FAMILY INVOLVEMENT IN POLICY MAKING:
A Final Report on the Families in Action Project

Nancy Koroloff, Ph.D., Principal Investigator
Richard Hunter, M.S.W., Project Manager
Lynwood Gordon, Graduate Research Assistant

Research and Training Center on Family Support
and Children's Mental Health
Graduate School of Social Work
Portland State University
RRI/P.O. Box 751
Portland, Oregon 97207-0751
(503) 725-4040

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published by the project under the title, *Parents as Policy-Makers: A Handbook for Effective Participation* (Hunter, 1994).

The findings of the project are reported in the following manner: Section 2 reports on the findings of focus group life history interviews; Section 3 examines five case studies of the experiences of parents and parent organizations in policy-making process; Section 4 presents the results of questionnaire data collected from site participants; and Section 5 discusses the implications of the findings for family members and policy-makers interested in enhancing family member participation on policy-making bodies as well as recommendations for further research. Finally, appendices that include copies of the instruments used in this study and other related project materials are provided.

It is our hope that the research, the training, and the resource development completed by this project will lead to greater understanding of family member participation in policy-making. The findings that follow are the beginning of investigation and documentation in this area. Nonetheless, it is a beginning that points toward the positive potential of parent and family member involvement at the decision- and policy-making level. Enhancing that potential, and increasing that involvement are two practical outcomes from the work of this project and from projects like it in the future.

SECTION II: RESULTS FROM FOCUS GROUPS AND LIFE HISTORIES

INTRODUCTION

During the early stages of the Families in Action project, the Research Consulting Group for the Research and Training Center encouraged staff to proceed with several exploratory activities because so little was known empirically about the conditions under which family members who are active on decision-making bodies must function. Three specific activities structured this phase: (1) a literature review; (2) focus group discussions; and (3) life history interviews. The results of the literature review are published as an annotated bibliography titled *Working Together for Children: An Annotated Bibliography about Family Member Participation on Policy Making Groups* (Gordon, Koroloff & Hunter, 1994). The following section of the final report will summarize the information obtained from the focus groups and life history interviews.

METHODS

Focus Groups

The data reported in this section are based on the ideas and comments of family members and professionals about ways to encourage family member participation in organizational and policy- level decision making. The research is qualitative in design using focus groups as the primary methodology. Data were collected through eight focus groups which were held throughout the United States in 1990. Two of the focus groups were attended by a total of 23 mental health professionals, primarily state level Child and Adolescent Service System Program (CASSP) directors, mental health planners and some clinicians. Three of the professionals were also the parent of a child with a disability. Five of the focus groups were attended by a total of 29 family members of children with serious emotional disorders. These groups were primarily comprised of biologic and adoptive parents, but foster parents and grandparents were also represented. One focus group was mixed, including 3 mental health professionals and 5 parents.

Specific efforts were made to reach family members from low income groups as well as culturally and racially diverse family members and professionals. This was done by holding one focus group in an urban area with a high minority population and by holding another focus group at a conference on the mental health service needs of youth from diverse ethnic and racial backgrounds. Seventeen percent of the family members and 54% of the professionals participating in the focus groups were from minority groups and one of the focus groups was conducted with the help of a Spanish translator. Family members from all income and educational levels were represented in the focus groups;

however, 45% of the family members reported family incomes above $50,000 and 44% had at least one college degree.

Originally, we intended to convene some focus groups with family members experienced in board membership and some groups with family members without that experience. This would have allowed examination of both what had been difficult (from the experienced group) as well as what was currently keeping parents from participating (from the inexperienced group). This plan was abandoned because family members who are not involved in advocacy work are more difficult to locate and lack relevant information about the process of board or committee membership. Seventy-nine percent of the family members involved in the focus groups were persons who had had some experience as a member of a board, committee, or task force. Many were also active members in parent support groups.

Focus group participants were asked to describe their perception of the barriers that kept parents from participating in policy groups, discuss what professionals could do to help increase family member involvement, and identify knowledge and skills that parents might need to be more effective. All groups responded to a series of six questions (see Appendix A). The questions for the family members and professionals were similar in content but slightly different in wording. Each focus group was facilitated by a researcher and was tape recorded. Tape recordings were transcribed and the typescript was coded for use in The Ethnograph, a computer program for qualitative analysis.

FINDINGS

The findings are presented in several major sections and include discussion of barriers to family member participation and strategies for increasing family member participation in decision- making bodies. Because the *Families in Action* project was involved in providing training and consultation to groups of family members, special emphasis was placed on ideas regarding training and how training might be delivered. In the following sections, quotes from the focus groups are used to illustrate each point. Quotes preceeded by an asterisk (*) were made by a person who is not the parent of a child who has a serious emotional disability. The rest of the quotes are from contributions made by parents or other family members of children with serious emotional disorders. The quoted material has been edited to delete extraneous words or phrases. Words enclosed in brackets have been inserted by the researchers to clarify the context of the comment or replace a name in order to protect the confidentiality of a parent or child.

Barriers to Family Member Participation

Barriers Associated With the Parent's Situation

Lack of time and energy. Almost all parents began by commenting about the amount of time and energy that caring for a child with an emotional disorder requires, leaving limited physical or emotional energy to invest in committee or board membership. Available time and energy for advocacy work was a special barrier for persons who work outside the home.

> There are days when you feel so emotionally drained, you think about holding down a job and then you come home to your second more than full-time job, which is your child in need, plus your normal children . . . you can only be stretched so far.
>
> Beyond everything is the emotional energy. The job that I do is very giving and draining, and then my child is very giving and draining. I feel like I need all of the time that I can grab to nurture myself--to be able to continue doing what I'm doing.

Most of the parents who attended the focus groups were women (90%) and many live in single parent households (38%). The general issue of available time and energy constituted a major barrier to these womens' participation.

Family crises. Another barrier to participation is the crises that often occur with children who have emotional disabilities. For some family members, anticipation of crisis makes them unwilling to agree to become a board members.

> When its going good for [my daughter], I try to get out as much as I can. But then during the crises time it holds me back from getting out and doing much that I would like in advocacy work.

For family members who are already involved in committee or board membership, crises involving their children may keep them from attending meetings or honoring commitments they make.

> There have been times when I haven't been able to make the phone call to say 'I'm not coming'. . . It depends on how bad the crisis is.

Children who are away from home. One theme that was mentioned frequently involved the increased availability of parents whose children are in residential treatment.

> But I never really came to a meeting until [my child] went away, because you can't leave him. You can't be anyplace until they're taken care of.
>
> I just wasn't able to attend meetings before [my child] was placed in a residential placement. I mean it seemed like the first couple of weeks . . . was like a vacation. You have no idea of the stress and the constant pressure and tension you're under until they're in a safe place where you don't have to worry . . .
>
> Those who are active are mostly those whose children are in residential placement, they are able to do the work.

We are not aware of empirical data that would support this last assertion, and our own experience suggests that many parents with children at home are actively involved in decision-making bodies in many states. However, if the service system is to have broad consumer input, it must be possible for parents with children in residential treatment as well as parents with children in community-based treatment to participate.

Disruption in home life. Another barrier is the disruption in homelife that is caused by one parent being away from home to attend meetings, conferences and retreats.

> Even if one parent can be home and do the caretaking . . . it's still 'Oh, he's not there again' or if he's home, then its 'Oh Mommy's not there again'. Or something like that. It's difficult. The children don't understand what we are trying to do for them.

In general, finding the time and energy to become a board or committee member is a major barrier for most family members. Professionals can be sensitive to the special time demands that are placed on parents who are caring for children with emotional disorders. This might include special attention to the number of parents who have membership on any one group.

Available child care. Another tangible barrier that parents who wish to be involved in decision-making groups often face is the lack of available child care. Family members expressed their frustration with the difficulty in finding reliable child care for children with special needs and the difficulty in paying for it. As the following quotes suggest, child care in general is lacking but child care for older children or child care during school vacations is particularly difficult to access.

> I am unable to plan my life more than a day or two ahead and I always have to be extremely flexible because if my daughter has a problem it upsets everything. It's similar to having an infant in the

> house that you have to put first, only the difference is I could get a babysitter for my infant. I can't always get help. There's no respite care available for a child with serious mental illness, so if you want to serve on a committee, you set up the date a week ahead and then if something happens the morning of the meeting, you can't get there.
>
> And there are always people who call me and say I would love to come but I just can't. There is no babysitting. The single parents have a very difficult time.
>
> Babysitting. Child care for your other kids or during the summer would be a helpful thing.
>
> How do you get a baby-sitter for a twelve or thirteen year old? What do you do with them? You have to bring them along, unless your husband's going to be home--if you're lucky enough to have a husband.

Blame or stigma. Feeling blamed for their child's disability is a barrier to participation for many family members. By agreeing to membership on a board or advisory group, parents are publicly acknowledging that their child has an emotional disorder. According to parents, this admission leaves them open to feeling blamed or stigmatized by other board members and by society in general.

> Our children are not only stigmatized but so are we as parents. People do not believe, if you have a child who has this [emotional disorder] that you didn't cause it, and you have to be a super person for them to even listen to you, and that's hard to get past, that bias.
>
> *To be a consumer, or a parent if you will, serving on a board, is to advertise to everyone that your child has experienced these difficulties and you have sought services, so the issue of stigma gets played out.
>
> *I had an educator tell me once that they don't have EH parents knocking down the doors of PTO meetings acknowledging that they are the parents of EH kids. They do with other conditions, but the EH parents, emotionally handicapped parents, simply do not do that.
>
> I think there are so many parents out there who have kids like our kids, but they're ashamed to talk with their mothers, to their sisters,

> to their neighbors, to their teachers, because they think God, what did I do to this kid to make this kid act this way.

Vulnerability. In addition to feeling blamed, parents often described a feeling of vulnerability that keeps them from speaking up or becoming active in advocacy. Because professionals are usually in a position of power over family members, parents often feel that the services their child receives could be taken away if they speak out too strongly for changes in the service system. One parent described how he refused to become involved with a state level advisory committee until custody of his son was returned to him for fear he would not get his child back. Other parents describe similar feelings of vulnerability.

> They're afraid to get involved with . . . group for fear that those services are going to be ripped out from underneath them. I've had welfare mothers say to me, 'I can't go. You can come to my house and we can have coffee and you can tell me all the things I need to know, but I can't show up at that group because the case worker might be there.'
>
> Whenever I speak I always think in terms of 'Oh my God, can this affect [my son]? Can what I say here...be used against my son?' and when you hear parent after parent telling you 'yes, it has happened to them' you start to wonder if it's worth it.

Barriers Raised by the Structure and Process of the Decision Making Body

Meeting time and location. A frequently mentioned barrier is related to meeting time and location. There is no easy solution to finding a meeting time that will please both family members and professionals. As the following quotes suggest, some objection can be found for almost any meeting time.

> If the meeting's held typically at 9:00 in the morning, which many of our meetings are, well the parents . . . are getting their kids to school.
>
> Couldn't be at night.
>
> *We've been working really hard to get the parents and professionals working together as a team, and when we plan things on a Saturday all the parents come and we get a handful of professionals. And when we plan it during the week, then all the professionals come and it's harder for the parents to get there.

One important guideline may be to consider the individual characteristics of the community and the parents who are trying to attend meetings. The following quotes are from the focus group held in Bushwick, New York, and illustrate the special needs of the urban family. The first quote is from a parent who explained that it is dangerous to allow children to walk to and from school unaccompanied.

> So it [the meeting] would have to be arranged between 10:00 and 11:00 so you could drop off the children and come to the meeting and then be ready to pick up the ones who are coming home from the lower grades. That's the kind of juggling that parents go through.
>
> *When you're talking about poor communities or dangerous communities, if you're talking about community meetings that are in the evenings you get a lot of reluctance to go to those for very good reasons. It's dangerous!

The location of meetings is another potential barrier to participation although less frequently mentioned. The main issue for parents seems to be the neutrality of the location and ease of access.

> Having all the meetings in a place that you have to drive a long way to get to, in a state type building is a barrier that we've lived with for a long time. There's no reason we couldn't go out and meet in different environments.
>
> We are trying to have our meetings in very easily accessible . . . you can easily get in and easily get out, neutral places . . . not the school and not the state building.
>
> We have several families call, inquire, write notes about [the location]. They were not comfortable coming to [the mental health center]. They do treatment there. So in that neighborhood to go to that facility means you're crazy.

The practice of setting the time and location of board or advisory meetings so that they will be easily accessible to professionals often erects barriers to participation by family members. One parent articulated the frustration felt by many consumers when their needs and preferences are not considered along with those of professionals.

> [I] sat and talked face to face with the commissioner and it was three days after their final hearings on their five year plan. She

> said to me 'I didn't see you testifying.' I said 'How could I testify, Commissioner? ' I said, 'Every one of your hearing hours were while I was in my permanent job. You want this input from me, but you're not doing anything to accommodate us getting there.' [And she said] 'I never thought of that'.

Attitudinal barriers to participation are comprised of both the attitudes of professionals toward parent participation in service system development as well as family members attitudes toward some of the activities that surround board or advisory committee meetings.

Reimbursement for expenses. Some barriers, such as child care, can be addressed in part by reimbursing the expenses of participating family members. Until recently, consumer or family member involvement on boards or advisory committees was considered a part of volunteerism reserved for the middle and upper income family, and no attempt was made to help with the expenses of participation. As more effort goes into attracting family members from all income levels, lack of money for transportation, parking, meals, child care and other expenses increasingly become barriers.

> I've heard when I've tried to recruit people for other committees that [lack of reimbursement] is a real detriment. Both how to get there--transportation at night--and not being able to have the money. I mean, I am privileged in many ways and those aren't issues for me but they certainly are for other people. This and the fact they'll lose their jobs if they get involved.
>
> I come from a large state and the regions are very different. If I want parents to come from different parts we have to have the commitment to pay for them, all of their expenses to participate in the process.
>
> Often parents are expected to do exactly the same amount of work and travel long distances . . . initially [she] was not even offered the same honorarium that everybody else was offered because she was a parent.

Family members who do not control their time at work must take vacation hours or lose wages when they attend meetings during the work day. This area of compensation is slowly being recognized as a barrier to family member participation.

> *Reimbursing their expenses doesn't reimburse the salary that they're losing to be there.

> *I think that the most difficult thing is time . . . working parents . . . as professionals that's what we get paid to do. They don't.

One parent described a situation in which the parents were reimbursed and the professionals were not.

> What they did was they provided child care and they provided stipends for the [hotel] rooms for families. If you were a professional you had to pay full shot, and I thought that was kind of neat because it's normally the other way around.

Professionals expect to attend most meetings during work time and to be reimbursed for any expenses incurred when they travel to and from meetings. Parents, on the other hand, are beginning to feel entitlement to recognition of their expertise and are expecting the same treatment. Many parents still refuse to claim reimbursement for travel or parking, even when it is offered, because they feel that they can afford the expense. This attitude is rarely seen among professionals. Some family members feel, however, that the failure to regularly reimburse expenses is a way of controlling which consumers are able to be involved.

> If they want advice from parents, it's usually targeted to white professional parents who can afford to have flexibility, who have more money, who can get off work during the day, who have transportation. Seldom have I seen that women of color, men of color, evening meetings, problems with not being able to afford child care have really been addressed.

> I could swear at times they choose people that are not going to be very controversial, that may not have good attendance . . . so they're not really looking for a child advocate, unless you get a professional that is trying to make some change . . . otherwise they tend to play very safe.

Representation. A major barrier intrinsic to the structure of some policy level groups is the problem of being the only consumer invited to participate--the token parent on the board. This situation is sometimes seen as manipulation or cooptation of parents.

> I was the token parent. I was the one who came forward in the county, and when they wanted to say we have parent involvement, there was [parent's name].

> The only reason we're there is because there has to be a meeting and the public law says that there must be parent advisory

> committees. I think that is even said sometimes in subtle ways to people.

Parents also report that being the only family member present during meetings may require them to represent all parents when they are only familiar with their own situation.

> I realize that on almost every committee I'm the only parent, and the burden just rests on me, and my shoulders are just not big enough most of the time.
>
> One of the things that concerns me is if a parent's on a committee or board and is expected to answer for every parent. It's like being the only person of color on a board and if there's an issue on race, turning to me and expecting me to make a comment for the entire African-American race.
>
> It's really nice to have other opinions, somebody that you can talk with and have it out with and say, 'Well, you know, maybe it needs to be presented like this or that,' and I think that it's been really useful to have somebody else that also backs up what you think and feel yourself. They get real tired of listening to me . . . when there's three of us and ten professionals, it's very different.

In addition, family members note that being the only consumer on the board requires them to spend extra time outside of the meetings finding out what other families are experiencing. This, in turn, adds to the time required of them and makes participation difficult.

> You learn an awful lot talking to [other] parents. You learn where the glitches are in the system. Otherwise, you only know your own situation.

A related issue raised by focus group members is that of requesting one parent to be on multiple committees. Since parents of children with emotional disorders may be hard to locate, well meaning professionals sometimes try to increase consumer membership on committees by asking one, often very effective, parent to sit on several decision-making bodies.

> Once you're on one committee, and if you're somewhat vocal, people want you on many committees, and you just can't do it, so much of it's just time and money.

Family members had a variety of comments to make about the number of parents that should be invited to join a board of directors or advisory committee.

> Insist on another parent joining too.
>
> Insist that they have two parents. Even if only one is voting, it doesn't matter.
>
> And never alone. Two for each group, because if you don't go to one meeting then the parent's voice isn't there. You need the support from one another. And what one isn't clear on, the other is.
>
> There's power in numbers, and if there's two parents sitting around the table of professionals, then you have a little more of a backbone to speak out and say what you feel, what really needs to be said.

There was little agreement on the exact number of parents that should be included. Some respondents felt that the minimum number is three. Others suggested that a proportion of the board be family members.

> For me the critical mass, though, is three. You never want a parent there by themselves. . .if [one] parent is absent, [the other two parents] have a partner.
>
> If you have a nine member board, then I think that you should have at least three parents on that nine member board, proportionately if the board is larger.
>
> I think twenty five to thirty percent [of the group] sounds right.
>
> *One of the things I've come to do is never put together anything like that without having at least half parents.
>
> *To what extent is this parent representative typical of parents? It's always that they are exceptional from the standpoint of their willingness and ableness to participate.

One parent noted that the qualities of the individuals are as important as the number present.

> A single parent can wreak havoc on a thirty-one person board. Likewise, you could have fifty percent of the board be parents and

> they simply sit there and are . . . ineffective . . . so the composition, traits, qualities of the individuals combined with the critical mass of three are the important elements to me.

One professional noted the lack of outreach to children with serious emotional disorders as consumer participants.

> *That's another area of input that we need and we haven't gone after a lot . . . is to have children talk about what their ideas are.

Appreciation for cultural differences. Another barrier that affects the participation of family members from non-majority cultures is the lack of appreciation for cultural differences that occurs in many decision-making groups. For example, several focus group participants noted that for persons from some minority groups and for persons from rural areas, personal problems are almost never discussed in public.

> *I think that in both the African-American and Latino community that it's not necessarily a positive thing to talk about what's happening to you personally in public. Usually you try to keep that in your family. You don't come and talk about it in public. But in order to really help with planning, sometimes you have to do that and sometime it's difficult.
>
> *In a rural area there's a real reluctance, first of all, to go to seek services, and then if you do go to seek services, to acknowledge the fact that you are.
>
> Rural is very different. The people I come in contact with are in eastern Kentucky and in Appalachia . . . you can't just say 'Are these people afraid of the system.' These people don't tell other people their problems. You suffer with them and you take care of your children and you do the best you can. It's more than just the system in those geographic areas. It's the cultural diversity among the people and the way that they're going to be able to respond to the problems that they have.

Language is also a barrier, particularly for parents who are most comfortable speaking a language other than English and are forced to express themselves in English during board meetings.

> Try to have . . . interpreters available or have the groups in English and Spanish so everyone is comfortable in expressing in their native language.

> *I think another issue is intimidation in language...may be in terms of ethnicity if you're a minority, but also in terms of language. You may feel comfortable speaking both Spanish and English for example, but if you have to speak just English you have some issue with that. I know our agency is a bilingual agency so we can do board meetings in English and Spanish.

Other barriers that are based on lack of attention to cultural issues are expressed in the following statements.

> For a lot of Latino families, if someone in authority tells them that this is what they need to do, they will not question ever, they will just follow. So that's another barrier--fear of authority.
>
> *When you're talking about poor communities and parents of color, they're not usually given the opportunity to be outspoken, to be an advocate, and so that's necessarily not something that you're going to find quickly.

Barriers Raised by Professionals' Attitudes and Behaviors

Professionals' attitudes to family member participation. The relationship between family members and professionals is often a tenuous one, even when both are fighting for the same cause. Both parents and professionals noted that a barrier is raised by the segment of professionals who give lip service to the concept of parent membership on important decision-making groups. Parents complained that these professionals did not value their input and were condescending and unwilling to take risks when discussing the quality of traditional services.

> *There is a huge percentage of the professional population that doesn't understand nor endorse or agree or support parent participation. I'm not sure how to address it because it's a real sticky issue and has lots of nuances, potentially a pretty emotional issue.
>
> *There's a lot of professionals who on the QT will take you aside and say "I don't agree with this stuff."
>
> I went, just went and showed up the first time, because I was so infuriated by my problems and the problems of other parents that I had talked to. And I said why does it take so long to get these kids placed and his answer was, 'Parents say the darndest things.' And that was it.

In some cases, professionals were willing to allow family members to be a member of the decision making group, but did not see them as possessing any expertise.

> It was the professionals who were not receptive and did not see the parents as empowered or as professionals in their own right . . . to be able to be a part of the discussion.
>
> *And there's still the belief that professionals are the experts and parents don't really have a great deal to offer in terms of their own conceptions.
>
> They just talk down to you like you don't know anything and then they tell you . . . that you're the one, you're the professional, you really know your child.
>
> *I think a barrier in the system is that many administrators don't understand the viability of parents in groups or they don't want them on boards and commissions. One of the barriers is attitudes.

Professional sub-culture. Professionals often know each other prior to membership on a board whereas, parents rarely know anyone when they join. Professionals usually have access to a powerful network of information and people that leaves parents feeling left out of the decision-making process even when they attend each meeting.

> The clubby atmosphere professionals bring. They all knew each other and everything just sort of meshed right in like they'd been doing this forever because they had been. The committee was new, the relationships on it weren't.
>
> Professionals always have their networking. It came out of the schools they went to. It comes out of their jobs. It's there. It's like management and we're labor.
>
> If anything happens between meeting one and meeting two, and it always does, the professionals will always find out about it through their connections, grapevine. As a parent on a committee, however, you find out about it when it's completely digested by the system.

Barriers Raised by the Service System

Change is slow. For many parents, the process of change in the bureaucracy is tedious, irrational and difficult to tolerate. Parents may sit on decision-making bodies that deal with many other child-related planning issues that do not directly relate to the needs of children with serious emotional disorders. Because of their awareness of the desperate needs of some families, these unrelated discussions may be difficult to tolerate. The slowness with which system change happens may also lead parents to feel that their contributions are insignificant.

> You do have to sit through an awful of other stuff . . . like the issue of child care for the toddlers . . . It makes you a little crazy sometimes because there are horrendous problems and when you see the way it works, it's very frustrating.
>
> *I think change comes very slowly in bureaucracies, and I think sometimes it is hard for parents to stay involved over long periods because it's not happening quickly.
>
> *I've been very impressed with their willingness to actually go through a fairly long process in serving on this advisory board, through numerous meetings where we hassle details. They work very diligently to become familiar with that and relate it to their own experiences.

> I feel hopeless sometimes when I go and I don't see that what I've said or what I've done has made any difference, and that becomes a barrier for me to continue to go on. I have to fight myself and my own issues sometimes and not say 'just give up, put my son in a private school and go to the mountains.'

Lack of available services. Finally, the lack of adequate and appropriate services, the very issue that brings most parents to board membership, may be one of the greatest barriers to their participation. Families who cannot access the most basic community-based services may be so preoccupied with supporting and protecting their child that they are unable to consistently make a contribution to changing the service delivery system.

> *I think its hard to talk about being a part of the planning process or an advisory process when there is such a great need for service.
>
> I think some parents don't become more empowered and get involved because they're so exhausted, because the demands of taking care of their children without community-based services--which often they don't have--leaves you with nothing left to give.

Strategies for Increasing Family Member Participation

Many of the comments made during the focus groups included suggestions and ideas for what could be done to improve the decision making environment leading to more effective participation on the part of parents. This part of the findings will be presented in two sections; ideas about the personal attributes and supports that parents need to possess, and strategies that could be adopted by the decision making body or service system to make parent participation more likely.

Qualities of Effective Group Members

One questions raised by both professionals and family members is related to the characteristic or personal attributes of an individual who is able to be effective on a board or decision-making body. Although all family members will probably find that they have something to offer, regardless of education or experience, the following personal characteristics were the most often mentioned in the focus groups.

Well informed.

> *The willingness to jump in when there's a lot of different issues that they might not know a lot about and be willing to learn it.

*She is very well informed and she is into everything, as far as giving information.

I was always out ahead of them. I would go to an expert. I'd ask my questions and present what I needed, and then they'd refer me.

*All the skills that are associated with networking, which is information, but more than that, it's information dissemination. Really liking people, and liking to set up the mechanisms for distributing information and to keep those telephone wires really burning in both directions.

Tenacious.

*I think that one of her greatest assets is that she doesn't say "no", she's very tenacious.

*Persistent. Just willing to hang in there and knock on doors.

I think tenacity. If you just say it over and over it starts to register. Every chance you get, every meeting you're at, every board you're on, every opportunity, just keep saying the same thing.

People close the door on you and you have to push it open and a lot of people just don't have the confidence or obstinacy or chutzpah to do that and they get left by the wayside.

Commitment and leadership.

*She's outspoken, she's well-organized and she's committed to improved services.

*She has committed her whole life towards advocacy, and she is always willing to be the volunteer parent and is a good speaker.

*She is a leader in both advocacy and in beginning and training other parents for support groups and recruiting other parents. The words I would think of to describe her would be "leadership" "assertive" and "commitment."

*One characteristic of an effective board member is a feeling of inclusion, rather than exclusion, that everybody's welcome. They are all articulate. They put their thoughts in a cohesive manner

> sentence-wise to project their ideas. They are outgoing, they are very committed and they share that commitment with all the members. They have a desire to change the system, and express that desire.

Ability to think broadly.

> You have to have people that are willing and able to be a little bit more objective and divorce themselves from their own personal issues so that they think more globally.
>
> An ability to see a whole organization rather than just a little part of an organization. The ability to synthesize information and to spew it back to people and an organizational mind.

Communication.

> *She has an eloquent ability to communicate to professionals what it is like to be the parent of a child with emotional disabilities. It's that ability, in addition to the way that she can rally the support of other parents behind her that makes her so effective.
>
> *I think the primary skill or expertise is the willingness or ability to speak up in a group and to share experiences and ideas about the system.
>
> *Articulate people, but articulateness comes in a lot of different forms. I don't mean people who can use five-syllable words particularly.
>
> *Well-informed and tireless. Just spending a lot of time and being able to express themselves in very diverse types of groups.

Assertiveness.

> * She can be assertive without being offensive, she can state her needs and refer back to needs rather than problems in the system or problems that aren't being served, but she focuses on what her family needs.
>
> *Another important issue is kind of a combination of advocacy and empathy. I think it's real important that a parent be an effective advocate but be able to, not necessarily back off from that

> advocacy, but be empathetic to the professional so that the advocacy doesn't become so shrill that it turns professionals off.
>
> *She is not intimidated by a bunch of professionals and she's able to state clearly what it is that she wants. Often she'll be the only parent in a whole group of professionals, and she's not afraid to say I don't understand this, and what's that acronym mean. She is just very comfortable with being herself.
>
> There's a difference between being aggressive and assertive, especially when we are trying to be collaborative. Once the words are spoken you can't unspeak them. You're better off with a few pat phrases that are going to get you through when you're feeling really angry. You don't want to hit your nose on the rungs going up and down.

Use of anger. Many parents described their anger with a service system that does not meet their children's needs. Anger, by itself, can be a barrier to becoming involved if parents believe that there is no possibility of things changing for the better. The family members below describe how anger drove them to become more active in advocacy work.

> I think our involvement has evolved from being so overwhelmingly angry at a system that wouldn't serve our child, to deciding how we could vent our anger in an appropriate way that will change services.
>
> What allowed me to get involved and stay involved is my anger. I see it as a productive use of anger, because I took three years of emotional battery, by professionals and I am one. I came out of the experience of receiving services for my son feeling like I had been victimized and when I found out that there were people in the world who thought that I had rights, I jumped on the bandwagon real fast.
>
> A catalyst for change in a parent is when you finally get angry enough and put down enough that you start to say 'My child is worth more than that, I'm worth more than that' and then you start to fight.
>
> But the angrier you get and the more services your children require and the closer you come to losing a child, the more you know the system's got to change and you've got to be heard.

As one professional noted, angry parents are threatening to many who work in the serv ice system and sometimes family members are most effective if they can keep their anger contained. Family members, on the other hand, often comment that professionals should be able to take parents' expressions of anger.

> *I think it's real important that a parent be an effective advocate but be able to be empathetic to the professional so that the advocacy doesn't become so shrill that it turns professionals off.
>
> The system views us as coming in as screaming parents, but then when you can go in with what I call calm anger. You tend to become effective in working with the system and in trying to get the services.
>
> When you bring up something that's negative, you're considered a complainer if it happens more than a few times. Its almost like you count your chips, like 'Oh no, how many negative things did I say this week and how many positive things.' Once you're called a complainer or are never satisfied with a system or with an agency, you're not listened to as much.

A sense of humor. Given the intensity of many of the issues faced by family members and professionals as they work together, another quality mentioned numerous times is the ability to see the humor in challenging situations.

> *A sense of humor. To be able to laugh with people at some level in order to let people be comfortable with some of the stuff that's being talked about.
>
> *There are two things she can do real well, she can laugh. She can laugh at the system, which really helps in intense moments, and she's empathetic. She can put herself in the role of the professional.

Support That Family Members Need

The family members who participated in the focus groups talked about the kinds of support they needed to fully participate on an advisory board or decision-making group.
Support from parent support group or network

One source of support came from parent support groups or statewide family networks. Sometimes parents were sent to an advisory group to represent a statewide family organization, in other cases the parent membership in such an organization was coincidental. In general, groups of family members were helpful either because they provided information or because group members provided emotional support.

> There is a presence now in which they know that the parent group is going to be around. They know that individuals in the parent group are ready and willing and able to be present. The system has changed its view of us.
>
> I'm not totally out there by myself. Not saying that I'm a hundred percent going to win. But I know there's somebody there that can give me some answers.
>
> Somebody in the group always has experienced whatever others are going through. We can find someone to link up with.
>
> And the (parent support) meetings are important because you meet people like yourself who are beginning to work outside of their problems for other kids too.
>
> They should have some resource group to go to get the information that they need before they go to the meetings.

Support received from other individuals. In addition to support received from support groups and networks, many participants mentioned support that they received from their spouse or other family members.

> The single thing that made it possible for me to participate to the level that I have, has been the support of my wife. She has been 100% behind everything and, in fact, at times has sacrificed things that she might otherwise have wanted to do so that I could continue. Without that I don't think I could have been nearly as effective as I have been.
>
> My husband who supported me in it all and who said 'Don't give up.'
>
> My other kids really suffered beyond anybody's belief. They were standing back of me saying 'Mom, you tell them how it is, because nobody will listen to us. We're little.' That's given me more courage at times than anything.

Strategies to Modify the Structure and Process of Decision-Making Bodies

Recognition of benefits of having family members on decision-making group. A starting point for changing the atmosphere within a traditional decision making group is to recognize the many benefits accrued through increased involvement of family members and other consumers. Sympathetic professionals may need help in explaining these benefit to other members of the decision-making body.

> *What would be helpful to me is information about the role, the activity, the value of parents, being told--not just to parents--but to professionals in the same room. So that at least they had one opportunity to leave the room together having heard the same story, whether they really understood it or not. At least they get the idea that there really is a value in this collaboration.

One of these benefits that deserves emphasis, is the way family members help the group to focus on the outcome or bottom line of the service system.

> *I think the parents have a way of interjecting thoughts that sort of refocuses the group, 'Oh yes, we're talking about children here.' The purpose of this meeting is not to generate cooperative team spirit, the purpose of this is to serve children with emotional disturbances.
>
> The parents bring it (success) up and it throws everyone. It's absolutely amazing. It's like a CEO saying 'Come on. Quit screwing around and get to work.' When a parent does that it's really interesting because there's a lot of respect. They are not getting wrapped up in the interagency debates but focusing directly on a result.
>
> *She does talk about her own situation, sometimes you don't want to hear about it any more, but she can cut through in three words all the hypocrisy that the professionals are putting up. She does it in such a way that it brings you to your knees. You have deal with what she has said because it is such honest, simple truth.

Roles family members assume. Another benefit that is often not emphasized is the multiplicity of roles that family members can assume as members of an advisory committee or governing board. Many parents assume leadership roles, becoming chair or co-chair of the committee or subcommittees. As the following comments suggest, parents are effective participants in the evaluation process, provide useful input on community needs and can often act as advocates for more and better services at times when professionals can't.

> *I see parents being very active in taking leadership roles, in being able to be advocates in both policy changes and service changes and in legislative changes.
>
> *We have a statewide parent advisory panel, but we also have parents involved on every other work group and task force that we have.
>
> *We need to put parents in the evaluation process. We do program reviews and I've got permission to start including parents on the review team as a partner, as an equal. They'll be doing the same checklist, looking at the charts, talking about treatment plans, assessing the service delivery.
>
> *When the agency provides a service, the only expert in that room is going to be that parent. They're the only ones who can tell you that yes, this is helping my kids or no, it's not. They have a role that to some extent is much more important and much more valuable than all the experts on finances and everything else on the that board.
>
> *I think one of the major advantages would be that parents could have an influence on changing the system by talking about some of the problems they may have in getting services. Parents could probably know the system a lot better and the community they live in and how well the services serve the people in that community.
>
> *It's made my job much easier. They're out there being the advocate where they can get more done. I could say the same things and I would get slapped on the wrist and threatened to be terminated or fired.
>
> *I was superintendent in a predominantly white school district and what saved me was the parents group. That group of parents came to the board and said 'Before he got here, look what was going on in residential and all the special education programs. Since he's been here look at the change. Forget about what color he is and look what he's done.'

> Being able to see that my presence is making at least some small difference. I can actually see where my being there has made a major difference in the direction that a certain board has taken in children's issues.

Strategies for Recruiting Parents to Membership

A major problem for organizations is the process of recruiting family members who will remain with the decision-making group despite many of the barriers and challenges that exist. The participants in the focus groups had many ideas about both how to find parents and how to engage them in the system change process.

Recruit parents who are angry.

> *The parents that are involved . . . are still in touch with their pain and struggle and anger as a parent, but has it resolved enough that they're able to couple that with letting people know what the immediacy of that experience is in a way that isn't continually draining to them.
>
> I think they put me on there hoping that it would keep me quiet, but I'm not so sure it's going to work that way.
>
> That group started out as eight parents who were very angry and very upset with what they were doing in the school system.

Recognize the benefits of participation for family members.

> I think a good marketing strategy is if we start talking about what the benefits are to parents and not deny the fact that the main reason that any of us would belong is because we hope to get something better for our child. We kind of diminish that aspect of what we're doing. That's the only reason any of us would do most of this.
>
> *The only people that I can get to show up are the people that are still looking for a placement...
>
> *The person that's been most effective, has been searching for a placement for her son, at the same time was showing up to tell us that we needed more placements for children like her son.

> I don't think it's as difficult as you might think it is. We should open the door and offer the invitation. If it's a board for a school that their child is involved in or a program that their child is involved in, you'd be amazed at how many parents will come. Even those hard to engage parents that we always believed were out there. There are always parents that are willing to get out there if they feel they will benefit their child in the long run.
>
> Whenever I become involved in a committee or something it is just the added information and support and networking that's available to me.

Recognize parents who ask to join.

> The state was asking for folks to be on this new sub-committee on children's mental health and she (child's therapist) thought I should apply, and so I applied. They didn't accept me but I went anyway.
>
> A friend recommended the Mental Health Advisory Committee to me. And of course, the board was filled with this doctor and that therapist . . . I wrote a letter and said I'm the parent of a 16 year-old, and I had difficulties finding services for him and I would like to sit on this board, and they said fine.
>
> I went into the Director of Special Education's office with a great big complaint, and he put me on a sub-committee of the Special Education Advisory Board immediately.

Other ideas and issues related to recruitment. The following quotes represent a variety of experiences and strategies that focus group participants mentioned regarding the recruitment of family members to sit on advisory groups and governing boards. The two issues that are mentioned at the end of this section are of particular importance. Parents who have children with emotional disabilities will eventually see those children move into the adult system. Although many parents continue to advocate for children's services after their child has aged out of the system, most parents prefer to retire from advocacy or direct their attention to the inadequacies of the adult service system. A related recruitment issue is seen in the quote about diagnosis. Since the labeling of children with emotional disabilities is imperfect and many mental health providers would like to avoid labeling, parent are often uncertain whether they fit the description of parent or family member sought for committee membership. Other quotes document sources or ideas for recruitment that have worked for the speaker.

My first experience on a board was not as a parent but as a professional. My first real parental advisory committee, was Little League. I knew I had to get my son involved in Little League so my husband was manager and I took on Secretary.

I've really found that the Mental Health Association in my state has been tremendous. They have been eager to get parents involved, they're constantly asking who's interested in attending different functions . . . . They're always eager to find parents that are willing to be involved. Having someone helping to finance my trip is something that's a tremendous help because I wouldn't be able to come otherwise.

*The other thing that works is to have parents contact other parents, say with the school or a classroom. Have them talk to them, parent to other parent, about the issues of parents and children with emotional handicaps, and the need to advocate on behalf of those kids. It's a little easier to come to grips with what you're dealing with when you know that other people are dealing with it too.

*We need to find ways to plan for leadership development in conjunction with parent support groups and the other parent networks that exists. If we can find the leaders, natural leaders within the ranks of the parents, and bring out those qualities, then those roles that we're talking about will be easier to fill.

*Fifty-one percent of the regional planning bodies have to be parents or advocates, non-professionals. There are a lot of professionals who would like to serve on those bodies, and the only way they can do it is to get a parent or a parent advocate to serve with them.

*One of the things we've done in order to engage the parents and have them come on board is for the president of the board to go and meet with parents on an individual basis and explain to them the function of the board, what their role will be.

One of the problems in finding parents is that pretty soon they're parents of young adults and very busy with the problems of work and vocational training. I would like to help people with what I've learned, but I don't know whether I'll have enough time or energy

> to do both, to keep advocating for my adult child and to go back and help people that have younger children.
>
> One of the difficulties with SED and mentally ill children is that the diagnoses are so difficult and sometimes change. Some parents don't know whether they would qualify to represent parents in your group, given their child's diagnosis.

Ideas for Providing Support to Family Members Who Participate.

Family members who agree to become a member of a decision-making body need a variety of supports to make it possible for them to continue their involvement. Following are some ideas from focus group participants about ways that support could be provided.

Mentor or buddy systems.

> *Having a buddy system or that mentoring system so that you have some more experienced parents on board with newer ones. There would be that level of exchange that would happen between the parent participants and not just the professionals.
>
> It works real good to have a buddy system, to put a parent with a professional and to put them on a committee where they are matched.
>
> *It's nice to have them buddied up if it's more than one parent, because usually the parents do better when they can all travel together. They try to work out some system of transportation together.

Developing family organization strategies.

> We sat down and we had a weekend meeting in which we planned our long-term goals and our short-term goals, and from that came out some very basic priorities. Everyone of us who serves in any capacity is advocating those same priorities.
>
> This group sat down and said 'What do we want to get out of this, what do we want to make sure is in those reports. What specific goals are we after.' Rather than a strategy of let's just be there and yell and scream and complain.

Advice from parents with experience on boards.

> You have to realize that the big issues are made up of a lot of little issues. You have to solve some little issues down at the bottom.
>
> Warn parents that they're going to get tired and not to throw in their cards because they've become tired and not to feel bad if they have to back off for awhile.
>
> Parents that are getting involved in this understand that their guts get laid out on the line, and it's okay to take a break from it.
>
> Be selective about the committees they are on, because you get one good committee person and you wear them out. You ask them to be on ten different committees. Then they burn out.

Strategies for collaborating with professionals. Focus group participants had some very specific ideas about how best to work out differences with professionals. These included developing negotiation and conflict management skills.

> It is extremely important to know what you're talking about as well as to make it very clear that you're not going to back down. You are not what they refer to as the exceptional parent because you're involved. It's extremely important to let them know that there are lines. There will be some flexibility, but you have to draw the line.
>
> It takes a lot of negotiating skills in terms of processing issues. Some of the social work skills that I have I think have come in handy in terms of trying to negotiate some issues that group needs to deal with.

Both groups of respondents suggested that professionals need to be more personal in their dealings with parents. Family members sometimes report that professionals can be remote and avoid friendship with consumers who sit with them on a board.

> *I think one of the most powerful things that I experience in terms of professionals and parents working together is when professionals open up and reveal something, you know, we as professionals tend to be very distant and not as open, but yet we expect our clients or our consumers to open up and throw it all out there for us.

> Come out of the closet about their own children. There are several politicians and professionals in high places who have children with schizophrenia, learning disabilities, are in special schools, all kinds of things, and we may find out about that informally, but nobody else ever does.
>
> I think they need to get to know you as a person and that, you know, you're not just this nasty parent that just wants to stir up trouble, you're somebody that wants something to happen that's positive and you're not threatening to them as individuals. Once you gain that kind of respect I don't think you really have a problem.

Training and Other Methods of Providing Information

Focus group participants were asked to comment specifically on the kind of training that family members needed to allow them to participate effectively in the decision-making process. This question was asked at the end of the focus group meeting; therefore, less time was available and fewer comments were captured. Many of the comments in earlier sections regarding the information that parents need are helpful in thinking about training or workshop content and are included in this section. This section of the report is divided into three parts; ideas about the information that family members need to be effective participants; ideas about ways of delivering training or consultation; and ideas about how family members and professionals could be brought together during training or workshop sessions.

Strategies for Providing Family Members with Information

The need for information was identified as a high priority barrier to effective participation by family members. Most comments pointed toward two kinds of information as the most useful: information specific to the board or decision making group the parent was being asked to join; and information about the children's mental health service system and its functioning.

Specific information needed about the board or decision-making body. Family members should ask whether it is a working board or an advisory board. It makes a difference in terms of time being put into that organization.

> I want to know whether or not there's sub-committees. A lot of times people say, 'Oh, there's only one meeting a month' and then you find out there's really an unwritten expectation for you to belong to three sub-committees besides that.

*Providing them with some type of orientation and letting them know very clearly what the expectations are for their role.

A description of what that board or advisory council does, the type of people that are sitting on it. Is this a local community thing? Is this an inter-agency thing? Are they discussing special education issues or whatever?

The minutes are real important to me. Time is always really important to me. I want to know that we're going to get in there, we're going to do what we say and we're going to get out of there. I want to stick right to those hours. If somebody's late we don't wait.

Before I consider whether or not I want to be on a board or committee, I'd like to see minutes of the last meetings. I'd like to find out if what people are telling me is what really is happening, I want to have a list of who the members are with their addresses and phone numbers so I know how to get a hold of them. I want to know what is expected of me as a member of the group . . . I want to know what the money commitment is, I want to know if they're always going to meet during the day or if there's any possibility that it could also be in the evening. I'd like to know the mix of professionals and parents. I'd like to know if there's a budget for us to work with. I also like to know whether or not we're going to be expected to do public speaking and write grant proposals. And whether or not there's secretarial help if you end up on the executive board...if you can expect any help from staff or if you really need to do it all by yourself.

Information about the service delivery system.

Provide insight into how the system works from the inside. They provide data, actual information that we need.

You have to know your alphabet really well and like acronyms. Everybody talks in letters and half the time you don't know what any of the letters are.

I'd like a map. I mean, a diagram of all the committees, sub-committees, councils, sub-councils, local, county and state level. Who is the person to contact regarding sitting on that?

Methods of briefing parents about issues. Another kind of information that family members mention, is help with understanding the politics and agendas of special interest groups within the decision-making body. Most felt that this kind of information could be best delivered through a briefing or consultation arrangement with a professional or an experienced family member.

> What they have done is brief us when we go into meetings, let us know what the hot issues are. They've come to some of our meetings and interacted with us in a way of showing us support, direct support by being there.
>
> [What] professionals really need to do is to develop some coaching ability. Ability to tell a parent, 'In this kind of a situation you should deal with it this way or this way.' To be more on an equal basis with parents in terms of coaching them through crisis situations.
>
> *I have been briefing the parents just like the professionals have been briefed before the meetings. What I think is happening on certain issues. I try to tell them the reason why I think the professionals may be bringing this up on the agenda. So many times there's a hidden agenda besides what's written on paper. The Steering Committee does the work for that council and I'm on that Steering Committee, so I have a pretty good idea of what's really on the agenda.
>
> For one committee I have a spy in the system who is keeping me pretty well informed of any little undercurrents that might be milling around between meetings.
>
> One of the things that we are doing is going by the seat of our pants as far as strategy is going. And it would be helpful to have a sounding board--to be able to say okay, here's the circumstances, here's where we are, what strategies have been moved to the next point that we want to go to.

Skills that need to be developed. In addition to information, focus group participants identified a group of skills that family members need to be effective in decision-making groups. These skills overlap with information at many points.

> *To be leaders. I would really like to see the parents know the legislative system, how to advocate, and taking communication

> another step. How to manipulate a bureaucrat, and there's some real skills in learning that.
>
> You are going to have to include some sort of basic assertiveness training.
>
> Training for parents on how to cope on a very personal level. How to learn where the line is beyond which it isn't their problem. What to do to take care of themselves.
>
> I think assertiveness training would be important, I think problem solving skills would be important for some people, understanding the role of being a leader in a group would be important for some people, and I really think that depends on who you are and what your skill level is. Understanding how you can take what you learn from being on one committee and transfer that knowledge to another committee.

Ideas about how training content should be delivered. Many ideas about how best to provide information were generated in the focus groups. These centered on helping family members gain access to information, as well as helping family members develop strategies for addressing major issues. A few focus group participants had very specific opinions about training techniques that would contribute to the usefulness of the educational experience. Some of the comments had to do with who should deliver the material and ideas for techniques to use to enhance participants' reception.

> Involve parents in the training, because parents aren't going to listen if there isn't a parent there.
>
> *It should be parents training other parents rather than professionals training parents.
>
> *It would be helpful to share information about how different parent groups and parent advocates and professionals and parents work together in different places. The kind of information sharing we do in conferences like this.
>
> Develop some neat role plays and some kinds of activities that would show what a really good committee would look like, how the chair could involve families, etc. I think the professionals are misinformed much of the time about committee work.

> Training may need to be different depending on the audiences. You may have a different way of training them (middle class parents) than you may have with a group of Hispanic parents or with African-American parents. One of the things that I thought was valuable with Families as Allies training, was when they did some switching in role-playing, and they had professionals being in the shoes of parents.
>
> When I think of training I really do think of a mixture. I don't think of just a conference or training. I think of written materials, I think of one-on-one's, I think of videotapes.

Training professionals and family members together. One format that was mentioned regularly, was training family members and professionals together or providing special educational opportunities for professionals about how to work with parents and other family members on boards.

> Training for the other side about how professionals on boards work with parents on boards.
>
> *It's the whole issue of being sure that the board is educated about the parents so that they respect and understand that there is a need to respect the parents' opinions and the parents' positions on things.
>
> You know, we're always doing workshops and telling parents how to act like professionals. We never tell professionals how to act, and I was at a workshop where we stressed to parents how to be positive, how to communicate well, and I knew that the parents who were going to go into certain meetings were going to meet hostile professionals.
>
> Professionals who do not have children who have these things are going to have prejudices. You see it in their eye. Right when they start talking to you they shut you off. If you could work through some of those things in group, I think you already just get a cohesiveness and a respect for each other that kind of transcends the education.

LIFE HISTORIES

The construction of life histories was a second technique adopted to explore the condition that allowed parents and other family members to become involved in governing boards or decision making bodies. Telephone interviews were conducted with eight individuals who are recognized as leading advocates for the special needs of families who care for children with serious emotional disorders. The persons who were asked to participate were selected purposely to insure geographic as well as cultural and gender diversity. Participation in the study was limited for some people because their schedule made them unavailable during the data collection period. Individuals who agreed to participate in the research interview were sent a consent form to sign, a short demographic questionnaire and a copy of the interview questions. The consent form and questionnaire were mailed back to the researcher prior to the telephone interview.

Description of the Participants

Seven of the interviewees were women, one was a man; seven were between 40 and 59 years old and one was younger. Five of the participants were married, one was divorced, one was widowed and one was single. The participants named spouse, friends and child's grandparents as the persons most helpful in raising their children. This group of parents indicated that involvement with advocacy, involvement with other parents and their careers had provided them with support in addition to the support received from friends and family. Five of the participants had someone who shared daily parenting responsibilities and three did not.

All eight of the interviewees had some college education, three had a bachelors degree and three had a graduate degree. Five were employed in a paid position as an advocate for children with disabilities. The yearly family income for all eight participants was above $20,000 and three of the interviewees reported family incomes above $50,000. Two of the participants were African-American.

The eight participants had a total of 17 children, 12 of whom were still living at home. Seven of the families had one child with an emotional disability, one family had two children with this disability. The children with serious emotional disabilities were between the ages of 12 and 22; six of the children were age 20 or older. Each child had multiple diagnosis with attention deficit hyperactivity disorder, learning disorder, schizoaffective disorder and depression being most common.

FINDINGS

Following is a summary of the responses given in the eight interviews. The findings are organized by the questions that were used in the interview. A copy of the interview schedule can be found in Appendix B.

1. *In thinking over your own history of involvement what events, issues, and/or people got you involved?*

The initial event that first pulled these interviewee's into the realm of advocacy and system change most often involved attending or starting a parent support group. Five of the participants said that they first got involved when someone encouraged them to attend a support group. Many of the individuals who participated in the interviews first got involved in the late 1970s or early 1980s and were therefore involved in starting the first parent support group in their area. Two people interviewed mentioned specifically being recruited as part of a small group of parents who met to start a local support group. One of these groups was formed by a Mental Health Association, another was invited to work with NAMI. One of the respondents got involved in a support group that was developed specifically to fight the closure of a special education program. Seven of eight people interviewed mentioned joining or starting a parent support group as the event that first got them involved in changing the children's mental health service system. The one interviewee who did not start with a parent support group lives in a very rural state with few resources. She got started by attending a conference which led to becoming involved with the state chapter of AMI.

A second theme that emerges from the responses to this question relates to the part played by professionals in encouraging family members to become involved in support and system change. Five of the interviewees mentioned specific professionals who had encouraged them to become more involved. Professionals mentioned included psychiatrist, social workers, special education director, professor, the director of the mental health association and a CASSP director. In one case, a neighbor knew about a support group and encouraged the respondent to attend. The role played by professionals in connecting parents to system change efforts is striking. Several interviews included comments about the importance of that encouragement, especially when it came from a person involved with their child's treatment.

2. *Regarding the groups that you felt were very significant in your history of parent involvement, what were/are the factors that made these groups significant? What were your supports initially? What are your supports now?*

For most of the respondents, involvement with other parents in a parent support group or involvement with other parents on a board or advisory committee was a significant source of support. The most frequently reported types of support were increased information, personal or emotional support, help with problem-solving and assistance with advocacy. One respondent noted that the collaboration with other parents who were members of her board was a significant source of support and that this collaboration helped her learn to listen and problem solve. Another respondent stated that the sense of community and the opportunity to provide support to others (as well as take support) were important resources for her. A third respondent noted that involvement in decision making groups provided recognition of her expertise and skills.

3. *Looking back over your history what factors made involvement difficult for you in the beginning? What now?*

Stigma or blame was the most commonly noted barrier to becoming involved in system change. Although stated differently, this barrier was mentioned in five of the eight interviews. Three barriers -- cost of attending meetings, child care and time pressure -- were each mentioned by three interviewees. The cost of attending meetings when added to the financial stress presented by the child's care was identified as an overwhelming barrier to both beginning and continuing involvement. Child care as a barrier was also associated with needing to be away from home overnight. Respondents noted that it was difficult to find child care for several days and that being away from home resulted in family stress and in some cases, increased anxiety for the child. Time pressures were most often discussed as the tension between time with family and child versus time spent in advocacy. The pressure was critical for one interviewee whose husband chose not to be involved in advocacy or system change. Two respondents reported that the frustration and defeat associated with getting services for their child distracted them from becoming more involved in system change. As one interviewee noted "many families develop the belief that they can't win and that there's no use in trying and they get so defeated that they don't become involved in trying to change the system."

Other barriers to becoming involved were mentioned by individual interviewees. One respondent noted that she was often the only person of color (either parent or professional) in the group and that made involvement difficult. Another respondent reported that the lack of information available about the service system and about opportunities to become involved was a barrier.

One interviewee reported that there were no factors that made involvement difficult for her, although she did have minor difficulties associated with child care for overnight meetings. This respondent had been a paid advocate from the beginning of her involvement.

4. *What have been/are some of the difficulties you encounter as a member on these decision making bodies?*

Seven of the eight interviewees said that they had experienced "lots" or "extreme" problems as a member of a decision-making group. One respondent reported no difficulties, although she had faced some attitudinal problems with the professionals involved. Two of the interviewees noted that because they also possessed professional credentials, they were most often treated like professionals and not like parents. The problems cited within the seven interviews included the negative attitudes of the professionals, issues of representation or tokenism, and the ongoing need to confront professionals. Four of the interviewees mentioned issues with professional attitudes. These included being patronized, judgmental statements, lack of understanding and being blamed for their child's illness. Four of the interviewees noted that ongoing confrontation and conflict was a difficulty. One respondent stated that "you have to be willing to disagree and fight for your ideas, you don't make any friends." Another mentioned continuing conflict between the funding of adult mental health services and children's mental health. Three of the people interviewed mentioned issues of representation or tokenism when they were the only parent or advocate in the group. Two respondents noted that they were seen as "exceptional" or "unusual" parents and told that "real" parents are different. One respondent said she was worried about others knowing so much about her personal life and that this might interfere with her job as a professional. Another respondent noted that she was frequently hassled in her (non-advocacy) job because she took so much time off for meetings and conferences.

5. *What did you or others do to help you overcome these difficulties?*

A variety of strategies for overcoming these difficulties were mentioned. The need to recruit more parents was mentioned several times, particularly parents that represent the needs of diverse cultures and a range of children's ages. Recruiting parents with good advocacy skills was another strategy mentioned. Getting as much information as possible out to parents, both about opportunities for involvement and about the service system might help attract more parents to system change efforts.

Several respondents mentioned the support given by professionals as an important way of overcoming difficulties with involvement. One person reported that the group had gotten good support from psychiatrists as well as other professionals, another noted that it was helpful when professionals reached out to parents and provided modeling of the board member role. Parents were seen by one respondent as a crucial resource in educating professionals.

One parent stated that being a paid staff had overcome many of the difficulties that she had experienced, and particularly led to being taken seriously and not seen as a token.

One interviewee commented "Parents have to be very patient and move past their anger and hurt, they have to focus on the issues."

6. *What kinds of personal skills and abilities did you bring with you as you became involved on groups?*

In thinking about what they had brought to their system change efforts, five of the eight interviewees mentioned their college degree or specific field of study (i.e. special education, early childhood education). One person mentioned education and technical knowledge in the medical area. Three respondents noted that they brought their experience as a parent to the advocacy table. Other discrete skills mentioned included negotiation, public speaking, writing, networking, political skills, communication, patience, and experience in management and leadership. One interviewee mentioned that she had a "viability" in the community because she was known there. Another noted that her ability to work well with diverse people had been developed well before her advocacy work through her travels as part of a military family. This respondent also mentioned that her ability to work with a team was developed through her participation in college athletics.

6a. *What have you developed through your experience of being involved on groups?*

In response to this question, most individuals mentioned the development of skills such as public speaking and writing. The following quotes portray the unique flavor of some of the interviews:

> I learned to listen to baloney, to sit and listen and maintain the parent perspective.
>
> I learned about self care and setting boundaries...learned to negotiate, not to accept no, be decisive and manipulative. (This interviewee also compared the children's mental health movement to the civil rights movement.)
>
> To be even more patient, give greater attention to self care and to the care of my child.

6b. *What further skills would you be interested in developing for yourself in order to become more effectively involved?*

Skills similar to those mentioned in 6a were repeated in response to this question. This included skills like speaking, writing, communicating, coordinating and attributes such as patience, listening and being organized. One respondent felt that she didn't need any additional skills. Another noted that she still needed more information about the system of services and how to change it. A third respondent stated that she still needed to learn how to balance her personal life and activism because her involvement in system change was very time consuming. And one respondent noted "Today it's more than being a parent and telling your story. You need to know the stories of many parents."

7. *What role have professionals played in your involvement and development of skills?*

Professionals have played a variety of helpful roles in the lives of these activists. Providing parents with information, such as giving out the results of research before publication was one activity mentioned. Two respondents noted the help that professionals had given to their organizations. This included help with funding, grant writing, planning activities, facilitating meetings and problem solving. One respondent noted that a professional had mentored her by giving her a part-time job and providing her with training. Another respondent stated that many professionals had helped, primarily by recognizing her lack of confidence and encouraging her.

8. *What has been the personal cost (i.e. physical, emotional, financial) to you and your family for your involvement? What makes the cost worth it to you and your family?*

Two major themes emerged in the responses to this question: financial costs to the family; and the emotional strain placed on the family as a result the respondents activities. Seven of the eight interviewees mentioned major adjustments made by their spouse or children as a result of the demands of their activities. Two respondents noted that their families were "not happy about" the amount of time they spent away from home. One respondent worried that she was neglecting her son. Two interviewees noted physical problems that had emerged, one cited increased drinking and another mentioned ulcers and migraine headaches. Both felt that these problems were a direct result of their frustration in getting services for their children and the subsequent attempts to change the system.

Six of the eight interviewees reported financial stress as a result of their involvement exacerbated by the financial drain associated with their children's services. One participant reminded the interviewer that she was paid part time but usually worked 16 hours a day. A paid advocate reported that she felt guilty about being paid because, "lots of people do it as volunteers." The financial cost of attending conferences and meetings was again raised as well as the financial needs of support groups (coffee, stamps) which is often born by the organizer or leader.

Three of the interviews contained comments about the personal costs associated with publicity and the loss of anonymity that accompanies advocacy work. One interviewee who felt there were no personal costs for her or her family related to her involvement, did note that, "There is no such thing as confidentiality." Another mother who was involved in a lawsuit noted that the publicity around the litigation had been difficult to handle and had caused her to pull back from her usual involvement in system change and advocacy.

9. *What sustains you in your effort to enhance services to children with emotional disabilities?*

The excitement of seeing change and progress and a commitment to children and families seemed to be the two main motivators for the individuals interviewed. Four persons cited the gratification of seeing change happen. One interviewee said "Once you see change, you continue to work for it." Another mentioned that she had seen a lot of progress and that it, "feels good that I am a part of bringing about change." Three of the interviewees discussed their commitment to children and families. One individual said simply, "The kids deserve it." Hoping to help other families avoid the problems they had faced in getting services and information motivated other respondents.

Two respondents commented on the part played by recognition. One had just received a major award and stated "That kind of recognition helps you feel you are doing something worthwhile." Three of the respondents cited the fun involved in meeting and maintaining relationships with the good people involved in advocacy. One respondent noted that she gets to meet a variety of people that she will maintain ongoing relationships with. Another reports that she continues to meet weekly and get support from a group of mothers.

10. *As a volunteer have you been reimbursed in some form for your involvement on committees?*

Five of the individuals interviewed held paid positions, either full- or part-time, as advocates. The respondents reported that they were reimbursed at least part of the time for costs associated with attending meetings such as gas, meals, and airline tickets. One of the unpaid advocates noted that she always asked for reimbursement but had to use personal leave time to be away from her regular job. Several respondents noted that child care is a problem and often is not unreimbursed. One respondent stated that when she has to take her child with her (because of lack of child care) the travel expenses for the child are a major financial problem. Another unpaid advocate reported that the initial outlay for airline tickets, hotel and food was financially burdensome and that few organizations have found creative ways to prepay these expenses.

11. *Describe an experience when you felt yourself an "effective participant"?*

The answers to this question varied with the experiences of the individual. One women reported that she, "always feels effective, even if she doesn't say anything." Another respondent said that she had just been named chair of a state-level committee and that this was very affirming since she was the only parent on the committee. Another respondent told how, as a member of a state conference planning committee, she had managed to get children's topics included in the conference schedule. She felt it wouldn't have been considered if she hadn't been there. This question was not asked in several interviews because the length of the interview was running longer than planned.

12. *Thinking over your own history do you have suggestions of how to recruit families to become involved?*

The issues of recruitment and training of parents for policy level committees sparked an assortment of comments from the respondents. Two respondents stated that parent support groups were the best place to locate parents and two respondents noted that children should also be considered as potential members of boards. Other unique ideas follow.

> Not all parents are ready for system-level advocacy. You have to wait until they can articulate their problems, can see the system problems, and are able to "let go" of blame. Then they are ready to recruited for system advocacy.
>
> Make it an invitation, not recruitment.
>
> Its helpful for families to have a credible statewide family organization behind them. It gives them support, coaching, and leverage.
>
> If more general information about children's emotional illnesses is given to the public, more parents will understand and come forward for system advocacy.

13. *What do you think is needed in developing a program for families to encourage them to become more involved in policy and decision-making processes effecting mental health services for children?*

A number of the skills mentioned earlier in the interview were also raised in response to the question related to training. Respondents felt that skills like public speaking, writing, communication, group facilitation and dynamics and ways to make a group meaningful should be included in training. Other respondents mentioned system change skills such as understanding the legislative process, how to impact decision-making and the budget process as important training elements. One interviewee noted that one of the hardest things to understand is the funding streams. Respondents also had some ideas about how training might be delivered.

> Advocacy training can be done in groups, but training about a specific board should be done one-on-one.
>
> Any training should be done by parents.
>
> If the organization values parents' input, it will train them like any other board member or policy-maker.
>
> We need development of leadership, probably through a mentoring system.
>
> Even parents who have lots of skills are afraid to get involved. Some parents need to ease in gradually by working with a more experienced parent.

14. *What do you think is needed in developing a program for professionals to encourage or support them in involving families in policy and decision-making processes?*

One theme dominated the responses to this questions, otherwise each idea was identified by one respondent and cover a wide range. Involving parents in professional training curriculum was suggested by four of the eight interviewees. One respondent stated, "Professionals need to open doors to professional training, have parents come and talk to class." Another noted that parents need to influence the curricula in professional schools. He mentioned a program that makes professionals attend parent support groups as a part of course requirements. Another concern with professional training involved the lag time between when research is done and the impact of the results on curriculum. One parent noted that professionals need a paradigm shift, to see things through others' eyes.

Additional ideas for either content or approach to training professionals to support parent involvement are interesting to consider.

> Professionals need an attitudinal change, they must learn to listen and be a team player. They must include many families, not just one.

> Professionals need to understand differences due to cultural diversity and see the positive. They should not allow stereotypical thinking.
>
> There has been a lot of positive support from professionals and this needs to be acknowledged.
>
> Professionals need much more skill in marketing. They need to learn how to sell their ideas, how to persuade others. Most professionals don't know how to make a two-minute, high-impact, issue-oriented marketing presentation. Professionals have the credibility but they aren't able to sell their own programs.
>
> Make professionals aware of success stories about where inclusion has worked.

SUMMARY

Taken together, the results of the focus groups and the information in the life histories present a consistent series of findings. Although the life histories probe more specifically into the experiences of individuals over a period of time, both data sets shed light on the challenges faced by family members who chose to involve themselves in policy and decision making bodies. The information provided a partial basis for the development of assessment and intervention activities that were carried out in the Families in Action Project. The next section of this report describes how this information was incorporated into that process.

SECTION III: CASE STUDIES OF INTERVENTION SITES

SITE SELECTION AND INITIAL CONTACTS

The identification of and selection process for demonstration sites began in the spring of 1991. To solicit potential sites, written descriptions of the FIA project were disseminated to state Child and Adolescent System Program (CASSP) directors and State Mental Health Representatives for Children and Youth (SMHRCY). This description asked their assistance in identifying possible sites and described the overall goals of the project. These goals included: (1) to work with local or statewide parent organizations in the development of strategies to enhance parent involvement in policy-making bodies affecting services to families of children with emotional disorders; (2) to develop training and other resource materials related to policy-making process and skills for family members; and (3) to gather data from family members concerning their experiences serving on policy-making bodies.

Interested family organizations selected as sites completed a "Policy Involvement Profile" developed by project staff (included in Appendix C). This profile collected information about the organization (e.g., membership, geographic area of operation, legal status, organizational activities), the history and current level of the organization's involvement on policy-making bodies, and the organization's assessment of the barriers to and potential for involvement in the local service system. In addition, the profile asked organizations to identify what policy changes or areas of influence they were most interested in achieving and the type of help or technical assistance they would need from the project.

While the profile was intended solely to be a tool for project staff to collect baseline information concerning potential sites, it became clear that the process engaged in by parent organizations in completing the form was in many ways an initial and unintended intervention. Several of the organizations eventually selected as sites (as well as organizations not selected to participate in the project) reported that the process of completing the profile had a number of immediate and positive impacts. Most sites completed the profile through a meeting of their general membership or with a group of active parents. Organizations reported this process not only motivated members to become active in the project, but provided an avenue for organization leadership to systematically examine their short and long term advocacy goals. A number of the groups completing the profile reported that this process brought the issue of policy change to the forefront of organizational goals and objectives.

Project staff reviewed completed profiles and information collected over the phone from parent organization leaders and state CASSP and SMHRCY representatives. In addition to information collected in the profile, project staff selected sites based on criteria providing for geographic diversity, differing arenas of policy-making change efforts (i.e., local, regional and state-wide levels), organizations with a diversity of membership socioeconomic status, and sites which had both extensive experience with parents serving on policy-making bodies as well as those with little or no history of family member involvement in the policy-making process. While particular efforts were made to engage a parent organization with a significant culturally diverse membership for inclusion in the project, these efforts were unsuccessful.

Four sites all located on the east coast were selected for inclusion in the project during the summer and fall of 1991. Initial project plans called for the addition of four sites located in the mid-west and western United States, but funding restrictions curtailed this phase of the project. Each parent organization was requested to identify a cadre of members active on policy-making boards or interested in serving in such capacities and willing to work with FIA project staff and provide information on their experiences serving on boards and committees. This participation would include periodically completing a questionnaire concerning their experiences and reviewing and commenting on training and resource materials produced by the project related to policy-making skills and strategies. In addition, key informants that included parents and service providers in each site knowledgeable about the parent organizations and the service system were identified. These key informants were periodically contacted by project staff to provide qualitative information concerning the overall receptivity of policy-making bodies to parent involvement and the quality of such involvement over the life of the project (a copy of the Interview Protocol is in Appendix D). A fifth site of convenience located on the west coast was added in 1993. This site involved a small number of parents active in a national demonstration project examining innovative models of financing and comprehensive service delivery to children with emotional disorders and their families.

By early 1992, FIA project staff had traveled to the initial four sites to meet with participating members of each parent organization. Using information collected from the Policy Involvement Profile, site participants and staff jointly began to identify short and long term goals of each organization regarding increased involvement in policy-making bodies. Possible training interventions and resource material development activities were also discussed, as was the data collection process. In addition to meeting with organization leaders and parents willing to provide data, FIA project staff also met with representatives of major public and private service providers in each site. The purpose of these meetings was to introduce the professional providers to the project, gather information on the extent of family member involvement at the policy-making level, and assess the receptivity of the professional service system to parental involvement. Beyond the stated purpose of information gathering, the meeting with service providers was also seen as a minor, yet important intervention designed to solicit service provider interest and cooperation in the project and to provide additional credibility to parent organization efforts with service providers through their affiliation with a university research project.

Based on these initial contacts, project staff engaged in a series of visits, consultations, training interventions, and data collection and materials development activities in cooperation with each site over the next two years. These site specific activities are described in the following section.

Despite the diversity of each site's goals and activities, one common need initially identified in all sites by participants was access to written materials related to understanding the policy-making process. This need included information on skills and knowledge necessary to serve effectively on a policy-making board or committee, and methods of strategic planning for organizations to recruit members to serve on boards and support and nurture their efforts. Accordingly, a major effort over the next two years was the development of a handbook for parents and organizations involved in policy change efforts; this handbook, *Parents as Policy Makers: A Handbook for Effective Participation* (Hunter, 1994) the major training product from this project. Drafts of the handbook were periodically distributed to sites for review, comment and revision, and the final copy was distributed to all participants in the fall of 1994. A copy of the table of contents is included in Appendix E.

Context for Case Studies

As noted in the introduction of this monograph, the Families in Action Project conceptualized a qualitative field study approach to interventions and material development in each site. That is, project staff purposefully avoided developing a uniform intervention procedure for all sites, preferring that each site develop goals and activities uniquely suited to their situation and experiences. Due to the variability of sites in terms of history regarding parent participation in the policy-making process, the level of policy-making activities (e.g., local agency or regional/state boards), and parent organization capacity, this approach appeared particularly suited to both the exploratory nature of the project and the relatively uninformed knowledge base related to parental experiences in the children's mental health policy-making process. While quantitative data were collected from site participants concerning their experiences (see Section V), a substantial amount of the information gathered on sites was qualitative in nature, including extensive field notes by project staff, key informant telephone interviews, and analysis of organization documents.

This section will report in case study fashion on the activities and experiences of each of the five sites involved in the project. For each site, the following information will be provided: (1) a context-setting description of the participating parent organization and the service system environment; (2) a description of the activities engaged in by sites and project staff relative to involvement in the policy-making process; and (3) a description of unique challenges and successes experienced in each site. Finally, a description of common themes surrounding effective family member involvement in the policy-making process will be briefly outlined. A broader discussion of the general implications of the findings of this project will be taken up in Section VI.

Site One

Site One consisted of 12 parent members of a statewide parent support and advocacy organization in the eastern United States. The organization had nine county chapters with approximately 30 active members ("active" defined as members regularly attending meetings or participating in organization activities) and a mailing list of over six hundred parents. Established in 1986, the organization published a newsletter, sponsored community workshops and forums on issues related to children's mental health, provided individual advocacy services for parents seeking services, and had a long history of involvement with local and state mental health agencies and service providers. Due to the organization's proximity to Washington, D.C., leaders of the organization were also frequently involved in providing testimony on federal legislation related to children's mental health as well as reviewing and commenting on federal polices and programs.

Organization members were participants on a number of policy related boards and committees at both the local and state level, including the mental health, special education and child welfare service systems. Members were often appointed to special, short term task forces at state and local levels as well, working on specific policies, reviewing grants, or participating in the development of requests for proposals related to children's mental health services. The organization worked closely with the state CASSP project and received some funding through that project. Despite this extensive involvement, representation on formal and ad hoc policy making bodies often fell to the organization's founder and leader, and a small number of persons active on the organization's steering committee. The burden of a few members serving on a large number of boards and committees was identified early on by the organization as a major issue to address, and a situation which drained the overall energy and capacity of the organization.

Upon selection for involvement in the FIA project, the organization established a Families in Action committee consisting of participating members. Information for the Policy Involvement Profile was collected through interviews with organization members by the state CASSP director and jointly completed by the organization's leadership and the state CASSP director and was reviewed with participants during an initial site visit. At the beginning of the FIA project, organization members felt overall that their representation on policy-making boards and committees was generally effective in obtaining the policy changes the group was seeking. However, members were dissatisfied with the level of parent representation on boards (often having only one family member sitting on any given board) and their inability to gain membership to policy-making groups they considered critical to the mental health and educational service systems. In this regard, members felt they often had to "fight our way" onto a number of boards and continually struggle against a historical resistance to parent involvement.

As they began work with the project, participants identified a number of barriers to their effective participation. These barriers, which correspond to the barriers mentioned in life histories, included time constraints related to conflicts between meeting times and parent employment, stigmatizing attitudes of professionals concerning parents of children with emotional disorders, a lack of sufficient information on the policy-making process and meeting skills, the financial burdens associated with participation (i.e., lack of compensation for service) and insufficient numbers of family members to serve on boards. Based on the information collected from the profile, participants began to develop target policy boards for representation and preliminary plans to recruit more parents able to serve on boards. Organized efforts were made by the leadership to identify and contact these target boards to request representation. Informal and formal contacts within the service agency community were approached for support and advice on obtaining membership on significant boards affecting children's mental health policy. The state CASSP director played a significant role in this regard by sharing information on state priorities and funding/service planning processes, and by including involvement in the Families in Action project as part of the state CASSP plan.

To assist the site in organizing their activities, in the spring of 1992, FIA project staff participated in an organizational statewide meeting. In a lengthy session facilitated by FIA staff, organization members reviewed their progress in the state and developed a series of short term and long term goals for policy change efforts. At the time of the meeting, the organization had substantially increased their membership on targeted committees, including the state 99-660 Advisory Committee, a state interagency committee representing child serving agencies from multiple service systems, a state advisory committee on mental health services, and several local mental health advisory and coordinating committees. The organization was also involved in a grant proposal with the major school system in the state to promote family involvement as well as planning on new state-wide children's mental health initiatives, and involvement on work groups assessing group home services, home instruction policies, and school system reform. Significantly, a number of the groups members now served on included multiple parent members, although not all were members of this family organization.

Despite their progress, organization members still identified increased recruitment of parents to serve on boards as a major need, as well as an organizational strategy to limit board involvement to those groups most influential in affecting services to their children. Although the increasing number of boards that the organization now had representatives serving on was an indication of increasing organizational recognition, the demands of board service continued to sap member and organizational energy. While the number of boards on which the organization was represented had increased, the number of individual parents serving had not kept pace, and as a result, members now served on multiple boards. The increased demands on their time, as well as the increasingly complicated work of the boards and committees, led members to identify the need for written materials from the project related to the policy-making process that were reader friendly and which could be put to practical use. Participants at the meeting identified the need for information on different types of boards and committees, board member rights and responsibilities, communication and meeting facilitation skills, and information on developing an organizational strategic planning process. Towards this end, and in keeping with needs expressed by other sites, FIA project staff began working on a draft handbook for policy involvement, soliciting periodic feedback from organizational leaders and participants.

Following this meeting, a number of events unfolded that would begin to create difficulty within the organization over the next year. Relations between the organization and the state CASSP director began to deteriorate as disagreements over funding priorities and processes arose. CASSP funding for some programs and activities were awarded to or shared with a rival group representing families of children with severe mental illnesses. Some members and leaders of the organization felt betrayed by the state's funding of rival groups, and communication and collaboration with the CASSP director became strained. At the same time, serious internal dissension concerning the direction and leadership of the organization arose, causing a temporary disruption of some organizational activities, including participation in the FIA project. This internal leadership crisis eventually led to several key members leaving the organization, moving into other existing local groups or attempting to establish a new family organization. Organization leadership experienced additional disenchantment in their failure to obtain a significant amount of operational funding through a federal grant to statewide family organizations.

Despite these setbacks, the organization continued efforts to increase representation on policy-making boards and committees, both in recruitment of parents to serve on policy-making bodies, and the provision of workshops and materials related to individual and system advocacy skills and techniques. A “Parent Council” consisting of members of the organization and representatives of major family and child service agencies was formed to examine the array of services provided in the state's most populated county and improve communication between families and agencies. FIA project staff assisted the council in the provision of the first of a series of well-attended workshops for professionals and family members on improving parent and professional collaboration and enhancing family involvement in the policy-making arena.

At the organization’s annual meeting in the fall of 1993, FIA project participants reviewed draft materials developed by FIA staff and provided feedback and suggestions for additional materials. New participants had been recruited for board and committee work, and the organization leadership had worked diligently to develop formal and informal opportunities for members working on boards to share their experiences and better coordinate their positions and actions on boards. While participants at the meeting felt they were increasing both their skills and influence on policy-making bodies, they also expressed concern that some agencies were recruiting parents on to boards who were new to the system and not connected to parent support and advocacy groups. In this regard, organization leaders wondered if this trend of agency selection of relatively uninformed consumer representatives was in reaction to the growing sophistication and clout of their members, and an attempt to blunt their growing influence.

During and following this meeting, efforts were undertaken to mend relationships with the state CASSP office and its new director. Significantly, the organization decided to expand FIA activities statewide and began working with a local state university to continue this effort.

Site Two

Site Two consisted of ten members of a newly formed parent support group in a rural county in the eastern United States. The support group was formed under the sponsorship of the county Mental Health Association and consisted of parents whose children had emotional and behavioral disorders and had been receiving a variety of services from the association. The parents in the group were primarily from a low income, working class socioeconomic status and dependent upon public agencies for services. At the time of their initial involvement with the FIA project, few of the parents had any experience serving on policy-making boards, and key informants reported that there was little or no history of consumer involvement in the county in terms of children with emotional disorders. The fledgling parent organization had primarily focused on providing members personal support, but there was a growing interest in expanding the group's activities to include individual advocacy and system reform efforts.

Initial information from the group's Policy Involvement Profile revealed that the parents perceived the service system as generally resistant to meaningful family involvement at the policy-making level, and that a primary initial goal of the organization was to improve the overall climate of communication and understanding between service providers and families. One incident in particular had motivated the parents to seek involvement in the FIA project: a member of the organization had been invited to testify on her experiences as a client before a local committee overseeing family services in county. This member reported that in the process of testifying, committee members (all professional service providers) began to provide her "counseling" rather than elicit her testimony, and that she and other parents present at the meeting felt humiliated by the experience. After this experience, the parents in the support group began to prioritize efforts to improve the level of understanding and communication between providers and family members.

FIA project staff made an initial site visit in early 1992, meeting several times with the parents and with representatives of public and private social service agencies serving families of children with emotional and behavioral disorders. These meetings confirmed the parents' perceptions that there was a broad skepticism among service providers as to the benefits of consumer involvement at the policy-making level, and in some key public agencies, a clear resistance to such involvement. In several interviews, providers recalled the occasion of the parent testifying before a local committee and cited this as an example of the inability of "dysfunctional" family members to serve on policy-making bodies. Other providers argued that the service community had a long history of close collaboration and that they were already capable of representing the need of their clients.

Despite the generally negative perceptions among providers concerning consumer involvement, some notable exceptions to this attitude existed, particularly within the mental health system, whose county director was strongly supportive of efforts to involve consumers. The support of this director would prove to be critical to the subsequent successes that the parent group had in their efforts to increase their role in the system.

In the initial meeting with the parent group, it was decided that the group would focus their initial efforts on improving informal lines of communication with the service system as a precursor to attempts to become involved formally on policy-making boards and committees. Parents in the group felt strongly that activities which would increase the general level of understanding and collaboration between families and service providers were essential before they would be accepted or gain entree as representatives on policy-making bodies. Accordingly, FIA project staff worked closely with the parents and representatives of the Mental Health Association to develop and sponsor a workshop on family-professional collaboration to be attended by members of the group and service system providers and administrators. Building on the supportive attitude of the county mental health agency director, the parents obtained his endorsement as well as that of the county social services commissioner for such a workshop to be held in the county mental health office. Invitations to attend the workshop were personally made by the parent group members and the mental health director to representatives of local mental health, child welfare and education agencies.

The workshop was held in the winter of 1992 and was well attended by a variety of service providers and administrators providing services to children with emotional disorders and their families, as well as parents from the support group. Built on the theme of developing a family-centered system of care, workshop participants reviewed the current status of family involvement and developed strategic plans to enhance family involvement at both the service deliver and policy-making level. The workshop was generally well received by agency participants, and a number of administrators present at the workshop open their advisory committees to parents of children with serious emotional disorders. Other decisions to improve family involvement in the development of inter-agency treatment planning and service evaluation were also endorsed by participants.

Following the success of this workshop, the parent group intensified their advocacy efforts over the next year. The parent group affiliated with the state-wide family support organization, and one member joined the editorial board of that organization's newsletter. Parents in the group became members of advisory boards to a new demonstration project providing family support services, a local program providing respite care to families, and a local coordinating council for children's services. They also increased their efforts to testify at public meetings and hearings, and were increasingly called upon by agencies to provide information on how to improve services to families. Members of the group were invited to share their experiences in a workshop at an annual conference of the state's Mental Health Association and at a national conference sponsored by the Research and Training Center in 1994. As in other sites, as the parents expanded their activities into membership on boards and committees, they requested written materials from FIA project staff about the policy-making process, communication and meeting skills, and strategies for individual and class advocacy.

At the conclusion of the FIA project, the parents were continuing their efforts to serve on policy-making boards, provide individual case advocacy and to expand their membership through the publication of a newsletter. The group was formally recognized by the Mental Health Association in 1994 in an awards ceremony for their advocacy efforts on behalf of children and their families. While the parent group had begun to make important inroads in their efforts to impact the policy-making process, they continued to be hampered by a small membership, lack of a coherent strategic plan, and the fact that representation on committees tended to fall upon the group's two leaders. Despite their representation on some advisory boards and committees, membership on the most influential county and regional policy-making bodies governing family services continued to elude them.

Site Three

FIA project involvement in this site began with a regional mental health planning board spanning nine, mostly rural, counties in a northeastern state. This state mandated board was responsible for the overall coordination and planning of mental health services affecting children with emotional disorders and their families over the nine county region. The board consisted of representatives from county public and private service agencies, and included four parents of children with serious emotional disorders drawn from county parent support groups formed as part of a state funded family support project. Initially, it was the intent of the FIA project to work with the board to examine the experiences of its membership concerning parent participation. However, after two site visits, it was determined with the board and parent members that more representative information concerning family member experiences could be obtained by broadening the scope of the site to the counties within the board's catchment area, where local county advisory boards initiated planning which was funneled to the regional board for approval or occasional modification. Given that the locus of parent involvement was found to be more active at the local county level, and that the regional board met only occasionally, the FIA project approached the local parent support groups in the region to participate in the FIA project.

Collectively these local support groups, formed in 1990 and 1991, reported fifty five active members. Each support group provided support services to families of children with emotional disorders in their county, sponsored educational forums or workshops, maintained a telephone "warmline" for parents, and served as local information and resource centers for families seeking information, support and advocacy related to services for their children. Each support group had members active on local policy-making and advisory bodies related to mental health, child welfare, and special education services.

While active on a number of policy-making bodies, all the participating groups felt dissatisfied with the level and extent of their involvement and what they felt to be the relative ineffectiveness of their participation. More specifically, the parents felt that their views were often ignored or discounted by other professional committee members, that the work of the boards was perfunctory in nature and had little impact on actual service delivery, and that they needed resources and information to better acquaint themselves with the policy-making process and how to operate as an effective committee or board member. At an early meeting with site participants, the FIA project agreed to provide participants materials and information related to effective board participation and provide technical assistance and consultation as requested. Representatives of the support groups active on boards also scheduled monthly meetings so that they could share their experiences and begin to jointly plan efforts.

As in other sites, participants felt that a prerequisite to their enhanced participation in the policy-making process was the need to improve the general level of understanding and communication between parents and service providers. Participants reported that notions of family-centered care were still largely foreign to providers and that the stigma attached to parents of children with emotional disorders continued to retard their efforts to influence the system. Accordingly, the group concentrated much of their effort on developing and providing local workshops on individual and system advocacy, legislative advocacy, respite care, and family-professional collaboration. In response to new state legislation in 1993 mandating increased family involvement in treatment planning and service delivery, the support groups sponsored a major conference on family-centered care and family involvement, well attended by families and service providers. FIA project staff were invited to attend and provide a keynote presentation on family involvement at the service delivery and policy-making levels, and to co-facilitate a workshop on advocacy and public education for children's mental health. Draft materials for a handbook on policy-making developed by the FIA project were also distributed to participants for their use and feedback.

Following the conference, participants continued to provide educational forums and workshops for members and the professional service community. Participants also became involved in the planning phase of the state plan for mental health services, in coordination and cooperation with the statewide parent organization operating in the state. Despite these positive efforts at promoting family-professional collaboration, the groups were not successful in gaining an overall increase in representation on policy-making bodies, and were hampered in strategic planning by the geographic spread of the individual groups and the lack of any specific leadership in their policy change efforts. Similarly, participants remained frustrated at the slow pace of the committees and boards they served on as well as the small number of parents serving on such bodies.

Site Four

Site Four consisted of twelve members of a statewide parent support and advocacy organization in a small northeastern state. The organization had eight support groups with approximately 45 active members and a mailing list of over 200 parents. The organization was established in 1989 and led by a professional employed by the state's Mental Health Association. The organization received a significant amount of its operating budget from the state's CASSP office and worked closely with that office to advocate for family-centered services and programs in the state.

Largely through the strong support of the CASSP director, the organization was represented on eight local CASSP coordinating councils and the state CASSP advisory board. Members of the organization also were represented on a large number of local committees and advisory boards related to children's mental health and special education services, although representation on any one committee was usually limited to one parent. Despite their representation on the local CASSP councils, many of the parents were unclear as to whether they served on the board as a representative of the parent organization or as a free standing member. The organization and the CASSP director also reported that parent attendance at council meetings and other policy-making bodies was irregular, making it difficult for a coherent and organized consumer voice to be heard. Adding to these problems, leaders of local support groups would come and go from the organization, and it was difficult to create a stable base of leadership for organizational development and cohesion.

At an initial meeting with site participants in March of 1992, further concerns and needs were raised relative to their work on policy-making bodies. Many participants felt that they did not have a clear understanding of what the functions and powers of the boards they served on were, and how their service on the boards related to the goals of the parent organization. Participants said they often felt intimidated in meetings by the presence of professionals who appeared more skilled at speaking and understanding the complicated language of budgets, policy formation, and meeting procedural rules. Participants expressed a strong need for information, materials, and resources related to how to be an effective board member, how to communicate effectively, and techniques for effective advocacy. The group also felt that their work was hampered by lack of understanding among professionals concerning the contributions that parents could make. Many expressed concern that parents were stigmatized and viewed as clients rather than partners in the policy-making arena. Finally, participants felt that the parent organization needed to develop a more coherent plan to coordinate the work of parents on policy-making bodies and develop a more cohesive leadership structure to support policy-making activities. Participants noted that while they were active on a number of boards, the primary focus of the parent organization had been on the development of support groups, and that as an organization they lacked a structure and vision related to work in the policy-making arena.

As a result of this initial meeting, it was decided that the FIA project would assist the organization in developing a long range strategic plan for involving its members in policy-making activities and work on the development of written materials and resources related to service on boards for participants. An initial workshop to be facilitated by FIA project staff was scheduled for later in the year to help develop a plan of action. It was decided that key service providers and administrators of family service agencies would be included to promote a collaborative approach to the project and to enhance working relationships between the parents and community professionals.

The resulting workshop, held in June of 1992, was well attended by both parents and community service providers and key administrators from the state mental health system. Participants at the workshop developed a mission statement supporting the inclusion of families in the development of services and the formation of policy related to programs serving children with emotional disorders and their families. A number of short term and long term goals were identified by the group to promote family-professional collaboration and parent involvement in policy-making. Among the long term goals, it was agreed that the parent organization needed to develop a list of policy change priorities, a plan to recruit parents to serve on policy-making boards, and a plan to educate and support members serving on boards and other advisory committees. In the short term, the group prioritized training and information on advocacy and lobbying, collection of information and data on the local systems of care, and a focus on working with the state CASSP to develop flexible, wraparound services for children and their families.

Despite the success of the workshop in bringing together members of the parent organization and the service community and the development of an initial plan of action, emerging external events and internal changes in the organization would at least temporarily derail substantial progress. At the time of the June meeting, the state was in a deep fiscal crisis that was resulting in program reductions, difficulties in meeting funding obligations to programs (including the parent organization) and temporary layoffs of employees, including the state CASSP director. This deep fiscal crisis diverted the enthusiasm and attention of service providers from innovative attempts at the inclusion of families to the day to day survival of existing programs and procedures. Perhaps more significantly, changes in the leadership and legal status of the parent organization would also shift attention and energy away from policy-making activities.

Shortly before the June meeting, the founder and director of the parent organization announced she was leaving, feeling it was time for a parent of a child with an emotional disorder to take over leadership of the organization. The outgoing leader was well respected by the organization's parent membership and the professional community, and her departure created concern and questioning among some members as to the future of the organization. Despite the outgoing leader's strong endorsement of the new director, a number of key members in the parent organization left or reduced their level of involvement. While supportive of the FIA project, the new director necessarily directed much of her energy and attention to establishing her creditability and support among the membership and its internal advisory board. A major goal of the organization to become an independent, non-profit corporation became the focus of the new leadership's efforts. Relations between the group and its sponsoring agency had become increasingly untenable and during 1993 and early 1994 the organization became free-standing, developed a board of directors, and obtained federal funding for operating expenses. During the process of incorporation and shortly afterward, differences of opinion over the direction and structure of the organization began to surface between board members, the director and some organization members. The director faced increasing difficulty managing the organization in the face of a divided board of directors and the FIA project staff was asked to assist in providing board development training.

As the FIA project came to an end, the organization was in the process of re-focusing its work on policy-making activities through involvement in a major federally funded state initiative to develop a comprehensive service system that emphasized parent involvement in the development, delivery and evaluation of services. While site participants continued their work on policy-making bodies and used and provided feedback on materials developed by the FIA project, issues of organizational change and survival necessarily superseded attention to a concerted focus on policy-making activities and strategy development.

Site Five

Site Five consisted of five parents receiving services from a national demonstration project examining a managed care approach to financing innovative mental health services to children and their families. This demonstration project, located in an urban county on the west coast, involved a number of public provider agencies in a pooled financing structure providing case management services for children with severe emotional disorders and their families. An advisory committee consisting of participating agency representatives and parents of children served in the project was established to review and comment on program planning.

The five parents in this site, who were active in serving on the advisory committee, began meeting as an informal support group upon the initiative of an employee of the demonstration project who was also a parent of a child with an emotional disorder. This employee contacted the FIA project in the late spring of 1993 to request our involvement with the parent group in order to assist them in their work on the advisory committee. FIA project staff met with the parents to discuss the work of the project and identify what kinds of technical assistance and consultation would be helpful. The parents all expressed a need for materials and resources related to information and skills necessary for serving on boards and committees. The parents felt that their service on the advisory committee was important to them but questioned the real value or impact of the committee's work on the actual services provided by the demonstration program. All the parents expressed a discomfort in their role on the advisory committee and feelings of inadequacy in their ability and skills to effectively participate in the committee's discussions and decision-making. The parents were also concerned about the small number of parents active in the policy-making process of the program and were interested in reaching out to more parents served by the project.

A strategy session was held with the parents to share a draft version of the policy-making handbook developed by the FIA project and explore directions the parents could take. A primary goal of the parents was to take on leadership positions in the advisory committee and to move the program to identify what services would be provided after program funding ended. The parents in the group were particularly concerned over the continuation of services to families whose children were not Medicaid eligible and were anxious to ensure that the county would continue serving those families currently in the program.

Another initial priority for the parents was to attempt to include more parents served by the program in a support group. The parents obtained the cooperation of the program in sending out a mailing inviting families to a potluck in early June. Despite their efforts to publicize the potluck, few new parents attended the potluck and the group then concentrated their efforts on their work on the advisory committee. The parents successfully obtained a decision by the committee to establish a co-chair arrangement consisting of a parent and a professional for committee governance and one of the parents was selected as a co-chair. The parents also lobbied for intensified planning to ensure continuation of program services past the federal funding and met several times with state and county planners to provide their input and advice. Parents utilized the materials developed by the FIA project and reported an increase in their skills and comfort level on the committee. While all of the parents continued to question the ultimate impact of the committee, they were encouraged by what they perceived as changing, positive attitudes and receptiveness of professionals on the committee toward parent-initiated concerns and suggestions.

Outside of their work on the advisory committee, the parents initiated contact with the statewide parent support and advocacy organization and became increasingly active in the work of that organization. One member also traveled to a national conference to speak on the demonstration project and the role of parents in the project and was invited to participate with FIA project staff in a statewide televised workshop for professionals on the development of family and professional collaboration.

At the conclusion of the FIA project, the parent group was continuing its work on the advisory committee, advocating for continuation of program services past the demonstration project's initial funding with state and county officials, and making use of the project's handbook on effective participation in policy-making.

Summary

Despite the unique circumstances and characteristics of the groups participating in the FIA project, a number of common themes and issues arose in their efforts to enhance their work on policy-making bodies. Participants in all sites shared a strong commitment to improving services for children with emotional disorders and their families. For most, their participation in public advocacy and policy change efforts originated in their struggles to obtain adequate services for their own children, and subsequently for all parents in similar circumstances. Their commitment notwithstanding, most of the parents involved in this project were frustrated and confused by the slow nature of policy change and the sometimes Byzantine procedures and structures of policy-making bodies. Few participants in the sites felt they possessed skills necessary for effective participation in the policy-making process, and many doubted the ultimate impact of the boards on affecting or changing services. Most of the participants expressed a need for information, materials and resources related to board service -- particularly information that helped them understand what policies consisted of, how policies affected the service system, and how they could communicate effectively on boards to advocate their positions and influence decision-making.

To varying degrees, the relative success of organized parent efforts in all the sites was affected by the ability of the organization leadership to adequately focus their attention on policy change efforts. The need to provide more traditional support and advocacy services for families and at the same time initiate new organizational attempts to influence policy often strained the resources and capacities of the organizations. The day-to-day demands of maintaining the organization, changes in leadership, and the impact of external political forces and events all negatively impacted organizations' abilities to develop and sustain a strategic plan of policy-change efforts. Likewise, attempts to recruit adequate numbers of parents to serve on various boards and committees were largely unsuccessful. The daily demands of parenting a child with an emotional disorder, the lack of financial incentives or reimbursement for such service, the fluctuating nature of parents' levels of involvement with a parent organization, and the extensive time commitments required for board service were some of the factors identified by sites as inhibiting their recruitment efforts. Many parents were sole representatives on boards and committees and felt isolated and outnumbered on boards dominated by professionals working in the system.

Participants did feel, however, that their work on policy change efforts enhanced their skills and ability to advocate for improved services, whether for their own child or for all children in general. Involvement in the FIA project did help organizations to consider what policy changes were most critical to their organizational goals and to begin a planning process to effect those changes. Despite the numerous obstacles faced by the sites, all continue to focus attention on these goals and policy change efforts.

SECTION IV: PROJECT EVALUATION: A SURVEY ON ADVISORY GROUP PARTICIPATION

INTRODUCTION

This section of the final report includes information obtained from the primary evaluative measure used by the Families in Action project. This measure, a questionnaire focusing on the experiences of individual family members during their participation on boards, was entitled *A Survey on Advisory Group Participation.* As a basis for the evaluation design of the project, staff developed several hypotheses about family member participation on boards. These hypotheses identified three potential outcomes related to involvement with the training and other educational efforts of the project. They included: (1) increased numbers of parents participating on boards; (2) the reduction of barriers to such participation; and (3) improved professional/provider attitudes toward family member participation. This section will both address these hypotheses and offer additional observations about the nature and direction of family member participation on advisory boards and other decision-making bodies.

METHODS

Instruments

The primary survey instrument was developed in consultation with Research and Training Center staff and local and national parent/professional advisory groups. Responses to initial drafts of the survey were solicited from selected participants in each site, and the version of the survey used for this report was finalized in December of 1992. The survey consists of 45 questions, eliciting quantitative, qualitative, and demographic data. A mix of four-point rating scales and open-ended questions predominate. For example, family members are asked, "Do you think this advisory group does important work?", and given the possible responses of "Very important," "Moderately important," "Slightly important," or "Not important." The open-ended item, "If you feel the group does important work, please describe some of the group's goals and accomplishments" followed. Demographic data collected included sex, ethnicity, relationship status, income, education and whether the respondent held a job as a mental health or social service professional. Family members were also asked the ages of all children in their family, if their child(ren) had an emotional or behavioral disorder, and where the child was living at the time the questionnaire was completed. The complete survey instrument, along with comprehensive tables of results, can be found in Appendix F.

In addition to the 45 items developed by project staff, respondents were asked to complete the 34-item *Family Empowerment Scale* (Koren, DeChillo & Friesen, 1992.)

This brief scale assesses empowerment in families whose children have emotional disabilities. It utilizes Likert-type ratings to measure empowerment across three levels: (1) the family; (2) the service system; and (3) the community and political environment. Use of the *Family Empowerment Scale* makes comparison with other samples possible, as well as providing additional evaluative data.

Design and data collection

The evaluation was planned to consist of three "waves" of surveys, each roughly six months apart. This design provided for collection of aggregate data sets over time that would yield both descriptive and evaluative information. The first wave, disseminated in the early winter of 1993, garnered an encouraging response of 29/55 (53%.) The second, mailed in the fall of 1993, had a discouraging and somewhat baffling--no responses were received from an entire site--response rate of 25% (13/53). The third and final wave was sent out in the spring of 1994, with 18 respondents returning completed surveys, a response rate of 34% (18/53). About six weeks after the original questionnaire was mailed, a reminder letter was sent out for waves one and three. No reminder letter was sent for wave two. Table 1 summarizes the numbers of responses returned/mailed by site, total numbers returned, and total response rate for each wave.

Table 1: Response Rates Across Sites

Site #	Wave 1	Wave 2	Wave 3	Matched sets (1 & 3)
1	8/15*	3/15	5/14	2
2	5/9	1/8	1/8	1
3	6/16	5/15	6/15	5
4	5/10	0/10	2/10	2
5	5/5	4/5	4/5	4
Totals	N=29/55	N=13/53	N=18/52	N=14
Rate	53%	25%	35%	n/a

*number of completed surveys returned/number mailed to site(s)

Disappointing response rates and respondent attrition over time may be attributed to a number of factors. When sites were recruited to work with the Families in Action Project an agreement was made that, in exchange for training and consultation, individuals at the site would participate in the evaluation. After the initial workshop, ongoing consultation and technical assistance was provided primarily to leadership in the organization. Other family members may have forgotten about the Families in Action Project. Turnover among the family members involved also contributed to the low response rate in later waves. In addition, site-specific changes within family organizations (discussed in Section III, above), and ongoing constraints on parents' time and energy contributed to the low returns. Because of these circumstances, the second smallest data set (n=13) was dropped from consideration for analysis. Fourteen sets of responses, consisting of respondents who had returned completed surveys to both the first and third waves, were included for analysis in this report.

Sample recruitment

A non-random, purposive sample was recruited for the survey from interested participants in training sessions held at each of the five sites of the project. As project staff attended meetings organized in each site, any family member who indicated an interest in serving on an advisory board or other decision-making body and who was willing to sign a Research and Training Center consent form became part of the initial sample. Participants were assured of anonymity through use of a respondent-chosen "personal identification code," with the suggestion that it be something stable and easy to remember, like the last four digits of a social security number or phone number. Use of this method of tracking respondents led to unforeseen difficulties when several family members forgot their code and used different numbers each time. Review of demographic data enabled project staff to match most mis-coded surveys. Both in hopes of increasing a flagging return rate to the final wave of surveys and as a way of thanking family members for their participation, survey participants were offered their choice of a free publication from the Research and Training Center's publication listings. This was the only gratuity offered participants.

Characteristics of respondents

Complete demographic data for all respondents to the first and third waves of surveys are included in Appendix H; only characteristics of the subset of 14 respondents will be considered here. All were women and all indicated "white" as their ethnic identity (see Tables 36 and 37 in Appendix G); 71% were married or in a marriage-like relationship when queried in the winter of 1993; by spring of 1994 one more respondent was married (see Table 38.) The percent of respondents sharing responsibility for daily parenting remained stable at 86% across sampling times. In most cases (12 of 14) a spouse was listed as the person who regularly shared parenting, although two respondents listed "friends" as that support person. Tables 39a and 39b in Appendix G detail participants' responses to these questions. A wide and well-dispersed range of income levels was reported (see Table 40 in Appendix G), with minimal change over time (two cases of higher, and one of lower, income were reported.) All respondents had completed high school, five indicated having taken some college coursework, and four had obtained either college or graduate degrees. At the time of the first survey, only two respondents held jobs as mental health or social service professionals; that number had risen to five by the spring of 1994. Documentation of these latter two characteristics can be found in Tables 41 and 42, respectively, in Appendix G.

The 14 families represented in the subsample were caring for 28 children. Tables 46a-c in Appendix G contain complete responses to questions regarding children. Sixty-four percent of the children had an emotional or behavioral disorder, a figure that not unexpectedly remained stable over time. Age distribution of the children changed predictably over the sampling interval; while 54% were school-aged (ages 6-12) at the time of the first survey, that figure shifted to 43% by the final response, when the percentage of teenagers (ages 13-18) rose to 50%. Most children (79% and 86%, respectively) lived at home throughout the time encompassed by the surveys; two remained in residential settings across time, while 2 of 3 children who had lived in a group home at the time of the first survey had returned home by the spring of 1994. One child was living as an independent young adult; another's condition had worsened to the point of hospitalization by the time of the final survey.

Given the small size of this sample, the lack of a control group, and the lack of diversity in gender and ethnicity among respondents, the findings that follow will be interpreted cautiously. We make no claims of broad generalizability; rather, we wish to note interesting trends and begin to describe family member participation in a systematic manner.

FINDINGS

The Survey on Advisory Group Participation had seven general content areas. The first content area included questions pertaining to the advisory group itself and the level of participation of individual respondents. The second focused on questions about the perceived benefits of membership. The third content area examined certain aspects of respondents' experiences as advisory group members, including relationships with other parents and professionals on and outside of the board. The fourth content area investigated meeting arrangements, including reimbursement (or lack thereof) for personal costs or expenses family member participants incurred as a result of their attendance at meetings. The fifth content area invited respondents to evaluate changes in their level of understanding of the children's mental health system and in their skills as group members and leaders. A series of items asking for demographic data was the focus of the sixth content area; included here is a twelve-item checklist of specific actions parents may have undertaken on behalf of their own or others' children. Finally, the seventh content area was comprised of the *Family Empowerment Scale* described above.

The findings section that follows is organized following this seven-part pattern. As a general format, data from the winter 1993 "wave" of questionnaires will be presented first, then compared and contrasted with data from the spring of 1994. Tables will be included in the text for selected data. Missing responses are included in the tables and in the percentage totals for all items where they occurred. Comprehensive tables corresponding to each item of the questionnaire can be found in Appendices G and H.

Characteristics of advisory groups and levels of participation of respondents

The first three questions provided information on respondents' membership status, the focus (possibly multiple) of the group they participated in, and the size and constitution of the group as a whole. Tables 1 through 3 in Appendix G contain the responses to these questions. Nearly all respondents (13, or 93%) were members of advisory groups or other decision-making bodies in the winter of 1993. One respondent (7%) had served on a board in the past and answered using that experience as her base of reference. Most groups (n=12, or 86%) were specifically focused on children's mental health, with several having additional emphases on public or special education (n=5, or 36%) and early intervention (n=4, or 29%.) Child welfare and juvenile justice were noted as foci of one group (7%) each, while the category of "other" was checked by four respondents. Eight groups (57%) were reported to have between 10 and 15 members, while four (29%) had 16 to 25 members, and one (7%) had 30 members. Missing responses are included in the percentage totals for all items; one respondent did not answer the question regarding group size.

By the spring of 1994, minor changes had occurred. Two respondents were no longer active on a board. Children's mental health remained the predominant focus of most of the groups, while substance abuse and juvenile justice were mentioned more frequently. The number of group members remained relatively stable as well, with slight movement toward larger group size.

Questions regarding the length of the respondent's membership on the group, how long the group had existed, and how often the group met followed. Tables 4 through 6 in Appendix G depict these data. Four (29%) family members had served less than six months at the first sampling; another four indicated service of six months to one year; and another four had served between one and two years on a board. One respondent (7%) noted service of three years and four months. Almost half (n=6 or 43%) of the groups were reported to have existed less than one year, while three (21%) had been in existence between one and eight years. Three respondents indicated they didn't know how long the group had existed, raising questions about the thoroughness of their orientation to the board they served on. A majority (n=11 or 79%) of the boards met monthly. Predictable increases in the length of respondents' membership and in the length of time the group had existed were reported in the spring of 1994.

Tables 2 and 3, containing information about regularity of attendance and the numbers of parents in the group, summarize the responses to two questions that are of particular import for evaluation. These tables can also be found in Appendix G, numbered Tables 7 and 8, respectively.

Table 2: Regularity of Attendance

	Winter '93		Spring '94	
	n=14	%	n=14	%
Always	12	86	13	93
Often	2	14	1	7
Seldom/Never	0	0	0	0

The consistently high regularity of attendance over time portrayed in Table 2 points toward maintenance of a high level of commitment on the part of family members surveyed. The dual movement towards both fewer and more "other family members in the group" found in Table 3 is particularly interesting. This shift is from none to three reporting no other family members and from none to five respondents reporting "more than five" other family members in the group. This suggests that, in some groups, family members were gaining representation while in others, family members were losing ground.

Table 3: Number of (Other) Parents or Family Members in Group

	Winter '93		Spring '94	
	n=14	%	n=14	%
0	0	0	3	21
1-2	2	14	2	14
3-5	9	64	4	28
5+	0	0	5	36
Missing responses	3	21	0	0

Questions regarding participation in subcommittees or as a leader or officer of the group were designed to provide insight into the amount of responsibility family members accepted (or were encouraged to accept.) Fifty percent (n=7) of the respondents from both samples reported that their group had no subcommittees. Four respondents (29%) reported current service on subcommittees; this figure remained stable over the two time periods. Participation as an officer in the group was relatively stable, with 29% (n=4) reporting current or past service as an officer on the first survey and 36% reporting holding or having held such positions at the time of the final survey.

Another intriguing trend reflecting apparent movement toward increased participation was found in responses to participants' rating of the following question: "Overall, how active are you as a member of this advisory group?" Table 4 (Table 11 in Appendix G) illustrates this trend.

Table 4: How Active as a Group Member

	Winter '93 n=14	Winter '93 %	Spring '94 n=14	Spring '94 %
Very active	5	36	10	71
Moderately active	6	43	3	21
Slightly active	3	21	1	7

This movement toward a higher level of activity contrasts interestingly with respondents' rating of their own activity level compared to other group members. Table 5 (found in Appendix G as Table 12) makes this contrast clearer:

Table 5: Activity Level Compared to Other Group Members

	Winter '93 n=14	Winter '93 %	Spring '94 n=14	Spring '94 %
Much more active	2	14	0	0
Slightly more active	1	7	6	43
About the same	10	71	6	43
Less active	1	7	1	7
Missing responses	0	0	1	7

Results from the first wave showed 2 family members (14%) rating themselves as "much more active" than other group members while most respondents (n=10, 71%) felt they were "about the same." Responses from the second survey were largely split between two categories. "Slightly more active," had six responses (43%), while "about the same" shifted downward to 43%. One interpretation of these figures suggests that as family members become more experienced and expanded their frame of reference about participation on boards, their perceptions of themselves and others become more realistic; for most this means somewhat lowered expectations.

An eight-item rating scale using examples of participatory behavior during group meetings enabled respondents to mark how frequently they did the activities listed in Table 6 (Table 13 in Appendix G.) For each item, respondents were directed to circle either "never," "sometimes," "often," or "regularly," with items coded from 0 (never) to 3 (regularly). Thus, the higher the mean score, the greater the incidence of the behavior in question.

Table 6: Participatory Behavior During Group Meetings

	Winter '93 (Mean Scores)	Spring '94 (Mean Scores)
Enter into discussions	2.2	2.2
Place items on the agenda	1.1	1.4
Introduce topics under "new business"	0.7	1.3
Make formal motions	0.4	0.9
Present draft position statements for the group to review	0.4	0.8
Disagree with others	1.2	1.4
Accept responsibility for a task	1.7	1.7
Other	0.4	0.3

Examples of other activities included one parent noting that she kept the minutes and prepared the agenda (she participated as a paid staff member who was also the parent of a child with an emotional disorder) and another respondent mentioning that she provided "information of use to members." The relatively low average scores across samples rise slightly over time for some of the items; however, the small sample makes any interpretation impossible.

Perceived benefits of membership

Table 7 (found in Appendix G as Table 14) depicts the change in participants' views of the importance of the groups' work.

Table 7: Perceived Importance of Advisory Group Work

	Winter '93		Spring '93	
	n=14	%	n=14	%
Very important	9	64	4	29
Moderately important	1	7	6	43
Slightly important	2	14	3	21
Not important	1	7	0	0
Missing responses	1	7	1	7

Respondents' remarks to the corresponding qualitative item, “If you feel the group does important work, please describe some of the group's goals and accomplishments,” were mixed across both surveys. These are two illustrative examples from the spring of 1994:

> The group seems to have little REAL influence, though the subcommittee works hard to develop an excellent statement about long range program goals for children.
>
> The group has helped children's mental health, public and special education.

Qualitative responses from the second wave of surveys also had both positive and negative themes. Two family members' statements capture these perceptions.

> We advise a larger body and are able to articulate our concerns, both positive and negative.
>
> [This] group has the potential to set key policy for the state--but it is stuck and has not accomplished anything significant.

It appears that family members participating on boards expressed continued hope for meaningful impact while they frequently--and simultaneously--felt frustrated over the perceived lack of significant change.

A cluster of questions exploring other potentially positive aspects of board membership showed minor change between the two points in time. Table 15 in Appendix G contains complete responses to question 15a on the survey: "Do you think that other parents who know of your membership on this advisory group respect and appreciate your work?"

Responses were basically positive, as figures for the first sample showed 21% felt "a lot" of respect and 57% felt "some" respect from other parents. These percentages shifted slightly by the spring of 1994, with responses in these categories evenly divided at 36% each. Only one respondent (7%) indicated no respect or appreciation was forthcoming from other parents. Qualitative comments were characterized by frequent themes of supportiveness and positive feedback on the one hand along with occasional resentment on the other. Examples of both the former and the latter themes follow:

> [Other parents] call to strategize with me, call for advice on boards, call regarding questions about the [children's mental health] system.
>
> Other parents who have children with disabilities have been excited to hear about my joining the board.
>
> [I] don't think people are aware of my involvement. They may act with resentment.

Personal satisfaction from group membership showed a decrease in intensity over time. While 6 respondents indicated "much" personal satisfaction and another 6 felt "some" personal satisfaction when responding in the winter of 1993, by the final survey 4 reported "much" satisfaction and 9 marked "some" as their response. No one indicated that they received no personal satisfaction, and only two in the first wave and one in the final wave of surveys reported "little" satisfaction from their advisory group membership (See Table 16 in Appendix G.)

When asked to compare their own personal satisfaction with their perceptions of other group member's satisfaction with membership (see Table 17 in Appendix G), 43% (n=6) felt "more" and another 43% felt "similar" degrees of satisfaction in the winter of 1993. Data from the spring of 1994 shows that more respondents marked "similar," (n=9.)

Another question in this section asked about the number of personal friendships respondents developed with other advisory group members. Data sets changed little from the first to the final samples (see Table 18 in Appendix G), with nearly all, and nearly equal, numbers of respondents marking "some" or "few" on both surveys.

The final qualitative measure in this content area asked participants to "briefly describe the aspects of advisory group membership that are enjoyable for you." Three themes dominated responses from the first sample. First, **providing a parent perspective** (five responses) was noted. Second, **receiving respect as a partner with professionals** was mentioned by four family members. As one parent put it, she enjoyed receiving respect as an integral part of a successful system of parents and professionals working together.

The third major theme was **enjoyment of discussions and information sharing**, also noted by four respondents.

By the spring of 1994, themes of enjoyable aspects of membership had shifted somewhat; six parents cited **input into policy or system change** as their primary source of enjoyment, while four viewed **information sharing and increased knowledge about the service system** as important to them. Both themes are conveyed by respondents' comments:

> [It's] great to be at a table where "ground is being broken" in children's mental health issues and being able to move discussion to my issues.
>
> [I enjoy] knowing first hand what's happening around our region and having a "say" on what is addressed.

Respondents' experiences as advisory group members

The next series of questions investigated the impact of family member participation on the group itself, the responsiveness of the group to family member recommendations, objections and issues, the attitudes of professional members of the group toward parent membership and participation, and interactions with group members and other family members in and out of the group.

Question 20 (found as Table 20 in Appendix G) asked respondents to consider their overall experience in the group, and then rate how much influence on the group's decision-making they had. Results from the winter of 1993 showed 14% (n=2) felt they had "a lot" and 64% (n=9) "some" influence on decision-making, with only two (14%) perceiving they had "little" and one (7%) feeling she had "none." By the spring of 1994, 10 family members (71%) felt they had "little" personal influence on the group's decision-making, while 3 (21%) felt they had either some (n=2) or a lot (n=1) of influence.

Following the pattern found earlier in the questionnaire, respondents were next asked to compare their personal influence on the group's decision-making to other members of the group (see Table 21 in Appendix G.) Results were nearly uniform across both surveys with nine respondents (64%) marking "about the same" as their rating of comparative influence. The rest of the responses were divided among "much more", "more" and "less".

Whether family members participating in the group had made recommendations, and how often those recommendations had been accepted, was the focus of the next item (Table 22 in Appendix G.) At the time of the first survey, responses were evenly divided (n=5, or 36% each) between the categories of "regularly" and "sometimes," with one respondent marking "never". Findings from the spring of 1994 were more positive with six respondents marking "often", two marked "regularly" and six indicated parent recommendations were accepted "sometimes."

The next question asked about the frequency with which the group changed plans due to parent objections (see Table 23 in Appendix G.) No responses of the group's changing plans "regularly" were recorded on either survey. Figures for the categories of "often" (n=4) and "never" (n=3) remained stable across surveys, while responses to "sometimes" moved from two at the time of the first survey to six at the time of the second.

An intriguing change on respondents' answers to the question, "Overall, is this advisory group responsive to the issues raised by parents and other family members?" is illustrated in Table 8 (Table 24 in Appendix G.)

Table 8: Responsiveness of Advisory Group to Issues Raised by Parents or Family Members

	Winter '93		Spring '94	
	n=14	%	n=14	%
Very responsive	10	71	4	29
Moderately responsive	2	14	7	50
Slightly responsive	2	14	3	21
Not responsive	0	0	0	0

A definite trend toward perceptions of decreased responsiveness is evident in viewing the change from "very responsive" toward "moderately responsive."

The next two items in the survey used both ratings and descriptive questions to explore what was expected to be a provocative issue for family member participants on boards -- the attitudes and behaviors of professionals involved on the boards. Results to the question, "Considering your overall experience with the professionals who are members of this advisory group, what is their attitude toward parent membership and participation?", are depicted in Table 9 (Table 25 in Appendix G):

Table 9: Parents' Perception of Attitudes of Professionals

	Winter '93		Spring '94	
	n=14	%	n=14	%
Generally positive	8	57	4	29
Somewhat positive	3	21	7	50
Somewhat negative	2	14	3	21
Generally negative	0	0	0	0
Missing responses	1	7	0	0

The total number of respondents who endorsed "generally positive" and "somewhat positive" remained the same over the two time periods. The corresponding open-ended item requested information about "either positive or negative behaviors on the part of professionals that let you know how they feel about you as a parent member." These examples of parents' comments from both "waves" of the survey are typical, and illustrate the mixed (although generally positive) perceptions of respondents:

[from the winter of 1993]

> Some will ask direct questions and show concern for our experiences. Others don't even acknowledge us at all.
>
> The professionals have verbalized the desire to have more input from parents, to have parents sit on various committees, are positive to having parents chair or co-chair the group.

[from the spring of 1994]

> [Professionals] ask my opinion [and] ask me to identify more parents for the board.
>
> Often, they ask our opinions. Many are very respectful and seem to value our input.
>
> [Professionals give] looks of "Oh, it's those pesky parents!" Our issues are still not getting full status.

A number of responses had the tenor of this comment:

> It seems every time a parent makes a suggestion it is quickly squelched, but if a professional makes the same suggestion it is picked up on.

However, themes of willingness to listen, valuing of family members' opinions, and general encouragement color most responses.

An attempt to gauge changes in those attitudes was the focus of the next survey question. Respondents rated how the attitudes of professional group members had changed (or if they had) since the respondent's membership (See Table 26 in Appendix G). Little change was evident over time for this measure, with 93% (n=13) of respondents indicating professionals' attitudes had "stayed about the same" or were "a little improved." Family members' comments to the corresponding qualitative item, "If their attitudes have changed, please describe how their attitudes have changed and what you think caused the changes" were mixed as well.

> I think they're finding that "Mother" has feelings and an education.
>
> [Professionals are] interested in my opinion but sometimes I still feel my membership is only polite accommodation if I strongly differ.
>
> There seems to be a different mindset in accepting parents as having valuable and important information and input.
>
> Mostly they have been receptive all along but now the follow-up is better.

Questions 27 and 28 elicited information about the frequency and nature of contact with other advisory group members, including contact with members who were also parents or family members of children with emotional disorders (see Tables 27 and 28 in Appendix G.)

Regarding frequency of contact with other group members between meetings, 14% (n=2) reported they "regularly" had such contact, and 36% (n=5) "often" had such interaction, at the time of the first survey. An additional 36% reported they "sometimes" contacted other members between meetings, while 7% (n=1) "never" did. Minor change in the pattern of responses was found in results from the second survey. While the percentage for "regularly" stayed the same, "often" responses decreased and "sometimes" responses increased.

Respondents were invited to describe the purpose of the contact in a corresponding question. Several strong themes emerged and were consistent across both surveys. These included **sharing information**, **getting or giving support**, **sharing and discussing ideas**, and **problem-solving** issues related to the board or to respondents' own children.

Regarding the nature of contact with other participating parents or family members of children with emotional disabilities (Table 28 in Appendix G), most respondents noted that they talked or met with other parents outside of meetings. Eleven (79%) respondents marked this category at the time of the first survey, and nine (64%) did so on the final survey. Corresponding comments fell into three major themes, again consistent across time, that included **strategizing**, **information sharing**, and **giving encouragement and support**.

A final question in this general content area asked the frequency of contact, and the nature of that contact, with other parents of children with emotional disabilities who were <u>not</u> members of the advisory group (see Table 29 in Appendix G.) At the time of the first survey, contact was weighted toward the responses of "never" (n=4) and "sometimes" (n=5.) Movement toward increased discussion with parents who were not members of the advisory group was indicated by the increase in the number of respondents who endorsed "sometimes," (n=10) and "often" (n=4.) The benefits of such contact, as reflected in brief comments by several respondents, centered around giving and receiving emotional support and sharing experiences, and educating other parents about the mental health system in their area.

Meeting arrangements: The logistics of participation

This next general content area takes stock of logistical arrangements of--and in some cases barriers to--participation on advisory boards that family members encountered. The first item in this area was a short checklist of requests respondents may have made in order to attend a meeting. Results are shown in Table 10 (Table 30 in Appendix G.)

Table 10: Special Requests by Parents Regarding Logistics of Meetings

	Winter '93		Spring '94	
	n=14	%	n=14	%
Asked for a change in the time of day	5	36	5	36
Asked for a change in the day of the week	3	21	4	29
Asked for a change in the meeting location	1	7	2	14
Brought their child to the meeting	1	7	0	0
Asked for a ride to the meeting	4	29	7	50

*Multiple responses possible.

The total number of requests increased slightly from 14 to 18 between the first and the third surveys. In light of the concerns about logistical barriers to family member participation raised in the literature, and reviewed earlier in this monograph, the relatively low proportions of respondents' requests regarding logistics is interesting, and will be returned to in the discussion.

Another variable that we expected to be important in maintaining and increasing the participation of family members on boards was the issue of reimbursement. Question 32 on the survey had four parts, each clarifying aspects of this topic (see Tables 32a-d in Appendix G). In order to provide a clearer and more informative picture of response to questions about reimbursement, data from all survey participants will be included as well (see Appendix H.)

The first question asked, "Are you reimbursed for personal costs or expenses associated with attendance at meetings?" and included a possible response of "Reimbursement is available, but I don't claim expenses." Table 11 portrays the results. The reality of reimbursement indicated by these findings is how infrequently it occurs.

Table 11: Reimbursement for Personal Expenses Related to Meetings

	Matched Data				Unmatched Data			
	Winter '93		Spring '94		Winter '93		Spring '94	
	n=14	%	n=14	%	n=26	%	n=18	%
yes, reimbursed	0	0	2	14	5	19	2	11
no, not reimbursed	13	93	12	86	19	73	16	89
reimbursement available but expenses not claimed	1	7	0	0	2	8	0	0

The kinds of expenses for which respondents could be reimbursed were included under five categories (see Table 32b in Appendix G and Appendix H.) The most frequently reimbursed expense was for mileage, parking or other related travel expenses; respite care or day care for a child; and meal or lodging expenses. “Other” was marked by one respondent, who noted that she could be reimbursed for telephone and duplicating costs. Reimbursement for lost wages was never noted.

A related question regarding the relative importance of reimbursement to the respondent's participation also had unexpected findings, given our assumption that reimbursement is important to respecting and encouraging family member participation on boards and committees. Table 12 again consolidates responses among those who did receive reimbursement, from all responses to the survey (see Table 32c in Appendices G and H.)

Table 12: Importance of Reimbursement to Involvement (If Received)

	Matched Data				Unmatched Data			
	Winter '93		Spring '94		Winter '93		Spring '94	
	n=1	%	n=2	%	n=7	%	n=2	%
Very much	0	0	0	0	2	29	0	0
Moderately	0	0	1	50	1	14	1	50
Slightly	0	0	0	0	1	14	0	0
Not at all	0	0	1	50	2	29	1	50
Missing responses	1	100	0	0	1	14	0	0

This pattern of mixed responses and varying importance given to reimbursement for personal expenses is repeated among respondents who did not receive such reimbursement. They were asked a separate question: “If you are not reimbursed, would reimbursement help you to increase your involvement?” Table 13 (see Table 32d in Appendices G and H) highlights the relatively low importance accorded reimbursement by respondents.

Table 13: Importance of Reimbursement (If Not Received) to Increasing Involvement

	Matched Data				Unmatched Data			
	Winter '93		Spring '94		Winter '93		Spring '94	
	n=13	%	n=12	%	n=19	%	n=16	%
very much	5	38	0	0	5	26	2	13
moderately	1	8	3	25	2	8	2	11
slightly	2	15	5	41	6	24	5	28
not at all	5	38	4	33	10	53	6	38

There is some evidence in both data sets away from endorsing “very much” importance. Whether this is due to a shift in the family members attitudes about reimbursement or a growing understanding that little reimbursement is available is unknown.

A final item in the general area of the logistics of participation looked at the cooperation by employers with respondents' participation during work hours. Parents who were self-employed or not employed outside the home were not included in this analysis (n=8 in the winter of 1993; n=5 in the spring of 1994.)

Employers were judged cooperative by three respondents (21%) at both survey times. Conditional cooperation on the employer's part was noted by one respondent (7%) in the winter of 1993, and by two respondents (14%) in the spring of 1994. Lack of cooperation was noted by two (14%) respondents at the time of the first survey. This figure rose to four (29%) respondents by the final survey, as more family members found work outside the home (see Table 33 in Appendix G.)

Changes in level of understanding and group skills

In this fifth general content area, respondents were asked to assess the effects of their participation in three areas: their understanding of the children's mental health system, their skills as a group member, and their skills as a group leader (see Tables 34, 35a, and 35b in Appendix G.)

A majority of respondents felt their understanding of the children's mental health system had increased "considerably" (n=7, 50%) or "moderately" (n=2, 14%) when first surveyed in the winter of 1993. By the spring of 1994, responses of "considerably" had decreased slightly (n=5, 36%), and responses of "moderately" increased to 6 (43%.) A corresponding open-ended question asked respondents to list the areas (of the children's mental health system) in which they had gained knowledge. The largest number of responses described increased knowledge about the mental health system in general, as the following comments illustrate.

> To know who the players are and how the system operates, [and] who to contact.
>
> [I gained knowledge about] system issues, interagency collaboration issues, and the larger picture of the variety of children's mental health issues...

Two comments mentioned gaining knowledge that was helpful to understanding or improving the condition of the respondent's own child, while two others mentioned learning about professionals' attitudes and (lower than expected) level of knowledge.

Comments from the spring of 1994 also included mention of learning about professionals' attitudes and roles within the system. Other comments were dispersed among themes of learning about legislative issues and policy-making, about operational issues ("budgets, placements, personnel", as one respondent wrote), and about the children's mental health system.

Questions 35a and 35b inquired if participation had increased respondents' skills as a group member and as a group leader, respectively. A cumulative 64% indicated that they experienced "considerable" or "moderate" increase in their skills as a group member (see Table 35a in Appendix G.) Ratings of skills as a group leader showed a trend toward slight increases in leadership skills (results are shown Table 35b in Appendix G).

The specific skills that respondents had acquired that made them feel more effective were inventoried by a final open-ended question. **Public speaking** was noted by six respondents to the first survey as a skill they had acquired through their participation. **Listening skills** were mentioned by three, and **negotiating skills** by two respondents at this time. The ability to **persuade others** was also mentioned. While **public speaking** remained the most frequently mentioned (n=7) area of enhanced skill in the spring of 1994, a new theme of increased skills in **conflict management** (n=3) emerged from respondents' comments at this time. **Negotiating skills** was an area of growth for two respondents.

Respondent activism

Two questions were used to assess the level of prior involvement or activism demonstrated by the survey participants. One question inquired about advisory group experience prior to membership in the current group. Only one respondent had "a great deal" of experience, five had "some," while two had "little" and five had "none" when surveyed in 1993.

A second question asked respondents to indicate which of a thirteen item checklist they had participated in. Results are shown in Table 14 (Table 44 in Appendix G).

Table 14: Specific Actions Undertaken by Parent

	Winter '93		**Spring '94**	
	N=14*	%	N=14*	%
Attended a parent support group	14	100	14	100
Attended a workshop or received training in advocacy	10	71	14	100
Phoned, written to, or visited a legislator to talk about services to children	11	79	12	86
Phoned, written to, or visited an agency or school administrator about the services your child has been or should be receiving	11	79	14	100
Prepared or given testimony to a legislative committee or other meeting regarding services for children	10	71	12	86

Given a speech or written an article about a children's issue	6	43	10	71
Assisted another parent in dealing with the service system	13	93	12	86
Written a letter to the newspaper regarding a children's issue	3	21	4	29
Been involved in legal or court action regarding services for children	5	36	4	29
Filed a formal complaint or grievance regarding services for children	2	14	7	50
Helped organize a group to discuss or advocate for children's services	4	29	7	50
Phoned, written to or visited a counselor, therapist or teacher about services for your child	14	100	14	100
Missing responses	0	0	0	0

*Multiple responses possible

Many activities (eight out of twelve) showed an increase in the number of family members who had engaged in them from the first to the final survey times. One item, "Attended a workshop or received training in advocacy," offers the most direct evidence of family member involvement with the Families in Action project training efforts.

Family Empowerment Scale (FES) results

Further confirmation of the high level of knowledge and activism among family members surveyed is offered by the results from the *Family Empowerment Scale (FES)* (Koren, DeChillo & Friesen, 1992), the final "piece" of the *Survey on Advisory Group Participation.* Readers are reminded that the entire survey instrument is contained in Appendix F. We elected to focus on aggregate scores for the three "levels of empowerment" named in the description of the survey instrument, rather than an item-by-item presentation and analysis. Table 15 (Table 47 in Appendix G) reports these findings.

Table 15: Mean Scores and Standard Deviations on Subscales of the Family Empowerment Scale

	Winter '93		Spring '94	
	Mean	SD	Mean	SD
Family	50.9	2.7	50.6	5.4
Service System	53.6	3.4	55.7	3.0
Community/Political	37.9	5.4	40.5	6.6

The small but noticeable increase across time in the last two of the three levels suggests potential change in the family members' feeling of empowerment with regard to the service delivery system that cares for their child and with regard to the political arena. A basis of comparison is offered by the results from the analysis of the *FES* reported by Koren, DeChillo and Friesen (1992.) In their analysis, a subgroup of family members active on "a task force or agency board concerned with children's mental health issues" (p. 316) were identified. When compared with the family members surveyed by the *Survey on Advisory Group Participation*, comparable scores were found. The Koren, et al sample had means of 49.9 for the Family Subscore, 53.6 for the Service System Subscore, and 41.4 for the Community/Political Subscore. These figures are very similar to the mean scores reported for this study's respondents.

DISCUSSION

Scope and limitations to this discussion

As noted in the preface to the survey findings, our conclusions will necessarily be cautious and tentative because of the very small numbers. As a framework for discussion, the seven-area format used in presenting the findings will be modified slightly, with the demographic and other characteristics of respondents consolidated with discussion of their empowerment as measured by the *Family Empowerment Scale*.

Discussion of characteristics of respondents, including advocacy activities and empowerment as measured by the *Family Empowerment Scale*

The fourteen respondents who returned surveys from both the first and third mailings, and whose responses make up nearly all the findings presented in this section, were diverse in education, income level, and amount of prior advisory group experience. The complete lack of racial diversity and relative lack of geographical diversity among respondents is notable, and contrasts with the diversity present among the life history interviewees in particular. All but four of the 28 children of survey respondents were still living at home, which may be a factor in many aspects of participation on boards, including level of commitment, special efforts needed to attend meetings, and requests for changes in meeting arrangements, among others. The checklist of advocacy actions on behalf of their own child, or behalf of children in general, provides evidence of a level of activism that not only began at a high level but increased over time. Similarly, the results from the *Family Empowerment Scale* point toward relatively high levels of empowerment. The slight upward shift in scores of two of the three levels of empowerment measured by the scale may reflect even more growth in the skills, attitudes and actions that make for empowered parents and family members. Whether participation in the activities of the Families in Action project, or participation on a board, committee or other policy-making body itself can be directly correlated to increased empowerment and activism is not clear. However, these findings do testify clearly to the commitment, energy and courage of these family members of children with emotional disorders.

Trends in the characteristics of advisory groups and levels of participation of respondents

The first trend in this area of investigation is the decline in active board membership. Reasons for leaving active membership were not elicited by the survey; however, the loss at a rate of roughly one in five members over a year's time seems comparable to patterns found on boards in general. It does underscore the realization that family members, no matter how committed to the need for change in children's mental health services, will move on to other activities.

Other findings of interest in this general area include:

- The consistently regular attendance at board meetings reported by this group of respondents, indicating the ability of these family members to surmount logistical barriers to participation;
- The mixed picture of fewer (in some cases) and more (in other cases) family members participating in boards, which suggests either progress toward or regression from the outcome of increasing family member participation on boards, depending on the site or board being evaluated;
- The relatively high percentage of respondents (of those who had an opportunity) who reported serving on a subcommittee or as an officer of the group;
- The clear increase over time (from 36% to 71%) in respondents' perceptions of themselves as "very active" as group members;
- A corresponding shift in respondents' views of their own activity level as compared to other group members in the direction of "slightly more active" than others; and
- The modest evidence of increased participatory behavior during group meetings offered by higher mean scores on five of eight behaviors representative of active participation in the day-to-day workings of a board.

Perceived benefits of membership

Findings from this general area of the survey lend more support to a trend toward "increased realism" (or, more pessimistically, discouragement or disillusionment) in respondents perceptions of themselves, their fellow board members, and the importance of their efforts. The findings are summarized as follows:

- A shift from perceptions of the group's work as "very important" to "moderately" or "slightly important";
- An overall decrease in personal satisfaction from "much" to "some" over time;
- A shift toward comparing oneself as experiencing similar, rather than higher, personal satisfaction than other group members; and
- The change in dominant themes among qualitative comments about positive aspects of group membership from the more global and process-oriented "providing a parent perspective" to comments that are more specific and focused on change--"input into policy or system change" and "increased knowledge about the service system."

Respondents' experiences as advisory group members

In this general area of inquiry, which included perceptions of family member influence within the group, the attitudes of professionals in the group toward family members, and degree and kind of interaction with other parents or family members within and outside the group, varying trends were evident. The first, reflecting movement toward lowered expectations or perceptions of realistic power or status noted already, was evident in responses to several items:

- The change in the direction of lowered perceptions of personal influence from 78% feeling they had "a lot" or "some" influence on decision-making to 71% feeling they had "little";
- The shift from perceptions that the advisory group was "very responsive" to issues raised by parents or family members to "moderately responsive to such issues"; and
- The moderate decrease in positive perceptions of professionals' attitudes, from "generally positive" to "somewhat positive".

The second trend in this area is that of neutrality, or mixed perceptions on the part of respondents about their experience. Support for this characterization is found in the following findings:

- The consistent rating of influence on the group's decision-making compared to other members of the group as "about the same" across both surveys;
- The variable experiences reported regarding acceptance of family member recommendations by boards, with movement toward a consolidated rating of such recommendations being offered and accepted "often", rather than split between "regularly" and "sometimes";
- The consistent rating of professional's attitudes toward family member participation as staying "about the same" or being "a little improved" over the time measured by the two surveys;
- The variability among comments regarding actions and attitudes of professionals, with most respondents expressing generally positive views along with a consistent minority reporting highly negative experiences; and
- The consistency of contact outside of meetings with other group members who were also parents or family members of children with emotional disabilities.

Finally, some evidence of enhanced experiences and increased participation on the part of family members is apparent in answers to some items in this area:

- Upward shifts in reported parent requests and objections indicate increased activity by respondents; and
- Movement toward greater discussion of advisory group issues with other parents and family members who were not group members, possibly reflecting a shift from representing oneself to representing a group of family members.

Logistics of--and logistical barriers to--participation

Meeting arrangements, including reimbursement for expenses incurred in participation and relative cooperation by employers with employed parents' participation, can be characterized as having relatively little to moderate flexibility. Respondents' feelings about this relative lack of flexibility, particularly in regards to reimbursement, were unexpectedly tolerant. These trends of interest are reflected in the findings:

- The relatively low number of reported requests for special consideration by parents in order to attend group meetings, which could be related to family members seeking to be accepted as equal members of the group rather than as "pesky parents" in need of "special" treatment. Alternatively, these findings could reflect adequate support from family members, support groups, or friends in meeting needs of respondents as they arose or simply that the circumstances of this group of respondents did not warrant additional special requests;
- The closely-related finding that changes in the time or location of meetings at parents' or family members' request occurred infrequently, which could again suggest either little flexibility ("So why bother to ask for changes?") or little need for such changes on behalf of family members;
- The low numbers of participants who reported being offered reimbursement is of particular interest, given the assumed desirability of such reimbursement for maximizing family member participation;
- The relatively low importance placed on receiving reimbursement by these respondents. This finding may in part be related to income levels of the respondents and changes in employment status (towards more parents being employed as mental health or social service professionals, sometimes as paid family advocates.) It may also reflect genuine change in parents' evaluation of the importance of reimbursement for participation in what, for most respondents, was a once a month meeting commitment; and

- The relative lack of cooperation by employers, with cooperation decreasing over time (only three of nine respondents employed outside the home reported their employers were "cooperative" in the spring of 1994) may represents a more significant barrier to family member participation than lack of reimbursement.

Growth in level of understanding and group skills

This final area of exploration offers the most satisfying and clear-cut findings from this research. A strong trend toward an initial increase in respondents' understanding of the children's mental health system, stabilizing over time as the amount of knowledge to be learned presumably decreased, is one positive outcome of participation on boards. Other positive outcomes are evident in additional results:

- Respondents' ratings of growth in skills as a group member were consistently high across surveys, and showed higher ratings over time; and

- A logical increase in growth of skills as a group leader over time was reported, reflecting both increased opportunities for leadership and increased comfort as active participants on the part of respondents.

Considering the findings as a whole, the trends toward increasingly active participation, toward identification with other group members' experiences, toward more realistic and pragmatic perceptions of boards' processes and importance and respondents' own personal satisfaction, and toward personal growth in knowledge and skill stemming from participation stand out. Returning to the three potential outcomes of family member involvement with the Families in Action project, results are mixed or inconclusive. The first evaluative outcome, increased numbers of parents participating on each board, found mixed support, as some boards increased the numbers of family member participants while others saw decreased involvement. The second outcome was the reduction of barriers to family member participation on boards; this outcome is clearly not supported, given the low numbers of boards that offered reimbursement, the relative inflexibility regarding meeting arrangements by boards, and infrequency of employer cooperation with family member participation. The low importance placed on reimbursement by respondents raises questions about how significant a barrier reimbursement was for this set of participants. Finally, evidence pertaining to the outcome of improved professional/provider attitudes toward family member participation is inconclusive. While a majority of respondents reported positive attitudes, a small group made consistent and strongly-worded negative characterizations of professional attitudes as well. Further experimentation using this instrument (modified as appropriate), drawing on larger, more representative samples of family members who have participated on advisory boards, committees or other decision-making bodies, could lead to clearer conclusions. The findings reported here, and these tentative interpretations, are additional beginning steps toward understanding family member participation in policy-making.

SECTION V: CONCLUSIONS AND DISCUSSION

The research and training endeavors discussed in this report represents an embryonic effort to study family member participation at the policy level through the Families in Action Project. Underlying this project is the assumption that consumers, in this case families who care for children with serious emotional disorders, have a vital role to play in planning, evaluating and monitoring the services provided for their children. The Families in Action Project undertook a series of exploratory research and demonstration activities intended to examine the supports needed and the barriers that impede family member involvement in advisory groups, governing bodies and policy or decision making committees. This section of the report highlights some of the major issues that have emerged and provides a beginning discussion of some of the remedies. More detailed conclusions can be found at the end of each of the preceding sections. As usual, this kind of report raises more questions that it answers. Following is a synthesis of what are, in our opinion, the most salient issues.

Involving more family members in the policy process. Family member participation in policy or decision making bodies is continually threatened by the small number of parents identified for membership. The effort to be involved at the policy level is often handled by from two to three dedicated family members each of whom are involved in several committees. Once a parent is recognized as articulate and not too outspoken, he or she is asked to join several different groups. Often the state's family advocacy organization receives multiple requests for a parent member and the same few parents are called on time after time to serve. The parents who participated in our focus groups, life history interviews, and to a lesser degree, key informant interviews, often mentioned being burned out, wanting to move on to other things and wanting to find other parents who would join them so they wouldn't be the only parent voice. Participants also talked about the need to involve parents who represented diverse cultural and ethnic groups and who had children from a variety of age groups.

One of the goals in each of the demonstration sites was to expand the core group of family members who were involved in policy and decision-making groups, both in terms of numbers and in terms of diverse representation. Expansion of family members who were available, willing, and interested in involvement at the policy level proved to be difficult and did not occur as planned in the demonstration sites. For the most part, other issues emerged that consumed the energy and attention of the family members and professionals involved. It is our conclusion that it takes a focused effort to recruit new parents to the policy process and that many newly involved parents need to be mentored for a period of time before they become committed to long term involvement. This mentoring, however, can be offered by either a professional who is sympathetic to the family advocacy movement or by another family member.

There is also some evidence that it is easier to involve family members in the system change process when it is focused around a specific issue or need for change. For example, one of the participants in the life history interviews first became involved because her child's special education program was about to be closed. Other family members describe becoming involved because their child needed a specific service that was not available, because a particular policy was problematic (e.g., custody laws) or when they started or joined a law suit or grievance. Practically, it may be easier to recruit new parents to the policy making process when they are asked to work on a specific issue that is germane to the family than when they are recruited generally to membership in a committee or group, with no specific agenda for change. The barriers to increasing the cultural, ethnic, and economic diversity of family members involved at the policy level echo those mentioned above. In addition, families of color and families who are poor face barriers that result from institutional racism, economic hardship and classism that society in general.

Policy making versus survival. For most families and for many family advocacy organizations, involvement in system change and in the policy process must take a back seat to issues of survival. There is ample documentation in this report of the crises that often arise for families who are taking care of a child with an emotional disorder and how these crises may interfere with their ability to regularly contribute as a member of a committee or governing body. Individual family crisis and issues of organizational survival provided diversion from goals of system and policy change in every demonstration site. Taking care of these issues had to come first, thereby delaying action toward involving more families in the policy process. For example, in one site threats to the funding of the family advocacy organization intervened. In another site, disagreements within the group which resulted in a splitting up of the organization provided the distraction. In yet another site, the illness of one of the core leaders derailed the group. Despite clear plans and strong interest, the progress in all five sites was less dramatic that would have been possible if the sites could have concentrated on policy issues. The general lesson is that crisis with children, in personal lives, in organizational arrangements, or even in the service delivery system will all take precedence over efforts to increase parent involvement in policy or decision making about the system. This more global level of change of necessity is secondary to individual and organizational survival.

Reimbursement as a partial answer. In the past few years, some attention has been given to the need to reimburse family members for the costs associated with their participation on policy-making groups. Reimbursement associated with travel, parking, meals and in some cases, child care are now fairly accepted processes. Reimbursement for the parents' time is still controversial. Our findings suggest two unexpected conclusions. First, few parents in our sample reported being reimbursed for the cost of participation. Second, few of these parents felt that reimbursement was important to their participation. Of course, the parents responding to the survey were already active at the policy level. These parents had already overcome any barrier imposed by the cost of participation. A different kind of research effort is needed to determine whether family members from a more diverse range of cultural, racial and economic groups could be attracted if reimbursement were more easily obtained. Another related finding suggests that parents who work outside the advocacy arena may have difficulty with employers over their absence from work for meetings and conferences. These responses do suggest that we need to look further at the part reimbursement plays in attracting diverse parents to the policy arena. Also, the development of strategies to educate and intervene directly with employers could be constructive.

Communication among parents. Ways to support communication among parents who are involved at the policy level have not been explored systematically. The assumption is usually made that parents who are associated with a family advocacy organization will make contact with other parents through the group's activities. This appears to be only partially true with some family advocacy organizations having organized activities that allowed family members to exchange ideas about how to work at the policy levels but with many having only informal connections. Another assumption is that if a policy-level group has several parents as members, these family members will talk with each other outside of group meetings. According to our survey data, this happened only rarely. None of the sites that we worked with found an effective or easy way to support regular communication among group members about policy work that was being done. When family members are expected to represent more than their own experiences, this issue of communication is one that must be solved.

A related issue exists for parents who are not associated with a larger family advocacy group. These individuals may have been recruited to sit on a governing board or advisory group because someone (often a professional) knows them. Although this is a good mechanism for recruiting new parent leadership, parents who don't have regular access to other family members can be in an isolated position with regard to policy work. They are without support or information that often comes from involvement in a larger parent organization. This lone position may also reduce the parents' power base and make them less able to influence the group's agenda.

The training imperative. A commonly held belief is that parents and family members need training in order to be effective participants at the policy level. This belief is held as strongly by family members as it is by professionals. To a limited extent, training is needed and helpful. The most commonly identified themes for training (e.g., public speaking, writing, group leadership) involve skills that most individuals, parents and professionals, could use help with. Many of the parents involved in our research and in the demonstration sites had some college education, and probably a reasonable degree of proficiency in these general communication skills. Further training might have enhanced their effectiveness, but their current skill level is probably sufficient for the work on most committees. Training in these areas might have served to enhanced self confidence and might have proven useful to parents with less formal education or whose employment did not require such skills.

Some training themes were identified that are particularly relevant to effective involvement in policy change. These include content such as knowledge of the service system, funding mechanisms and the process by which policies are initiated and changed. This is content that is probably needed by most members of the board or committee, parents and professionals alike. Sessions that address these content areas are best held with all members of the committee in attendance and with no sub-group singled out as particularly in need of education. Training programs in general, and for parents in particular, should not be seen as a panacea for the difficult issues related to involving families on policy or decision-making groups.

Of greater importance than training in specific content areas is the need to address the mutually held biases and misconceptions of both parents and professionals. This emerged as the starting place for almost every demonstration site. In order to work well together, parents and professionals need an opportunity to discuss the stigma felt by parents, the attitudes of professionals toward parent involvement and other communication issues. These attitudinal issues can be addressed through training-like activities that explore the relationships between parents and professionals working on a policy-level group together and seek to improve communication and collaboration. Addressing parent professional collaboration at the beginning may have been at least partially responsible for the generally positive attitudes of professionals toward parent participation as reported by family members from each site who completed the *Survey on Advisory Group Participation.*

Benefits to family members. Little attention has been given to identifying those aspects of involvement in system change and policy making that offer an advantage to the family members involved. These motivating factors need to be identified and enhanced. The *Survey on Advisory Group Participation* attempted to measure some of the aspects of participation that the literature suggested as benefits. Many of these benefits were not experienced by parents, were experienced at a moderate level or declined over time. Parents reported an overall decrease in personal satisfaction with their involvement and called their advisory group work "very important" less frequently over time. They also perceived a decline in the amount of influence they had in the group and found the rest of the group becoming less responsive to issues raised by the family members. Few parents had contact with other group members outside of meetings and few reported making friends with other members of their advisory group. Family members did report that at least some other parents respected and appreciated their work on policy level boards and most reported some increase in knowledge and skills as a result of their policy group involvement. The fact remains that the greatest benefit for most parents is the chance to develop or obtain better services for their child. This is parallel to the benefit derived by most professionals who serve on committees -- the opportunity to watch out for the interest of their organization or their job. Other kinds of rewards appear to be ambiguous, intangible and erratic.

The role of the "friendly" professional. The role played by professionals who are knowledgeable about family involvement and believe in its importance should not be underestimated. Sometimes referred to as "system champions", individuals who are a part of the service delivery system and understand that process can give family members valuable guidance and support. Each of the demonstration sites had one or more supportive professionals that helped the involved group of family members through various stages of development. In many cases these individuals were from the state mental health division or CASSP office. In other cases, however, these were people from statewide advocacy organizations such as the Mental Health Association. In general, these were individuals who were committed to involving family members in the design and evaluation of the service system and who were willing stay with the process, even when conflict erupted.

Another role played by "friendly" professionals emerges through the life history interviews. Several of the participants noted that they first became involved because a professional concerned with their family recognized their abilities and encouraged them to advocate for change. The encouragement of this professional was very important because it included messages of competency as well as a non-blaming attitude. When viewed from this perspective, all service providers have a responsibility to begin to identify and encourage family member involvement in planning, evaluating and making decision about services.

<u>Change in the service system</u>. The most important research question that has yet to be answered is, "Does the involvement of family members at all levels of decision making result in a more efficient, effective, and family-centered service delivery system?" In other words, does the involvement of parents at the policy or decision making level result in changes in the service system. In this project we have begun to explore different ways of quantifying variables related to this question. However, much developmental work needs to be done before it will be possible to explicitly measure the impact that family members have on the policy-making bodies they inhabit. Until this conceptual and measurement quandary is resolved, there are many questions about family member participation that will go unanswered.

The discussion about family member involvement at the policy level has changed over the past five years. Few among us are concerned about <u>whether</u> family members should participate at the policy or decision-making level. Discussion today centers around <u>how</u> to make family member involvement happen effectively. As the ideas behind consumer involvement in services continues to gain acceptance and develop, answers to some of the dilemmas posed by this paradigm shift will begin to emerge. Exploratory research, such as that reported here, is needed to increase the knowledge, the awareness and the strategies available to all those involved. To summarize our recommendations for the direction further research should take:

> *investigate factors that promote long-term family member involvement on advisory or governing boards;
>
> *encourage qualitative research on the reasons for decrease in or termination of participation;
>
> *explore and evaluate strategies that increase minority family member participation; and

*conceptualize and develop measures of the impact of family member involvement on the policies developed and decisions made regarding service delivery.

REFERENCES

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APPENDICES

APPENDIX A

Focus Group Questions

FAMILIES IN ACTION FOCUS GROUP PROTOCOL

Questions for parents with policy making experience:

- Think back to the first time you joined an advisory or policy making body. Briefly describe how you got started.

- Now let's talk about some of the things that have helped you be an effective participant in these groups. By this I mean, what are some of the skills you have, experiences or information that have helped you.

- What kinds of things can professionals do to make it easier for you to participated and to help you be more effective?

- As parents who have been involved in this kind of activity, what would you suggest we include in a program to help parents who want to be more involved?

- In one or two sentences, say something about why your involvement at the system level has been worth it for you. What was satisfying, or what benefit(s) have you gotten from being involved?

Questions for parents without policy making experience:

- What do you think would be the advantages for parents becoming more involved in advisory committees or decision making bodies related to children's mental health services?

- Thinking about yourself, what would you have to take care of in order to become involved in an advisory or policy group?

- Thinking about the parents you know, what kind of people would be most effective on decision making bodies?

- Suppose that some agencies were trying to recruit parents or other family members to be on their advisory board. What should they do to make it possible for parents to participate?

- If our project came to your community, what would you suggest we include in a program to help parents who want to become more involved in decision making about services?

Questions for professionals:

- Thinking about a particular parent you have know to be involved at the policy level on boards or committees, describe some personal qualities and skills that individual had that made them effective.

- In general, what are particular skills, abilities or personal qualities that a parent should possess to be an effective member of a board or committee?

- What, if any, are the barriers that parents face in being involved on boards or committees?

- What can be done to promote and support parent involvement on boards and committees? / How can parents be best supported or educated in being an effective board or committee member?

- What could a program such as ours do to assist parents in becoming more effective participants at the policy level?

- What could a program such as ours do to assist professionals in their work with parents as participants at the policy level?

APPENDIX B

Life History Interview Schedule

INTERVIEW QUESTIONS

The following questions are those we plan to cover during our interview. As you prepare for the interview we ask that you read them over and keep in mind that we are interested in your history of involvement and how your experience can help us develop a training program for parents and professionals to become more effective participants on decision making bodies (i.e. committees, advisory boards, policy making boards, etc.).

If you have concerns about the interview please feel free to call one of us or discuss your concerns when we call to set up an interview time.

QUESTIONS

I. In thinking over your own history of involvement what event, issue, and/or person got you involved?

2. Regarding the groups that you felt were very significant in your history of parent involvement, what were/are the factors that made these groups significant? What were your supports initially? What are your supports now?

3.. Looking back over your history what factors made involvement difficult for you in the beginning. What now?

4. What have been/are some of the difficulties you encounter as a member on these decision making bodies?

5. What did you or others do to help you overcome these difficulties?

6. What kinds of personal skills and abilities did you bring with you as you became involved on groups? What have you developed through your experience of being involved on groups? What further skills would you be interested in developing for yourself in order to become more effectively involved?

7. What role have professionals played in your involvement and development of skills?

8. What has been the personal cost (i.e. physical, emotional, financial etc.) to you and your family for your involvement? What makes the cost worth it to you and your family?

9. What sustains you in your effort to enhance services to children with emotional disabilities?

10. As a volunteer have you been reimbursed in some form for your involvement on committees?

11. Describe an experience when you felt yourself an "effective participant"?

12. Thinking over your own history do you have suggestions of how to recruit families to become involved?

13. What do you think is needed in developing a program for families to encourage them to become more involved in policy and decision making processes effecting mental health services for children?

14. What do you think is needed in developing a program for professionals to encourage or support them in involving families in policy and decision making processes?

Portland State University

Research and Training Center on
Family Support and Children's Mental Health
P. O. Box 751 Portland, Oregon 97207-0751

egional Research Institute
for Human Services

Graduate School
of Social Work

Date

Dear

The Families in Action Project is an activity of the Research and Training Center on Family Support and Children's Mental Health, at Portland State University. The Families in Action Project is seeking to develop and test strategies that encourage family member involvement in child mental health policy making bodies.

One step in our process is to collect information from family members parenting children who are seriously emotionally disordered. We have done this through group interviews and now are asking you to participate by describing why and how you have been involved in governing boards, committees, task forces, etc.

Our goal is to gather information from you about the factors that led to your involvement on a policy level and what factors sustain that involvement. This involves a two step process, completion of the enclosed questionnaire followed by a telephone interview. We ask that you complete the background and information form and return it to us in the enclosed envelope. Please return it as soon as possible. We will refer to this information during the interview.

When we have received the completed questionnaire, Judy Mayer will contact you to set up a convenient interview time. The interview will last approximately one hour. Enclosed you will find a list of the areas we will cover in the interview.

In preparing for the interview please think over your history of involvement in the planning and evaluation of services for children. This may include membership in a variety or bodies including governing boards, advising committees, task forces or other groups. What factors, issues, people, situations were occuring when your first got started? Where are you today in your involvement? Also, think how your experiences can help us prepare a program for family members who wish to become more involved on a decision making level.

503/725-4040 Facsimile 503/725-4882
Family Resource Clearinghouse 800/628-1696

Street Address: 1912 S.W. 6th Avenue, Suite 120
Portland, Oregon 97201-5298

Information from the questionnaire and interview is confidential. We will not associate your name with any comment made during the interview. We do plan to publish the results of these interviews along with other data collected by the Families in Action project. If you are well known as a family advocate it is possible that some readers may recognize your comments. The information will be used to help the project develop strategies and materials for encouraging family member involvement on policy making bodies.

Your willingness to participate in this project is greatly appreciated. If you have any questions please feel free to contact us.

Nancy Koroloff, Principle Investigator

Judy Mayer, Research Assistant

(503) 725-4040

INFORMED CONSENT

I, ________________________, agree to participate in the Families In Action Project conducted by the Research and Training Center on Family Support and Children's Mental Health, Regional Research Institute for Human Services at Portland State University. I know that the project is seeking to learn about effective methods of family member participation on policy making bodies at community and state levels that impact upon services to children with emotional disorders and their families.

I understand that my part of the study involves participation in completing a questionnaire and being interviewed over the phone by project staff. I further understand that only persons with a legitimate interest in the research will have access to the information and that the responses I give are for research purposes only. I have been assured that all information I give will be kept confidential and that my name or identity will not be used in reports or for public discussion purposes.

I understand the above and I agree to participation in this research study.

Date __________ Signature ______________________

If you have questions about the research, please contact Nancy Koroloff or Richard Vosler-Hunter at the Regional Research Institute for Human Services at Portland State University, (503) 725-4040.

If you want to discuss concerns about this research, you may phone the Secretary of the Human Subjects Research Review Committee, Portland State University, (503) 725-3417; or Barbara Friesen, Director, Research and Training Center on Family Support and Children's Mental Health, (503) 725-4040.

I. BACKGROUND AND INFORMATION

1. NAME: ____

2. AGE: _____20-39 _____40-59 _____60 +

3. SEX: _____Male _____Female

4. CURRENT MARITAL STATUS

_____Married _____Divorced _____Widowed _____Single _____Other

SOURCES OF SUPPORT

The following information will be used to compare the kinds of support you have used with data from another parent survey. Your completion of this section will be helpful in that comparison.

5a. *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
2. ___Your "significant other"
3. ___Your ex-spouse
4. ___Child's grandparents
5. ___Friends
6. ___Neighbors
7. ___Other children
8. ___Other family member List______________
9. ___Other List______________
10. ___None

5b. Please circle the number above of the one who has been most helpful.

5c. How has the person been helpful to you?

1. ___Provides emotional support
2. ___Baby-sits
3. ___Helps me find appropriate services
4. ___Helps me financially
5. ___Gives me advice
6. ___Other List__________________________

5d. Please circle the number above of the type of help that is most helpful.

5e. Overall, who is the person who has provided you with the <u>most</u> help in raising your child?

1. ___A professional
2. ___A friend or family member
3. ___Other List__________________________

6A. *OTHER SOURCES OF HELP*. Besides support from professional 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
2. ___Involvement with other parents of children with emotional problems
3. ___Your own career
4. ___Your own hobbies
5. ___Community volunteer activities
6. ___Recreational activities
7. ___Involvement in advocacy
8. ____ Other activities List__________________________

6b. Please circle the number above which has been the most helpful.

6c. Please describe the activity and explain below why it has been helpful in coping.

____

____

____

7. Do you have someone who shares daily parenting responsibilities with you? (Spouse, significant other, friends, neighbors, etc.)

______yes ______no

DEMOGRAPHICS

8. What is your highest level of education?

______Some high school or less	______College degree
______High school diploma	______Some graduate school
______Business or trade school	______Graduate degree
______Some college	

9. What is your occupation? ____

10. Do you have a paid position as an advocate for children with disabilities and/or their families?

______Yes ______ No

If yes:

What is your position?____

FTE_________ Funding source______________________________________

11. What is your yearly family income?

______Under $10,000	______$30,000-$39,999
______$10,000-$19,999	______$40,000-$49,999
______$20,000-$29,999	______$50,000 or more

12. What is your race?

______ White	______ Hispanic
______ Black	______ Asian or Pacific Islander (including Hawaiian)
______ American Indian or Alaskan Native	______ Other

13. List all your children, oldest child first.

Age	Where live now	Relationship to you (natural, adopt, step, foster, etc.)	Indicate which child(ren) have a disability
______	__________________	____________________	____________________
______	__________________	____________________	____________________
______	__________________	____________________	____________________
______	__________________	____________________	____________________

12. How many persons currently live in your home? ___________

II. INFORMATION ON CHILD(REN)

PLEASE COMPLETE QUESTIONS 1-4 FOR EACH CHILD WHO HAS A DISABILITY(IES).

1. How old is this child?__________

2. What type of disability does your child have? Please check all that apply.

______ Emotional
______ Learning
______ Mental retardation
______ Physical
______ Other (please indicate)____

3a. Have you been given a name (diagnosis) for your child's condition? ______ Yes ______ No

3b. If yes, what is the name ____

3c. What was the age of your child when the diagnosis was made? _________

4. Regarding your child with an emotional disability, what was the age of your child when you first felt he/she had an emotional disability?_________

Comments:

____

____

____

****

1. How old is this child?__________

2. What type of disability does your child have? Please check all that apply.

______ Emotional
______ Learning
______ Mental retardation
______ Physical
______ Other (please indicate)____

3a. Have you been given a name (diagnosis) for your child's condition? ______ Yes ______ No

3b. If yes, what is the name ____

3c. What was the age of your child when the diagnosis was made? _________

4. Regarding your child with an emotional disability, what was the age of your child when you first felt he/she had an emotional disability?_________

Comments:

____

____

____

III. GROUP INVOLVEMENT

Throughout the questionnaire and during the interview "group" refers to committee, advisory board, decision making or policy making bodies, etc.

PLEASE LIST GROUPS TO WHICH YOU BELONG OR HAVE BELONGED THROUGHOUT YOUR HISTORY OF PARENT INVOLVEMENT.

____

____

____

____

____

____

****

PLEASE COMPLETE INFORMATION FOR EACH GROUP THAT YOU FEEL HAS BEEN <u>VERY</u> SIGNIFICANT TO YOUR HISTORY OF PARENT INVOLVEMENT.

Name of the group______________________________

a. Purpose of the group______________________________

____

b. Dates active in the group____________________________

c. List any offices held______________________________

____

d. List any other roles (i.e. subcommittee, committee representative. . .)________________

____

e. How did you become a member of the group?________________________

____

____

f. What is/was the composition of the group (i.e. professionals, parents)?________________

____

____

g. Did you serve on this group as a representative from another organization that is involved with children and mental health issues? ______Yes ______No

If yes, what organization(s) do you represent? __________________________

____

Name of the group____

a. Purpose of the group____________________________________

b. Dates active in the group________________________________

c. List any offices held____________________________________

d. List any other roles (i.e. subcommittee, committee representative. . .)____________________

e. How did you become a member of the group?________________________

f. What is/was the composition of the group (i.e. professionals, parents)?____________________

g. Did you serve on this group as a representative from another organization that is involved with children and mental health issues? ______Yes ______No

If yes, what organization(s) do you represent? ______________________________

****

Name of the group____

a. Purpose of the group____________________________________

b. Dates active in the group________________________________

c. List any offices held____________________________________

d. List any other roles (i.e. subcommittee, committee representative. . .)____________________

e. How did you become a member of the group?________________________

f. What is/was the composition of the group (i.e. professionals, parents)?____________________

g. Did you serve on this group as a representative from another organization that is involved with children and mental health issues? ______Yes ______No

If yes, what organization(s) do you represent? ______________________________

APPENDIX C

Policy Involvement Profile

Research and Training Center on Family Support and Children's Mental Health
Portland State University, P.O. Box 751 Portland, Oregon

POLICY INVOLVEMENT PROFILE

A. INFORMATION ABOUT YOUR ORGANIZATION

1. Name of organization: ______________________________

2. Mailing address: ______________________________
____
____

3. Contact person/persons: ____________________ **Phone #:** ________
____________________ **Phone #:** ________

4. What year did your organization begin? ______

5. Is your organization incorporated? ___ Yes ___ No

6. What area does your group draw members from (check all that apply):

___ local neighborhood
___ local city or town (specify: ______________________)
___ county (specify: ______________________)
___ statewide

7. How many active members do you have in your group? ______
(By active, we mean members that attend meetings or participate in your group's activities on a regular basis)

8. What kinds of activities does your group currently engage in: (check all that apply)

___ support meetings for members

___ sponsoring educational forums or workshops for members and/or public

___ group representatives serving on community boards or committees

___ preparing or providing testimony at public meetings and hearings

___ active advocacy for individual family members seeking services

___ publish newsletter (approximate circulation: ________)

___ telephone warmline or 1-800 number

___ information/resource center

___ other: ____

9. Of the above activities, which are your top three priorities?

10. Ideally, of the above activities which ones would your organization like to develop or spend more time on?

11. How many members of your group serve on a local community or state policy making board or committee?

____

12. Of those serving on committees or boards, how many do so as formal representatives of your organization?

______

13. **Please list the boards/committees your members currently serve on, indicate with a word or phrase the nature of the board (i.e., special education, mental health, etc.), and note the number of members from your organization on the board/committee:**

Name of Board/Committee	Nature or focus	# members serving

14. **Where you have representation on policy boards/committees, what led to a member of your group getting on the board (check all that apply):**

____ formal invitation to our group from a board/agency to send a representative

____ formal invitation to a specific member from a board/agency

____ our group initiated the request for representation

____ our representative was on the board prior to joining our organization or for reasons other than being a member of our organization

____ responded to public notice or advertisement for membership

____ other: ____

15. **Overall, how effective do you believe your representation on boards or committees has been in effecting the changes your group is seeking?**

16. **Overall, how satisfied is your group with the extent and quality of representation your organization has on community/state policy boards and committees?**

17. **How satisfied are you with the numbers of members you have able to serve on advisory boards or committees? What would be an improvement?**

18. **How satisfied are you with the diversity of your membership in terms of being representative of parents in your community (e.g. ethnicity, income, geographic, etc.) What would be an improvement?**

19. **When you think about instances or times your group's representation on policy boards and committees has been effective, what reasons or factors do you think contributed to this effectiveness?** (This may include such items as the attitude of the agency or board members, qualities and skills of your representatives, etc.)

20. **When you think about what would you like to accomplish in terms of representation on policy boards or committees, what barriers come to mind?**

(In answering, think about system barriers (i.e. agency attitudes, meeting times and locations, reimbursement or lack thereof, etc.) and those of your own organization (i.e. level of group support for representatives, personal qualities and skills, demands of other group activities, etc.

21. **Some groups have discussed the difficulties in sorting out the role of a board or committee member in terms of when and how a board member represents the parent organization or themselves individually. Has this been an issue for your group and how does your organization deal with this issue?**

B. INFORMATION ABOUT THE SERVICE SYSTEM

1. **Generally speaking, what agencies or service systems in your community provide the majority of services to children with emotional disorder and their families?**

2. **Are there professionals in your community who are your allies in terms of supporting your organization and the concepts of parent/family involvement and could be resources to you in this area?**

3. **When you think of the positive aspects of services and policies currently benefiting your children and families, what would be the top five you point to (this may include programs, agencies, specific services, etc.):**

4. **When you think about service or policy needs that are currently unmet, what are the top five that come to mind?**

5. In view of the existing policy/service strengths and weaknesses you just identified, are there existing policy boards or committees that address (or could address) those issues?

If yes, what are those bodies and which of these policy/service needs do they address:

6. Do these boards/agencies currently have consumers or family members on their boards?

7. How would you characterize the attitudes/supportiveness of each of these boards/agencies towards family member involvement on their boards or committees?

8. **Ideally, which of these boards/committees would your organization most like to serve on (or, assist in creating a policy/advisory board)?**

9. **Thinking generally about improving or increasing your organizations involvement with these boards/committees/agencies, who are some key people you would need to involve or get support from (such as agency directors, influential community leaders or citizens, etc.):**

10. **Finally, when your group talks about increased involvement in board/committee work, what do you think you will need the most help with (think about such things as information needs, strategy, specific training, organizational issues, etc.)**
    (use additional page if necessary)

Please return a copy of this form to Richard Vosler-Hunter at the Research and Training Center, P.O. Box 751, Portland, OR 97207 (503) 725-4040

APPENDIX D

Key Informant Interview Schedule

FIA Key Informant Interview Schedule -- STANDARD

1A. On a rating scale of one to five with "1" representing few parents and "5" representing many parents, please tell me how you would rate the current level of parent participation on decision-making boards.

1	2	3	4	5
Few				Many

1B. **(FOLLOW-UP ONLY)** Does this rating represent an increase, a decrease, or about the same number of parents participating on decision-making boards since the first interview?

Decrease About the Same Increase

1C. How adequate is the number of parents currently participating on decision-making boards?

1D. Please estimate the number of parents currently on boards.

2A. On a rating scale of one to five with "1" representing not seriously and "5" representing very seriously, please rate how seriously professional members take the ideas and opinions of parent members of decision-making bodies.

1	2	3	4	5
Not Seriously				Very Seriously

2B. Discuss professional members' responses to the ideas and opinions of parent members of decision-making boards. How seriously are the ideas and opinions of parent members considered by the professional members?

3A. On a rating scale of one to five with "1" representing no influence and "5" representing a great deal of influence, please rate the level of influence of parents' ideas and opinions upon the mental health service delivery system.

1	2	3	4	5
No Influence				Great Influence

3B. Discuss examples in which parents' ideas and opinions have been able to influence the mental health service delivery system.

4. Can you think of anything else related to parent participation on boards that you'd like to mention? Are there any other influences or barriers you can think of that may affect parent participation? Is there anything specific you would like to see the Families in Action Project do in this site?

FIA Key Informant Interview Schedule -- Family Organization

1a. On a rating scale of one to five with "1" representing few parents and "5" representing many parents, please tell me how you would rate the current level of parent participation on decision-making boards.

1	2	3	4	5
Few				Many

1b. How adequate is the number of parents currently participating on decision-making boards?

1.c Please estimate the number of parents currently participating on decision-making boards:

2a. On a rating scale of one to five with "1" representing not seriously and "5" representing very seriously, please rate how seriously professional members take the ideas and opinions of parent members of decision making bodies.

1	2	3	4	5
not seriously				Very Seriously

2b. Discuss professional member's responses to the ideas and opinions of parent members of decision-making boards. How seriously are the ideas and opinions of parent members considered by the professional members?

3a. On a rating scale of one to five with "1" representing no influence and "5" representing a great deal of influence, please rate the level of influence of parents' ideas and opinions upon the mental health delivery system.

1	2	3	4	5
No Influence				Great Influence

3b. Discuss examples in which parents' ideas and opinions have been able to influence the mental health service delivery system.

4a. Discuss the numbers of parents in the family organization who are available for board membership. How does the number of parents who are available for membership on boards compare to the family organization's goal regarding parent representation on such boards?

4b. On a rating scale of one to five with "1" representing a poor fit and "5" representing an excellent fit, please rate the current fit between the number of parents available for membership on decision-making boards and the number of parents the family organization needs on such boards.

1	2	3	4	5
Poor fit				Excellent fit

5a. Are there parent members on those decision-making bodies the family organization feel are most critical?

5b. On a rating scale of one to five with "1" representing very far from goal and "5" representing very close to goal, please rate how close the family organization is to its goal of achieving parent representation on boards it considers critical.

1	2	3	4	5
Very far				Very Close

6a. Do parents who are members of boards and decision-making bodies discuss board issues with other parents in the family organization? Do they receive information and support from the family organization for the positions they are taking on such boards?

6b. On a rating scale of one to five with "1" representing little discussion, information, and support and "5" representing a great deal of discussion, information, and support, please rate the current level of interaction between parent members of boards and other members of the family organization.

1	2	3	4	5
Little Discussion				Great Discussion

7a. Do parents of the family organization who are members of boards represent the opinions of the family organization or do they represent their personal opinions? Is board representation organizational or personal?

7b. Are parents clear as to who they are representing -- the family organization or themselves? Do they distinguish between instances in which they are representing the opinions and positions of the family organization and instances in which they are voicing their own opinions?

What happens to a parent's level of activity in the family organization when she or he accepts membership on a decision-making body? Does she or he become more, or less active in the family organization?

8b. On a rating scale of one to five with "1" representing a decrease in activity in the family organization and "5" representing an increase in activity in the family organization, please rate parent members' activity level once she or he becomes a member of a decision-making board.

1	2	3	4	5
Decrease		Same		Increase

9. Can you think of anything else related to parent participation on boards that you'd like to mention? Are there any other influences or barriers you can think of that may affect parent participation? Is there anything specific you would like to see the Families in Action Project do in this site?

APPENDIX E

Parents as Policy Makers: A Handbook for Effective Participation

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PARENTS AS POLICY MAKERS:
A HANDBOOK FOR EFFECTIVE PARTICIPATION

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APPENDIX F

Survey on Advisory Group Participation

SURVEY ON ADVISORY GROUP PARTICIPATION

Families in Action Project

Research and Training Center on Family Support
and Children's Mental Health

Portland State University

The purpose of this questionnaire is to gather information about your experiences as a member of an **advisory group.** By "**advisory group,**" we mean a policy or decision-making body that influences services to children with emotional disabilities and their families. These groups include task forces, committees, governing bodies, and boards. For the purposes of this research, please exclude parent support groups and statewide parent organization groups. Include only those groups that have both parents and professionals as members. The term "parent" includes any caretaker of a child with a serious emotional disability.

Regional Research Institute for Human Services • Portland State University • PO Box 751 • Portland, OR 97207-0751

(Use back of page for additional writing space, if needed.)

Some questions about your advisory group:

1. a. If you are currently a member of an advisory group, write the name of the advisory group that you are most involved with. Answer the questions in this questionnaire with this group in mind:

   ____

   b. If you are not currently a member of an advisory group, think of an advisory group you were a member of in the past. Write the name of this group here and answer the questions in this questionnaire using your experiences in this group:

   ____

   c. If you have never been a member of an advisory group, please check here and go to Question 36.

   ☐ **I have never been a member of an advisory group.**

2. What is the focus of this group? *(Check as many as apply)*
   _____ Children's mental health
   _____ Public/Special education
   _____ Substance abuse
   _____ Juvenile justice
   _____ Child welfare
   _____ Developmental disabilities
   _____ Early intervention
   _____ Other: ______________________

3. How many members does this group have? _________

4. How long have you been a member of this group?
   _____ Years _____ Months

5. How long has this group existed?
   _____ Years _____ Months _____ Don't know

6. How often does the group meet?
   _____ Weekly _____ Monthly
   _____ Quarterly _____ Yearly
   _____ Other: ______________________

7. How regularly do you attend meetings of this group?
   _____ Always
   _____ Often
   _____ Seldom
   _____ Never

8. Not counting yourself, how many other parents or family members have membership in this group? *Include parents of children with emotional disorders who are also professional service providers.* _________

9. Do you serve on a sub-committee of this group?
   _____ Yes, currently
   Please specify: ______________________
   _____ Yes, in the past
   Please specify: ______________________
   _____ No, but chose not to participate
   _____ No, never volunteered or been asked
   _____ This group has no sub-committees

10. Have you ever been an officer or held a leadership position in this advisory group?
   _____ Yes, currently
   Title: ______________________
   _____ Yes, in the past
   Title: ______________________
   _____ No, chose not to hold office
   _____ No, never volunteered or been asked
   _____ This group has no officers

11. Overall, how active are you as a member of this advisory group?
   _____ Very active
   _____ Moderately active
   _____ Slightly active
   _____ Inactive

12. Compared to other members of the group, how active are you?
   _____ Much more active
   _____ Slightly more active
   _____ About the same
   _____ Less active

---

13. During advisory group meetings, how often are you likely to... *(Circle your responses)*

a. Enter into discussions	REGULARLY	OFTEN	SOMETIMES	NEVER
b. Place items on the agenda	REGULARLY	OFTEN	SOMETIMES	NEVER
c. Introduce topics under "new business"	REGULARLY	OFTEN	SOMETIMES	NEVER
d. Make formal motions	REGULARLY	OFTEN	SOMETIMES	NEVER
e. Present draft position statements for the group to review	REGULARLY	OFTEN	SOMETIMES	NEVER
f. Disagree with others	REGULARLY	OFTEN	SOMETIMES	NEVER
g. Accept responsibility for a task	REGULARLY	OFTEN	SOMETIMES	NEVER
h. Other: ______________________	REGULARLY	OFTEN	SOMETIMES	NEVER

PLEASE CONTINUE –

(Use back of page for additional writing space, if needed.)

Some questions about the benefits of membership:

14. a. Do you think this advisory group does important work?
_____ Very important
_____ Moderately important
_____ Slightly important
_____ Not important

b. If you feel the group does important work, please describe some of the group's goals and accomplishments:

____
____
____
____

15. a. Do you think that other parents who know of your membership on this advisory group respect and appreciate your work?
_____ Yes, a lot
_____ Yes, some
_____ Yes, a little
_____ No

b. Please describe either positive or negative behaviors on the part of parents that let you know how they feel about your membership in this advisory group:

____
____
____
____

16. In general, how much enjoyment or personal satisfaction do you get from being a member of this advisory group?
_____ Much
_____ Some
_____ Little
_____ None

17. Compared to other members of the group, do you think you get more or less personal satisfaction from membership?
_____ More
_____ Similar
_____ A little less
_____ Much less

18. Have you developed personal friendships with other members of the advisory group?
_____ Many
_____ Some
_____ Few
_____ None

19. Briefly describe the aspects of advisory group membership that are enjoyable for you:

____
____
____
____

Some questions about your experiences as an advisory group member:

20. Considering your overall experience with this group, how much influence on the group's decision-making do you have?
_____ A lot
_____ Some
_____ Little
_____ None

21. Compared to other members of the group, do you feel you have more influence or less influence?
_____ Much more
_____ More
_____ About the same
_____ Less

22. How often have recommendations made by the parents in this group been accepted?
_____ Regularly
_____ Often
_____ Sometimes
_____ Never
_____ Don't know
_____ Parents have not yet made recommendations

23. How often has this group delayed or changed its plans because of objections raised by parents?
_____ Regularly
_____ Often
_____ Sometimes
_____ Never
_____ Don't know
_____ Parents have not yet raised objections

24. Overall, is this advisory group responsive to the issues raised by parents and other family members?
_____ Very responsive
_____ Moderately responsive
_____ Slightly responsive
_____ Not responsive

PLEASE CONTINUE →

(Use back of page for additional writing space, if needed.)

25. a. Considering your overall experience with the professionals who are members of this advisory group, what is their attitude toward parent membership and participation?
_____ Generally positive
_____ Somewhat positive
_____ Somewhat negative
_____ Generally negative

b. Please describe either positive or negative behaviors on the part of professionals that let you know how they feel about you as a parent member:

____
____
____
____

26. a. Have the attitudes of the professional group members toward the parent members changed since you became a member?
_____ Much improved
_____ A little improved
_____ Stayed about the same
_____ Gotten worse

b. If their attitudes have changed, please describe how their attitudes have changed and what you think caused the changes:

____
____
____
____

27. a. How frequently do you have contacts with advisory group members between meetings?
_____ Regularly
_____ Often
_____ Sometimes
_____ Never

b. If you have contact, what is the purpose of that contact? (*For example, to get more information on issues related to the group, to get or give information related to your children, to get or give support*)

____
____
____
____

28. a. If there are other parents of children with emotional disabilities in the advisory group, what i the nature of your contact with these parents?
_____ No contact
_____ See or talk with them only during meetings
_____ Talk or meet with them outside of meeting concerning the work of the group
_____ No other parents in this advisory group

b. If you have contact with other parents, what is th focus of contact? (*For example, information sharing, strategizing, etc.*)

____
____
____
____

29. a. How often do you discuss issues raised during advisory group meetings with other parents of children with emotional disabilities who are not members of the advisory group?
_____ Regularly
_____ Often
_____ Sometimes
_____ Never

b. If you have contact with other parents, what are the benefits of those contacts?

____
____

Some questions about meeting arrangements:

30. In order to attend an advisory group meeting, have you done any of the following? (Please check all that apply)

_____ Requested a change in the time of day for the meeting
_____ Requested a change in the day of the week that the group meets
_____ Requested a change in the meeting location
_____ Brought your child to a meeting
_____ Asked for a ride to a meeting

31. Has the advisory group made changes in the times or locations of meetings based on your request or the request of other parents?
_____ Regularly
_____ Often
_____ Sometimes
_____ Never

PLEASE CONTINUE -

(Use back of page for additional writing space, if needed.)

32. a. Are you reimbursed for personal costs or expenses associated with attendance at meetings?
_____ Yes
_____ No *(If no, go to Question 32d)*
_____ Reimbursement is available, but I don't claim expenses

b. What can you be reimbursed for?
_____ Mileage, parking or related travel expenses
_____ Respite care or day care for child
_____ Meal or lodging expenses
_____ Lost wages
Other expenses: ______________________________

c. If you are reimbursed, how important is this to your involvement?
_____ Very much
_____ Moderately
_____ Slightly
_____ Not at all

d. If you are not reimbursed, would reimbursement help you to increase your involvement?
_____ Very much
_____ Moderately
_____ Slightly
_____ Not at all

33. If you are employed outside the home, does your employer allow you to attend advisory group meetings during work hours without affecting your pay or job status?

_____ Yes
_____ Yes, with the following conditions: __________
____
____
____

_____ No
_____ Doesn't apply
_____ Don't know

As you think about your participation with this advisory group...

34. a. Do you feel your participation has added to your understanding of the children's mental health system?
_____ Considerably increased
_____ Moderately increased
_____ Slightly increased
_____ No increase

b. In what areas have you gained knowledge?

____
____
____
____

35. a. Do you feel your participation has increased your skills as a **group member?**
_____ Considerable increase
_____ Moderate increase
_____ Slight increase
_____ No increase

b. Do you feel your participation has increased your skills as a **group leader?**
_____ Considerable increase
_____ Moderate increase
_____ Slight increase
_____ No increase

c. What specific skills have you acquired that make you feel more effective? *(For example, public speaking, persuading, negotiating, conflict management)*

____
____
____
____

Some questions about you:

36. Your sex:
_____ Male
_____ Female

37. Your race:
_____ Native American/Alaskan Native
_____ Hispanic/Latino American
_____ Black/African American
_____ Asian/Pacific Islander
_____ White
Other: ______________________________

38. Your relationship status:
_____ Married*
_____ Single
_____ Divorced
_____ Separated
_____ Widowed
***either a legal marriage or a marriage-like living situation**

39. a. Do you have someone who shares daily parenting responsibilities with you? (*This can be a spouse, parent, friend, etc.*)
_____ Yes
_____ No

b. If yes, please describe this relationship: (*For example, friend, neighbor, spouse*)

____

PLEASE CONTINUE →

(Use back of page for additional writing space, if needed.)

40. Your household gross income before taxes:
    ____ Under $10,000
    ____ $10,000-$19,999
    ____ $20,000-$29,999
    ____ $30,000-$39,999
    ____ $40,000-$49,999
    ____ $50,000-$59,999
    ____ $60,000-$69,999
    ____ $70,000 or more

41. a. Your highest level of education:
    ____ Some high school or less
    ____ High school diploma or GED
    ____ Business or trade school
    ____ Some college
    ____ College degree
    ____ Some graduate school
    ____ Graduate degree

    b. What are/were your areas of interest in school?

    ____

42. Do you hold a job as a mental health or social service professional?
    ____ Yes
    ____ No

    Job Title: ______________________________

43. Prior to your work with this advisory group, how much advisory group experience did you have?
    ____ A great deal
    ____ Some
    ____ Little
    ____ None

45. Please check if you have done any of the following:
    ____ Attended a parent support group
    ____ Attended a workshop or received training in advocacy
    ____ Phoned, written to, or visited a legislator to talk about services for children
    ____ Phoned, written to, or visited an agency or school administrator about the services your child has received or should be receiving
    ____ Prepared or given testimony at a legislative committee or other meeting regarding services for children
    ____ Given a speech or written an article about a children's issue
    ____ Assisted another parent or family in dealing with the service system
    ____ Written a letter to a newspaper regarding a children's issue
    ____ Been involved in legal or court action regarding services for children
    ____ Filed a formal complaint or grievance regarding services for children
    ____ Helped organize a group to discuss or advocate for children's services
    ____ Phoned, written to or visited a counselor, therapist or teacher about services for your child

PLEASE CONTINUE

(Use back of page for additional writing space, if needed.)

46. List all children in your family and indicate their age(s):

	AGE OF CHILD	CHECK IF CHILD HAS AN EMOTIONAL/ BEHAVIORAL DISTURBANCE	WHERE DOES CHILD LIVE?
1.			
2.			
3.			
4.			
5.			
6.			

Please create a personal identification code which you will remember over time. (We suggest the last four digits of your social security number or phone number.)

______ ______ ______ ______

Please continue on and complete the Family Empowerment Scale.

FAMILY EMPOWERMENT SCALE

Instructions: Below are a number of statements that describe how a parent or caregiver of a child with an emotional problem may feel about his or her situation. For each statement, please circle the response that best describes how the statement applies to you.

1.	I feel that I have a right to approve all services my child receives.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
2.	When problems arise with my child, I handle them pretty well.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
3.	I feel I can have a part in improving services for children in my community.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
4.	I feel confident in my ability to help my child grow and develop.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
5.	I know the steps to take when I am concerned my child is receiving poor services.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
6.	I make sure that professionals understand my opinions about what services my child needs.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
7.	I know what to do when problems arise with my child.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
8.	I get in touch with my legislators when important bills or issues concerning children are pending.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
9.	I feel my family life is under control.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
10.	I understand how the service system for children is organized.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
11.	I am able to make good decisions about what services my child needs.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
12.	I am able to work with agencies and professionals to decide what services my child needs.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
13.	I make sure I stay in regular contact with professionals who are providing services to my child.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
14.	I have ideas about the ideal service system for children.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
15.	I help other families get the services they need.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
16.	I am able to get information to help me better understand my child.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
17.	I believe that other parents and I can have an influence on services for children.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$

PLEASE CONTINUE →

18.	My opinion is just as important as professionals' opinions in deciding what services my child needs.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
19.	I tell professionals what I think about services being provided to my child.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
20.	I tell people in agencies and government how services for children can be improved.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
21.	I believe I can solve problems with my child when they happen.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
22.	I know how to get agency administrators or legislators to listen to me.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
23.	I know what services my child needs.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
24.	I know what the rights of parents and children are under the special education laws.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
25.	I feel that my knowledge and experience as a parent can be used to improve services for children and families.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
26.	When I need help with problems in my family, I am able to ask for help from others.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
27.	I make efforts to learn new ways to help my child grow and develop.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
28.	When necessary, I take the initiative in looking for services for my child and family.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
29.	When dealing with my child, I focus on the good things as well as the problems.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
30.	I have a good understanding of the service system that my child is involved in.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
31.	When faced with a problem involving my child, I decide what to do and then do it.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
32.	Professionals should ask me what services I want for my child.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
33.	I have a good understanding of my child's disorder.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$
34.	I feel I am a good parent.	NOT TRUE AT ALL$_1$	MOSTLY NOT TRUE$_2$	SOMEWHAT TRUE$_3$	MOSTLY TRUE$_4$	VERY TRUE$_5$

Reference: Koren, P.E., DeChillo, N. & Friesen, B.J. (1992). Measuring empowerment in families whose children have emotional disabilities: A brief questionnaire. Rehabilitation Psychology, 37(4), 305-321.

Research and Training Center on Family Support and Children's Mental Health.
Regional Research Institute for Human Services, Portland State University, PO Box 751, Portland, OR 97207-0751.

APPENDIX G

Survey Data from 14 Respondents with Matched Pre- and Post-Test Scores

Table 1: Status of Advisory Group Membership

	Winter '93 N=14	%	**Spring '94** N=14	%
Currently a member of an advisory group	13	93	11	79
Not currently a member, but served in the past	1	7	3	21
Never been a member of an advisory group	0	0	0	0

Table 2: Focus of Group

Specific Focus	**Winter '93** N=14*	%	**Spring '94** N=14*	%
Children's Mental Health	12	86	13	93
Public/Special Education	5	36	4	29
Substance Abuse	0	0	3	21
Juvenile Justice	1	7	3	21
Child Welfare	1	7	4	29
Developmental Disabilities	5	36	2	14
Early Intervention	4	29	3	21
Other	4	29	3	21

*Multiple responses possible.

Table 3: Number of Group Members

	Winter '93 N=14	%	**Spring '94** N=14	%
10-15	8	57	5	36
16-25	4	29	5	36
26-35	1	7	2	14
Missing data	1	7	2	14

['93 range= 10 to 30 members; '94 range= 10 to 35 members]

Table 4: Length of Individual Respondent's Membership on Board

	Winter '93 N=14	%	**Spring '94** N=14	%
< 6 months	4	29	1	7
6 months to 1 year	4	29	6	43
> 1 to 2 years	4	29	3	21
> 2 to 3+ years	1	7	4	29
Missing responses	1	7	0	0

['93 range= 2 months to 3 years 4 months; '94 range= 4 months to 3 years]

Table 5: How Long Group has Existed

	Winter '93		Spring '94	
	N=14	%	N=14	%
0 to 6 months	2	14	0	0
7 months to 1 year	4	29	2	14
> 1 year to 3 years	1	7	5	36
3+ years	2	14	2	14
Don't know	3	21	4	29
Missing responses	2	14	1	7

['93 range= 0 to 8 years; '94 range= 0 to 9.5 years]

Table 6: How Often Group Meets

	Winter '93 N=14	%	Spring '94 N=14	%
Weekly	0	0	1	7
Monthly	11	79	11	79
Bimonthly	1	7	0	0
Quarterly	1	7	1	7
Yearly	1	7	1	7

Table 7: Regularity of Attendance

	Winter '93 N=14	%	Spring '94 N=14	%
Always	12	86	13	93
Often	2	14	1	7
Seldom/Never	0	0	0	0
Missing responses	0	0	0	0

Table 8: Number of (Other) Parents or Family Members in Group

	Winter '94		Spring '94	
	N=14	%	N=14	%
0	0	0	3	21
1-2	2	14	2	14
3-5	9	64	4	28
5+	0	0	5	36
Missing responses	3	21	0	0

Table 9: Subcommittee Participation

	Winter '93		Spring '94	
	N=14	%	N=14	%
Currently serving on a subcommittee	4	29	4	29
Past service on a subcommittee	1	7	3	21
Chose not to participate on a subcommittee	1	7	0	0
Never volunteered or been asked	1	7	0	0
No subcommittees in this group	7	50	7	50

Table 10: Participation as an Officer Within the Group

	Winter '93		**Spring '94**	
	N=14	%	N=14	%
Currently an officer within the group	3	21	2	14
Past service as a group officer	1	7	3	21
Chose not to hold office	2	14	2	14
Never volunteered or asked to serve	3	21	1	7
No officers in this group	5	36	6	43

Table 11: How Active as a Group Member

	Winter '93		**Spring '94**	
	N=14	%	N=14	%
Very active	5	36	10	71
Moderately active	6	43	3	21
Slightly active	3	21	1	7
Missing responses	0	0	0	0

Table 12: How Active Compared to Other Group Members

	Winter '93		Spring '94	
	N=14	%	N=14	%
Much more active	2	14	0	0
Slightly more active	1	7	6	43
About the same	10	71	6	43
Less active	1	7	1	7
Missing responses	0	0	1	7

Table 13: Participatory Behavior during Group Meetings

	Winter '93	Spring '94
	(Mean Scores)	
Enter into discussions	2.2	2.2
Place items on the agenda	1.1	1.4
Introduce topics under "new business"	0.7	1.3
Make formal motions	0.4	0.9
Present draft position statements for the group to review	0.4	0.8
Disagree with others	1.2	1.4
Accept responsibility for a task	1.7	1.7
Other	0.4	0.3

[0= never; 1= sometimes; 2=often; 3=regularly]

Table 14: Perceived Importance of Advisory Group Work

	Winter '93		**Spring '94**	
	N=14	%	N=14	%
Very important	9	64	4	29
Moderately important	1	7	6	43
Slightly important	2	14	3	21
Not important	1	7	0	0
Missing responses	1	7	1	7

Table 15: Do Other Parents Respect and Appreciate Your Work on this Advisory Group?

	Winter '93		**Spring '94**	
	N=14	%	N=14	%
Yes, a lot	3	21	5	36
Yes, some	8	57	5	36
Yes, a little	2	14	3	22
No	1	7	1	7

Table 16: Personal Satisfaction from Advisory Group Membership

	Winter '93 N=14	Winter '93 %	Spring '94 N=14	Spring '94 %
Much	6	43	4	29
Some	6	43	9	64
Little	2	14	1	7
None	0	0	0	0

Table 17: Personal Satisfaction Compared with other Group Members

	Winter '93 N=14	Winter '93 %	Spring '94 N=14	Spring '94 %
More	6	43	2	14
Similar	6	43	9	64
A little less	2	14	2	14
Much less	0	0	1	7
Missing responses	0	0	0	0

Table 18: Personal Friendships with Advisory Group Members

	Winter '93 N=14	Winter '93 %	Spring '94 N=14	Spring '94 %
Many	0	0	1	7
Some	8	57	9	64
Few	4	29	3	21
None	2	14	1	7

Table 19: Idiosyncratic Data; Content Themes Summarized in Text

Table 20: Personal Influence on Group's Decision-Making

	Winter '93		**Spring '94**	
	N=14	%	N=14	%
A lot	2	14	1	7
Some	9	64	2	14
Little	2	14	10	71
None	1	7	1	7

Table 21: Personal Influence Compared to Other Group Members

	Winter '93		**Spring '94**	
	N=14	%	N=14	%
Much more	1	7	1	7
More	2	14	1	7
About the same	9	64	9	64
Less	2	14	2	14
Missing responses	0	0	1	7

Table 22: Frequency of Acceptance of Parent Recommendations in this Group

	Winter '93		**Spring '94**	
	N=14	%	N=14	%
Parents have not yet made recommendations	1	7	0	0
Don't know	2	14	0	0
Regularly	5	36	2	14
Often	0	0	6	43
Sometimes	5	36	6	43
Never	1	7	0	0
Missing responses	0	0	0	0

Table 23: Frequency of Group's Changing Plans Due to Parent Objections

	Winter '93		**Spring '94**	
	N=14	%	N=14	%
Parents have not yet raised objections	3	21	0	0
Don't know	2	14	1	7
Regularly	0	0	0	0
Often	4	29	4	29
Sometimes	2	14	6	43
Never	3	21	3	21

Table 24: Responsiveness of Advisory Group to Issues Raised by Parents or Family Members

	Winter '93 N=14	Winter '93 %	Spring '94 N=14	Spring '94 %
Very responsive	10	71	4	29
Moderately responsive	2	14	7	50
Slightly responsive	2	14	3	21
Not responsive	0	0	0	0

Table 25: Parents' Perception of Attitudes of Professionals

	Winter '93 N=14	Winter '93 %	Spring '94 N=14	Spring '94 %
Generally positive	8	57	4	29
Somewhat positive	3	21	7	50
Somewhat negative	2	14	3	21
Generally negative	0	0	0	0
Missing responses	1	7	0	0

Table 26: Parents' Perception of Change in Attitude of Professionals

	Winter '93		**Spring '94**	
	N=14	%	N=14	%
Much improved	0	0	1	7
A little improved	7	50	6	43
Stayed about the same	6	43	7	50
Gotten worse	0	0	0	0
Missing responses	1	7	0	0

Table 27: Frequency of Contact with Other Parent Members of Group Between Meetings

	Winter '93		**Spring '94**	
	N=14	%	N=14	%
Regularly	2	14	2	14
Often	5	36	4	29
Sometimes	5	36	8	57
Never	1	7	0	0
Missing responses	1	7	0	0

Table 28: Nature of Contact with Other Parents

	Winter '93		**Spring '94**	
	N=14	%	N=14	%
No contact	1	7	0	0
See or talk only during meetings	0	0	1	7
Talk or meet outside meetings	11	79	9	64
No other parents in group	1	7	4	29
Missing responses	1	7	0	0

Table 29: How Often Group Issues Discussed with Other Parents

	Winter '93		**Spring '94**	
	N=14	%	N=14	%
Regularly	1	7	0	0
Often	3	21	4	29
Sometimes	5	36	10	71
Never	4	29	0	0
Missing responses	1	7	0	0

Table 30: Special Efforts by Parents in Order to Attend Group Meetings

	Winter '93		**Spring '94**	
	N=14*	%	N=14*	%
Asked for a change in the time of day	5	36	5	36
Asked for a change in the day of the week	3	21	4	29
Asked for a change in the meeting location	1	7	2	14
Brought their child to the meeting	1	7	0	0
Asked for a ride to the meeting	4	29	7	50

*Multiple responses possible

Table 31: Advisory Group Change in Time or Location When Requested by Parent

	Winter '93		Spring '94	
	N=14	%	N=14	%
Regularly	1	7	0	7
Often	0	0	1	7
Sometimes	5	36	7	50
Never	5	36	5	36
Missing responses	3	21	1	7

Table 32a: Reimbursement for Personal Expenses Related to Meetings

	Winter '93		Spring '94	
	N=14	%	N=14	%
Reimbursed for personal costs or expenses associated with attendance at meetings	0	0	2	14
Reimbursement available, but expenses not claimed	1	7	0	0
Not reimbursed	13	93	12	86

Table 32b: Kinds of Reimbursement for Personal Expenses Associated with Attendance at Meetings (If Eligible)

	Winter '93		Spring '94	
	N=1*	%	N=2*	%
Mileage, parking or related travel expenses	1	100	1	50
Respite care or day care for child	1	100	2	100
Meal or lodging expenses	0	0	0	0
Lost wages	0	0	0	0
Other	0	0	0	0

*Multiple responses possible

Table 32c: Importance of Reimbursement to Involvement (If Received)

	Winter '93		Spring '94	
	N=7	%	N=2	%
Very much	0	0	0	0
Moderately	0	0	1	50
Slightly	0	0	0	0
Not at all	0	0	1	50
Missing responses	1	100	0	0

Table 32d: Importance of Reimbursement (If not Received) to Increasing Involvement

	Winter '93		Spring '94	
	N=13	%	N=12	%
Very much	5	38	0	0
Moderately	1	8	3	25
Slightly	2	15	5	41
Not at all	5	38	4	33

Table 33: Relative Cooperation with Participation during Work Hours by Employer if Parent Employed Outside the Home

	Winter '93		**Spring '94**	
	N=14	%	N=14	%
Employer cooperative	3	21	3	21
Conditional cooperation	1	7	2	14
Employer uncooperative	2	14	4	28
Doesn't apply	8	57	5	36
Don't know	0	0	0	0
Missing responses	1	7	0	0

Table 34: Increased Understanding of Children's Mental Health System

	Winter '93		**Spring '94**	
	N=14	%	N=14	%
Considerable increase	7	50	5	36
Moderate increase	2	14	6	43
Slight increase	3	21	2	14
No increase	2	14	1	7
Missing responses	0	0	0	0

Table 35a: Increased Skills as a Group Member

	Winter '93		Spring '94	
	N=14	%	N=14	%
Considerable increase	2	14	5	36
Moderate increase	7	50	4	29
Slight increase	2	14	3	21
No increase	3	21	2	14
Missing responses	0	0	0	0

Table 35b: Increased Skills as a Group Leader

	Winter '93		**Spring '94**	
	N=14	%	N=14	%
Considerable increase	1	7	1	7
Moderate increase	4	29	7	50
Slight increase	3	21	4	29
No increase	5	36	2	14
Missing responses	1	7	0	0

Table 36: Gender of Respondents

	Winter '93		**Spring '94**	
	N=14	%	N=14	%
Male	0	0	0	0
Female	14	100	14	100
Missing responses	0	0	0	0

Table 37: Race or Ethnicity

	Winter '93		Spring '94	
	N=14	%	N=14	%
White	14	100	14	100

Table 38: Relationship Status of Respondents

	Winter '93		Spring '94	
	N=14	%	N=14	%
Married/Marriage-like relationship	10	71	11	79
Single	1	7	0	0
Divorced	2	14	2	14
Separated	0	0	0	0
Widowed	1	7	1	7

Table 39a: Shared Responsibility for Daily Parenting

	Winter '93		**Spring '94**	
	N=14	%	N=14	%
yes	12	86	12	86
no	2	14	2	14

Table 39b: Relationship of Person(s) Sharing Daily Parenting

	Winter '93		**Spring '94**	
	N=14	%	N=14	%
spouse	10	71	10	71
ex-spouse	0	0	0	0
friend	2	14	2	14
no one/not applicable	2	14	2	14

Table 40: Household Pre-Tax Income

	Winter '93		Spring '94	
	N=14	%	N=14	%
Under $10,000	0	0	1	7
$10,000-$19,999	3	21	2	14
$20,000-$29,999	2	14	2	14
$30,000-$39,999	3	21	2	14
$40,000-$49,999	3	21	2	14
$50,000-$59,999	1	7	2	14
$60,000-$69,999	0	0	0	0
$70,000 or more	1	7	2	14
Missing responses	1	7	1	7

Table 41: Highest Educational Level Attained

	Winter '93		Spring '94	
	N=14	%	N=14	%
Some High School or less	0	0	0	0
High School Diploma or GED	5	36	5	36
Business or Trade School	0	0	0	0
Some College	5	36	5	36
College Degree	2	14	2	14
Some Graduate Study	0	0	0	0
Graduate Degree	2	14	2	14

Table 42: Job as a Mental Health or Social Service Professional

	Winter '93		**Spring '94**	
	N=14	%	N=14	%
Yes	4	15	6	33
No	22	63	12	37
Missing responses	3	12	0	0

Table 43: Prior Advisory Group Experience

	Winter '93		**Spring '94**	
	N=14	%	N=14	%
A great deal	1	7	1	7
Some	5	36	3	21
Little	2	14	4	29
None	5	36	6	43
Not applicable	0	0	0	0
Missing responses	1	7	0	0

Table 44: Specific Actions Undertaken by Parent

	Winter '93 N=14*	%	**Spring '94** N=14*	%
Attended a parent support group	14	100	14	100
Attended a workshop or received training in advocacy	10	71	14	100
Phoned, written to, or visited a legislator to talk about services to children	11	79	12	86
Phoned, written to, or visited an agency or school administrator about the services your child has been or should be receiving	11	79	14	100
Prepared or given testimony to a legislative committee or other meeting regarding services for children	10	71	12	86
Given a speech or written an article about a children's issue	6	43	10	71
Assisted another parent in dealing with the service system	13	93	12	86

Written a letter to the newspaper regarding a children's issue	3	21	4	29
Been involved in legal or court action regarding services for children	5	36	4	29
Filed a formal complaint or grievance regarding services for children	2	14	7	50
Helped organize a group to discuss or advocate for children's services	4	29	7	50
Phoned, written to or visited a counselor, therapist or teacher about services for your child	14	100	14	100
Missing responses	0	0	0	0

*Multiple responses possible

Table 45: Mean Scores and Standard Deviations on Subscales of the Family Empowerment Scale

	Winter '93		**Spring '94**	
	Mean	SD	Mean	SD
Family	50.9	2.7	50.6	5.4
Service System	53.6	3.4	55.7	3.0
Community/Political	37.9	5.4	40.5	6.6

Table 46a: Ages of Children

	Winter '93		**Spring '94**	
Age in years	N=28	%	N=28	%
0-5	3	11	1	4
6-12	15	54	12	43
13-18	9	32	14	50
19+	1	4	1	4

Table 46b: Children with an Emotional or Behavioral Disturbance

	Winter '93		**Spring '94**	
	N=28	%	N=28	%
Child diagnosed with an emotional or behavioral disturbance	18	64	18	64

Table 46c: Where Children are Living

	Winter '93		**Spring '94**	
	N=28	%	N=28	%
Independent	1	4	1	4
At home	22	79	24	86
Group home	3	11	0	0
Residential setting	2	7	2	7
Hospital	0	0	1	4

APPENDIX H

Survey Data from All Respondents

Table 1: Status of Advisory Group Membership

	Spring '93		**Spring '94**	
	N=29	%	N=18	%
Currently a member of an advisory group	24	83	12	67
Not currently a member, but served in the past	2	7	6	33
Never been a member of an advisory group*	3	10	0	0

*Respondents in this category were instructed to skip to item 36; accordingly, Tables 2-35 will have an N of 26 (except as noted).

Table 2: Focus of Group

	Spring '93		**Spring '94**	
Specific Focus	N=26*	%	N=18	*%
Children's Mental Health	22	85	16	89
Public/Special Education	10	39	5	28
Substance Abuse	1	4	3	17
Juvenile Justice	3	12	3	17
Child Welfare	4	15	4	22
Developmental Disabilities	7	27	2	11
Early Intervention	5	19	4	22
Other	8	31	4	22

*Multiple responses possible.

Table 3: Number of Group Members

	Spring '93		Spring '94	
	N=26	%	N=18	%
10-15	13	50	7	39
16-25	6	24	6	33
26-36	4	15	3	18
Missing data	3	12	2	11

[Range= 10 to 36 members]

Table 4: Length of Individual Respondents' Membership on Board

	Spring '93		Spring '94	
	N=26	%	N=18	%
< 6 months	4	15	1	6
6 months to 1 year	8	31	8	44
> 1 to 2 years	10	38	3	18
> 2 to 3+ years	2	8	5	28
Missing responses	2	8	1	6

[Range= 2 months to 3 years 4 months] [Range= 4 months to 3 years]

Table 5: How Long Group has Existed

	Spring '93		Spring '94	
	N=26	%	N=18	%
0 to 6 months	7	27	7	39
7 months to 1 year	5	19	2	11
> 1 year to 3 years	4	15	6	34
3+ years	6	23	1	6
Missing responses	4	15	2	11

[Range= 0 to 20 years] [Range= 0 to 9.5 years]

Table 6: How Often Group Meets

	Spring '93		Spring '94	
	N=26	%	N=18	%
Weekly	0	0	1	6
Biweekly	3	12	0	0
Monthly	17	65	13	72
Bimonthly	2	8	1	6
Quarterly	3	12	2	11
Yearly	1	4	1	6
Missing responses	0	0	0	0

Table 7: Regularity of Attendance

	Spring '93		Spring '94	
	N=26	%	N=18	%
Always	16	62	15	83
Often	9	35	3	17
Seldom/Never	0	0	0	0
Missing responses	1	4	0	0

Table 8: Number of (Other) Parents or Family Members in Group

	Spring '94		Spring '94	
	N=26	%	N=18	%
0	1	4	4	22
1-2	6	23	3	17
3-5	10	38	5	28
5+	4	16	6	34
Missing responses	4	16	0	0

Table 9: Subcommittee Participation

	Spring '93		Spring '94	
	N=26	%	N=18	%
Currently serving on a subcommittee	7	27	4	22
Past service on a subcommittee	3	12	5	28
Chose not to participate on a subcommittee	3	12	1	6
Never volunteered or been asked	1	4	0	0
No subcommittees in this group	12	46	7	39
Missing responses	0	0	1	6

Table 10: Participation as an Officer Within the Group

	Spring '93		**Spring '94**	
	N=26	%	N=18	%
Currently an officer within the group	4	16	2	11
Past service as a group officer	2	8	3	17
Chose not to hold office	4	16	3	17
Never volunteered or asked to serve	5	20	2	11
No officers in this group	11	38	7	39
Missing responses	0	0	1	6

Table 11: How Active as a Group Member

	Spring '93		**Spring '94**	
	N=26	%	N=18	%
Very active	10	38	12	67
Moderately active	11	42	5	28
Slightly active	4	15	1	6
Missing responses	1	4	0	0

Table 12: How Active Compared to Other Group Members

	Spring '93 N=26	%	Spring '94 N=18	%
Much more active	4	15	0	0
Slightly more active	7	27	10	56
About the same	12	46	6	33
Less active	2	8	1	6
Missing responses	1	4	1	6

Table 13: Participatory Behavior During Group Meetings

	Spring '93 (Mean Scores)	Spring '94
Enter into discussions	2.3	2.2
Place items on the agenda	1.4	1.4
Introduce topics under "new business"	1.1	1.5
Make formal motions	0.8	0.9
Present draft position statements for the group to review	0.7	0.8
Disagree with others	1.3	1.4
Accept responsibility for a task	2.1	1.8
Other	0.2	0.4

[0= never; 1= sometimes; 2=often; 3=regularly]

Table 14: Perceived Importance of Advisory Group Work

	Spring '93		**Spring '94**	
	N=26	%	N=18	%
Very important	18	69	5	28
Moderately important	4	31	6	33
Slightly important	2	8	5	28
Not important	1	4	0	0
Missing responses	1	4	2	11

Table 15: Do Other Parents Respect and Appreciate Your Work on this Advisory Group?

	Spring '93		**Spring '94**	
	N=26	%	N=18	%
Yes, a lot	11	42	7	39
Yes, some	11	42	6	33
Yes, a little	3	12	4	22
No	1	4	1	6
Missing responses	0	0	0	0

Table 16: Personal Satisfaction from Advisory Group Membership

	Spring '93		Spring '94	
	N=26	%	N=18	%
Much	13	50	4	22
Some	10	39	12	67
Little	3	12	2	11
None	0	0	0	0
Missing responses	0	0	0	0

Table 17: Personal Satisfaction Compared with other Group Members

	Spring '93		Spring '94	
	N=26	%	N=18	%
More	6	23	2	11
Similar	16	62	12	67
A little less	4	15	3	17
Much less	0	0	1	6
Missing responses	0	0	0	0

Table 18: Personal Friendships with Advisory Group Members

	Spring '93		Spring '94	
	N=26	%	N=18	%
Many	4	15	2	11
Some	13	50	11	61
Few	5	19	4	22
None	4	15	1	6
Missing responses	0	0	0	0

Table 19: Idiosyncratic Data; Content Themes Summarized in Text.

Table 20: Personal Influence on Group's Decision-Making

	Spring '93		Spring '94	
	N=26	%	N=18	%
A lot	6	23	2	11
Some	15	58	12	67
Little	4	15	3	17
None	1	4	0	0
Missing responses	0	0	1	6

Table 21: Personal Influence compared to other Group Members

	Spring '93		Spring '94	
	N=26	%	N=18	%
Much more	2	8	1	6
More	3	12	1	6
About the same	16	62	12	67
Less	5	19	3	17
Missing responses	0	0	1	6

Table 22: Frequency of Acceptance of Parent Recommendations in this Group

	Spring '93		Spring '94	
	N=26	%	N=18	%
Parents have not yet made recommendations	2	8	0	0
Don't know	3	12	0	0
Regularly	7	27	2	11
Often	5	19	7	39
Sometimes	7	27	8	44
Never	2	8	1	6
Missing responses	0	0	0	0

Table 23: Frequency of Group's Changing Plans Due to Parent Objections

	Spring '93		Spring '94	
	N=26	%	N=18	%
Parents have not yet raised objections	3	12	0	0
Don't know	4	15	1	6
Regularly	1	4	0	0
Often	4	15	4	22
Sometimes	8	31	8	44
Never	6	23	4	22
Missing responses	0	0	1	6

Table 24: Responsiveness of Advisory Group to Issues Raised by Parents or Family Members

	Spring '93		Spring '94	
	N=26	%	N=18	%
Very responsive	16	62	4	22
Moderately responsive	5	19	8	44
Slightly responsive	5	19	5	28
Not responsive	0	0	1	6
Missing responses	0	0	0	0

Table 25: Parents' Perception of Attitudes of Professionals

	Spring '93		**Spring '94**	
	N=26	%	N=18	%
Generally positive	14	54	10	56
Somewhat positive	8	31	5	28
Somewhat negative	2	8	3	17
Generally negative	0	0	0	0
Missing responses	2	8	0	0

Table 26: Parents' Perception of Change in Attitude of Professionals

	Spring '93		**Spring '94**	
	N=26	%	N=18	%
Much improved	2	8	1	6
A little improved	10	38	7	39
Stayed about the same	12	46	9	50
Gotten worse	0	0	1	6
Missing responses	2	8	0	0

Table 27: Frequency of Contact with other Parent Members of Group between Meetings

	Spring '93		**Spring '94**	
	N=26	%	N=18	%
Regularly	3	12	2	11
Often	7	27	5	22
Sometimes	13	50	9	50
Never	2	8	2	11
Missing responses	1	4	0	0

Table 28: Nature of Contact With Other Parents

	Spring '93		**Spring '94**	
	N=26	%	N=18	%
No contact	2	8	0	0
See or talk only during meetings	2	8	4	22
Talk or meet outside meetings	18	70	9	50
No other parents in group	3	12	5	28
Missing responses	1	4	0	0

Table 29: How Often Group Issues Discussed with Other Parents

	Spring '93		Spring '94	
	N=26	%	N=18	%
Regularly	5	19	0	0
Often	8	31	7	39
Sometimes	7	27	11	61
Never	5	19	0	0
Missing responses	1	4	0	0

Table 30: Special Efforts by Parents in Order to Attend Group Meetings

	Spring '93		Spring '94	
	N=26*	%	N=18*	%
Asked for a change in the time of day	9	35	5	28
Asked for a change in the day of the week	7	27	4	22
Asked for a change in the meeting location	2	8	2	11
Brought their child to the meeting	2	8	0	0
Asked for a ride to the meeting	5	19	7	39
Missing responses	1	4	1	6

*Multiple responses possible

Table 31: Advisory Group Change in Time or Location When Requested by Parent

	Spring '93		Spring '94	
	N=26	%	N=18	%
Regularly	2	7	0	0
Often	2	7	1	6
Sometimes	10	35	7	39
Never	8	28	7	39
Missing responses	4	24	3	17

Table 32a: Reimbursement for Personal Expenses Related to Meetings

	Spring '93		Spring '94	
	N=26	%	N=17	%
Reimbursed for personal costs or expenses associated with attendance at meetings	5	19	2	11
Reimbursement available, but expenses not claimed	2	8	0	0
Not reimbursed	19	73	16	89

Table 32b: Kinds of Reimbursement for Personal Expenses Associated with Attendance at Meetings (If Eligible)

	Spring '93		Spring '94	
	N=7*	%	N=2*	%
Mileage, parking or related travel expenses	5	71	1	50
Respite care or day care for child	1	14	2	100
Meal or lodging expenses	2	29	0	0
Lost wages	0	0	0	0
Other	1	14	0	0

*Multiple responses possible

Table 32c: Importance of Reimbursement to Involvement (If Received)

	Spring '93		Spring '94	
	N=7	%	N=2	%
Very much	2	29	0	0
Moderately	1	14	1	50
Slightly	1	14	0	0
Not at all	2	29	1	50
Missing responses	1	14	0	0

Table 32d: Importance of Reimbursement (If not Received) to Increasing Involvement

	Spring '93		**Spring '94**	
	N=19	%	N=16	%
Very much	5	26	2	13
Moderately	2	11	3	19
Slightly	2	11	5	31
Not at all	10	53	6	38

Table 33: Relative Cooperation with Participation during Work Hours by Employer if Parent Employed Outside the Home

	Spring '93		**Spring '94**	
	N=26	%	N=18	%
Employer cooperative	5	20	4	22
Conditional cooperation	2	8	2	11
Employer uncooperative	6	24	5	28
Doesn't apply	13	52	7	39
Don't know	0	0	0	0

Table 34: Increased Understanding of Children's Mental Health System

	Spring '93		**Spring '94**	
	N=26	%	N=18	%
Considerable increase	14	54	7	39
Moderate increase	6	23	7	39
Slight increase	4	15	2	11
No increase	2	8	1	6
Missing responses	0	0	1	6

Table 35a: Increased Skills as a Group Member

	Spring '93		**Spring '94**	
	N=26	%	N=18	%
Considerable increase	5	19	7	39
Moderate increase	11	42	4	22
Slight increase	3	12	3	17
No increase	7	27	3	17
Missing responses	0	0	1	6

Table 35b: Increased Skills as a Group Leader

	Spring '93		Spring '94	
	N=26	%	N=18	%
Considerable increase	3	12	2	11
Moderate increase	8	31	7	39
Slight increase	4	15	5	28
No increase	10	38	3	17
Missing responses	1	4	1	6

Table 36: Gender of Respondents

	Spring '93		Spring '94	
	N=29	%	N=18	%
male	1	4	0	0
female	27	93	18	100
missing responses	1	4	0	0

Table 37: Race or Ethnicity

	Spring '93 N=29	 %	Spring '94 N=18	 %
White	27	93	17	94
Other (Jewish)	1	4	0	0
African American	0	0	1	6
Missing responses	1	4	0	0

Table 38: Relationship Status of Respondents

	Spring '93 N=29	 %	Spring '94 N=18	 %
Married/Marriage-like relationship	22	76	15	83
Single	1	3	0	0
Divorced	4	14	2	11
Separated	1	3	0	0
Widowed	1	3	1	6

Table 39a: Shared Responsibility for Daily Parenting

	Spring '93 N=29	%	**Spring '94** N=18	%
yes	25	86	16	89
no	4	14	2	11

Table 39b: Relationship of Person(s) Sharing Daily Parenting

	Spring '93 N=29	%	**Spring '94** N=18	%
spouse	22	76	13	72
ex-spouse	1	3	0	0
friend	2	7	2	11
no one/not applicable	4	14	3	17

Table 40: Household Pre-Tax Income

	Spring '93 N=29	%	**Spring '94** N=18	%
Under $10,000	1	3	1	6
$10,000-$19,999	5	17	3	17
$20,000-$29,999	3	10	2	11
$30,000-$39,999	5	17	3	17
$40,000-$49,999	5	17	2	11
$50,000-$59,999	1	3	2	11
$60,000-$69,999	2	7	1	6
$70,000 or more	4	14	3	17
Missing responses	3	10	1	6

Table 41: Highest Educational Level Attained

	Spring '93		**Spring '94**	
	N=29	%	N=18	%
Some High School or less	1	3	0	0
High School Diploma or GED	8	28	5	28
Business or Trade School	1	3	0	0
Some College	10	35	6	33
College Degree	3	10	2	11
Some Graduate Study	0	0	0	0
Graduate Degree	5	17	5	28
Missing responses	1	3	0	0

Table 42: Job as a Mental Health or Social Service Professional

	Spring '93		**Spring '94**	
	N=29	%	N=18	%
Yes	4	15	6	33
No	22	63	12	67
Missing responses	3	12	0	0

Table 43: Prior Advisory Group Experience

	Spring '93		**Spring '94**	
	N=29	%	N=18	%
A great deal	5	17	1	6
Some	9	31	6	33
Little	2	7	4	22
None	8	28	7	39
Not applicable	3	10	0	0
Missing responses	2	7	0	0

Table 44: Specific Actions Undertaken by Parent

	Spring '93		Spring '94	
	N=29*	%	N=18*	%
Attended a parent support group	28	97	18	100
Attended a workshop or received training in advocacy	19	66	18	100
Phoned, written to, or visited a legislator to talk about services to children	22	76	15	83
Phoned, written to, or visited an agency or school administrator about the services your child has been or should be receiving	25	86	17	94
Prepared or given testimony at a legislative committee or other meeting regarding services for children	17	59	13	72
Given a speech or written an article about a children's issue	13	45	13	72
Assisted another parent in dealing with the service system	24	83	14	78
Written a letter to the newspaper regarding a children's issue	8	28	5	29
Been involved in legal or court action regarding services for children	10	35	4	24

Filed a formal complaint or grievance regarding services for children	8	28	7	39
Helped organize a group to discuss or advocate for children's services	14	48	9	50
Phoned, written to or visited a counselor, therapist or teacher about services for your child	27	93	17	94
Missing responses	1	3	0	0

*Multiple responses possible

Table 45: Mean Scores and Standard Deviations on Subscales of the Family Empowerment Scale

	Spring '93		**Spring '94**	
	Mean	SD	Mean	SD
Family	49.6	5.3	50.2	5.1
Service System	53.3	4.4	54.9	3.5
Community/Political	38.9	6.7	40.1	6.4