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AUTHOR	Friesen, Barbara J.
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ABSTRACT

This paper presents findings of a 1987-1988 survey of 966 parents of children with serious emotional disturbances. The questionnaire addressed issues concerned with seeking and receiving information and services, sources of formal and informal support, and perceptions of the effect of their child's disability on family life. Among specific issues addressed are requirements that parents relinquish legal custody when seeking publicly funded residential treatment (one-quarter of parents had faced this issue) and parents who felt physically threatened by their children (44 percent sometimes felt physically threatened). Other issues addressed included: involvement with professionals (social workers and psychologists were most frequently named); service needs and utilization (financial assistance, support groups, and respite care appeared to be unmet needs); information needs and utilization (information about transition planning and help for siblings were identified as most needed and most difficult to obtain); and effects of the child's emotional problems on family life (most parents said most aspects of family life were negatively affected); and sources of support (72 percent of parents reported emotional support as being most helpful). Recommendations keyed to these findings are offered. Tables detailing demographic and response information are appended. (DB)

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SURVEY OF PARENTS WHOSE CHILDREN HAVE SERIOUS EMOTIONAL DISORDERS:

Report of a National Study

Families as Allies Project
Barbara J. Friesen, Ph.D.
Principal Investigator
August 4, 1989

Research & Training Center on Family Support
and Children's Mental Health
Portland State University
P.O. Box 751
Portland, OR 97207-0751
(503) 464-4040

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Appendix A: National Profile

SURVEY OF PARENTS WHOSE CHILDREN HAVE SERIOUS EMOTIONAL DISORDERS:

EXECUTIVE SUMMARY

This report contains a summary of a study involving parents whose children have serious emotional disorders. The study is based on responses from nearly 1000 parents from 45 states and the District of Columbia collected between May, 1987 and September, 1988.

METHOD

Purpose of the Study. There has been virtually no research about the needs and experiences of families whose children have serious emotional disorders. The study summarized here was designed to begin to fill this information gap by exploring families' perspectives of their problems, needs and experiences. Areas addressed included family members' experiences with seeking and receiving information and services for themselves and their children, sources of formal and informal support upon which they rely, and their perceptions of the effect of their child's disability on family life.

Research Approach. In order to include parents from around the country, national distribution of written questionnaires was selected as the method for gathering information. The questionnaires were accompanied by a letter of explanation and a self-addressed, postage paid envelope. Respondents returned the questionnaire anonymously. Also included with the questionnaire was a postcard that respondents could mail back separately to request that they be added to our mailing list, to ask for a summary of the study results, and to give their permission for follow-up interviews. The postcard was returned by 760 parents.

The use of written, mailed questionnaires as a method of data collection does carry some limitations. Response rates may be lower here than with other approaches such as person-to-person or telephone interviews and the sample may be biased in that persons likely to return written questionnaires tend to be better-educated and of a higher income level than those who do not. Nevertheless, we opted for this approach because it allowed us to survey a wide range of parents across the country at relatively low cost. Alternative approaches, such as collecting information from a smaller sample of parents in a few locations, would have allowed us to speak with more confidence about the characteristics and responses of parents in a few states or communities. However we were less concerned about formally generalizing our findings to all families whose children have serious emotional disorders than with obtaining an initial base of information about the needs and preferences of families from a wide variety of communities. By examining the characteristics of the families who did participate in the survey, we can estimate the extent to which they resemble, or deviate from other populations.

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 pre-tested with family members in parent support groups and were also reviewed by personnel from state Child and Adolescent Service System Programs (CASSP) and State Mental Health Representatives for Children and Youth (SMHRCY). A copy of the questionnaire is attached to this report.

Questionnaires were distributed in a variety of ways. First, family members attending four regional Families As Allies conferences during May and June, 1987 were given the opportunity to complete the questionnaire. Second, the 215 parent organizations listed in our national directory of parent organizations were invited to distribute the questionnaire to their members. Third, questionnaires were distributed to state-level mental health departments, usually through the Child and Adolescent Service System Programs (CASSP) or the State Mental Health Representatives for Children and Youth (SMHRCY) representatives. These state-level 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 we do not have solid information about the number of questionnaires that actually reached parents. The 966 questionnaires represent eight percent of the total that were distributed at conferences, through parent organizations, and through state mental health programs. It is very likely, however, that some of these questionnaires never actually reached parents, so the return rate for those who had an opportunity to respond is probably higher.

Given the return rate and 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 disorders with which to compare our respondents, so unfortunately, this question cannot be answered. We compared characteristics of parents in our respondent pool to the general U.S. population (1980 U.S. Census), however. Our respondents are more highly educated; 66 percent attended at least some college, compared to 32 percent of the U.S. population and nine percent of the parents in this study had less than a high school education, compared to 34 percent 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 percent 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 percent).

The ages of the respondents' children with serious emotional disorders covered the full range from 0 to 21 years of age. Seventy-three percent of these children were boys and 27 percent girls. This is consistent with the proportion of boys compared to girls who are referred for service, and possible explanations for the disparate proportions of boys and girls in service are important. First, some high incidence disorders which are more likely to result in referral for service are more common to boys. For example, Campbell and Werry (1986) summarize a number of studies illustrating that boys outnumber girls by three to one for both conduct disorders and attention deficit disorders. There are, of course, other disorders, such as anorexia nervosa, that are more common in girls. It is also likely that girls are underserved because their behaviors are often less troublesome to others than those commonly exhibited by boys.

The distribution of racial and ethnic groups represented by the respondents also resembles the distribution in the general population. The children described in the study were 86 percent white, 7.3 percent black, 2.6 percent Asian or Pacific Islander, 2.3 percent Hispanic and 1.2 percent Native American. This compares to an overall white to non-white U.S. population distribution of 85.1 and 14.9 percent non-white (Rosen, Fanshel and Lutz, 1987). Overall, these comparisons suggest that the parents who responded to the survey are somewhat better educated than the general population, and represent fewer parents in the $10,000 to $30,000 annual family income range and more in the over $50,000 range than the general population. How they compare to the more circumscribed population of parents with children who have emotional disorders is unknown, although sex-of-child ratios are roughly comparable. The pool of respondents does represent a wide range of income, education, racial and geographic backgrounds, and this at least suggests that the data collection approach was successful in obtaining a diverse sample.

FINDINGS

About the Respondents. Demographic information about the respondents is displayed in Table 1. The questionnaires were completed by parents or other caregivers whose children have serious emotional disorders. These included biological, step, foster and adoptive parents, and other relatives, such as grandparents and aunts. Eighty-seven percent of the respondents were mothers and 13 percent fathers. Two-thirds of the respondents were married (using a definition of marriage that included a marriage-like relationship). Seventy percent of the respondents also said that they had someone with whom they shared daily parenting responsibilities. As might be expected, having this help tended to parallel marital status, although not entirely. Ninety-four percent of married respondents said that they had someone with whom to share daily parenting responsibilities, whereas only 24 percent of the unmarried respondents said that they did. On the average, there were more than three children in each family, including the child with an emotional disorder.

We asked parents about two issues that many parents had told us were important problems before the study was begun. The first problem is that parents who seek placement in publicly funded residential treatment centers or other out-of-home placements are often required to relinquish legal custody of their children. One-quarter of the parents in our study said that giving up custody of their children in order to get services had been suggested to them. Of those, 27 percent had given up legal custody (nine percent of all parents in the study).

The second problem is that of parents' feeling physically threatened by their children. Forty-four percent of the parents in the study reported that they had at some time felt physically threatened by their children's behavior.

The responses to these two issues clearly raise many other questions, and call for further research into these problems. Further information about issues related to the custody problem is available through our Resource Service.

Involvement with Professionals Parents were asked about the types of professionals most involved with the family. Tables 2 and 3 contain a summary of the responses to this question. Social workers and psychologists were those named most often (each 23 percent), followed by teachers (20 percent), counselors (14 percent), and psychiatrists (10 percent).

Parents were then asked to indicate how important each of a number of helpful professional behaviors was to them, and how often this helpful behavior occurred. Of interest are the characteristics chosen as "very important" by a large percentage of parents. Leading the list are honesty, rated as very important by 87 percent of parents and a respectful, non-blaming attitude (82 percent). Also identified as "very important" by 70 percent or more of the parents were supportiveness to the child, supportiveness to the parents, and efforts to include parents in decision-making. In general, parents reported that the "very important" behaviors of professionals occurred either "sometimes" or "often."

In all instances, the percentage of parents who said that a particular professional characteristic or behavior was "very important" was larger than the percentage of parents who said that the attribute "often occurs." This suggests that parents' expectations (or hopes) about the professional service they receive are not completely met by the professional with whom them have been most involved. Overall, however, the parents in our study appear to have had generally positive experiences with the professional with whom their family has been the most involved. It should be noted that the parents in the study were describing one specific professional, not their general experience with professional services.

Service needs and utilization. The survey asked about services used by families (see Table 4). All parents who responded indicated that they were currently using one or more services for their child with emotional disorders. This finding is not at all surprising, given that the children of these parents had been identified as having an emotional disorder, and thus were likely to be receiving services.

A large number of service needs were also identified by parents. It is important to note that parents were asked about the extent to which they needed a number of services, including those they were currently receiving. Thus, indicating a need for a given service did not necessarily mean that the need was unmet. Five services were identified by more than 80 percent of the parents as needed "somewhat" or "very much." These were special education, the services of a psychologist, counselor or psychiatrist, and access to a parent support group. Special education and parent support groups were rated as "somewhat" or "very" difficult to obtain by a little more than half of the parents. Access to services of individual helpers was apparently somewhat less difficult. The five services identified as the most difficult to obtain were financial assistance, respite services, sibling (brother and sister) support, residential treatment and day treatment.

One way to think about identifying unmet need is to examine the discrepancy between the percentage of parents who said they had used a particular service and those who said they needed it. Four services had a difference of thirty percentage points or more between these two categories. These were financial assistance, parent support group, support groups for brother and sisters, and respite care. These services may represent areas for improving what is currently available to families.

Information needs and utilization Responses to a series of questions about the use of information, parents' needs for information, and their assessment of how difficult the information was to locate are displayed in Table 5. Three-quarters or more of parents said that they had used information on diagnosis of the child's condition, accurate assessment, advice about child rearing, and special education services. In contrast, fifty percent or fewer of the parents said that they had used information about the child's legal rights, what to do in a crisis or emergency, long-range (transition) planning, and help for brothers and sisters of their child with an emotional disorder.

Parents expressed a need for a wide range of information. In particular, more than 90 percent said they needed information about assessment, available treatment, causes of the disorder, how to cope with raising a child with an emotional disorder, and long-range (transition) planning. Much of this information was also identified as difficult to obtain, particularly information on transition planning, how to cope with raising a child with an emotional disorder, causes of the disorder, available treatment, service coordination, and assessment. All of these topics were identified by three-quarters or more of the respondents as somewhat or very difficult to obtain information on. Of particular interest are the items, "transition planning," and "help for siblings," which were identified as among the least used, most needed, and most difficult to obtain information.

Effects of the Child's Emotional Problems on Family Life. Parents were asked to estimate the effects of their child's emotional problems on various aspects of their family life. These aspects, which included the family's relationships with others, relationships among family members, effects on other children, and health of parents, are listed in Table 6. For each of these, some parents said that the child's emotional disorder had a positive effect. The percentages of parents who reported a positive effect, however, were very small, with one exception: a third of the parents who had a spouse or partner said that the child's problems had a positive effect on involvement by both parents in the care of the child. In the next most frequently mentioned categories, only ten percent of parents said that the presence of the child's problems had enhanced the family's ability to plan and participate in social activities as a family, and their relationship with their spouses or partners.

The areas reported by parents to be least affected by the child's problems were the father's health (54 percent) and the mother's health (40 percent). In most areas, however, more than 50 percent of parents said that the child's problems negatively affected family life. The area most frequently identified as problematic was "effects on other children in the family," (78 percent), followed by parent's opportunity to have time away from children, the amount of attention parents provide to other children, the ability to plan/participate in social activities as a family, and the family's relationships with family, friends, and neighbors. The only two categories identified as problematic by fewer than 50 percent of the parents were "father's health," and "involvement by both parents in the care of the child." Thus, although it is clear that some parents believe that their child's emotional problems have a positive effect on family life, this appears not to be the case for most.

These findings are important to consider in light of efforts to identify the positive contributions to families of children who have disabilities and a parallel attempt to avoid emphasizing negative effects of these children on their families. While these efforts are very important in overcoming the stigma, negative publicity, and other trends that emphasize differences rather than similarities among people, our findings suggest that we should also avoid under-estimating the difficulties experienced by families whose children have emotional, mental, or behavioral disorders. Many families need a considerable amount of support and help with coping, and many of their problems appear to be related to the emotional, physical, social and financial stresses of dealing with the needs of such children.

Sources of Support. In addition to information about formal services and service providers, parents were asked to identify others such as family members, friends, and neighbors who were helpful in raising their child with an emotional disability, and to indicate how these persons had been helpful. Parents were also asked which activities or interests, in addition to support from other people, were helpful in coping. This information is contained in Table 7. Respondents first checked all the people who were helpful to them, and then indicated which of those persons had been the most helpful. In general, the respondent's spouse was most frequently identified as the most helpful (51 percent), followed by grandparents (13 percent) and friends (10 percent). Among the respondents who were not married, grandparents (28 percent) and friends (24 percent) were seen as the most helpful.

The most helpful type of support provided by others was clearly emotional support, identified by 72 percent of respondents. Other types of help such as baby-sitting, financial help, advice, and help in finding services, were considered as the most important by very few parents. This response from an overwhelming majority of parents deserves strong emphasis. Researchers, policy-makers, administrators and practitioners may tend to underestimate the importance of emotional support from informal sources as we focus on improving the formal service delivery system.

In addition to support from others, parents indicated activities or interests that were helpful in coping with raising a child with emotional handicaps. The activity that was chosen as most helpful by the most parents was involvement with other parents of children with emotional problems (29 percent), followed closely by involvement in religion (27 percent). Seventeen percent of respondents said that their career was helpful in coping. The remaining activities on the list were selected by fewer than eight percent of study participants.

RECOMMENDATIONS

The information presented in this summary reflects the initial analysis of the data from the parent survey; much analysis remains to be done. Our findings to date, however, suggest a number of areas that merit attention from parents and other advocates, planners and service providers and researchers:

- *One-fourth of parents in the study said that it had been suggested that they relinquish legal custody of their children to gain access to services.* A re-examination of both mechanisms for mental health financing and child welfare policy is needed, since they each contribute to this problem. Further examination of the effects on children and families of this phenomenon is also sorely needed.

- *Nearly half of the parents reported that they had been physically threatened by their children.* While much more study into the nature and extent of this problem is needed, it is apparent from parents' comments that many currently face serious injury or worse. Information about how to deal with assaultive children, as well as concrete assistance should be provided to families now.

- *Parents provided much rich information about their expectations of professionals, along with their actual experiences.* This information should be used in the development and revision of professional education programs.

- *Specific services identified as particularly difficult to gain access to included financial assistance, support groups for parents as well as brothers and sisters, and respite care.* More attention might be given to including these services in new or existing programs. In general, our findings lend support to the commonly accepted need for improvements in the quantity, quality and variety of service options for families.

- *Information needs identified by families include a better understanding of the causes of emotional disorders as well as specific information about the nature and appropriate treatment of their children's problems.* Parents need better access to existing information and, perhaps, more direct consultation with professionals about their own circumstances. While much remains to be learned about childhood emotional disorders, improvements can be made by sharing what is known. Information as well as additional research are needed.

- *Parents also identified the need for better information about coping for themselves and for their children.* Transition services is an area where information appears to be especially sparse and sorely needed.

- *Many effects of childhood emotional disability on family life were identified by parents.* Our findings support current practice impressions that many families experience heavy caregiving burdens with insufficient relief. Family support programs that specifically address the needs of families who have children with serious mental or emotional disorders and that include respite care, parent support mechanisms and help for brothers and sisters should be developed and carefully evaluated.

- *Parents reported that they received support from a variety of informal sources, especially relatives and friends.* Overwhemingly, emotional support was seen as the most important aspect of help from these informal sources. The important contribution of informal support to the well-being of families should be emphasized in professional training programs, as well as through information and training opportunities for family members and their support systems.

- *Involvement with other parents was identified by a large number of parents as the most important source of help in coping.* This finding confirms and supports current efforts to expand the availability of parent groups and other parent support systems. Additional study is also needed to understand the most effective forms of parent-to-parent support.

- *Religion as a source of coping for family members was identified as important by a large number of parents across all income and educational levels.* This finding suggests a need for further research in this area as well as program development aimed at increasing the awareness and involvement of churches and other religious organizations in addressing the needs of families.

There is much interesting and useful information yet to be extracted, examined and reported. Some studies are in progress and several others are planned. Currently we are looking more closely at the experiences of minority families and comparing the responses of parents who are members of parent support groups with those who are not. In the coming months we will be examining in depth the data about the characteristics of professionals and the effects of the child's disability on family life. These research reports will be made available through our Resource Service as they are completed.

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ABOUT THE TABLES:

Table 1. DEMOGRAPHIC INFORMATION: Presents demographic and descriptive information on respondents and their children. The information is presented for those with children 0 to 5 years old, 6 to 11 years old, and 12 years or older. In addition, the information is summarized for the total group. The percentages under the age categories of children constitute a single sub-table for each demographic characteristic and sum to 100% (approximate because of rounding error). For example, 3% of respondents had a male child 0 to 5 years old, and the percentages of male and female children for all three age categories sum to 100%. The percentages under the "TOTAL" column combine the age categories; for example, 73% of respondents had a male child of any age and the other 27% had a female child of any age.

Table 2. INVOLVEMENT WITH PROFESSIONALS: Presents information on professionals with whom parents were most involved in dealing with their children's disability. Percentages for each of 8 major types of professionals are presented for those with children 0 to 5 years old, 6 to 11 years old, and 12 years or older. All percentages under the age categories of children constitute one sub-table, that is, they sum to 100% (approximate because of rounding error). In addition, the percentages are summarized across age categories under the "TOTAL" column; these percentages also sum to 100%.

Table 3. CHARACTERISTICS OF PROFESSIONALS WITH WHOM FAMILY IS MOST INVOLVED: Presents ratings of both importance and frequency of professional activities, all in reference to the professional with whom the family is most involved. The information presented is based on two rating scales, each of which has three points. For the importance scale, the points are *not important, somewhat important,* and *very important*; for the frequency scale, the points are *never occurs, sometimes occurs,* and *often occurs.* The table presents only the percentages from the top two points in each scale, since the percentages from bottom-most points can be inferred by subtraction from 100%. For example, 37% of parents said that professionals' efforts to help them cope with parenting was *somewhat important,* and an additional 55% said that such efforts were *very important.* By inference, only 8% of parents (100% minus (37% plus 55%) equals 8%) said that such efforts were *not important.*

Table 4. SERVICES FOR CHILD: Lists a range of services that a child or family could receive and presents the percentage of parents who ever used each service, needed each service, and found each service difficult to obtain. The percentages on need reflects those parents who said that they needed a given service *somewhat* or *very much*; similarly, the percentages on difficulty obtaining services reflects those parents who said a given service was *somewhat* or *very difficult* to obtain. Each percentage in the table is independent from the

others and can attain 100%. So, for example, if 79% of parents reported using regular classroom services for their child, it can be inferred that 21% reported *not* using this service.

Table 5. INFORMATION REGARDING CHILDREN'S EMOTIONAL HANDICAPS: Lists a range of topics on which parents might obtain information and presents the percentage of parents who ever used such information, needed such information, and found such information difficult to obtain. Like Table 4, the percentages on need reflects those parents who said that they needed a given type of information *somewhat* or *very much*; similarly, the percentages on difficulty obtaining information reflects those parents who said a given type of information was *somewhat* or *very difficult* to obtain. Each percentage in the table is independent from the others and can attain 100%. So, for example, if 71% of parents reported using information on the causes of emotional handicaps, it can be inferred that 29% reported *not* using this information.

Table 6. EFFECTS OF CHILD'S EMOTIONAL PROBLEMS ON FAMILY LIFE: Lists a range of possible effects that a child's emotional disability can have on family life and presents the percentage of parents who reported that their own child's disability had a negative, positive, or neutral (no) effect. This table is presented only for the total sample, that is, all states combined.

Table 7. SOURCES OF SUPPORT TO FAMILIES IN RAISING A CHILD WITH AN EMOTIONAL DISABILITY: Lists types of individuals, personal services, and activities that a parent may find helpful in raising a child with an emotional disability. Next to each is presented the percentage of parents who reported the individual, service or activity as *most* helpful in that category. The emphasis here is on informal support rather than support provided through formal services. For example, focusing on the types of individuals who might provide help, 51% of parents reported their spouse as being most helpful in their child-raising responsibilities. Similarly, 29% of parents reported that involvement with other parents of children with emotional disabilities was the most helpful activity or interest. Like Table 6, this table is presented only for the total sample, that is, all states combined.

APPENDIX A

NATIONAL PROFILE

ALL STATES
ALL PARENTS WHO RESPONDED TO SURVEY

TABLE 1

DEMOGRAPHIC INFORMATION

	AGE OF CHILD			
	0-5 YRS n= 42 (4%)	6-11 YRS n=359 (37%)	12+ YRS n=564 (58%)	TOTAL n=965 (100%)
Sex of Child:				
Male	3%	30%	40%	73%
Female	1%	8%	18%	27%
Race of Child:				
White	3%	33%	50%	86%
Hispanic	0%	1%	1%	2%
Black	1%	2%	4%	7%
Asian	0%	1%	2%	3%
American Indian	0%	0%	1%	1%
Other	0%	0%	1%	1%
Person Completing Survey:				
Mother	4%	28%	39%	71%
Father	0%	3%	6%	9%
Stepmother	0%	0%	1%	1%
Stepfather	0%	0%	0%	0%
Foster Mother	0%	2%	2%	4%
Foster Father	0%	0%	1%	1%
Adoptive Mother	0%	3%	7%	10%
Adoptive Father	0%	1%	2%	2%
Other	0%	1%	1%	2%
Marital Status:				
Married	2%	25%	39%	66%
Single	2%	12%	19%	34%
Highest Level of Education of Respondent				
Some HS or Less	0%	4%	5%	9%
HS Diploma	1%	9%	14%	24%
Business/Trade School	0%	3%	6%	10%
Some College	1%	11%	14%	27%
College Degree	0%	4%	7%	11%
Some Grad School	0%	3%	5%	8%
Graduate Degree	0%	4%	8%	12%

ALL STATES
ALL PARENTS WHO RESPONDED TO SURVEY

TABLE 1

DEMOGRAPHIC INFORMATION - CONTINUED

	AGE OF CHILD			
	0-5 YRS	6-11 YRS	12+ YRS	TOTAL
	n= 42 (4%)	n=359 (37%)	n=564 (58%)	n=965 (100%)
Yearly Family Income:				
Under $10,000	1%	9%	10%	20%
$10,000 to $19,999	2%	8%	12%	22%
$20,000 to $29,999	0%	8%	13%	22%
$30,000 to $39,999	1%	6%	9%	16%
$40,000 to $49,999	0%	3%	5%	9%
$50,000 or More	0%	3%	9%	12%
Average # Other Children per Family	3.19	2.77	2.78	2.79
Someone to share daily parenting responsibilities?				
Yes	3%	28%	40%	70%
No	2%	10%	19%	30%
Diagnosis given for child's condition?				
Yes	3%	28%	43%	73%
No	2%	10%	16%	27%
Has giving up custody been suggested?				
Yes	1%	7%	18%	25%
No	4%	31%	40%	75%
IF SO, was custody given up?				
Yes	0%	5%	23%	28%
No	3%	23%	46%	72%
Child's behavior physically threatening?				
Yes	2%	13%	30%	44%
No	3%	24%	29%	56%

ALL STATES
ALL PARENTS WHO RESPONDED TO SURVEY

TABLE 2

INVOLVEMENT WITH PROFESSIONALS

	AGE OF CHILD			
	0-5 YRS n= 42 (4%)	6-11 YRS n=359 (37%)	12+ YRS n=564 (58%)	TOTAL n=965 (100%)
Professional Most Involved With Family:				
Teacher	1%	11%	8%	20%
Physician	0%	3%	2%	5%
Lawyer	0%	0%	0%	1%
Social Worker	1%	7%	15%	23%
Psychologist	1%	8%	14%	23%
Psychiatrist	0%	3%	6%	9%
Clergy	0%	0%	0%	1%
Counselor	1%	4%	9%	14%
Other	0%	1%	3%	4%

ALL STATES
ALL PARENTS WHO RESPONDED TO SURVEY

TABLE 3

CHARACTERISTICS OF PROFESSIONAL WITH WHOM FAMILY IS MOST INVOLVED

% PARENTS WHO SAY --->	SOMEWHAT IMPORTANT	VERY IMPORTANT	SOMETIMES OCCURS	OFTEN OCCURS
Helps cope with parenting	37%	55%	55%	34%
Is supportive to parent	22%	75%	38%	57%
Is supportive to child	18%	79%	31%	66%
Gives accurate evaluations	27%	68%	46%	47%
Advocates for child	24%	65%	40%	44%
Is non-blaming	15%	82%	25%	71%
Gives treatment information	27%	63%	45%	41%
Gives parenting information	36%	49%	46%	34%
Is readily available	31%	43%	33%	27%
Includes parents in decisions	21%	73%	35%	57%
Follows up	29%	64%	40%	50%
Is honest	12%	87%	23%	75%
Gives resource information	28%	62%	46%	40%
Is consistently involved	35%	55%	42%	45%
Makes home visits	20%	17%	17%	12%
Is involved with future planning	35%	50%	45%	36%

ALL STATES
ALL PARENTS WHO RESPONDED TO SURVEY

TABLE 4

SERVICES FOR CHILD

	% WHO EVER USED SERVICE	% WHO NEEDED SERVICE	% WHO SAID IT WAS DIFFICULT TO GET
Regular classroom	79%	76%	42%
Special education	77%	86%	58%
Psychiatrist	74%	83%	47%
Nurse	21%	25%	23%
Lawyer	31%	41%	33%
Counselor	74%	84%	43%
Social worker	68%	73%	36%
Psychologist	81%	85%	41%
Minister	45%	61%	22%
Psychiatric hospital	37%	47%	55%
Residential treatment	33%	53%	66%
Foster care	15%	25%	44%
Day treatment	22%	45%	62%
Advocacy services	31%	56%	54%
Financial assistance	44%	74%	75%
Parent support group	53%	83%	56%
Sibling support group	15%	65%	69%
Crisis intervention	27%	56%	56%
Respite care	17%	67%	74%
Other	69%	98%	76%

ALL STATES
ALL PARENTS WHO RESPONDED TO SURVEY

TABLE 5

INFORMATION REGARDING CHILDREN'S EMOTIONAL HANDICAPS

	% WHO EVER USED INFORMATION	% WHO NEEDED INFORMATION	% WHO SAID IT WAS DIFFICULT TO GET
Causes of handicap	71%	93%	81%
Available treatment	74%	93%	80%
Child-raising advice	77%	88%	58%
Available medications	65%	76%	56%
Coordinating services	54%	83%	79%
Handling a crisis	49%	77%	68%
Accurate assessment	81%	94%	77%
Child's legal rights	50%	74%	65%
Parent's legal rights	52%	77%	68%
Special education laws	58%	78%	59%
Setting up an educational plan	64%	81%	54%
Available special education services	75%	86%	68%
Child's diagnosis	82%	94%	73%
Help for siblings	33%	67%	72%
Coping with child's emotional handicap	68%	93%	81%
Long-range planning	45%	90%	83%
Other information	85%	100%	90%

ALL STATES
ALL PARENTS WHO RESPONDED TO SURVEY

TABLE 6

EFFECTS OF CHILD'S EMOTIONAL PROBLEMS ON FAMILY LIFE

	Better	No Effect	Worse
Family's relationships with family friends, and neighbors	6%	32%	63%
Parent's opportunity to have time away from children	8%	22%	70%
Involvement by both parents in care of child *	33%	27%	40%
Ability to plan/participate in social activities as a family	10%	27%	63%
Relationship with other spouse or partner	11%	29%	60%
Amount of attention parents provide to other children	6%	27%	67%
Effects on other children in the family *	5%	18%	78%
Mother's health *	3%	40%	57%
Father's health *	4%	54%	42%

* When applicable

ALL STATES
ALL PARENTS WHO RESPONDED TO SURVEY

TABLE 7

SOURCES OF SUPPORT TO FAMILIES IN RAISING A CHILD WITH AN EMOTIONAL HANDICAP

Person who has been the most helpful:

Spouse	51%
Significant other	6%
Ex-spouse	3%
Child's grandparents	13%
Friends	10%
Neighbors	1%
Other children	3%
Other family member(s)	7%
Other persons	3%

Most helpful type of support provided by above person:

Providing emotional support	72%
Bbabysitting	9%
Help in finding appropriate services	2%
Financial help	7%
Advice	4%
Other	6%

Activities or interests (in addition to support from people) that have been most helpful:

Religion	27%
Involvement with other parents of children with emotional problems	29%
Career	17%
Hobbies	6%
Community volunteer activities	2%
Recreational activities	7%
Involvement in advocacy	6%
Other activities	5%

Parent Survey

Card 1
2 ☐ 7

Thank you for participating in our survey. Many terms are used to describe problems of an emotional nature such as "emotional disturbance," "behavior disorder," or "mental illness or disorder." In this questionnaire we use the terms "emotional handicap" and "emotional problems."

This study is about your experiences with the child in your family who has emotional problems. If you have more than one child with an emotional handicap, select the child with the most serious problems while answering the questions.

INSTRUCTIONS: Please enter the number of your answer to the right of each question in the box provided. If a question is not applicable, skip that item, but continue with the rest of the questions. All answers are strictly confidential; there is no way we will know your name or that of your child.

I. Family Information

A. How many years old is your child? 8 ☐ 9

B. What is your child's sex?
1. Male
2. Female
☐ 10

C. What is your child's race?
1. White
2. Hispanic
3. Black
4. Asian or Pacific Islander (including Hawaiian)
5. American Indian or Alaskan Native
6. Other ____________________
☐ 11

D. How many other children live in your home? 12 ☐ 13
List their sex(es) and age(s):

Child	Sex	Age	Child	Sex	Age
#1	____ 14	15 ____ 16	#4	____ 23	24 ____ 25
#2	____ 17	18 ____ 19	#5	____ 26	27 ____ 28
#3	____ 20	21 ____ 22	#6	____ 29	30 ____ 31

E. How are you related to the child?
1. Mother
2. Father
3. Stepmother
4. Stepfather
5. Foster Mother
6. Foster Father
7. Adoptive Mother
8. Adoptive Father
9. Other ____________________
☐ 32

F. How many people live in your home? 33 ☐ 34

G. Are you:
1. Married*
2. Single
3. Divorced
4. Separated
5. Widowed
☐ 35

* Either a legal marriage, or a marriage-like living arrangment

H. Do you have someone who shares daily parenting responsibilities with you? (This can be a spouse, mother, or friend, etc.)
1. Yes
2. No
☐ 36

I. What is your yearly family income?
1. Under $10,000
2. $10,000 to $19,999
3. $20,000 to $29,999
4. $30,000 to $39,999
5. $40,000 to $49,999
6. $50,000 or more
☐ 37

J. What is your highest level of education?
1. Some high school or less
2. High school diploma
3. Business or trade school
4. Some college
5. College degree
6. Some graduate school
7. Graduate degree
☐ 38

K. What is your zip code? 39 ☐ 43

L. Have you been given a name or diagnosis for your child's condition?
1. Yes
2. No
☐ 44

If yes, by whom? (doctor, teacher, etc.)
______________________________ 45

What is the name/diagnosis?
______________________________ 46

Card 2
2 ☐ 7

II. Family Issues

Sometimes a youngster's emotional problems have an effect on family life. For each family issue, indicate whether having a child with emotional handicaps:

Makes it better
Makes it neither better nor worse
Makes it worse
Does not apply to our family

	Child's Effect on Family				
Family Issue	makes it better	neither	makes it worse	does not apply	
Family's relationships with family, friends, and neighbors	☐	☐	☐	☐	8
Parent's opportunity to have time away from children	☐	☐	☐	☐	9
Involvement by both parents in child	☐	☐	☐	☐	10

	Child's Effect on Family				
Family Issue	makes it better	neither	makes it worse	does not apply	
Ability to plan/participate in social activities as a family	☐	☐	☐	☐	11
Your relationship with spouse or other partner	☐	☐	☐	☐	12
Amount of attention parents provide to other children	☐	☐	☐	☐	13
Effects on other children in the family	☐	☐	☐	☐	14
Mother's health	☐	☐	☐	☐	15
Father's health	☐	☐	☐	☐	16
Other areas: ____________	☐	☐	☐	☐	17

III. Characteristics of Professionals

Information about how you as parents view the professional help you have received will be used to train professionals about how to be most helpful to families. From the list below, please pick the one professional with whom you have been most involved in dealing with your emotionally handicapped child. Place an X in the box next to his or her title:

18 ☐ Teacher
☐ Physician
☐ Lawyer
☐ Social Worker
☐ Psychologist
☐ Psychiatrist
☐ Clergy
☐ Counselor
☐ Other ______________

Please keep this one professional in mind while you read the following list.Then rate the following:

How important is what this professional does for you?
How often does the professional you have in mind help you in this way?

Place a check in the appropriate box.

	Important to you?			How often does this occur?		
	not at all	somewhat	very	never	sometimes	very
Helps you cope with raising your child	☐	☐	☐ 19	☐	☐	☐ 35
Is supportive to you	☐	☐	☐ 20	☐	☐	☐ 38
Is supportive to your child	☐	☐	☐ 21	☐	☐	☐ 37
Provides an accurate evaluation of your child's handicap	☐	☐	☐ 22	☐	☐	☐ 38
Advocates for your child's needs with the appropriate authorities	☐	☐	☐ 23	☐	☐	☐ 39
Treats you with respect (non-blaming)	☐	☐	☐ 24	☐	☐	☐ 40
Provides information about available treatment methods for your child	☐	☐	☐ 25	☐	☐	☐ 41
Provides information about practical child-raising techniques	☐	☐	☐ 26	☐	☐	☐ 42
Is available to you on a 24-hour basis (i.e., in times of crisis)	☐	☐	☐ 27	☐	☐	☐ 43
Includes you in the decision making about the care of your child	☐	☐	☐ 28	☐	☐	☐ 44
Follows up to see how things worked out	☐	☐	☐ 29	☐	☐	☐ 45
Is honest with you	☐	☐	☐ 30	☐	☐	☐ 46
Provides useful information about resources available to you	☐	☐	☐ 31	☐	☐	☐ 47
Is consistently involved in the care of your child	☐	☐	☐ 32	☐	☐	☐ 48
Makes home visits	☐	☐	☐ 33	☐	☐	☐ 49
Is involved with future planning for your child	☐	☐	☐ 34	☐	☐	☐ 50

IV. Sources of Support

Card 3
2 ☐ 7

A. Family Members/Friends:

Which of the following family members/friends have been helpful to you in raising your child? (Check all that apply):

1. Spouse ☐ 8
2. Your "significant other" ☐ 9
3. Your ex-spouse ☐ 10
4. Child's grandparents ☐ 11
5. Friends ☐ 12
6. Neighbors ☐ 13
7. Other children ☐ 14
8. Other family member: ☐ 15
   List: ______________
9. Other ☐ 16
   List: ______________
10. None ☐ 17

Please circle the box above of the one who has been the most helpful. ■ 18

How has this person been helpful to you?
(Check all that apply)

1. Provides emotional support ☐ 19
2. Babysits ☐ 20
3. Helps me find appropriate services ☐ 21
4. Helps me financially ☐ 22
5. Gives me advice ☐ 23
6. Other ☐ 24
   List: ______________

Please circle the box above of the type of help that is most helpful. ■ 25

Overall, who is the person who has provided you with the most help in raising your child?

1. A professional
2. A friend or family member
3. Other ☐ 26
   List: ______________

B. Other sources of help.

Besides support from professionals and support from family and friends, has involvement in the following areas been helpful to you in coping with raising a child with emotional handicaps? (Check all that apply.)

1. Religion ☐ 27
2. Involvement with other parents of children with emotional problems ☐ 28
3. Your own career ☐ 29
4. Your own hobbies ☐ 30
5. Community volunteer activities ☐ 31
6. Recreational activities ☐ 32
7. Involvement in advocacy ☐ 33
8. Other activities ☐ 34
   List: ______________

Circle the box of the one above which has been the most helpful. ■ 35

Please describe the activity and explain in box below why it has been helpful in coping.

V. Custody

Has it ever been suggested that you give up custody of your child to get services?

A. Yes ☐

No ☐ 36

B. If yes, have you given up custody?

Yes ☐

No ☐ 37

If yes, please describe the circumstances.

VI. Behavior

Have you ever felt physically threatened by your child's behavior?

A. Yes ☐

No ☐ 38

Comment:

VII. Services

Please tell us about the services you have used for your child with emotional handicaps and your experience with getting the services you need. Check the appropriate box. **Please answer all items for each type of service, whether you used it or not.**

Have you *ever used* the service?
Are you *currently using* the service?
How much do you (or did you) *need* this service?
How *easy or difficult* to obtain was this service?

	Ever used?		Currently using?		Needed service?			Difficult to obtain?			
Type of Service	yes	no	yes	no	not at all	somewhat	very much	not at all	somewhat	very	never looked
Regular Classroom	☐	☐ 39	☐	☐ 40	☐	☐	☐ 41	☐	☐	☐	☐ 42
Special Education Classroom/Services	☐	☐ 43	☐	☐ 44	☐	☐	☐ 45	☐	☐	☐	☐ 48
Services of a Psychiatrist (M.D.)	☐	☐ 47	☐	☐ 48	☐	☐	☐ 49	☐	☐	☐	☐ 50
Services of a Nurse	☐	☐ 51	☐	☐ 52	☐	☐	☐ 53	☐	☐	☐	☐ 54
Services of a Lawyer	☐	☐ 55	☐	☐ 56	☐	☐	☐ 57	☐	☐	☐	☐ 58
Services of a Counselor	☐	☐ 59	☐	☐ 60	☐	☐	☐ 61	☐	☐	☐	☐ 62
Services of a Social Worker	☐	☐ 63	☐	☐ 64	☐	☐	☐ 65	☐	☐	☐	☐ 66
Services of a Psychologist	☐	☐ 67	☐	☐ 68	☐	☐	☐ 69	☐	☐	☐	☐ 70
Services of a Minister	☐	☐ 71	☐	☐ 72	☐	☐	☐ 73	☐	☐	☐	☐ 74

Card 4

2 ☐ 7

Psychiatric Hospitalization	☐	☐ 8	☐	☐ 9	☐	☐	☐ 10	☐	☐	☐	☐ 11
Residential Treatment	☐	☐ 12	☐	☐ 13	☐	☐	☐ 14	☐	☐	☐	☐ 15
Foster Care	☐	☐ 16	☐	☐ 17	☐	☐	☐ 18	☐	☐	☐	☐ 19
Day Treatment Program	☐	☐ 20	☐	☐ 21	☐	☐	☐ 22	☐	☐	☐	☐ 23
Advocacy Services	☐	☐ 24	☐	☐ 25	☐	☐	☐ 26	☐	☐	☐	☐ 27
Financial Assistance	☐	☐ 28	☐	☐ 29	☐	☐	☐ 30	☐	☐	☐	☐ 31
Support or Self-Help Group for Parents	☐	☐ 32	☐	☐ 33	☐	☐	☐ 34	☐	☐	☐	☐ 35
Support or Self-Help Group for Siblings	☐	☐ 36	☐	☐ 37	☐	☐	☐ 38	☐	☐	☐	☐ 39
Crisis Intervention	☐	☐ 40	☐	☐ 41	☐	☐	☐ 42	☐	☐	☐	☐ 43
Respite Care (child care to give parents relief)	☐	☐ 44	☐	☐ 45	☐	☐	☐ 46	☐	☐	☐	☐ 47
________________	☐	☐ 48	☐	☐ 49	☐	☐	☐ 50	☐	☐	☐	☐ 51

Card 5
2 ☐ 7

VIII. Information:

What kinds of information have you sought for your child with emotional handicaps? Check the appropriate box. Please answer all items for each type of information, whether you used it or not.

Have you *ever used* this information?
How much do you (did you) *need* this information?
How *difficult* was this information to obtain?

Type of Information	Ever used?		Needed information?			Difficult to obtain?				
	yes	no	not at all	some-what	very much	never looked	Looked, never found	not at all	some-what	very
Causes of the emotional handicap	☐	☐ 8	☐	☐	☐ 9	☐	☐	☐	☐	☐ 10
Various treatment options available	☐	☐ 11	☐	☐	☐ 12	☐	☐	☐	☐	☐ 13
Practical advice on child-raising	☐	☐ 14	☐	☐	☐ 15	☐	☐	☐	☐	☐ 16
Medications available	☐	☐ 17	☐	☐	☐ 18	☐	☐	☐	☐	☐ 19
How to coordinate services for child	☐	☐ 20	☐	☐	☐ 21	☐	☐	☐	☐	☐ 22
What to do in a crisis or emergency	☐	☐ 23	☐	☐	☐ 24	☐	☐	☐	☐	☐ 25
An accurate assessment of your child	☐	☐ 26	☐	☐	☐ 27	☐	☐	☐	☐	☐ 28
Child's legal rights	☐	☐ 29	☐	☐	☐ 30	☐	☐	☐	☐	☐ 31
Parents' legal rights	☐	☐ 32	☐	☐	☐ 33	☐	☐	☐	☐	☐ 34
Special education laws (P.L. 94-142)	☐	☐ 35	☐	☐	☐ 36	☐	☐	☐	☐	☐ 37
How to set up an educational plan (IEP)	☐	☐ 38	☐	☐	☐ 39	☐	☐	☐	☐	☐ 40
Special education services available	☐	☐ 41	☐	☐	☐ 42	☐	☐	☐	☐	☐ 43
Child's diagnosis	☐	☐ 44	☐	☐	☐ 45	☐	☐	☐	☐	☐ 46
Help for brothers and sisters	☐	☐ 47	☐	☐	☐ 48	☐	☐	☐	☐	☐ 49
How to cope with raising a child with an emotional problem	☐	☐ 50	☐	☐	☐ 51	☐	☐	☐	☐	☐ 52
Long-range planning for child's future (transition)	☐	☐ 53	☐	☐	☐ 54	☐	☐	☐	☐	☐ 55
Other information: ________	☐	☐ 56	☐	☐	☐ 57	☐	☐	☐	☐	☐ 58

IX. Preparation for Adulthood

A. Has any professional discussed what training, educational or vocational services your child will need in order to prepare for adulthood?

1. Yes ☐ 2. No ☐ 8

If yes, check all the services you have discussed. Then put a check in the boxes of the three most important areas for future planning with your child.

	Discussed with professional	Three most important
Education	☐ 9	☐ 20
Job training	☐ 10	☐ 21
Life skills/community living	☐ 11	☐ 22
Financial responsibility for child in future	☐ 12	☐ 23
Legal responsibility if child can't be responsible for self	☐ 13	☐ 24
Treatment after age 18	☐ 14	☐ 25
Wills, financial planning	☐ 15	☐ 26
Housing/living arrangements	☐ 16	☐ 27
Family expectations	☐ 17	☐ 28
Sex education and family planning	☐ 18	☐ 29
Other List: ________	☐ 19	☐ 30

C. Age at which you feel planning for lthood should begin: 31 ☐ 32

X. Comment

Card 6
2 ☐ 7

What is the most important issue you have had to deal with in raising a child with an emotional handicap?

Thank you for your participation. Please use the rest of this page for any additional comments you would like to make. Add more pages if you need more space.

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Printed Name/Position/Title: Kaye J. Exo

Organization/Address: Research & Training Center on Family Support and Children's Mental Health

Telephone: 503-725-4040

FAX: 503-725-4180

E-Mail Address: exok@rri.pdx.edu

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of research results to persons with disabilities and their families. Implicit in this discussion is a concern about both the nature and form of the information to be disseminated (I.e., how useful and understandable is the information?) as well as the methods for reaching intended audiences (I.e., how best can we assure that family members have access to this useful information?).

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Friesen, B. J. (1989). Child mental health training in schools of social work: A national survey. *In L. Abramczyck (Ed.), Social work education for working with seriously emotionally disturbed children and adolescents (pp. 62-84). Columbia, SC: South Carolina College of Social Work: National Association of Deans and Directors of Schools of Social Work*

Abstract: This paper focuses on the current preparation of social work personnel at the baccalaureate, masters and doctoral levels of education. It presents the findings from a survey undertaken (Between Dec. 1988 and February 1989) to ascertain the extent to which social work programs currently prepare social work students to work with children with serious emotional problems and their families.

Click here for further information on this publication and others not available from our Center.

Friesen, B. J. (1989). National study of parents whose children have serious emotional disorders: Preliminary findings. *In A. Algarin, R. Friedman, A. Duchnowski, K. Kutash, S. Silver & M. Johnson (Eds.), 2nd annual conference proceedings. Children's mental health services and policy: Building a research base. Tampa, FL: Research and Training Center for Children's Mental H*

Abstract: A presentation of results from the preliminary analysis of data from a study involving parents whose children have serious emotional disorders, based on responses from nearly 1,000 parents from 45 states. There has been virtually no research about the needs and experiences of families whose children have serious emotional disorders. This study was designed to begin to fill this information gap by exploring families' perspectives of their problems, needs and experiences.

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Friesen, B. J. (1986). Interpersonal aspects of administration in social welfare. *Encyclopedia of social work, 18th Edition*