Puerto Rican families with children with special needs in Puerto Rico: parental views about life, family support and services.

Carmen D. Rivera-Bermúdez

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PUERTO RICAN FAMILIES WITH CHILDREN WITH SPECIAL NEEDS IN PUERTO RICO: PARENTAL VIEWS ABOUT LIFE, FAMILY SUPPORT AND SERVICES

A Dissertation Presented

by

CARMEN D. RIVERA-BERMúDEZ

Submitted to the Graduate School of the University of Massachusetts Amherst in partial fulfillment of the requirements for the degree of

DOCTOR OF EDUCATION

February 1995

School of Education
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Finally, to my father, whose example guided me through this process.
ABSTRACT

PUERTO RICAN FAMILIES WITH CHILDREN WITH SPECIAL NEEDS IN PUERTO RICO: PARENTAL VIEWS ABOUT LIFE, FAMILY SUPPORT AND SERVICES

FEBRUARY 1995

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Directed by: Professor Patricia Gillespie-Silver

This study surveyed parental experiences with children with disabilities as a means to enhance existing knowledge about families with special needs. More specifically, the inquiry centered on the following research questions: 1) What is the process of becoming aware of their child’s disability for Puerto Rican parents living in Puerto Rico?; 2) What are some of the specific coping mechanisms adopted by families to deal with their situations?; and 3) What are the perceptions of these parents about the information, direct family support and availability of services? For instance, the notion of stages has been used in explaining parental process in becoming aware of their children’s disabilities. The stage theories of Fortier and Wanlass (1984) and Blacher, (1984) reflects a lack of study of the experiences of families living in Puerto Rico.

Fifteen (15) primary adult caretakers of young children with special needs from 13 different towns in Puerto Rico were interviewed. Results suggested that
1) families faced the notification of their children's disability with diverse reactions that raise questions about the specific stages posed by Fortier and Wanlass (1984) and supports more ample ones; 2) coping was experienced as both an internal and external process. Some of the internal mechanisms were passive appraisal, reframing, personal characteristics of the parent, definition of women's roles as keeping women home as the primary caretaker and instances of economic related coping. External mechanisms were related to the support of family, friends, religious groups, service providers and people in the community. 3) Families described difficulties with access to parent support, free and appropriate education to support services and transitions. Discrepancies between what is mandated by the law and services which were actually offered existed in the areas of child find, timeliness for procedures, education and support services offerings. Differences were also reported on the awareness and utilization of available resources.

The results provide ample opportunities to evaluate parent's beliefs and practices and to generate ideas for service strategies and useful policy responses. Recommendations presented were directed at service providers and monitoring agencies.
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CHAPTER I
INTRODUCTION TO THE STUDY

Early childhood special education practices in Puerto Rico have undergone major changes that relate to modifications in the laws in the United States. One of the most important is the requirement for family focused services for educational programming. Recent directives for early childhood parent's components are based in the notion of the central importance of the family in the education of young children.

These directives affect practice in Puerto Rico in several ways. As a policy they require early intervention teams "to enhance their capacity to provide quality early intervention services, expand and improve existing services being provided to handicapped (disabled) infants, toddlers, and their families" (Dokecki & Heflinger, 1989, p. 60). They also encourage research on family background issues and socio-cultural experiences (Gallagher, Trohanis & Clifford, 1989).

Both policy and current practice fosters a view by which young children are not seen in isolation. They are thought of as being influenced by their family and their social context. Family influence is perceived as being greater and more pervasive in this stage of their development than in other ages. From a service perspective the family is viewed as the center of young children's experiences. Consequently, programs are aimed at providing support to families in their dealings with their children with disabilities.

Because families vary in composition, demographic characteristics and experiences, services offered should be individualized and based on the conditions experienced by the family (Meissels, Harbin, Modigliani & Olson, 1988). This
individualization requirement encourages service providers to consider special cultural, and linguistic differences among families. Thus, as a population in need of services, it is important to define the experiences, characteristics and perceptions of Puerto Rican families in order to achieve a comprehensive implementation of the law and to provide better services for this population.

Statement of the problem

General reports about parents of children with special needs in the United States describe their process of becoming aware of their disability. They also assert the problems with the accessibility, type and quality of the services received. Another set of factors considered are the family's socioeconomic status and the availability of family support system, together with the child's level of disability. All of these elements are then related to the parental capacity to cope and their level of stress (Crnic, Friedrich & Greenberg, 1983; and Beckman, 1983). Available and accessible resources from the extended family, community members and service providers have also been related to the quality of life people experience.

Factors that in turn are related to the accessibility of resources have been discussed by Puerto Rican parents and teachers in anecdotal reports. Accessibility of resources may respond to culturally based beliefs expressed by parents in terms of deference to educational professionals and their decisions; their degree of social support, their level of education and information. These and other factors may influence recognition of services available thus affecting their children's access to appropriate services.
Also related to the accessibility of resources is the information that a minority family may have about organizations and parents groups. As far as this type of information is concerned Lowry (1983) states that for Black parents of children with disabilities:

whether or not the organization in various communities are providing the service is not the major concern. The fact that a large group of parents believe this service is not provided is critical. (p. 58)

In general, this discussion points to the importance of considering cultural, informational and environmental aspects that might influence parental views of their situation and responses to services.

Purpose of the study

In order to understand the dynamic relationship between the factors that influence family initial experiences and their perception about services received and other intervening factors, this research will examine the views of Puerto Rican families on three major levels: child/immediate family, extended family/friends and the community. Also important are the environmental or ecological factors that affect family functioning, as reported by the caretaking family member.

The statistical lumping of people of different Spanish speaking backgrounds under the labels "minorities" and "Hispanics" as a unified group creates a limitation. While discussing this topic, Waggoner (1984) states that "Mexican Americans, Puerto Ricans, Cuban Americans, and other Hispanics...differ in their immigration histories, in their language characteristics, and their socioeconomic characteristics" (p. 99). She recommends monitoring characteristics and outcomes separately in order to identify
similarities and differences in experiences within the Hispanic group. However, limited consideration of this suggestion is reflected in the literature I reviewed. Accurate accounts of perceptions of Puerto Rican parents concerning special education services and the situations faced while attempting to obtain services are absent from the literature.

One of the leading assumptions of this study is that some barriers to services are related to information about and the accessibility of services and resources. Barriers to access can be explored through observations and research. Observation and interviews are research activities obtained directly from the family. This approach will help determine which portion of the existing information is relevant to people living in Puerto Rico, and thus assist in revising service approaches.

Further complicating the issue of barriers to services is the concept held by many Puerto Ricans about the access to opportunities that may differ from that of the general population. These discrepancies are related to perceptions of self and the reactions to those who provide services. For instance, Delgado (1980) comments that Puerto Rican parents may be suspicious of early childhood services. That may account for the reduction in participation of their children in available preschool services. Also, as Meissels, et al. (1988) documented, in the United States there are substantial differences in the availability of services depending on the place of residence. This could be true in the island of Puerto Rico as well. Thus an approach that brings the distinctive features and define the state of affairs for the Puerto Rican parent is necessary.
Research questions

The specific questions this study investigates are:

(1) What is the process of becoming aware of their child's disability for Puerto Rican parents living in Puerto Rico?

(2) What are some of the specific coping mechanisms adopted by families to deal with their situations?

(3) What are the perceptions of these parents about the information, direct family support and availability of services?

Definitions of terms

Family - A couple or group of people related by legal or common law marriage or parentage who live together and share economic, household and, possibly child care responsibilities (Gough, 1980, p. 24).

Extended family - Relatives by blood or marriage not living in the family dwelling.

Community members - People living in the vicinity or in places the family visits with whom they have contacts.

Coping - strategies used by the family in handling, adjusting and working through with common situations and problems. These include the resources used to improve family, social, economic and service situation. It involves both internal and external mechanisms. Its internal mechanisms are actions or beliefs that help reduce the stressfulness of an event or reach a resolution. External mechanisms includes strategies used to avail oneself and organize the exterior resources to satisfy child's and families' needs (Turnbull & Turnbull, 1986, p. 304) and to reduce stress.
Family roles - positions or tasks, actions and responsibilities ascribed to or assumed by each family member.

Services - Options available for providing appropriate programming that meets children's varying conditions. These options cover perceptual, communication intellectual, physical and emotional needs.

Importance of this study

This study yields additional information about the experiences, perceptions and needs of Puerto Rican families with children with special needs. Acquiring information about the families of Puerto Rican preschool children with special needs is important for several reasons. First, it will enable us to gain some understanding of family needs and dynamics of Puerto Ricans. It will, in turn, provide opportunities to evaluate the applicability of general beliefs about families with young children with disabilities, based predominantly in a non-minority population. With this information, the construction of an appropriate plan for families, will be much more possible.

Second, although the exploration of family dynamics of members from different cultural groups is important, there has been little effort to look at the current family systems theory from the perspective of minority groups. An awareness of how families from different backgrounds view and understand the situations they face and their perceived access to family, community support and services will provide tools to professionals in the field to evaluate their own beliefs and practices. Ideas and suggestions generated from the information provided by Puerto Rican parents living in different
communities might also serve to evaluate and enhance strategies designated to work with families in general.

Furthermore, information about the interaction between social services and educational agencies such as special education ones, about how services are offered and used, and about other supports in the community (i.e., friends, church, agencies) will strengthen offerings and service provision. The strength will come by acknowledging the supports and needs of people in different communities.

Delimitations of this study

Findings will only be applicable to Puerto Rican families of preschool special needs children living in Puerto Rico. Even within the Puerto Rican population, this researcher does not claim universality because the sample parents were those who contacted a parent support group based in the metropolitan area of San Juan, Puerto Rico. Also, sample size was narrowed by the desire for depth and completeness in the responses, methodological constraints and time considerations.

The chapter which follows presents existing literature about families in Puerto Rico with children with special needs. The Puerto Rican Public Schools system and the current status of special education programs are also described.
CHAPTER II
REVIEW OF THE LITERATURE

Introduction

Current early childhood special education programs are required to assign a central role to parents and families. Implicit is the belief that children, families and programs benefit from this type of participation. But views about results of this participation differ. Major results to parental participation applicable to populations with special needs have been reported in the literature (Douglas, 1988) and in articles related to people from limited-English proficient background (Ramírez, 1989; and Utley, & Marion, 1984) that can be summarized as those advocating for parental rights, emphasizing educational benefits and those entailing democratic processes.

Parental rights view—looks at the parents as having a significant role in their children's schooling. These rights allow and/or encourage their active participation, and accepts their advocacy. Thus the likelihood of alienation from their children's educational process is reduced. For instance, parents have had an important role in being political advocates for their children. This includes their role in making legal challenges to improve services and to help develop laws beneficial to people with disabilities.

The educational benefits view—parents are seen as the major source of intervention at an early age since parental connections with their children are viewed as a foundation for children's development. Their information and comprehension of their children is increased through parental involvement. The importance of family
participation in the development of new parental skills has been documented by Safran (1974), Steinburg (1988) and Zeldin (1989). At the same time, these efforts may translate into benefits for children. Research by Bronfenbrenner (1977) has also identified parental participation as a crucial factor in maintaining the advantages derived from early intervention. These programs are viewed as responsible for providing orientation to those parents that need or want it (Eyman, Boroskin, & Hostteter, 1977).

Parental participation also offers benefits for teachers and school administrators. For teachers, parental participation increases the possibility of obtaining parental support and understanding of their children’s educational process. Administrators are also helped by enhancing and tailoring their strategies to the needs and desires of the population served (National Clearinghouse for Bilingual Education, 1988; Zeldin, 1989; and Safran, 1974).

Democratic process—some programs consider parental participation as a way of reducing perceived helplessness, which is sometimes associated with low income status. Participation may also increase parental skills, self-development and confidence so that they can become active participants in educational decisions (Bergin, 1980; Bronfenbrenner, 1977; and Topacio, 1979). Douglas (1988) states that for some parents this involvement has resulted in an interest in formal education and employment.

Personal reasons—among the personal reasons for involvement is the opportunity for parents to discuss the developmental issues they face as parents of
young children with special needs. Under this category, parents groups have been identified as important sources of support, solidarity, and help in reducing isolation and in viewing their situation in a more positive light (Russell, 1983). Some authors (e. g., Cunningham, 1983; and Turnbull & Turnbull, 1986) claim that there has been a historical progression in approaching parental participation. Their information tends to support the notion that different approaches to parent involvement exist at different periods moving towards a more solid notion this partnership centered in the active role of parents.

Ecological arguments - ecological reasons are related to the environment in which the child grows. Consistent with the ecological model, these environments are seen as affecting the child, the family and their behaviors. Mittler and Mittler (1983) maintain that to understand the development of children, it is necessary to consider the interactive effects between the child and the setting in which the child grows. They establish the need to consider and include the study of environmental influences when planning interventions.

Education related arguments - in special education contexts, as Mittler and Mittler (1983) have stated, one of the aims of preschool special education is to foster the child’s educational progress. Parents have the right to participate in educational decisions and to shape educational programs. Preschool children with disabilities educational benefits from parental participation are multiple. The sharing goals and knowledge about the child benefits both parents and teachers alike and serves to improve the quality of the program for children. The increased parental participation
informs parents about methods and strategies used during interventions so that expectations in both the school and home environments can be supportive of each other. This common effort provides additional opportunities for generalization of learning.

Although the importance of parental participation has been established for educational settings, many school systems still report problems with parental involvement. For instance, a survey of United States Educational Agencies appears as relevant today (Steinberg, 1988) as it was then (Safran, 1974). In that survey, there were findings of parental apathy, professional and administrative obstruction at the school building and central office levels, problems of communication and role confusion. Some misconceptions existed where parents thought their role would be directed towards the development of policies rather than limited to offering advice. These discrepancies are believed to have affected the level of parental involvement in the states surveyed. Although these factors are recognized as hindrances for programmatic progress, the type and level of participation necessary to obtain good results remains to be defined from an administrators perspective (Steinberg, 1988; and Ascher, 1987).

In special education contexts, the type of parental participation is important because of the additional levels of participation that are required. These requirements follow an expectation that all parents must become involved as advocates and educators as a means to ensure that quality services are offered to their children. However, recent studies in regular classrooms report the tendency of school systems
to reduce parental participation to a minimum and to accept only volunteer work aimed at helping teachers in their classroom tasks, fundraising and classroom conferences (Epstein, 1986; and Steinberg, 1988). Steinberg (1988) has also documented the limited attendance of parents in meetings for the development of individualized plans.

While these general findings appear to hold true for the population of families with children with special needs, the challenge to design parental involvement policies is compounded when dealing with culturally different populations like Puerto Rican families. Most special education studies reviewed do not include minority populations in their reporting. Low income families and families of limited English-proficient background who are in regular education in the United States have been reported as having limited involvement in their children’s education, limited or no participation in school activities (Bergin, 1980) and reduced involvement in day care programs (Delgado, 1980). A combination of existing and newly designed research that yields information about the experience of families from Puerto Rican backgrounds is necessary to ascertain the particular situations faced by them.

In the following section, some of the relevant research about minority parents and families of young children with special needs will be discussed. The aim of the section is to define characteristics and conditions of both families and school systems that are perceived to influence families during their process of obtaining or improving services for their children.
In order to understand the context and experiences of Puerto Rican people, one cannot avoid descriptions of the Department of Education of Puerto Rico. This is necessary since it frames the Special Education Program. Physically, the system has been described as "organized into one hundred school districts, each headed by a superintendent...These districts are then organized into seven regional areas whose main function is to relay the policy, as well as the norms and guidelines on administrative, personnel and curricular matters..." (Quintero, 1989, p. 351).

The norms and guidelines originate and are designed at the Central Office level of the Department of Education. Quintero (1989) states that the administration is homogeneous and centralized. Although the Department of Education is in the process of decentralization due to the requirements of the Organic Public Law of Education (Law 68, 1990), rules and procedures are still applied to all communities. Recently, efforts at privatizing health services and changes in the structure of the Department of Education that create "community schools" (described by some as being similar to the school based management initiatives in the United States) have produced changes whose effects in the special education systems are still to be observed. Dealing with these centralized procedures poses a variety of challenges to parents of young children with special needs, some of which will be discussed in this section.

Special Education in Puerto Rico. The Office of special education has offered services since the 1958-59 school year. That year they offered services to a group of
18 educable mentally retarded children in the town of Bayamón. By the 1964-65 school year, centralized services were offered in every educational region. In the 1966-67 school year, more than 2,400 students in 138 groups were served (Colón-Berrios, 1970, p. 69). But according to Rivera-Vidal (1971), services were limited, inadequate and affected by a lack of accessibility.

It is important to notice that the years of growth for special education in Puerto Rico appear to be tied to federal economic support for special education. The timing coincides with the first federally administered intervention in the special education field. In 1957, time and money for research programs and teacher training were given to some states (Vaughan & Shearer, 1986). A year later, in 1958, offerings were started in Puerto Rico. In 1965, which was another year of growth of services in Puerto Rico, a grant program for special education was established within the Elementary and Secondary Education Act in the United States. This program provided support for direct classroom services (Vaughan & Shearer, 1986, p. 4-6).

After the passage of PL 94-142 of 1975, the program in the Department of Education of Puerto Rico was created by the Law #21 of 1977, known as the Special Education Act. The possibility of an early intervention component for children from infancy to three years was included. This is done through an Interagency Agreement between the Department of Education and the Health Department.

Early Childhood services are provided by both the Health Department and the Department of Education. Under Law 21 there are also provisions for registration, identification and education of children with special needs (infants through 21 years of
An islandwide interagency committee is in charge of policy making and creating rules and procedures for referrals, service coordination and implementation. The responsibility for registration, as presently defined, lies within the Department of Education.

Services for infants and toddlers are provided through regional centers. Families from different points of the island have to take their children to those centers once or twice a month in order to receive services. Some parents get transportation through their municipal government; others provide their own transportation.

At the preschool level (between ages three to five) both the Department of Education and Head Start provide services. Through an interagency agreement, the Department must follow-up on children with special needs placed in Head Start.

To verify if these descriptions conform with reality it is important to begin to look at the Department of Education, since it has been central to the development of the field of special education. Systemwide, there is the impression that educational programs in Puerto Rico are not very susceptible to change (Quintero, 1989). Quintero (1989) describes it as a system based on the administrative paradigm of logical positivism, for which:

The implicit assumptions...are that laws that govern human behavior exist independently of human control and that the units of analysis in social systems are highly similar over time and space...(Quintero, 1989, p.352)

Thus, the educational system is managed in an islandwide manner and standardized for the benefit of the children. Mosley (1988) described health field organizations in developing countries with highly centralized administrative systems
similar to the one in Puerto Rico as described by Quintero. He states that health systems create policies and strategies frequently without regard to consumers. Their policies also lack a mechanism allowing consumers to be instrumental in policy changes. Finally, it fosters hierarchical employee relations where it is difficult for teachers to assume an advocacy role. These descriptions apply to the Puerto Rican public educational system at most of its levels.

At the consumer level, special education services are very limited despite the claim and the attempts to provide services beginning in infancy. As can be reasonably assumed from the number of preschool children identified in Table I that follows, there is no proper procedure for the identification for children with special needs of infancy, toddler and preschool ages (zero to six years old). For instance, the difference in reported incidence in all categories except that of "other disabilities" by age is readily noticeable. This table shows that school age children are more likely to be identified. Some reports have suggested ways in which the system's procedures slow and sometimes halt the process of serving children. Among these, for instance are the long delays in medical and evaluation assistance reported by Zapata-Vega (1989, p. 3-4). She reports that children's needs are not followed up without constant intervention from their teachers. For children and families who do not have advocates difficulties might be greater. These claims are supported by the monitoring report of the Office for Special Education Programs (1991).

Even at the elementary school level, full services are not provided. For instance, a 1988 study done by Morales-Rodríguez in the rural town of Coamo,
## TABLE 1
Incidence of Disabilities
Children Ages 0 - 16
All Sexes

<table>
<thead>
<tr>
<th>CONDITION</th>
<th>0 - 6 YEARS OLD</th>
<th>6 - 16 YEARS OLD</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sight</td>
<td>0</td>
<td>8,597</td>
<td>8,597</td>
</tr>
<tr>
<td>Hearing</td>
<td>721</td>
<td>4,872</td>
<td>5,593</td>
</tr>
<tr>
<td>Speech</td>
<td>1365</td>
<td>31,065</td>
<td>32,430</td>
</tr>
<tr>
<td>Speech Senses</td>
<td>721</td>
<td>14,898</td>
<td>15,619</td>
</tr>
<tr>
<td>Learning Dis.</td>
<td>0</td>
<td>9,473</td>
<td>9,473</td>
</tr>
<tr>
<td>Mental deficiency (deficiencia mental)</td>
<td>644</td>
<td>6,694</td>
<td>7,338</td>
</tr>
<tr>
<td>Absence or loss of part of the body</td>
<td>721</td>
<td>634</td>
<td>1,355</td>
</tr>
<tr>
<td>Paralysis</td>
<td>0</td>
<td>1,862</td>
<td>1,862</td>
</tr>
<tr>
<td>Other disabilities</td>
<td>31015</td>
<td>36369</td>
<td>67,384</td>
</tr>
<tr>
<td>TOTAL</td>
<td>33,822</td>
<td>83,399</td>
<td>117,221</td>
</tr>
</tbody>
</table>

concludes that some resource teachers consistently lacked or were placed in inappropriate rooms. They also lacked materials, did not receive in-service training and were burdened with other responsibilities in the school. Similar results were found in the town of Corozal (Vélez-Alicea, 1988), where the researcher found little orientation to families, delays in evaluations (from months to years of delays), limited psychological testing services, general parental complaints, a non-existent evaluation (service plans made without seeing the student), lack of educational meetings, no materials, poorly located and inadequate space for special education classes. Zapata-Vega (1989, p. 59) also reports that parents lacked opportunities for orientation about their rights. A study based on a sample of parents in San Germán states that most parents felt they were not receiving adequate services and were not aware of what they could do to improve their situation.

The complaints from regular education teachers dealing with mainstreaming were no different. Another study, aimed at obtaining information about teachers’ attitudes towards integration (Torres-Mercado, 1988), raised the concerns of regular education teachers. They stated that mainstreamed students are integrated without considering their excessive class sizes (up to 50 sometimes) leaving little room for individualizing their education. They also lacked planning time and received little support for their endeavors. Thus, parents and teachers are still struggling to obtain basic services or a placement for their children.

In Puerto Rico, courts are sometimes the only recourse to obtain services (Zapata-Vega, 1989, p. 57). Most legal service offices have staff and time assigned
for special education cases as a result of a class action filed and the non-compliance that still exists. The Rosa Lydia Vélez and others vs María Socorro Lacot (civil number PE 80-1738 Superior Court) is a class action that was brought by the Puerto Rico Legal Services Office representing parents of children with special needs. The system is still being monitored, but Legal Service lawyers claim that they file cases of non-compliance frequently. There appears to be a wide gap between what is mandated and what is implemented.

These descriptions do not imply that all children with special needs in Puerto Rico are poorly served. In fact, some heterogeneity in the quality of services exists. While some children, especially those with mild needs, seem to be served reasonably well, others lack essential services. This variation implies that some children will be appropriately served while others will receive poor or no service (Zapata-Vega, 1989; and Morales-Rodríguez, 1988).

Although parents’ groups are active in Puerto Rico, some researchers claim that most parents of children with disabilities face difficulties in obtaining educational and related services (e.g., Zapata-Vega, 1989; and Office for Special Education Programs, 1991). Some of these difficulties, are caused by the bureaucratic process that reduces access to service on the part of families. For instance, waiting periods for services of more than two years are not unusual. Some parents who experienced longer periods of waiting, have given up and kept their children at home (Zapata-Vega, 1989, p. 56). In Puerto Rico parental struggles, together with the laws have succeeded in obtaining improvements in the quality of services for some children.
However, there is a limited attempt to make services equal for all children on the island.

A major reason for the difficulties that parents face may be that while the economic support for this endeavor has grown, the level of consciousness from bureaucrats has remained unchanged. Some of the difficulties experienced by families can be considered an outgrowth of this lack of awareness. It is possible that because the growth and development of services in the Department of Education appears to be related to the funding from the United States it has not been tied with a widespread awareness of the rights of the disabled and the responsibilities of schools and social service agencies. Thus special education procedures are not based on realistic appraisals of what the educational system can or is willing to do. This results in a continuous discrepancy between offerings and service needs. A lack of tradition or a resistance to working with parents in an advocacy role could also be one of the reasons for this state of affairs. On the other hand, this externally generated type of program development has provided some parents with resources to force the administration to move faster.

In Puerto Rico, young children with disabilities and their families face other obstacles in obtaining services. Among these obstacles are the attitudes about people with disabilities and the invisibility they experience. An example of these attitudes is provided by Zapata-Vega (1989, in her Appendix A) regarding regular teachers' perceptions about the mainstreaming of elementary-school children with special needs. Her study documents feelings of insecurity and incompetence among teachers,
coupled with a lack of teacher training. One third of all teachers did not want children with special needs in their classroom. Furthermore, special education teachers reported feelings of alienation and negative attitudes from other members of the school team. Zapata-Vega (1989, in her 1989 Appendix A) also found that parental support is lacking. These findings are consistent with those previously reported by Rivera-Valentín (1978).

In light of the regional and individual differences the need to examine the contextual factors for each of the families is established. The need to examine the service delivery system and its impact from standpoints other than those of educational administrator's and service providers is evident.

Families of young children with special needs

The family's cultural background may affect parental perceptions about and involvement in the special education process. It has been said that in studying services provided to Spanish speaking populations, consideration should be given to the questions of availability and appropriateness (Bergin, 1980; and Montalvo, 1984). Both Bergin (1980) and Montalvo (1984) state that in order for services to be appropriate, they must consider the disability as well as the cultural and linguistic diversity in families and communities. The relation between service provision components in early childhood special education and the characteristics of families with children with special needs is then of critical importance.

While the need for adequate services has been identified, knowledge of what is necessary to provide appropriate services for Puerto Rican families with children with
disabilities is scant. This section includes information about socioeconomic and cultural factors that are believed to be shared with the population in this study and a general discussion about minority families with children with disabilities.

Also included is information about Puerto Rican families in which there is presumably no great variation between families with and without children with disabilities. It is important to remember, as Delgado (1980) points out, that while some generalizations are possible, values, beliefs, or patterns of actions vary among individual's. Collier & Hoover (1987) further claim that, while the process of assimilation may cause changes in the person's values, beliefs or life style consistent with those of the new culture, some aspects of their native culture will remain. The combination of cultures is an individual, family and a geographic issue. Because of the influence of contextual issues and their effects in the lives of Puerto Rican people, a description of their distinctiveness is necessary in order to develop a common frame of reference.

General descriptions of Puerto Rican families

Researchers have discussed aspects of Puerto Rican life for decades. This line of research presents a diverse and complex view of families, describing socioeconomic and culturally related family characteristics (Bergin, 1980; and Delgado, 1980). The literature about Puerto Ricans in the United States has presented a view of Puerto Rican families as having strong extended family relationships, changing family roles, strong religiosity and predominantly low income status (Delgado, 1980).
Insight into these characteristics provides an idea of factors that may influence family life.

**Extended family relationships.** For Puerto Rican families, the extended family is believed to work as a network of relatives and close friends who lend their support and financial resources in time of need. Families are extended beyond the nuclear family to include grandparents, aunts, uncles, cousins and other family members. They may include those "related by blood and marriage" as well as those "tied through custom" (Delgado, 1980, p. 27).

Reciprocal obligations and supports exist in these relationships" (Delgado, 1980, p. 27). For example, "godparents" (compadres) are expected "to fulfill parental roles in case the parents cannot take care of the child" (Delgado, 1980, p. 27). Delgado (1980) describes these relations as forming the initial influences for some Puerto Rican children. Delgado (1980) also states that for some families the extended family network is called on to help in periods of crisis (housing, childcare, etc.) and with the care of elderly and special needs family members. Family members are also expected to provide economic support when needed (Fitzpatrick, 1982).

For many Puerto Ricans urbanization and migration are causing an erosion of the extended family network. This erosion calls for a reconsideration of the assumption that extended family support will always be available. Reports from parents serve to confirm this contention. For instance, some Puerto Rican parents have stated that they did not have any family member to help them cope, either because they moved from their hometown or because of factors related to their child's
disability or appearance. These reports are also consistent with those about African-American families with elementary school children (Lowry, 1983). As a result, extended family support seems related to the level of disability and the family’s and community’s understanding and acceptance of it and not simply to ethnic background or relations with their family.

Other factors affecting the general population believed to be related are those of household composition and those related to poverty. While there are reports of high divorce rates and a high number of single parent headed households for the general population in Puerto Rico (Conferencia del Gobernador para el Fortalecimiento de la Familia, 1987), there are no studies on the effects of this situation in the family’s ability to cope with their child’s disability. A reasonable assumption is that a single headed household, tied with the resulting reduction on income or poverty represents additional stress, specially where parents do not have the time, or energy to maintain the necessary social contacts to preserve extended family support.

Single headed families may also lack time for in school participation (Conferencia del Gobernador para el Fortalecimiento de la Familia, 1987; Junta de Planificación, 1984; and Montalvo, 1984). Tasks that families, and frequently the mothers, are expected to do are affected because of this lack of time. These factors confront providers with the need to understand the diverse situations within a particular group and to modify services and their hours to support all families.
Socioeconomic status. From the Hispanic groups in the United States, the Puerto Rican group has been reported as having the lowest income (El Nuevo Día, 1994, p. 4). Puerto Ricans in Puerto Rico have a substantially lower income than their counterparts in the United States. For the census of 1990 the median income for a family in the United States was $35,225 (United States Department of Commerce, Bureau of the Census 1990-a), for Puerto Ricans in the United States was $20,041 (El Nuevo Día, 1994, p. 4), while in Puerto Rico it was $9,998 (United States Department of Commerce, Bureau of the Census, 1990- b). The mean for that same year was $43,803 in the United States and only $14,866 in Puerto Rico. According to the 1990 Census (United States Department of Commerce, Bureau of the Census, 1990-b), 13.6 percent of the Puerto Rican families in Puerto Rico have annual incomes of less than $5,000, and nearly 5% of the families have incomes under $1,000. The total percentage of Puerto Rican families in the island below poverty level was 55.3% (United States Department of Commerce, Bureau of the Census 1990-c), while it was 22.3% of the Hispanics in the United States and 10% of the total population of the United States (United States Department of Commerce, Bureau of the Census 1990-d).

This high representation in the lower values are related to the high unemployment rate in Puerto Rico, 20.4% (United States Department of Commerce, Bureau of the Census 1990-e), according to that same Census, which some estimates place at a much higher rate. For the same year the unemployment rate was 6.3 % in the United States (United States Department of Commerce, Bureau of the Census,
Puerto Ricans in the island also face a high cost of living (Junta de Planificación de Puerto Rico, 1987). For instance, the Economic Report to the Governor of 1992 (Estado Libre Asociado de Puerto Rico, 1993) states that the purchasing power of the dollar for consumers (that considers each dollar as having a 100 cent value), faced a reduction from the previous years from 34 to 33 cents relative to the value of 100 cents that it had in the 1966-67 year. A similar measure in the United States for that year yielded a reduction in value from 73 to 71 cents (United States Department of Commerce, Bureau of the Census, 1993, h).

A reasonable conclusion based on this information is that lower family income together with low purchasing power may affect the access to necessary services by reducing the capacity of families to pay for the services that need to be paid. Family income is an important variable in a service context in which the state does not offer reduced cost or free services and which are costly to acquire privately.

Religion. There is a great deal of participation of Puerto Rican families in church. Besides being a center for the expression of their spirituality, churches provide socialization opportunities, activities, possibilities to make friends, and sometimes support (El Nuevo Día, 1994, p. 44). Thus, the church may be an important resource and a source of support for some families with children with special needs.
Early Childhood Education and Hispanic Families

Delgado (1980) made a careful attempt to summarize some Hispanic families' cultural traits affecting early childhood services. He precedes his assertions with the caution that although "...adherence to traditional values and beliefs is a question of degree ... even modern Hispanic families differ considerably from the average Anglo family in the United States" (p. 27). These statements consider that the existence of an "average Anglo family" may also be questionable. But as Collier and Hoover (1987) have stated:

...assimilation, in which the native culture (C1) is replaced by the second culture (C2), rarely happens completely. The more common outcome of acculturation is the integration of elements of the new culture with elements of the native culture... (p. 39).

Even though some group traits can be defined, families should be considered as unique in their characteristics and responses.

Delgado (1980) and others discuss some family values that might differ from the values held in the "mainstream." These values point to the variety of viewpoints that a provider may have to consider when working with Puerto Rican families. Some of these are: views about childcare, expectations about teachers and gender role definitions for family members.

Childcare. For many Hispanic families, childcare is perceived as a mother's role. Delgado (1980) mentions that, "...failure to carry out the responsibilities associated with these roles is a serious matter" (p. 29). Participation in preschool services is sometimes reduced or influenced, in part, by the belief about gender role
expectations that early care should be done at home and schooling is better left for older children; that young children are better off if cared by their mothers.

**Gender role definitions.** In traditional patriarchal Puerto Rican families, "...the male head of house" fulfills "a strong authoritarian role". This role is sometimes moderated by beliefs, socioeconomic status and the needs of the family (Delgado, 1980, p. 27). It should be a factor to be considered in the planning of home visits or when expectation exists that portions of the educational plan are to be performed by parents.

The characteristics reviewed here require some consideration. First, as with any generalizations, caution should be exercised since they may not apply to all individuals in the group. Second, factors like degree of acculturation, social class, and family composition may, in similar situations, cause different reactions and attitudes. Thirdly, the image of supportive and caring extended Hispanic family is not always true. Contrary to this impression, some parents have reported that fear, mistrust and lack of desire to help expressed by family and friends affects their capacity to live a normal life. Thus, any study attempting to look at families should deal with the fact that each family confronts unique situations and that reactions of family members may be varied and sometimes conflicting. In this research it is also useful to define how parental decisions affect and are affected by the availability of appropriate services for the family and the child, as well as their perceptions of the availability and quality of these services.
This discussion of parental issues has only touched general information about Puerto Rican families. The theoretical framework for this study and related research about families of young children with special needs will be discussed in the next section with the aim of further refining the definition of a series of characteristics and conditions that influence families and their situation.

Children’s impact in the family-Stages of reaction to the disability

Several studies describing the impact the child with a disability has on family life will be examined. This research creates a picture of changes in parental reactions and perceptions during the process of coping with their child’s disability; and relates family characteristics to their reactions.

Most articles used for this review, as is true for most special education literature, are either based on predominantly white mainland populations or do not report the subjects’ ethnicity. In general, the lack of such reporting is taken as a sign that there was no minority representation in the sample. Based on this assumption, conclusions derived from these studies, without corroboration of their relevance to Puerto Rican families are questionable. Thus, there is a need to look critically at the application of generalizations based on research about populations other than those addressed. Furthermore, this quest for equitable representation in research can also lead to the definition of areas of convergence, even if we find evidence that previous conclusions are not completely relevant. A discussion follows of the most frequently discussed themes.
An understanding of family experiences is viewed as assistance for both the helping professional and the family in dealing with their changes and their concomitant emotions. In particular, it is during the early years of a childhood that the disability is discovered, its consequences are measured and the family’s future with the child is pondered. Financial requirements, time involvement with the child, school and health system programs all begin to be factors to be dealt with at this time (Seligman and Darling, 1989, p. 21).

Some authors (Blacher, 1984; and Fortier & Wanlass, 1984) have organized their views of the responses of parents of children with disabilities into developmental stage theories. The stages were identified by looking at similarities on issues and situations derived from parental reports. Although these authors have different names for these stages, they appear to concur in general terms.

Fortier and Wanlass (1984) report five stages of adjustment after the diagnosis of a child with disabilities. Based on a review of the literature, these are: impact, denial, grief, focusing outward and closure. A short explanation of each stage follows.

**Impact**-This period of crisis occurs when the diagnosis of the disability is received. Parents are confronted with a situation most people are not prepared for nor expect. At the beginning, they may feel overwhelmed and helpless since they face a situation out of the ordinary for which they may have no problem-solving resources.
These initial feelings may be deepened by the reduced reciprocity in interactions with their child with disabilities, which consequently might reduce their motivation characteristic of interactions between parents and children (Calhoun & Rose, 1989).

At this stage parents may reflect some level of anxiety, disorganization, withdrawal and tension, believed to serve to move all energy to contain their discomfort. Their perceptions and feelings about the situation are in turn, influenced by their capacity to cope (i.e. ability to create a routine), even when faced with difficult situations.

Denial—Parents may refuse to accept their child’s disability. They may hope and look for another diagnosis, look to each other for a cause of the disability or refuse to see their child as one with special needs.

Grief—Feelings of "sadness, guilt, and anger" sometimes emerge when the condition can no longer be denied. These feelings are mixed with an incipient acceptance of the condition. At this level, they may also begin isolating themselves by avoiding family, friends and other children, or may react angrily at people. The authors argue that these may be natural reactions to a very stressful situation.

During this stage, Solnit and Stark (1963) suggest that families go through a period of mourning comparable to the process suffered by people who experience the death of a loved one. This mourning is claimed to be a necessary step before parents are able to accept their children as they are. The authors feel that the efforts of
caring for a disabled child may force a delay of the grief process which frequently provides parents with coping tools to deal with the situation.

**Focusing outward**- In this stage "adequate coping begins". Parents begin their adaptation process, by being more receptive to information, accepting suggestions and making decisions and plans for the future. Also beginning at this point are planning, asking for help, looking for information and services.

**Closure**- Changes required by sharing life with a child with disabilities may be recognized and accepted. "There is a realistic sense of hope that despite hardship the family can and will survive" (Fortier & Wanlass, 1984). This acceptance does not necessarily mean that families will not experience again the uncertainties and difficulties of previous stages. Particular transitions and stressful events may bring back feelings of helplessness (Olshansky, 1962).

In what may be considered a variation of Fortier and Wanlass's (1984) work, Blacher (1984) reports three major categories of parental stages of adjustment: initial crisis responses, continuing feelings and responses, and adjustment or acceptance. She has also identified patterns through a process of identifying similar themes and stages on parental comments. According to Blacher (1984), each of these stages will last from a few days to years, depending on the family.

**Initial crisis**- The stage of initial crisis includes responses to the birth of their child with disabilities such as shock, denial and disbelief. Unlike Fortier and Wanlass, Blacher includes the denial reaction in this first stage. Parents may move around looking for cures or deny the child's condition altogether. Her initial stage is
similar to the first and second stage in Fortier and Wanlass’ theory (1984). Likewise, these reactions are viewed as part of the developmental process of parental adjustment and as common and normal for parents.

**Continuing feelings and responses**- Parents begin the process of awareness of the reality of their child’s condition in this stage. They experience what has been described as a time of "emotional disorganization". Parents may experience reactions such as disappointment, anger, aggression (directed to the child, the other parent or other family members), sorrow, "detachment in relationships and physical symptoms such as insomnia or loss of appetite". Also discussed in this theory is the possible loss of self-esteem associated with the child’s lack of responsiveness. Since the child might make little developmental progress during some periods, or have limited responsiveness to the care and communication attempts of others, parents may feel hopeless and frustrated. This stage is similar to the grief stage in Fortier and Wanlass (1984).

**Adjustment or acceptance**- This is the stage of reorganization, adjustment, and acceptance. Parents begin, to focus on situations and problems outside themselves. As a result of this new focus, they may become involved in advocacy organizations that improve conditions for both their child and others. They may feel more confident with their ability to handle the situation and develop special attachments to their child.

Although there is not a complete overlap, there are some areas of similarities in the stages of Fortier and Wanlass' (1984) and Blacher’s (1984) theories. Blacher
reduces the stages to three major groupings that cover most of Fortier and Wanlass' statements, and adds the advocacy aspect to the last stage. By making categories broader, Blacher increases the possibility of confirming the categories.

As it relates to the current study, it is noticeable that the stage theory literature reviewed here fails to address similarities or differences in reactions of people of different cultures, or those with different access to resources. These practices of exclusion, involuntary as they may be, make possible this study's questioning of how common these stages and feelings are when faced with different service provision situations, differences in resources, access to services and social support.

Part of the criticisms made of this literature include the possibility that the interpretations and events upon which these stages are based might be culture bound; different ethnic groups who experience other circumstances may not react in such clearly definable fashion. For instance, Seligman and Darling (1989) have documented some differences in the reactions of Hispanic families. They state that initial protectiveness and acceptance of children's differences is not uncommon. These observations tend to contradict stage theories. Furthermore, there are possible differences resulting from geographic experiences that have not been explored. Thus, conducting research based on the perspective of Puerto Rican families will add to the critical discussion of these stage theories.

Theoretical framework

The family systems perspective. The general systems theory, as applied to the study of family and social relations, will inform the theoretical framework of this
study. The following discussion will be based on writings by Rappaport (1977), Hoffman (1981), Waltzawick, Beavin, & Jackson (1977), and Bateson (1972).

Studies from a systemic framework are part of a movement derived from the mental health field and from the clinical care of psychiatrically disordered patients. Only recently has the systems theory been adapted to the special education context, as it looks at social interactions, and focuses on the communication process. However, its use is growing in the special education field, since it is more responsive to the needs of people than traditional approaches.

The systemic approach is seen as a radical departure from previous practices. From studying behavior and problems of the child with disability, it moves its focus to interactions among members of the family system. By viewing the study of each family as unique in its relational and communicational behaviors, the understanding of the patterns of interactions and rules of behavior, and how these relate to their present situation, becomes the center of the work with families.

In instances in which system's research has been restricted to a single family, the work has been geared to attempts at understanding their uniqueness at a certain defined point in time. This approach attempts to understand the family's pattern of relationships. This pattern of relations has been conceptualized as a family paradigm. Its definition includes the experiences, communication interactions, member and context influences and cannot be restricted to any one of them. These understandings reached about the family processes and its functionality are temporal. They relate to
the situations families face at certain points in time, and may be irrelevant during other periods.

Besides the individual and family levels, there are major units called supra-systems that are ordered by their complexity. These include the primary groups (which include the extended family and friends), and the major system/society (which include organizations and social systems).

In their quest for a dynamic equilibrium, systems have several deviation countering mechanisms serving to control the behavior of groups and individuals. This theory describes boundaries within which people and groups are thought to behave and how participants in the social fields relate. In studying live systems such as the ones in this study; that is, lasting systems that exchange energy and information among its elements, theorists have focused on several basic principles that direct their actions. What follows are definitions of these principles based on Rodríguez-Quiñonez’s (1987) and Bateson’s (1972) work.

Change and adaptation are necessary in order to be a live system, but interactions follow patterns of regularity or constants. These patterns allow changes in the system while maintaining its basic structure. This means that the system can move from a random state to a dynamic order in response to changes in the environment (also known as flexible regularity). This mechanism insures growth, adaptation and survival over time.

Related to this adaptation mechanism are the boundaries which are the unifying elements or rules for role, action and consequences for each member of the system.
They could be understood as underlying agreements defining appropriate conduct and ways of relating for each element of the system. These could be clear, diffuse or rigid, depending on the level of communication or degree to which the limits are discussed and applied. Enforcement of the limits is done by the feedback, a regulating mechanism by which norms and individual behaviors are defined. This regulating mechanism causes processes where boundaries for roles and definitions for appropriate behaviors are enacted, thus resulting in changes that maintain the system's consistency. It is also a mutual reaction process defined by the feedback provided about its action (Hoffman, 1981, p. 50).

Thus, elements on each system depend on and affect each other. The interdependency can describe a chain of exchanges in which an action by a subject affects that of others while at the same time being affected by their response. In family systems, it translates to actions from one member which influence and are influenced by those of the other members. Family behavior may be affected by or be the result of more than one system at a time. Thus, an understanding of individual acts cannot be achieved without considering those of others in their relational systems. At the same time, actions may also be influenced by activities in levels such as primary groups, organizations and social systems.

An important factor for families and their adaptation is the balance achieved by the system over time. The family acquires a definite character over time, they become more specialized and resistant to change. This resistance to change allows family members to maintain their identification over time. However, the system can
move from a period of disarray or unbalance to a period of equilibrium, and likewise from a period of equilibrium to unbalance. Momentary family breakdown creates the potential for redefinitions. Families in trouble are defined by their inability to move from periods of lack of balance to periods of adaptation. Problems might not arise from the family structure but from the family's ability or lack thereof to change and adapt to the situation.

While systems may have similar functions it is accepted that their actions are unique. It is recognized that similar results can derive of a variety of causes and a particular situation might motivate a variety of responses. As a result family attributes experience constant changes depending on the experiences and reactions in time. Families move from characteristics near one extreme (more authoritarian) or the other (more flexible), depending on what their needs are at the time.

In this study, the system's theory will guide the gathering and analysis of information from the context of the immediate and extended family levels. This is done because this type of approach also promotes viewing the family as a unique whole. The in-depth study of interaction processes and their concomitant rules serves to understand behavior in context (Rodríguez-Quiñonez, 1987). The focus of analysis moves from the individual children, their condition and consequences, to an interpersonal and systemic view. There is an attempt to broaden the scope of inquiry to include events outside of the child, the family and the wider social context, in a quest to understand how they interact and affect each other.
Based on the literature it must be stated that the family system theory provides an approach to attain a more complete definition of the organization of human action. These definitions are gathered from an interest in describing their social context, each act, and uncovering the intent and result of these activities. Additionally, these explanations go beyond the family context since actions derived from other processes can be defined via these understandings. In the next section elements of the ecology of human development theory will be discussed to add to the scope of family systems.

Ecological theory of human development. Social ecology involves a series of conceptions that are consistent with some of the social system theory definitions previously presented. Both the social systems approach and the ecological theory facilitate the observation of changes in individual families and organizations and of their interrelationships as one unit of analysis (Bronfrebrenner, 1979). Thus, similarities of concepts can be readily noticed in these descriptions. Social ecology also guides observation beyond the immediate family environment. The discussion that follows is based primarily on Bronfrebrenner's (1979) work, but it also includes some general views presented by Rappaport (1977).

While the social system's theory is primarily geared to evaluate and plan for the family level, the ecological theory moves beyond that to include the community and public policy levels with more detail. The ecological "principles" that guide the process of assessment and planning have been summarized by Rappaport (1977, pg.
154) and are the principle of interdependence, of cycling of resources, of adaptation and of succession.

The principle of interdependence emphasizes that "whenever any component of a natural ecosystem is changed, there are alterations in the relationships between all other components in the ecosystem" (Rappaport, 1977, p. 154).

The principle of cycling of resources addresses the formal and informal rules for distribution of resources within a particular community. These rules may be different in different settings and are affected both by what is available and what is perceived to be available.

The principle of adaptation (also known as the reciprocity factor) describes the mutual and interacting type of influence the environment has on the individual. Interactions affect actions in both directions: that of the environment and the individual. One is constantly affecting and adapting to the other. The developing person is seen as a "growing dynamic entity that progressively moves into and restructures the milieu in which it resides" (Brofrenbrenner, 1979). In order for the organism to develop, adaptation and change must be continuous. Similarly, connections with other levels and settings are considered part of the environment, as well as influences in more ample settings.

The principle of succession expands on the previous concept by describing the continuous change of communities through the dynamic equilibrium they attain (p. 154). It represents the long-term outcome of a series of changes and adaptations.
These principles lead researchers to an analysis that encompasses several levels. They suggest that each level and environment studied be analyzed as a system, in their dynamic relations and their effect on each other. The levels of analysis discussed by Brofenbrenner (1979) are the following:

The microsystem level gives recognition to the people in the children’s immediate environment who might have an effect on their life. He states that "...A microsystem is a pattern of activities, roles, and interpersonal relations experienced by the developing person in a given setting with particular physical and material characteristics" (p. 7).

At the microsystem level the study about "other persons present in the setting, the nature of these links, and their indirect influence on the developing person through their effect on those who deal with him at first hand" is encouraged (p. 7). It involves the "interrelationships in the immediate setting". For example, you may study not only the mother and child but also any important person such as grandparents, aunts or other adults living in the same house.

Thus, the study of molar activities-permanent behaviors which, in the case of families, could be individual, or related to others. Part of the family history is related to the scope of molar activities with and by others. The understanding of these activities requires concentration on the process as well as on its contents and the environment. It drives research to look at activities at the direct-interpersonal level, as well as at people’s perspectives and roles in the settings where the action takes place.
The concept of transition is also important in this study. "An ecological transition occurs whenever a person's position in the ecological environment is altered as the result of a change in role, setting, or both" (p. 26). Transitions involve changes, such as becoming a mother or the child's involvement in school. They cause changes in the environment, as well as in those involved, through the process of mutual accommodation.

The **mesosystem** level includes interrelations among settings in which the person participates. A mesosystem is a series of microsystems that comprise a mayor system:

A mesosystem comprises the interrelations among two or more settings in which the developing person actively participates (such as, for a child, the relations among home, school, and neighborhood peer group; for an adult, among family, work, and social life) (p. 25).

The ecological model also studies the mesosystem through reports people make regarding the setting. The extent to which the activity invokes other "...objects, people, and events not actually present in the immediate setting" is important. It further states that "...if a person in a given setting speaks about her own activities in some other setting, either in the past or in the future, she is exhibiting the ability to create a 'mental mesosystem'" (Brofrenbrenner, 1979, p. 47). Thus, the model allows for the study of the mesosystems based on what individuals say about them.

Since the environment's objective properties are as important as the perceptions of those who live through them, the phenomenological nature of this approach is of crucial importance. It is the person, in constant interaction with the environment who decides what are the most influential or salient aspects affecting
their conduct. It is contended that behavior cannot be understood solely from viewing and describing an environment without understanding how people react and experience it (Bronfrenbrenner, 1979, p. 28).

The **exosystem** level deals with the interrelation between persons and settings in which they do not become involved that affect their immediate situation.

An exosystem refers to one or more settings that do not involve the developing person as an active participant, but in which events occur that affect, or are affected by, what happens in the setting containing the developing person" (p. 25).

Examples of this are: parents' workplace, schooling available, friends of the family, local politicians.

The **macrosystem**:

... refers to consistencies, in the form and content of lower-order systems (micro-, meso- and exo-), that exist or could exist, at the level of the subculture or the culture as a whole, along with any belief systems or ideology underlying such consistencies...For example, within a given society...a school classroom, park, playground, cafe, or post-office looks and functions much like any other, but they all differ from their counterparts... in other places (p. 26).

It is defined by an invisible "blueprint". The "blueprints" differ also for groups within the general society (socio-economic, ethnic, religious and others).

In summary, the ecology of human development approach studies development as the result from the interaction of organism and their environment. It looks at development of the mutual accommodation between the person and the changing setting. It further promotes giving attention to the person and the environment, looking at the fit or balance between the person and the environment; and, not removing individuals from their context in order to study them. It also makes the
scope of the study more ample by describing two major spheres of observation: that of interpersonal relations and small groups and the one of relations and their effects in more than one setting.

The ecology of human development theory is proposed as an expansion "...and then a convergence of naturalistic and experimental approaches; more precisely, an expansion and convergence of the theoretical conceptions of the environment that underlie them." Hypotheses are tested in the natural setting and in collaboration with target people from that setting (Rappaport, 1977). Experimental information is thus used as a heuristic tool which makes verification of each research approach possible.

Studies applying the Family system perspective and ecology of human development

Various authors have defined the impact of the experience of having a child with special needs in the family. Turnbull and Turnbull (1986) have applied the family systems theory to the experience of families with children with disabilities. However, there have been limited reports about minority families’ reactions to children’s disabilities.

In the family system theory families are seen as stable interactional systems: those that include relationships that are lasting and important for participants as well as for groups (Waltzawick, Beavin and Jackson, 1977). In this context, Turnbull and Turnbull (1986) have identified important aspects that shape the system and its processes and are essential in understanding family dynamics. Among those categories, family structure, family resources and family functions serve the purpose of this research. It is the study of the ways these categories relate to each other.
within the family context that will help define families’ priorities and needs. Thus, what is important is the families’ reactions and interactions within their immediate context.

**Family structure.** This area covers characteristics of families that are both similar to those of members of a general group, as well as those that make them unique. It encompasses ways in which families could be described. Among them are the families’ size/composition, cultural style, and child’s type and level of disability.

The size, composition and resources of the family have been found to influence conditions for and responses to their children with special needs. For example, the number of parents in the household has been identified as a factor affecting opportunities for family coping (Friedrigh, 1979). A recent review (Allred, 1992) points to the effects of living in a two-parent household. Of importance are the findings that state that fathers play an important role in the family’s acceptance of a child with disabilities (although not consistently supported by all research). Also, great differences were found in the level and type of involvement by fathers. Differences in involvement have been also related to the child’s characteristics such as level of disability.

On the other hand, living in a one parent household without the support of other adults, with a child with disabilities, has been associated with higher levels of stress (Beckman, 1983). The lack of support from other adults may also make it difficult for the parent to get a job. It is reasonable to claim that within the general
populations, as well as in families with children with special needs, women who face motherhood alone frequently experience a substantial reduction in their salaries. Those who lack family and community support in parenting are faced with added responsibilities that may increase their loneliness and isolation. In general, single parenting has been related to reporting additional stress, leading to more difficult financial situations and isolation (Simpson, 1982).

Furthermore, from the research reviewed, there is no indication that the effects of disabilities in families can be tied to the child's type of condition. Some families with children with varying degrees of disabilities appear well adjusted and organized from the beginning, while others do not. However, some of the family's reactions might be related to the child's level of development (which is certainly related to their type of disability). Children's aging creates the expectation of new stages of development. Because of their disability, however, they will not achieve the expected stages or take longer to do so. Parents are then faced with long term implications of their children's disability in the child him/herself and their family life.

Children with disabilities place several demands on their families. These vary with respect to their type and level of disability. Warren (1985), for instance, reports, families with children with more severe or obvious disabilities experience a lack of community acceptance that frequently leads to isolation, and problems with obtaining informal family/friends-based respite care. Related to this isolation, the children's condition as well as their attractiveness (Strain, 1985), if obvious to the eye, might cause immediate reactions or judgments.
Seligman and Darling (1989), have discussed the reaction to this stigmatization as resulting from the difference between discredited and discreditable conditions. They state that:

Individuals with discreditable defects and their families engage in what Goffman calls 'impression management' to appear normal...In the case of discredited conditions, which are immediately obvious to strangers the problems of impression management are different; 'passing' as normal is not possible... (p. 90).

Interactions never become close because of the perceived possible consequences for the non-disabled person of being confused 'as defective', or their unwillingness to deal with unfamiliar situations. These beliefs are not discussed but they nevertheless exist and are frequently hidden under a facade of courtesy. These reactions from people who do not have disabilities are described by Seligman and Darling (1989) as leading to similar experiences as those of minority group members. They are also viewed as one of the reasons some families with children with disabilities choose the company of people perceived as facing similar situations. These observations could mean that some families experience the period of adaptation to their child without a supportive group in which to merge. In sum, assuming consistency in the reactions and effects resulting from different types of disabilities is not consistently substantiated by the reports in this review.

A family system is a "set of objects, the relationships between objects and its attributes." (Waltzawick, Beavin, & Jackson, 1977, p. 117). Each system can be subdivided into sub-systems. Turnbull and Turnbull (1986) described four subsystems, which may vary because of family characteristics. These are the marital,
parental, sibling and extrafamilial subsystem. Only the marital, parental and 
extrafamilial subsystems will be discussed in this section.

The marital subsystem considers the interactions between parents or parental 
figures. It also fosters a view about how children and their disability affects parental 
interaction and are, at the same time, affected by them. For instance, parents may 
fear the long term implications of having a child with a disability for themselves and 
their other children. These events may be new for parents, situations for which the 
learned maternal or paternal responses to the non-disabled child may not be 
appropriate (Thomas, 1982). In a related point, there are claims that parents, faced 
with the unexpected event of the birth of a child with disabilities, may lack both a 
"temporal developmental framework" and a concept of future, and develop concerns 
over their inability to predict the future for both the child and the family.

Within a traditional family role and work division, different responsibilities 
may be shared or divided. But the situation with the care of a special needs child 
seems to be different. In relation to nuclear families, some authors state that even 
within the two-parent family, "much of the impact of the care falls on the mother" 
(Edgerton, 1979, p. 35). Edgerton (1979) states that mothers suffer more stress 
because of the practical problems presented by the care of their child. This could 
also be due to the fact that "fathers and brothers tend to be less involved with the day 
to day care" of a child with disabilities (Edgerton, 1979, p. 35; also indirectly 
supported by Allred, 1992).
In Puerto Rico there appears to be institutional support for traditional gender division in the care of young children. For instance, in some hospitals in Puerto Rico there is still the unwritten, but enforced, policy that mothers or female members of the family are the only ones who can stay with their hospitalized children. This places mothers in the difficult position of having all the responsibility with no support in hand. This practice is not consistent with research findings. Research with Black parents in the United States sustain the need for social support. Lowry (1983, p. 57) found the "presence of a friend, spouse or another parent, beneficial as they attended official events such as school meetings concerning their child's program". In that study, a substantial percentage (20.8%) were unaware of parent groups. For that group at least, the support they lacked at home was unavailable in other settings (Lowry, 1983).

After viewing the situations faced by couples dealing with disabilities in their families, it is easy to understand the difficulties faced by single parents dealing with similar situations by themselves. In the process of meeting head-on the challenges of raising any child, single parenthood presents additional difficulties in the economic, emotional and social areas (Brazelton, 1989). When one or more of the children have disabilities, difficulties may increase. As a result of this, Thomas (1982) believes that issues of single parents deserve special attention.

Since family characteristics and their consequences are not static or universal, a final conclusion based solely on the factors discussed in this section seems difficult. For instance, if the family is one with limited financial resources, other factors such
as type of family support may come into play to compensate for additional needs. A conclusion would require looking at their specific situations and environmental supports.

Studies of the parental subsystem category are concerned with interactions between the parents and the child with disabilities and their other children. Concepts such as family homeostasis are of importance. In this concept there are notions about the capacity of each member of the family to influence the family as a whole. After patterns of behavior and interactions are established, there may be great resistance to change. Some authors point out to the stress and difficulties found in parenting in general, even when dealing with non-disabled children (Brazelton, 1989). When faced with a child with disabilities, there are the challenges related to the "unusual requirements of caring for the child" and to reduced rewards as a result of the caregiving job (Beckman, 1983, p. 152).

There are limited reports of the father’s participation and interaction in family dynamics. It is reported though, that they tend to be less active in the childrearing process (Allred, 1992; and Edgerton, 1979) and tend to differ in their evaluations of their children with disabilities. It is claimed that fathers who wanted to participate, may have felt more isolated and incapable, since most of the training and information has traditionally been channeled through the mother, particularly when the father participates in the labor force (Seligman & Darling, 1989).
Family functions. The area of family functions has been defined as the area of activities in which families engage to "meet the individual and collective needs of their members" (Seligman & Darling, 1989, p.9). Turnbull and Turnbull (1986) have divided this area into seven subcategories that encompass most types of family needs: economic, domestic/health care, recreation, socialization, self-identity, affection, and educational/vocational. While these divisions facilitate our discussion, the boundaries between these areas are not as rigid because happenings in one area has repercussions in the others. For instance, family employment may affect the options of housing and schooling for the child with special needs. The subcategories considered relevant for this research will be discussed in some depth.

Various characteristics relating to family size and resources have been found to influence family life and responses to their children with special needs. Examples of this are the economic difficulties that arise if a single parent is prevented from getting a job because of childcare and medical responsibilities (Friedrigh, 1979).

Also reported in the literature are differences in recognition and use of rights and options families have as parents of children with disabilities. In general, there is documentation of limited participation by low income parents in educational decisions pertaining to their children with disabilities, and of delegating decisions to professionals more than those of higher income backgrounds (Weatherley, 1979). When these findings are applied to the Puerto Rican population they should be taken with caution because Puerto Ricans have a greater representation in the lower socioeconomic levels. Within this low income group there is great variation in
educational attainment and levels of assertiveness. Although from similar 
socioeconomic backgrounds, there are differences in the willingness of some parents 
to deal with institutions; even when facing what could be considered hostile situations. 
Thus, family aspects such as parental level of knowledge of service systems, 
education, recognition of opportunities and language proficiency, are often compensatory factors balancing social class.

Related to the area of economics is the effect of the disability on family's 
finances. Although not true for every family, the increased economic demands on 
families with members with disabilities can be readily perceived. Caring for that 
child might decrease the family's opportunities to economically provide for the 
family. A child's disability may reduce the family's ability to obtain paid 
employment, thus preventing them from paying for services necessary to deal with 
their child's disability. Families living in the United States (Turnbull, Summers and 
Brotherson, 1984) claim that they have faced the need to relocate leave jobs, to accept 
a reduction of personal options and loss of friends in order to better provide for 
their children with disabilities. Families living in Puerto Rico face similar challenges.

Parents in Puerto Rico have also reported that some basic services had to be 
paid for if continuity and frequency of care was desired. The availability and 
appropriateness of some of these services has also been questioned. Access to 
services has important implication on parental feelings of control and might affect 
their participation in their children's educational process.
Several studies (Brotherson, Houghton, Turnbull, Bronecki, Roeder, Gordon, Summers & Turnbull, 1988; and Friedrich, 1979) relate domestic and health needs to other family variables. For instance, some state that the social network of families helps in the process of family adaptation to the young child. The type of disability has been related to the existence or lack of social support (Klein & Scheifer, 1989). Also related to domestic needs, are the concerns parents express over the evergrowing physical and/or mental demands on them as their children grow older while remaining dependent. The degree of difficulty may relate, amongst other factors discussed, to the children's disability level and to their family's capability to deal with it.

Access to resources and to a social network is deemed important in the process of family adaptation. Several studies (Friedrich, 1979, and Brotherson, et al., 1988) state that the social network of families can help in the process of adjustment to the young child's condition. Some researchers (e.g., Friedrich, 1979) view the child's type and level of disability as factors very related to being able to acquire a social network of support and help. For several disabilities an understanding of the impairment and its consequences might be necessary in order to obtain the necessary support. Frequently, however, individuals who are possible sources of likely support avoid contact even before this understanding is achieved.

Several studies point to the importance of contacts among people with and without disabilities (Hersh, Carlson, & Lossino, 1977). Research about mainstreaming present the difficulties experienced by families attempting to obtain the necessary school/community support. For instance, in a study about Puerto Rican
teachers' attitudes regarding the integration of children with special needs (Torres-Mercado, 1988), teachers reflected moderate acceptance of children tempered by the student's type of exceptionality. They were not willing to teach "children who show disabilities that may affect their own and other's learning". They opposed the integration of children with chronic behavior problems, speech and language difficulties. Consistent with this study, a summary discussion of studies about the perceptions of the children with disabilities in schools made by Roberts, Pratt and Leach, (1991) shows that: (a) the disabled are viewed negatively or with indifference; (b) increasing contact does not necessarily lead to an improvement in attitudes or acceptance; (c) there is a tendency among children with disabilities to interact less with their 'nondisabled peers' than for the disabled to play among themselves; (d) activities to promote interactions need to be designed even for students with mild disabilities (Reis, 1988; and Fox, 1989).

As previously stated, difficulties with care and integration increase with the severity of the disability and the community's perceptions about it. An example is the lack of acceptance and understanding that has been felt and reported by parents of profoundly retarded people (Boggs, 1985, p. 39). Furthermore, the appearance of the child may affect the reaction of family, friends and members of the community.

Formal support/System sphere. So far, this literature review has focused on family and community characteristics described as those that impact the stability of the family of children with disabilities. Schools have an important influence too, and
is another level that should be considered in obtaining a complete picture of the environment in which the family is involved.

It is clear that educational programs might provide support to the families through their instructional components and the enhancement of opportunities for access to resources (such as transportation specialists, social and educational services). Differences in resource availability by geographic location or disability levels, as well as in perceived program quality, have been reported in the literature and by members of families (Meissels, et al. 1988). These differences are important for the quality of life and for decision making for their children. A discussion of some of these aspects follows.

Literature about the current status of special education services in the United States (Meissels, et al., 1988; and Turnbull & Turnbull, 1986) reports a variation in support services by geographic areas. A survey by Meissels, and his colleagues (1988) investigating early childhood intervention policies in the 50 states and the District of Columbia, documented variations in offerings, and in policies regarding funding, administration, and interagency cooperation from state to state. They also documented shortages in trained personnel.

Other regional variations among states were found by Meissels and his colleagues (1988) concerning the availability and level of services provided related to their age level and disability category. Differences in access by geographical region for children with more severe disabilities and younger children were found in Calhoun and Rose’s (1989) study. Turnbull and Turnbull (1986) similarly report differences in
conditions for children and families in rural areas of the United States where families suffer greater isolation. Since frequently there are not as many disabled children, the services needed may either not be available or be far from the child’s community. Besides unavailability, there are claims that limited parental knowledge of resources affects access of families to these resources (Seligman & Darling, 1989, p. 58).

These differences in service availability caused by geographic location may also be present in Puerto Rico.

Relating this information to the present study, program characteristics are seen as part of the ecological environment affecting quality of life. Some studies claim that child’s enrollment in programs are related to positive results. These studies state that enrollment provide caretaking members a more typical family life. Programs allowed parents to get involved in parenting tasks instead of continuously being directly involved in stimulation and educational tasks. They also allowed parents to pursue career and other personal interests and provided a source of information and support (Hanline & Halvorsen, 1988).

There has also been consideration has been given to parental perceptions of program quality or to how services are delivered (Hanline & Halvorsen, 1988). In this area, parental perceptions are as important to service delivery as the "type and quality of services offered". For instance, McDonnell (1981) points to the differences in perception between parents who had children enrolled in integrated programs and those with children in special schools. Families of children in special schools predicted more negative experiences for their children and felt they would lose quality
and type of services. Concerns about safety issues, personnel knowledge and training come forth frequently (Calhoun & Rose, 1989; and Hanline & Halvorsen, 1988). Finally, the need for transportation is another concern frequently mentioned by parents regardless of type of placement or ethnic background (Delgado, 1980; and Hanline & Halvorsen, 1988). The needs discovered after placement were to have an active participation in decisions; to choose not to have participate thus allowing for personal time and space; to share and receive information, and the need for transportation.

The educational/vocational component includes issues of work/career selection, and attitudes towards school and work. Educational and vocational needs is an area of major emphasis by school systems. According to Turnbull and Turnbull (1986) the vocational aspect appears as a more predominant concern for parents in the more advanced developmental stages, whereas schools emphasize the child’s educational/vocational development from an early age. Thus, this is also an area in which much parental and cultural conflict may develop. Dealing with self-reported parental concerns in this study may provide an indication of general concerns related to the vocational area at the early years among Puerto Ricans.

Deserving a separate discussion is the possibility of disagreement between parents and preschool programs in terms of quality and type of parental involvement that is appropriate. Phillip (1980) points that, in some preschool programs in San Francisco, parents of developmentally disabled children and personnel, have differences in perceptions on the amount of contact that parents should have with the
program. She views these differences in perceptions as possibly having an effect on parental satisfaction.

Research about parental involvement, from the standpoint of parents of children with disabilities, can clarify the question about differences in perceptions about parental participation. Polifka (1981) found, through a questionnaire study of Northern Iowa parents, that at certain parts of the process there is a need for formal contacts with school personnel. He found that parents preferred the most formal staffing to less formal contacts when they were in the process of enrolling their children in the programs.

The studies of Bergin (1980), Steinberg (1988), and Winton and Turnbull (1981) point out different and sometimes conflicting views of parent involvement held by administrators and parents. Winton and Turnbull (1981) used an interview procedure and found that, although parents wanted to be involved, their perception of the necessary involvement differed from that of program professionals. While programs stress structured activities such as conferences and counseling, most parents reported the need to be selectively involved or the desire not to be involved. Other parents reported that frequent informal contacts with teachers was all they wanted or needed at the time when they leave their children in the center.

Polifka (1981) reports parents who wanted a greater role in decision making and administration of programs but their activities were limited to tutoring, classroom help and support for school activities. Such information points to the desirability of
holding a flexible view of parent involvement allowing diverse options in parental participation.

Another important issue is that of parent's perceptions held concerning direct service provision. It is at the direct service level that parents continue developing notions of their children's capabilities and of the family's capacity to cope with their new demands.

Family members' perceptions of their situations and their notions of their ability to cope will be affected by procedures used for initial reports, and by subsequent intervention by medical and school personnel. For instance, there are parental reports of different ways of dealing with informing parents, which include waiting until parents notice the disability. There are reports from parents that indicate that some feel satisfied with this process (Turnbull, 1985), while others resent the wait-and-see attitude of medical professionals (Calhoun & Rose, 1989; and Thomas, 1982). Others report professionals who lack sensibility to accept parental concerns or who move too quickly to act to rehabilitate, without concern for parental or family processes (Thomas, 1982; and Turnbull, 1985). Most parents state the need to be informed immediately as a central concern.

At a later period, upon coming in contact with school personnel, parents may be concerned about the school's personnel capacity for dealing with their child's disabilities. If their child is going to be placed in an integrated setting, concerns about attitudes of regular staff and students have been documented (Hanline &
Halvorsen, 1988). Parental perceptions of services is an unexplored area in Puerto Rican research literature.

The development of appropriate modifications to programs components is one of the most challenging planning aspects for service provision to preschool children with special needs. Inhibition from participation has been associated with a lack of flexibility in program hours and inadequate identification procedures for children with special needs (Baca & Cervantes, 1986, pp. 188-189). A case in point are reports from the United States that a portion of mothers with children with disabilities worked outside the home. Only a few programs considered mother's employment as a possibility that make daycare needs important concerns (Winton & Turnbull, 1981). That study also reports needs as "taking a break from full time educational responsibility..." (p. 14), and their desire to have fewer and more informal contact with teachers. Some parents expressed an interest in not being involved at certain times. To insure participation from all families at this level, there is a need to also recognize the influence of these factors.

As a summary, children's impact in the family has been described in this section. It is during the early years that the disability is discovered. Also, developmental stage theories organizing reactions to the birth and continuous presence of a child with disabilities were described.

The methodology for this study, consistent with these theoretical approaches will be presented in the following section.
CHAPTER III

METHODOLOGY

This study was based on a naturalistic methodology, a flexible approach which allows the use of a previously developed and evolving interview format (Guba & Lincoln, 1985 and 1988; and Campbell, 1989). The goals of this study were to identify the parent’s process of awareness of a child’s disability, their perceptions of information, family and community support and services, and coping mechanisms used by families living in Puerto Rico.

Consistent with the naturalistic approach, this study was shaped under several beliefs about the nature of knowledge and the relation of the researcher to what is studied. One such belief is the separation of the observed from the observer; on which the erroneous assumption of complete objectivity is based. The theoretical biases and assumptions held by researchers determine the selection of facts and influence the perceptions of what is important to study. That is, how and what data is gathered and the way conclusions are presented (Campbell, 1989). Theories as a result, are shaped by personal or group held beliefs. Thus, the definition of the study, the data collection process and the resulting conclusions are all influenced by the authors’ opinions and value judgements. Given all this, this description of methodology will include a recognition of those assumptions that provided the framework and shape of this research.

Primary assumptions are those related to the population of the study. In this study it was assumed that people with children with special needs of preschool age in Puerto Rico face difficulties with access to services, with their position in their
communities and with their social life. This limited availability, accessibility of services, and support in Puerto Rico was seen as resulting in generalized levels of dissatisfaction. This discomfort, being more so for families with children with severe medical or educational needs, who are more likely to require additional external (medical and social) services.

As was previously discussed, a major concern in this study was that the existing literature about families of young children with special needs often fails to consider the ethnic composition of their families. This literature, disregards the regional, ethnic and language dominance issues as a variables affecting the access and responses to services. Furthermore, the lumping of families of children with special needs into one category-be it special needs, minority or Hispanic-fails to acknowledge the diversity under these labels. In like manner, few researchers consider the perceptions of Puerto Rican parents as a basis for creating public policy and direct service practice (Campbell, 1989; and Waggonner, 1984). Since decisions taken on the basis of research made in the United States affect services both for Puerto Ricans in the United States and Puerto Rico, research that addresses their specific situations should be developed.

Research Questions

Consistent with the naturalistic research paradigms discussed, data was not gathered to support or refute a specific hypothesis. This research attempted to develop concepts around the issues of parents of young children with disabilities in Puerto Rico. The specific questions that this study investigated are:
(1) What is the process of becoming aware of their child's disability for Puerto Rican parents living in Puerto Rico?

(2) What are some of the specific coping mechanisms adopted by families to deal with their situations?

(3) What are the perceptions of these parents about the information, direct family support and availability of services?

Approach to the Problem

In an attempt to apply the systems and the ecology of human development theories to the study of families of Puerto Rican children with special needs, a survey research method was selected. This methodology follows Bronfenbrenner's (1979) definition which states that:

An ecological experiment is an effort to investigate the progressive accommodation between the growing human organism and its environment through a systematic contrast between two or more environmental systems or their structural components... (page 37).

This type of research serves to identify both properties and processes in the system in order to better understand it. Its final goal is to define a series of determining factors affecting the family's quality of life.

This researcher obtained information about perceptions held by families of children with disabilities about their beliefs, attitudes and personal experiences. To obtain this information data was collected through the use of an informal, open ended interview format.

The possibility of variation in responses to interview questions at different time periods was considered. Results of this research will describe particular trends
reflected by the respondents at the time of the interviews. Since the subject in his/her interaction with the environment creates, recreates and defines reality, results will reflect a unique experience which, at different points in time would yield somewhat different information. Although this belief could lead to limits on the generalizability of findings, this study provides a comprehensive picture of experiences as they are construed by the actors at a particular time. This approach yields descriptive information about the direction in which parents cope with a child’s disability in the real world. Also, these limits in generalizability are seen as true for research using any kind of methodology. In this regard, Guba & Lincoln (1985) claim that in research the only possible generalization is that there is no generalization.

The instrument developed was used for the first time in this study. The questionnaire that was used for this study (see Appendix A) was organized by following previous research on the experiences of families with children with special needs from the general population in the United States (Turnbull & Turnbull, 1986, pp. 20-21). Following is a description of three categories that were used to organize this study:

1. **Family socio-demographic characteristics and resources** - This category relates to descriptive elements, such as the characteristics of the exceptionality of the disability (type and severity) and those of the family (composition, type, socio-economic status and type of dwelling). In addition, the internal adjustment made to deal with their situations was assessed.
2. **Family interactions**- This category includes the interaction among subgroups of family members on a daily or weekly basis, and their effect on the family’s well being. In this study, information for this category includes extended family and community contacts based on caretaker reports of their perceptions.

3. **Family functions**- Deals with different categories of activities or needs for which the family is responsible, and their impact on functioning. These include child’s services as well as transitions related to children’s development. In this category perceptions of services were probed through descriptions and assessments made about their conditions and quality.

An additional area of family history and process was examined. This area was comprised of a general discussion on the history of the family related to their children with disabilities. Broad and specific questions that require historic information as well as their feelings about the events were posed.

Working with a prepared questionnaire provided the opportunity for accruing the benefits of knowledge gained through the literature. It also allowed the questionnaire to be evaluated by others knowledgeable in the field. For this study one of the initial phases of instrument development involved the screening of the questionnaire by professionals and parents. After making the initial protocol, several informal discussions with researchers and service providers facilitated the process of refining the questionnaire in order to make it sound and to insure the usefulness of the results.
The outcome of this process was a final questionnaire consisting of 77 items divided into five areas. These areas were inquiries about family and their family history, their socio-economic status, family and community networks and services (see Appendix A). In this questionnaire some items were geared to obtain specific information about history, living and family situations, and services. Aggregate descriptions were made to derive an understanding of existing patterns of characteristics or actions. As an attempt to unveil the subjects' experiences as they see them, broader questions that elicit discussions of feelings, reactions and responses were posed.

Both Turnbull and Turnbull's (1986) categories, and the research questions, provide a structure by which to define the themes in the questionnaire and the research. By looking at those areas in a systematic, yet flexible manner, personal aspects of the individual family situation, as well as the intergroup aspects (the shared components of their situation) were discussed. This made possible to obtain a genuine view of the aspects affecting the lives of these families. This will indirectly allow the identification of factors that help provide appropriate services to these populations.

The importance of the subjects' self direction in an interview process led to enable respondents an opportunity to help shape research, define and interpret reactions and responses. Since people had as much control over the interview process as possible, the questionnaire format was alterable at the moment of the interview. In this research this flexibility in the interview format meant that although a familiar
format was followed, no interview was completely the same. In fact, as a result of these differences, the length of the interviews ranged from approximately an hour to three hours, and differed in focus depending on the families responses, their experiences and expressed desires. The researcher attempted to reduce her influences and biases stemming from personal values, social class and other factors by following the directions and interests of the interviewees.

Research Sample

A total of 15 Puerto Rican families of young children with special needs, represented by their primary caretaking adult were included in the sample. While sample size appears small other factors were more critical. Bronfrenbrenner states:

> It is not the size but the structure of the design that is critical...Furthermore, stratification does not necessarily demand the addition of more subjects but a systematic recognition of the different ecological contexts from which research subjects come and a deliberate selection to insure that at least the most critical and unavoidable contrast are represented systematically rather than left to chance. The lost in degrees of freedom associated with stratification is, I suggest, more than compensated for by the gain in knowledge about combinational context effects (1979, p. 39).

Careful attention was given to subject selection. A parent organization based in Río Piedras, Puerto Rico (Asociación de Padres con Niños con Impedimentos-APNI) was contacted, and its director agreed to cooperate in the process of subject identification. The sample identified is a non-probabilistic non-random sample. A sample of maximum variation was intentionally chosen on the basis of key characteristics previously identified from research such as: 1) demographics: type of family, as well as the socioeconomic information-(working, unemployed); 2) child's disability-type and level; 3) geographic-degrees of urbanness or ruralness; and their
social and service characteristics. Also considered was the number of contacts with the agency that helped in initial contact with the sample. To assure anonymity of their clients, a worker willing to help in this identification matched key characteristics with those of the people on their mailing list.

A letter of invitation was mailed to 50 people. It was necessary to send three mailings before the proposed number of families were obtained. As responses arrived their characteristics were matched with previously selected criteria of inclusion so that the next mailing would go to families with characteristics that were not represented. From these mailings, fourteen families agreed to participate and one was selected based on the recommendation from a previously interviewed parent. People that agreed to participate returned a self addressed-stamped envelope with a form indicating their initial interest in participating in this study and a phone number to contact them.

It is clear that this type of sample does not include or represent all subjects or groups nor was it intended to do so. It was only an attempt to make the sample as representative of a wide variety of needs, geographic and service conditions as this type of research allow.

Data Collection

As stated previously, the categories have been selected based upon the work of Turnbull and Turnbull (1986), and Bronfrenbrenner (1979). This particular study addressed family history, structure, interaction and functions. This approach considered factors within the immediate and extended family, social and
environmental factors directly and indirectly affecting the family’s perceptions of their situations.

All interviews were made by this researcher. At the time of the interview each subject received and signed a consent form (See Appendix B) which describes the confidentiality guidelines required of studies that involve human subjects. At a later time they received a transcript of their interview with a letter suggesting to read and approve the contents of the transcript.

The questionnaire was administered at the person’s home following an open interview format (Winton & Turnbull, 1981). The open format helped maintain flexibility and accept new themes evolving from discussions brought forth by the subjects during the interview process, thus making it more complete.

The interview process spanned from March 18, 1992 to November 15 1992, an eight month period. In the month of September no interviews were held due to the researcher’s professional responsibilities and lack of volunteers. The 15 interviews were recorded with a cassette recorder. The recorder was used to insure accuracy and avoid dependence on the researcher’s memory or field notes. Transcriptions were done verbatim and were completed on January 1993. Also, information about the site was gathered by direct knowledge, observation, field notes, information provided by the interviewee, government publications and newspaper clips.

Data Analysis

The interview was tape recorded and transcribed. These transcripts were read, summarized and coded using previously defined categories developed to yield answers
to the research questions in the study. These categories were further refined as the analysis developed leading to the inclusion of new categories and the elimination of those no longer applicable.

Previous and newly developed categories (see Appendix C) served to categorize the interview transcripts. These categories were used in the search for responses that answered the research questions and summarized the information. At the same time unexpected themes were accepted in the analysis as a way to include important issues that were discussed by parents.

Then a search for repeatable regularities (p. 67) was made in an attempt to look for patterns or explanations. Some exemplary instances of the repeated theme is included as an illustration with an indication of the number of families it represents. Unique salient themes were included too. There were other excerpts included in order to provide context and to add meaning.

Several perceived relationships or insights that were initially developed were explored further through informal conversations with several expert reporters. These took the form of the key interview in which the reporters were confronted with key information and conclusions uncovered to get reactions and ascertain the credibility of the conclusions attained. These were three parents, one special education service provider and two legal aid lawyers who have been in charge of special education cases. The notion of triangulation is important here. Triangulation "is useful for verifying information on the same event from different actors or participants...Once a proposition has been confirmed by two or more measurement processes, the
uncertainty of its interpretation is greatly reduced..." (Guba & Lincoln, 1988, p. 257). This process also helps establish valid conclusions. In terms of validity, Bronfrenbrenner’s (1979) definition eight is relevant:

Ecological validity refers to the extent to which the environment experienced by the subjects in a scientific investigation has the properties it is supposed or assumed to have by the investigator. (p. 29)

This definition relates validity directly to the setting of the investigation and states it is directly influenced by it. The setting is seen as influencing both the subjects and the researcher’s interpretation of the subject’s experience. It also supports the notion that states that:

...the significance of much of the behavior taking place in a given social setting can be understood, provided the observer has participated in a given setting in roles similar to those taken by the participants and is a member of or has had extensive experience in the subculture in which the setting occurs and form which the actors come (p. 31).

In this study, reliability and validity notions were defined according to Miles and Huberman (1984), Guba and Lincoln (1988), and Bronfrenbrenner (1979). For reliability, double categorization by only one coder was used since it was not possible to obtain volunteers to do the cross person coding. A simple formula suggested by Miles and Huberman (1984) was used (reliability = # of agreements/total number of agreements + disagreements). This means that the information gathered from all the sources was analyzed at two different periods, using the categories presented on Appendix C and then looking for commonalities on the categorization. In fact, for the lone researcher Miles & Huberman (1984) advise an index of 90% before going on (p. 64) and the initial one was 80% which is an appropriate level for two coder.
In order to counteract any error, audits were made by the researcher at several different points in data analysis.

One of the problems found as analysis started was that although categories were unidimensional—differences between categories were clear and excerpts with consistent similarities could be categorized within them—the same was not true for the data. Excerpts for categories were not mutually exclusive, and some overlapping occurred. The recoding also allowed the reconsideration of those excerpts placed on several categories. After getting a validity index, a decision was made in the excerpts with multiple categories as of which category was most applicable.

One important aspect that is frequently considered when discussing research topics such as these, where people are required to make retrospective accounts, is the effects of memory on our ability to obtain accurate conclusions (Richardson, 1990). Although Richardson study is based on a theme not directly related to the case in point, the possibility of the effect of distortions caused by memory in this study should be considered. Families of preschool age children were selected with the expectation that they at least would have passed by the first major transition in gaining their awareness of the child’s disability. It is expected, however, that by working with families that have preschool children at the time of the study the negative effects of memory will be reduced to the lowest level possible.
CHAPTER IV
PRESENTATION AND ANALYSIS OF DATA

This section describes the data obtained through direct interviews of the families selected. The information is presented in two parts. In the first part the demographic information of the families is presented. The second part analyses the data according to the research questions posed in this study using the qualitative procedures described by Guba & Lincoln (1985 & 1988) and Miles & Huberman (1984).

Demographic information

This section serves as an introductory sketch of the global sample description, important aspects of the places in which they live, and finally a short summary of the discussion of the most salient issues for each of the families presented.

The sample comprised of fifteen (15) families with young children with disabilities (ages three to five years of age). Parental ages ranged from 27 to 43 years of age for males, and 24 to 40 the females. All except four respondents were married and only two were single female head of households. The remaining two were involved in what appeared to be stable consensual relationships. Table 2 describes families according to marital status, employment, offspring and children with disabilities.

There were variations in terms of ages and exceptionality (see Table 2). Children ages fluctuated between three years to children who had just become five years of age. Those in the five years bracket were four at the time of initial contact.
Table 2
Selected Family Characteristics

<table>
<thead>
<tr>
<th>ID</th>
<th>marital status</th>
<th>employment status</th>
<th>children in dwelling</th>
<th>children with disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>FA1</td>
<td>married</td>
<td>salesman(\delta) housewife? (NW)</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>LE2</td>
<td>married</td>
<td>realtor(\delta) Gov. planner?</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>CI3</td>
<td>married</td>
<td>Legislator clerk (\delta) Teacher?</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>OO4</td>
<td>consensual marriage</td>
<td>Paint/construct(\delta) housewife? (NW)</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>SU5</td>
<td>married</td>
<td>hamburger stand(\delta) housewife (NW)</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>GA6</td>
<td>married</td>
<td>ice cream sales(\delta) student/housewife? (NW)</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>AE7</td>
<td>married</td>
<td>water co. worker(\delta) clerk?</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>LI8</td>
<td>married</td>
<td>carpenter(\delta) housewife? (NW)</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>EO9</td>
<td>divorced</td>
<td>rehab. counselor?</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>LA10</td>
<td>married</td>
<td>municipal brigade worker(\delta) housewife? (NW)</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>SE11</td>
<td>divorced</td>
<td>housewife? (NW)</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>NE12</td>
<td>married</td>
<td>computer programmer(\delta) housewife? (NW)</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>SI13</td>
<td>consensual marriage</td>
<td>disabled worker(\delta) housewife? (NW)</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>MO14</td>
<td>married</td>
<td>production comptroller(\delta) housewife? (NW)</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>AU15</td>
<td>married</td>
<td>construction(\delta) housewife? (NW)</td>
<td>3</td>
<td>1</td>
</tr>
</tbody>
</table>
and were considered appropriate for the study since they had no contact with elementary level school services. The types of exceptionality that were described by parents were Down’s syndrome (3, 20%), spina bifida and hydrocephaly (one, 7%), cerebral palsy (five, 33.%), hearing and visually impaired (one each, 13.3%), metabolic disorders of an undetermined type (one, 7%), autism (one, 7%), Cornelia D’Lange (one, 7%) and two undiagnosed (13%). These disability related characteristics led to differences in the periods when they became apparent and thus in the times when families started dealing with them.

One of the important factors to be discussed in this study was the level of the disability. In pages to come, relations to parental reactions, and the type of coping strategies will become clear. As seen in Table 3, this sample there was one (7%) child with mild conditions and two (13%) described as mild to moderate, six (40%) families with children with moderate level conditions, one (7%) with moderate to severe conditions and five with severe conditions of differing diagnosis (33%). Table 3 describes the geographic, age, and type of conditions for the selected sample. In it family income reflected some fluctuation.

In terms of their employment status, most families had at least one working member, but there were 13 % in which adult members were unemployed. The majority of the households with working people (67%) had only one member working. In all of them (67%), women stayed at home. In those situations women were responsible for the care, health needs, and service provision for their children.
<table>
<thead>
<tr>
<th>ID</th>
<th>TOWN</th>
<th>AGE</th>
<th>TYPE OF DISABILITY</th>
<th>OTHER CONDITIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>FA1</td>
<td>Bayamón</td>
<td>3</td>
<td>Cerebral Palsy</td>
<td>Motor language level: severe</td>
</tr>
<tr>
<td>LE2</td>
<td>Río Piedras</td>
<td>3</td>
<td>Metabolic Disorder</td>
<td>Not identified Level: severe</td>
</tr>
<tr>
<td>* CI3</td>
<td>Mayagüez</td>
<td>4</td>
<td>C.P. Congenital Hemiparesis</td>
<td>Motor speech language Level: mild-moderate</td>
</tr>
<tr>
<td>004</td>
<td>Juncos</td>
<td>3</td>
<td>C. P. Cuadriplegic</td>
<td>Severe asthma language Level: mild to moderate</td>
</tr>
<tr>
<td>*SU5</td>
<td>Bayamón</td>
<td>4</td>
<td>Visual</td>
<td>Mother C. P., brother behavior Level: mild</td>
</tr>
<tr>
<td>GA6</td>
<td>Ponce</td>
<td>4</td>
<td>Hearing impaired</td>
<td>respiratory problems, infections. Level: Mod.</td>
</tr>
<tr>
<td>AE7</td>
<td>Trujillo. Alto</td>
<td>5</td>
<td>Cerebral Palsy</td>
<td>Gross and fine motor speech Level: Mod.</td>
</tr>
<tr>
<td>*LI8</td>
<td>San Germán</td>
<td>3</td>
<td>Down’s syndrome microcephalus</td>
<td>Speech motor respiratory Level: severe</td>
</tr>
<tr>
<td>*EO9</td>
<td>Río Piedras</td>
<td>4</td>
<td>Cornellia D’Lange</td>
<td>Motor, speech Level: moderate-severe</td>
</tr>
<tr>
<td>LA10</td>
<td>Naranjito</td>
<td>3</td>
<td>Undiagnosed</td>
<td>Slow development Level: Severe</td>
</tr>
<tr>
<td>SE11</td>
<td>Gurabo</td>
<td>4</td>
<td>Autism</td>
<td>Level: Severe</td>
</tr>
<tr>
<td>*NE12</td>
<td>Caguas</td>
<td>3</td>
<td>Spina bifida, Hydrocephali</td>
<td>Epileptic Level: Moderate</td>
</tr>
<tr>
<td>*SI13</td>
<td>Camuy</td>
<td>3</td>
<td>Undiagnosed</td>
<td>Language motor Level: Moderate</td>
</tr>
<tr>
<td>*MO14</td>
<td>Vieques</td>
<td>3</td>
<td>Down’s syndrome</td>
<td>Language Motor Level: Moderate</td>
</tr>
<tr>
<td>*AU15</td>
<td>Arecibo</td>
<td>5</td>
<td>Down’s syndrome</td>
<td>Language motor Level: Moderate</td>
</tr>
</tbody>
</table>
with disabilities as well as for homemaking duties. In 13% of the families both parents worked. In these cases they made different arrangements in the distribution of responsibilities which will be discussed later in another section.

Table 4
Family income

<table>
<thead>
<tr>
<th>Income category</th>
<th># of respondents</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>$2,000-$6,000</td>
<td>4</td>
<td>27</td>
</tr>
<tr>
<td>$6,001-$10,000</td>
<td>2</td>
<td>13</td>
</tr>
<tr>
<td>$10,001-$14,000</td>
<td>4</td>
<td>27</td>
</tr>
<tr>
<td>$14,001-$18,000</td>
<td>2</td>
<td>13</td>
</tr>
<tr>
<td>$18,001-or more</td>
<td>3</td>
<td>20</td>
</tr>
</tbody>
</table>

The majority of the respondents fell under the level of $14,001, lower than the average income in Puerto Rico. Of the highest income category, two workers' incomes were boosted by employed in the federal government, or under a federal contract the other through a federal proposal. The lowest income was that of a family from San Germán whose unemployed father reported a family income of $3,456.

Family jobs were within the professional, sales, skilled and semi-skilled categories, with two self employed people. Of those in the professional category, there was a realtor, a government planner, a legislative clerk, a teacher, a computer programmer and a rehabilitation counselor. In the sales category there was one toy store salesman. Skilled and semi-skilled jobs included a paint & construction workers, a water company worker, a private postal clerk, a municipal brigade
worker, and a production comptroller for the NAVY. Self-employed people were a hamburger stand operator, and an ice cream truck operators. The majority of the women (73%) were working as housewives. The unemployed people were a disabled worker, and a worker who had recently lost his construction work. Table 5 summarizes this data.

The selection process led to subjects in a variety of settings. Some respondents were from the northern towns of Bayamón, Río Piedras, Trujillo Alto, Arecibo and from the southern town of Ponce. In the northwest the town of Camuy and in the west were Mayagüez, and San Germán were visited. Towns represented in different parts of the center of the island are Naranjito, (to the west) Caguas, Gurabo, Juncos. A respondent from an adjacent island, Vieques, was also included. Urban sites represented sliding fee projects for low to moderate income people, private homes in urbanizations or the center of towns, and apartments set in cooperative arrangements. Of those dwellings, the ones located in the metropolitan urban areas included urbanizations (rows of similar houses built by a contractor), one apartment in a cooperative building and two in housing projects. Rural respondents comprised residents from three houses in mountains and three from barrios (low income wards of family built homes). All Educational Regions, as defined by the Department of Education, were represented (see figure 1, Appendix D).

These housing facilities offered different conditions for families with children with disabilities. They varied from private to public housing, from apartments with swimming pools to low income barrios (low income wards of family built homes).
<table>
<thead>
<tr>
<th>Id No.</th>
<th>Town of residence</th>
<th>Employment status</th>
<th>schooling</th>
<th>Income</th>
</tr>
</thead>
<tbody>
<tr>
<td>FA1</td>
<td>Bayamón</td>
<td>Salesman Housewife</td>
<td>Univ. 1 year&lt;br&gt;Univ 2 assoc degrees</td>
<td>$6,000-10,000</td>
</tr>
<tr>
<td>LE2</td>
<td>Río Piedras</td>
<td>Realtor Planner</td>
<td>MA planning&lt;br&gt;MA planning</td>
<td>14,000+</td>
</tr>
<tr>
<td>CI3</td>
<td>Mayagüez</td>
<td>Legislator clerk&lt;br&gt;Teacher</td>
<td>BA&lt;br&gt;BA</td>
<td>14,000+</td>
</tr>
<tr>
<td>OO4</td>
<td>Juncos</td>
<td>Paint &amp; construction Housewife</td>
<td>Associate Degrees both</td>
<td>10,000-14,000</td>
</tr>
<tr>
<td>SU5</td>
<td>Bayamón</td>
<td>Hamburger stand Housewife</td>
<td>High school&lt;br&gt;High school</td>
<td>10,000-14,000</td>
</tr>
<tr>
<td>GA6</td>
<td>Ponce</td>
<td>Ice cream salesman student/housewife</td>
<td>Univ (2 years)&lt;br&gt;Univ (1 year)</td>
<td>6,000-10,000</td>
</tr>
<tr>
<td>AE7</td>
<td>Trujillo Alto</td>
<td>Water Co. worker&lt;br&gt;Private Post clerk</td>
<td>Voc. High School degree&lt;br&gt;Assoc. degree</td>
<td>10,000-14,000</td>
</tr>
<tr>
<td>LI8</td>
<td>San Germán</td>
<td>Carpenter Housewife</td>
<td>elementary school both</td>
<td>2,000-6,000</td>
</tr>
<tr>
<td>EO9</td>
<td>Río Piedras</td>
<td>Rehabilitation Counselor</td>
<td>BA. + 1 year graduate</td>
<td>14,000 +</td>
</tr>
<tr>
<td>LA10</td>
<td>Naranjito</td>
<td>Municipal Brigade Housewife</td>
<td>High school&lt;br&gt;High School</td>
<td>2,000-6,000</td>
</tr>
<tr>
<td>SE11</td>
<td>Gurabo</td>
<td>Housewife</td>
<td>Bachelor Arts</td>
<td>10,000-14,000</td>
</tr>
<tr>
<td>NE12</td>
<td>Caguas</td>
<td>Computer programmer&lt;br&gt;Housewife</td>
<td>Assoc Degree&lt;br&gt;Univ. 3 years</td>
<td>10,000-14,000</td>
</tr>
<tr>
<td>SI13</td>
<td>Camuy</td>
<td>Disabled worker Housewife</td>
<td>High School&lt;br&gt;High School</td>
<td>2,000-6,000</td>
</tr>
<tr>
<td>MO14</td>
<td>Vieques</td>
<td>Production comptrol&lt;br&gt;NAVY&lt;br&gt;Housewife</td>
<td>High School&lt;br&gt;High School</td>
<td>14,000 +</td>
</tr>
<tr>
<td>AU15</td>
<td>Arecibo</td>
<td>Construction Housewife</td>
<td>High School&lt;br&gt;Univ-one year</td>
<td>10,000-14,000</td>
</tr>
</tbody>
</table>
Most importantly, they differed in the access to services they afforded. The following vignettes summarize the most salient features discussed in the interviews.

1. Bayamón-The married mother of a preschool child was interviewed. This couple lives in an apartment in a very big sliding fee scale housing project in the town of Bayamón. This town is very close to the main metropolitan area of San Juan. The project has closed access and people have to identify themselves to get in. The streets were empty on several occasions I visited. The husband works as a salesman and the wife stays at home although she is trained as a secretary. Her son’s disability related requirements keeps her home. They have one boy with Cerebral Palsy.

A few years before the birth of her only child, this mother had delivered a premature baby that died within a few hours. In her second delivery, she had a premature baby of 33 weeks. Her wish for information about the child’s conditions had been partially fulfilled when, after looking for the doctor for several days, she was casually informed that her child had suffered from lack of oxygen at birth (apnea). She reported that at that time she felt anger at the doctor for not taking the time to explain the condition to her and from the sparse explanations given when he was forced to. She was fearful but hopeful about her child’s condition.

The baby was sent to the Public Hospital which had the services the baby needed. The hospital he was in was not equipped to deal with a premature baby with complications. Although the baby’s situation was considered an emergency and she is willing to pay in cash for some services. Although some services were covered by
her medical plan, she had to wait for the Medical Plan authorization. Due to bureaucratic delays, the baby was not received for care until the following day.

As soon as the baby was placed in the public facility, she returned to the secretarial work she held at the time, without a real sense of her baby’s situation and continued visiting the baby in the hospital. Work took her mind away from the situation, but also presented her from realizing the baby’s conditions. After the baby’s arrival to the house, she had to go to the Medical Center for the baby’s follow ups. This mother did not realize the seriousness of what her son had because she had no previous experiences with babies. She saw his inability to nurse, and other behavior, as part of baby’s normal range of behaviors. She worked, so this meant that, for the first few visits to the pediatrician, the child was accompanied by a babysitter whom the mother felt knew about his development better. By the time she was directly informed about his disability the baby was 6 months old. Time had allowed her a period of understanding and acceptance. She also felt that if she had been told earlier she would have looked for help.

Her awareness of the child’s disability was slow in coming and she identified several factors related to this slowness. She also had serious complaints about the limited help given by her husband, and about her difficulties with her child’s placement in any program of the Department from Education.

2. Río Piedras-The second interview represents a couple living in a closed access middle class urbanization in Río Piedras, a section of San Juan. It should be noted that San Juan is considered part of the most important metropolitan urban area
of Puerto Rico. It is also the place where most centralized services are found. He
works as a realtor and she is a planner in a government office. They have a girl with
metabolic disorders.

The mother had a previous miscarriage and during this pregnancy she
experienced complications. The girl was born through Cesarean section and cried
well. She, nevertheless, had a twitch in her eyes and hand, noticed by her aunt’s
neighbor while babysitting her. The girl was taken to the hospital the following day
with convulsions and testing was started to figure out what she had. Reports provided
comfort because they confirmed the girl did not have some conditions considered as
the "most terrible". The mother also started noticing the full implications of the
disability by comparing her child with another child, her niece. Her girl was much
slower.

The diagnosis is metabolic disorder but the type is still unknown. They had a
stable diet but they did not know if it was the right one, nor about the full
implications of the disability nor of its impact on the child’s future.

3. Mayagüez-Mayagüez, the largest city on the west coast, was home to this
couple. Her parent’s house, a big wooden house in town, near the main commercial
center is their residence. Their house is also near the centralized medical center and
other regional services for the disabled. This married couple were both working (he
as a legislative clerk and she as a teacher). They have two (2) children, one (1) of
them with cerebral palsy. Both children were present during the interview.
Her first pregnancy was complicated by a fibroma that made them feel unsure of whether the pregnancy was going to come to term. During pregnancy she was also anemic and bleeding. She had an apparently normal delivery and for a while the baby seemed to be doing fine.

Through the first year the child appeared to be developing normally. It was his paternal grandfather, the physician, who discovered the disability. He made careful observations, noticed the condition and informed them. The child was immediately taken to his pediatrician and they confirmed the diagnosis. That led to a change in pediatricians since they were concerned about the fact that they had been taking the baby to a doctor for a full year who had not detected the condition.

That started them in the process of testing and inquiry. During that process they were given several erroneous diagnoses. They were directly referred to the early intervention services available in the medical center. At the time of the interview they were in transition to services from the Department of Education and discovering their way in the service maze.

4. Juncos-The family from Juncos consisted of a consensually married couple and their four children. They lived in a rural community, in the farming area of town. Their cement house was left to her by her father when he died. It is placed in a rapidly developing community of houses that appeared to have been constructed by their owners. They have no sewer service but have all the other commodities. He works in a paint and construction company and she is a housewife. One of their four children has Cerebral Palsy.
The pregnancy went well but the mother went into labor the seventh month. Labor was long and difficult, and the baby was weak. Physicians decided to let it be born naturally. Retrospectively, she felt it was the wrong decision since he suffered perinatal suffocation. The child was born weighing 3.14 pounds and was placed in an incubator. The pediatrician advised them immediately about the possible consequences that his prematurity and low birth weight might have and asked them to observe.

During his first month, they were only worried about his survival. Upon the couple's request, the child was sent home after a week, still very small. Home care gave very good results, for after a couple of months he grew to 20 pounds of weigh.

Their child received follow ups in the Regional Medical Center in Caguas. He was later referred by his pediatrician in Caguas to the Pediatric Center in Río Piedras because he was not doing what was expected of a child his age. They did not really realize their child's condition until the child started in the clinic in this Pediatric Center (at around 5-6 months). While waiting for her turn in one of her first visits to the Pediatric center, the social worker invited her to a conference where cerebral palsy and different motor conditions that it involves were explained. She remembered hearing about quadriplegia without realizing that her son had it. She went to the scheduled visit and the physician informed her about the child's condition in a very dry manner. He showed little concern for the mother's feelings. During that visit she started worrying, wondering about the implications of his condition. She described
that moment as a bomb which had exploded. Among other things she worried that he might be a "vegetable". The social worker was very helpful at the time.

Their child was referred to public services but they provided him with fewer services than what he was supposed to get. They also described problems with other health professionals. Through a neighbor she got him into a service center ran by a nun in Juncos. It is there that her child gets satisfactory, flexible and comprehensive preschool services.

5. Bayamón-This married couple and their three children live in a small low income housing project in the town of Bayamón. This community consists of several buildings with row apartments of four to five units. On school days he works as a hamburger stand salesman and she is a housewife. Of their three children, two have disabilities. The mother participated in this interview.

She began her second pregnancy with an increase in epileptic seizures and bleeding. She had X-Rays and was given antibiotics during this pregnancy. She, nevertheless, had a good delivery.

The girl’s birth and the next two months appeared uneventful. Her disability was detected by observation and comparison. When her daughter was three months old she discovered strabismus but her doctor did not pay too much attention to the mother’s claims. Dissatisfied by his response, she decided to ask the doctor who was treating her son’s disability. She (the doctor) agreed with the mother, and gave the girl the referral when she was about nine months. Because of this referral the girl is accepted into the strabismus clinic.
At the beginning the mother worried about having to deal with two children with disabilities. She also expressed concerns about her competence to deal with a disability she did not know anything about: that of sight. She felt initially rebellious but after two or three days started looking for information about what to do. With this, her second child with disabilities, she accepted it more quickly than with her first, a boy who is behaviorally involved.

The girl was almost two and a half when she got her into early intervention. It was during one of her brother’s appointments that the social worker noticed that during their long wait the girl was very quiet and passive. Besides the strabismus, the girl did not talk for her first two and a half years. The doctor suggested to her that taking care of her sight might help with her speech. Accordingly the girl started talking a few months after she got the glasses.

The early intervention service was delayed because, although she got the referral, the person that deals with the appointments was on vacation. No provision for substitution of personnel was done. The mother called frequently and spent about two months waiting for their first appointment. After the girl was in early intervention the information flow became easier. Although she did not get information or referral for services from the strabismus clinic she got it from the early intervention staff. They helped make a smooth transition to Head Start, where she made good progress. At the time of the interview the mother was organizing her transition to regular services in the local public school.
6. Ponce-The largest city and urban area in the south of the island was home to the sixth family. This family lived in a poor barrio (a low income ward of family built homes) halfway between the highest and lowest point of a hill barren of trees not too far from the center of town. Their house was a wooden rented house with a beautiful view of the valley. They are a married couple. He works as an ice cream truck salesman and she is a student. They have two children and both are hearing and language impaired.

Doctors had already suggested the possible birth of a child with disabilities because of a miscarriage and a previous difficult birth. The birth was of a full gestation boy who was hurt at birth with the forceps. She had two hemorrhages after that birth and a natural abortion. She was hospitalized because her uterus was swollen and had an ulcer that did not heal. Prior to the procedures she was given a pregnancy test which was negative but two weeks later she was notified pregnant.

At the third month she started having problems with her pregnancy. The fetus was too low and had hemorrhages because of the ulcers. Soon after she entered her sixth month of pregnancy she experienced abortion symptoms and the medical staff helped her maintain the pregnancy for three more weeks. While she was in the hospital taking care of her son who was ill the delivery started. When the physicians checked she did not have much amniotic fluid.

The delivery process was difficult. Her doctors had an argument over the advisability of continuation of the delivery, although the delivery was already in process. They decided to try to hold the delivery unsuccessfully. The girl was a
premature baby-six and a half months. Because the hospital was crowded she gave
birth in a hospital cot. The baby was very swollen because of all the liquid she had
swallowed.

A month or two after her daughter was born she started having problems with
the ears. Due to ear secretions her daughter’s first operation, (in which she got ear
tubes) was done when she was eight months. After several operations her ears
produced more water and a green mucosity. The family had several bad experiences
with the health services at the Ponce regional hospital. During that time they found a
doctor willing to provide services for payment in installments and a comprehensive
service center run by a well known nun in Ponce.

7. Trujillo Alto-The family from Trujillo Alto consisted of a married couple
and their child with cerebral palsy. He worked as a water company brigade worker
and she as a private post office clerk. They live in a humble one story wooden
house built on her father’s property.

During her fifth month of pregnancy she had the premonition that something
might go wrong. She did not buy clothes for the baby until the seventh month, the
month in which she also went into labor. Since the baby looked like he might be
premature she was referred to the public University sponsored Hospital because they
have the equipment and the experience for these types of children. She spent two
days waiting and delivered her child with a placenta abrupt. She blamed this
condition to the amniocentesis that was performed on her by interns at the University
hospital. The interns also performed many tests on her after the baby was born due
to high fevers that she felt were unnecessary. Her perceptions were confirmed by the attending doctor when he arrived.

She was released from the hospital in two days and the baby two months later. During that time, the baby was in the Neonatal Intensive Care Unit for a month and then another month in the high risk nursery- where they place babies after being in the Neonatal Unit. She spent those months, while recovering from a cesarean, going to the Public Hospital every day, taking two public buses. Immediately after the child was released he was referred to the high risk clinic and the continuity clinic. Because of that they started getting different types of appointments.

They started noticing differences while in the Nursery. Doctors could not ascertain his condition since his health was very delicate and they continued testing. Two months after birth they were told that there was cerebral palsy and a brain hemorrhage. Two months later he was given a CT Scan which identified damage. The baby was then referred to a neurologist.

The mother noticed additional differences in his development and asked to be referred for physical evaluation. She asked for services related to his physical disability and was kept waiting. For instance, she got an appointment when the child was eight months which was canceled and, had not been rescheduled. A similar thing happened to her referral to the orthopedist. The Public Hospital lost her child’s referral and she waited a year for an appointment. Sacrificing their scarce resources the family started taking him to a private optometrist and orthopedist. The orthopedist’s referral was found later on the child’s record.
She was also the one that noticed his recurrent colds which led to the diagnosis of asthma. This condition has brought about hospitalizations on four or five occasions. About a year before the interview was held, medication was discontinued. After the first hospital stay due to his asthma she substantiated the previously noticed differences in development. He would not crawl nor move like other children. The early intervention program is a service separate from the others. She was able to place him in early intervention and was directly transitioned into Head Start.

8. San Germán-In the mountainous part of the town of San Germán lives the eighth family interviewed. This town, the second oldest town of the island, is near Mayagüez. The family lived in a house in a marginal road on a mountain. They were a married couple: an unemployed carpenter, his wife a housewife, and three children one of which had Down’s syndrome.

She had an uneventful pregnancy and when their child was born she was informed her child was healthy. When she saw him she noticed he was chubby and had Asian features. The nurses even asked whether his father was asian.

During his hospital stay of about seven days they could only see him from the outside of the Neonatal Unit. A few days after his birth, she noticed that her child was moved from the regular nursery to where they place children that were not well. As a result of this, she knew something was wrong but "did not want to know". Four to seven days later these parents still did not know why their child was moved since the doctor did not explain their child’s situation clearly.
The child was followed through in Mayagüez Medical Center with limited testing and medical follow ups in the clinic. They were referred to the regional center in Mayagüez for educational services, but it was too far and they could not take him every day. At the time of the interview they had not received educational or therapeutic services for their child.

9. Río Piedras-This family is constituted of a divorced mother and her young child with disabilities residing in Río Piedras (a town that is part of San Juan). She works as a rehabilitation counselor in a Vocational Rehabilitation Office.

This mother claims to have had premonitions in which she felt something "abnormal" during her pregnancy. Several times during her pregnancy she started uncontrollably crying due to her anguish. She discussed it with her friends who disregarded her concerns. The physicians noticed her abdomen was too little and started testing.

The eighth month of pregnancy also coincided with moving and problems with her husband who did not help in moving, nor in any of the economic aspects of family life due to his drug habit and violence (both verbally and physically). This domestic violence was seen as detrimental during pregnancy. Furthermore, she thought he was only addicted to liquor but, while attempting reconciliation, she discovered his involvement with heavy drugs and decided to divorce him.

Her parents helped her by babysitting at their home but she has to go to their house every evening to feed him and put him to bed. She raised complaints related to
the limitations this arrangement caused in her social, and personal life, and about the effects of child related changes in her career.

10. Naranjito-The married mother from a family from the town of Naranjito was interviewed. Naranjito is a town in the mountainous center of the island. The father works as municipal brigade worker and the mother as a housewife. They have four children two of which have disabilities.

Her last two daughters had the same severe disability. These children went through a similar developmental process. They both looked normal and very healthy when they were born, but after a few months they started having numerous epileptic seizures and started losing their developmental gains. One of them had died eight months before the interview.

She discovered the disability by comparing her child’s progress to that of other children. She realized her second daughter had the same disability as the first one. She cried, became very nervous, scared and desperate. She locked herself in and did not talk to anyone except to her mother. She did not accept her child’s condition because she knew it represented a big change in her life. For a while, she was angry at the doctors, at her husband and at her children. She complained about the lack of cooperation and participation from her husband and other family members. As time went by, her ability to manage the disability, together with her participation in religious groups, helped her change her perceptions and reframe her situation.

11. Gurabo-The mother of this family from an urbanization in Gurabo, a small town near Caguas, is a divorced housewife. She gets child support which helps
her get by economically. She has three children one of which has a disability: autism.

The boy was born apparently well and at about two years of age started regressing. She also noticed that he became very active and restless. At the age of two, upon recommendation of an family member who worked there, he was taken to the Neurological Reorganization Center. This recommendation helped reduce the program waiting time for their son so that the boy began the therapy without diagnosis. She started worrying about the child because of his behavioral differences and his regression in language, through comparing her child with older autistic children and with the comments other mothers made.

At that time the mother was in the beginning stages of her divorce. The only support for their child she got from the child's father. Some neurological tests came out negative. She was then referred to the developmental pediatrician who confirmed what she suspected and recommended resignation and their speech therapy program. She described her feelings about her son's situation as harder and more lasting than the difficulties and emotions felt in the divorce process.

Early after his diagnosis she was faced with a choice: placing her child the Neurological Reorganization Program, which was private or the Autism Center, which was a Health Department facility. She believed the Neurological Reorganization Program was better and her child was enrolled since May. She was referred by the neurologist to the Medical Center's autism program and she refused to take him, which later she regrets. She left The Neurological Center because of
differences with their parental policies. It has since been closed because of economic problems. At the time of the interview the child was placed in a Head Start Program and received private speech services, the only services available to the child, although they were not completely to the mother’s satisfaction.

She also described difficulties in obtaining cooperation and participation from her family members in order to work or for leisure activities. She claims loneliness.

12. Caguas-A family from an urbanization in the town of Caguas has an only child: a girl with spina bifida mielomeningocele. They live in a recently developed urbanization in one of the town’s limits.

At around the third month of gestation she had abortion symptoms which repeated around the sixth month. She then had to quit her job as a cashier in a Department store in order to rest. All through her pregnancy she had intuitions that something was wrong.

During pregnancy she had a clue. In her doctor’s office there was a machine used to make office "sonograms" and the mother noticed some stains which she felt were "not the normal ones". She asked the doctor about them because she felt they were strange but his response was that they were normal. Diagnosis came as a result of a sonogram for which she was referred during the seventh month of pregnancy. Her doctor made her get a sonogram at around 7.5 months as an emergency procedure. It is then that she first heard the word hydrocephali and asked him about it, but he refused to tell her.
As diagnosis was confirmed they went through a series of testing that led to a cesarean. The family found out more about their daughter’s condition in the hospital. Although fearful of the family’s request, she went to see the baby in order to baptize her and discovered that she was not as bad as she expected. Doctors had made them believe that she would be completely abnormal and when she went to see her she noticed there were others that looked worst. Also the positive comments of the nursing staff made her feel better.

At the time of the interview they felt well organized. The husband was working and studying and the woman a housewife who did house and child related errands. They were starting to have family amusement and activities as a couple.

13. Camuy—This family from a rural community in the town of Camuy were in a consensual and stable marriage relationship. Neither one of the adults were employed. He stated that he was disabled and she worked as a housewife. They have three children, two of them have disabilities. They get economic assistance through food stamps.

During this pregnancy she lost 15 pounds not knowing it was due to thyroid complications and gestational diabetes. She was hospitalized on the third month of the pregnancy with asthma. It was complicated with a bronco-pneumonia and was medicated for each of the conditions. Although the doctor assured her that the medication would not harm the baby, she relates her daughter’s condition to all the medication she was given during pregnancy. She did not have as many complications with her other children.
She got some realization about the disability when her daughter was born because of her differences. For instance, she had strabismus. At the same time, she was referred both to the medical center and to the clinic for children with disabilities. Through these appointments they discovered that the girl had slow motor development. Information, given to her by a doctor she trusted, led them to notice that the girl did not develop appropriately. She also noticed, by comparing with other children her age, that her daughter was different. When she asked the doctor about this she confirmed her perceptions about her daughter's delays. She stated that at her 3.5 years of age she behaved like a girl who is only two months old. At the time of the interview the mother had been given a 1.5 years equivalency age.

They described difficulties attending to the girl's appointments in the centralized center in San Juan because of economic problems and with transportation.

14. Vieques-This family lived in a small island near the south-eastern part of Puerto Rico, between Puerto Rico and the Virgin Islands. There are ferries and planes that provide transportation to the island. Vieques is 21 mile long and much of it has been taken by the U. S. Navy since World War II. The family consists of a married couple and their two children, one an adolescent the other a preschooler with Down's syndrome. The husband is a production comptroller in the local United States Navy base and she works as a housewife. They have a comfortable cement house in one of the island's central communities.

During a pregnancy she was recommended rest for two weeks because of abortion symptoms. She did not know about the baby's condition because she did not
get an amniocentesis. The father immediately noticed there was something wrong with their child’s legs but the doctor did not express much concern. After the third day, the doctor started explaining what he thought the child had. Then, he suggested testing that had to be sent to the United States for analysis. They had to borrow $300 for that test since she wanted to know exactly what the baby had. A month after his birth the official letter came confirming his disability.

The mother did not know about Down's syndrome and started getting curious about the condition. First, she went to see the baby, and after seeing him and holding him she started to feel better. When the baby was taken home she started looking at him and noticed his protruding tongue, but as he grew, it became less apparent. At the moment of the interview the child had been well integrated to family life but had only received a year of physical therapy and no educational services.

15. Arecibo-This family lives in Arecibo, a town in the north west of the island. This family is comprised of a married couple, he is a construction worker, she a housewife and their three children, one of which has a disability-Down’s syndrome. They live in a small barrio (a low income ward of family built homes). Theirs is a comfortable yet humble wooden house with a surrounding yard fenced in. Other residents in the street seem to be related to her husband.

The mother came to this town to study. However, she could not finish her studies because of her mother’s illness. After caring for her for a while she decided to get married. She had two girls prior to the birth of the boy with disabilities. She had also had a miscarriage prior to this pregnancy. There were several signs: differences
between this and other pregnancies, a lack of breast growth, and blisters on the belly bottom and hands. Her doctors did not give importance to these signs but after she got the blisters, the mother was tested for them but never went for the results. The child’s birth came at eight months. The child was born with respiratory problems and blood infections and was changed from the private hospital he was born in to the public Regional Hospital, due to a lack of equipment to deal with these cases. She was released one day after delivery and he stayed eleven days in the hospital. He was described as low muscle tone.

The notification was extremely traumatic for her. She was given literature explaining the condition which only served to increase her fears. After birth she spent close to a year paralyzed. She then started looking for services and taking him to therapy. At the time of the interview he had finished his last year in Head Start. She described the loneliness of having to take him to appointments by herself and of the isolation in which she was living.

In the following section the research questions will be addressed.

Analysis of Responses: Process of Awareness

This section of the analysis responds to question 1 which asked: What is the process for parents becoming aware of their child’s disability among Puerto Rican families living in Puerto Rico? For the purpose of this study awareness was seen as a long term process which includes the evolving notions of what the meaning and implications of the disability is for them and for their families. Thus, in order to get
a notion of this process from the responses of the respondents, pertinent initial feelings, definitions and perceptions will be included. These terms will be briefly defined. This discussion is organized using as the central focus the period at which awareness occurred: before birth, at the delivery (or soon after), and at a longer period after birth.

**Knowledge prior to birth.** Some parents (#7, 46%) did not ponder about issues of children with disabilities prior to the birth of their children. For most of these parents lack of prior awareness was tied to previous insufficient information and personal experience. About this, the mother of a quadriplegic young boy from Juncos stated:

004-143-92... You just don’t notice that, because you are not in that situation. It is not necessary to be in the situation, only to be a little more conscious of it...

The mother of another quadriplegic boy from Bayamón concurred while discussing this issue further:

Fal-123-153...I have a family in which everything is practically normal, and I have always been a happy person in that sense. I have not had any preoccupation or problem. My family is normal. Not even deaths have touched us...Big sufferings...never existed. This has been the first thing that has made me think and value what one has, what one is...

For the father of a profoundly retarded girl with metabolic disorders from Rio Piedras a lack of awareness and thought about the possibility of having a child with disabilities coexisted with lack of contacts and information with such children:

...There might be parents with children with disabilities who understand a little bit more what a person or a child with disabilities is. Others, like in our case, thank God, previous to our daughter we had no such experience. We did not
know the meaning of a person with disabilities, how to deal with the situation...

For people with prior knowledge of others with disabilities ignoring or lack of involvement were described as common traits that could be related to this general lack of knowledge prior to the birth of a child with disabilities. The mother of a boy with Cerebral Palsy from Trujillo Alto developed a unique type of understanding after having a child with a disability:

AE7-104-131...I never had contact with disabled people...never paid attention to them. When you are not affected, unfortunately, you do not give importance to it...Because if you have not been through the situations you cannot understand them...But to understand what other persons go through...that it could happen to you, as it did happen to me. I did not think about it...

Similarly, deep comprehension was not attained by the mother prior to the birth of her son with Cerebral Palsy:

AE7-86-95...Before going through this situation, maybe I could not understand a child with problems. For me [it was] "Oh, what a pity!" but I could not understand what the mother nor the child were going through. Now I understand, when they tell me that there is a child with disabilities, what he is going through: be it the family member, the child himself and ...the teacher...

The world of families with disabilities was opened to a mother of a boy with autism from Gurabo after discovering his disability. About this she states:

SE11-122-99...Well imagine, it is as if you do not know a world, as if you did not live in a world and you do not know it, and you are not even interested in it. Because before this you saw a child with a problem you felt pity but maybe you did not understand them and you were not even interested in understanding them and it was not even your problem. But now, when you have one you meet so many, many cases...
Other parents had family members with disabilities with whom they had minimal contact. Nevertheless, that experience was not tied to their own possibilities as parents. A couple from Mayagüez recalled their lack of interest in issues of the disabled previous to her first experience with another family member with physical disabilities:

CI3-53-47 [him]...but I never thought I would face a child like this...
[her]...In my case, they amputated my father’s leg but you do not see things as you see them when you go through a few experiences. Since, at a given moment, you do not see the problem as yours, it did not affect me. I had never given thought to that...

Correspondingly, the mother of an autistic boy from Gurabo who had a bedbound cousin with cerebral palsy said:

...I did not think it would happen to me. Simply when I was in her house I talked with her a lot. She listened to you well and understood you well, everything you said until she died. And when she died I was 14 or 15 years old. I was not close to the time to think in my own family...

A mother of two severely disabled-undiagnosed girls of Naranjito summarizes previous comments by tying her understanding to her own experience:

LA10-137-111...I never thought I would go through all this. Never...And I saw children with disabilities and I’d get afraid. I said that I’d never had a child with disabilities because I would not know how to deal with him. I’d had to pass through this sour experience, since it affected my life, that of my children, my husband’s too...It is not easy...

At another point during the interview, she stated that prior to the birth of her girls she dreaded the possibility of having children with disabilities. These comments reflect how current beliefs toward the disabled stigmatize individuals with disabilities:
AE10-105-87... I was not aware of what really was coming, of the responsibility that I was going to have with my children. It was something [new] for me. For instance, when I looked at my sister-in-law’s boy, he was more disabled since he was born really very disabled: a vegetable. Then I looked at him and said "My goodness how can you deal with him?"..."Hey, girl if I had a kid like this I would not know how to deal with him. I think I'd die..."

On the other hand, some mothers had received vague hints of their child’s disabilities during their pregnancies. There was a group of mothers who stated that they had premonitions about their children’s disabilities. The mother of a boy with Down’s syndrome from Arecibo talked about hers:

Au 15-19-10...When I was pregnant I had the premonition that something was wrong, but I did not give too much importance to it...

Similarly, a woman whose child was diagnosed as having the Cornellia D’Lange syndrome did not discuss her concerns with the medical staff but confided in a co-worker prior to the birth of her child.

EO9-19-9...They say that when one is pregnant, there are people who feel that there is something happening to the child they are carrying in their womb. In my particular case, I noticed I felt there was something abnormal in my insides...I did not tell the doctors...

Mothers who discussed their concerns with others, faced professionals, friends or family members who disregarded these premonitions. For instance, a mother of a girl with spina bifida and hydrocephaly from Caguas also discussed coinciding concerns with her mother:

NE12-3-3...The doctor who took care of me used to tell me that everything was alright but since I got pregnant I had the premonition that something was not right. I told my mother "Mom, I have a premonition that the baby is not coming normal"...

Her mother’s response was to dissuade her from thinking or talking about it.
Also, during her last pregnancy, a mother of two girls with undiagnosed disabilities from Naranjito, discussed her concerns with her husband who disregarded the issue:

LA 10-27-25...I had a dream in which I saw myself in L’s delivery and the physician, when he pulled her out told me: "It is a pity that [she] has soft legs." When I woke up I told my husband [about it]. "Oh, my goodness! I had this dream"...And he told me: "With M’s problem, you think that it is going to be the same. Maybe she won’t have a disability at all". I told my husband: "No, I know that she is going to be disabled"...

She also discussed her worries with her physician who also dismissed her fears:

...I went to the hospital to tell the doctor: "Look I have this problem. My belly trembles and I think my girl is having convulsions". And she said: "No, the thing is that you are so traumatized because you think that she is going to come out also like that but you have to be patient and have faith"...

The results, as described by the mother, were as follows:

LA 10-28-24...She was born with the same condition. She was born well...[Then] the first convulsion started. Besides the reflux she had many [other] problems. She had pneumonia...and was for about a month in the hospital...

Others did not discuss their concerns because they were worried about the possible resulting negative reactions. That was the case of the mother of a young boy with cerebral palsy from Trujillo Alto:

AE7...Well I don’t know if all things like this happen to primiparae but..., around the fifth month, I had the feeling that something was going to go wrong. I did not know what it was but I felt really strange. I did not tell anyone so that they would not think that I was being negative...[or that] I did not want him and was already negative. But I felt as if something was wrong, and suddenly something started [to be] wrong, at the seventh month...
Her delivery was premature with placenta abruptio. Her child was brain damaged which affected his mobility and his speech.

Respondents obtained some awareness before delivery through physician orientation about the possibility of the disability. To that effect a young mother from Ponce who has a girl with hearing impairment states:

GA6-111-116...I was somewhat prepared since when I went to the gynecologist, the gynecologist said that if I did not get operated I would have a very difficult delivery [since] I had already lost a baby...The doctor stated...I could have children with problems or with any disability...I tried to prevent it at any cost...something happened [and] I got pregnant...And when...[the abortion symptoms] started, I started worrying. I was fearful that things would not come out well...

Her daughter has many health related problems and a hearing condition that required prolonged hospitalizations for more than a year.

The only mother of this sample that was notified a few days prior to her daughter’s birth was the mother of a girl with spina bifida, melingomyelocele from Caguas. She was notified prior to the birth and got an immediate cesarean. Her reactions to the notification and birth were strong negative emotions. She stated that at the beginning she expressed feelings of depression over her daughter’s condition:

NE12-26-26...At the beginning it was so hard. It was like a hard-to swallow mouthful. When people asked me that was a trauma for me. But now it is not...I did not want to go and see her... I said: My God, but why me?... It was as if I was ashamed, as if I was scared to be asked to show the baby,... I thought of her as a deformed baby. They had told me that she was going to have a very big head...

These reactions started to change as she saw her baby:

NE12...And then...after two days, my mom told me: "Look, let’s baptize the girl so that you go and see her. Because she was scheduled to undergo surgery supposedly on the second day...Well, that day I
went to the nursery and there were...babies with completely different but very severe conditions. And when I arrived the nurse told me "Look that is your baby.", and she looked completely normal. When I saw her...I felt happy because I was expecting a phenomenal baby completely deformed and I thought that after they talked like that...

Her husband's comments about this moment coincided in giving importance to the moment of initial contact with his daughter:

NE12-93-100...We did not feel that well because we did not really know how she was going to be and what was going to happen. But after seeing her, when she was born I went to see her and she looked normal. She did not look as they were describing her, that she was going to be a monster...

A factor in this change were the positive remarks occasionally heard from the nursing staff.

Notwithstanding the modern technology such as amniocentesis and ultrasound which could have helped some of these mothers with prenatal diagnosis of some of the disabilities, the interviews do not reflect that testing was done as a timely regular procedure. The need for some form of preventive testing is suggested in the following excerpt:

Fa1-5-3... It worried me a lot...I mean to know what was the condition...The reason why I had a premature delivery. The gynecologist...made me believe [that] I was going to have a normal delivery. I mean, even though I had the first one premature...and died...He made me believe that everything was going to work out all right. And, in fact it was very uncomfortable for me to face again another premature delivery...with the fear of losing the baby, [in the] same hospital as before. Later I felt more uncomfortable in the sense that I realized [that he could have] prevented certain things...

A woman whose child has a low incidence syndrome (Cornellia D' Lange) also talked about her need for testing:
The amniocentesis test that determines any abnormality in the fetus was not done. That is supposed to be done at eight weeks more or less. I had 33 years; that was not a risk in terms of pregnancy. But I say that doctors base themselves on the age and right now Mongoloids are being born to very young couples 20 to 25 years of age, even if it is the age to have children...

The physicians noticed the disability when the child was born as soon as they saw the baby.

In the case of the woman from Caguas, an amniocentesis was performed on the last trimester of a troubled pregnancy. She had abortion symptoms at the third and sixth months of her pregnancy, and was sent to get tested in order to determine the need for a cesarean:

... They always stated that everything was normal. But they have a small machine to make sonograms in [the doctor’s] office...and [the sonograms showed] some stains, not the normal ones that you usually see, but others. I would ask him what was that and he’d say that was normal. Something was strange...

Later she was referred for further testing. Before going she overheard the name of the disability and started worrying:

...I heard him say hydrocephali, but...what did I know about illnesses and things and names? But it [sounded] strange to me... I associated it with water and I asked. And he said: ’No go ahead and get it done and I will explain [it] to you later’;...I went and got the testing done and it revealed that the baby was coming hydrocephalic... I was almost eight months...

Testing was never suggested for a woman who got pregnant at a high risk age:

MO14-4-2...I really did not know what was coming since I never got an amniocentesis test. That was not done to me...

She had a boy with Down’s syndrome.
Meyerson (1983) has discussed the importance of genetic testing and counseling. Simply put, it consists of providing diagnostic information which could also include discussion about the possibility of "treatment, prognosis or recurrence risk for family members." Furthermore, "the family can be presented with information that will allow alternatives in the decision making process concerning treatment modalities and future pregnancies." As discussed previously a few of these interviews suggest respondent's desire for that kind of orientation.

On the other hand, other interviews reflect contradictory opinions about the usefulness of the information derived from this type of testing. A woman in Río Piedras, whose child had a hereditary syndrome, considered it useful in a preventive manner:

EO9-37-32...The doctor had suggested a genetic testing to find out if the genes combination between my husband and I coincided with this type of syndrome [so that] if we were to have other children we would be alert...

Another woman, the mother of a child with Down's syndrome from Arecibo, felt that the procedure would only lead to anxiety beforehand:

AU15-19...I also did not know about those tests...But I would not have gotten them done. It would have been worse. [Maybe the] physicians did not request them since they thought I was young. And if I had it done I would have been very disturbed from that day on, awaiting to know if it was...

In turn, a woman from Trujillo Alto complained about the inappropriateness of the moment they tested her. She felt it did not add anything to the diagnosis and it only caused further difficulties to her delivery:
AE7...They did an amniocentesis that was not necessary since my gynecologist had [sent notice] that the baby was coming with immature lungs and then they worked to make an amniocentesis to verify it. But of course, since they were all hospital interns that is what they wanted to do, practice...

Thus, opinions about the usefulness of testing appear to be dependent upon it’s timeliness and its compatibility with personal beliefs.

While some people perceived testing or prevention as useful, this sample does not show that the opportunity for being informed and evaluated was provided in a timely and systematic manner. One possible reason is the cultural tradition admonishing against termination of pregnancies (Meyerson, 1983). This tradition could lead professionals to avoid testing which has as a result been perceived as culturally inappropriate, as offensive to the patient or as against some physician’s beliefs. Another issue, which will be discussed in the service section, is the increasing tendency amongst service providers to require patients to pay for routine tests. As the following comments, made by the father of an undiagnosed girl from Camuy illustrates, this requirement has serious pernicious effects in their access to important testing:

SI13-31-22...That was in the Medical Center, in the Children’s Hospital [we were told] that if we did not bring them money to pay, they could not make the test for our girl. I told them: 'How were we supposed to get the money if we did not have the resources to pay?'... and they did not make the tests...

Due to the high cost of genetic testing it is unaccessible to most people. In Puerto Rico major medical plans do not cover genetic or prenatal diagnostic testing.
Thus, families face reduced diagnostic opportunities to know about their children’s condition in advance.

The Birth. Only one family was notified about the child’s disability soon after the child was born. The mother of the child with Cornelia D’Lange in this sample recounted her experience by saying:

EO9-32-27...As soon as the baby’s face began to appear, he [the doctor] started: 'What a pity! I am sorry. What a pity! Until I asked: 'Doctor, what is going on? And he said that 'your baby was born with this condition’. And it was as if he was speaking to me in Chinese because I had never heard [about] it in my life...And when I asked: 'What is your pity?' He said: It is one of those conditions that is related to Mental Retardation. And that is when I said to myself: He is talking about serious matters...

She had an unusual neutral reaction. She stated:

EO9-32-28...To comfort myself I told him: "Well doctor I, as a coincidence am a rehabilitation counselor and definitely nothing scares me...

But the majority of parents interviewed were not notified right away. However, some parents report cues that gave them hints that led them to believe that there was something wrong. The father of a young child with Down’s syndrome from Vieques stated:

14...I saw him immediately. When I saw him for the first time, when they were taking him out I noticed something rare but I did not say anything. What he has is that he is clubfooted. And he did not say anything. But he looked strange...

The mother of this child elaborated:

...And later he noticed that, ... he was with other babies and he was jumping. He was the only one who was jumping from here to there. The others were still and he was the only one that jumped. Because of
his temperament it was there that they noticed that something was not right...

Another family had as a cue the placement of the baby in a particular hospital ward and the comments from hospital staff. The mother of the child with Down’s syndrome from San Germán gave the following statement about the moment she realized that something might be wrong:

I was well into the ninth month [of pregnancy]. When he was born the doctor told me he was born healthy. When he was born he looked very chubby...He looked Chinese. They said: "Oh!, Is the child Chinese? Is his father Chinese?". "No he is not Chinese," I said. Then when I went to see him they had him where they have all the children who are well and the next day I went there, they had moved him to where the other children [those who are not well] are... We did not find a doctor whom we could ask. He [the doctor] was never [there]...We wanted to know what he had that he was placed apart...

The mother of two girls with undiagnosed disabilities from Naranjito, had premonitions but her certainty that her child had disabilities came from similarities shared by the girls.

One of these families was informed a few days after delivery of her child’s disability, Down’s syndrome. The mother from Vieques, to which we referred previously, discussed how she was informed:

MO14-5-3...When the baby was born, as he was being born the physician noticed his traits. That is, when I woke up, he told us. He said it to my husband [first], that he noticed the traits and that we had to test him and send them [the tests] to the United States and after that, to wait. After about a month they sent a letter stating that he had the condition...

She described her process as going from anxious questioning to becoming a routinary event:
After the storm you think: Thank God he has been raised normally. For me the storm was related to the...thought about How is he going to be? How am I going to care for him? When he was born I thought: "My God! Will he get sick?" Because of what they told me: These children generally get sick a lot...

This mother expressed going through perceptual changes and added uncertainties. Incipient acceptance was related to their developing understanding of what it was required to deal with their child's disabilities:

Before having my child I looked at these children and I said: "My God how is it that they deal with these children?" You wonder how could it be. Then you have one. I had always asked that question...but I never thought that I was going to have a child with a disability... After one has them...you notice that it is not as difficult. It is difficult in the sense of dealing with him but as time goes by and you deal with him it becomes easy...

For the mother from Arecibo, notification about her son's disability was fairly quick, a couple of weeks after the birth of the child. She stayed several times in the hospital with him. But her depression immobilized her for a year causing a delay in her quest for related services:

Because I was so depressed that I did not dare to go, not even to where there were children like this one. It scared me. I was very frightened because of the pictures and what I received [information sent about the syndrome by mail] I was scared by it. I had nightmares [in which] he had a giant head and it exploded. An incredible thing!...[The Children's Hospital of Arecibo is] where I took him to for the first time, and the baby was almost a year old. I mean that if I had started when he was born he would have been better...

For other parents the medical, hospital procedures and delayed information did nothing to reduce the feeling of confusion. Several families reported that no staff member provided them information about their child's condition. Parents were forced
to look for the physicians taking at times several days to find them. The following excerpt, from the family from San German, further illustrates their situation:

LI8-6-4...He did not come to me [the physician]. My husband was the one who [went and] talked to the doctor...At about the third day we went to visit him [their son] and we saw the doctor...It was then that we found out what he had...

Even after the initial information her husband commented that the knowledge they needed was more specific and practical than the diagnosis they received:

72-36...I wanted to know what was our child's real disability. If he was going to talk. That worried me a lot. But as time went by, thank God, the baby...walks. He does not talk well...

His issues and concerns were somehow resolved as the child developed and as he noticed the impact of the disability.

A woman from Bayamón, mother of a severely disabled boy with Cerebral Palsy expressed more severe feelings about similar procedures:

FA1-9-8...It seemed to me that he simply was not thoughtful enough to communicate us something that was really important. Whether the baby was well or ill, I think it is his duty to talk to us and inform us that the baby is well or is ill. I think that is very important for a woman [that has] a baby...

They too had to wait a few days for information from the pediatrician:

Fa1-5-5...Even, the pediatrician...When I was discharged on the third day, I located him in the hospital... and...I asked him about FA. He said "Oh! I was going to go to your room in the next few hours"...I had been three days in there and it was then that he was going to go. But at that moment he was not going in the direction of my room neither...

As in this case, there were families that did not get the necessary information and support to realize their child's disability.
A feeling of what could best described as sadness, with an underlying sense of vulnerability, was part of the experience of the woman from San German:

LI8-11-6...I went there to cry, every time I saw him. Whenever I saw him I said, "Oh! So chubby and so beautiful and look he was born sick [me salio enfermito]..."

Applicable here is the comment that Meyerson (1983) makes about the term "enfermito" for Chicanos. Implied in it she states that there is the "recognition of the condition coupled with the affection for the child". She further states that "enfermito" is:

...a term that connotes both responsibility for caring for the sick one and a sense of love, shown by the use of the diminutive. The acceptance of reality may be part of the philosophy of fatalism, which is often malign by sociologists. It is apparent, however, that acceptance can be a very positive feature in avoiding 'cureshopping' and getting down to the business of living with a child [with disabilities]...(p. 294)

Although several authors suggest that parents should see their child as early and as frequently as their condition allows (Seligman and Darling, 1989, p.39; and Whaley & Wong, 1983) differences in Neonatal Intensive Care Unit procedures prevented some parents from opportunities for early bonding and for developing an understanding of the care required by their child with a disability. That was the case for the mother from Río Piedras, whose child with Cornelia D'Lange syndrome was hospitalized for nine days. She was hesitant but wanted to see him right away, she was discouraged by the nurses from seeing her son. She described it as follows:

EO9-35-30...I wanted to see him. I wanted to touch him, it did not matter how he had been born. And the fact that restricted me were the nurses that did not allow me... But after they discharged me I went to see him everyday and...they allowed me to have him for an hour. In
the same hospital [that did not allow me to see him for four days] they allowed me to have him for an hour! Well, I touched him completely. And he was as happy as can be. There are times when a child needs his mother...

The woman from Bayamón described the discouraging policies in the hospital that cared for her premature boy with Cerebral Palsy. She stated:

FA1-17-20...He was going to be in intensive care. We only had the opportunity of seeing him for 15 minutes during the morning and in the afternoon. And he was like that for, I think it was, approximately 15 days in intensive care...

According to her reports, the lack of initial orientation affected her opportunities for breastfeeding too.

In a similar fashion, the mother of a boy with Down's syndrome from San Germán described the lack of contact with her child as a disempowering experience. She states:

...He was there [in the Medical Center in Mayagüez] for seven days...We always went to see him ... from the outside. We could not do anything else...

The parents of a boy with Cerebral Palsy from Juncos described a somewhat different experience with the Neonatal Intensive Unit of the Caguas Regional Hospital. They were allowed longer periods of interaction with their baby. They were also provided with important information about his care and were allowed to interact with him:

OO4-19-9...(him) Yes [we could see him] only at a certain hour. (her) Only an hour each day. (And what did you do on that hour?)...We made sure to talk to the pediatrician and the pediatrician explained to us in his own words so that we would understand... He [the child] was there for a week...(he) We had to wear a robe...(he) I used to hold him, put the hand in the incubator, we touched him. It
was the first time I had a baby. I held him, put my hand in the incubator and touched him. They gave us permission to touch him...(her) And we talked to him and all, too..

This opportunity for contact, information and modeling was meaningful since they took home their very small premature baby after a week.

Delayed Diagnosis. The majority of children diagnosed after birth spent most of their first year going back and forth to the hospital. It appears that as their health situations began to stabilize, their condition would surface. An important area of concern for parents during the first year was the children’s well being and survival.

The mother of a child with an undiagnosed disability talked about her concerns over her daughters’ physical fragility:

SI 13-9-10...The doctor called me "the crying one" [la lloronicita]. Just imagine, do you know what it is [being there] all the time, since delivery, you do not recuperate at home and all the time you are there...and to think that something could happen to my girl. Oh my goodness, I think about it and I still feel like crying...

The mother of a mildly hearing impaired girl from Ponce described disempowering medical practices. According to the mother, her daughter spent most of her first year hospitalized with high fever and infections. During her first operation, (at 8 months), she had ear tubes inserted:

Ga6-17-18...I became afraid that if they didn't operate her she was going to become deaf. Or if they didn’t operate her we’d have to be careful not to get her wet. That she could not fall if she fell her tube could burst in blood. Many things could happen. All those fears came to us but we decided that it was worse if she became deaf...
As a result of that operation her daughter bled from the ears and secreted pus. Like two other parents, she felt that something was wrong, but doctors would not listen to her:

p.25...I always fought with the pediatricians because they were always right. Never were the others right...

It has been previously mentioned how the development of an understanding and ability to deal with the child's condition was also a factor in the evolution of their long term awareness.

The length of hospitalizations also affected the well being of some mothers as in the case of the mother of a hearing impaired girl in Ponce. By taking care of her daughter she could not take care of herself and the mother became ill:

GA6-53-12...While the girl was in the hospital I had to go to the Emergency Room many times, too. In several occasions the nurses told me 'I'll watch her', so [that I could] go and get my medication. When I came back, she would be in a pool of blood. She had pulled out the I. V. liquids. All of that made me feel upset...

This family also went through a lot of discussion and disagreements about medical procedures with ear, nose, and throat specialists at the area public hospital. Adding to their confusion they found a doctor who during a hospitalization offered them other possibilities for treatment. He was however hindered from treating the girl since it was another doctor's case:

GA6-24-79...That is what he told me: Since she is S.'s case I do not deal with her. If she had been mine I would [resolve]. But if he made a mistake let him solve it...

Due to differences of opinions and what they saw as unwillingness to serve they went through several serious incidents with the attending physician. Their dissatisfaction
with the physician’s lack of action led them to attempt to get another doctor to provide medical care. These efforts were unsuccessful since interns stated that it was the specialist’s responsibility. The parents felt disappointed about the specialist’s procedures who, instead of solving the situations, wanted to get rid of them:

p30...(him)...He got tired and he told us: ‘Go to the United States. I am not God’...

Even though they were not satisfied with the service provided by this doctor the case was not released so that they could get service from another physician. They finally got a doctor who they met in the public hospital, who showed concern about their daughter’s medical needs. He even served them in his private practice and made a payment plan to benefit them. They also found, in the Sor Isolina Ferré Center, other pediatric services they had been lacking. All these events made them notice the possibility of a special needs condition but they did not have much concerns since the child did not seem too disabled:

GA6-113-120 That was after a year. I did not believe that she was going to become mute or become deaf. She tried to talk but it was as if she needed a little more help. It did not seem so serious since, among all the others they seem normal. For me it did not imply that she had disabilities...

While all this was happening, hospital policies hindered the father from providing care his child needed in the hospital while his wife recuperated. This state of affairs, while unwritten, is supported by reports of several parents in this sample. An example follows:

SE13-45-36...(she) It has to be a woman the one that stays with the children. They did not explain why. They told me that it had to be a woman the one who stayed. And since I did not had anyone who could stay, because my family did not stay with her and neither did his, well
I had to stay. Except for one day when permission was requested and he stayed while I came to take care of the children...

Differences in reactions between husband and wife were reported by a woman from Trujillo Alto. She expressed that her child’s special needs due to cerebral palsy requires additional help and time:

AE7-72-73...Also because he is not like other children [that you tell them] put your feet [in the shoes] and that is it, put on this and they put them on quickly...he cannot put them on by himself...

At the beginning, anxiety and depression immobilized her:

AE7-94-117...I think the same happens to everyone. You get blocked and do not know what to do...[with] your arms crossed because you are dying inside. But you say: What can I do? I cannot do anything. If that help was available, at least you could be more tranquil in the sense that there are people who know those things happen and how they can help you carry on...

His characteristics were hard for her husband to accept. The need for professional help or counseling was still felt at the time of the interview:

AE7-74-73...Because [my husband] did not accept the situation...in this regard we did not have professional help...

Other fathers, while initially reacting negatively, changed to being more involved with their children:

NE12-20-22... For my husband, his change with the girl. I think that it was the time. And also that the girl makes you love her. She is one of those loving persons and she spends her time winking...

Comparisons and evaluative comments from others also contributed to the process of awareness. That was the case of a mother in the town of Naranjito whose discovery of her child’s disability was based on the knowledge acquired from previous pregnancies. Her mother in law corroborated her observations:
LA 10-9-5...When they gave her to me they told me she was well. She developed well, healthy. After a month I noticed that she did not turn. Because at a month they already turn. My mother in law would tell me: "I see something strange in the girl since she does not turn as a baby should."...

She also noticed seizures. For about six months her observations were denied by the doctors and testing was not done.

LA10-17-15...At around four months I noticed that her hands would get stiff all of the sudden. And the girl yelled...so strongly that my husband and I woke up very quickly and went to her room. And the girl was out of this world as if she was cyanotic and he [doctor] used to tell me that all that was normal. And if you say the opposite they sometimes get mad at you, then maybe it is as he says, normal...

She started then the process of testing. Initially she "wanted them to tell me something more specific... about what the girl had..." In this quest she was given several different diagnosis:

...And then I was seen by so many doctors. They'd tell me she has this, she has that, and I [felt] Oh, my goodness I did not know what to do. And I was [wondering] what am I going to do? If she [the doctor] says she has this, that we have to do these studies. The studies again, and they did not tell me what was it that she really had...

She went through several erroneous diagnoses, her being blind and deaf. The last diagnosis was cerebral palsy:

LA10-23-19...For instance the neurologist told me about this condition that we believed she had, that it was cerebral palsy but [when she was]...two years [old] they told me it was another thing, that they could not assure me because they did not know well...

She responded with a similar devotion as she had done with the first girl. For instance, she reported:
LA 10 37-27...and I was very watchful of them all the time. I slept with them because I'd sleep on the floor in a mattress...and I'd observe them both...

For a while she reflected her desperation with other members of the family. She stated:

10-45-33...Well I changed with the boys, I'd yell a lot. I was destroyed...

A closure was achieved by the mother of two undiagnosed girls from Naranjito. Acceptance of the disability is achieved as a greater concrete understanding of the situation and its implications:

LA 10-76-55...I took it easy. Later when I started understanding I took it even more easy. When my daughters were born it was a burden in the sense that the task is very hard but there is a feeling that when one has love for the child, it is different...

Her participation in religious groups also helped her deal with the situation. Finally, she decided to give up the quest for a diagnosis.

She faced similar delays in the process of diagnosis with her oldest daughter, who had the same disability. She started the evaluation process of her first daughter in the Regional Hospital of Bayamón and the hospital lost the results. Most importantly, this time she felt less uncertain with the management of their disabilities.

Other parents were still unsure about what their child's disability was at the moment of the interview. For the woman of Rio Piedras diagnosis was still unknown:

LE2-11-15...In fact, it is a problem associated with the metabolism, but they have not identified what it is....
They started noticing their daughter’s condition as a result of the careful observation some new parents and their relatives give to their babies. Her observations were confirmed through a sister, who was taking care of the newborn girl while the mother went to the hospital for complications from her cesarean delivery. They noticed the seizures, took the girl to a pediatric nurse that lived nearby and then to the pediatrician. They then began their quest for reaching a diagnosis. By comparisons with children from close relatives they noticed her daughter’s developmental delays:

LE2-15-19...We knew that her development was not like [my niece’s]. That the other girl did more things, having a similar age. I mean she [the niece] was doing much more and she was limp, she did not have neck control, she did not laugh nor did she have the same reaction to the environment that the other girl had...

At the moment of the interview, the mother described the process of understanding the implications of the condition they were experiencing as slow although they initially felt hopeful. This was also associated to other aspects of her disability that were uncertain, such as the metabolic condition and its effect on her development:

LE2-6-11...Since we were told that she required a diet, well-we thought that maybe she was like diabetic children that they give them some diets and everything is controlled. I mean and in the lack of knowledge, well we did not give the importance, the seriousness to the matter, since we always thought that everything was going to change but for the better. We were positive in that sense...

They continued the testing trying to find what the condition was:

LE2-8...And then, for us we were discarding what would be worse. And in that sense,...every time they told us: "Look it is not this. Look, it is not that." and it was something sufficiently serious...if it had been that complication, well, it was a great relief that it was not any of those things...
They finally did the metabolic testing and it is there that they found altered aminoacids and high ammonias. About this the mother stated:

...Since we did not know what a metabolism problem was, what it beard. And we made questions but the physicians were not categoric, they could not tell us how that was going to determine her future...If she was going to have delays, things that worried us at that moment...And we could think anything...

At about the third month their daughter was referred to early intervention by a geneticist. It appears that this information served only to confirm previous observations. It was not related to major changes or reactions:

LE2-24-31...We knew then, that it was not simply our observation, but we already knew that she was not developing like other children...

The delays in diagnosis led them to a prolonged period of search which took them to physicians in the United States. Through their quest they hoped to further clarify issues of the disability itself:

LE2-17-21...We realized that it was really a process of trial and error and in that sense we thought that maybe, if we took her out to any specialist, well-we would get more accurate results. And that opportunity happened...

They went through several changes in diets to attempt to control the condition. When interviewed, they were still uncertain of how effective their dietary interventions were.

A mother from Camuy also found comparisons with children of similar ages useful. This is illustrated by her in the following excerpt:

SI13-12-14... She acted different from the others...when they are a year I know that they start taking steps or crawling. She did not. She’d stay where you left her and I found that strange...Then...she [the doctor] started telling me that she was slow, that she was not normal...
Families with children with health involvement the separation from other family members during hospital stays influenced negative feelings towards the disability:

SI 13-8-9...I did not feel good since I had to be all the time at the hospital and my daughter was going backwards, she did not go forward...One feels bad about having to leave the others and that...I was afraid that something would happen to my girl...

The central concern of her husband was the lack of diagnosis which is exemplified in the following excerpt:

SI13-14-16...When they cared for her in the Medical Center at the Children’s Hospital, there was a conference involving all physicians that had checked her for different things. I asked the physicians what was the girl’s situation since...’ we bring her here, she is seen by different doctors but you never tell us what is really happening with the girl’...

A mother from Trujillo Alto with a child with moderate cerebral palsy remembered the moment when she was notified about the disability. Her son stayed in the hospital for about 21 days, and then intermittently during the first year. As he left the hospital she was warned of possible problems. When she noticed her son did not do many things he was supposed to she realized he was disabled. Her son was already a year old when they were finally informed about their son’s brain damage in a visit to the neurologist:

AE7-34-28...We stood there mute since there were so many things that we had gone through with him. Every time we went he had something different...We were impacted all the time. But the one that really shocked me, and I cried, [was that one]... I had always heard that word as in cases in which people are left bad in their bed...Even if you are supposed to ask, at that moment I felt in such a big shock-and my husband-that we did not ask. We were so worried asking ourselves what did he meant by that...
On a visit for a second opinion they asked about the child’s condition and its implications.

For the mother of an autistic boy in Gurabo, it was not until her child’s second year that something strange in her child’s behavior was noticed. Although confused, comments from other mothers led her to pay attention to children with similar conditions. She described these events in the following manner:

SE11-14-6...During that summer I started getting alarmed because I was seeing other cases...And I started seeing other children, listening to other mothers talk. And specifically one, her son was already five or six years old. And, she started to alarm me because she [started]: "That is how such and such did when he started." Oh! It feels as if I was listening to it now. Then looking at the severity of her boy’s case: he was a very hyperactive boy that ran constantly, that broke everything...That moment was very painful for me...

As in other cases the implications of the child’s condition were by discovered by contact with other children with similar circumstances. Even the informing mother was very discrete in the details she provided:

...She did not say that this is going to happen but once in a while she’d say: 'Don’t worry that you are going to have someone to help you’ or 'then he is going to do this or do that’...

She got a final diagnosis about three months after receiving those initial comments from other mothers. Retrospectively, on her quest for a final diagnosis she feels she forced the diagnosis from the doctor’s mouth. The pediatrician finally recommended her to accept the diagnosis with resignation; since there was no way to fix it. She cried as she described that moment as 'the most terrible day, the greatest sadness'.
A mother from Juncos whose boy had five (5) months when he was finally
diagnosed with cerebral palsy described the experience as a 'bomb which had not
exploded'. It 'went off' when she was invited to a conference given by her physician
about different disabilities. During that visit the doctor evaluated the baby and she
was notified that he had one of the conditions described in the conference as
quadriplegia. They were told that:

OO4-48-26...He might be a boy unable to swallow well... not able to
defecate well not able to walk, ...a child that might not be able to reach
18 years of age because of his condition...

Her reaction when the same doctor notified her of the condition, was of confusion,
puzzlement and surprise:

When I got there I was left...mute. I thought How can this be? My
son is not going to reach 18 years? He is going to be a vegetable on a
bed? I have to find out well and I talked with the social worker the
same day...That was a very tragic thing. We were not prepared. I did
not think the problem was so difficult. At that moment I thought,
forget it, the bomb exploded...

Her husband also reported his initial reaction as a very intense one:

OO4-51-28..When I heard the news I started crying because I had so
much affection and so much love for him. And to find out about those
news I said:
"My first son and look at how he came out to be..."

As for others, their feelings changed as their ability to deal and understand their
child’s condition increases:

OO4-56-31...I feel sorry... [remembering] that moment. But now we
do not feel that way. We already know the work, we are already
organized...
Other parents discovered their child's disabilities from differences in their children's features. For instance, a mother from Bayamón, whose third child has a visual disability, noticed, at around her third month of age, that her child was turning one eye inward. This woman reported that her doctor's found her "hysterical" since, according to him, "all the babies turn their eyes inward...The physician "convinced" her that the child was normal.

After that response she asked another physician about other conditions she noticed such as her child not talking nor moving around to explore. The second doctor, her son's physician, was very supportive. She accepted her observations, checked on them, and made recommendations. This physician also referred her to the strabismus clinic where she was notified of the disability and received services. Her reaction was:

SU5-18-16...I felt a little rebellious and mad since I said I already have a boy that I have to deal with and now another one with some other different thing. But later I said oh, forget it. I will deal with it as I can. That was about four days later...

Being a woman with disabilities, she reflected upon how her experience and that of her oldest son, which helped sort out her feelings:

SU5-18-13...I am really not bothered by the disability since I am a person with disabilities. Really, I have four children and I know how to guard myself very well. When I discovered her disability, I said: "My God what is going on?" Because I have met people who had other kinds of disabilities but I have never met one with an eye [disability]. And...I said: but what is going on with the girl? Why is she putting the eye inward? But when the doctor told me it could be strabismus, I went quickly and looked for the word strabismus in the dictionary. Where does it came from...and how I could deal with her...
Her own and his son’s disability helped her come to terms quickly with her younger child:

SU5-24-19...I accepted the girl more quickly ... The boy shocked me more since he was the first child. Since I wanted a boy, the disability shocked me a lot. Later I said: "Well I am like this [disabled], the kids are going to be like this too, so I have to continue working for them since no one here is going to do it for me"...For the girl I was more prepared...

For a couple from Mayagüez, their son’s disability was not identified until his first year of age. The grandfather, who is a physician himself, observed the child while in play, and told them that he thought the child had a cerebral lesion. He was taken immediately to the pediatrician who had not yet noticed, and then to the neurologist. The process of testing and evaluation started. Their initial reaction was:

CI3-7-13...When my father-in-law told me I did not cry...but later I fell over C., crying. I said 'My God, let it not be true. And then when they confirmed it my heart sank to the toe of my feet...My husband was a little more restrained. Worried but not like us women. We women, are a little more desperate, we start crying. He got despaired and showed preoccupation that the child was not going to walk. Since we were told that he had hydrocephaly I thought his head was going to get big...

Anxiety due to self blame was also reported by this mother:

CI3-17-19...At the beginning I felt: Why me? Later I blamed myself: It is my fault...because I did not take care of myself because of what the doctor said.

As was also shown by the woman from Bayamón with a baby with cerebral palsy, parents of premature babies were informed at a later time. This mother of a severely delayed boy with cerebral palsy, stated that at the beginning no health professional talked to her directly about her child’s problems. She was already back
to work as a secretary at the time of 2.5 month appointment and could not take her baby. She was required to attend the next appointment out of which she came out uninformed about her child’s disability. This led her to a slow realization of the severity of her child’s condition at a later time:

FA1-30-36...Well I said, It is all right I will go to the next appointment, but they did not say anything specifically. They sent word that because of his being born premature and because of the condition he reflected in the brain, [that] he had reflected in the sonogram,...he was a high risk child. That he’d need follow-up. That it would be good to register him in the Children’s Hospital...When they started using words was when I was already, starting to...ask myself certain things...

Her awareness was delayed by the informing physician’s tone of voice. His intonation and projected feeling affected her understanding of her child’s condition:

...I mean, what he led me to believe, since he said it with so much indifference, that I really did not give it the importance that it had. Since [the way] he said it [was] so indifferent. He has spasticity: [I said] OK, he has spasticity. It did not occur to me to ask what spasticity was...and then in the next appointment they informed me...

She maintained the hope during all that period and part of her child’s first year:

FA1-21-23...And then, from that moment on, you start to have fears but, at the same time you still maintain the faith that maybe everything is going to be all right. So many premature babies, so small, smaller than F. A., in worse conditions, with more tubings...

At the beginning observation did not help, since he was her first baby. He was very small and she thought everything he was doing was normal. Once informed she was left to wonder about the disability.

Her feelings about the slowness of the awareness process were conflicting.

She expressed contradictory desires for immediacy right after the child’s birth to that
waiting was better. About the positive aspects of being immediately notified, she said it served to provide understanding and impetus to move:

...to have a clearer vision of everything. To say well, this is like this, and to start to deal with the situation. In the other sense the fact that they have not said it is good since everything was understood little by little and maybe there was not a very big shock so I would be affected as such. And as I started gradually understanding well ...I understood it. Right now I know how to overcome the situation and it was not a rude strong shock...

Remarks about the lack of sensitivity to parental feelings on the part of notifying physicians were made. An example follows:

OO4-50-27...No he did not notice [how I felt]. He kept on telling me everything...He gave me information and nothing more. But I went out of there and talked with the social worker. She is a very sensitive person and gave me a lot of documentation and orientation. I was disoriented and with a sense of: who do I tell all this? I felt bad. I was not confused in the sense that I really had my child but, what to do...

Feelings About the Disability. At the basis of the process of awareness are the definitions and understandings parents make about their child’s disabilities and about their future. The challenges faced by parents while caring for a child with disabilities had an effect on their appreciation for this type of parenting. In this section their expressed emotions toward their children will be discussed followed by a section examining their expectations for the future.

Parents expressed themselves in general terms about their children’s disabilities. Positive comments were expressed by a mother from Mayagüez for her child with mild Cerebral Palsy:
CI3-17-19... I do not look at it from the viewpoint I have a child with a disability what a trauma or anything like that. In fact I see C. as something special in my life...

The woman from Juncos who described her first awareness of the child’s disability as a bomb, depicted her current feelings as follows:

OO4-94-54...I feel good. I have my baby with a condition, and I do not feel bad. We have already accepted it because [the trick lies] in accepting...

On the positive side, the situation was described as a challenge, a sacrifice which for some was not seen as negative. As stated by Meyerson (1983) this notion of sacrifice implies an acceptance of the work required by the condition. For instance, being able to deal with difficult challenges gave a special feeling of pride, of overcoming a very difficult challenge, and of strength to the mother from Caguas:

NE12-28...Maybe it is not easy to deal with a child with disabilities...It is not easy. I would say that it is for all your life. But I tell you that I feel very proud. I am a very proud mother since every anger that I went through, everything that my girl does I enjoy it...She was a blessing from God. And she was also a test given to both of us...

There is a sense of fate and randomness in the expressions of the father of the child with Cerebral Palsy from Mayagüez whose disability is reported to have occurred during the delivery process:

CI3-35-33...It is a challenge: The least I thought is that he was going to be a person with disabilities. It is a new experience. It is like a lottery. If you draw a white ticket you win a house, if not you lose...

On the other hand, resignation was the underlying feeling expressed by a mother from San Germán:
Now, I am happy to have him because all that God gives is good. And I cannot do anything else but to love him as I love the others...

The mother of the boy who has Cornellia D’Lange syndrome felt a strong identification with her child’s suffering. The following excerpt describes a sense that what happens to her child also affects her:

I do not have, thank God, a disability but I...feel I have the disability. I feel I have the disability of my child since... I am practically living his life. We are like twins. Virtually I feel what he suffers. If I see him suffering, well I suffer a lot. Sure thing since I have a thinking head and I move forward to some things. He lacks the ability to think. I have to think for him. But I feel, I feel with his disability...

As seen in previous sections, most parents feel their worst at the beginning. Competence in their ability to care, focusing on their children’s similarities to typical ones, or resignation, were one of the factors that helped some families move from this initial feeling. The woman from Caguas, mother of a child of spina bifida, reported initial reactions of shame, anxiety and confusion. For her these perceptions changed to more positive views when she saw the normal look of her baby:

When I saw her I said: But what is this? I felt happy because I was expecting a completely [deformed] baby. [and it was not like that]...

In some excerpts parents focused on the need for acceptance by emphasizing the similarities shared with other children:

I understand that my son has to be treated as a common person. I mean that he is a human being like any other, and he has some needs like everyone...
About the issue of comparisons a woman from Trujillo Alto clarified:

SE7-53-51...It makes you notice that the problem is not so serious as that of others and you don’t to give so much importance to things so that then you know how to face them better...

On the issue of similarities, several families recognized that treating children in a way that resembled that of their non disabled children helped them in organizing their daily living. For instance the mother of a girl with an undiagnosed disability stated:

SI13-25-23...I treat her as if she was one of the others. I feel glad to have her and I feel one of the others. Even though sometimes I...think...what happens is that she cannot be like same as the others, but I feel happy to have her...

Another source for positive appreciations was found in opportunities for meeting and making comparisons with other children with their child’s condition, since they often felt that their child fared positively:

MO14-23-12...We went to the Medical Center. There I found myself with children with cleft lip; you become impressed. I said Oh my God! You see those children all cut and with well pronounced traits but M is not like that...Forget it, my child is well...You get desperate and when you see others...with more severe conditions you notice that you suffer but that there are other parents who suffer more...

Health related issues were also central in ongoing feelings toward disabilities. A woman from Ponce expressed her situation in the following manner:

GA6-80-74... Right now there are times that I feel bad because I would like her to be completely normal, that she would not get sick so much. The struggle that I have every day to get her to drink the medicines. She is fed up with the medicines...
Some parents expressed feelings of depression related to the intensity of care required by the child. An example of this was given by the mother of the child with severe Cerebral Palsy from Bayamón:

FA1-37-46...I sometimes feel very depressed...I try to be strong, not to allow myself to be overtaken by that feeling, because I know that I can hurt him. And I want him to see me as positive...as [enlivened] as possible. But there are times I want to have even five minutes of rest. At least five minutes, but I cannot even do that...

Feelings of fear mixed with the recognition of the child’s fragile health were expressed by the mother of a severely retarded boy with Down’s Syndrome:

Li8-50-27...I do not like to leave him with no one [to care for him]. Because I think that no one is going to care for him as I do. I worry that something might happen to him. I go out and I am worried. I am not at ease until I get back. With the other it did not happen...Since the doctor told me when he was born that he could die, that is what comes to my mind, that he could die...

A woman from Caguas described how her views about her daughter’s condition changed as she understood her development:

NE12-27...I do not care whether my daughter walks or not. At the beginning people asked me and I [said]: Yes maybe with the operations and all that I imagine that close to a year and a half she’d walk. Unconsciously I wanted the girl to walk. But no. I would like my girl to learn to excel a little bit in whatever she can. I am giving her the maximum...

Transforming experiences were reported by some families that helped reframe their initial feelings and perceptions about their children’s disabilities. One occurred during the contact the woman from Ponce had with another mother of child with a similar disability. About this encounter she stated:

NE12-11-14...[Up to] a month, more or less, I spent locked up in my room. I was still sort of not accepting reality. A mother who has a
boy with the same disability came close and told me: Mother, you have to confront it because it is not easy. The thing is that she sort of illuminated me, she gave me strength to carry on and thanks to that mother I have decided to struggle for my daughter...

Finally, an optimistic outlook about her daughter's possibilities was reached:

NE12-93-100 [her]...Now I accept her the way she is. She is really very well considering other young boys I have seen. For me she is normal...

An important factor in changes towards more positive feelings was the interaction with others. The couple from Mayagüez moved from blaming themselves to a feeling of being chosen for a very special and difficult task:

CI3-17-19...At the beginning I felt: Why me? Later I blamed myself: It is my fault...because I did not take care of myself because of what the doctor said...Then a reading given to me by the ESPIBI center [that stated] that having a child with a disability was not bad, that it was that God had chosen us a parents. I mean that a couple that is going to be the parents of a child with disabilities is a special couple and they are going to do a special work for that child.

Professionals were also mentioned as sources for simple incidents leading to acceptance:

004-51-29...Sometimes when you do not understand but I kept a paper that the social worker gave me about a special child...We are believers but at that time we had not clinched more to God and we were a little reluctant, even upset at God because of the baby's situation, at ...how he sent our son to us...

On the other hand, another simple intervention, designed to inform, augmented parental fear and confusion. The mother of a child with Down's Syndrome with a severe condition from Arecibo the informative literature sent to her:

AU15-12-7...A literature that they sent me about the condition, Down's syndrome, talked about all the physical and mental problems they could have. And what it did was that it made me feel worse since, I did not know anything about those children. I thought that my child was going
to have all that, that it was a child that was going to die. I got very scared...

Parents identified several aspects that affect their feelings towards their children and their related situations. For instance, the young woman from Bayamón authenticated the notion that support from other people makes a difference in parental feelings about the disability. When asked about her feelings about the disability she responded:

...I suppose that people that have support of others, then maybe...but I think that if a responsibility would be distributed among different people...and one had a period to rest, then, I think, it would be easier. In my case I cannot have that opportunity. I am with FA 24 hours...

The mother from Arecibo agrees with her comments concerning a lack of help from others and her opinions about their life with their children:

AU15-23-13...Now I do not feel so bad but sometimes I do. Because there is no help...

She further related lack of support from others, the company provided, feelings of loneliness and depression. The mother of a child with Down’s syndrome from Arecibo expressed this in the following manner:

AU15-78-70...I saw a young woman, her girl is already 15 years old, with Down’s syndrome and she was talking about all the places she went. But she always mentioned that she went with a friend. You know she did not feel alone. I did not, I had to go alone every where. If I did not go with my husband to appointments or that. But things that were like this, I had to confront them alone... [And how did you feel] Well imagine, very lonely...

To some mothers the husband’s reactions to the children helped in the evolving process of acceptance. For instance, the husband’s attitude helped a woman from Mayagüez in her process of acceptance:
But then after seeing C. [the husband]'s attitude, because many men do not understand that nature gave us a child with a disability. His attitude helped me a lot to accept this. He always treats him as a normal child. He tells me not to overprotect him...

Other ways in which husband's were helpful was in their active participation.

Her husband's participation was described positively by the mother of a child with Down's syndrome from Vieques:

He helps a lot. He has a lot of work because he works at the base, plus he also works here outside as an electrician. But he takes time every day to play with him. He gives him a lot of therapy...

Another example of this was given by the woman from Arecibo who felt that she viewed her husband's feelings as being different from hers:

My husband always gave me support. If he felt the same, he tolerated it better than me...

This was not the case for a mother from Caguas, who in a way described her initial role as that of being the cornerstone of the family:

After having struggled with myself well I had to struggle with my husband plus help the girl. It was not easy...

According to the following description, her husband's feelings and experience with the disability did not evolve in the same manner as hers:

Well he was very negative. For him it was not easy. I say for one to accept and to be resigned you need the help of other people, and I, thank God, had it. But him with his family did not have it...Because they are healthy people and, why was she born that way? He'd ask me why she was born that way...He would blame me as if the girl was born that way because of me...In the course of time, thank God, he was able to accept reality, even if it was not easy. Now he adores the girl...
A woman from Bayamón who has a cerebral palsy, perceived that it was easier for her husband to accept her disability, than that of her children. She stated:

SU5-27-25...He did not even notice that I was a person with disabilities, I had to tell him...It seems that he was only looking at a person with good feelings instead of at a person with disabilities...But, regarding his child, he changed. He could accept that his wife was a woman with disabilities but not that his daughter was. He rejected her completely...

This woman with disabilities faced the raising of her first child with disabilities by herself because of the husband’s rejection:

SU5-27-26...He said it himself: Move that boy away. That boy is crying too much. I’d tell him: Hold the boy over there. No, I will not do it, I am going out into the street not hear that boy crying. He would never say his name. He’d say "that boy". That is why it was a greater struggle with the boy than with the girl because with the boy I had to struggle by myself...

The woman from Bayamón described her husband’s feelings as fluctuating between pity and strength. Pity, in general, was not seen as a positive force but as one that they needed to come out from in the initial reactions:

FA1-43-52...He sometimes feels bad because he would like the baby to come running to him and hug him and tell him "Daddy, how are you?" and anything, what babies normally do. Or that he could take him to the beach and see him play and it hurts him that it is not like that. Then there are times when that he starts, he says "What a pity", and I say "no" what a pity, no!" Try to control your feelings, to be positive but let’s not allow ourselves to be carried away by that negative feeling...It happens to both of us. He overcomes it and I overcome it...I have gone through very difficult moments. In my case because I spend more time with him...

A father from Vieques stated that he went through feelings of pity himself prior to having his child with disabilities. In talking about his present feelings he stated:
...I have always seen them and treated them with pity. But now, since we have this one, I see a child like this and one kind of feels that one loves them more now. The pity changed...Now it is a greater closeness with them...

A woman from Juncos talked about the feeling of pity being a problem:

OO4-55-31...It is bad, I sometimes say: Do I Love him more than the other children? But it is not like that. And it is not to love them with pity because one should not love a boy with pity...

Although no clarification about what was the problem with pity came out of most interviews, the comments from a woman with Cerebral Palsy in Bayamón, whose daughter has visual disabilities might help clarify this issue. She stated that pity has a disabling side associated with it as she noted:

SU5-25-20...I think that the preparation that I had with my mother [helped]. Mommy treated me so well that no one can tumble. [What did she do?] When I fell she would say: Stand up...One feels pity. One feels that the world is going to fall but the world continues turning around. Pity does not do anything...

The following excerpts suggest that from a different standpoint participating fathers went through a progression of strong feelings that needed to be addressed:

004-51-29...I blamed myself a lot and said to myself: "But what did I do my God!"...

A father from San Germán expressed deep emotions which led to stronger ties with his child:

LI8-77-39...For me as a father it has been the greatest thing that can happen to any one, since one does not know the value of a child until, one really has a child with a physical disability. This changes up to the last thing. Because to know that a child is born to one and that we are going to have him sick from one thing or the other; well we have to give ourselves fully with that child as I am now with that child...this is when you really know the feeling for a child, for the human being...That is something serious and sad...
Another factor was the discrimination faced in the community and service provision that led to lack of access to necessary services:

CI3-54-47...What I have always thought is that there is a lot of discrimination. There are people who could really have more benefits. I think that a disabled adult should be given more opportunity, more emphasis, more rehabilitation centers, more opportunities. It is as if there was too narrow a field...

On the other hand, positive reactions from community members also helped in developing feelings of acceptance:

MO14-18-10...Oh, no! Now we are happy. Just imagine, time goes by and one already knows that he really has a condition. Well, just imagine. He is the king of the barrio. Here everyone loves him in the family. He has been a quiet boy. We adore him...

Others compared her quality of family life with parents of children with more severe disabilities. The woman from Juncos made the following comment:

004-84-47...Well sometimes you feel tense, you get exhausted and say: Can it be that I am the only one that has so much to do? And sometimes you look back or forward and see a mother that has more work than I do...

Depression that was tied to the reduced opportunities for personal development for several women, cannot be ignored. For instance a woman from Arecibo stated:

AU15-103-98...Because that is what prevents me from living my life. That I can say: "I am going to go forward, I am going to study, I am going to work." Because if not, you stay stagnated. All your life taking care of that child and then you get depressed. More so, because you blame him that because that child is there you have not been able to excel, because of that...

A woman from Gurabo who was a single parent of a child with autism, expressed similar feelings about job opportunities. She said:
I have learned that I do not have to struggle so much against that. If at any time you can work...but right now you can’t. At the beginning it was very difficult for me because I was seeing myself as a person who is supported and I did not want to see myself like that. But I finally accepted that there was no other way to bear the situation...

This section will be summarized and discussed in Chapter V.

Future expectations

The parents in this study, embarked on planning for their future early in their children’s lives. Their children’s disabilities have an influence in this planning. Parents in this study faced uncertainties about the identification, prognosis, and effect of their children’s disability which, in turn, seem to affect their perceptions of their children’s future. Parents with children with what they described as mild to moderate disabilities were more hopeful about their children’s future. Parents of children with severe to profound disabilities experienced mixed feelings and reserved hope.

The following quote from a mother from Mayagüez represents the lifelong sense of responsibility for her descendant. This feeling of responsibility is traditional of Hispanic families, merged in this case with her perceptions of her son’s long term needs, and her hopes for his future:

CI3-19-22...Up to when God says Amen, to help both of them to get ahead and to think that specially C. needs more from us. I do not think about worrying about whether he goes to the University or not... [To let him] develop by himself. Not to force him; you have to do this, you have to do that. No. I have a lot of hope that if God did not give him the gift of having his hand as it is supposed to be, then to intellectually or in other aspects get ahead...

Again, comparisons with children with other more severe disabilities provided a source of comfort to this mother:
Sometimes I start thinking. I say "My God, what would he do when I am not around [anymore] or if he were with his friends? How would other people accept him? But I think that I should not be so negative. That there are other people in wheelchairs. Others that have severe disabilities...

Implied in that comment were also concerns about the long term consequences of the child's disability in family life and in his/her own life. Similar concerns were described by the mother of a girl from Caguas:

NE12-86-95...N's condition is a task for all our lives and we need to help her up to the last minute. If we do not help her, who is going to do it?...

On the other hand, the mother of a child with mild hearing disabilities from Ponce did feel that the mild hearing disability's impact on her daughter's life was going to be negligible. Similarly, the mother from Bayamón has normal wage earning expectations for her daughter with mild visual disabilities.

SU5-67-68...They could give the maximum. The goal that she has for herself. That she holds a job where she earns her money by the sweat of her brow. She may be picking up trash, but she has to understand that is the job she chose...

For the couple from Juncos, although their son had moderate language and physical disabilities associated with his Cerebral Palsy, they were open to the possibilities of new developments, and willing to let their child develop:

004-11-62...It is as if he there was nothing wrong with him. You worry so much that you can make a storm in a teacup...You should not even worry. You worry, but you have to allow him freedom for his own benefit in the sense of [letting] the child express himself. If you give him that freedom you know what the child can give you... My baby can study...since he is a child that shows promise. He shows promises of even walking by himself...
Furthermore, these were their long term hopes for him:

004-115-64 [him]... To get married and work. [her]... We have even talked about it: When the boy is older we have to get him a car...

For the mother of a girl with spina bifida in Caguas, changes in perceptions about her daughter’s future were related to the child’s characteristics, her evolving perceptions and adjustment to/acceptance of the disability:

NE12-26-29 ...I do not care whether my girl walks or not. At the beginning people would ask me and I [responded]: Maybe with the operations and all, well...I imagine that in a year she will walk. I..., unconsciously I wanted the girl to do that. But no. I would like for the girl to learn to better herself a little bit in whatever she can. I am giving her the maximum...

She realized her daughter might not accomplish the general goals she previously had for her and these were modified.

NE12-34-38 ...I hope that N gets, at some moment, I do not know how long it will take...my goal is ...that N. walks at least from here to the balcony or at least inside the house with her braces. I know it is not going to be easy. It is a long- term goal...The second one is that N can go to a regular school...My goal is that at least she graduates from High School...

Her husband’s opinion did not coincide in some aspects, but was as hopeful as hers:

LE12-93-100 ...She is going to walk....Her learning is not as quick as that of other children but she retains...What she learns she retains. She is going to come out all right. She will give herself a little more time...

Parents of severely and profoundly disabled children expressed more uncertainties. That is the case in the quotes that follow. For instance, the future for a child diagnosed with microcephali and Down’s syndrome from San Germán was indefinite. That made it necessary to focus on the present:
LI8-73-36...We still do not know what it is that he is going to give. We are caring for him, we do everything we can for him but what awaits us only God knows, nothing more...

The results of their quests for services added to his doubts:

LI8-85-45...We do not know nor we knew about anything else [except the ESPIBI Center. In reality we have our son here. But we know about what he is living today. About what is going to happen tomorrow we do not know yet...

A young mother of a severely retarded boy with cerebral palsy from Bayamón deals with her situation by not thinking about the future. She described increasing challenges as her son grows up:

FA-113-142...What I do is that I try not to think a lot about the future so as not to become affected by it. Not to become affected in the sense of thinking about how exhausting it has been up to now and that he is going to continue growing and to continue demanding some things, and I do not receive the support of my husband in a series of things. Even in something as simple as a bath. It is becoming more difficult to bathe FA...And I already started asking myself, when FA is bigger it (will) then become difficult to get inside the bathtub to shower with him...if my husband is not there as he is now, really collaborating in these things, learning these things, I do not know...

Similarly, when asked to describe her boy’s future, the mother of an autistic boy described confusion and constraints in her planning for the future:

SE11-53-35 ... In that I am very confused. I have thought about moving to the United States. And I think about how difficult it would be for me. Very [general] things but not really. I do not really see a future of any shape. I do not visualize anything. I visualize myself with him for all my life. I do not see anything, nothing, everything is confused [crying]. That is always there, it is daily...

Even though her child’s situation is difficult, she maintained some faint faith:

SE11-122-101...The hopes are very slim, but one always thinks that something could happen, that one day you are going to wake up and
you are going to see something that is going to direct you,…that is going to change your life or that can make your son talk...

A glimpse of hope for improvement is presented in the following quote:

SE11-124-103...But I am almost sure that there will come a stage at which he is going to moderate his conduct. I think that he will progress very little by little. I don’t have the slightest idea about what is required to get there...

Her perceptions about his future included changes in other people’s reactions. She knew that people are more tolerant with disruptive behavior from younger children.

As he grows this shield will be eliminated. About other people’s reactions she stated:

SE11-98-71...I think that it is going to be more difficult since as he grows up, more is going to be expected of him. The environment that surrounds him is going to expect more of him...

Similarly, the couple from Río Piedras, with the severely delayed girl with metabolic disorders described an uncertain future:

LE2-43-44...We are still...uncertain...We have seen progress in her, slowly, but we have seen progress. The things that were expected, like when we said that it was hyperglicinemia, that she was not even going to be able to turn well. We passed through all that and everything has been more positive than what we expected. Although we do not know how things are going to be in the future, we are very prepared in case things are not as we would want them to be. I mean, we know she has a condition that limits her and that she will probably be limited in the future...We are as realist as we can be. We see achievement, and we hope those achievements continue, and that she can do something...

The mother of a severely involved child with Down’s syndrome from Arecibo was very confined in her expressions about her child’s future. She seemed low keyed in her expectations for what she felt were her child’s abilities:

AU15-50-38...I mean that one cannot think that he is going to be a completely normal child but teachers... neither...
The mother of another severely retarded child with Down's syndrome expressed ambivalence stemming from recognizing her son's limitations but hoping for something better in the future:

LI8-17-9...I hope he is fine and that he gets better. I do not know how to explain it. I think that he is going to stay like that... That he is always going to be a baby for me...

Her husband stated:

LI8-79-41...I tell you that I do not know, I think that he is not going to grow too much. And us, well, I do not know what to tell you, about what we could expect. I am devoted to my three children, but mainly with him I am doing what I can. I am going to help him in everything I can until we see where he can get...

The mother of the child with Cornelia D'Lange saw her son's long term dependency on her as their future:

EO9-61-51...He is going to be dependent on me in all his daily living activities. Even to take a bath.

Major concerns about his future were related to the quality of his educational options within the school system.

EO9-61-51...In terms of the schooling, I am worried about something. The Department of Education tries to offer what is cheap. Really, what they offer to special education children does not work. And, as a fact, I have the experience with my own clients, that they are people that have left special education [programs] completely ignorant. Children that may have the capacity of retaining,...have not learned what they need to...

About her future needs, a mother from Trujillo Alto saw the need for help from others as important:

AE7-104-131 ... For instance, the weight of these children. They go on growing up and if they do not walk, who is carries him is the one who suffers. I had to go to the doctor for a chest check up because all
of it hurt when I breathed... The doctor...said that I had all my chest muscles were swollen. [He said]: "But unless you stop carrying him, it is not going to go away"...

For the mother of the severe undiagnosed child from Naranjito, thoughts about the future were precluded by her certainty that her daughter was going to die early, as did her older daughter who had the same disability. When she was asked about her feelings for her daughter's future she responded:

LA10-63-47...Well, I am going to be sincere, I do not think that L. is going to last a lot. Since the physicians have told me that her time cannot be long, that it is limited...

A summary for this question, and formulation of conclusions will be presented on Chapter V.

Coping Mechanisms

This section addresses responses relevant to question two which states:

What are some of the specific coping mechanisms adopted by families to deal with their situations?

As described by Turnbull & Turnbull (1986, p. 304) coping involves both internal and external mechanisms. Several mechanisms for both internal and external coping that were discussed by parents will be presented.

Internal coping. This part describes only the mechanisms that relate to internal coping. Internal mechanisms are actions or beliefs that help reduce the stressfulness of an event or gain a resolution (Turnbull & Turnbull, 1986, pp. 304-305). These types of mechanisms will be described as personal arrangements developed by primary caretakers to solve or ease their situation. One arrangement which was frequently mentioned by
parents of children with severe disabilities was resignation. This resignation provided made the situation workable by redefining motherhood duties. For instance, for the mothers from Naranjito and San Germán, this was seen in their complete devotion to both children with disabilities.

Another form of coping was to overlook the situation. An example was mentioned by the mother of a boy with severe Cerebral Plasy from Byamón in handling her feelings of depression. She stated:

FA1-35-44... I try to do this, I say: I am going to live the day of today, I am going to solve what develops today with respect to these things, without thinking that tomorrow I am going to have this or that situation...

Similarly, the mother of a child with autism from Gurabo deals emotionally with her feelings of inadequacy by avoiding thoughts about her circumstances:

SE11-60-39...I rarely start thinking: How do I deal with it? Not even if I do it well or badly. Sometimes I feel that I criticize myself because I am not being sufficiently disciplined in the therapies. Because I am very beaten and I do not present the boy the program every day....

Not all the ignoring was related to severe disabilities or perceptions of extreme difficulty with situations. For a family in Juncos, not focusing on their child’s disability allowed them to lead a normalized life:

OO4-32-20...Here we cope as any other [family] does. We treat him as a normal child. We do not have special considerations in his care. We treat him as one of the others. If we have to spank him, we do. For me he does not have any disability...

There were instances in which ignoring was not an involuntary mechanism. The refusal to participate in parent associations that continuously discuss children’s conditions is one form of intentionally downplaying the importance of the situation.
For instance, a mother from Río Piedras felt that constant discussion of parents' groups puts into the forefront their child's conditions and its associated difficulties. Furthermore, for this mother, parent groups seemed to separate parent of "normalcy" by the fact that their discussion underscores the child's disability:

EO9-71-61...I can be wrong...but at this moment I am not interested in sharing with anyone because of what I always say. I have a child with disabilities, and so what. And we continue talking about the same things. I want a normal life, as if he was a common child...I mean just because I have a child with disabilities I have to associate with people with disabilities? At one time or another I would; as I told my phone number to a young woman to share. Because you need support once in a while but it is not that I need that support every day to the point that I would be crying every day. In that I am very independent and very different...

For relaxation, instead, she preferred arts and crafts activities that took her mind off the situation.

Other forms of appraisals that have been discussed in the section dealing with question 1 was the inability of some parents to think about or view their child's future. They stated that this avoidance resulted from the feeling that, although what was to come was not clear, their visions were fraught of work and tension.

The internal mechanisms such as reframing were also used. This has been described as:

"the family's ability to redefine a demanding situation in a more rational and acceptable way in order to make the situation more manageable " (Turnbull & Turnbull, 1986; p. 305).

An example of this was the previously discussed way in which families made the disability more acceptable by focusing in the positive. By comparing with other children when they felt that theirs were "not as bad as the others". In an analogous
way, attempts to focus on similarities to other more typical children, seemed in some
cases to alleviate the extreme feelings of self blame. These comparisons also led to
the frequent recognition of their child’s disabilities. Balancing by weighing children’s
disabilities while maintaining their similarities with other typical children was
sometimes perceived as necessary. As a father from Camuy stated:

SI13-25-23...I treat them the same...I do riot have preferences. I have
a little bit more care with her since she has more problems than the
others, the difference is very big but I try to understand her. She
sometimes gets so mad that she throws herself in any place. I try to
lure her so that she does not act in such way. But it is hard. It is hard
because sometimes she tries to tell me something and I do not
understand her...

Defining positive aspects which provide a more optimistic outlook was another
form of reframing. For instance, a mother from Trujillo Alto described the special
sensibility her child’s disability gave him. She used this special sensibility to help
advance his understanding and acceptance of his own disability:

AE7-105-133...But...I do not see it now as a disability. What I do is
to thank God because this boy is very receptive. You talk to him and
he has an ability to comprehend things that we sometimes [do not].
Because sometimes, in situations involving feelings towards other
people, [he understands]. For instance, there was a car crash, I saw it
and I stopped to see if I could help. He asked me: "Mom, what
happened?". I explained to him that a young woman’s leg got ruined.
Two days later he told me: "Mom, why don’t you call the young
woman to see if she got her leg fixed?"...But it is ...that one makes
him conscious that he himself has problems but that things happen to
other people not because they want to...

Another form of reframing was derived from looking for rewards on other
places besides children’s achievement. An instance of these rewards to hard work
and perseverance offered by parental success in working through the service maze.
This helped the mother of a child with Cerebral Palsy from Bayamón build a positive personal attitude and empowerment:

FA1-119-181...Whatever services I have gotten with FA is because of that. Because I move and I go to other places...

Furthermore, personal characteristics that helped in achieving services were also described as important. One such characteristics that helped a woman from Bayamón cope could be described as her analytic and persuasive power:

FA1-115-179...My capacity to be able to see the situation, to get to people is very important...what I did is that I took advantage of [the fact] that I knew people in private companies and I asked for donations to buy equipment...I [asked for voluntary contributions] I put an ad in which I requested donations...and many people sent donations and that is how I got the equipment he needed...

Parental experience with their children imposed changes in their temperaments that helped in their coping. A woman from Trujillo Alto developed more assertiveness in her quest to fulfill her boy’s needs:

AE7-39-34...I would say that experience made me change a lot because I was very shy. I did not dare to do things. But that year I dared to go wherever I had to because he was so sick that I said: No, he cannot stay like this. Someone has to help him in some way...

Important differences in assertiveness between parents who obtain services, and those who do not, where identified by this mother:

FA1-116-180...I know parents who are active that do not dare to ask, that do not dare to go to the people [and say]: I have these rights and I am not getting this service...they do not dare to deal with the situation and then they go back and put a barrier and do not do anything...

Characteristics such as perseverance were described as factors in a mother’s success in obtaining services and adaptive devices:
I think that I had a lot of luck. I have also been looking for information and [have been] putting pressure. I call today and if by next week I have not gotten what I expected, they get me. I call next week. I say, well, be it because they want to do it or because they get tired of seeing me, they are going to have to provide the service... If you are not like this, you do not get things done...

Personal characteristics such as their profession and the age of the caretaking parent were viewed as helpful. Some parents identified resources by their private means. For instance, even as a vocational counselor, a woman from Río Piedras faced initial difficulties in identifying services on her own, although she had the mechanisms to do so for others. Reaching out to her own list of resources helped her move through quickly:

Because it is one thing to provide the services to your clients where you master what you have and another thing is to look for what you do not know about. I was...simply...confused. I was looking for a response to questions and questions...The only thing that occurred to me was to take my notebook, my directory of professionals in my office...

Additionally, she described the age of the caretaking parent as having an effect in the additional patience required to handle her child’s disability:

When he is here you cannot be in a hurry because he is not in a hurry and that is an adjustment I had to make since I tend to be fast. And to find myself with a slow person, well, you go insane...Thank God that this maternity hit me at a mature age because I would have otherwise beaten him. But I do not do it...

External context coping. In addition to the mechanisms and definitions derived from internal resources there were some that came from external sources. External mechanisms included strategies used to avail oneself and organize the exterior resources to satisfy child’s and families’ needs (Turnbull & Turnbull, 1986, p. 304) and to reduce stress. Parents in this sample were compelled to move towards services
some time after they discovered the disability. An extensive description of service situations faced by families will be presented later as it pertains to question 3. This section will only illustrate coping mechanisms related to couples, the extended family, and the community. Following the models in the existing literature, couple and extended family help will be discussed separately, although for some Puerto Rican families that distinction is not relevant. Also this discussion about coping will be divided into issues related to couples/familial arrangements, economic related arrangements, social and religious support, and recreation and socialization.

Due to the requirements related to their child’s disability, families were often forced to make a variety of arrangements in their roles and relationships. Modifications and the organization of couple relationship were reported as part of that coping. One of the first coping mechanisms described by several mothers, including that of a child with Down Syndrome from San Germán, was the emotional support provided by the husband:

LI8-12-7:.I said, I do not want to go and see him because I go there and start crying...and he’d say "Do not cry. You must resign yourself since...he was born. He is our son." He always gives me support for everything...

Other families reported that after some initial short period of confusion they became at ease with their new situation and the experience has become a positive one. Some people in couple relations found comfort and support from each other. A couple from Juncos, parenting a child with moderate cerebral palsy claim a new closeness in dealing with their child:
Further strength and support was reported by the couple from Mayagüez too. A mother in Arecibo also reported changes in her husband related to their child's disability:

AU15-27-16...This also has caused changes in his life. He now is more homely, more watchful of the child. He did not do that with the girls. If the is sick he wakes up and is with him. He puts him to sleep...

It was not unusual to find that, in order to deal with the demands of the disability, families made a reorganization in their life. A couple from Vieques described what appeared to be a smooth general adjustment of their family life:

MO14-61-50...When the girl is here, since she studies, she watches M. because he is so active. But from there on watch him. I do my things...My husband also helps. He lays down on the floor and the boy plays horsey with him . My husband, thanks God, devotes time to him every afternoon...

Fathers were required to participate in the reorganization sometimes in response to stressful situations. One such instance was found in dealing with Health Services during hospitalizations. As a result of those unwritten policies in some of Puerto Rican hospitals, requiring women to be the only family members allowed to care for their sick children while in the hospital, some males were compelled to take care of children left at home. The husband of the woman from Ponce, described this intense period in his life:

GA6-99-100...I used to finish work tired, go to see her, and share with her a little bit; and I was tired and, if it had been only for one week,
but it was a process. When I started working it was when she [the girl] fell ill. It was the most difficult time...

During this time he was also worried about the conditions his wife was facing in the hospital. This couple stated that in the facility there was no provision for mothers to stay. She had to sleep on the floor and there were no bathrooms in their daughter's ward.

Similarly, for a family in Naranjito, the birth of the first girl, and her prolonged hospitalizations with disability, provoked a reorganization in which husbands participated:

LA10-35-8...The first year of M. I was in the hospital all the time. She started to get ill. She had seizures, pneumonia, seizures, pneumonia, urinary infections and again seizures and pneumonia...My husband stayed with the other children when I was with M. at the hospital during the first year...

Contrary to previous reports in the literature (Council for Exceptional Children, 1988, and Beckman, 1983), of incidents of tension in family relations, parents in this sample asserted that these strains were not directly related to situations stemming from living with a child with disabilities. But some changes in family routine caused by the care requirements seemed to have exacerbated existing tensions, or created new ones. In one interview we get glances about how these changes might disrupt marital routine. The father of a girl with severe disabilities from Río Piedras, described the strong effects this situation had on their marriage:

SE2-67-69...It does not, up to a certain point, [fulfill] the expectations of what a marriage is, of what children are, since we are not prepared for it. And when the situation arises we have to face it...what it requires from you, in financial terms, in terms of time, in terms of the family and social interrelation, since it is a process that requires its
time and, as I said we have to face it. You cannot turn your face and say "It does not exist. It is not our situation"...

For other families there were several ways in which the couple relationship was shaken or tested. For a woman from Caguas the birth of the child was perceived as having an important weighty effect on her relationship:

NE12-94-102...The relationship between the couple is affected. It is affected because the girl really needs the time. I do understand that, but there are also other people, that need the time...

One associated aspect that varied between couples was the use of gender role division as a coping mechanism. For instance, strict sex role division reported by a mother from San Germán was not uncommon:

p 34...He does whatever has to be done on the outside of the house and I do that of the house. Because he says that the woman is the one who has to be attentive to the business of the house...

Most families dealt with the added responsibilities related to care and appointments by having an adult family member, the mother, stay at home. Some women were compelled to leave their job or were hindered from looking for one, because of demands on caring for child with disability.

LA10-76-55... At the beginning when my daughter was born I felt like that. I did not understand I asked myself: "My God, why me? I had so many dreams, to work; I always wanted to be a nurse. Well I could not accomplish it, and I was mad at myself. And I asked myself: "My God, why do those things happen to me? My God, it cannot be true!"

The limited possibilities for work was also the experience of a woman from Trujillo Alto who had difficulties in meeting her mothering and employment demands:
AE7-44-44...I have always liked to work but now, with this situation, I prefer to stay at home. Because it has happened that because I am not here, I have not been able to pay attention to his needs...

These situations women face are better understood by examining the tasks they confront. A woman from Bayamón described all the chores related to her child’s disability:

FA1-127-159...I have to take him to therapies, medical appointments. Then between medical appointments, ...his therapies, the follow up. I have to clean the house, cook and make payments, look for information in the Department of Public Instruction, all the appointments I have to have follow up on different things. It takes an incredible amount of time...

Similarly, a family from Juncos understood that sex role task differentiation helped them deal with the caring for a premature very small baby at home. She described the arrangement:

OO4-123-69...I am the one who mostly takes care of him. But my husband mostly provides. Then I more or less manage the situation with the baby, school, home management, medical appointments and all that...

In other cases there was some collaboration while maintaining the sex role related task division. A family from Ponce described their division as follows:

GA6-106-95...Sometimes, since I knew that she had not slept for many nights, I woke up at night to take care of the girl. I helped her a lot...I have met fathers that let the mother handle their children alone. I, at least, if something happened to the girl...I would always wake up. Or we would both wake up and deal with the girl...

Their frequent division of labor was that while he is gainfully employed she handles the child’s schooling, transportation, pays the bills, does house chores and other homemaking related affairs. It is important to notice that for couples who both
work these responsibilities were shared. The ones who had or decided to work faced difficulties to the lack coordination between service and job requirements.

Although these were common arrangements that helped organize and deal with the external demands from the disability, not everyone was satisfied with them. Some women strongly complained about their marriage and related arrangements which are discussed in the excerpts that follow. Among them were also the expectations for support that were not fulfilled by the partner. Such were reported by the woman from Naranjito, who said:

LA11-1103-80...And many times I waited until three in the morning for an ambulance to bring me home because my husband did not have a car. Well, he could have asked his sister or my sisters to loan him a car! But he always raised his cries to the sky: "But the girl is in the Regional [hospital] again!" Instead, [when I said] the girl is at the Regional [hospital] again, [he should have asked]: "What happened? I am going to look for a car to pick you up as soon as you finish."...

She further described differences in perceptions between partners that strained their marriage:

LA10-37-29... He says he has suffered a lot with this. But I think that here the one who has gone through all the traumas is me. Because my husband...I have seen him so calmed...

In some cases existing problems with their sex role division and patterns of communication were exacerbated as the family faced the added requirements of the disability. One of the youngest women interviewed, a mother of a severely retarded boy with cerebral palsy noted differences in leisure activities:

FA1-126-160...[My husband] generally has Sunday off. Then on that Sunday he wants to do other things, he wants to rest. To rest means to do things out of our interests. We cannot share then neither... so few
times we go to the beach or to the movies...Once every two months, maybe...

Three of the four couples reported serious disharmony in their marriage, described as related to problems with alcohol or drug addiction. Such was the case of the families in Bayamón, Naranjito, and Río Piedras. An instance of this was discussed by a mother from Bayamón whose daughter has visual problems. She described how her husband’s drug and alcohol related problems and his "machito" attitude led to his reduced participation in the children’s life:

SU5-28-29...He lived at home so that he would have somewhere to sleep. Because he was a very "machito" man. He believed that if he bought everything [we needed] that was enough. And that is not enough. You have to give 100% of yourself...

Some wives find the husband’s actions related to the children’s characteristics. While a father from Vieques, had no trouble sharing with the child and his family after work, a woman from Arecibo described how a child with similar behavioral characteristics faced reduced interaction with her father. As a consequence, his mother is the person most responsible for his care:

AU15-7-63...If you release him in a big space you lose him. And he [the father] sometimes comes and after a little while brings him back. Since he cannot be trailing after him...

She described other behaviors of the child which did not contribute to his being accepted in social situations, reduces father’s participation in his care:

AU15-63-51...When he [the child] sees a lot of people he behaves badly. He throws himself on the floor...
A typical example of parental interaction is:

Well I have left [the child] with him [my husband] ...He takes him when he pleases for a ride, puts him in the car and takes him along. Sometimes to put some gas in the car or to do something around and just for the ride...But he, too, gets tired because this child is kind of electric...

Although service resources characteristics will be discussed in the following section they were also mentioned as a coping mechanism. These were, the sliding fee status in the school, subsidies for medical and therapeutic services, physician’s payment plans and help to defray the extended medical help, and petitioning social agencies. Examples of them follow.

The sliding fee status in the school available to the child with cerebral palsy from Juncos allowed his family to pay for services and to have money for additional things for the child. Similarly, a woman from Río Piedras identified getting subsidies for medical and therapeutic services in the form of a green card, as a resource that helped her get by:

EO9-76-64...It is not simply the physical therapy. It is giving follow up in audiology, nutrition, and occupational therapy. With the help of the green card money is just enough...

A couple in Ponce was helped by a physician payment plan to defray the extended medical help their daughter needed to care for her hearing impairment. The father described it:

GA6-76-79...Thank God we found him [the physician]. And he helped us to place the girl in the Damas [Hospital]. I have paid him well...sometimes I pay him little by little. He talked to his colleague...[who] is an ear, nose, and throat specialist and the specialist also gave me a special price. He was the one who operated her adenoids and of a tube...
A woman from Trujillo Alto was offered and received a free operation as a reward for "being a special mother":

AE7-69-70...Once he needed an operation that had a cost of 1,400 dollars. The Medical Plan paid only $400.00. I had to pay the other $1,000. The doctor did not want to charge me. He said he did not want to charge me because: "There are not many mothers like you. And you have also been good to me." He said a series of things. I left the office hysterically crying of happiness...That was the greatest thing that happened...

In a similar occurrence, the woman from Río Piedras felt she received information about the Medicaid Card others did not have because of her fulfilling her duties responsibly.

Since in Puerto Rico most related services are not available gratuitously, parents coping relates to the economic reorganization of the families to deal with the economic requirements of the disability. Some families did not report a lot of disability related expenses because they could not find appropriate services. For a woman from Gurabo, the lack of appropriate services available for autistic children reduced her need to obtain additional money:

SE11-80-54...Since I have really not seen any place where I can say: "Here is an private institution that can help my son if I pay"...Lately I have been attending a speech therapist of a school that is here in town...If only you could say that each therapy session is such a big advance that it is worth to pay $100 or $200 but in these cases it has to be continuous...

A child with severe retardation secondary to Down's syndrome, did not receive the services he needs because there are none available in their town. A family from Camuy was hindered to receive what appeared to be basic health related services for their child due to economic difficulties:
SE13-41-34...[her] It is a misfortune because, if we didn’t have to take her to the doctor so much, we would spend [money], because you always spend [money], but it is an additional expense and a big one...

Similarly, other difficulties, as a result of the health care requirements, identified were related to the severe changes in the family’s routine and economic difficulties:

SI13-18-20...This week we have three appointments on Tuesday, Thursday and Monday. That is too much since it is very expensive...

They also experienced inability to defray the expenses for needed medical care:

SI13-29-26...Right now we need to have some studies made. Those analysis are made out of the country, I think that in Connecticut. Those analysis cost $329. Since we do not have the money, they did not do them...

This couple from Camuy had no wage earner in their house. In that way, coping with the requirements of the disability was made difficult. The girl only received the services that were free and available, and some services were not delivered.

The family living in Vieques faced several additional expenses related to the centralization of services in the main island. One of the first expenses was that of the diagnostic test which was $305 and others related to his orthopedic condition:

MO14-54-43...Then tests were made to the boy in order to find out about his illness, his condition. We had to pay too... because the plan did not cover [such tests]...

Their medical plan did not cover his orthopedic shoes nor the therapies...

They had to go to the main island for health care (sometimes weekly) which implied additional transportation costs. All of these expenditures reduced their ability to pay other necessary services:

MO14-34-21...[him] We had to make plane trips. [her] Plus the taxi. The taxi charged $60 every time we went...
Due to their inability to pay, another form of priorities was avoiding some essential services that were not offered free of charge by the responsible Agencies:

AU14-68-56...If I had the money I would pay them on my own, the therapies. I would look for someone to give them to him...

Similarly, the father from Vieques states that they can get by because they do not provide all the services their son needs:

MO14-52-41...According to the book, the child is supposed to be taken there [to the main island] and he should have more contact, well then [money] would not be enough. If we carry on like this without taking him as we should... We cannot give him more follow up... because money is not enough. We are in an island apart here. Everything is very costly on the other side...

As previously stated, for most mothers who worked prior to the birth of their child with disabilities it was not uncommon that they stopped working due to the demands on their time related to the health and service related appointments. As a result, these families faced a reduction of income. At the same time their expenses increased disproportionately due to the disability. Thus, a representative situation is the one that follows:

NE12-53-59...If I take her to private therapy it is $40. In addition I have to travel during the week to San Juan two or three times... I mean there are many expenses... And there is less income since I had to stop working because of the girl. Since if the girl was well I would be working...

There were two families in which both parents remained as wage earners after the birth of their child with disabilities. In those cases the one with a flexible schedule managed the appointments errands:

LE2-37-38...[him] My schedule is more flexible and that allows me to go with the girl to the various places she has to go to get her services...
These arrangements entailed a time or emotional sacrifice. In this instance, the husband worked until late at night and his wife requested changes in her work schedule to fulfill her daughter's strict dietary requirements. These changes meant that she slowly used her vacation time, and she would not get vacations that year.

Another job arrangement was that of a woman from Río Piedras who was forced to redefine her professional aspirations because of the errands related to her child's disability. The changes in this single mother's life related to her child's needs affected her career possibilities:

EO9-50-43...I do not deny that having a boy with disabilities changed my life. I had some plans for changing jobs, and I could not do it...

Even while remaining at the same job she faced substantial changes:

I gave priority to his therapy for which you had to take time from your job to attend...Not only the therapy but the medical appointments. And they were endless. More so at the beginning when they were evaluating things. That is why they are so tedious. And they were so many. Imagine how that interrupts your work...and you have to compete with other people who are not limited...

A woman from Bayamón was released with a 4.5 pounds baby. At the time of the child's birth she was working as a secretary. Two months after birth she went back to work. Her job performance as a secretary was affected too. She stated:

FA1-88-115...When there were important appointments I had to go. And I felt too tired since...even though she [the babysitter] cared for him, F. A. almost did not sleep at night. He slept 15 to 20 minutes and woke up, all night long. Sometimes I had sleepless nights with him only to wake up next day, again, to go to work. It was very tiring. I spent the day in the office at a daze, in another world. And the boss started to put pressure on me. They had been very considerate to me, up to that point...

She ended resigning.
A similar situation was faced by a woman from Arecibo whose child with Down's syndrome faced many health related difficulties during her son's first year:

AU15-24-14...I had to be absent from work and they put pressure on the job. Since it was a factory, factories are very strict and I spent my time like this until the factory closed in '89. They closed and I did not look for another job since I could not work. It was too much pressure! And also there was no one who could care well for him...Even today I have not moved because of that...

Comparable difficulties in their employment were experienced by the mother of the girl who has hydrocephaly and spina bifida:

NE12-51-57...I was working for two years and my mother took care of my girl but I had to definitely quit my job. One reason was that I did not have anyone to take care of her, being like this. The girl had already grown up. My mother could not deal with her anymore. On the second place, it was too much. Too many appointments. I was already tired because sometimes in my only day off, which was Wednesday, I had to go out of my way and attend a lot of appointments plus the therapies. I mean, it was very tight, so I made the decision and stopped working...

Having other family members nearby in disposition of care allowed a mother from Trujillo Alto to work for a while:

SE7-55-53...Well I have enough help because as you see, over there [next door] lives my mother. When my mother had to leave, he'd stay with my sister ...My parents in law...are extraordinary people... They never say no when I need them. And right now it is his grandfather who takes him Tuesdays [to the therapies]...I have not had difficulties...

The individual changes in purposes due to conditions hindering her personal and employment life, made by the mother from Gurabo, are reflected in the following example:

SE11-123-102...My life changed completely. To feel that you are not as free as before, that you cannot aspire to any position, to work, to
relate with others, to lead a normal social life, to go to all the places
that you would want to and would want your other children to go to...

Although mothers were the ones who saw themselves forced to quit their jobs
because of the requirements of the disabilities, some fathers’ jobs were affected too.
For instance, a working father from Mayagüez described the conflicts between their
work and their son’s school schedules in this simple manner:

CI3-28-29...[him] I have never been able to get to my work early
neither...

The father of the child from Juncos also reported problems in the job due to
absenteeism. The resolutions to this situation represented a coping mechanisms. He
stated, for instance:

...I was absent a lot sometimes, but I had my reasons: What happens
is that I have a child with disabilities. My child cannot miss
appointments. My wife alone cannot take him because they have to go
to the Medical Center of Río Piedras...On the previous job, that was in
painting, I left the company and left the doors open. The boss was
very good with me and little by little they all began to understand. On
the contrary, there were sometimes when I was absent and they would
sign me in for the day...

In this as in other accounts, there is an underlying need for flexible arrangements on
the job setting.

The experience of a family from Vieques represents that of some working
fathers who were used to share the economic burden of the family and are forced to
make arrangements to make up for the lost income. This father was required to work
more hours because of the reduction of his wife’s income:

MO14-58-48...[him] The only thing that has happened is that from the
moment that she stopped working, I had to go into the streets. The
money that she made in her job, that money that she did not earn, well
I had to make it myself to be able to cover the expenses. I have to work seven days a week...

The economic challenges faced by these families also required a variety of other income producing arrangements on the part of the breadwinner. For a woman from Río Piedras, the economic reorganization, facing economic challenges head on, and generating informal avenues for income appear to have been helpful:

EO9-65-54...Since I got married for the first time I have felt a lot of responsibility and I like to be the principal head. And I get by very well. As a matter of fact, I work...so at least my income helps me cover my needs. When I find myself economically restrained, I look for things to do. I bake cakes, I sew or I invent something. I always have alternatives...

Additional expenses forced several creative solutions to the economic difficulties. For other mothers this creativeness took the form of soliciting, saving and making priorities. Several women reported that they petitioned family members, the general public, social agencies, and sold goods while waiting for their husband's payday. A woman from Naranjito, for instance described her common practice of asking for donations in agencies, major's office and from family members:

LA10-68-51...I buy Pampers and when I'm in need, I go to Social Services...I receive very little help from Social Services, and always with a "but". Besides my mother who helps me, what I really get are the food stamps. And when medication is scarce [in the hospital]...I go to the major's office and I request it...I sell things "pasteles", fried goods and all that, because I always have to honor [my obligation to them]...

Asking for donations and requesting free services was also reported by a mother from Caguas:

NE12-53-58...It's not easy but we try to survive as much as we can. With the girl there are more expenses, for instance the chair was worth
$2,000 or more, the braces she has come up to $3,000. You have to buy her special boots. I had to get moving. For instance the wheelchair was donated, the braces were partially donated...

Another way of fulfilling economic needs was borrowing and saving for appointment related expenses:

SU5-41-45...Sometimes I have to borrow, sometimes I tell him [my husband], about five weeks ahead of time: "Look I have to go to the Medical Center", and he gives me or puts away five dollars, and five dollars, and five dollars until he has saved 20 dollars...

Regular creative avenues for obtaining additional money were hindered for the mother of a child with autism, who tried several home businesses. She had difficulties related to her child's characteristics:

SE11-77-52...For instance, one of the enterprises that I tried to set, not with much enthusiasm, because it is not what I like to do the most was a cosmetic business... But it required that you had at least the time...to invest...even if it was a minimum. I earned some money but the thought about who could take care of the boy tired me. I was counting on my mother who did not like it very much...I had to quit...

Other economic issues for some families were solved by making priorities based on their economic abilities. For instance, selling possessions useful for the family was a mechanism used by a family from Camuy to obtain medications and services. They had to sell a car in order to buy medication for her. When there was no other thing to sell they were forced to eliminate necessary medication or services. As described by the mother:

SE13-37-30...Oh!, Right now I am not giving her the epilepsy medication. It is difficult for me to get it. She has missed two or three appointments these days and on Tuesday she has an appointment at the Medical Center and I do not know if I am going to be able to go because I do not have money. Transportation is very difficult. His
[My husband’s] car won’t take us that far. And even if it did, you have to provide for gasoline and to eat...

Some covered their regular expenses but were left with little money for others necessary things such as the therapies. Likewise, a mother from Arecibo described her dealing with extra expenses related to transportation:

...If I go from here to town it is 60 cents and then from town to there [the hospital]. Now from here to Dominguito where he gets the therapies it is almost a dollar...With the boy is approximately $3.00. And sometimes I also take the girl with me...so that she can help me with the boy...

It was not uncommon for them to take their children to private health and therapeutic facilities because of the long waits faced on public ones. A woman in Naranjito reported taking her daughter to private doctors because of the lengthy waits in public hospitals. This, together with the regular expenses related to her daughter’s disability, make their economic situation difficult:

AE10-135-109... Salary is very low for five people and for keeping her on Pampers. Weekly we have to buy her medicine. If I buy a box of gloves...for instance, the mineral oil does not last. We have to buy it weekly...And we have to buy the Pampers weekly...more so, the cost of taking her to private physicians...because to take her to a public one is to die [waiting]. That is why I take her to private [ones]...

Parents of this sample frequently gave importance to social support in the form of assistance from family, friends and people from the community, who supported them at some periods. Although differing in extent and type, their support was considered essential by most families. Other people made comments that helped organize themselves and/or attended a variety of needs.
In terms of the family and extended family support, reassuring comments from partners have already been mentioned by main care takers in a previous section.

Additional complications were experienced by women without or with reduced father’s support. For instance, a woman from Trujillo Alto described her struggle to obtain support from her husband and other family members:

AE7-71-72...There comes a time when you say: "No one lends me a hand!" And then sometimes I asked him to bathe [the boy]. Well, he’d have a lot of trouble because you have to hold him, you have to help him take a bath...Things like that...

In a similar instance, a woman from Bayamón, mother of a child with visual disabilities, expressed her frustration about the lack of cooperation:

SU5-53-34..I [face the challenges] by myself since my husband goes nowhere. Now the child has an appointment...to talk with the doctor. Since she says that it suffices that I carry this responsibility by myself and that is not fair...

The mother of a child with Cerebral Palsy from Bayamón, who faced a similar situation got relief once a week for two hours when the itinerant teacher visits:

I do house chores, but it is like something completely different since I am relaxed, and not thinking about F. A., whether he is going to be well or bad, no. F. A. is with her and I forget about him...

On the other hand, any source of support available in a couple relation was reduced or eliminated when divorced:

SE11-20-11...He made all contacts because he already knew the Medical Center but all his cooperation amounted only to that. When the tests ended it stopped there. Really, he shows that he does not have any preoccupation. I feel that it is that he has disconnected...He continued his life and his children do not belong to a family nucleus he is probably going to form. In fact I do not recognize in him any sense of family. He is he and we are something else...
Assistance from close and extended family members, although sometimes difficult to obtain, was also helpful. Obtaining help in routine chores was a recurrent way of coping:

CI3-26-28...Mrs. L. [mother in law] stays with the two of them during the morning. I take C. [the boy with disabilities] to school at 11:30, then Mrs. L. picks him up...

In this case, as well as in others in this sample, some grandparents on the mother’s side were a readily available support for mothers:

CI3-83-80...[she] When we are working, mainly who helps a lot is my mother. Sometimes things get hard and I ask her: "Mommy, please!" and my mother comes and takes care of the children. She is the one who has always taken care of them...I would say that 98% [of the occasions] has been mommy... Right now she is the one who takes him to school, picks him up and brings notes from the school...

Care and general support from the grandparents in maternal side became the source for babysitting for a single working mother of a child with a low incidence disability in Río Piedras:

EO9-60-55...He simply stays all week at my parent’s home with my father. I take him Sunday afternoon and I pick him up Friday. I go [to my parent’s house] every day, I feed him, bathe him. It is truly painful since I would always like to come directly, but Mom made an agreement with me that in order for the child to stay there and avoid temperature changes in the morning I had to do that...

They also provide economic and general support:

EO9-80-70...The only ones I can count on for economic and other help are my parents. Others are pure talk...

But this grandmother has expressed some desire to put an end to their parenting years:
And mommy always repeats the same... That I should look for someone to take care of the boy. But that is not so easy. And I am not going to put the cart before the horse. My father is old. He is 72 years old and I really understand that at any moment he might get sick or die. My mother works. But she tells me that she is not going to spend her whole life taking care of children. And I understand her because that is not her responsibility. She already took care [of her children]...

When support on the mother's side was lacking, difficulties in the intense care required by a girl with health related problems were magnified:

GA6-55-63...[she] I started suffering seeing there was no help from my own family. That hurt me. [he] When a sick person helps another one, there is a problem that is not easy [to solve]...While taking care of the girl, she [my wife] had high blood pressure and had to go several times to the emergency room...so that the doctor would see her...

In a few instances, maternal sisters provided balance and help with disability related chores:

AE7-76-76...My two sisters live close by...My mother takes care of him. My two sisters are married but the one that got married last year lived here and she came to live with us when he was five (5) or six (6) months old. She was of great help to me because she helped me take care of him and, since she studied nursing...she helped me understand that I did not have to worry too much...

Parental sisters were also providers of economic and emotional sustenance for a father from Ponce:

GA6-101-107...My sisters help too. For instance, if I need to buy the antibiotics prescription and I do not have money...I at least have their support...I know they are not going to say no...Even if I have to pay them back...

A sister provided few of the limited opportunities for support to a single woman living with an autistic child:
As I told you my sister shows herself as the person with whom I can count on. She is now working. Before, I could count on her at any moment during the day because she was at home...My parents are far away. Before, I counted somewhat on them with certain suspicion. There were always problems there. But now they live too far...

Most of the help received by a mother from Naranjito was provided by female members of her family:

LA10-87-64...My mother lives downtown. She helps me, for instance when I don’t have Pampers. Just that only. My sisters and a sister-in-law go with me to the regional hospitals and offer transportation. They help a lot with that. No one else [helps]...

As seen, it was frequently the female members of the families who provided direct care, as was the case of a mother from Juncos:

OO4-52-29...My family was very watchful. I have one sister and a sister-in-law that we are always very united, my nieces are...very alert and we are very close together. He is their and our baby...We are very attached to one another. Each one puts a little bit...

Sporadic help by brothers who lived in the neighborhood in emergencies was available:

GA6-105-110...The one next door is my brother...I leave and feel more assured that if the girl has a seizure...[or] something happens in my house, there is a telephone and no tragedy is going to occur...

Likewise, the mother from Juncos received sporadic but appreciated support from her brother:

OO4-39-79...[she] My brother...did not help in the sense of taking care of him. He helped in the sense that if we need something for him...[he] and support...[she] Yes moral support...
The same was true for the mother of an autistic child from Gurabo:

SE11-51-33...I, for instance, go to my brother's house very little. Not only because of the child's condition but...because we see each other in other places and not very often. Once in a while, when he finds a person that he thinks can help me he calls me...He is watchful and worries, even if I do not see him a lot...

Many unplanned needs were served by allowing child's visits to a moderately mentally retarded child and by accepting family members in the neighboring houses.

An important function was that these visits teach social and communication skills:

AU15-74-67...During his frequent visits to the neighbor's house [who is a sister-in-law] he learns more. There he learned some phrases. He knows how to say: "I am sorry." He learned to say: "Hi, how are you?", to make requests, when he is hungry, he sits down, and says: "Give me rice." He is learning to unfold...

The support, concern and nurturing of some people towards the mother herself was greatly valued:

LA10-97-76...The closest ones that know me and help me and know about my problems are my mother and my sister, and R. (a man from the church). [And what do they do?] They do not make comments. They show love and you see the sincerity when they help you... They worry about me. Because there are people who see it as a rare case and as a lot of work...

A woman from Bayamón, mother of a child with Cerebral Palsy, lacked the support from the extended family. The difficulties identifying resources for babysitting are reflected in the following excerpts:

FA1-93-120...I am from Ciales. All my family is there in the town of Ciales. My husband is from Costa Rica and only his mother is in Puerto Rico. That means that in the town of Bayamón we are by ourselves...His mother lives now in Puerto Rico...But she is a person that works and has all the economic responsibilities...And then she cannot make the time to help me...And my family neither...[since] no one [lives] close to me...
There were several concerns about leaving their children with babysitters. A woman from Río Piedras described her hesitancy and the obstacles in obtaining family babysitting resources:

LE2-93-103...It is more because of the diet. If they are going to be as strict as you are. She cannot consume sugar. In my family there are other children and there may not be the same control...And then...it is no fun. I, for instance, would have to prepare everything beforehand. It's the same work that I always have even if I am going out. To leave him with them to then go to do other things. Or to give all the instructions and make sure that they understand...

Furthermore, concerns about the quality of care offered by people outside the family hinders the use of possible community resources. She stated:

You first fear that he might be abused or that something happens...And then you have certain insecurities and certain things. And on top of it he [my husband], who definitely does not agree, [thinking about] what other people can do to him [the boy]. Then he is making me more responsible...

Similar reasons were provided by the mother of an autistic boy from Gurabo, as follows:

SE11-96-67...I have not considered a lot [the care from people] because communities are not as trustworthy as before, as part of your life...

On the other hand, the fact that many people worked outside of their house in the communities parents lived reduced opportunities for support:

LI8-41-21...[Family members] live close by but they work and this place is always like this. Peaceful...Mom is always sick, she has a heart condition and daddy too...My sister helps but since she studies it is now occasionally...
Thus, the employment of others is one factor in the reduction of their natural resources of support. For that reason, care by others outside the family was not feasible for a family in Mayagüez:

CI3-83-82...It is impossible. Almost all the people I know work outside of their home or have small children...Basically it is that everyone is busy...

Some parents resorted to taking all their children with them when doing errands and to attend appointments, when care was not available:

AU15-74-65...For the most part I take care of the boy...There have been instances in which, if I do not have anyone to take care of him, I take him with me. If it's someplace where I have to go...Since I already know....

For others, the person’s effectiveness in coping was related to the willingness of other family members to deal with the children’s characteristics. One such instance was that of the single mother of an autistic boy. She recognized the difficulties involved in obtaining family support due to their reaction to her child’s unusual behavior.

SE11-88-61...I think that the type of behavior the child has, that he is not a very easy person and my family is not the type of family that has patience to teach and accept. In that respect, I have not seen myself very supported by them...

The fact that after her parents moved, their visits are less regular, has eased the difficulties with the grandparents:

SE11-85-58...I see them regularly almost every Saturday; we visit them. The children spend a very pleasant time because they live on the beach. The boy enjoys the water and them a lot. Since they do not see them [the children] so often... they welcome us with more affability...
Other family members provide incidental and superficial encounters:

60...His family does not help...I maintain some relationship with two of his sisters...They call me every now and then, they visit me once in a blue moon, and we make plans to go out together. And another brother who calls me when there is a birthday...

A mother perceived this lack of support as resulting from the limitations in orientation or understanding about their difficulties:

SU5-73-73...There are no people that are providing sufficient help to people that have children with disabilities, and to the person who does not have children with disabilities so that he/she understands how hard it is to carry that burden... so they can provide some help to that person. Because if you do not know what that person is going through, how can you help?...

Another family member mentioned some instances in which their children had been supportive. In some cases, the siblings of children with disabilities provided a source for sustenance for the child’s primary caretaker. For a woman from Naranjito the husband does not provide much assistance, but her children provide limited but more reliable help:

LA10-96-73...My husband has no patience for this but the children have learned a lot. When I go out my daughter sits there to watch that girl, and she really watches her...For instance, she knows how to take rectal or oral temperature...she takes care of her very well. Well sometimes I sit down to watch television and she plays with her, she dresses her, undresses her, combs her hair...She is her doll...Not the boy, because if the girl has a seizure, he goes out of control...

A mother of a child with autism states that their typical children have a special sensibility and a way of accepting their sibling’s disabilities:

SE11-123-107...I practically have not done much. This has been a beautiful process because I think the love they have for each other as siblings has been able to make them understand each other... Maybe it
is that they see him as a baby...and they have to understand him and they feel a lot of love. They love him a lot...

The mother from Arecibo also reported help from her daughters:

The girls understand him as I do. Even the language. They are the ones who understand him and help me. If he asks for something to eat and I am not there at the time they give it to him, they change him, they watch him sometimes. When he escapes, they go and get him... I explained to them since they were little, the problems he was going to have, how different he was from the other children and how we had to treat him...

Neighborly help was readily available during personal and children's health related emergencies for several families. That was the case of a woman with disabilities from Bayamón:

Su5-48-52..If I feel sick or if I have a seizure my friend or my neighbor tell me to leave the girl with them, to take the boy too...I feel that these favors amount to more than when you are told I love you, I adore you all the time, and they do not help you...

Assistance in emergencies was also available for the mother from Ponce and her children:

GA6-88-97...Once, the girl had a seizure and the neighbor helped me. I did not have a phone nor a way of communicating with my husband...[him] When we lived in El P. and I had to work, different neighbors helped her. At my house my sisters would go quickly and help her, too...

Comments from other people with disabilities have been already discussed as a form assistance and support at several occasions. Information from other parents was another support mechanism. A woman from Vieques described how they obtained, through other parents, the necessary information that was otherwise not available by service providers:
MO14-44-37...I quickly looked for information. And where I worked the secretary also has one [son with disabilities]...that one I think is 20 years of age now. And I went to her house...When I asked her, for me it served as information on how to deal with him...No one else had offered that help. Here in Vieques there is nothing, nothing...

A woman from Bayamón, obtained and provided information through conversations with other parents facing similar situations:

One learns a lot from them and has the opportunity to...offer every kind of information. There are so many parents who do not have any idea about Public Instruction...According to my experience the greatest percentage of people...

Meetings also provide opportunities to identify strategies to help themselves:

OO4-83-46...In the school we talk....Sometimes in those [APNI] meetings you share with them and you say: "Look, you are not the only one." I too have a baby just like that and I manage my house this way, and I manage the situation this way. Sometimes a word another couple says could be good for me...

Meetings with other parents were also useful since they provided information about other disabilities and provided encouragement to move forward:

SE7-52-50...In the APNI Association I went to an assembly and we shared very well. Aside from those occasions, we do not see each other...It has been useful because I have seen cases worse than mine and [I've learned] how they can deal with that situation well. It is as they say: Look back to see that there are others worst than one. That helps...

Even informal meetings with other parents in different places sometimes served to discuss and clarify positions about children with disabilities:

LA10-73-54...When I talk to them I have commented about ways in which we help [our children], we comment on many things. I think that I counsel them more than they do to me. Because they have taken their children's condition differently. The condition is not a burden and they do not understand it. [They say] that it is God's punishment and I say no, those children are not a punishment from God. They have
conditions, and so many conditions in the world, that one has to accept them and love them and care for them—I explain. And they respond: "Oh! But why me?"

A special understanding resulting from these shared experiences was one of the advantages identified by a mother from Caguas in exchanges with other such parents:

NE13-50-60..When there are meetings we call each other. There is a small group of mothers with children with disabilities...It helps a lot because sometimes we share things that maybe other people who have normal children do not understand. And one mother may tell me: "Look the child does this, or responds to this." I mean, maybe I have gone through the same things...When our children do something new we enjoy it, we make the most of every one of their movements. We might tell other people but it does not mean anything [to them]...

There was also emotional bonding on these encounters:

SE11-121-101...You look for them because they are your equals, the ones who are going to understand you, the ones who know what is going on, your family. They were not in my environment before...

A mother developed special friendships with some of the parents she met during appointments. Her encounters served for conversation, advice and support:

LA10-72-54... Well, this girl whom I met...we developed a good friendship and she came on Saturdays, we talked a lot regarding her children and we helped each other, we gave each other advise. In town there is another one...who has a child with the same condition as L. I see her very little, sometimes passing by...

On the other hand, there were situations in which expectations for information and solidarity from close members of the family were not fulfilled:

LA10-55-38...Then my sister-in-law had a baby...[who] had seizures...and was disabled, too. Her baby died when he was four and a half years old, when I had M. I expected that she; having had a child like that would counsel
me, would tell me. She did not. She just said: "That is God's will." The normal stuff that people say to you. "You have to take it easy. You have to learn how to deal. That is the only thing I can tell you." I expected her to sit down with me and tell me: "I had this problem too and I know how to deal"... that she would tell me: "You have to do it this way"...

Difficulties with parent groups reduced the opportunities for accruing their complete benefits:

EO9-71-60...Here they have meetings but right now I am totally disconnected because they do not send notification. I find out through other parents. [Why is it like that?] They are poorly organized. Here in Arecibo there is a doctor organizing it and he has a child with Down’s syndrome, and he has dedicated himself to help... For other things I’ve found myself guessing...

While most parents were positive or neutral about the parent groups a mother withdrew from them, perceiving them as a somewhat worthless exercises:

EO9-71-60...No, I practically do not know anyone. I would say that I do not even have relationship nor do I know anyone. [Have you attended a meeting of the parents’ support groups?] No ... I do not like the bustle, I get tired...When something is not there it just not there. Many times people believe they have a lot of rights but...some rights [are directed] towards some services that do not exist. I am not going to struggle for something invisible. That is what they do not see..

One of the coping mechanisms identified by families in this sample was spiritual practices in the form of organized religion. These practices provided opportunities for giving interpretation to particular events or life in general. There were several aspects within the coping opportunities religion gave such as: redefining the disability and their family in a more positive manner, providing peace of mind, hope and being a source for social support to isolated families. It should be noticed that religion was not for everyone, some even rejected it as means to manage.
Church also provided possibilities for redefining the disability and their family in a more positive manner. As previously seen, being able to say: 'He was made by God and God cannot make something wrong' was a simple form of reframing, of accepting their condition and getting on with life. For a mother from Naranjito who had two daughters church attendance had a profound effect in her understanding of her situation:

LA10-48-36...And I started with the same devotion with her as with L. but since I lived in town I started taking biblical studies and these helped me a lot to understand many things. And then I included my children and my husband in the problem with L. and M. I started to have more patience with them and I started to see other things. Because I was really blinded by their problem...

Religion also provided peace of mind and hope for a mother with two severely disabled girls from Naranjito. She stated:

LA10-74-55...But I am Christian and I hope there will be a new order in which they will be healthy and I base myself in that. That is why I have taken it so peacefully. That is why people tell me "You act as if you did not have children with disabilities since you are fat and rosy and you are always happy..."

For a couple from Ponce a fact that could have been seen as negative, the birth of a girl with health problems, was reframed by their religion into a positive understanding. The mother stated:

GA6-39-51...I considered it a miracle. I prayed for the girl. We are evanglic. If it had not been because of the Lord, the girl would have been dead there. Definitely our girl would have died...

Others families reframed by seeing themselves as with special missions in life.

Besides giving meaning to the parenting experience and peace of mind, organized religious groups were helpful in providing social support for isolated
families. People belonging to religious groups were reported to have been helpful by providing emotional support, guidance, acceptance of the children and frequent company. A woman from Río Piedras, who is the mother of a girl with metabolic disorders stated:

LE2-98-112...There are people belonging to different religious groups who, even if they know that one is not of the same group as they are... worry about her, tell us that they have her in their prayers. At a certain time we went to a Baptist Church, and those people write to us too. I have Pentecostal friends, of all religions...It seems that people want to help in different ways...

Not everyone was receptive to spiritual practices in this sample, though. A mother from Río Piedras saw it as a crutch and rejected it as an option to deal with the emotional impact of the disability:

EO9-107-99...Look, sometimes people tell me: "seek God." I am not a person that would seek shelter in any religion. If you are thirsty, drink water. Why get milk if what you want is water?...I would like to have some support from a partner for the rest of my life, because I do not want to remain alone...

One of the least recognized family functions is that of recreation. Recreation deals with leisure activities in which a family is engaged for the individual member’s benefit and that of all family members. It may also take different forms for different members of the family. Its importance resides in that, while it may not take care of member’s physical or survival needs of its members, it assures the stability of the family system.

In a few of the interviews some of the factors affecting the main caretaker’s recreational opportunities were discussed. The aspects that affected their recreation were: the possibility of incorporating the disabilities into the family’s regular and
recreational routines; intensity of child's needs, the feeling of responsibility, the hardship of having only one family member responsible for all the child related care; and, the economic costs for activities that were identified. As a result of all this, most families resorted to modification and/or elimination of enjoyable activities.

Three (20%) of the families in this study described frequent regular activities and outings held with their children. These were for the most part families with children with less severe disabilities (mild to moderate). For instance, a family from Mayagüez described amusement activities that include the child with disabilities:

CI3-87-90...Yes, we go out but...during the weekdays we keep a program...There are times when it is seven in the evening and he is working...Do you know what we do sometimes?...we come and pick up the children so we can share with them. We pick them up and we go. He is working and I am with him and the children...Now, we make time on weekends...

The fact that they both work create difficulties attending special school activities held during the daytime:

CI3-93-97...For Halloween we made a very deep sacrifice because he didn’t go to his work and neither did I... The four of us went to the zoo, on a Wednesday. We dressed up the boy and he won a prize for most scary child, because the whole time he went: "Booooo!" But now he has a field day, on April 4...

A family from Juncos mentioned that even with difficulties they integrated their child with moderate disabilities into all their activities.

OO4-83-48...And sometimes they do not know that at the beginning is hard because you cannot deny it is difficult. But after you make it a habit..., we never get into the car without him...
They were able to integrate him in all the family's activities:

OO4-71-40...I have placed him in a school [almost] since he was born. [And] he goes with us...He is not a child who's here and just because does not walk he is left there...

By including him in regular activities they found that the lack of sensitivity for children with disabilities as an added obstacle in their amusement possibilities. In one such instance, she addressed the issue immediately:

OO4-141-89...We took them during Christmas to the Enchanted Forest. When we arrived, since almost all of them are in wheel chairs, what are we to do if we have to climb about three steps?...What did we do? We turned on the video camera and we started recording. "Look, there is no ramp for us"...We went there so the children would enjoy something that all children enjoy...and we complained. Then, a very well-dressed man came and some pieces of wood appeared...

She also wondered about the lack of adaptation for other recreational activities such as basketball courts.

For families with children with more severe disabilities adjustment was even more difficult. A somewhat integrating view was taken by the Río Piedras couple parenting a daughter with severe retardation due to a metabolic disorder. They opted for activities they can do together as a family. The fact that they both work outside their home affects their opportunities for leisure. They accommodated to their child's need and strict dietary schedule requirements, and to her routine by finding some time to spend together:

[him]...We do not do exactly what we would like to do because we do not have available time for amusement as any family does. {And what do you do?}[her] Well, we go to the beach because she can make exercises at the beach too and he likes to swim. We have to go at certain hours because she has to take her breakfast. One has to accommodate; the time that you are going to go, too... The three of us
have to share. And since his job requires a lot of field work ... we go with him in the car and travel... For us is an outing, even though for him is a job...

For the most part, their couple’s outings were reduced to child’s appointments and to very limited activities. For instance, for this young couple, their possibilities for outings were reduced to lunch although the husband yearned to go out for entertainment. This yearning represents a source of uneasiness which had not been dealt with prior to the interview.

For a woman from Bayamón and her husband, their perceptions of their child’s limitation has reduced their family’s activities:

FA1-43-52... For him there’s the fact that he cannot share certain activities with FA like a normal child: he cannot go out with him. We are going to be limited in certain things, in the sense that there will come a time when you have to carry him and take him as if he was a baby...

Limitations to finding babysitting help were also discussed in relation to the family’s amusement opportunities. An instance of this is discussed in the following excerpt:

... [While in Costa Rica] One night in which my husband told me that he would like to go out to dance or visit some place, but she [the grandmother] did not dare to stay with him. "I do not dare because he cries a lot, he is going to stay crying, and I do not know how I am going to care for him"... and then you don’t feel close enough to say: "Well, let us see how you can learn to help him so that you can then take care of him in future occasions"...

The request for care was also refused for a woman with two children with disabilities from Bayamón:

SU5-46-49... If I say: "Take care of my children while I go out." , they are going to say: "Why don’t you take them with you?" I do not want that. I want the person to tell me: "If you want to go out, go"... Once I told my mother-in-law that I wanted to go to a hotel with
my husband by ourselves for a weekend. Because I have never been alone with him. And she said: "Oh! I am sorry that I cannot help you..."

The woman from Río Piedras, whose parents provide care for her boy, which enables her to work, has a difficult time obtaining the same type of care when she is going out for amusement. It also placed her, a grown woman, in a role similar to that of a child:

EO9-83-71...[If going out] I talk to my mother in advance, I mean, I ask for permission. In other words if I may go to the place. Besides them, no other person [helps]...

As a result of these disclosed limitations, some families resorted to modification and/or elimination of enjoyable activities. The most frequent situation was that of a woman from Camuy who described her outings as follows, (SE13-50-39) "...I do not go out, except for the appointments"...

A single woman from Río Piedras described her situation as of renunciation and limitation:

EO9-53-45... I am self-sacrificed all the time. I have a monotonous life all the time. I arrive here and either I start sewing, watch TV, but this is routinary. I try then to buy things to see something different...But many times one fantasizes. This is not what you really want. I want to have a normal home...

For a woman in Caguas, regular outings such as shopping were more difficult to schedule due to their girl’s frequent hospitalizations:

NE12-85-94...and he goes places such as the supermarket, and Kmart. Well, now we are enjoying ourselves a little, but we restrained ourselves a lot and of many things when the girl was born. And it was not easy...
Some excerpts reflect the difficulties faced by parents of severe children in adapting regular family activities to deal with their child’s condition. The added difficulties in shopping with a child with severe disabilities and mobility impaired can be appreciated in the description by a woman from Bayamón:

FA1-115-146...Look if I go to the supermarket by myself...I am trying to limit that a little, since it gets me drained, doing it by myself. What I do is I take him then, I do not take the wheel chair since I have to walk with the shopping cart and carry him. Well, what I do is I take...a sort of cushion, I take F. A., I put him on the part where you put the children. I have to be watching him all the time because if I do not, he may fall to one side or the other, and I hold him there while I buy my groceries...

Traditional family outings such as graduations or trips to the beach are challenges. A woman in Ponce, whose child was frequently hospitalized during her first year, described how some hospitalizations affected her participation her boy’s school activities and personal events. Speaking particularly about her wife’s participation he stated:

She has felt very bad due to all of our son’s activities, the graduations of our son. Our boy attended an early intervention camp when he was three years old and they had activities, graduations, many little things. She has been in the hospital with the girl and she has missed all those activities. Furthermore, on the day of her own graduation, she had to go to the Medical Center with the girl...

For a mother of a severely retarded boy from Bayamón trips to the beach were burdensome since all the responsibility for the child with disabilities was left to her:

FA1-16-160...Well when we go out I am still carrying F.A. I mean, I go to have fun but my responsibility is still F.A. He is with him, is with F.A., for only five minutes...
The only time it was different was when she visited her family. They are very supportive but live in a town very far from her:

FA1-95-11...What I do is that on the weekends that I have the opportunity of going over there, I go. And then he likes it a lot. Because when he arrives, there are children of all ages. And they share with him and love him. When he gets there [they say]: "There is F.A.!" and he goes crazy when he sees them and starts talking... Then I rest and I am there for a weekend. You share on that instant and nothing else...

Such was the case for a mother from Río Piedras with a child with Cornellia D' Lange syndrome. She presented some of his behavioral characteristics as reasons for difficulties in going out with him:

EO9-51-44...For me to go out with him is a problem. The boy does not have much tolerance to be in places. He would start a tantrum. That he wants to sleep, that he wants to get out of the stroller, it is a mess sincerely...

Similarly a mother of an undiagnosed child of Camuy felt the need to eliminate one of her few outings; church attendance because of her child's behavior:

SE13-95-46...We were going to the catholic church but it is difficult with S. because S. is very hyperactive and is dreadful at church and everywhere...She gets mad and she throws herself on the floor. It does not matter where she is. She hits herself or bites you...

Respite care was not an alternative for these families. As already described, it was not rare for parents to have concerns about babysitting arrangements. The mother of a child with autism from Gurabo made a comment about babysitting which is representative of others:

SE11-93-64...I have never thought about it [leaving the child with a babysitter]. I am so fearful that something might happen to him...I think that my boy is very difficult to deal with...Sometimes I have been here, standing, and he has passed running by my side, and he has gone
to the street...and I have gone out the streets looking for him. He does not have any sense of danger...

Outings without the children were also very difficult. A factor impeding their outings was the perceived intensity of child's needs, and the feeling of responsibility that something might happen if they are not with their children. As stated by the mother of a child with an undiagnosed disability from Naranjito:

Another thing, is that L. has a lot of seizures. If I go to one activity and I do not take her with me I am always nervous. I cannot be at ease in those places. If I go to an appointment, I am calling home: "Is the girl doing well? How is the girl doing?" And wherever I go, I am in a hurry. My life changed completely since I had my girls. It changed completely...

That feeling was shared by several women, including one from Trujillo Alto. She stated that at the beginning it was difficult for her to resume her normal activities since she felt it necessary to always be there for her child. Later, when ready to accept aid she could not find anyone to help her:

AE7-100-123...But my fear was that by not being there something would happen to him. And what was I going to do when I arrived and found something wrong? I did not dare [go out without him], ever...I wanted to monopolize everything...It was a fear that after a year... of giving him those... special cares that I wanted to maintain, and that made it a little bit hard...

Similar difficulties were experienced when going for other outings. There are other circumstances that make a simple outing difficult. A woman from Bayamón alluded to difficulties she experienced at a dinner outing:

FA1-119-150...Out of the ordinary things... F.A. [my husband] tells me "Let's go out to dine." and we go out to dine, but I take F.A. [my son] with us. While F.A. is sitting on my lap I say to myself: "If I at least had the opportunity of dining out calmed and enjoying that dinner!" I cannot do it...
Other families discussed the complications experienced while taking their children to regular extended family events, and regular recreational activities. The social appropriateness of the child's behavior related to his condition caused several concerns about going out:

AU15-84-76...Sometimes, if there is a lot of noise or people talking, he, for instance, says "caca" (shit) and he pulls out the finger like this [the middle finger] and says: "Go away," as if he was upset.

But before, sometimes he said "look" and he used to pinch [you] or kick you...But now he does not... It is because I take him to town, even if he bothers me, even if he does misbehave, I take him so he may learn...

A frequently considered alternative for care are extended family members. Sometimes the cooperation from the extended family is lacking (or reduced) due to the special requirements of the child:

LE2-63-68...Care is strictly [provided during] the time we are working, since we do not have family members who know her diet. To say: "Let's go to the movies. We'll leave her at her relative's house." or "Let's go to that meeting", as other parents do. I'll leave her with her grandparents or I'll leave her with her aunt, that we do not have...

As that mother stated, the limited understanding of the disability on the part of extended family members had a lot to do with the lack of volunteer help for a family with a child with autism. For instance, perceptions about the behavior of the son of a woman from Gurabo affected the possibility of obtaining help from the grandmother:

AU15-71-60...My mother helps. I sometimes leave her with him but...she does not like it. She sometimes...thinks that he does things on purpose. She does not have much patience. I do not take the risk [of leaving him with her]...because he sometimes does misbehave...
A woman from Naranjito also mentioned the criticisms she received from family members about her management of the intense health related needs of her daughters with disabilities:

LA10-42-32...and I had many problems with the children because I dedicated myself only to M. I separated myself from my children and my husband. In the sense that I dedicated myself only to the girl. For me the world was M. I did not notice because what I wanted was for the girls to be well, because for me she was going to get better... My husband would say: "I am tired, you take the girl for anything to the hospital, for anything..." And the children: "Mommy, you do not pay attention to us as before. Now your life is only M."

Similar demands were faced by a woman from Ponce. Her being continuously away from her house due to her daughter’s hospitalizations took a toll on her feelings and reactions with the older son who remained at home. As she stated:

GA6-27-33...And I also had the family pressure. Being unable to see the boy... I noticed certain rejection from the boy when I went there. He had not seen me for a long time and sometimes I saw him and...I did not feel the same love for him as for my daughter. Then when I saw him, it was as if I did not feel any love for him...

Descriptions of the primary caretaker’s individual recreational needs are also important. Glimpses of the caretaker’s personal situation as it relates to amusement activities were gathered. As already reported, the majority of people in this sample present limited or no leisure activities. Most stated that their life was centered on their child’s needs. For a mother of a child with severe mental retardation related to Down’s Syndrome, the only amusement they could identify was to play with their child with disability. As the mother described it: "My time is for the boy".
Another example can be found in the experience of a woman in Bayamón, mother of a child with Cerebral Palsy. For her, watching soap operas was one of her principal entertainments:

FA1-119-150...In that lapse of time, in that little bit, I mean, to watch the soap opera with FA in my lap, kind of pulls me away from all and that, let's say, is my amusement for the day. That little while during which I watch the soap opera, in which I forget about all other things...

For a divorced mother, amusement is made difficult by the responsibilities involved in caring for her child on her own:

EO9-51-43...Now that I am practically by myself, that I am divorced, it is not the same to have a child with disabilities. My social life is very limited. I do not have friends. I do not have where to go and amuse myself or anything, because during the week I come here practically the time that I spend awake is two to three hours to sleep and then to go to work. On Friday I bring him...

This woman expressed loneliness that made her, on occasions, reach out to anyone she found:

EO9-107-99...Many times I'm just too talkative. That it is also part of my loneliness. Almost no one calls me and really when someone talks to me, well you would like to tell him your life history and it should not be so. I notice that they quickly cut: "Oh! I'll see you"...

Her feelings of loneliness resulting from the intensity of care and personal isolation also affected her job performance:

EO9-53-46...This situation of loneliness is affecting my job. My job consists of writing, I cannot write, my ideas do not make sense sometimes...

A summary, and the recommendations will be presented on Chapter V.
Family reactions. The perceptions grandparents had about their children with disabilities were considered of great importance by parents. Thus reactions of grandparents to the birth or life with such child were sources of frequent comments. Direct comments that reflected family discussions about feelings and reactions were few although inferences from them can be made.

The emotional support that some grandparents provided at initial periods has already been described. As seen in other sections, grandparents and other family members were sources of help for some families in the initial phases:

LA 10-40-31...As surprising as it was for me when I had the girl, for my mother it was the same since in my family there were no children with conditions. When I had a girl with a condition they supported me a lot. They gave me all their help. For them my problem was theirs, specially my sister and my mother and my mother-in-law too and my father...

Some grandparents remained neutral to the disability by not showing any reaction. By ignoring the situation they played down the disability:

CI3-12-15...[she]...my father, may he rest in peace, told me not to take him to any place, that he did not have anything: that was his reaction. He does not have anything. I do not know if it was fear. He never really told me what his fear was...
Other parents did not discuss their child’s disability with the grandparents. For the family from San Germán, grandparents were left with limited knowledge because the disability was not discussed:

LI8-78-40...They honestly have not told me anything about that because they do not know truly that the child has a serious disability, or a disability for life...

Acceptance, emotional support and direct help were provided by family members of a girl from Caguas:

NE12-25-25...On the part of my family members thank God, I have felt the support. They helped me a lot. They accepted her as a blessing from God and [said] that we have to help her until the end. They are all crazy with N. They all sit to play with her and she knows them all by name. They helped her and helped me and my husband...

The mother’s parents were no exception. They maintained a close relationship, with frequent encounters with their grandchild:

NE12-27-31...In my mother’s house she is the apple of my father’s eyes...She lives most of the day in my mother’s house and then here. Every day she goes to her grandparent’s house...

Although a grandfather from Río Piedras provided childcare that enabled his daughter to work, no comments were made about the child’s condition:

EO9-58-49...My father is neutral. He does not give many opinions. He accepts him, loves him a lot. In fact he is the one who takes care of him, but he remains relaxed...

Maternal family members provided another source of caring hands and support:

MO14-72-61...In my family I have a sister who is the most watchful and helps us too. Everyone loves him a lot,...I have not seen any difference in that...

Other families became providers of support and acceptance to the child which was greatly appreciated:
In that house [aunt’s house] next door he gets a lot of attention and he is wild about being there. Since there even the cat spoils him...He prefers going there every day...

The grandmother of this child from Arecibo showed initial disinterest and even rejection which, as she got to know the child, slowly changed into acceptance and collaboration:

In the reaction of family members I did not notice rejection. It was the same as with the others. They did not say anything. At the beginning my mother-in-law was a little rough...sometimes the boy did something and she’d say: "Oh, this boy is such a beast. He pinched me..." and I’d get mad. But not anymore. They have noticed. Or I do not know if my husband has told her. She behaves better now. And she loves him a lot...

Approval from family members included supportive comments that encouraged and inspired them:

They all accepted him. All the family went to see him. Since we are from Vieques they already knew that there was the possibility that the child had the condition. When they arrived they already knew. They told us not to worry, that in this there were studies and things; trying to cheer us up...

Before they went to see the child my husband had communicated to them that the child had the condition...

The use of comforting words caused different reactions. For instance, for a mother from Arecibo, anxieties were increased by such comments:

Since my husband was the one who went to see me at the hospital and brought me food and all, he informed them [the family members]. They found out quickly...They did not go to see him. None of them went. When he came home, they came to see him...His sister used to tell me that was nothing, that sometimes they were mistaken. But I was sure that it was not a mistake...I noticed that he did not move, that he did not do anything as other children...
Grandparents varied in their level of acceptance and involvement. While some were very receptive, others showed their lack of acceptance or understanding of the disability in different ways. There were two (13.3%) instances in which it was the grandparents from the husband’s side who provided the help. For instance, a father from Ponce received the support from the father’s side of the family:

GA6-101-108...For instance, when we go to the Medical Center we leave the boy home...at my mother’s house. And there he feels as if he was with us...or if we have to go with the boy, we leave the girl with them...If we have to leave both of them because she is sick...my family stays with the children, feeds them, takes them around. My mother cooks and also sends me food...

Grandparents, a frequent source of emotional and babysitting support, sometimes fail to provide it because of concerns about their ability to care. For instance, the mother-in-law of a woman with a severely disabled boy from Bayamón refuses to care for him because of fears:

FA1-103-150...In the case of his mother who is the closest one we have, she works and the time she has available...I notice that she gets fearful of watching him. She does not know how to care or manage him...

An analogous experience was reported by a woman from Río Piedras:

SE2-64-68...At my parent’s house they care for other grandchildren but they do not care for L. because for my mother, aside from being old, is hard...If she gets sick...she gets scared. Even though they love her and support us but there are several things in which [their treatment] is not the same...

For the family from Mayagüez, grandparents from the husband’s side of the family were seen as less accepting:

CI3-12-15...Mother was more reserved. I think she had my same fear and she did not say. I always say that the ones that have not been able
to assimilate C’s disability yet are C’s [the father’s] parents...they have never accepted the fact that they have a grandchild with disabilities...

This mother viewed grandfather’s demands of normal behavior as demonstrating his lack of acceptance by:

CI3-14-17...His insistence is not only to improve. When they see him, the father tries to push his hand: "Use both hands" [he says]...CI3-21-24...Furthermore, not long ago my father-in-law told me that the had told him: "This hand does not work."...That worried me because I always try to emphasize, "you can"...

On the other hand, her husband views the situation differently:

CI3-18-21...The family itself has taken it as something natural already. As a matter of fact, when C. stops going [they say]: "Oh! Look C. has already improved."...

The grandparents of a child with autism were informed about the condition but only constructed its implications from contacts with him. Still at the time of the interview they did not comprehend the disability and tried for the child to behave like an ordinary child:

SE11-86-59...It is difficult to accept the disability for older persons that have never been able to be so patient. SE11-47-30...[When I noticed] I talked to my parents but I don’t think they understood. They saw him as common person who does not understand a lot about the issue do, I told them...that we had to work with him because he was not normal. But there was not an acceptance of what I thought...Of course, when the boy ran and took things they got upset with him but they did not accept it as an atypical conduct...

Conflicts ensued from these differences in understanding:

SE11-51-32...They accept him. I think that I am the one who has to worry about facing the consequences because I am the responsible one. They see me as if I could hold him...
In the example that follows, a person’s disposition to ask for help may have been reduced by previous experiences when obtaining help made the activity more stressing or was refused altogether:

LA10-102-78...But I do not look for help because people do not understand. If, for instance, they take me to the Regional [Hospital]...They do not understand the problem: you have to be patient. They always take you in a hurry or if you tell them the night before: "Look, I have an appointment at the Regional"...they mostly have excuses. They do not understand the problem...

In an instance in which help was available, the prolonged status of the requests, the sense of imposing a demanding chore to only one person, and the guilt of not fulfilling her motherly duties was perceived as a difficult burden that caused her to make plans to quit her job:

AE7-42-43...I know that no one can help me as my father-in-law is doing but it’s not easy to ask him to go and pick him up at school and take him to the therapy. Or take him to therapy and then take him to school. I have never liked that. I understand it’s my responsibility and it should be attended by me...

She also felt that others did not take the initiative to offer help because she was seen as the responsible one:

AE7-76-77...No because...I know if I ask for it they will provide it...If I do not ask for it maybe no one will take the initiative. [It is that] everyone expects me to be the one to do it...

For a family living with a child whose metabolic condition implied long term chronicity of care, refusals to help from their family members was not a problem. Nevertheless, little relief was experienced as a result of these offerings because of the special care requirements related to the condition:
The family on both sides always say: "Leave her with us."...But we have never left her ...Because what happens is that in order to leave her, I would have to give the diet explanation and this and that and it sort of does not give me [the feeling of] security. You have to weight and bring everything...

People's reactions to the behavior the mother of an autistic boy made her avoid asking for help:

It is not that I do not dare to ask for help but I think that in our case everyone finds him very strange, too hyperactive. If at any time I find myself in desperation, in an emergency, well, yes, I can call someone. If she is there tell him/her "Look, I need you..."

A woman from Naranjito also mentioned the criticisms she received from family members about her management of the intense health related needs of her daughters with disabilities:

and I had many problems with the children because I dedicated myself only to M. I separated myself from my children and my husband. In the sense that I dedicated myself only to the girl. For me the world was M. I did not notice because what I wanted was for the girls to be well, because for me she was going to get better... My husband would say: "I am tired, you take the girl for anything to the hospital, for anything..." And the children: "Mommy, you do not pay attention to us as before. Now your life is only M."

Similar demands were faced by a woman from Ponce. Her being continuously away from her house due to her daughter's hospitalizations took a toll on her feelings and reactions with the older son who remained at home. As she stated:

And I also had the family pressure. Being unable to see the boy... I noticed certain rejection from the boy when I went there. He had not seen me for a long time and sometimes I saw him and...I did not feel the same love for him as for my daughter. Then when I saw him, it was as if I did not feel any love for him...
A woman from Bayamón, mother of a child with Cerebral Palsy, lacked the support from the extended family. The difficulties identifying resources for babysitting are reflected in the following excerpts:

FA1-93-120...I am from Ciales. All my family is there in the town of Ciales. My husband is from Costa Rica and only his mother is in Puerto Rico. That means that in the town of Bayamón we are by ourselves...His mother lives now in Puerto Rico...But she is a person that works and has all the economic responsibilities...And then she cannot make the time to help me...And my family neither...[since] no one [lives] close to me...

A mother with a severely disabled boy Cerebral Palsy from Bayamón faced limitations with the support provided by her mother, and had no support from her parents in law.

SU5-44-46...[Apart from immediate family members no other family member helps] because my mother is sick and she cannot mind the children. If I get sick, she takes the children to her house but I cannot ask her to do that all the time...[My] in-laws don’t inquire about me and I do not look for them either. The responsibility is mine in everything!...

Reduced help from the husband’s side of the family puts the responsibility of two girls with severe disabilities on the mother:

LA10-87-64...They all have their jobs and they cannot help me. The care of my children is mine. I am going to tell you one thing: These days everyone attends to his own stuff. On my parents side and my in-laws that is how we live. Aside from my mother who is very watchful and helps...I have felt very sad because the family on my husband’s side does not give me support. That has been a very big problem for me...

There were several concerns about leaving their children with babysitters. A woman from Río Piedras described her hesitancy and the obstacles in obtaining family babysitting resources:
LE2-93-103...It is more because of the diet. If they are going to be as strict as you are. She cannot consume sugar. In my family there are other children and there may not be the same control...And then...it is no fun. I, for instance, would have to prepare everything beforehand. It’s the same work that I always have even if I am going out. To leave him with them to then go to do other things. Or to give all the instructions and make sure that they understand...

Furthermore, concerns about the quality of care offered by people outside the family hinders the use of possible community resources. She stated:

You first fear that he might be abused or that something happens...And then you have certain insecurities and certain things. And on top of it he [my husband], who definitely does not agree, [thinking about] what other people can do to him [the boy]. Then he is making me more responsible...

Similar reasons were provided by the mother of an autistic boy from Gurabo, as follows:

SE11-96-67...I have not considered a lot [the care from people] because communities are not as trustworthy as before, as part of your life...

On the other hand, the fact that many people gainfully worked outside of their house in the communities parents lived reduced opportunities for support:

LI8-41-21...[Family members] live close by but they work and this place is always like this. Peaceful...Mom is always sick, she has a heart condition and daddy too...My sister helps but, since she studies, it is now occasionally...

Thus, the employment of others is one factor in the reduction of their natural resources of support. For that reason, care by others outside the family was not feasible for a family in Mayagüez:

CI3-83-82...It is impossible. Almost all the people I know work outside of their home or have small children...Basically it is that everyone is busy...
For a family living with a child whose metabolic condition implied long term chronicity of care, refusals to help from their family members was not a problem. Nevertheless, little relief was experienced as a result of these offerings because of the special care requirements related to the condition:

LE2-93-103...The family on both sides always say: "Leave her with us."...But we have never left her ...Because what happens is that in order to leave her, I would have to give the diet explanation and this and that and it sort of does not give me [the feeling of] security. You have to weight and bring everything...

For others, the person’s effectiveness in coping was related to the willingness of other family members to deal with the children’s characteristics. One such instance was that of the single mother of an autistic boy. She recognized the difficulties involved in obtaining family support due to their reaction to her child’s unusual behavior:

SE11-88-61...I think that the type of behavior the child has, that he is not a very easy person and my family is not the type of family that has patience to teach and accept. In that respect, I have not seen myself very supported by them.

The fact that after her parents moved, their visits are less regular, has eased the difficulties with the grandparents:

SE11-85-58...I see them regularly almost every Saturday; we visit them. The children spend a very pleasant time because they live on the beach. The boy enjoys the water and them a lot. Since they do not see them [the children] so often...they welcome us with more affability...

People’s reactions to the child’s condition also resulted in hesitancy to find (or look for) care within and outside the family:

FA1-104-129...You really do not have the resources and then you also limit yourself in the sense that you see that people are so afraid to care
for these children. In F. A.'s case he has seizures, he has no self-help skills. Well, what happens? That people show fear. And to keep them from feeling uncomfortable, you limit yourself...

Other family members provide incidental and superficial encounters:

60...His family does not help...I maintain some relationship with two of his sisters...They call me every now and then, they visit me once in a blue moon, and we make plans to go out together. And another brother who calls me when there is a birthday...

A woman from Bayamón who has a child with severe disability reports her difficulties and resistance in asking for help and care:

...Because if they don’t tell you: "Teach me, help me because I want to help. Teach me how I can manage him so that I can help." If you’re not told that clearly and directly, you remain always with the fear that they are people who maybe do not feel committed and are going to do it because they have to, not because they really want to do it..

She faced difficulties identifying babysitters:

FA1-103-125...The problem is that you only have one resource. If you could have more resources, you could look for one person to take care once in a while...

A mother perceived this lack of support as resulting from the limitations in orientation or understanding about their difficulties:

SU5-73-73...There are no people that are providing sufficient help to people that have children with disabilities, and to the person who does not have children with disabilities so that he/she understands how hard it is to carry that burden... so they can provide some help to that person. Because if you do not know what that person is going through, how can you help?...

Even families for which a good network of family support was available the main caretaker felt isolation and loneliness in fulfilling the repetitive, ongoing, long term tasks related to the disability by themselves:
AE7-39-34...At times I felt lonely, even though that my family supported me. But I felt sort of lonely, since I was the one who took him to all the clinics: alone to all therapies. No one accompanied me. I tell you, many times I felt lonely. It was as if I was doing it alone. No one was helping me. And that first year was very hard. I was exhausted...

Other family members were also interpreting the disability based on their contacts and observations:

SE11-49-31...I do not remember if I said it or if my brothers commented it in the family. I cannot explain the reaction. They know there is a condition but not that the child is not going to be as the others. They noticed by seeing the child. I think that the experience is the only thing that can convince you that there are problems...

The family members' lack of support dismayed parents who expected their concern and interest in the family's well being:

LA 10-97-77... Cousins, uncles, grandparents: they do not understand the problem itself. For instance, my mother comes here and sits with L. and tells her: "My baby, my beautiful baby, How is my girl?" But my father comes here, stays in the car and says "How is the girl doing, well?" Take this to buy her Pampers." You do not see the interest...I could say, they do everything to fulfill their duty. The same with my sister-in-law ...She goes: "OK, see you", and then she comes the following year...It is as if they didn't care. That is your own problem, deal with it. Not my sister, she sometimes calls every day...She worries. She is interested and shows concern...

Other close family members, likely sources of support, did not spend time with the girl:

NE12-25-26...His family members were a little reluctant. They sort of did not accept it and they still, at this time,...look at her but they do not see her like that. They do not devote time to her...

The grandmother of a child with a low incidence condition expressed her distress by looking for reasons for the disability in the mother:
Mommy is the one that gets upset and is always telling me the same thing. Look, did you, by any chance, take contraceptive pills? Trying to look for a cause. But why now. The harm has already been done...

She also blamed it on the father by accusing the husband of causing the disability:

My mother felt disappointed by the situation. But specifically she considers that the boy's condition has been a consequence of the things my husband did and it could [really] have a relationship...

Her anger remained during the child's three years:

[Has your mother been able to overcome the rage?]...No...The rage will always be there. But with the child she is very loving, a spoiler with him...

Social gatherings at which family members met were sources of conflict. In them some family members accepted and included children with disabilities while others ignored and even rejected them:

Everyone celebrates L., [everyone] carries him around ...[her] In that type of activity...even if there are several things that are more subtle...For instance, I have many nieces, girls with different ages and there are some that have more or less her age...I have a sister who has two girls, one 10 years old and the other one around six. Well, they socialize a lot with L. If they come here, they throw balls [at her], and even if L. does not respond but you see them...trying to get her to do [something]...And you see a real desire to share and they do not care [that L. is disabled]...

Other parents also participated in family events. The meaning of these events changed from amusement opportunities to desperate watch for the child's misbehavior and ensuing disapproval:

At the beginning it bothered me very much because there were other kids, great grandchildren. They meet at parties. A. is never still. Sometimes he pushes the other kids. And I have to be on the defensive all the time, watching that if the child his height hugs
him, he might grab him by the throat. There were times in which the mother
would get upset. And I would have to take the kid away. There were times
in which I would bring him back home. That affected me the most...I sort of
saw the rejection...

Nevertheless, these opportunities for exposure to the boy gave other children an
understanding that enabled them share with him:

AU15-74-67...But the children already know him and they have
changed. They are not afraid of him anymore...And they have learned
that they should not let him touch their face...

During these gathering others family members used modes of discipline
perceived by parents as ways of condemnation and rejection:

AU15-74-67...I have seen there are some adults who scold him. You
notice that they do not like him. But these are only some, two or
three...

Community reactions. Both the family system's theory, and the ecology of
human development perspective considers parent's interaction in their social
environment and how these interactions affect both their daily affairs and the
adaptation to their children. Pertinent comments about these issues follow.

When going out to the community with their children, parents face a variety of
sometimes opposing reactions to their children. For instance, stares could have
positive meanings:

LI8-81-42...[he] Some stare at him and tell me that he is beautiful.
They tell you that this woman has a girl like this...Well some get
curious about his physical appearance...I tell you honestly that if they
say it in a happy tone I do not get mad when they tell me that...
Although children were young, they elicited a variety of contradictory reactions. These were sometimes positive and other times distressing. One such reaction, about how children react when they go out is stated in the following excerpt:

LI8-48-24...[when go out how does people react?] Many people stare at him and tell me "love him a lot, I have one like that"...Some people tell me "That boy is "sickly". And I do not like for them to say that. And I say: No he is alright...

This same parent was the recipient of inappropriate stares from other community members. She perceived these differences were due to a lack of knowledge:

People who do not have children like that stare. They look, I do not know, as if he was different. I do not like it. I do not like for them to look at him like that...

Her husband explained:

What one gets...is sadness, sentimentality. I at least feel pity. I say hey, they are in seventh heaven because they do not have a child, a brother that has a disability, maybe that is why they say that about an angel like this...

Their children were sometimes the victims of hostile and saddening stares:

LA10-106-83...I have seen people who look at them insignificantly. As if they were a thing instead of...And I say, How can they have that reaction to those children? It is a child that does not hurt anybody...

Stares were perceived with an open-minded view by other parents. The mother of the girl from Caguas held a flexible attitude about the stares:

NE13- They look at her. Well, if I carry her they do not look at her because the girl looks normal. But if you put her in the wheel chair, they look. They look because that is something natural... Suppose we
did not have the girl, we would have a tendency to look. I do not get upset...

Ignoring the stares was one solution that permitted a mother from Caguas to deal with them:

NE12-60-67...I react normal because she is my daughter and one learns. She is my daughter and I do not care what people think. I go forward and I take her everywhere...

Feeling constantly observed in her outings was reported. For instance, people’s stares made a mother self conscious in an outing to a restaurant. To enjoy outings in public places looks had to be ignored:

FA1-122-152...Yes they look at me a lot. I notice that they observe me a lot. For instance, in order for him to eat I have to use my fingers to tear his beef. I do it, it does not matter where I am. To some that might seem uncomfortable, others are indifferent. What they do is look at me. I simply forget about the world around me...

Neighbors expressed fear being in a situation unknown them. In the case of the family from Juncos, parents were understanding of these feelings:

OO4-30-15...[he] Some neighbors did not want to come, because the ones that had come, saw the baby and since they saw him so little...they were afraid he’d die...[she] And our neighbors, since they are of old age, well for them it was shocking, too...

As children grow, parents seem to have relaxed a little more. Parents do not allow the variety of reactions they confront to affect them:

AU15-83-25...We always take him with us to the supermarket. We get him in the cart, since he starts running and calls people just to say hi and does a lot of other things; but I do not give to much importance to it. Some say hi, others do not. They almost always notice he is like
that and do not give too much importance to it. It does not affect me that much anymore...

A similar mechanism was used by a mother from Gurabo to be able to do what she had to:

SE11-73...I give little importance to what people from the community may think because I have to go out with him. If I do not go out with him I do not go out at all. You have to balance things. If you are going to be bothered by the fact that it annoys others, you will be throwing another burden upon yourself...You get used to everything. You start getting used to the fact that your life is like that, even if you do not want it to be that way...

Another approach was to directly confront people. Meeting the issue head on meant for a mother from Naranjito to take advantages of her errands to attempt to change others attitudes. One way was to consciously take her daughter to town and, through the visit, challenge people's attitudes about her children with disabilities:

I take my daughter in the wheel chair, I go downtown. I love to go with her, I like for them to see her in the wheel chair. But I do not like to be told "You have a child with disabilities". Many people ask me: How is your abnormal daughter? And I say: "Listen lady, my girl is not abnormal, My girl has a disability, and is fine." Because people have those expressions. I do not get upset because sometimes people are ignorant of these problems. Sometimes they are dumb and express themselves mistakenly. They are not to blame either. They do not know what the child's condition is and say it like that...

Another method of confronting was correcting inappropriate comments. This is illustrated in the following excerpt:

LA-105-81...Many people find her strange. They stare at her very surprised. Many ask: "Is the girl abnormal?" and I [reply]: "No the girl is retarded." "Oh! I am sorry"-they respond. I do not feel bad in general...When I had M. and started noticing the problem I found it
strange too. I said: "My God but this is so rare to have a child like this"…

As seen, some children were viewed negatively. A the lack of response from a young child with autism would turn people away:

SE11-97-69…Sometimes (not anymore because, since he is big, (people do not pay so much attention to big children) but when he was little people would come close and talk to him. And seeing no reaction from him they stopped paying attention to him or they would say: "Oh! You do not talk!" But they did not know…

Offensive and hurtful incidents required the family from Trujillo Alto to adapt and tolerate their responses:

AE7-97-121…And sometimes you see how mothers run to save their children from children like him… but it is that he is so rough. He still does not know how to measure his strength. And he has involuntary movements of force. Sometimes what he wants is to hug a child and what he does is squeeze him…Is the only thing that bothers me. But I try to understand it…

Subtle insults were common for some parents. In the following excerpt, the comment set the child in a differential status which is extended to the parents and others around them:

[she][and what do you do?] I ignore them. I have never made a comment to Mom, never anything about the boy being like this, sickly and mom told me: Look I met someone in town and she asked me: "How is your daughter, the one that has a mongoloid son?...And then I asked her who could have been because they …they never ask me. I did not like that either... for them to call me the daughter who has a mongoloid son…

The unconstrained social curiosity was expressed appropriately by some and negatively by others’ through actions or attitudes:
EO9-100-86...[Reactions of adult neighbors?] The only thing that they ask is what does he have, where is he being followed up. It is cordial. It does not show lack of respect. They stare at him, but I have learned to stare back at them. I react violently, because there are times people do not know how to conceal their curiosity. Many times you have to teach them, be it with words or with your eyes, to kill any comment that there may arise...

People's curiosity revealed their lack of knowledge about disabling conditions. A mother of a boy with autism saw this gap of information all around her:

SE11-98-69...People tell me everything is alright but they do not really know what it is. Sometimes you talk about the condition but it is not well-known. Sometimes I have mentioned the word autism. Some look at you and say: "Oh, yes", and others ask "What does that mean?" Others think it has to do with the ear because it sounds "au"...

In her case, this lack of knowledge from members of the community cause preconceptions based on the behavior of typical children. Their judgments seem place the blame on the mother for child's behavior:

SE11-100-72...The majority of people think that if he repeats something a lot, [the problem] is that you do not discipline him...In a way they blame me but I do not feel guilty anymore. I do not expect everyone to understand. I cannot explain it to everyone, neither I have the need to do it...

Similar comments that placed the blame on mothers and did not consider the difficulties she was facing were encountered by a mother of two children with disabilities from Bayamón:

SU5-27-24...I have found that type of reaction more with the boy than with the girl. Because the boy used to cry eight (8) and nine (9) hours daily...People sometimes told me that he was spoiled but when I held him he would continue crying. Then the doctor told me that it had to be an emotional problem...
Sometimes, even incidents involving benevolent comments were not viewed as such by the receiving person. For instance, making optimistic comments to ease the situation lead to constant explanations:

AE7-101-124...They look at him and almost always they ask me about him and they make suggestions. Because sometimes they think that is that he needs shoes. "Look that happened to a child and they put shoes on him and it got fixed." But [since] I am not going to get into details because I would have to explain what happened to him and that it is not a shoe what he needs, then I say: "They are already looking into that or something like that." Or sometimes if I can tell them a little bit more I do...

A father whose girl had a health related condition and faced prolonged hospitalizations complained about the commiseration he met. Parents who were trying to remain hopeful seemed to obtain limited relief from comments and lamentation:

GA6-37-98...For instance when you have a family member who is ill and people come and start mourning...That is nothing bad but it makes you even sadder. Because one has faith in God almighty to heal...

Other rejected comments were those of pity. As previously discussed, instead of providing support these comments lessened their child to a manifestation of the disability:

OO4-90-49...I feel mad because they feel pity for them. I do not like for them to see him like that...Sometimes we have him in the stroller, people stare at him [sort of asking] what's the matter with that boy or why is that boy like that? I do not like it. Or, "how pitiful that he does not walk!" They do not give support, but pity...It does not get me upset. But I do not like it because in that way they make him of a person. Because when they see him with a limitation, they say: "That baby, the poor thing cannot do this."...
A similar refusal to commiserate with their child is reflected in the following comment made by a mother from Caguas:

NE12-60-65...At the beginning when we moved here, I explained the girl’s condition. And some neighbors said "What a pity!" and I taught them to look at N. not because of her disability but as a human being who does not walk. But in everything else...they see her as normal in the sense that they treat her very well...

Pity towards the mother was an unacceptable, offensive action as well:

Silly things but I do not like them. "This girl weights a lot. How can you [deal with her]?" I do not like those expressions. For me they are offensive, because they don’t see the child’s problem as something that exists and is unavoidable...

The unpredictable behavior of a child from Trujillo Alto due to his motor impairments resulted in public watchfulness. People lacked the patience and understanding his mother felt they should have:

AE7-97-119...These people should be given some classes that there are people like that in the world and that you have to understand them. For instance, since he does not have coordination when he walks, ...he falls, and as everyone else, he holds from whatever there is near him. And some people have seen him suddenly falling and they think that he is being mischievous or something like that...

As children grew, parents also seemed to develop competence in managing their children’s actions in social encounters and the ensuing reactions from others. People went around their daily activities with their children ignoring actions and reactions from those around them:

SE11-97-70...Another thing is what he does at the supermarket. Whenever he goes by people in the shopping cart he has to hold someone. Some laugh. The majority of the people still have pleasant
reactions. But it startles them...I am already used to it and I say "No S. Do not pull him." At the beginning I did not know what to say to people but I do not say anything anymore. I simply talk to the child...I sort of do not worry so much about their reactions...

Not all problematic reactions came from adults in the community. A mother from Río Piedras faced the insensitivity of older children. Difficult responses from children to her boy’s physical differences are described in the following excerpt:

EO9-88-88... Since I do not like to be the center of attention. I like to pass unnoticed because I do not think I am a monkey, nor is my child, for them to be telling me things, to be criticizing me. Because I have not asked for their opinion. Neither are they out of sight beings that is why I reply as I do. Because I am not used to criticize anyone’s defects and you have to teach children. In fact you have to scold that child a little...

Typical children made unfriendly comments to this mother from Río Piedras. She found it necessary to respond strongly due to the continuous nature of the harassment:

EO9-88-73...They notice the disability. As a matter of fact, to see such a tiny, hairy child it is strange...and he is microcephalic and very skinny. As a matter of fact there are children who made such comments and you have to learn to defend yourself. In one occasion I was waiting for the elevator. There were two children staring at him, they would not take their eyes away from him. And I asked them, "What are you looking at so much?" [They replied] "It is that this one here asks why does he have such skinny legs?" And I responded "Does he think that he has them chubby? I responded in a funny tone but disturbed...

Another awkward incident with children’s insensitivity is represented in the following excerpt:
In one occasion I had an experience that will surprise you. I was buying the boy some shoes and a boy came close and started touching his hands and said aloud: "What an ugly boy!" The mother looked at me and I retorted: "Just like you!" And then I smiled at the mother and continued as if nothing had happened. Then the boy said the same thing again and the mother hit him...When he saw that whenever he said it, the mother hit him, then he said: "Mommy the boy is pretty." And I had to laugh because I saw that he did it with a purpose...

This mother gradually learned how to respond to these insensitive comments in a pugnacious manner:

EO9-88-89...It took me a while to get to that position. The first time one is shocked. The least you expect is for a child to say...: "Oh, what an ugly boy!" And I respond: "Do you think you are pretty?"

In time she has developed her own style of handling insulting incidents:

What I do is baffle them, that they see that I too have a very original response and then people stare at me... I have learned. At the beginning I remained quiet...

Another type of insensitive comments were comparisons with typical children. One such incident is described in the following excerpt:

LE2-94-105...Sometimes one sort of feels uncomfortable with comparison comments. Because they have children and some are much smaller than her. And then they ask: "How about L., is she already walking? Oh, my son is already standing..." and this and that. Sometimes not noticing and sometimes bragging thing...

Children directed insensitive comments to other children too:

Su5-60-62...At her age can you believe that there are children that call her four-eyes at school?...

A mother recognized the possibility of this type of stigma and felt the need to prepare the child for uncomfortable situations she foresaw:
AE7-97-120...I am explaining it to him...That there are going to be children that are going to make fun about the way he walks, or that he does not know how to cut with scissors. I told him that it does not matter because you are going to be able to do it some day...

A father from Río Piedras understands that people’s reactions have to do with a lack of direct experience with a child with disabilities:

SE2-62-64...[him] In this process the knowledge that you obtain in relation to the people with disabilities comes from your own experience within the family nucleus. It is not a process that you learn because you’re taught about it, about what is a person with disabilities and how to deal with him/her...

On the other hand, his wife thinks that the provision of information about people with disabilities can increase their understanding:

[her]...I also understand that it is not so difficult for other people to understand that even if there are no cases near them...The thing is that the information gets to others. Everyone has good intentions for people with disabilities, the thing is that they do not know what they need, nor how, from their position, can they do something...

Coworkers ignorant of children with disabilities provided incidental social support that serves as evidence of her contention. She felt the support of her counterparts in response to a daycare center refusal to admit her daughter due to her disability. Although rejected by the daycare, this incident gave her a feeling of support:

[I felt] much better even though I knew that I was not going to attain that much. But that brought me the [flexible] schedule. Before that they had not even thought about giving me the schedule that I needed...
The following comment made by a family from Juncos shows the importance for inclusion of children in church activities:

OO4-125-70...They take him in to the church itself. They treat him more or less equally. Because children have active participation and he has it too, like a normal boy. In the church itself they give him a part, such as singing...

He was also well accepted by church leaders:

OO4-125-70...They call him by his name, they talk and he answers...Even the pastor...says he fell in love with this boy...because this boy is always smiling...

The mother of a blond and blue-eyed girl with hidrocephali and spina bifida from Caguas received many compliments about her appearance on outings:

NE12-60-66...I sometimes take her to malls. Since her chair says Barbie and is pink and violet, they say: "Oh what a beautiful girl!" They look at her...

Several mothers received comments about their child's appearance. The mother from Gurabo who has an ordinary looking boy said that people did not believe he had an unusual condition:

SE11-29-16...you'd tell someone and they say "Such a beautiful boy, so beautiful, so healthy. That boy does not have anything, look at him..."

Because of his "normal" looks, her cautionary, comments were regularly ignored. That made her hesitate to leave him with others:

SE11-94-65...If that happens to me [running by her into the streets], that would probably happen to the neighbor, who is not used to him. He might talk to him and believe that he is going to understand or obey. That happens mostly with people whom he communicates with, that they talk to him and believe that he is a child who is three or four
years old. Since he has that height and physically looks as a normal child. And they expect that he react as any child and that is where [the problem is]...

She decided to play along, by not telling in advance, seeing it too complicated and not worth the effort. People's changes in perception about them start from being a normal family and quickly evolves to a different, sometimes non acceptable one is discussed in the following excerpt:

SE11-97-67...Almost every time it is a surprise after they observe you for a while, because you enter with all your children, and they look well. For instance, in the pediatrician's office you enter with the three of them and they are considered children that go to the pediatrician. When the child starts moving a certain way, starts to act rough, some people think that you do not discipline your child...[You know by their] attitude, how they look at you. Before, people used to communicate and tell you: "Look at what your child is doing." Now people do not talk, but their gestures tell you all...

According to a mother from Bayamón, reactions differ when his disability is noticeable. People make demanding comments when the child sits on his chair:

FA1-116-147...Since his physical traits do not appear to have any type of damage, the face, they see him reclined on me and they think he is sleepy: "Oh, he is sleepy, he is sick the poor thing". I mean they do not notice that he has a problem, that he has a disability...If I have him in the stroller they notice that he is in fact a child with disabilities...because he cries most of the time he is on the wheel chair because he wants to be carried around. Then people start making comments: "Oh, the poor thing. He is tired of being there", or "That chair is too hot", or "That chair is making him feel uncomfortable." "What happens? Does he feel bad?"...

Thus, she found that the lack of understanding from people in the community turned their helpful attempts into uncomfortable situations. They placed the burden in
the mother of looking for quick solutions in a situation where there are none. These comments made her feel oppressed, self-conscious and uncomfortable due to the implied accusation that again puts the burden on her. Playing along with the perceived expectations helped deal with accusing looks. In this case it was easier for the mother to respond as others expected:

...I mean, they start making those types of comments, to look at you in such a way that sometimes you unconsciously immediately pull the child out of the stroller and hold him in order to avoid that type of look. Because you feel as if one is being accused of abusing the poor child since he is in the stroller and because he is feeling uncomfortable...

Furthermore, children with unusual appearances tended to elicit undesirable attention. Some even were targets of ruthless comments. As seen before a woman from Río Piedras handled it assertively:

EO9-100-86...I have learned that you have to teach them because sincerely I do not have to tolerate that from anyone that does not know what’s involved, does not know what the child might feel. For him to be insulted: "Oh, what an ugly boy!" or they say: "Oh, that boy is so mean!" I say "Are those necessary expressions? [To say] that my boy is mean?"

A similar issue was recognized by a mother from Naranjito in a situation in which rude remarks from adults were directed to a child with a more uncommon appearance than her own girl:

LA10-106-83...Let me tell you one thing, I am lucky that my girl is a beautiful girl...For instance, I was talking with this mother who has a boy with disabilities and the boy is a little deformed, he is always drooling and I was noticing that there are people who look at him with a reaction of disgust. I have heard expressions [such as]: "Oh, my goodness, what an ugly boy! If I have a child like that..." And I have
felt so sad because I say: If they knew that they are not to blame for being like that...

Some community members recoiled at the physical appearance of some children. Although not directed at her child, this mother experienced people’s insensitivity to children with extremely unusual appearances:

LA10-106-83...We [the other mother and I] coincided in the appointments and many times [the children] would touch my girl and hers but they would not look at him and the mothers would tell their children: "Do not touch that child!" Many mothers who were at the appointment did not allow their children to touch the boy. And many times I saw her on the brink of crying. And I would tell her: "No, you should not feel like that! He is your child and you love him...those mothers react like that because they do not understand...

Service component. The desirability of early service opportunities for children with disabilities is widely accepted. In fact, this approach has been for some time viewed as part of the best practices. All families in this sample were served to some extent, but early intervention and preschool programs received were not homogenous. This part presents descriptions of the programs based on parents impressions.

Service /Characteristics. In Table 6 service characteristics are presented as reported by parents. All families received a variety of health services. While most went to the medical center in their town, some complemented these services with frequent trips to the Regional Medical Center and the Central Medical Center in San Juan.

As it is noticeable in Table 7, four families stated that they did not receive educational or related services. Two of these families lived in remote areas, one in a
<table>
<thead>
<tr>
<th>ID #</th>
<th>Location</th>
<th>Type of service and frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>FA1</td>
<td>Medical Center</td>
<td>Every two weeks.</td>
</tr>
<tr>
<td>LE2</td>
<td>Pediatric hospital</td>
<td>Once a month health. Weekly therapies.</td>
</tr>
<tr>
<td>CI3</td>
<td>Pediatric Hospital school of the Pediatric Center.</td>
<td>Daily educational and speech therapy.</td>
</tr>
<tr>
<td>O04</td>
<td>Medical-Caguas and Juncos.</td>
<td>Monthly or bimonthly</td>
</tr>
<tr>
<td>SU5</td>
<td>Strabismus clinic Medical Center</td>
<td>Strabismus-4 or 5 appointments per month. Health included.</td>
</tr>
<tr>
<td>GA6</td>
<td>Centro Playita Sor Isolina Ferré Ponce Public Hospital and Medical Center (R. P.)</td>
<td>Gets medical related to child’s condition. Evaluations and health.</td>
</tr>
<tr>
<td>AE7</td>
<td>Medical Center</td>
<td>Different types of evaluations, health and related services.</td>
</tr>
<tr>
<td>L18</td>
<td>Diagnostic and treatment center in town. Mayagüez Medical Center.</td>
<td>Limited medical services.</td>
</tr>
<tr>
<td>EO9</td>
<td>Pediatric Hospital Developmental Clinic</td>
<td>Comprehensive evaluation, medical and therapies.</td>
</tr>
<tr>
<td>LA10</td>
<td>Diagnostic center in town. Areceibo Medical Center.</td>
<td>Health treatment, evaluations and therapies.</td>
</tr>
<tr>
<td>NE12</td>
<td>Regional [Hospital] in the Pediatric Center</td>
<td>A physical therapy per wweek. Urology, pediatrician, orthopedists, etc.</td>
</tr>
<tr>
<td>SI13</td>
<td>Areceibo Medical Center</td>
<td>Therapies are once a week, medical are two or three times per week. No speech.</td>
</tr>
<tr>
<td>MO 14</td>
<td>Public and private physicians in the island. Medical Center and others</td>
<td>General medical disability specific treatment.</td>
</tr>
<tr>
<td>AU15</td>
<td>Public Hospital Areceibo</td>
<td>Medical services.</td>
</tr>
<tr>
<td>ID #</td>
<td>Location</td>
<td>Type /frequency</td>
</tr>
<tr>
<td>------</td>
<td>-----------------------------------------------</td>
<td>------------------------------------------------------</td>
</tr>
<tr>
<td>FA1</td>
<td>Department of Education</td>
<td>Two hours/once a week, home-based.</td>
</tr>
<tr>
<td>LE2</td>
<td></td>
<td>NO EDUCATIONAL.</td>
</tr>
<tr>
<td>CI3</td>
<td>Pediatric Hospital school</td>
<td>Daily educational.</td>
</tr>
<tr>
<td>OO4</td>
<td>Naguabo Centro de Promoción Escolar</td>
<td>Daily educational.</td>
</tr>
<tr>
<td>SU5</td>
<td>Head Start</td>
<td>Gets schooling through Head Start.</td>
</tr>
<tr>
<td>GA6</td>
<td>Centro Playita Sor Isolina Ferré</td>
<td>Daily educational.</td>
</tr>
<tr>
<td>AE7</td>
<td>Head Start</td>
<td>Daily educational.</td>
</tr>
<tr>
<td>LI8</td>
<td></td>
<td>NO EDUCATIONAL SERVICES.</td>
</tr>
<tr>
<td>EO9</td>
<td></td>
<td>Mother refused educational.</td>
</tr>
<tr>
<td>SE11</td>
<td>Head Start</td>
<td>Daily Educational.</td>
</tr>
<tr>
<td>NE12</td>
<td>Head Start</td>
<td>Daily Educational.</td>
</tr>
<tr>
<td>SI13</td>
<td>Department of Education</td>
<td>Daily educational.</td>
</tr>
<tr>
<td>MO14</td>
<td></td>
<td>NO EDUCATIONAL SERVICES.</td>
</tr>
<tr>
<td>AU15</td>
<td>Head Start</td>
<td>Daily educational.</td>
</tr>
</tbody>
</table>
rural area and the other in the island of Vieques. Two have children with severe disabilities, and the mother of one of these children felt educational services would not benefit her child. For those receiving educational services, these were offered as home or center based instruction. Two children received home based services from the Department of Education once or twice a week. Services based in centers were being delivered by Head Start to five children the Health Department served one child, the Department of Education another, and two by private providers. These private providers were El Centro de Promoción Escolar in Naguabo, and Sor Isolina Ferré Center.

Service/Geographic location. Regional differences were described in terms perceived program accessibility and quality. These descriptions are consistent with previous reports of differences in service availability by geographic location or disability levels (for instance Meissels, et. al. 1988).

A third of the sample mentioned that they lived where they did because family members lived nearby, or that their house was sold, loaned or given to them by family members. The woman from Arecibo had been living there for almost ten (10) years at the time of the interview. She described her immediate neighborhood as an extended family:

AU15-11-73...In a dead-end road of eight houses seven are his relatives...The only one that helps is the wife of my brother in law, who lives next door...
For one family from Juncos, a rural area on the east of the island, the main reason to stay in town was that they lived in what used to be her father’s house, and they procured satisfactory services for all their children in her town:

OO4-127-72...Because here the school is close by...Since I have a car I manage very well...We always go places where they have accessible parkings...comfortable ...Here we know the people. We have always lived here...My father died and left the house to me. My mother lives right behind. We are comfortable. We do not pay rent...We are not doing bad, since we have a car to manage...

On the other hand, regional services are offered in another town and they face long trips to regional health services:

OO4-75...The farthest thing we have would be the hospital and access to specialists that are very far but we have our car and can manage. We are not uncomfortable going with the boy. The boy has his car and his chair, his stroller...

A family from Camuy faced similar long trips for centralized and specialized health related services:

SE13-20-21... Specialists that are there are lacking around here, at least in Crippled Children (Niños Lisiados)... And to move her here is not possible. Even if they take their time...but the geneticist that has to be there and special testing that they make has to be there...

For this family, trips were harder, frequent, farther and more costly:

SI13-19-20...There are times that I leave dark in the morning and I come back dark, almost at six. And in a few days she has appointments one after the other. She has two appointments in the same day. It is a bit tiring...

Transportation was one of the greatest difficulties. There was no direct public transportation to appointments, and it is costly:

SE13-62-47... It is far to the Medical Center, but even to Arecibo is far. Everything is far. I live in the country and you have to go to
town to take a public car and if it is from here to Arecibo I have to take about three cars. Or you have to charter one. And they ask for about $50 or $60. [him] You have to take one from here to Camuy, from Camuy to the District Hospital and then to the where the cars that come back to Camuy park. It is a puzzle...

A frequent comment stated by parents who lacked transportation or only had one car was about the additional hardships of public transportation:

AU15-79-71...I do not like it either because places are too far. For instance the Regional Hospital I have to go from here to town and from town to the regional. It is not so far but transportation requires [all those trips]...

In rural areas there were differences in access and service conditions for children with severe disabilities. Their isolation and a lack of resources seemed to have an effect on how they perceived their children were served. For instance one of the families interviewed lived in a small community in a mountain of San Germán. Their only access is a small community road and no public transportation available. They had no neighbors or friends to help with transportation. This made things difficult when the mother had to travel with her child by herself:

LI8-23-12...[no public transportation pass by here] You have to go walking up to the Route #2. It is about two miles. He does not walk. When one goes out he is carried and nothing else...and then I tell him: "Walk honey that I am tired." and he stays there...

The regional nature of services rendered them both unavailable in town or when offered, far from the child’s community:

LI8-24-13...[If there was a schooling center in the medical center it would be better]. About the Medical Center I would go there to the Health Center and there I would take an ambulance that goes to the center every day...There it is easier because almost always there are people I know that go back and forth. Some work there and live
around here. It would be easier for me. Around here there is no service...except the one on ESPIBI...

Besides unavailability, there were also claims that some services were more centralized than others. For instance, services with limited availability were frequently placed in the metropolitan area of San Juan. About this a parent from Mayagüez stated:

CI3-54-4-[him] Look, I have noticed that almost all Rehabilitation Centers are in San Juan. All government centers are found in San Juan. The only one that there is here is the ESPIBI center and the Medical center and in limited cases and badly handled...

These conditions were more problematic for the family from Vieques:

MO14-104-92...That is a service for the metropolitan area. It is not for anyone else...Look Vieques and Culebra are also part of Puerto Rico!...

Sometimes this centralization extends to parent support group services:

SE13-91-71...Through help for the disabled they sent me to SER and APNI. In APNI I have gone to meetings in Arecibo. Once they gave two consecutive days and I attended. But that was a long time ago. It was about the care of early childhood children with disabilities. They have sent me invitations to go but almost always they are in San Juan and there is not possibility for me to go...

Some parents were forced to move to gain access to health and therapeutic services primarily offered in the medical center. In the following excerpt problems faced by people in rural areas are noticeable:

LA10-91-69...[I live here] because I am close to the Hospital. That is what I am most interested in, to be close to the hospital and the school. If I go to the country it would be more difficult. Here I am close to the school. If I have to go downtown walking I go well with may girl...Here it is easier...
Differences in support services by geographic areas are also conveyed in the following excerpt which compares resources in the town of Ciales (central town near the north west) and Bayamón (very close to the metropolitan area of San Juan).

Noticeable here are differences in waiting lists and the implied notion of possibility of not receiving services at all:

FA1-91-118...In Ciales there are no resources of any kind. In Ciales the closest thing, I think is in Manatí or Barceloneta where there are therapy centers. But as I understand...waiting lists are interminable...[To move there] would mean to prepare myself and my family as therapists to care for F.A. Because to depend on any center to receive any service would be impossible...

On the other hand, moving away from the location where her family lives presented a problem for the mother of a child with Cerebral Palsy in Bayamón.

While having negligible help from her husband and his mother, she also faced limited access to support from her own family, which had offered help with her child.

The lack of access to services was an additional factor in the decision taken by a family from Mayagüez to relocate. Although they had a low income house in Aguadilla, regional services were received in Mayagüez, and their employment was nearby. They returned to her parent’s house in the center of town:

CI3-80-71...I bought a low income [house] which was a bargain. But what happens? That I...work in Cabo Rojo, she works here in Mayagüez, our house is in Aguadilla. Our children, one is in the school at the Medical center in Mayagüez. The therapy is up the hill 10 minutes from here...All we do is in Mayagüez. What I am going to do is to move...
A family from Vieques faced additional difficulties due to the centralization of services on the island. Traveling to services meant very expensive long trips. About this the father stated:

MO14-82-69...[him] It is difficult. I am not going to be traveling every day by plane because they are not going to pay it, so that the child is there at 8:00 or before....

Because of this the services offered on the main island had to be refused:

MO14-103-91...[her] I am supposed to take him to see what they say. I keep all the papers. Here you have to keep all...After three months the physician gave the diagnosis and referred him to participate in a program for disabled children or early stimulation. He recommended physical and occupational therapy with follow-ups. We had to decline it because I cannot be traveling frequently. It is too much...

This family faced limitations in their access to facilities because they lived in Vieques. At the moment of the interview they had acknowledged that there were no services in town and they were starting to have concerns about these lacks:

MO14-78-64...[him] We are thinking about that because the child is growing and you have to look to give him education and that has us thinking. We have to think about him...He is growing and you have to give him education and there is nothing here...

The closest service she was aware of is in Fajardo which means that she would have to travel by car and by ferry every day:

MO14-104-93...[she] In Fajardo there was one of at least 2 times per week that one takes the child at least at 8:30...up to 3 in the afternoon. You would have to sacrifice yourself and do it. If it was going to be done it would be me. I would not send the child with anyone and least to the big island...
Service providers did not seem to have flexibility to take into consideration difficulties parents encountered with transportation. One such instance is represented in the following excerpt:

SE13-62-47...There are times when we get there late and I lose the appointment because I get there late. There are times that I waste the time, when I go to Arecibo, because I can rarely get to the Medical Center by Public car. To come back is difficult too. [him] If we go by the government buses, they go there on Tuesdays and Thursdays. If the girl’s appointment is on Friday they do not take her because they do not go there on Friday...

Some parents with cars faced other transportation obstacles in keeping their appointments and household errands. Certain municipalities offered limited accessible parkings:

OO4-77-43...In Juncos there is none. The miserable parkings that you find are occupied. Because one of the parkings that we need is one in Caguas, when it is not used by the police, it is used by the ones that are eating in front or other one by the doctor who works in front who is disabled. It looks like they made it for him...

There appeared to be little provision for transportation needs for the disabled and their families in the rural town of Juncos:

OO4-81-45...Sometimes when I have to take him, that I have to pay the electricity, the water or something...I have to go down to the water utilities parking where there is a parking for the disabled...Almost always the parking is occupied, then he [the policemen] asks the person who is in the parking to get out parking and he accommodates me. But in town, in Juncos there is nothing...

Service /Medical. Essential to having children with disabilities are the contacts with health related professionals. Communication with physicians and other personnel were sources of significant comments. This section is concerned with the descriptions parents made about this type of communication.
At initial periods the way information was conveyed was important. In some instances fathers were informed and later the news were discussed with the mother too:

MO14-6-4...The doctor did not explain [immediately]. Afterwards, when I felt well, the doctor started talking about the baby. That in these conditions many children are intelligent. That we should not worry, that he was going to be well. That they had made many studies and things...

As discussed in question one, some physicians took care of the child but did not acknowledge parental needs and concerns. In fact, a doctor who kept a family waiting for a information was mentioned in the discussion for question one. About this doctor this mother said:

FA1-7-7...[He acted] normal, completely indifferent...And for him FA's condition was so indifferent, that he informed us that he could be in that hospital for three more days, that there was no risk...[when it was not true]...

Being told the truth was hard but greatly appreciated by parents. For instance, a family of Juncos was informed since the beginning at the hospital, as is described in the following excerpt:

004-27-14...Because he was very sincere with us and told us: "Look the baby was very sick." I liked him because he was very sincere. He would tell me: "Look, the baby has been very doing very bad, we do not know if he is going to get through the night." For me it is better to be told the truth and not to be holding the things from you...

While truth was important, the manner in which it was told was important too. Some excerpts describe the harsh, insensitive manner in which professionals presented disability related information. This was discussed by a mother from Naranjito:
NE12-31-34...At least with N.'s pediatrician, she gave me orientation. But it was very hard in the sense that she is one of those doctors that go straight to the point, that do not know how to say things. There are doctors who tell you the truth but they look for a way of not hurting you so much, of not making you feel so bad. She did not: "To call a spade a spade..." It did not matter if it broke your heart...

The narratives of some parents described how several professionals gave incomplete information about the disability and about assistance to deal with it:

SE13-25-14...It is sad to see the reaction. That is why I almost always [cut their conversation] ...Because no one told me you could do this. They would tell me: "This is a condition for all his life, you have to accept it." No one gave you any hope...[I would have liked] for someone to tell me look there is a place where they can help you...

Contacts with physicians over the years have left the mother of a child with an undiagnosed disability with little information, and more confusion than before:

SI13-22-22...The doctors sent me to a social worker. I feel they did not want to tell me. I felt very confused...You go there to alleviate the distress and talk, in that sense it was worth it. That was when she was about two years old. But she did not refer her to any place or talked about any service. That area has always remained the same, with the same services, the same medical attention...

An unclear diagnosis caused unnecessary unproductive confrontations for this family. Doctor's recognition of their limitations in the search for a diagnosis would have provided the relieve of a second opinion:

SE13-35-29...I asked the doctor what does my girl have? because you have been caring for her for such a long time and you do not give me a clear impression. Right now she is epileptic. Other doctors would say: "Since I cannot deal with that I am going to refer you to another doctor who can deal with your girl." None of that; there is no orientation about that...
There was also the feeling that information was being withheld intentionally:

SI13-15-19...[she] I do not know, here the doctors do not communicate everything to the patient, nor to the family members. [he] It is not like out there. Out there they tell you: "Look your girl has this problem." and you are more serene. Here they do not hide what the children have...

Other professionals were seen as withholding information that was perceived as essential, too. A mother of a child with Down’s syndrome from Arecibo perceived as lack of knowledge about conveying difficult information:

AU15-14-7...I have noticed that doctors themselves are not prepared to tell you the truth. Now I have no fear. They themselves, do not know how these children are. I went to some doctors and they did not tell me anything...

Professional demeanor that causes unnecessary distance reduces the possibility of appropriate communication between physician and the family. In one instance the use of jargon at the moment of notification reduced parental understanding. This is illustrated by the following excerpt:

NE12-4-8...He talked to me about meningocele and I did not know what it was. That was in the Medical Center. I remember an office, the doctor sat on the desk and I in a chair. And he told me "Besides being meningomyelocele and hydrocephali, she is going to be completely paraplegic and we expect her to be a phenomenon", on those words. He did not explain the terms...

The importance for some parents of the use of clear, hopeful language in communicating with families is exemplified in the following excerpt:

NE12-31-36...The neurologist, thank God, I tell you that is a doctor that always saw N. [as a girl that could do things] despite her condition. She knew how to say things, and she would say them in a simpler, softer manner and not so drastic as others. Thank God she always helped me and told me: Help that girl go on; that I see her more beautiful each time. I see she’s improving a lot...
Communications issues, caused by the use of jargon left clarification as a parental responsibility for parents who asked. Those who did not ask were left lacking understanding, sometimes puzzled and in need for information. The doctor depicted in the following excerpt did not consider families’ feelings and understanding:

AE7-35-29...I stopped taking him to [that doctor] because although he is a good doctor, he does not know how to break the news. He says them so suddenly that you stay [shocked]. It is not lack of sensibility. Because he is a doctor, who gives love to children...It is that he knows so much and wants to explain it in the doctor’s way that when you hear words...you do not understand...

Understanding seemed to be another work placed in parental hands. For this mother some comprehension was achieved during a follow up by another doctor. She had then an opportunity to ask her and obtained information:

AE7-35-31...She is colder, but if you ask she responds what you want to know...When I told her: "Look, it is that the doctor told me that my boy had cerebral palsy and I do not know what that means in his case." She responded: "But why didn’t you ask?"...And I told her: It is that we were shocked." She answered very well and then I felt better...From then on I learned to ask even if I felt bad...

The description of initial orientations in the following excerpt did not develop in a manner that they could grasp. The family was left them with a vague sense of what the disability involved:

LI8-8-35...The doctor told me that he had a disability but he explained in a way: Look, do you know. There are some children of some country that they call them mongoloids or something like that. But that word did not fill the thoughts I had of what he was saying. And it did not explain what I wanted to know...We noticed as time went by because of his physical features...
What they wanted was practical information that would help them in their daily dealings with their child, suggestions about what to do and where to go. He suggested that this was not provided:

LI8-84-38...He as a professional, had the duty to explain to us with details what he knew about the boy’s analyses, what he knew about what was wrong with the boy. That the boy died the following day we did not know, nor did he explain anything so that we made other efforts that the Medical Center could not do. I mean, that we brought the child home without knowing, to be placed in God’s hands. But up to now, thank God, he is here and we are struggling with him...

The drop by drop approach through which some parents received information, meant that physicians provided information only if asked and strictly about what the parents asked. This meant that in some instances, parents were left in need for information for prolonged periods and had to reach out in order to obtain it:

FA1-14-15...The pediatrician appeared at two thirty in the afternoon. Totally serene, indifferent to what [we were going through]...At no time did he communicate with the hospital to say: "Look mother the child can wait, don't worry."...

In terms of characteristics, physician's attention to baby’s conditions was also appreciated:

OO4-60-35...The physiologists very cold. Too fast checking him. Take this and leave...Without studying well the baby...

In a similar comment, physicians that took the time to attend to the children thoughtfully were described positively:

GA6-45-54...Her capacity to deal with...[the children]. If she has to be two hours looking at a child...she'd do it...Unlike other pediatricians who arrive and quickly [dismiss you]...
An analogous interest in children was perceived as a favorable attitude. Such was the case of a physician from Ponce, who was seen as placing their girl’s well being before his economic interest:

GA6-67-73...He has not been interested [in money]. ..."When you have money you bring her, when you do not have it, you bring her too."...we still owe him money. He made us a payment plan in which we are supposed to pay every month...

In the next excerpt the same family talked about a physician who showed the exact opposite behavior. He was the doctor in charge of their daughter in the Regional Hospital. In one instance, different demeanor was perceived on the part of this physician when he saw them in his private practice where they paid:

GA6-67-75...It seemed that he did not like to work here in the Regional [Hospital]...that he did not dare to become independent because of problems or something like that and he showed it upon patients [from the public hospital]...In [his private office] he treated her more lovingly...[her] ...In a different way from the way he treated her in the District [Hospital]... He’d talk very nicely to us. He’d communicate with us and tell us everything...

On the other hand, some professionals discounted parental perceptions of concerns. This left parents to contend with their doubts, questions on their own:

NE12-31-35...It is as if I was to tell you: "Look doctor, the girl moves her feet." She would say: "That is your imagination, that is what you want for the girl to do."...That is one of the stages I went through when N. was born...

Physician’s disregard of mothers comments and concerns caused longer waits for services for children:

SU5-7-5...He was good but if I said that something was happening to my daughter, he would not pay the attention he should. He would check her but he would tell me that it was normal. That children had to turn their eyes inward. But for me it was not normal. Later he noticed that the girl really had a problem...
This mother found another physician who noticed the disability and moved quickly to provide useful information and referrals:

SU5-11-8...The doctor helped me a lot. Had it not been for her...I think that if I did not know anyone, the process would take longer...

Differences in control in the service relationship were cause of concerns. This lack of balance of authority in making health related decisions about interventions. This was felt by a family from San Germán and a family from Ponce. Problems with lack of basic information and cooperation with parents was described by a father of a boy with Down’s syndrome from a remote community in San Germán:

LI8-15-47...We are doing the maximum, taking care of him, and taking him to doctors but they do not explain anything. It is sad how we parents of a child with disabilities, are lacking help and support from the doctors or the Health Department.

The next excerpt from the family from Ponce addresses the lack of unbiased mechanisms of complaints that left the family unsatisfied:

...GA6-25-32...[he] Dr. S. never sent her to get the X -Rays. It was not a costly study. I got mad because over there they have X-Ray machines... [she] I went to see the medical director. I talked to him, I explained the situation. That the doctor did not want to help us after operating her, and that he told us that he was not God ...GA6-41-53...The subdirector...told me...[that] C. V. is a good specialist. Is one of the best specialists. The thing is that he did not want to give me the referral...

Finally hospital regulations seemed to place the authority for decisions in service professionals. This family understood that service rules in that hospital were that doctors were assigned and could not be changed. They attended on a certain day of the week and their appointments would be made accordingly. Also, an unspoken medical code by which a physician could not care for patients that had been treated by
others appeared to be at play. This reduced the opportunities for this family to get second opinions:

GA6-23-29...One thing that I noticed is that no physician wanted to deal with other patients that were not his. As that female doctor said: "If he made the error let him be the one to solve it," because no one wants to deal with problems of another doctor...

**Service/ Information.** Recent regulations require family focused services. Accordingly, information about preschool disabilities, program availability and other services should be more readily accessible to parents. In this respect, another issue discussed by parents were the ways in which the passage of the law facilitated or hindered their attempts to obtain information. For the purpose of this discussion comments will be divided into those enacted by parents and those service related.

A frequent source of information were other parents. There were two general ways of parental provision of information: as advocates for their children and as sources of necessary facts.

Some parents in this sample took the role of advocates for children and families by providing quick information and support:

SU5-31-32...Not so much with my children because ...they have a mild disability...but when I see a mother and she tells me "I do not know what to do because I am trying to look for a school for my son." I answer...Because many people don't understand that the child’s disability does not matter, that the child has the right to receive an education...

Parents obtained information most readily from reports from other mothers. Such was the case for the mother from Bayamón who got general information while waiting for appointments:
While we waited our turn to start, while the children were in therapy...well mothers talk, they tell their experiences, this is what is happening to me...Well I grasped it and always tried to take advantage of it, of the information I could get...

Other mothers frequently provided important knowledge about resources:

AU7-25-22...That was someone...I think it was one of the mothers that were there. She told me: "If you go to the Municipal [Hospital, you can get them]. But because I am from Trujillo Alto I was not supposed to be there. But since I entered the medical plan, I was saved...I also had the green card because I had to quit my job. Well, I continued with Medicaid and he took the therapies as it corresponded...

Parents became regular sources for information which the school system is mandated to provide. In the following excerpt they were providers of information about registration:

FA1-51-60...Well, originally I listened to parent's comments: "Did you register your child?" Then I registered him in Public Instruction...

A mother from Naranjito found out about the registration procedures by word of mouth in a casual encounter some time after her child was born:

LA10-84-62...I went first with M. I went to Public Instruction. I was in a food stamps appointment and a mother said: "Did you register your daughter?" "How's that?" I asked. That was when she was about two and a half years. And she told me: "Because one registers children with disabilities in Public Instruction. They have certain rights". I did not know anything. I went and registered her and now a teacher comes to give her therapies...

Second hand information proved useful in obtaining information to change misunderstandings about services:

AE7-101-124...I found out from my sister that told me a lady had told her that she had a license plate because her daughter had disabilities. I said: "Oh, I thought that was only for adults." Since they do not explain things, you get some ideas out of nowhere, because no one has told you that...When I went to the APNI seminar I got the complete information...
A mother whose child had uncommon disabilities was less prone to get and accept information from formal sources, but obtained it from other parents:

SE11-72-48...The information that has been given to me about the disability has come primarily from the mothers themselves. It has been articles from American magazines that show various types of disabilities and things like that. And from Dr. Linares' program, I once went there and picked up...

Some procedures to provide information in some cases placed the responsibility on already burdened families:

LA10-59-38...[I did not get orientation from the medical personnel]. They took care of telling me that she had a condition and that I had to deal with her in such and such a way. They referred me to a social worker but I did not go because I had so many problems. To deal with the children, L's appointments...When the social worker's appointment arrived I was in intensive care. Well, I missed the appointment and did not go to see the social worker...

To get around limitations in information frequently required involvement of outside resources. Alternative parent groups filled the void for information some parents faced:

SE11-54-35...I [got information about rights from] the APNI seminar. I found out who is supposed to help me: The Department of Instruction. I see so many limitations in that do not encourage me to struggle with them...

Sources for identified parent groups varied. The most frequently mentioned were those in APNI and SER:

NE12-38-41... Last year...the social worker from SER did several meetings with parents and I received orientation. The last one I received is the one in APNI...

Other opportunities to listen to parent is testimonies were given at central meetings:
MO14-28-16...To say that it has helped me it has not helped at all. But at least they showed movies and gave orientation and parents with these conditions in older children spoke. And you listen and say: "I am going to be like that. I am going to deal like that with my children..."

Participation in parent organizations sometimes served to fill information gaps:

GA6-83-90...[her] Yes I belong to an organization called APNI which provides us seminars and I have received information. [him] And they sent us a small book with all the laws there are for children with disabilities... OPI The organization of parents with children with disabilities. I am going to their meetings...We talk about the laws that are coming out and many new things...

Parent organizations' activities were also instrumental in obtaining other services, and clarifying misconceptions:

AE7-80-92...I thought that Head Start was part of Public Instruction. I did not know the difference. Nor the services. I did not know anything. I understood that it was the same as a school but that they had it separate because it was for little children...

Knowledge about ways of handling service providers was also enriched by participation in parent groups:

CI3-16-18...Well, therapist in one way or another always give orientation: "Look in you house you have to do this to help him." But an open orientation, no...The last thing we did was become members of APNI and we had a socialization meeting with some parents. That helped a lot, but to provide lots of information [they did not provide]...

In addition to providing information about the disability, necessary and appreciated legal information was provided in those meetings:

GA6-90-99...All the information I have received I have gotten it there in the Sister Center...The director is a doctor who really cares about the laws, she is always up-to-date in that respect. ...She tells parents about any information or conference so they can go. She also brings many resources...
Parents from remote areas on the island faced problems with access to information. Parent orientation activities were limited in reaching their remote region of the island:

MO14-87-...APNI...did not come here. I went to Fajardo. But at least they wrote to us so that we enrolled. I quickly enrolled because I wanted the orientation...I went and came back by plane and they paid for that service...

On the other hand, while these meetings are useful, the need to develop other information avenues parents who cannot attend meetings was reported by a mother from Caguas:

NE12-49-53...I once enrolled in the Spina Bifida Association. They sometimes send information by mail or they make activities and meetings but I rarely go. Because I really have a very rushed life. And it is far away, it is close to Bayamón. But they send information about her condition...

A similar situation was confronted by parents who faced scheduling limitations related to their employment, or their work as parents with children with disabilities. Their responsibilities hindered their participation in regular parent activities, as seen in the following excerpt:

NE12-77-84...[I could not attend] parent meetings because sometimes they scheduled them in times when the girl was in therapies or I when had to take her to the doctor or maybe in afternoons when I could not go. Now to the meetings for parents with children with disabilities I went...

Some parents' scheduling difficulties hindered them from obtaining information by regular means:

LA10-66-49...I have not received information about their rights. They have been sending information about the centers over there to have interviews and share with other mothers...and give each other support
and information...but I have not attended because of the girl’s health problems...I received some information by mail, but not about her rights...

On the other hand, while parent groups were a source for identification of services for some, they were not an alternative for everyone. Some parents described their need for individualized opportunities to access information:

EO9-93-77...I do not discard that these organizations are interesting, but I do not participate actively because to have many people over me tires me. And is something personal. I know what they offer and if I need it I call without any problem...

For other parents information about the child’s disability was limited although mailings became a source to fill some of the void:

SE7-10-49...APNI sends newsletters about laws about things that are happening. About situations that happen to other people that you read and fit in them. And you can work things out...

Besides individual activities and parent groups, information was gathered from different sources such as associations, newspapers and brochures provided by physicians:

AU15-20-11...Information about children’s rights from Head Start, and the Department of Education...Besides sometimes I receive brochures from APNI and from the Association of Children with Down’s syndrome...General information from newspapers, and brochures the doctor gave me...

Some service providers supplied orientation about existing services. This orientation related to the care for children, and services. For instance, physicians provided quick practical information about disability management and guidelines about how to work with their children:
SU5-17-12...I went to talk with her doctor...and she told me I should try to get her to raise her voice..."You have to get down to listen to her", [she said]...

Physicians also provided information about procedures, support and health treatment:

LA10-59-38...The advise that they'd give me was: you have to be very careful, avoid noises so that she does not have seizures, keep her medication up-to-date. But to give me hope for improvement, they did not...

Service provider’s parental orientations were also useful to parents as noticed on the following excerpt:

NE12-43-48...I also have her enrolled in Public Instruction and I received certain orientations from professionals who work there that have helped me...move and get what I want. About the help that they provide and that maybe many parents...do not get...

Several parents claimed they have not received any or very limited information about their child’s disability. Some of the obstacles involved in obtaining general information about their children’s disability exist also for those people whose child’s disability has been diagnosed:

CI3-29-29... Look, I have not received information but C’s cousin, who is a dentist, told me that she was going to try to get information. But I do not receive clear and concise information about what the condition is. Simply what I have told you...

Families may experience limitations on initial details about their children’s conditions. Lack of orientation and services were reported by several families of children requiring more specialized health care. For instance, limited explanations were given to the parents from San Germán leaving the mother with questions about her child with Down’s syndrome from San Germán:
LI8-85-45...Look, we have not received orientation either from other people or from the Health Department...LI8-85-45...[How about in the Medical Center, do they give you orientation?] In the Medical Center no one talks about his condition. They just make some analyses and some things, and they send us home saying "the boy is fine"...

Some physicians did not appear to guarantee parental understanding:

LI8-71-35...I asked two or three times and he explained that, but ...[He could have said], because he is the doctor: "Look the boy has this, this is going to happen to him, expect this." He did not explain anything. I asked twice, and as always, he sent me home with the same story. "Look something about this or that country."...I do not know them. What happens here is that unless the press covers it we do not know...

Initially, parents took some time to process their understanding of the information given. For some, information about the condition was also difficult to obtain, and when given not fully understood:

FA1-80-107...But then at the beginning I do not know if maybe out of fear or because if I asked this and that...but a lot of gaps remained...

Parents, in particular those whose children had undiagnosed conditions, talked about their need to understand the disability:

SE11-16-10...They explained it to me but not with a diagnosis. [They told me:] "Let's do this." It is advisable that you give him this type of therapy... but they would not say what he had...

A father from Río Piedras affirmed that during his child's therapies they explained positioning and helpful procedures for feeding and playing. Parental questions and concerns about their children's future abilities suggested their need for additional knowledge. This support not provided to this family from San Germán:

LI8-71-35...That he was not going to walk. I mean, when he spoke in such a way I understood that it was that the boy was going to be all the time in bed, prostrated, or in a wheel chair or something like that...
A mother from Bayamón suggested that the quality of information provided varied according to the gender of the recipient. She views differences in the awareness process between fathers and mothers since different patterns of participation are expected from programs. She described parenting activities in which information is provided that accept father's absences but not the mother's:

FA1-116-145 I struggled so that F. would go with me to those conferences. They were [held] on Wednesdays, that he could make arrangements in his job. Furthermore, the first months his day off was on Wednesday, I mean that he did not have any reason not to accompany me...to this conference at which you learn a lot, where one grows so much...If he accompanied me to two or three...at the most...

When basic knowledge was achieved they moved to other information needs.

For parents an undiagnosed child this need is ongoing:

SI13-64-51...[She: At the beginning, I would have liked] for them to explain the situation more. [him] That they'd really tell us what was wrong with the girl. So that you can be more satisfied and serene knowing what you're dealing with. Right now we are taking the girl to the doctor and whatever it is that she has no one knows. Because they do not tell us...If it is good or bad, we do not know if she is going to recuperate later. We do not know because they do not tell us...

The use of jargon hindered communication among parents who were already overworked and emotionally charged. Requests for clarification of terms was an added burden:

FA1-31-39...I really, [had] problems in my job, problems in my marriage, problems from a lot of responsibility and I at that moment, they told me he had a lot of spasticity, and really it did not dawn on me at any point to ask...

The parent's need to recapitulate understanding is clear from the following excerpt:

FA1-33-42...And coming to think of it, I being so inquisitive, that I always try to go the extra mile on things, I fell into that...I wonder
[what happens] to other people who are not so conscious of certain things. That are more limited in other aspects...

Similarly, even after receiving orientations a mother expressed an ongoing need for support:

NE12-15-19...Yes, the social worker was there and also the therapists. One physical and an occupational [therapists]. They checked the girl and explained [what to do]...But I did not feel completely oriented, because they do not explain everything to you...

Teachers were also sources for important information about the process and procedures which enabled services:

AU15-95-92...Teachers themselves helped me. They told me that they accepted children with disabilities and that I could go and help. My second daughter was in the program. That he could be two years in the service...

Service providers were sources for information about registration procedures:

FA1-62-82...The first information about registering him in Public Instruction was through the occupational therapist. But no one really sat down to tell me E....You should register him in Public Instruction...She did not tell me the importance it had...

Other school related personnel were also a source for information to parents:

NE12-78-86...Well I found out through a person I know who worked in the Head Start program...And she explained the program, I liked it and said let's do it. She referred the girl...She told me when the pre-enrollment would be and this day when she is attending her second year of Head Start...

Another source for important information was the social worker:

OO4-58-33...I am grateful to the social worker...She provided information about the legal rights of the baby...God also puts other hands to help you and those are the ones that you have to look for...
Some general information was provided by parents when they dropped off and picked up their children:

NE12-75-83...I spoke with teachers on a daily basis. Because I had to take N. and pick her up...

In order for services to be effective general and specific information targeted at parental needs was requested:

NE12-49-54...I have papers from APNI but they do not explain the condition. In SER I get orientation meetings but nothing specifically, Because...there are many children with that condition in SER...

Some parents had limited knowledge of service organizations, a need for information which the service managers could fulfill. Organizations were also important in providing information about services:

AE7-41-38...APNI [The speech therapist told me ]..This association is dedicated to provide orientation to parents. Then I wrote and asked for information and over phone...One of them gave me a good orientation about Head Start. I also went to an assembly and a person having to do with Head Start...told me that even if he was not toilet-trained they had to accept him because that was what Head Start was for...I thought that if he was not toilet trained they would not accept him anywhere...

Information by mail became one of the few sources for connection for a busy mother of two children with disabilities:

LA10-116-92...Well the only one that has cared about sending me information is PRO convalescents]. It's in the metropolitan area. They sent me information about how to deal with the situation and how to share with other mothers. They provide orientation to us...

Other respondents reflected their need for further orientation in their misunderstandings about services:
I think that Head Start in Caguas is a Municipal agency. I do not know how many child’s rights can apply there since the rights are for the Department itself...

Parental differences in individual educational attainment was perceived to have an effect in parental level of information obtained regarding services and rights. This can be inferred from the following description:

CI2-101-104...The importance of parent orientation: We are educated people but there are people that do not have any type of education, any type of orientation...Let’s provide orientation to those people according to their capacities, and their education...

On the other hand, there were some parents who actively searched for facts such as a father from Mayagüez:

CI3-42-38...I am still inquiring and I looked for information. I got into the State Department... asking about the aids that people with disabilities have...But not everyone finds out...

Furthermore, the need for information varied as parent and child relationships developed and parental knowledge about the implications of the disability in their child’s life became more clear. Some parents became focused on obtaining services after becoming knowledgeable on how to deal with their child. This implied a process by which the need for information changed in nature:

AU15-44-36...I do not need more information about the condition. I already know that...but of available help. For instance, the school. Right now one of my concerns is the school for next year...

For example, some parents were not notified of the possibility of enrolling their children immediately:
SE13-90-70...I found out from disabled children. And I did not know that it existed. It coincided with the moment at which we were told to enroll in the list. If I had known it since she was born I would have taken her...

In relation to information about services, having to make several visits to obtain basic information was not uncommon for some parents in this sample. The following excerpt reflects such an instance from the mother from Vieques:

MO14-83-70...I am going to have to go to the school again to ask where is what he is supposed to get: if it is speech therapy or occupational...

Similarly, to get the necessary information required a search for information, and while on it they faced barriers:

SU5-36-38...I have not received any kind of information but I have gone and I have asked many questions. Really, if I do not ask they do not provide the information...

Refusal from governmental authorities to provide the information they are required to provide was not an isolated event:

CI3-23-26...They did not want to give me the copies and I had to go to the State Department where I found out about the rights of the child with disabilities...After the meeting at APNI the young woman there got the information...

Schools which were a feasible provider of information frequently failed to fulfill their role as expected:

CI3-71-65...But in terms of information, in terms of orientation, in terms of a guide to follow with the children, what do they do? nothing!... Things, as if it was a normal school, but nothing about these are the children’s rights and responsibilities, you should follow this treatment...

Some parents looked or obtained little information from sources such as the Department of Education. One of the reasons mentioned was the government
departments' use of procedures to delay services which parents knew they had a right for:

FA1-113-125...They are very limited in providing information. If you are conscious about what you want to know and you pull out that information from them, even then, they try to see if you mean what you say...They leave you in certain doubt...

The government worker's refusal to provide information made the regular process of obtaining services harder. Employee's attitudes and their unwillingness to provide information caused problems that are noticeable from the following excerpt from a mother from Bayamón:

FA1-51-62...They...Public Instruction, I see that they fight for that money as if it was the employees' money...They despise giving information to anyone about the rights that the children have. I personally was informed of everything by APNI...FA1-62-77...I have to pull the words from them. Even applying for things they do not tell you have those rights for this or for that. They do not...They limit themselves to remain quiet and to respond to what is being asked...

Her experience with the Department of Education was that responses seemed cautiously measured so to insure that parents did not get more than what they asked for.

A mother from San Germán reported that general information was not provided:

LI8-9-6...[Have you received an orientation about the rights of your child?] I never did. Only the letter that they sent me...

Although difficult to attain, parents felt that information opened the doors to new opportunities for their children which they did not know they had. Such appears to be the experience of the father from Mayagüez:
CI3-23-27...[The information has helped] because now I am demanding some rights that I did not know existed. The right to transportation, for him to be evaluated by the Department of Education, and thirdly to be placed in a school for physically disabled. And I am reaching that objective but by forcing them...

Some parents faced lengthy waits on their requests for services without receiving any information on the status of their requests. A mother from Bayamón was receiving home based services at the time of the interview. Although she had officially expressed her interest in obtaining more ample educational school based services by the end of the school year she had not given received a final word. The official’s use of rude remarks is also noticeable:

FA1-127-170...The person that was giving me the information in Public Instruction, when I exposed to her the need for F.A. to start school in August she told me that it was not a nursery. I asked her about what was it specifically that F. A. would need to be doing to be accepted in school ...Then she did not want to say...Now that I’ve come back they tell me that I have to wait until May, when they are going to review his I.E.P...

Lack of timely information posed barriers to equal access to services:

[Have you received any information about the early intervention services?] What I know I have been told by Public Instruction [and through the media] but to say that I have received information I have not...I did not find out about it on time [to enroll him]...They stated [services] were available in the area but that there were too many children and that I would have to wait...

In some programs, the type of information provided was dependent on its philosophy. A mother whose child has autism described the information received from the Program of Neurological Organization:

SE11-46-29...[Did they make any recommendation to deal with the disability?] Not that I remember. At school they’d give me constant advice about how the discipline should be. That you had to be stern.
That you had to organize him. But almost always they would say: "Listen, the child does not accomplish this because you are not working with him..."

Limited opportunities for parent participation and for observation of the education service were reported by a father from Mayagüez. According to him that opportunity could have been done in unobtrusive ways:

CI3-54-56...That [place] should be set up another way, with a two-way glass. And to say: "Look, this is done like this and like that"...Where you see how he is functioning...CI3-106-111...But it is not an access like to say I can show up and see C.’s performance because regulations say that parents cannot be there. Not even through the windows or anything...

These parents also requested opportunities to observe teaching strategies from a program in Mayagüez which did not allow parental observation:

CI3-3-55-49...It is not to intrude in the therapy but to learn therapies are because it is not the same to say...and you do it like this and like that...She is the teacher and has to teach some skills but if you don’t apply them in the house and memorize them in the house what good is the school?:..

A mother showed concerns about the local programs’ inability to meet parental needs as required by law:

MO14-25-14...Well the APNI group, told us about many rights, but I do not get any. When I went to both interviews, from 8 to 3 in the afternoon, they showed me a full program. There, at the school, many people have it but not the ones from Vieques. The only thing I got was the therapy and it was not ongoing because many times she was absent...

The following excerpt presents an instance in which information about financial aid aimed at making services available to families was not disseminated:

CI3-40-36...I did not know because being in the ESPIBI center and even my wife, who works in the Department of Education, have never found out about
the aids. And by chance someone gave us the advise. That was the counselor at her school, who also has a child with disabilities. If it had not been for that bit...I would not have found out about those aids...

Parents also requested agencies to be better equipped to provide information that reflects their accountability for their money and services:

MO14-108-97...As far as I found out, those are federal funds that the federal government sends to the Department of Public Instruction through federal employees working here, for the students. There is a lot of federal money for transportation and for children with disabilities. What do they do with those funds?...

Service/Waiting periods. Evaluation and enrollment procedures were discussed from the perspective of timing and continuity. All children in this sample were registered in the Department of Education at the time seen but services were not similar in scope or adequacy.

For most parents the initial registration process was easy and short. Comments like the one that follows were common: NE12-43-50...I registered her easily. It was not difficult...

Most comments centered on their experiences after registration. The delays and indirect denial of treatment resulting from difficulty in following the sequence of registration, evaluation and receival of services as should have been done, had adverse effects. For instance, some children who were almost four had never received educational or related services. Such was the case of a child with Down’s syndrome from San Germán:

LI8-75-36...We registered there and supposedly they were going to call us. We are still waiting. But seeing that they have not done anything, well, it means that they do not worry about anything...
This was consistent with claims from other parents that about children they knew who had to wait until school age to be served. These policies seemed disruptive since similar services could be made available in other locations:

SU5-73-71...In the Special Education [Program the process of] helping the children with disabilities is very slow. If you discover the condition at an early age, why wait until first grade to provide the services they need? Since an early age [they can learn] to deal with the school. And here they are not doing that. Here they wait and wait until there’s nothing you can do about it, then they start working. I think it is better that they deal with them at the beginning when the problem is not so big or so grave...

A mother from Trujillo Alto made the only description of a facility that included an easy transition process from the NICU to therapy services, which expedited the process. The mother from Trujillo Alto described advantages from this practice:

AE7-66-67...The clinic was good but...I do not know if it just was in my case, [but]...I found out from mothers whose children were already receiving therapies and then, afterwards I found out that the Municipal Hospital is, I believe... the only one that is doing it; as soon as a child leaves the NICU he/she immediately goes to therapy. It is not a referral and then you’ll have to wait. It is immediate, very direct, very quickly. I mean from there they give parents referrals so that they go...

There were also instances in which related services were available to parents in a timely fashion. These were provided by some offices from the Health Department as described here:

LE2-109-121...But maybe I do not have the same opinion regarding the Health Department’s Public Services. Because I told you that her therapy started when she was 4 months old, it was recommended when she was three months old and at four months she had already started the therapy. And the Pediatric [Hospital] appointment arrived a year later...
Sometimes delays and longer waits resulted when parents were required to do burdensome errands which could have been dealt internally with appropriate administration. For instance a mother of a child with Down’s syndrome from Arecibo had to travel to San Juan to get her son’s medical record to enroll him, only to find out that the sole person that could give it to her was absent. She did not go back:

AU15-86-77...I went and enrolled him in a waiting list. That was when he was about three years old. They placed him in a list for early stimulation but they never called him. They said that his record had not arrived, and that I had to go and look for the Record in the Medical Center...I went to the Medical Center [in Río Piedras] but the young man was absent and the child remained there [without placement] for that year...

For some families, problems ensued from the lengthy waits that children faced in order to obtain an evaluation and services. A frequently used reason was that there were too many children, as discussed by the mother from Arecibo:

AU15-87-78...After the second year all the information arrived and they called me to start making him a psychological evaluation but they also took their time...[almost two years]...I used to go] twice a year. I went back, they would attend him but they did not give too much importance to [his case]. They would tell me that I had to wait, that there were too many children. The same happened in physical therapy...of the Pediatric Center for Children with Disabilities... It was at the same time that he was accepted in Head Start that they also told me that they [The Department of Education] had accepted him—when he was four years old). Head Start made the evaluations...

After getting the evaluations done, another area of repeated delays was that of related services. One description of this type of delay in Head Start was provided by the same mother:

AU15-97-95...Well, as for occupational therapy, he is going onto his second year and it is now that he is getting his occupational therapy. And from the
Medical Center they have never called me. At Public Instruction, they told
me when I registered
him: "accept services from whomever first offers services to you."

Delays on appointments for initial evaluations were reported by several
parents. For instance, a mother from Río Piedras stated:

LE2-26-34... There you had to wait your turn for the evaluation for therapy.
He was three months old when the need for [an evaluation] was determined
and she was almost a year old when the appointment for the evaluation
arrived...

In some instances, referrals appeared to have little practical significance, since
they took a long time to process them:

AU15-66-54...She gave me a referral and with that referral I went to the
Medical Center where they'd give me the service. But now I am on a waiting
list, since they have too many...

Referrals resulting from evaluations did not necessarily lead to appropriate services.

A mother from Río Piedras described the waits she faced after the evaluations:

CI2-25-27...What good is it to have a child evaluated and be told that your
child has a condition? You have to wait, be included in a waiting list, and if
in that waiting list you do not get a good turn, look, you're doomed...We have
seen many cases [like this]...

Ongoing waits from three months to up to a year were faced by parents in
Caguas:

NE12-45-51... I applied for physical therapy in January and I still
have not received anything. And now I moved and applied. We'll see
in August...

Longer waits of more than a year were also reported:

LI8-74-37...I think we are on a waiting list. Waiting to be called and they
have not told us anything. It is been a year or two of that...
Contracted services provided as necessary might represent a reduction but not an elimination of the waits:

LA10-62...Well, they told me that [she is on a waiting list]. Yes, it was done and they sent all the papers to SER. The girl from Public Instruction said: "We are waiting for their acceptance." And that is where we are at...

Waits of up to a year were commonly described in that private setting:

NE12-43-50...In the therapies I first went and the physiotherapist gave it to me in SER, and then filled the record...and talked with the social worker and all. For her to be able to enroll in SER I had to wait a year. N. was about a year and a half old and was able to enter at two and a half...

Not all service facilities delivered belated services. For instance, a private facility in Ponce directly referred a girl with mild hearing impairments to the early intervention services:

GA6-65-69...Right now she is receiving early stimulation. They referred her to an early stimulation group. They looked for it themselves...

Even when enrolled and participating in related services parents faced service discontinuity. Such was the case of a child from Vieques, who was served in a discontinued fashion for a year. After that year the child did not receive any other services:

MO14-17-9...I had to enroll him in [Public] Instruction so they would give him physical therapy. The boy was already a year old when they gave him what they gave him. From there on they have not given him anymore [therapies]. He received [therapies] for a year, from August to June...

Long waits for at the time of appointments caused several inconveniences. A woman from Arecibo described how inappropriate long waits are for children with disabilities in public health facilities which affect the child’s amenability to therapy:
Going to the doctor is another problem if you have to wait a lot with him...The last time that I went [to the public hospital] was about a year ago and he did everything that he pleased. Because he was upset and tired too. We returned home and without getting his prescription...

The length of waits children faced on each visit to a public governmental facilities affects service effectiveness by reducing child's receptiveness to the therapy:

No, you had to wait your turn to be [attended] and F. A. was sleepy, hungry, tired, and when the time for therapy came he would not respond well to the therapy. And I automatically said: "It is not worth it"...

Another factor that increased delays were the problems with the service staff's accountability to parents. This lack of accountability happened when the professional was absent and appointments were changed. It was not uncommon to lose appointments due to those absences and lengthy waits for rescheduled appointments followed:

They change the appointment, you wait for the new appointment and it never comes. It is like right now the speech. For speech we are still waiting for the appointment and it has not arrived...It has been more than a year...

Also available appointments were limited and rescheduling them was a problem. Rescheduled appointments required waits of up to three months. The mother from Bayamón described this situation in the following excerpt:

The problem is that I can tell him: "I have an appointment for that day." [he'll respond:] Oh, then it will be for the following month. Because there is no opportunity until next month [or two months]"...It is better to remain quiet...If they give the opportunity that, for instance, the neurologist or the orthopedist tend me, I better accept it disregarding the conditions that they place...
A mother from Bayamón reported that if a staff member quits they are not replaced and thus further delays:

**FA1-48-55**...You have to wait until there is a new contract and a new therapist comes up, and that they can then cover [her post]. Then we have the problem that therapists are absent a lot, when it is an agency like that. At SER it does not happen, since apparently it works differently. But, for instance, in the Capital Hospital they were frequently absent...

The Health Department did not receive many complaints about the quality of their services when provided, but about the delays in providing the appointments.

These delays and interruptions, led some parents to pay costly private services:

**NE12-46-51**...Because I was taking N. to private physical therapy but the cost is too high. It is $40.00 an hour but I have been waiting 7 months for the Instruction Department...

Even in urgent routinary needs parents faced delays in delivery. Such was the experience of a mother from Naranjito:

**LA10-137-112**...I think that Social Services should provide more when you go and ask. I understand that there are many children and that maybe many mothers go for economic resources, but they should be more humane. Because when you go to them a need and it is urgent. Well, they sometimes make you wait a month or three weeks until Bayamón tells them whether you are eligible or not...

Lengthy waits were perceived as resulting from not giving the importance which to parents deserve. In one instance, lack of interagency coordination of documents forced parents to make endless errands:

**SU5-56-59**...All I see is that I give you this paper and then [they ask you to] look for the other paper. Everything is papers. Almost no one wants to really help. Then you take the time of the person, and you take time waiting for papers...
In the following excerpt a parent was not sympathetic to the agency’s administrative incompetence. Their losing important documents, increased the parent’s wait for services:

AE7-19-18...It is not a question of waiting for a doctor to give him a referral...For me it is laziness. Since it is not their problem you see them with that attitude. And that happens not only to me because I saw it happen to many mothers, too. They work only to get paid but they do not care if they lose a paper or not...There is a lot of that...

Also, two mothers mentioned that they waited through out the summer, without confirmation for the continuation of educational and related services. Such situation left them without the capacity for long term planning. One of them was the family in Trujillo Alto:

AE7-91-109...Now I have to wait until August for them to tell me what his schedule is going to be. According to that, then I’ll have to talk with the CETI therapist so they tell me how they are going to schedule him...

For some parents their only recourse was to wait. According to some parents there were others who did not know where to obtain resources:

FA1-71-92...Other people I know have been waiting several months for evaluations and those evaluations do not come. And I understand that it is because there are really too many children with those needs and there are no centers to provide them...

Obstacles for services for children with severe disabilities were formidable. For instance, a difficult incident occurred when a Head Start offered a extremely limited schedule to her daughter:

SE2-58-58... [I waited until]...the afternoon to be told that [the service would be provided] two hours twice a week [ by Head Start]. It was then that I faced the reality of not knowing where to take her now?...
A job sponsored daycare had already rejected her daughter because she had disabilities.

A comment from this mother of a severely retarded girl blames the delays and refusals on the administration:

SE2-86-93...We understand that there are federal assignments to cover all types of needs: services for children with special needs. The response in practice is the opposite. A lot of delays, no follow-up at the central level, in the educational regions...

A common complaint was the one about the delays in payments. That was frequently the case of transportation expenses:

They enrolled my child and asked personal information, even on our family income,...and then they made the studies, and finally a check came. There are problems because I have still not received a penny from them since August [and it was already April]...

Service/Program evaluation-positive aspects. Parents were keenly aware of both the positive aspects and the problems of the services their children received.

Many comments were devoted to providing an evaluative view of services. This section will present the positive aspects discussed as they relate to program and parental participation issues.

Most parents were accepting of placement for their children. A positive factor that was recognized was the developmental opportunities which placement offered.

Reasons for their acceptance can be summarized as follows:

AU14-92-83...So that he would learn and would become more independent from me...
Several program characteristics were positively regarded. In the following excerpt the nondiscriminatory policy attributed a service provider was viewed as positive:

GA6-3-1...Here in Ponce there is an institution that is placed near Ponce’s seashore, that belongs to Sor Isolina Ferré. There is a program called Helping Hands. There they give therapies to the children without distinctions...

Other programs were perceived as being committed to serving children with disabilities. Head Start services for instance, linked education with related services were viewed as positive in:

SE11-113-87...There is a commitment to observe the changes that he has aside from the therapies that may be done...

In some instances, the participation in these programs, while viewed positively, led to further expectations and more demands for programs:

NE12-68-73...I am satisfied with the program. Head Start has helped me a lot and N. is a little more aware. The purpose for N. to be there is that she would share a little bit more...This year I demanded from the program a little more, to get out of her a little more...

On the other hand, parents with severe and unusual conditions expressed relief and some level of satisfaction when they found a place in which their children would be accepted. An example of this is given by the mother of a child with autism:

SE11-58-38...This Head Start Center had been unique in terms of accepting them. There are three rooms in the center and in each one of them there is a child with disabilities...A parent’s support group who had these children with disabilities from that Center was formed...

All parents had registered their children in the Department of Education. The process required that they visit the office get an appointment and register them by submitting the requested documents. For some it was a very simple process:
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SI13-71-56...In Instruction they registered her. I simply went there and I talked and told them what she had, took the papers as evidence. They registered her in the program. They gave me an appointment and quickly registered her. From there she was sent to the audiologist and the ENT, to a pediatrician. She was seen by a therapist....

Transitions for educational services were easy for a child with an undiagnosed disorder from Arecibo who has benefitted from the program:

SE13-72-57...I find that the process with Instruction has been very good because she is in school. First they sent a teacher to school and then after, when she was close to two and a half years...they took her in the school. And from there on my daughter has recuperated a lot. She has been improving in many areas with the teacher...

For the family from Mayagüez entry into a program was a simple process too. Their experience was unique since staff from the Health Department facility in which the child was placed communicated directly with the Department of Education. This eased parent’s process:

CI13-41-37...[him] I only had to bring the birth certificate, the social security and the vaccination certificate. He already has the evaluation in the ESPIBI center and the Department of Education communicated with ESPIBI directly. From there they brought down C.’s record. It was not such a difficult process...

The flexibility that some programs demonstrated was also acknowledged as helpful by parents from Vieques:

MO14-35-34...Look Dr. I am from Vieques, so that you tell the secretary to place me ahead or at least second so that I have enough time to take the ferry or the plane and he agreed and they gave me priority. I would call the day before to get in the list. [I would tell them:] "Remember I am from Vieques and she would place me in the list". I would get there around 10...

That flexibility was also demonstrated in a private school that offered a mother the opportunity for professional development:
He absorbs time. Because now he is placed and he is certain hours in the school that I could have a part-time. He could be there up to three. The teachers themselves say: "Leave him here and work that we'll take care of him"...

Daily contacts with teachers at drop-up and pick-up times were valued by another mother:

NE12-75-83...I spoke with the teachers daily, every day. Because I had to take N. and pick her up...

While not in complete approval of the services given by Head Start, they offered practical help for a single mother with a child with autism. She did not find that type of help anywhere else in her community. Her gratitude was expressed in the following excerpt:

SE11-64-43...In the moment that you see that someone is going to cooperate even if it is the institutions that have to do it by obligation well you feel at least that you are accomplishing something...

A similar situation was faced by the mother of a girl with metabolic disorders. Having faced rejection from other day care services a sense of gratitude was manifested about her child being accepted by a church related day care:

LE2-49-51...Thank God that it was from the Methodist Church and they met with the ladies that care and they saw the case from the religious point of view, more than from the work that it was going to take. That was what made them make the decision to help her. Because the most severe one that they had seen was a reflux that they had. It was the most difficult experience that those ladies had...

This mother also felt positive about the related services she received but was still struggling for others:

LE2-109-121...We have had the experience through the Pediatric Hospital, the experience through private services and the experience now with the Head Start program. I would say that they have all been good...Even if they are
public, when you get the service, the service is good...Where we had to
appeal it has been for the educational services...

Although her daughter was not offered all the she needed, this mother maintained a
positive attitude about her accomplishments through appeals:

LE2-109-121...In the Head Start case we have had attainments. According to
what they said she was going to be the first girl with multiple disabilities that
was going to the classroom...The ones who are in the classroom are children
who mostly have mild speech problems. We have accomplished with them
[something] through appeals but the process has been hard...

Parental decisions about services also had to do with the positive benefits to be
accrued from enrollment:

SI13-85-62...She does not talk. How is she going to do? She is not
going to adapt. I said if it is a service they give and the girl is going to
prosper a little well let us see. If it is not good well I withdraw but let
us try...What did you do to reduce fear? To meet the teacher first of
all. The teacher was very good with them., very loving...

Parents also felt positive about specific educational alternatives which they
requested. For instance, the mothers from Gurabo and Caguas recognized
opportunities for integration as one of the benefits from Head Start, as the following
statement from the mother from Caguas exemplifies:

NE12-71-75...[In enrolling her] I wanted her to interact with other normal
children and that at the same time she would learn that she has her condition
and limitations but that she can be with the same persons and that in a future
she is not raised with frustrations...not to feel shy or with fear or to be
ashamed that she cannot walk...

Head Start offered safety, a valued factor, that was lacking in the Public

Schools:

AU15-96-93...I like how they work. I like that they have the children well
cared in the room...and they are safe. One does not have to worry abut them
much with them. If you are going to leave them to Public Instruction you
have to be watchful because if the teacher is absent you have to pick up the child. Here if one is absent the other is in. There are always three or two...If there is no class they tell you ahead of time...

While recognizing Head Start is not the optimal placement for her child, its safety; and the modeling from typical children, was also appealing to the mother of a boy with autism:

SE11-56-37...It is not that I think that it is the best place, but at least for the two hours that he is there I find him very secure and since he is also with children who in the most part do not have behavior problems I think that those are the models that, even if he does not pay attention to them, are there...

This mother appreciated the program's efforts to deal with her very special son:

SE11-64-43...[In Head Start] I am satisfied with the attempt that has been done directed toward my son. I mean that they have dealt with everything they have. The truth is that these are new cases that they do not know about. The majority of them had not dealt with autism...But to be [completely] satisfied with the service, I am not...Not yet...

Greater program offerings were positively regarded by parents regardless economic situation:

SE13-78-62...Since the room was bigger and the other group is a small group their room was moved. because the teacher has much equipment to give them treatments...[she] They have computers and take the children. Something very modern almost like out there. And even air conditioning unit that we had gotten. I mean that a father got with our signatures...

Inservice training provided by some programs were recognized by parents as having direct positive consequences on their children:

OO4-125-80...The professional that works there she educates him/her. She gets funding for the school and gets funding for her personnel...
Parents made positive comments about their children’s teachers with regards to their constructive communication:

SE13-89-69...She always looks for alternatives she always attempts to make one happy even last year when he changed schools...As soon as I found out about her disability I quickly told her. When she finds something more abnormal than it should be in the children she communicates it. She asks or she says it. But she always looks for the way to be in contact with you about what they have...

A few families described teachers as supportive and understanding of parental needs and desires:

FA1-142-174...She has communicated with me a lot. And also, she is not supposed to deal with her, we talk all these things, but I have already talked with her about my interest for F. A. to start in school in August...She told me "I think that...F. A. can start in school" ...

Ongoing communication at arrival and pick up times provided by some private programs was appreciated.

OO4-132-85...Every time I go and pick him up she tells me. Today he was wonderful. He did this thing, this thing, this thing. This he did good. In this he is sort of slow but do not worry I will work hard with him ...Sometimes she explains the situation in a very funny way. He does not get upset. She is one very accessible person. I am not going to tell her things in a bad way either...

Some personal interactions with Head Start teachers were evaluated as satisfactory:

SE11-113-88 She is very respectful with me. In fact she is much older than me and treats me formally. And she listens to my recommendations...

Similar respect was valued by a mother who, by virtue of her professional role, deals with similar populations:

EO9-98-85...They ask me and they respect me because remember that I am a help professional. In fact, I gave a conference there itself in my program. One of the things that the doctor...asked me if she could say that I have a
child with disabilities and I said yes...That would be to reject yourself...For me confidentiality is when you have something to hide...

The way teachers interacted with their children was also the source for positive comments:

Are you satisfied with what she does with the children?] Yes, even thought she does not spank them, she scolds them...[Other teachers have been] very good and very loving and I know them so much that I cannot complain...

Some Head Start programs held Individualized Educational Plan meetings with related professionals:

AU15-94-90...[Do teachers ask you what you know about the child?] Yes because the teacher has training in special education. She had already worked with moderate children with mental retardation, she already knew. Besides that in Head Start at the beginning when one goes to the program a psychologist goes and various persons meet to see how they are going to deal with the child...

Preschool services are required to foster parent participation. This participation should take several forms so as to enable everyones' different needs and desires. In this sample there was some discussion about issues of parental participation in service programs. Programs such as Head Start foster parental interaction with staff a reason for frequent positive comments:

AU15-96-88...I go every day. Sometimes I am there for a little while with them. And they tell me how the boy is doing, if he has done something ...That conversation is as if we were friends. Since I had the other two girls there I already know them...

Meetings between parents were another form some programs used to foster participation. As discussed in the following excerpt, these activities served parents for reframing their experience:
CI3-34-32...For me those meetings...have been helpful by seeing people that are in worse conditions. Children that do not move, children with X disability that you really have to have a lot of love and a lot of courage in your heart to be able to attend to them. And we have seen that God was not so [hard] on us. He was good. Because I do not know how we would have taken another disability. It has done us a lot of good to share...

Some services were accepting of parental input as in the case of Head Start.

The following excerpt in turn presents the Department of Education as placing barriers to communication:

LE2-105-110...For Head Start and everything related to the medical services our input solves a lot. One feels that one is participating. With the Department of Education what we have had is a series of claims that I have not shared so much with evaluators that belong to that system..

In Head Start some parents felt they were influential in the daily affairs of their children through short visits and daily contacts at arrival and pick up times, as stated by this mother:

SE11-114-88...I visit him every time that I take him and I go to pick him up and sometimes I stay...There was a teacher in whom I did not trust...And I went to fight and they paid attention to me and they changed the teacher to another group and they brought this one...

There is flexibility with parental actions, parents can take the role of aids and even refuse the role when it is not desired:

SE11-114-90...I have stayed in some occasions in that for instance the aid does not come or the teacher does not come. Sometimes one of them is absent and I take the boy. But since the time is so little I almost always stay or leave and trust that he is going to be alright...

This mother of a boy with autism recognized the importance of early schooling too:

SE11-111-85...There are days that he resist it and there are days that he goes very happily and is there. I think that whatever is around him is not of much
interest to him, I mean the other children. But I think that it is better that he goes out of his house because the more hidden he is, the worst [he will be]...

Parents felt included in the planning decisions in Head Start:

SE11-117-93...almost always when it is time for the evaluations and all they ask you and accept your word...

Head Start also provided a complete team meeting for the development of the individualized educational plan:

NE12-77-85... In those meetings the social worker the nutritionist, the speech therapist, the director of the program for children with disabilities and the psychologist met with me and discussed what they want from N. The improvement that could be gotten from her and all that...I could be in disagreement and they included my suggestions...

Some private services offered timely evaluations and team meetings, to which education and related service providers and parents attended:

AE7-131-84...The children have evaluations...The psychologist,...the occupational therapist does the evaluations. [In the discussion] about the boy’s IEP I have to be there. I check all, I read and since they more or less during that period of time have had me informed it is nothing new...

Another behavior demonstrated by a teacher in the public schools was the flexibility with parents:

SE13-86-67...[Could you go into the room?] Yes even though you had to ask for many permissions to the director. And the director is very strict. I many times arrived late to pick up the girl and the teacher would stay with her, feed her. I would ask the boy how did it go and he’d tell me: the teacher is good....

Service /Evaluation-negative aspects. Parents also cited problems in their interaction with service providers. The discussion in this section will be divided between program issues and parental participation issues too.
Parents described several manners in which programs failed to provide
children and their families with the support and services they felt were necessary.

The Department of Education failed to fulfill the offer public services for their
preschoolers of some rural areas:

OO4-125-76...Here there are no services from Public Instruction. The
Governor said many beautiful things that in reality do not exist. I was
watching him yesterday. They presented some lovely schools. In the
educational reform special education shows some lovely schools but it is not
like that...At the school where the girls are now, it is now that they are
making the ramps. There was a boy in a wheel chair before but they do not
bring him anymore...

Similar lacks were faced by a family from San Germán:

LI8-34-18...[Have you taken him anywhere to have him evaluated?] No, I was
told to go in August to the registrar to ask. I was told by the social worker to
whom I went to talk with. She told me "Well, I am going to help you. Come
back in August because we have too many children..."

Some family members were placed on waiting lists or were told that there was
no space available. There were no mechanisms to voice their concerns or to
corroborate information they were given. This lack of corroboration caused
complaints about program's accountability:

CI3-44-39...In Vocational Rehabilitation they tell me that right now there is no
space: an absurd thing. I am not going to open the books to see if they have
space or not...I doubt it. If they pass a law, why don't they provide some
adequate services?...

Transitions to other settings (Head Start and/or the Department of Education)
were sources of concern for parents who otherwise had positive regard for Health
Services:

LE2-109-121...We have had the experience through the Pediatric Hospital,
experience through private services and experience now with the Head Start
program. I would say that they have all been good...Even if they are public, when you get the service, the service is good...Where we had to appeal was for educational services...

A mother of Trujillo Alto was moving into a similar transition. As her son prepared to go to go from Head Start to the Public Schools, this mother could foresee the hardship ahead of them:

AU15-51-39...[At Public Instruction there] ...is a continuous struggle with the teachers. They do want to accept them, if they have a condition. I worry about how they are going to treat him. I have to be behind him. I know that I am going to be after them to guarantee that they are giving him services...

Parents of children with severe disabilities were also very critical of the failure to provide opportunities for children's integration. One such comment was made by a father from Río Piedras:

SE2-60-62....[him] We live in an education system that has not internalized the new theories specialists in psychology and sociology. I mean that we continue dealing with archaic systems of education...They offer things and there is no such integration...You apply for services and these are not offered. I do not know if it is an administrative problem or what...

The mother from Arecibo perceived the segregated settings in which his child was going to be placed as a reduction of positive modeling:

AU15-46-36...In public schools I think it is going to be different because he is not going to be with children that are well. He is going to be with children that are like him or with other problems ...I think that is going to affect him more than help him. Because he copies everything that you do...

Also, approaches to academic integration were perceived as limited in programs that only placed children together:

NE12-73-81...She did part of what she had to. I take N., she would put her to play with other children, she'd give her play dough, but to sit and teach her
about the colors she might do it once a week and then, after two weeks, she'd come to the same thing...

Other concerns were manifested about the organization of services. Some programs arranged their education component in ways which did not encourage parental visits. Their routines were organized to prevent them from doing so, as described in the following excerpt:

CI3-110-117...There is a hall before the room... You have to wait there until the teacher comes for them...and she takes them to the room...The same when he comes out...

Parents also faced limited in opportunities of learning by observing their child in the classroom context. A father from Mayagüez who wanted to see the usual school routine was provided staged visits:

CI3-110-116...If we want to visit the program we have to get an appointment and then they put the room very pretty...It is not the routine, but that visitors are coming...

Some programs lacked the flexibility to consider the needs of working parents. A family from Mayagüez received from a Health Department facility, a half day program and no transportation. The following excerpt describes one of their fruitless attempts to discuss their difficulties:

CI3-110-118... [she] About the arrival and exit, we tried to make them understand that we were working and that it was difficult for us and she said that there were many parents that were in the same situation and they picked them up at the scheduled time...

She further described the organization's inflexibility towards the needs of parents that work:

CI3-100-114...[she] When we went to the IEP [meeting] one of the things that they scolded us for...was that we had to take C. at one
specific time and pick him up at one specific time. Not everyone, we told her, that not everyone worked, [and] that we worked...That came out in the IEP [meeting] that we had to "pick him up at one time, not at the time we pleased"...

Most families reorganized so that mothers would stay at home. Nevertheless, the small number of families who had two members working faced difficulties securing day care. Such was the situation of the parents of a girl with severe retardation and metabolic disorders.

The single-mother of an boy with autism described another way services did not take the consumer into account. The Center for Neurological Development required family members to be involved in ongoing daily interventions. Bratt (1989) described a similar organization in which participating parents were required to become involved in strenuous and time consuming exercises, for which this mother from Gurabo lacked resources:

SE11-71-48...And in the recommendations almost always they ask me to sit him down and they say that you have to be stern and follow a discipline, that at some point he is going to accept it. That requires a lot of energy and requires of people who can help you...

If parents could not follow the suggested activities they were considered part of the problem. According to the mother this program seemed to imply that failures were the result of parental inadequacies as described next:

SE11-61-40...At the Center they told me that his lack of progress was due to the fact that I was not following the discipline...

She viewed the staff as not open to feedback about program's results from parents. Nor were child's individuality and interests given consideration:
The information that you read, that you get from another mother or from some book in your hands [was that it works]. But I also noticed that maybe with some children these things work. It could be that with yours it does not. It could be that yours, as mine did, refuses constantly when you sit him down to do something. I think that with many children it is like that...

The Center also lacked the flexibility to adjust to the needs of parents from far away locations:

...I already had problems with the teacher. The teacher was very strict in her program. You could only get there up to 8:30. If you arrived a minute late you could not enter. I traveled from here and...she did not let me go in and I had to return. Do you know the traffic-jam you have to get into from here? And I had to take the boy and leave. And things like that showed the level you were at as a parent. There was no support for parents who were the ones who suffered all the consequences of what they did...

This mother quietly took the child out of the program after a few attempts to work with school and many economic sacrifices. The only other specialized option for autistic children, had been previously discarded because the negative comments she heard about it from the Center’s staff:

...At that time I had received a continuous barrage, by the staff of the Center where I was, about how that program did not work. They said that because they thought that the one that worked was theirs. You know, because programs attack each other...I accepted it. I said: "I am not going to go there because they do this and that"...I mean, I was receiving continuously comments that those services were not going to work for him...

By the time she decided for this placement alternative, more stringent requirements were in place, which her child did not meet:

...As a matter of fact the last thing was that they dismissed a lot of children that were there. I struggled a lot to have him accepted and I asked a lot of people to intercede for me but there was no break. And even more, afterwards they evaluated the boy and he came out as a low functioning boy.
They want the best, they want those who function better. They are very choosy...

The magnitude of care requirements and the limited school options were significant in her placement decision:

SE11-64-43... I did not have an option. I thought about everything, that he was too young, but I did not think that I was going to have the strength to keep him all day long. That even for two hours I needed someone to stay with him...

Lacking alternatives she applied in Head Start, which did not offer an appropriate alternative either:

SE11-118-93...I know that day I was sort of desperate and I did not see alternatives. I said let me go in here in order to have a safe place to take him to...because I did not find anything else...SE11-112-86...The program does not have people who are really prepared in special education besides the therapists, but the teachers have a lot of experience...

The needs for transportation of a family from San Germán were not considered when they received a recommendation for services in a nearby town:

LI8-85-45...We were sent to the ESPIBI Center but I could not take him there... There was a conference but I do not know what they said. I do not remember what the woman explained. But what they said was for us to take him three times per week or two times and it was impossible for me. Impossible because I had to work in the farm. I would have been losing three days during the week. She does not drive neither. The center’s transportation I think was local for the Mayagüez area...We could not take him...

Getting their daughter with metabolic disorders placed in this daycare did not end their problems for a family from Río Piedras. Procedures were not coordinated with the family and the daycare staff placed conditions that went in contradiction to the family’s normalized expectations:
LE2-46-48...The center has up to kindergarten but at the beginning the smallest ones go to the nursery up to when they are a year old. Then they go to another level where they give them toilet training and...other skills of older children. But in her case, almost up to three years old, she was not promoted from one level to the other. They always treated her like a baby. To me [it seemed] that since she did not show a progress as to go to the other level, they did not push her...

Furthermore, personnel at this daycare had not been properly trained and many important health issues were not followed up. Mixed feelings derived from facing the limitations of this placement while recognizing the difficulties in securing another:

LE2-49-50...Not much follow-up to the feeding requirements was given either. I would bring her a spoon and plate and more solid food but they always ended up diluting it in the bottle and giving her a bottle. [It was not] until I took my time on vacation and started to feed her that she learned how to eat with a spoon. I mean that the nursery did not help in that. I am very grateful that they accepted her with her condition because it is not easy either for [these children] to be accepted and further when they tell you that they do not have the trained personnel for those cases...

The transition to preschool services was difficult. In order to accept the girl, Head Start requested a teacher from the Department of Education which the Department would only provide for two hours twice a week. This schedule was extremely limited and did not consider their needs as working parents:

SE2-58-58... Then in the afternoon to be told that[ by Head Start]. Two hours twice a week. It was then that I faced the reality of where am I going to take her to now?...

The Department also offered a segregated placement only. This was not seen as an acceptable alternative for the mother:

se2-56-57...But that was not what the therapist had told me. The therapist had told me for her to socialize with children her age due to the fact that the child is another resource that could help...What she was offering me did not fulfill what was recommended by the
therapist... It was not that I rejected the alternative that she was giving me...

Other private services had requirements which her daughter did not meet and were not an alternative for her daughter:

SE2-59-60...Besides that, I made once an approach to Nilmar and others...In her case she hasn't taken a psychological test. They told me she needed to have a diagnosis, even if it was a preliminary one, of mental retardation and that I needed to authorize that it appeared in the record. Another requirement was that she walked. And she would not qualify because she did not have the diagnosis and she did not walk...

She was promised a wheelchair, later to be told that Department does not provide assistive equipment. This last issue was validated by another mother:

AE7-81-92...The Department of Public Instruction does not give help for the equipment. They can inform you where you can obtain help to get it...They do not help but in Head Start I only had to take a referral that stated that he needed it and in a matter of a month or two he already had the chair. Same thing with the glasses...

She had to attend to several administrative meetings and organize parents in order to get a hearing that included both agencies. Then when Head Start offered her more time of services (half day, every day) if she could negotiated the teacher's placement. She immediately started the process with the Department of Education but at the end of the school year no teacher had been appointed.

Appeal processes were grounds for more difficult incidents. For instance, during these meetings she was also infuriated by the staff's insensitive comments:

LE2-87-95...The Department...sometimes I say, but are they special educators? Because sometimes their expressions do not reflect any commitment with that population. Look at what the general supervisor of special education of the San Juan Region told me. That she did not know why I advocated so much for L.'s socialization with children her age, since her daughter who was two years old socialized in any setting
with anyone, including a 60 year old man...And I replied: It is like that because you daughter does not have the special needs that mine, who is three years old, has. But you, belonging to special education, should know more than me because you are the special educator, not me...

Parents faced hostility when advocating for their children. This hostility included implied accusations of having hidden plans. For instance, this mother also felt the subject of previous conversations:

LE2-87-96...The Department is affected by politics [in terms of party politics]...It is a very upsetting thing that you have a real need and the agency who is obligated to help you...and over that when you claim your right [they accuse you] of having another intention!!!...They gave me an appointment for that day for the first time...But when I was in the hallway an employee asked me: "Are you the lady who works in the Environmental Quality Board?" I do not work in the Environmental Quality Board but I work for the Department of Natural Resources ...And then I said [to myself] how is it possible that a person I do not know has that information? And why didn't she ask...can I help you with something? Which is the most logical question when you see someone like that, who is lost in an agency...

Service scheduling was sometimes determined without consideration of parents needs and in contradiction with their desires. Another example was provided by a working mother from Río Piedras in her dealings with Head Start:

LE2-75-76...And they took her for two hours twice a week. That has to be the result of an evaluation. Then I suspected it had not been the evaluation, but the condition the Department had placed...and also because L. had a problem with swallowing; maybe they were afraid of assuming that responsibility and they did not want the Head Start teacher to face that...

Inequality in service access existed in several forms. Needs of children whose parents had diminished educational and participation levels were not being addressed. Parents with limited education were seen as severely lacking opportunities for services that other people had:
CI3-62-54…I think that what I said about that there are many people who have children with disabilities, that their schooling, their way of thinking, their childbearing do not provide to have other views, other things for their children with disabilities. There are not means to counsel those people that do not have schooling…

She also identified the necessity of parental involvement in the quest for services in order to obtain them:

CI3-63-55…[she] I think that a lot of children with severe disabilities...that if a parent does not move and do something the child stays there...[he] This is a [tireless] quest but if one does not move, the services pass by your side and one does not notice...

Adding to parental dissatisfaction were some administrative policies that obstruct service quality:

CI3-41-121…I see it limited. A lot of promises, those who were supposed to do so: a lot of bureaucratism...When the written things are fulfilled [then] one says: "this is an exceptional center"…

While facing all these difficulties television brought home images of the possibilities that exist in other places. These images increase and give shape to their expression of discontent:

AU15-95-86…I have seen magazines and I have seen that in the United States they have computers for children with special needs. They have children with Down’s syndrome and they have many things for them. Here you do not see any of that. The teacher herself who worked in the United States says that they provided all the materials. That she did not have to buy anything. It is not like that in here, she has to buy the materials that she is going to use in her room, she has to pay for them from her own pocket...

A father suggested that not taking the service context into account reduces the possibility of fulfillment of the laws in Puerto Rico. This is addressed in the following comment:
CI$3$-55-71... That is the problem here, [is that] right now for the issues of children with disabilities there are many laws, a lot of fantasy but they do not get to the reality of what Puerto Rico is. Here there is a lot of discrimination with this... The law has to be fulfilled... Right now how many laws for people with disabilities are there for children like C... and they do not do anything in terms of the rights they have?...

Other parents also suggested that monetary governmental aids to improve services had little practical effect.

One required component in special education programs is the development of Individualized Educational Plans (IEP). Parents faced an IEP process that was diverse. For a mother from Camuy an IEP meeting only included the teacher. The procedure did not provide for parental recommendations:

SE13-74-58...[she] Well, when it is through Public Instruction the [evaluations] get to the teacher's hands. The teacher gives us an appointment and tells us verbally whatever is there... she looks there reads and reads but to say have this, look she does not... [Do you have a meeting to discuss the situation with all the evaluators? she]... With all of them together, no. One of the mothers, who has children in the school, told us that [at the meeting] the school director, the teacher, the superintendent, the doctor, and the parent have to be there. It has never been like that...

Other irregularities in the process of IEP development were also identified. For instance a mother from Bayamón was not provided opportunities of participation. Neither did she participate in a formal discussion about placement or the content of the plan:

FA1-136-169... They are going to review the IEP, which is the program that they make to work with F. A. Now, in May they are supposed to review it and based on the decisions, they are going to tell me if he goes to the school or not... [Do you participate in those decisions?] At no time. They prepared it over there and when the teacher came, she told me: "This is the program for F. A., for next year" and I glanced through it. I asked for copy and they did not give it to me either...
Finally, the parents who were interested in obtaining a copy of their IEP were not provided one:

SE11-113-88...[I do not have a copy of the IEP]. No I saw it at the meeting I was in and I signed it, but I never got one. In fact they asked me, "Don’t you have a copy?"...

Since promises for services were not fulfilled some parents saw the time spent during the year in parent’s legal orientation meetings as being fruitless:

OO4-68-37...It is that look...APNI... gave beautiful [labor] but then, you go to Public Instruction, and even having friends in [Public] Instruction, you do not get anything. Just imagine a person who does not even have a friend in a more personal level...

Conferences offering legal information were rendered useless due to the agencies’ inability or lack of disposition to provide what children needed.

Dissatisfaction with the usefulness of legal protections due to bureaucratic and professional inefficiency reported. When parents claimed they knew their rights they faced negative reactions:

CI3-68-63...Here in Puerto Rico...why do they make laws if they are not fulfilled. And professionals themselves put lots of barriers. A lot of bureaucracy...a lot of philosophy but let us put in practice that philosophy; and when you come and see, there is nothing...

In terms of parental comments about their children’s teachers, there were a few parents whose children were receiving itinerant (home-based) services. One of the mothers whose daughter had severe retardation and degenerative condition had disagreements with the teacher about the outcome of their efforts:

LA10-128-98... The person that comes to give therapy to M. is an older person. She is very good, but I do not think that she is apt to give therapies. Because she tells me: "M. has improved" and I retort: "M. has not have any improvement!" It seems she cannot understand it...
She raised concerns about the quality of the actual intervention:

LA10-119-94...The teacher comes every year but for the past three years she has given her the same therapy. And I have not seen any improvement. I have wanted to drop her out of the program...But the teacher [convinced me not to]...

Issues about personnel accountability were also raised by this mother:

LA10-128-98...Many times she arrives tired. Since she comes from other places where she gives therapies to other children...And sometimes she falls asleep. She has fallen asleep many times. The other girl had bitten her many times...Because she has a condition and takes medications. I tell you, she is not giving her maximum...

The way the home based program ran, suggested it was the responsibility on parents for employee supervision and follow up:

LA10-132-107...The program is good but you have to really know the child’s condition and send the appropriate therapist and give adequate therapy. With my girl they have failed on that. But maybe it is that I have not talked. Because I really have not complained...

Inadequate communication and/or little program accountability to consumers was another complaint. Misunderstandings which could have been prevented with discussions about procedures ensued:

54-56...Since the pay is so little, supposedly then what the teachers do is a lot of games with the students and the therapy itself is 10 to 15 minutes...There is no time to finish and they are very punctual finishing...

Administrative problems were also identified among them losing documents without proper accountability to consumers. For a family from Mayagüez it meant taking several trips to get duplicates from documents. This was also identified as a factor in delaying services:
You have some documents because they require documents (for example C's status); after three months they ask for that document and you swear again and again that you handed that document to them. At the Department [of Education], at school and in other agencies they do the same. Then I have to go back from the first to the last place looking for...

Frequent personnel absences without advance notice of cancellations meant that parents had to make unnecessary trips:

FA1-129-119...With occupational therapy I had the problem that the therapy was by order of arrival and sometimes I would arrive in the morning and had to wait until 11 to receive one therapy. And even though the woman was good, she was absent a lot...and I sometimes would go from Bayamón to the Medical Center to go to therapy and she would not go...

People whose children were placed in center based settings faced similar situations with cancellations due to absences. In center based services, concerns were also raised about staffing patterns. Although Head Start demonstrated a willingness to teach special children, a lack of training on effective approaches to work with autism was noticed and was a source of concern for a mother:

SE11-110-84...Sometimes she screams: "S., don't." She gets desperate but does not have the knowledge to make the child understand her a bit because she does not understand the child neither...I imagine a person with the capacity of inventing all methods that there may be ...

Some actions towards her son were viewed as reflecting a lack in of understanding of the disability:

SE11-109-83...For instance, when the boy wants to leave, she stops him. I think she is treating him as a hyperactive child but the difference of their condition they do not understand. Come now, we have to do a puzzle. She limits herself to those activities with this or the other. I do not think they understand him completely...SE11-55-37...I worry about the type of discipline that is given, the group that is
formed, the type of attention that might be given that is positive for him...

In public schools, there were instances in which communication with parents was strained by difficulties between a teacher and the school administrator:

SE13-76-60  Up to this moment I do not complain about the teacher because the girl has had some improvement. She treats the children right and helps them. But sometimes, she would point things out to the director and the director would put it aside...As for the disagreements with her, she communicates well and she responds well. On the contrary what she tells us is that we parents should come to an agreement...

Some teachers and providers were described as having some inadvertent biases in favor of children with milder disabilities:

CI3-100-102...I have thought too that...when they [teachers] see C., whose disability is mild, they have sort of pushed us more, to do these things, the school, the therapies. They have facilitated things more...It is my inference that maybe if it is a child who has a severe disability they stagnate in some things because they think with that one there is no possibility...

Other parents further claim that even special education teachers lack the skills to deal with children with disabilities in their classrooms. This situation was a source of concern and discussion:

OO4-125-77...I have talked to other parents from public schools who have children with disabilities and they tell me...They place those teachers and they do not investigate them first, they do not evaluate them and they do not try them out for a while. Sometimes teachers who do not know. They are special education teachers that should not be special education teachers...

Parent involvement was seen as crucial in obtaining basic services. In the following excerpt a parent presents a view about the Government as obstructing access to resources:
CI3-61-54...Because if the government itself does not provide the key for you to continue opening doors. If it is not for us the child stagnates because...if you don’t move, the government does not give anything to you neither...

On the other hand, in some instances even when diligently looking for services parents may end up without them:

AU15-104-98...That he gets the services is dependent upon how I move and even if I go places. If they do not have the services I have to wait. It is not that you do not go, it is that you go places and there is nothing...

Again this difficulty in securing needed services is viewed as the result children’s therapies not being enough to cover the needs:

LE2-32-36...If there were more resources the [therapies] could be up to 2 or three times per week... because her condition demands and requires so...

Traditional avenues for parent participation such as school involvement in meetings were hindered for parents who work during the day:

CI3-49-42...And they...make some flamboyant meeting during the week knowing that I am a public employee, that she is a public employee and [we] cannot attend...

This father suggested they schedule some of the meetings during the summer.

Parental feedback about their program was not accepted in programs such as the Center for Neurological Organization:

SE11-45-26...There was a parent meeting every year and it was not so that anyone would expose his/her points against the program or anything. If at any time you exposed them you were censored. They did not consider you. I am talking specifically about the one who directed the school, who was the teacher of the child. My aunt, who [also] was the one who evaluated the children she did not present an opinion. She simply she let the director of the school to impose her rules...
The personnel at that center did not encourage nor accepted suggestions to help in school administrative and economic concerns:

SE11-45-27...Specially a mother and I devoted ourselves to look for alternatives so that the school would not close because we believed in the program...Because all that was there constantly were commiserations. We thought that the Department of Instruction could approve us the same way they do with private schools. But that was frowned on by the school direction...And then there started to be certain antipathy toward us...In fact we carried meetings and they made you believe that they were grateful. But on the other hand they felt intimidated...

Finally the center had to close its school.

In some towns parents had to buy adaptive devices which school programs did not provide and which children needed:

AU15-97-88...The only change I made there was that I brought a different swing than the one they used there, so that he could get on. He also used an urinal that I bought for him...to adapt the toilet...[I understand by this that if adaptations are needed you have to provide them?] yes...

On the other hand, a father perceived that the requirement for supportive participation from parents was excessive, specially for parents who worked:

CI3-59-52...[he] and the school [wants] parents to live in the community of the ESPIBI center and the school. That if there is a problem with the plumbing, parents would fix it without pay. Then, how about all the money they get from United Funds, all the money they get from us?...If they want [maintenance] let them make an activity but not to abuse the parents. Right now, I do not have time. I would have to quit my job to then give all the time to the school...

In an instance personnel from the Central Level of the Department of Education did not consider parental input as important while similar opinions from the school Superintendent were readily accepted:
Then she became inflamed at me. She told the superintendent: "I have never seen a thing like this" but told him: "we are going to solve that of the preschools with that of socialization". It means that she did not accept it coming from me a mother but, on the other hand, there in her conversation with him [the superintendent], whom she considered her equal she accepts that they have a problem in terms of socialization.

Services that aid the family in their daily chores and those which help the child with educational, recreational, daily living activities and education are included in this section as related services. For a mother support services are in contradiction to the of parent’s need for intimacy:

LA10-94-75...I know I need help but I do not have it because I do not want it. Public Instruction sent me a housekeeper but I do not want it...I do not like it because of my privacy. I do not like to have a person so early in the morning [at the house]. I have always said that the day I cannot care for L., I’ll call her but up to now I have managed...I think that a housekeeper does not understand the problems that one has and mostly they send older people...

This woman from Naranjito faced a service system which could not accommodate absences to appointments. Even when this mother needed to respond to medical emergencies of other family members, the agency quickly eliminated her from needed services. She stated:

LE12...When L. was in therapy she had a seizure and was seven days in intensive care. During those days I was absent twice to therapy and they dropped her. I sincerely did not excuse myself. I got to an appointment and was told: "Mother remember that if you are absent three times there are hundreds of children that have to be dropped, if they are absent three times"; even if it is because of medical conditions...

Locating appropriate services also proved to be another a challenge to parents, specially when no observations are allowed:
But that is still in a way that I do not know if it is going to work. Because they are very sporadic, they are once a week and I do not know if that therapist is the appropriate person. Because she sees him and comes out even more disappointed than I am about what the child is. Because maybe he is the only child that she has seen like this. She gives the lesson and does not even invite me to go in. That is one of the things that I do not like. I am considering if I should continue...

Related services offered to this autistic child from Gurabo were also less than what he should have received:

Not very adequate for what the child needs but they must know because they always have their measures. She recommended the speech therapy that they themselves have and in fact I took him to two or three therapies. With a good therapist, very understanding. What led me to quit is that I saw that the therapies were very sporadic and they were not going to take me anywhere...

The same was experienced by the mother of a severely retarded child from Río Piedras. Health services were positively regarded but other children’s related services were not enough:

Health services are much better than educational services in Puerto Rico, for the same population...

As discussed in question one, services that are not covered by Medicaid were not available because Puerto Rico is not covered by the Supplemental Social Security Income provisions. Medication was also lacking in public facilities in rural areas:

Yes, because you go to the Municipal Hospital and after you are there, there are no medicines. Unless it is something simple for a cold; for something more serious they do not have the medicines. Even if visits are free, you have to get the money for the medicines. Another problem that made me stop going is that you have to wait a long time and he [is not still]...

Procedures for appointments did not accommodate families in general and families with children with behavioral involvement in particular:
[for speech]. Then you had to get a turn in a place where there were a lot of people waiting. It was not convenient sacrificing so much for what was accomplished. And there are other children with other disabilities with him; you go with them serene and they wait. Imagine, sometimes you wait an hour or two. I, knowing that, used to go at the last minute. There are people who go early and have to wait more. Knowing the problem, I go later...

When services were offered parents and children faced long waits. Public services being by order of arrival made taking children to appointments difficult:

FA1-44-54...Originally it was a blessing to get to the Medical Center because they really offer very good services but regarding treatment to special children...But in the case of therapies as such, it is by arrival order. You can arrive in the morning, two or three parents arriving at the same time. And then each child takes 45 minutes and I consider that it is unfair for you to wait 45 minutes for each of the people they are going to attend, because they should assign an hour for each appointment.

Efficient models for scheduling appointment was recognized by another mother:

FA1-45-55...In SER they function well in that sense because they give one hour [with appointments] for the therapy. There is no problem with that...

Most appointments, however were not organized to ease parental responsibilities. An illustration of this is stated by this mother:

FA1-40-50...Well, some weeks I practically devote to his appointments. For instance, last week I was in the streets doing different things: the therapies, pediatrician, urologist. There are weeks like that, that I spend practically all week [in that]...

Some parents reported receiving services which were later discontinued:

SI13-73-57...I would like to have more services, more therapists, that services were continuous instead of every such time. They send us to the physician every now and then but the evaluations take a while. Right now she needs to continue in speech therapy while she is seen by the doctors too...
On the other hand recruitment of personnel from the island to the United States also reduced the pool of available service providers:

AU15-98-95...Because Public Instruction does not have much personnel neither. The ones that prepare themselves leave to work in the United States because [here] they are paid little, they do not have the equipment to work the program. They do not have facilities and work displeased...

In terms of other health related services, a mother was forced to look for private services well beyond her economic means because of the unconventional procedures she faced from public providers. A dentist offered to tie her retarded son to a chair in order to work with him:

AU15-66-53...Head Start gave me an appointment with the pediatric dentist. The dentist wanted me to bring a little blanket to wrap him for the next visit. That meant that you have to tie him down. I did not want to. AU 15-68-55...He does not understand what they are doing to him. He is going to panic and when he grows up no one will be able to sit him down. I myself am very afraid of that. Because of the experiences I have been through. The dentists sometimes are such brutes...

She felt forced to look for private services:

Then I went by myself looked for the money and went to Río Piedras to look for a pediatric dentist specialist in children with disabilities. She told me that she had to put him in the operation room so he would not get a trauma by tying him. But it was very costly, over $1,000...

Some private providers lacked related services which parents perceived as necessary. Such was the case of the Center for Neurological Development:

SE11-40-23...At the time he was attending there was no [speech]. Once there was one speech therapist but she was not there anymore. Besides the school where the teacher presented a very rigorous plan according to their philosophy, there was no therapy (besides the physical one). No communication...
Other private facilities offered services but left the evaluations to the Department of Education. This meant parents were caught moving between two providers in order to obtain services:

[For instance] I talked to the social worker of my son’s private school for the orthopedic evaluation and I have not been able to get them through Public Instruction...I have filed all the papers. She tells me evaluations have to be through Public Instruction...

The mother of an autistic child was troubled by the unwillingness to serve her child of professionals responsible for it:

SE11-[Head Start] They gave him one speech therapy during the year because there were problems with the therapists...She had no intention to deal with my child...

Other parents faced reduced communication with providers during meetings. Because of these problems with communication, disagreements in the process could not be directly addressed. Also, feelings of disappointment were expressed about school’s professionals were not going as far as they should in helping these children:

92...But I don’t know, I see all the problems with children that are well. There are many children who do not learn, that need to go to the social worker. The social worker gives them an appointment and that’s it, it goes to sleep and the child remains the same...They do not give him any help...

Some parent organizations were difficult to reach and did not offer timely support:

SE11-105-79...I know about the association for autistic children and adults but I tried to communicate with them in several occasions...If I leave a message they say they are going to call and [they do not do it]...It seems that [it is run] by volunteer parents themselves...I called two or three times and they did not reply...
The manner in which transportation is handled represents a common problem for parents. A lack of transportation represented a problem for families whose attendance to services required it. That was the case for the mother of two severely retarded girls from Naranjito:

LA10-101-78...In terms of M. I always took her to therapies up to 5 years of age. With L. it has been more difficult because of many things: [Lack of transportation], and because of her weight I cannot walk [with her]. With the older one...I carried her. People would say, C. "Do not do it, you are hurting yourself", and I responded: "She is my daughter and I love her and I'll take her where I have to take her until the day I cannot do it anymore"...With L. it has been harder...

She was not able to take the regular public vans because they did not allow the wheelchair:

LA10-81-59...In the public van they do not allow the wheelchairs. That was also the problem. That they did not even allow conventional strollers in the bus. I always went to give L. therapy while they allowed wheelchairs. But afterwards since I could not carry her I stopped going...

By that time her first daughter with disabilities had died. The strain of continuous care and appointment maintenance without transportation had taken a toll on her. She stopped making the effort:

LA10-81-59...Besides that when my daughter died well, I also became a little irresponsible. I stopped going to therapies since she is so chubby and there is no car, it was difficult to take her, very difficult...Now by public transportation you cannot take her because to carry that girl by public transportation it is too difficult. And all those things disappointed me...

Problems with transportation also included those who had been accepted as participants of the transportation "scholarships". An application to obtain transportation assistance did not secure the aid. To get a final word required several
trips for follow up and time. As seen in the next excerpt, these errands required parents to pay their transportation daily and to then face long waits for refunds:

NE12-62-69...The process has been one that requires you to go several times. I applied for the transportation scholarship when the girl entered SER and I received the first year a few months ago...I mean that I had to be there, watchful, talk to the superintendent so that they would process the papers because if I did not they would not process them. I mean that to deal with Public Instruction is another case. To be able to get what you want you have to be there...

It was not unusual to face long waits and to receive less in refunds than what was actually spent:

FA1-61-75...She informed me that they were going to pay for transportation what I paid for it and I understood that they were going to pay what corresponded to my economic expense [and they didn’t]...

A mother provided an example of how procedures to make transportation claims also served to disempower parents:

FA1-61-75...They paid for the 41 days of therapy, during which I took him to Hato Rey. They paid me $82. When I received that check, I went to file a claim. They told I had lost all my rights to claim a larger amount...because I had not done it previously. And I said, "How could I know I had to claim anything since you never told me the amount that you approved?.."

The son of a family from a rural area of San Germán was offered services in another town and was not provided transportation:

LI8-85-45...We sent to the ESPIBI Center but I could not take him there... She does not drive neither. The center’s transportation I think was local for the Mayagüez area...We could not take him...

In that way, lack of services in town and transportation became the final impediments for their child to be served:
LI8-19-10...No I was picked up from the ESPIBI center, but that's too far. There is no one to take him and they do not offer transportation. It is the closest there is...

A general discussion of these findings follows in the next chapter.
CHAPTER V

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

In this chapter a summary of the study, its conclusions and recommendations will be presented. The aim of this section is to integrate the findings of this research. In this way, this section will focus on findings related to the research questions as related to the literature and the implications for policy making. Descriptive research of this sort has proven useful for both theoretical (Lowry, 1983) and practical reasons.

Process of awareness/Stage theory

Some variations were reported by parents in the period in which the disability was discovered. Four families (27%) found out about the disability at or soon after the birth of the child and 11 (73%) faced a slow awareness process. For all parents the disability was a surprising and unexpected event, including those who had some premonitions. The variety of reactions to the birth of their child with disabilities raises questions about the stage theory as Fortier and Wanlass's (1984) have posed them. The stages of impact, denial, grief, focusing outward and closure are not reflected in this sample as orderly and definitely. The stages presented by Blacher (1984) more closely described what was expressed by parents. The following section discusses the data in this study according to these theories.

Review of Fortier and Wanlass' theory. 1. Impact- All families reported some type of initial strong feelings in the form of anxiety, depression, desperation, shock, sorrow or disbelief. The birth of their child with disabilities was a situation for which they reported not to be prepared for.
A crisis took place when the diagnosis of the disability was received. At the beginning, they appeared to have many questions. Shock about their children's birth was related to the lack of previous awareness and personal experience, and/or insufficient information about the disability itself. At this moment parents presented some level of disorganization, withdrawal or tension which differed in length. The period of emotional disorganization could be the result of not having knowledge or resources to deal with the unexpected situation. Specific reactions include anger at medical staff, hostility directed to the other parent, or at the situation.

At the beginning they spent time trying to understand the disability and how to deal with it. There was anger, frustration and loneliness expressed. Their beliefs and personal characteristics, comments from other people or their support and acceptance, seemed to have helped them move ahead from those possibly paralyzing initial periods.

**Time of notification - At birth.** Some parents were officially notified some time after the delivery. These parents expressed depression, desperation, shock, sorrow and disbelief. Some feared the sight of children with disabilities. Again, fear was a reported initial reaction but seeing their children helped a few parents move out of their apprehensions. Nevertheless, difficulties with hospital and medical procedures that affected these initial interactions and understanding of the disability were mentioned during this stage. Although contact with their children served positively, some parents were prevented by the Neonatal Unit's staff from spending
time with their children. Neutral reactions were also expressed by others who from the beginning had a great desire to see and care for their children.

Feelings of fear and apprehension coexisted with a wish at or near the moment of birth to see and deal with their child. Other parents needed a helpful comment to reach to the child. As suggested by Thomas (1982), in this group several families moved towards integration of the child with a disability into the family unit. These families were able to include their child quickly into the family and sometimes into community life. Factors in this quick rethinking period appear to have been related to the husband’s and extended family’s support, religious beliefs, child’s level of disability, and personal characteristics of the caretaking parent and the family. Professional intervention was also mentioned several times.

**Time of notification-Later notification.** For parents whose child’s disabilities were or could not be identified immediately after delivery, parental reactions immediately after the time of identification ranged from feelings of anxiety, depression, guilt, fear, anger, desperation, disbelief, sadness and relief. Those families went through a process of facing and understanding their children’s disabilities which varied in length. There were some who, at the moment of the interview, were not certain of their children’s condition. In this respect, the manifestation of stages seem to be affected by uncertainty with their child’s identification.

Notification by the physician, observations and comparisons with other children and comments from other adults were means to identify the disabilities.
Some spent different lengths of time impatiently looking for a confirmation of a disability they had already discovered, but faced delays in the diagnosis. Also, the moment of awareness of the condition and parental feelings appear to have been related to the length of children's hospitalizations, disability related characteristics and their medical fragility.

All families experienced significant impact once notified about their children's disabilities. Besides the impact stage, they did not seemed to have gone through the stage progression described by Fortier and Wanlass (1984). After the initial impact, some families seemed to be relieved at the confirmation of the disability, others reported feeling sorrowful.

From their descriptions, one can view a movement to of reorganization from the beginning. Some did not express any grieving at all. It seemed that for others, the efforts for caring for their child and the service quests caused a suspension of the expected process. This suspension of their sorrow was noticeable through the conflicting feelings expressed. It could be that expression of feelings were postponed, since they manifested themselves when questioned about certain things. For most families in this study sentiments did not preclude their work with their children.

At the denial stage Fortier and Wanlass's theory suggests that parents refuse to accept their child's disability by looking for another diagnosis, at each other for a cause of the disability, or refuse to see their child as one with special needs. Reactions that could have been perceived as denial were present in this sample. These reactions were given alternative explanations by parents. Instances of looking
for several diagnoses were seen as quests for more definition about the diagnosis. This search for clarity was viewed by parents as being part of a process of understanding and adjusting to the disability and to its meaning for their child and the family. In fact, two families stopped the quest as soon as they felt competent with their ability to care for the child.

There were also illustrations of delayed identification of their child as one with special needs. These delays were perceived by parents as hope. Reframing their children’s disability, and the situation, in a hopeful manner became a means of protecting their family integrity. In one situation, defining their child as an ordinary one helped parents live a normal life. The instances in which denial appeared to be in place were explained by parents as hope for the better, as acceptance of the disability and the work it entailed. The lack of understanding of the terminology or of the implications of the disability was also mentioned.

The grief stage has been described as feelings of "sadness, guilt, and anger" that emerge when there is not possibility for denial of the condition (Fortier and Wanlass, 1984). Occasionally these emotions are mixed with an acceptance of the condition, and with isolation from others. This stage did not appear to be an existing stage for all families with disabilities but, in some instances, as an underlying feeling, mixed with other more hopeful ones. The instance in which a mother reported detachment from their family and events lasting close to a year is the only one that strictly fits this description.
Although some parents expressed ongoing feelings of guilt and sadness, not all did. Other parents appeared to have this grief as an underlying feeling, manifested in different ways. Periods of achieving integration, acceptance or adaptation of the child to family life were also described. Some families that faced delayed diagnosis slowly transitioned into awareness and experienced relief from the diagnosis. Those who felt sadness expressed it as mixed with proudness of the work done.

The focusing outward stage was defined by Fortier and Wanlass (1984) as the one when "adequate coping begins" and at which parents become more receptive to information, and accepting of suggestions. It should be noted that parents in this sample were thrown outward as soon as notification came, in response to the need to attend to the child’s needs. Their work with providers, their acceptance and receptiveness to their suggestions can be inferred from their comments, although they differed in their reports of initial levels of understanding.

Closure or the sense of surviving hardships is at the center of this stage. At the time seen all families seemed to have a routine and organization. There was a sense of what the disability meant in their lives. The child seemed to be included in family life and in some cases to their extended family. Some attempts to integrate them in their communities and to include them in services were reported. It seemed that some level of closure at the preschool level had been achieved. Some were preparing for a transition to elementary school which led to further questions.

Review of Blacher’s theory. Blacher’s more encompassing definitions of stages provides a somewhat more appropriate organization tool that accepts a wider
variety of responses people give. Her theory also allows for the parent’s quest for
definitions and avoids leading the service provider into the expectation of parental
reactions to be in one predictable direction. Nevertheless, there were several points
in which it was not representative of comments provided by parent’s neither. To
follow is a discussion of the data using the framework of these theories.

The stage of initial crisis-includes responses to the birth of their child with
disabilities such as shock, denial and disbelief. In this way parents that looked for a
more definite diagnosis and those who did not accept the child’s condition could fit
into this initial stage.

It should also be considered that the existence of each stage was dependent on
the time the disability became clear. The fact that some parents were not told or did
not become aware of the child’s real situation immediately but gradually, led to
similar feelings of shock, sadness and anxiety. Parents dealt with the situation by
devoting themselves to the care of the child, with depression at the strain of care, fear
of what could happen, and distress at having children with disabilities. Later
confirmation brought in relief, shock or sadness. It further led them to different
processes since some parents already knew aspects involved in caring for their child.

The continuing feelings and responses follows in the continuum. While at the
initial stage parents experienced a time of disorganization, later in this process parents
were more concretely experiencing the disability. As seen in their stories, most
parents felt worse at the beginning. Competence in the care, or resignation, were
factors which helped some families reduce this feeling. Also, perceptions became
more positive by noticing how their children compared to others as they developed. Positive comments included perceptions of their child being something special in their life, their acceptance of conditions leading to a more positive outlook, focusing on the differences but also on the similarities, and comparisons with other children with similar condition in which their child fared positively. Also service providers, with their positive interventions, were helpful. But receiving written information with insufficient explanation only caused fear and confusion in parents.

Some parents expressed feelings of depression related to the intensity of care required by the child. Fate and randomness in the form of fatalism, and extreme identification with the child’s suffering were reported. Although in some instances sadness and a sense of fate and randomness and fatalism was expressed, an underlying suggestion of duty and responsibility permeated their conversations. These feelings of sadness and anger were also present when the caretaking parent knew what it meant to deal with service providers, family members actions and attitudes.

Long term responses of disappointment, anger directed not at the child, but at the other parent, or other family members that did not do what was expected of them as family members, were described. Contacts with other community members with a similar disability led both to positive and negative feelings. Meeting other children with the child’s condition and comparing them to their children’s frequently led to a positive appreciation for the child, and in developing an understanding of what was required to deal with their child’s disabilities and growth.
There were variations in families' reactions that manifested in several ways. These can be grouped as internal variations in that some families expressed contradictory feelings that appeared as acceptance to the child, but concerns or frustration about their responsibility, their children's future, or their quality of life. Furthermore, feelings of depression, pain and loneliness, a sense of ill fate and randomness, fatalism, extreme identification with the child’s suffering, special attachments to their child, detachment at work or in relationships, and physical symptoms such as insomnia were also reported. For a mother of a boy with a severe disability an extreme identification with her child’s suffering caused constant pain and feelings of loneliness. These symptoms could be the result of the severe physical and psychological duty involved in the care of their children.

In general, there were several sources that helped shape perceptions and ideas about the situation. Support from other people made a difference in parental feelings about the disability. Limitations in avenues for personal development were reported. Both acceptance and disapproval were tied to reduced opportunities for personal development by several women. On the other hand, it was found that some parents achieve a great sense of self esteem by fulfilling the disability related work. There were claims of strong identification with the children. In some instances, depression coexisted with acceptance and pride at accomplishing a hard task, sometimes by themselves.

In the families at which children had been integrated to family life in different forms, several sources of conflicting views and feelings between parents existed. At
this time they seemed to have worked out an initial understanding of their family life with this child and incipient definitions about their future were also provided at the time of the interview.

Their expressions about the future for children varied according to their evolving notions and implications of what their child’s disabilities were. They seemed to include consideration of their children’s differences and perceived possibilities. Consistent with Hispanic cultural norms, children were seen as a lifelong responsibility. Some parents of children in the mild to moderate range perceived negligible impact of the disability and had normalized wage earning expectations. In general they were open to the possibilities of new developments and hopeful. Evidences of an evolving notion of the disability entailed their beliefs in their children’s possibilities for growth and an understanding of how to deal with their children.

Parents of severely and profoundly disabled children expressed uncertainties and conflicting feelings. Some stated not thinking about the future as a result of the intricate challenges experienced. Thoughts about the future were also precluded by the confusion about the impact of child’s condition because of its evolving nature. The outcome in these cases was a vague hope for improvement. In others, thoughts of long term dependency on the parents were manifested. Adjustment of parental goals for their children resulted from observations of other children. But when compared with other children with disabilities, most parents reported they could also
find children that were worst than theirs. These comparisons provided a source of comfort and a way for balancing their present and future views about their children.

In the adjustment or acceptance stage reorganization, adjustment, and acceptance is begun. It is noticeable though, that parents describe that some reorganizing starting when they took their children home. Most of them seemed to have moved quickly out of the disorganization and claimed to have been effectively organizing from the moment they found out about the disability. Feelings of sadness did not necessary exist in families that moved quickly into acceptance. Some parents also seemed be propelled into achieving a better understanding of their child’s condition, and others by the need to do something to improve their child’s situation. Pessimistic feelings were also balanced with accomplishments in the work related to their children, a source of pride and comfort.

This movement did not happen in similar timeliness for all families. Some moved out from initial feelings quickly, while for others, it was through the process of dealing with the needs of their children immediately. There was only a mother whose initial depression lasted about a year and who delayed her quest for services. At the time of the interviews none was immobilized even if on occasions they expressed sadness or loneliness. Parents accepted or adjusted, but for some complaints and concerns about several aspects of their lives were raised. It appeared that the child’s entry to school also incited a process of reorganization.

According to Blacher, parents also became involved in advocacy organizations in their quest to improve conditions for their child. There was no indication of their
reaching to advocacy organizations except for the some of the services they might provide. At the time of the interview they expressed some confidence in their ability to handle the situation.

In terms of the stage theory, the variety in reactions does not support the notion of distinct stages since what is described as the stage of adjustment and acceptance is an ongoing process starting at birth. Probably their use as a continuum of descriptive cyclical themes without the stage framework would be more appropriate.

Coping

This study considers coping as the means to deal with the needs of the family system related to their engagement with the child with disability. Primary caretakers used internal and external means of coping. One of them was passive appraisal. This was done through ignoring the situation, avoiding thoughts about it, or, for some parents an inability to think or view their child’s future. Acceptance or resignation to the situation was frequently mentioned by families with children with severe conditions.

A form of reframing for parents came from defining rewards in their successes in fulfilling their children’s needs. For instance, comparing with other children and feeling they were "not as bad". The parents’ personal characteristics in providing care such as perseverance, analytic appraisal abilities, and persuasive power were mentioned as attributes that helped people cope. For a woman her learning derived
from her own personal disability which helped by providing a model from her own experience.

Economic related coping was also reported since most families faced a reduction of income. Services not provided by the public sector had to be paid by families. There was also a redefinition of some women's roles by having her stay at home to care for her children. There were only two families in which both parents remained as wage earners. For them reorganization of member's duties were used as a form of coping (i.e. parents with flexible schedule took care of errands).

The economic challenges faced by families forced several responses. Some mothers generated informal avenues for income such as selling possessions that were useful for the family, and by adjusting their priorities by not providing some essential services due to their inability to pay, (for instance, elimination of necessary medication or appointments), saving for appointment related expenses, asking for donations and requesting free services. These avenues for obtaining additional money were restrained for people with children with behaviors difficult to handle), Instances were also reported in which no additional economic need was experienced due to the lack of appropriate services for the child.

Several individuals experienced professionals and services themselves as a coping mechanism. For instance, coping mechanisms related to professional help were also discussed. For some parents teachers, therapists, counselors and other parents with children with disabilities provided emotional support and helpful information. As for services, there were the sliding fee status obtained from the
school, health and related services, physician’s payment plan and connections, incidental free medical services to pay the medical expenses. Other sources for obtaining services were petitions to family members, social agencies, and selling goods. A continuous quest for official information allowing them to obtain services was reported. Some procured necessary information through other parents.

Religion and spiritual practices seemed to have provided interpretations for unusual events or life in general. Faith also provided possibilities for redefining the disability and their family in a more positive manner and for acceptance and getting on with life. Religion furnished peace of mind and hope or helped them see themselves as with a special mission.

In social terms religion was helpful by providing emotional support, guidance, acceptance of their children and frequent company. It also provided sustenance for isolated families. Religion was not a solution for everyone, though. Some saw it as a way to deviate thoughts from directly dealing with their problems.

External family support mentioned came from several sources such as family, friends, service providers and people in the community. It was particularly mentioned by those having older children with disabilities. It was useful in providing help with the requirements of the disability, comfort and in information gathering.

Researchers are starting to develop an interest in fathers opinions (Upshur, 1991). In the parents in couple relationships, some husbands provided support, mostly in the form of initial encouragement and ongoing emotional and economic backing.
It was suggested that fathers and mothers rely on different coping strategies in adjusting to the stress of having a child with disabilities, or to the process of family development with such a child. Father participation was reduced and sometimes geared to specific aspects of family life (i.e. economic and incidental care of the children). Families in which both parents worked were the exception since they divided their tasks informally or by perceived or ascribed skills.

Some divorced women lacked the father’s support. In three couples the husband did not provide assistance. Families with older typical children received help from them. They also were viewed as having developed a special sensibility towards people with disabilities and an acceptance that provided comfort to the caretaking parent.

A few grandparents provided emotional and babysitting support, while others failed to provide it due to their concerns about their ability to care, their old age, or demands of the disability. Female members of the extended families were mentioned as those who provided direct care and transportation support. Sporadic help and incidental information was provided by parental brothers who lived in the neighborhood specialty during emergencies.

Parent groups represented a form of assistance and support by providing: 1) a source for information from other parents about other disabilities, for opportunities to discuss and clarify positions about children with disabilities with other parents, and resources for the development of special friendships; 2) a basis for rapport, emotional bonding, identification and special understandings resulting from the shared
experience; and 3) a basis for identification of strategies such as of child advocacy
and of encouragement to move forward.

Most parents were positive or neutral about the parent groups but there were
dissenting views perceiving them as a somewhat futile exercise. For several parents
these benefits were not fulfilled when: 1) meetings and conversations with other
parents were limited to superficially sharing; 2) they faced difficulties stemming
from residing in the differing locations which reduced the opportunities for supporting
each other out of the meetings; and 3) they were poorly organized.

While personal amusement is one important need for the psychological well
being of the individual, most primary caretakers faced difficulties in meeting these
needs. Factors affecting personal and family recreation were: 1) the possibility of
assimilating the disabilities to family’s regular routines; 2) the intensity of the child’s
needs; 3) the feeling of responsibility for the child’s well being; 4) having only one
family member responsible for all of the child related work; and 5) the economic
difficulties faced by the family. These factors resulted in modification and/or
elimination of enjoyable activities for most families.

There were families that found special activities to include their children with
disabilities or did so in their regular activities and were satisfied with this. Others
developed extreme modifications to their activities integrate their children. For
instance, the only amusement for parents with children with more severe disabilities
could identify took place in the house with activities such as watching television and
playing with the child, simplified or modified outings.
Most recreational activities were limited as a result of their schedules and disability related responsibilities. As a result, some primary caretakers defined severe difficulties in opportunities for personal amusement and expressed discomfort about this. For divorced mothers, amusement opportunities were very limited or eliminated, and some felt lonesome.

Father support was identified as an important coping mechanism. Institutional treatment of parents did not seem to recognize its importance. In some cases there were reports of little understanding of fathers feelings and misunderstandings by health professionals. No procedures were found to insure that fathers were as informed as well as mothers and that they understood the disability and its implications. Furthermore for most there was no advanced help or counseling provided. These differences could result in differences in the way family members coped with their situation.

External context

This section will look at the extended context in response to question 3 which asks about parental perceptions about external support including perceptions about the extended family and community members.

Parental perceptions about grandparents reactions to the disabilities were for the most part not discussed directly. In some families it seemed like an issue which had never been addressed. Nevertheless, the grandparents actions made visible some of their feelings about the disability.
Grandparents varied in their reactions to the children’s disabilities. Some expressed accepting, neutral, and negative reactions. Some grandparents were supportive from the initial periods. They provided acceptance, emotional support and direct help, such as frequent encounters with their grandchild, and childcare while his parents worked, direct acceptance to the child, and supportive comments that encouraged the family. Other grandparents pushed families and children with disabilities away by demanding from children normal behavior, expecting children to behave like ordinary ones, refusing to spend time with the child, and looking for justification for the disability in the parents.

The intensity and length of care requirements affected family’s and community’s reactions. Previous experiences in asking for help also affected a person’s disposition to request it. If requests were made and refused aid was not seeked in other occasions. Lack of support resulted from the people’s limited orientation or understanding about their difficulties. These reactions also had repercussions in parent’s willingness to find or look for care within and outside the family. This was so even from husbands, grandparents and parents’ siblings from which support was commonly expected, caused conflicts between them, and concern in parents since their expectations of family participation and support remained unfulfilled.

Another consideration was the prolonged status of the requests, which caused a sense of imposing demands on others. There was an implied sense that it was the
mother's responsibility to care for the child. A caretaker valued the support, concern and nurturing expressed by others directly towards her was valued. The main caretaker in one case mentioned isolation and loneliness felt while fulfilling the tasks by herself.

Finally, participation in family events where sources of contradictory reactions. While children were included they were often ignored and some family members rejected them. Also the child's behavioral differences was a source for tension and disapproval. Nevertheless, the exposure was helpful for some typical children to develop relationships with them and for children with disabilities to develop socialization skills.

Going out of the house with children with disabilities meant getting ready to encounter a variety of reactions. Sometimes there were instances of acceptance and integration in regular activities. Acceptance was expressed in many ways. In an instance of discriminatory daycare enrollment standards, a family received emphatic backing from a group of coworkers who seemed otherwise unconcerned.

Stares and comments from people were discussed by several parents. The stares were bestowed with several meanings by parents: they were viewed as positive, indifferent, hostile, curious, and negative. Some parents were victims of the insensitivity of both typical children and adults by their inconsiderate comments and comparisons with normal children. Statements of commiseration were not appreciated since they demanded constant explanations and reduced their hope. Parents also rejected expressions of pity which reduced the child to a disability.
Caretakers also faced subtle affronts and offensive remarks. In some instances, blame for unusual behavior was placed on mothers for conducts related to the condition. In one situation, uneasiness on the part of the public was caused by the unpredictability of a child’s motor coordination related to his disability was mentioned. Parental worries related to people’s reactions appeared to ease as children grew.

Finally, appearance seemed to be a factor determining people’s reactions. While some children received compliments about their appearance, others whose disability was more noticeable and those with unique appearances, faced rude remarks and actions. Community members cringed at the physical appearance of some children. A mother, who recognized the possibility of her child facing this type of stigma, prepared her child for uncomfortable situations.

The way services were delivered were considered as important as their quality. Several aspects of service provision were discussed.

During the initial periods of awareness, the manner in which information was conveyed by the medical staff was as important as being informed. Some physicians took care of the child but did not acknowledge parental needs and concerns. Some informed fathers only, others discussed the news with the mother too. Some were too slow in providing information, or hard to find in order to respond to the family’s initial questions. There were physicians who provided information only if asked, and focused strictly on what they were asked, thus leaving parents in need for information for prolonged periods. Parents mentioned the need for practical information about
services and procedural suggestions to help them deal with their child. That type of information was not provided by these professionals who had initial contacts with them.

Furthermore, some professionals discounted parental perceptions of concerns. This left parents to contend on their own with their doubts and questions. Some parents had to look for other physicians who would provide useful information and referrals. Others were hindered from doing that because of the way services were organized.

Most families stated that being told the truth was hard but greatly appreciated. While veracity was appreciated, the manner in which the "truth" was conveyed was important also. Some excerpts described the harsh, unsensitive manner in which physicians presented the disability, lacking at times information which could facilitate understanding, direction and hope. Consideration and understanding about the families' feelings was requested by respondents.

Undiagnosed disabilities make contacts with physicians necessary over the years and leave parents confused and in more need for information. The search for understanding seemed to be another task placed on parents. Physicians lack of explanations caused unnecessary concerns and confrontations to parents who were left uneasy about the possibility that information be withheld intentionally. The need for physicians to recognize their limitations and allow others to help in the search for a diagnosis was suggested. Second opinions and comments from other doctors were perceived as useful for information and corroboration.
the family. Doctors lost patients because of communication issues. In one instance the use of jargon was a factor that reduced understanding at the moment of notification. The importance of the use of clear, and hopeful language in communicating with families was stated. Also, their attention to and interest in the baby's conditions was also considered important, since physicians who demonstrated concern for children were described positively.

Issues of control in the service relationship and the lack of balance of authority in making health related decisions were problematic. Doctors who were assigned and could not be changed, and in some instances could not care for patients who had been treated by others reduced opportunities for second opinions with unbiased mechanisms for complaints. Another factor which could not be questioned was the frequency of appointments specially those with specialists.

Sources for information came from both parent groups and services providers. Parents served as advocates, providing quick information and support. They sometimes filled the void left by physicians and service providers who did not give the required notification of the possibility for enrollment in services immediately after the disability was identified. Some parents had limited knowledge of service opportunities. The lack of timely information acted as barriers to equal access to services. Institutions with responsibility to provide information were seen as unable or unwilling to do so.

Some physicians did provide practical information about disability management. However, parents faced extensive searches for information and undue
obstacles in obtaining general information about their children’s disability. It should be noticed that after receiving initial orientations parents needed ongoing reiteration and maintenance since they stated a need to clearly understand their children’s disability.

Information needs changed as parental knowledge about the implications of the disability were better understood. Once basic understanding was achieved they needed such as basic recommendations on how to deal with their child and suggestions for obtaining services. This suggests an evolution in information needs that change in nature as their relationship with their child evolves.

There were differences between fathers and mothers in their patterns of participation, which in turn, may lead to differences in their perceptions and levels of information.

Timing and continuity of services was the focus of discussion for most parents in this sample. Although all children were registered in the Department of Education and the initial registration process was an easy short one, this did not mean that they were receiving the services they needed. Parent’s reports pointed to several ways in which services were delayed and sometimes functionally eliminated. The following points characterize their concerns:

1. service providers did not follow-up the process of registration, evaluation and services as they should have. It was dependent on parental follow-up.
2. children were almost four who had never received educational or related services. This coincided with parents' claims of knowing about other children who had to wait until they were of school age or older to be served.

3. lengthy waits that children faced in order to obtain an evaluation, educational and related services.

4. long time to process referrals, which reduced their value.

5. service discontinuity between the time of enrollment and the time the interview took place.

6. delays in payments for transportation.

Further delaying the access to services were:

1. the requirement for parents to do administrative errands that should have been dealt internally.

2. lack of accountability to parents on the part of service staff when professionals or parents were absent. Children lost appointments and faced long waits for reschedules.

3. inconveniences faced at the time of the visits due to the inappropriately long waits for appointments. These inconveniences affected children's willfulness to therapy.

Only one description of a facility that included a timely transition process from the NICU to therapy services, was made. Other instances of timely services had to do with related services in the Pediatric Health Department Center. Being served by a private provider did not eliminate the delays. But some private facilities outside of the metropolitan area, such as the one in Ponce and the one in Juncos, provided the full range of services children needed in a timely basis. As can be inferred this were
not generalized practices but serve as evidence that there are the basic mechanisms to make these efficient procedures common practices. All public service providers: Head Start, the Department of Education, and the Health Department had these problems and contracted services.

Delays were perceived by parents as professional insensitivity by not granting the importance to parents that they deserve. This led to problems of communication. Increasing these problems was the common lost of important documents. Mothers were also left waiting during the summer for confirmation of their children’s educational placement and other related services. This reduced their ability of long term planning. Ignorance about preschool services, insensitivity and abusive behavior toward parents probably made their quest longer and harder. The possibility that children with severe disabilities face rejection in several public programs was also raised.

Most parents claimed that registration in the Department of Education was a simple and quick process. However, what happened after the registration process varied. The opportunities for autonomy and development which the placement offered was an appealing factor in their decision to place. These attractiveness gave parents a reason to struggle to obtain services.

Although the process of obtaining services was slow, a few service providers expedited the process by their administrative dealings. Relief was experienced by parents with severe and unusual conditions from finding a place in which to take their children. Related to the speed of obtaining services were parental requests of specific
educational alternatives such as integrated services and the suggestions they made about service organization.

In terms of parent participation some of the positive issues discussed about parental participation in service programs were 1) parental interaction with staff; 2) meetings shared by parents helped by providing another frame for their experience; and 3) services acceptance of parental input.

Parents also described several manners in which programs failed to provide children and their families with the support and services they felt were necessary. Among them was the lack of services for preschoolers offered by the Department of Education to residents from some rural areas. Procedures that served as dismissals were:

1. Being sent home without a notification of acceptance. Providers placed children on waiting lists for a long time or told them that there was no space available. No opportunities to voice their concerns or to corroborate information they were given were in place. Several problems with accountability were also identified.

2. Placement out of town became a factor that limited children’s participation in services. A lack of consideration for family needs and circumstances occurred when children were recommended services out of town without providing transportation.

3. Stringent admissions requirements left children with certain conditions without service alternatives.
4. Parents whose limited educational and interest levels were perceived as facing more difficulties in obtaining services and more lacking of opportunities than other parents. On the other hand, sometimes even actively involved and well educated parents also ended up without the services.

5. The need identified by several parents to be involved in the quest for services which their children had a right to in order to obtain them. This caused inequality in service access due to differences in parental requests of services.

Some concerns about the organization of programs were identified:

1. Parents faced difficulties with transitions from Health Services to Head Start and/or the Department of Education.

2. Parents were also very critical of lacks of children’s integration with other children. Segregated settings were not the place of choice for parents because of the limited positive modeling. On the other hand, some parents found approaches to academic integration to be limited in programs that only placed children together.

3. Some programs were arranged their parental participation aspect in ways which prevented or did not encourage parental visits. Parental opportunities for learning by observing their children interact with other children were denied to parents.

4. In terms of educational health or related services, for most children they were less than what they should have been.

5. When children started receiving services their lack of continuity and appropriateness made some rescind them. Parents saw themselves forced to look for costly private services because of limitations in the amount of services provided and
the procedures used with special needs (i.e. dentist). Some private providers lacked related services perceived as necessary by parents. Other private facilities offered the services but left their evaluations to the Department of Education. This meant parents were caught moving between two providers in order to obtain full services, sometimes under difficult conditions.

6. Lack of recognition of the needs of single parents when scheduling participatory interventions was reported. Some were required to become involved with their children in strenuous and time consuming exercises for which they did not have support. Failures in results were claimed as resulting from parental inadequacy following up procedures.

7. Differences in expectations and care procedures followed among parents, regular daycare and school staff. These expectations at times contradicted the child’s needs and family plans.

8. Services and medications not covered by Medicaid were denied. It should be noted that Puerto Rico is not covered by the Supplemental Security Income provisions for children with disabilities.

Concerns about personnel actions were described as:

1. Their lack of consideration for the needs and desires of families in which both parents were employed when scheduling services.

2. Appeal procedures were made difficult and tense than they should be. There were also extreme delays in resolving these situations.

3. Commitments to provide services were made and later not fulfilled.
4. Reduced opportunities for children’s integration and for parental visits due to school’s organizational structures.

5. Children with milder disabilities were perceived as being favored by program provision and attention, and limited offerings for children with low incidence and severe conditions.

6. Staff not used to receive feedback from parents, and lacking flexibility to accommodate to parental needs.

7. Reduced communication with providers during meetings and therapy sessions which led to disagreements not being addressed.

Accountability issues were identified as:

1. Parents who wanted to learn by observing their children in usual school setting but who were provided with staged visits instead.

2. The process of development of Individualized Educational Plans was diverse. Sometimes it only included the teacher and was a procedure in which parents’ suggestions were excluded and no discussion of the contents or the placement took place.

3. Services were determined without consideration and sometimes in contradiction to parental desires. Although some programs showed willingness to admit special children, lack of training on effective approaches to work with low incidence disabilities were reported. Other parents further claimed that even some special education teachers lacked the skills to serve children with special needs.
4. There was concern with the quality of actual intervention. Disagreements with the teacher about the content and outcomes of their work were not being addressed to the parents' satisfaction.

5. Personnel's accountability in terms of their ability, their losing important documents and their frequent of absences caused concerns which were not addressed. Some professionals were unwilling to even deal with children to whom they were responsible for. Finally, the responsibility for employee follow up was, in some cases, left to parents. All these situations meant making several trips, reduced quality and delays in services.

7. Accountability on the use of monetary governmental aids to improve services was lacking. Parents faced negative reactions when demanding their rights and their needs were not recognized in some organizations.

8. No assistive technology devises were offered by any agency. This lack of equipment caused many physical and mobility difficulties when going to school and related service appointments. One Head Start requested adaptive devices from parents for use in school.

9. Tied to the centralization of services was the required transportation which was for the most part not provided.

When carriers or transportation "scholarships" were requested the process for application was not self-operating. Parents needed to follow-up, and faced long waits for refunds that did not come in full or at all.
Parents whose children had mobility impairments were not able to take regular public vans because they did not allow wheel chairs or strollers. The extreme difficulties with transportation made some parents stop their efforts.

The following issues related to parental participation were raised:

1. Closing avenues for participation such as involvement in meetings for parents who work in the daytime.

2. Not accepting parental participation in program decision making and fundraising.

3. Forced parental work in programs as a form for participation was rejected as excessive and as the only way that a program allowed parental participation.

The issue that Puerto Rico faces a harsher service reality and a lack of fulfillment of the law is not taken into account by regulating agencies. There seem to be a different yardstick in place by federal agencies to measure the results in Puerto Rico.

These findings direct to the delineation of specific suggestions that follow.

Recommendations

Previous findings (Edgerton, 1979, p. 35) in which the author claim that the major impact of the care of a child with disability falls on the mother seems supported by most families in this study. There were different degrees of acceptance or rejection of this female responsibility with comments ranging from those mothers who claimed complete adherence to the role to those for which those requirements were unacceptable. Divisions of tasks were justified according to presumed couple's
skills. In cases of divorce it was the woman who had all the responsibility. Instances were reported in which the couple shared the responsibilities equally, specially in couples in which both parents were employed. In order to make intervention more appropriate, recognition of the variety of families' organizations and reactions to them is recommended.

The need to include fathers in ongoing interventions and parental groups was established by respondents in this study. For a few fathers, unattended emotional needs added difficulties to already demanding situations. Some mothers also recognized variation in father's responsiveness according to their child's developmental status, which could also have been dealt through orientation.

Father participation represented an important variable in the primary caretaker's circumstances even in instances where the mother was solely responsible for the child's related errands. In families who had a member who stayed at home, fathers were in some way seen as the natural breadwinner. By doing this the mother, in her caretaker role, was more available to attend to the child's needs and all the other tasks required by the family. Reasons for this could have been the gender ascribed roles, the ease by which women seemed to assume the nurturing caring role, and their previous experience with children.

Besides being the breadwinner, the father seemed to have the role as provider of emotional support and of some forms of caretaking. As reported by Allred (1992), and Edgerton (1979) most fathers tended to be less active in the childrearing process of their children with disabilities. When fathers' participation was desired by one
woman it was made difficult by organizations which channeled most of the training and information through the mother. Care of hospitalized children was institutionally regulated to be the mother's responsibility, which caused difficulties for all family members and rejected fathers who wanted to provide care. The hospital policies which require female members of families to be ones providing care for hospitalized children are discriminatory and should be reviewed.

It is apparent from the parent's comments that the expected support from other extended family members necessary to deal with feelings of fatigue and physical strains derived from the care for a child with disability was there, as Delgado (1980) suggested, in the initial moments of crisis. For people in this sample grandparents, aunts, uncles, cousins and other family members were sometimes available to provide help for the initial periods of crisis (if at all). But often they was not there for the ongoing help necessary for the daily needs of the child. This lack of support represented an area of frustration for several families.

The growth of a child with a disability creates a long term, ongoing and serious need. Most of the family support did not remain, possibly because the intense support required and provided by the family in moments of crisis leads them to believe that the need is short term. The reduction or fading of family and community support should be taken into consideration when planning interventions. Interventionists could consider the need for long term assistance, communicate it to extended family and community members, while working to develop alternatives which recognize the diminishing effect of time.
The child's appearance and behavior, and the extent of care requirements related to the disability seemed to affect family support. For children whose appearance did not show a disability some grandparents blamed the mother's childrearing. For some children with severe disabilities, regular supports such as grandparents shied away from direct care. These situations could possibly be eased by the inclusion of fathers, grandparents, extended family members and friends into training about the disability.

In this sample problems with support systems were not addressed at their utmost by service providers. In other instances extended family members appeared to be willing to provide help but were not linked to the family's needs. No formal intervention helped this happen. Identification of the natural support system and systematic structuring of that participation may facilitate their participation.

By the accounts it seemed that service activities were focused on mothers. The need to include other family members in service activities in order to build support for parents is imperative. The inclusion of other members of the family in training sessions could enhance family support by allowing other family members to realize how they can help. This awareness of the necessary care might also lead to more participation on the part of fathers. Teaching family and friends about the disabilities and establishing their roles as support agents for the child is recommended as a means to sustain the care and support over the child's life.

This unmet need for support also contradicts the perception that Hispanic extended families spontaneously accept and integrate the child with disability as their
responsibility. Although this study cannot disregard the notion that the extended Puerto Rican family is caring, it raises questions about the immediate acceptance and integration belief. Parents reported reduced extended family help caused by fear, mistrust and a lack of understanding about the disability. This lack of support affected their life in many profound ways.

It is important not to stereotype Puerto Rican families as being in less distress or as being able to cope differently on their discovery of their child’s disability. Comments such as that of Seligman and Darling (1989) claim that caring "and acceptance of the disabled child may be more common in these groups than the shock, disbelief, guilt and depression that have been attributed to mainstream parents by many writers" (p. 188) should be taken with caution. Parental statements should be used to accept their experiences in their uniqueness and not to further stereotyping.

In the case of the families in this study the status of single parent headed families did not seem to have a bearing in family income. Both women who were heads of family received enough income to make ends meet either by working or through child support. In some instances, this income was more than that of couples in which husband worked while the wife took care of the children and the household. Thus the assumption that single headed household have a lower income or experience poverty cannot be supported by this sample. It nevertheless, affected social and recreational opportunities.
In terms of the service component, considering the activities essential to the fulfillment of the law described by Dunlap (1989, p. 10), specific changes in eight areas related to the Department’s administrative functions are necessary:

1. Public awareness and referral- The awareness goal of ensuring "that persons seeking a particular service are advised of the appropriate agencies that deliver this service, and that referrals are followed up at least until the service is initiated" (p.11), was not fulfilled. Specifically, the responsibility of providing information to parents was not rendered or done in a limited manner. Parents seemed to depend on using a "lay referral structure" (Darling, 1989), an informal system of support or advice about services. Dependence on the informal structure leads to an unequal distribution of services. Although the informal structure is available as a useful tool, it should not be used to justify a reduction in the service provider’s responsibility.

2. The need for management and coordination- Many parents had to go through great difficulties to coordinate services. This coordination was made more difficult by administrative inadequacy. Some of the difficulties families face in access to services might be eased by having an internal structure in which providers effectively coordinate within their service network. Interagency collaboration would ease a significant load which is presently carried by parents.

3. Children in this sample face a need for improvement on the availability of educational and related service components. These services must become accessible in a timely manner. Some public services, some Head Starts and some private organizations were described as effective but they were limited in capacity. Also, the
fact that not everyone knew about them raises a problem of equal distribution and delivery. This problem of dissemination of resources results in organizations and services which could be available but to be rendered nonexistent, as a result of parental lack of knowledge about them. Differences were also apparent in the service providers' willingness to serve children with more severe disabilities.

The requirement for unnecessary work from parents was mentioned, which could be solved with the increase in case management. Limitations within service components were commented by most families and were acute in geographic areas far from the metropolitan area of San Juan. Differences in program availability and quality in rural settings were documented. However, full programs were in place in some rural areas and while parents seemed to be content with their quality they were not satisfied with their quantity and scope. In other words, what they received was good but they were lacking related services, or were in need of more frequent services. Also those same parents who expressed positive regard about the services received, found that services for other children should be improved.

The fact that free services were only provided on a limited basis forced some families to cover their children's needs with private services. Because these services were expensive, families with very limited income, or those out of the Metropolitan area found it impossible to purchase educational or related services. This meant that, because of service or income limitations their children would either receive less services than they needed or no service altogether. Regardless of income, there were services that did not exist or existed in such limited extent that they could not be
bought. The family who earned the most in this sample saw their income substantially reduced because of traveling from Vieques to their monthly appointments in the big island. A few rural areas were spared of this expense since they had an organized private service provider. This state of affairs goes contrary to regulations which state:

...free and appropriate education means special education and related services that-
(a) Are provided at public expense under public supervision and direction and without charge.
(d) Are provided in conformity with an IEP that meets the requirements of §§300.340-300.350. (Federal Register, 1992, §300.8 Free appropriate public education, p.44802).

Also increasing opportunities for children's integration with typical children was viewed as necessary.

4. Program flexibility-While some private programs and some Head Starts were appreciated for their flexible approaches, there were problems with the overall flexibility of programs. Program availability differed in resources for different conditions, for family support and by geographic location. Programs should be structured so that all children are served.

This discussion gives support to the view that if the needed arrangements for services were in place, geographically accessible and in adequate quantity, then obtaining services would not be contingent to parental abilities or assertiveness as parents seemed to imply. It further leads the view that local and federal enforcement agencies, which are responsible for insuring of the fulfillment of special education regulations should take a more active role in monitoring and enforcing the appropriate
implementation of those programs. More specifically, monitoring procedures to insure follow up in the development of educational plans should also be made. These findings also defy providers to appreciate the diverse situations parents face, to include systematic parental evaluations in their monitoring procedures, and to modify delivery practices to support all families.

5. Transportation is included in those services which allow for the benefits of special education to be accrued. The organization of transportation services should be reviewed since problems with transportation services were consistently mentioned. Service programs relied on families for transportation. The fact that some families did not have a car available for school errands affected children’s attendance to related service appointments and to school. The procedures for transportation "scholarships" lacked standard strategies for application, for notification of results and, in their timeliness for payment when they were granted. The cost and the lack of accessibility to regular transportation was also reported.

Programs could insure participation and continuity of services by providing transportation services. The "scholarship" procedure already described does little to solve the immediate economic or practical need related to transportation. Since scholarships are granted at the end of the year, the parents’ daily need for transportation money is not solved. Second, scholarships for public transportation users should cover more than only the child’s fare since parents have to escort their children. Some of these issues would be solved if school based transportation was offered.
Also a recognition and provision for the economic needs placed on these families as a resulting from the service provision conditions is imperative.

6. Information- The use of ongoing information about the child’s disability to integrate different family members is established. Some reports about instructional activities were done at the time or near the time of birth which faded over time. Activities were not ongoing nor did they change with growing child’s needs. Informational activities appeared to be geared to mothers and their children without efforts to integrate fathers. There was no instance in which fathers were required or recommended to attend to counseling, parent groups or meetings with social worker. However, there were reports of father’s needs to do so, and some fathers went out of their own initiative.

Another hinderance to information was found in learning from observation on therapy and education session, even for who had to accompany their children and were willing to do so. Opening avenues for parental observation and learning were requested by parents and recommended by best preschool practices (Zeldin, 1989, p. 21).

There is a need to address issues of professional and service demeanor with parents. Two important issues about professional demeanor are worthy of attention. Some physicians represented a lack of concern about parental needs for information. Hence, information about the impact of children’s disability was not appropriately discussed with parents. Also, professional feedback to parents about their performance in caring for their children was handled by telling some that they were
good parents and providing privileges based on those subjective observations. These evaluations should not be the criteria for service provisions since many parents do not meet that subjective standard would be denied access.

In that respect, guidance and training to professionals could include the consumer centered approach to service delivery. These could include using techniques of perspective taking, through taking the role of parents they serve; viewing the need for information as ongoing there need to be suggested and corroborated regularly; providing means for parental voicing of their needs and to fulfill them.

In addition patterns of service delivery must be observed and resources increased where demand exceeds service availability. This fundamental axiom to service delivery is crucial in an overwhelmed system which must also accommodate the extended family, friends and significant others.

8. Legal-Serious consideration should be given to parental complaints about governmental opportunities and about children's rights that are not fulfilled. Some parents believed that the effects in their lives of legal gains of people with disabilities are negligible. Parents recognized the gaps between what was offered and what was actually received. Although the majority of parents indicated they had received information about the legal rights of children with disabilities, their responses reflected skepticism about their impact on their lives.

The Individualized Educational Plan, an important legal document, is only an important aspect in the determination of appropriate services. There were several
instances in which the actual process differed from what was intended in the law. Families lacked participation in its preparation, were denied opportunities to see the document and reported problems with administrative procedures. Acceptance of parental participation in its development also varied.

In this sample, parents repeatedly mentioned their perception that only assertive families achieved desired services. They also reported that many people had given up. Closer examination of parental experiences revealed families within the sample who lacked services and who had also tried everything they knew in order to access necessary services. While it is important for parents to take charge, define, and shape their circumstances, the needs of children whose parents who are not willing or able should be accommodated. It must be insured that their children will obtain equal of opportunity of education regardless of their parent's assertiveness style or willingness to participate. Affirmative efforts must be made to address the inequality of access in service provision present in this sample.

Assertiveness training to parents geared at situations they face should be developed. This training should include ongoing support to build their strength and increase their competence.

Opportunities for a timely appeals process were also denied to some families. For instance, although appeals halt the placement process there were respondents who had gone through administrative procedures lasting more than a year without a resolution. In addition, some administrators created an intimidating environment for parents by maintaining a confrontational professional attitude in meetings.
Confidentiality in the appeals process was not insured and the school official’s judgmental actions appear to blame parents who were following up on their children’s rights. These conditions might hinder parental willingness to advocate for their children or their use of the mechanisms provided by the law. This state of affairs established the need for evaluations of compliance of the established process of Individualized Educational Plan Development and the mood and timeliness of administrative procedures. The need to create and evaluate procedures that ease the appeal process for parents was established.

Descriptions by Quintero (1989) characterize the Puerto Rican school system as resistant to change. State and federal monitoring agencies responsible for enforcing the laws and regulations should take a more active role in fulfilling their monitoring functions to insure that change takes place. Their leniency has placed the responsibility for necessary transformations on parents or teachers, who have not been allowed to be instrumental in the policy changes process but fully experience their consequences.

Data also suggested the need for a plan to address the family’s ample needs. Among the needs discussed were those related to childcare, parent group organizations, and recreation.

Although parental reports support the notion that childcare is viewed as a mother’s responsibility, the importance of care outside the home for the improvement of children with disabilities is acknowledged by parents. Still parents with children with severe conditions faced limited childcare options. Training to child care
providers should be prepare them to care for children with disabilities and to help in their integration into the mainstream. Supportive follow up procedures should be provided to enable appropriate integration in regular childcare and home care providers.

Self help support groups should be made more generally available and should encourage informal support outside the meetings. Even parents with children placed in integrated settings expressed a desire to interact with other parents with children with disabilities. These groups could provide parents with support and pertinent information on effective ways to deal with their children. Information applicable to children with disabilities could be integrated into full school meetings, too.

Family enrichment according to Bailey, Winton, Rouse, & Turnbull (1990) includes activities leading to improvement of the quality of family life. However, many families maintain a schedule centered around the needs of their children and missing opportunities for amusement as couple and as a family. Several parents discussed limitations posed by care requirements in their opportunities for activities as a family, as couples or as individuals.

The lack of appropriate support for caregiving affected their amusement opportunities. For some families there was little help from others while others it saw no existing alternative. Single mothers faced difficulties balancing their children’s needs and their own personal life. Entertainment was very limited for these young single mothers. The recognition of the need to develop options to enable the need
for caretaker recreation was expressed but the time or the conditions to obtain it was non existent.

People in this sample sometimes had the help of grandparents, aunts, uncles, cousins and other family members available initial periods of crisis and to provide economic and childcare. These parents felt the need for ongoing help necessary for the long term family and child’s needs.

Likely sources of support are often apprehensive and unaware of their capacity to help. For some children regular supports such as grandparents shied away from direct care due to social stigma, lack of information and the extent of care requirements. Other means for the development of care and support are necessary for some of these families.

Also, avenues for relaxation or activities of personal choice are necessary. Demonstration projects that establish volunteer programs to deal with issues of parental support and social isolation of families and children should be developed and studied (Cooley, Singer, and Irvin, 1989). One such model suggests the development of informal relationships between college student volunteers and children with developmental disabilities. Besides the development of activities for leisure for these children, caretaker needs opportunities for time off. This research was promising in that it provided a low cost alternative in which students learned in a supervised environment. Alternatives such as this, could be of applicable to underfunded areas, in Puerto Rico, where money for respite care is limited. Additional efforts should aim at obtaining further sources of funding.
Future research

Community based alternatives that explore innovative modes for service and support delivery should be studied as efforts to respond to the needs of underserved populations such as those in some rural locations and with children with severe disabilities.

Research on effective sensitivity training for professionals about issues faced by parents with disabilities is needed.

Pilot programs to enlarge support systems need to be developed.

A survey of coping mechanisms could be developed. This listing serve as basis for service professional discussion with parents and to develop other information gathering tools.

Given the family centered focus of the newer amendments to the law, easy procedures must be developed to include parental concerns. Provisions for proper implementation of these concerns must also be developed.

There is a need to develop models of systems of evaluation and accountability of services related to IEP procedures, service provision, and professional and administrative responsibility towards parents that include parental views.

Culturally and contextually appropriate evaluation surveys need to be developed and implemented and means must be developed that ensure that recommendations are followed into practice.

Future research focusing on father’s views is recommended.
Limitations of this study

It should be noted that this study focused only on the initial stages of a child's disability. Other researchers should pursue questions related to lifelong reactions and feelings about the impact of the disability in their life as a family.

By virtue of this study's selection of the principal caretakers as respondents, fathers were given only marginal attention. Nevertheless, some attention resulted from their willingness to participate. This research follows others that attempt to accept or include fathers in the interview process. Recognition to the possibility that different information could have been gathered due if both spouses were requested to participate.

The data presented here is characteristic of the sample and is insufficient to generalize to any other population. This study was based on a small sample size and all the subjects in this sample were white Puerto Ricans. Thus these results are not generalizable to other families with special needs. Also the great length and variety of themes covered affected the depth of information on the specific topics. However, because of its comprehensiveness, this study provides ample descriptions and trends to be studied further.
I would like to gather information about the situations faced by your family and how you and your family feel about the services that your son or daughter has received or is currently receiving, if any.

**General information about the family**

1. Town of residency ________
   1-78 (see coding manual)

2. Type of community
   1. rural
   2. urban

3. How long have you lived in this community?
   1. less than a year
   2. 2-3 years
   3. 4-6 years
   4. more than 7 years

4. Are you ...
   1. single 2. married 3. cohabiting
   4. widowed 5. divorced 6. separated

5. How old are you?

6. How old is your partner (if you have one)?

7. How many grades has you completed in school?
   0. none
   1. 1-6 grades
   2. 7-9 grades
   3. 10-12 grades
   4. 13 grades or more

8. How many grades has your partner completed?
   0. none
   1. 1-6 grades
   2. 7-9 grades
3. 10-12 grades  
4. 13 grades or more  

9. Number of children  
   Write the number from 1 to 10  

10. How many of them have disabilities?  

11. Type of disability  

12. Order of the children with disability  
   1. first  
   2. second  
   3. third  
   4. fourth......  
   10. combinations (first and third, etc...)  

13. Degree of disability  
   1. mild  
   2. moderate  
   3. severe  

14. What was your experience when your child was born?  
   What happened? What were you told?  

15. When did you find out that your child had a disability? How?  

16. What made you suspect that your child had a disability?  

17. What recommendations were you given when you learned about the disability?  

18. What kind of help did you receive at the time?  

19. How do you feel about having a child with a disability?  

20. How do you think your partner/husband feels?
21. Have you received any information about the rights of your disabled child (state and federal laws)?
   1. yes 2. no

22. From whom have you received that information?

23. Has this information helped you?
   1. yes 2. no

24. How do you cope with family challenges? Define the challenges.

25. Do you receive information about your child’s disability?

26. What type of information?

27. From whom?

28. Do you know any other parents with children with disabilities?

29. How did you meet?

30. How frequently do you see each other?

Socio economic status

31. Do you have gainful employment?
   1. yes 2. no

32. What do you do?

33. Type of schedule
   1. part time
      1. days
      2. nights
   2. full time
      1. days
      2. nights

34. Are you in need of childcare?
   1. yes 2. no
35. Is there any other adult in your home that is gainfully employed?

36. How is he/she related to you?
   1. spouse or partner
   2. son/daughter
   3. parent
   4. other _______________________

37. What does he/she do for a living?_____________

38. What is your monthly family income?
   (Include all members that contribute)
   0. less than $2,000
   1. $2,000-$6,000
   2. $6,000-$10,000
   3. $10,000-$14,000
   4. over $14,000

39. Is this income enough to cover your family’s needs?
   1. yes 2. no

40. What effect does your income have on you and your child?

Support network/familiar

41. How many other adult members are there in your household?
   1. one 2. two 3. three 4. four....

42. How does each member of your immediate family contribute to the care of your child with a disability?

43. Is there any other family member who helps?
   1. yes 2. no

44. How does he/she help?

45. Extended family that lives in the immediate area (state kinship or names)
46. What kind of help have you received from them?

47. Difficulties in identifying family resources.

Support system/community

48. What reasons have led you to live here?

49. How satisfied do you feel about living here in terms of the needs your child with special needs?

50. Do you need help?
    1. yes 2. no

51. Are you used to asking for help?
    1. yes 2. no

52. Is there any neighbor or friend who helps?
    1. yes 2. no

53. How frequently?____________________

54. What does he/she do to help?

55. Difficulties faced in the identification of resources for the support network.

Services

56. Which organizations do you know?
    -for children with disabilities
    -for their parents

57. Do you participate in them?
    1. yes 2. no

58. What do you do?

59. Did you receive any information about early intervention services for preschool children?
    1. yes 2. no

60. Does your child attend school?
    1. yes 2. no
61. Are you satisfied with this program?
   1. yes 2. no

62. Why?

63. What aspects did you consider in your decision to enroll your child in school?

64. Are you well acquainted with the people who work with your child?

65. Do you attend school meetings to discuss your child’s progress?

66. How do you view your child’s teacher?

67. Are you able to talk openly with him/her?

68. How many times do you visit the program?

69. Do you feel you can disagree with decisions made by the staff?
   1. yes 2. no

70. Give examples.

71. Do they consider your schedule and needs in planning events?

72. Do they ask you about your knowledge of your child’s condition? Do they consult you when planning the services?

73. How did you learn about this program?

74. What is your opinion about the program?

75. Who pays for the teaching and related services?

76. How frequently are they received?
77. Which other activities would help you to cope with your situation?
APPENDIX B
WRITTEN CONSENT FORM
Families of preschool children with special needs in Puerto Rico

To: ____________________________
Parent of: _______________________

My name is Carmen D. Rivera-Bermúdez. I am a student at the University of Massachusetts in the Special Education Program. At this point I am in the process of doing the research for my doctoral dissertation. The dissertation topic will be the study of perceptions of Puerto Rican families of preschool children with special needs concerning services and their life situations.

Your name was suggested as a person with a family that fits the description of families in this study. As part of this research, I will be interviewing the primary caretaking person about his/her relations with and care of the child with special needs, the experience with service providers, with the family and the community. Upon your agreement to participate in this study, you will be asked to take part in an interview at your convenience. A review meeting will be subsequently scheduled to answer questions about said interview.

In addition to this, it might become necessary to visit the center attended by your child in order to observe the services provided. My role in this setting will be limited to that of an observer. As such, I may ask questions that you will have an opportunity to approve beforehand. From your child’s service setting, I will get some information to clarify any doubts I might have about the services provided to your child.

I will personally transcribe each interview session. Only four other persons will have access to your information. These will be people who work in the special education field or parents who also have children with some type of disability. These consultants will have access to your data only after the identifying information has been removed. The data will be grouped by topic and categories and used for my doctoral dissertation. Because of the importance of the data generated, it might also be used in presentations, workshops and professional publications. The questionnaire requires your personal information because its use is important in the initial stages of data gathering, since it helps in identifying families who require follow-up after the initial interview.

Although your participation is important for the success of the study, you must understand that you are under no obligation to take part in it. This researcher is in no way related to the institution that provides your family with funding or services. The
services you receive will not be affected by your participation in this study and, even after agreeing to it, you are free to withdraw.

In order to participate in this study I need your written consent. Your signature in this form means that you are willing to participate in the study under the conditions established in this document. It also means that your participation will be entirely voluntary and gratuitous.

If you have any questions call me at 751-3505. Thank you for your cooperation and interest.

Carmen D. Rivera-Bermúdez

Parental consent:

I, ____________________________, agree to participate in this study. I am aware of and accept the conditions set forth in this document.

___________________________________________________________
Signature of parent

___________________________________________________________
date
APPENDIX C
CODING CATEGORIES

Internal Context
IC: CHARACTERISTICS: Demographics
IC: CLIMATE:
IC: NORMS AND RULES
IC: FAMILY ROLES
IC: FAMILY ACTIVITIES
IC: CHILD EFFECT
IC: COPING

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External Context
EC: GEOGRAPHIC
EC: SERVICES
EC: SERVICES/CHARACTERISTICS
A: AVAILABILITY LOCATION
EC:SERV/CH/AV/LO
B: WAITING PERIODS
C: QUALITY & APPROPRIATENESS
EC:SERV/CH/QUAL
& APPR
D: INFORMATION PROVIDED
EC:SERV/CH/INFO
EC: EXTENDED FAMILY
EC: EXTENDED FAMILY REACTIONS
EC:EXTFAM.REAC
EC: COMMUNITY MEMBERS & FRIENDS
EC: COMMUNITY MEMBERS & FRIENDS REACTIONS
EC:COMMEM.REAC

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DYNAMICS AND CHANGES
D&C: EVENT CHRONOLOGY
D&C: INITIAL REACTION
D&C: CRITICAL EVENT
D&C: TRANSITION

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Internal-external Assistance
ASSI: SOURCE
ASSI: LOCATION
ASSI: TYPE
ASSI: EFFECT
ASSI: ASSESSMENT BY RECIPIENTS
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