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ABSTRACT

This report discusses the findings of a study that examined the views of 15 Puerto Rican families of young children with special needs. Information about the beliefs, attitudes, and personal experiences held by these families was collected using an informal, open-ended interview format. Redefinition was a form of internal appraisal focused management used by the families to help them deal with their situation. Resignation was the most frequently mentioned type of redefinition used by the parents of children with severe disabilities. Reframing was also used by some parents by comparing their children to other children with more severe difficulties or attempts to focus on similarities to other more typical children. Religion provided possibilities for redefining the disability in a more positive manner. In addition to internal resources used for coping, there also were some coping mechanisms related to external sources, including relying on family support and parent support groups. Findings relating to the economic management of the disability are discussed, including the need for mothers to stay at home to care for their children with a disability. Fathers were less active in the child-rearing process of their children with a disability. Recommendations for considerations when planning interventions are provided. (Contains 10 references.) (CR)

The culturally unique management strategies of families of young children with special needs in Puerto Rico

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Introduction

Early childhood special education practices in Puerto Rico have undergone major changes that relate to modifications of the laws in the United States (for instance, Part H in 102-119 for Early Intervention, 101-476-the Individuals with Disabilities Educational Act and L. P. 100-407-the Assistive Technology Act). Based on the notion of the central importance of the family in the education of young children, these changes encourage research on family background issues and socio-cultural experiences (Gallagher, Trohanis & Clifford, 1989).

Nevertheless, few mainland researchers consider the perceptions of Puerto Rican parents as a basis for creating public policy and direct service practices (Waggonner, 1984). As a population in need of services, it is necessary to understand the experiences, characteristics and perceptions of Puerto Rican families in order to achieve a comprehensive implementation of the laws and to improve the services for this population. 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 culturally specific situations should be conducted.

In order to understand diversity within the special education field it is necessary to establish the applicability of the typical forms of research findings to minority populations. The statistical lumping of people of different Spanish speaking backgrounds under the labels "minorities" and "Hispanics" as a unified group is viewed as a limitation in this research. 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 (Meissels, Harbin, Modiagliani & Olson, 1988). However, limited consideration of this suggestion for Puerto Ricans is reflected in the literature.

This research examined the views of Puerto Rican families about management strategies. This article is a portion of a larger research effort relative to families living in Puerto Rico.

Methodology

This study was conducted using naturalistic methodology (Guba & Lincoln, 1985 and 1988). Consistent with the naturalistic approach, data was not gathered to support or refute a specific hypothesis. This research aimed to develop in depth descriptions of various topics related to specific management strategies adopted by families to deal with their situations.

To collect data a questionnaire consistent with the family systems and the ecology of human development theories was selected. Information about the beliefs, attitudes and personal experiences held by families of young children with disabilities in Puerto Rico data was collected using an informal, open-ended interview format. The questionnaire that was used for this study was developed following a review of the literature on the experiences of families with children with special needs from the general population in the United States (Turnbull & Turnbull, 1986, pp. 20-21).

After the development of the initial questionnaire, it was discussed with and critiqued by other researchers and service providers to establish its validity. The final questionnaire had 77 items divided into five areas. These areas were inquiries about family characteristics, their history, experiences, extended family and community networks and services.

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 (See table 1). While sample size appears small, other factors were more critical. About this Bronfrenbrenner states:

> ... 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 contrasts are represented systematically rather than left to chance...(1979, p. 39).

The sample identified is a non-probabilistic non-random sample. A sample of maximum variation was intentionally chosen with the help of a parent organization based in Río Piedras, Puerto Rico. The selection was based on key characteristics

Table 1

Selected Family Characteristics

ID #	marital status	employment status	children in dwelling	children with disabilities
FA1	married	salesman♂ housewife♀ (NW)	1	1
LE2	married	Realtor♂ Gov. planner♀	1	1
CI3	married	Legislator clerk ♂ Teacher♀	2	1
OO4	consensual marriage	Paint/construct♂ housewife♀(NW)	4	1
SU5	married	hamburger stand♂ housewife (NW)	3	2
GA6	married	ice cream sales♂ student/housewife♀(NW)	2	2
AE7	married	water co. worker♂ clerk♀	1	1
LI8	married	carpenter♂ housewife♀ (NW)	3	1
EO9	divorced	rehab. counselor♀	1	1
LA10	married	municipal brigade worker♂ housewife♀ (NW)	4	2
SE11	divorced	housewife♀ (NW)	3	1
NE12	married	computer programmer♂ housewife♀ (NW)	1	1
SI13	consensual marriage	disabled worker♂ housewife♀ (NW)	3	2
MO14	married	production comptroller♂ housewife♀ (NW)	2	1
AU15	married	construction♂ housewife♀ (NW)	3	1

identified from previous research such as: demographics; child's disability; geographic; and their social and service characteristics. 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 would allow.

Data Collection and Analysis

The interview process spanned from March 18, 1992 to November 15, 1992, an eight-month period. The interviews were at the subject's home, and were tape-recorded and transcribed. These transcripts were read, summarized and coded using previously defined and newly developed categories that could yield answers to the research questions in the study. Unique salient themes were included too.

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 one coder was used. This means that the information gathered from all the sources was analyzed at two different periods, using the categories and then looking for commonalities on the categorization. In order to counteract any bias, audits or triangulation-discussion with Puerto Rican experts identified categories before their acceptance to ensure their appropriateness were made at different points of the analysis of the data.

Education in Puerto Rico

In order to understand the context and experiences of Puerto Rican people, descriptions of the Department of Education of Puerto Rico (DEPR) are pertinent 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).

Quintero (1989) states that the administration is homogeneous and centralized. System wide, there is the impression that educational programs in Puerto Rico are not very susceptible to change (Quintero, 1989). Also, policies and strategies are frequently created without regard to consumers and lack a mechanism allowing consumers to be instrumental in policy changes (similar to those described by Mosley (1988) for health systems in developing countries). Finally, they foster hierarchical employee relations that make it difficult for workers (in this case teachers) to assume an advocacy role. The issues hereby described affect full implementation of the special education law.

Furthermore, in Puerto Rico, there appears to be a wide gap between what is mandated by law and what is implemented. Several ways in which the educational system's procedures slow and sometimes halt the process of serving children have been documented. Among these, are the long delays in medical and evaluation assistance reported by Zapata-Vega (1989, p. 3-4 and the Office for

Special Education Programs, 1991). Waiting periods for services of more than two years are also usual. Some parents, who have experienced longer periods of waiting, have given up and kept their children at home (Zapata-Vega, 1989, p. 56; and Morales-Rodríguez, 1988). There appears to be inconsistent attempts to make services appropriate for all children on the island. This is the service context from which the children in the sample received services. Some of their management strategies might reflect a reaction to the form of service delivery derived from this system.

Management strategies

This article reports on modes of adaptation which were discussed in the interviews. Management is viewed as similar to coping, personal arrangements developed by primary caretakers to handle, solve or ease their situation, and involves both internal and external strategies (Turnbull & Turnbull, 1986, p. 304). Also used to shape this presentation were Miles and Carter's (1985) three forms of organization categories. These are appraisal-focused management, problem-focused management and emotion focused management. The ones discussed by parents in this sample will follow.

FINDINGS

Internal management. This section presents only the strategies that relate to internal management. This variant has been defined by Turnbull & Turnbull (1986, pp. 304-305) as actions or beliefs that help reduce the stressfulness of an event or the achievement of a resolution.

Appraisal focused management involves "attempts to understand and make meaning of the situation" (Meyer and Bailey, 1993; p. 196). Redefinition was a form of appraisal which was used to help families deal with their situation. This has been defined 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).

Resignation was the most frequently mentioned type of redefinition used by parents of children with severe disabilities. This resignation sometimes took the form of: He was made by God and God cannot make something wrong, thus making the situation more manageable. For two mothers in this sample this led to a complete devotion to their children with disabilities.

Another example of redefinition was the way in which families made the disability more acceptable by reframing. Reframing was described by some parents in their focusing on the positive by comparing with other children when they felt that theirs were "not as bad as the others" or attempts to focus on similarities to other more typical children. It did not appear to imply a denial of the disability but an attempt to keep in mind positive aspects of their children. Another way of handling their situations was downplaying its seriousness. For a family in Juncos, not focusing on their child's disability allowed them to lead a more normalized life:

> ...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... For me, he does not have any disability...

Similarly, looking and 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 has. She used this special sensibility to help advance his understanding and acceptance of his own disability:

> ...But...I do not see it now as a disability...This boy...has an ability to comprehend things that we sometimes [do not]. Because sometimes, in situations involving feelings toward other people, [he understands]. For instance, there was a car crash, I saw it and I stopped to see if I could help...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, and that things happen to other people not because they want to...

Another form of management was to <u>overlook the situation</u>. An example was mentioned by a mother of a boy with severe Cerebral Palsy from Bayamón in handling her feelings of depression. She stated:

> ...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...

Another form of <u>overlooking the situation</u> was found in their inability of some parents to think about or <u>view their child's future</u>. They stated that this inability resulted from the feeling that, although the future was not clear, their visions were fraught with work and tension.

<u>Religion</u>

A form of emotion-focused management used "to maintain emotional equilibrium" (Meyer and Bailey, 1993; p. 196), and a form of resignation and redefinition that deserve separate attention is that provided by spiritual practices or participation in organized religion.

Religion provided possibilities for redefining the disability and their family in a more positive manner. 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 with severe disabilities church attendance had a profound effect in her understanding of her situation:

> ...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 this mother:

> ...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 the birth of a girl with health problems was reframed through their religious beliefs into a positive understanding. The mother stated:

> ...I considered it a miracle. I prayed for the girl. We are evangelic. If it had not been because of the Lord, the girl would have been dead there. Definitely our girl would have died...

Other families did likewise by seeing themselves as having 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 provided emotional support, guidance, acceptance of the children and frequent company. About this a woman from Río Piedras, who is the mother of a girl with metabolic disorders, stated:

> ...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 you, 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...

Nevertheless, not everyone was receptive to organized spiritual practices in this sample. 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:

> ...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? ...[what] I would like [is] to have some support from a partner for the rest of my life, because I do not want to remain alone...

External context management and/or Problem focused.

In addition to the internal resources there were some that were related to external sources. Strategies used to deal with external situations or problems 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 (Meyer and Bailey, 1993). These will be the topic of this section.

Several aspects, modifications and the organization of the couple's relationship were reported as part of their ongoing attempt to cope. Some families reported that after some initial short period of confusion they became at ease with their new situation. People in a couple relationship 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. Another mother claims her husband has demonstrated positive changes in some aspects of his behavior that she associated to their child's disability:

> ...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 child is sick, he wakes up and is with him. He puts him to sleep...

It was usual 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:

> ...When the girl [my daughter] is here, since she studies, she watches M. because he is so active. But from there on I 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, thank God, devotes time to him every afternoon...

One related aspect was the use of gender role division as a management mechanism. 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. For instance, a strict sex role division reported by a mother from San Germán was common:

> ...He does whatever has to be done 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 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 a child with disability:

> ... 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! ...

These decisions women faced are better understood by examining the additional tasks they confront. A woman from Bayamón described all the chores related to her child's disability:

> ...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...

Other couples collaborated while maintaining the sex-role related task division. It is also important to notice that for some couples who both gainfully work these responsibilities were shared. 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:

> ...[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...

They faced difficulties related to the lack coordination between service and job requirements. The 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.

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. There are unwritten policies in some of Puerto Rican hospitals that made female family members the ones allowed to stay with their sick children while in the hospital. As a result of these policies some males were compelled to take care of children left at home. A father from Ponce, described an intense period in his life related to one of his child's hospitalizations:

> ...I used to finish work tired, go to see her, and share with her a little bit. 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...

Although these gender-based division of roles were common arrangements that helped organize and deal with the external demands from the disability, there are many comments that challenge their inclusion as management skills. Those arguments were conveyed by female participants who were dissatisfied with their arrangements. Some women strongly complained about their marriage and their family organization. These complaints included the expectations for support that were not fulfilled by the partner, differences in perceptions between spouses that strained their marriage (such as those differences in opportunities for leisure activities), and serious disharmony in their marriage.

Employment/Economic management

Some aspects of management relate to the employment/financial reorganization of the families to deal with the new economic requirements related to their child's disability. There were instances in which mothers who worked prior to the birth of their child with disabilities had to stop 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 disproportionally because in Puerto Rico most necessary related services are not free of charge.

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

> ...[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...

In another job arrangement of a single mother from Río Piedras was forced to redefine her professional aspirations because of the errands related to her child's disability. These changes, related to her child's needs, affected her career possibilities. 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... And they were so many. Imagine how that interrupts your work...and you have to compete with other people who are not limited...

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 briefly described the conflicts between their work and their son's school schedules as:

> ... 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 flexibility demonstrated by the employer was an aspect that helped them deal with their needs. He stated:

> ...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, which 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 example, as in other accounts, there is an underlying need for flexible arrangements on the job setting.

Although service resource's characteristics will be discussed in other articles, they were also mentioned as a form of economic management. Some parents they could not find appropriate services, a key aspect in their claim of not having a high disability related expense. For a woman from Gurabo, the lack of appropriate services available for autistic children reduced her need to obtain additional money:

> ...I have really not seen any place where I can say: Here is a 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 you could say that each therapy session is such a big advance that it is worth to pay $100 or $200 [I would take him]...

On the other hand, families were forced to avoid some essential services that were not offered free of charge by the responsible Agencies, due to their inability to pay for them.

The couple from Camuy had no wage earner in their house. In that way, the girl only received the services that were free and available. Some services were not delivered. This family had previously used the option of selling possessions useful for the family to obtain medications and services. They had to sell a car in order to buy medication for their daughter. When there was no other thing to sell they were forced to eliminate necessary medication or services. As described by the mother:

> ...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...

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

> ...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...

Some families, out of their own resources were able to identify some service providers with characteristics that helped them manage their children's conditions. These characteristics 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. It is clear from their comments that the uneven availability and inconsistent access caused many difficulties to some families in this sample.

The economic challenges faced by these families also required a variety of other income producing arrangements on the part of the breadwinner. 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, the Major's office and from family members.

Family and Social support as management

Parents of this sample gave importance to social support in the form of assistance from family, friends and people from the community, who sustained them at some crucial periods. Although differing in extent and type, there were people that helped families 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 caretakers as positive factors. 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:

> ...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...

Another mother expressed her frustration about the lack of cooperation of her husband:

> ...I [face the challenges] by myself since my husband goes nowhere...Since he says that it suffices that I carry this responsibility by myself and [I think] that is not fair...

Assistance from close and extended family members, although sometimes difficult to obtain, was also valued. Obtaining help in routine chores was a recurrent way of management that allowed people to continue working. For instance, care and general support from the grandparents in the maternal side became the source of economic, general support and babysitting for a single working mother of a child with a low incidence disability in Río Piedras:

> ...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 [home] 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...

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]...

The support, concern and nurturing of some people specifically directed to the mother was greatly valued:

> ...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...

For others, family members' reactions to children's characteristics had an adverse effect in the caretaker's ability to identify sources of help. A single mother of a boy with autism recognized the difficulties involved in obtaining family support as related to their her child's unusual behavior.

> ...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...

Another mother perceived this lack of support as resulting from the limitations in understanding about their child's difficulties:

> ...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 or she understands how hard it is to carry that

> burden...so that they can provide some help to that person. Because if you do not know what that person is going through, how can you help? ...

Parent as information sources

Comments and information from other parents facing similar situations were discussed as a form assistance and support. A woman from Vieques described how they obtained, through other parents, the necessary information and identified strategies to help themselves. That information was otherwise not available through service providers:

> ...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 special understanding resulting from these shared experiences was identified as one of its advantages by a mother from Caguas:

> ...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...

While most parents were positive or neutral about the parent groups a mother withdrew from them, perceiving them as a somewhat worthless exercise:

> ... [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 is just not there. Many times people believe they have a lot of rights but...some rights [are directed] toward some services that do not exist. I am not going to struggle for something invisible. That is what they do not see...

Discussion

This investigation was designed to describe management strategies reported by families. Management was viewed as the means of handling the needs of the family system related to their engagement with the child with disability. In general, primary caretakers used internal and external means of management. One of the internal strategies was passive appraisal. An instance described was the comparison with other children and feeling they were "not as bad." Other forms were ignoring the situation, avoiding thoughts about it, or, for some parents an inability to think or view their child's future. On the other hand, acceptance or resignation of the situation was frequently mentioned by families with children with severe conditions.

Edgerton (1979, p. 35) claims that the major impact of the care of a child with a disability falls on the mother. This seems to be supported by most families in this study. In the families who had a member who stayed at home, fathers were in some way seen as the breadwinner. As reported by Allred (1992), and Edgerton (1979) most fathers tended to be less active in the childrearing process of their children with disabilities. Father support 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. There were also different degrees of acceptance or rejection of female's ascribed responsibility with comments ranging from those mothers who claimed complete adherence to their role to those for whom those requirements were unacceptable.

A few grandparents provided emotional and babysitting support, while others failed to do so due to their concerns about their old age, or the demands of the disability. In order to make intervention more appropriate, recognition of the variety of families' organizations and to the need to include family members in ongoing orientation and intervention activities is recommended.

Recommendations

It is apparent from the parent's comments that the expected support from other extended family members was there, as Delgado (1980) suggested, in the initial moments of crisis. But often their support decreased for the ongoing help necessary for the daily needs of the child. The reduction or fading of family and community support should be taken into consideration when planning interventions. This study raises questions about the prevailing reliance on the ongoing acceptance, nurturing and support that the extended Puerto Rican family provides (Seligman and Darling, 1989). Identification of the natural support system and systematic structuring of that participation may decrease the fading of family support.

Care of hospitalized children was institutionally regulated to be the mother's responsibility, which caused difficulties for all family members and denied fathers the opportunity to provide care. Hospital policies which require female members of families to be ones providing care for hospitalized children are discriminatory and should be reviewed.

Economic related management was extensively mentioned since most families faced a reduction of income and a substantial increase in family expenses. Services which were not provided by the public sector had to be paid by families. To deal with the additional responsibilities there was also a redefinition of some women's roles by having most mothers stay at home to care for the children. There were only two families in which both parents remained as wage earners. For them, as for single mothers, reorganization of their duties were used as a form of management (i.e., in couples, the person who had the most flexible schedule took care of errands).

For families with individuals with disabilities, looking for professionals and services with certain characteristics became a form of management because the additional access to resources they provided. These characteristics were the sliding fee status obtained from schools, health and related services, the use of physicians' 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.

Religion and spiritual practices seemed to have provided interpretations for the events they faced or life in general. In social terms it was helpful because church members provided emotional support, guidance, acceptance of their children and frequent company. On the other hand, a respondent saw it as a way to deviate thoughts from directly dealing with their problems.

On the whole the results of this research point to the variety of culturally unique alternatives for management used by Puerto Rican families. This information provides practitioners alternative views of the backgrounds of children they serve.

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