

Chapter 1

UNDERSTANDING SELF-HELP GROUPS

*"Friendship is born at the moment when one person says to another,
"What! You too? I thought I was the only one."*

- C.S. Lewis

AN INTRODUCTION TO SELF-HELP GROUPS

- Phyllis Silverman, Ph.D.

It has always been important to me to be able to bring the personal and the professional together. I believe that very often what excites us in our work is connected to the experiences of our daily life. People who work in the mental health field are expected to keep these lives very separate. I don't think this works in reality. These two worlds are not distinct; each informs and enriches the other. Thus, my sustained interest over the years in self-help was fed by my appreciation of the help I received as a new mother from the La Leche League. I was having difficulty in nursing my first child. She slept very little, required frequent feedings, and fussed when left alone in the crib. A mother of ten, the local La Leche League leader said to me, "Get an infant seat for the kitchen table so she can watch and be part of the family, and when you nurse lie down in bed with her." With those two statements, she changed my entire relationship with my newborn and made the first year of our life together a very wonderful and exciting period. That experience introduced me to the value of "mutual help" and the knowledge gained from experience that no physician could provide me with. My gratitude remains to this day, and one of my most satisfying activities is to share with new mothers what I learned to this day. My experience with La Leche League led me to be more open to a finding in the research I was doing to learn more about the experience of newly widowed women. This finding pointed to another widow as the most appropriate helper at this time in a woman's life. In light of my experience as a new mother, this made very good sense and it led to the demonstration project called Widow to Widow that laid the foundation for what became known as the Widowed Persons Service sponsored by the American Association of Retired People.

The word self-help may be a misnomer. What I saw was an exchange; the helper was often helped as much as the person who was the recipient. It is often difficult to find the right word for something that is not always easily defined. Basically, we are talking about an exchange that occurs when people, who share a problem or predicament, come together to help one another. Mutual help may be a more appropriate name for this phenomenon. In the broadest sense, life as we know it is not possible without some exchanges of resources and mutual aid. Usually this aid is casual and informal and is the essence of what has been called natural helping networks. In this source book the focus is

on organizations that provide people with opportunities to come together to help each other with a common problem. They have moved beyond the informal to make their services available to a larger audience. Alcoholics Anonymous is one of the oldest organizations of this sort. As you will see in glancing over the pages of this directory, in our heterogeneous, mobile society in this new millennium, the number and variety of organizations is quite extensive. In part, this is a result of the growing consumer movement that in some ways is a response to the depersonalization of consumers in the delivery of human services. To some extent, mutual help organizations have helped to "humanize" the human service system by helping their members become more informed consumers, and by lobbying for change in the formal health care and human service system. However, the development of these organizations is mainly due to people's need to find others like themselves who have experienced a similar problem. There is a growing awareness in our society that there is something special that people who share a common problem or difficult experience have to offer each other. Mutual help groups are especially attractive to persons undergoing a transition that requires a shift in social roles whether they are recovering alcoholics, former mental patients, new parents or tragically today, survivors of violence and terrorism.

There are many groups that are small (10-20 people) and constantly struggling to survive. They meet in people's homes or in other centers in their communities. They may list their activities in the local newspaper but would not find their way into this directory. Most groups mentioned here have, over time, incorporated and acquired non-profit status and their membership extends beyond their own communities. Some have been in existence for a long time. Whatever their history, these organizations do not follow one model for governing themselves. Some groups govern themselves wholly by consensus, sacrificing efficiency for maximum participation, making the rules up as they go along. Other groups follow parliamentary procedures, establishing committees and electing officers. Some set themselves up as service delivery systems with authority vested in a national office and leadership recruited through an elaborate ascending hierarchy. Some national organizations have a name that applies to a loose network of autonomous groups. The most common is an association supported by dues from affiliated local branches or chapters that are authorized to use its name. Many of these national associations have paid staff that develop program materials for the local groups and provide consultants from regional offices. Regardless of the way the association is organized, the member's common problem is the driving force in what these organizations do.

In these organizations, the helper and the beneficiary are peers. Learning is made easier when the teacher is a peer. His or her knowledge is something that does not require a special education or unique credentials. Helpers are qualified by virtue of having grappled with the common problem and are readily available to those who are in the recipient role. In this kind of relationship, the participants are not bound to the role of either helper or recipient. They are members, not clients. They can move between roles and this in itself can have therapeutic value. Discovering that others have the same problem, members no longer feel alone. Their feelings and experiences are legitimized; they no longer feel defective or deficient. Given the circumstances, their experience can be seen as typical and there are things that can be done about it. They are provided with a framework for coping: "The most important thing for me was finding someone like me.

When I walked into the room and found 50 other widows, I can't explain the good feeling it gave me." Once having established the common groups for discussion, they can now expand their options about what can be done about it.

Each organization develops a body of relevant information and strategies: "When I get nervous now I follow the guidelines I learned at the meeting; it really works." The best known of these is the "Twelve Steps" of Alcoholics Anonymous, which have been adapted to the needs of many other anonymous groups that you will find in the directory dealing with problems such as gambling, overeating and drug abuse. Groups concerned with disabilities or with such universal problems as bereavement use a more flexible approach. The wisdom of experience amassed in these organizations provides a unique contribution distinct from the professional knowledge learned in schools. One member of such a group commented, "When she said she understood I knew she meant it. I needed to hear how she managed before anything else." Another person said, "I needed to have a name for what was bothering me. I could figure out what to do when someone explained what I needed, given my situation." A woman with crippling arthritis found a way to eat in a restaurant, "I learned that I could ask to have my food cut up in the kitchen and I didn't have to be embarrassed having someone else do it at the table. It was so simple but it would never have occurred to me."

There is no one way of helping in these organizations. The assistance provided by mutual help groups may include educational seminars, one-to-one exchanges and social gatherings, in addition to the basic sharing of personal experiences and small informal meetings. Some organizations have hotlines, others have outreach programs in which members make unsolicited offers of help, and others publish a regular newsletter. Today the use of the Internet makes geographic distances between members shrink. Many organizations have formal orientation or training programs for outreach volunteers, facilitators in small group discussions, and for officers and leaders. There are no fees for services. If money is exchanged it is for membership dues, for supporting a particular event or activity.

The role of professional in these organizations varies. Some organizations have professional advisory committees that provide medical information enabling members to become competent consumers of the services they need. Others use professionals to facilitate support groups they sponsor as part of their programs. Resources and policy however, is controlled by the membership. Some organizations choose not to involve professionals.

The American Self-Help Group Clearinghouse has been instrumental in promoting increased awareness and utilization of groups through their information, referral and consultation services, and by continuing to make this directory available to a national audience. They are helping people develop new self-help mutual aid organizations as witness their activity following the tragedy of September 11. They are encouraging and supporting survivors as they develop their own mutual help networks.

The organizations listed in this directory remind us that the basic dignity of each of us is expressed and affirmed in our capacity to be involved in these reciprocal helping

exchanges. Out of this compassion comes cooperation and enhances the caring we want to encourage in our own community. We live in a society in which there is a tendency to abdicate responsibility for many human problems to professionals. We often accept that we do not have the training and qualifications to help others. Sometimes this is true, but as we learn more about the organizations listed in this source book, we come to appreciate the vast amount of experience most of us amass as part of living, and the special value there is in making it available to each other. In a sense, they speak for all of us since even those of us who study these groups as professionals are consumers.

Dr. Silverman is a Professor Emeriti at the Institute of Health Professions of Massachusetts General Hospital. She also holds an appointment in the Department of Psychiatry at Harvard Medical School. She has served as consultant to several task forces on bereavement, mutual help and prevention. She developed the concept of the widow-to-widow program and directed the research that demonstrated its effect. Her most recent research was a longitudinal study of the consequences of the death of a parent for children between the ages of 6 to 17. In addition to her social work degree from Smith College of Social Work, she holds an MS in hygiene from Harvard School of Public Health and a Ph.D. from the Florence Heller School for Advanced Studies in Social Welfare at Brandeis University. She has published extensively and her works include Helping Each Other in Widowhood; If You Will Lift the Load, I Will Lift It Too; Mutual Help Groups: A Guide for Mental Health Professionals, Mutual Help Groups: Organization and Development, Helping Women Cope with Grief, and Widow to Widow. She is co-editor with D. Klass and S. Nickman of Continuing Bonds: A New Understanding of Grief. Her most recent book, Never Too Young to Know: Death in Children's Lives reports on her research with bereaved children that includes a section on how the bereaved help each other.



*"If someone listens,
or stretches out a hand,
or whispers a kind word of encouragement,
or attempts to understand a lonely person,
extraordinary things begin to happen."*

- Loretta Girzatlis of P.H.O.B.I.A., a panic & anxiety support group in NJ

TO BETTER UNDERSTAND THE TERM "SELF-HELP GROUP"

Have you ever noticed when you have a problem, how it helps to talk with someone who has had a similar problem? Simply finding others who have "been there" and then realizing that "you are not alone" can be very comforting and helpful. The [Sourcebook](#) has been compiled to help you more easily find and form a self-help group—one that can provide such needed support, as well as practical information, education and sometimes advocacy.

The self-help groups listed on the following pages can better be described as "Mutual Aid Self-Help" groups because they derive their energy from members helping one another, without forms or fees. In examining the hundreds of national organizations, societies and foundations that exist for different illnesses, addictions, parenting and other stressful life situations and transitions, we have sought to identify those organizations that provide these mutual help opportunities. In addition to "**mutual support**," three other key characteristics of self-help groups that constitute our general criteria are: that the group be **composed of "peers,"** people who share a common experience or situation; that the group or network be primarily **run by and for its members**, who therefore have a sense of "ownership" for the group or network; and that the group be **voluntary, non-profit**, i.e., they can "pass the hat," charge dues, or fundraise, but there are no fees for services.

Dr. Silverman, in her introduction to self-help groups, describes some of the characteristics and dynamics of self-help groups, and how these differ from professionally-run groups and services. Self-help groups can provide benefits that professional services cannot. However, self-help groups are not meant to replace needed professional services, although they supplement, support and sometimes even develop them, as well as often prevent the very need for them.

We should point out that there are other types of community organizations that are sometimes described as self-help, including civic, housing, fraternal, business, ethnic, church and political groups. However, these groups, by their very numbers and broader focus, would warrant or already have separate directories of their own.

Also, please understand that the quality of individual self-help groups differ, sometimes even among those with the same name. Contact and visit the group to see if it is for you. While initial research reflects the value of self-help groups, the ultimate evaluation and very survival of any self-help group is determined by those who attend it and decide to stay and contribute to it.

*"Self-help is when a person takes responsibility for themselves.
But we cannot take responsibility for ourselves in a vacuum."*

- Betsy Wilson, founder of "Let's Face It" in the USA, and former
Chairperson of the National Council on Self-Help and Public Health

UNDERSTANDING WHAT SELF-HELP GROUPS DO AND HOW THEY DO IT

Self-help groups help their members cope with a wide variety of illnesses, disabilities, addictions, bereavement, parenting and many other stressful life problems. From groups for parents of children born prematurely to those families caring for an elderly-frail parent, there are hundreds of self-help groups listed within these pages that address different problems but function in very similar ways.

WHAT THEY DO

Mutual help groups, as often reflected in their written mission statements, usually have three or four basic functions or purposes in that they provide:

1. **Social Support** - relief from isolation, experiencing the stress-reducing support of others who truly understand. As one group leader expressed it..."The heart of our message is: 'You Are Not Alone.' Our strength has come from sharing our hardship and giving hope to others." In some groups, this support represents genuine "community." Duke University researchers who studied the value of social support to the life expectancy of cardiac patients (as reported in New York Times of Feb. 5, 1992) concluded, "A support group may be as effective as costly medical treatment. Simply put, having someone to talk to is very powerful medicine."
2. **Practical Information** - on the problem or disorder, how to cope on a 24-hour a day basis (sometimes using a particular "program," e.g. the 12-steps), what professional services and other resources are available, alternatives, self-care techniques, research, etc. These help people to recognize that they are not helpless.
3. **Education** - primarily derived from the pooling of members' experiences and coping skills, as well as information on and familiarity with professional services; referred to as "**experiential knowledge**" (Dr. Thomasina Borkman, 1975). Secondly, their ability to attract professionals to share their **professional knowledge** (e.g., to speak at meetings, workshops and/or contribute to newsletter), often leading to collaboration in **joint learning, education, treatment and research** development efforts.
4. **Advocacy** (an optional function) - advocating to address problems or deficiencies that the members cannot resolve within in their group, but exist in the larger society. Historically, these groups are the seeds for the development of many long-standing health foundations, societies, and movements dealing with various illnesses, disabilities, and health concerns. Not all groups (e.g., 12-step groups) involve themselves in pursuing an advocacy purpose and activities.

HOW GROUPS DO IT

Some of the specific principles and group dynamics to be found at work within mutual-help groups and networks are:

1. **The "Helper Therapy" principle** - wherein those who help others are themselves helped (Dr. Frank Riessman, 1965). As heard in some groups, "if you help someone up the hill, you get closer to the top yourself."
2. **Positive Role Models** - those, who have been through it, demonstrate to new members that success, coping and/or recovery is possible ("do-able"). Their example and actions often provide needed encouragement and hope not otherwise available.
3. **Accessibility** - there are no fees, so they are financially more accessible. They are also psychologically more accessible in several ways: in that they require no forms be submitted; often, as in the many "anonymous" groups, no names need be given; and one can go to a group simply to learn, and does not have to assume "patienthood" to get help. Many groups also have convenient meeting sites in the community, at times that are more convenient than most professional services.
4. **Pooling of Knowledge and Resources** by members, so that all can take advantage of the experiences of many.
5. **Acceptance** - being accepted and understood, often for the first time.
6. **Empowerment** of members by their taking a more active rather than a traditional passive role.
7. **Normalization** - when they see how their experience is similar to others, they finally feel "normal." For what range of differences do exist, their basic human need for feedback (as to how they are doing) is finally met.
8. **Anonymity** is provided by many groups.
9. **The Prevention Equation** (of psychologist Dr. George Albee, 1982) reflects how groups contribute to the prevention of psychopathology and stress-related illness:

$$\begin{array}{l} \text{Incidence of} \\ \text{Dysfunction} \end{array} = \frac{\text{Stress + Constitutional Vulnerabilities}}{\text{Social Support + Coping Skills + Competence}}$$

10. Groups provide **social support, coping skills, and increase competence**, thereby reducing incidence. To varying degrees, self-help groups serve a prevention function by enhancing social ties and connections that can serve as a buffer to stress, and by promoting the competency of people to cope with stress and adversity for a full spectrum of life transitions and crises. Dr. Phyllis Silverman (1985) of Harvard University points out that many stressful life transitions cannot be prevented, but that mutual help groups may be "one of the more powerful modalities" for facilitating the learning of coping skills subsequent to stress.
11. **Options and alternatives** are generated for resolving or coping with problems. Where previously a new member was despairing, thinking they had no options, other

members often provide a range of strategies and solutions, based upon their own experiences.

12. Groups are a source of **altruism** and **meaning** because many human beings seek needed meaning in their lives and find it in helping other through their personal and group efforts. This accounts for why many experiences members remain after they are helped. Yet self-help groups are a neglected form of volunteerism.
13. Groups **turn** what society considers a **liability** (e.g. one's experience as an addict, widow, etc.) **into an asset** (their unique ability to provide understanding and help others).

Unfortunately, an understanding of these functions and dynamics traditionally has been missing from most professional training curriculum. In 1987, then Surgeon General C. Everett Koop held a national conference that explored the value and potential of self-help groups to public health. The recommendation given the highest priority of over 60 developed at the two-day conference was the need to educate professionals to self-help groups. Dr. Koop later noted:

"My years as a medical practitioner, as well as my own first-hand experience, has taught me how important self-help groups are in assisting their members in dealing with problems, stress, hardship and pain... Today, the benefits of mutual aid experienced by millions of people who turn to others with a similar problem to attempt to deal with their isolation, powerlessness, alienation, and the awful feeling that nobody understands... Health and human service providers are learning that they can indeed provide a superior service when they help their patients and clients find appropriate peer support." - Former Surgeon General C. Everret Koop (in his 1992 foreword to Self-Help: Concepts and Applications, edited by Dr. A. H. Katz et. al., p. xviii).

References:

- Albee, G.W., "Preventing Psychopathology and Promoting Human Potential" in American Psychologist, 37 (9), pp. 1043-1050, 1982.
- Borkman, Thomasina, "Experiential Knowledge: a New Concept for the Analysis of Self-Help Groups" in the Social Service Review, vol. 50, number 3, pp. 445-456, 1975.
- Riessman, Frank, "The Helper Therapy Principle" in Social Work, vol. 10, pp. 26-32, 1965.
- Silverman, Phyllis, "Tertiary/Secondary Prevention - Preventive Intervention: the Case for Mutual Help Groups" in The Group Workers' Handbook, R. K. Conyne (Ed), Springfield, IL: Charles C. Thomas, pp. 237-258), 1985.

TEN BENEFICIAL WAYS PROFESSIONALS INTERACT WITH GROUPS

1. **Identify and refer** to local groups in your community. They often will reciprocate.
2. **Communicate/collaborate with local groups**, e.g., identify contact person, request their literature, keep brochures on hand, subscribe to their newsletters, liaison, etc.
3. **Involve groups in your training and conferences**, e.g., as speakers at in-service trainings, workshops and conferences; or host group demonstration/presentation at staff meeting or for clients.
4. **Provide speaking engagements and/or training** that local groups desire.
5. **Offer actual agency support**, e.g., meeting room, mailings, copying, clerical aid, etc.
6. **Identify need for new groups** in your community and educate others to the potential for developing a specific group based upon a particular national model.
7. **Identify and encourage potential "group starters,"** possibly from veteran patients.
8. **Provide networking help** to meet their needs for speakers, advisors, consultants, referrals, researchers, special services or training, loan of newest equipment, etc.
9. **Educate other professionals** to the availability and value of groups, e.g., report upon what you've learned here at agency meetings or professional conferences.
10. **Advocate for increased awareness** and understanding of groups, e.g., development of a local listing or directory that includes them, presentations before agency coalitions or associations, etc.

"Mutual support groups, involving little or no cost to participants, have a powerful effect on mental and physical health. . .

The psychological and physical health importance of this diffuse community is striking. . .

The self-help movement, both in face-to-face and virtual arenas, has tremendous therapeutic potential."

- Feb, 2000 issue of American Psychologist feature article Who Talks?: The Social Psychology of Illness Support Groups, by K.P. Davison, H.W. Pennebaker, and S.S. Dickerson. (55) 2, pp. 205-217.

PUBLICATIONS BY PROFESSIONALS ON SELF-HELP

Most of the books and references that best describe mutual aid self-help groups can be obtained from the self-help group contacts listed in this directory. Their materials can often express the purpose and value of the group better than any textbook can. Here are some references, which, for the most part, examine self-help groups in general and are written primarily for a professional audience.

The International Journal of Self Help & Self Care, Fred Massarik, Editor. While not a book, this journal is a unique resource with a broad range of articles by both professional and self-help group writers. It was the brainchild of the late Dr. Alfred Katz. Go to www.baywood.com and click on "Journals" to learn more, review abstracts of past articles, read author's guidelines for writing and submitting articles, and more.

Understanding Self-Help/Mutual Aid: Experiential Learning in the Commons by Thomasina J. Borkman, based upon her years of working with and researching groups, it examines the increased popularity of self-help groups, who participates and why, and their relationships with professionals. Rutgers University Press, 1999.

Self-Help and Support Groups, by Linda Farris Kurtz, is an excellent classroom text since it provides discussion questions, classroom exercises and assignments for most of the eleven chapters that provide scholarly overviews of group dynamics, membership professional relationships, and other related issues. Published in 1997 by Sage Publications, 2455 Teller Rd., Thousand Oaks, CA 91320.

Redefining Self-Help: Policy and Practice, by Frank Riessman and David Carroll, reflects how people with problems can be viewed as resources through self-help groups. With illustrations from various groups, the authors demonstrate how health and human service agencies can benefit from their tapping into the power of self-help organizations. Concepts such as the helper therapy principle, self-determination, and consumer as producer are updated. Published in 1995 by Jossey-Bass, 350 Sansome St., San Francisco, CA 94104.

Understanding the Self-Help Organization, edited by Thomas J. Powell, includes 17 chapters on research on self-help groups and professionally-run support groups. Published in 1994 by Sage Publications, P.O. Box 5024, Beverly Hills, CA 90212.

Self-Help: Concepts and Applications, edited by Alfred Katz, H.L. Hedrick, D.H. Isenberg, L.M. Thompson, T. Goodrich, and A.H. Kutsche, is an informative collection of over 30 perspectives on self-help group dynamics and professional interface. Several chapters examine the value of groups for conditions like AIDS, hearing loss, cancer, death of a child, lupus, and others. There are several chapters that look at professional and self-help group relationships, including the first chapter on empowerment that provides and extensive and updated review of policy and partnership developments. The book, published in 1992, is available from Charles Press, P.O. Box 15715, Philadelphia, PA 19103.

The Self-Help Way: Mutual Help and Health by Jean-Marie Romeder with contributions from Hector Balthazar, Andrew Farquharson, and Francine Lavoie, provides an overview of the growth and development of the self-help groups, while probing the dynamics of "the self-help way." With an introduction by former U.S. Surgeon General Koop, it provides a variety of views and insights that would be of interest to both the general public as well as professionals. This 158 page book, published in 1990, is available from Canadian Council on Social Development, P.O. Box 3505, Station C; Ottawa, Ontario K14 4G1, Canada.

Helping One Another: Self-Help Groups in a Changing World, by Alfred Katz and Eugene Bender (22 chapters examine specific types and general development of self-help groups in relationship to changing social, economic and political scene), 1990, 266 pages, Third Party Publishing, Oakland, CA 94661.

Working With Self-Help, edited by Thomas Powell, includes 17 chapters written primarily for professionals that vary from a look at 12-step programs to self-help and Latino communities, from bereavement groups to parents of the mentally ill in Israel. Printed in 1990, 338 pages, American Association of Social Workers, 7981 Eastern Ave., Silver Spring, MD 20910.

Rediscovering Self-Help: Its Role in Social Care, edited by Diane Pancoast, P. Parker and C. Froland, 1983, SAGE Publications, P.O. Box 5024, Beverly Hills, CA 90212.

The Surgeon General's Workshop on Self-Help and Public Health, printed by the U.S. Department of Health and Human Services, Public Health Service, (summary of presentations and recommendations), printed 1988, 60 pp. (Check with any local self-help clearinghouse serving your area to determine if they can provide a copy).

Self-Help Organizations and Professional Practice, by Thomas Powell, 1987, 366 pages, National Association of Social Workers, 7981 Eastern Ave., Silver Spring, MD 20910.

Helping People To Help Themselves: Self-Help and Prevention, edited by Leonard Borman, Leslie Borck, Robert Hess and Frank Pasquale, 1982, 129 pages, Haworth Press.

Mutual Help Groups: Organization and Development, by Phyllis R. Silverman (guide to starting groups, with attention of professional relationship and roles), 1980, 143 pages, SAGE Publications, P.O. Box 5024, Beverly Hills, CA 90212.

The Self-Help Revolution, by Alan Gartner and Frank Riessman, (Series of 18 essays that review particular groups, professional interface and evaluation), 1984, 266 pages, Human Sciences Press, 72 Fifth Avenue, New York, N.Y. 10011.

Rediscovering Self-Help: Its Role in Social Care, edited by Diane Pancoast, P. Parker and C. Froland, 1983, SAGE Publications.

Helping People to Help Themselves: Self-Help and Prevention, edited by Leonard Borman, Leslie Borck, Robert Hess and Frank Pasquale, 1982, 129 pages, Haworth Press.

Self-Help Groups for Coping with Crisis, by Morton A. Lieberman and Leonard D. Borman (review of literature and research on groups), 1979, 462 pages, Jossey Bass Publishers, San Francisco, CA.

"Hospitals and Self-Help Groups: Opportunity and Challenge" by E. Madara and W.D. Neigher. Health Progress, Vol. 67, No. 3, April, 1986, pp. 42-45.

Mutual Help Groups: Organization and Development, by Phyllis R. Silverman (guide to starting groups, with attention to professional relationships and roles), 1980, 143 pps, SAGE Publications, P.O. Box 5024, Beverly Hills, CA 90212.

Self-Help in the Human Services, by Alan Gartner and Frank Riessman (reviews range, variety and principles of groups), 1977, Jossey Bass Publishers, San Francisco, CA.

Support Systems and Mutual Help: Interdisciplinary Explorations, edited by Gerald Caplan and Marie Killilea, (contains excellent chapter on literature review by Marie Killilea), 1976, 325 pages, Grune and Stratton, Inc.

The Strength in Us: Self-Help Groups in the Modern World, edited by Alfred H. Katz and Eugene I. Bender (history, typology, political aspects), 1976, 258 pages, New York: New Viewpoints Press.

The Recovery Resource Book, by Barbara Yoder (Describes different self-help groups, agencies, books, and other resources dealing with various addictions and dependencies - providing samples of groups' materials), 1990, New York: Simon and Schuster, 314 pages.

"Clergy and Self-Help Groups: Practical and Promising Relationships" by E. Madara, and B.A. Peterson, The Journal of Pastoral Care, Vol. 41, No. 3, September, 1987, pp. 213-220.

"Introducing and Tapping Self-Help Mutual Aid Resources," by C.J. Paskert, and E.J. Madara, Health Education, (written for school personnel), Vol. 16, No. 4, Aug/Sept., 1985, pp. 25-29.

"The Self-Help Clearinghouse Operation: Tapping the Resource Development Potential of I & R Services," by E. Madara. Information and Referral: The Journal of the Alliance of Information and Referral Systems, (written primarily for I & R agencies) Vol. 12, No. 1, Summer, 1985, pp. 42-57.

"Self-Help and How We Teach Tomorrow" What's New in Home Economics, (written primarily for teachers), Vol. 17, No. 4, December, 1983, pp. 1 and 4.

*"When the wise healer's work is done, the people say,
'Amazing. We did it all ourselves.'"*

- Lao Tze

A Self-Help Story... "Self-Help – What It Means to Families of Children With Special Needs"

- Beth Randall, President, "Mothers from Hell 2"

I had a lot of great ideas backed up by impressive research findings for this - my writing a short piece on why self-help is crucial for families of children with special needs - really I did! I also had good intentions of polishing it up.

But, the day I set aside to start work on it I...

attended our local family support group meeting where a mom whose child was recently diagnosed with a neurological disorder asked, "What is respite care?" Ever the optimist I replied that surely hadn't the child's physician, nurse, case manager, teacher, schools social workers, *someone* explained how a respite caregiver funded through the state Department of Human Services could give her family precious hours of relief from the intense care her child needs 24 hours a day, seven days a week? A bewildered look was her response. I offered to gather information on the local respite care resources for her, and while I'm at it why don't I prepare some respite information for those professionals, too? "That's great!" she says, "and by the way, the speech therapist suggested we look into something called sensory integration. Do you have anything on that?" Why, of course. Another batch of information to prepare for this parent and the aforementioned professionals. While I'm at it, I better pull together stuff on educational rights, as this child is obviously not receiving all of the services he is entitled to.

Then, the next day that I set aside I...

sat in on an Individual Education Program meeting at a parent's request. Apparently, her child had been spending less and less time in the regular education classroom, as he wasn't quite working at grade level and there were some new behavior concerns. So I ask what strategies have been employed for the behaviors, what has been done to adapt the curriculum and that supports are in place for the child to receive an appropriated education in his Less Restrictive Environment of the regular education classroom? Hearing stammering and vague responses I offer to provide the team with information on inclusive education, related services and supports and behavior management.

Trying again, I...

end up chasing my nine-year-old son down the street as he tries to "run away to New York City" (we live in Illinois!) for the fourth time this week. He is wearing only underwear. I am dragging him home; kicking, screaming, biting, (him) and crying (me). I restrain him for about an hour until we are both sweaty, sobbing and exhausted. He says, "'I'm sorry Mommy.'" I tell him I am sorry, too. We collapse in a heap and watch cartoons. I contemplate installing one of those "invisible fences for dogs, but reconsider because there is no place on my little Houdini that the collar would stay on. Instead I call that parent I met at a conference on my child's disability who mentioned a heavy duty spring loaded door lock—for the *inside* of the door and only when we are home, of course. Really now, who else besides other parents of "runners" that fear nothing and have no concept of danger would understand the sheer terror a mother feels as she hears the door slam just as she thought it was safe to take a two-minute shower? With whom

else could you discuss in all seriousness seeking AMA approval of tranquilizer darts for children?

I will get this done!!! But first I...

call my best friend to whine about how this is the fourth week I have set aside an afternoon to write this article, and it still isn't done! When she says, I know how you feel. I don't wince like I usually do when the nurse at the clinic says it. She really does know—her three kids have special needs, two of my four do. I wonder aloud if this wouldn't be the perfect time to commit a crime, a small one mind you, but one severe enough to warrant a few days of incarceration. No phone, no fax, no computer, no cooking,...no *kids!* She says it sounds too good to be true. She suggests that I better not chance it.

Anyway, I would have loved to express how valuable opportunities for self-help are to families of children with special needs. How they allow for the exchange of information parents glean from personal experience, professional contacts, support group and committee meetings, etc. as well as the very unique support only those who have "walked the walk" can give, but I guess it'll just have to wait for another afternoon....

"Mothers From Hell 2" is a national grassroots parent's organization facing the unique challenges of raising children with special needs with combustible humor; and advocating for disability rights...we will not be silenced!



A Self-Help Story... "The Rewards of A Personal Touch"

- Nancy H. Patterson, Founder, Grave's Disease Foundation

The Graves' Disease Foundation provides a personal touch that is sorely needed by those when the diagnosis of a hyperactive thyroid comes along. Many of those people feel alone and frightened. In addition to the many physical changes that are ravaging their bodies, the emotional imbalance caused by the overactive thyroid hormones can cause tremendous upheaval. Many of our phone calls are late in the evening, take a long time, and the person on the other end is quite grateful. However, we do not always hear from them again. That makes the following e-mail a special indication of what we do:

"I think it was you I spoke to on the phone a couple of months ago when I called the NGDF. I just wanted to say how wonderful you were, through my very hysterical time. I had been crying and unable to function for over three days due to false information I had been given. After my phone conversation with you, I felt a thousand times better and was able to calm down right away. Just wanted to thank you again for your calm, kind, and excellent information."

This note was forwarded to one of our Board of Advisors at the Mayo Clinic, and his reply is the kind of thing that keeps us going on: "What a lovely indicator of the value of your work."

