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ABSTRACT

This report describes a national survey of organizations of and for parents of children and adolescents with serious emotional disabilities. The telephone survey located 207 parent organizations of which 26.7 percent were publicly affiliated and 72.9 percent were either private, non-profit, or informally organized. About 54 percent were part of national organizations and 42.5 percent were affiliated with state or local organizations. Organizations were located in all but three states. Almost all (99 percent) of the organizations provided information/education services, parent training (88.9 percent) and advocacy activities (85.5 percent). Most provided direct assistance (79.2 percent) and support groups (63.3 percent). Approximately 95 percent provided services to professionals. Programmatic difficulties identified included involving parents and developing leadership. Most organizations found it easier to establish working relationships with local than with state level agencies. The average age of the organizations was 14.2 years (though 27.1 percent had been established in the 4 years prior to the study). Service delivery issues were identified in the areas of service comprehensiveness, service quantity, interagency coordination, and access to services. Tables and figures detail the findings. Survey forms are appended. (DB)

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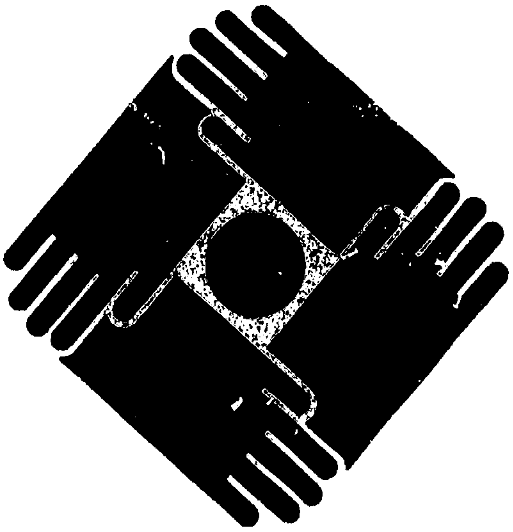

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Organizations for Parents of Children Who Have Serious Emotional Disorders: Report of a National Study

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INTRODUCTION

This report describes a study of organizations of and for parents of children and adolescents with serious emotional disabilities. The study was jointly conducted by the Technical Assistance for Parent Programs (TAPP) and the Research and Training Center on Family Support and Children's Mental Health at Portland State University in Portland, Oregon. This study was conducted from July 1985 to February 1986 and was coordinated by the Research and Training Center.

The primary purpose of the study was to locate and describe organizations of and for parents of children and adolescents with serious emotional disorders. Although family groups and organizations that provide emotional support, information and advocacy serve an important function in many disability groups, little was known about the extent to which families whose children have serious emotional disabilities were separately organized or were included in multi-disability organizations. This information was needed to establish a baseline of current participation, to identify barriers to starting and maintaining parent organizations, and to learn about the technical assistance and information needs of existing groups. Information was gathered about the history of these parent organizations' activities and services, program operation issues, development of training programs and materials, and plans for the future. An immediate, practical use of the data was publication of a national directory, which lists and describes these organizations and their services (Yoakum & Friesen, 1986; Norman & Friesen, 1988).

METHODOLOGY

Definition of Parent Organization

The study focused on parent groups and organizations that provide selected services to parents of children with serious emotional disorders. These services were those often not provided by social service, mental health, or educational agencies, including: (1) **information and education** for parents about topics such as the nature of emotional disorders in children, the rights of children and parents under P.L. 94-142, the Education for All Handicapped Children Act (1975), and referral to other information sources; (2) **parent training services**, including information about coping effectively with their children's needs and behaviors and how to effectively advocate at the case and/or systems level; (3) **advocacy services**, in helping individual families obtain necessary resources and services or promoting system change to improve services for children with disabilities; (4) **parent support groups** emphasizing provision of emotional and tangible support (as distinguished from groups designed mainly to improve parenting ability); (5) **direct assistance**, such as respite care, homemaker services, child care, transportation, food, shelter and financial assistance.

Educational, mental health or social service agencies were expected to provide some of these services to parents and thus qualify for inclusion in the study. Formal service organizations were included if their services: (1) were available to all parents of children with emotional disabilities in their service area; (2) involved an identifiable parent group or entity; and (3) were not restricted to parents who were or would become clients of the agency.

Data Collection Procedures

The data were collected through a two-stage telephone survey process. The first stage involved screening organizations to determine their appropriateness for an interview, gathering names of other organizations to include in the survey, and scheduling the telephone interview. The telephone interview was scheduled with the director or a primary contact person approximately two weeks after the screening call. In the two weeks before the interview, potential respondents received a letter explaining the survey and a copy of the interview guide. Through this process, 207 parent organizations were identified and surveyed. All organizations identified were included in the study to obtain as much information as possible regarding the extent of involvement by parents of children with emotional disabilities. Copies of letters to organizations, telephone screening instruments, interview guide and other related survey materials are included in the Appendix.

At the time of the study, the Technical Assistance to Parent Programs (TAPP) Project was organized into four regions in the United States. Screening calls and telephone interviews were conducted by personnel from three of the four TAPP regional centers. Research and Training Center staff conducted most of the screening and telephone interviews in the Northeast region.

ANALYSIS

Auspice

This category includes parent organizations' affiliations, form of government and funding sources. Fifty-five parent organizations (26.7 percent) described themselves as publicly funded or affiliated and 151 (72.9 percent) reported that they were either private, non-profit, or not formally constituted as an organization. Eighty-eight percent of the organizations stated that they had a policy-making board.

Of the 207 parent organizations in the study, 111 (53.6 percent) were part of a national organization and 88 (42.5 percent) were affiliated with state or local organizations. Twenty-six groups did not identify themselves as part of a national, state, or local organization but were affiliated with other organizations such as churches, school systems, the U.S. Army, United Way, local coalitions and child advocacy groups. Table 1 displays the most frequently reported national and state affiliations. At both the state and national level, Mental Health Associations were the most frequently mentioned.

Table 1

ORGANIZATIONAL AFFILIATIONS OF PARENT ORGANIZATIONS

National Organization	N	%
National Mental Health Association	38	35.2
Technical Assistance for Parent Programs	20	18.5
National Association for Protection and Advocacy	11	10.2
National Alliance for the Mentally Ill	8	7.4
Association for Children with Learning Disabilities	6	5.6
National Association of Retarded Citizens	6	5.6
National Parent Chain	5	4.6
National Council Community Mental Health Centers	4	4.6
(Separate Organizations mentioned once or twice)	10	9.2
Total	108	100.0

State	N	%
Mental Health Association	25	41.0
"This is the state organization"	18	29.5
Association of Retarded Citizens	5	8.2
Alliance for the Mentally Ill	3	4.9
State Mental Health Dept.	3	4.9
Association for Children with Learning Disabilities	3	4.9
State Council Community Mental Health Centers	2	3.3
United Cerebral Palsy Association	2	3.3
Total	61	100.0

Funding

Respondents were asked to list the three major sources of funding for their organizations. Figure 1 reflects the responses and major categories of funding. Many organizations depended on several sources of revenue. Over half (53.1 percent) received some revenue from individual donations; the second largest source was state contracts or grants (49.3 percent). Federal grants comprised the third most frequent funding source (45.9 percent). Seventy organizations (33.8 percent) had membership fees and 46 (22.2 percent) charged a fee for service. About one-quarter of the organizations reported foundations as one of the most important sources of support; cities, counties and private organizations also provided funding through grants and contracts. Some important resources listed by parent organizations and contained in the "other" category include United Way (18.4 percent), fundraising (3.4 percent), and sources such as school districts or special events.

Geographic Area Served

Parent organizations were located in all but three states and served widely varying geographic areas as illustrated in Figure 2. The geographic domain of these organizations ranged from a single city (21 organizations, or 10.1 percent) to nationwide (one organization). Eighty-four organizations (40.6 percent) provided statewide services within a single state. Slightly more than 20 percent served single counties and a similar percentage served a region within a state (two or more communities or counties). Four organizations (1.9 percent) reported serving several states and the one organization claimed a national service area through distribution of written materials.

Population Focus

Another question examined the extent to which organizations provided services exclusively to parents of children with emotional disorders, or to those with all types of disability. Sixty (29.0 percent) of the 207 organizations exclusively focused on emotional disorders and did not include other disabilities. Only nine organizations (4.3 percent) specifically served parents of children with emotional disorders. Services were provided only to parents with children under age 21 and addressed only mental or emotional disabilities. Those organizations serving families of children with a wide range of disabilities (71.0 percent) tended to have developed in response to P.L. 94-142 (Education for All Handicapped Children Act) and maintained an emphasis on the public schools and special education services.

The distribution of disabilities addressed by the responding organizations is displayed in Figure 3. By definition, all parent organizations (100 percent) in the study provided at least some service to families whose children had serious emotional disorders. After emotional disorders, the childhood disabilities addressed by the greatest number of organizations were mental retardation/developmental disabilities (65 percent) and learning disabilities (64 percent). Other disabilities addressed by 55

Figure 1.
Sources of Funding for Parent Organizations
(Top Three Sources Listed by Each)

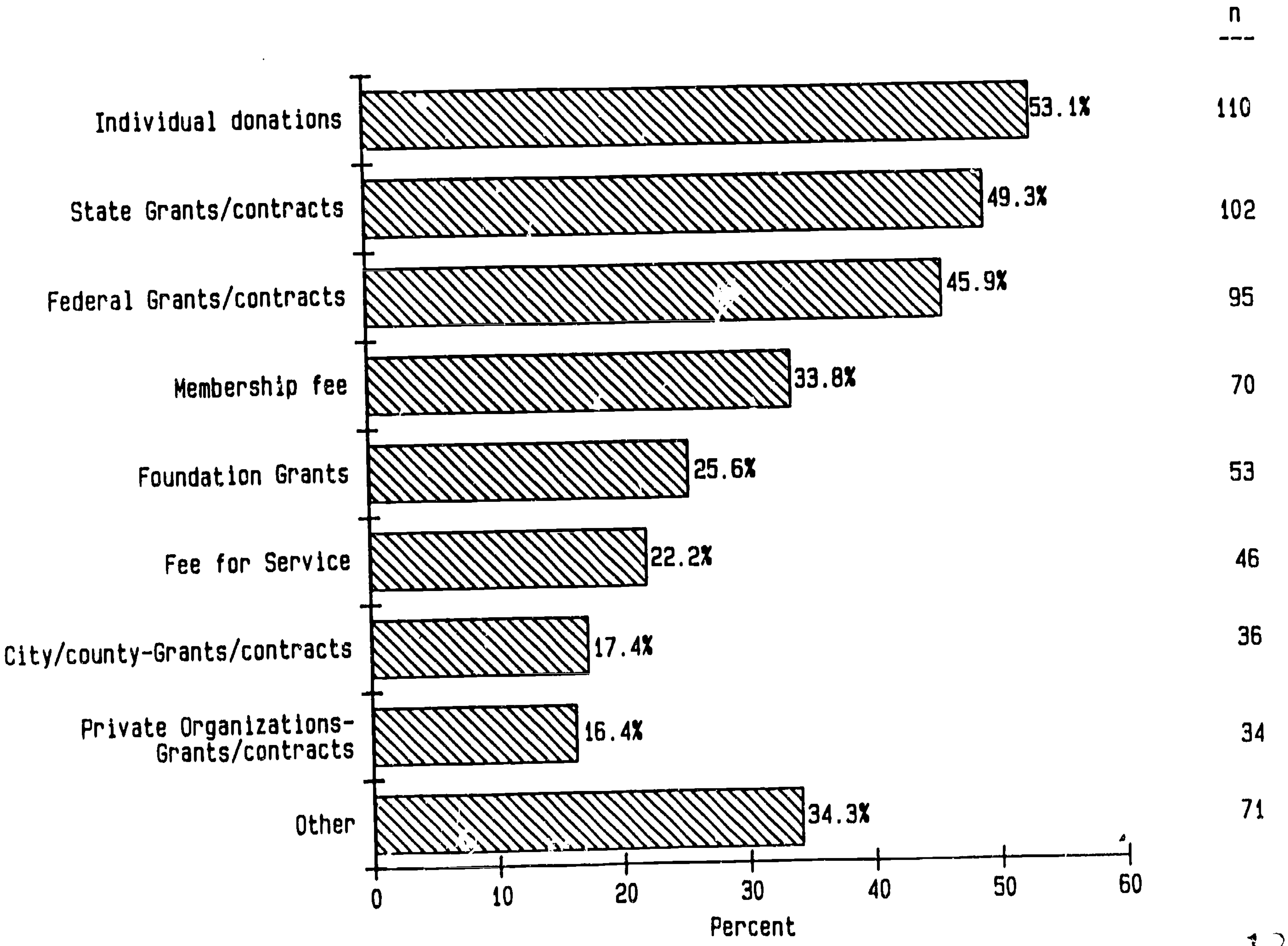


Figure 2.
Geographic Area Served By Parent Organizations

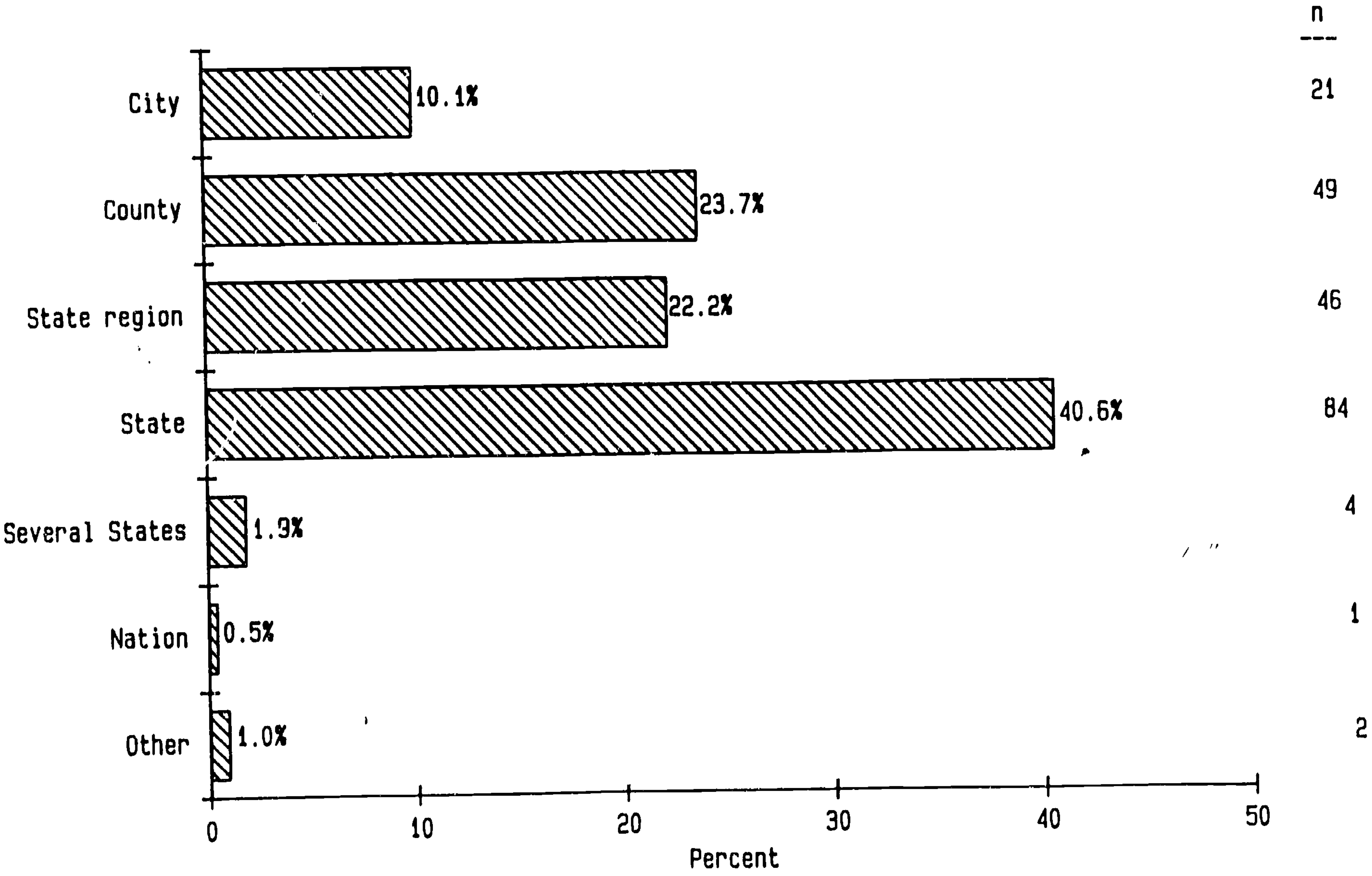
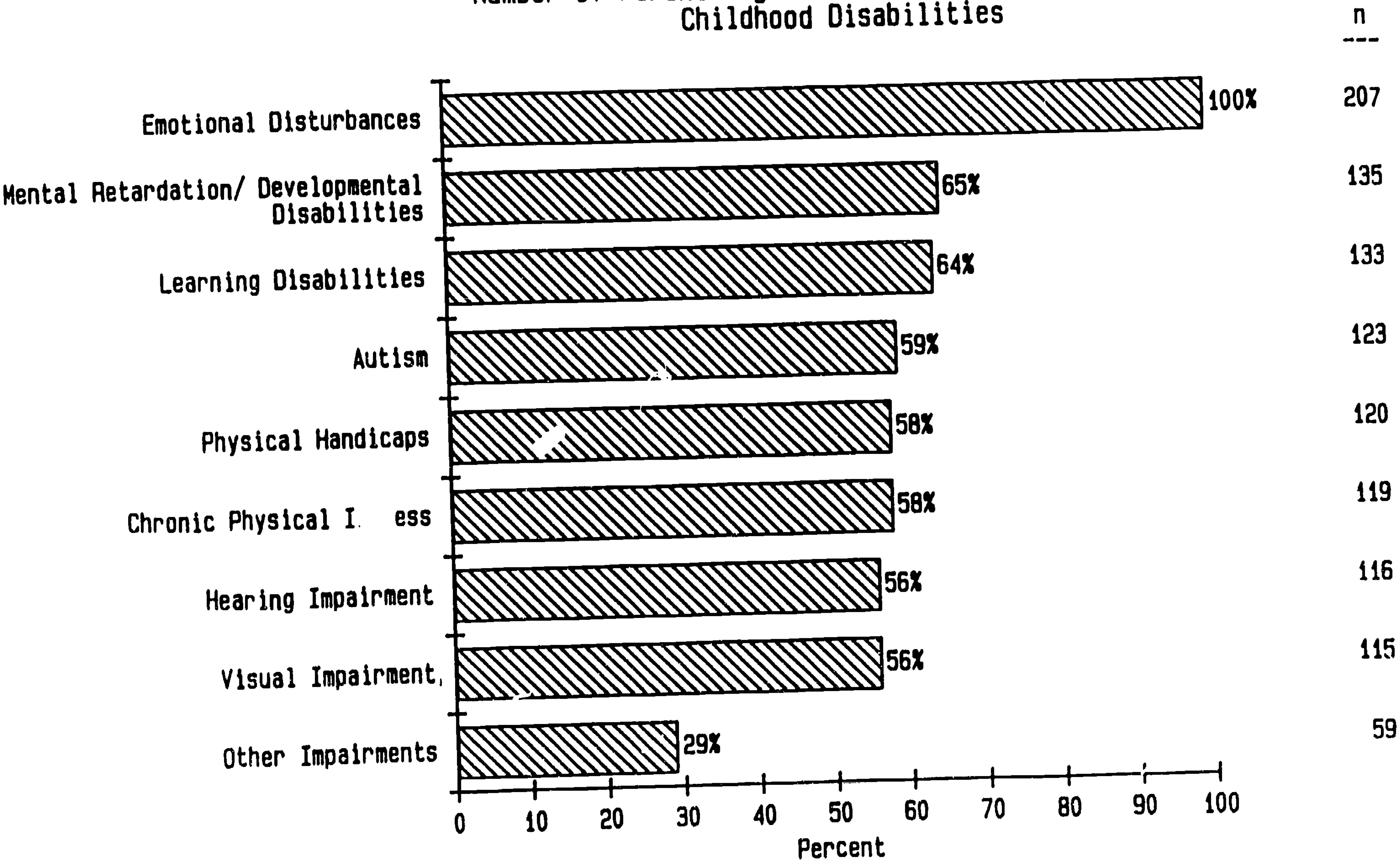


Figure 3.
Number of Parent Organizations Addressing Specific Childhood Disabilities



to 60 percent of organizations surveyed were autism, physical handicaps, chronic physical illnesses, and hearing and visual impairments. Twenty-nine percent of the organizations either addressed all disabilities or other populations such as children who have been abused, are gifted, or have speech impairments.

Figure 3 displays the number of parent organizations that provided any service to families whose children had serious emotional disorders, but does not give information about the relative emphasis given to these families. To gain this information, respondents from each parent organization were asked to estimate the percentage of parents of children with serious emotional disorders within the total number of parents served. These estimates are displayed in Table 2. The population served by 35 percent of the organizations (N=73) consisted of 10% or fewer families of children with serious emotional disorders. Only 8.2 percent of the organizations (N=17) served these families exclusively. Eight of these 17 organizations included families of children who were no longer minors. Thirty-seven organizations (17.9 percent) were unable to estimate the percentage of services provided to parents of children with emotional problems.

The number of parents served and the primary type of service varied widely among parent organizations. As shown in Table 3, the number of parents served ranged from zero to over 5,000 per year in each service category: (1) face to face services, (2) information and referral, and (3) mailed written material. More than 65 percent of the organizations (N=136) published a newsletter or bulletin.

Goals

Organizations were asked to describe their original goals or purposes. Within ide range of responses, the strongest emphases were on community education, pare education and training, support, advocacy, and information. When asked about changes in goals over time, most organizations had not changed their primary service goals but had increased the number of clients served or number of services provided within a particular service area.

Services Provided to Parents

Respondents were asked a series of questions about five major types of services: (1) information/education regarding disorders, referrals and rights of parents and children; (2) parent training including coping and advocacy; (3) advocacy activities on the case or systems level; (4) support group sponsorship; and (5) direct assistance, such as respite care, child care, transportation or homemaker services. The responses to these questions are summarized in Table 4.

Information/Education. All but two parent organizations provided some type of information or educational service to parents. These services include information about emotional disorders (78.8 percent), referrals to other sources of information or services (95.7 percent), and information about the rights, under P.L. 94-142, of children

Table 2

PARENTS OF CHILDREN WITH EMOTIONAL DISABILITIES AS A PERCENTAGE OF TOTAL NUMBER OF PARENTS SERVED

Percent of Parents Served Whose Children have Serious Emotional Disabilities	Number of Organizations	
	N	%
1-10%	73	35.3
11-20%	26	12.6
21-30%	14	6.8
31-40%	10	4.8
41-50%	8	3.9
51-60%	5	2.4
61-70%	2	1.0
71-80%	6	2.9
81-90%	8	3.9
91-99%	1	0.5
100%	17	8.2
Don't Know	37	17.9
TOTAL	207	100.0

Table 3

NUMBER OF ORGANIZATIONS PROVIDING DIRECT SERVICE TO PARENTS BY SERVICE TYPE

	Number of Organizations Providing Service to Parents in Each Category						
<u>Type of Service</u>	<u>None</u>	<u>1-50</u>	51 <u>to 100</u>	101 <u>to 500</u>	501 <u>to 1000</u>	1001 <u>to 5000</u>	Over <u>5000</u>
Face-to-Face Service (Support Groups, workshops, etc.)	27	32	19	74	27	22	6
Information and Referral	46	23	11	63	31	31	2
Mailed Written Materials (newsletters, brochures)	69	14	7	50	19	39	9

Table 4

NUMBER AND TYPES OF SERVICES PROVIDED TO PARENTS
N=207

Services Provided	N	%	Total	%
Information/Education			205	99.0
Information regarding emotional disorders of children	159	76.8		
Referrals to other sources of information	198	95.7		
Information about the rights of children and parents under P.L. 94-142	162	78.3		
Parent Training			184	88.9
How to cope effectively with the needs of children and adolescents with emotional disorders	123	59.4		
How to be effective case advocates for their own children	139	67.1		
How to be effective systems advocates	111	53.6		
Advocacy Activities			177	85.5
Case advocacy--help individual families of children with emotional disturbances get needed services	150	72.5		
Systems advocacy--work to improve services for all children with emotional disabilities	145	70.0		
Support Groups			131	63.3
Focus on issues regarding children's needs and behavior (emotional disorders only)	52	25.1		
Focus on issues regarding children's needs and behavior (all disabilities)	78	37.7		
Emphasize parents' needs and issues (emotional disorders only)	56	27.1		
Emphasize parents' needs and issues (all disabilities)	82	39.6		
Direct Assistance			164	79.2
Assistance to parents in dealing with service agencies or the public schools	143	69.1		
Respite care	21	10.1		
Homemaker service	8	3.9		
Child care	25	12.1		
Food, shelter, money	14	6.8		
Transportation	22	10.6		

with serious emotional disabilities and their families (78.3 percent). Other types of services mentioned were library services, workshops on specific topics, financial assistance information, and parent networking.

Parent Training. These questions addressed the specific types of parent training offered. Respondents were asked about provision of training in three areas: (1) coping with the needs of children and adolescents who have emotional disabilities; (2) effective case advocacy for children; and (3) effective systems advocacy. Eighty-nine percent of the organizations (N=184) provided some type of parent training. Of those, 123 organizations (59.4 percent) trained parents to cope effectively with their children's needs, 139 groups (67.0 percent) taught parents effective case advocacy for their children, and 111 organizations (53.6 percent) taught parents systems advocacy to improve services for children and adolescents with serious mental or emotional problems.

The responding organizations also provided training in other areas, such as information about P.L. 94-142, Individual Education Plans (IEP), positive parenting and a variety of other topics. Some organizations offered in-home training to parents.

Advocacy. For the purpose of the survey, advocacy was defined as activity directed toward obtaining needed services from existing resources and/or attempting to improve the service system for children with emotional disorders. Thirty of the 207 organizations surveyed (14.5 percent) did not engage in advocacy activities. However, these results must be interpreted with caution because of organizations' reluctance to report advocacy activity for fear that federal funding could be withdrawn. Of the 177 organizations that reported advocacy activity, 150 (85.0 percent) stated that their efforts were directed toward case advocacy to assist individual families in obtaining needed services; 145 (82.0 percent) engaged in system change efforts to improve services for all children and youth with emotional disorders.

Support Groups. Interview questions concerning support groups were designed to determine whether the primary focus was on the needs of the children, parents, or the entire family. These survey questions also sought to identify the extent to which support groups exclusively addressed emotional disorders.

Nearly two thirds (63.0 percent) of the organizations reported sponsoring or providing support groups available to parents of children with emotional disabilities. Only 52 organizations (25.0 percent), however, reported providing support groups that exclusively focused on issues concerning emotional disorders in children. Fifty-six organizations (27.0 percent) characterized their support groups as focusing on the needs of parents of children with serious emotional disabilities.

Direct Assistance. Direct assistance refers to specific one-on-one services provided to individual parents. Seventy-nine percent of the parent organizations reported that they provided some direct assistance to parents. The most frequently provided direct service (69.0 percent) was assistance in dealing with service agencies or public schools, such as accompanying parents to IEP conferences. Other forms of direct service included: respite care (21 organizations), homemaker services (eight organizations), assistance with child care (25 organizations), assistance with food, money, or shelter (14 organizations), and transportation (22 organizations). Some organizations also reported providing scholarships for parents to attend seminars or training, counseling, funds for legal services, and in-home crisis intervention.

Services Provided to Professionals

The survey also examined the extent to which parent organizations provided training or other services for professionals. As displayed in Figure 4, only 11 of 207 organizations stated that no services were provided to professionals (i.e., almost ninety-five percent of the organizations surveyed provided some service designed for professionals). Approximately 72 percent (149 organizations) provided information to professionals about the needs of families whose children have serious emotional disorders. Approximately two-thirds of the organizations listed specific topics for professional training. Seventy-two percent of the organizations also offer services to improve the working relationship between family members and professionals.

Program Operation

To identify program operation issues that might be problematic for parent organizations, respondents were asked to estimate their level of difficulty in dealing with a number of specific issues. These issues included parent recruitment and participation, program development and delivery, and acquisition of necessary program resources. The results are graphically displayed in Figure 5.

Certain program operation issues regarding parent participation presented a substantial challenge for many parent organizations. Respondents from more than half of the organizations reported that locating parents in need was very easy or easy; only 12.8 percent saw these issues as presenting any difficulty. However, parents were apparently more difficult to involve, with 21.7 percent of respondents reporting getting parents to participate in one-to-one settings as difficult or very difficult and 34 percent indicating the same level of difficulty with involving parents in groups.

Developing leadership also appears to be an important issue. Nearly 37 percent of respondents reported difficulty in helping parents build the skill and confidence to assume leadership roles; fewer than 20 percent suggested that this task was easy or very easy.

Developing the programmatic aspects of the organization appeared to present less difficulty. Very few respondents (1.4 percent) reported difficulty in finding topics of interest to parents and only 11 percent identified development of appropriate training and educational programs as difficult. Locating services and information for parents was considered difficult or very difficult by approximately 20 percent of respondents. However, almost half of the organizations found this task to be easy or very easy.

Figure 4.
Services Offered by Parent Organizations to Professionals/Agencies

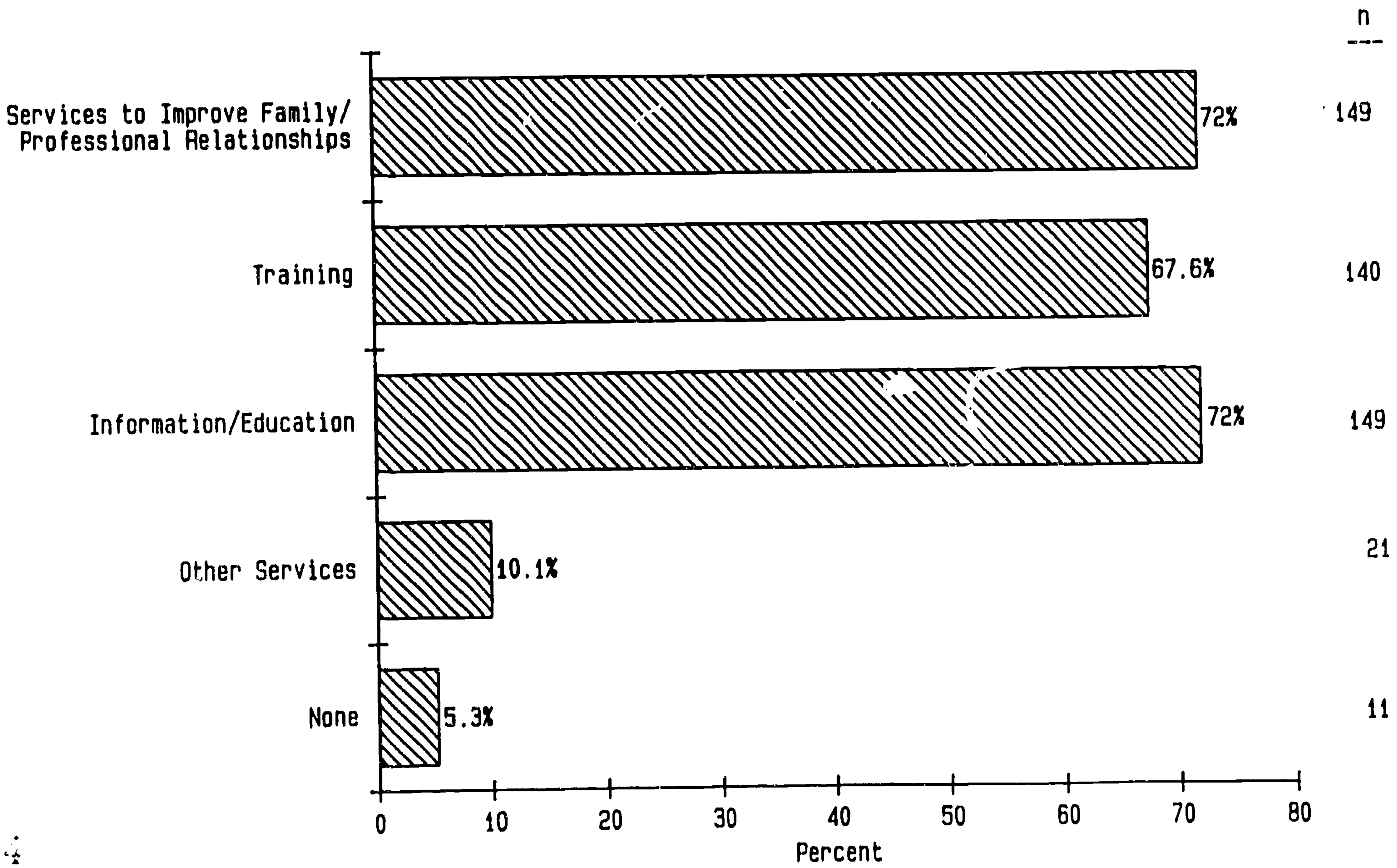
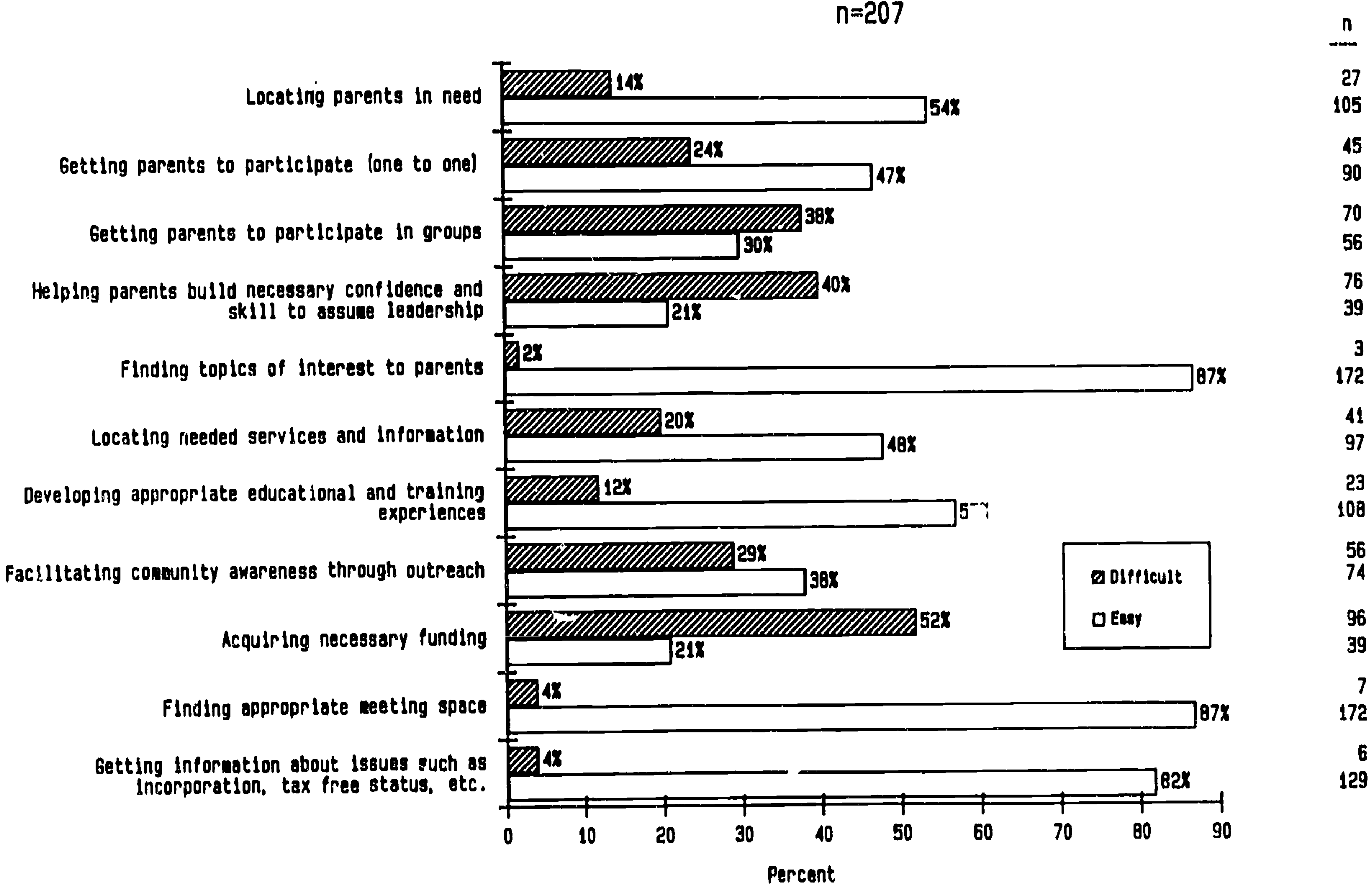


Figure 5.
Program Issues: Estimates of Ease or Difficulty
n=207



Estimates were fairly evenly distributed across response categories regarding the difficulty of effective outreach to facilitate community awareness.

Funding was the organizational issue identified as difficult by the greatest number of respondents (46.4 percent). This finding is not surprising, given the number of parent organizations whose funding came from multiple, temporary sources.

Two other program resource issues appeared to be difficult for only a few organizations: locating appropriate space for meetings and obtaining information about the technical aspects of forming and maintaining an organization.

Relationships with Other Local or State Organizations

Respondents' estimates of the difficulty in establishing working relationships with a number of local and state organizations are summarized in Figure 6. These data reveal a clear pattern; in every case, working relationships were considered easier to establish with local agencies than their state system equivalents. This pattern is even more pronounced when non-responses are considered. In many instances, respondents did not make an estimate when an effort had not been made to establish a working relationship; existing relationships were reported with local agencies but not at the state level.

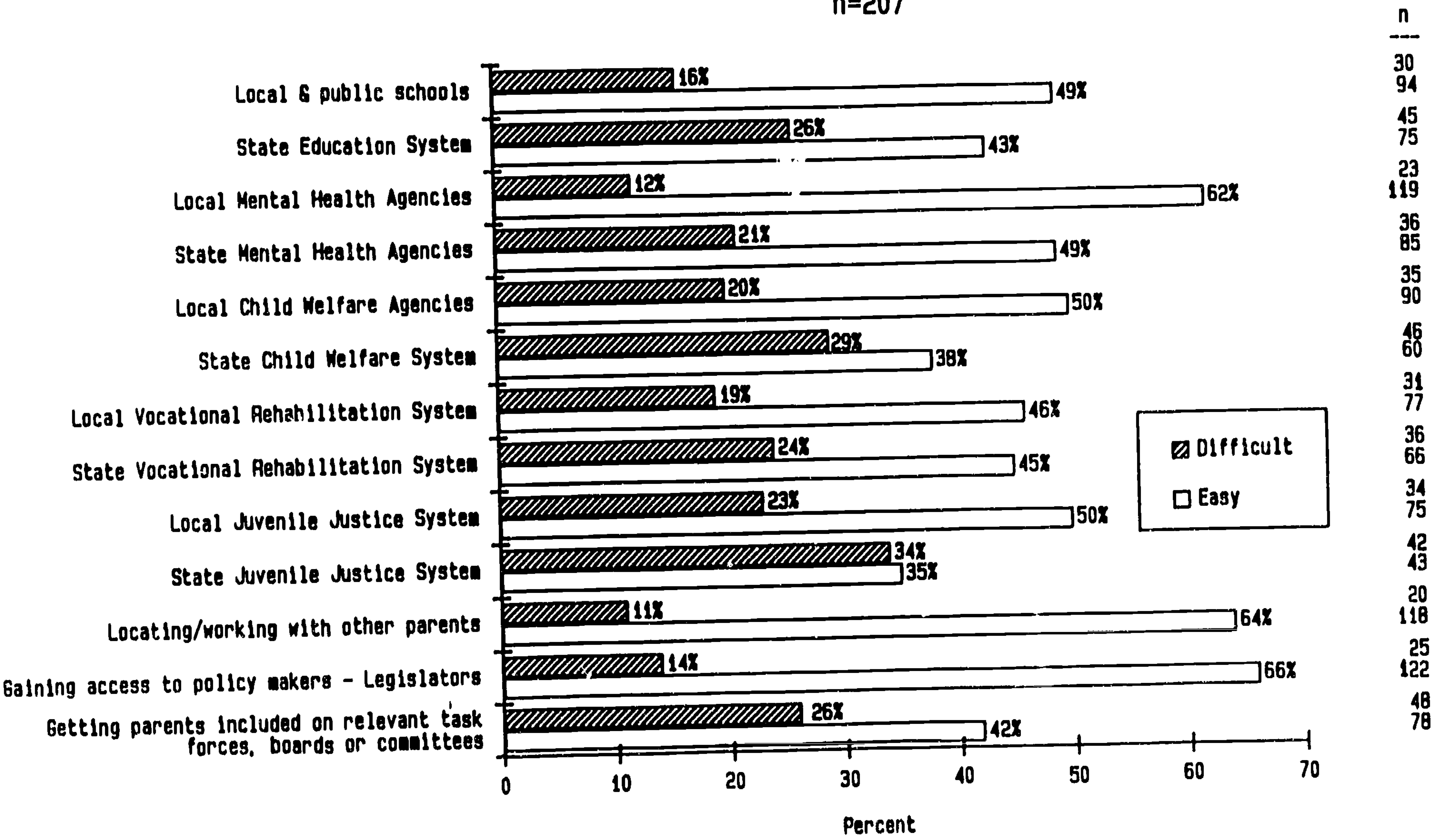
The mean estimates for each category are all at or below the midpoint of the scale, suggesting that working relationships with external agencies and organizations were seen as relatively easy to establish. However, this averaging approach ignores important differences among systems. For example, local mental health agencies constitute the only portion of the formal service system for which working relationships were considered easy or very easy to establish, as reported by more than 50 percent of respondents. Between 40 and 50 percent of respondents indicated ease in developing relationships with local and public schools, the state mental health system, and local child welfare agencies. Three state systems were identified by more than 20 percent of respondents as difficult or very difficult: education, child welfare, and juvenile justice.

Locating and working with other parent organizations and gaining access to legislators and policy-makers, were reported as easy or very easy to accomplish by more than 50 percent of respondents. Nearly 40 percent of respondents reported ease in including parents on relevant task forces, boards and other committees.

Stage of Development

The organizations surveyed have been in existence for varying amounts of time. Although the average age of the organizations was 14.2 years, 27.1 percent (56 organizations) had been established in the four years prior to the study. More than

Figure 6.
Estimates of Ease or Difficulty of Establishing Relationships with Other Organizations
n=207



half of the organizations were established in the ten years prior to the study (1975-1985). One organization began as an orphanage more than 100 years ago and evolved to its present state.

Respondents were also asked to estimate the stage of development achieved by their organization. Figure 7 indicates that approximately 85 percent of respondents characterized their organizations as either "middle moving" (61 or 29.5 percent) or "advanced" (116, 56.0 percent). Thus, fewer than ten percent of the parent organizations were described as in the beginning stage of development and in need of accomplishing initial organizing work.

Most organizations were also perceived by respondents as relatively healthy; only nine organizations (4.3 percent) were characterized as having lost enthusiasm, even before reaching all of their goals.

Future Plans

In order to obtain a preliminary view of the training and information needs of participating organizations, questions were posed regarding the future plans of the organizations. Respondents were asked to identify their priorities if existing programs could be expanded and/or new service areas could be included in their organization. Respondents were asked to select their three highest priorities from the list of choices displayed in Table 5. The two priorities identified most often were education/information services (109 organizations) and parent training (102 organizations). Four other areas were chosen by 60 or more of the organizations: (1) advocacy; (2) support groups for parents; (3) services to improve parent-professional relationships; and (4) direct assistance to parents.

Respondents were also asked to choose *the* highest priority area for future expansion. As seen in Table 6, the top five choices all involved services for parents: advocacy (19.2 percent), parent training (17.7 percent), direct assistance to parents (15.3 percent), parent education/information services (14.8 percent), and support groups (9.9 percent). Services to professionals were given highest priority by 3.9 percent of the organizations and 7.9 percent of all respondents gave highest priority to activities aimed at improving parent-professional relationships.

Service Delivery System Issues

Respondents were also asked to give their reactions to a number of statements about the service delivery system for children and youth with emotional disabilities. The statements dealt with issues such as the range and number of services, cooperation between agencies, degree of difficulty in finding and accessing services, and geographic accessibility and family income (see Table 7).

Figure 7.
Estimate of Organizational Stage of Development

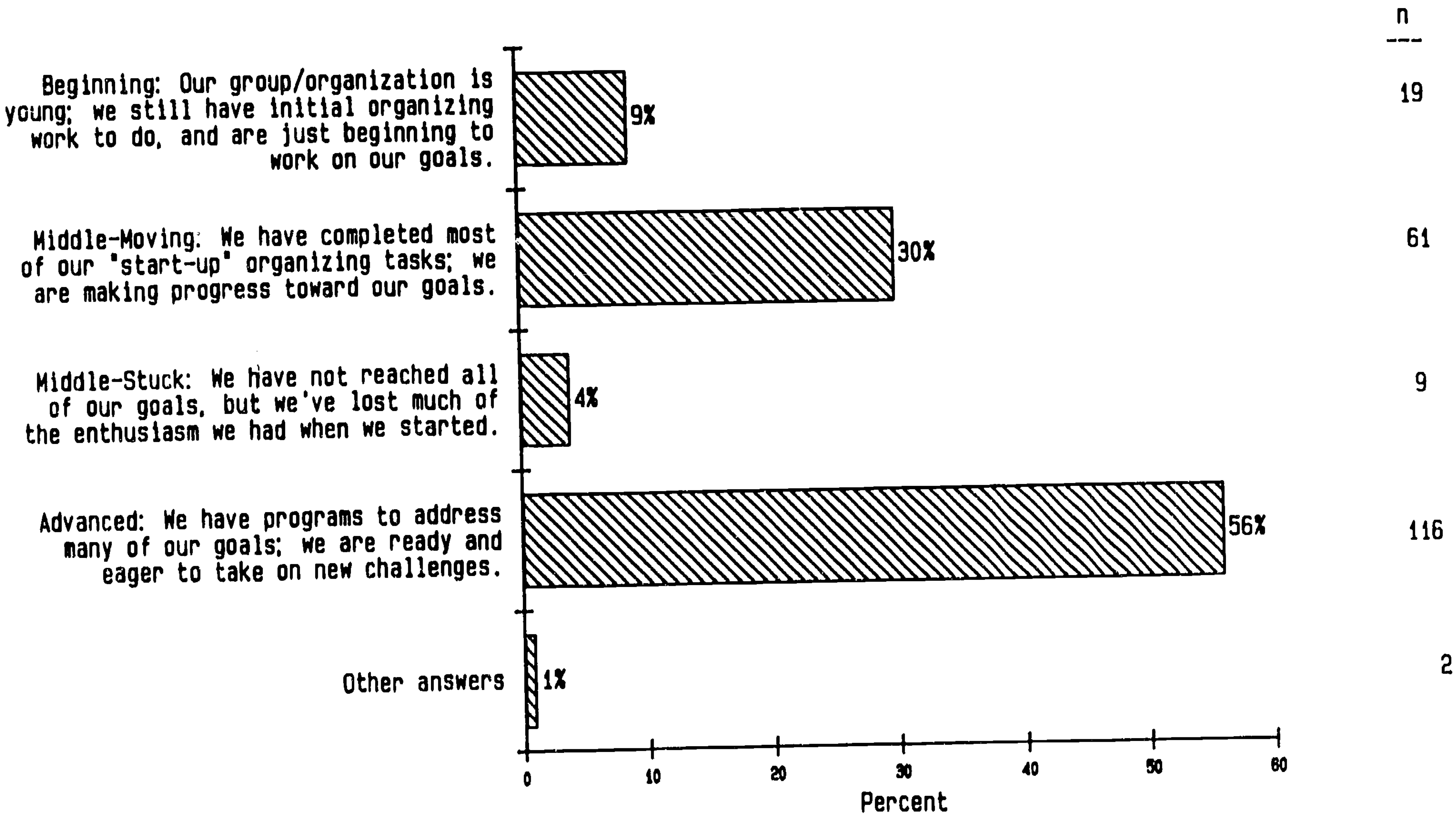


Table 5

AREAS OF DESIRED PROGRAM EXPANSION
(as one of three choices)

	N
Education/information services	109
Parent training	102
Advocacy	84
Support groups	70
Direct assistance	61
Counseling for parents	44
Services for professionals	29
Services to improve parent/professionals relationship	63

Table 6

AREAS OF DESIRED PROGRAM EXPANSION
(first priority only)

Future Service Area	N	Percent
Education/information	30	14.8
Parent training	36	17.7
Advocacy	39	19.2
Support groups	20	9.9
Direct assistance	31	15.3
Counseling for parents	7	3.4
Services to professionals	8	3.9
Services to improve family/ professional relationships	16	7.9
Other	16	7.9
TOTAL	203	100.0

Table 7

ORGANIZATIONAL RATINGS OF SERVICE DELIVERY ISSUES IN THEIR GEOGRAPHIC AREA

N=207

	1 Very True		2 True		3 Neither True nor False		4 False		5 Very False		
	N	(%)	N	(%)	N	(%)	N	(%)	N	(%)	Mean
A full range of service to meet the needs of children and their families is available.	8	(3.9)	22	(10.6)	44	(21.3)	58	(28.0)	72	(34.8)	3.8
There are not enough services for all the children who need them	132	(63.8)	36	(17.4)	20	(9.7)	7	(3.4)	8	(3.9)	1.6
Various agencies that serve "emotionally disturbed" children(e.g., mental health, welfare, schools) work well together	11	(5.3)	35	(16.9)	63	(30.4)	44	(21.3)	50	(24.2)	3.4
Services are difficult to find: it is not easy for a child of a family to get accepted for service	57	(27.5)	56	(27.1)	52	(25.1)	29	(14.0)	10	(4.8)	2.4
Services are available to children and their families no matter where they live	17	(8.2)	12	(5.8)	17	(8.2)	58	(28.0)	96	(46.4)	4.0
Low income or lack of insurance prevents some families from obtaining services for their children with serious emotional handicaps.	104	(50.2)	41	(19.8)	26	(12.6)	17	(8.2)	13	(6.3)	2.0

Service Comprehensiveness. A large percentage of respondents believed that comprehensive services were not available. Fewer than 15 percent of respondents stated that it was true or very true that a full range of services is available to meet the needs of children and their families. Conversely, 62.8 percent of respondents disagreed with this statement, reporting that it was false or very false.

Service Quantity. An even larger percentage of respondents (81.2) believed that there are not enough services for all children in need. Only 7.3 percent of respondents considered existing services to be sufficient in addressing the needs of these children.

Interagency Coordination. Slightly more than one-fifth of respondents were of the opinion that the various agencies worked well together in serving children with emotional disorders. Approximately twice as many respondents (45.5 percent) stated that agencies did not work well together and another 30 percent said that this statement was neither true nor false.

Access to Services. More than half of the respondents (54.6 percent) agreed that services are *hard to find*, while nearly twenty percent disagreed with this statement. Issues of *geographical inaccessibility* were also considered important by a large number of respondents. Nearly three-quarters of the respondents disagreed with the statement that "services are available to children and their families no matter where they live." Thus, there appears to be widespread agreement that geographical barriers and maldistribution of services creates a very uneven system of care for his population. Seventy percent of the respondents also agreed that *low income or lack of insurance* prevents some families from obtaining services for their children.

Needed Improvements in Specific Services. Respondents were also asked about the number and quality of existing services. The questions addressed the extent to which the supply of services is adequate in various service areas and improvements needed in existing services. The responses are displayed in Table 8.

More than 50 percent of respondents in each area felt that the numbers of services needed to be increased. Respite care was seen as the service that was most needed, with 180 of 195 respondents (92.3 percent) wanting to increase availability of these services. Twelve respondents indicated that respite care was non-existent in their area or state. Many respondents (81.2 percent) also indicated a great need for expanding transitional services.

In all service areas, at least some of the respondents indicated a need for improvement in the quality of existing services. The greatest number of respondents (71.8 percent) identified improvements needed in public school educational programs.

An interesting contrast was found in respite care programs. Although most respondents thought that services needed to be expanded, existing respite care services were viewed by very few respondents as needing improvement in quality.

Table 8

NEEDED IMPROVEMENTS IN THE SERVICE DELIVERY SYSTEM
N=207

	Increase the Number of Services		Improve the Quality of Services	
	N	(%)	N	(%)
Outpatient treatment (psychological/ psychiatric) for affected children	155	(79.5)	132	(67.7)
Outpatient treatment for family members	148	(76.3)	129	(66.5)
Residential program for "ED" children	138	(73.8)	109	(58.3)
Treatment programs/ residential settings	116	(63.4)	110	(60.1)
Educational programs in residential settings	102	(59.6)	100	(58.5)
Educational programs in public schools	132	(67.7)	140	(71.8)
Respite care	180	(92.3)	77	(39.5)
Information and advice for parents	146	(75.6)	105	(54.4)
Transitional services; from residential to family settings (home/foster care)	155	(81.2)	120	(62.8)
Transitional services; from school to work and/or community living	164	(84.1)	122	(62.6)
Vocational services	151	(76.3)	124	(62.6)
Day treatment	147	(78.6)	99	(52.9)
Diagnostic services	103	(57.2)	104	(57.8)
Crisis services	151	(80.7)	107	(57.2)
Recreation/leisure programs	151	(81.2)	91	(48.9)
Life survival skills	147	(79.9)	97	(52.7)

Respondents' comments encompassed many aspects of services in their geographic area. No fewer than six respondents in each service area listed in Table 8 commented that they did not know about the availability or quality of existing services. Some respondents stated that residential care was so limited or nonexistent that children and adolescents with serious emotional disorders were placed out of state; these respondents identified a need for more residential services.

Conversely, other respondents were not in favor of residential treatment and indicated that more community-based services were needed. Several commented that more community-based services for families would prevent residential placement for their children.

Other comments addressed the need for respite care, recreational programs, and life survival skills.

CONCLUSION

This survey was conducted to locate and describe parent organizations of and for parents of children and adolescents with serious emotional disorders. It is the first study of its kind, providing a picture of the functions of parent organizations, the services provided, and perceptions of service needs and future plans for parent organizations. The data regarding the types of services provided and the number of clients served help to describe the current availability of services to parents of children and adolescents with serious emotional disabilities.

The 207 parent organizations surveyed provided a wide variety of services, with most offering general services such as referrals to other agencies and information about emotional disorders in children. As services become more specific, individualized, and costly, fewer organizations provided them. For example, respite care and financial assistance were provided by fewer than ten percent of the organizations.

The study data also suggests the need for professionals to gain greater understanding of emotional disorders and greater accessibility for families to professional services.

Respondents considered existing services to be inadequate in each specific service area in meeting the needs of the client population; certain services were non-existent in many geographic areas. Even when services were available, access was limited by factors such as parents' lack of knowledge, transportation, financial resources, and geographic or other barriers.

A directory of the parent organizations (Norman and Friesen, 1988) lists each participating organization and the services it provides. It is updated on a regular basis through our Resource Service.

REFERENCES

Norman, L.K. and Friesen, B.J. (1988). *National Directory of Organizations Serving Parents of Children and Youth with Emotional and Behavioral Disorders, 2nd Edition.* Portland, OR: Portland State University Research and Training Center on Family Support and Children's Mental Health.

Yoakum, K.S. and Friesen, B.J. (1986). *National Director of Organizations Serving Parents of Seriously Emotionally Handicapped Children and Youth.* Portland, OR: Portland State University Research and Training center on Family Support and Children's Mental Health.

APPENDIX

Families as Allies: Parent Organization Survey

Survey of Organizations of and for Families of Children and Adolescents with Serious Emotional Handicaps: Instructions for Interviewers

Screening Interview Guide

Parent Organization Screening Form

Parent Organization Survey: Telephone Interview Appointment Form

Sample Letter to Parent Organizations

Parent Organization Telephone Interview

Parent Organization Survey Worksheet

FAMILIES AS ALLIES
Parent Organization Survey

Description:

A national survey of organizations of and for parents of seriously emotionally handicapped children and youth conducted during the months of July-November, 1985.

Purpose of the Families as Allies Project:

To promote collaboration between service providers and families of children and adolescents who are seriously emotionally disturbed.

Purposes of the Study:

- To locate and describe organizations throughout the country that provide education, support, training, advocacy, and other services to families of seriously emotionally disturbed children.
- To gather information about program operation issues faced by parent groups.
- To describe aspects of the relationship between parent organizations and agencies, schools, and other parts of the child-serving system.
- To gather impressions about needs, resources, and the current service delivery system for children with serious emotional handicaps from the perspective of parent organizations.

Study Method:

A two stage telephone survey designed to (1) locate and screen potential respondent organizations, and (2) conduct extensive telephone interviews with representatives of participating organizations.

Study Products:

- A national directory of organizations for families of seriously emotionally disturbed children and youth. Published and distributed throughout the U.S. during fall, 1985.
- Research reports and working papers.

For further information, contact:

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October, 1985

SCREENING INTERVIEW GUIDE:

Organizations of/for Parents of
Seriously Emotionally Handicapped Children and Adolescents

INTRODUCTION: (Something like the following):

Hello, my name is _________. I'm calling from (city) , from the (name of Regional TAPP Center). We are calling organizations that provide services to parents of children and adolescents with emotional handicaps. I'd like to speak with your Director, or another person who can give me information about your organization.

(To Director, or other contact person):

My name is ________, and I'm calling from (Regional TAPP office) in (city). We are interested in locating parent groups or other organizations that serve parents of emotionally handicapped *children and adolescents.* We want to include as many parent organizations as possible in a national directory we are putting together. By emotionally handicapped, we mean for example, children who have been identified as seriously emotionally disturbed by the public schools, or who have been diagnosed as mentally or emotionally ill by a mental health agency. *(We do not intend to include organizations that exclusively serve parents of autistic children).*

I am interested in finding out whether your organization serves parents of emotionally handicapped children, and if you know of other organizations that do. Can you give me a few minutes?

1. Do you (does your organization) provide any of the following services to parents of *children and adolescents* with emotional handicaps? (RECORD ON PARENT ORGANIZATION SCREENING FORM)

2. (IF NO, GO TO QUESTION 3): IF YES:

   The directory I mentioned will include information about organizations such as yours from across the country.

   If you are willing, I'd like to schedule a time when we could talk further by phone. We are interested in the history of your organization, more about the services you provide, your funding, and other such questions. This should take about 30-40 minutes. What time would be convenient for you? (SCHEDULE INTERVIEW ON PARENT ORGANIZATION SCREENING FORM)

   We will send you a copy of the questionnaire so that you can look over the questions before the interview.

3. Can you suggest other parent groups or organizations that provide information, support, or other services to parents of children or adolescents with emotional handicaps? (RECORD ON PARENT ORGANIZATION SCREENING FORM). May I use your name when I call the groups you have suggested?

   Thank you very much for your help. Let me give you my address and phone number). If you think of any other parent organizations that should be included in our directory, please let me know.

Thanks again!

PARENT ORGANIZATION SCREENING FORM

Region_________	Interview Scheduled: Y N-NA* N-R**
Interviewer:______________	(*NA=Not Appropriate; **R=Refused)
Length of call:___________	Interview Date:__________Time_______
Date this Call___________	Letter Sent (Date): _______________

1. NAME OF ORGANIZATION____________________________________
2. ADDRESS____
   (Street or P.O. Box) (City) (State) (Zipcode)
3. TELEPHONE: (____) __________________ (____) _______________
4. NAME OF DIRECTOR, PRESIDENT, ETC.:__________________________
5. CONTACT PERSON: ____
6. SERVICES PROVIDED: [Corresponds to Question 1 on Screening Guide]
   - a. Information about emotional disturbance of children. Y N
   - b. Training re: emotional disturbance and related topics. Y N
   - c. Referrals to other sources of information and/or services. Y N
   - d. Case advocacy; help individual families get needed services. Y N
   - e. Systems advocacy; increase/improve services for all children. Y N
   - f. Assistance in dealing with service agencies or the public schools (e.g., help in understanding the IEP process). Y N
   - g. Support groups for parents that:
     - 1) Focus on issues re: on emotional disturbance. Y N
     - 2) Focus on all disabilities, including emotional handicaps. Y N
   - h. Personal or psychological counseling services. Y N
   - i. Other____________________________________ Y N

If the organization provides any of services (a) -- (g), schedule an interview. If only counseling (h) is provided, do not interview unless information in (i) suggests the organization should be included.

7. OTHER ORGANIZATIONS TO CONTACT: [Question 3 on Screening Guide]

Name of Organization	Contact Person	Telephone	City
		( )	
		( )	
		( )	
		( )	
		( )	

8. Permission to use name when calling organizations in #7? Y N

PARENT ORGANIZATION SURVEY
Telephone Interview Appointment Form

TO: (Name): ______________________________

(Organization: ______________________________

(Address): ______________________________

____

____

(Telephone): (____) ______________

Your telephone interview is scheduled for

(Time): ____________ a.m./p.m. on ______________________ (Date)

______________________ (Interviewer Name) will call you on that day from the Regional

TAPP office in ______________________ (City) on that day. If for any reason

you are unable to keep this appointment, please call (____)______________

Thank you for participating in this survey!

&Name&
&Organization&
&Organization2&
&Building&
&Street&
&City/state/zip&

&Date&

Dear &Name&:

Thank you for participating in our survey of organizations of and for families of children and adolescents with serious emotional handicaps. The national directory that will result from this study will be very useful to both families and service providers throughout the country.

This study is jointly sponsored by the Technical Assistance for Parent Programs (TAPP) project in Boston, and the Research and Training Center for Seriously Emotionally Handicapped Children (RTC) in Portland, Oregon. The staff of these two organizations share a conviction that families of emotionally disturbed children need more support and information than is commonly provided by the formal service system, and that parent organizations can serve an important function in meeting these needs.

Enclosed in your copy of the questionnaire that will be used during the telephone interview, along with a confirmation of the date and time of your appointment. You don't need to complete this questionnaire; your answers will be recorded in writing by the interviewer. You may wish to use your copy to make notes about certain questions, however, as you prepare for the interview.

The questionnaire covers information in a number of areas. In addition to gathering information for the directory, we want to describe what is happening among parent organizations across the U.S. We are also collecting some information about issues related to the service delivery system for emotionally handicapped children and their families from the perspective of parent organizations.

The directory will include the name, address, phone number, services and fees (if any) for each organization. You will have an opportunity to review the directory entry for your organization before it is published. Information not included in the directory such as the history and future plans of organizations, funding sources, and opinions about the service systen will be summarized in a report in which no information about individual organizations will be identified. This report will be used primarily by the "Families as Allies" project of the RTC to improve the ways that parents and professionals work together on behalf of emotionally handicapped children and adolescents.

The interviewer from the Regional TAPP center will be happy to answer questions that you may have about this study. You may also call the study coordinator, Barbara Friesen, for additional information.

Thanks again!

Martha Ziegler, Project Director
Technical Assistance to Parent
Programs (TAPP) Project
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PARENT ORGANIZATION TELEPHONE INTERVIEW

Region:__________________ | Interview date: ___ _________

Interviewer:____________________ | Length of Interview:_________

IDENTIFYING INFORMATION

1. Name of Organization______________________________________

2. Acronym______________________

3. Address: ______________________ _________________________
Building Department

____________________ _________________________ _____ _____
Street City State Zip

4. Telephone (_____)________________ (_____)_________________

5. Director:_________________ 6. Co-Director: ________________

7. Other Contact Person(s): ____________________________________

8. Auspices (Sponsorship):

   a. Is your organization ____PUBLIC, or ____PRIVATE (check one)

   b. Are you part of a national organization? (Which): Y N

   ____

   c. Are you part of a larger state or local organization? (Which): Y N

   ____

   ____

   d. Other sponsorship? (What): Y N

   ____

   ____

FUNDING

9. Do you charge a membership fee? Y N

10. Fee: $_______ One time only_____ Yearly _____

11. Funding Sources: (Check all that apply) — Please indicate the 3 major funding sources, with 1=primary:

_____ Membership fees _____

_____ Fee for services _____

_____ Grants or contracts from state (public) _____

_____ Federal grants or contracts (public) _____

_____ Grants or contracts from city/county (public) _____

_____ Grants or contracts from foundations (private) _____

_____ Grants or contracts from private organizations _____

_____ Individual donations/contributions _____

_____ Other _______________ _____

_____ Other _______________ _____

GEOGRAPHIC SERVICE AREA

12. What geographic area do you serve?

NAME OF SERVICE AREA

_____ a. Single city (which) _______________

_____ b. Single county (which) _______________

_____ c. Region within a state _______________

_____ d. Single State _______________

_____ e. Several states _______________

_____ f. Nationwide _____U.S.A._____

_____ g. OTHER (What?): _______________

POPULATIONS SERVED

13. Does your organization focus exclusively on children and/or adolescents (NOT ADULTS)? Y N

14. Does your organization focus exclusively on mental or emotional disturbance? (If yes, go to #16) Y N

15. What disabilities do you include: (Check all that apply)

_____ a. Mental or emotional disturbance

_____ b. Physical handicaps

_____ c. Visual Impairment

_____ d. Hearing Impairment

_____ e. Mental retardation/developmental disabilities

_____ f. Learning disabilities

_____ g. Autism

_____ h. Other populations? (What?):______________________

SERVICES TO PARENTS

16. To about how many parents do you provide the following per year:

_____ Face-to-face service (support groups, workshops, etc)?

_____ Information & Referral, or other telephone service?

_____ Mailed written materials?

17. Do you publish a <u>bulletin</u> <u>or</u> <u>newsletter</u>? Y N

18. Newsletter #1:

Title: ______________________

Publication Schedule:__________

Cost/year:____________________

19. Newsletter #2:

Title:______________________

Publication Schedule:_________

Cost/year:___________________

20. <u>Education/Information</u>: What services do you provide for parents of emotionally handicapped children? (Check all that apply):

_____ a. NONE

_____ b. Information re: emotional disturbance of children

_____ c. Referrals to other sources of information/services

_____ d. Information about rights of children/parents under P.L. 94-142

_____ e. Other ______________________________

21. <u>Parent Training Services</u>: Which of the following do you provide? (Check all that apply):

_____ a. NONE

_____ b. How to cope/deal effectively with the needs of emotionally disturbed children/adolescents.

_____ c. How to be effective case advocates for their own children.

_____ d. How to be effective system advocates (advocacy to improve quantity/quality of services for emotionally disturbed children in general.

_____ e. Other training for parents: ______________________________

____

____

22. <u>Advocacy</u>: In which of the following advocacy activities does your organization engage? (Check all that apply):

_____ a. NONE

_____ b. Case advocacy--help individual families of emotionally disturbed children get needed services

_____ c. Systems advocacy--work to increase/improve services for all emotionally handicapped children

_____ d. Other: ______________________________________

____

____

23. <u>Support Groups</u>: Do you provide or sponsor groups that (check all that apply):

_____ a. NONE

_____ b. Focus exclusively on issues re: emotional disturbance in children/adolescents?

_____ c. Focus on all disabilities, including emotional handicaps?

_____ d. Focus on other issues? (What?): ______________________

____

24. Direct Assistance: Which of the following services do you provide to parents of emotionally disturbed children/adolescents:

_____ a. NONE

_____ b. Assistance to parents in dealing with service agencies or the public schools (e.g., help in going through an I.E.P. process).

_____ c. Respite care.

_____ d. Homemaker services.

_____ e. Child care services.

_____ f. Food, shelter, financial assistance.

_____ g. Other: ______________________________

____

____

25. What other services to parents of emotionally handicapped children & adolescents do you provide?

____

____

____

SERVICES TO PROFESSIONALS/AGENCIES

26. Which of the following activities/services for professionals do you provide? (Check all that apply):

_____ a. NONE

_____ b. Information/education to help professionals understand the needs of families of emotionally disturbed children

_____ c. Training for professionals on specific topics

Topics: ______________________________

____

_____ d. Other: ______________________________

____

27. Do you offer services/activities aimed at improving the working relationship between family members and service providers (professionals)? Y N

Describe: ____

____

____

____

____

____

HISTORY OF YOUR ORGANIZATION

28. Year established ______ 29. Year incorporated ______

30. (Brief) description of original goals/philosophy/purpose:

____

____

____

____

____

____

____

31. How have these goals & purposes changed over time?:

____

____

____

____

____

____

32. PROGRAM OPERATION ISSUES: How easy or difficult are the following issues for your organization:

	Very Easy				Very Difficult
a. Locating parents in need?	1	2	3	4	5
b. Getting parents to participate (one-to-one)?	1	2	3	4	5
c. Getting parents to participate in groups?	1	2	3	4	5
d. Acquiring necessary funding?	1	2	3	4	5
e. Finding appropriate meeting space?	1	2	3	4	5
f. Getting information about issues such as incorporation, tax-free status, etc.?	1	2	3	4	5
g. Finding topics of interest to parents?	1	2	3	4	5
h. Locating needed services/information?	1	2	3	4	5
i. Developing appropriate educational/ training experiences?	1	2	3	4	5
j. Others?________________________	1	2	3	4	5

33. RELATIONSHIPS WITH OTHER ORGANIZATIONS/EXTERNAL SYSTEMS: How easy or difficult are the following issues for your organization?

a. Establishing working relationships with:	Very Easy				Very Difficult
a.1 local public schools	1	2	3	4	5
a.2 the state educational system	1	2	3	4	5
a.3 local mental health agencies	1	2	3	4	5
a.4 the state mental health system	1	2	3	4	5
a.5 local child welfare agencies	1	2	3	4	5
a.6 the state child welfare system	1	2	3	4	5
a.7 local vocational rehabilitation agencies	1	2	3	4	5
a.8 state vocational rehabilitation system	1	2	3	4	5
a.9 local juvenile justice agencies	1	2	3	4	5
a.10 state juvenile justice system	1	2	3	4	5

	Very Easy				Very Difficult
b. Locating/working with other parent groups	1	2	3	4	5
c. Gaining access to state legislators, or other policy makers.	1	2	3	4	5
d. Getting parents included on relevant task forces, boards, or committees.	1	2	3	4	5
e. Other issues? ____________________	1	2	3	4	5

ORGANIZATIONAL STAGE OF DEVELOPMENT

34. Choose one of the following statements that comes closest to describing your organization's stage of development and growth:

_____a. Beginning: Our group/organization is young; we still have initial organizing work to do, and we are just beginning to work on our goals.

_____b. Middle: We have completed most of our "start-up" and organizing tasks; we are making progress toward our goals.

_____c. Advanced: We have programs in place to address many of our goals; we are ready to take on new challenges.

FUTURE PLANS FOR PROGRAM DEVELOPMENT

35. If your organization were able to expand its services/scope of operation, which three areas would you emphasize?

_____a. Education/information services.

_____b. Parent training services.

_____c. Advocacy.

_____d. Support groups.

_____e. Direct assistance

_____f. Counseling for parents.

_____g. Services to professionals.

_____h. Services to improve the relationship between family members and professionals.

_____i. Other____

37. To which of these areas (Question 36) would you give the highest priority? (Circle one check mark above).

Comments about future plans: ____________________

____

____

____

____

CHILD AND ADOLESCENT SERVICE SYSTEM PROJECT (CASSP)

37. Had you heard about the Child and Adolescent Service System Project (CASSP) before this survey? Y N

38. Does your state have an NIMH funded Child and Adolescent Service System (CASSP) project? (If no, skip to question 41). DON'T KNOW Y N

39. Is your organization involved with the CASSP project in any formal way? (E.g., contract, or agreement about participation, exchange of information or services). Y N

How?: ____________________

____

____

____

40. Is your organization involved with the CASSP project in informal ways? Y N

How?: ____________________

____

____

____

____

56

SERVICE DELIVERY SYSTEM ISSUES

41. Please indicate the extent to which the following statements describe the service delivery system for seriously emotionally handicapped children and their families in your service area:

	Very True				Very False
a. A full range of services to meet the needs of children and their families is available.	1	2	3	4	5
b. There are not enough services for all the children who need them.	1	2	3	4	5
c. Various agencies that serve emotionally handicapped children (e.g., mental health, child welfare, schools) work well together.	1	2	3	4	5
d. Services are difficult to find; it is not easy for a child or family to get accepted for service.	1	2	3	4	5
e. Where children and their families live does not have an effect on whether services are available to them.	1	2	3	4	5
f. Low income or lack of insurance coverage prevents some families from obtaining services for their emotionally handicapped children and adolescents.	1	2	3	4	5

COMMENTS:

43. PLEASE INDICATE BELOW WHAT IMPROVEMENTS YOU THINK ARE NEEDED IN THE SERVICE DELIVERY SYSTEM FOR SERIOUSLY EMOTIONALLY HANDICAPPED CHILDREN AND ADOLESCENTS AND THEIR FAMILIES (Check all that apply):

	Increase the NUMBER of services	Improve service QUALITY	OTHER	COMMENTS
a. Outpatient treatment (psychological/ psychiatric) for affected children.				
b. Outpatient treatment for family members.				
c. Residential placement for seriously emotionally disturbed children.				
d. Treatment programs in residential settings.				
e. Educational programs in residential settings.				
f. Educational programs in public schools.				
g. Respite care.				
h. Information and advice for parents.				
i. Transitional services; from residential to community settings.				
j. Transitional services; from school to work and/or community living.				
k. Vocational services				
l. Day Treatment				
m. Other________________				
n. Other________________				

COMMENTS:____

BEST COPY AVAILABLE

THANK YOU VERY MUCH FOR YOUR PARTICIPATION IN THIS SURVEY. I'LL MAKE SURE THAT YOU HAVE AN OPPORTUNITY TO REVIEW THE DRAFT OF THE INFORMATION ABOUT YOUR GROUP/ORGANIZATION FOR THE DIRECTORY, AND THAT YOU RECEIVE A RECEIVE A COMPLIMENTARY COPY. THE DIRECTORY SHOULD BE AVAILABLE BY ______________.

PARENT ORGANIZATION SURVEY WORKSHEET

Interviewer: ____________________

For Time Period from ________

to ________

Region: ____________________

DATE	INTERVIEW STARTING TIME	INTERVIEW ENDING TIME	PERSON CALLED	CITY CALLED	TELEPHONE NUMBER	LENGTH OF INTERVIEW	REVIEW TIME	TOTAL TIME
					(___)			
					(___)			
					(___)			
					(___)			
					(___)			
					(___)			
					(___)			
					(___)			
					(___)			
					(___)			
					(___)			
					(___)			
					(___)			
					(___)			
					(___)			
					(___)			

(Interviewer Signature)

(Regional Director Signature)

SURVEY OF ORGANIZATIONS OF AND FOR FAMILIES OF CHILDREN AND ADOLESCENTS WITH SERIOUS EMOTIONAL HANDICAPS

Instructions for Interviewers

I. INTRODUCTION

This study of parent organizations is being conducted throughout the US during the months of July and August, 1985. You are one of several interviewers in each of the five TAPP regions making telephone calls first to locate, and secondly to interview organizations that provide services and support to parents of emotionally handicapped children and adolescents. This set of instructions is designed to answer many of the questions you may have about the study, and also to help you answer questions that may be posed by the people you interview. Although this guide is fairly complete, you may have questions that are not covered here. When possible, get your questions answered before you conduct interviews; it is very important that the interviews be done in a similar way in each region. Barbara Friesen (503) 229-4040 at the Research and Training Center in Portland, Oregon is coordinating the study. Ask for her, or for Marilyn McManus when you have questions.

II. PURPOSES OF THE STUDY

The major purposes of this study are outlined below. Become familiar with this information, as some of the people you call during the screening phase will want to know "what's it all about" before they answer any questions. This is of course their right; this information should help you avoid being treated like a telephone solicitor (many of whom also begin the conversation by claiming they are doing "research"):

1. To gather information about organizations providing support, education, training, information and referral and other services to families of seriously emotionally disturbed children and adolescents. *Uses: This information will be included in a national directory of organizations of and for parents of emotionally handicapped children.*

2. To learn about the history, current experiences, and stages of development of parent groups or organizations serving families of seriously emotionally handicapped children and adolescents. *Uses: This information will help us understand the patterns and pitfalls experienced by these organizations, and should be useful in improving the quality of consultation, training and technical assistance provided to them.*

3. To learn more about the future goals and aspirations of parent organizations throughout the country. *Uses: First, it will be interesting to see if there are patterns in the directions in which parent organizations are developing. More immediately, this information will be used to select a few organizations as sites for developing and testing training materials.*

4. To obtain information about important service system issues from the perspectives of parent organizations across the country. *Uses: This information should be useful to both parent organizations and service providers in planning activities aimed at improving services to seriously emotionally handicapped children and adolescents and their families.*

III. THE SAMPLE

The organizations we want to include in the study fall into two general categories:

1. Parent groups or organizations; organizations started and run by parents for themselves and other parents. These groups will vary greatly in size and degree of organization (e.g., some will charge dues and have "members" in a formal sense, others will not; some will be incorporated and have written bylaws, mission statement, and goals, others will not). In spite of this variety, these groups and organizations will fall generally into the category of "parent self-help organizations."

2. Organizations that support, encourage, or sponsor parent self-help activities or information, education, training, support and/or advocacy activities. Some organizations may address a number of purposes, one of which may be to provide services to parents of emotionally handicapped children and/or to promote self-help activities among families. An example of this type of organization may be local mental health associations, which may sponsor, fund, or support parent organizations in some way. These organizations should be included in the sample, since they have services that are available to anyone who inquires, and we want to include them in the directory. When it is the case that there is a larger sponsoring organization, and the parent services are one part, or component of the larger operation, the interview should focus on the parent service or support component.

For example, you might find a project called "Parents Helping Parents" sponsored by a Mental Health Association. The project is new; they use the telephone number of the Mental Health Association, and don't have a membership list, or any formal organizational structure. So far, the project consists of about a dozen families who have come to at least one meeting. When doing the Parent Organization Telephone Interview, the interview should be done with someone in the project (a coordinator?); the Mental Health Association should be described as an "affiliate" (Question 8, "Auspice"), and the section that addresses "history" should be used to find out about the "Parents Helping Parents" project, not the Mental Health Association.

Organizations that generally should not be included in the sample are formal service agencies such as mental health treatment programs for children, or public child welfare agencies. Some of these agencies may provide training for parents as a part of their overall treatment or service program, but their services are usually limited to parents whose child is enrolled in their program, and are not oriented toward "self-help." Exceptions to this general rule may occur, as in the case where a mental health center serves as a sponsor for a parent group to get started. In this case, however, we are interested in the parent group, not the mental health clinic.

These distinctions may not always be that clear - you may need to check questionable cases with the study coordinator before deciding whether to include a group or organization in the sample for the full telephone interview. It may help to remember the title of the study: "Survey of Organizations of and for Families of Children and Adolescents with Serious Emotional Handicaps." Our interest is in organizations that focus on the needs of parents. Parents have these needs for information, support, and training because they have a child who has been diagnosed, or labelled as seriously emotionally handicapped.

IV. GENERAL PROCEDURES

A. Interviews

This survey has two steps. First, you conduct a short (5-10 minute) telephone interview to establish whether the organization is appropriate for our sample. If you decide during the screening interview that the group or organization should be included, then you schedule an appointment for a telephone interview at a later date (2-3 weeks later).

Parent organizations that you schedule for an interview will receive a joint letter from TAPP and the Research and Training Center explaining the survey. They will also be sent a copy of the questionnaire to be used in the telephone interview which they can review ahead of time, and use as a guide during the interview.

Procedures for notifying the Research and Training Center about who should get letters and questionnaires are addressed below in Section V: "Communication."

1. **Screening Interview:** The purpose of this phone call is to decide whether an organization is appropriate to include in the study sample and to get suggestions about other organizations to contact.

   The "Screening Interview Guide" contains fairly complete instructions about how to complete the Parent Organization Screening Form.

   When you are calling organizations suggested during these screening interviews, access to the new organizations will often be easier if you use the name of the person who gave you the referral.

2. **Parent Organization Telephone Interview:** Many of the questions in this questionnaire are self-explanatory. The process of pilot testing suggested some questions that need more explanation (see below). If you find other questions that are ambiguous or confusing, please call Barbara Friesen. Following are comments about questions that appear to need more explanation:

Question #8: Auspices (Sponsorship):

Here we are concerned about the structure and governing body of the organization (i.e., from where do the by-laws, policies, etc. come?). We want to know only about organizations of which the Parent Organization is formally a part. This might be, for example as a local chapter of a national organization (some Mental Health Associations), or as a part of a larger local organization, such as a Community Mental Health Center.

Question #25:

Any services not covered in questions 20-24 should be noted here.

V: COMMUNICATION

A. **General:** When in doubt about something, call Barbara Friesen to discuss your questions. It is important that the interviews in all TAPP regions are conducted according to the same instructions.

B. **Completed Parent Organization Screening Forms:**

1. Each Wednesday and Friday, call the Research and Training Center (503) 229-4040 with the names, addresses, phone numbers, dates, and times of each appointment for telephone interviews. Ask for Jan Worthington, who will complete a Survey Information Appointment Form and mail it, along the the letter explaining the survey and a copy of the questionnaire to the persons with whom you have made appointments.

2. Transfer pertinent information (name, address, phone number, appointment time, etc.) from the Screening Form to the Parent Organization Telephone Interview questionnaire, and mail all completed Screening Forms to the Research and Training Center once a week. Be sure to make a note (or a copy) of suggestions of other organizations to contact (#7., Screening Form) before you mail them.

C. **Completed Parent Organization Telephone Interview Questionnaires:**

1. Immediately after each telephone interview, check each questionnaire for accuracy, clarity and completeness.

2. Once a week, mail the completed questionnaires to:

Barbara J. Friesen
Research and Training Center
Portland State University
P.O. Box 751
Portland, OR 97207

VI. RECORD-KEEPING

Record the name of each person you call, the telephone number, city, and the length of the call on the "Parent Organization Survey Worksheet." Also indicate the time that you spent reviewing the questionnaire after each interview. We have estimated that you will need to spend approximately 10 minutes reviewing each questionnaire to be sure that the answers are completely and accurately recorded.

Every two weeks, give the completed worksheets to your supervisor, who will use them to prepare invoices so that your time, and the telephone calls, can be reimbursed. Copies of the worksheets should be forwarded to the Research and Training Center with the invoices.

HAVE A GOOD TIME!

Organizations for Parents of Children Who
Have Serious Emotional Disorders:
Report of a National Study

EVALUATION FORM

1. Who used the report? (Check all that apply.)

___Parent ___Educator ___Child Welfare Worker

___Juvenile Justice Worker ___Mental Health Professional

Other (Please Specify)________________________________

2. Please describe the purpose(s) for which you used the report:

____

____

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

Definitely Maybe Conditionally Under No Circumstances

Comments:____

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

Excellent Average Poor

Comments:____

5. Please offer suggestions for the improvement of subsequent editions of this report:

____

____

____

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We appreciate your comments and suggestions. Your feedback will assist us in our effort to provide relevant and helpful materials. Thank you.

Please fold, staple and return this self-mailer to the address listed on the reverse side.

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