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ABSTRACT

A 1-year, two-state research program attempted to find effective methods to increase the ability of Spanish speaking parents and siblings to cope with the needs of handicapped children and to determine if problems and strategies would differ in the two settings. One group of 33 families was served in a Texas border area; the other 12 families were served in central Washington state. The sites represented extremes in terms of proportion of Spanish speakers in the general population. The study found that Washington families were more likely to be recent immigrants, with lower economic and educational status than their Texas counterparts. Relying on translators, Washington families had a poor understanding of their child's handicapping condition and were less able to deal with the strains it placed on family life. Variables significantly related to positive behaviors on behalf of the handicapped child included: severity of handicap, level of mother's education, cohesive/supportive family structure, mother's knowledge of English, and greater economic resources. In most cases, the mother was the handicapped child's primary caregiver. Key factors for successful recruitment of parents into support efforts were issuing personal invitations, providing transportation, and making parents comfortable about bringing their child to meetings. (NEC)

PARENTS OF HANDICAPPED PROGRAM: A PARENTAL INVOLVEMENT PROJECT FOR SPANISH SPEAKING FAMILIES

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PARENTS OF HANDICAPPED PROGRAM: A PARENTAL INVOLVEMENT PROJECT FOR SPANISH SPEAKING FAMILIES

ABSTRACT

This is a one year research program involving Spanish speaking parents of handicapped children. Its purpose is to find effective methods to increase the ability of parents and siblings to cope with the needs of a handicapped child.

One group of families was served in a Texas border area; the other group of families were served in central Washington State. The two sites represented opposite extremes in terms of proportion of Spanish speakers in the general population. The purpose of a two site study was to see whether the problems for Spanish speaking families would differ in these two settings, and whether strategies to assist the families would also be different.

The study found the families in the northern site were worse off than their counterparts in Texas and less able to access needed community services. Relying on translators, families had a poor understanding of their child's handicapping condition and were less able to deal with the strains it placed on family life.

Variables significantly related to positive behaviors on behalf of the handicapped child included: severity of the child's handicap, level of mother's education, cohesive and supportive family structure, mother's knowledge of English, and greater economic resources.

PARENTS OF HANDICAPPED PROGRAM: A PARENTAL INVOLVEMENT PROJECT FOR SPANISH SPEAKING FAMILIES

EXECUTIVE SUMMARY OF PRIMARY FINDINGS

This was a one year research program involving Spanish speaking parents of handicapped children. Its purpose was to find effective methods to increase the ability of parents and siblings to cope with the needs of a handicapped child.

Bilingual paraprofessional field workers served Spanish speaking families in a Texas border area where there was a high density Spanish speaking population, and in central Washington state, in which Spanish speaking families were a scattered minority. The purpose of the two state study was to see if the problems for Spanish speaking families would differ in the two settings, and whether strategies to assist them would also be different.

The field workers serving families had three goals. The first was to help families become more independent in dealing with health, school and social service agencies. The second was to provide support groups. The third was to help parents learn ways they might help their handicapped child through home activities.

The primary findings were as follows:

**The profile of families in the two sites indicated Spanish speaking families in the northern area were more likely to be recent immigrants, with a generally lower economic and educational status than the Spanish speaking families in Texas. Some key statistics are given below:

Percentage of mothers born in Mexico:	WA 92%	TX 52%
Percentage of mothers 4 years or less education:	WA 50%	TX 30%
Percentage of homes overcrowded:	WA 100%	TX 58%
Percentage no father in the home:	WA 33%	TX 9%
Percentage very limited English:	WA 92%	TX 45%
Percentage six or more in family:	WA 83%	TX 64%

**In general, families in the northern area were much less able to access community resources because of language barriers than those in Texas. Relying on translators, families had a poor understanding of their child's handicapping condition and were less able to deal with the strains it placed on family life.

**Project staff was most effective at increasing the ability of parents to access community resources, at encouraging their participation in support groups, and least effective at encouraging more home activities. The parents in Washington made comparatively less progress in all of these areas than the parents in Texas.

**Whether a family ranked high in its comparative ability to access community resources, participate in support groups, and provide home activities was found to be significantly related to the following variables:

- --A high degree of severity in the child's handicapping condition.
- --Whether the mother had attended five or more years of school.
- --A family that was cohesive and supportive of primary caregiver.
- --A higher ability of the mother to speak and read English.
- --Mother's ability to drive.
- --Absence of other family problems (i.e., poor health, frail elderly, etc.).
- --Members of extended family living nearby.
- --Family has use of a vehicle. Mother can drive.
- --Greater economic resources (better housing, phone, income, employment).
- --Children in family have the same parents.
- --High density population of Spanish speakers.
- --Mother's age over 40.
- --Mother born in the United States.

**In nearly all cases, the mother was the primary caregiver of the handicapped child. Correspondingly, all variables related to the father were found to be not significantly related to the family's rating of high or low on the participation scale in the three activities.

**Parents interviewed as to desirable characteristics in a field worker serving them in a parent involvement project were as follows:

- --Preferred that worker be parent of handicapped child: 84%
- --Preferred that worker be female: 74%
- --Preferred that worker be Hispanic and speak Spanish: 71%

**Siblings were found to be relatively uninvolved with helping care for the handicapped child in both locations. When a sibling was involved, it was most likely to be a teenage child.

**The key factors necessary to successful recruitment of parents from this population into support group efforts were: 1) personal invitations, rather than posted notices; 2) providing transportation if needed; and 3) making parents comfortable about bringing their child to the meeting.

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BACKGROUND OF STUDY

The latest census figures indicate that at present one child in ten in the U.S. comes from a home in which the family uses a language other than English. The projections are that the proportion of our population made up of linguistic minorities is going to increase. This project focuses on one linguistic minority group -- low income, primarily migrant Spanish speaking families who have handicapped children. It looks at their needs and at ways to overcome linguistic and cultural barriers in order to provide assistance to families in the form of support groups, access to community resources, and in activities in the home to benefit their handicapped child.

In 1983 the U.S. Department of Education, Office of Special Education, announced a priority for funding of research projects dealing with parental involvement. The projects were to be of one year's duration. This proposal was submitted through Pasco School District in Washington state for an interstate project that would look at the problems of Spanish speaking families of handicapped children in two opposite sociolinguistic environments: in an area with a low density of Spanish speakers--central Washington state, and in an area with a high density of Spanish speakers--a border area with Mexico in south Texas. Planning for the project was done cooperatively with Yolanda Barrera, the Handicapped Coordinator of the Texas Migrant Council, and the Texas portion of the project was carried out from one of the regional offices of the Texas Migrant Council. Their active cooperation made the project possible. To provide greater anonymity to families, the precise geographic areas served by the program will not be further identified.

The intervention objectives set out in the proposal were that parents or siblings of handicapped children would, as a result of participation in the project:

1) Increase their involvement with community schools and other agencies and professionals providing services needed by their handicapped child.

2) Increase their participation in support groups in which they meet with other parents/siblings of handicapped children.

3) Increase activities carried out in the home toward the development of their handicapped child.

all as measured by the project developed family participation scale (descriptive information is included in the appendix.)

The research objectives were to study:

1) The characteristics that differentiate families with a high level of participation from those with a low level.

2) The difference in project effectiveness in increasing participation in support groups, home activities and with provider agencies; and parental reaction to the benefits of project services in each of these areas.

3) Any differences in parental participation for Spanish speaking migrant parents living in a predominantly English language background (Washington state) and those living in a predominatly Spanish language environment (South Texas).

4) Differences in the level of participation by siblings of handicapped children living in Washington and those in Texas.

5) Differences in level of family participation among families assigned to a field worker who was a parent of a handicapped child or one who was not; and differences in parental preferences as to desirable characteristics of field workers, including whether or not they were parents of a handicapped child.

6) Field observations of what "worked" or did "not work" in references to project strategies used to encourage each of the three types of parental involvement.

A great many studies document the fact that Hispanics underutilize all types of social and human services. There have been many explanations offered for this underutilization. Some propose "cultural" explanations--that the Hispanic has less need for services than other ethnic groups owing to the support they receive from the extended family structure intrinsic to their culture. Some feel the services are seen as irrelevent because of their culture. Some feel they do not trust the agencies of the dominant culture and prefer to solve their problems within the confines of the barrio or within la familia, the family.

Apart from these factors related to "cultural" explanations, there are obviously a host of other reasons why the Hispanic can not gain access to needed services -- poverty, location of resources, bureaucratic barriers, segregation or separation, social distance between majority personnel and minority clients, language differences, myths and stereotypes. (Fishman, 1979; Cuellar, 1981; Smart, 1983)

Lynch (1981) did a study in California of the involvement levels and barriers to participation of lower socioeconomic Black, White, and Hispanic parents of special education students. Her study found that only 11% of Hispanic parents had taken an "active role" in planning their child's individualized educational plan (IEP) compared with 21% of black parents and 61% of white parents.

The literature on participation of Hispanics in support groups is more sparse. There are now support groups for nearly every kind of handicapping condition, but membership roles in these organizations indicate that they primarily serve a membership drawn from the English speaking, mainstream culture. A very few support groups have been established especially for the Spanish speaking such as the Coalision de los Padres in San Francisco. There has been little or nothing published as to the origins and effectiveness of such groups.

There have been more parent involvement programs directed to increasing the role of parents in teaching their child, i.e. the "parent as teacher" model. Halvorsen (1982) in reviewing the research literature on these programs noted that: 1) few dealt with families from a lower socioeconomic level; and 2) few identified the ethnic background of participants. Since the teaching and training materials published by these projects were produced in English, she concluded that most projects must have excluded the linguistic minorities.

In summary, there appears to be a need for further research into parent involvement as it relates to linguistic minority parents of handicapped children.

THE STUDY DESIGN

THE SAMPLE

Because of the greater concentration of Spanish speaking families with handicapped children in Texas, the largest part of the research was carried out there. The final sample from which the statistical analysis was made consisted of 45 families; 33 in Texas and 12 in Washington.

The project provided services to 50 families in Texas and to 18 in Washington. The reduction to the final sample was because of families moving away, mostly to obtain work in another area. Some were dropped because diagnosis did not confirm the child's handicapping condition.

Characteristics of the sample in each state are included in the discussion of findings later in the report. Criterion for acceptance of the family into the project was that the family be Spanish speaking, and that they have one or more children with a diagnosed handicapping condition. Priority was given for families who were migrants, because of the cooperative relationship between the grantee, Pasco school district in Washington, and the Texas Migrant Council.

In Texas, where there was a much larger pool of families to recruit from, the project elected to give priority to families with children under the age of three since these families were not yet eligible for as many community services as families with older handicapped children. In Washington, because there were relatively few Spanish speaking families with handicapped children in the two communities from which the program operated, a broader age range was used. The project attempted to serve most of the Spanish speaking families of handicapped children from infancy upward into school age.

PROJECT STAFFING

A part time field research assistant was employed in Washington and another in Texas who trained and oversaw the work of the field staff, carried out the intake interviews and most of the exit interviews with families. This person also managed the flow of paperwork necessary to document contacts with families and with community agencies.

Four field workers were employed in Washington state, each working approximately five to ten hours a week depending on the time they had available and the needs of the families assigned to them.

In Texas, two full time field workers were employed, and this was augmented by another full time worker employed by the Texas Migrant Council (not from project funds) who worked part of the time with project families. There were from three to five part time field workers most of the time, working varying amounts of time as fit their schedules and the needs of families. There was a good deal of turnover in staff in Texas. Most project staff worked from six to eight months (as a one year project, start up time reduced the period of field operations). The original dates of project operation were from June 1, 1983 through May, 1984. A three month extension was granted so the project could continue through August, 1984.

Because one of the variables of the research had to do with acceptance of field workers related to whether they were or were not the parents of a handicapped child, one of the two full time field workers was the mother of a handicapped child and half of the part time field workers employed were parents of a handicapped child (or in one case, a field worker who was herself handicapped.)

AN ETHNOGRAPHIC FIELD STUDY

This was designed as an ethnographic field study using the data furnished through structured interviews and from participant observer notes. Since it was searching for effective intervention strategies (rather than testing predetermined methods or hypotheses) it used the process of systematic variance, and planned repetition.

To clarify, in looking for effective types of support group structures it used systematic variance by planning several types of formats for support groups so their effectiveness could be compared. For example:

A "one-on-one" format (bringing two families together whose children have the same type of handicap). One of these families might have already gone through something the first family is just anticipating (surgery, adjustment to school, etc.).

Another format would be the information meeting, a larger meeting with a speaker or film intended more for conveying information than for exchange of personal feelings.

A sharing meeting, usually for no more than six to eight parents, using a format designed to allow families to describe their own experiences and feelings.

A social meeting--pot luck supper, party, afternoon visit; where the purpose is social but the secondary purpose is to form bonds between families creating a support network for them.

A field trip--designed to preview facilities the family will be considering in the future (for example, school programs for parents of infants and toddlers; residential centers for older handicapped youth no longer in public school programs or living at home).

A sibling meeting, or a fathers only meeting, etc. These are all examples of planned variance in support group activities.

The other side of this method is <u>planned repetition</u>. Planned repetition involved repeating the meeting type. For example, more than one field worker set up sibling support group meetings, and there were several "sharing groups", a series of field trips, etc., in order to see if the effectiveness held up in different circumstances.

The same methodology was used to test and evaluate strategies for helping families work with agencies, and ways of fostering home activities. When a successful strategy was found, it was shared through staff meetings and systematically repeated by other staff with other families, so that we could see if its effectiveness could be implemented by others and was not dependent on the personal style or personality of one field worker or the receptivity of one or two families.

THE INSTRUMENTS USED AND METHODS OF ANALYSIS

The primary instrument used to organize and provide some quantitative means of dealing with the data was a project developed instrument called the FAMILY PARTICIPATION SCALE, or FPS rating.

It has three subscales relating to the three types of project intervention activities. For each, there is a descriptive classification system which is used to make a comparative rating of families on their level of participation in that activity. The four levels of participation used in the FAMILY PARTICIPATION SCALE are briefly described below.

The top level was labeled "independent/advocate". This level was used for families who were able to do things independently, and the advocate level indicated they were able to provide leadership or assist others. This was the highest rating group on the scale.

Below that was the level labeled "active/supported". This level was used for families who were active on behalf of their handicapped child but needed some support--help with referrals, transportation, translation, etc. Families at this level took initiative but were not yet "independent" for various reasons.

The level below that was labeled "passive/supported". This level was for families who were cooperative with third parties who might want to assist them--school or day care personnel, for example, who had identified a child's handicap--but took little initiative on their own.

The lowest of the four levels was labeled "negative". This was used for families that were ignorring a child's handicapping condition and were indifferent or noncooperative, even hostile, to others who might attempt to assist them. The FPS rating form, in the appendix, provides greater detail on the profile of families at different levels.

Once families had been placed at one of the four levels, they were comparatively assessed in terms of other families at that level on a five point scale; i.e. families in the "negative" category might have an assigned rating of anywhere from 1 to 5, families classified as "passive/supported" might have an assigned rating of 6 through 10, "active/supported" rated as 11 through 15, and "independent/advocate" as 16 through 20. When the family rating on each of the three subscales had been determined, the composite of these scores determined their rating on the overall instrument, the FAMILY PARTICIPATION SCALE.

Since an initial rating was determined for each family, and a final rating, it could be used as a measure of comparative change either for the composite FPS scale, or for one of the subscales referring to specific areas of project activities. By rank ordering the families on the FPS scale and then dichotomizing them into "high" or "low" rating groups, it was possible to correlate a high or low participation level with various characteristics of the population served.

There were four sources of information used to derive these ratings. The first of these was the Intake Interview which provided information on family characteristics (ages, family composition, education, etc.). It also obtained information on how the family learned about the child's handicapping condition and the treatment sequence. This asked whether the parent or a third party had located whatever resources were used (medical providers, financial resources)--who took the child to obtain treatments (whether both parents involved, only one parent, third parties, etc.). This provided a basis for judging whether the family had taken initiative on their own in reference to the child's handicap or relied on others to assist them.

The Intake Interview asked questions to determine what natural support network was available to the family (whether extended family lived near, other families they knew and associated with who had children with handicaps, etc.). And it asked about any formal group activities they had participated in. It also contained questions about any special home activities they did with the handicapped child and whether these activities had come from their own reading, or had been suggested by teachers or some other source. These questions provided the baseline of information on previous participation by the family in support group and in providing home activities for the child. (A copy of the Intake Interview is in the appendix.)

The second source of information came from field worker reports on every contact with the family whether through home visits, phone contacts or in support group settings. The forms used for these reports obtained not only narrative descriptions of what took place, but questions about what had taken place since the last family contact. For example, it asked what agencies or individuals the parent had been in contact with (by phone or in person) since the last field worker report -- whether the parent or the field worker initiated this contact. This provided a way of tracing the extent to which the parent was taking initiative in accessing community resources. The reports asked whether parents appeared to be doing home activities (and by what evidence this judgment was made). For example, if parents told the field worker the child was now able to do something and had the child demonstrate, this would be included in the field worker report. (See copies in appendix.)

In reference to support group contacts, the report included information on how much interaction took place during the ride to the meeting (if transportation was furnished), during the intermissions or after the meeting, as well as during the meeting (to provide a key to how much the parent was using these opportunities to share with other parents), (See Support Group Report form, in the appendix.)

In summary, the reporting format attempted to structure the workers' recorded observations so that it related to the degree of initiative and independence shown by parents in each of the target areas of activity.

The third source of information was an Exit Interview with each family. This tapped the parents' views of their greatest needs, and the benefits they had obtained through project assistance in reference to each of the three activity areas. It also obtained information on parents' views of important qualities for an effective field worker in this type of program. (See Exit Interview forms in the appendix.)

The final source of information came from a third party interview. The project interviewed one or more persons outside the project who had been working with the family to get their perspective on the parents' ability to access community resources, the understanding of the father and mother of the child's handicapping condition and whether they appeared to be carrying out appropriate activities in the home to help the child. It also asked if the family participated in support groups.

The purpose of the third party interview was to enable the use of a technique known as "triangulation", meaning obtaining three or more independent ratings and using a composite of these three sources for the final rating. Since one of these sources is outside the control of the program, it increases the degree of objectivity which is important in any ethnographic study where measurement depends on judgment. In this case the primary investigator provided one rating, the coordinator for each site another, and the third came from the third party interview.

The questions on the third party interview were coded to place the family into one of the four levels of the FPS scale. The comparative position within the levels was done only by the project staff who had access to comparative information about all of the families. The only category in which this proved unworkable was in reference to support groups. Usually the third party providers had little to do with support group activities and simply did not know whether or not the family was interested or active. (See Provider's Questionnaire in the appendix.)

STATISTICAL ANALYSIS

Data on the families was coded for computer entry. Because of the relatively small size of the sample, most variables were coded into two, or at most three ratings (e.g. high or low educational level, severe or less severe handicapping condition, etc.). This enabled cross-tabulation analysis of 2 X 2 tables, or 2 X 3 tables. A larger table would have reduced too many cells to a number of cases too small to support statistical analysis.

Kendall's Tau b was used as a measure of association between two ordinal level variables (dichotomies are treated as ordinal even though there is no inherent order between the categories). Kendall's Tau c was used for a 2 X 3 table. This measures whether the order is concordant for every possible pair of cases in the table, and provides the signficance of the association between the variables. The formula used is that provided by the SPSS statistical package (Nie, et al 1970). Chi square analysis, corrected for a small n, was used to determine if the FPS ranking was independent of field worker characteristics.

FINDINGS

1. HIGH/LOW ANALYSIS OF FAMILY CHARACTERISTICS

<u>Research Question</u> What are the characteristics that differentiate families with a high level of participation from those with a low level?

As already defined in the section on methodology, "participation" level is in terms of knowing how to access community resources, participation in support groups formal or informal, and the degree of their participation in home activities for the development of their handicapped child.

From the ratings of parents on the level of their participation in the three categories of activities described above, a composite rating was given the family on the FPS (Family Participation Scale). The final sample of 45 families were then ranked from high to low. The top 24 families were classified "high" on the FPS, the bottom 21 families were classified "low". (This slightly uneven distribution was made in the two groupings because of ties in the FPS scores at the median rating.)

Table 1, which follows shows the patterns of association between 26 selected variables and a high or low ranking on the FPS scale, arranged in descending order by the degree of correlation.

As shown on Table 1 the severity of the child's handicapping condition was the variable most strongly associated with high or low ratings on the FPS scale. For this analysis severity of handicap was dichotomized into "more" and "less" severe. Handicapping conditions considered more severe were those which set the child apart more from the normal activities of other children of comparable age, those which

TABLE 1

RELATIONSHIP OF SELECTED VARIABLES TO HIGH OR LOW RANKING ON THE FPS SCALE

Variable on which families are being compared	Classification on variable	Percent of total sample in each class.	Final ranking of family on "Family Participation Scale"		Correlation between variables (Kendall's Tau)	
			LOW	HIGH	r	sig.
1. Severity of child's handicap.	Less	42%	16	3		
	More	58%	5	21	.64	***
2. Mother's education. (More or less than five years)	Less	36%	14	2		
	More	64%	7	22	.60	***
3. Family Support Index. (See Note)	Less	52%	17	7		
	More	48%	4	15	.55	***
4. Personal Resources Index (See note)	Less	56%	17	7		
	More	44%	4	15	.50	***
5. Multiple Problem Family	Yes	50%	16	6		
	No	50%	5	17	.50	***
6. Economic Resources Index (See note)	Less	59%	17	9		
	More	41%	3	15	.48	**
7. Mother can drive car.	No	67%	17	9		
	Yes	33%	2	11	.47	**
8. Family supportive of primary caregiver	No	47%	13	8		
	Yes	53%	4	20	.47	**
9. Mother's knowledge of English. ("More" means speaking plus some literacy skills)	Less	64%	18	11		
	More	36%	3	13	.42	**
10. Extended family nearby.	No	23%	8	2		
	Yes	77%	12	22	.38	**
11. Family has use of vehicle.	No	23%	8	2		
	Yes	77%	12	22	.38	**

(continued on next page)

***Statistically significant, $p < .001$
**Statistically significant, $p < .01$
*Statistically significant, $p < .05$
ns Not statistically significant, $p > .05$

TABLE 1

(continued)

Variable on which families are being compared	Classification on variable	Percent of total sample in each class	Final ranking of family on "Family Participation Scale"		Correlation between variables (Kendall's Tau)	
			Low	HIGH	r	sig.
12. All children in family have same parents.	No	16%	6	1		
	Yes	84%	15	23	.34	*
13. Density of Spanish speakers in area. (Low-WA High-Texas)	Low	27%	9	3		
	High	73%	12	21	.34	*
14. Mother's Age.	18-29	36%	9	7		
	30-39	44%	11	9		
	40+	20%	1	8	.29	*
15. Regularity of employment and earning level.	Least	24%	7	4		
	More	40%	9	9		
	Most	36%	5	11	.27	*
16. Mother was born in the U.S.	No	62%	16	12		
	Yes	38%	5	12	.26	*
17. Whether home was adequate (less than 1.4 persons per room)	No	78%	16	15		
	Yes	22%	3	9	.24	ns
18. Whether family had a telephone.	No	49%	11	7		
	Yes	51%	7	12	.24	ns
19. Poor health in other family members.	Yes	48%	11	8		
	No	52%	8	13	.20	ns
20. Whether father could drive car.	No	3%	1	0		
	Yes	97%	14	21	.20	ns
21. Whether family owned, rented, share (or other) their home.	Other	27%	5	7		
	Rent	32%	10	4		
	Own	41%	5	13	.19	ns
22. Number of people living in the home.	7+	33%	9	6		
	5-6	36%	6	10		
	2-4	31%	6	8	.15	ns

(Continued on next page)

***Statistically significant, $p < .001$
**Statistically significant, $p < .01$
*Statistically significant, $p < .05$
ns Not statistically significant, $p > .05$

TABLE 1

(continued)

Variable on which families are being compared	Classification on variable	Percent of total sample in each class	Final ranking of family on "Family Participation Scale" LOW	HIGH	Correlation between variables (Kendall's Tau) r sig.
23. Distance from stores & medical facilities.	More	68%	12	11	
	Less	32%	4	7	.15 ns
24. Father's knowledge of English.	Less	68%	15	12	
	More	32%	4	9	.13 ns
25. Whether father was born in U.S.	No	51%	7	12	
	Yes	49%	6	12	.04 ns
26. Father's age.	18-29	24%	2	7	
	30-39	34%	7	6	
	40+	42%	5	11	.01 ns

***Statistically significant, $p < .001$
**Statistically significant, $p < .01$
*Statistically significant, $p < .05$
ns Not statistically significant, $p > .05$

NOTE: The Family Support Index combines the variables on: extended family nearby, children have same parents, family supportive of primary caregiver, whether family has multiple problems, and whether other family members have poor health all of which seemed related to family cohesiveness and support for or burdens on the primary caregiver.
The Personal Resources Index combines the variables on: mother's ability to speak English &literacy skills in English, mother's education, whether she can drive a car and mother's age which all seemed related to the mother having sufficient experience, communication skills and independent mobility to utilize resources available to help provide for the handicapped child.
The Economic Resources Index combines the variables: family has a phone, use of a vehicle, employment and earnings level, home ownership, whether home is adequate, and number of people in the home since all of these seemed to relate to the families financial burdens or resources.

A multiple problem family was one in which other members had serious health problems, or other types of burdens on the primary caregiver such as care of frail elderly, family members in jail or legal difficulties, marital discord, history of family violence, child abuse or neglect, etc.

Family supportive of primary caregiver included families where both parents cared for child, took to doctors, met with school personnel, were able to accept child's handicap and agree upon treatments. children assisted, etc. Nonsupportive families were families where there was no father in the home, or one spouse had not accepted the child's handicap or disagreed on need for treatment, family members offered little help to primary caregiver, etc.

might leave the child dependent on others throughout his or her life, multiple handicaps, or conditions that were life threatening. Children considered to have less severe handicaps were those able to participate in most activities normal for their age, some with orthopedic handicaps eventually correctible, developmental delay, communications disorders, or a partial hearing or vision loss.

The strength of this relationship with this population group had not been anticipated, although other research has also shown that parents of children with more serious handicaps were more assertive in seeking services for their child (Davis, 1980). In this project, parents of children with more severe handicaps were the ones who appeared most eager to participate in support groups, and the continuing groups that developed tended to be among parents with children who had similar handicaps. Families of children with severe handicaps were also, in general, more persistent in seeking help for their child, and field workers spent more time helping them identify and access community resources because of their greater need.

Because all of the families in this study were in a very low socioeconomic group, it may be that parents whose child had a relatively minor handicap were inclined to ignore it because they had so many other problems to cope with resulting from severe poverty, unemployment, and illness. (As noted on Table 1, 48% of the families reported that other family members besides the handicapped child were in poor health.) When the child's handicap was more severe, however, the parents could not ignore it, whatever other problems they may have faced.

The variable next highest as a predictor of high or low FPS status was the level of the mother's education; in this case a "low" educational level meant a mother who had less than four years of schooling (often considered the minimum to achieve a functional literacy) and "high" educational level meant mothers with a fifth grade education or better. As shown on Table 1, over a third of the mothers in the sample had less than a fourth grade education and out of this group only two achieved a high ranking on the FPS scale.

The overall level of education in this migrant, Hispanic population was obviously quite low. Only 20% finished high school (compared to the U.S. average of 88% among non-Hispanics, and 58% of Hispanics who finish high school). Eight percent of the mothers in our sample had never been to school at all. The overall average years of schooling of mothers in the project was eight years. Only two of the mothers had any education beyond high school. Within this range of educational levels, however, those with more school were on the whole far better able to deal with agencies, understand their child's handicap and provide appropriate home support, and to be leaders in support group activities.

Three composite variables were used in this analysis. These created an index combining the scores from several variables which appeared to be related. These combinations of variables proved to be highly predictive of which families would rate high or low on the FPS scale.

Of these three combined variables, the one that proved to be the best predictor of which families would have a high or low FPS status was the FAMILY SUPPORT INDEX. This combined single variables which related to how much or how little other family members provided support for the primary caregiver, and variables related to whether the parents had to cope with serious problems related to other family members in addition to caring for the handicapped child.

The variables used in the FAMILY SUPPORT INDEX were: whether members of the extended family lived nearby, whether all the children in the household had the same parents (this was seen as an indicator of family stability), whether other family members had good or poor health, whether the family was judged to be "supportive" of the primary caregiver, and whether the family had "multiple problems".

As defined in the note at the bottom of Table 1, a judgement that a family was, or was not, "supportive" of the primary caregiver related to such factors as whether both parents took a part in doctors or school visits or taking a child to therapy, whether siblings in the family were reported as helping with the handicapped child, the presence or absence of marital discord, and whether parents were in general agreement or in conflict over their assessment of the disability and the needs of the handicapped child. The "primary caregiver" in our sample refers to the mother in all but three cases. In two families the grandmother was the primary caregiver; in the other the mother was constantly sick and the father was indicated as the one who took primary care of the handicapped child.

A family was considered to have "multiple problems" based on a combination of circumstances such as: 1) whether the parent or other family members were in poor health; 2) if there were frail elderly to be cared for or similar responsibilities outside the immediate family taxing the time and resources of the parents; 3) if there was a history of family violence, child abuse or neglect, or similar factors.

As shown in Table 1, the correlation between a high or low rating on the FAMILY SUPPORT INDEX and high or low FPS status was .55, statistically significant beyond the .001 level. And the combination of these variables produced a higher predictive level than any one of the variables taken by itself.

Another of the combined variables was called the PERSONAL RESOURCES INDEX. This combined variables which represented skills, knowledge or experience the mother could draw on, making it possible for her to be more independent and to provide help and leadership to others.

The variables used in this index were: degree to which the mother could speak English, could read and write English, years of schooling, whether the mother could drive, and the age of the mother (assuming experience went with age, more points for older mothers). All of these variables taken separately were significantly related to high or low FPS Ratings, as shown in Table 1. But taken together they had a stronger predictive relationship than any one alone, with the exception of the variable on years of schooling.

The third combined variable used for analysis was called the ECONOMIC RESOURCES INDEX. This project dealt with some very very poor families. Although the primary investigator has had many years experience with the level of poverty found among migrant farm worker families it was still a shock to find how much worse off the families with handicapped children were than the norm for migrant families as a whole. The average income of migrant families is between $5,000 and $10,000 a year. Census figures show that the 1982 average income in the U.S. was $24,000 for non-Hispanic families, and $16,000 for Hispanic families. With this low level of income, migrant families had to support four children, on the average, compared to the U.S. average number of children per household of 1.9 for non-Hispanic families, and 2.3 for Hispanic-origin families (Ockerman, 1984).

One reason the families in our sample were worse off than other migrant families was that in most migrant families both adults and many of the children work--one Oregon study found that the income of the father contributed slightly less than half of the total family income for migrant families. In one survey (Ockerman, 1984) it was found that 82% of migrant mothers worked. However the birth of a handicapped child, particularly if the handicap is severe, usually takes one adult out of the work force. In our sample, only 36% of the mothers reported outside earnings and this was usually limited to intermittent employment in the fields. Many of the 64% of mothers who did not work outside the home reported that they had worked in the past, but did not work now because of the needs of the handicapped child. As a result families in our sample had their income cut roughly in half at the same time their expenses increased because of the special needs of the handicapped child.

Some of the statistics shown in Table 1 provide an indication of the poverty. For example, 23% have no car or other vehicle, 49% no telephone, 78% live in overcrowded housing (defined as more than 1.4 persons per room). Perhaps a more meaningful expression of the poverty would be some exerpts from field worker notes. (First visit report: "I kept asking the necessary questions and both parents would look at each other before answering and their answers were very limited. ... Mr... asked me if the housing manager had sent me. ... He apologized saying they were not supposed to be living with the...(relative) but as he is unemployed they don't have a home to live in and so move back and forth between...(this house) and another...(with wife's relatives)." Later visit report: "There are 20 people living in this three room house. Some sleep during the day, others at night. Two people appeared to be sleeping in a car parked in the yard." Later visit report: "Mrs. ... called me at home because she was desperate. It was the second day her children had had only water and sugar and they had run out of milk, cereal and all food...")

This level of poverty affected the project in many ways. One complaint of a local agency providing physical and occupational therapy was that among the Hispanic clients there was an extremely high "no show" rate for therapy sessions --sometimes as high as 50%. This greatly increased the costs to the agency. Asked if they had attempted to follow up with families and find why they failed to bring their children back to therapy, they replied that it was a lost cause trying to keep track of them because most of them had no phone and many had no address. This was, in fact, the case. Many of the families live on unmarked back roads (in an area where no housing codes would prevent them from building inadequate shelters) and have no street addresses. Many do not have even a post office address because in this border area the post offices have a high demand for box numbers and obtaining a post office box often entails a long wait. Such families may get their mail at a relative's house, and because of lack of transportation only pick it up once a week. With such families, the only practical means of communication is a home visit--time consuming, costly, and frequently fruitless if the family happens to be gone.

One of the project objectives in terms of helping the families learn to access community resources was to help them become accustomed to making and canceling their own appointments for doctors, therapists, school personnel, etc. This was obviously more difficult for the 49% of families who had no telephone (variable 18, Table 1). Another objective was to help them find ways of getting their child to therapy, etc. since few of the provider agencies offer transportation. This was made more difficult because 23% of the families had no vehicle (variable 11, Table 1) and if they did have a vehicle it was frequently not in running condition, or they did not have enough money for gas. An even greater barrier to independence in terms of transportation was the fact that 67% of the mothers could not drive a car--or did not have a license. (Variable 7, Table 1). There were some instances when families failed to attend a support group activity because they were embarrassed not to have food they could bring to share.

Many of these variables related to economic conditions were combined into the ECONOMIC RESOURCES INDEX. These were: the extent to which the family had at least one member with regular employment, whether they had a vehicle available, whether they owned, rented, or shared a home without cost, whether the home was adequate (i.e. not overcrowded), whether they had a phone, and the number of persons in the home (less points for more people assuming that more people meant fewer resources). As shown in Table 1, the correlation between this ECONOMIC RESOURCES INDEX and high or low FPS status was .50 which was statistically significant beyond the .001 level.

Variable 9 in Table 1 is the mother's knowledge of English. Sixty-four percent of the mothers had little or no knowledge of English. It should be noted on variable 16 that 62% of the mothers were born in Mexico. Unless the mother had moved to the U.S. while still young enough to attend public school, few of them ever acquired a working knowledge of English. It is interesting to note that over half of the families in Texas who reported almost no knowledge of English said that they did not find lack of English to be a "problem". In this part of Texas it is possible to obtain nearly all services from Spanish speakers. Among the families in Washington state, however, lack of English proved to be an almost overwhelming problem. (This is discussed more fully in the section dealing with differences between the two sites.)

Variable 12 notes that in 84% of the families all of the children had the same parents. This is in line with other research which has reported that among Hispanics the family unit is comparatively stable. Of the families in this sample there was no father in the home in seven out of 45 families--a comparatively low percentage of female headed households. For the few families in which some of the children were step children, however, this variable was quite damaging; i.e. six out of the seven households where children did not all have the same parents were in a low FPS status.

As shown in Variable 14, the older mothers tended to achieve a higher FPS status than the younger mothers.

Variables 20, 24, 25 and 26 all deal with characteristics of fathers. As shown in Table 1, none of these were significantly related to the family FPS rating. Since the mother was in nearly every instance the primary caregiver for the handicapped child, the variables having to do with the mother appeared to be far more pertinent to the participation level as measured by the FPS scale.

2. PARTICIPATION CATEGORY ANALYSIS

Research Question: How does the level of family participation vary in comparing family ratings among the three types of project activities?

The three types of project activities were as follows:

AGENCIES--helping families acquire independence in locating and accessing services from agencies in the community;

SUPPORT GROUPS--increasing active participation in formal and informal support group activities;

HOME ACTIVITIES--increasing home activities that would benefit the handicapped child.

Table 2 indicates the rating on the FPS scale as to the families' level of activity in each of these three areas when they came into the project and at the end of the project.

There are three findings that stand out from looking at the change in ratings of families resulting from project participation.

First, the program appears to have been most successful in the area of AGENCIES, in that 53% of the families are in the category of "active/supported" and 9% in the highest category "independent/advocate" in the final rating. Combined, this makes 62% of the families, nearly two-thirds, with a comparatively high rating on the FPS scale. This is a larger percentage of families given a high rating than are found in the other two areas of project activity.

The second finding, relative to Table 2, is that the area of project activity where families had the lowest initial rating was participation in SUPPORT GROUP activities. Very few families had ever been given an opportunity to participate in a support group before they became involved with this project. The enthusiasm with which they responded to efforts to organize support groups, and parents' initiative to expand support group activities came as somewhat of a surprise to project staff--the literature had led us to expect that it might be a

TABLE 2

NUMBER AND PERCENTAGE OF FAMILIES IN FAMILY PARTICIPATION SCALE (FPS)* CATEGORIES BEFORE AND AFTER PROJECT INTERVENTION

		Negative		Passive/ Supported		Active/ Supported		Independent/ Advocate	
Subscale	Time of Rating	No.	%	No.	%	No.	%	No.	%
AGENCIES	Initial	9	20%	18	40%	16	36	2	4
	Final	5	11%	12	27%	24	53	4	9
	CHANGE	-4	-9%	-6	-13%	+8	+17%	+2	5%
SUPPORT GROUPS	Initial	8	18%	27	60%	9	20%	1	2%
	Final	3	7%	17	38%	17	38%	8	18%
	CHANGE	-5	-9%	-10	-22%	+8	+18%	+7	+16%
HOME ACTIVITIES	Initial	11	24%	17	38%	14	31%	3	7%
	Final	7	16%	18	40%	13	29%	7	16%
	CHANGE	-4	-8%	+1	+2%	-1	-2%	+4	+9%
COMPOSITE	Initial	8	18%	26	58%	10	22%	1	2%
	Final	5	11%	15	33%	18	40%	7	16%
	CHANGE	-3	-7%	-9	-25%	+8	+18%	+6	+14%

*The Family Participation Scale is described in the text and the guide to use of the rating scale is included in the appendix.

very uphill task to establish support groups that would be utilized by the Hispanic population served by this program.

Participation in SUPPORT GROUPS was the activity in which there was the greatest increase in FPS ratings. Eight of the 45 families had a final classification of independent/advocate which indicated they were taking leadership roles and had become advocates for programs for the handicapped that went beyond the needs of their own family. Because of this leadership, a number of the support groups set up continued to meet after the termination of the project. And project families in Texas organized an advocacy group for families of handicapped children known as Parents for MASH, Inc. (medical assistance and support for the handicapped).

The third finding derived from the data in Table 2 is that there was relatively little change or increase in the area of HOME ACTIVITIES, and this was the area where the majority of families at the end of the project were still given a low FPS rating, i.e. in the negative or the passive/supported categories.

Research Question: Which (of the three) types of activities did parents find was the most helpful in meeting their needs? In which areas did they feel they had made the greatest change?

The findings reported above on the areas in which greater or lesser changes occured reflect parent priorities. In the Exit Interview parents overwhelmingly said that they felt that their greatest need was to learn about the resources available to them and how to obtain services for their handicapped child now and in the future and this was the way in which the project had benefitted them the most. The opportunity to participate in support groups was the next most frequently cited benefit of the program. Although some parents talked about how the project had helped them learn new ways of interacting with their child, these benefits were never included at the top of their list of "most important" benefits.

This is a significant finding in that the preponderance of parent involvement programs described in the literature have had as their exclusive or primary focus the "parent as teacher" model--training parents to be better teachers, interacting with their children in new and beneficial ways. Some researchers have proposed that the "parent as teacher" model, by itself, is an inadequate approach for working with parents, one which may reflect the priorities of the professional educator more than the priorities of the parent (Halvorsen, 1982). Turnbull (1978) noted that it may be difficult to get a parent to focus on learning of new ways of interacting with their handicapped child when they are concerned with where their next meal is coming from. Nor, would it seem, is this order of priorities restricted to families from a lower socioeconomic background. Vincent et al. (1980) in a state of the art study of parental involvement projects, indicated that when projects started not from preconceived objectives but with an assessment of the needs among families there are two areas of needs referred to consistently. These are: 1) the need to identify community resources; and 2) the need to acquire information on how to gain access to these resources.

The extent of participation in support group activities also seems a significant finding in that it goes counter to some widely circulated opinions about why Hispanics do not participate in support group activities.

The literature frequently contains references which imply that sharing feelings with strangers in a support group setting would be contrary to the cultural tradition of the Hispanic. These writers note that the Mexican-American believes that problems should be handled by <u>la familia</u>, the family, and state that many Mexican-Americans feel that personal crises should not be dealt with outside the family.

Another opinion on the matter is that Hispanics do not participate in support groups because they do not need this support. This was the opinion expressed by the person in charge of parent activities in one agency in the project area. She explained that they had tried to organize parent meetings without much success in the past. They were about to do so again at the urging of one client who had been in a support group when she lived in another state and badly wanted to be in one again. However, this effort to organize support groups would be directed only to the English speaking clientele of the agency. The Hispanic clients were not interested in support groups, she explained, because they live together in extended family groups and this provides a built in support group for them.

In fact, this and other research indicates that the "extended family" may not be as common among U.S. Hispanic populations as is commonly believed. In our sample, six of the 45 families were living in an extended family situation (13%) and the rest were living as nuclear families. A 1984 study by Ockerman of migrant families in three northwest states (79% of whom were Hispanic, primarily Mexican origin) also reported the predominance of the nuclear family."Migrant families typically had two parents present and rarely were 'extended'." (Ockerman, 1984, p.4)

Parents in our study also did not share the opinion that a close family structure precludes the need for support groups with other parents who have handicapped children. This is illustrated from notes in one family file. The parent, in this case, had two young boys with hemophilia. She related her story at a support group meeting, reported by the field worker as follows: (" 'I had another boy who would be fifteen years old now. I didn't know it then but I believe he had hemophilia too. He was six when he died. It was very hard for my husband because I went crazy. I lost hope in God. I blamed Him for everything. I went around breaking crucifixes. My mother told me it was God's will. But I didn't want to hear. I didn't go to church for a long time. Then I had my first girl and I asked God for forgiveness. When my two little boys were born I asked God for help and He has helped me.

'We are a very close family. My husband's family and my family are very united. They come often to my house very concerned about my two younger children who have hemophilia. But they can't understand what I go through. I met this lady at ... who had a child with the same sickness. We didn't know each other. But we wept there in the street and hugged each other, as if we had known each other for years. That is how I feel right <u>now</u>. We're strangers in this room but we share a common bond--our children's hard life-time illnesses.' Mrs....and the group wept for a long time.")

3. LOCATION STUDY

<u>Research question:</u> Are there differences in parental participation level for Spanish speaking migrant parents living in a predominantly English language background (Washington State) and those living in a predominantly Spanish language environment (South Texas)?

In Table 3, the difference in rating of families on the Family Participation Scale is broken down by program sites. This analysis shows that parents in Washington began the project with much lower ratings in all three categories than their counterparts in Texas, and project intervention produced much more limited gains.

Some explanation for the differences may be found in the characteristics of the families in the two locations. Spanish speakers in the project area in Washington are a small minority of the general population. Because of this there are strong economic and social pressures for language shift with the result that within one generation families have normally made a shift from Spanish to English as their primary language. The Spanish speaking families in this area therefore tend to be recent immigrants. They also tend to be more isolated, more subject to family breakdown, and worse off economically than their counterparts in Texas.

TABLE 3

PERCENTAGE OF FAMILIES IN FAMILY PARTICIPATION SCALE* CATEGORIES BY SITE

Subscale	Site and Time of Rating	Negative	Passive/ Supported	Active/ Supported	Independent Advocate
Dealing With Agencies	WA Initial	33%	42%	25%	0%
	WA Final	25%	42%	33%	0%
	Percentage Change:	-8%	0%	+8%	0%
	TX Initial	15%	40%	40%	6%
	TX Final	6%	21%	61%	12%
	Percentage Change:	-9%	-19%	+21%	+6%
Active In Support Groups	WA Initial	25%	50%	25%	0%
	WA Final	8%	50%	42%	0%
	Percentage Change:	-17%	0%	+17%	0%
	TX Initial	15%	64%	18%	3%
	TX Final	6%	33%	36%	24%
	Percentage Change:	-9%	-31%	+18%	+21%
Provides Home Activities	WA Initial	33%	50%	14%	0%
	WA Final	17%	58%	25%	0%
	Percentage Change:	-16%	+8%	+9%	0%
	TX Initial	21%	33%	36%	9%
	TX Final	15%	33%	30%	21%
	Percentage Change:	-6%	0%	-6%	+12%
Composite Rank	WA Initial	25%	67%	8%	0%
	WA Final	17%	50%	33%	0%
	Percentage Change:	-8%	-17%	+25%	0%
	TX Initial	15%	55%	27%	3%
	TX Final	9%	27%	42%	21%
	Percentage Change:	-6%	-28%	+15%	+18%

*The Family Participation Scale is described in the text and the guide to use of the rating scale is included in the appendix.

Some of the population characteristics of the two samples of families are shown below.

Percentage of mothers born in Mexico:	WA 92 %	TX 52 %
Percentage no father in the home:	WA 33 %	TX 9 %
Percentage of homes inadequate (overcrowded):	WA 100 %	TX 58 %
Percentage low on Economic Resources Index:	WA 82 %	TX 52 %
Percentage mothers 4 years educ. or less:	WA 50 %	TX 30 %
Percentage children have different parents:	WA 25 %	TX 12 %
Percentage families own their home:	WA 28 %	TX 49 %
Percentage six or more in family:	WA 83 %	TX 64 %
Percentage very limited English:	WA 92 %	TX 45 %

The families in the northern site collectively seemed to suffer much more from a sense of helplessness related to economic factors and their dependence on others for all necessary communications with the general community. This had a pronounced effect on the project. The field workers in Washington state had the same objectives and used many of the same techniques as those in Texas to help families acquire the skills and information needed to cope with the problems of their every day lives in providing for their own needs and that of their handicapped child. But it proved much more difficult to develop higher levels of participation among this group of parents. None ever reached the independent/advocate level.

Some illustrations of the techniques used by field workers in Texas which could not be used effectively in Washington are as follows. In helping parents deal with agencies, one method used by field workers to develop independence was to give the parent information on exactly who to contact for a given service, what to expect in terms of information that would probably be required, and then leave it to the parent to make the phone call or the contact by themselves asking that they then "let the field worker know" what they were able to learn.

In taking families to doctor's offices or to agencies, the field workers were instructed to step back and let the parent do the talking and explaining to receptionists, nurses, etc. So the parent would know that she or he was expected to do the talking, the field worker might "preview" the situation enroute to the office, explaining that the field worker would hold the baby while the parent talked to people, reassuring them about what was going to happen and what would be expected of them.

In filling out forms, the field workers were instructed that they were to have the parent fill out as much as they could, with the field worker only there as backup. In Texas, many of the agencies had their forms printed in either Spanish or English so, except for the parents who were illiterate in both languages, it was usually possible for them to fill out at least part of the information on their own.

These methods worked well in Texas. In Texas, however, most agencies had personnel who spoke Spanish so that it was not a problem if the parent spoke only Spanish since it was still possible to communicate without an intermediary.

In Washington, none of the health providers used by the project families spoke Spanish and none had nurses or office staff who did. Even a Migrant Health Center in the area (serving primarily Hispanics) had a sign in the window saying "Bring Your Own Interpreter". The social service agencies tried to have some staff who could speak Spanish but this person was not often the person who answered the phone and frequently the parent had hung up before anyone who could speak Spanish could be brought on the line. Eleven out of the twelve families in Washington could not read or write English, so they were unable to understand or take any part in filling out forms which were invariably in English.

In summary, providing information and encouragement often worked to help the parent in Texas seek out services or information on their own, and it was possible, over time, to build up self confidence to the point where parents would feel comfortable doing this and even offer to help other parents deal with these same agencies. In Washington, providing information on where to get information was seldom enough as an intermediary was required in order to communicate.

The best the project field staff could do in Washington was to try to help the family find where to go to locate someone to act as intermediary. The schools usually had outreach personnel, paid for by the migrant program, who spoke Spanish. There were some Spanish language churches in the area which could sometimes locate volunteers. In families with older children, the children had usually acquired more English than the parents. However, most of the children who might have helped were of school age and could not accompany the parent during school hours without missing school. In any event, it was soon evident that the level of their English was usually so limited that they were not much help in interpreting information provided by a doctor, or being able to work their way through forms required by social agencies.

The next problem was that the older children, volunteers, and even the outreach personnel employed by the schools were not likely to know the Spanish words for medical terms in order to make clear to the parents something the doctor wanted to explain. It was equally likely they wouldn't know enough English to adequately express the fears of the parents or explain their doubts and questions to the doctors (or teachers or agency personnel). The field workers hired for this project could and did act as interpreters but with difficulty. All were paraprofessionals so that they had only a layman's understanding of medical terminology, and didn't always know these words in Spanish. In addition, the extremely low level of education of the parents meant that the terms had to be explained in a simple enough way so parents could understand. One field worker reported that she had gone with a parent to a doctor who decided that the child needed to have a brain scan. She said that she was at a loss as to how to explain a term like brain waves so that the parent wouldn't think they were planning to plug the child into an electric socket.

In both states, the field workers tried to develop mutual self-help networks--for moral support, friendship, and practical help with emergencies, with transportation, translation and similar needs. Parents were introduced to other parents going to the same meetings or the same agency for therapy, and out of this came car pools, friendships, mutual support, interpreters. In Washington this was more difficult because there were many fewer bilinguals among the parents, or among their neighbors or relatives, who could bridge the gap into the English speaking world. And the families were more uniformly poor, lacking transportation or other resources to share with one another.

In Texas, it was found that getting parents to attend support group meetings depended first on establishing a relationship of concern and friendship with them, making the invitation to the meeting personal (families did not respond to meetings held by agencies who relied on posted notices, or impersonal general invitations), and finally by providing transportation if needed. Parents' interest in continuing to come to a support group depended on how comfortable they were in the group and for some types of support groups (ones where parents shared their feelings and told of personal experiences--as opposed to simply an informational meeting with a speaker) comfort in the group related to feeling something in common with the other participants. A parent whose child had a relatively minor handicap was not very comfortable with parents whose childrens' handicaps were much more severe.

In Washington, because there were so few Spanish speaking families of handicapped children, it was more difficult to bring together a group whose children had similar handicaps. None of the cohesiveness ever developed in the gatherings of parents in Washington, and the levels of sharing were much more superficial. Unlike Texas, the parents did not take initiative to keep support groups going--offering their homes, suggesting meeting times, mentioning other parents they thought would benefit.

Some information meetings were set up for parents in both states--with speakers or films in Spanish on topics of interest to families with handicapped children. In Washington, because of the low density of Spanish speakers in the population it was necessary to draw in participants from a wider geographic area and the time and cost of travel from these distances was a deterrant reducing attendance. Despite this, the families were generally favorable to the idea of meeting with other Spanish speaking families who had handicapped children. And in the Exit Interviews, parents mentioned as a benefit of the program that these meetings had been important for them because it let them know that they weren't the only Spanish speaking family with a handicapped child.

4. SIBLING STUDY

<u>Research Question</u> Are there differences in the level of participation for siblings living in Washington and those in Texas?

Prior research by the primary investigator into family language use patterns in Spanish speaking families had led to inclusion of this question in this study. The earlier research had shown that Spanish speaking families in a predominantly English speaking environment tend to use their children as interpreters and that frequently the children at an early age take on more of an adult role in contacting teachers, doctors and other agencies on behalf of their parents. It was shown that younger children in the family interacted more with their siblings (usually in English) than they interacted with the parents (with whom they usually communicated in Spanish) as they made a conscious shift to conform to community pressures to use English (McConnell, in press). In families living in areas of the U.S. in which there was a large Spanish speaking population, the younger children interacted more with their parents than with siblings and all interaction in the home tended to be in Spanish with either parents or siblings. The older children were also less likely to be called upon to help with community contacts. It was therefore reasoned that siblings might have a different role in relationship to the care of a handicapped child in the northern site than was true in Texas.

This did not turn out to be a fruitful line of inquiry. In general, it was found that the mother was the primary caregiver for the handicapped child and that siblings in both locations played a very minor role. It seemed, in fact, that they might have played less of a role than would have been the case if the family had not had a handicapped child. At both locations there was some tendency for the mothers to be quite protective of the handicapped child and to insist on providing all care for the child to the exclusion of others who might have been willing to help.

In nearly every case where a family reported that siblings helped with the handicapped child, it was a teenage child. There were some differences in the age distribution of children in the families in the two locations which might have had some effect on these findings. In Texas, the program primarily recruited families whose handicapped children were under three. In Washington, the handicapped children represented a broader age range.

Statistics relating to siblings in the sample of families in the two project sites are given below:

Percentage of families with siblings:	WA	92 %	TX	88 %
Percentage with teenage siblings:	WA	75 %	TX	61 %
Percentage who reported siblings helped:	WA	25 %	TX	36 %

Handicapped child is only child:	WA	8 %	TX	12 %
Handicapped child is youngest child:	WA	17 %	TX	76 %
Handicapped child is middle child:	WA	58 %	TX	9 %
Handicapped child is oldest child:	WA	17 %	TX	3 %

The types of help provided by siblings included: helping with specific therapy, with school work, with transportation, with translation, with babysitting, "watching out for" children who were in danger of injury because of blindness, seizures, or similar conditions. There was little difference in type of help provided by siblings in the two locations.

5. STAFFING STUDY

<u>Research Question</u> Are there differences in level of family participation (FPS scale rating) based on whether the field worker assigned to the family was a parent of a handicapped child or one who was not?

Half of the field workers hired for the project were parents of a handicapped child or were themselves handicapped. The purpose of this division was to see if this factor made a difference in acceptance by parents which, in turn, influenced the effectiveness of the project in achieving its goals.

The staffing did not stay equally divided, however. The field workers who were handicapped or who had a handicapped child were much more subject to family crisis and personal health problems than those who were not. The result was that some quit the program, others had to take leave of absence for a time, or reduce hours and case load. In the end, of the 45 families in the final sample, ten had been served primarily by field workers who were parents of a handicapped child, and 35 by field workers who were not.

Table 4, below, shows the proportion of families who were high or low in their final FPS rating for field workers who had a handicapped child and those who did not.

TABLE 4

		Whether parent of handicapped child	
		NO	YES
FPS Rating	LOW	15	6
	HIGH	20	4

Chi square corrected for small n: 0.4 ns

ns=not statistically significant

As noted in Table 4 on the preceeding page, a somewhat higher proportion of families who ended up with a high FPS rating were served by field workers who were not parents of a handicapped child. The differences are so small that the results have no statistical significance.

> Research Question Are there differences in level of family participation (FPS rating) based on whether the field worker assigned to the family was full-time or part-time.

The project employed two full-time field workers in Texas and three to four who were part-time. In Washington, four part-time workers were used. The purpose of having part-time workers was, in part, to increase the number of field workers overall so that the number would be enough to allow some statistical comparisons of effectiveness.

The importance of whether the workers were full-time or part-time turned out to be more critical than anticipated. It was much easier for full-time workers to adapt their schedules to the needs of the family. The part-time workers who had other time committments (other part-time work or studies) had a very difficult time serving the families since the work frequently involved going with them to doctors or therapy sessions and the time for these appointments could not always be set to the convenience of the field worker. The handicapped children were more susceptible to colds and infections and parents therefore frequently had to change plans because of the weather or the health of the child. Part-time workers who were primarily at home during the day, who were free to change their schedule as needed, were able to manage quite well.

The others often had to ask someone else to fill in for them and the rapport with the family was never as good as that of the workers who could serve them more consistently.

Table 5, below, shows the proportion of families whose final FPS rating was high or low based on whether the field worker assigned was full-time or part-time.

TABLE 5

Whether field worker was full-time or part time:

Final FPS rating:	Part	Full
Low	13	8
High	11	13

Chi Square 0.6 ns

ns=not statistically significant

As noted in the table above, slightly more of the families with a high FPS rating were served by field workers who were full-time, but the differences were so slight that there is no statistical significance to these findings.

<u>Research Question</u> Did families indicate a preference for certain characteristics in field workers?

The Exit Interview with families included a number of questions posed in terms of what kind of field worker would be best at another time or place for a project like this one. One of these related to whether they would prefer having a field worker who was the parent of a handicapped child. The other questions dealt with whether they would have preferences relative to the sex, age, language or culture of the field worker and what general characteristics they thought would be important.

The preference for a field worker who was the parent of a handicapped child was 84%. The parents expressed a feeling that being the parent of a handicapped child would enable a field worker to be more understanding, that it would mean that they would have more knowledge about handicapping conditions, and that the fact of their being able to speak from their own experience would have been reassuring.

Most of the families in the project at the time of the exit interviews were served by field workers who were <u>not</u> parents of a handicapped child. We had wondered to what extent parent responses might be tempered by not wanting to imply dissatisfaction with the field worker who had served them--since in most cases a bond of friendship had been developed between the parents and the field worker. This did not seem to have altered their response to this question. On other characteristics they would sometimes name qualities they would prefer in a field worker adding "...like (field worker name)". The implication was that they had liked the field worker very much, but still felt it would have helped if the field worker had also been the parent of a handicapped child.

The other side of this coin was that in the few cases where parents did voice complaints about the field worker, it was about field workers who were parents of a handicapped child. As noted earlier, there seemed to be more emergencies in the families of the field workers who had a handicapped child with the result that they missed appointments, failed to fulfill committments to families, and were subsequently complained about by the parents who had depended upon them. Some of the field workers hired by this project had been fired from other positions. In nearly every case it was because they had a conflict between work and family needs which they resolved in favor of family to the dissatisfaction of the employer. The number of people involved with this project was small. However if any generalization is warranted it might be that in a future project of this kind it would clearly be an advantage to attempt to employ field staff who had first hand experience as the parent of a handicapped child. It might also be necessary to be prepared for a greater degree of work irregularity because this same criterion means that the stresses in their lives could affect their job performance.

The next most strongly held opinion of parents interviewed was that it was important for the field worker to be a woman (74%). Some of their explanations were: "A woman would understand better." "Woman to woman would be better to build confidence and trust." "My husband would not care if field worker was a man, but it might be easier to have conversation if it was a woman." "It would have to be a woman because my husband is very jealous." "No husband would like it for a man to provide transportation for his wife." "Ladies feel more confidence expressing their feelings to a woman." "It would be better with a woman. A mother would feel more confident in sharing and asking about certain things."

If the family did not express a preference for a woman they usually said simply that "it wouldn't matter" or "it wouldn't matter as long as they did their job."

The field worker should be Hispanic in the opinion of 71% of the respondents. Some hedged this restriction by saying it might not matter as long as the field worker spoke Spanish.

Fifty-two percent of the family interviews expressed some opinion about the age of the field worker. In general, they preferred someone close to their own age, or a little older -- old enough to have quite a bit of experience.

Other factors mentioned as desirable qualities for field workers included: trustworthy, friendly, helpful, caring, knowledge of community resources and knowledge about handicapping conditions, able to be friends with fathers as well as mothers, experienced and patient.

6. INTERPRETIVE FIELD NOTES ON PROJECT ACTIVITIES

> <u>RESEARCH QUESTION</u> What types of activities appeared to "work" or to "not work" in reference to each of the types of parental involvement the project was attempting to encourage.

The discussion of which techniques "worked" is not based on any quantitative examination of effectivenes, but is the interpretation of the primary investigator and field staff. The purpose of including this section is to provide descriptive information about what was actually done with families to flesh out the findings already presented. It is hoped that some of the techniques presented may be found useful by other practitioners providing services to Spanish speaking families with handicapped children.

AGENCIES--TECHNIQUES THAT WORKED TO HELP PARENTS DEVELOP INDEPENDENCE

As is clear from reading this report, much of the work with families on this project was in a social work context. People usually think of social workers as "helping" people by dispensing various services, and the field workers employed for this project flung themselves with enthusiasm into "helping" the families to whom they were assigned. It took several weeks of training before field workers began to understand that just doing things <u>for</u> the families would not accomplish the project objective. Our objective, ultimately, was not just to help the families but to HELP FAMILIES HELP THEMSELVES -- we were interested in building INDEPENDENCE rather than DEPENDENCE.

Training consisted mainly of going over contact reports and suggesting alternative ways they might have encouraged a parent to take some reponsibility instead of taking over for them. Once field workers began to understand this new mode of working with families, many of them became very adept at finding ways to help families help themselves. They did this by encouraging the parents to develop new communication skills, to find resources they could use when this project had ended, and, perhaps most important, to create a social network to fall back on instead of living in isolation with their problems. The following are some examples.

Because of limited English and limited educational backgrounds, most of our parents were intimidated in their contacts with professionals -- in the schools, in public agencies, in medical offices, etc. If accompanied by one of the field workers to one of these offices, they fell easily into the pattern of expecting the field worker to step up to the receptionist to say that Mr. or Mrs. ... was here to see... for (whatever purpose), and to allow the field worker to continue to be an intermediary in answering questions, taking over filling out forms, etc. This also felt natural to the field workers. They were being paid to help and they weren't intimidated by the situation so they stepped forward and took charge.

It was, at first, confusing to the field workers to be told that this was <u>not</u> what we wanted to happen. We wanted the parent to become accustomed to announcing herself or himself to receptionists, to answering questions from doctors and therapists and teachers. And we wanted parents to learn how to fill out forms for themselves (if they knew how to read and write in the language the form was printed in). On the other hand, we weren't subscribing to a policy of non-assistance (--like the method of teaching swimming that says throw them into the deep water and they will either drown or swim).

PREVIEWING

We had field workers use a technique we called PREVIEWING. This meant talking about what to expect before they got to an agency; for example, an agency like Easter Seals, where their child was to receive therapy. The field worker would explain that when they got there it would be necessary for the parent to go up to tell the receptionist who they were and what they had come for. The field worker would say something like, "I will hold the baby for you, so you can talk to the people." And when they got to the office, the field worker was to step back, allowing the parent to go ahead.

Frequently, the people at the agency would do things to sabotage this effort to put the parent into the forefront. They had learned that it was easier to get questions answered from the person who appeared least intimidated by the situation and would therefore address questions to the field worker instead of the parent, or give forms to the field worker to fill out for the parent. In some cases they would defend this request by mentioning another agency which "always took care of all the enrollment information because it saved so much time."

It did, indeed, take more time for parents to try to fill out the forms by themselves. And they might not be able to answer all of the questions. Whatever they were able to do would be praised by the field worker saying something like, "See, it is really not so hard to fill these things out. Next time it will be a lot easier." In time, the field workers got a sense of which families might have an unusually hard time filling out forms and they would therefore get copies of the forms to work on at home with them -- in a setting where they weren't under as much pressure from a wiggly child in an unfamiliar situtiion.

Getting the parent accustomed to taking responsibility for communicating with personnel in agencies was much harder to achieve in the northern sites where the field worker was almost always an intermediary because of the necessity of being a translator. Even here, however, field workers used PREVIEWING. For example, in anticipation of a meeting with school personnel over a child's IEP, the field worker would discuss with the parents the kind of questions they had a right to ask about their child's program, and probe for anything the parents might be concerned about and encourage them to bring it up. Then at the meeting, the field worker would attempt to be <u>only</u> the translator--if the teacher directed her questions to the field worker instead of the parent saying, "Does she think...", the field worker was to convey the question to the parent and the parent's response to the teacher instead of volunteering (on the basis of earlier discussion) to answer for the parent.

With a number of the parents at the northern site, it was the very first time they had asked any questions or given any opinions or offered any information in an IEP conference, and it was very exhilerating to them. They seemed to feel more "in charge" than in their previous mode of listen, sign, and leave. They began to take more interest in the school program from this point. And it was mentioned as one of the "primary benefits" they had received from the project by some parents in their Exit Interview.

TRANSPORTATION

Providing transportation for parents to doctors, therapists, meetings, etc. was frequently necessary (as mentioned in the earlier sections, 23% of the families had no vehicle at all, and 67% of the mothers could not drive). Once other agencies in the community learned that our field workers could supply transportation ,they began making referrals to us under the belief that supplying transportation was our primary purpose. Field workers tended to do more and more transporting since this was a comfortable function -- they felt they were being helpful. It was clear that the field workers were making no effort to help families find ways to provide transportation for themselves.

Again, it was confusing to field workers when we insisted that by supplying transportation every time requested, we were building dependence rather than independence. We were also not helping parents find the resources they would need when our short term research project ended. We therefore asked field workers to come up with ideas of how they could help families secure transportation for themselves more often. One field worker took the approach of appealing to the family that in order for it to appear that she was doing her job of helping them become more independent, that it would help a great deal if she only took them to therapy sessions every other time and they found some way to get there on their own the rest of the time. They rallied to the cause and found relatives they could ask, a neighbor out of work they could pay to take them, etc. The field worker responded with enthusiasm and appreciation each time they did find a way to provide transportation for themselves, and within a few months some mothers were supplying all of their own transportation. (A social worker in one agency we were working with was so impressed by this technique that she said she was certainly going to use it herself in the future.)

There were a number of other approaches to helping families solve the transportation problem. Project parents were introduced to one another and this sometimes made car pools possible if one parent had transportation and the other did not. In one northern site, there was some public transportation. The field worker found the parent was afraid to use the busses for fear of getting lost (not speaking any English she was afraid to be on her own away from home where she might not be able to get help if she needed it). The field worker therefore rode the busses with her until she felt quite secure in knowing how to pay, where to get off, when the bus would come, etc. and was willing to try it on her own.

AT least two mothers were taught how to drive or helped to get their license by project field workers. One mother already knew how to drive, but was only willing to drive around their small town and not on the highway, which was necessary to get to medical offices her child needed. She had to be coaxed to try driving on the highway when the field worker was with her until she gained enough confidence to try a longer trip on her own. Some parents know how to drive but not how to read a map or follow road signs (which even in Texas are always printed in English). In these cases, it became necessary to take them to a destination once so they could remember where it was and how to get there, and they could thereafter get there on their own.

REFERRALS WITH FOLLOW UP

As the field workers began understanding the difference between providing help that would lead a family to greater independence rather than dependence, they became more adept at setting up situations which the parent would be encouraged to handle on their own. Instead of making appointments or getting information for them, they would give the parent the name of person they would need to talk to, and a phone number or address so they could make the contact on their own. They would also give as much information as they could about what they had a right to request from that agency, what questions they might be asked, so they could be better prepared when they made the call. Then they would ask the parent to call them back that afternoon, or the next day, to tell them what had been learned or when the appointment was. If there was no follow-up call, the field worker would contact the family and provide more help if it was needed--or to convey interest in what had happened so that the family knew the field worker was concerned.

If the parent failed to get the information or assistance they needed, the field worker might suggest they try something else. Or, after the parent had made the initial effort, the field worker might go with them to the agency or make a follow-up call on their behalf. If the parent had made the first approach to the agency, they were usually quite attentive to see what the field worker did to get the information or assistance desired. This made it more likely that they would be successful in their next effort.

APPOINTMENTS

Having appointments which must be kept, and canceling them if necessary, was not a familiar concept to many of the project families.

They were genuinely surprised to learn that agencies expected to be informed if they could not keep an appointment. Often getting to a telephone to cancel an appointment was not easy (particularly if the nearest phone was half a mile away, and they had to walk, and the reason they couldn't come to the appointment was because either they or the child was sick). But with the field workers making a point of giving parents a calendar to keep track of appointments, and asking if the appointments had been made, or insisting that they cancel, most families did make a real effort to conform to the expectation that they would keep or cancel appointments. In their own lives, migrants have little experience with someone counting on their presence. Working in the fields, one pair of hands is easily replaced by another pair of hands and the only difference it makes to anybody is that if you don't work, you don't get paid.

MEDICAL RECORDS

One final subject that should be discussed in connection with project efforts to help families deal with professionals is that of helping families get and keep records on their child's condition and treatment. All families of a handicapped child find that each new doctor that sees their child requires endless information on what has gone before. For migrant families, this is much more keenly felt than for the general population, because migrant families may relocate two or three times a year. No doctor in a new area can accept the diagnosis of a doctor in the old area, and the family has to expect to have the child reexamined before any continuing services can be provided. For families who have spent days and days making contacts with health providers and securing diagnosis for their handicapped child, to have to do so repeatedly in new locations represents a serious burden--both financially and in terms of the time it takes. Our project also found that families were, for the most part, woefully lacking in any systematic way of keeping the medical history on the child, and that depending on their memory was not helpful in terms of supplying information that might be needed for correct diagnosis and treatment.

Project field workers supplied notebooks and other record keeping devices. At support group meetings this topic was discussed, and a few parents, who did keep good records, were asked to describe how they did it, and why they did it. The parents exchanged their frustrations at doctors for not taking time to explain things to them, and encouraged others to be more aggressive to get information.

The progress of one mother in building a useful file of medical records is worth describing as an example. This mother knew no English, and in general project mothers who had little education and no English never overcame their sense of inadequacy and ended up with a low FPS rating. This mother was an exception. Her child had very frequent seizures (the doctors were trying to determine an appropriate medicine level to control the situation but were having great difficulty). The child wore protective clothing to protect him from falling, but even so appeared to be a very battered child and the family was extremely frustrated. There had been numerous crises when the child had to be rushed to the hospital.

The mother began demanding that the doctor write out everything he had found from each examination, and identify exactly what medicines and instructions he was giving. She explained that even though she was illiterate and could not read it herself, that she had to have this information because other people would need to know it and she wouldn't be able to tell them. She even plucked the cartons that sample medicines had come from out of the wastebasket and kept them so she would have the names of all medications the child had received.

She encountered resistance -- doctors don't like to take that much time, and prefer to keep their records in their own offices rather than giving copies to patients. But she would sit in the office and insist that she needed to wait until he had written everything out for her before she would leave. She immediately showed these records to someone who knew enough to answer her questions and could tell her if the records made sense--if not she would ask them to call and get clarification for her. In summary, even a mother who could not read or write English, with encouragement, became a good manager of her child's necessary medical records and was aggressive enough to do what her situation demanded.

SUPPORT GROUPS--TECHNIQUES THAT WORKED FOR DEVELOPING SUPPORT GROUPS

EXPERIENCES OF OTHER AGENCIES WITH PARENT GROUPS

Other agencies in each of the project areas were asked what their experience had been with regard to involving Spanish speaking families in any kind of parent meetings. In general, the pattern that emerged was that voluntary associations without staff often recognized that there was an unmet need (by linguistic minorities) but said they had no services (no publications, no outreach, no recruitment effort) aimed at non-English speakers. The only minority families that appeared on their membership lists were families comfortably bilingual and able to function very well in an English speaking group.

Some agencies with a large Hispanic clientele had tried having periodic evening meetings. These were usually scheduled as large group meetings with a speaker or film, intended to convey information about some handicapping condition. The usual method of informing parents about the meetings was through posting a notice somewhere, or by sending notices home with young clients when they came in for therapy. In Texas, care was usually taken to have these notices in both Spanish and English -- there was less likelihood of this in the Washington site.

Staff at these agencies reported that typically few Spanish speaking parents came to these evening meetings and if they came once they usually did not come back to the next meeting. Parents said that if the meeting was in English, with someone to provide translation in Spanish, the Spanish speakers did not ask questions because it was awkward taking the time for translation of both question and answers.

In Texas, there had been some group therapy tried with clients of mental health agencies. These groups had been in Spanish and parents were reported to have been very enthusiastic about them. Parents were personally invited to come and the groups were kept small and intimate. The agency had discontinued the groups mainly because of time demands on the Spanish speaking professionals of the agency.

The schools reported that their experience with parent groups was primarily with parent advisory groups for various federal programs where having a parent advisory group was mandatory by agency regulation. Some project parents had attended these meetings -- particularly parent advisory groups for migrant programs where there was active monitoring by the state agency to make sure that parent groups were active. The invitations to these meetings were done partly in person (by outreach personnel employed to contact parents, particularly non-English speaking families) and partly through notices sent home with the children. None of these were specifically for parents of handicapped children and when parents had attended it was usually in connection with one of their other children. The topics were not selected to be of special interest to parents of handicapped children, nor was it a place where they would be likely to meet and talk with other parents of handicapped children.

A number of reasons were offered by personnel in other agencies to explain the lack of participation by Hispanics in parent group activities. Among the reasons given was the belief that Spanish speaking families did not need support groups because Hispanic families gained all the support they needed through the extended family. Another opinion was that it was contrary to their culture to share highly personal situations with strangers; that it was also contrary to their culture to meet with strangers in an organizational setting -- that this was an anglo pattern of conduct and Hispanics simply were not "joiners".

From all of this, we expected that it might be a very uphill struggle to devise support group structures that would be seen as valuable and meaningful by the project population. It turned out to be much easier than we had anticipated. Some of the factors that seemed important in securing participation of parents and siblings in support groups are outlined below.

KEY FACTORS FOR ENCOURAGING PARTICIPATION IN SUPPORT GROUPS

PERSONAL INVITATIONS

It was evident from the experience of others that Spanish speaking parents did not respond to posted notices but when personal contacts had been made, in Spanish, the parents had responded. Invitations to meetings were always personal within the project setting so that families were invited with a sense that it really mattered to someone whether or not they came. If the family did not come, someone always asked them why they weren't able to make it, which reconfirmed the idea that someone really cared whether they were there.

TRANSPORTATION

The project often had to provide transportation. And after a few experiences in which families had said they would drive to the meeting on their own, we learned that they frequently got lost if it was a location they had never been to before. It would have been better to take them the first time, and let them find their own way thereafter.

WELCOMING CHILDREN

A third factor that seemed to be make a difference (besides personal invitations, and transportation) was making it comfortable for parents to bring their child if they wanted to. Families in our project seldom used a paid babysitter and many were uneasy with having a stranger taking care of the child even if the meeting provided babysitting services. If they could not find someone familiar to them to care for the child, they usually took the child or children along. In some of the sharing support group meetings parents sometimes seemed to <u>prefer</u> having their child with them because other parents would hold the child, cuddle and love it, and this seemed very reassuring to the parent. The interest taken by the other parents and their approval of the child seemed quite comforting.

It sometimes took two or three invitations, under these circumstances, for a family to make it to a meeting. Once they had attended, it was much easier (usually) to get them to another meeting. And some became very enthusiastic about the support groups and took the initiative to offer to host small groups at their house, offered to provide food, offered rides to one another, and proposed projects for their mutual benefit that they might discuss.

Although many Hispanics may not have had much experience in groups and may be reluctant to try something new, our conclusion was that it is not contrary to their culture in any way. Most families were very positive to the experience and would have liked more opportunity to get to know other families of handicapped children.

NEEDS VOICED BY PARENTS REQUIRING DIFFERENT TYPES OF SUPPORT GROUPS

The parents were asked in the Exit Interview which types of support group meetings had been most important to them and why. There were three themes that appeared again and again in their responses. These are outlined below, in the order of importance according to the parent interviews, with a description of the support group structures used successfully and unsuccessfully to meet these needs.

THE NEED TO KNOW YOU ARE NOT ALONE

Sharing Groups The project set up several of what we referred to as "sharing" groups. These were meetings of a small number of parents, usually less than eight and sometimes only three or four. There was some continuity in these groups which met together more than once.

In these meetings, the parents talked about their own experiences and shared their feelings. Sometimes there would be a theme and sometimes not. One parent would offer or be asked to start, and then usually each parent would take a turn.

The first time this type of meeting was tried, project staff were uncertain whether parents would open up. The meeting was therefore set up to start with a film, so that in the sharing session parents could just react to the film if they wanted to. The parents enjoyed the film, but the fear that parents would not open up with their feelings was not warranted. Their talking about their experiences went far beyond reaction to the film. Later meetings were set up just for such sharing, "without props" such as a film or planned topic of discussion.

There were several variations of the sharing sessions with special groups. Some mothers, whose children shared the same handicap, set up a continuing "mother's" group that met first at one home and then another about every other week. Different sibling groups were organized. Within the time limits of the project, these never became very well developed. The children shared some of their feelings about having a handicapped brother or sister--mostly, however, they just seemed to enjoy being together as a social occasion. Coming from poverty homes, few of them had been to such establishments as a Pizza Parlor, and they were dazzled by the social aspect of going out to such a place.

Another aspect of the sibling group that seemed very beneficial, but was quite unexpected, was the gratitude of the parents. Some who had been quite reserved with field workers warmed up noticeably when asked if the children would like to go to a social occasion where they would meet other children who had a handicapped sibling. This, evidently, convinced the parents that the project really cared about the whole family. And they were very grateful, voicing often their sorrow that the needs of their handicapped child took away so much time from the other children.

<u>One-on-One Support Groups</u> A variation of the sharing groups above was a structure the project referred to as a one-on-one support group. This would be a meeting arranged between two families who had something in common. For example, many of the Down's Syndrome children also had heart problems. A one-on-one would be arranged between parents in a family whose child would soon be having surgery, and another whose child

had already been through it. As another example, migrant parents were very leery of operations for their children, even quite minor ones. A one-on-one was arranged between a parent whose child had required ear tubes with another that was hesitating about having ear tubes for their child, despite the doctor's advice that it was necessary to protect the child's hearing.

The project promoted a great many one-on-one opportunities for parents--some directed to a specific purpose as described above, and others just intended to build up a social support network for parents. The sense of isolation felt by Spanish speaking families in a northern community is very intense--and this was heightened for some families because fewer of them had extended family nearby, one-third of the mothers had to raise their large families without any father in the home. In Texas, too, many parents were very isolated. Because of the handicapped child, the family would split up with the father going north to obtain work. Many of the families lived in remote rural areas, on roads that became impassable in rainy weather, where the nearest stores were miles away and the family left behind was without transportation. Some parents in both sites were isolated because they were so tied down by the nature of their child's handicap such as needing to attend to a breathing monitor 24 hours a day or spending hours feeding a child that had cleft palate.

Project field workers set goals for these families: 1)that they would be introduced to a number of other parents,2)Know where they live, and 3)have their phone number if there was a phone. These one-on-one meetings were brought about informally --the field workers became very good at making the most of time parents spent in waiting rooms to help them get acquainted with another parent. The time in cars or vans going to meetings or appointments was used to develop new contacts between parents. After an appointment, the field worker might suggest to two parents they they go with her or him to share a box of chicken together and visit. If a number of parents were being taken home from a meeting by van, the parents first dropped off dropped off would sometimes invite the other parents in to see their children and visit.

There were many important benefits that came out of this informal level of contact between families. Parents became resources to one another on intimate matters such as birth control. One mother, who had made no particular effort to do things independently, picked up the sense of pride another parent expressed in being able to do things for herself and followed her example. One father had been hostile about the time his wife spent taking their child for therapy. He became much more understanding after becoming acquainted with another father who talked enthusiastically about the progress his child was making through therapy and even showed off some equipment he had made so the family could do similar kinds of therapy with the child at home.

Social Groups represents a larger version of the informal sharing described in the one-on-one. The project held a number of these occasions -- potlucks, barbecues, and a birthday party. Families frequently provided some of the refreshments for these occasions, and being able to give something back to the project was important to them.

Couples would come to the social meetings, and since fathers were less willing to come to something like the sharing meetings, this became an important place for fathers to be in contact with other fathers.

The social times were very important to some of the families who were new to the area and not acquainted with many people. It was also important for those who were very tied down at home with a severely handicapped child. Usually the families could find someone to watch the child for a few hours. They might call home four times to check on things during the evening, but it was a big event in their lives to have some place to go and something to get dressed up for.

These social events, and meetings between just two people, are mentioned because people thinking of "support groups" may think only of meetings with a formal structure and topic. All of these types of groups produced a sharing and a sense that the parent was not alone.

The project was <u>not</u> successful with two types of "sharing" groups it tried to set up. The first was a group just for fathers. Quite a number of fathers came out to the first meeting. They were quite open in sharing with one another and talked about future meetings. The second meeting, only one father came. After that, several tries were made to set a date for a father's meeting, and the number of excuses offered as to why fathers could not come defeated the effort. The project never did discover what it would take to get a successful father's group going.

The other unsuccessful effort was to set up a structure whereby project parents could be called by local hospitals to visit with parents of new-born babies with handicaps who might need some comfort and support. Since the parents in the project were very grateful for the change in their lives owing to the support they received from each other, they said they would like to help others. Field staff met with the local hospitals a number of times to see if this could be arranged, but the bureaucratic procedures for clearing such a plan through boards and hierarchies easily defeated the plan. Possibly if the project had been funded for a longer time, it would have been possible to develop this.

THE NEED TO LEARN ABOUT HANDICAPPING CONDITIONS AND ABOUT PROGRAMS

The next most frequently mentioned reason for support group activities voiced by parents was their need to learn more about handicapping conditions, and to learn about programs available for their children now and in the future.

Because these were Spanish speaking families, living in an English speaking country, they have far fewer written sources of information available to them from which to learn about their child's handicapping condition. Because of a limited educational level, most parents were not equipped to learn what they needed to know to understand their child's condition through books. This made the spoken word their main source of information, and they were very grateful for Spanish speakers who were able to explain about the causes and treatments of various handicapping conditions, the effects on the family and how other families have coped with it, and similar topics. The project sponsored a number of these, and took families to meetings sponsored by other agencies.

The other type of informational support group used by the project was the field trip. These were extremely successful. Parents who visited a preschool program for handicapped children at an excellent school in the area came away with most of their doubts swept away as to whether they wanted to entrust their child to such a program when he or she was old enough for it. Parents whose children have life-long disabilities were very encouraged to visit a facility for independent adult living of handicapped people. Schools and institutions offering special services were visited.

THE NEED TO BAND TOGETHER FOR MUTUAL SELF HELP

The final theme expressed by parents on the need for support groups was their need to work together to achieve some things they couldn't do alone. Setting up a formal organizational structure to work on common goals was the most complicated of the support group efforts made by the project. Several planning meetings were held and some leaders came out of the project families who were willing to continue this initiative. It seemed that there would not be enough time to get such a group organized, but the project was granted a three month extension. This made it possible for a field worker to continue working with the families to form this group. Within that time, the group was able to complete an organiational structure. It has since become incorporated, as Parents for MASH, Inc. MASH stands for medical assistance and support for the handicapped.

Parents for MASH, Inc. may develop other goals, but it started with one prime purpose--to acquire a treasury that could be used as a source of emergency help for families with handicapped children. None of the project parents have jobs that provide health insurance benefits. Most of the families have, at one time or another, faced emergencies requiring hospitalization. Among their greatest fears is that there will be a life threatening situation for one of their children and they will lack the cash required by the hospital before the child can be admitted.

Some families have, from meager earnings, acquired a special money reserve for just such an emergency. But this has its problems too. The story about one project family will illustrate the dilemma. This family had a number of children including three who were handicapped. One child had died. The mother, through fierce determination to protect the other two, had managed to set aside a small bank account which the family would not touch for anything else because it was there as an emergency fund in case these children needed hospital care.

The family was then caught in the disastrous winter of 1983-84, when the worst freeze ever to occur in that part of Texas wiped out all of the citrus crops and took away most of the jobs that families depended on for winter income. The family was in pretty desperate circumstances and finally applied for food stamps. They were told they were ineligible because of the emergency bank account. They needed food--and had other children besides the handicapped children. Which was the greater priority?

The organization they set up was to raise money so that collectively they would have access to funds for such emergencies. Having such a resource to fall back on in emergencies would have solved the problem for the family described above.

Another common problem faced by families is that many of them have children who are eligible for SSI benefits, but for some reason most families have been turned down three and four times before the eligibility is granted. Each time it costs the money for doctor's diagnosis reports that are required as part of the application process. Sometimes lack of a sum as little as fifteen dollars had kept the family from being able to reapply. The organizational treasury was meant to cover such a need. Thus far, the group has made an outright gift of money to families that required assistance. But they expect that families will make donations back to the group treasury when they are able to do so.

HOME ACTIVITIES--TECHNIQUES THAT WORKED TO ENCOURAGE HOME ACTIVITIES

Field workers in this project worked to encourage home activities mainly through helping parents learn about appropriate activities from professionals in other community agencies. Most of the handicapped children were involved in some type of occupational, physical or speech therapy. These therapists were able to provide suggestions of appropriate home programs. In both communities there were also home teachers funded to provide assistance to parents of handicapped preschool children, and the schools served the older children. In many cases doctors had advised the parents of the need to carry out certain procedures. Despite the availability of these resources, the majority of families reported on the Intake Interview that they had no home activity program for their handicapped child.

The Exit Interviews indicated that parents had less interest in receiving assistance with home activities than in other types of help the project offered them. And field workers felt that in many cases they had made little or no progress in this area. However, they did report three "techniques" which were modestly successful in increasing parental involvement in home activities, and these are described below.

The value of demonstrations. At one agency serving families, the parent was expected to come in with the therapist and sit down on the floor alongside the child and participate in the therapy session. At another agency, the parent was expected to sit on a chair in the hall and wait until the child was finished with the therapy.

The project parents who were involved in home activity programs with their children were much more likely to be part of the program of the first agency. In this program they became more interested in the child's progress because they saw the therapy demonstrated and had its purpose explained. They were treated as part of the teaching team and coached in how to do things which made them more confident to try activities at home with their child.

Parents whose children were seeing therapists at the second agency complained to the project field workers about their frustration at not being able to see and hear what the therapists were doing with their children. The field workers encouraged parents to voice these complaints. One result was that the agency installed a viewing booth with earphones so parents could listen to the speech therapy program. Parents were allowed to come in to the physical therapy sessions, and the therapists demonstrated the things they could do with their child. After these changes were, parents became much more interested in the therapy. They were receiving hands-on demonstrations of how it was carried out. The field workers felt that this resulted in an increase in parental interest in carrying out a home activity program.

Involving other family members In some families, the parent, usually the mother, who was trying to carry out exercises or other prescribed activity with the handicapped child, had little support from the husband or other children in the family. Some were resentful of the time this therapy required. If some members of the family did not think there was "anything wrong with" the handicapped child, they were likely to be impatient.

Field workers assumed that if the other family members understood more about what was being done and why, or had more interest in the therapy, it would ease this competitiveness. When they could, they encouraged the spouse or other children to go with the parent and child to the therapy. Because of work and school, this was not often possible. An alternative used by field workers was to take pictures of the child in therapy and give these to the family, using the pictures as a reason to talk about and explain the child's therapy. Other children were quite interested in pictures, and it became clear that the parents had explained very little to them about what was "wrong with" their brother or sister and they were both fearful and curious. This method was therefore more successful.

Involving siblings and both parents in activities with the other project families also helped them to understand and accept the home situation with the handicapped child. In some families, this increased the willingness of different family members to help with home activities necessary for the handicapped child.

Providing reinforcement The primary tool field workers had to encourage home activities was offering reinforcement for what families were doing in this regard. By asking about the child's progress and showing interest, they began to see parents take pride in the child's gains and it seemed that home programs were being carried out more regularly. Since field workers had to think in terms of where this reinforcement would come from when the project had ended, whenever possible they involved parents in communication with other parents whose children had similar handicaps, and they provided much reinforcement to each other. By changing the system for working with families at the one agency, they increased reinforcement parents received because therapists would ask them questions about the child's progress and parents were eager to show off new accomplishments in this setting.

The area in which the program was least successful in terms of home activities was in encouraging parents to follow some course of action recommended by a doctor even though their child would cry. The project tried many things to help one mother learn more about nutrition, and pay attention to her child's diet and weight. The handicap was an orthopedic one, and overweight made it much worse. She felt sorry for the child and giving treats was her way of compensation. Holding back on the sweets would make the child cry and the mother caved in at once. In another case the child needed to wear braces, but the braces were uncomfortable and the mother could not bring herself to put them on regularly. In yet another case, the physical exercises to produce some flexibility of movement were painful, and the family could never stand to do these things which made the child cry.

Since this was a study focused on only one cultural group, there is no way of knowing whether this tenderheartedness is a "cultural characteristic" of the Hispanic families in this project, or a more universal trait. The project did not develop successful techniques to help families do what would be best for the child in these situations.

IMPLICATIONS FOR FURTHER STUDY

With the non English speaking families becoming a greater part of our population every year, there is clearly a great need for many more studies that will illuminate the needs of linguistic minorities, and successful methods of providing services to them. This study has shown that the sociolinguistic environment is also important in considering the needs of language minorities. What will serve the needs of Spanish speaking families in a high density area of Spanish speakers will not apply to Spanish speaking families in a low density area.

This project yielded some successful techniques for increasing the ability of parents of handicapped children to cope with their needs and the needs of their handicapped child. Other agencies in the area where the demonstration projects were operated have already adopted some of these techniques. Another measure of the success of the program was the organization and incorporation of an advocacy group for mutual self help among Spanish speaking families of handicapped children in Texas.

It is important for research to report its failures as well as its successes, however. The fact that similar techniques were not as effective in the northern site as in the Texas border community indicates that further research is clearly needed. This study documented that recent immigrant, language-minority families living in relative isolation in a low density area of Spanish speakers are comparatively much worse off that their counterparts in a high density Spanish speaking area. And the plight of a handicapped child in a family that is cut off from the resources of the community through language, culture, and poverty is a very bleak one that is not being addressed by current programs.

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APPENDIX

EL PROYECTO PHP

ENTREVISTA DE ADMISION

Fecha de entrevista____________Nombre del Entrevistador____________

Nombre del niño(a)____________Fecha de nacimiento____________

Forma de incapacidad____________________________

SERIE DIAGNOSIS:

¿Que edad tenía el niño(a) cuando penso que podía estar incapacitado? ________________. ¿Fue algo que la familia noto o alguien le dijo que el niño(a) podía necesitar ayuda especial?__________ Si la familia lo noto, ¿cual miembro de la familia?____________Si fue alguien fuera de la familia, ¿quien fue, y en que forma vieron al niño(a) que les indicara que necesitava ayuda especial?____________________

CONTINUACION: SERIE DE TRATAMIENTOS (MEDICO O TERAPEUTICO)

¿Quién hizo referencia o encontro proveedor medico?____________

¿Que edad tenía el niño(a)?____________________

¿Como lo encontro y quién hizo contacto?____________________

¿Quién asistió a la cita?____________________

¿Donde (cuidad, estado) fue encontrado el proveedor medico o referencia? ____________________(Nombre de la agencia y persona si lo sabe.)

____

**Repita toda la información acerca de las prequntas anteriores por cada evento posterior en la serie de tratamientos.____________________

____

____

____

¿Ha tenido contacto la familia con algúna de las siguientes agencias?

Si/No__________

¿Quién hizo contacto con la agencia o fue referencia?__________

Si emigrá, mencione agencias con las cuales tuvo contacto.__________

Qué asistencia obtuvieron de las siguientes agencias:

EASTER SEALS__________

CRIPPLED CHILDREN__________

WELFARE DEPT.__________

SSI__________

MIGRANT CLINIC__________

PROGRAMA WIC__________

ESCUELAS__________

REGION 1__________

MHMR__________

¿Cuales otras agencias le han dado asistencia (financiera o material)?

Nombre de la agencia__________¿Como supo de ella?__________

¿Quién hizo contacto, en que le asistieran?__________

¿Esta usted haciendo algo especial en casa para ayudar a este niño(a) que sea diferente de lo que hace con los otros niños? (Si es así, ¿usted penso en hacerlo o alguien se lo sugirio?)__________

¿Le han sugerido los medicos, u otra gente medica o maestros algúnos metodos que le puedan ayudar con las necesidades especiales de su niño(a) dentro de el hogar? (Si es así, ¿que miembro de la familia lo hace, con que frecuencia, que tan efectivo es el metodo?)__________

ENTREVISTA DE ADMISION Page 3

¿Le ayudan los otros niños de la familia con el niño incapacitado?

(Si es así, de nombres y edades y que es lo que hacen.) ____________________

____

____

¿Le ayudan los niños fuera de casa con traducciones, llevarlo a las citas, etc.? Diga usted. ____________________________________

____

¿Hay algúna persona fuera de la familia immediata que le ayude con el niño(a) incapacitado? (Amigo o pariente, contacto informal-no de agencia.)

(¿Si es así, ¿quién es, de que forma la ayuda y con que frecuencia?)

____

____

Cuando el niño(a) incapacitado está en casa, cuales miembros de la familia comparten más tiempo con el (ella). Enlistelos en orden del 1-4

Padre ____________________ Hermano(as) ____________________

Madre ____________________ Otros - Quienes ____________________

Comparte el niño(a) tiempo con alguien fuera de la familia (niñera, vecina, pariente, amiga.) Diga usted. ____________________________

____

¿Quién vive con el niño(a) incapacitado(incluya a las personas que no sean familiares - el de más edad primero)?

			Donde Nacio	(Idomia Usado) Ingles - Espanol 0=Nada 1=Algo 2=Muy Bien		
Parentesco con el niño(a)	Apellido, Nombre	Edad	Estado. Pais	Hablar	Leer	Escribir
			I E			
			I E			
			I E			
			I E			
			I E			
			I E			

¿Es el idioma un problema para usted o su esposo(a), para conseguir ayuda para su niño(a)? ____________________

¿Cuanto tiempo ha vivido la familia en esta area? (Dirección o señas de la casa.) Dirección fisica y dirección postal. ____________________

____

¿Donde vivío antes y por cuanto tiempo? ____________________

¿Emigrá la familia? Si/No (Si es así, ¿adonde y por cuantos meses del año?)

¿Cuales miembros de la familia emigran? ____________________

____

¿Tienen casa propia, rentan o comparten la casa? Cuantos cuartos tiene la casa? ____________________

Educación del Padre ____________________ (Si estudio fuera de E.U., indique en donde.)

Educación de la Madre ____________________

Ocupación de los miembros de la familia que trabajan. ¿Esta empleado actualmente, es seguro su trabajo, tiene seguro de salud para la familia? Si/No ¿Desune el trabajo a la familia? Diga usted. ____________________

Padre ____________________

____

Madre ____________________

____

¿Algún miembro de la familia (excluyendo al niño(a) incapacitado) tiene problemas de salud frecuentemente? ¿Quién? Diga usted. ____________________

____

¿Todos los niños en el hogar tienen los mismos padres? ____________________

____

¿Hay otros parientes de la familia viviendo con ustedes o cerca de ustedes? (Si es así, ¿cuanto tiempo disfruta la familia junta?) ____________________

____

¿Entre sus amigos cercanos o parientes hay algunas personas con impedimentos? (Si es así, ¿que clase de impedimento? ¿Con que frequencia la familia ve o habla con estos otros miembros de la familia?)

¿Conoce usted otras personas (que no sean amigo cercanos o parientes) que tengan niños con impedimentos? Por ejemplo, ¿algunas otras familias le han llamado a usted pidiendo información o ayuda de algúna clase para con su niño(a) incapacitado?

¿Es usted o su esposo(a) miembro de algún grupo de padres? (Si es así, ¿que tipo de grupo es? ¿Que tan activo es usted dentro de el?

¿Alguna vez asistió usted a reuniones o programas especiales para padres de niños incapacitados? (Si es así, ¿con que proposito? ¿Con que regularidad se reunen? ¿Con que frequencia asiste usted a reuniones semejantes o grupos?)

¿Tienen algún tipo de ayuda para su familia o sus niños incapacitados que pueda usted obtener? (Describalo.)

¿Que distancia tiene la tienda de abarrotes mas cercana?__________________

--el medico del niño(a)?__________________

--centro de terapia?__________________

¿Tiene la familia carro? Si/No__________________

¿Es dependiente? Si/No__________________

¿Esta disponible? Si/No__________________

¿Puede usted manajar un carro? ¿Madre,__________? ¿Padre,__________?

¿Tiene usted licencia de conducir? ¿Madre,__________? ¿Padre,__________?

THE PHP PROJECT

INTAKE INTERVIEW

Date of interview____________________Name of interviewer________________

Name of child______________________Child's date of birth______________

Type of handicap____

DIAGNOSIS SEQUENCE

How old was the child when you first thought he/she might have a handicap?

_______________. Was it something the family noticed, or did someone else tell you the child might need special help?______________________

(If the family noticed, who in the family?)______________________

If an outsider, who and how did they happen to see the child?__________

____

TREATMENT SEQUENCE

Who made the referral or located the medical provider or other agency?

___________________________. How old was the child at that time?_______

Who arranged the contact?____

Who went to the appointment?_____________________________________

Where (city and state) was the medical provider or other agency located?

_________________Name of the person that was seen, if you know it, and name of the agency.____

**Repeat all the information in the above questions for each subsequent event in the treatment series._______________________________

____

____

____

INTAKE INTERVIEW Page 2

Has the family had contact with some of the following agencies? Yes/No

Who made the contact with the agency, or was it a referral? ____________

If the family migrates, include agencies with which they had contact during the migration. ____________

What assistance was obtained from the following agencies:

EASTER SEALS ____________

CRIPPLED CHILDREN ____________

WELFARE DEPT. ____________

SSI ____________

MIGRANT CLINIC ____________

WIC ____________

SCHOOLS ____________

REGION 1 (TEXAS) ____________

MHMR (TEXAS) ____________

What other agencies have given assistance (financial or material)?

Name of Agencies	Who Learned About It?	Who Contacted?	What Assistance Was Given?

Are you doing something special at home to help this child that is different from things you do with your other children? If so, did you think of doing this or did someone else suggest it?

Have doctors or other medical people or teachers suggested any ways you can help with your child's special needs at home? If so, who in the family does what, how often, and is it helping?

INTAKE INTERVIEW Page 3

Do other children in the family help with the handicapped child? If so, give names and ages and what they do. Do children help outside the home with translation, driving to appointments, etc.? Describe.

Is there some other person outside the immediate family who helps the handicapped child (friend or relative--an information contact, not from an agency). (If so, who, what do they do, and how often?)

When the handicapped child is at home, which persons in the family spend the most time with him/her? Rank order 1-4

Father____________________ Siblings______________________

Mother____________________ Other (who)___________________

Does the child spend much time with someone outside the family (babysitter, neighbor, relative, friend)? Describe.___________________________________

____

Who lives with handicapped child (include unrelated people who live in the house - list the oldest first).

			(Country or State)		(Language Use) English - Spanish 0=none 1=some 3=pretty well		
Relationship to child	Last name, first name	Age	Where Born		Speak	Read	Write
				E S			
				E S			
				E S			
				E S			
				E S			
				E S			

INTAKE INTERVIEW Page 4

Is language a problem for you or your spouse in getting help you need for the handicapped child?____

How long has the family lived in this area? (Address or directions to home.) Street address or postal address._____________________________

____

Where did you live before and for how much time?_______________________

Does the family migrate? If so, where, and for what months of the year?

____

____

Which members of the family migrate?___________________________________

Do you own, rent, or share a home?____________________________________

Father: Years education____ Education in U.S._____ or Mexico____

Mother: Years education____ Education in U.S._____ or Mexico____

Occupation of working members of the family. Currently working? Yes/No

Father______________________________ Is the work steady? Yes/No

Mother______________________________ Does the job include health insurance for the family? Yes/No

Other_______________________________ Does the location of the work cause the family to be separated? Yes/No

Do family members other than the handicapped child have frequent health problems? Who? Describe.

Do all children in the household have the same parents?

Do members of the extended family live with you, or near by? If so, how much time do you spend with them?

INTAKE INTERVIEW Page 5

Among your close friends or your relatives, are there any people with handicaps? If yes, what kind of handicap? How often does your family see or talk with this other family?

Do you know other people (not close friends or relatives) who have handicapped children? For instance, have any other families called you to ask for information or help of some kind having to do with a handicapped child? If so, name of family, in general where they live, type of handicap, and how were you able to help them, if at all?

Are you or your spouse a member of any parent group? If so, what type of group? How active are you in it?

Have you ever attended meetings of special programs for parents of handicapped children? (If special program, for what purpose? Was this a group that meets regularly? How often do you attend such meetings or group?)

Are there types of help your family or your handicapped child need that you have been unable to get? Describe.

How far is it from your home to grocery stores?________________

How far to your child's doctor?________________

How far is it to a center for therapy?________________

Does your family have a car, or other vehicle? Yes/No

Is it dependable?________________

Is it usually available for going to appointments or to meetings? Yes/No

Do you know how to drive a car? Mother____________ Father____________

Do you have a driver's license? Mother____________ Father____________

EL PROYECTO PHP

ENTREVISTA DE SALIDA

Nombre de la familia ______________________

Niño(a) dentro del proyecto ______________________

Nombre del trabajador social ______________ Entrevistador ______________

Fecha de la entrevista ______________

Estamos pensando en empezar un programa similar a este del cual usted ha estado recibiendo servicios. Sus respuestas a las preguntas siguientes seran gratamente apreciadas.

1. Enliste 1 o 2 maneras en las cuales el proyecto le ha estado ayudando mas. ______________________

____

2. Enliste los nombres de programas/agencias/doctores con los cuales ha tenido contacto dentro de este tiempo. Le ha ayudado el proyecto con algúna de estas agencias y de que manera? De ejemplos especificos.

____

____

____

3. ¿Encuentra fácil obtener respuestas a sus preguntas/aclarar sus dudas y en general tratar con las agencias/programas/doctores que han estado en contacto con su familia? Si/No Explique(Comentarios y ejemplos)

____

____

4. ¿Le ha provisto el proyecto con experencias, consejos y/o información que le ha ayudado en sus tratos con estas agencias/programas/doctores? Si/No (Comentarios y ejemplos)____________________

____

____

5. ¿Cree usted que es significativo reunir un grupo de apoyo dentro de los padres de niños incapacitados, hermanos, hermanas, padres solos, madres solas? ¿Si/No? ¿Porque? ¿Que sería discutido? (Comentarios)

Padre__________________________________

Madre__________________________________

Hermano(a)______________________________

6. (Nota:) En este punto, esté seguro de definir los diferentes tipos de reuniones para los padres, asi como hacerle preguntas sobre ellas.

   a. ¿Fue usted invitado a una reunión para dos personas? Si/No ¿Asistió usted? Si/No (Comentarios acerca de la reunión actual, ¿asistió usted?, y porque ellos piensan que una reunión como esta sería de gran ayuda.) ¿Cuantas veces asistió?__________

   ____

   b. ¿Fue usted invitado a una reunión grupo de apoyo? Si/No ¿Asistió usted? Si/No ¿Cuantas veces? (Comentarios)__________

   ____

   c. ¿Fue usted invitado a una cita de información (presentación, viaje al campo)? Si/No ¿Asistió usted? Si/No ¿Cuantas veces? (Comentarios)__________________________

   ____

   d. ¿Fue usted alguna vez invitado a una reunión social? Si/No ¿Asistió usted? Si/No ¿Cuantes veces? (Comentarios)__________

   ____

e. ¿Fue usted invitado a una cita de organización? Si/No ¿Asistió usted? Si/No ¿Cuantas veces asistió? ____________________

____

7. ¿Si usted asistió a más de un tipo de citas, cual de ellas le parecío mejor, en cual encontro más ayuda, y porque? ____________________

____

____

8. ¿En que maneras la ha provisto el proyecto información, consejo, y/o ayuda, que fue mas usada en ayudar a su niño(a) en actividades de la casa? (Ejemplos). ____________________

____

9. Describa usted cual debería ser la personalidad ideal de un trabajador social, para trabajar con familias de niños incapacitados. ____________________

____

10. ¿Haría el sexo, edad, cultura, o raza del trabajador social una diferencia? Si/No ¿Porqué? ____________________

____

____

11. ¿Que clase de educación y experiencia debería tener un trabajador social? ____________________

12. ¿Si el trabajodor social fuera padre de un niño(a) incapacitado haría una diferencia? Si/No ¿Porqué? ____________________

____

Otros Comentarios: ____________________

____

____

____

THE PHP PROJECT

EXIT INTERVIEW

Client Family ____________________

Project Child ____________________

Field Worker Assigned to Family ____________________

Date ____________________

We are thinking of starting up a program smiliar to the one that you have been receiving services from. Your answers to the following questions would be greatly appreciated.

1. List 1 or 2 ways in which the project has been the most helpful to you. ____________________

   ____

2. List the names of the programs/agencies/doctors with which you have contact at this time. Has the PHP project helped you with obtaining the services of these agencies in any way? Give specific examples.

   ____

   ____

   ____

3. Do you find it easy to get your questions answered/doubts cleared up and in general deal with the agencies/programs/doctors that have contact with your family? Yes/No (Comments and examples)

   ____

   ____

   ____

   ____

EXIT INTERVIEW Page 2

4. Has the PHP project provided you with experiences, advice, and/or information that has helped in your dealings with these agencies/programs/doctors? Yes/No (Comments and examples) ____________________

____

____

5. Do you feel that there is value in getting together parents of handicapped children, siblings of handicapped children, fathers alone, mothers alone? Yes/No Why? What would be discussed? (Comments)

Father ____________________________________

Mother ____________________________________

Siblings ___________________________________

6. (Note: At this point, be sure to define the different types of meetings to the parents as you ask them the questions.)

   a. Were you ever invited to a one-on-one meeting? Yes/No Did you attend? Yes/No (Comments about actual meeting, if attended, or why they think a meeting like this would be helpful.) How many times did you attend? ____________________

   ____

   b. Were you ever invited to a support group meeting? Yes/No Did you attend? Yes/No How many times did you attend? Comments.

   ____

   ____

   c. Were you ever invited to an informational meeting (presentation field trip)? Yes/No Did you attend? Yes/No How many did you attend? Comments. ____________________

   ____

   d. Were you ever invited to a social gathering? Yes/No Did you attend? Yes/No How many times did you attend? Comments ______

   ____

e. Were you ever invited to an organizational meeting? Yes/No
Did you attend? Yes/No How many times did you attend? ____________

7. If you attended more than one type of meeting, which did you like best or find most helpful, and why? ____________

8. In what ways has the project provided information, advice, and/or help that was useful in helping your child at home? (Examples) ____________

9. What do you feel would be the ideal personality of a field worker working with families with handicapped children? ____________

10. Would the sex, age, culture or race, of the field worker make any difference to you? Yes/No (for each) Why? ____________

11. What kind of education or experience would be useful for a field worker to have? ____________

12. If the field worker was the parent of a handicapped child, would this make a difference to you? Yes/No Why? ____________

Other comments ____________

THE PHP PROJECT - THIRD PARTY INTERVIEW
PROVIDER'S QUESTIONNAIRE

PROVIDER ____________________

AGENCY ____________________

PROJECT CHILD ____________________

1. How long have you been serving or treating the project child and family? ____________________

2. Mom/Dad (circle one or both) show an adequate understanding of their child's condition or disorder.

   Disagree 0 Agree 1 Strongly Agree 2

   Comments: ____________________

3. Mom/Dad show an adequate understanding of your treatment and involvement with their child.

   D 0 A 1 S A 2

   Comments: ____________________

4. Mom/Dad initiate questions when they are in doubt or when the need arises.

   D 0 A 1 S A 2

   Comments: ____________________

5. Mom's/Dad's responses to your questions are adequate and informative.

   D 0 A 1 S A 2

   Comments: ____________________

6. Mom/Dad communicate effectively with you and others at your agency.

   D 0 A 1 S A 2

   Comments: ____________________

7. Mom/Dad keep appointments on a regular basis.

   D 0 A 1 S A 2

   Mom/Dad cancel appointments in advance.

   D 0 A 1 S A 2

   Comments: ____________________

THE PHP PROJECT - THIRD PARTY INTERVIEW
PROVIDER'S QUESTIONNAIRE Page 2

8. Mom/Dad show accomplishment in following up your referrals and recommendations.

D 0 A 1 SA 2

Comments:

9. Mom's/Dad's participation with their child at home is one that encourages and enhances the child's development and independence.

D 0 A 1 SA 2

Comments:

10. Mom/Dad have asked for suggestions on ways they could help their child at home.

D 0 A 1 SA 2

Comments:

11. Mom/Dad have volunteered information on ways they are trying to help their child at home.

D 0 A 1 SA 2

Comments:

12. Have you ever invited Mom/Dad to a parent meeting or activity? yes/no
If yes, did they attend? yes/no
What kind of meeting was it?

How would you describe their participation with parents and professionals at the meeting?

Passive	Enthusiastic	Actively Enthusiastic
1	2	3

Comments:

13. Are these ratings and impressions due to recent growth and development in the last 4-6 months since the PHP project has been working with the family, or have parents always been like this?

14. How would you compare this family with other families of similar backgrounds who are not clients of the PHP Project?

15. Any Additional Comments:

THE PHP PROJECT
HOME VISIT/TELEPHONE CONTACT

Project Child______________________

Field Worker______________________

Date________________

1. Who was involved in this telephone contact or home visit?

2. List how actively these people participated with you.
Rate 1 - 5 (1 being the most active).

___father ___mother ___brother ___sister ___other ___other

3. Describe the purpose of your contact/visit, and in detail describe the actual happenings and your impressions.

Purpose:

Description:

THE PHP PROJECT
HOME VISIT/TELEPHONE CONTACT   Page 2

AGENCIES

4. List agency and professional contacts that you have made on behalf of the family since your last contact with them.

Agency/Professional	Nature of Contact

5. List agency and professional contacts that the family has made on their own since your last contact with them.

Agency/Professional	Who Contacted	Nature of Contact	Prompted by You

SUPPORT GROUPS

6. Was there any discussion about Parent Support Groups? (Either comments about past meetings, comments about desiring a meeting/gathering, your attempts at organizing future meetings, etc.)

HOME ACTIVITIES

7. a. Describe your involvement in providing information, assistance and/or training in the area of Home Developmental Activities for the child.

   b. How involved are the parents in providing home activities for the child? How much of an influence were you in their involvement?

TECHNIQUES

8. Are there ways in which these parents are showing independence and interest in helping their handicapped child or themselves? Are they showing leadership or helping others?
   Give Examples:

THE PHP PROJECT
HOME VISIT/TELEPHONE CONTACT Page 3

NOTE: These goal statements do not have to be filled out after every home visit, but must be filled out periodically so that there is evidence that there is some effort on your part to work towards independence.

A. Describe ways in which you feel the parent might achieve greater independence in providing for their family needs, including those of the hendicapped child, or extending themselves to assist other families with handicapped children.

B. How do you plan to work with the parents to achieve these goals (remember that you want to encourage independence and mutual self-help, so think of ways that parents can take responsibility for meeting family needs as much on their own as possible, or ways in which they have something to offer other families)?

GOAL STATEMENT

GOAL: ______________________________

____

Planned steps to reach/achieve above goal:

1. ______________________________

____

2. ______________________________

____

3. ______________________________

____

THE PHP PROJECT

SUPPORT GROUP REPORT

Project Child________________ Parent's Name_____________________
Field Worker_________________ Date_______________

Purpose/Topic of Meeting ____

____

1. Discuss your attempts at informing parents about this gathering. (Check your visit reports for much of this information.) What were the parent's responses to your attempts?

TRANSPORTATION

2. Provided by: ___Field Worker
   ___Selves
   ___Other, Explain____________________________
   ____

   a. If the parents provided their own transportation, either on their own or through some other means, explain how much of an effort or sacrifice it took to get there. If you as the field worker had anything to do with arranging transportation, please explain.

   b. If you provided transportation for the parents, was it because it was the only way the parents could get there? yes/no If no, what was the reason?

   Describe the parent's enthusiasm in asking for or accepting transportation.

   c. Describe the parent's interaction with you and other parents (if applicable) during the drive to the meeting. (What was talked about, what were parents feeling, how active was their involvement with you and with others, etc.)

THE MEETING/GATHERING

3. a. Describe parent's interaction with others prior to the start of meeting.

b. Describe further the purpose of the meeting and it's presentation topic.

c. Describe parent's interaction with others during the formal part of the meeting. ***Some meetings or get togethers may not be formal at any time.

d. Describe parent's interaction with others during breaks or other informal times. ***Some meetings may be completely informal.

TRANSPORTATION BACK

4. a. Describe parent's interaction with you and other parents during the drive back home.

Was there a difference in their behavior when compared to their behavior on the way to the meeting? yes/no Explain.

b. List comments and impressions that parents shared with you about the meeting. ***If you did not transport them back home, make sure to get their feedback on your next visit and include it on your next visit report.

Positive Comments Negative Comments

THE FAMILY PARTICIPATION SCALE

KEY TO RATINGS:

The family participation scale is a means of quantifying the initial and final position of project families, in relationship to one another, on a set of skills and activities relating to their handicapped child. The information is gathered from the file on the family including the Intake Interview, field worker reports (Home Visit/Phone Contact Report, and Support Group Reports), the Exit Interview and a third party interview with someone from another agency serving the family (The Providers's Questionnaire). . Copies of all of these instruments are included in the appendix to this report.

There are three subscales: AGENCY, SUPPORT GROUPS, HOME ACTIVITIES.

The first step is to make an evaluation of the family in terms of four levels of participation on each of the three subscales according to whether the family generally fits the characteristics ascribed to each of these levels. The four levels are: negative, passive/supported, active/supported, and independent/advocate (the characteristics for each of these levels is defined in more detail below).

After determining which level best fits the family, the next step is to compare all the families assigned to a given level, and to assign a rating to them in comparison to the other families on a five point scale within each level. This process is carried out twice, first to assign an initial rating to the family reflecting the level of participation when they came into the project, and then a final rating reflecting any changes occurring during the period they were served by the project.

After rating the family on each of the three subscales, add the scores together to form a composite rating.

AGENCY--PROFILE OF FAMILY CHARACTERISTICS AT DIFFERENT LEVELS

NEGATIVE. This would include families that have avoided any clinical evaluation of a child-even in the face of fairly clear evidence of abnormality. On the Intake Ikkerview there might be mention that a doctor advised the parents at birth of a possible handicap, but they did nothing about it for some time--possibly ignoring it until they brought the child to a day care center and the physical examination revealed something wrong. The history of the diagnosis and treatment of the handicap would indicate that third parties had taken the initiative and the parents had given no support, and appeared somewhat indifferent to the handicap or the possibility of treatment. They might attempt to hide the child's handicap from others. Their relationship with field workers from the PHP project would be guarded, appearing to tolerate the contact only for some possible economic benefit. The parent would be cold and uncommunicative toward field workers, possibly talking at the door rather than asking them in, or "disappearing" and sending a child to say that no one was home on some visits.

PASSIVE/SUPPORTED. This would indicate a family that does not reject help when someone else takes the initiative (a relative, day care personnel, or school, for example) but relies on third parties to arrange the contacts. The parent may go along to a doctor's examination, but offers little information and asks no questions. It would include a family faced with obstacles in communication (little English, little education), if the family allows these obstacles to become a reason not to try. The same applies to obstacles like poverty or lack of transportation--the parent at this level would not demonstrate much initiative to try to overcome these obstacles in order to get the care the child needs. The parent would show little persistence. If turned down for SSI, for example, they don't bother to appeal or try again. If the child is furnished with glasses, braces, or other equipment, they would show a general apathy toward it, not taking care of it nor helping the child to use it properly.

ACTIVE/SUPPORTED. This would indicate a family that takes the initiative to seek help from third parties to overcome their own lack of resources (seeks translators, transportation, someone to help with referrals if the family does not know where to go for help). It would imply an active role--if accompanying the third party to a doctor, would take an active part in furnishing information, seeking answers. It would also be a family that shows persistence, appealing if turned down for necessary help, and one that makes choices and decisions, making suggestions at an IEP interview, changing doctors if unable to get answers from one, etc. The family would make some contacts on their own, but still be in the supported category if, in most contacts, they require assistance because of illiteracy, need for a translator, etc.

INDEPENDENT/ADVOCATE. This would indicate a family that can independently locate resources they need. It would be one where the family has read up on the handicapping condition and searched out resources on their own. It would be a family that can be independent of third parties in communication, transportation, and assuming costs if they are not eligible for free services. They would understand the child's handicapping condition and be active in seeking appropriate therapy or education or medical treatment. The advocate level would indicate a family able to help others with forms, referrals, or transportation.

AGENCY:

INITIAL RATING

Negative	Passive/Supported	Active/Supported	Independent/Advocate
1 2 3 4 5	6 7 8 9 10	11 12 13 14 15	16 17 18 19 20

Reasons for rating:

FINAL RATING

Negative	Passive/Supported	Active/Supported	Independent/Advocate
1 2 3 4 5	6 7 8 9 10	11 12 13 14 15	16 17 18 19 20

Reasons for rating:

SUPPORT GROUPS--PROFILE OF FAMILY CHARACTERISTICS AT DIFFERENT LEVELS

NEGATIVE. On the Intake Interview the family at this level would not indicate participation in groups of any kind. Once in the project, the parents might offer continual excuses not to attend group activities or simply refuse to participate. They might, seeking to avoid a hassle, agree to go when they had no intention to do so--and then not be there when someone came to pick them up, or not show up, giving a fairly vague excuse later.

PASSIVE/SUPPORTED At this level, a family might be vague about any parent group participation in the past on the Intake Interview, indicating they might have gone to something but took little or no interest in it. Their participation in project sponsored support group activities would be one of willingness to go sometimes, provided all arrangements were made for someone to pick them up and bring them home. At the meeting they might show little enthusiasm and take very little part in the discussion or the activity.

ACTIVE/SUPPORTED. A family would be assigned to this level if they responded on the intake interview that they had attended parent meetings in the past, and could indicate their interest by being able to recall topics discussed, but did not indicate regular attendance or any leadership role. The family at this level would be one one that relies on the initiative of others to set up the meeting or to provide transportation, but who takes an active interest in attending and participates with enthusiasm.

INDEPENDENT/ADVOCATE. A family who reported on the Intake Interview that they had participated in groups of some kind in the past, taking a leadership role on some kind, would be assigned to this level. Parents at this level would show interest and enthusiasm for the project-initiated support group activities to the extent that they would rearrange their work schedule in order to attend, and would get there on their own if necessary. They might show their interest by offering to have meetings at their home, and be willing to help others to participate by offering transportation, inviting other parents, leading discussions, or serving as an officer if the group formally organized.

SUPPORT GROUPS:

INITIAL RATING

NEGATIVE	PASSIVE/SUPPORTED	ACTIVE/SUPPORTED	INDEPENDENT/ADVOCATE
1 2 3 4 5	6 7 8 9 10	11 12 13 14 15	16 17 18 19 20

Reasons for rating:

FINAL RATING

NEGATIVE	PASSIVE/SUPPORTED	ACTIVE/SUPPORTED	INDEPENDENT/ADVOCATE
1 2 3 4 5	6 7 8 9 10	11 12 13 14 15	16 17 118 19 20

Reasons for rating:

HOME ACTIVITIES--PROFILE OF FAMILY CHARACTERISTICS AT DIFFERENT LEVELS

NEGATIVE. Parents would be at this level if they seemed apathetic about their child's condition. If doctors, therapists, or teachers proposed some things their child needed by way of home care or stimulation, they would show lack of interest by not asking for demonstrations or asking questions. Field worker reports might indicate that they ignored these activities and might do the opposite. At this level, there might be some evidence of neglect, such as bringing a child to therapy when it is ill, or a child that is always dirty, etc. The parent would show little understanding of the child's condition. On the Intake Interview they would respond negatively to all questions about home activities.

PASSIVE/SUPPORTED. At this level would be the family that shows some interest in home activities, but appears to do them mainly when there is someone there to take an interest. There is little evidence through the child's progress that the parent has provided activities at times when they are home alone with the child. Or there might be other indications that nothing much is being done (equipment apparently unused, etc.). If the child requires physical therapy that is painful or if the child needs a special diet, the parent easily gives up if the child makes a fuss about it. In the Intake Interview a family at this level might be vague about home activities, indicating some idea of appropriate activities but lack of interest.

ACTIVE/SUPPORTED. This level would refer to families that are active in helping the child, with different members of the family reported as helping. The child's progress (as reported by teachers or therapists, or as seen by field workers on home visits) would indicate that family members are working with the child on some regular schedule. The family, at this level, would rely on others to offer suggestions of appropriate home activities, but would ask questions of therapists or teachers, seek to observe them with the child, and otherwise show active interest in learning as much as they can about how to help in the child's development. On the Intake Interview, the parent would be able to describe things the family has been doing to help the child at home.

INDEPENDENT/ADVOCATE. This would characterize a family that, on their own, has read up on the child's handicap and has a good understanding of it. They have shown independent initiative in some way--seeking out some teacher or agency that could provide them with recommended home activities, writing for materials or making equipment. The advocate level would indicate that the parent discusses the importance of home activities in conversations with other parents and serves as a model for them in terms of demonstrating and making suggestions to them. On the Intake Interview, the parent would respond to questions about home activities in a way that shows they have used initiative in learning what would help in their child's development.

HOME ACTIVITIES

INITIAL RATING

NEGATIVE	PASSIVE/SUPPORTED	ACTIVE/SUPPORTED	INDEPENDENT/ADVOCATE
1 2 3 4 5	6 7 8 9 10	11 12 13 14 15	16 17 18 19 20

Reasons for rating:

HOME ACTIVITIES

FINAL RATING

NEGATIVE	PASSIVE/SUPPORTED	ACTIVE/SUPPORTED	INDEPENDENT/ADVOCATE
1 2 3 4 5	6 7 8 9 10	11 12 13 14 15	16 17 18 19 20

Reasons for rating:

COMPOSITE RATING

INITIAL______ FINAL_____ (Total of three scores; total possible 60)

Note: The final FPS rating used for statistical analysis in this report was arrived at by reconciling the independent ratings from three sources: (1) the primary investigator; (2) the field research coordinator at each site; and (3) a rating of the family derived from coding the responses from the Provider's Questionnaire (the third party interview with someone from another agency also working with the project family.)