

SUPPORT GROUPS FOR PARENTS OF CHILDREN WITH EMOTIONAL DISORDERS: A COMPARISON OF MEMBERS AND NON-MEMBERS

Nancy M. Koroloff, Ph.D.
Principal Investigator, Families in Action
Research and Training Center on Family
Support and Children's Mental Health

Barbara J. Friesen, Ph.D.
Director
Research and Training Center on Family
Support and Children's Mental Health

ABSTRACT: This study involving more than 800 parents whose children have emotional disorders focuses on comparisons between parents who are members of support groups and those who are not. While no difference was found between members and non-members on most demographic variables, members reported needing and using more information and services and found each more difficult to locate than non-members. Thirty-one percent of all respondents identified involvement with other parents as the most helpful activity in coping with their child's problems.

INTRODUCTION

Although a small number of support groups for parents of children with emotional disorders have existed for many years, they have been isolated from one another and few in number until recently. Now, although there is increased enthusiasm and support for these parent groups, there is great variation in their membership, format, and duration. Furthermore, there has been virtually no study of how these groups are helpful and to whom; in our review of the literature no published studies specifically addressing support groups for parents of children with emotional disabilities were located. Thus, little is known about who joins these support groups, how they function, and their effects on participants. In the absence of published research, it appears that funding agencies, policymakers, administrators, practitioners and family members may make decisions and shape practice based on incomplete information and untested ideas.

In this paper we present information that begins to address this information gap. We examine selected beliefs about support groups for parents of children with emotional disabilities and report on findings from a survey of parents. The focus of the analysis is on comparing parents in this study who participate in parent support groups with those who do not, in relation to current assumptions about support group membership and benefits.

REVIEW OF AVAILABLE RESEARCH

Caring for a child with an emotional disorder may be one of the most invisible and difficult burdens for parents to bear. Parents of children with emotional disorders may believe that they caused the disorder and are sometimes ashamed of their children. Parents may also be blamed for the child's condition by friends, relatives, and professionals (Caplan & Hall-McCorquodale, 1985; Lamb, Hoffman, Hoffman & Oliphant, 1986; Johnson, 1986; Wahl, 1989). Their attempts to articulate their needs or the needs of their

children may receive little response from professionals who consider parents part of the client system. And, when professionals do join with parents to plan for the educational and therapeutic needs of children with emotional disorders, appropriate services are often not available (Knitzer, 1982; Dougherty, Saxe, Cross, & Silverman, 1987). In addition to a lack of services focused on the needs of the children, family support services such as respite care, financial assistance, transportation, and access to recreational opportunities are totally lacking in many parts of the country.

Participating in support groups is one useful mechanism for easing the caretaking load for parents of children with emotional disabilities. Several parents (usually from 4 to 20) meet on a regular basis to discuss the problems they are facing and to help each other with encouragement and ideas. These groups may serve a combination of functions including information-giving, parent-to-parent support, and advocacy for better services. They may be formally constituted and affiliated with larger formal organizations or may involve relatively informal meetings of a small number of family members.

Recently there has been increased interest in support groups for parents of children with emotional disorders. The interest is tied, in part, to federal support for this strategy (Friesen, Griesbach, Jacobs, Katz-Leavy, & Olson, 1988) and, in part, to the rise in consumerism in the mental health field (Newsome & Newsome, 1983; Lamb, Hoffman, Hoffman, & Oliphant, 1986). The perceived failure of institutions and service delivery systems to provide adequate care and nurturing for children with emotional disorders has also provided an ideal medium within which the support group movement can grow. Both the general self-help literature and conventional wisdom contain a number of beliefs about support groups that are mostly implicit and not formally stated. Other ideas are promulgated through workshops, training, and casual conversation at meetings and conferences. In the next section we examine selected beliefs about support groups.

Characteristics of Group Members

The first belief we propose to examine is that *certain types of people are more likely to join support groups than others*. Conventional wisdom about self-help groups is that group members are likely to be white, middle income, and well educated. Among persons interested in support groups for parent of children with emotional disabilities there is also the belief that fathers do not participate in support group activities and that members will most likely be single mothers.

These beliefs about the demographic characteristics of support group members are at least partially supported by published studies. For example, Hinrichsen, Revenson & Shinn (1985) found that parents of adolescents with scoliosis who were participants in a support group were better off financially, better educated, and older than parents who did not join the group. They were also more active in other organizations than comparison group parents. Similar profiles of members of self-help groups for families of adults with psychiatric disabilities are reported by Hatfield (1981), Lewine (1983), and Biegel & Yamatani (1987).

Although participants in many studies of self-help groups tend to be from middle and upper levels of income and education, this phenomenon is not universal. Knight, Wollert, Levy, Frame & Padgett (1980) provide evidence that self-help group participation can encompass a wider membership than is generally assumed. They describe members of nine self-help groups as "basically working class persons with some training past high school" (p. 60). Similarly, a majority of the participants in a support group described by Telleen, Herzog, & Kilbane (1989) were from lower educational and income ranges.

Another theme addressed by the literature concerns the severity of problems experienced by those who join groups compared to those who do not. Videka-Sherman (1982), reporting on support groups for bereaved parents, found that the parents most preoccupied with the loss of a child were most likely to turn to a support group as part of their coping strategy. Lieberman and Videka-Sherman (1986) concluded that widows who joined a support group were more distressed on a number of psychosocial measures than a probability sample of widows. Hinrichsen, Revenson & Shinn (1985) found that parents of adolescents with scoliosis who participated in support groups had children with more severe medical conditions and children who had undergone more rigorous treatment than parents in a comparison group.

Benefits of Support Groups

A second commonly held belief is that *parent support groups provide positive outcomes for members*. Frequently identified tangible benefits involve information about a variety of topics including the disorder itself and available services as well as advocacy and individual problem-solving. Benefits such as emotional support, reduced isolation and help with coping constitute some intangible advantages of group membership (Gartner, 1984).

The informational aspects of self-help group membership have been addressed by a limited number of researchers. For example, Wintersteen and Young (1988) surveyed members of three chapters of Kansas Families for Mental Health. These group members most often cited information and support as the attributes that attracted them to the group. Members of an eight week support group for family caregivers of persons with Alzheimer's disease reported that participation had a variety of benefits (Barnes, Raskind, Scott & Murphy, 1981). The most helpful result of group participation identified by these members was a better understanding of the disease. Similarly, in a study of benefits to members of a group addressing depressive disorders in the Chicago area, Kurtz (1988) reported that family members most often identified information as the most significant group benefit.

Two studies which include the intangible aspects of support groups emphasized emotional support and help with coping as functions of groups rather than exploring their effects on members. Hinrichsen, Revenson & Shinn (1985) used factor analysis to identify clusters of goals mentioned as important by persons with scoliosis and their families. These goals include receiving emotional support, receiving information, and helping others. Similarly, Beigel and Yamatami (1987) identified activities such as empathy giving, catharsis, and mutual affirmation in their description of the most frequent activities occurring in self-help groups for families of persons with mental illness.

METHODS

The present study, conducted between May 1987 and September 1988, explored a broad range of issues regarding the lives and struggles of parents whose children have emotional disorders. A written questionnaire was used to gather information from family members in the following areas: (1) impact of the child's disability on various aspects of family life; (2) types of services used; (3) parents' needs for information and their experience with obtaining information; (4) service needs and availability; (5) sources of informal social support; (6) relationships with helping professionals; and (7) transition issues.

Parents were also asked whether or not they participated in a parent support group, and it is this distinction that forms the basis for the current study. Detailed information about the parents' support groups of which respondents were members was not collected. Rather, the focus of this analysis is on the extent to which parents who are members of parent support groups resemble or are different from those who are not members in relation to beliefs and assumptions about the characteristics of support group members and the benefits of group membership identified in the previous section. The review of literature about self-help and support groups and an examination of the prevailing beliefs about parent support groups suggested the following research questions:

1. How do the demographic characteristics of parents whose children have emotional disorders and are members of parent support groups differ from those who are not members of parent support groups?
2. How do the service and information needs of group members differ from non-group members?
3. How does group members' utilization of services and information compare to that of non-group members?
4. How do the coping patterns of parent support group members differ from non-group members?

Parents of children with emotional disabilities are difficult to locate. They do not belong to a single organization nor is there a single point of entry into the service delivery system where they can be contacted. The effects of the stigma associated with parenting a child with an emotional disability make parents difficult to access as do the confidentiality laws that govern treatment programs. Random sampling of the entire population is impossible because a reliable sampling frame does not exist. Thus, this study depended on the goodwill of family members to identify themselves and respond to the questionnaire.

National distribution of written, mailed questionnaires was selected as the method for gathering

information. This approach was chosen to allow as many parents as possible to participate and because of the relatively low cost involved for wide distribution. Limitations of written questionnaires include lower response rates than some other approaches such as person-to-person interviews, and possible sample bias. Persons who return written questionnaires tend to be better educated and of a higher income level than those who do not (Selltiz, Wrightsman & Cook, 1976; Warheit, Bell & Schwab, 1977).

The questionnaire was prepared using information from studies involving families of children with other mental and physical disabilities, studies involving families of adults with long-term psychiatric disabilities, unpublished information from other researchers who had collected information from parents whose children had emotional disorders, and information and concerns gathered informally from parents in many parts of the country.

The questionnaire items were pretested with family members in parent support groups and were also reviewed by mental health professionals. The questionnaire was entitled "Parent Survey," and was targeted at parents of children with emotional disorders. We defined the age range as between 0 and 21 years of age. Because of the variety of terms used to describe emotional disorders across systems and geographic areas we included an introductory statement at the beginning of the questionnaire which listed a number of commonly used terms so that parents could decide whether to complete the questionnaire.

The questionnaire was made available to families in a variety of ways. These included distribution at regional Families As Allies conferences, through parent organizations listed in a national directory, and through state-level mental health departments. These departments then asked mental health agencies and, in some instances, child welfare or public school programs to distribute the questionnaire to parents.

A total of 966 usable questionnaires were returned by August, 1988. It is difficult to estimate the actual return rate, since accurate information about the number of questionnaires that reached parents is not available because of the variety of distribution methods. Of the 966 parents of children with emotional disabilities who returned questionnaires, 315 (38%) indicated that they were currently attending a parent support group and 519 (62%) reported that they were not. These questionnaires (834) became the basis for the analysis reported in this paper.

Given the data collection procedures, one issue that arises is the extent to which the parents who responded to the questionnaire are representative of all parents of children with emotional disorders. There is no national data set about parents of children with emotional disabilities. We did, however, compare characteristics of parents in our respondent pool to the general United States population (1980 U.S. Census). Our respondents are more highly educated than the general population: 66% attended at least some college (compared to 32% of the U.S. population) and 9% of the parents in this study had less than a high school education (compared to 34% of the general population). The income of families who participated in the study is also somewhat higher than the general U.S. population. Thirty-six percent of respondents had family incomes above \$30,000, compared to 25% of the U.S. population. It should be noted, however, that the percentage of families in the lowest income category (under \$10,000) was exactly the same for the study population and the general population (20%). Overall, these comparisons suggest that the pool of respondents represent a wide range of income, education, racial and geographic backgrounds.

FINDINGS

This portion of the paper presents a discussion of the findings regarding each research question. Comparisons to findings in other studies are included where appropriate literature is available.

Demographic Characteristics

1. How do the demographic characteristics of parents whose children have emotional disorders and are members of parent support groups differ from those who are not members of support groups?

Table 1 presents a comparison of the demographic characteristics of parents who are group members and parent who are not. Based on a chi-square analysis, there is a significant relationship between group membership and three variables: (1) income; (2) whether the respondent had someone who shared daily parenting responsibilities; and, (3) whether the respondent lived in a state receiving a federal Child and Adolescent Service System Program (CASSP) grant. The data on income suggest that both

high income parents (those making more than \$50,000) and low income parents (those making less than \$20,000) are less likely to join a parent support group than parents with incomes in the middle ranges (\$20,000-\$50,000) ($X^2=19.649$, $df=1$, $p=.00$).

Table 1. Parents' Demographic Characteristics by Group Membership Status

	Parent Group Member	Not Parent Group Member	p=*
Income			
Under \$10,000	42 (14%)	115 (22%)	
\$10,000-\$20,000	56 (18%)	113 (22%)	
\$20,000-\$29,999	72 (23%)	102 (20%)	.00
\$30,000-\$39,999	62 (20%)	73 (14%)	
\$40,000-\$49,999	39 (13%)	39 (8%)	
\$50,000 or more	38 (12%)	64 (14%)	
Education			
H.S. graduate or less	83 (27%)	177 (34%)	
Business or trade school	27 (9%)	49 (9%)	
Some college	89 (28%)	134 (26%)	.10
College degree	44 (14%)	53 (10%)	
Graduate school	71 (23%)	106 (20%)	
Sex of respondent			
Male	32 (10%)	73 (14%)	
Female	282 (90%)	436 (86%)	.10
Marital status			
Married	223 (71%)	337 (65%)	
Single	89 (28%)	181 (35%)	.07
Has someone to share daily parenting			
yes	237 (75%)	354 (68%)	
no	78 (25%)	165 (32%)	.04
Lives in a CASSP state			
yes	230 (73%)	333 (64%)	
no	85 (27%)	186 (36%)	.01

* Significance tested by chi-square.

There is a significant relationship between membership in a parent support group and help with daily parenting tasks ($X^2=4.358$, $df=1$, $p=.04$). Seventy-five percent of respondents who attend parent support groups report having someone to help them while 68% of non-group members have help. There is no significant difference between the two groups, however, on sex of respondents, marital status, or education level.

At the time of this study, 27 states and the District of Columbia had received and implemented CASSP grants from the National Institute of Mental Health. There is a significant relationship between residence in a CASSP state and participation in a parent support group ($X^2=6.608$, $df=1$, $p=.01$). Respondents who lived in states with CASSP grants were more likely to participate in parent support groups than respondents who did not. Since one of the federal CASSP initiative goals is the development of parent support groups, it is not surprising that there are more groups in these states and hence more parent participants. Table 2 presents a comparison of the characteristics of children with emotional disabilities by parents' group membership status. Although the ages of the children cover the full range from 0 to 21 years of age, well over half of the respondents are raising children who are teenagers with emotional disabilities. Overall, 73% of the children and adolescents are boys and 27% girls. This proportion is consistent with prevalence studies for a number of disorders (Campbell and Werry, 1986). The racial and ethnic groups represented by the respondents resembles the proportion reported in the U.S. Census (1980). The majority of the children (86%) described in the study are Caucasian, and about 7%

are African American, with smaller percentages of Asian or Pacific Islander, Hispanic and Native American. This compares to an overall U.S. population distribution of 85.1 % Caucasian and 14.9% non-Caucasian (Rosen, Fanshel and Lutz, 1987).

Two of the relationships reported in Table 2 are statistically significant: (1) whether the child has a diagnosis, and (2) whether the parents have ever felt physically threatened by the child. Seventy-five percent of all respondents indicated that they had been given a diagnosis. Eighty percent of the participants in support groups have received a diagnosis as compared to 72% of the non-participants ($X^2=6.230$, $df=1$, $p=.01$). A significant relationship also exists between membership in a parent support group and feeling physically threatened by the child with an emotional disability ($X^2=3.727$, $df=1$, $p=.05$). Forty-six percent of all respondents report that they have felt threatened by their child with 50% of the parents in parent support groups reporting that they felt threatened as compared to 43% of non-group members. This may, to some extent, be influenced by the age of child under care, since an older and larger child may be more threatening to an adult. The difference between the two groups on the age of the child partially supports this idea. The statistical relationship between the two groups approaches significance ($X^2=5.726$, $df=1$, $p=.06$) with group members caring for older children.

Table 2. Children's Demographic Characteristics by Parents' Group Membership Status

	Parent Group Members	Not Parent Group Members	p=*
Child's sex			
Male	234 (74%)	374 (72%)	.56
Female	81 (26%)	144 (28%)	
Child's age			
0-5	18 (6%)	19 (4%)	.06
6-11	100 (32%)	203 (39%)	
12+	197 (62%)	297 (57%)	
Relationship between parent and child			
Total biological parents	242 (77%)	420 (82%)	.07
Total not biological parents	72 (23%)	89 (17%)	
<i>Stepparent</i>	2 (1%)	12 (2%)	
<i>Foster parent</i>	19 (6%)	20 (4%)	
<i>Adoptive</i>	51 (16%)	57 (11%)	
Race of child			
Total not minority child	280 (89%)	446 (86%)	.24
Total minority child	34 (11%)	72 (14%)	
<i>African American</i>	6 (2%)	14 (3%)	
<i>American Indian</i>	2 (1%)	8 (1%)	
<i>Asian/Pacific Islander</i>	7 (2%)	14 (3%)	
<i>Hispanic</i>	15 (5%)	34 (7%)	
<i>Other</i>	4 (1%)	2 (<1%)	
Child has a diagnosis			
yes	250 (80%)	362 (72%)	.01
no	63 (20%)	142 (28%)	
Child's behavior threatening			
yes	156 (50%)	224 (43%)	.05
no	154 (50%)	295 (57%)	

*Significance tested by chi-square.

Biological parents are less likely to join support groups than foster, adoptive or step-parents

combined, however, this relationship is not significant when examined using chi-square analysis ($X^2=3.321$, $df=1$, NS). We also examined the data to explore the belief that parents of minority children do not participate in support groups. This relationship is not significant when tested by chi-square analysis ($X^2=1.1394$, $df=1$, NS). Parents of Caucasian children are somewhat more likely to belong to parent support groups (39%) on a percentage basis. However, about 1/3 of the parents of African American children (30%), Hispanic children (31 %) and Asian/Pacific Islander children (33%) are also members of parent support groups. Although the numbers for each minority group are small, this represents a higher rate of membership among minorities than is popularly believed.*

Information and Services

Two research questions were posed regarding parents' needs for different types of services, utilization of these services, and their need and utilization of different kinds of information.

2. How do the service and information needs of group members differ from non-group members?
3. How does group members' utilization of services and information differ from that of non-group members?

The respondents were presented with a list of 16 kinds of information commonly needed by parents of children with emotional disabilities. Items on this list range from information on "causes of emotional handicap" to "help for brothers and sisters." Respondents indicated: (1) whether they had ever used each type of information, (2) if they needed each type, and (3) how difficult the information was to obtain. Respondents were also presented with a list of 19 services commonly used by children with serious emotional disabilities including special education, services of various professionals, psychiatric hospitalization, residential treatment, and day treatment, among others. Respondents indicated: (1) whether they had ever used each of these services, (2) if they were currently using the service, (3) whether it was a service that they needed, and (4) how difficult the services were to obtain. Table 3 presents a summary of the differences in responses between the two groups of parents.

Table 3. Parents' Reported Need for and Use of Information and Services By Group Membership Status

Item	Parent Group Members	Not Parent Group Members	f=	df=	p=*
Average number of types of information needed	13.0	12.2	4.75	1, 815	.03
Average number of types of information used	10.5	9.3	11.50	1, 815	.00
Average difficulty in getting information (1-5 scale)	2.0	1.9	6.22	1, 815	.01
Number of services needed	6.3	5.7	6.37	1, 771	.01
Number of services currently used	2.5	2.1	18.11	1, 771	.00
Number of services ever used	4.2	3.8	5.63	1, 771	.02
Average difficulty in obtaining services (1-5 scale)	2.0	1.8	7.79	1, 771	.00

*Significance determined ANCOVA with income and education controlled.

*The data presented here are for the race of the child—not the race of the parent. Some of the minority children in this study may be living with non-minority parents. Information on the race of the parents was not collected in this study.

As Table 3 illustrates, parents who are support group members report a need for more information and services than parents who do not participate in parent support groups. In addition, group members report using more information and services and also report more difficulty in obtaining both services and information. For the seven items in Table 3, analyses of covariance (ANCOVA) were performed controlling for income and education of the respondent. These are analogous to t-tests for independent groups with means adjusted for income and education. The mean differences for each item were significant, suggesting that there are differences between group members and non-members that remain after the effects of education and income are removed.

There are at least two interpretations of these findings. One of the benefits that parents report getting from support groups is access to information and idea about services. The finding that group members need and have more information and services would support the existence of this benefit. It might also be concluded that parents who attend support groups are more aware (via their contact with other parents) of what information and services are possible to obtain and therefore have higher expectations. This interpretation does not explain why group members report more difficulty in obtaining information and services.

Another explanation of group members' greater need for information and services is suggested by the literature. Several researchers report that persons who join support groups have more severe problems than those who do not (Videka-Sherman, 1982; Hinrichsen, Revenson & Shinn, 1985; Lieberman & Videka-Sherman, 1986). This line of reasoning would suggest that parents who join support groups have children with more severe emotional disabilities and therefore need more information and more services. Although no clear indicators of the severity of the children's emotional problems were included in the questionnaire, we did examine two variables, residential treatment and custody status, that were potentially relevant. Children with the most severe emotional disabilities may be more likely to be in residential treatment. Twenty-three percent of the respondents indicated that their children were currently in residential treatment and 34% reported that residential treatment had been used at some time in the past. There is no statistical difference between group members and non-group members regarding either current use or past use of residential treatment.

Whether or not parents have relinquished legal custody of their child may be another indicator of severity since release of custody is often associated with enrollment in residential treatment programs or psychiatric hospitalization. Twenty-six percent of the parents reported that giving up custody had been suggested to them and 10% have actually given up custody of their child. There is no statistical difference between the two groups of parents on these variables. Thus our data do not support the belief that parents who join support groups focusing on emotional disorders have children with the more severe problems.

Help with Coping

4. How do the coping patterns of parent support group members differ from non-group members?

The first set of variables related to coping examines support received from various family members and friends. There is no significant difference between group members and non-group members regarding their perception of the support they received from these sources. The second set of variables examines seven different activities that are believed to help parents cope with raising a child with an emotional disability. Respondents could check as many of the items as they wished. These results are presented in Table 4. In addition, respondents were asked to indicate which of the activities is most helpful.

When looking at the sources of support for parents who belong to parent support groups and parents who do not, three significant differences emerge. As might be expected, a high percent (80%) of parents who participate in parent support groups report that they receive support from involvement with other parents ($X^2=163.11$, $df=1$, $p=.00$). In addition, 34% of the parents who are not members of a support group also cite involvement with other parents as a source of support. Volunteering in the community ($X^2=17.880$, $df=1$, $p=.00$) and advocacy ($X^2=53.924$, $df=1$, $p=.00$) are two sources of support that are reported more often by group members than non-members. This is consistent with findings that support

group members are more likely to be active in other organizations than their non-support group counterparts (Hinrichsen, Revenson & Shinn, 1985; Lieberman & Videka-Sherman, 1986). There are also differences between the two groups regarding the activity that was the single most helpful source of support. As might be expected, parents who are members of support groups name involvement with other parents as the most important source of support (50%); this is followed by religion (16%) and career (12%). Non-group members named religion (32%), career (20%) and involvement with other parents (13%) as the most helpful sources of support.

Table 4. Comparison Of Helpful Activities By Parents' Group Membership Status.

Item	Parent Group Members	Not Parent Group Members	p=*
Religion	159 (50%)	256 (49%)	.78
Involvement with other parents	251 (80%)	176 (34%)	.00
Own career	120 (38%)	196 (38%)	.97
Own hobbies	88 (28%)	154 (30%)	.66
Community volunteer activities	82 (26%)	73 (14%)	.00
Recreation	101 (32%)	179 (34%)	.53
Involvement in advocacy	123 (39%)	84 (16%)	.00

*n=835

**Significance for each item tested by chi-square.

DISCUSSION

One of the more important assumptions to examine about parent support groups and, to some extent, self-help groups of all kinds, is the accepted wisdom that they appeal only to a Caucasian, middle-class population. Our mixed findings parallel those of previous studies. On the one hand we did find a difference in the incomes of those who participated and those who did not. Both persons with the highest income levels and persons with the lowest income levels were less likely to join a support group than those in the middle. It should be emphasized however, that the pattern is curvilinear; i.e., the findings do not suggest a simple relationship between income and group membership. Although income is often highly correlated with other variables that are indicators of social class (such as education), we found no significant difference between group members and non-group members on the variables of sex, race, education, and marital status. In fact, we have presented evidence that a reasonable proportion of each racial group, educational level, and marital status does participate. This strongly suggests that if some members of these categories participate then support groups are likely to be a useful resource for a much wider array of parents than is commonly thought. Our findings also contradict the prevailing belief that group participants are more likely single women and that men do not participate. Although the number of men who responded to the questionnaire was low, those who responded were as likely to belong to support groups as women respondents.

Since it is apparent that parent-to-parent support is important to many parents it is reasonable that we should continue to look for ways to make participation in support groups possible and attractive for parents from a variety of backgrounds. Focused research on the barriers that exist for parents should include issues such as child care and transportation, particularly with regard to low income parents. The effects of different types of outreach and publicity efforts on individual decisions to join should also be studied. A third line of inquiry should explore the perceptions and attitudes of non-members about parent

groups.

A second conclusion is that members of parent support groups need and use more information and services than non-members and find each difficult to locate. Talking with other parents who are experiencing the same stressful caretaking activities may give parents an expanded perspective on what information and services are available. Obtaining information from other parents may also result in increased expectations about what the service system and professionals should deliver.

Support groups were also an important source of emotional support and help in coping for the parents who participated in this study. Our findings strongly suggest that parent-to-parent support—whether in the form of support groups or in other forms—is important to many families. Many parents in this study reported that involvement with other parents contributed to their ability to cope with raising a child with emotional disabilities. In addition to parent support groups, other ways to bring parents together such as warm lines, newsletters, buddy systems, workshops, and conferences should be employed. These non-group support mechanisms must also be studied in order to understand the range and effectiveness of family support services needed by parents who care for children with serious emotional disabilities.

REFERENCES

- Barnes, R.F., Raskind, M.A., Scott, M. & Murphy, C. (1981). Problems of families caring for Alzheimer patients: Use of a support group. *Journal of the American Geriatrics Society*, 29(2), 80-85.
- Biegel, D.E. & Yamatani, H. (1987). Help-giving in self-help groups. *Hospital and Community Psychiatry*, 38(11), 1195-1197.
- Campbell, S.B. & Werry, J.S. (1986). Attention deficit disorder (hyperactivity). In H.C. Quay and J.S. Werry, (Eds.), *Psychopathological disorders of childhood* (pp. 111-155). Third edition. New York: Wiley.
- Caplan, P.J., & Hall-McCorquodale, I. (1985). Mother-blaming in major clinical journals. *American Journal of Orthopsychiatry*, 55(3), 345-353.
- Dougherty, D.M., Saxe, L.M., Cross, T., & Silverman, N. (1987). *Children's mental health: Problems and services*. Durham, NC: Duke University Press.
- Friesen, B.J., Greisbach, J., Jacobs, J.H., Katz-Leavy, J., & Olson, D. (1988). Improving services for families. *Children Today*, 17(4), 18-22.
- Gartner, A. (1984). Widower self-help groups: A preventive approach. *Social Policy*, 14, 37-38.
- Hatfield, A.B. (1981). Families as advocates for the mentally ill: A growing movement. *Hospital & Community Psychiatry*, 32, 641-642.
- Hatfield, A.B. (1984). The family. In J.A. Talbott (Ed.), *The chronic mental patient: Five years later*. Orlando, FL: Grune & Stratton.
- Hinrichsen, G.A., Revenson, T.A., Shinn, M. (1985). Does self-help help? An empirical investigation of scoliosis peer support groups. *Journal of Social Issues*, 4(1), 65-87.
- Johnson, H. (1986). Emerging concerns in family therapy. *Social Work*, 31(4), 299-306.
- Knight, B., Wollert, R.W., Levy, L.H., Frame, C.L. and Padgett, C.P. (1980). Self-help groups: The members' perspectives. *American Journal of Community Psychology*, 8(1), 53-65.
- Knitzer, J. (1982). *Unclaimed Children*. Washington, D.C.: Children's Defense Fund.
- Kurtz, L.F. (1988). Mutual aid for affective disorders: The manic depressive and depressive association. *American Journal of Orthopsychiatry*, 58(1), 152-155.
- Lamb, H.R., Hoffman, A., Hoffman, F., Oliphant, E. (1986). Families of schizophrenics: A movement in jeopardy. *Hospital and Community Psychiatry*, 37(4), 353-357.
- Lewine, R.R.J. (1983). Parents: The mental health professionals' scapegoat. In I.E. Sigel & L.M. Laosa (Eds), *Changing Families*. New York: Plenum Press.
- Lieberman, M.A. and Bond, G.R. (1978). Self-help groups: Problems of measuring outcome. *Small Group Behavior*, 9(2), 221-241.
- Lieberman, M.A. and Videka-Sherman, L. (1986). The impact of self-help groups on the mental health of widows and widowers. *American Journal of Orthopsychiatry*, 56(3), 435-449.
- Newsom, B.L. and Newsom, M. (1983). Self-help in the United States: Social policy option. *Urban and Social Change Review*, 16(2), 19-23.
- Rosen, S.M., Fashel, D. & Lutz, M.E. (1987). *Face of the nation, 1987: Statistical supplement to the 18th edition of the encyclopedia of social work*. Silver Springs, MD: National Association of Social Workers.
- Seltiz, C., Wrightsman, L., & Cook, S. (1976). *Research methods in social relations*. New York: Holt, Rinehart and Winston.
- Telleen, S., Herzog, A., & Kibane, T.L. (1989). Impact of a family support program on mothers' social support and parenting stress. *American Journal of Orthopsychiatry* 59(3), 410-419.
- Thompson, E. & Doll, W. (1982). The burden of families coping with the mentally ill: An invisible crisis. *Family Relations*, 31, 379-388.
- Videka-Sherman, L. (1982). Coping with the death of a child: A study over time. *American Journal of Orthopsychiatry*, 52(4), 688-698.
- Videka-Sherman, L. & Lieberman, M. (1985). The effects of self-help and psychotherapy intervention on child loss: The limits of recovery. *American Journal of Orthopsychiatry*, 55(1), 70-82.

- Wahl, O.F. (1989). Schizophrenogenic parenting in abnormal psychology textbooks. *Teaching of Psychology, 16*, 31-33.
- Warheit, G.J., Bell, R.A., & Schwab, J.J. (1977). *Needs assessment approaches: Concepts and methods*. Rockville, MD: U.S. Department of Health, Education, and Welfare.
- Wintersteen, R.T. & Young, L. (1988). Effective professional collaboration with family support groups. *Psychosocial Rehabilitation Journal, 12*(1), 19-31.

ACKNOWLEDGMENT: This publication was developed with funding from the National Institute on Disability and Rehabilitation Research, U.S. Department of Education and the National Institute of Mental Health, U.S. Department of Health and Human Services (NIDRR grant number G0087C0222-88).

NOTE: This manuscript was originally published in 1991 in the *Community Mental Health Journal*, 27(4), 265-279. The official copy of record is available at www.springerlink.com.