

Support networks for the Greek family with preschool or school-age disabled children

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Abstract

Introduction. The interaction of the family with disabled children with the support networks is a research area of high interest (Hendriks, De Moor, Oud & Savelberg, 2000). It has been shown that support networks may prove to be very helpful for a family and especially for a family with a disabled child. Support networks play a primordial role in the families' efforts to adapt to the disability and respond to its members' psychosocial needs (DeMarle & Le Roux, 2001). The target of the present research is to depict the support networks and the degree of satisfaction from the support experienced by 30 Greek families with disabled children of preschool or school age and then to compare their experience with that of 30 families with non-disabled children.

Method. The sample consists of 60 nuclear families, in total 120 parents of medium socio-economic status, all permanent residents of the island of Rhodes, Greece. Data collection used: 1) *Genogram* (Bowen, 1978), 2) *Family's Ecomap* (Hartman, 1978a), 3) *Social Support Questionnaire* (Sarason, Sarason, Sherin & Pierce, 1987), and 4) Semi-structured interviews.

Results. According to the findings of the study families with and without disabled children share common support networks (family of origin, friends, religion) but the families with a disabled child also use different support networks (other families with disabled children, specialists). All families express satisfaction when referring to support networks composed of individuals. The degree of satisfaction varies when they refer to institutionalised support networks.

Conclusion. The families with a disabled child don't feel sufficiently supported by social structures (school, intervention centres). This is due to the fact that the geographically remote regions of Greece suffer from a lack of structures to support these families. Besides, the families feel anxiety and anger because of the lack of social support (services, specialised personnel, discriminatory practices).

Keywords Support networks, disability, family, satisfaction.

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Introduction

Social support may prove to be very helpful for a family and especially for a family with a disabled child (Kraus, 1997). The interaction of the family with disabled children with the support networks is a research area of high interest (Hendriks, et. al., 2000). Support networks play a primordial role in the families' efforts to adapt to the disability and respond to its members' psychosocial needs (Dale, 1996; DeMarle & Le Roux, 2001; Hendriks, et. al., 2000; McCubbin, Thompson & McCubbin, 1996; Weisz & Tomkins, 1996).

The social support offered may take two forms: the *informal*, which includes the support offered by the family's relational and familial network and the *formal* which includes the broader social support networks (schools, medical centres, social services) (Dale, 1996; Seligman & Darling, 1997).

Researchers (Crinc, Greenberg, et al., 1998 as cited in Seligman & Darling, 1997) have examined social support in terms of three ecological levels: 1) intimate relationships (e.g. spousal), 2) friendships and 3) neighbourhood and community support.

Irrespectively of social or cultural background, there are many individual families with a disabled child who seem to cope very effectively. It cannot be assumed that these families do not have many problems and difficulties in their lives. But what seems to distinguish them from other families is that they present greater resilience in the face of adversity and crises and greater ability to handle stressful experiences. "*Protective factors*" are those which have been associated, in current research literature, with lower levels of stress and higher satisfaction in the life of parents of disabled children (although there are some differences between mothers and fathers) (Dale, 1996). They appear to provide resilience to stressful events and to increase coping ability. These include:

- A supportive social network: friends and relatives that are experienced as being supportive. It must be mentioned that social networks can be a source of stress as well as support; parents with a highly supportive network feel more positively about their child, but also express more symptoms of stress (Waisbren, 1980 as cited in Dale, 1996).

- Support from and friendship with other parents of disabled children.
- An ability to acquire social support (for example, being able to ask for help from friends, being able to participate cooperatively with professionals).
- Satisfaction with the marital relationship.
- A cohesive, adaptable family system, including open communication between the parents and harmony in parenting.
- Utilitarian resources (for example, employment –including maternal–, adequate finance, adequate housing, etc.).
- A positive outlook.
- A practical coping style.
- Problem-solving skills for tackling problems.
- Health and energy of individual family members.
- Few unmet needs for help from services (Sloper & Turner, 1993; Dale, 1996).

According to McCubbin & Patterson (1981), social support is an important external coping strategy. Specifically, they suggest that coping styles can be classified into internal and external strategies. *Internal strategies* include passive appraisal (problems will resolve themselves over time) and reframing (making attitudinal adjustments to live with the situation constructively), whereas *external strategies* include social support (ability to use family and extra familial resources), spiritual support (use of spiritual interpretations, advice from glerymen).

Informal social support has been shown in the research to be highly important for family wellbeing; a parent's satisfaction with social support is a highly predictive factor of positive adaptation. Parents who can turn to relatives, friends or organisations of parents of disabled children are likely to have greater wellbeing and family adaptation than those who are very isolated and unsupported. Moreover, for some families informal support is well provided for and the involvement of professionals is of secondary importance and may even obstruct their opportunity for social relating (Dale, 1996).

The outcome of the support a family with disabled children receives can be depicted in the following domains: a) it fosters the family's strength to cope with the condition of the disability, b) it helps the family obtain a sufficient level of autonomous functioning and integration in its social environment, c) it fosters the family's capacity to respond to the psycho-

social needs of its members and assure a certain quality of life for the whole family (Dale, 1996; Singer, 2002; Sloper & Turner, 1993). Besides, Marsh (1993) and others have reported the important role of social support in promoting parents' positive feelings about disabled children.

Support networks composed of adults with disabilities and parents of children with disabilities serve a number of functions, including: a) alleviating loneliness and isolation, b) providing information, c) providing role models and d) providing a basis for comparison (Seligman & Darling, 1997).

Byrne, Cunningham & Sloper (1988) suggest that parents with children with severe physical difficulties and severe health problems are likely to be very restricted in their leisure and social activities and will also need generous access to respite care with skilled carers, who can cater for the very disabilities of the child, as well as needing assistance from well coordinated and integrated service provision.

For the support offered to be effective, it is essential to respond adequately whenever needed and desired by the family itself. That is, it should be available at any time during the family's life cycle (Singer, Powers & Olson, 1996). The degree and the effectiveness of the existing social support, influence the families' level of stress (DeMarle & Le Roux, 2001; Dale, 1996; Honig & Winger, 1997; Suarez & Baker, 1997; Weisz & Tomkins, 1996).

In Greece the quality of services of state or governmental structures (schools addressed to children with disabilities, medical centres addressed to children) is poor. It is also important to note that in Greece, and more specifically in the areas situated in the periphery – like the island of Rhodes – , there is a lack of supportive structures. Furthermore, in Greece the existing structures either do not have a sufficient number of specialised personnel and/or the roles of the existing staff are not clearly specified and designated (Besevegis & Giannitsas, 2000). This lack of supporting social structures and discriminatory practices in the periphery has a lot of negative consequences on the families with disabled children. One of these consequences is that the consistency of the families is affected because some of the family members (usually one or both parents with a disabled child) have to travel to the capital (Athens) or another big city to take the child to the doctors. The rest of the family stays behind, sometimes for long periods of time. To cover the lack of formal support, the parents try to find

other sources of support, such as extended family, friends/neighbours, local community and other parents of disabled children (Tsibidaki, 2007).

The purpose of this study is twofold: on the one hand, to explore the relationship of the Greek family with the surrounding support networks, namely: friends, school and specialists and other social groups present in its social environment, and, on the other hand, to find out any differences, in terms of support networks, with the families with non-disabled children.

The questions that the present research aims to answer are the following:

- 1) *What kind of support networks do the families of the study have?*
- 2) *Do the families with and without disabled children use the same or different support networks?*
- 3) *What degree of satisfaction do the families get from these support networks? Are there any differences in the degree of satisfaction between the families with and without disabled children?*

We consider the above questions important because they have not been sufficiently answered by the existing research on the Greek population.

The hypothesis of the study is the following: since there is a lack of formal (governmental) support networks –specially– in the periphery of Greece, then Greek families with disabled children turn to other informal sources of support for help.

Method

Participants

Research participants were 60 nuclear families, 30 with a disabled child and 30 with non-disabled children. The total number of research participants was 120 parents. The average age for men was 38 years (SD= 5.81) and for women was 36 years (SD=7.67). All families had children of preschool or school age. All were of a medium socioeconomic class. This was

measured by information derived from parents by occupation and income. Besides, all participants were permanent residents of the island of Rhodes, Greece.

The total number of disabled children was 30 (15 boys and 15 girls). Age range: 4 to 12 years (mean=8.07, SD=3.02). The types of disabilities were the following: cerebral palsy (33.34%), mental disability (20%), multiple disabilities (13.34%), syndrome Down (10%), microcephalia (6.67%), autism (6.67%), emotional and behavioural difficulties (3.34%), syndrome Klinefelter (3.34%), syndrome Simpson-Golabi-Behmel (SGB) (3.34%). Diagnosis took place at different times of the child's life: 18 children (60%) were diagnosed immediately after birth, 4 (13.33%) during preschool period and 8 (26.66%) during primary school. All the disabled children of the study are officially diagnosed as presenting, according to official medical diagnosis, a disability which varies from severe to profound.

The participant families were at first contacted by phone and then visited at their home.

Procedure

The families were randomly selected. The selection took place in two phases: firstly, families with a disabled child were randomly selected from archives, catalogues of the Association of Children with Disabilities of Dodecanese, and secondly, families with non-disabled children were randomly selected from the directory of the 11 municipalities of Rhodes. The sample was composed of families with a disabled child with the following criteria:

- *All families were intact.*
- *The age of the disabled child varied between 4 and 12 years old.*
- *The child with disabilities lived with his/her family.*
- *All the families of the sample were permanent residents of the periphery (island of Rhodes).*
- *The disabled child was the only individual in the family who presented the disability.*

After the completion of the gathering of the population we proceeded to the selection of the 30 families with a disabled child and 30 families without a disabled child. The sam-

pling between the families with and without disabled children followed the following criteria of comparability:

- *Place of residence. All families of the study lived in the periphery (island of Rhodes). The same number of families was selected from each municipality.*
- *The number of family members.*
- *The sex and age of the siblings (with deviation ± 2 years).*
- *The socioeconomic status of the family (except in one case). This was controlled by the fathers' occupation and family income.*
- *The educational level of parents.*

Measures & Statistical Analysis

The data were collected with the following instruments:

- *The Genogram (Bowen, 1978).* It is a valuable mapping and graphic assessment tool. It provides information about the family system as well as its internal and external structures. Information depicting the family along the intergenerational and historical lines is drawn using symbols. Genograms can illustrate different aspects of the family patterns. A family geneogram may be drawn to show intergenerational relationships, cultural identity, conflicts and supports, and traditions and rituals (Thomilson, 2002). The usual practice is to draw three generations of the family showing family composition, structure relationships, and other information over time. Family members are placed on horizontal rows to signify a generation, such as a marriage or co-habitation. Children are represented by vertical lines and rank-ordered from left to right with the eldest child. Males are denoted by squares and females by circles. Names and ages appear in the square or circle. Just outside the circle or box, important information can be placed. For the purposes of the present study the genogram focused mainly on the support networks of the familial environment. At the beginning, we referred to the Genogram as a family tree. We explained to the families we will be asking them questions about their background that are important for gaining a picture of the family and their situation. Using a large piece of paper, we drew the genogram and family's ecomap allowing everyone to see what you were recording, explaining what the symbols mean as we were drawing.

- *The Family's Ecomap* (Hartman, 1978). The ecomap represents the family's interaction with various systems. Ecomaps depict systems the family interacts with and indicate where changes may be needed with the environmental systems to provide improved interactions and support for a family. Information about the family's social context is shown using squares or circles to represent social support. Ecomaps indicate the flow of resources between the family and other significant people, agencies, and organisations that may support or cause stress to the family environment (Thomilson, 2002). The the family's ecomap and the genogram were used in the first contact for the "warming up" with the family. We derived useful information for family's support networks inside and outside the family system.
- *Social Support Questionnaire* (Sarason, Sarason, Sherin & Pierce, 1987. Translation & adaptation in Greek: Kafetsios, 2000). This is a six-item version of the original 27-item scale. For each of the six questions subjects are required to list all persons who can provide support of the type described in the question (min 0 max 9) and also indicate how satisfied they are overall with that level of support (six point scale). Hence, the scale provides a quasi-structural measure of social support (number of persons available for support) and one perceived global satisfaction measure. The two parts had good internal consistency ($\alpha=.92$ and $\alpha=.89$ respectively).
- *Semi-structured interview*. The semi-structured interview was centred on the following thematic areas: a) the capacity of the family to use networks of support; that is the families' boundaries within their social environment, b) the degree of satisfaction derived from the interaction between families and their support networks (extended family, school, friends, specialists or other groups in the broader community). Some of the questions were: "*When you discovered your child's disability were you helped by anyone? Who?*", "*Do you get any help at the present? What kind of help? From whom?*", "*According to your opinion, which is the most valuable support? Why?*".

Data were analysed using S.P.S.S. 12. Content analysis was used for the qualitative data derived from the semi-structured interviews. Quantitative data analysis was based on

comparisons between the research groups with the t-test criterion for two independent samples.

Results

According to the findings of the study, families with and without disabled children share most common support networks. Families of disabled children use two support networks not found in families with non-disabled children, namely that of specialists, and other families with disabled children (Table 1).

Table 1: Support networks

| | Father with a disabled child | | Mother with a disabled child | | Father with non-disabled children | | Mother with non-disabled children | |
|--|------------------------------|--------|------------------------------|--------|-----------------------------------|--------|-----------------------------------|--------|
| | N=30 | % | N=30 | % | N=30 | % | N=30 | % |
| <i>Family of origin</i> | 9 | 29.99% | 9 | 29.99% | 7 | 23.33% | 22 | 73.33% |
| <i>Friends</i> | 7 | 23.33% | 4 | 13.33% | 10 | 33.33% | 4 | 13.34% |
| <i>Religion/spiritual father</i> | 4 | 26.66% | 5 | 16.66% | 6 | 20% | 1 | 3.34% |
| <i>School</i> | - | - | - | - | 7 | 23.33% | 3 | 10% |
| <i>Other families with disabled children</i> | 9 | 29.99% | 10 | 33.33% | - | - | - | - |
| <i>Specialists</i> | 1 | 3.34% | 2 | 6.66% | - | - | - | - |

The common support networks –which parents reported on their interviews and during the construction of the genograms and ecomaps– are the following:

- *Religion*: faith in God and the relationship with a priest seems to be a main support network for the families with a disabled child. Although the relationship with a priest and faith in God is also a support network for the families with non-disabled children, though it seems to play a less important role compared to the families with a disabled child (for families with disabled children: fathers 13.33% & mothers 16.66% and for families with non-disabled children: fathers 20% & mothers 3.33%). A mother of a disabled child says: “*I received a lot of help from God. One gets a lot of courage from the priest. I confessed that I didn’t want to appear publicly with my child because I was ashamed of him. One has this kind of feeling towards one’s child. Talking to the priest helped enormously. I would tell him all we were going through with Alex. Now I feel much stronger and able to give courage to other women who have the same problems*”. A father of a dis-

abled child says: “...at the beginning I was hurt, I was very unhappy but my faith in God encouraged me and supported me...”.

- *Friends:* friends are for families with and without disabled children an important support network (for families with disabled children: fathers 23.33% & mothers 13.33% and for families with non-disabled children: fathers 33.33% & mothers 13.34%). A mother of a disabled child says: “I have a friend. She is always there to help me with everything I need”.
- *Family of origin:* although the family of origin is a very important support network for all families, it is even more so for the families with non-disabled children. This is due to the fact that the majority of mothers with disabled children do not work (unlike the mothers with non-disabled children) and therefore undertake the upbringing of their child themselves. A common point for all families is that support is derived mainly from the wife’s family of origin (for families with disabled children: fathers 29.99% & mothers 29.99% and for families with non-disabled children: fathers 33.33% & mothers 13.34%). A father with a disabled child tells us: “If it wasn’t for my mother in-law, we would most certainly not have been able to manage the difficulties we came up against with our child. She has been, and still is, a constant help”. A mother of non-disabled children says: “My mother is there for me on a twenty-four hour basis. She is there for me for everything I need”.
- *School:* While the families with non-disabled children report a satisfactory relationship with school (for fathers 23.33% & for mothers 10%), for the families with disabled children it constitutes a great source of anxiety. Findings concerning school were derived from the semi-structured interviews: Out of 30 disabled children, 8 children (26.7%) (4 children with multiple disabilities and 4 children with cerebral palsy) were following no educational program. This is due to the fact that there is no specialised school on the island of Rhodes. 4 children (13.3%) follow integration classes (3 children with syndrome Down and 1 child with emotional and behavioural difficulties), 10 children (33.3%) attend special school (4 children with cerebral palsy, 2 children with microcephalia, 2 children with autism, 1 child with syndrome Klinefelter and 1 child with syndrome Simpson-

Golabi-Behmel) and 8 children (26.7%) (6 children with mental disability and 2 with cerebral palsy) attend mainstream school. Although the current educational demands try to create “*A School for All*” on the island of Rhodes this demand is at a very primary stage. For 8 of the children no suitable educational environment was found. They were excluded from education and were, therefore, obliged to remain at home without any professional intervention. Furthermore, the parents of 22 children (80%) who follow special school or integration classes tell us that their communication with the school staff at the beginning of the year was so bad that the children could not begin schooling on time. Some parents (20%) stated that their children have not been handled with the proper care by their educators. A mother of a disabled child states: “*Each year, when school starts, I say to myself: my God what are we going to go through again?*”. Another difficult task families have to undertake is their obligatory presence in the school yard during school hours. The reason for which a member of the family has to accompany the child during its school days is that the school staff cannot cover the needs of the child. According to a mother of a disabled child: “*I have to be with the child constantly. It’s like going to school again. I spend all morning in the school yard and during the breaks. I feed my child; I escort him to the toilet. It is so tiring. For me it’s like going to work every morning*”. A father of a disabled child says: “*At school there is no staff specialised for disabled children. So, my wife has to go with him to school every day to take care of his needs*”. The Greek family with a disabled child has to undertake roles that should normally be undertaken by the school.

- School is experienced very differently by families of non-disabled children who declare that they are quite satisfied with it. Their only concern is their children’s school performance and their future. A father says: “*Our children like school and they want to go to university. They are good students and we have no problem with school*”. A mother states: “*We sometimes feel anxious when our eldest daughter has exams. I sometimes worry because she works very hard. I also worry that although she is good she might not succeed in the entrance exams, as competition is very high. On the other hand, there is the option of her going away to study at a university in another town, away from home. We try not to show her our worry, though, because we don’t want to put more strain on her*”.

Support networks used only by families with disabled children:

- *Specialists*: Specialists are not considered as satisfactory support network by families with a disabled child. Only 3 parents (1 father and 2 mothers) of children with multiple disabilities report specialists as support network. It is important to note that there is a lack of specialised centres and supportive services on the island of Rhodes. As a result, the families are obliged to travel to Athens or abroad. This is a main source of stress because, according to the families, it is a costly enterprise and it also disrupts the family's life. Some parents say: "*The state? What state? The state is completely absent. I regret that we finally did not move to U.S.A. The child would be different now. We would have found all the services needed for the child there*" (father of a disabled child), "*The problem is commuting to Athens. Every time we have to go to Athens, I am burdened and worried about what I am going to face again*" (mother of a disabled child).
- *Other families with children with disabilities*: It is important to note that a great percentage of the friends of the families with disabled children are other families with children with disabilities. This support network appears exclusively within these families (fathers 29.99% & mothers 33.33%). According to a mother of a disabled child: "*Before I met other mothers with children with the same problems, I believed that they would be different, that is, they would be terribly disappointed, desperate. But, when I first went to the intervention centre and I saw them laughing and acting normal, I took heart. I believe that talking to them helped me to get over my fears enormously and also answer some of the questions that had been tormenting me*".

According to the quantitative analysis (t-test criterion) of the *social support questionnaire* there was no statistically significant difference between fathers with and without disabled children, and between mothers with and without disabled children *in the number of persons reported as social support networks* [for fathers: $t(58) = -.388$, n.s & for mothers: $t(58) = -1.445$, n.s] (table 2).

Table 2: Number of persons who can provide support

| | N | Mean | Std. Deviation |
|--|----|-------|----------------|
| <i>Father of disabled children</i> | 30 | 15.77 | 8.67 |
| <i>Father of non-disabled children</i> | 30 | 16.50 | 5.66 |
| <i>Mother of disabled children</i> | 30 | 17.23 | 8.53 |
| <i>Mother of non-disabled children</i> | 30 | 20.73 | 10.16 |

Besides, data analysis concerning *the degree of satisfaction of fathers and mothers from the social support received* showed that there was no statistically significant difference between fathers [$t(58) = -1.195, n.s$] and mothers [$t(58) = -.441, n.s$] (table 3).

Table 3: Level of satisfaction with support

| | N | Mean | Std. Deviation |
|--|----|-------|----------------|
| <i>Father of disabled children</i> | 30 | 30.73 | 5.57 |
| <i>Father of non-disabled children</i> | 30 | 32.23 | 4.03 |
| <i>Mother of disabled children</i> | 30 | 31.83 | 4.69 |
| <i>Mother of non-disabled children</i> | 30 | 32.33 | 4.06 |

Discussion and Conclusions

The target of the present research was to depict the support networks and the degree of the satisfaction from the support experienced by 30 Greek families with disabled children of pre-school or school age and then to compare their experience with that of families with non-disabled children.

The findings of this study suggest that families with disabled children interact with various support networks, which seem to play a primordial role in the families' efforts to adapt to the condition of the disability of their child. This finding is consistent with those of other research findings (Dale, 1996; DeMarle & Le Roux, 2001; Hendriks, De Moor, Oud & Savelberg, 2000; McCubbin et. al., 1996; Weisz & Tomkins, 1996). According to the model proposed by Cronkite & Moos (1984), social support is a factor that plays a vital role in the maintenance of the family's effort to respond to its members' psychosocial needs.

An important support network for the families with and without disabled children is faith in God and the relationship with a priest and the congregation consisting of "*brothers*"

and “*sisters*” (15% & 11.67%). This finding is consistent with those of other studies (Dale, 1996; Lin, 2000; Marshall et al, 2003; Treloar, 2002) which suggests that religious commitment is an important source of support for the parents and the disabled children (Singh & Wilton, 1994).

The priest seems to play a “*parental*” role. He is there to console but also to remove guilt due to anger caused by frustration and fatigue as a result of the difficulties imposed by the disability. The religious community seems to function as a context in which families with disabled children find support. This function is achieved by the following activities: there is always a member of the community to listen, to help and to assist in every way the families who have disabled children. There is also financial help available from the members of the church, if needed. This function of the religious community makes up for the lack of the state structures in Greece and even more so in rural areas.

In the Research of Kapa Company (2005) related to religious beliefs of Greeks, showed that belief in God has been increased and it is higher levels compared to countries of Western Europe. Over 92% of Greeks reported that they believed in God and prayed regularly. The corresponding percentages in the USA were 91%, in Nigeria 99%, in Mexico 95%, in Israel 86%, in N. Korea 70% and in United Kingdom 67% (Research of Kapa Company, 2005). Besides, research in the values of young Greek people showed that confidence in church is in very high percentage in Greece (Research of New Generation, 2005). It must be mentioned that the Greek population is composed of a 97% of Christian Orthodox. The rest of the population is Muslim, Roman Catholic and Jewish. More specifically, religion is present in many different sections of the Greek society. For example, the Orthodox Church is very present in the education sector and children have obligatory religious courses and pray all together every morning before starting the classes in all the schools, private or public. The Orthodox Church is also much integrated into the politic matters of the country and every time a new decision taken doesn't suit with the Orthodox principals, it is always followed by great disapprovals from Church's representatives. Even if getting in the process of Europeanization and Globalization, Greece still remains a profoundly religious Christian Orthodox country full of beliefs, traditions, customs and religious feasts (Greeka.com, 2007).

Friends are another support network for all the families of the study (18.33% & 23.33%). This difference lies in the fact that the friends of the families with disabled children

are also families with children with disabilities (31.66%). This finding is consistent with those of other studies (Dale, 1996; ESAEA, 1999; Parent Partnership Scheme, 1997; Wright, Granger & Sameroff, 1984). The contact with other families facing the same experiences has a positive effect on the parents of the disabled children because they feel that they have the possibility: a) to share their problem with other people who can understand them, b) to exist and interact in a group they can identify with and therefore not feel “*excluded*”, and c) discover that other people have found ways of coping successfully with the challenges imposed by the condition of their disabled child.

The extended family is another essential support network for all families of the study. In the Greek culture, the family of origin constitutes a very important support network for the family. The Greek family appears to be a nuclear family, in the sense that they live separately from their families of origin but they function as an extended family: the children usually choose to live within very close proximity to their parents and they communicate many times daily and share their problems. This type of family has been called “*extended urban family*” (Georgas, 2000). It seems that the Greek family changes in its own way. Adolescents, on one hand, reject values associated with the patriarchal, rural family (a domineering father and a passive mother) and on the other hand, they believe in values associated with collectivity, the obligations of parents towards their children and of the children towards their parents and ancestors, equally. Bonds with the extended family are still very powerful (Georgas, 1999, 2000). Another important finding of the present study is that support is mainly offered from the maternal family of origin in all families of the study. This is probably due to the fact that women and their families of origin are mainly assigned the role of “*caregiver*” in the Greek culture (Mousourou, 1999). Grandparents play an equally important role when it comes to supporting the families. This finding is consistent with that of other studies (Hornby & Ashworth, 1994; Scherman, Gaeder, Brown, & Schutter, 1995; Seligman & Darling, 1997).

The findings concerning the importance of support from the networks of religion, family and friendly environment are consistent with those of other studies on families with a child with cerebral palsy. Research on 274 families with a child with cerebral palsy in United States suggested that five factors underlie family coping behaviors. These factors, the presence of which is necessary for the family to adapt to the conditions of a disability, are: positive family appraisal, support from concerned others, spiritual support, personal growth and advocacy, and positive social interaction (Lin, 2000).

Families with a disabled child describe their interaction with specialists (medical personnel, social workers, occupational therapists, speech therapists and physiotherapists) as impersonal, formal and in many cases terribly insufficient. They express the belief that this interaction has an effect on the child. Parents describe the role of specialists as purely peripheral or even inexistent. This is due to the fact that in Greece the quality of services of state or governmental structures (schools addressed to disabled children, medical centres addressed to children) is poor. It is also important to note that in Greece, and more specifically in the areas situated in the periphery, there is a lack of supportive structures. This is the opposite compared to other countries in Europe and the United States where there is a tendency to create "*A School for All*" (Ainscow, 1997; DfE, 1994; DfEE, 1994; DfEE, 1997; DfEE, 1998) with an inclusive orientation in an inclusive society which creates schools developing practices that can reach out to all learners (Ainscow, 2005). Furthermore, in Greece the existing structures either do not have a sufficient number of specialised personnel and/or the roles of the existing staff are not clearly specified and designated (Besevegis & Giannitsas, 2000).

The lack of supporting social structures and discriminatory practices in the periphery has a lot of negative consequences on the families with disabled children. One of these consequences is that the consistency of the families is affected because some of the family members (usually one or both parents with a disabled child) have to travel to the capital (Athens) or another big city to take the child to the doctors. The rest of the family stays behind, sometimes for long periods of time. Another source of anxiety is the financial burden that these families have to carry. The result of such discriminatory practices is obvious: Poor families can not afford any support.

The parents of the study state that information from specialists which is necessary to face the illness of their child, is inadequate and in some cases they were only given the diagnosis. To cover the lack of information, the parents try to find other sources of information, such as from parents of other families with disabled children. The information they were given, that in some other countries there are specialised structures and professionals for the children with disabilities, filled them with even more bitterness, disappointment and anger towards the Greek state and the way the specialists face them. Adequate information on the condition of disability is an important factor which contributes to the effort made by these families to come to terms with the disability (Hornby, 1989; Pain, 1999). Information has to

be abundant and continuous and it has to concern expected changes associated with the development of the child in relation to the ongoing effect of the disability (Dyson, 2001).

The findings of the present research concerning the difficulties in the relationship between families with disabled children and specialists are consistent with those of other studies (Mittler & Mittler, 1982; Pugh, 1988; Turnbull & Ford-Turnbull, 1990; Woolfson, 1991). It is obvious that these families should be supported throughout their life cycle, whenever needed, provided they are open enough to receive it (Dale, 1996, Singer, Powers & Olson, 1996).

For the families with disabled children of the present study school is not experienced as a support network but rather as a source of stress. According to parents, schools have no special educators. This finding is, on one hand, consistent with those of other studies on the Greek population (Panteliadou & Botsas, 2000); yet on the other hand, according to other studies, special schools' personnel and families with disabled children maintain a positive interaction (Westling, 1996). Research on the interaction between families with disabled children and schools has shown conflicting findings (Singer, 2002). Some argue the dysfunction of the special education system as a whole. So, on one hand, it has been suggested that special education leads to social exclusion and reinforces stigmatisation (Andrews et al., 1996). On the other, according to research findings, the majority of parents have a satisfactory relationship with special education (Westling, 1996) and that school functions as a positive support network for families with a disabled child (Antzakli-Xanthopoulou, 2003).

One of the consequences of the lack of an educational structure and specialised professionals on the Greek family involves mothers. The mothers of the disabled children complain that they are the ones who mainly undertake the child's care and they feel that they have less possibilities of entering the workforce and less chances of self-actualisation. This is consistent with other findings in Greece (Antzakli-Xanthopoulou, 2003; Matinopoulou, 1990), some of which also suggest that the above mentioned consequences seem to be a permanent, long term problem for these mothers since they have to support these children from birth to adulthood (Panteliadou, 1995).

According to the findings derived from the Social Support Questionnaire, the degree of satisfaction from the networks of support is the same for all families when it comes to individuals (friends, family). Both fathers and mothers from all families of the study state being

“*very satisfied*” with the persons of their immediate environment. Although, according to the findings derived from the interviews, genograms and ecomaps, when parents report to the support from services and institutions (specialists, school), then the degree of satisfaction differs. Families with disabled children feel bitterness and anger for not having received proper care and help and for being “*ignored*” by the “*Greek state*”. The extended family and friends are the main support networks and seem to make up for the lack of social structures in the Greek periphery. These findings are consistent with those of other studies according to which families of disabled children use the “*protective factors*” which have been associated with the ability to acquire social support and the ability to participate cooperatively with the support networks (friends and relatives) (Sloper & Turner, 1993; Dale, 1996).

The findings of the study suggest that:

- Families with disabled children share common support networks with families with non-disabled children (friends, extended family) but at the same time they interact with other networks of their own (specialists, other families with disabled children).
- The most important support networks of families with a disabled child are the family of origin (especially grandparents), the relationship with a priest and faith in God and other families with disabled children.
- The degree of satisfaction from friends and familial environment is the same for all families. When it comes to services and institutions (specialists, school) then the degree of satisfaction differs. Only the families with disabled children express anger because they feel that they are not supported by the state. To make up for the lack of social support and to face the challenges of the disability of their child, the families turn to the existing support networks which are the extended family, faith in God, their priest and other families with disabled children. The families seem to try to find ways of keeping its homeostasis by using all the available support networks.

Implications for practice

The continuing care of children with disabilities is stressful for all families. Although the disability has a significant impact on the family, some families have strong coping

capabilities and others may need much more support. The results of the study have several implications for practice: First of all, a basic implication relates to the developing and conducting formal family intervention activities and centres in the periphery of Greece, in which families can find practical support and will have the right to suitable information in order to make an “*inform choice*” for their disabled children (Young, Hunt, Carr, Hall, McCracken, Skipp & Tattersall, 2005). Second, educational programmes and empowerment of the existing informal support networks (grandparents, siblings, friends). Third, educational programmes for special educators in order to provide adequate counselling and support to these families.

Finally, the study presents certain limitations: a) the sample is situated in the periphery of Greece. It would be most useful to carry out a comparative study between the sample of the study and others situated in the capital in order to see other possible networks of support, ways of coping and level of satisfaction of these families, and b) a comparison between different degrees and categories of disabilities would be most desirable.

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