NEIGHBORHOOD ANALYSIS OF EARLY INTERVENTION SUPPORTS AND SERVICES: DATA FROM A GRASSROOTS PERSPECTIVE

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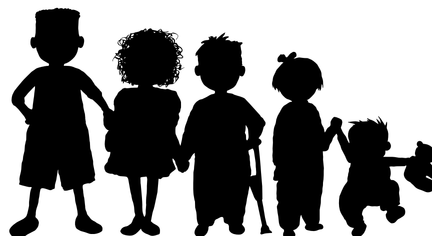

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I. INTRODUCTION

Background

There is a need to enhance the capacity of communities to provide high-quality early intervention services. Fiscal support and leadership is needed for the design of innovative models of service delivery that are driven by *state of the art* thinking about child/family development and support, family empowerment, professionalism, and intervention.

It has been twelve years since the Infants and Toddlers Program of the Individuals with Disabilities Education Act (IDEA) was enacted. The successful accomplishment of the intent of the legislation depends on how well the policies and practices emanating from it are implemented and monitored. There have been national studies such as the Carolina Policy Studies that looked at state-level organizational structures and elements of the state policy environment. Equally important but much less aggressively pursued are the kinds of studies directed at the grassroots *practice* level where much work needs to be done to ensure that structures and regulations dictated by legislation and policy do not become an end in themselves but rather a means to the ultimate end of providing truly comprehensive and high-quality supports and services to children and families. There is a need for national as well as localized investigations presenting exemplary approaches to program surveillance, quality appraisal, and efficacy assessment. Are we including children with special needs as a priority in our overall planning for childcare? Has the community explored the feasibility of a transdisciplinary model for serving the very young child with special needs as the intent of the IDEA legislation suggests? Have funders come together to address the diverse needs of families to ensure that adequate supports are in place that promote family cohesion and empowerment?

Currently there is a concern that the building of administrative structures and the monitoring of regulations are taking undue precedence over the development and delivery of innovative services that reflect current thinking about young children and families. There is the concern that services are too fragmented and poorly conceptualized. This neighborhood analysis study was undertaken in the recognition that the entire service delivery system might need to be reconceptualized and redesigned.

Rationale and Conceptualization

At the heart of the analysis is a recognition of the ecological framework. An ecological model recognizes that development is a product of person-level inner biological workings and also external social and environmental forces. Bronfenbrenner (1979) notes the varying levels of the ecology of human development and also the interactions among the various levels (microsystems, mesosystems, and exosystems) that influence the development of the child. In the ecological context, the central theme is that the social networks/supports and the persons and events that are embedded in them influence each other to impact development.

Consistent with family ecological models is the philosophy of family-centered, family-focused, and family-empowered care, which is the *professed* philosophy of most early intervention programs today. However, despite this stated philosophy, there is a significant fixation to traditional conceptions of early intervention services. For example, many still continue to think of intervention only as *parent coaching, child therapy,* and *skill teaching.* Early interventionists across all disciplines must demonstrate the courage to break away from this traditional mindset.

It must be cautioned, however, that the solution does not lie in repudiating traditional therapies. In reality, many children with special needs do need and benefit from some form of therapy. The solution lies in conceptualizing intervention models with enough breadth and flexibility to encourage the development of intervention approaches which truly enhance the capacity of families to meet the developmental needs of their children.

Reconceptualization

The developmental context of infants and toddlers differs from that of children in the 3- to 5- or the 5- to 8-year range in one significant regard. Whereas most preschool and early school-age children spend a great deal of time in formalized childcare settings and receive varying amounts of didactic instruction within structured curricula contexts, the typical developmental environment for children in the birth to 3-year age range encompasses significantly more home- or family-based interactions. Even when very young children spend part of their day in formalized childcare settings, they are exposed to less structured activities. Early intervention services must revolve around the family and emphasize strategies and options that regard the family and the family context as the central driving force behind the development and care of the child with special needs (Marfo, 1996; 1999). However, actual practice lags behind the ideal. Professional knowledge and expertise must be harnessed and applied in ways that provide the support and resources families need to guide their children's development and well being.

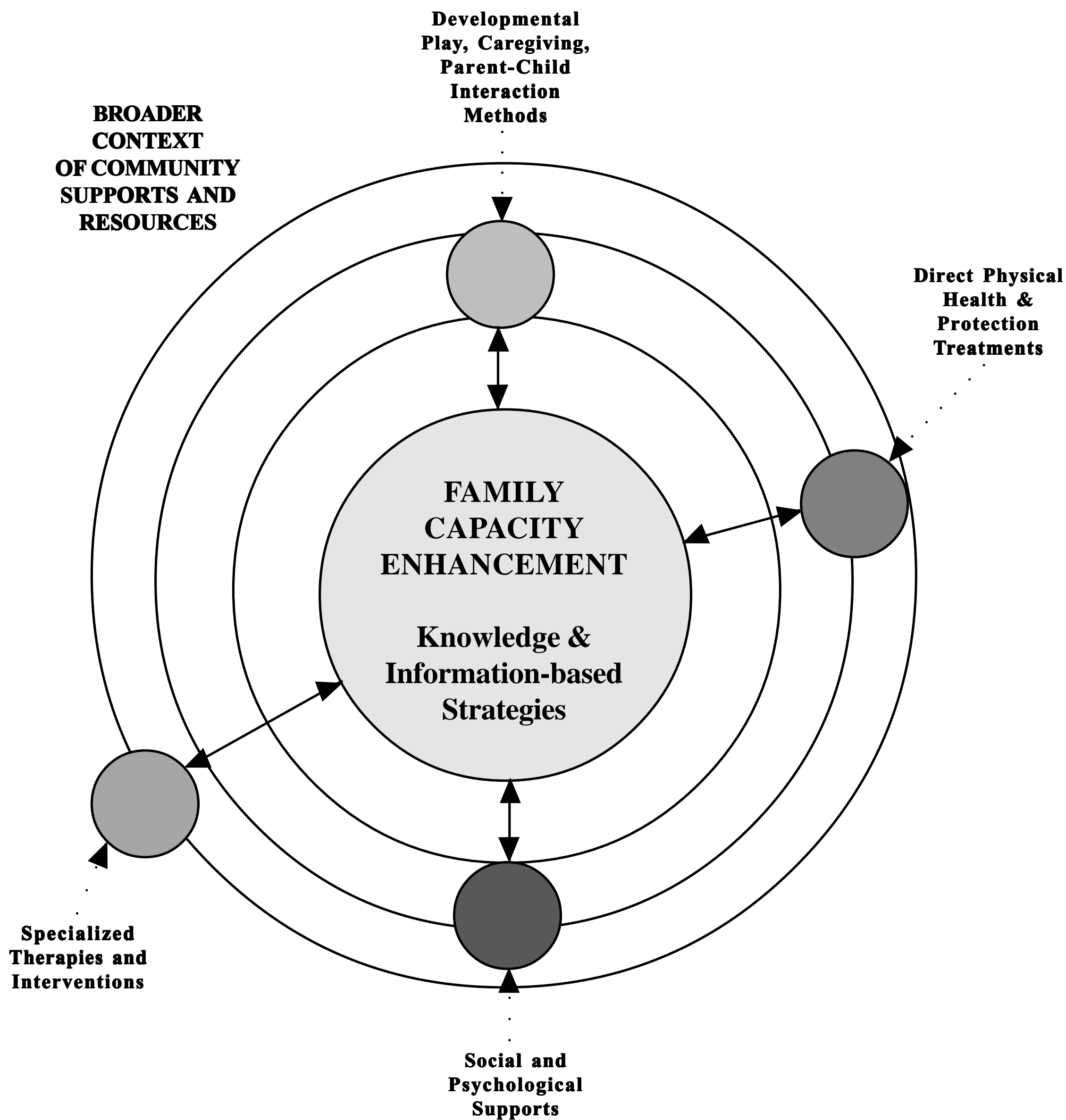
Boothby, Grosz, Marfo, & Graven (1996) developed a model of early intervention that embodies the theme of building family capacity through choice and variety of intervention options. In the updated version of the model, families may access information support services, physical health services, psycho-social support services, care-giving mediation and play interaction services, and specialized therapeutic interventions at different times depending on their needs and resources (Illustration A).

Problem Validation

What we often find lacking in our current delivery system is the noticeable lack of supports which information, physical health, psychosocial, care-giving mediation, and play interaction services could provide. This issue is readily apparent in the current allocation of dollars for early intervention services as documented in the statewide Early Intervention Program database. A relatively small number of children consume a major portion of the resources from the Part C (Infant and Toddler Program) dollars and Medicaid allocation while relatively large numbers of children receive minimal services and very little early intervention support services. The graph on the services provided during the last three fiscal years in the State of Florida for children enrolled in the Early Intervention Program (Behal, 1999, Figure 1) illustrates this problem. The line graph documents the dollars from Part C and Medicaid that were spent on the various early intervention services. Traditional therapies and developmental day programs were the largest expense items all three years. There was an increase in the cost of "other early intervention" services during 1996–1997 but this dropped again in 1997–1998. The number of children receiving the various services, while fluctuating slightly from year to year, did not change significantly except for those receiving care coordination services, a change of over three thousand children in the three year period. The greatest number of children across all categories received care coordination services at a relatively small cost when viewed in comparison to the cost of direct services.

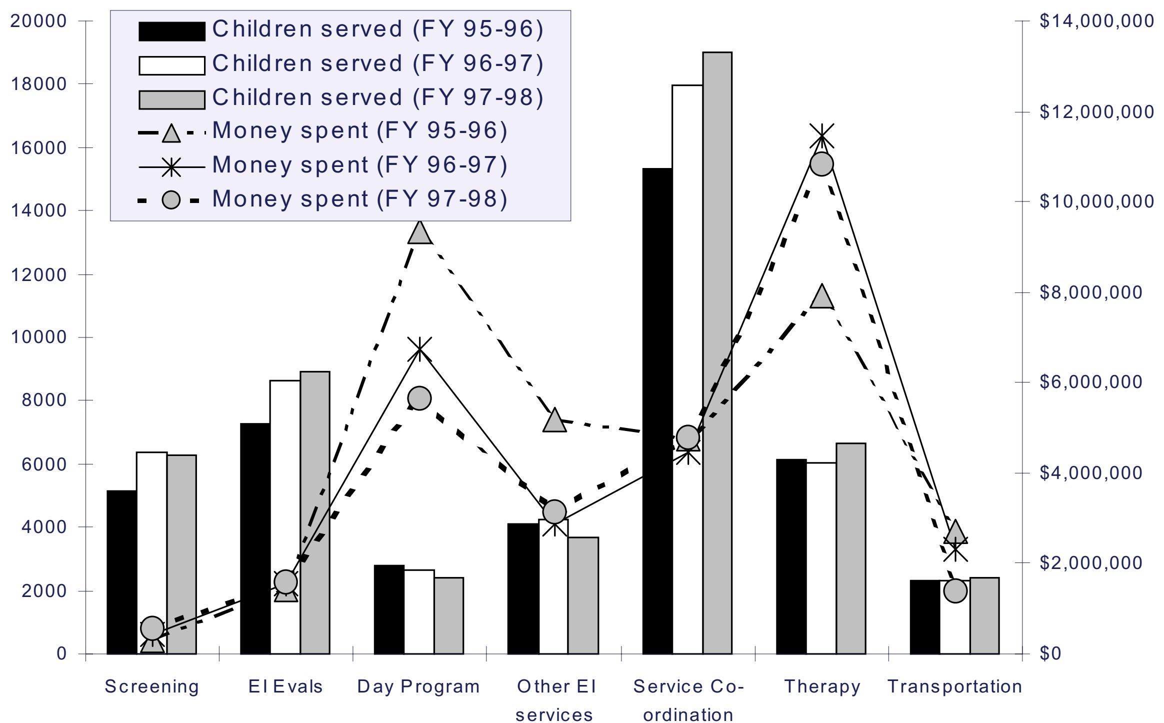
Illustration A

The Early Intervention Process as Enhancement of Family Capacity: A "Constellation" of Service Delivery Options.



The Early Intervention Program at the University of South Florida, in partnership with the Hillsborough County Part C Community Development Committee, has begun to shift service delivery patterns for young children with special needs to include more home and naturalistic childcare environments. Initiatives such as the Family Peer Support Council and the Bridges to Worship Initiative sprang up in recognition of the need for families to have emotional and care-giving support in the neighborhoods where they live. However, it is still the trend for families to be referred to child-focused interventions without regard to family need and for services more often to be provided outside of their neighborhoods.

Figure 1: **Annual Trends for Dollars Spent on Selected Services vs. Number of Part C Eligible Children Served**



Source: Behal, R. (1999)

Dimensions of the Problem, A Grassroots Perspective

In an attempt to break away from the traditional early intervention models toward a system that recognizes the ecological context of development and the need to build neighborhood supports for families where they live and work, the following analysis was initiated with funding provided by Children's Board of Hillsborough County, the local children's service council. The analysis was piloted to see how well the current early intervention service delivery model meets the needs of the children and families currently enrolled in the Early Intervention Program. Two high-risk target zip code areas within the city limits of Tampa in Hillsborough County, where it is already known that services are sparse when measured in the traditional sense, were chosen from the five-county area served by the Early Intervention Program. Secondly, we also wanted to measure the capacity of resources that might be organized in the neighborhoods where the families reside, to see if it is realistic to expect communities to implement new models of service delivery.

The targeted area covers a large geographic area and is comprised of a variety of income neighborhoods, from the very low, such as the area bordering the University of South Florida—an area known for its highly transient population—through the middle income area of Forest Hills, to the mid-to-upper income area of "old" Carrollwood. The area is rich in community resources such as the University of South Florida, 113 churches of numerous denominations, and large and small businesses of every type, including the University Square Mall. It is noted that these zip codes represent those identified by the county's Healthy Start Coalition as

target zip code areas because of the number of high-risk women and infants residing in the area. Data provided by the Healthy Start Coalition gives a snapshot picture of mothers and babies in the area at the time of the study (see Table 1).

Table 1: **Data from Healthy Start Coalition**

% represents percent of total births in the county

Characteristics	Zip code area #1[1]	Zip code area #2[2]
1. Total number of births	– 659	– 470
2. Births to white mothers	– 401 (60.8%)	– 318 (67.7%)
3. Births to non-white mothers	– 258 (39.2%)	– 152 (32.3%)
4. Births to Hispanic mothers	– 106 (16.1%)	– 86 (18.3%)
5. Births to mothers less than 18 years old	– 47 (7.1%)	– 25 (5.3%)
6. Received first trimester prenatal care	– 80%	– 80%
7. Received no prenatal care	– 13 (2%)	– 7 (1.5)
8. Reported tobacco use during pregnancy	– 114 (17.3%)	– 74 (15.7%)
9. Low birth weight infants	– 65 (9.9%)	– 52 (11.1%)
10. Infant deaths (total, white, non-white)	– 7, 1, 6	– 8, 4, 4
11. Reports of child abuse/neglect	– 612	– 385

[1]33612 [2]33613

In zip code area #1, 342 (51.9%) of the mothers were unmarried. In zip code area #2, 246 (47.7%) of the mothers were unmarried. This exceeds the percentage for the county, which is 4878 (36.2%), of all births to unmarried mothers. At the time of the study, there were 113 families in the two zip codes who were enrolled in or were recently discharged from the Early Intervention Program. When the analysis was proposed, there were only 13 in zip code #1 and 9 in zip code #2 who were recorded in the state database as accessing services paid by Infant and Toddler Program dollars and we questioned if this was an accurate number of children and families receiving services. In actuality this was not the case at all. We found that formal services in addition to developmental evaluations and service coordination were received by 67 (approximately 66%) of the children, but were paid with dollars other than those provided by Part C, primarily by Medicaid, and, to a lesser extent, by other payer sources such as insurance and school district FTE (full time equivalency) dollars for children with visual or hearing impairments. Payer source was documented by review of the charts including the Family Support Plans of the children in the two zip codes. However, we did find that the interventions provided did not meet the comprehensive needs of families who have young children with disabilities or developmental delays as will be described in the results section.

Partners in the Analysis

Since the analysis was focused on community partnerships to solve issues, several community partners were approached to participate in the process. Partners in the analysis

process included Luther Village, a church preschool in one of the target areas that agreed to act as fiscal agent for the project. Partners also included representatives from several colleges at the University of South Florida: the College of Medicine (Department of Pediatrics, Division of Child Development and Neurology), the College of Public Health, the College of Education (Department of Special Education), the College of Arts and Sciences (Department of Communication Sciences and Disorders, and Department of Psychology), and the College of Nursing. Community partners participating on the advisory group for the project include representatives from the Family Network on Disabilities, Parent to Parent, Gentle Transitions Early Intervention Home Visiting Provider, Bridges to Worship (formerly Faith in Action), the Children's Board of Hillsborough County, Children's Medical Services, County Social Services, Department of Children and Families, the USF Early Intervention Program, the Part C Community Development Committee, four developmental preschools, the Early Childhood Council of Hillsborough County, and the Hillsborough County School district.

II. METHODOLOGY

Methods for the Analysis

The analysis was two-pronged:

1. Families: There were attempts to contact each family enrolled in or recently discharged from the Early Intervention Program for possible enrollment in the analysis. Each family who consented to participate received a home visit for the purpose of documenting a measurement of the home environment and the resources available within the family unit, as well as the needs identified by the family. These were measured using four instruments and an open ended interview. The instruments used were the *Home Observation of the Measurement of the Environment (H.O.M.E.)*, the *Family Needs Survey*, the *Family Support Scale*, and the *Family Empowerment Scale*. There were 113 potential families in the two zip codes who were eligible for inclusion in the study. The project located 104 of the children served in these two zip codes. Child-specific information such as age and diagnosis of disability were collected as well as family ecology factors for 98 families representing 104 children.

2. Community Survey: Survey instruments were developed for interviews with representatives from churches, schools, select businesses, and civic organizations. The survey protocols were refined from originals provided by Dr. Carnot Nelson from USF Department of Psychology. The purpose of the community survey was to determine which groups might be utilized as resources to develop initiatives documented by the analysis.

Graduate assistants from the Department of Communication Sciences and Disorders (College of Arts and Sciences) and from the Department of Community and Family Health (College of Public Health) at the University of South Florida collected the data. They interviewed the families, completed chart reviews, reviewed the data from the early intervention database, and collected the community surveys under the supervision of the researcher. A Family Resource Specialist from the Early Intervention Program also assisted the researcher.

Instruments

The *Home Observation Measurement of the Environment* (H.O.M.E., Caldwell, 1978; Caldwell & Bradley, 1984) is the most widely used measure of the home environment. Observers must achieve high inter-rater reliability to administer the protocol, and graduate assistants were .95 reliable. The H.O.M.E. version used in this study is a 45-item yes/no observational protocol that is divided into six sub-scales. Low total scores or low scores on individual sections indicate intervention needs. The sub-scales are: 1) emotional and verbal responsivity of the caregiver; 2) avoidance of restriction or punishment; 3) organization of the environment; 4) provision of appropriate play material; 5) maternal involvement with the child; and 6) opportunities for variety in daily stimulation.

The *Family Empowerment Scale* (FES, Koren, DeChillo, & Friesen, 1992**)** consists of 33 items, each of which is rated on a five-point Likert scale. Items on the FES reflect the families' attitudes, knowledge, and behaviors indicative of level of perceived empowerment. In addition to the total scale score, there are three subscale scores corresponding to empowerment at the level of family, service delivery, and community/ political action.

The *Family Needs Survey* (FNS, Bailey & Simeonsson, 1988; revised, 1990) provides a rating of families' expressed needs in the following areas: 1) information; 2) family and social support; 3) financial; 4) explaining to others; 5) childcare; 6) professional help; and 7)

community services. Families choose from the three response items: “I definitely do not need help”, “Not sure”, or “I definitely need help”.

The *Family Support Scale* (Dunst, Trivette, & Jenkins, 1988) is a two-part scale. The first part lists 18 sources of support and has two additional blanks that families can fill in to indicate additional sources of support. The families rate the sources that have been helpful to the family. The second section provides a comparable list of sources and asks that the families rate the sources upon which the family can depend. For the analysis, we recoded the sources as informal or formal sources of support. Examples of informal supports were parents, extended kin, spouse, friends. Examples of formal supports were child’s or family’s physician, social workers, therapists, public health agencies, schools or daycare facilities.

Research Questions

There were specific questions that the analysis addressed:

Family:

1. What is the relationship between the quality of the home environment and a family’s feeling of empowerment?
2. Do the type of disability and the number or type of interventions have a relationship with a family’s feeling of empowerment?
3. What do families consider to be their areas of greatest need? ***This question has social policy implications as it looks at what families consider their greatest areas of need.
4. What are the sources of formal and informal support and which do families access?
5. Do families rate formal and. informal supports as differentially helpful?

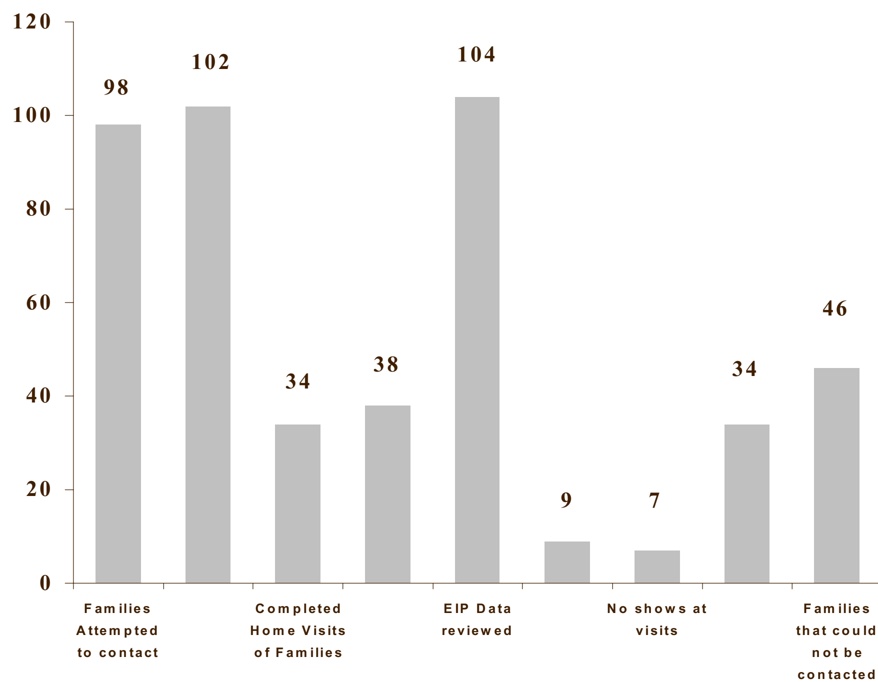
Community

1. What supports are churches, businesses, schools, and clubs currently providing?
2. What supports are they willing to provide in the future for families who have children with special needs?

Sample

Family surveys: The project attempted contact with 98 families representing 104 children regarding participation in the study. Chart records and database information were reviewed for all 104 children. Of the 98 families, thirty-six (36) families representing 40 children agreed to home visits and were enrolled in the study. Graduate assistants interviewed 34 families (representing 38 children) during the home visits. Two other home visits did not result in interviews as one child had died and the other family indicated that they were in the middle of a move overseas. Nine families declined to enroll when contacted. Seven additional families indicated interest but were not home or could not be reached again to complete the interviews. Two children were in Children & Families’ special placements and their families were not interviewed. Two families had moved out of state and could not be reached. There were multiple attempts to contact 42 other families via phone or during clinic visits. Over 80% had phones that were disconnected or were the wrong number. At least three attempts were made to contact each family. The fact that many of the families moved is not surprising given the demographics of some of the areas in the zip codes. For example, in the University Community Area, 81–91% of the residents live in rental housing (Marsh, Garcia, Campbell, Landry, Tvedt, 1997). See Figure 2 for a breakdown of family surveys completed.

Figure 2: **Overview**



III. RESULTS

Demographic Information

Figures 3 A–E provide the breakdown by Medicaid eligibility, marital status, maternal race and education, and income for the 98 families, representing104 children whose records and database information were available for review. Figures 4 A–E provide a similar breakdown for the 34 families interviewed.

Results of Quantitative Analysis

Family data were subjected to descriptive analysis procedures including frequencies, means, standard deviations, and ranges. A cross-tabulation procedure was also used to compare individual subject responses across the variables. A paired difference t-test was computed for the *Family Support Scale* to determine if the families' utilization of informal and formal supports differed significantly. Paired difference t-tests were also computed to compare each individual sub-scale of the *Family Needs Survey* to each other and also to demographic variables. Correlational analyses were used to identify relationships among key variables. Tables 2 and 3 present a summary of significant correlations from the analyses.

1. What is the relationship between quality of the home environment and a family's feeling of empowerment?

The total scores for 34 family participants representing 38 children who have been interviewed on the *Home Observation Measurement of the Environment* (H.O.M.E.) are summarized in Figure 5. The relatively low scores for two-thirds of the group seemed to indicate that more or a different type of intervention services to support a family's capacity to care for its children might be needed.

When planning intervention strategies we recommend that the following relevant findings from a correlational analysis of home environment (H.O.M.E. total and individual sub-scales), family empowerment (FES total and sub-scales), and demographic variables be considered. Following are relevant findings:

- Families that feel empowered to care for their children provided a more organized home environment.
- The less organized the home environment and the less a family felt empowered, the greater the reported need for information concerning the disability and services.
- The more organized the home environment, the greater the family's perceived competence and responsibility and control in meeting the developmental needs and challenges related to the target child.
- Families who provided appropriate play materials for their children indicated that they felt more empowered to advocate at the community level regarding the provision of services for children.
- Families who provided appropriate play materials documented less need for financial support or assistance in meeting childcare needs.
- Families who scored higher on the H.O.M.E. documented less overall needs.
- Families who indicated that they felt empowered to care for their children documented less overall needs including financial needs.

Figure 3A: **Medicaid Eligibility** (n=98)

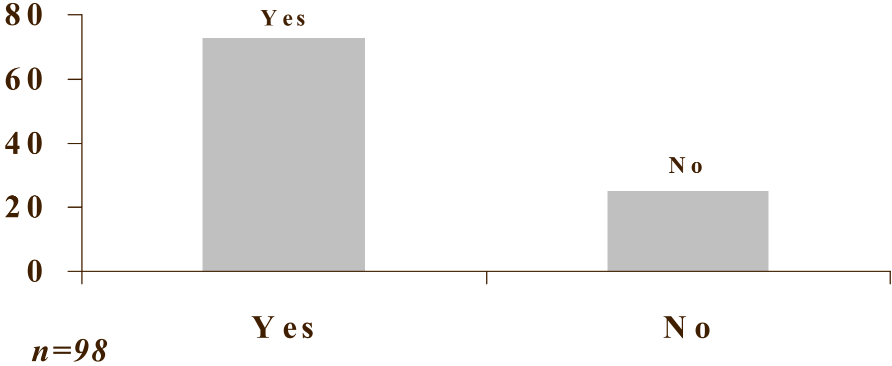


Figure 4 A: **Medicaid Eligibility** (n=34)

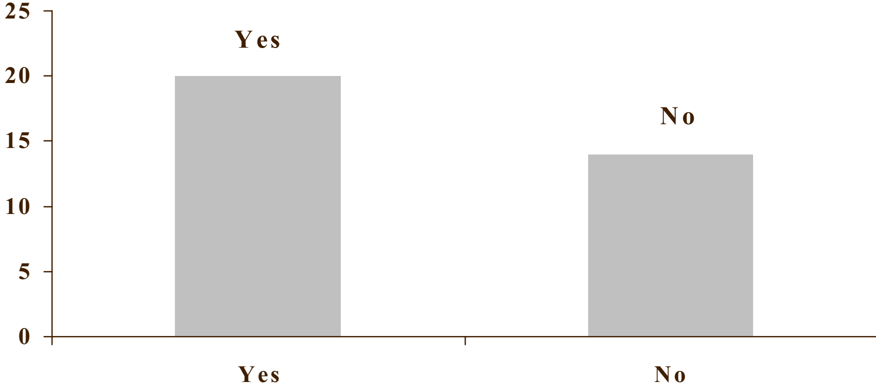


Figure 3B: **Mother's Marital Status** (n=98)

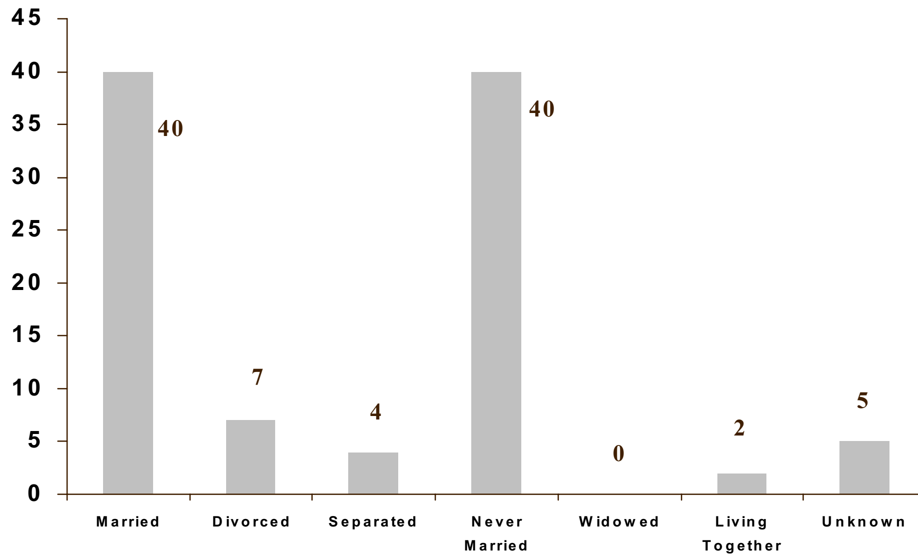


Figure 4 B: **Mother's Marital Status** (n=34)

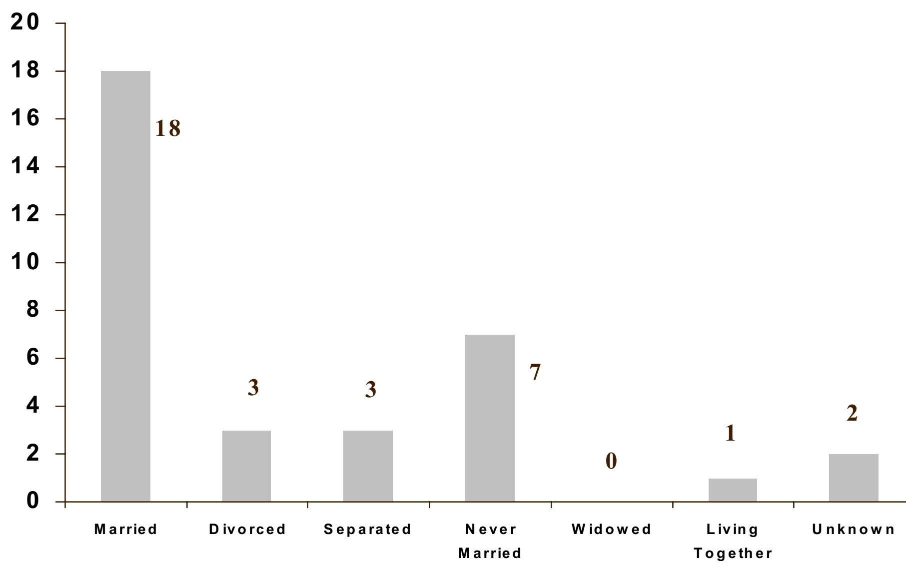


Figure 3 C: **Mother's Race** (n=98)

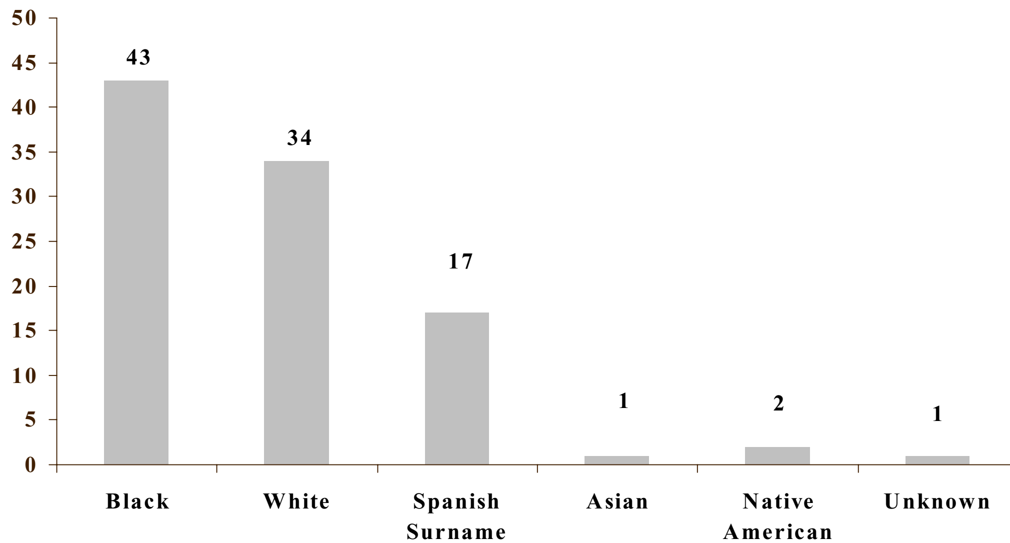


Figure 4 C: **Mother's Race** (n=34)

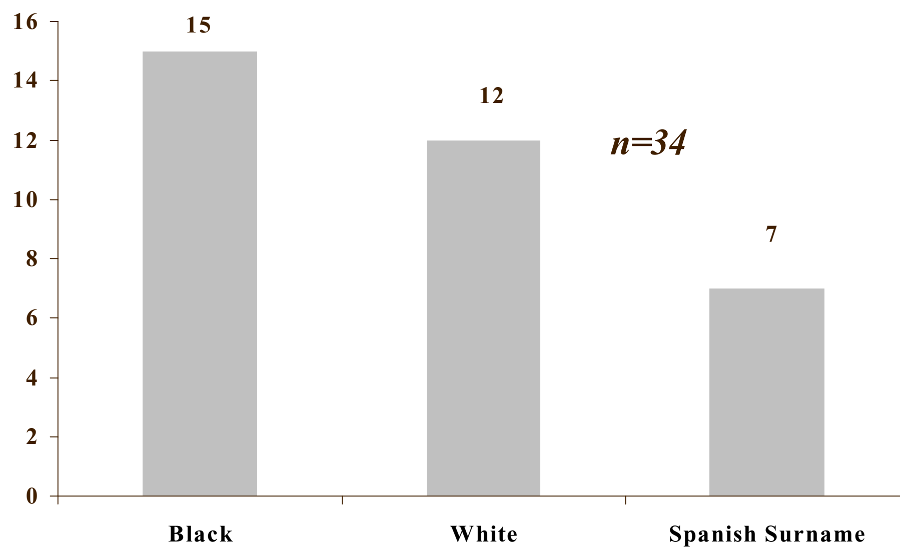


Figure 3 D: **Annual Household Income** (n=98)

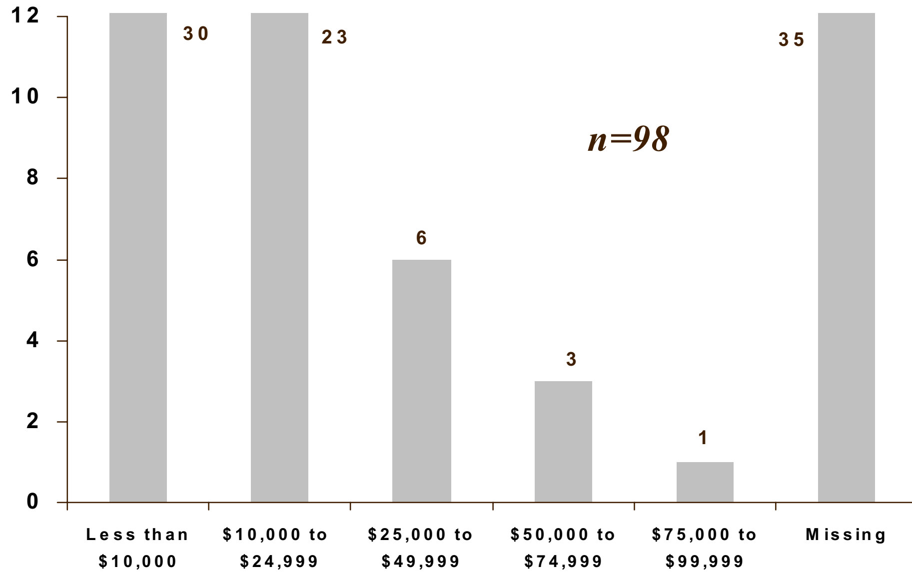


Figure 4 D: **Annual Household Income** (n=34)

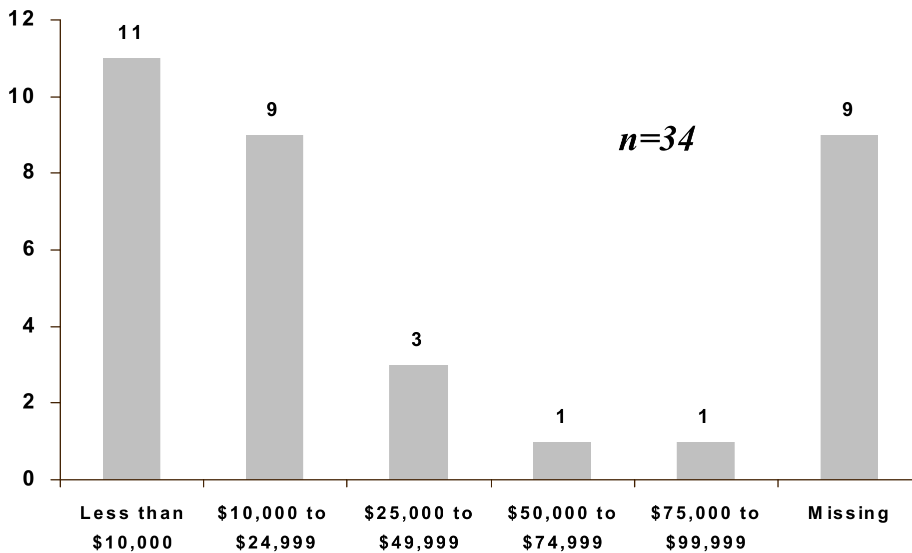


Figure 3 E: **Maternal Education** (n=98)

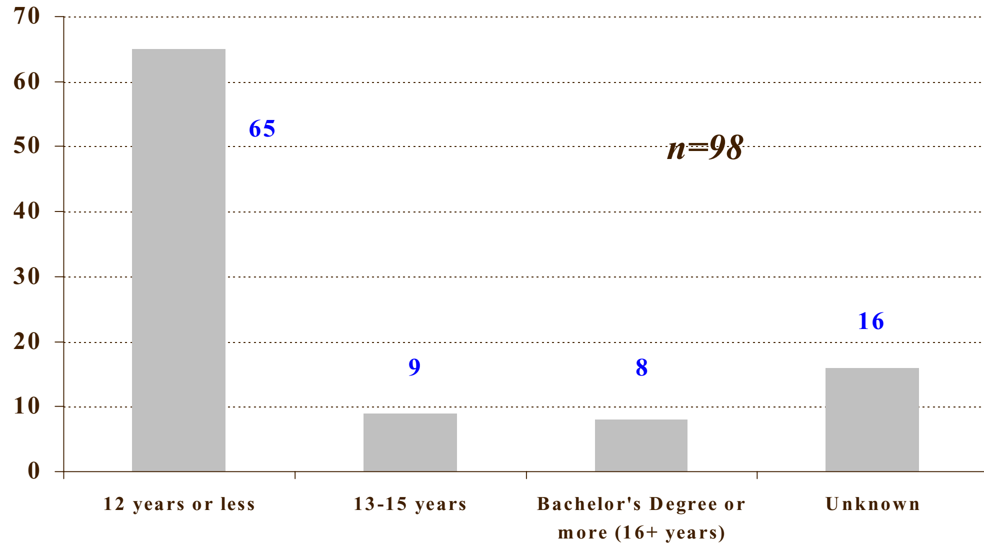


Figure 4 E: **Maternal Education** (n=34)

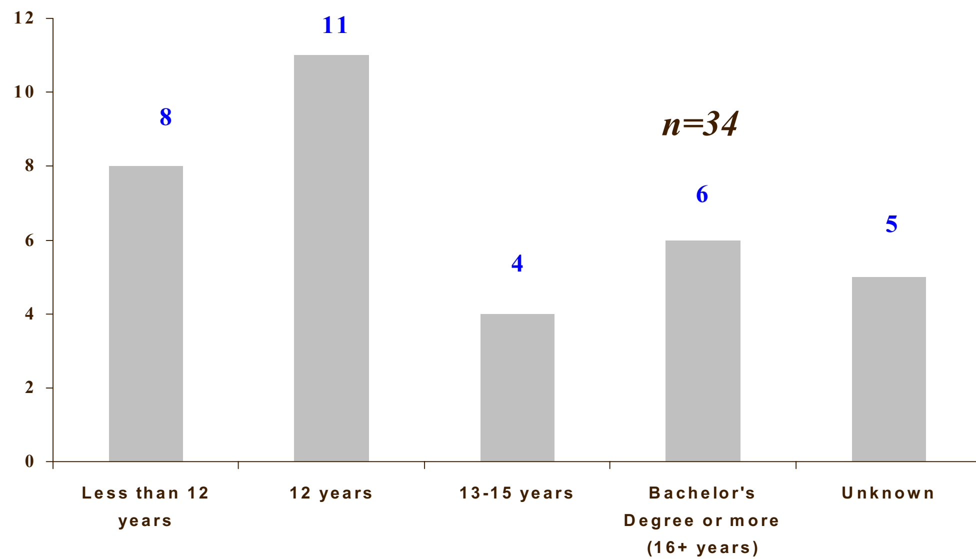


Table 2. Significant correlations with HOME.

VARIABLES	HOME Subscales						HOME Total
	H1	H2	H3	H4	H5	H6	
HOME Subscale: H1	—	0.44*		0.41	0.55***	0.38	0.83***
HOME Subscale: H2		—		0.42	0.35		0.66***
HOME Subscale: H3			—				
HOME Subscale: H4				—		0.42	0.75***
HOME Subscale: H5					—		0.71***
HOME Subscale: H6						—	0.51**
HOME Total score							—
FES: Family Level Subscale			0.44*				
FNS: Total score					-0.37		-0.34
FNS: Need for Information			-0.45*				
FNS: Need for Family & Social Support					-0.40		
FNS: Need for Financial Support				-0.38			-0.34
FNS: Need for Care				-0.40			
FSS-1: Total Score							
FSS-1: Informal Supports					0.43	0.35	
FSS-1: Formal Supports		-0.40					
FSS-2: Total Score							
FSS-2: Informal Supports					0.42		
FSS-2: Formal Supports		-0.36					
Mother's Marital Status	0.49**	0.36		0.63***	0.38	0.49**	0.69***
Mother's Education		0.53**		0.46	0.44		0.52**

NOTE: All Pearson correlation values shown are at least significant at p<.05
*denotes .01>p>=.005 **denotes .005>p>=.001 ***denotes p<.001

Table 3. Significant correlations with other scales (total scores and subscales).

VARIABLE		Family Needs Scale (FNS)					Family Empowerment Scale (FES)			
		info	**fs**	**fina**	**care**	**total**	**fam**	**ssrv**	**cp**	**total**
F N S	**Information (info)**	—	0.53**	0.51**	0.34	0.80***	-0.53**	-0.42	-0.51**	-0.55***
	Family & Social Support (fs)		—	0.43		0.75***				
	Financial Support (fina)			—	0.57***	0.76***	-0.36		-0.38	-0.39
	Care (care)				—	0.58***				
	Total score					—	-0.38		-0.43	-0.42
F E S	**Family level (fam)**						—	0.87***	0.55***	0.91***
	Service System level (ssrv)							—	0.58***	0.93***
	Community/Political level (cp)								—	0.80***
	Total score									—
F SS - 1	**Informal supports (fssinf)**									
	Formal supports (fssfor)									
	Total score									
F SS - 2	**Informal supports (ffsinf)**									
	Formal supports (ffsfor)									
	Total score									
Mother's Marital Status							-0.64			
Mother's Education										

NOTE: All Pearson correlations values shown are at least significant at p<.05

*denotes .01>p>=.005 **denotes .005>p>=.001 ***denotes p<.001

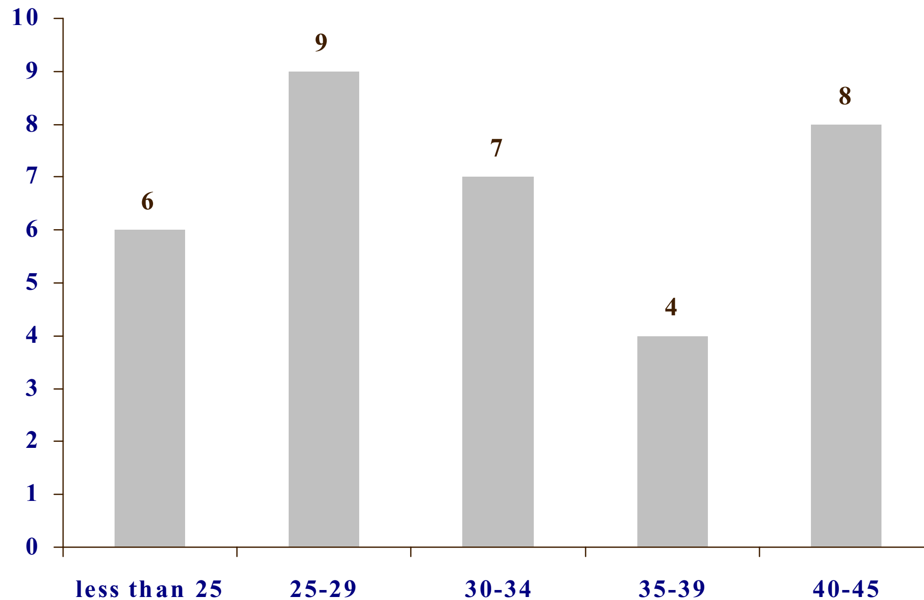
(continued),

Table 3 continued.

	VARIABLE	Family Support Scale - 1 (FSS-1)			Family Support Scale – 2 (FSS-2)		
		fssinf	fssfor	total	ffsinf	ffsfor	total
F N S	Information (info)				-0.36		
	Family & Social Support (fs)	-0.36					
	Financial Support (fina)				-0.44*		-0.39
	Care (care)						
	Total score				-0.47**		
F E S	Family level (fam)				0.38		0.39
	Service System level (ssrv)						
	Community/Political level (cp)				0.34	0.44*	0.47
	Total score				0.36	0.38	0.44*
F S S - 1	Informal supports (fssinf)	—		0.88***	0.65***		0.56***
	Formal supports (fssfor)		—	0.61***		0.70***	0.47***
	Total score			—	0.53**	0.57**	0.66***
F S S - 2	Informal supports (ffsinf)				—	0.36	0.79***
	Formal supports (ffsfor)					—	0.86***
	Total score						—
	Mother's Marital Status						
	Mother's Education						

NOTE: All Pearson correlations values shown are at least significant at p<.05
*denotes .01>p>=.005 **denotes .005>p>=.001 ***denotes p<.001

Figure 5: **H.O.M.E. Scores**



Note: Generally scores less than 30 indicate a need for intervention

- In families where a spouse was present, the analysis revealed: a) increased emotional and verbal responsivity of the caregiver; b) greater avoidance of restriction and punishment; c) greater provision of appropriate play materials; d) increased maternal involvement with the child; and e) greater provision of opportunities for variety in daily stimulation.
- Higher levels of maternal education correlated positively with a) avoidance of punishment; b) greater provision of appropriate play materials; and c) increased maternal involvement.
- Homes with two parents/caregivers and in which maternal education was higher had higher H.O.M.E. scores regardless of race.
- Mothers with higher educational levels who did not have a spouse tended to provide less organized environments.
- There was no correlation between higher education or marital status and a family's feeling of empowerment.

2. To what extent is empowerment related to severity of disability and the number or type of interventions?

To determine if the severity of a developmental condition correlated with the amount of intervention received, we computed an intervention index by coding the severity of the child's condition by the amount of intervention received. This severity index was also correlated with family empowerment.

- There was a significant correlation between severity of child condition and the number and types of interventions received. Children with more severe conditions received a larger number of interventions.
- It is noted that children with the most severe disabilities were usually in developmental day

programs such as Easter Seals, United Cerebral Palsy, Tampa United Methodist Center, and St. Peter Claver. These centers are not in the zip code areas of the families' residence.
- Severity of a child's condition did not correlate with a family's feeling of empowerment.

3. What do families consider to be their areas of greatest need? ***This question has social policy implications as it looks at what families consider their greatest areas of need.

4. What are the sources of formal and informal support and which do families access?

To answer the questions relating to need and supports, we correlated the total and sub-scale scores of the H.O.M.E., FES, the *Family Needs Survey* (FNS), the *Family Support Scale* (FSS), and demographics and also looked at the descriptive statistics of frequencies, means, and standard deviations.

- The need most often expressed by families was the need for information.
- When the variables of the FNS were correlated, the need for information correlated significantly with all other needs that families expressed. This suggests that families need information to provide care for their children with special needs and to also avail themselves of the other types of support that may be available.
- Families who indicated that their information needs were met felt more empowered to care for their children, seek services for their children, and also advocate for services.
- Families who felt empowered indicated less need for information, less need for financial assistance, and less need for support overall.
- Families who scored higher on maternal involvement with their children indicated less overall need for support including less need for family and social support.
- Families who scored higher on maternal involvement with their children also had more informal supports in place and indicated that they were reliant on them.
- Families who scored higher on the H.O.M.E. indicated less overall need for support.
- Families who scored higher on feelings of empowerment actually had greater support networks in place.
- Families overall were dependent on both types of support but more so on informal. However what they received most often was support from formal sources.
- Families with high needs don't tend to rely on informal supports as much as other families because they probably are not there.
- Families with the most financial resources also had the greatest amount of informal support. By the same token, families with less financial resources also received less support from informal and also from formal sources.
- Higher income did not correlate with less dependence on supports.
- In general there was an indication overall of insufficient sources and actual support for most families in the area.

5. Do families rate formal and informal supports as differentially helpful?

For a more complete picture on the types of support that families find most helpful, the sections of the *Family Support Scale* were analyzed. Items were recoded as informal (e.g., family, friends, neighbors) and formal sources of support (e.g., agency).
The top nine sources of support that families cited by order of reliance were:

1. Early Intervention Program
2. professional helpers such as social workers, teachers, and therapists
3. their spouse
4. their family or child's physician
5. their own parents
6. their extended kin
7. social services agencies such as public health
8. friends
9. school and daycare.

It is noted that spouse's parents were number 13 on a list of eighteen.

Even though findings suggest that families feel that their informal supports are the most helpful to them, what they are generally most dependent on are the formal supports. A look at the data from the completed *Family Needs Surveys* documents families' expressed desires for the availability of more natural supports. As an example, Figures 6 A–C look specifically at the item addressing childcare needs. Of the families interviewed, 16 indicated a need for babysitters or respite care, 12 expressed a need for day care or preschool, and 4 needed care during religious services.

Figure 6 A: **Need for Babysitters / Respite Care**

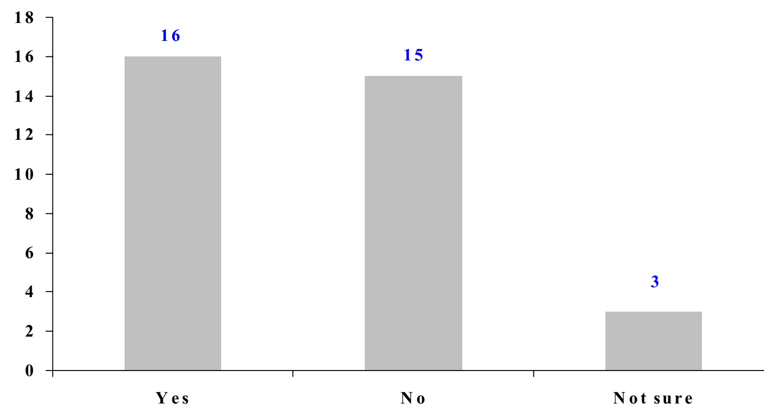
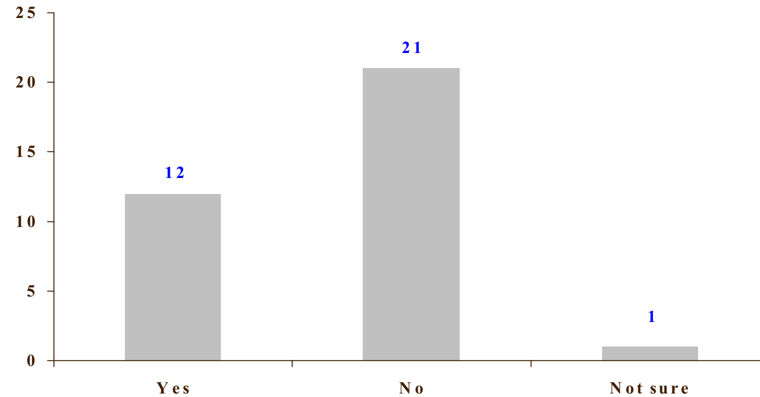
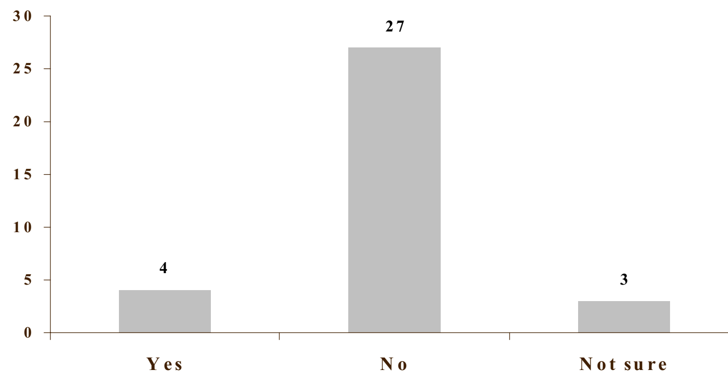


Figure 6 B: **Need for Day Care / Preschool**





The lack of adequate childcare is an issue for many families but becomes a greater concern for families who have children with special needs. Barriers to inclusion include restrictive admittance requirements, lack of staff to meet ratio requirements, lack of trained personnel, fear by childcare agencies of not meeting the child's needs, and the need to coordinate therapies and early intervention (Markos-Capps & Godfrey, 1999. Kelly & Booth, 1999).

Qualitative Data

Community data were qualitative in nature and were analyzed for trends. To lend more meaning to the quantitative data, a log was maintained of participant responses to six open-ended interview questions pertaining to issues faced by the families, supports upon which families relied, services the children and families received, and linkages. The responses were reviewed by the researchers and the following trends are noted:

1. There was an overwhelming indication that ***families need more or different types of supports or services*** in addition to or in place of what was received. Twenty-four respondents expressed needs that were not met. Some families live in isolation with few supports provided from the community where they reside.
   Expressed concerns included: a) fear that their children would not be accepted; b) concerns for safety in their neighborhoods; c) lack or loss of funding; and d) few or inadequate linkages both within and outside of the community of residence. There were several who related the lack of close family or neighbors. It is noted however that even though more or different services are needed by most of the families interviewed, at least a third of the families indicated satisfaction with what had been provided. Only three responses indicated that additional supports or services were not needed.
2. The primary special issues faced by the families were developmental concerns, medical concerns, and time and scheduling problems related to receiving services. Other issues noted included lack of information, transportation difficulties and access issues, childcare, respite, funding related to insurance, and anxieties regarding transition and placements. Nine families noted that they had parenting issues or were coping with stress related to caring for their children. Two specifically indicated the need for a

playgroup for their special child. Three stated very specific concerns for the safety of their children in the neighborhood.

3. Even though families indicated that they were often isolated or coping on their own, family and close friends were the major sources of support cited by the respondents. Formal agency supports were cited as the second most helpful source of support. There were fewer neighborhood support linkages cited. Seven persons cited nuclear family, 24 cited extended family, 8 cited close friends as sources of support, and one person cited no help from family or friends. Agency linkages as sources of support cited include the following: EIP/Part C (10), Medicaid (6), Children's Medical services (4), Easter Seals (2), United Cerebral Palsy (1), Mary Carroll/Therakids (1), Tampa United Methodist Center (1), Healthy Start (2), Beth Ingram & Associates (2), WIC (2), SSI (3), insurance (1), and Vocational Rehabilitation (1). The most often cited community support were neighbors (8). Other community entities listed were: YMCA youth clubs (3), city recreational center (1), neighborhood parks (5), childcare centers (2), schools (2), churches (3), babysitter (1), and businesses (2). One person listed no support from the community.

Community Surveys

1. What supports are churches, businesses, schools, and clubs currently providing?
2. What supports are they willing to provide in the future for families who have children with special needs?

Churches: Of the 113 churches in the area, 23 randomly selected churches were picked for interviews, 18 were contacted and 14 agreed to be surveyed. There was an attempt by the project to contact five more churches without success. The membership of the churches that were surveyed were comprised of predominantly Caucasian members. Only one church knew of any members having children with special needs in the congregation. The churches indicated that all provide many activities in evenings and on weekends. All those surveyed were willing to let their premises be used by providers of early intervention for the purposes of playgroups upon receipt of an official request. Only one noted a member of the congregation with specific qualifications in the care of children with special needs. The National Council on Disabilities estimates that less than one per cent of faith congregations have disabilities or special needs conditions and this is far below the national prevalence rate.

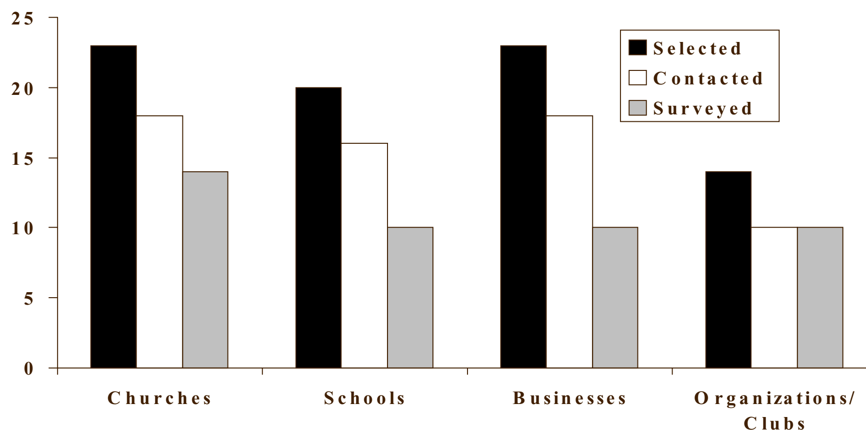
Janet Atkinson, the Family Resource Specialist for this project, presents at community as well as faith-related conferences and to individual pastors and congregations. She shares the message of the loss of support experienced by families when a child with special needs is born or diagnosed and gives examples of the help congregations can provide. Janet piloted a successful playgroup for young children with special needs at the Van Dyke Methodist Church in the Town and Country area three years ago. This year the group will expand to provide an organized parent support group with the help of Dr. Jim Messina who also was instrumental in the creation of the pilot in the Idlewild Baptist Church in North Tampa. In the specific zip code areas of this project, only the fiscal agent, Luther Village, is noted to actively request help in locating young children with special needs to enroll in their preschool early intervention program.

Schools: Twenty schools which included elementary schools and several childcare centers in the area were selected for surveys. Ten (10) agreed to participate in surveys. Six (6) declined an interview and four (4) were unavailable for contact. All schools surveyed had a diverse mixture of racial groups. The elementary schools provide special education and specialized therapies to eligible students. Therapies provided are for the purposes of meeting "an educational" goal and are not necessarily based on clinical need. The elementary schools all indicated that they provide some after-school programs. Only one childcare center in the area of those contacted had special children attending with typically developing peers. All indicated some level of funding problems. Most indicated their willingness for premises to be used by the community if officially requested. Mort Elementary School has provided the site for regularly scheduled outreach clinics of the Early Intervention Program.

Businesses: The area is rich in business resources such as University Square Mall, multiple strip malls, an abundance of restaurants including major fast food chains and several large car dealerships. Twenty-three (23) were selected for interviews. Based on the recommendations of the advisory group, the businesses were chosen because they were types that any young family in the community would be apt to frequent. Eighteen (18) were actually contacted and five could not be contacted. Of those surveyed, most employ local youth. All say they are involved in the local community. Business managers admit that they haven't heard or seen any special needs children brought into their premises; however they say they would help programs for special children by either donating consumable items such as beverages at fundraisers or helping to publicize special events.

Organizations/Clubs: Fourteen organizations/clubs were selected for surveys. Of these 10 were surveyed and four (4) were unable to be contacted. Some have direct involvement with local churches. Most indicate that they assist local events yet all admit that they did not know about the program for young children with special needs. These local clubs are willing to help by providing babysitting or in assisting in the organization of special events. Status of community entities surveyed to date are outlined in Figure 7.

Figure 7: **Community Surveys**



IV. DISCUSSION AND CONCLUSION

SUMMARY OF KEY FINDINGS

An overall summary of key findings from the analysis is presented here:

- Families indicate that informal supports are considered more helpful to them yet what they are generally provided and must depend on are formal supports.

- Families indicate that their number one need is for information and that this information is important for access to other needed supports.

- Several families with high needs lacked a natural support network.

- Maternal education and marital status correlated with higher H.O.M.E. scores. This suggests the possibility of a lesser need for interventions focusing on the home environments for mothers with higher education and for mothers who are married. It does not suggest a lesser need for support.

- Children with more severe conditions received the greatest number and variety of interventions but access to services was usually outside of their neighborhoods.

- Families expressed needs in all spheres identified in the model by Boothby, Grosz, Marfo, & Graven (1996). This includes the need for information, and intervention for developmental concerns, physical health concerns, parent and caregiver mediation, and therapeutic services.

- There is an indication of need for services to be built or expanded in the neighborhoods in these two zip codes and there exists community supports that could be tapped.
- Improved access to existing services and improved transportation for families with young children with special needs is indicated.

- Neighborhood safety was a concern of several of the families.

- The concern for a loss of funding as children transition from the Part C to the Part B program or back to the community is an issue for many families.

- There was overall indication that the Early Intervention Program met the federal mandates but the program might be more effective if interventions were more consistently implemented at the neighborhood level and owned by the community.

Though this study is small, the information suggests that families remember their effective early intervention services, and can articulate what is needed and desired in the way of services and supports. When Part C was enacted it was envisioned that there would be a community collaborative process that would ensure family focused, transdisciplinary models of service delivery and supports for children and families in naturalistic environments. Though this is the

vision, it is hard to implement at the local level. If we are to shift the early intervention field toward a more ecological orientation that recognizes that a child's needs must be met in the context of the family, then family participation in the design and delivery of effective intervention services is essential. It is quite possible that families can become true collaborative partners in the redesign of the system. The Part C Community Development Committee and the Part C Regional Policy Council are attempting to increase family members who will be more than token representatives but rather will become true collaborative partners. Some unique system strategies are being piloted. These include video-teleconferencing hook-ups with the Redland Christian Migrant Association to increase participation by monolingual Hispanic parents and also hook-ups in homes for family members who cannot attend meetings because their child is ill or the distance is too great to travel. Another strategy is Jump Start training which has been recently provided for twelve parents to increase their skills in advocating for their children (October 9, 1999 at Shriner's Hospital).

It is envisioned that families who have young children with special needs will have more access to information and support services in the home or neighborhood where they live particularly given that families cite their need for information as their number one need. Therefore it is recommended that services provide a full continuum of early intervention supports. These include the development of information networks, psychosocial supports, care-giving mediation and interactional interventions, physical health interventions, as well as traditional therapeutic interventions.

Community resources that were identified in or near the area that might be mobilized to develop or assist in the implementation of new service delivery initiatives from the information provided in this analysis include the following:

1. The new **Center for Infant and Young Child Development** has provided the partnering opportunity for the Early Intervention Program to participate in a national research conference on Down syndrome. The center located on the USF campus is available for more research on evidence based practices for young children with special needs. The center is supported by donations. The legislature provided a $1.5 million match last session. It is anticipated that the linkage between this center and the EIP will be strong.

2. **Luther Village**, the fiscal agent for this analysis project, is expanding services in Fall 1999 to include three more bachelor's prepared early childhood educators who will provide developmental classrooms for infants and preschool age children. Luther Village has served children with special needs in the Early Intervention Program since 1993 and indicates an interest in providing more family-focused services and in providing a naturalistic and developmentally appropriate environment for young children. Play and support groups could be located at this preschool. The school would also qualify now as a "developmental day program" that could integrate children with more complex needs. It is noted that Luther Village has a vision to create a "children's village" on eight acres adjoining their current premises. Children in this village will receive care in centers that resemble houses and will eat in a village type café.

3. **Florida Easter Seals** has expanded their home visiting in the area and is the largest provider of services for Part C children in Hillsborough County. Interventionists from

Easter Seal could provide more play and chat groups if they had a facility located in the area where the groups could be provided. Or, these could be organized in local churches during the week and in the schools during the weekends.

4. The **Weed and Seed** project, a community revitalization project, is located in the area. The **Florida Center for the University Community Area** (Marsh, et. al., 1997) presented a master plan for the revitalization of the area. They proposed a schedule of infrastructure improvement totaling roughly $20,000,000 over nine years. Projects to improve the stabilization and enhancement of safety and health were given priority status. In this project a Head Start Center opened as part of a "one-stop shopping" this fall. This **Head Start Center** could be approached regarding the inclusion of Early Head Start Program in which Part C children could be included.

5. The **school district** has worked with the Early Intervention Program to establish an outreach developmental clinic utilizing a public school site in one of the target zip code areas. The first outreach clinics were piloted in the Mort Elementary School as the project was implemented. They are now provided on a regular schedule and staffed by a developmental specialist and a service coordinator from the USF Early Intervention Program. A small team from the USF Early Intervention Program is available to evaluate eligible children in the program at the school site on a regular basis. This pilot might be refined and expanded with community support to other elementary schools in the area.

6. A large pilot program that has been initiated in the 6,000-member **Idlewild Baptist Church** located near one of the zip code areas, but not in the targeted area, could be approached to share their newly learned expertise. The church has developed a core group of members who support family members with respite care for their disabled family members during church services. Key members of the congregation are employed by United Cerebral Palsy. Dr. Jim Messina piloted this initiative of Bridges to Worship, formerly Faith in Action. The group is an effort of local congregations from all faiths who are working to include persons with disabilities in their worship.

7. There has been increased enrollment of and participation from multiple **Part C early intervention providers of instructional and therapeutic services** who can provide model programs in homes and childcare centers. This increased number of providers includes one nurse and one speech language pathologist who are bilingual to serve families who speak Spanish. It is noted that the Part C Regional Policy Council is monitoring Part C home visitors this fall. Preliminary reports from the monitoring indicate that Part C home visitors across all disciplines could benefit from training in mediated learning strategies. A mediated learning curriculum for infants, *Raising Competent Caring Children* (1993) was developed by Gulitz, Coulter, Rosenberg, and Kraybill from USF College of Public Health. The emphasis of the curriculum is empowering the caregiver to interact more effectively with the infant. We believe that a pre- and post-analysis of families trained in these techniques might document an increase in their feelings of empowerment and an enhancement of their care-giving capabilities.

8. **Northside Mental Health Center**, located in 33612, has submitted applications to Medicaid for their licensed clinical social workers to become early intervention providers. This would increase the availability of social support and mental health services for Part C children. There has been difficulty getting these seasoned workers enrolled as early interventionists with Medicaid. Their enrollment will provide support for families who may be struggling with the acceptance or grief associated with parenting a child with special needs. Fiscally, the increased use of Medicaid would preserve Part C dollars for other uses.

9. The Early Intervention Program has recently contracted with **Florida Mental Health Institute (FMHI)** for the services of a licensed school psychologist to provide transition evaluations. A collaboration with the school district's **Florida Diagnostic Learning Resources Services (FDLRS**) will result in the funding of the assessment instruments for the children transitioning from Part C to Part B.

10. **The University of South Florida, College of Education, Department of School Psychology** invited the Early Intervention Program to tour eight evaluation rooms which are miked for sound and observation mirrors. If a collaborative arrangement becomes feasible, there is the potential to increase the opportunities to provide screening and evaluation services closer to the neighborhood where the families reside. The preparation of a cadre of psychology majors who are familiar with the needs of infants and toddlers and their families and skilled in their assessment would benefit the entire system. The site could also be used to prepare speech language pathologists, special educators and other professionals to work on a multidisciplinary team. For families, the site would provide more convenient access to evaluation services for the area.

11. The newly organized **College of Physical Therapy** can also be utilized as partners when exploring the efficacy of early intervention methods. They also are partners in the Down syndrome conference.

Some additional tangential accomplishments of this project include: 1) translation of the *Family Needs Survey*, the *Family Empowerment Scale*, and the *Family Support Scale* into Spanish for use in other projects; and 2) a student award for a paper developed regarding the correlation of race and maternal education on empowerment which was based on data gathered for this project (Ryan, 1999).

RECOMMENDATIONS

RECOMMENDATION #1

The USF Center for Infant and Young Child Development with the USF Early Intervention Program, the Hillsborough Part C Community Advisory Committee, and the USF Collaborative which is comprised of members from multiple colleges at the university, could be instrumental in developing initiatives in conjunction with representatives from the Children's Board and United Way. It is suggested that supports and services be targeted at the

neighborhood level such as the schools, parks, businesses, and churches where the families reside to include linkages with the above mentioned resources. Initiatives should include the provision of all spheres of the model developed by Boothby, Grosz, Graven, and Marfo (1996). Community funding to support the center would increase benefits to all young children with special needs in our state as well as in the two targeted zip codes.

RECOMMENDATION #2

Training Needs: Some immediate systemic needs have been identified and funders might address these for the whole county. These are the need for home visitors to be trained in mediated learning techniques (Gulitz, et. al., 1993) and for more families to have access to the Jump Start training which is estimated to cost approximately $50 per participant. It is also recommended that partners acknowledge the need for more intense training of childcare personnel regarding children with special needs. The district will have a training opportunity for 35 childcare providers to participate in *AHEAD* (At Home & At Daycare) this fall. A location and provision for breaks would enhance the training. All participants will receive free curriculum manuals. This training needs to be well advertised through the Central Agency for Childcare.

RECOMMENDATION #3

Physical and Developmental Needs: Since the first person other than family members that families come to for assistance is the primary pediatrician and since physical and development needs are intertwined, it is recommended that the Department of Pediatrics through its Early Intervention Program sponsor a IFSP training for physicians. The American Academy of Pediatrics has recently identified the need for physicians to participate in IFSPs and also in Individual Educational Programs (IEPs) for children (American Academy of Pediatrics, Committee on Children with Disabilities, 1999, see abstract in appendix).

RECOMMENDATION #4

To ensure that the inclusion of special needs children in childcare centers is a priority, it is recommended that a representative from the local Part C Council be included on the School Readiness Coalition either as a voting member or as a liaison.

RECOMMENDATION #5

It is recommended that forums for experts on the transdisciplinary model of service delivery be provided for the members of the local Part C Advisory Committee.

RECOMMENDATION #6

It is recommended that more churches and synagogues be approached regarding the use of facilities or the development of networks for respite and that members might be recruited to provide "play and support" groups. Other ideas for faith organizations include the support of parent libraries as resource spots for parents to glean the information that they need regarding care giving and community supports. The special collections section of the downtown library

might also be made more accessible to local branch libraries with advertisement of these types of resources made available at local pediatricians and public health offices.

RECOMMENDATION #7

We would suggest that the revitalization project (Marsh, et. al., 1997) be completed and that the Hillsborough County Sheriff's Department and community funders work together to ensure safer neighborhoods as envisioned.

RECOMMENDATION #8

Community funding to support Luther Village's vision of a "village" concept for childcare would assist in the realization of a center in the neighborhood where several Part C children and their families reside, thus increasing the options for service in a naturalistic environment with typically developing children.

RECOMMENDATION #9

Lastly, the issues regarding the loss of funding or services as a child turns 3 years old could be addressed by expansion of the types of services provided by the Early Intervention Program to the age of 5 years. This is not to imply that the Early Intervention Program should expand to age 5, but rather that the services be assured so that there are more options for families as children exit the Part C Program.

ACTION PLAN

1. **The Regional Policy Council for Part C will work with representatives from several colleges at the university so proposals for 2 USF Collaborative grants that focus on new ways to structure service delivery for the Infants and Toddlers, Part C Program can be submitted for consideration.** The first proposal will be to support the planning activities for restructuring service delivery with community and USF partners. The second will focus on the implementation of new models.

    a. A retreat is scheduled March 3, 2000 at the Radisson in Sabal Park. Partners from the collaborative, members of the Regional Policy Council and other invited community partners such as a Children's Board representative, the FASST-2 Coordinator, and the Healthy Start Coalition Director are invited. Dr. Graven will facilitate the sessions. Discussions may include the need to increase the role of the Regional Policy Council in responsibilities for the direct services for Part C children and/or children birth to five with special needs.

    b. The Mediated Learning Training for early intervention providers and the training for physicians on IFSPs and IEPs as well as the AHEAD training for childcare workers and the Jumpstart training for parents may be included as a component

in one of the proposals. If the group determines, other funding strategies will be generated by the Part C Regional Policy Council.

c. Forums for promoting the transdisciplinary model may be included in the proposal or the training plan that must be developed by the Regional Policy Council for Part C.

2. **In order to implement the recommendations regarding the expansion of services at Luther Village, the following are proposed:**

a. The EIP Program Director will conduct training for the Luther Village staff as preparation for meeting the qualifications to become a center-based program for Part C services in April, 2000.

b. Luther Village will complete all necessary paperwork and personnel credentials necessary to become a center.

c. Luther Village is scheduled in June for a certification and monitoring visit by the community team that is chaired by the EIP Program Director.

d. In the interim, the service coordinators will increase referrals of children to Luther Village for individual sessions if they live in 33612 or 33613 zipcode areas.

e. The EIP Program Director will participate on the planning committee for the Luther Village Project.

f. A major fund raising project is planned by the Luther Village Board for the new Luther Village concept. In preparation for this, a needs assessment of the area immediately surrounding the current center will be conducted by the Luther Village Board.

3. **The Regional Policy Council and the EIP Director will continue to pursue linkages with School Readiness Coalitions.**

a. The Hillsborough Part C Advisory Committee requested a seat on the School Readiness Coalition. The local chairperson was interviewed and at the present time is considered only as a liaison. She will serve as an advocate to push for inclusion opportunities for young children with special needs in childcare.

b. The EIP Program Director is a member of the USF School Readiness team and has also participated with some of Hillsborough's Readiness Coalition committees as have some other members of the Part C community.

c. The EIP Director is a member of the Florida Interagency Coordinating Council for Infants and Toddlers (FICCIT). FICCIT meets twice a year with the state's

School Readiness Coalition. Both councils recommended that the local Regional Policy Councils and School Readiness Coalitions meet to better integrate services for all children birth to five years. The EIP Director will encourage the Part C Regional Policy Council to request meetings with each School Readiness Coalition in the five county service delivery area served by the USF program.

4. **To ensure more widespread knowledge of the federal program and the community intent of the legislation, the following are planned:**

    a. The EIP Director and the Family Resource Specialist will present lectures in various colleges at USF, both at the undergraduate and the graduate level regarding Part C. In the interim since the recommendations were presented, there have been lectures provided in four colleges this semester.

    b. This team will also plan and present at local churches and will train other advocates to utilize their presentation materials. A presentation is planned for March 30, 2000 at the Van Dyke Methodist Church for Sunday school teachers to encourage their expertise in promoting their model to other churches interested in play and support groups.

    c. A subcommittee of the Early Childhood Council working with the Hillsborough Part C Community Advisory Committee will distribute posters, brochures, and bus placards about the program to childcare agencies, Hartline, and clinics. This has already begun with a distribution to 75 childcare centers and an approach to Hartline by a parent member of the council.

    d. The Hillsborough Part C Community Advisory Committee will create a proposal and send a representative to the downtown library to seek more accessibility of the Special Collections at local branch offices and physicians' offices.

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