feedback
- Sense of giving and "making a difference" for other parents
- Acquisition of ideas and new resources
- Acquisition of new skills
- Sense of empowerment - of gaining new power and strength
- Opportunity to receive and give peer modeling and peer coaching
- Reduction of stress
- A wider perspective on one's problems
- A sense of hope
Functions of a Parent Support Group

- Provide ongoing support
- Help in time of crisis
- Reinforce positive coping behaviors
- Help focus anger and use its energy in positive ways
- Share information, ideas and resources
- Provide training for parents to increase skills
- Help in dealing with educational, medical and other service agencies
- Give an opportunity to relieve loneliness and form new friendships
Elements

**What You Need to Get Started**

- A core group of committed parents with leadership skills
- A common cause
- A minimum of bureaucracy
- A structure determined by the members
- A commitment to open communication and active listening

**Qualities you need to get started and keep going**

Consider your individual strengths. Look at the table below and rate yourself, 1 being low and 5 being high. We all have different strengths and talents. If you are low in some areas, you may or may not want to change. Realize that a parent support group is a collaborative effort and other members of the group will complement your talents and skills.

<table>
<thead>
<tr>
<th>PERSONAL QUALITIES</th>
<th>Low</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>High</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sense of humor</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Patience</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Energy</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Willingness to make the impossible possible</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Willingness to receive as well as give help</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
</tbody>
</table>
The Role of Professionals in Parent Support Groups

Almost one third of self-help groups are started with the help of professionals. What is the role of the professional after the group has begun to function? To be a self-help group, the members who are experiencing the common concern or problem must be in control. The roles played by professionals vary with the purpose and structure of each group.

The California Self-Help Center has developed the following list of the roles professionals may take in relation to self-help groups:

- Start a group—identify and network people in similar circumstances, meet with core group, model leadership skills at first few meetings,
- Act as consultants—take directions from needs and requests of an established group,
- Refer clients to appropriate self-help groups,
- Provide material support—meeting place, mailing and copying,
- Inform or educate colleagues,
- Develop resource materials for use by self-help support groups.

It is recommended that professionals who want to start a support group get experience by becoming a member of a support group themselves, or by sitting in on some open support group meetings.

How Would You Describe Your Group?

Write a short statement that describes the parent support group that you envision or belong to.
## Action Plan

<table>
<thead>
<tr>
<th>What: (Describe the Action)</th>
<th>Who: (Person Responsible)</th>
<th>When: (Date Action will be Accomplished)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Parent Support Groups

Summary

Parents of children with disabilities have long been forming and participating in self-help support groups. Self-help support groups are made up of people who come together in order to help each other cope more effectively by exchanging emotional support, information and resources.

Some direct benefits that parents may experience as members of support groups

- Opportunity to express freely their thoughts and feelings in an emotionally supportive atmosphere
- Reduced sense of being all alone
- Development of active coping skills
- Validation and feedback
- Sense of giving and "making a difference" for other parents
- Acquisition of ideas and new resources
- Acquisition of new skills
- Sense of empowerment - of gaining new power and strength
- Opportunity to receive and give peer modeling and peer coaching
- Reduction of stress
- A wider perspective on one's problems
- A sense of hope

Functions of a parent support group

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- Provide training for parents to increase skills
- Help in dealing with educational, medical and other service agencies
- Give an opportunity to relieve loneliness and form new friendships
What you need to start a parent support group

Elements

- A core group of committed parents with leadership skills
- A common cause
- A minimum of bureaucracy
- A structure determined by the members
- A commitment to open communication and active listening

Personal Qualities

- Sense of humor
- Patience
- Energy
- Willingness to make the impossible possible
- Willingness to receive as well as give help

Roles of professionals in relation to self-help groups

- Start a group—identify and network people in similar circumstances, meet with core group, model leadership skills at first few meetings
- Act as consultants—take directions from needs and requests of an established group
- Refer clients to appropriate self-help groups
- Provide material support—meeting place, mailing and copying
- Inform or educate colleagues
- Develop resource materials for use by self-help support groups

Parent support groups provide parents with a safe place to share their struggles and concerns and to acknowledge their victories.
Bibliography

Books/Magazines/Resources


*Parents helping parents and other parent support activities*. National Information Center for Handicapped Children and Youth (NICHCY), Post Office Box 1492, Washington, D.C. 20013.

Poyadue, F. *Steps to starting a peer support organization*. Parents Helping Parents, 535 Race Street, Suite 220, San Jose, CA 95126.

*Self-help/mutual support groups resources catalogue*. California Self-Help Center, UCLA, 2349 Franz Hall, Los Angeles CA 90024.
### Evaluation

Your responses to the questions/statements below will assist us in improving this module. Please respond to all items. Your participation in this evaluation is completely anonymous. DO NOT place your name anywhere on this evaluation.

Based on a scale of 1 through 10, how much of the information presented was new to you?

1 is not much new; 10 all new.

<table>
<thead>
<tr>
<th></th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Undecided</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>I am aware of the meaning of “self-help” and “support group”.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2.</td>
<td>As a result of this session I am aware of the history and evolution of parent support groups.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3.</td>
<td>This session helped me identify some benefits of belonging to a parent support group.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4.</td>
<td>This session made me aware of the functions of a parent support group.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5.</td>
<td>Because of this session I can identify some key ingredients needed for a successful parent support group.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6.</td>
<td>The material presented was sensitive to all cultural groups.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7.</td>
<td>The material covered information which was appropriate to all handicapping conditions.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8.</td>
<td>Material presented matched my needs.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9.</td>
<td>I will use some of the information/resources that were introduced.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10.</td>
<td>The instructors did a good job.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

11. Specific suggestions to improve this module: