ANA MARIA DA SILVA PEREIRA HENRIQUES SERRANO

FORMAL AND INFORMAL RESOURCES AMONG FAMILIES WITH YOUNG CHILDREN WITH SPECIAL NEEDS IN THE DISTRICT OF BRAGA, PORTUGAL

INSTITUTO DE ESTUDOS DA CRIANÇA
UNIVERSIDADE DO MINHO
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Dissertation submitted in conformity with the requirements for the degree of Doctor in Child Studies (Special Education) under the supervision of Raymond Pat Gallagher, PhD, California State University – Dominguez Hills, U.S.A., and Luís de Miranda Correia, PhD, Instituto de Estudos da Criança, Universidade do Minho – Portugal.

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CHAPTER I

Introduction

INTRODUCTION

1. Rational of the Research Study

The purpose of this study was to identify formal and informal resources used by families with young children who are either considered at-risk for disabilities or have been diagnosed with disabilities. All the children in this study are under three years of age and live in the District of Braga, Portugal. The knowledge and experiences in the complex field of Early Intervention (EI) led me to conclude that families of children with or at-risk for disabilities require systemic supports that help them to maintain their integrity and fulfill their parenting roles. While there is a wide variance in the number of supports and their level of intensity, families rely on both an informal and formal support system.

Early research efforts (Dunst, 1997; Affleck, Tennen, Rowe, Roscher & Walker, 1989), demonstrate that there are relationships between social support and different aspects of child, parent and family functioning (Dunst 2000). According to Dunst (1999), research findings demonstrate that social support, personal well-being, parenting interactional styles, and child development are both conceptually and empirically related, and that variation in child development is attributable to a family's level of social support. Furthermore, the well-being of the family appears more related to social support than to the families Social Economic Status (SES). As such, social supports can be viewed as essential requisites to the successful intervention for young children and their families. Dunst

(1985), goes further by proposing a social systems definition of early intervention as the "...provision of support, i.e. resources provided by others, by members of a family's informal and formal social network, that either directly or indirectly influences child, parent and family functioning"(p.179). Social support can be established using formal and informal networks. Examples of informal social support networks include individuals from a persons extended family, friends, neighbors, or social groups, e.g. religious groups, clubs, volunteer organizations. Formal networks are comprised of organizations and/or individual professionals who provide assistance to a child and their families, e.g. special educators, educators, social worker's, doctors, therapists (Dunst, 1995a). While research has outlined the importance of formal support in helping families to cope with crises, it also demonstrates that formal supports are not the only sources for assistance that help families. Informal social support sources are also potential sources of change and adaptation for families, and in many instances, become more important than formal support structures (Dunst, Trivette & Deal, 1988; Dunst, 1995a).

According to Dunst *et al.* (1988) extra-family resources and social support include "...the emotional, physical, informational, instrumental, and material aid and assistance provided by others to help maintain the well-being and balance of the family" (p.28).

The practical implications from all of the assumptions described above, force us to conceptualize EI services as a diverse range of experiences provided to families with children at-risk that include both formal and informal support networks. This broadened concept of the intervention umbrella values the contributions of informal supports provided to families and acknowledges their role in stabilizing families by empowering and strengthening their autonomous functioning (Dunst, Trivette & Deal, 1988).

Based on the conceptual assumptions concerning the importance of social support for EI, the purpose of this research project was the identification of community-based resources available to families of children at-risk from birth to three years of age of the District of Braga – Portugal. With this goal in mind, the results of this study increases our understanding of the resources most used by these Portuguese families within their communities. Additionally this information, will help policy-makers by providing practical information concerning the progress of EI services in Portugal.

To guide this study the following four research questions were posed:

I. What types of services, institutions and programs, i.e. formal community resources are used by families with children with Special Needs (SN) (birth to three) in the District of Braga, Portugal?

II. What is the composition of the informal support networks, e.g. extended family, friends, neighbors, religious groups, of families with young children identified as at-risk in the District of Braga?

III. What service system characteristics, e.g. directed and reciprocal, geographical proximity, frequency of contacts, types of support functions, congruence between help needed and support provided, are related to a family's general satisfaction of their support networks?

IV. What are the needs of the families with children with SN (birth to three) in the District of Braga?

2. Research Overview

The aim of this study was to extend the work of Dunst and his collaborators, concerning social support and its significance within contemporary models of EI.

EI constitutes a contemporary issue in the field of Special Education. (Caldwell, 1970; Condry, 1983; Shonkoff, & Meisels, 1990; Dunst, 1996) and it is the focus of researchers, educators an other professionals who work directly with young children with disabilities and their families (Peterson, 1987; Shonkoff & Meisels, 1990; 2000; Brambring, Rauh & Beelman, 1996). The United States of America were pioneers implementing EI programs and services. In 1986 the EI service delivery system was mandated for children with disabilities from age 3 years through 5 years of age when Public Law (P.L.) 94-142, The Educational for All Handicapped Children's Act, was amended with the passage of P.L. 99-457. For children from birth to 3 years old, Part H of the law, provided modest assistance to states to develop and/or maintain statewide, comprehensive, coordinated, multidisciplinary, interagency systems that offer early intervention services to eligible infants and toddlers and their families. Currently the law in its reauthorized form designated as Individuals with Disabilities

Education Act (IDEA; Public Law 101-476) has replaced Part H with Part C. In spite of reauthorization and various amendments IDEA in its current form does not require states to participate in part C. Thus, to services for children who are less than 3 years of age continues to be encouraged but not mandated for states. However the legislation continues to provide assistance to states who choose to furnish such services. Although the legislation encourages service delivery to children and families, the type and intensity of those services are not stipulated. However, Part C legislation does specify that EI services to children and families be "family-centered". According to Dunst (1997), "family centered practices are considered a special case of participatory and empowering help giving that places families in central and pivot roles in decisions and actions involving both the family as a whole and individual family members (Dunst & Trivette, 1996)" (p.76).

One of the primary vehicles for guaranteeing such family participation is the development of an Individualized Family Service Plan (IFSP), which has replaced the Individualized Education Program (IEP) for children under the age of three years (Espe-Sherwindt, 1996). The IFSP is a plan written jointly by the parents and professionals that describes the needs of the child, the needs of the family in relationship to the child, and how those needs will be addressed and by whom.

In Portugal legislation concerning EI was enacted in October of 1999, Despacho Conjunto 891/99. This project-law contains the basic guidelines for EI services implementation, and its philosophical and theoretical bases are similar to the ones described in Part C of IDEA; Public Law 101-476.

When comparing characteristics of EI programs with program models serving older children with special needs, there are clear differences. In EI there has been a fusion of legislation, theory, and best practice that has resulted in a more comprehensive view of children. A child-centered educational intervention model that has guided much of our practice in the past has given way to the notion that a child is an important contributor in a family (Simeonsson & Bailey, 1990; Beckman, 1996b; Dunst, 1985; Dunst, Trivette & Deal, 1988; 1994; Singer & Powers, 1993), i.e. family-centered. This more comprehensive view of the child as a part of the family establishes a more complex interactive model for understanding families with EI seen as one support to that family. The conceptual framework for viewing the relationship between EI and families in this way is reinforced in the ecological model (Bronfenbrenner, 1972; 1976; 1979), the transactional model of development (Sameroff & Chandler, 1975) and the research by Dunst (1985), Dunst *et al.* (1988; 1994) and Gabarino, (1990). Instead of viewing EI as compensatory (Dunst, 1995b) where targeted efforts are designed to remediate specific disabling characteristics, the ecological model for intervention acknowledges the importance that multiple factors play in a child's development. This more complex multi-factored model assumes that development is interactive on a variety of different levels with many contributing variables and experiences. In this environment, development is viewed as a process that is continual with broad-based contributions from many internal and external factors. Interventions therefore are targeted to do one of the following; prevent disabling conditions, remediate the effects of a particular disability or compensate for disabling conditions that alter a child's developmental course. Whatever intervention regimen is determined it is understood that the child's opportunities for development are to be maximized within a family-centered orientation. (Dunst, 1995b). Of particular interest to the efficacy of EI are those contextual factors related to social support provided the family, by friends, and the community in general. Of no-less importance are the availability of financial and material resources to families; the degree of family coherence and other related contextual factors. These factors interact with the child's individual characteristics, e.g., temperament. The combined effect of these family, community, and child factors establish patterns of family interaction that heavily influence child development (Guralnick, 1997). Under this conceptualization of EI, a family's level of social support becomes a crucial issue for research and practice within EI. The goal of this study is to identify formal and informal resources used by families with young children (birth to three years of age) who are either considered at-risk for SN or have children who have been diagnosed with SN, and living in the Northern part of Portugal. The end product of this study will yield a richer understanding of the importance of social support networks to families and the nature of the supports that are used by families.

3. Research design

The 13 families who participated in this study were selected according to the following descriptive variables: urban versus rural; with children who were identified as either at biological risk versus established risk; children manifesting either moderate/severe versus mild disabilities; and families who were identified as Low SES versus Medium/High SES. Data were collected with the aim of identifying characteristics of the formal and informal support networks available to these families and their level of satisfaction with their child's current developmental status and level of support they are receiving. The geographic, economic, and disability variation among these families combined with their use of informal and formal support networks helped us understand how these many factors interact to determine effective EI services. Data were collected using extensive family interviews and two instruments: Inventory of Social Support (Trivette & Dunst, 1988), and The Family Needs Survey (Revision, 1990b), (Bailey and Simeonsson, 1990). The within-case and cross-case analyses compared the characteristics of networks and the resources used by these families. Using a collective case study design, family interviews were taped and then transcribed. Content analyses of the interview transcripts was completed and each case was analyzed. The data from these within-case analyses were then analyzed across cases. This latter analysis provided important information for comparing similarities and differences among the families who participated in this study.

4. Relevance of the study

In Portugal we are beginning to develop the first steps in establishing an EI service network. The data were obtained before enacting this legislation, i.e., before 1999. The information obtained by this research project established baseline information that can be used to compare the affect Portugal's EI legislation has had enhancing services for young children and their families. As such, these data will assist in planning, implementing, and evaluating these newly instituted EI programs. In addition these data provide information important in the preparation of professionals who will provide EI services to families and children with disabilities in Portugal. Careful evaluation of social support networks will assist the service system to better define intervention targets, and document interventions that lead to positive outcomes for children and families. For example, we found that among some families the strength and extent of their support network and the availability of resources enhanced the perceived effectiveness of the EI services for families. The results will enable service providers to better understand the networks used by families and help Portugal institute their mandated EI service system by establishing more robust services. Through this and similar efforts Portugal can be more responsive to the needs of individual families and establish service networks and programs that are both effective and family-centered.

This study provides important information on the informal and formal networks of families with children at-risk and adds to our information base on families from different ethnic and cultural groups. As the number of studies like this increase, they provide valuable information on the effectiveness of EI worldwide and advance our growing knowledge-base on ethnically diverse groups like a similar studies completed in the United States as studies with Puerto Rican Families (García-Preto, 1982; Delgado & Humm-Delgado, 1982; Delgado & Rivera, 1997; Reyes-Blanes, Correa, & Bailey, 1999), and research conducted by Dunst et. al (1988), .

5. Limitations of the study

I choose to do my research project in the general field of Early Intervention (EI). For the past thirteen years I have been professionally involved in EI by training individual teachers and support services personnel who are charged with serving the educational and intervention needs of young children and their families. As a student, EI specialist, college teacher, my professional preparation and experiences have been devoted to seeking the best methods for meeting the educational and intervention needs of young children and their families. The interests in this topic grew out of this commitment to the field of EI; a commitment that is based on a philosophy of equal, mutually informing and supportive partnerships between families and professionals. One of the limitations of this study as cited by Espe-Sherwindt (1996), is its “bias” toward a family centered perspective. Family/professional relationships have been ruled for decades, by a hierarchical and controlling style by professionals. Professionals traditionally made decisions for families arresting from them control over their lives. More recently the role of professionals has taken an altered view; a view that asserts a family centered perspective. Instead of professionals as sole decision-maker for the family they become agents of families and responsive to their hopes, desires and concerns. However the research subject of this study enters the domain of subjectivity in human studies. And as Gabarino (2000), says:

> Human studies is the study of meaning that a person recognizes and the processes and strategies for communicating those meaning. This voice demands of us that we allow room for a perspective which moves beyond the constraints of a purely scientistic focus on objectivity and verification. It demands that we allow for subjective information to became a valid vehicle for understanding developmental issues. Human studies focus on the narrative accounts of subjective experience.... Human studies seek to illuminate subjectivity while acknowledging that such effort can only be partial. It recognizes that no matter how good the story, how poignant and evocative the language of that story, and how diligent the listener's efforts, there is always loss of validity from the teller of the story to the listener (p.43).

We must acknowledge that this shift in how information is shared and who controls the process of communication remains essential to the process. It is necessary for all the stakeholders to make things clear and keep in mind that communication is imperfect and inherent to human kind.

An additional limitation of this study is that there is no involvement of EI professionals and support services providers. Despite this fact the study dealt with issues of parent satisfaction, with services and formal resources of families, and family needs. It would have been interesting to collect data from service providers, agency personnel and EI professionals to complement the information gathered from parents. But time constraints and limits imposed by the purpose of the study didn't allow this to happen.

Summary

This chapter provides a brief overview of the study, describing the research context of the topic under analysis, the research questions, the research design used, the significance and limitations of the study.

CHAPTER II

Historical and Research Context

1. THE FAMILY IN EARLY INTERVENTIION: THE EVOLUTION OF FAMILY CENTERED SERVICES

1.1. Introduction

Early childhood education has been built on a foundation that has multiple and varied influences. The writings of the European philosophers of the seventeenth and eighteenth centuries such as Comenius (1592-1670), Locke (1632-1704), Rosseau (1712-1778), and Pestalozzi (1746-1827) provide it core concepts. No less important are the societal changes occurring during the 20th century. The changes in family structure, their movements from rural to urban settings, and the economic demands that have resulted in ever increasing need for women to enter the work force have all influenced our understanding of young children. One of the most important catalysts that promoted those social changes was World War II. While many of the social changes were well under way, World War II speeded the process up considerably. The war took many men away from their families and by necessity mothers' filled positions that required that they work outside the house, leaving childcare to others. Finally our understanding of young children has been radically changed through research. The research base has provide an empirical base that clearly demonstrates the importance of child's early years in the developmental cycle of human life.

Like the field of early childhood, special education can trace its roots to 18th century and 19th century European thinkers. Among those who have been influential are Itard and his attempts to teach "the wild boy of Aveyron", and Edward Seguin who developed approaches for working with children with disabilities, and Maria Montessori whose work with poor, urban Italian children gave birth to a worldwide early childhood movement. They were firm believers of the education of children with special needs (SN). Since then the recognition of the rights of individuals with disabilities has been the work of many, including researchers, teachers, parents, politicians and advocates. In spite of this general interest in young children who were diagnosed as disabled, it was not until the 1960's that much attention was given to young children with SN. Interest in early childhood education and general concern for education and welfare of children with SN became the cause of many parents, professionals and some key politicians who had family members with SN, e.g. President J.F. Kennedy, Senator Hubert Humphrey and Senator Lowell Weikert. These many individuals contributed to a significant shift in attitude at about the same time as the compensatory models for education of children who were considered environmentally at-risk were emerging. The resulting shift in attitude toward children with SN resulted in new public policy that encouraged research and development of model programs for early intervention (EI). Among the laws that emerged from the policy shift were three important pieces of federal legislation: P.L. 88/156 in 1963; P.L. 90/538 in 1968; and P.L. 94/142 in 1975. This federal legislation stimulated the development of a number of experimental EI programs in 1970's and 1980's, and resulted in research on the efficacy of these programs (Shonkoff & Meisels, 1990; Dunst, 1996).

One of the important legacy's of our early efforts in researching the efficacy of EI programs is the acknowledgement that the family is an essential focus of EI with children with or at risk for SN. How we arrived at this point is the primary purpose of this brief historical perspective that follows.

The decade long shift from a child oriented focus for EI to a focus on the family is one of the most revolutionary movements in the field of EI in the United States (US), and this changed emphasis has altered the way professionals work with parents (Beckman, 1996a). EI services in the US in the early 1970's focused on the individual child, with parents relegated to the role of passive bystander (Simeonsson & Bailey, 1990). Influenced by the emerging popularity of the behavior modification movement in the 1960's, the role of parents shifted from passive bystander to that of active participants as co-teachers for their children. However even with this change in focus the child remained the center of EI efforts and the family unit was still not recognized recipient of services. Finally, with the passage of the Public Law 99-457 in 1986, and the subsequent reauthorizations of the Individuals with Disabilities Education Act (IDEA) the family unit, i.e. the child and the child's parent(s) or caregiver(s) became the recipient and mediator of EI services. The evolution of the parent as playing a central role in the EI process was finally recognized legally. With this dramatic shift it was legally mandated that parents become active participants in their child's intervention process. In short, parents have become brokers, mediators and partners in the delivery of EI services for their children. This expanded focus on who is involved in the EI process continues as we uncover the important variables that influence a child's developmental outcome. For example, we initially focused on the child, however, as we expanded our understanding of children and their role in families, we shifted our focus of EI efforts from the child, to the parent, to the family, and now we find ourselves seeing the importance of extending our efforts to include the family in their community context (Simeonsson, 1996). This shifting of focus is grounded in conceptual contributions from several sources including; the Ecological Model of Human Development of Bronfenbrenner (1979), and the model of Transactional Development of Sameroff & Chandler (1975), among others. As such, services for children with SN and their families are now family centered with an ecological perspective and designated as *family centered* (Bailey *et al.*, 1986; Beckman, 1996b; Dunst, 1985; Singer & Powers, 1993). This paradigmatic shift meant that associated changes in philosophy and thought regarding support for families of children with SN has occurred. The shift in emphasis meant that service providers attended to the needs of the child, using a family systems approach that acknowledges the family as the primary organizing structure in the development of a child (Bronfenbrenner, 1979). As Gabarino (1992) states that "families are "the headquarters of human development" (p.71). Families mediate between individual and society. The family system is also embedded within a larger ecology of social systems and is thus affected by changes in the community and in society. This more complex systems perspective understands the interdependence of the many factors that influence children's general development. For example we are beginning to understand the influence extended families, friends, and neighbors, play in providing primary support structures to help parents to accomplish the complex tasks of parenting. Therefore, with the advent of family centered care the family is at the center of all decisions that affect the family ecology (Roberts, Rule & Innocenti, 1998). Family centered care as a principle recognizes the right of families to make decisions that affect their lives and enlists the support of others as appropriate. Furthermore, those providing the services must respect family rights and their preferences. The decision-making process of family centered care should includes identifying family needs, setting family established goals and priorities, choosing intervention strategies and selecting the service provider. As Roberts, Rule & Innocenti (1998), state, "... the degree to which families serve as the ultimate decision makers in this process is one measure of family centeredness" (p.56). Implicit in the concept of family centered care is the belief that families are capable of making decisions. Furthermore, even for those families who may have difficulty in making decisions, with support, they can become participant decision-makers. Another significant shift using this family centered approach is the way the family is viewed and how services are defined. Rather than seeing a family's service need from a deficit perspective, the family is viewed as manifesting strengths that can be used as intervention resources. As such, a family's strengths factor into the EI equation. These family strengths and their estimated needs determine the type of services needed and the resources, necessary to meet those needs. As such, strengths of families are emphasized as opposed to the view held by traditional service models that assumed that families manifested deficits and were structurally pathological because of the burdens of caring for a child with a disability (Singer & Powers, 1993). Family centered practices demonstrate more "hopeful and realistic view of families as having strengths and needs as opposed to the long-suffering and needy" (Friesen, 1993, p.ix) traditional view. By implication this strengths-based collaborative approach used to work with families, values contributions of both parents and professionals as opposed to a more expert oriented, professional centered "provision of service" model that existed previously. This shift in approach is illustrated in a statement by Carpenter (1997), "the days of professionals as experts have gone; what are needed now are informed supporters" (p.29).

1.2. A Historical Perspective

The family support movement consists of many grass-roots efforts to strengthen and empower families in their traditional caregiving roles (Singer & Powers, 1993). This movement surfaced as a major policy initiative in the field of SN. Parents of children with disabilities persuaded policymakers that families served as the primary source of support for the majority of these children (Singer & Powers, 1993). Family support programs were developed in order to help families take care of their own members.

This focus on family support in the field of SN is an extension of a larger international movement, a movement that reinforces the traditional role of the family. The consideration of the family as the focus for our EI efforts is particularly important at a time when high divorce rates, economic problems, geographic mobility, and mothers working outside the home are challenging the integrity of the family. These social and economic realities add to the general stresses of modern life to create difficult challenges for families and service providers' alike (Turnbull, Garlow & Barber, 1991, Singer & Powers, 1993, Gallagher & Tramill, 1998). The cumulative effect has been a change in the public debate toward family support policies in many countries during the 1980's and 1990's.

The concept of family support has not been universally adopted. However, some of the factors undermining family support include: "the movement for deinstitutionalization, the parental advocacy for change, critiques to the medical model, the elaboration of the social systems theory and an increase in the willingness of politicians to consider the adoption of family oriented policies" (Allen & Petr, 1996, p.59). Also parents' disappointment about their lack of participation in programmed decisions for their children, as well as their lack of decision in previous traditional models made them the principal agents of such a change (Turnbull & Turnbull, 1990).

Two concepts; *family-centered care* and *family support programs,* are fundamental concepts in the field of EI. Dunst, Johansen, Trivette and Hamby (1991), suggested that family centered care and family support share a common core of principles but also maintain an identity within their framework, which indicates that they are not a uniform principle. According to Roberts, Rule & Innocenti (1998):

> The distinction between the two is perhaps best understood by viewing family-centered care as the philosophical base of service systems that ensures that families are treated as equal partners in decision making with formal public and private human agencies. Family support, however, recognizes that every family requires some type of support and that it is society responsibility to provide such support. Each one is addressed separately (p.61).

Traditionally, through the 1970's, EI services were directed to the child as the sole recipient. This child centered approach is rooted in a mentality of the early 20th century when the out-of-home care of children was supported by a social science *zeitgeist.* Such a paradigm espoused that the heart of a child's difficulties were basic character or genetic flaws traceable to their parents. On this basis professionals determined that parents had no moral right to rear their children with disabilities (Collins & Collins, 1990; Petr & Spano, 1990; Turnbull & Summers, 1987).

Professionals in such a model were seen as the experts and the power of decision was clearly on their side. Families and children were left with no choices. While the social sciences model influenced care and treatment of children, advances in medicine were supporting the formation of a competing treatment model. This competing and more optimistic medically oriented treatment regimen was based on empirically based medical diagnosis and specific treatment protocols. Unlike the social sciences model that often couched the disease in terms of the parental flaws that seemed resistant to treatment, the medical model was premised on specific treatments to meet patients needs. This shift in thinking was critical in how medical and psychological services were delivered. The medical model played an essential role in viewing patients with treatable diseases and it influenced the notion of child centered practices which became an important reference for human services delivery. However, the medical model is not without its critics. This model, sees the locus of difficulty within the child, as such, diagnosis and treatment protocols established to “fix” the difficulties were professionally centered (Hanson & Carta, 1995). A lack of child progress in this model is often not viewed as a fault of the treatment protocol. Instead, like the social science view point, lack of treatment effect was attributed to lack of adherence on the part of the child or the family for not doing enough or not doing the right things for their children. Related to this model was the notion that formal services could or should “fix” families and children. Although this medical orientation was more optimistic than preceding models, its orientation to fix or heal the individual created its own set of issues, e.g. its deficit orientation. By seeing the individual from a deficit perspective the professional assumed the role of expert, i.e. the person who will take the responsibility to treat that deficit. The family was not considered part of the intervention process. Having neither strengths nor weaknesses the family was seldom consulted and certainly was not an integral part of the treatment plan. The concept of families being contributors and partners, i.e. family centered, was a model yet to be discovered. The medical model

"... has been criticized for its focus on the professional or facility rather than on the consumer, its limitation of consumer choice and responsibility, its concentration on pathology or deficits, and its too-narrow focus on the individual client as the recipient of care and the resource for change" (Bazyk, 1989; Donahue-Kilburg, 1992; Dunst, Trivette, Davis, & Cornwell, 1988; Larimore, 1993, Turnbull & Turnbull, 1990, cited in Allen & Petr 1996; p.59).

Within this reductionistic orientation where there is a prescribed treatment for an individuals diagnosed problem, the family was not considered. Moreover, when the family was included in the treatment it often meant that it was seen as a source of problems, or a barrier to overcome, but the family was always seen in a pathological perspective (Simeonsson & Bailey, 1990; Singer & Powers, 1993; Turnbull & Turnbull, 1990). An example of this type of judgment and its repercussion in practice are the parents of children with autism and psychoses in the 1940's and 1950's (Turnbull and Turnbull, 1990). In this era parents of children with autism were portrayed as being rigid and perfectionist and manifesting their own pathologies such emotional and depressive problems (Kanner, 1949; Marcus, 1977; Bettleheim, 1950; 1967). Bettleheim (1950) asserted that some parental attitudes, feelings and child rearing practices expose a child to such extreme stress that he/she responds with severe withdrawal, characterized as autism. The solution he proposed to solve this problem was a kind of "parentectomy", i.e. remove the children from their parents and institutionalize them so that they could be treated in a less primitive way. This attitude generated decades of guilt among parents of children with autism, when it is well known nowadays, that autism is related with neurological and organic problems and "no known factors in the psychological environment have been shown to cause autism" (National Society for Autistic Children, 1977).

Another example of this type of judgment and how it affected parent – professional relationships in a negative way is clearly described in Gallagher & Gallagher (1985) testimony about their experience as parents of a child with bronchial asthma:

> "One of the unfortunate components of the era in which our child was growing up was the predominant theory that parents could be the cause of bronchial asthma, rather than being among their victims. (...) Our feeling, which remains constant to this day, was to accuse parents of creating the problem whether the problem was asthma or autism or whatever, is akin to accusing the thunder of causing the storm" (p.237).

In the 1970's, the movement for deinstitutionalization forced rethinking ways of delivering services to families (Dunst, Trivette, & Deal, 1988; Turnbull and Turnbull, 1990). As it was described above, families were traditionally viewed as unable to care for their children with disabilities, and so the majority of the solutions found to overcome their lack of ability involved institutionalization. The movement for deinstitutionalization, which was based in normalization principles (Nirje, 1970; Wolfensberger, 1969; 1972), and the advocacy for persons with disabilities stressed the importance of providing the family adequate supports to care for their own children. While the concept of deinstitutionalization is based on sound research, ethical treatment and good public policy principles are very real pressures that put pressures on families and agencies alike to obtain and provide necessary supports. First, the numbers of children and families requiring services is increasing. The technological advances in the field of health have lengthened the lives of individuals with disabilities, which create new needs that require attention by families. This is particularly true concerning the number of children born prematurely or with low birth weight. Even though this is not a new condition the increased number of low birth weight and premature children surviving has created challenges to our service delivery system. Approximately 300,000 newborns weighing less than 2500 grams are born in the U.S.A. each year (Gallagher & Tramill, 1998). As more of these children survive social services and medical professionals are pressed to design services to support these children and their families.

Another historical influence that had an important role in shaping family centered practices, was the elaboration of family systems theory. Paralleling our understanding of overall child development, the 1960's and early 1970's gave rise to our grasp of the many interactive factors that influence our understanding of family functioning (Beckman, Robinson, Rosenberg, & Filer, 1994). Within this paradigm, the development is best understood by examining the family and the transactions among its members as well as the different ecological contexts were the family exists (Sameroff & Chandler, 1975). Within this systems approach it is insufficient to isolate one member from the family as a whole. That is, an individuals developmental outcome is the end product of the behavioral transactions among those who comprise the entire family unit. More recently family systems theory applications have been enlarged to families of children with disabilities (Bailey & Simeonsson, 1988; Bronfenbrenner, 1979; Dunst, Trivette, Hamby, & Pollock, 1990; Fewell & Vadasy, 1986; Gabarino, J. & Associates, 1992; LeLaurin, 1992; Turnbull & Turnbull, 1990).

According to Simeonsson and Bailey (1990), when we do an analysis of the historical evolution of parent involvement in the field of SN we can identify four distinct phases:

(1) In the 1950's, parents played a more passive role, and the responsibility of programming was totally devoted to professionals, whom designed and implemented the programs in an outside facility or at home; (2) In the beginning of the 1970's we can see a new phase where both professionals and parents saw the need for a more active involvement in programming for their children. This importance was recognized and formalized by the American legislation in 1975 – Public Law (P.L.) 99-142 – The Education for All Handicapped Children Act, nowadays designated Individuals with Disabilities Education Act – IDEA. Some years later the Portuguese legislation (Decreto-Lei n° 319/91, de 23 de Agosto) reflected the same the principles of the American legislation concerning family involvement; (3) With the progressive and active involvement of parents we can describe a new phase were the image of parents as cotherapists and coteachers is consolidated. This aspect implemented the training of parents and other family members, so that they could play the roles of

therapists and teachers. Many professionals believed that parents should be teachers, and, ultimately, that "good" parents were those who adopted the teaching role under the supervision of the professional (Benson & Turnbull, 1986 cited by Espe-Sherwindt, 1995). The behavior modification model and its utilization in the field of special education, was in part responsible for the extension of the above roles to parents, demonstrating the success of parents in modifying child behavior (Kaiser & Fox, 1986). Albeit the increased involvement of the family, the focus of intervention at this time was exclusively child centered; (4) In the 1980's and with the Early Intervention programs the family and the child began to be seen as both in need of services and the target of intervention. The family is itself recipient of services and this is formally recognized through the requirements for family assessment, family goals, and family services described by the provisions of PL.99-457 of 1986, now PL.105-17 of 1997.

Family involvement in EI must be considered as an answer to family needs in "an inclusive and systems oriented manner and not only focused on concerns directly linked with the needs of the handicapped infant" (Simeonsson & Bailey, 1990, p.433).

The goal of family involvement in EI is helping parents become competent and capable, through the provision of resources (formal and informal) within the community, so they can influence in a positive way the education and development of their children with or at risk for SN (Dunst, Trivette, & Deal, 1988). This systems oriented manner of helping families is reflected in Bronfenbrenner's (1979) statement:

> Whether parents can perform effectively in their child-rearing roles within the family depends on the role demands, stresses, and supports emanating from other settings... Parent's evaluations of their own capacity to function, as well as their view of their child, are related to such external factors as flexibility of job schedules, adequacy of child care arrangements, the presence of friends and neighbors who can help out in large and small emergencies, the quality of health and social services, and neighborhood safety. The availability of supportive settings is, in turn, a function of their existence and frequency in a given culture or subculture. This frequency can be enhanced by the adoption of public policies and practices that create additional settings and societal roles conducive to family life (p.7).

The family empowerment model, described by Dunst, Trivette, & Deal (1988), that will be elaborated on in following chapters, is a specific example of this form of family involvement.

The concept of family-centered was first used in the health care field in the 1960's as part of efforts to improve both obstetric and nursing practices (Hungerford, 1964; Widenbach, 1967, cited in Trivette *et al.*, 1995). According to Trivette *et al.* (1995), Bronfennbrenner (1975) introduced the term to the EI field in the 1970's. Since then the term family-centered has been widely used but there is considerable differences in how to define and operationalize the term among the different fields. According to Dunst & Trivette (1996), family centered helpgiving is comprised of both relational and participatory elements. Relational elements comprise behavior commonly associated with good clinical practice such as active listening, compassion, empathy, respect, being nonjudgmental, and so on, as well as professional beliefs about and attitudes toward families, especially those pertaining to parenting capabilities and competence. The participatory elements comprises practices that are individualized, flexible and responsive to family concerns and priorities, and that provide families with opportunities to be actively involved in decisions and choices, family-professional collaboration, and family actions to achieve desired goals and outcomes. It is the simultaneous use of both elements by professionals that differentiates the family-centered approach from other approaches to working with families (Dunst & Trivette, 1996).

Allen and Petr (1996) worked on a consensus definition of the term family-centered. In order to do it they reviewed more than 120 articles from various disciplines around the concept of family centered and they found 28 definitions of the concept. Using a content analysis of the definitions they synthesized a new definition that was debated and modified among various professionals and parents. Two variables, *family choice* and *the adoption of a strengths perpective*, were determined as essential to the concept of family centered and together they guide the debate. The new definition is:

> *Family-centered service delivery,* across disciplines and settings recognizes the centrality of the family in the lives of individuals. It is guided by fully informed choices made by the family and focuses upon the strengths and capabilities of these families (p.68).

According to Allen & Petr (1996), "family choice in family-centered practices means that the family is seen as the director and consumer of the service delivery process, as the party with ultimate decision-making authority" (Bailey *et al.* 1992; Bazyk, 1989; Donahue-Kilburg, 1992; Dunst, 1991; Kramer *et al.*, 1991; McGonigel, 1991; Nelkin, 1987; Summers, Turnbull *et al.*, 1989) (p.68). Family choice as described by Allen & Petr, (1996) in family centered practices should then regard different areas such as:

- **The Definition of the Family**

  "A family is two or more people who consider themselves family and who assume obligations, functions, and responsibilities generally essential to family life" (Barker, 1991, p.80). The membership and structure in a family is a function of cultural and ethnicity aspects. For some cultures, extended family is an important support. Also, the family nowadays is not the traditional family composed of father, mother and children. For example there are a number of different structures such as single parents, grandparents and grandchildren. The family-centered professional has to respect and consider the choices of family membership that each family makes.

- **Who Makes the Decisions**

  Family-centered professionals recognize that parents or caregivers are the primary decision-makers and they ultimately are responsible for making choices regarding care.

- **The Unit of Attention**

Family-centered professionals respect who the family wants to involve in the process of service delivery. The child-caregiver dyad may be a start to establish the initial relationship with professionals, but then the family may want to reduce or expand this unit.

- **The Nature of the Family-Professional Relationship**

  The recent emphasis of the family-centered approach places families in control of the service delivery process, with the professionals serving as "consultants".

- **The Sharing of Information**

  Information between families and professionals flows in both directions, and families, as members of the intervention team, have access to the same information as professionals. Families can choose the form in which the material is provided and communication should be free of jargon, match the developmental demands and abilities of the recipient and take into account the different languages that families may speak.

- **The Identification of Needs, Goals and Intervention.**

  Families in family-centered practices are active partners in identifying their needs and establishing goals and priorities. Professionals address other potential areas of concern to the family, but the family may accept or refuse these ideas.

Nevertheless when we consider the issue of family choice it is important to refer also some of the limits to choice such as (Allen & Petr, 1996):

- the capacity of the person involved to make the choice;

- parent and family *readiness* to take responsibilities;
- the legal framework within which choices must be made;
- the logistical aspects.

Shelton, Jeppson and Johnson (1987) of the Association for the Care of Children's Health, presented a list of key elements of family-centered care that comprise the following elements:

> 1. Recognition that the family is the constant in the child's life while service systems and personnel within those systems fluctuate;
> 2. Facilitation of parent/professional collaboration at all levels of health care;
> 3. Sharing of unbiased and complete information with parents about their child's care on an ongoing basis in an appropriate and supportive manner;
> 4. Implementation of appropriate policies and programs that are comprehensive and provide emotional and financial support to meet the needs of the families;
> 5. Recognition of family strengths and individuality and respect for different methods of coping;
> 6. Understanding and incorporating the developmental needs of infants, children and adolescents and their families into health care delivery systems;
> 7. Encouragement and facilitation of parent-to-parent support;
> 8. Assurance that the design of health care delivery system is flexible, accessible and responsive to family needs (p.60).

The type of interaction among families and professionals in family centered practices is the one of collaboration and equality, but a more recent emphasis of this model places the family as the main decision maker (Allen a & Petr, 1996). Families value the professional knowledge and expertise but feel that only they have can determine how to incorporate the professionals recommendations in a way that is successful to their needs (Levinton *et al.*, 1992).

Overall and with this evolution what is desirable is that parents became *primary decision-makers* in responding to their needs as a family and to the specific needs of their children with special needs. Professionals within the family-centered model function as "consultants" to the families who in turn are firmly in control of the service delivery process (Bazyk, 1989; Donahue-Kilburg, 1992; Dunst *et al.*, 1988b; Roberts & Magrab, 1991; Lee, 1993; Tower, 1994, cited in Allen & Petr, 1996). Family/professional collaboration, becomes a crucial issue concerning the success of EI programs and services.

The other core element in family-centered practices is families' strengths and capabilities. All families have strengths and capabilities and we as professionals should be able to identify the existing strengths in order to built on them, instead of correcting deficits; a more traditional role of professionals in more traditional practices (Dunst, Trivette, & Deal, 1988). Family-centered practice places a premium on professionals respecting the inherent strength and capabilities of all family members (Dunst, Trivette, & Deal, 1988; Simeonsson & Bailey, 1991). The more one belives in families strengths and capabilities and their capacity to make decisions, the more choice they will be provided, which contributes to an increase in families' sense of competence (Allen & Petr, 1996).

Finally and according to Allen & Petr (1996), "Standards for family-centered practice must be based on the dual, interrelated cornerstones of *choice* and *strengths*, which are both at the core of family-centered practice and establish the context for a variety of other decisions and interactions to take place" (p.74).

2. PRACTICAL AND THEORETICAL ASPECTS UNDERLYING FAMILY-CENTERED PRACTICES

2.1. Practical contributions

2.1.1. Programs for disadvantage children

The assumptions of family-centered practices were built on a number of practical and theoretical considerations. In terms of practical contributions the roles of parents as co-teachers or co-therapists, program reports indicating variability of family participation in parent-mediated intervention, changing family patterns and the growing compensatory education movement directed toward families with children at environmental risk (Robinson, Rosenberg, & Beckman, 1988).

The compensatory education movement is an important precursor to EI (Peterson, 1987), and to effective ecologically based ecological intervention. The concept of EI came primarily through poverty programs such as Head Start and Follow-Through, the two most visible compensatory education programs. These programs were aimed to compensate for real and perceived deficits in the early experience and education of children classified as economically disadvantaged. These educational intervention programs were part of a massive federally funded anti-poverty program established in the mid-1960's in the United States of America. Resulting from the political climate of the 1960's during the Kennedy and Johnson administrations federally subsidized programs were establish to alter the lives of nearly 35 million citizens who were estimated to be living in poverty and without adequate education, food, housing and health care. They viewed these problems and conditions of poverty so widespread that it was deemed a threat to the nation's social and economic well being. In order to ameliorate this situation they called for immediate action and massive anti-poverty federal programs emerged. This War on Poverty encircled a basic belief that education would help children to break out of the cycle of poverty (Zigler & Valentine, 1979). Head Start was one legacy of this period (Zigler & Valentine, 1979). What began as the responsibility of the Office Of Economic Opportunity; Head Start constituted the first comprehensive approach to early childhood intervention. It emphasized the development of a multidimensional and comprehensive system of compensatory education, health services, nutrition, social services and parent involvement to minimize developmental risks among preschool children (Zigler & Valentine, 1979). The program was designed to be a family-based comprehensive anti-poverty program, not just an early education or child-care program. It comprised a multi-component, comprehensive, multidisciplinary intervention approach that addressed needs of both children and families encompassing preschool education classroom programs, and programs providing medical-dental services, nutrition program, psychological supports, social services, parent education, and a volunteer programs (Peterson, 1987). It also included staff training to prepare low-income parents for job roles within Head Start Centers. Head Start emphasized parent involvement much beyond the traditional prekindergarten or elementary school practices of the day. Its view of family/professional relation as a shared decision making process was revolutionary (Shonkoff & Meisels, 1990). The idea was to bring parents into full partnership with professionals in the intervention process with their child and in the operation of a social action program in their own community (Peterson, 1987). Because of its comprehensive approach, Head Start brought to the intervention process a range of different professionals from various disciplines. The Head Start characteristics described above included comprehensiveness, parent involvement practices, and a multidisciplinary approach made it a precursor to the EI practices of today. In 1972, an amendment to the legislation that created the Head Start, P.L. 94-424, mandated services for children with special needs. This legislation was an important contribution to providing services to children who were traditionally excluded from EI. Furthermore, the legislation acknowledged the importance of EI service for children with disabilities. Under this legislation Head Start Programs reserved no less than 10 percent of its enrollment for children with special needs.

Although the target of a number of critics (Condry, 1963; Westinghouse Learning Corporation, 1969; Jensen, 1969), Head Start's successful, contributions and its legacy are incontestable. Head Start remains an important educational program in the lives of millions of disadvantaged children and their families each year. Its value has been rewarded with increased funding and increasing enrollment targets (Dunst, 1996). The Early Head Start program was created to provide comprehensive, intensive and continous child development services to low income families with children under age three (Meisels & Shonkoff, 2000).

The lasting effect of Head Start experiences were questioned, when research findings suggested that cognitive gains made by children who participated in Head Start washed out during their elementary grades. These results suggest that a short-term preschool program was not enough to overcome the pervasive effect of impoverished environments on the development of young children. To offset these findings additional federal funding was made available to create Project Follow-Through; an upward extension of Head Start into the elementary school. This program, like the original Head Start program, maintained the philosophy of comprehensive services (Peterson, 1987).

According to Dunst (1996), other compensatory programs initiated in the 1960's became important to demonstrate the experimental effects of environmental interventions. These included the *Perry Preschool Project* (Weikart *et al.*, 1978), and the *Early Training Project* (Gray & Klaus, 1970) and the *Institute for Developmental Studies Early Enrichment Project* (Deutsch *et al.*, 1983). These programs, among others, were included the Consortium for Longitudinal Studies (1983), a group of eleven early intervention projects to study the efficacy of serving children and families who were considered at environmental risk (Leitão, 1989; Dunst, 1996,). The consortium was created to verify the outcomes of these environmental interventions for children of low-income families. These studies provided clear "...evidence that high quality preschool educational programs had positive, long-term effects on subsequent school experiences of participating children" (Condry, 1983, p.28).

Another important program included into a new generation of experimental EI programs for disadvantaged children was the Carolina Abecedarian Project initiated in 1972 by the University of North Carolina – Chapel Hill. This was a preschool educational program for children for low-income families who were randomly assigned to experimental and control groups (Ramey & Campbell 1991). Experimental subjects participated in a child-care program from birth to age 5 years with a curriculum specifically designed to stimulate development across domains including language, cognitive, fine motor, social, adaptive and gross motor development. At school entry, half of each group was randomly assigned to a kindergarten to second-grade school-age resource teacher who worked with parents and teachers. Both experimental and control groups continued to received nutrition and social services. The follow-up research studies demonstrated clear differences between the two groups of children starting at 12 months-of-age. The children who attended the preschool scored significantly higher than the controls on measures of cognitive development (Ramey & Campbell, 1977, 1984). According to Bryant & Maxwell (1997), the Abecedarian Intervention Project was an important program because it lasted longer (from birth to age 8 years) than other programs provided for disadvantage children. This length of intervention may be the explanation for the maintenance of cognitive and language gains into adolescence. As described earlier, many EI programs were aimed to ameliorate the adverse conditions effecting the development of young children and their families who were at environmental risk.

These pioneering programs demonstrated the positive effects of early education in overcoming the negative affects of poor child rearing environments. Other groups providing similar positive results with children who were considered as representative of either biological or established risk categories. Introduced by Tjossem (1976) a developmental risk classification system was developed and is the most widely used approach to classifying risk conditions among infants and young children. The three categories can be defined as:

1. Established risk refers to children whose early developmental disabilities are presumed to be related to diagnosed medical disorders. Examples of such disorders include Down syndrome, inborn errors of metabolism (e.g., Untreated PKU and other disorders of the body's chemical system), multiple congenital anomalies (e.g., cleft palate);
2. Biological risk refers to children who have a history of biological factors during their prenatal, neonatal, or postnatal periods that could have developmental sequelae. Such factors include metabolic disease and nutritional deficiencies in the mother, obstetrical complications, low birth weight, anoxia, and prematurely, among many others;
3. Environmentally risk refers to children whose experiences are significantly limited during early childhood in areas of maternal attachment, family organization, health care, nutrition, and in opportunities for physical, social and adaptive stimulation. Such factors are highly correlated

> with a probability of delayed development. (Meisels & Anastasiow, 1982, p.260)

The concerns with the education of young children with SN are a cumulative result of historical influences among the fields of regular early childhood education, the education of children environmentally at-risk and the general field of special education, i.e. children considered at-risk because of either biological or established diagnoses. In short, our general understanding of risk conditions and the efficacy of intervention efforts are the result of the combined influences of social-historical and political developments, advocacy on the part of parents, and scientific influences.

Based on our emerging understanding of the many factors that appear to influence general child development, federally funded research and demonstration projects were designed to assess the efficacy of EI. While each project had its primary focus they all targeted young children with the goal of altering developmental outcomes. Among these many projects a few are notable for they findings and they include: *The Milwaukee Early Intervention Project* (Garber & Heber, 1977; Garber & Heber, 1981). It was designed to reduce the incidence of mental retardation among poor, urban families at high risk for producing such offspring. *The Carolina Project (*Ramey & Campbell, 1977), *The Project "Field"* (Field, 1981), and *The Battelle Institute Evaluation,* (Stock *et al.*, 1976) targeted similar poor children and families to test the efficacy of EI (Peterson, 1987). For example, the latter study evaluated the outcomes of children who participated in 32 Handicapped Children's Early Education Program (HCEEP), a model intervention program for young children with

SN. The outcome reports that children who participated in these EI programs not only demonstrated developmental gains, but these early educational experiences also had a positive impact on their families and generally improved the quality of their lives (Peterson, 1987).

Considering the research done in the field of EI it is important to underline the distinction made by Guralnick (1989, 1993) about what he postulated as the first generation research and the second generation research. The first generation research tried to ask questions about the global efficacy of early intervention, posing questions such as: "Was early intervention effective?"

According to Guralnick (1997), despite the existence of a set of methodological problems, "the results of two meta-analysis (Casto & Mastropieri, 1986; Shonkoff & Hauser-Cram, 1987) as well as more traditional views of effectiveness (Guralnick & Bennett, 1987) support the generally held opinion that early intervention programs are indeed effective, producing average effects sizes falling within the range of one half to three quarters of a standard deviation" (p.11). These results come from research conducted prior to 1986 and were essentially comparative studies between children and families receiving newly developed early intervention services and children and families receiving no services or supports. In 1986 the passage of PL. 99-457 and the mandate for the Individualized Family Service Plans (IFSPs) lead to a new context for the delivery of services in EI programs for young children and their families. The rapidly evolving service system, further stimulated by the new law has altered permanently the ecology of EI programs for children and their families, creating opportunities for a much broader understanding of the effects of early intervention on children and families (Guralnick, 1997). This marked a new generation of research designated by Guralnick (1989, 1993) as the second generation research. According to Guralnick (1993),

> In contrast to the more global scientific and political questions addressed by the first generation investigators, second generation research... is designed to address questions about specificity, ... [and] ... the far more demanding task of identifying the child characteristics, family characteristics, and program features that interact to optimize one or more outcomes within the framework of contemporary early intervention services (p.137).

Thus second generation researchers ask questions about the conditional and unconditional effects of EI provided to children and families under specifiable conditions (Dunst, Trivette, & Jordy, 1997). According to Krauss (1997) research on early intervention, in the 1990s is less concerned with substantiating the impact of participation on families and is more concerned with substantiating the means by which early intervention programs can be supportive of a range of families (Bailey, Buysse, Edmondson & Smith, 1992; McBride, Brotherson, Joanning, Whiddon & Demmitt, 1993).

2.2. Theoretical contributions

The phases of parental involvement described in the beginning of this chapter are reflective of the expanded target of intervention efforts. Drawing from our increasing understanding of the factors that affect children's development, EI has progressed and changed through the years. For example, while EI began as a child centered endeavor, we soon realized that participation from parents enhanced the effectiveness of the intervention. Stemming from other research EI expanded the system of delivering services to include other family members and the community as a whole. The end product of this evolution has established a conceptual basis for the field of EI that is best described as ecological and systemic (Simeonsson, 1996; McWilliam, Winton, & Crais, 1996). This conceptual metamorphosis borrowed heavily from the fields of child development, and family systems theory.

The past one-half century has seen a tremendous growth in our understanding of infants and young children and the field of EI has been a beneficiary of this growth in knowledge. Our understanding of the capacities of infants and young children, as well as the impact environment plays on overall development has helped clarifying the importance of early caregiver-child relationships on a child's early development. Furthermore, we now understand how these early experiences influence children's general health and development. In short, these vital theoretical connections have provided the field of EI a basis for understanding the contributions of various individual factors that determine a child's general development and to identify specific patterns of environmental stimulation likely to optimize developmental outcomes (Guralnick, 1997). Of particular importance to the field of EI was research that provided the conceptual foundation that influence our understanding that boarder context plays in influencing overall child development. According to Guralnick (1997):

> "Of special interest were those contextual (and more distal) factors related to social support provided by family, friends and the community in general; the availability of financial and material resources to families; the degree of family coherence; the level of marital stress; and parenting practices and developmental expectations established through intergenerational and cultural standards" (p.5).

These contextual factors together with child characteristics will influence closer interaction patterns within the family and determine the ultimate outcome on child's development. Guralnick (1997), identified three family interaction patterns:

1. The quality of parent-child interaction;
2. The extent to which the family provides the child with appropriate experiences with surrounding social and physical environment;
3. The way which the family ensures the child's health and safety. (p.5)

The complex interchange among these influential factors establish the foundation of contemporary developmental models. For the purpose of this research I will first summarize our current understanding of general child development. I will then outline three models that have provided us essential conceptual frameworks that are fundamental to our understanding of the contexts in which child development takes place; Transactional Model (Sameroff, 1993; Sameroff & Chandler, 1975), Ecological Model (Bronfenbrenner, 1979), and Social Support Model (Dunst, 1985).

2.2.1. Child development

According to Dunst (1996), in the 1950's and 1960's key contributions to the field of child development stressed the importance of a child's early years in their general development. Contributions to this changed view of children and their overall development included several books authored by eminent researchers. Among those works are a few that provided a strong foundation for our understanding of children including a book published by Hebb (1949), *The Organization of Behavior*, where he asserted the value of early perceptual learning as a basis for later learning. Following Hebb a book by Hunt (1961), *Intelligence and Experience*, in which he extensively reviewed important research postulated the relationship between a child's intellectual development and environmental influences. He proposed that children should be provided with an array experiences in their early years and by optimizing their interactions with the environment children will achieve at a substantially faster rate of intellectual development. Finally, a book by Bloom (1964), *Stability and Change in Human Characteristics* provided yet another key piece to the development puzzle. After reviewing a number of longitudinal studies on human development Bloom like Hunt affirmed the critical nature of the early environment and experience in determining a child's later developmental accomplishments. Combined, these three authors helped establish the vital role played by environmental factors in determining a child's behavior and overall development outcomes in their early years, i.e. if their ultimate developmental outcome is either positive or negative.

Another important figure in the field of child development was Arnold Gesell, a pediatrician and psychologist who through systematic observations of infants compiled a large body of normative data on human development (Gesell, 1925, 1929, referred to in Peterson, 1987; Shonkoff & Meisels, 1990). Like the above authors, Gesell also regarded the early years as critical to a child's future development.

Two other pioneers in the field of psychology are vital contributors to our general understanding of the development of young children. While they approached child development through two different portals both arrived at the same point and emphasized the influence of environment on development. Although worlds apart in terms of theoretical principles, the theories developed by Watson (1928) on infant operant learning theory, and Piaget (1952) on infant cognitive development (Dunst, 1996; Peterson, 1987; Shonkoff & Meisels, 1990) contributed a rationale for EI.

During the first half of the twentieth century the behaviorist view of development gained a relevant place. The behaviorists believed that developmental outcomes among children are controlled by environmental forces. They contended that children developed and became what they were through complex stimulus-response interactions with their environment. To them development was a continuos process with no divisions or defined stages. Development occurs as children learn, and learning is a gradual cumulative process.

The most charismatic early representative of behaviorism was John B. Watson who wrote: "Since the behaviorists find little that corresponds to instincts in children, since children are made not born, failure to bring up a happy child, a well adjusted child – assuming bodily health – falls upon the parents shoulders. The acceptance of this view makes child rearing the most important of all social obligations" (Watson, 1928, p.8, referred to in Shonkoff & Meisels, 1990). Watson concluded that environment is the supreme force in child development. Children's behavior could be molded in any way adults wish by carefully controlling stimulus-response associations.

Behaviorism stressed the role of environment and stimulation in child development and it had a tremendous impact on the intervention practices in the field of special education.

Around 1950 the work of Jean Piaget created a revolution in terms of developmental thinking. Postulating an interactive view of development. Piaget set the stage for the rapprochement in the polarized nature-nurture debate, i.e., neither the environment nor the organism were responsible for development, but they mutually influence one another (Shonkoff & Meisels, 1990). Piaget's (1960, 1963, 1970) stage theory of cognitive development conceptualized cognition as a biological system, and like all biological systems it is governed by two basic aspects organization and adaptation. Cognition functions with an organization, and as an adaptive system, allowing the organism to adapt to its environment. For Piaget the process of adaptation is comprised of two complementary elements assimilation and accommodation. These elements are complementary because of what Piaget considers to be a fundamental factor in development the notion of equilibrium. Piaget proposes that an organism's adaptation to its environment involve an equilibrium between the activity of the organism on its environment and the activity of the environment on the organism. The organism is always striving for balance in this system. Balance or equilibrium is never achieved because of either environmental demands on the organism or the organism's demands on the environment. The factor of equilibration is the energy behind all cognitive development. The double process of assimilation and accommodation that contributes to adaptation makes the child capable of forming what Piaget called a schema; an organized response sequence to environmental events that adapts as interaction with the environment and experiences demand. A schema is the basic component or foundation of cognitive development. Thus for Piaget, intelligence is a developmental process, it is not fixed, it evolves through experience with one's environment. He outlined a hierarchical set of four distinct developmental stages through which all individuals pass in the same order, albeit at different rates:

Stage 1: Sensorimotor Intelligence from 0–2 years;
Stage 2: Preoperational Thought from 2-7 years;
Stage 3: Concrete Operations from7-11 years;

Stage 4: Formal Operations from 11 years on.

Each stage is prerequisite to the next one with each stage building upon the intellectual achievements of its precursor. The child integrates knowledge and thought from the previous stage into a new knowledge structure which is qualitatively changed, transformed and adapted. Cognition becomes increasingly more sophisticated in each successive stage.

In looking at early development from a Piagetian point of view several basic implications are evident. Intelligence can be modified through experience. An outcome of a child's constant interaction with the environment is an active engagement in problem solving, evaluating discrepant situations, and constant revaluation of the events. The end product of these constant interactions between a child and the environment is general cognitive development. If we provide the child a variety of environmental experiences we assume that he/she develops an enhanced cognitive understanding of the world. If a child's experiences are limited due to a deprived environment, including conditions created by a disability, learning more sophisticated cognitive schema may be limited. A child's failure to achieve the cognitive milestones of a particular stage will intercede with the movement to more advance forms of cognitive thought. This relationship between environmental events and general cognitive development clearly demonstrates the importance of a rich environment for promoting a child's optimum development, but also stresses the importance of early experiences in a child's life.

psychoanalytic framework he described the developmentally destructive impact of sustained isolation and understimulation on infants living in orphanages. These poorly staffed institutions eventuated in a condition that Spitz (1945) characterized as a syndrome called *hospitalism.* Spitz described a set of symptoms he observed among infants who were deprived a nurturing early relationship. These particular infants manifested growth retardation, maladaptive social relationships and health problems as a consequence of such deprived environments.

A parallel set of studies were conducted by Skeels and Dye (1939) to determine the extent to which negative developmental outcomes of infants attributable to their early environmental deprivation could be modified if richer environments were provided. Skeels and Dye transferred 13 children under the age of 3 from a deprived environment in an overcrowded orphanage into an institution for women with mental retardation, where they receive a great deal of attention and stimulation. The results showed clear differences between the group of children who had been transferred and the control group, children who stayed in the orphanage. The first group of children showed a mean IQ gain of 27.5 points, compared to a mean loss of 26.2 IQ points among the control group. Skeels & Dye (1939) demonstrated that a responsive and stimulating environment could reverse the effects of negative and deprived early experiences. In a follow-up study twenty-five years later, Skeels (1966) compared the two groups and found that the group differences remained. These impressive results attested to the lasting effects EI can have on the participants. The positive effects of EI were evident early on and they maintained themselves into adulthood.

According to Shonkoff & Meisels (1990), " the growing empirical literature generated by such studies highlighted the malleability of early human development, thereby establishing a rationale for intervention within the early years of life" (p.13).

Along with Sptiz and Skeels and Dye it is important to discuss the contributions of Bowlby (1951). With the support the World Health Organization Bowlby studied the problems of homelessness and maternal deprivation and their consequences for mental health in children (Shonkoff & Meisels, 1990). From this work Bowlby (1951) developed his theory on *attachment*, a concept he used to describe the privileged affective relationship that the baby establishes with his mother or primary caregiver during the early years of life. He also demonstrated the vital importance of the mother child-relationship for healthy child development.

Based on the foundation established by these and other researchers the Kauai Longitudinal Studies from Werner, Bierman and French (1971), followed up from prenatal period through adulthood, more than a thousand children born on the Hawaiian island of Kauai. This study documented that when family and cultural variables nurture development, children with perinatal complications had generally positive developmental outcomes. However, when family and cultural variable impede development there is an increased probability that even children without biological complications will develop developmental deficits some time later. This study provides empirical evidence of the importance of a quality caregiving environment and maternal education for determining positive developmental outcomes for children (Shonkoff & Meisels, 2000).

The research presented above reinforces the importance of primary relationships for determining positive development for children. These data also help us to understand the additive affects that EI can have when parents and families are directly involved in the intervention process. In this way the scope of EI is expanded to include the proximal relationships of the child, namely the mother, father and the significant others, i.e. the family.

Grounded in this growing knowledge base on development our understanding of children continues to evolve. This growth has cumulated in changed models for understand overall child development, i.e. new schema. For the last several decades, a number of contemporary models for development were conceptualized. They have played important roles in determining how EI is implemented and this evolved theory base provides the foundation for newer models that will determine the organization of EI practices of tomorrow. The following section will provide a glimpse of the models that influence today's practice.

2.2.2. Transactional Model of Development (Sameroff & Chandler, 1975)

The transactional model, initially articulated by Sameroff and Chandler (1975) in an attempt to explain the variations in the developmental outcomes among of infants at-risk. According to Shonkoff & Meisels (2000), their model is one of the most influential conceptualizations of the reciprocal relationship that exists between an organism and its environment. Sameroff & Chandler (1975) argued that neither biological nor environmental factors alone are enough to predict outcomes for high-risk infants. Their approach considers both environmental and biological contributions to development, but stresses that the impact of these contributions is mutual and they change as a function of time. Neither organism nor environment is necessarily constant over time. Characteristics of both the child and his/her environment change at each moment, month or year. Furthermore these differences are interdependent and change as a function of their mutual influence on one another. The child changes his/her environment and in turn is changed by the altered environment that he/she has helped to created (Sameroff & Chandler, 1975). Building on the notions of previous researchers who proposed the concept of interactions between an organism and its environment, these authors propose a more dynamic theory that incorporates the term transaction. The concept of transaction introduces time into the model. Such a model is assumed to be a dynamic process of change over time among the complex interactions between the child and his/her environment that explains development. As with Piaget's model, there is an assumption of reciprocity but in this model it is assumed that both the actor and the agent are changed as result of their exchange. This means that a child's specific characteristic may trigger a response from the parent, which in turn influences child's behavior at a different time. According to Sameroff & Fiese (2000) "changes in behavior are the result of a series of interchanges among individuals within a shared system following specifiable regulatory principles" (p.149). Changes in behavior not only occur over time, as result of the transactions between the child and his/her environment, but we also need an interpretive framework to analyze those changes. Figure 1 illustrates the developmental regulations through transactions between parent and child behavior, preconceived by this model. Those transactions make both the parent and the child changed from an initial state to a different state at succeeding points in time. The child's arrows get thicker as the child increases in age, because of the rate of learning and development that occur during that period of time. The arrows from child to parent represent changes in the child that transact with the parent and ultimately change the parent's behavior or attitudes. The downward arrow reflects changes in the parent that are directed toward eventual changes in the child.

In this model the authors considered three important variables that influence development, and they are the environtype, the genotype, and the phenotype. The environtype has a social organization that regulates development just as the genotype has a biological organization. Each individual's environtype contains regulatory patterns and it is comprised of subsystems that not only transact with the child but also transact with each other. The interaction among these subsystems is complex and transactive (Sameroff, 1975; 1983). That is, the impact of an event is due to the ongoing reciprocal transactions among the systems (Sameroff & Chandler, 1975). They consider three levels of environmental factors within the environtype, the culture, the family and the individual parent. (Sameroff & Fiese, 2000). At each level there are regulatory patterns that guide development. These regulatory patterns are named codes and they

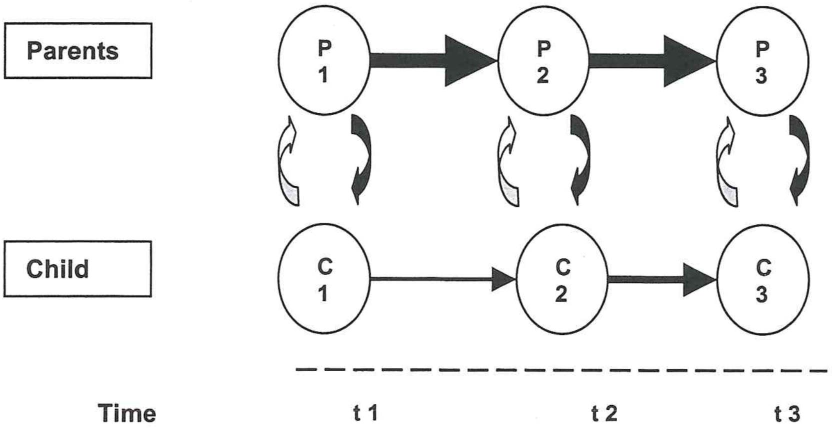


Figure 1. Developmental regulations through transactions between parent and child behavior (Adapted from Sameroff, J.A. & Fiese, B. (1990). Transactional regulation and early intervention. In S.J. Meisels & Shonkoff, J.P. (Eds.), *Handbook of early intervention.* Cambridge: Cambridge University; p.135.)

influence the experience of the developing child partially through the beliefs, values and personality of the parents – the individual code of the parent; partially through the family's interaction patterns and transgenerational history – the family code; and partially through socialization beliefs, controls and supports of the culture – the cultural code (Sameroff & Fiese ,2000).

According to (Sameroff & Fiese, 2000), "The overall model of developmental regulation, the child behavior at any point in time is a product, of the transactions between the phenotype (i.e., the child), the environtype (i.e., the source of external experience) and genotype (i.e., the source of biological organization)" (p.143).

Of equal importance was the fact that Sameroff and Chandler (1975) transactional model introduced the notion of "continuum of caretaking casualty" to describe the transactional effects of the environment and experience on development. This notion contrasts with the previous existing paradigm of "the continuum of the reproductive casualty" (Pasamanick & Knoblock, 1961), adopted by the maturationist view of development. "Although reproductive casualties may play an initiating role in the production of later problems, it is the caretaking environment that will determine the ultimate outcome" (Sameroff, 1975, p.274). The conceptualizations that the transactional model presents are of extreme importance and have major implications for the field of EI. First, because they provide guidelines for effective interventions with children and families, and tell us that intervention programs cannot be successful if changes occur only in the individual child. Second, environmental changes have to be orchestrated to enhance the existing competencies of the child. This way they enlarge the risk analysis and intervention to the family and community, and they help us understand why initial conditions do not determine outcomes, either positively or negatively. This takes us to another premise, that is, how environmental insults can be remedied by environmental factors and developmental problems can have social and environmental causes. Certainly this premise is a fundamental argument to make EI a priority in policies and establish structures for intervention programs to serve the needs of populations of children ages birth through five.

2.2.3. Model of the ecology of human development – Bronfenbrenner

The model of the ecology of human development has its roots in the general systems theory that is attributed to the work of Ludwig Von Bertalanffy (1968), who saw biology as an organized system. In 1930 he asserted an interdisciplinary doctrine that elaborated principles and models that apply to systems in general, independent of the particular kind of elements or forces involved. Classical science, which concentrates its interests on particular elements of the observed universe, assumes to understand the whole by adding individual elements together. In contrast, Von Bertalanffy asserts that to understand science one needs to understand not only the individual elements but even more importantly, their interrelations. His theory asserts that all living systems are composed of a number of interdependent parts. Fundamental to his view is the association among the parts of the system; change to one part is likely to affect change to all. Interaction among the parts creates characteristics of the global system that are not present in any of the parts individually.

According to Sameroff (1983) the interpretation of development has used three different models, organismic, mechanistic and contextualist. Those who used the mechanistic model to describe the universe compared it to a machine and as such it is seen as being composed of discrete pieces. The pieces and the interrelation between them form the basic explanation for all other complex behavior. This idea comes from the Newton's perspective of the cosmos: "The same laws that apply to irreducible fundamental elements, and their interactions also apply to all more complex interactions" (Sameroff, 1983, p.245). The source of motivation for this model is extrinsically and the human being is a passive receiver that only becomes active when stimulated by outside forces (Reese & Overton, 1970, referred to in Sameroff, 1983). From an epistemological perspective the human being apprehends the world as reality comes to him. Understanding comes to him and his role is more a passive observer.

The organismic model differs from the above one in the sense that the universe is a living organized system and its parts, although important, can only become comprehensible when embedded in the whole. The comprehension of behavior does not depend on the parts *per si*, but rather its relations with the whole. "For example, the vision a property of the visual system is not reducible to the sum of its parts – the cornea, retina, optic nerve, and the brain" (Sameroff, 1983, p.245). From an epistemological perspective the human being is active and constructs knowledge in interaction with external reality.

The contextualist model stressed the importance of the structure of environment in development. Contextual thinking should be seen as an addition to other models rather than as a substitute for them. We can include here the general systems theory, which can combine the models described above. "Each system exists in a context of hierarchical relationships and environmental relationships. The analysis of hierarchical interfaces combines both organismic and mechanistic elements" (Sameroff, 1983, p.273).

Within developmental psychology, the use of general systems theory and the development of ecological models to understanding of social behavior have been the work of Bronfenbrenner (1977, 1979, 1983).

The research questions that provide the framework for this dissertation are divided into three categorical levels; child, family and community. Although each level could be considered discrete it is important to view them as interactive as suggested by Bronfenbrenner's (1979) ecology of human development. This approach is distinguished by its concern with ongoing and progressive accommodation between individuals and their environment. In this particular dissertation, I am suggesting that the child's immediate and future outcome is directly influenced by the transactive nature (Sameroff & Chandler, 1975; Sameroff, 1983) of overlapping subsystems, e.g., the EI program, the family, and the community. Reigel (1975) suggests that any individual change must be viewed within the context of the larger social and cultural system. From an EI perspective, the specific settings of most relevance to the development of the young child are the intervention setting, the family, and the community in which the family lives. The articulation between and among these levels of influence or sub-systems generates a developmental context for the young child.

The systemic and ecological perspective views individuals as being in a constant and dynamic process of development, which progressively causes them to pass through different contexts. During this active process individuals do not simply pass through, instead they are subject to environmental perturbations that alter our understanding. Thus, individuals enter and leave a contextual event changed but they also effect change thus restructuring those contexts. From a systems perspective all individuals are viewed as growing and dynamic, who progressively move into and restructure the settings in which they find themselves. Bronfenbrenner (1979) suggests that the ecological contexts or settings in which an individual develops are "...nested structures, each inside the next, like a set of Russian dolls" (p.22). These ecological contexts are the microsystem, mesosystem, exosystem, and macrosystem. Figure 2 demonstrates the model. According to Kurdek (1981), the systems are interdependent, and the nature of this interdependence is dynamic. Bronfenbrenner refers to several levels in this model. In this dissertation I will focus on only three of the levels or ecological contexts, the microsystem, mesosystem, and the exosystem.

The Microsystem is the pattern of activities, roles, and interpersonal relationships experienced by the individual in the setting in which (s)he is functioning. In the home, the microsystems include relationships between parent and child, child and each sibling, and among family members. When viewing the child in a context such as the learning/educational setting, the microsystem includes the relationships between and among children, the child and the adults in that setting, and the child's ability to cope with the vicissitudes in the general environment. In this proposal, the microsystems issues are studied through the home, and the intervention setting and how the child and family negotiate the child's evolving social and structural realities within the family.

The Mesosystem represents the interrelations among two or more settings, e.g., the microsystem, and exosystem in which the individual actively functions. This may include the interrelations among home and program, home and service agency(ies), home and neighborhood, and the program and peer group. For example, non-majority culture children, in this case children from poor families, may be challenged by interrelationships between their home and preschool culture when they transition into the school-based culture. Parent-interventionist, family-community interactions have interactive effects on the child and family. Interactions among subsystems have immediate influence on the outcome of children as they and their families negotiate their daily lives in the intervention environments and the community.

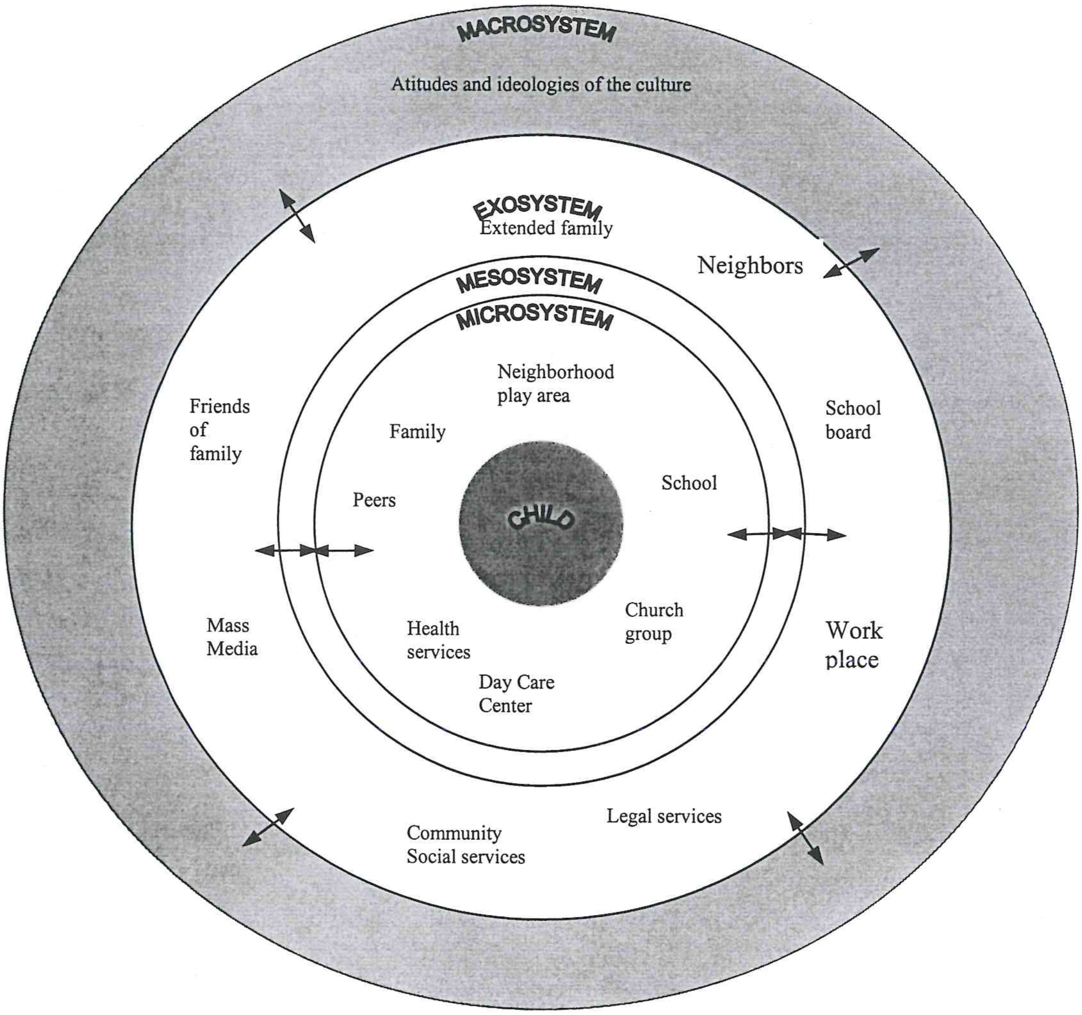


Figure 2. Bronfenbrenner's ecological model of the environment as series of nested structures. (Adpated from *The Child: Development in a Social Context*, edited by C.B. Kopp and J, B. Krakow, 1982, Addison-Wesley Publishing Co., Reading, Massachusetts; p. 648.)

The Exosystem represents those settings that do not involve the individual directly. However, events occurring within the exosystem affect, or are affected by, what happens in other levels or subsystems, i.e., reciprocal transactions, in which the individual functions. The exosystem factors to be addressed in this research include the level of service integration for families and associated community changes that have occurred across time to address the needs of young children with disabilities and their families.

The Macrosystem involves the majority culture's belief system. These are broad social factors that impinge on each of the inner levels or sub-systems within which the individual functions. Society's general perspective on poverty, children and families, supports and from where they come, and community values, all impact a child's education and family's ability to cope (Riegel, 1975). While this level of influence will not be a specific focus of this study there will be attention paid and discussion that will focus on its influence on the other levels, e.g. policies, regislation, potential increases services.

The interaction among these subsystems is complex and transactive (Sameroff, 1975; 1983). That is, the impact of an event is due to the ongoing reciprocal transactions among the subsystems (Sameroff & Chandler, 1975). The use of a social systems framework and the relative transactive process of development provides a context for this research to reach beyond the unidimensional cause and effect studies. Rather, the social systems perspectives insists that we recognize the complexity and interdependence of the many issues related to EI, the role families play in this endeavor, and how all players interface with their communities. The reciprocal nature of this model assumes that change at all levels is constant.

As stated above, the ecological model is viewed as a system comprised of subsystems that are interrelated and mutually interdependent like, "... nested structures, each inside the next, like a set of Russian dolls" (Bronfenbrenner, 1979, p.22). Using this model, there is an assumption that development for a child must always be viewed as the product of all the interrelated factors that comprise the different contexts in which the child and his/her family encounter in their daily lives (Portugal, 1992). Such a model can be used to develop an index of risk conditions for a child/family, i.e. ecological risk. By including a broader ecological view of the child and family attention is paid to all the environmental contexts that influence the development of a child or the functioning of the family, e.g. family, neighborhood, school, church and other environments that do not require the immediate presence of the child, such as social geography, attitudes and ideology of a culture and physical environment. According to Hardin (1966; referred to in Gabarino, 1990), the fundamental law of ecology is that "... we can never do just one thing. Intersystem feedback insures that any single action may reverberate and produce unintended consequences" (p.80). The ecological conceptualization forces us to enlarge the concept of risk that extends beyond a narrow intraindividual and intrafamilial dimensions. Instead, by including interindividual/system factors that acknowledges the mutual influences individuals and systems have on one another we improve our interventions as well as our comprehension of development.

2.2.4. Family Centered Support Model (Dunst, 1985)

The work of Carl Dunst and his associates is based upon an ecological and social systems perspective of child development. His family centered model of assessment and intervention evolved through clinical and model demonstrations, professional training, research and evaluation activities for more than seven years (Dunst, 1998; Dunst & Trivette, 1988a; Dunst, Trivette, 1988b; Dunst Trivette, Gordon & Pletcher, 1989; Dunst, Trivette & LaPointe, 1992).

Intervention within this model should be centered on the help provided to parents for obtaining services and competencies, which facilitate family and child adaptation and development. Another essential aspect of this model is the identification and establishment of needs and priorities which strengths the family unit. Positive outcomes for this intervention model are the developmental progress of children at-risk and an increase in the effective use of resources and supports by families.

The concepts of empowerment and enabling are crucial to their approach of working with families. The development of those concepts is based on the work of Dunst, Trivette, & Deal (1988); Rapport (1984) and Shelton, Jeppson & Johnson (1987).

> By "enablement," we mean creating opportunities for ALL family members to display and acquire competencies that strengthen family functioning. (...) By "empowerment" we mean a family's ability to meet needs and achieve aspirations in a way that promotes a clear sense of intrafamily mastery and control over important aspects of family function (Dunst, Trivette, & Deal, 1988, p.x).

In order to be effective, help giving practices in this model should promote experiences and opportunities, which will enable and empower the family. Enabling and empowering families will make them capable of an effective use of community resources to meet their needs and aspirations. To make this happen assessment and intervention within this model should consider three fundamental aspects (Dunst, Trivette, & Deal, 1988):

- Needs and aspirations
- Family functioning style
- Support and resources

Figure 3 illustrates the major components of the help-giving behavior within this model.

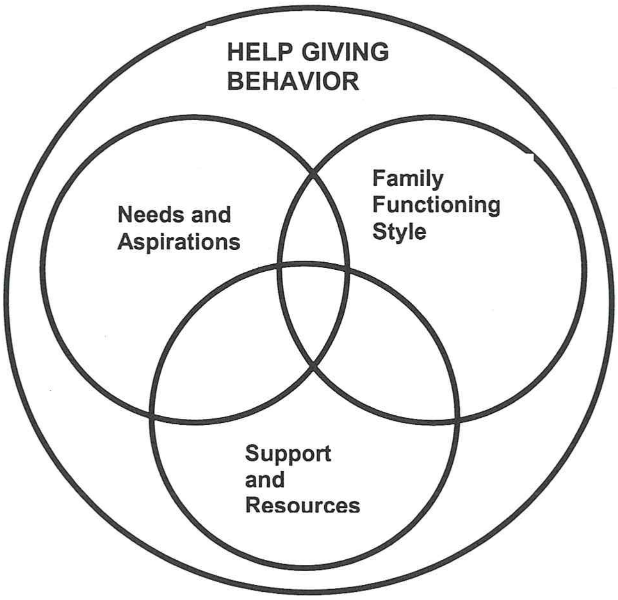


Figure 3. Four major components of the Assessment and Intervention Model and their Relationships.
Source: Dunst, C., Trivette, C., & Deal, A. (1988). *Enabling and empowering families. Principles and guidelines for practice.* Cambridge, MA: Brookline Books (p.10).

The help giver should have a clear picture of the needs and aspirations of the family, should have knowledge of the family functioning style, strengths, values, belief system and culture, and should identify sources of community support for the family. It is the interrelation among these factors that will regulate the help-giving behavior in order to enable and empower the family.

To guide the implementation of this model Dunst, Trivette, & Deal (1988) set up four key principles:

1. Identify family aspirations and projects using any number of needs-based assessment procedures and

> strategies to determine the things the family considers important enough to devote time and energy;
>
> 2. Identify family strengths and capabilities to emphasize the things the family already does well and determine the particular strengths that increase the likelihood of a family mobilizing resources to meet needs;
> 3. "Map" the family's personal social network to identify both existing sources of support and resources and untapped but potential sources of aid and assistance;
> 4. Function in a number of different roles to enable and empower the family to become more competent in mobilizing resources to meet its needs and achieve desired goals. (p.51)

In summary this model is based on the assumption that social support, a more distal contextual factor, directly and indirectly influences family well being and functioning, and child development.

Research on social support, that will be elaborated on following chapters, has proven the existence of links between social support and health and well-being outcomes (Dunst, Trivette, & Jodry, 1997). Nevertheless we cannot forget that social support is one of many variables that influence behavioral outcomes. Within an ecological and systemic perspective developmental parenthood tasks imply support and resources from the different contexts where the family is embed, in order to enhance positive family functioning. This is true for all parents, but it is particularly important when we are dealing with parents of children at-risk. For those parents the burdens of caring for a child with or at-risk for SN, can jeopardize family well-being and functioning, if necessary supports and resources are not mobilized to meet their needs. So this led

Dunst (1985), to propose a social system definition of early intervention as the "... provision of support (and resources) to families of infants and young children from members of informal and formal social support networks that impact both directly and indirectly, on parent, family, and child functioning" (p.179).

Recently, Dunst (2000) reviewed and modified some of the previous concepts of his model to include advances in research, practice and model and theory development done since the publication of "Rethinking Early Intervention" in 1985. Dunst (2000) described his recent model as the *third generation* model of EI, and according to the author it emerges for two basic reasons. First, to eliminate doubts about the intervention targets of family service intervention, and the second, to include further advances made in research about other aspects of environmental influences and interventions (Dunst, 2000). The parent-child and child features should be explicitly incorporate in any proposed and useful model to avoid confusion about the targets of family service intervention in a family systems approach, i.e., the family as a whole as well as the individual members, including the child as the focus of entering into EI (Dunst, 2000). The other recent feature of the model includes the research based evidence about the contextual and sociocultural foundations of child learning and development and parenting and child rearing roles and styles most conducive to promote child competence (Bornstein, 1991; Bronfenbrenner, 1999; Göncü, 1999, Lancy, 1996; Rogoff, Mistry, Göncü, & Mosier, 1993, cited by Dunst, 2000). So as described by Dunst (2000), the conceptualization of EI in the third generation model includes children's learning opportunities (Dunst & Burder, 1999), parenting supports (Cowan, Powell, & Cowan, 1998), and family/community supports (Trivette, Dunst, & Deal, 1997) provided in a family centered manner (Trivette & Dunst, 1998). These components of the model are respectively:

> Development-enhancing child learning opportunities are ones that are interesting, engaging, and competency producing and result in a child's sense of mastery about his or her capacities. Parenting supports include the information, advice, and guidance that both strengthen existing parenting knowledge and skills and promote acquisition of new competencies necessary to carry out childrearing responsibilities and provide development-enhancing learning opportunities. Family and community supports include any number and type of intrafamily, informal, community, and formal resources needed by parents to have the time and energy to engage in parenting and childrearing activities. Family centered practices place families in central and pivotal roles in decisions and actions involving child, parent and family priorities and preferences (Dunst, 2000, p.101).

According to Dunst (2000), besides the basic elements of each dimension of the model, represented by Figure 4, the intersections of the overlapping dimensions consider additional elements crucial to effective practices. These elements are parenting styles and instructional practices, participatory opportunities that parents have within their networks and that will influence parenting attitudes and behavior, and family/community activity settings, i.e., the sources and contexts of natural learning opportunities as part of family and community life (Dunst & Burder, 1999).

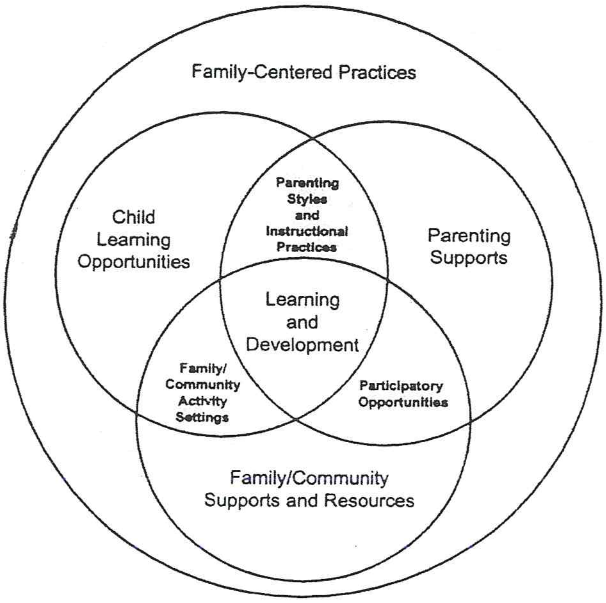


Figure 4. Major components of an integrated evidence-based model of early intervention and family support.
Source: Dunst (2000). Revisiting "Rethinking early intervention". *Topics of Early Childhood Special Education*, 20 (2), 95-104. (p.101).

Within this research context, knowledge and understanding of the family social support networks, among other variables influencing child development, acquires an important role for planning and implementing quality EI services for children and families.

2.2.5. The Family as a Social System

Family systems theory views family as a social system with unique characteristics and needs. A basic premise of this theory is that the individual members of a family are so interconnected that any experience affecting one member will have an effect on all members (Carter &

McGoldrick, 1980). Just as children develop within the family microsystem, families are situated within the larger context of society. When viewing the relationship between a family and the larger society there exists an influential and critical linkage to each of the remaining system levels, i.e. the mesosystem, exosystem and macrosystem. While each level has particular attributes that can affect a family and its outcome, it is important to view the entire system to understand the family, its decisions, and its particular level of development.

Despite diverse cultures throughout the world with widely differing family structures, the universal essence of the family remains "…a small kinship structured group with the key function of nurturant socialization" Reiss (1980, p.29). Gabarino (1992) builds on this common concept of family when he states that individual families share many common attributes. However, he also challenges this notion by suggesting that families vary along three different dimensions:

1. Membership: Families take many forms according to its participants. For example, a nuclear family with two members cohabiting, married or related by blood (eg. a father and a child, a grandfather and a grandson), or a family comprised of many members such as an extended family who join other nuclear families;

2. Development: Family's assume various developmental stages as they progress through their natural life cycle. While the general cyclic nature of family remains constant, variation among families emerges when a family developmental pathway is examined. Several authors propose models that suggest developmental stages that families go through, from

marriage through the growth of children and parents. Even among what might be considered consistent epochs that collectively comprise a typical life cycle we can find considerable variation. For example, some families begin without marriage, some families remain childless, other families dissolve with individuals forming new family units;

3. Cultural and historical context of the family: Family norms are consistent with ethnic, religious and socioeconomic subcultures. These cultural forces eventuate in tremendous variation among families. They influence family attributes like form and membership, demographic trends, sex and age-dependent roles in the family, values, intergenerational relationships and critical aspects of parent-child relations to name a few.

This range of diversity among families creates has helped to create the notion that each family is unique. However, if we examine the family through a lens that focuses on developmental cycles many common features among families emerge.

All families experience change as their members are born, grow up, leave home, bring new members into the unit through marriage or other permanent relationships, retire and die. An understanding of families and change lies within the domain of the life cycle theory. The family life cycle is a series of developmental stages through which families advance.

Stages are established based on three criteria: a change in family size, the age of the oldest child and the work status of the parents (Beckman, *et al.*, 1994). Duvall (1957) has originally proposed eight stages; establishment, childbearing family, family with preschoolers, family with school age children, family with adolescents, family launching center, family in middle years, and family in retirement. According to Carter & McGoldrick (1980), over the years theorists have identified as many as 24 and as few as 6 life cycle stages for a family. The family functions and roles played by each individual in the family unit change in each stage in the life cycle. The transition from one stage in the cycle to the next is a source of major stress felt by families.

There are several important factors that can have dramatic effect on the developmental path assumed by a family. One such factor is the birth of a child with SN. Using the research on family life cycle Turnbull & Turnbull (1986) adapted these models to the families of children with SN. Because of the overall impact the birth of a child with a disability they assume that these families tend to experience more general family stress and stress in transitions. A summary of the stages that they propose and the areas of major stress for families with children with SN, through the life cycle can be seen in Table 1.

Beckman *et al.* (1994) cautioned against the use of the life cycle approach with families of children with SN. They argued that change for those families is not restricted to the transitions but rather stresses can also occur within a particular stage. For example, a family can experience significant stress if a child does not accomplish particular developmental milestones. Another significant stress on a family can be attributed to ongoing medical attention that many disabilities require. As such, children who have long periods of hospitalizations influence the family's general developmental state as well as their family life cycle. Other important factors that impact a family's development include: changing of demographic patterns that influence family composition; divorce in which children live in more than one household, and other children live in single-head-of- household homes. Among these latter cases it is hard to identify clear stages of the life cycle and for those families there may be multiple and extremely stressful transitions. Thus, according to Beckman *et al.* (1994), while the life cycle approach provides an important framework to analyze families it cannot transcend what individual families identify as their needs at a particular time.

Table 1
Family Life Cycle with a child with SN

Stage	**Areas of Special Stress**
Couple	Usual expectations about having children. Usual adaptation to living with a partner.
Childbearing and Preschool	Fears that the child has a disability. Diagnosis. Finding treatment. Telling siblings and extended family about the disability.
School age	Reaction of the other children and families to the exceptional child. Schooling
Adolescence	Peer rejection. Vocational preparation. Issues around emerging sexuality.
Launching	Living arrangements. Financial concerns. Socialization opportunities.
Post parental	Long term security for the child. Interactions with service providers. Dealing with the child's interest in dating, marriage and childbearing.
Aging	Care and supervision of the child with SN after 'parents' death. Transfer of parental responsibilities to other family subsystem or service providers

Source: Adapted from A. Turnbull, J. Summers & M. Brotherson, (1986). Family Life Cycle. In J. Gallagher & P. Vietze (Eds.), *Families of Handicapped Persons*. Baltimore: Paul H. Brookes.

The concepts of the family systems theory have been adapted for our understanding of families with children with SN by Turnbull, Summers & Brotherson (1984), Turnbull Brotherson & Summers (1985). These authors proposed a conceptual framework, which integrates the concepts of family systems theory with the understanding of how families cope with their children diagnosed with SN. Their conceptual framework of family functioning containing the four essential components that can be seen in Figure 5.

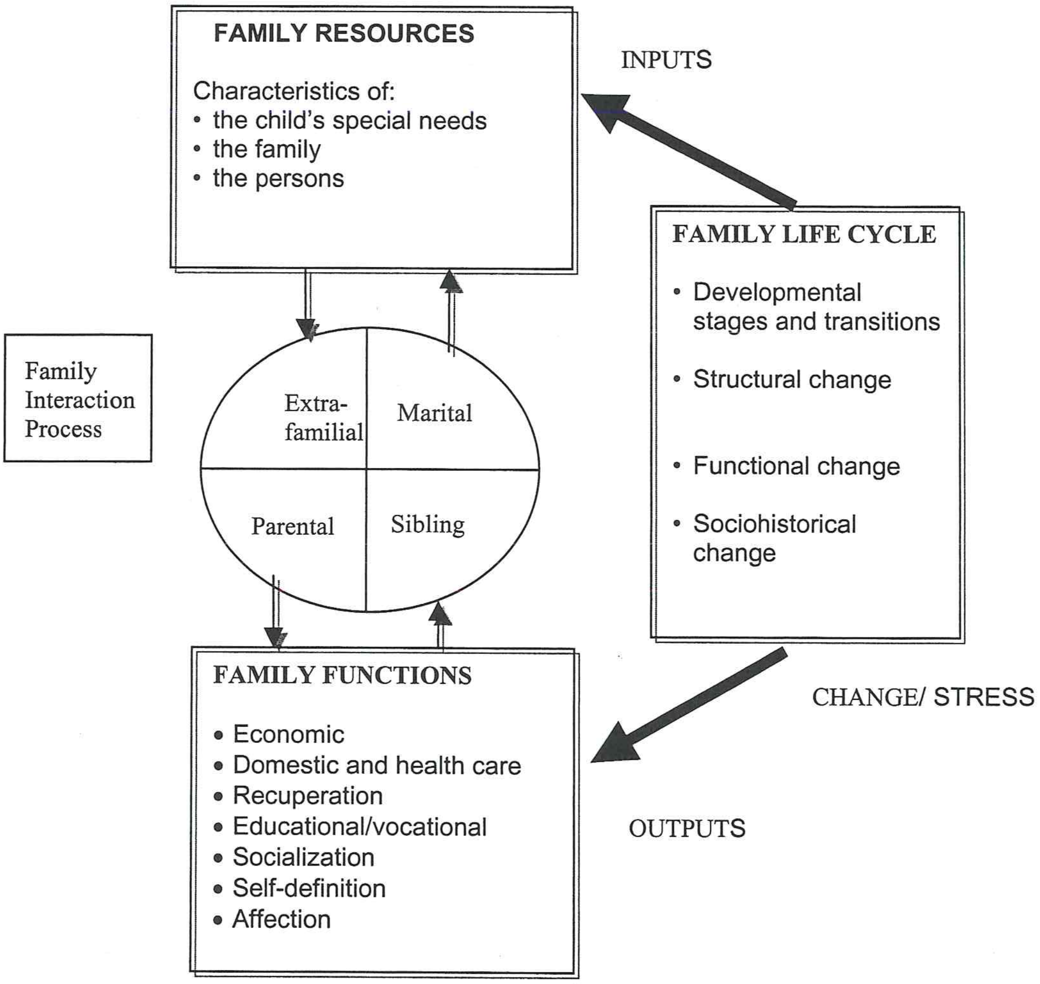


Figure 5. Family Systems Conceptual Framework (Adapted from Working with Families with Disabled Members: A Family Systems Approach (p.60) by A. P. Turnbull, J. A. Summers, and M.J. Brotherson, 1984, Lawrence ,KS, Kansas University Affiliated Facility, University of Kansas.

The four major components of this conceptual model of family functioning are described in table 2.

Table 2
Four components of family functioning

Family Resources	Consists of the descriptive elements of the family including characteristics of the exceptionality (eg. type, level of severity); Characteristics of the family (eg. Sizes and forms, cultural backgrounds, socioeconomic status, geographic locations); and personal characteristics (eg. health, intellectual capacity, and coping styles). From a systems perspective, resources can be thought of as the *input* into family interaction.
Family Interaction	Refers to the relationships that occur among subgroups of family members on a daily and weekly basis. These relationships, the process of interaction, are responsive to individual and collective needs.
Family Function	Represent the different categories of needs the family is responsible for addressing. The purpose or *output* of family interaction is to produce responses to fulfill the needs associated with family functions.
Family Life Style	Represents the sequence of developmental and nondevelopmental changes that affect families. These changes alter family resources (eg. a child is born) and family functions (eg. mother stops working outside the home, which provides more time for child rearing but less family income). These changes, in turn, influence how family interacts.

Source: Adapted from Turnbull, A.P. & Turnbull, H.R., III. (1986). *Families, professionals and exceptionality: A special partnership (p.20-21).* Columbus,OH: Charles E. Merrill Publishing.

Professionals working with families should have a clear understanding of these components and the complex interaction among them. Beyond a basic understanding of these components, it is important that the professional comprehend the influences they exert in the family unit. This will help planning for more effective interventions and improve family-professional relationships.

Another important family model that contributed to our understanding of family functioning was the ABC-X Model developed by Hill (1958). Hill is a sociologist who was intrigued with the fact that different families responded in different ways to the same catastrophe. In trying to understand why these differences among families emerged he developed the ABC-X Model of family functioning. His model assumes that families perceive stress events differently. Hill (1958) considers several variables as important in dealing with crisis: 1. The crisis event (A); 2. The family's resources (B) must be considered; and, 3. The perceptions that the family hold about the crisis event (C). The capacity to adapt (X) depends on those variables. Hill's model can be used to understand a family's ability to adapt (X) to the birth and subsequent development of a child with SN. The family's outcome or their capacity to adapt, depends on the characteristics of the disability including its level of severity, age of the child onset and the disability level of visibility (Heward, 2000) (A); as well as the family resources to cope with the needs of the child with SN, his/her siblings, and the family unit, (B); and the perceptions, values, lifestyle and cultural background of the family (C).

Hill's Model was later expanded by McCubbin & Patterson (1983), at which time the Double ABC-X Model was developed. This later Model focused on three aspects of family life (stresses and strains, family coping, and family resources) that determine how well the family adjusts to normal transitions and change. McCubbin and Paterson (1983) expanded Hill's Model by adding two critical elements to its original formulation: time and coping skills. Their model acknowledges that over time additional stressors may come into play, as new resources are acquired or required. The introduction of time assumes that the family unit evolves and its abilities to cope with change alter over time. This notion of change is a critical variable in defining and redefining the event's affect on the status of the family. Another factor affecting family adaptation in the Double ABC-X Model is the coping abilities of the family members, how the family's resources are mobilized, and how the stressful events are interpreted (Krauss, 1997). This model is important because it helped organize existing research on families of children with SN and is instrumental in promoting multidimensional, multivariate approaches to understanding differences in family outcomes (Wilker, 1986, cited in Krauss, 1997).

According to Bailey & Simeonsson (1988) the acceptance of these models when working with families of children with SN, calls for an assessment strategy that emphasizes strengths, resources and perceptions rather than simply identifying the problems and pathology and interpreting developmental outcomes from a negative or deficit perspective.

Still within this particular field of family perceptions the research done by family sociologists (Olson, McCubbin, Barnes, Larsen, Muxen, & Wilson, 1983) with families of tipically developing children, presented the importance of perceptual coping strategies in dealing with stress. The authors found that families dealt with stress in two ways: (1) *passive appraisal,* a type of denial or avoidance of the problem, and (2) *reframing,* the family's capacity to identify the aspects of the problem over which they have some control. By reframing the problem the family can also redefine those aspects of the problem beyond their control in ways that make it easier to cope. Olson and his associates stressed that the family's capacity to view the problem event as something that could be overcome, through reframing, or ignored for the present time, through passive appraisal, kept the family from being overwhelmed by the crisis.

According to Bailey & Simeonsson (1988), the research undertaken by Olson *et al.* emphasized the important role that denial may play in protecting the family from being overwhelmed, particularly when we consider families of children with SN. Instead of being a condition that should be eliminated, they suggest that denial should be recognized as an adaptive strategy that the family uses for protection.

Olson and McCubbin (1982) presented yet another key model for our understanding of family functioning called the Circumplex Model of Marital and Family Systems. They argued that emotional cohesiveness and adaptability are core dimensions of family life, which vary across families and are predictive of how families respond to stress and interventions.

According to Krauss (1997), "...the relevance of these concepts for families served in early intervention programs was recognized quickly and spurred programmatic interests in understanding parental coping strategies and in helping families "reframe" the meaning of disabilities" (p.613).

These theoretical models of family functioning are crucial on emphasizing the many complex factors affecting families. They forced the research community to rethink the expected outcomes of an early intervention program's impact. Shifting the outcome from the narrow parental change perspective to change analyzed from a broader family perspective. These studies that analyzed the efficacy of EI demonstrated the complexity of the process and that change requires a broader analysis of the array of influences that affect a family's development during the early childhood period.

The importance of the family and the interactions of family members with the child are summarized in Meisels (1985) words:

> The family and its sociocultural and economic context is the crucible in which forces for good and ill are transformed into developmental patterns for high risk and handicapped children in the first years of life. The evidence from a whole generation of research demonstrates that the quality of parents behavior as caregivers and as teachers makes a difference in the development of infants and young children (p.9).

3. IMPLEMENTATION AND ORGANIZATIONAL ASPECTS OF FAMILY-CENTERED PRACTICES

3.1. Legislation

The practical implications, which derived from the diverse influences of both the empirical and theoretical influential spheres that we have described, have had repercussions in the efficacy of working with families of children with or at risk for SN. The adoption of transactional, systemic and ecological theoretical perspectives, has implications at several levels, including: politically and legislatively, the organization of EI programs, the focus of research efforts and personnel training. This chapter will begin with a review of the legal and political realities of EI in the United States of America. This will provide an important understanding of the evolution the EI field has taken in the United States of America because they were pioneers in developing and implementing EI programs and services.

Children with or at-risk for SN and their families require effective responses to their needs. However, we know that to provide the best outcome it is necessarily to actively involve the family in this helpgiving intervention process. The efficacy of EI programs that actively involve parents is a fact that has been demonstrated through research (Simeonsson & Bailey, 1990; Peterson, 1988). But we cannot ignore the families of children with SN. While the child often remains the focus of the EI process the family has needs that are often masked by the pressing demands of the child. However, if attention is only on the child the overall effect of EI process may be compromised. In other words, overall attention to the family inclusive of the child with SN contributes directly to the child's developmental outcome (Bailey, 1987; Dunst, 1985; Simeonsson & Bailey, 1990). Another basic principle for family centered EI is that infants and children under three are particularly dependent on their families for their survival and nurturance (McGonigel, 1991). This developmental dependence means that EI is an intimate service (Healy, Keesee, & Smith, 1989), that must serve these young children within the context of their families. Thus consistency with goals and priorities established by the family, and the supports, is necessary to attain those goals and priorities constituted as appropriate and fundamental to best practices in EI (Bailey & Wolery, 1992). Bailey, McWilliam, Winton, & Simeonsson (1991), cited by Wolery, Strain & Bailey (1992), identified seven themes of family centered services that are based on family values and priorities, which are:

- Services are focused on the entire family and the child as a member of the family unit;
- Services assist families in making their own decisions, finding their own resources, and becoming independent of professionals;
- Families' needs for information, social support, explaining their child's disability to others, community services, financial assistance, and help in general family functioning should determine the nature and amount of services;
- Services should help families a normalized life style(i.e. a lifestyle similar to what they would have if their child did not have disabilities);
- Services should be sensitive to the cultural diversity of the families;
- Services should be individualized;

- Services for families should be coordinated across agencies. (p.101)

These seven themes are the underlying foundation to the EI legislation and its practical implementation in the United States of America. A first piece of landmark legislation guaranteeing a free and appropriate public education for students with disabilities was a basic tenet of Public Law 94-142, the Education for All Handicapped Children Act (EAHCA) passed in 1975. Parents through their advocacy and legal efforts were instrumental in the passage of this legislation.

The EI service delivery system was mandated to provide service for children with disabilities from age 3 through 5 years of age in 1986 when P.L. 94-142, The Educational for All Handicapped Children's Act, was amended with the passage of P.L. 99-457. Although the evidence concerning the importance of EI was considerable, before 1986 it was not a mandated program for children with disabilities. Instead of broad-based national programs there was an uneven distribution of services generally funded on a state and/or local basis (Allen, 1984). Federal funds were available to support research in the field, (Gallagher & Gallagher 1992) and to establish and pilot projects in EI (DeWeerd, 1981) but the permissive nature of the legislation allowed states to choose to serve or not serve on a voluntary basis. This period of voluntary program availability ended when the need for services was established and P.L. 99-457 was passed. P.L. 99-457 is comprised of two sections. Part C of the remains voluntary and recommends that states and local agency's provide intervention services for children under 3 years of age. As such, many states have created services for children from birth, they are not mandated by law to do so. This portion of the law is written in such a manner that criteria for services have been broadened to include children who are at-risk for developmental disabilities along with children who have been traditionally served and are diagnosed with established disability characteristics. Another aspect that sets Part C apart is its intervention focus on the family. Previous intervention efforts were child-centered and educational-based. Under Part C the unit for intervention efforts extend beyond the individual child and involve the entire family in planning and implementing intervention plans. In this context the Individual Family Service Plan (IFSP) was created.

The other component of the law, Part B is a downward extension of earlier legislation and mandated EI services for all children with disabilities after they reach three years-of-age. In this portion of the law all children with disabilities in a state must be served as soon as they celebrate their third birthday, thus extending coverage for children between ages 3- and 5-years-of-age. Like earlier versions, this portion of the law maintains an educational child-centered focus but acknowledges the importance the family plays in intervention efforts.

Given its educational focus the Individualized Education Plan (IEP) guides all intervention/educational efforts. The IEP must contain the following elements: 1) the child's present levels of educational performance; 2) the annual goals and short term instructional objectives in each area of intervention; 3) the specific educational services to be provided and the extent to which the child will be participating in regular education programs; 4) the projected beginning date and anticipated duration of services; 5) appropriate objective criteria and evaluation procedures; and 6) schedules for determining, at least annually, the extent to which the instructional objectives are being met. A second difference from Part C is the narrow, disability orientation that guides decisions on who will receive services. Children who qualify for services are categorized according to the type and severity of their diagnosed disability. Both sections of the law call for, "... a statewide, comprehensive, coordinated, multidisciplinary, interagency program of early intervention services for all handicapped infants and their families" (P.L. 99-457, Sec. 671).

There are several other differences when comparing Parts C and B in the legislation. In spite of the differences there remains a commitment to creating services to remediate the effects of disabilities and/or to prevent the potential delays that environment, biology, or disability might have on the overall development of children from birth. This legislation created opportunities for children and families that did not exist previously. Although compliance with the law had a 5 year period during which States established plans for how they were going to serve this new constituency, this legislation created a common EI politic.

A summary of the major milestones in EI and preschool policy at federal level can be seen in Table 3.

Table 3
Milestones in federal legislation supporting children with disabilities and early intervention policy

Year	Legislation Description	Public Law #
1958	[1]Provided grants for preparing teachers in the education of handicapped children, related to education of children who are mentally retarded	P.L. 85-926
1963	[2]Maternal and child health program expanded	P.L. 88-156
	[1]Authorized funds for research and demonstration projects in the education of the handicapped	P.L. 88-164
1964	[2]Head Start program established	P.L. 88-452
1965	[1]Elementary and Secondary Education Act. Title III authorized assistance to handicapped children in state-operated and state-supported private day and residential schools	P.L. 89- 10
	[2]Elementary and Secondary Education Act (ESEA) amended to allow for grants to state-operated or state-supported facilities serving children with disabilities, ages birth to 21 years	P.L. 89-313
1967	[1]Amendments to P.L. 88-164. Provided funds for personnel training to care for individuals who are mentally retarded, and the inclusion of individuals with neurologic conditions related to mental retardation	P.L. 90-170
	[2]Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program added to Medicaid program	P.L. 90-248
1968	Amendments to P.L. 89-10. Provided regional resource centers for the improvement of education of children with handicaps	P.L. 90-247
	[1]Handicapped Children's Early Education Program Provided grants to develop and implement experimental programs in early education for children with handicaps, birth to age 6.	P.L. 90-538
1969	[1]Amendments to P.L. 89-10. Title VI consolidated into one act – Education of the Handicapped Act (EHA) – the previous enactments relating to children with handicaps HCEEP folded into Part C of the EHA	P.L. 91-230

Year	Legislation Description	Public Law #
1974	[1]Amended and expanded Education of the Handicapped Act in response to right-to-education mandates. Required states to establish goal of providing full educational opportunity for all children with handicaps, from birth to 21 years	P.L. 93-380
1975	[2]EHA amended to create the Education for All Handicapped Children Act. Required states to provide a free appropriate education for all handicapped children between the ages of 6 and 21	P.L. 94-142
1975	[1]Expanded services to preschool children with handicaps ages 3 through 5 years with the provision of preschool incentive grants	P.L. 94-142 (Section 619)
1983	[2]EHA amended to allow use of funds for services to children with disabilities from birth and provide funding to states for systems planning	P.L. 98-199
1986	[2]EHA amended to extend mandated services to children from 3 years and create early intervention (Part H) programs for infants and toddlers and their families	P.L. 99-457
1990	[2]EHA amended and renamed the Individuals with Disabilities Act (IDEA)	P.L. 101-476
1991	[2]Part H of IDEA reauthorized and amended	P.L. 102-119
1996	Debate on reauthorization of IDEA Personal Responsibility and Work Opportunity Reconciliation Act of 1996: Federal Welfare reform budget action that reduces federally funded programs that support the medical, nutritional, and income needs of poor families and their children	no action
1997	IDEA Reauthorization	P.L. 105-17

Sources: Behr, S., & Gallagher, J. (1981). Alternative administrative strategies for young handicapped children. *Journal of the Division of Early Childhood*, 2, 113-122.

[1] Gallagher, K.S., & Gallagher, R.J. (1992) Federal initiatives for exceptional children: The ecology of special education. In D. Stegelin (Ed.), *Early Childhood Education: Policy Issues for the 1990's*. Norwood, NJ: Ablex Publishing Corp.

[2] Smith, B.J., & McKenna, P. (1994). Early intervention public policy: Past, present, and future. In L.J. Johnson, R.J. Gallagher, M.J. LaMontagne, & J.B. Jordan, J.J. Gallagher, P.L. Hutinger, & M.B. Karnes (Eds.), *Meeting early intervention challenges: Issues from birth to three, 2nd ed* (pp. 251-264). Baltimore: Paul H. Brookes Publishing Co.

By the end of the 1990's, all states have provisions for serving qualified children under the age of six years, and all states are serving children under Federal mandates (Gallagher, 1993; Smith & McKenna, 1994).

According to Gallagher & Tramill (1998) two factors have converged in the delivery of services for children and families under the early intervention umbrella. The first of these important factors is the Individual Family Service Plan (IFSP), a formal document that outlines the service plan for the child and the family. The second factor was a shift in how very young children qualify for services. Rather than determining services based on a rigid system based on disabilities categories eligibility was defined on a basis of risk (see page 40 for a description of these categories). Together these factors shifted the unit of analysis from a focus on children with particular disabilities with their families viewed as only marginalized participants, to a service delivery system that is risk oriented and includes families as integral players in developing and implementing service programs.

By redefining who qualifies for services and changing the focus from the child to that of the family altered the relationships between the professionals providing the services and the families with whom they were interacting. To meet the needs of the families involved in the EI process, the services providers were mandated to enter into a collaborative dialogue; a dialogue that includes all the professional stakeholders, their agencies, and the family (Gallagher & Tramill, 1998). This new family-centered relationship views the family as an active participant in the intervention process and a primary service delivery resource. Families and their children bring to the EI process a variety of needs that range in the complexity from chronic and comprehensive to temporary and episodic. Given this range in complexity intervention services require varying levels of attention and time. As such, there is no predetermined set of strategies that can be applied to a child based on presumed attributes of a particular disability category. This approach is very different from previous intervention models that were often narrowly based on a particular set of attributes thought to characterize all children within a particular category of disability or level of involvement (Gallagher & Tramill, 1998). Instead, intervention decisions, educational placements and curricular judgments under this new model are determined on the needs of the child and family. These two different approaches to entry into the special education and EI system have differential impacts on how services are planned and implemented. The risk model is programmatically indeterminate and family-centered. Given that families and their children change over time both the type and intensity of the services they receive will change. Decisions concerning the intervention process are the product of a collaborative relationship established between the family and various service providers. Ideally this collaboration among all stakeholders will establish intervention services that match the needs of the child and family with the service system's capacity to deliver. The key to this approach is the collaborative arrangement between the family and service community that results in the working agreements among the service providers and concludes with effective services for the child and the family.

The brief description provided above gives a glimpse on the breadth of influence federal legislation has had on the current status for providing intervention services to young children who are developmentally at-risk and their families in the United States of America. The result of this legislation has been the creation of state and local intervention programs that serve the needs of young children with identified disabilities as well as those children who are considered at-risk for developmental difficulties and their families.

3.2. Individualized Family Service Plan

When P.L. 94-142 was amended with the passage of the P.L. 99-457 in 1985 a new door was opened in the context of service delivery. This legislation mandated each State to develop a system that would establish broad-based early intervention programs for children from beginning at three years of age and provided incentives for States to establish intervention programs from birth to three years in the United States of America. Among the most dramatic and far-reaching provisions for children under 3 years-of-age who qualify under the law was the mandate for the development of IFSP. These family-focused intervention plans were both evolutionary and controversial but as the heart and soul of part H (now Part C) the IFSP gives “voice” to the mandates family-centered principles. The IFSP effectively redefines the service recipient as the family, as opposed to the child alone, and it requires explicit statements about the family's service needs, and reconstitutes the decision making team by mandating family representation (Krauss, 1990).

According to Espe-Sherwindt (1996), the legislation itself outlines the significance of families:

> The Congress finds that there is an urgent and substantial need
>
> 1) to enhance the development of handicapped infants and toddlers and to minimize their potential for developmental delay;
> 2) to reduce the educational costs to our society, including the Nation's schools, by minimizing the need for special education and related services after handicapped and toddlers reach school age;
> 3) to minimize the likelihood of institutionalization of handicapped individuals and maximize the potential of their independent living in society;
> 4) *to enhance the capacity of families to meet the special needs of their infants and toddlers with handicaps* [italics added]. (Education of the Handicapped Amendments of 1986, Sec. 671[a], cited in Espe-Sherwindt, 1996, p.30)

The IFSP is intended to be the basis for services provided to children with SN and their families Thus it is intended to be both a planning process and a document that supports the capacity of families to care for and nurture their infant and toddler with SN. This mandate indirectly sets a requirement for family assessment, since the IFSP must be based on family concerns, priorities and resources (Winton & Bailey, 1990). The Federal Register (June 22, 1989) describes the contents of the IFSP and the following is an outline of its necessary components:

1) A statement of the infant or toddler's present levels of functioning;
2) A statement of the family's strengths and needs relating to enhancing the development of the family's infant or toddler with a disability;
3) A statement of the major outcomes expected to be achieved for the child and the family; The criteria procedures, and timelines used to determine the degree to which progress toward achieving the outcomes is being made; and whether revisions of the outcomes or services are necessary;
4) A statement of specific early intervention services necessary to meet the unique needs of the infant or toddler and family, including the frequency, intensity, and method of delivering services;
5) The projected dates for initiation of services and the anticipated duration of the services;
6) The name of the service coordinator who will be responsible for implementing the plan and coordinating with other agencies and persons; and the steps to be taken supporting the child's transition to Part B preschool services, if appropriate (Federal Register, June 1989).

The development of an IFSP is an on going decision-making process in which professionals work collaboratively with families. The first IFSP is to be developed within 45 working days of a family's entrance into the early intervention system. Each document is to be reviewed and renegotiated with the family at regular intervals, reflecting the ongoing relationship among all stakeholders i.e. the family and the service providers. The IFSP plan is the end-product of a collaboration process between the family and professionals, as such it should be responsive to the unique needs of each infant/toddler and family. It is intended to be the result of equal and joint collaboration between families and professionals (Espe-Sherwindt, 1996). The goal of this collaboration is to identify characteristics and resources that may affect the family's participation in implementation of the IFSP (Beckman *et al.*, 1994). In contrast with the professionally-driven IEP, the IFSP is family-directed and family-driven (Campbell, Strickland, & La Forme, 1992 cited in Espe-Sherwindt, 1996).

The field of EI immediately became more broadly defined as the focus shifted from the child to the family. The IFSP is the practical translation of that shift. The IFSP centers its attention on the ultimate goal of finding more effective means to meet the needs of children with or at-risk for SN and their families. The IFSP creates new challenges for both parents and professionals. The undeniable and direct message of the IFSP is clear; the family is the key component for an effective intervention.

McGonigel, Kaufman, and Johnson (1991), working with a parent–professional IFSP task force, have provided a set of guiding principles underlying the IFSP process (Table 4).

Table 4
Principles underlying the IFSP process

- Infants and toddlers are uniquely dependent on their families for their survival and nurturance. This dependence necessitates a family-centered approach to early intervention;
- States and programs should define "family" in a way that reflects the diversity of family patterns and structures;
- Each family has its own structure, roles, values, beliefs and coping styles. Respect for and acceptance of this diversity is a cornerstone of family-centered early intervention;
- Early intervention systems and strategies must honor the racial, ethnic, cultural and socioeconomic diversity of families;
- Respect for family autonomy, independence, decision-making means that families must be able to choose the level and nature of early intervention's involvement in their lives;
- Family/professional collaboration and partnerships are the keys to family-centered early intervention and to successful implementation of the IFSP process;
- An enabling approach to working with families require that professionals reexamine their traditional roles and practices and develop new practices when necessary – practices that promote mutual respect and partnerships.
- Early intervention services should be flexible, accessible and responsive to family-identified needs;
- Early intervention services should be provided according to the normalization principle - that is, families should have access to services provided in as normal a fashion and environment as possible and that promote the integration of the child and family within the community;
- No agency or discipline can meet the diverse and complex needs of infants and toddlers with special needs and their families. Therefore, a team approach to planning and implementing the IFSP is necessary.

From Guidelines and Recommended Practices for the Individualized Family Service Plan (p.9), by M.J. McGonigel, R.K. Kaufmann, and B.H. Johnson, 1991, Bethesda, MD: Association for the Care of Children's Health.

3.3. The state of art of EI in Portugal

3.3.1. Integration of children and adolescents with SN in Portugal: Historical evolution.

Before analyzing the field of EI in Portugal it is important to review some of the important Portuguese legislative actions which, that directly affect the education and integration of children with SN of today.

The integration of children and adolescents with SN in the regular education structures in Portugal, has been a slow and difficult process. During the second half of the 19th century the notion that children with SN needed protection was predominant. Fund raising efforts resulted in gaining support for children with SN were a common practice. A number of asylums and institutes were established. With few exceptions where education and habilitation was the goal, most of these organizations were premised on the notion of protecting the children and adolescents. The first ones that appeared were dedicated to serve children with visual and hearing disabilities. Later their mission was expanded and they extended their services to other categories of disability (Lopes, 1997). The majority of the institutions and asylums were dependent on private organizations that were of a beneficent nature. The development of these specialized institutes lead to the segregation and labeling of many children according to their disability (Correia & Cabral, 1997, cited in Martins, 2000).

While the primary care for children with SN was in institutions, alternatives begin to appear in the middle of the 20th century. In 1944 the first special education classes appeared in regular schools in association with the Instituto Aurélio da Costa Ferreira. Located in Lisbon, this Institute was the first to formally prepare special education teachers.

The first integrated education programs appeared in 1968 in the districts of Lisbon, Coimbra and Oporto. Under the responsibility of the "Instituto de Assitência a Menores (IAM) of the Ministery of Social Affairs (MAS) (Correia & Cabral, 1997; Lopes, 1997, cited in Martins, 2000), these programs were aimed to support students with visual disabilities who were in the 2nd and 3rd cycle of the basic education system and in the secondary education. The students had support from teachers specializing in visual disability. Students spent the majority of school time in a special education resource room and received specialized instruction. This experience constitutes an important mark as far as being the first step toward integration of children with SN into the educational community. Two years later this experience was expanded to include several 1st cycle schools in the collaboration of the Ministry of Education.

It was not until the 1970's that we begin to see general concerns for the integration of children with SN into the educational system. This fact was a consequence of what was called the Education Reform of Veiga Simão, named after the Minister of Education at that time. For the first time educational reform included the needs of children with SN into the general education goals. From this moment on the Ministry of Education gradually assumed the education of children with SN, which was until then, the responsibility of the Ministry of Social Affairs (Bénard da Costa, 1981). In 1972 the Ministry of Education created the Divisions of Special Education for the basic and secondary school systems. At this time the integration targeted small groups of children for educational services. For example, only the students with motor or sensorial disabilities who were capable of following the common national curriculum of our educational system were provided general educational experiences. The much larger majority of students who comprised other disability categories particularly those diagnosed with mental retardation, were provided educational services in the special education classrooms. However, the majority of children with SN were not receiving services, i.e. were in home care.

Within this framework, parents were confronted with lack of educational and general service structures to address the needs of their children, and they were forced to join and/or create Parent's Associations. These Associations became segregated special education schools and they played an essential role in the education and service delivery for children with SN in 1970's and the 1980's. In 1975 the Ministry of Education enacted legislation to assist in the support to Parents Associations. This legislation provided some financial aid and funding for teachers to these schools.

Gradually the integration of children with SN became a reality in Portugal. The 1980's and 1990's saw major changes concerning the education of children with SN in the regular educational system, these changes were particularly evident for children with mental retardation. These changes were influenced by the Warnock report (1978) in England and by P.L.99-142 and P.L.99-457 in the United States.

Thus, in Portugal as in many other countries, there was a growing sense of responsibility for the education of children and adolescents with

SN in regular schools, and this responsibility is clearly stated in the Portuguese Basic Law of the Educational System (1986) – "Lei de Bases do Sistema Educativo". This law in its 7° article clearly states that the education of children with SN should happen in the context of regular education, and to do so "... it is necessary to create the conditions that are adequate to their development so that they can reach the full potential of their capacities". Table 5 shows the major Portuguese legislative measures in the field of special education.

The progressive changes concerning the education of children with SN culminated when a major piece of legislation– the Decreto-Lei 319/23 was enacted in August 1991. This law introduced considerable innovation in the Portuguese legislation with respect to the education of children and adolescents with SN. It provided schools with the legal support to organize the attendance of children with SN and introduced innovative principles derived from previous integration experiences namely (Correia & Cabral, 1997):

- The concept of "disabilities" was replaced by the concept of "special educational needs (SEN)" shifting the view of SN from a deficient focus to an educational focus. The concept of SEN reflects the integration philosophy premise, and appeals for the equal rights and non discrimination based on race, religion, physical and intellectual characteristics of all children and adolescents in the educational system;

- Abandons the categorization of students with SN according to their disability and based on medical decisions, introduces an educational approach to describe the problems of these students;
- In a perspective built on the concept of “School for All” (World Declaration on Education for All, 1990), and consistent with the normalization principle that values the maximum integration of students with SN into regular school, makes the school responsible for achieving this goal;
- Explicitly recognizes the role of parents in the education of their children and mandates their participation in the process of elaboration and revision of the Individualized Educational Plan – Plano Educativo Individual (PEI).

Table 5
Milestones in the Portuguese special education policy

Legislation	Content
Lei de Bases do Sistema Educativo Lei nº 46/86 de 14 de Outubro	Establishes the general frame work for the structure and organization of the educational system. Scope, goals and organization of Special Education
Despacho conjunto 36/ SEAM/SERE/88 de Julho	Creates the Special Education Teams
Lei de Bases – Lei 9/ 89, de 2 de Maio	Basic Law for prevention, rehabilitation and integration of citizens with disabilities. Focus on its 9 article the Special Education
Dec. – Lei 35/90, de 25 de Janeiro	Defines the regimen of free and mandatory education
Dec. – Lei 190/91 de 17 de Maio	Creates within the scope of the Ministry of Education psychological and counseling services
Dec.-Lei 319/91 de 23 de Agosto	Defines the special education regimen to apply to students with SEN of basic and secondary levels of education
Despº 173/ME/91 de 32 de Outubro	Regulates the necessary procedures to apply the aspects of D.L. 319/91
Despº Normativo 98-A/92, de 20 de Julho	Defines the evaluation system for the students of the basic level of education
Portaria 611/93, de 29 de Junho	Extend the legal dispositions of D.L. 319/91 to children with SEN of the preschool level
Portaria 613/93, de 29 de Junho	Applies the dispositions of the D.L. 319/91 to the Mediated Basic Education
Despcº 178-A/ME/93, de 30 de Junho	Clarifies the concept of pedagogical support and describes its modalities and strategies
Despacho conjunto 105/97, de 1 de Julho	Creates the educational support services
Despacho Conjunto nº 89/99, de 19 de Outubro de 1999	Guidelines for early intervention services for young children with or at risk for SN and their families
Despacho 6/2000	Defines the educational regimen to apply to students with permanent SEN

Source: Translated from Martins, A. P. (2000). O movimento da escola inclusiva. Atitudes dos professores do 1º Ciclo do Ensino Básico. Unpublished master dissertation. University of Minho, IEC: Braga.

This law was designed to serve students with SN from the basic and secondary education levels and it was not until 1993 that the law was extended to the preschool years (3 to 5 years of age). This happened with the enacting of Portaria 611/ 93.

More recently, and under the influence of the Declaration of Salamanca on Principles, Politics and Practices in the field of Special Education Needs (1994) a new agenda of debate begin to take place within the Portuguese teaching and research community. This new debate is a logical extension of earlier discussions concerning the most effective educational practices for children with SN and now focuses on aspects concerning educational best practices and their full *inclusion* in the educational process.

3.3.2. Means and statistics of special education in Portugal

According to the data supplied by National Institute of Statistics, cited in Correia, Martins & Serrano, 2000, we find that there is an average student population of 1,600,000 (INE, 1986) in Portugal. Based on this figure, Table 6 provides an estimate of the total number of children and youths with SEN and the number of children receiving assistance from the educational system.

Initial analysis of these data reveal the considerable difference between the population with SEN receiving assistance (24% of the total number of the population with SEN) and of those qualified children who are not receiving assistance (76% of the total number of the population with SEN). In spite of the differential between those served and those who remain without services, the overall increase in special education services in the country during the last few years can be considered noteworthy.

Table 6
Estimate of the total number of children and youths with SEN and number receiving assistance

Estimated population 0-16 years old (INE)	Population with SEN	Population with SEN being served
1,600,000	**160,000 – 240,000**	45,915
100%	10-12%	**2.6%**

Source: From Correia, Martins & Serrano (2000). *The state of art of Inclusion in Portugal.* Paper presented at CEC Annual Convention, Vancouver.

In spite of the modest gains in the past decade, it is important to note that children with SN still obtain their educational experiences in different kinds of settings. Figure 6 provides such a breakdown for the 45,915 children who are receiving educational services. Nearly eighty percent (n=36,519) of the children are receiving their education in integrated schools, while just over twenty percent (n= 9,396) of the children are in special schools or other support settings.

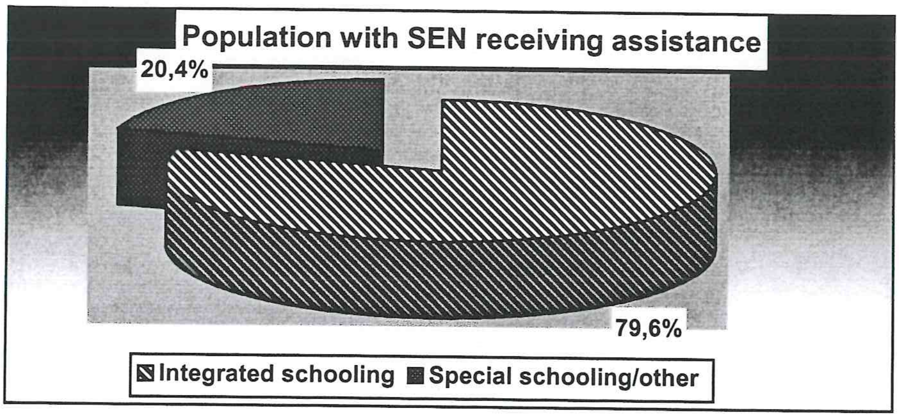


Figure 6. Population with SEN receiving assistance.
Source: From Correia, Martins & Serrano (2000). *The state of art of Inclusion in Portugal.* Paper presented at CEC Annual Convention, Vancouver.

It is not enough to know that the children are being served. It is also important to understand where they are being served in terms of their grade level. Using data on students school grade assistance, from the National Education Council – NEC (1998), there are some important findings as shown in Figure 7. Most of those students who are housed in regular educational settings are found in the basic school (58%). A much smaller group of students (8%) are entering school at an early age and are obtaining preschool services, while only a few students (3.5%) are found in secondary educational settings. Finally, a small number of students (2. 1%) are being supported in their homes.

This situation indicates the assistance to students with SEN is greater at the primary level. There is a dramatic decline in the number of children being served at the other educational levels or in their homes. The lower percentage of attendance at the pre-school level may be partially explained by the shortage of proper procedures identifying children early who might qualify for services because of their "at-risk" status, and that the pre-school service network is still under development.

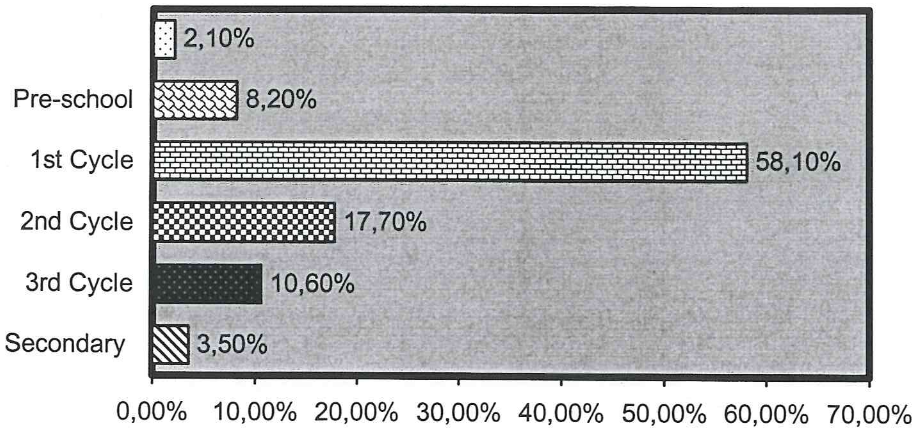


Figure 7- Attendance structures by level of education
Source: From Correia, Martins & Serrano (2000). *The state of art of Inclusion in Portugal.* Paper presented at CEC Annual Convention, Vancouver.

Now that we have considered the population with SEN in our country we would like to go back to Figure 6, in which we can see that the support to students with SEN is given mainly through mainstreaming in regular schools. However, this does not mean that all students are placed in the regular classroom. Our system still follows the integration model, which considers different placement levels (least restrictive environment) according to the severity of the problems. In this way the system seems to attend the students with SEN using a Deno type "Cascade (Deno, 1970) of services model.

However, public resources (human and financial) are frequently allocated to private institutions thus shifting the responsibility of educating children with SN from regular schools to segregated settings (Correia, Martins & Serrano, 2000). Most of these private institutions are organized and operated by parent's associations. As such they constitute powerful lobbies with strong political connections. Given the influence of these institutions, it is not surprising that a large number of students continue to be assisted by these parent directed schools. This placement option is particularly salient for children with more severe involvement. A breakdown of the number of students who are placed in special schools is provided in Figure 8.

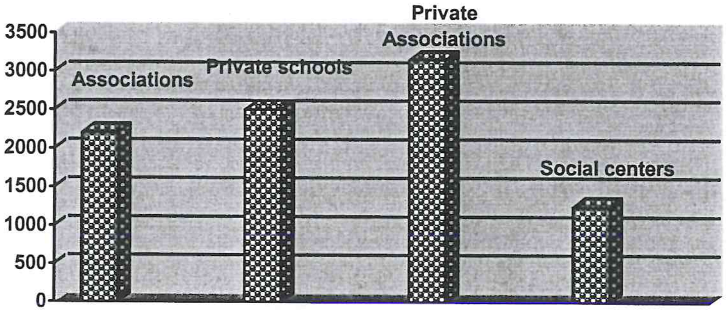


Figure 8- Number of students assisted in special schooling (NEC, 1998).
Source: Correia, Martins & Serrano (2000). *The state of art of Inclusion in Portugal.* Paper presented at CEC Annual Convention, Vancouver.

3.3.3. Historical evolution and value of early childhood education in Portugal

Concerns with the public early childhood education (ECE) in Portugal date from the 1st Republic (1910-1926). During the dictatorship (1926-1974), ECE was eliminated from the public school system. The rationale for this decision was argued from the perspective that young children should stay home with their families (Cardona, 1997, cited in Oliveira-Formosinho, 1998). Despite the loss of public preschools, private schools for young children prevailed in Portugal until the Educational Reform of Veiga Simão (1973). With this reform ECE was once again incorporated into the public educational system. Beyond the recreation of early childhood schools the first schools to train early childhood educators appeared. With the social changes in our society since the Revolution in April 1974, and the growing number of women working outside the home, these public, private or half-private (the Private Institutions of Social Solidarity) preschool settings that are dependent of the Ministry of the Social Affairs or of the Ministry of Education, have proliferated. In 1977 after the approval of the Law 5/77 of 1st February an official network of preschool education programs dependent on the Ministry of Education were established. In 1986 the Basic Law of the Educational System – Lei de Bases do Sistema Educativo" (Law 46/86, of 14th October) was enacted. This law established preschool education as a formal educational level in the educational system. However, even with this legal boost between 1989 to 1995 there was a stagnation in the expansion of the official preschool network. This was mainly due to critics on the organizational aspects of the preschools. For example, it was suggested that the preschool schedules covered only limited periods of time that were often inconvenient for families and that the preschools did not provide meals for children. In 1994, a report conducted and distributed by the National Council of Education on the status of preschool education suggested several areas that needed improvement. The report provided impetus for the field to seek change in preschool services. Moreover, the report became a matter of concern for politicians, early childhood educators and the research community in Portugal (Oliveira-Formosinho, 1998). The report revealed many of the deficits within the preschool system including its low rate of coverage and its underutilization by those whose children qualified for services. Portugal had the smallest rate of coverage of qualified preschool children among European countries. The net effect of the report was to bring preschool education to the fore and it became a focal issue that was used by the government as an election promise. The political awareness of the need for a quality early childhood educational system culminated in 1997 with the enactment of an important piece of legislation – Lei Quadro da Educação Pré-Escolar (Law 5/97, of 10th February). This law established two important precedents. First, early childhood education was seen as the first step in the basic educational system, and second early childhood services were established as a basic social support service for families (Formosinho, 1997). The law mandated the unique tutelage of the Ministry of Education concerning pedagogical aspects. It also mandated the physical accessibility of this service for all children which requires the geographically coverage for all areas in the country. Finally, the law appealed for the organization of global curricular guidelines for early childhood education.

While the Lei Quadro da Educação Pré-Escolar established preschool education as part of the overall education continuum it is important to note that the legal age to qualify for services is 3 years of age. This leaves out a great number of children in a very important phase of their development. The education of children below 3 years of age remains under the service umbrella of private or semi-private institutions that receive support from different Ministries. Institutions serving children under the age of 3 years are not officially required to hire early childhood educators. So the majority of these institutions have under trained personnel which effects the quality of their care.

Table 7 shows the administrative and pedagogical diversity of educational services that exist in Portugal for attending to the educational and intervention needs of young children, and Table 8 shows the rate of coverage for preschool services (3 to 5 years).

Important to the understanding of Table 7 is a description of some of the services described in the table. The services for children under the age of three are placed in small and/or family nurseries, under the guardianship of the Ministry of Social Affairs. Small nurseries are small organizations resembling a more familiar home type of environment. In 1988 only 5 units of this type existed in the country (Oliveira-Formosinho, 1998). Family nurseries are comprised of a network of twelve to twenty family care providers who live in the same geographical area. The network of providers is under the supervision of larger coordination organization. In 1988 only 18 unites of this type existed in the country (Oliveira-Formosinho, 1998).

Table 7
Early Childhood Educational Services in Portugal

PROPRIETARY	PUBLIC ADMINISTRATION			PRIVATE ADMINISTRATION				
TYPE OF ATTENDING SERVICES	Ministry of Education	Ministry of Social Affairs	City Council	Private schools	IPSS Non-profit	Private institutions	Enterprises	Associations & Coop.
FAMILY CARE PROVIDERS		◆						
NURSERIES		◆	◆		◆	◆	◆	◆
SMALL NURSERIES		◆						
FAMILY NURSERIES		◆						
DAY CARE		◆	◆	◆	◆	◆	◆	◆
LEISURE ACTIVITY CENTERS		◆	◆	◆	◆	◆	◆	◆
ITINERANT EARLY CHILDHOOD PROGRAMS	◆							
PRESCHOOLS	◆		◆	◆		◆	◆	◆

Source: Parecer nº1/194 do Conselho Nacional de Educação, *A Educação Pré-Escolar em Portugal.*

Table 8
Rate of coverage of preschool services in Portugal

	Rate of Coverage		
Attendance Modalities	**1988**	**1992**	**1997**
Informal Contexts	68%	47%	
Public Preschools of the Ministry of Education	9%	21%	
Private Preschools of the Ministry of Education	6%	8%	
Public Preschools of the Ministry of Social Affairs	3%	1%	
Private Preschools under the Tutelage of the Ministry of Social Affairs	14%	23%	
Total Rate of Coverage	**32%**	**53%**	**60%**

Source: National Educational Council and Bairrão *et al.*, 1997 cited in Oliveira-Formosinho, 1998.

Despite the clear evolution in the rates of coverage since 1988 as seen in Table 8, these percentages are still under the goals established by the Program of Educational Development for Portugal (PRODEP). The percentages of coverage proposed to attend by 1993 were 90% of coverage for children of 5 years of age and 50% for children of ages 3 and 4 (Oliveira-Formosinho, 1998).

From 1998 to 2000, the Organization for European Cooperation and Development (OECD) conducted a study of *Preschool Education and Infant Care* . Twelve countries of the European Community participated in the study including Portugal. The following excerpts are from the written report which directly target the status of preschool and infant care in Portugal. Included in the report are both country's identified deficits and some important recommendations (Ministry of Education, 2000):

- The Ministry of Education is derelict in not considering infancy care from the ages 0 to 3, which contradicts the tendency verified in many other European countries. According to the report the Portuguese Ministry is wasting "a valuable opportunity of reinforcing the foundations of a life learning for the youngster Portuguese citizens";
- In 1996, 87% of the children from age's birth to three years of age were not provided any type of formal educational support;
- Professionals working with children under the age of 3 years of age have generally less training and a lower status than professionals who work in preschools with children over 3 years of age. They recommend training for the professionals working with children under the age of

three in order to improve their professional development and the quality of care that they provide;

- The access to services, and the quality of those services is still restricted to geographical location and the social-economic status of the families. Services are not generally available based on the child or family's real needs. They recommend the development of more initiatives for environmental at-risk children and financial support for families with lower incomes. The report stated: "In a country where preschool education is considered an integrative part of the national policy for fighting social exclusion, this matter needs an urgently solution". (p.198/199)

They stressed the notable goals that Portugal have achieved concerning early childhood education recently. Namely the adult/ child ratios which are among the best when compared with the majority of the European countries. However, regardless of the advances in the field it is clear that Portugal has a long way to go concerning universal access to quality educational services for all children birth to five years of age.

3.3.4. EI in Portugal

Portugal has a few pioneering EI projects and the country has a clear concern for providing developmentally appropriate services for children either diagnosed with disabilities or at-risk for them.

Some of the first experiences in this field can be traced as early as the 1970's when the Cerebral Palsy Center in Lisbon, developed a center-based EI program for children with cerebral palsy. And during the 1980's an important contribution was the support provided from Direcção de Serviços de Orientação e Intervenção Psicológica that became the mediator for the EI Portage Program in Portugal, translating and using its materials in their work with young children with SN and their families on a home based program (Pimentel e Almeida, 1999). However, at this time few such programs exist particularly when one considers children under three years of age. Existing EI programs reflect a big geographically heterogeneity and asymmetry. There are regions where we find a significant number of projects while other regions of the country have few or no projects. The country's organizational structure until 1999, when the EI legal framework was established did not support what is considered appropriate EI practices. Concerning health services there are a number follow-up programs for high-risk new borns in maternity and pediatric clinics in many of the major hospitals in the country. Through a network of primary care health centers and local, secondary and tertiary hospitals Portugal's National Health Service provides free health care to most of the population. In recent years there has been a significant increase in the quality of maternal and child health services that has resulted in a dramatic decrease in the infant mortality rate from17.8% in 1985 to 5.9% in 1998 (Ministério da Saúde, 2000). Considering social security there are a number of financial initiatives to support environmentally at-risk families. For example social security provides a minimum wage (Guaranteed Minimum Income Program) for poor families who have no other financial resources. Also the Ministry of Social Security provides EI educational services for children with SN below the age of 3. Another initiative within the arena of social security is a financial support program (Ser Criança) designed to encourage private institutions to develop programs for young children. This program is regulated by Despacho nº26/95 from the Ministry of Social Security and by Portaria 1102/97 of the Ministry of Education. The Ministry of Education formally recognized the need of EI programs with the enacting in 1997 of Portaria nº52/97 de 21 de Janeiro. This law requires the special education schools under the tutelage of the Ministry of Education, in consort with the special education teams working in the public school system, to develop EI programs for qualified children. Nevertheless this law did not present any specific recommendations or guidelines concerning services implementation. All the programs mentioned above, while structured on the notion of being child centered are organizationally isolated and function in an individual way. This lack of articulation with other services that also serve the needs of children and families, e.g. social services, health services, educational services, and justice among others leads to fragmented service delivery (Peterson, 1991; Gallagher, Johnson & LaMontagne, 1994). This fragmented structure often leaves families frustrated and the very services that will help their child(ren) unavailable or difficult to find. The asymmetries found in Portugal are reflective of the existing political framework until recently. But there is an exception to the rule. This exception is an integrated and comprehensive EI program that provides a wide array of services on a regional basis. Based on the assumptions that undergird interagency collaboration (Peterson, 1991) and service integration needs of children and families can be most successful if they are community-based (Cohen & Syme, 1985; Dunst, *et al.* 1988; Gallimore *et al.* 1989). This ecological perspective espoused by Bronfenbrenner, 1972; 1979 provides the theoretical foundation for the following successful EI program for delivering comprehensive services for young children and their families: "Projecto Integrado de Intervenção Precoce do Distrito de Coimbra".

The Coimbra Project was initiated in 1989 in the north of Portugal in the region of Coimbra. This project grew out of the willingness of a group of professionals from different agencies to coordinate their services to provide EI (Boavida & Borges, 1994). The Coimbra Project developed the first coordinated interdidisciplinary interagency EI program, involving health care, education and social work, using the existing resources in the community. An interagency coordination team with one representative from each agency, provides not only coordination but also the necessary organizational support including planning training, supervision, regular meetings and most of the development and implementation of services from the Project (Boavida & Borges, 1994). Health is represented by Coimbra Children's Hospital Child Development Center and the Regional and Primary Care Administration which is the agency that coordinates the local public health centers. Educational services are provided by the Regional Public Special Education Department and an association of private special education institutions. Their role is to provide special educators and psychologists to local teams. Social service is represented by Coimbra's Social Security Center which is the public agency that provides most of the financial support to families. Each agency has to accomplish specific goals that reflect their mission and expertise and they provide an allocation of specific resources to support the overall mission. At the community level there are 17 different EI teams, comprised of professionals coming from different agencies operating in that specific community as show in Figure 9 and Figure 10.

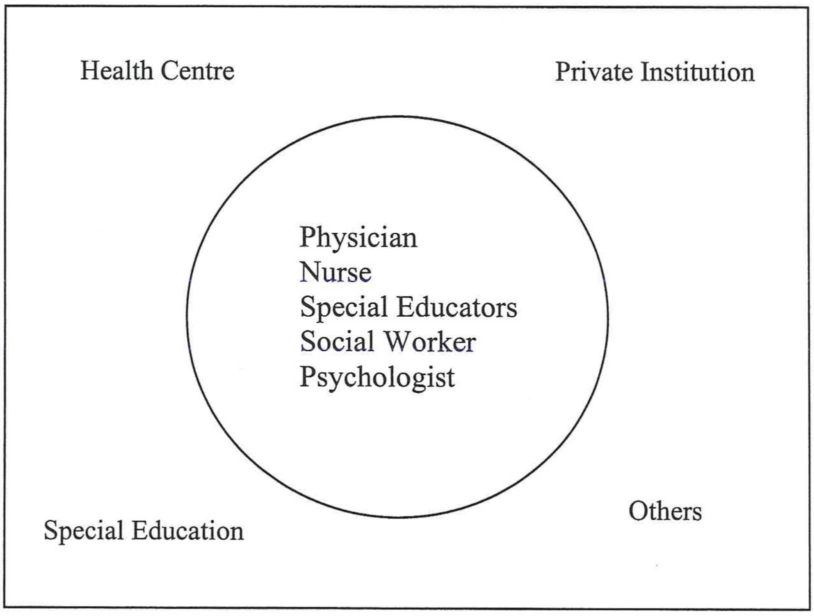


Figure 9. EI community team of the Coimbra EI Project
Source: Boavida, J., Espe-Serwindt, M., & Borges, L. (2000). *Child: Care, Health and Development*, 26, (5), 343-354; reprinted by permission.

The program is now region-wide and currently supports more than one-hundred families whose children are diagnosed with particular disabilities or are at risk for SN. The project's success contributed to professionals and policy-makers awareness of the need to integrate and coordinate multiple community agencies and develop regulations on the provisions of services.

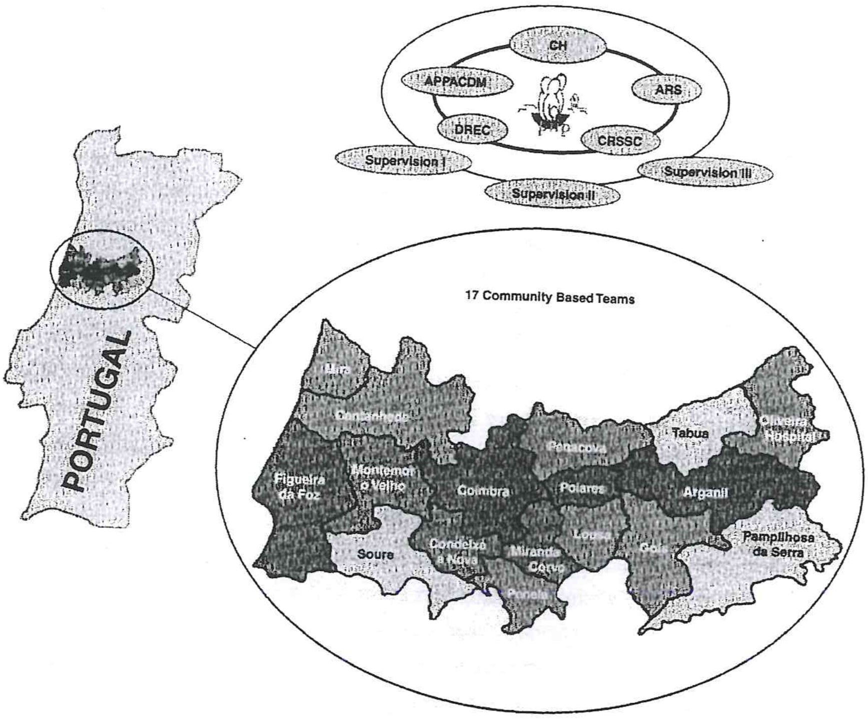


Figure 10. Structure of the Coimbra Early Intervention Project. ARS = Regional Primary Care Administration; DREC = Regional Public Special Education Department; CH = Children's Hospital; APPACDM = Association Private Special Education Institutions; CRSSC = Coimbra's Social Security Center.
Source: Boavida, J., Espe-Serwindt, M., & Borges, L. (2000). *Child: Care, Health and Development*, 26, (5), 343-354; reprinted by permission.

Considering the legal framework of EI in Portugal it was basically non-existent from birth to 3 years until October 1999 when the first piece of legislation was enacted. Concern for EI services began five years before in 1994. A task force was established, comprised of representatives from the Ministry of Education, Ministry of Social affairs and Ministry of Health. The task force was charged to develop the first EI project-law aimed to establish and organize delivery services for young children with SN and their families. The project-law designed by this task force was finally enacted in October 19, 1999 and it is designated Despacho Conjunto 891/99.

It contains basic guidelines for the implementation of EI services in Portugal and the philosophical and theoretical bases of this document are similar to the ones described in P.L.99-457.

The document determines that children with or at risk for SN from ages birth to five years of age and their families are eligible for services. According to the law EI services require three basic aspects: family involvement, multidisciplinary team work including professionals from different community agencies according to the needs identified by the family, and the development of an Individualized Intervention Plan (IIP). Despite the fact that this document recommends a family-centered approach to EI services, the word *family* was eliminated from the designation of the plan, an issue that demonstrates some inconsistency.

As can be verified below the PII presents some similarities with the IFSP. The Portuguese EI law (Diário da República – II Série, nº 244 – 19-10-1999) states that

> "6.4.1 – The PII should contain the following elements:
>
> a) Global diagnostic of the child's situation within his/her life context, with the identification of the child's health aspects, competencies, capacities and behavioral characteristics;
> b) Identification of the child and family resources and needs, done with the family collaboration and sharing of information;
> c) Designation of the types of supports to use with the family, done in a consensus between professionals and the family and after giving the family detailed information in order to facilitate their decision process among the various existing options;

> d) The dates for the initiation of services and the anticipated duration of the services;
>
> e) Periodicity of the evaluation process;
>
> 6.4.2 – The PII should also contain the necessary procedures for the child's transition to a formal educational context, namely to school (p.1567)."

This law is a primary step for the provision of EI services in Portugal and we hope that some of its premises can be transferred into practice and became a reality for families of young children with or at-risk for SN in a few years. The law is in an experimental phase for 3 years and at the end of this period it will be reevaluated. Comparing the status of other European Community countries, e.g. England, Sweden, Norway and Denmark, this legislation situates Portugal among the more updated European countries with respect to EI policy and services provision.

Opposite to what happened for the younger ages, services to children with SN with ages 3 to 5 were being provided through legislation approved in 1993 (Portaria 611/93, de 29 de Junho). As referred to earlier this happened because the Ministry of Education in Portugal considers the outset of formal education at the age of three. So there were clearly concerns with the attendance of these age group long before the age group of birth to three. In practice the nature of the services being provided to the older age group can be described as basically educational services and using child centered models of intervention. This is either due to the lack of human resources, personnel training, financial resources or collaboration from other services.

Training of professionals in the field of EI also became an important issue in Portugal and a number of EI programs have been established to operate in the main universities in the country. Recently two Master's EI programs were developed by the Universities of OPorto and Minho, and a third program is being developed by the Faculdade de Motricidade Humana da Universidade Técnica de Lisboa.

Both Master's programs in Minho and Oporto, collaborate with EI experts from well known American University programs that prepare professionals in the field of early childhood education and early childhood special education.

This is a field of evolving nature and the recent legislation is creating a new energy to conceive and develop quality services for young children with or at risk for SN and their families. As such the opportunity of this dissertation because it contributes to understand Portuguese families needs and supports in order to develop appropriate and effective services for them.

4. IMPORTANCE OF SOCIAL SUPPORT WITHIN FAMILY-CENTERED PRACTICES

4.1. The concepts of social support and social network: A review

The concepts of social support systems and social networks are increasingly popular foci of inquiry for both social science researchers and practitioners. Resulting from this line of inquiry theorists from a variety of fields have realized the importance of social support for individual well being (Bronfenbrenner, 1977; Caplan, 1974; Cochran & Brassard, 1979; Erickson, 1975; Hobbs, 1975; Weiss, 1974). Continuing research validates such beliefs by demonstrating the role that social support plays in buffering individuals from the negative effects that stressful events can have on their lives (Cassel, 1974; Cobb, 1976).

The concepts of social support and social networks are important in furthering our understanding of individuals, families and communities because: (1) they offer operational means of learning more about the everyday lives of persons in communities; (2) the linking of social support to various aspects of psychological adaptation offers a theoretical base for developing broad-based preventive interventions (3) they suggest a way of developing resources that puts less emphasis on formal treatment and more emphasis on embeddedness within a naturally occurring network of non-professional supportive relationships (Mitchell & Tricket, 1980).

According to Pierce, Sarason, Saranson, Joseph & Henderson, (1996), researchers in the social support tradition have typically credited investigators such as Cobb (1976), Cassell (1974;1976) and Caplan (1974) as the early pioneers in this field. Their work in the mid-1970's marks the emergence of a field of study that identifies itself as focusing on the primary elements that define the social support construct. No less important is the long tradition of research in the field of family studies that maintain the primacy of the family environment in shaping the child's social development. The importance played by a supportive caring environment in the development of the child is particularly salient in the work of Symonds (1939) cited in Rollins and Thomas (1979) as an early pioneer in the study of parental support. Thus two groups of researchers have been interested in the field of social support and these groups, to date, have pursued their research and their theory building independently.

An important contribution made by both social support and family researchers has been the acknowledgment that the construct of social support is broad and embraces many different components (Pierce *et al.*, 1996).

According to Pierce *et al.* (1996), we can distinguish two broad views of social support; (1) a situation-specific view in which social support is bound to the notion of how an individual or family copes with a particular stressful situation (Cohen & Wills, 1985), and (2) a developmental approach in which social support is seen as a contributor to personality and social development (Rollins & Thomas, 1979). The former can be identifiable with the social support research tradition, while the latter with the family research tradition.

The concept of social support has been defined in a myriad of ways, which demonstrates the multiple interpretations. The opaqueness of the construct is best described by Trivette *et al.* (1996) who state that the term tends to be operationalized differently depending upon the perspective of the researcher analyzing social support. Despite this diversity there is general consensus that social support is complex and multidimensional in nature, and that different aspects of support influence individual and family functioning differently (Trivette *et al.*, 1996).

In spite of this confusion there is some definitional agreement among researchers with the most widely referenced definition of social support provided by has been proposed by Cobb (1976; cited in Mccubbin *et al.*, 1980). Cobb considers "social support as information exchanged at the interpersonal level which provides the individual: (1) emotional support, leading the individual to believe that he or she is cared for and loved; (2) esteem support, leading the individual to believe that he or she is esteemed and valued; and (3) network support, leading an individual to believe that he or she belongs to a network of communication involving mutual obligation and mutual understanding" (Cobb, 1976 cited in Mccubin *et al.* 1980, p.863).

Social support refers to the resources, potentially useful information and artifacts provided to individuals and social units (e.g. a family) in response to the need for help and assistance (Cohen and Syme, 1985; Dunst, Trivette, & Deal, 1988).

Tardy (1985) systematizes five different factors that comprises the social support construct:

1. Direction Social support is both given and received;
2. Disposition Social support is available or enacted. Support availability refers to the quantity or quality of support to which people have access. The actual utilization of these support resources is referred to as enacted support;
3. Description/Evaluation Social support can be described or evaluated. Evaluation refers to people's satisfaction with their social support;
4. Content The content of support varies greatly depending on the situation. House (1981) presents a typology of support content where he identifies four types of support: emotional support which involves care; instrumental support which involves loaning money or giving one's time and skill; informational support which refers to advise; and appraisal which refers to evaluative feedback, e.g. "you are doing a good job!";
5. Network Refers to the social dimension of social support. Possible members of a network can be family, close friends, neighbors, co-workers, community or professionals among others.

According to Pierce and al. (1996) social support is a complex construct and comprises three components: support schemata, supportive relationships and supportive transactions. These components are not mutually exclusive, they overlap and mutually influence each other in important ways. *Support schemata* embrace one's expectations about the forthcomingness of the social environment in providing aid should one need it (Pierce *et al.* 1996).

The authors suggest that the support schemata are influenced by the individual's primary relationships established early on. Children whose interactions with their parents are supportive, sensitive and match their needs develop generally positive expectations about the disposition of others to provide support. Conversely, children whose needs for support are not met within their primary relationships develop a generalized view of others as reluctant or incapable to help to meet their needs for support. Moreover, children whose needs are being met learn the roles of both participants in a relationship, i.e. they learn not only how to receive support but also how to provide support. "Perceived social support", referred to as the perceptions of the availability of others upon whom they can rely for support, is one of the various ways that social support is assessed. It has proven to be the most consistent and strongest predictors of an individual's personal adjustment (Pierce & al., 1996). *Supportive relationships* refers to the expectations that an individual has about how specific supportive others are likely to respond should assistance be needed. Finally, the *supportive transactions* involve behavioral exchanges between at least two individuals. Supportive transactions usually involve each of the following elements; 1) efforts on the part of the potential support recipient to elicit support from another person, 2) the enactment of supportive behaviors on part of the provider, and, 3) the receipt of supportive behaviors by the individual who attempted to elicit support (Pierce *et al.*, 1996).

Barrera (1986), considers that despite the diversity in social support concepts that we find in the research literature, it is possible to organize these concepts and their operationalizations into three broad categories: Social embeddedness, perceived social support, and enacted support. Social embeddedness is that social support concept that refers to connections that individuals have to significant others in their social environments. Perceived social support is a concept that characterizes social support as the cognitive appraisal of being reliably connected to others. Enacted support is a concept that refers to actions that others perform when they help the focal person.

Ryan & Solky (1996) advance another important concept within the social support arena by positing the notion of *autonomy support* (Deci & Ryan, 1987, Ryan, 1993). They hypothesize that for social contacts to enhance psychological well being, they must be characterized by autonomy support. This construct refers to the contact and encouragement of the self within the context of interpersonal interactions i.e., the readiness of a person to assume another's perspective or internal frame of reference and to facilitate self-initiated expression and action. Thus autonomy support usually requires confirmation of the other's perceptions and acceptance of the other's feelings without attempts to control the other's experience and behavior (Ryan, & Solky, 1996). Caring for the true self of others, by listening and facilitating its expression and exercise we support the other's autonomy (Ryan & Solky, 1996). According to Ryan & Solky (1996) "autonomy-supportive relationships are not simply beneficial as buffers during episodes of stress (Cohen & Wills, 1985), but rather are more generally facilitative of psychological development and integration (Ryan, 1993)" p.253. Autonomy support has been linked with varied indices of psychological development and integration such as augmented self-esteem, self-confidence, achievement, volition and vitality (Ryan & Solky, 1996). Even the impact of other dimensions of social support, namely tangible supports (e.g. financial assistance, material goods, volunteering time, help or guidance) may be strongly dependent on the extent to which they are provided in a context of autonomy support vs. being used in ways that feel like controls, pressures, or messages of incompetence. If tangible support is provided in a context of respect for autonomy vs. a vehicle of control, then it is likely to be experienced as nurturance, and thus it will strengthen both well-being and one's relational connectedness (Ryan & Solky, 1996). In contrast, if tangible support is provided in a climate of control and pressure it is likely to be viewed as non-supportive by the receptor and consequently it will not impact positively the receptor's psychological well-being.

Social support of various types is provided through social networks. The degree that one's social network provides the individual necessary social support is based on matching the need with the amount of technical and tangible assistance, emotional support, feelings of being cared about, and/or self-esteem, that network provides social support. As the interest in this field of research increased, so has the diversity which researchers have approached a definition of networks. Mitchell (1969) defines social network as "a specific set of linkages among a defined set of persons, with the property that the characteristics of these linkages as a whole may be used to interpret the social behavior of the persons involved" (p.2). Bott (1971) more simply defines social networks as "all or some of the social units (individuals or groups) with whom a particular individual or group is in contact" (p.320). Vaux (1988) considers the social support network as a part of a larger social network, upon which the individual has recourse to or may have recourse to in order to help him cope with daily life demands and to attain his/her goals. These demands can be highly stressful ones such as the death of a beloved one, or the finalization of an important project, or less important ones such as the breakdown of a car. So social support "rather than being a static personal characteristic or environmental condition, involves a dynamic process of transaction (that is, mutual influence) between the person and his/her support network that takes place in an ecological context" (Vaux, 1988, p.59). It is in this permanently evolving ecological context that a social support network develops and is maintained. One of the prominent functions of social support networks, whether good or having limited effects, is that they complete the capacities of each individual (Vaux, 1988).

Cochran & Brassard (1979), completed a review of literature bearing on both the transmission of network influence and the possible impacts of the personal network upon parents and children. They suggested that network characteristics are best conceptualized within three general network dimensions:

- Relational characteristics that include those aspects of personal network which either derive from or directly affect the interactions between the parent or child and a specific network member. The authors include, *the content of each dyadic relationship* (exchange of goods and services, information, sharing, recreation, and emotional support), *the direction of each relationship*, that is related to the ability to influence (power) the relationship, as well as the reciprocal nature of the exchange process, and *the intensity of the dyadic relationship*, that refers to the relative willingness of the child to forgo other considerations in order to fulfill the needs of a network member or ask support to that member;

- Structural properties that include the network size, personal interconnectedness, and the diversity of network membership types;
- Location in space and time that include geographic proximity and continuity of network members.

In a review of the research literature within social networks Mitchell & Trickett (1980) also found several operational definitions of criteria for defining network membership. A few of the definitions follow:

- "The individual in question and the focal person must know each other by name, they must have an ongoing personal relationship, and they must have some contact at least once a year" (Tolsdorf, 1976, p.408 *cit. in* Mitchell & Trickett, 1980, p.29).
- "We define the primary group as being made of all kin, nominated friends, work associates, and neighbors" (Henderson, 1978, p.77 *cit. in* Mitchell & Trickett, 1980, p.29).
- "Name all the people over groups who are *important* in your life at this moment whether you like them or not" (Llamas, 1976; Pattison,

DeFrancisco, Wood & Crowder, 1975, cited. in Mitchell & Trickett, 1980, p.29);

- "Respondents were asked to list the initials of all adults with whom they saw at least once a month and whom they consider to be *important* in their lives" (Brim, 1974, p.435, cited. in Mitchell & Trickett, 1980, p.29).

According to Mitchell & Trickett (1980), the criteria for defining network membership seems to vary in agreement with three dimensions: (a) listing of all members of the social network or a representative subset; (b) the level of contact with the focal person (some contact v.s. significant contact); (c) the degree of frequency with which contact has to occur for an individual to be considered an active member of the network.

Concerning the dimensions along which social support networks are described Mitchell & Trickett (1980), in their review, composed a list of the structural and the component linkages that characterize the social networks. Structural characteristics refer to properties of the overall network, whereas characteristics of the component linkages refer to properties of individual relationships. The list can be seen in Table 9.

TABLE 9
Characteristics of Social Networks

I. Structural Characteristics of Networks

A. *Size or range*: The number of individuals with whom the focal person has direct contact. Different criteria have been used to define membership.

B. *Network Density*: The extent to which members of an individual's social network contact each other independently of the focal person (Mitchell, 1969). It is computed as the number of actual ties among network members divided by the total number of possible ties. Some researchers have suggested that rather than looking at the average density across the entire network, one should look for dense clusters within specific network sectors (i.e., family sector, co-worker sector, etc.).

C. *Degree of connection*: Related to network density, the average number of relationships that each member has with other members of the network.

II. Characteristics of the Component Linkages

A. *Intensity*: The strength of the tie. It has been measured in terms of the reciprocal functions or services which characterizes the tie (Shulman, 1976), and the individual's rating of the strength of the feelings or thoughts toward each member of the network (Llamas, 1976).

B. *Durability*: The degree of stability of the individual's links with others in his or her network. This has implications in terms of the length of time the focal person has known persons in his or her network (Shulman, 1976), and the individual's rating of the degree to which each of his or her relationships is changing (Llamas, 1976; Henderson *et al.*, 1978).

C. *Multidimensionality (or Multiplexity)*: The number of functions served by a relationship. If serves only one function, it is unidimensional, and if serves more than one function, it is multidimensional. The proportion of multidimensional relationships is than calculated. One unresolved issue is the manner in which one categorizes and codes relationships according to content function. Sobolovsky *et al.* (1978) have argued for content categories based on observational analysis of the specific social settings involved, while others have used more general a priori categories (e.g., advice, support, feedback).

D. *Directedness and Reciprocity*: The degree to which affective and instrumental aid is both given and received by the focal person. This has been measured by asking focal persons to rate the degree of assistance, support and so on that they give and receive in each relationship (Tolsdorf, 1976; Llamas, 1976).

E. *Relationship Density*: The concept that tries to examine the extent to which the focal person's relationships serve a variety of functions. Given that one has defined relationships as potentially serving x number of functions (e.g., support, advice, feedback, etc.), relationship density is calculated by dividing the average number of functions per relationship by x.

F. *Dispersion*: The ease with which the focal person can make contact with members of his or her network. Typically, is measured in terms of geographical proximity.

G. *Frequency*: The frequency with which the focal person makes contacts with members of his or her network. Contact has been variously defined to include contact by phone and letter as well as face-to-face contact.

H. *Homogeneity*: Although seldom used, a concept that refers to the extent which members of a network share common social attributes (e.g., religious affiliation, socioeconomic status, etc.).

III. Normative Context of the Relationship

A. *Primary Kin*
B. *Secondary Kin or Extended Family*
C. *Friend*
D. *Neighbor*
E. *Work Acquaintance*

Source: Mitchell, R.E. & Trickett, E.J. (1980). Task force report: Social networks as mediators of social support. *Community Mental Health Journal Vol. 16*(1), Spring, p.31.

The types of support provided by the social networks correspond to specific actions that the majority of the members of a culture recognize as intentional efforts to assist the focal person. The support actions that others perform to render assistance to the focal person can happen spontaneously, or upon being solicited (Vaux, 1988).

Support–seeking attempts can be either direct or indirect (Pierce *et al.*, 1996). Direct attempts to elicit support from others involve making explicit requests for assistance; indirect attempts focus on communicating one's need for support without asking for assistance (e.g., by displaying distress with the goal of drawing a potential support provider's attention to one's need for aid).

The type of support provided by the network is another important dimension when analyzing networks. The literature review completed by Mitchell & Trickett (1980), found several viewpoints concerning the general functions served by the social networks. An outline of these functions can be seen in Table 10.

Table 10
The Functions Served by Social Networks

Brim (1974)	Caplan (1974)	Tolsdorf (1976)	Walker *et al.* (1977)	Weiss (1974)
Concern	Emotional support	Support	Emotional support	Attachment
Assistance	Task oriented assistance	Advice	Material aid and services	Exchange of services
Value similarity	Communication of evaluation and expectation	Feedback	Maintenance of a social identity	Guidance
Desired interaction	Sense of belonging		Diverse information	Social integration
Trust			Access to new social contacts	Sense of alliance
				Reassurance of worth
				Opportunity to provide nurturance

Source: Mitchell, R.E. & Trickett, E.J. (1980). Task force report: Social networks as mediators of social support. *Community Mental Health Journal Vol. 16*(1), Spring, p.32.

According to the supra cited authors many of the categories delineated in Table 10 can be summarized into the subsequent functions: “(a) emotional support; (b) task-oriented assistance; (c) communication of expectations, evaluation, and a shared world view; and (d) access to new and diverse information and social contacts" (p.30).

4.2. Influences of social support for families of children with or at-risk for special needs

The way in which social support functions as EI for families of children with/or at-risk for SN, and interacts with other factors such as child, parent and/or family functioning has been the focus of the work completed by Dunst and his associates (Dunst, 1982, 1983, 1985, 1986a, 1986b; Dunst & Trivette, 1984, 1986, 1988a, 1988c; Dunst, Trivette, & Deal 1988; Trivette *et al.*, 1986; and Trivette & Dunst, 1992). The conceptual framework concerning social support from which Dunst *et al.* derive their theoretical considerations are the ecology of human development (Bronfenbrenner, 1979), already mentioned, the social support theory (Cohen & Syme, 1985), and the help-seeking theory (DePaulo *et al.*, 1983) cited in Trivette *et al.*, (1996). The first two were already described earlier and the latter, the help seeking theory analysis the conditions that affect the decision to ask for help from a favored individual, and the nature of help-seeking itself, as well as, the type of the actual help giving exchanges (Dunst & Trivette, 1987, 1988b)

Dunst and his associates adapted most of the knowledge on social support to families of children with/or at-risk for SN, and in the research that they conducted they analyzed the effectiveness of providing social support for these families.

From a social systems perspective, their theory includes the contention, that social support has both direct and indirect influences on child behavior and development. Moreover, Dunst *et al.* (1997), generally recognize the influences of social support are best understood as a transactional process within a social system, ecological context. However, they remind us that within a social-ecological context, social support is only one of several intrapersonal, interpersonal and environmental variables that can influence later developmental outcomes (Dunst *et al.*, 1997). Peralin & Schooler (1978), cited by Dunst, Trivette, & Deal (1988), consider two types of resources that families use to meet needs and cope with life events: (1) the social resources- extrafamily resources; and, (2) the psychological resources – intrafamily resources. Social resources are the sources of support and external resources potentially available to a family when necessary. Psychological resources constitute the inter- and intra-individual family member characteristics that are used to respond to crisis situations and to cope with normative and nonnormative life events that promote growth and development in all family members. Dunst *et al.* (1988), refer to the psychological resources of the family as the *family function style*, and the social resource as *social support.* Using these factors as a foundation to their investigation Dunst and his associates have proposed a paradigmatic framework to clarify how these factors interact or interfere with developmental outcomes for children and families (Trivette, Dunst, & Hamby, 1996; Dunst, Trivette, & Jordy, 1997). The paradigmatic framework is :

$$B= f\,(F, I, S, C, E)$$

> in which B is an outcome or criterion measure (e.g., parent, family, or child functioning), and the relationship between B and the variables on the right side of the equation is of the form B varies as a function of F (parent and family characteristics), I (interpersonal coping), S (social support), C (child characteristics), and E (environmental characteristics). Accordingly, one would expect to find *parental family characteristics* (parental age and educational level, SES, income, etc.) *intrapersonal coping* (coping style), *social support* (relational, structural, functional, etc.), child characteristics (age, sex, level of functioning, etc.), and *environmental* factors (living arrangements, neighborhood characteristics, etc.) having both cumulative and interactive effects on behavioral development. (Trivette, Dunst & Hamby, 1996, p.240).

The three sets of variables (parent, family and social support) play an important role on a family's adaptation (Richman & Flaherty, 1985; Roskin, 1982; Shapiro, 1983; Toldsorf, 1976, cited in Trivette *et al.* 1996) to both normative (e.g., marriage) and nonnormative (birth of a child with special needs) life events. Direct and indirect influences on parent health and well-being can be explained through the combination of all five (F, I, S, C, E) sets of variables (Cohen & Syme, 1985).

Dunst, Trivette, & Deal (1988), present a definition of social support as "the emotional, physical, informational, instrumental, and material aid and assistance provided by others to maintain health and well-being, promote adaptations of life events and foster development in an adaptative manner (p.28)".

Operationally social support can be differentiated between formal and informal sources of support (Dunst *et al.* 1988). Informal sources of support can be individuals (extended family, friends, neighbors) or social groups (religious groups, clubs, volunteer organizations). Formal support sources include both support service professionals, e.g. medical doctors, early childhood educators, social workers, and agencies, e.g. hospitals, EI programs; health departments.

The research done within the field of social support has demonstrated that the formal sources of support are an important aspect of help-giving behavior, but they are not the only source, the informal sources may play an even more important role on satisfying family needs and aspirations (Dunst *et al.* 1988). As Gottlieb (1983) stated: "...when people recognize that they have needs they generally consult family members, friends, workmates, and neighbors, calling upon them for advice about community resources that are best matched to their needs" (p.210). The findings from research conducted and reviewed by Dunst, Trivette, & Jordy (1997), also demonstrated a pattern that informal rather than formal support showed the strongest relationship with any number of outcomes they studied. According to the authors, psychological affinity and mutual caring characterize social support exchanges among personal network members. These complex factors influence the degree to which support has positive effects on the family (Duck & Silver, 1990; Miller & Lefcourt, 1983; Sarason, Pierce, & Sarason, 1990, cited by Dunst, Trivette, & Jordy, 1997).

Social support influences upon families are equally dependent on other factors, i.e. their components and specific dimensions within components (Cohen *et al.*, 1985; House & Khan, 1985 cited in Trivette *et* *al.* 1996). Figure 11 shows the ways in which five such components are related.

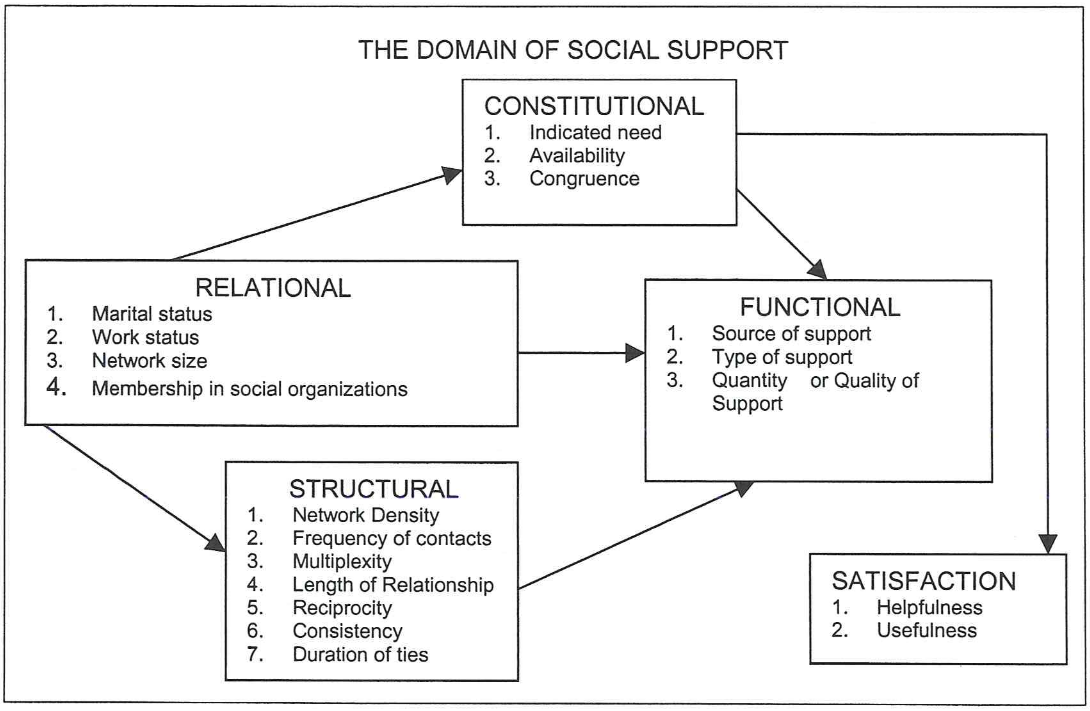


Figure 11. Five Major Components of the Social Support Domain and Their Relationships.
Source: Dunst, C., Trivette, C., & Deal, A. (1988).*Enabling and empowering families. Principles and guidelines for practice.* Cambridge, MA: Brookline Books (p.29).

According to Trivette *et al.* (1996), these components are:

- **Relational support** refers to the existence and quantity of social relationships (e.g., marital and work status, number of persons in one's personal social network and membership in social organizations);
- **Structural support** refers to a number of quantitative aspects of personal social networks, including physical proximity to social network members, duration and stability of relationships, frequency

of contacts with the network members and reciprocity (give and take) in social relationships;

- **Constitutional support** refers to the indicated need for help and the congruence or match between the needed support and the type of support offered or provided. What is considered a good resource to solve one family's problems might not be the same for another family and so this concept is highly personalized. Moreover this notion evolved from Dunst and his associates work as one of the most important determinants of positive influences on family functioning (Dunst & Leet, 1987; Dunst, Leet & Trivette, 1988; Dunst & Trivette, 1988d). That is the efficacy of family support is greater when resources match what each family specifically needs;
- **Functional support** refers to the type (e.g., emotional, informational, material), quantity, and quality of aid and assistance. Quantity refers to how much support is provided by the network members. Quality of support refers to the mode in which support is requested from and provided by network members (e.g., willingness of relatives to provide financial aid in an emergency);
- **Support satisfaction** refers to the extent to which aid and assistance is viewed as helpful and useful. (p.235/237)

Within the dynamic of social support exchanges, we can identify one or more of the components described above, which in turn will influence differently the behavior and development of those receiving the support.

Accordingly to a revision completed by Dunst Trivette, & Deal (1988) there is a growing body of research which indicates that social support directly and indirectly influences parent, family and child behavior. This revision can be seen in Table 11.

Table 11
Research evidence of social support influences on parent, family and child behavior

Factor	**Researchers**
Personal and familial health	Cobb & Kasl, 1977; Cohen & Syme, 1985; Embry, 1980; Gore, 1985; Kasl & Cobb, 1979; McCubbin *et al.*, 1980; Mitchell & Tricket, 1980; Patterson & McCubbin, 1983.
Parenting attitudes and behavior	Colletta, 1981; Crnic *et al.*, 1983; Crnic *et al.*, 1984; Crnic *et al.*, 1986; Crokenberg, 1981, 1985; Dunst, 1985; Dunst & Trivette, 1984, 1988; Dunst *et al.*, 1986; Dunst, Trivette & Cross, 1988; Epstein, 1980; Hetherington *et al.* , 1976, 1978; Wandersman & Unger, 1983 ; Wandersman *et al.*, 1980; Weinraub & Wolf, 1983
Parental perceptions of child functioning	Affleck *et al.*, 1986; Dunst & Trivette, 1984; Dunst *et al.*, 1986; Lazer & Darlington, 1982; Trivette & Dunst, 1987
Child behavior and development	Crnic *et al.*, 1983; Crnic *et al.*, 1984; Crnic *et al.*, 1986; Crockenberg, 1981; Dunst, 1985; Dunst & Trivette, 1984; Dunst *et al.*, 1986; Dunst, Trivette & Cross, 1988; Trivette & Dunst, 1987

Source: Adapted from Dunst, C., Trivette, C., & Deal, A. (1988).*Enabling and empowering families. Principles and guidelines for practice.* Cambridge, MA: Brookline Books (p.31).

Social support has direct, indirect or mediation influences and moderating influences on the behavior and development of children with SN and their families (Dunst, Trivette & Jordy, 1997). Dunst, Trivette and their colleagues (Dunst & Trivette, 1988a, 1988c, 1988d; Dunst, Trivette, Hamby & Pollack, 1990) conducted a series of studies guided by a social systems model that postulates the direct and indirect influences of social support on parent well-being, family functioning, parent-child interactions and child behavior and development. They conceptualized a model to describe those influences and Figure 12 shows a version of this model. A similar model has been proposed by Marfo & Dinero (1991) with the specific purpose of studying EI efficacy. According to Dunst & Trivette (1988c, 1988d; Dunst, Trivette, Hamby & Pollack, 1990), social support and resources exert their influences on the health and well-being of a support recipient; both support and health/well-being influence family functioning; support, health/well-being, and family functioning influence caregiving interactive styles with their children; and all these variables both independently and in combination influence child behavior and development (Dunst, Trivette, Hamby & Pollack, 1990).

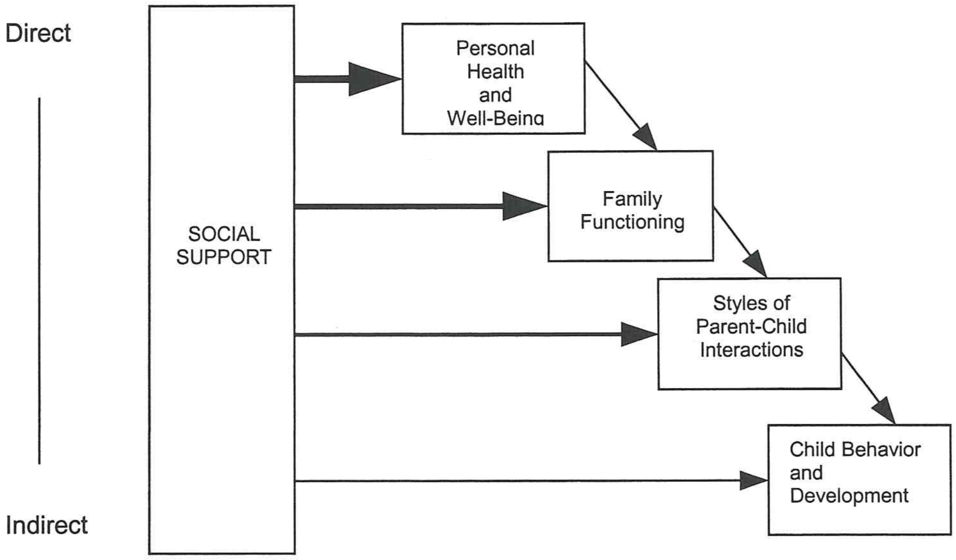


Figure 12. A Model of The Direct and Indirect Influences of Social Support.
Source: Dunst, C., Trivette, C., & Deal, A. (1988).*Enabling and empowering families. Principles and guidelines for practice.* Cambridge, MA: Brookline Books (p.31).

Another important aspect that resulted from the research on supportive relationships during early childhood years is the fact that it primarily provides evidence of indirect associations to children's development (Crnic & Stormshak, 1997; Dunst, Trivette & Jordy, 1997). That is, the positive relationship between positive supportive relationships for parents, positive parental functioning, and the generally positive child outcomes, however, direct links between parental support systems and children's development have been more illusive to describe (Crnic & Stormshak, 1997). Dunst *et al.* (1997) too, found that social support has the most direct influences on the behavior of the support recipient and has mediational (indirect) influences on other family members and their interactions with others. In a prospective longitudinal study that compared support to mothers of children with or at-risk for poor developmental outcomes and of children at no risk for poor outcomes, Dunst *et al.* (1997) analyzed the relationship among such variables as informal support, personal well-being, family functioning, parenting and child development. They found that social support had the strongest relationship with personal well-being and the weakest relationship with general child development and that, parenting had the strongest relationship with child development. These results indicate the need to change traditional EI practices from practices that are basically aimed to ameliorate the child's problems through direct support to the child, ignoring the other aspects of the child's ecology, to practices that support the family and the child.

The practical implications of the research concerning social support and its influences on the behavior and development of children with SN and their families, led Dunst (1985) to purpose a social systems definition of EI as "...the provision of support (and resources) to families of infants and young children from members of informal and formal social support networks that impact both <u>directly</u> and <u>indirectly</u>, on parent, family, and child functioning" (p.179).

Another aspect crucial to understand recent perspectives of EI is the concept of resource-based versus service-based approach to EI. This broad conceptualization of EI results from the research done by Dunst and colaborators on social support. Contemporary EI practices are to a large degree based on specific services to meet child and family needs (Trivette, Dunst & Deal, 1997). This way of conceiving EI is both limited and limiting because it fails to value other sources of support apart from formal professional support, and at the same time funds to provide all the services that children and families need might never be enough if we keep this professional based solutions to meet the needs (Trivette *et al.*, 1997).

Conversely what characterizes resource based EI services is the importance and emphasis placed on community support. According to Trivette *et al.* (1997), the concept of community here has to be understood in a broader sense than neighborhood. So resource-based approaches scrutinize a variety of community people and organizations as sources of support with important resources for meeting child and family needs. Consequently a resourced-based approach to intervention does not rely on a single type of professional help or assistance but rather utilize and mobilize multiple sources of informal and formal community resources. The term community resources according to Trivette *et al.* (1997), means personal social networks, organizations, associations groups, community programs and professionals, specialized professional services and so on that can be used by families of young children to provide both the children and the parents the opportunities and experiences that have a positive impact on child, parent, and family behavior and development.

Summary

In this chapter, I have completed a review of the literature on the historical evolution of family centered services as well as the practical and theoretical contributions underlying the concept of family centered practices. Then I described the practical implementations and organizational aspects of family centered practices in EI. I briefly presented the EI service system in the United States of America and a historical overview of the educational attendance of children with SN in Portugal as well as the evolution of EI services in Portugal. I then moved to the specific focus of this study which was social support and its importance within the context of EI. From there I proceeded with the review of the concepts of social support and social network. Research in this field expanded considerably in the last several decades. The multiplicity of researchers' interests and disciplinary backgrounds contributed to a myriad of different ways of defining those concepts. Despite of this diversity there is general consensus that the construct of social support is complex and it is multidimensional in nature. This overview includes a review of the social support network concepts and analysis of its components and characteristics. It also includes a review of what we know as far as social support influences for children with disabilities and their families as described by Dunst and his colleagues' adaptation of the knowledge on social support to the field of early intervention.

CHAPTER III

Research Methodology

RESEARCH METHODOLOGY

This chapter is devoted to the methodological aspects of the research and is comprise of two parts. The first part addresses both conceptual and practical aspects of qualitative research, and serves as the theoretical foundation for the methodological choices made in this study. The second part describes the procedures that were followed in selecting the site and subjects, collecting data, analyzing data and addressing the issue of trustworthiness in a qualitative inquiry.

1. Qualitative Research

Qualitative research methods are increasingly important modes of inquiry for the social sciences and applied fields such as education and management (Marshall & Rossman, 1995). Despite the difficulties of definition, qualitative methods are widely used among researchers from different disciplinary perspectives, to understand naturalistic phenomena. Denzin and Lincoln (1994) define qualitative research:

> ...is multimethod in focus, involving an interpretive, naturalistic approach to its subject matter. This means that qualitative researchers study things in their natural settings, attempting to make sense of or to interpret phenomena in terms of the meaning people bring to them. Qualitative research involves the studied use and collection of a variety of empirical materials (case study, personal experience, introspective life story, interview, observational, historical

> interactional, and visual texts) that describe routine and problematic moments and meaning in individual lives. (p.2).

According to Denzin & Lincoln (1994), qualitative research, should be seen as a collection of interpretative practices, that analyzes various natural artifacts and not a single protocol that is identified with a particular a theory or paradigm. Many theoretical paradigms claim to use qualitative research methods and strategies, including Marxism, cultural studies, feminism and constructivism.

Bogdan & Biklen (1994), describe essentially five characteristics of qualitative research:

1. Qualitative research is field focused and takes natural settings as a source for data. Qualitative researchers spend enormous amounts of time in schools and neighborhoods, with families, and in other naturally occurring environments to conduct their studies. The researcher becomes the key instrument for data collection and analysis. Qualitative researchers have direct contact with the environments they study as they contend with human actions. From this perspective the researcher feels that behavior(s) can be better understood within the contexts where they naturally take place;
2. Qualitative research is descriptive, i.e. the data are collected as naturally occurring words or pictures and actions not number. Qualitative researchers describe all aspects of what is being observed in narrative form. As an objective recorder, the researcher assumes that no behavior is irrelevant and that everything, action and context, provide for an enriched understanding the object of study;

3. For qualitative researchers, outcome is viewed as a process rather than a product. They are interested in understanding reality as it unfolds. Inherent in this approach is the assumption that naturally occurring environments are dynamic where change is constant. Thus making the researcher more attentive to the process rather the results;
4. Qualitative researchers analyze data inductively – Data are not collected with the aim of confirming or invalidating previously constructed hypothesis, instead their abstractions are constructed based on the emerging details that come along as the study proceeds;
5. The qualitative approach focuses on the participants' perspectives and the purpose or meaning for their actions. Consequently, meaning acquires a vital importance for qualitative research. To fully understand the dynamics of a process the researcher attempts to unveil the perspectives to explain the actions of those who are participants.

Historically Denzin & Lincoln (1994, p. 6-11) describe the following five epochs in the development of qualitative research:

1. The traditional period begins in the early twentieth century and continued until World War II. It was an outgrowth of the ethnographic research conducted by Malinowski (1916) and the Chicago School in sociology. During this period, qualitative research was interested in attempting to objectively describe and interpret the unique, the foreign or the strange. Used in this fashion ethnography became interested in describing foreign cultures and the sociology of outsiders within one's own society;

2. The modernist phase lasted until the 1970s and was characterized by attempts to formalize qualitative methods. Given this aim textbooks describing qualitative research were published;
3. From 1970's up to the mid 1980's the developments are characterized by blurred genres (Geertz, 1983). Researchers explored various theoretical models. These competing methods stood beside which resulted in various theoretical models for understanding the human condition. The product of this period of emerging paradigms included; symbolic interactionism, ethnomethodology, phenomenology, semiotics or feminism;
4. In the mid-1980's, a double crisis of representation and legitimization confronted qualitative researchers in the social sciences. This crisis had its genesis with the rise of poststructuralism and postmodernism and its association with the interpretive, linguistic and rhetorical influences on social theory. This linguistic shift clashed with two key assumptions of qualitative research. The first posited that qualitative researchers can directly grasp experience. Such experience, is now argued to be constructed by the researcher in his/her written text. Which means that qualitative research becomes a continuous process of constructing versions of reality. This is the representational crisis, i.e. the interpretation someone presents to an interview does not correspond exactly to the interpretation he or she would have conceived at the moment when the reported event occurred. Therefore, the researcher who interprets this interview and presents it as a part of his or her findings, yields a new version of the whole. Later, different

readers of the book, article, or report explain the researcher's version differently, so that further versions of the originally observed event surface. As Stake (2000) said:

> "...the case researcher emerges from one social experience, the observation, to choreograph another the report. Knowledge is socially constructed, so we constructivists believe, and, in their experiential and contextual accounts, case study researchers assist readers in the construction of knowledge" (p.442).

In this context, the evaluation of research and findings becomes a main topic when discussing methodology. The second assumption questions the validity of traditional criteria when conducting qualitative research and, if other standards should be applied for assessing the validity of qualitative research. This is the legitimization crisis. As Denzin & Lincoln (1994) say "... any representation must now legitimate itself in terms of some set of criteria that allows the author (and the reader) to make connections between the text and the world written about" (p.11). This makes the process of displaying knowledge and findings a substantial part of the research process;

5. The recent situation described by Denzin & Lincoln (1994) as the fifth moment is distinguished by the change where narratives have replaced theories, or theories are read as narratives. This epoch is described as the end of great narratives. Instead, the emphasis shifted towards theories and narratives that fit specific, circumscribed, local historical situations and problems.

Beyond this overview of the historical epochs in the development of qualitative research, qualitative researchers overlay a tradition of inquiry that utilizes the methodology and methods advanced by researchers in the disciplines of sociology, psychology, anthropology, and humanities. Creswell (1998) systematized the varieties of qualitative research and identified five traditions of inquiry which differ in form, terms and focus. These traditions are the biographical study, phenomenological study, grounded theory study, ethnographic study and case study.

The biographical study is the study of an individual and her or his experience as told to the researcher or found in documents and archival material (Creswell, 1998). Denzin(1989a) defines the biographical method as the "...studied use and collection of life documents that describe turning point moments in an individual's life" (p.69). The roots of biographical study can be found in different disciplines such as literacy, history, anthropology, psychology, and sociology as well as in interdisciplinary views from feminist and cultural thinking.

The phenomenological study describes lived experiences for several individuals about a concept or the phenomenon. As opposed to the biographical study that reports the life of a single individual. Phenomenologists seek to understand and provide meaning to the structures of consciousness in human experiences (Polkinghorne, 1989 cited in Creswell, 1998). This form of research has its roots in the philosophical perspectives of Husserl, Heidegger, Sartre, and Merleau-Ponty and it has been used in the social and human sciences, particularly in sociology, psychology, nursing and health sciences and education (Creswell, 1998).

Whereas the phenomenological study emphasizes the meaning of an experience, the grounded theory study's intent is to generate or discover a theory, i.e. an abstract analytical schema of a phenomenon, that relates to a specific situation (Creswell, 1998). Grounded theory researchers are interested in situations where individuals interact, take actions or engage in a process in response to a phenomenon. They study how individuals act and react to this phenomenon and in the process of doing it they collect primarily interview data, make different visits to the field, develop and interrelate categories of information, and write theoretical propositions or hypotheses or present a visual picture of the theory (Creswell, 1998). The pioneers of this research tradition were two sociologists, Glaser and Strauss who in 1967, presented the first grounded theory research. Those authors continued to elaborate on this research theory, and it has been mainly used within the disciplines of sociology, nursing, education and other social science fields (Creswell, 1998).

The ethnographic study is a description and interpretation of a cultural or social group or system (Creswell, 1998). The researcher observes the patterns of behavior, customs and ways of life of a specific group. The process of an ethnographic study involves prolonged observation of the group in which the researcher becomes a participant observer embedded in day-to-day lives of persons or through one-on-one interviews with the members of the group (Creswell, 1998). Researchers interests are the meanings of behavior, language and interactions of the culture-sharing group (Creswell, 1998). The roots of ethnography are founded in cultural anthropology through authors such as Boas, Malinowski, Radcliffe-Brown, and Mead and their studies of comparative cultures (Creswell, 1998).

Finally the fifth tradition is the case study, which I will describe in more detail as it concerns the research methodology I choose to conduct in this particular study.

According to Creswell (1998), "...a case study is an exploration of a bounded system or a case (or multiple cases) over time through detailed in-depth data collection involving multiple sources of information rich in context (p.61). The case can be a program, an event, a person, a process, an institution or a social group. Thus, the case might be selected because it is an instance of some concern, issue or hypothesis and it is bounded by time and place (Merriam, 1988). Multiple sources of information collected for the case study include observations, interviews, audio-visual material, and documents and reports. Stake (1998), differentiates the intrinsic case study from the instrumental case study. In the first, the case itself becomes the focus of study because of its uniqueness, whereas in the latter, the focus is on an issue or issues, with the case used instrumentally to illustrate it. Case study is a basic design that can serve a variety of disciplinary perspectives, as well as philosophical perspectives (Merriam, 1988). Case study research has a long and demarcated history across many disciplines. Hamel (1993) analyzed the origin of modern social science case studies through anthropology and sociology. He identifies French sociologist LePlay's (1855) study of families, anthropologist Malinowski's (1922/1953) study of Trobriand Islands, and the case studies of the University of Chicago's Department of Sociology in the 1920's and 1930's as precursors of qualitative case study research. This research tradition has also received considerable attention in educational research and particularly in the evaluation of educational development programs (Walker, 1980). Case studies continue to be used extensively in social science research including the traditional disciplines of psychology, sociology, political science, anthropology, history and economics, as well as practice oriented fields such as urban planning, public administration, public policy, management science, social work and education (Yin, 1994).

In conducting case study research the data collection is extensive and draws on multiple sources of information, such as observations, interviews, documents, and audio-visual materials. Through this data collection process, a precise description of the case emerges, as do analyses of themes or issues and an interpretation or assertions about the case by the researcher (Stake, 1998). This analysis is rich in the context of the case or setting in which the case presents itself (Merriam, 1988). The researcher narrates the study through different techniques such as chronology of major events followed by a detailed perspective about a few incidents. When there are multiple cases, a typical format is to first provide a detailed description of each case and themes within the case, named a within-case analysis, and next provide a thematic analysis across cases, called a cross-case analysis, as well as assertions or an interpretation of the meaning of the case (Creswell,1998). As Lincoln &

Guba (1985), notice in the final interpretative phase, the investigator reports the "lessons learned" from the case.

A qualitative case study, as with any research, is concerned with producing valid and reliable knowledge in an ethical manner. According to Merriam (1988), the qualitative approach to research is based upon different assumptions and a different worldview from the ones assumed by the traditional research. Thus, most investigators argue for employing different criteria in assessing qualitative research. So the question of internal validity, i.e. the extend to which one's findings are congruent with reality, is addressed by using triangulation. Triangulation relies on the researcher to continually check interpretations with individuals interviewed or observed, staying on-site over a period of time, asking peers to comment on one's findings, involving participants in all phases of the research, and clarifying researcher biases and assumptions (Merriam, 1988). Triangulation is a process of using multiple perceptions to clarify meaning, verifying the repeatability of an observation or interpretation (Stake, 2000). This process is used by the researchers to reduce the likelihood of misinterpretation and it comprises basically two procedures, redundancy of data gathering and procedural challenges to explanations (Denzin, 1989b; Goetz & LeCompte, 1984, cited by Stake, 2000). Reliability is the extent to which there is consistency in one's findings and it is enhanced by the investigator clarifying the assumptions and theory underlying the study, by triangulating data, and by describing in detail how the study was conducted and how findings were derived from the data (Merriam, 1988). Finally, external validity or the extent to which the findings of a case study can be generalized to other situations continues to be the object of much debate. A common complaint about case studies is that it is difficult to generalize from one case to another. Critics typically state that single cases offer a poor basis for generalizing. According to Yin (1994), such critics are implicitly contrasting the situation to survey research, in which a "sample", if selected correctly, easily generalizes to a larger universe. As Yin (1994) states:

> "This analogy to samples and universes is incorrect when dealing with case studies. This is because survey research relies on the statistical notion of generalization, as opposed to case studies that rely on analytical generalization. In analytical generalization, the researcher is striving to generalize a particular set of results to some broader theory" (p. 36).

According to Merriam (1988), as alternatives to this statistical notion of external validity, qualitative researchers use four concepts namely, working hypotheses (Cronbach, 1975), concrete universals (Erickson, 1986), naturalistic generalization (Stake, 1978), and use or reader generalizability (Wilson, 1979; Walker, 1980).

1. Cronbach (1975), uses the term working hypotheses to substitute the notion of generalizations in social sciences research. He states:

> "Instead of making generalization the ruling consideration in our research, I suggest that we reverse our priorities. An observer collecting data in one particular situation is in a position to appraise a practice or a proposition in that setting, observing effects in context. In trying to describe and account

> for what happened, he will give attention to whatever variables were controlled, but he will give equally careful attention to uncontrolled conditions, to personal characteristics, and to events that occurred during treatment and measurement. As he goes from situation to situation, his first task is to describe and interpret the effect anew in each locale or series of events...generalization comes late...
> When we give proper weight to local conditions, any generalization is a working hypothesis, not a conclusion" (Cronbach, 1975, pp.124-125 cited in Merriam, 1988, p.175).

2. Erickson (1986), argues that when considering interpretative research the goal of production of generalizable knowledge is inappropriate. In attending to the particular, concrete universals will be discovered, i.e. the general can be found in the particular.

> "The search is not for abstract universals arrived at by statistical generalizations from a sample to a population, but for concrete universals arrived at by studying a specific case in great detail and then comparing it with other cases studied in equally great detail" (Erickson, 1986, p.130 cited in Merriam, 1988, p.175).

3. Stake (1978), uses the concept of naturalistic generalizations based on tacit knowledge, personal experience and intuition. As he states:

> "Readers assimilate certain descriptions and assertions into memory. When the researcher's narrative provides opportunity for vicarious experience, readers extend their memories of happenings. Naturalistic, ethnographic case materials, to some extent, parallel actual experience, feeding into the most

> fundamental processes of awareness and understanding. Deborah Trumbull and I have called these processes *naturalistic generalizations* (Stake & Trumbull, 1982). The reader comes to know some things told, as if he or she had experienced it. Enduring meanings come from encounter, and are modified and reinforced by repeated encounter" (Stake, 2000, p.442).

4. A fourth concept is the one presented by Wilson (1979), and Walker (1980), the reader or user generalizability which involves leaving the extent to which a study's findings apply to other situations up to the people in those situations (Wilson, 1979, cited in Merriam, 1988). " It is the reader who has to ask, what is there in this study that I can apply to my own situation, and what clearly does not apply?" (Walker, 1980, p.34 cited in Merriam, 1988, p.177). It is similar to law and medicine where the suitability of one case to another is determined by the practitioner.

A strategy often used by case study researchers to deal with this question of generalizabilty of findings is cross-case or cross-site analysis. In cross-case analysis, the use of purposeful sampling, predetermined questions, and specific procedures for coding and analysis enhances the generalizabilty of findings in the traditional sense (Firestone & Herriot, 1984; James, 1981; Burlingame & Gesk, 1979; Yin, 1994 cited in Merriam, 1988). Miles and Huberman (1984), assert that "...by comparing sites or cases, one can establish the range of generality of a finding or explanation, and at the same time, pin down the conditions under which that finding will occur" (p.151). A qualitative inductive mutlicase study seeks to create abstractions across cases (Merriam, 1988). Glaser and Strauss (1967), argue that comparing groups is a way to strengthen a theory. Groups, or cases, should be picked for their power both to maximize and to minimize differences in the phenomenon of interest. These authors say that "...comparing as many differences and similarities as possible ...tends to force the analyst to generate categories, their properties, and their interrelations as he tries to understand his data" (Glaser & Strauss, 1967, p.55 cited in Merriam, 1988, p.154).

Five traditions of qualitative research have been described and, although they represent separate research traditions, researchers often select procedures from the several traditions when conducting their studies.

When comparing these five differing traditions Creswell (1998) notes that each methodology can be used effectively to meet the primary objectives of a study. Exploring a life is different from describing the behavior of a cultural group or generating a theory. Some traditions have single-disciplinary traditions, e.g, grounded theory generating in sociology, ethnography founded in anthropology or sociology, whereas others have a broad interdisciplinary unfolding, e.g. biography and cases study. These traditions also vary in terms of the extent as well as the emphasis of data collection.

Comparing the five traditions an issue of overlap between ethnography and case study approaches arise and needs clarification. While in ethnography we investigate a cultural system, in case study we investigate a bounded system and this might create some confusion.

However, according to Creswell (1998), there are some fundamental differences. Ethnography studies an entire cultural or social system, except in a microethnography, while case studies examine smaller units such as a program, an event, an activity or individuals and explores a range of topics, only one of which might be cultural behavior, language or artifacts (Creswell, 1998). Besides, the anthropological concepts, e.g., myths, stories, rituals, social structure used in an ethnographical study when examining a culture-sharing group, are not necessarily present in a case study (Creswell, 1998).

We can situate qualitative research within the larger discussion about philosophical and theoretical frameworks that researchers bring to their studies. This is a complex arena, and Creswell (1998) based on the "principle" issues advanced by Guba & Lincoln (1988), identifies a set of basic philosophical assumptions as central features to all qualitative studies. Thus qualitative researchers guide the design of their investigations with a certain paradigm or worldview, i.e. a basic set of beliefs or assumptions. These assumptions are related to the ontological issue or the nature of reality, the epistemological issue or the relationship the researcher has to that being studied, the axiological issue or, the role of values on a study, and the methodological issue or process of research (Creswell, 1998). Table 12 summarizes these assumptions with its implications for practice.

Table 12

Philosophical assumptions with implications for practice

Assumption	Question	Characteristics	Implications for Practice (e.g.)
Ontological	What is the nature of reality ?	Reality is subjective and multiple, as seen by participants in the study	Researcher uses quotes and themes in words of participants and provides evidence of different perspectives
Epistemological	What is the relationship between the researcher and that being researched ?	Researcher attempts to lessen distance between himself or herself and that being researched	Researcher collaborates, spends time in the field with participants, and becomes an "insider"
Axiological	What is the role of values ?	Researcher acknowledges that research is valued laden and that biases are present	Researcher openly discusses values that shape the narrative and includes own interpretation in conjunction with interpretation of participants
Rhetorical	What is the language of research ?	Researcher writes in a literary, informal style using the personal voice and uses qualitative terms and limited definitions	Researcher uses an engaging style of narrative, may use first-person pronoun, and employs the language of qualitative research
Methodological	What is the process of research ?	Researcher uses inductive logic, studies the topic within its context, and uses an emerging design	Researcher works with particulars (details) before generalizations, describes in detail the context of the study, and continually revises questions from experiences in the field

Source: Creswell, J. W. (1988).Qualitative inquiry and research design. Thousand Oaks Sage Publications (p.75).

These philosophical assumptions mark all qualitative research studies. Summing up to these assumptions the researcher may employ a contemporary ideological perspective. The ideological perspectives derive broadly from postmodern concerns and specifically from orientations such as critical theory, feminism and constructivism. And they represent a conscious choice of the researcher (Schwandt, 1993, cited by Creswell, 1998).

1.1. Qualitative Research with Families

Families are a unique focus of study. The singular nature of families as social groups is characterized by several aspects: privacy; a collective consciousness that is generally not available to nonfamily members; relationships embedded in blood ties, adoption contract or marriage and intended to be permanent; shared traditions; intense involvement; and a mixture of individual interests, experiences and qualities (Daly, 1992). These aspects make families, according to Daly (1992), "...one of the most closed and private of all social groups (p.4). Qualitative research methods have the advantage of allowing for the construction of rapport and trust, which are needed to gain access to the more private interactions that provide a deeper understanding that gives meaning about families. In the study of families, qualitative research is what Handel (1992) referred to as a "research tradition that is as old as social science itself" (p.12). Ever since the publication of Les Ouvriers Europeens from Frederic LePlay

(1855) and Thomas and Zaniecki's (1927) The Polish Peasant in Europe and America, qualitative modes of inquiry have gained increasing recognition in the social sciences. LePlay was the first social scientist, according to Silver (1982), "to undertake field research of the 'monographic' type, to collect his own data specifically to test hypotheses, and to undertake systematic, comparative cross-national research" (p.3). What LePlay (1982) called a monograph would be later called a case study. However "it was not until Thomas and Znaniecki published their book that qualitative research was fully recognized" (LaRossa & Wolf, 1985, p.533).

Brofenbrenner (1979) ecological model, is a framework that informs studies of child and family development. In special education such work has become more important. For example, Gallimore, Weisner, Kaufman & Bernheimer (1989) are involved in a line of family research based on *ecocultural theory,* which pursues to identify the effects of ecological variables by examining the activity settings of families' daily routines (Harry, 1996). The naturalistic basis of such research is quite different from the traditional, experimental model. The need for an ecological view provides the reactant for researchers to ask questions that can best be answered through the study of naturalistic settings and the use of inductive methods (Harry, 1996).

A challenging aspect of family research according to Daly (1992) is the unit of analysis. Survey research usually takes the individual as the unit and focuses on that individual's characteristics, attitudes, and behaviors. In the other pole qualitative research can accommodate multiple perspectives and deal with families, marriages or sibling relationships as units and enable richer accounts and closer approximations of lived family experiences (Handel, 1989, cited in Daly, 1992). In qualitative research the focus on the whole picture of a family constitutes a strength, even when researchers have to focus on one family member at a time. Nevertheless, it is important to remember that families, as part of their boundaries, have spokesperson's who present the family to the outside world (Daly, 1992). Research questions should determine with whom we speak in the family. A particular challenge in qualitative family research is to recruit men to talk about their perspectives of family experience (Daly, 1994).

Another issue frequently found when doing qualitative research on families has to do with the ethical dilemmas researchers face and that should be recognized or anticipated by them. Daly (1992) identifies some of these ethical issues, such as:

- Recognizing boundaries of privacy;
- Drawing boundaries between research and therapy roles;
- Constraining one's judgments about participants' experiences;
- Preventing the occurrence of uninformed consent as a result of emergent and changing research design;
- Recognizing that increasing intimacy may lead to participant's unanticipated self-disclosure.

So when doing research with families, a respectful stance to an informants' privacy is a useful ethical guideline. This might involve checking out periodically with participants their comfort levels, and if necessary, withdrawing parts of data from the record (Daly, 1992).

2. Research Design and Methods Used in the Present Study

This study was a qualitative inquiry designed to identify formal and informal resources used by families with young children who are either considered at-risk for disabilities or have children who have been diagnosed with disabilities. All of the children in this study are under three years of age and live in the district of Braga, Portugal.

Four research questions guided the study:

I. What types of services, institutions and programs, i.e. formal community resources are used by families with children at-risk (birth to three years) in the District of Braga, Portugal?

II. What is the composition of the informal support networks, e.g. extended family, friends, neighbors, religious groups, of families with young children identified as at-risk in the District of Braga?

III. What service system characteristics, e.g. directed and reciprocal, geographical proximity, frequency of contacts, types of support functions, congruence between help needed and support provided, are related to a family's general satisfaction of their support networks?

IV. What are the needs of the families with children with SN (birth to three years) in the District of Braga?

2.1. Selecting the participants

To answer these questions an instrumental and collective case study design was used. Thirteen families consented to participate in detailed interviews. I used the strategy of maximum variation sampling (Patton, 1990) in selecting the study participants. Patton (1990) suggests that heterogeneity in a small sample can be turned into a strength: "Any common patterns that emerge from great variation are of particular interest and value in capturing the core experiences and central, shared aspects or impacts of a program" (p.172). Collectively the families represented different dimensions critical to this study: urban versus rural; families with children considered as either biological-risk or established-risk; children diagnosed with either moderate /severe or mild disabilities; and families from either low SES or medium/high SES (see Appendix A for the construction of these variables). Table 13 describes the families and children who participated in the study. Families were informed that they could bring to the interview whomever they decided within their family. Furthermore, the interviews were scheduled to fit family's convenience. All interviews with the exception of one, the mothers were the key informants for the families. The one exception involved a father and the mother in the interview (Case 3). Almost half of the mothers in the sample worked at home (n=6), and one mother was a single mother. The other remaining families (n=7) had both members employed. Still among these families (n=7) mothers were primary respondents. This fact is not unique to this study, i.e., and the majority of

Table 13
Selected Characteristics of the Families participating in the Case Studies

	Demographic Characteristics					Characteristics of family member with Special Needs		
CASES	Family size	SES	Geographical Location	Race	Level of Education	Risk Category/ Chronological age at the date of the interview	Level of severity	Diagnosis
CASE 1	3	Medium/ High	Urban	White	F- College M- College	Established / 3years 10 months	Moderate/severe	Cerebral Palsy
CASE 2	5	Medium/ High	Urban	White	F-High School M-High School	Established/1 year 5 months	Mild	Down Syndrome
CASE 3	4	Medium/ High	Urban	White	F-High School M-High School	Established/2 years 3 months	Moderate/severe	Cerebral Palsy
CASE 4	8	Low	Urban	Gipsy	F- Primary M-- Illiterate	Biological/3 years 11 months	Mild	epilepsy
CASE 5	8*	Low	Rural	White	F-Less High S. M-Less High S.	Established/3 years 3 months	Moderate/severe	Cerebral Palsy
CASE 6	6	Low	Urban	Gipsy	F- Illiterate M- Illiterate	Biological/3 years 3 months	Moderate/severe	Metabolic Problem
CASE 7	3	Medium/ High	Rural	White	F-High School M- College	Established/3 years 5 months	Moderate/severe	Down Syndrome
CASE 8	5	Medium/ High	Urban	White	F- College M- College	Biological/3 years 11 months	Mild	Developmental delay
CASE 9	6*	Medium/ High	Rural	White	F-High School M-College	Biological/2 years 6 months	Mild	Hydrocephalus
CASE 10	2	Low	Urban	African	M- LessHigh S.	Established/3 years 7 months	Mild	Imperfect Congenital Osteogenesis –Type 2B
CASE 11	6	Low	Rural	White	F- Primary M- Primary	Biological/3 years 10 months	Mild	Cleft Palate – Congenital defect of the hand
CASE 12	3	Medium/ High	Urban	White	F-Less High S. M-Less High S.	Biological/3 years 2 months	Moderate/severe	Blind
CASE 13	4	Medium/ High	Rural	White	F-High School M-College	Established/3 years 6 months	Mild	Developmental Delay

*Grandparents included

studies in the literature concerning the issue of family resources evaluation interviewed mothers making them, this way, representatives of the family (Dunst, Leet & Trivette, 1988; Trivette & Dunst, 1992; Coutinho, 1996). Dunst et al. (1988), conducted a study concerning family resources and personal well being in EI, and used mothers rather than mothers and fathers as informants. In doing so they assumed that mothers had been and continued to be the family member asked to assume primary responsibility for implementing child-level interventions as part of home based programs for preschool children. Concerning this issue Allen & Petr (1996) say: "Although professionals may consider the entire family as the unit of attention, in actual practice, involvement and collaboration may be limited to the parents, to a parent-child dyad, or even solely to the primary caregiver, who usually is the mother (Larimore, 1993; Mahoney et al., 1990; Marcenko & Smith, 1992; Panel on Women, Adolescents, and Children with HIV Infection and AIDS, 1991; Sparling, Berger, & Biller, 1992; Turnbull & Summers, 1987)" p.67.

2.2. Gaining access to families

I contacted several formal EI programs in the district of Braga serving children birth-to-three years of age, namely Segurança Social, an EI program of Vila Nova de Famalicão and another EI program in CerciFafe. I presented them a matrix were I defined child and the family dimensions in which I was interested. Based on this matrix, the staff and I selected the families for the study. After describing the goals of the study, discussing issues of confidentiality and outlining the data gathering procedures the staff assisted me in recruiting families that matched the criteria outlined in the matrix. The program staff first contacted each family. Once families agreed to participate in the study I was allowed to contact each family directly. In three weeks time in June 1998, I receive permission to contact the families and start the interviews. In order to meet all the criteria I mentioned above it was planned that 16 families would be interviewed. However, in spite of considerable effort on the part of staff at the different EI programs, we were not able to recruit a family with a child that fit the criteria of Biological risk; with Moderate/Severe disabilities; from Medium/High SES and living in a Rural setting. Two other families were not able to complete the interviews. One mother withdrew from the study after experiencing a negative experience with the EI program that served her child. She feared her participation in the interviews might jeopardize her daughter's enrollment in the program. Although she was assured that her responses would be kept confidential she was not persuaded and withdrew. Consistent with a commitment to family centered principles and the voluntary nature of the study her decision was respected. A third family was unavailable and I was never able to make contact with them. The remaining thirteen families agreed to participate. The majority of the initial contacts with the families were accomplished through a telephone contact at which time I scheduled an appointment for the interviews. The interviews took place in several different venues. Some parents immediately invited me into their homes, others requested a meeting at a coffee shop after which we moved into their homes. For other parents, the interviews took place either at their work place or at their child's EI program. This variability demonstrates the diversity among families and decisions regarding having people coming into their homes. This also was a demonstration of a commitment to a family centered perspective as an EI professional or researcher. We need to be sensitive to families and their wishes and be able to adjust thus respecting their decisions. During the first meeting I introduced myself and explained the purpose of the study. We discussed issues of confidentiality and participants signed a consent form (see Appendix B for a sample consent form).

2.3. Data Collection

Data collection occurred between September 1998 and August 1999. The study involved in-depth interviews with each participating family. Previous to engaging in these formal structured interviews there was an extensive warm-up period of unstructured time with the mothers that was devoted to answering questions and getting acquainted. Typically, the interviewer spent 3 hours with each family during this process. The plan was to interview the families individually, without the presence of their EI specialists. For eleven of the thirteen families, this procedure was followed. Two remaining families had their EI specialists present at the beginning of the interviews. When the families were selected there was some concern that these mothers would not talk easily to a stranger. Given this circumstance I was concerned that the parents would not be candid in their responses with their EI specialists present. However, this fear was short-lived because they remain in the room for only a part of the interview and I was able to reintroduce any topics that I thought might been affected in the first part of the interview when they left.

All interviews and my experiences were recorded as text using my personal computer. These field notes, described impressions of the family and child, their stories that detailed descriptions of each family's experiences. During this time I also made notes on the environment where the interview took place. These detailed field notes comprise the corpus of the data for my study. Finally, for each interview a contact summary form was completed. The contact summary form is a strategy to help summarize the main points on each filed contact (Miles & Huberman, 1994). After each formal interview, a single page, contact summary form was completed answering the following questions:

1. What were the main issues or themes that struck you during the contact?
2. Summarize the information you got (or failed to get) during the contact.
3. Anything else that struck you as salient, interesting, illuminating, or important?
4. What new (or remaining questions) do you have in considering the next contact with the person?

A sample of a completed summary contact form is contained in Appendix C.

Two instruments comprised the consistent structure for the family interviews: the *Family Needs Survey (Revision, 1990b),* (Bailey & Simeonsson, 1990) was used to understand and evaluate family needs, and the *Inventory of Social Support,* (Trivette & Dunst, 1988) provide a consistent instrumentation to evaluate a family's support structure (see Appendixes D and E for these instruments).

The Family Needs Survey was used to evaluate the respondents' perceptions about unmet family needs. According to the authors this instrument has 35 items organized into 7 empirically derived domains: information, family and social support, financial, explaining to others, childcare, professional support, and community support and service (Bailey, Blasco & Simeonsson, 1992). Each item required one of three responses; 1 *definitely not a need,* 2 *not sure,* 3 *definitely a need.*

The Inventory of Social Support, according to the authors, is an instrument that provides a way of determining the types of help and assistance given to a family by different individuals, groups and services that make up the family network. The instrument is comprised of two parts. The first part evaluates the "frequency-of-contact" that the respondent maintains with the different members of his/her social support network. The second part indicates whom he or she goes to or receives help from for 12 different types of aid and assistance. The scale is a self report scale and includes 19 sources of support such as individuals, groups or services, as well as different types of support provided included in categories such as: information, emotional, companionship, instrumental, and material support. The sources of support and types of aid and assistance are organized in a matrix format. A completed matrix provides a graphic display of the family social network in terms of both source and type of support. For this study I choose to use only the second part of the scale because the information concerning frequency of contacts was obtained in the social network maps that families draw during the interview.

2.4. Formal interviews

I conducted the interviews using a semi-structured interview guide (Flick, 1998). It is characteristic of these interviews that more or less open questions are brought to the interview situation in the form of an interview guide. The questions were answered freely by the interviewee. The questions for the interview guide were based upon House's model (1981; House & Khan, 1985) for assessing the multiple dimensions of social support designated Systematic Assessment of Social Support Inventory (SASSI). According to Dunst & Trivette (1990) the following types of information are obtained using SASSI:

1. The indicated need for particular types of support;
2. The members of an individual's or family's personal social network;
3. The types of support generally offered by personal social network members;
4. The nature of social ties with personal social network members;
5. Satisfaction with aid and assistance obtained from social network members.

Table 14 shows the specific support dimensions that are measured by each of the five SASSI categories.

Table 14

SASSI support categories and corresponding support components and dimensions

SASSI categories	Support components	Dimensions
Need for support	Constitutional	Indicated need Congruence
Social network members	Relational	Network size Existence of social relationships (e.g., marital and work status) Social group membership
Types of support	Functional	Source of support Type and amount of support Quality of support exchanges
Social relationship ties	Structural	Frequency of contacts Closeness Utilization and dependability Reciprocity Relationship stability
Support satisfaction	Satisfaction	Helpfulness Usefulness

Source: Dunst, C.J. & Trivette, C.M. (1990). Assessment of social support in early intervention programs (p. 336).. In S. J. Meisels & J. P. Shonkoff (Eds.), *Handbook of Early Childhood Intervention.* Cambridge: Cambridge University Press.

These were topics that I was particularly interested in discussing with the interviewees, as they would help answer the research questions for this study. A sample of the Interview guide can be seen in Appendix F.

2.5. Data Analysis

Family interviews were taped and then transcribed. A content analyses of the interview transcripts was completed. These data provide the necessary information for the within-case analyses. The data were also analyzed across-cases. This latter analysis provides important information for comparing similarities and differences among the families who participated in this study. According to Miles & Huberman (1994), one aim of studying multiple cases is to increase generalizability, reassuring that the events and processes in one case are not idiosyncratic. The present study did not attempt to meet the positivist criteria of generalization, but it sought to attain the naturalistic criteria of transferability as described before in this chapter. Even though the number of families in the study was small and not necessarily representative of families in general, multiple cases adequately sampled and analyzed carefully can help us understand if these findings make sense beyond a specific case. A second more fundamental reason for cross-case analysis is "to deepen understanding and explanation" (Miles & Huberman, 1994, p.173).

A valid coding system was developed based on the conceptual framework of the research done by Dunst & Trivette (1990), as well as from the research questions. This was a long process, which required some revision, remaking and validating a series of category systems and some choices were made. Reliability of the coding process was determined with the help of a faculty member of the Special Education Department of the University of Minho. This colleague received a transcribed version of a randomly selected interview, a list of codes and their respective definitions, and the instructions she should follow in her coding. The researcher also coded the same interview. In order to determine the reliability of the category system, the researcher used the formula proposed by Miles and Huberman (1994, p.64):

$$\text{Reliability} = \frac{\text{Number of agreements}}{\text{Total number of agreements + disagreements}}$$

The reliability value found for the check-coding was 86%.

The category construction which according to Merriam (1988) is a form of content analysis, was done with the help of NUD*IST a computer program described later in this chapter. The *unit of analysis* (i.e., word, line, sentence, paragraph or other) that was used throughout the coding process was the paragraph.

The codes used for this research project are what Miles and Huberman (1994), called "...descriptive codes; they entail little interpretation. Rather you are attributing a class of phenomena to a segment of text"(p.57). Codes were then organized in a hierarchical, tree-like category system (see Table 15), according to which the text units could be classified under a series of categories and respective subcategories. An example of each code taken from the families' interviews can be found in Appendix G

Table 15
System of categories

1	**Demographic data**
1.1	Family characteristics
1.2	Child characteristics
1.2.1	Risk category
1.2.2	Level of severity
1.2.3	Social economic status
2	**Type of formal support**
2.1	National Health Centers or Hospitals
2.2	Financial support from social services
2.3	Special Education Centers
2.4	Private Therapy
2.5	EI Programs
2.6	Early Childhood Care
2.7	Charity Institutions
2.8	Municipal Support
3	**Effective support**
3.1	Formal
3.1.1	Rational
3.1.1.1	Emotional Support
3.1.1.2	Information
3.1.1.3	Availability
3.1.1.4	Referral
3.1.1.5	Positive Interaction
3.1.1.6	Financial Support
3.1.1.7	Schedule Flexibility
3.1.1.8	Public/Private Collaboration
3.2	**Informal Support**
3.2.1	Rationale
3.2.1.1	Routine functioning
3.2.1.2	Emotional support
3.2.1.3	Material support
3.2.1.4	Information
3.2.1.5	Referral

4	**Ineffective Support**
4.1	**Formal Support**
4.1.1	Rationale
4.1.1.1	Non sensible relationship
4.1.1.2	Giving opinions without knowing the family
4.1.1.3	Ignore the request for eligibility in a program
4.1.1.4	Bad Management
4.1.1.5	Non existence of specialized educational support
4.1.1.6	Discrimination
4.1.1.7	Medical Negligence
4.1.1.8	Not Adequate Information
4.1.1.9	Dishonesty
4.1.1.10	Personal Incompatibility
4.1.1.11	Program drop out
4.2	**Informal**
4.2.1	Rationale
4.2.1.1	Moving away
4.2.1.2	Advising the mother to abort
4.3	**No negative experiences to report**
5.	**Family Priority Needs**
5.1	Financial
5.2	Information
5.3	Childcare
5.4	Health Needs
5.5	Household
5.6	Minimum Habitat Conditions
5.7	Housing Space
5.8	Child Development
5.9	Transition
5.10	Social/Emotional support
5.11	Adulthood
5.12	Therapy
5.13	Specialized Educator

2.6. Computer Program Used for the Analysis

Another important aspect in the process of data analysis concerned the use of a computer program to code data. A program called NUD.*IST (Non-numerical Unstructured Data Indexing, Searching and Theorizing; Richards & Richards,1994) was selected in this research. NUD.*IST is a computer package designed to aid users in handling Non-numerical and Unstructured Data in qualitative analysis by; a) supporting processes of coding data in an Index System, b) Searching text or searching patterns of coding and c) Theorizing about data. This program belongs to a group of programs sharing two main features; 1). they are both *code-and-retrieve,* and 2). *theory builders.* This type of program allows the researcher to divide data text into segments, attach codes to segments, and find and display any coded segment or combination of coded segments. The later feature of this program allows the researcher, "...to make connections between codes (categories of information); to develop higher-order classifications and categories; to formulate propositions or assertions, implying a conceptual structure that fits the data; and/or to test such propositions to determine whether they apply" (Miles & Huberman, 1994, p.312). The NUD*IST program also presents a feature designated *tree diagram.* In the process of categorizing the information, categories are identified, and these are developed into a *visual picture* of the categories that displays their interconnectedness. The tree diagram is a hierarchical tree of categories based on a "root" node at the top and parents and siblings in the tree. Thus allowing the researcher to generate a picture of the analysis, the major categories, and how the information from the text is grouped. The NUD*IST in this research was used mainly to help the researcher in the coding, retrieving and displaying tasks. Like in most computer programs the researcher has to decide which *unit of analysis,* i.e., word, line, sentence, paragraph or other, he/she wants to use throughout the coding process. The unit of analysis chosen for this research project was the paragraph.

2.7. Issues of quality and accurateness

According to Stake (1998), case study requires extensive verification. During or after a study qualitative researchers ask, "Did we get it right ?" (Stake, 1998, p.94).

To answer this question the present study used some of the verification procedures presented by Creswell & Miller (1997), and often described in the literature as a trustworthiness criteria for qualitative studies:

- Triangulation were researchers make use of multiple and different sources, methods, investigators and theories to confirm the emerging findings (Stake, 1998; Merriam, 1988; Miles & Huberman, 1994). In this study the researcher used four different strategies for the purposes of triangulation; 1). used different methods of data collection, interviews and two instruments, the *Family Needs Survey (Revision, 1990b),* (Bailey & Simeonsson, 1990), and the *Inventory of Social Support,* (Trivette & Dunst, 1988), 2). used the cross case analysis, which triangulated data from different cases representing different dimensions, 3). worked with a colleague to determine the reliability of the category system, and 4). triangulated theories comparing the results of my study with theories of social support, as well as results of other research studies in the field;

- Peer review is another procedure, which provides an external check of the research process (Lincoln & Guba, 1985; Merriam, 1988). Lincoln & Guba (1985) describe the role of the peer debriefer as a "devil's advocate" who provides the opportunity to give feedback about the researcher's process and procedures. In the present study the researcher worked with other colleagues to discuss informally the data and procedures and this happened in several occasions along the study;
- Rich, thick description, which means the writer, should present solid descriptive data so that the reader can make decisions regarding transferability (Lincoln & Guba, 1985; Merriam, 1988). In presenting the results of this study the researcher will be providing as "thick a description" as possible.

Summary

In this chapter I described the methodological aspects of research study. The first part presented both conceptual and practical aspects of qualitative research, to help the reader understand the methodological choices made in this study. And then I described the procedures that were followed in selecting the site and subjects, collecting data, analyzing data and addressing the issue of trustworthiness in this qualitative study.

CHAPTER IV

Data Analysis

DATA ANALYSIS

1. Results of the first research question: What types of services, institutions and programs, i.e. formal community resources are used by families with children with SN (birth to three) in the District of Braga?

The first research question concerns the formal support networks serving these families with children at-risk for disabilities and the types of services to which they have access in their communities. To answer this initial question, a content analysis of the family interviews was combined with information from the Family Network Maps. From these data, it was determined that families utilized the following formal services:

- Public Health Centers;
- Hospitals;
- Financial Support from Social Services (Centro Regional de Segurança Social);
- Special Education Centers (run by Parents Associations which are Private Institutions of Social Solidarity, i.e. private non-profit organizations);
- EI Programs (run by Parents Associations which are Private Institutions of Social Solidarity (IPSS), i.e. private non-profit organizations);

- Early Childhood Care Services run by Private Institutions of Social Solidarity (IPSS), or private institutions;
- Charity Institutions such as Caritas and Cruz Vermelha and São Vicente Paulo;
- Municipal Support (translated in either financial support, housing programs or transportation for the families);
- Private Therapy;
- Private Medical Services.

It is important to point out that in Portugal, all families had access to free medical services either through Public Health centers or the Central Hospitals. The mean distance that all families who participated in this study, rural or urban, had to travel to secure specialized services was 32 Km. Transportation to the hospitals for the poorer families was supported by Social Services or the Municipality. Parents from medium and high SES categories had greater access to private medical and therapeutic services. Two of the families whose children were diagnosed with severe developmental problems and were categorized as low SES, had access to private doctors and therapy through financial assistance from Social Services (Case 10) or privately furnished resources provided by their informal support networks (Case 5). Figure 13 is an analysis of the number of families who used particular categories of formal services according to their SES. The X-axis lists the formal support categories provided to families while the Y-axis provides the number of families who utilize the particular programs categorized by their SES. The formal support categories are:

- National Health Centers or Public Hospitals;
- Financial Support from Social Services;
- Special Education Centers;
- Private Therapy;
- Early Intervention Programs;
- Early Childhood Care;
- Charity Institutions;
- Municipal Support.

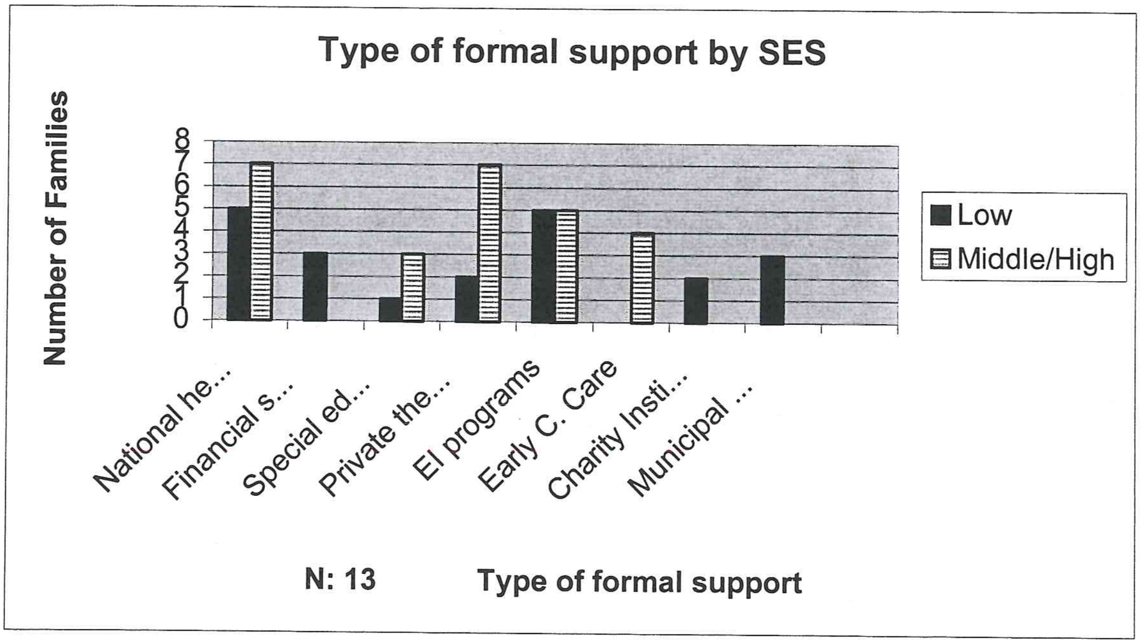


Figure 13

These data demonstrate that 12 of 13 families used the National Health Centers and Public Hospitals. The one exception was one family (Case 8) classified as High SES, which used private medical services. This nearly universal use of the public system can be attributed to the easy access that families have to the health system; a direct result of the Portuguese health policies that were described earlier (see page 115). The National Health System provides free health care to their citizens and is an important support from which all these families benefited because their children's chronic medical problems required ongoing medical services. For example, the child from Case 6 has a metabolic disorder and requires a sophisticated diet. The diet, plus the medication that the child is taking is expensive, yet it is provided free by the hospital (Field notes – Case 6). Financially, this family could never cover these expenses on their own. From this example one can see that for some families in this sample having their health care needs covered improves their general quality of life.

Another important factor to understanding a family's use of formal support system is based on where that family lives, i.e. rural or urban settings. An analysis of these data yielded patterns of access for the families living either in rural areas and urban areas. The analysis of the use and access of formal services by the families according to their geographical location can be seen in Figure 14.

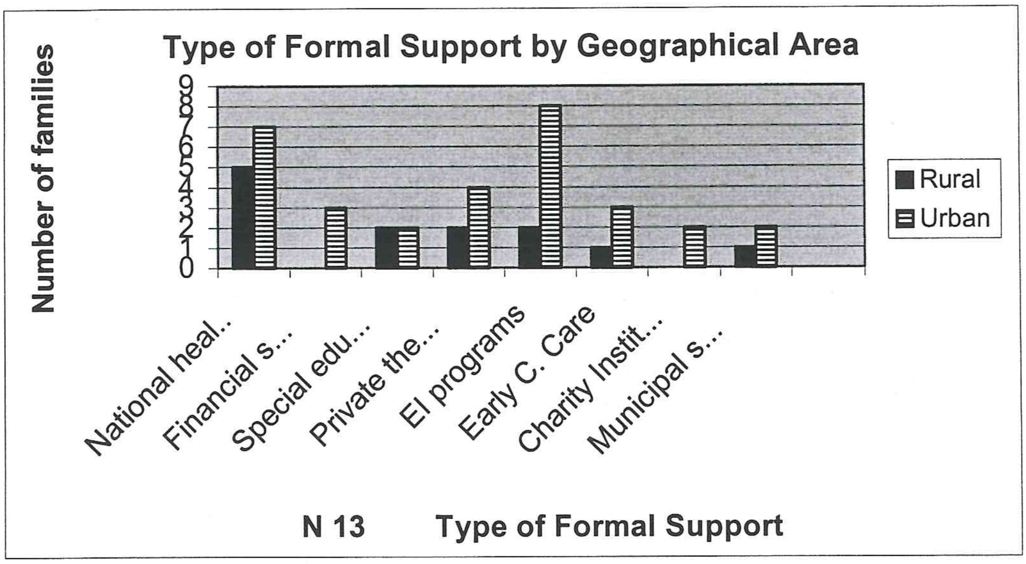


Figure 14

Accessibility to National Health Centers or Central Hospitals appears not to be a problem for families from either urban or rural areas.

Another important factor for accessing formal services is financial assistance. Only 3 of the 5 families from low SES were receiving financial support and all these families lived in urban areas. Information is not available to help understand this geographical disparity. It is unknown if financial resources are more available in urban settings or there is lack of funding in rural areas. We also do not know if there is a general lack of information concerning the availability of financial support programs. This is an area that merits further investigation when planning future services.

For this particular group of families, i.e. low SES and urban, access to EI programs is improved. These data are consistent with what we know about EI programs in Portugal. There are asymmetries in program availability throughout Portugal. Although these regional disparities continue, recent legislation (Despacho Conjunto 891/99) as well as the financial support programs from the Ministry of Social Affairs "Ser Criança" improve general access to EI programs. These changing conditions, if properly applied, will be felt countrywide but especially in traditionally undeserved rural areas where EI programs have been less available.

Concerning access to regular Early Childhood Care, is easier for families living in urban centers, but still only 4 of the 13 families interviewed had their children in Early Childhood Care. The mother of Case 6 reported that she did not want her child enrolled in any type of childcare, because of her child's serious metabolic problem and special diet. In her eyes she could not entrust her child's care to anyone else. She said:

> … we let him come here (the EI program)because it happens at a later time and at that time he had already eaten, if it wasn't at this time he could not come…that is the reason why he is not going to any child care. He cannot go because someone could give him a cookie or something and that is bad for him.

Overall, the data suggest that access to Early Childhood Care for many families in Portugal is difficult, which confirms the OECD Report on Early Childhood Education and Care Policy. Concerning care for children with ages between 0 and 3 years of age in Portugal this report stated:

> A substantial issue which the team thought to be an essential prerequisite to the long term development and well-being of children in Portugal, was the scarcity of provision for the birth to three years of age group, the inequitable access to such

> provision and in general, its lack of quality (Ministério da Educação, 2000, p.199).

The analysis of the type of formal support by level of severity, which can be seen in Figure 15. This figure presents evidence that families who have children diagnosed with moderate/severe disabilities use more formal services when compared with the families who had children diagnosed with mild disabilities. An exception to this result was found when comparing both groups use of health services and EI programs. Both groups of families used these two services similarly. Three families with children diagnosed in the moderate/severe range reported private therapy as opposed to only one family with a child diagnosed in the mild range. We can say that for these families the severity of their child's problem also determines procure of formal services.

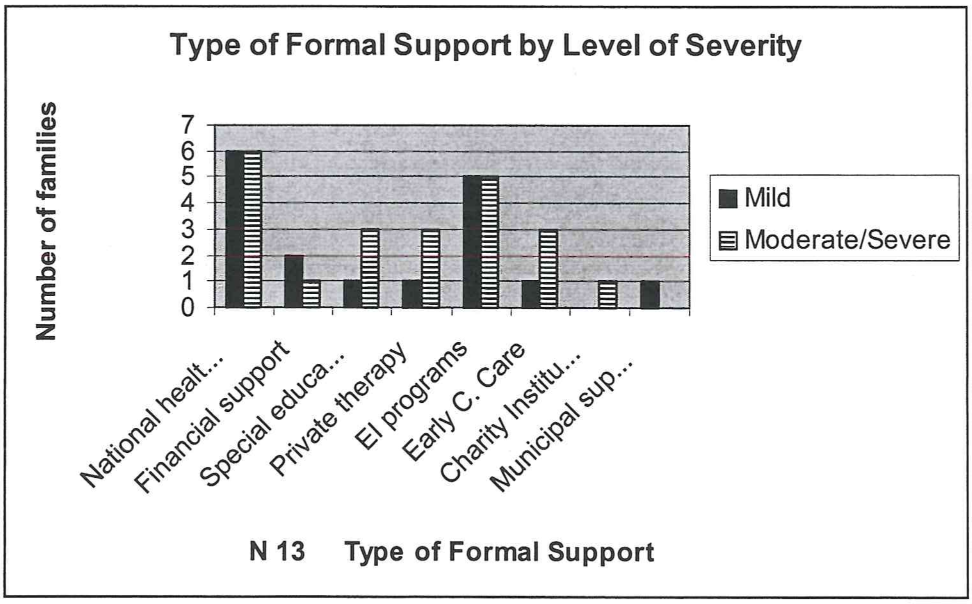


Figure 15

Figure 16 is an analysis of the rationale that families use to evaluate the effectiveness of different types of formal support services. Nine out of the thirteen families rated the formal support services they were receiving as effective. Their positive rating was in part based on the service agency providing them with information. From this result it is important to understand that one important support function of formal services is providing families with accurate and timely information. This is consistent with the results that came out of the Inventory of Social Support (Trivette & Dunst, 1988) which we used for this study with the families. The data from the Inventory also reveals that providing information to families is a primary support role for agencies that furnish formal support services. In addition to providing information, three families reported that the emotional support they received was effective formal support. The mother in Case 1 stated:

> Because he [the doctor] gave us some hope and helped us realize that the problem was severe, and we knew it was severe, but they were good for us, they would help in what we needed in the future and whenever we needed support.

A mother in Case 10 reported:

> And from that point in time I had a big support, since I took that medication to kill myself I had a big support from the obstetrician that was following me, ...so she gave me all the support, she was concerned if I was feeling well or not well. The psychologist at the hospital was great with me too. ...she [the obstetrician]even asked me if I wanted to live with her, and I said: "No, no it is not necessary, I can handle it" . And so I felt a big support from that side."

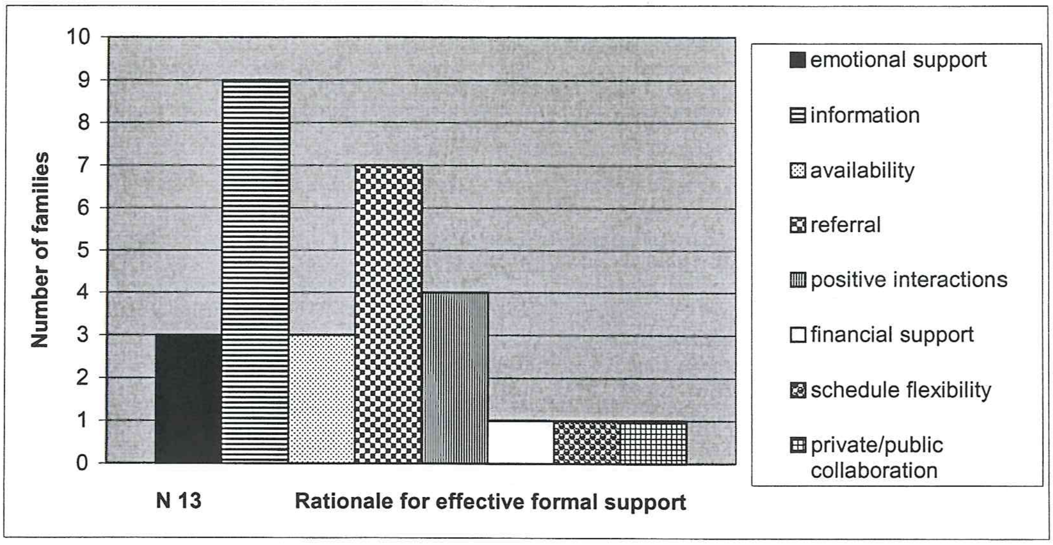


Figure 16

A mother in Case 2 said:

> ... and then I had the doctor, she was a great help that I had inside [the hospital]. Then I had a nurse who had been with me during labor, that come the next day to talk to me, and give me strength...it was very important in those moments that I was by myself.

Another factor that families reported as being related with effective support was availability. For example, the single mother from Case 10, who had a constellation of problems including housing, stated:

> I mean she did everything that was needed, ultrasounds...my obstetrician come to a point of inviting me to move in with her.

The mother from Case 3 said:

> She uses a phrase that I found very funny at that time and nobody had told me before: "Do not bother for bothering me".

And the mother from Case 9 said:

> He had been almost the whole day with that symptom and only in the evening we decided to take him to the pediatrician [at the local hospital]. And the pediatrician immediately said: "This is a serious case and I am not telling you what is going on yet, because I do not have enough information, but we have to leave immediately to the Hospital [located at 33Km away, and the doctor went with the family].

Another aspect that emerged from the analysis of Figure 13 was that the role formal support services assumed as a referral agency for families. Seven of the thirteen families said that effective formal support was related to the assistance they received that guided them to other necessary services. Most of the transcriptions of the families concerning this particular aspect, mentioned how personal contacts from either doctors, nurses, social workers or early childhood educators helped the families find other necessary services or helpful professionals. In other words, families saw agencies that comprised their formal support network having a duel role. First and foremost, agencies functioned as a direct service provider, but they filled a secondary role as a referral agent that helped families located additional services when needed. The following are but few examples of this latter role.

As the mother in Case 6 said:

> I asked help to Doctor A and she helped me in everything. She talked with the social worker of the hospital, and then she in turn contacted the social worker here.

Or as the mother in Case 9 who states:

> ... the pediatrician took us there [to the hospital in OPorto]himself, and he knew lots of people there, so he [their child] was with a team of doctors that he [the pediatrician] knew, which left us more relieved.

Four families stated that they were happy with their formal services because they provided them positive interactions. For example, from Case 4:

> [Referring to the social worker at the social service agency]. She talked really nice with me, very well, she treated me well, she talked in a gentle way, and I...

The mother from Case 11 said:

> In Oporto I was always nicely taken care (or well attended???). The doctor was from here, from Braga but he worked also in Oporto, and he was a very good person, he [their child] was always nicely taken care there.

Only one family reported financial support as an important aspect of effective formal support. This family (Case 6) is a family living in very poor conditions with 4 children. The mother said:

> Now for example I had always and for a long time, for many years the support of the people from Saint Vincent DePaul Conference, in this case ...they paid me water, electricity, rent and often times they would give me food supplies.

Finally one family (Case 6) mentioned schedule flexibility of their EI program as a positive condition of their formal service. Another family mentioned that they liked the medical support that they were getting because the private doctor was also a doctor at the public hospital. This connection made them more comfortable if something was to happen to their child that required a hospital visit.

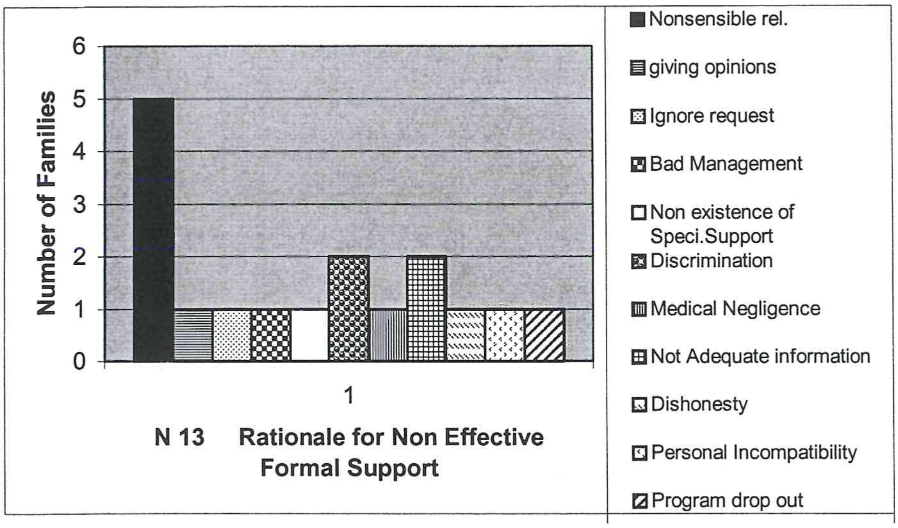


Figure 17

Figure 17 provides an analysis of the arguments families provided to describe ineffective formal support experiences. Five families described their reasons for considering their experiences with formal services as negative. They stated that professionals showed them little respect and were insensitive to their feelings, and their problems.

For example, the mother in Case 12 described the following unpleasant interaction, which left her, hurt and confused;

> Some doctors particularly the doctor at the Santo António Hospital [in OPorto], I felt really sad when we went there, because we parents, we parents became desperate and so we do not look for one doctor, even when they tell us that there is no solution to our child's problem, and yet if it is your first child, being the first time, I couldn't believe when he [the doctor] said...this is a lie it can't happen, my child probably has something but it shouldn't be so serious. He is probably wrong...and so we went to several doctors and they all really said the same thing. My husband' boss schedule us to go to Barcelona [to a famous eye clinic], and we went to Barcelona. When I arrived I was honest with the doctor and I told him: "Doctor, you probably have all the reason, you were honest with us, but I did not believe in what you told us". He started smiling, and he looked like... he didn't laugh, no, but...he smiled like he was deriving pleasure from this. And the doctor that was with him a colleague said: You need to go abroad to know. Here we have ...we have... what did he say... specialists, we have specialists and specialties as good as outside. And I said: "You are right but we parents became so concerned to a point where we don't believe, it is a wrong way of reacting from our side, but we don't believe and so we try to find a solution". And the doctor said: "You did well, you did well". And then I said: "You had schedule an exam for my child that I signed because it had to be done under general anesthesia, are you still doing it to my child?" "Yes I will do it but not for now only when I can." And so I felt with this that he was offended.

It is important to note, that after this encounter the mother neither went back to this Hospital nor to this doctor.

Another mother (Case 5) who has a child with severe cerebral palsy remembered her unpleasant experiences with a particular doctor. She said:

> He had fever and he got to 40°C. And so, I went back and forth from home to the hospital several times. At last the doctor said: " Go home and give him this medicine and then a bath with tepid water. If the temperature drops, it drops. If it doesn't, call me here." So I did called back and it wasn't the same doctor. It was another one. I call and they told me to go there, because it was another doctor. And I didn't like because I was there until past midnight with the baby and using wet-dressing bandages in his forehead to drop the temperature and at the end the doctor said [with a very contemptuous tone according to the mother] "You are always here! Always here! He was here during the day wasn't he?" and I said "Yes, but the doctor who saw us said that if he didn't get better to come back here, and to call before coming here". And the doctor replied "Oh lady you have to be resigned (to conform), because that baby one day or the other is gone! You have to know that with a ..." how did he say ? " ...a pneumonia, a pneumonia that child is gone. You have to know that". And I was like...! Because the way he talked...and with the temperature that he had, he would die. I was really shocked. Since then I always avoid going to the hospital in Braga. I avoid going there, and even when my child has a cold I take him to the hospital in Vila Verde, because there they do vaporization.

This family did not have a car and they had to ride a motorcycle each time they went to the hospital which was 12 km away from their home. Moreover, this happened during the cold and dump of mid-winter.

The mother from Case 2 who had a baby with Down syndrome said that she felt the support from the early childhood special educator was ineffective because of her premature observations and opinions, provided before knowing anything about the family:

> No, because she got here without knowing the family, and without knowing the first thing she said was that the baby

> should be with a nanny. "The baby should be with a nanny. These babies need to be with other kids, they should be with a nanny". ... I don't want her to be away from school, no way I am going to prevent her from playing with other children, inversely I want this for my child, but I think that each thing has its own time. If my other children, that are normal children, went to preschool at the age of 3 years, why shouldn't this one go too?

The other categories that surfaced as the rationale for ineffective formal support were ignoring requests for admission in services, bad management of public funds by some the IPSS (Private Non-Profit Institutions) special education centers usually run by Parents Associations. One family (Case 3) complained that his child was in a IPSS preschool center and he received no special education support. The personnel at the early childhood care center never informed them of their child's rights or the supports they were qualified to receive under our legislation (Decreto-Lei 319/91 e Portaria 611/93). The child with cerebral palsy was receiving therapy and other services through the Cerebral Palsy Center in Braga, and was receiving services through the EI program of Social Security. However these service agencies according to the parents, were operating independently and made no effort to contact the preschool to either consider special education support for the child.

Another aspect that families presented as an argument for ineffective support were, professionals who did not present adequate information to parents. The mother from Case 12 knew since her child was 6 months old that he was developing atypically. She kept saying to his pediatrician that there was something wrong with her child, something wrong with his vision. And the pediatrician told her:

> He has no problem, his sight is normal, lady you would like that your baby was born walking and talking .His sight is ok and everything is normal.

This mother went to search for another opinion and went to ophthalmologists in the main hospital in Oporto and they found out that his child had a severe vision loss. He was 9 months old when they diagnosed this problem. Another mother from Case 7 who had a child with Down syndrome, said about inadequate information that they got from the doctor who was following them after her child's birth:

> In the hospital we begin to have developmental consultation with a pediatrician, but he too didn't tell us much, he asked questions and that was all. If we didn't know anything about the problem, with him we knew even less. So, their consultation, I think, was not personalized. She was followed up to a point and at that point my husband and myself decided "No, that is enough. What are we coming here for?", so that the doctor can take her measure, weight, ask if she can or cannot roll, if she moves well, if she ate well, I sincerely and fortunately must say that we have a doctor in the family, and a good pediatrician. What we really missed, the main thing we didn't found...so what are we coming here for? Spend gas, fatigue the child, and fatigue us. No, that, we found with the doctors whom we trust.

Another family (Case 7) whose child was diagnosed with Down Syndrome talked about issues of honesty with the doctor that followed her pregnancy and delivery. The mother said:

> M: Well, I think that the doctor, the obstetrician should had talked with me, to explain me everything, and I think that he was a person that, from the beginning...
> E: You felt that he was someone that wasn't honest with you?
> M: No, he wasn't, he wasn't. And it's funny that some time ago I heard an interview with a mother that had a child with a serious problem and she felt exactly the same about this same doctor as I did.

And finally one family (Case 11) mentioned personal incompatibility as inadequate support and another family (Case 13) said that they dropped out of therapy because their daughter was not adapting to the therapists or the place.

2. Results of the second research question: What is the composition, of the informal support networks, e.g. extended family friends, neighbors, religious groups, of families with young children with SN (birth to three) in the District of Braga?

The answer to this question was analyzed using the family support networks that families drew during the interviews, which resulted in ecomaps as seen on pages 206 through 210.

The following elements were part of the informal networks of the families of the case studies:

- Partner in the couple (husband or wife)
- Grandparents
- Uncles and aunts

- Great grand parents
- Friends
- Other relatives
- Older children in the family
- Neighbors
- Babysitter
- Local Store

Analyzing the informal networks of these families suggests that the extended family remains an important factor for family support and this is also corroborated the results from the Inventory of Social Support (Trivette & Dunst 1988) (see page 228 for these results). From these data the grandparents are the most important support for families living in the Northern part of the country. (see ecomap on page 207). For one family (Case 12) the great-grandparent was also an important person providing help to this particular family. The mother said that the great-grandmother helped with daily tasks as she lived in an apartment above theirs. As with formal supports, access to the support is influenced by geography. For example, the geographical distances between where grand-parents and the nuclear family lived influenced the level of support provided the family. These distances can be seen in Table 16.

Geographical separation is directly influenced by each person's mobility. Mobility is an issue for the Portuguese families particularly for families living in urban centers. Nevertheless, for the families that we studied in the District of Braga, the grandparents were still living relatively close to the nuclear family which made them an important informal support group.

Table 16
Geographical distance of grandparents to the nuclear family

Grandparents from mother and father side	Distance in Kms	
Case 1	20	30
Case 2	1	300
Case 3	51	1
Case 4	0,8	——
Case 5	Living together	6
Case 6	0,1	0,1
Case 7	0,3	0,3
Case 8	20	33
Case 9	Living together	4
Case 10	20	Living in Angola
Case 11	50	0,3
Case 12	Living in the same building	1
Case13	2	0,6

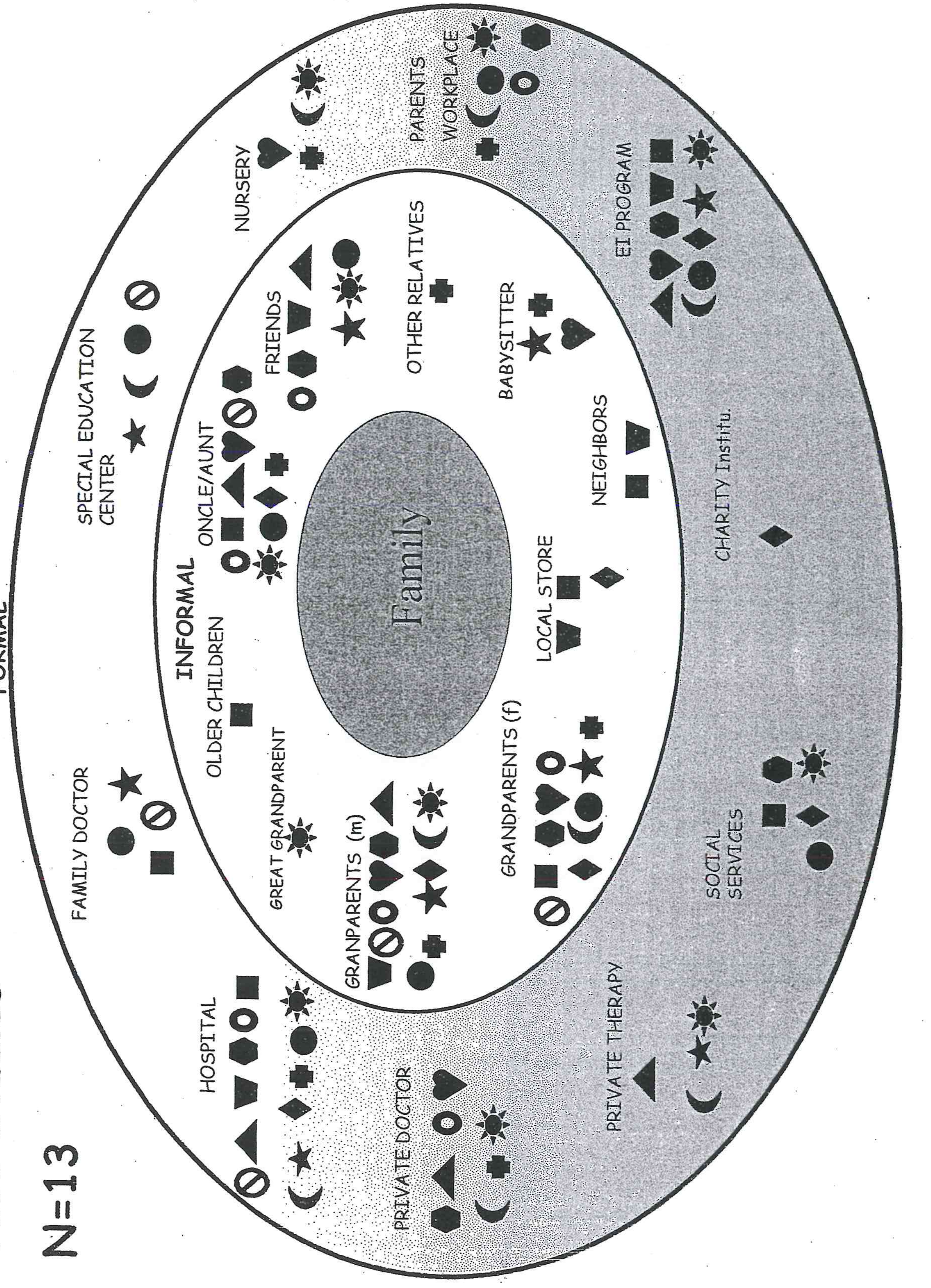
ECOMAPS

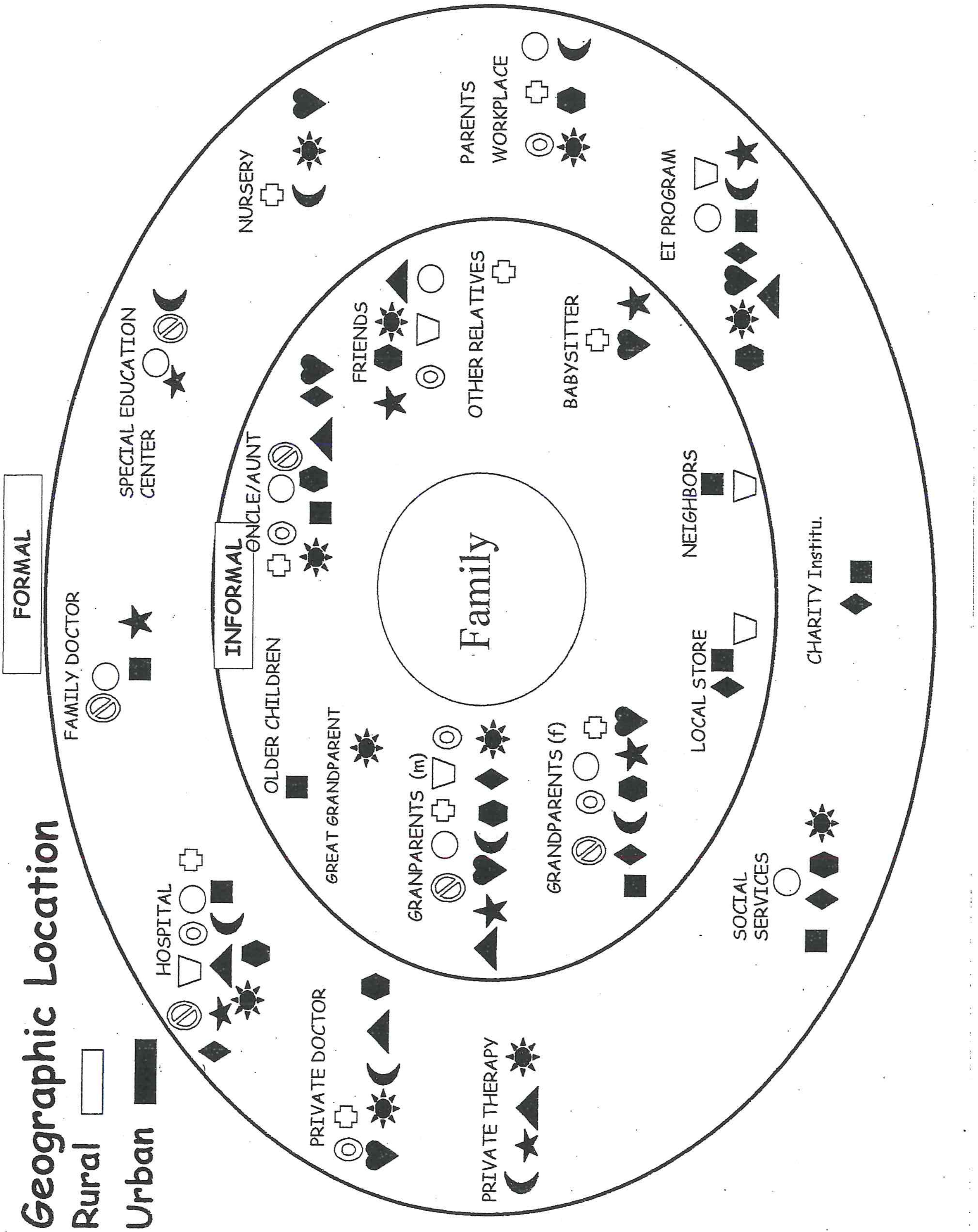
LEGEND

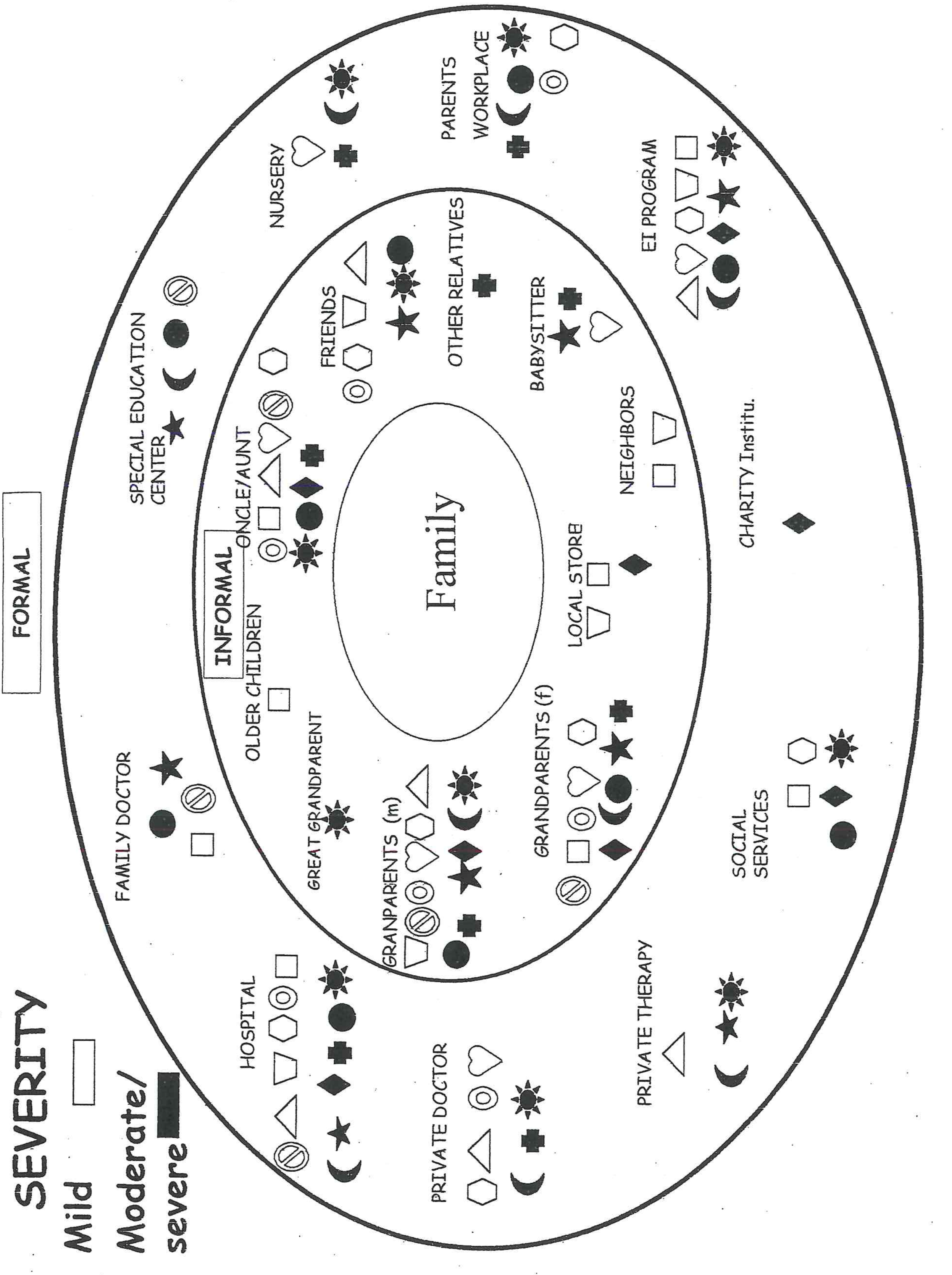
CASE 1 ——— ★
CASE 2 ——— ▲
CASE 3 ——— ☾
CASE 4 ——— ■
CASE 5 ——— ●
CASE 6 ——— ◆
CASE 7 ——— ✚
CASE 8 ——— ♥
CASE 9 ——— ○
CASE 10 ——— ⬢
CASE 11 ——— ▼
CASE 12 ——— ☀
CASE 13 ——— ⊘

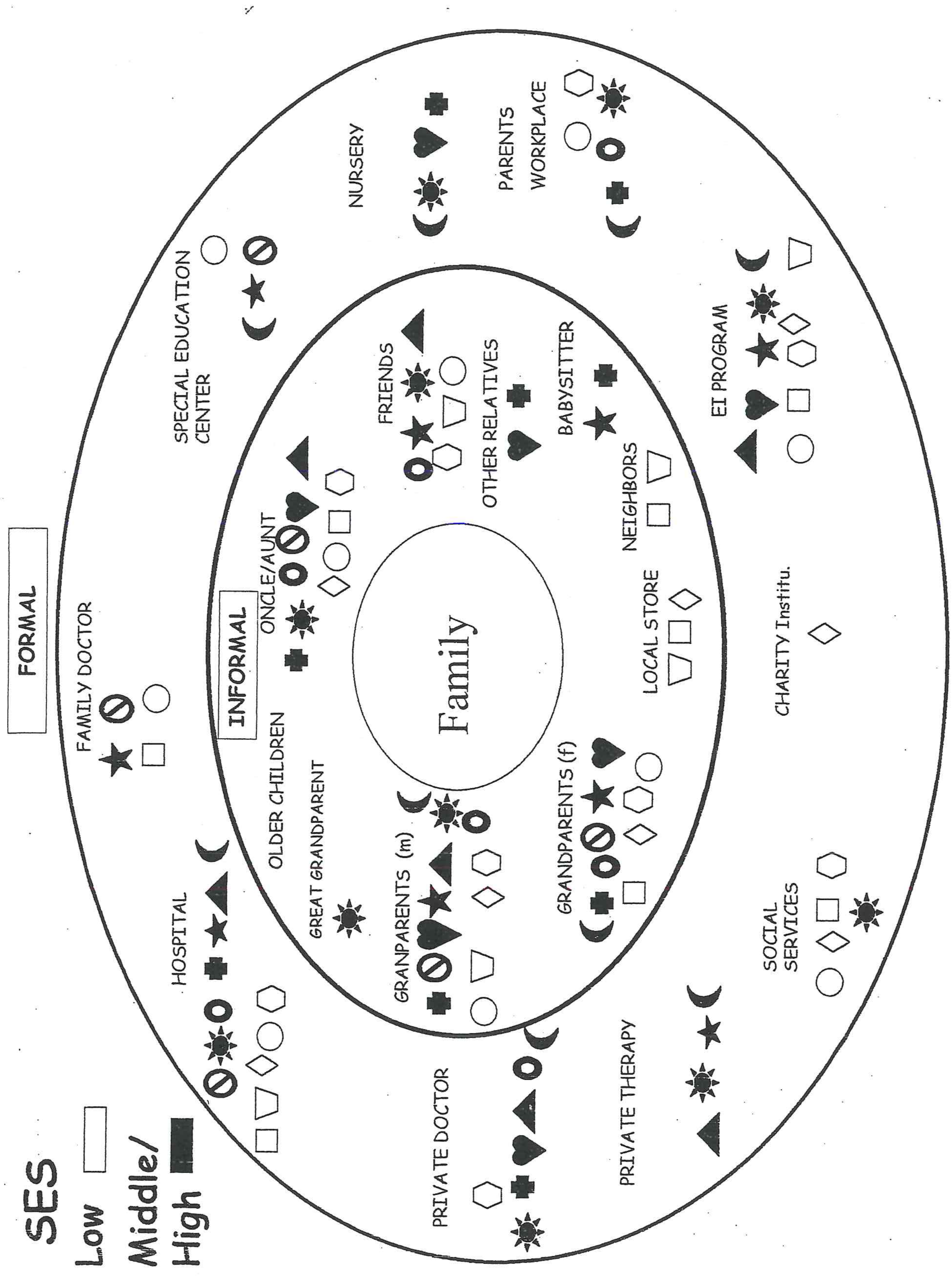
Case Studies

N=13




Geographic Location
Rural ☐
Urban ■
FORMAL
INFORMAL
Family
FAMILY DOCTOR
SPECIAL EDUCATION CENTER
NURSERY
PARENTS WORKPLACE
EI PROGRAM
CHARITY Institu.
SOCIAL SERVICES
PRIVATE THERAPY
PRIVATE DOCTOR
HOSPITAL
OLDER CHILDREN
UNCLE/AUNT
FRIENDS
OTHER RELATIVES
BABYSITTER
NEIGHBORS
LOCAL STORE
GRANDPARENTS (f)
GRANPARENTS (m)
GREAT GRANDPARENT


SEVERITY
Mild
Moderate/ severe
FORMAL
INFORMAL
Family
FAMILY DOCTOR
HOSPITAL
PRIVATE DOCTOR
PRIVATE THERAPY
SOCIAL SERVICES
GRANPARENTS (m)
GREAT GRANDPARENT
GRANDPARENTS (f)
OLDER CHILDREN
LOCAL STORE
NEIGHBORS
CHARITY Institu.
SPECIAL EDUCATION CENTER
UNCLE/AUNT
FRIENDS
OTHER RELATIVES
BABYSITTER
NURSERY
PARENTS WORKPLACE
EI PROGRAM


SES
Low □
Middle/ High ■
FORMAL
INFORMAL
Family
FAMILY DOCTOR
HOSPITAL
SPECIAL EDUCATION CENTER
NURSERY
PARENTS WORKPLACE
EI PROGRAM
CHARITY Institu.
SOCIAL SERVICES
PRIVATE THERAPY
PRIVATE DOCTOR
OLDER CHILDREN
GREAT GRANDPARENT
GRANPARENTS (m)
GRANDPARENTS (f)
ONCLE/AUNT
FRIENDS
OTHER RELATIVES
BABYSITTER
NEIGHBORS
LOCAL STORE

Another important element that we found in the informal support network among this group of families, is the local store. Storeowners were important to families, particularly families from low SES group, by providing food supplies and other basic items for the families during the month. The families paid the store at the end of the month when they received the money from Social Services. For one family (Case 6) the local store also provided her a scale, that she needed to weigh the food for her child's carefully prescribed daily diet.

Another level of analysis for informal support compares dimensions of rural and urban families (see ecomap on page 208). There are not large differences between these two groups. Families living in urban centers compared to those in rural areas appear to have the same elements comprising their informal support networks, and again, extended family and grand-parents play a primary role in their informal support networks. The local storeowner remains an important element for both rural and urban families.

When we analyze the informal support networks using the child's level of disability as a fixed variable, e.g. mild and moderate/severe disabilities (see the ecomap on page 209) the families with children diagnosed with moderate/severe problems tend to use more formal resources than informal resources then the group of families who have children diagnosed with mild disabilities. These data suggest that the complexity and severity of the child's involvement influences the families increased use of formal intervention services to meet their needs. Another area of support these families received was from their workplace. This was mentioned by four families (Cases 3, 5, 7, 12). For example the father and mother in Case 3 said:

> F: The person that I depend on (at work) always say: "Whenever you need there is no problem"
> M: In that respect, even when I was in the hospital, he (the chef) always gave you permission. He always said "go".
> M: And every time we need to go to OPorto for a doctor's appointment, never, nobody...
> F: The law gives one of us the right to go right? Not for both of us. But we always go together.
> M: Yes, my chef does not pose any problem, and does not demand a declaration to prove where we have been, we think that they really trust what we do.
> (Both parents in this case work together for the same employer).

Another mother, Case 12, said about her employer:

> Yes, where I worked before I established myself (as an employer), the lady there really understood, she was the boss and she was really very understanding, I missed work and I could always slip work, and she never said anything. And then I tried to help her, then even at night I would go to work up until midnight or one am. I would start at 6 am because my work was delayed, and so I would go to compensate...she understand that.

These cases refer to the support they get from their employers creativity by providing a schedule flexibility, thus enabling the parents to accompany their children to therapy, doctor's appointments or hospital visits. Among these families, employer accommodation is needed most by the parents of children diagnosed with moderate/severe disabilities.

Parents also mentioned financial supports (Cases 5 and 12) and emotional support (Case 7). Among families whose children are diagnosed with moderate/severe disabilities the informal support network plays an important role. As stated earlier, central in this informal network are the grand-parents of the children. Among families with children identified with mild disabilities it appears that they require fewer services from the formal support network, and they appear to rely more on their informal support network, than the families whose children are more involved.

Finally, a comparison was made in the use of informal support networks among families from the low SES group and medium/high SES group (see ecomap on page 210). This comparison revealed that the informal support network of the families representing the low SES group differs little from the medium/high SES group except in their use of the local store owners . This difference of course is related to the role that the local store plays assisting poor families by helping provide basic goods for the part of the month when financial resources are lacking. Neighbors were an additional support element that only emerged in the informal network of the Low SES families.

Across both SES groups grandparents seem to be equally crucial elements for the informal support networks either for low SES as well for Medium/High SES families.

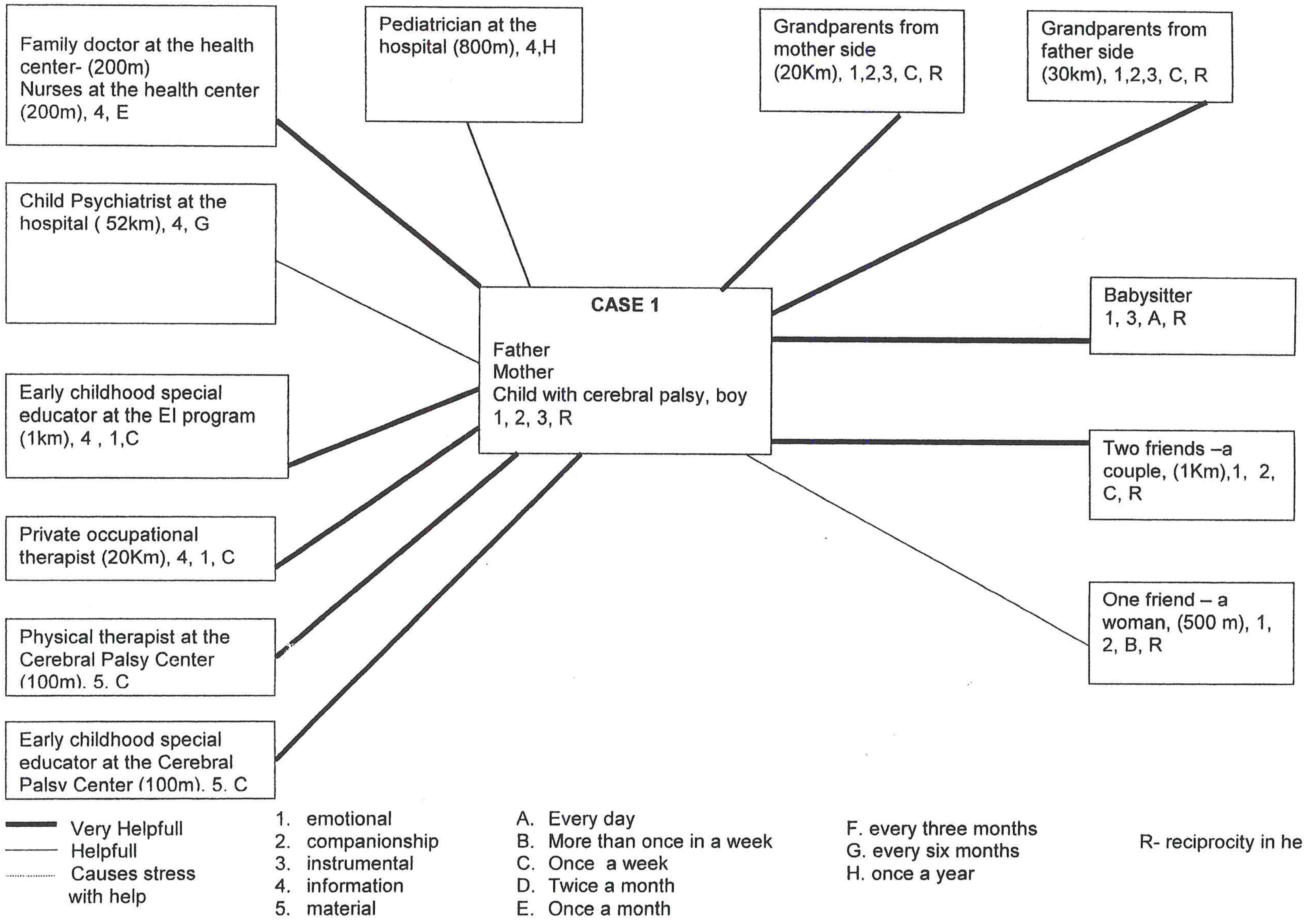
3. Results of the third research question: What service system characteristics, e.g. directed and reciprocal, geographical proximity, frequency of contacts, types of support functions, congruence between help needed and support provided, are related to a family's general satisfaction of their support networks?

To answer question number 3 required the researcher to create a map of each family's support network. These maps indicate all persons or services involved in providing each family help and support; formal and informal. Furthermore, each person and service in the support network is characterized by the type of help provided, the frequency of their contacts with the family members, the reciprocity in help, and the family's level of satisfaction with the help provided. Each map has a legend of these formal and informal supports that each family noted. These Network Maps are displayed for each of the thirteen families from page 215 trough page 227. The instructions that I used to explain the families how to draw and legend the maps can be seen in Appendix C.

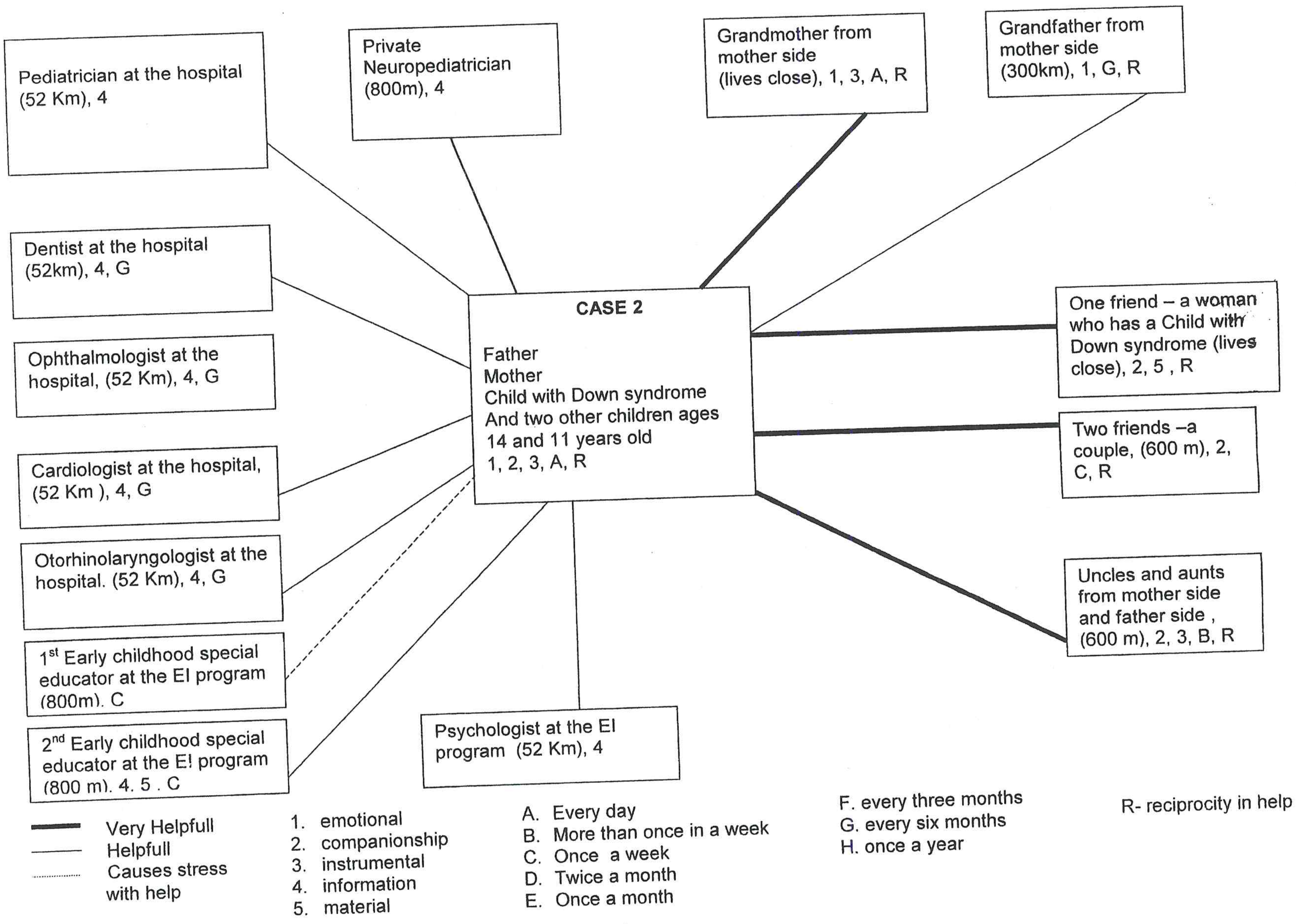
An analyze of these data is synthesized as follows:

- Families from the medium/high SES group and whose children were diagnosed with moderate/severe disabilities (Cases 1, 2, 3, 7, 12) received more medical and therapeutic services, particularly private services than families than families from the low SES group and families with children diagnosed with mild disabilities from both SES groups;

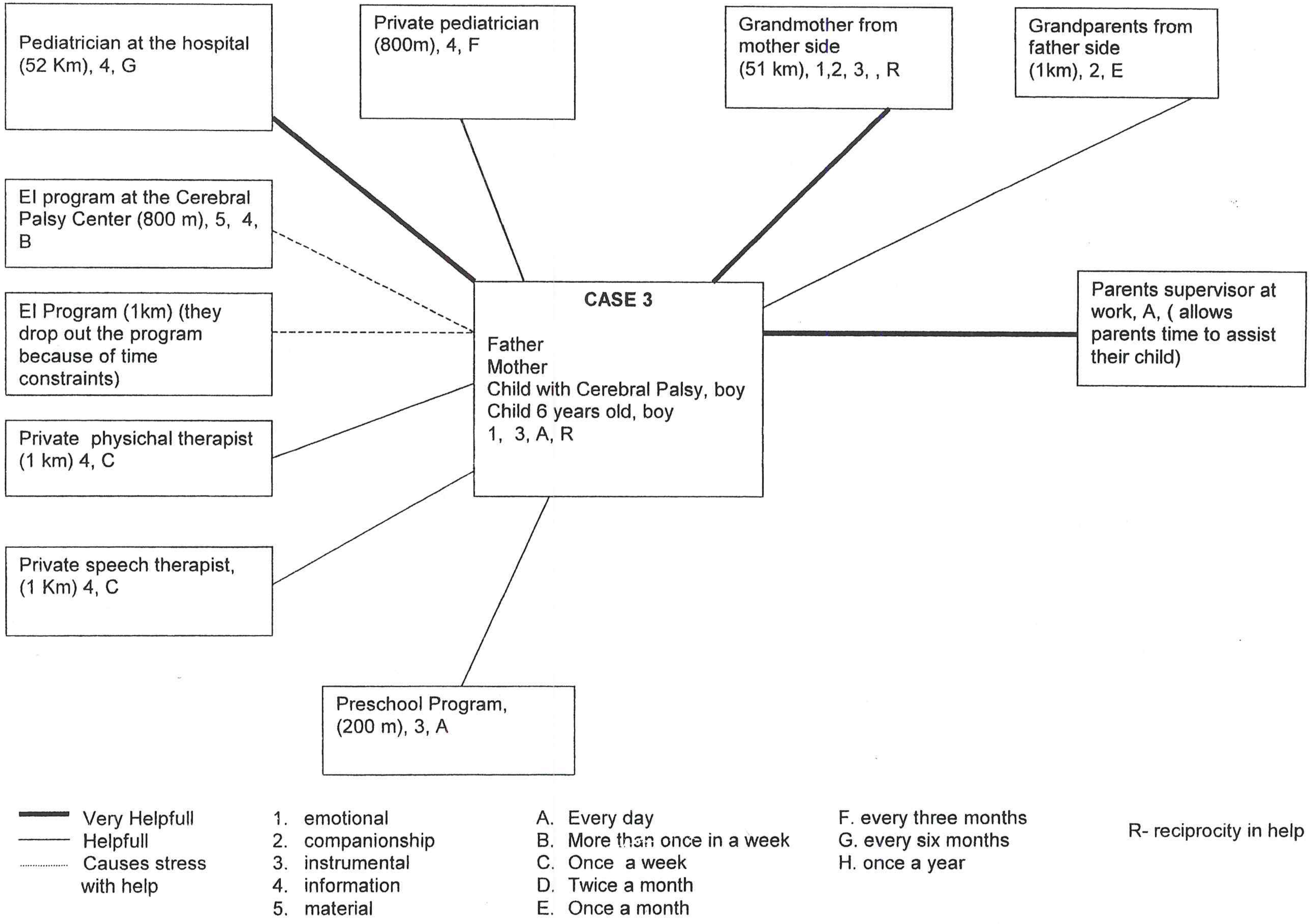
FAMILY NETWORK MAPPING



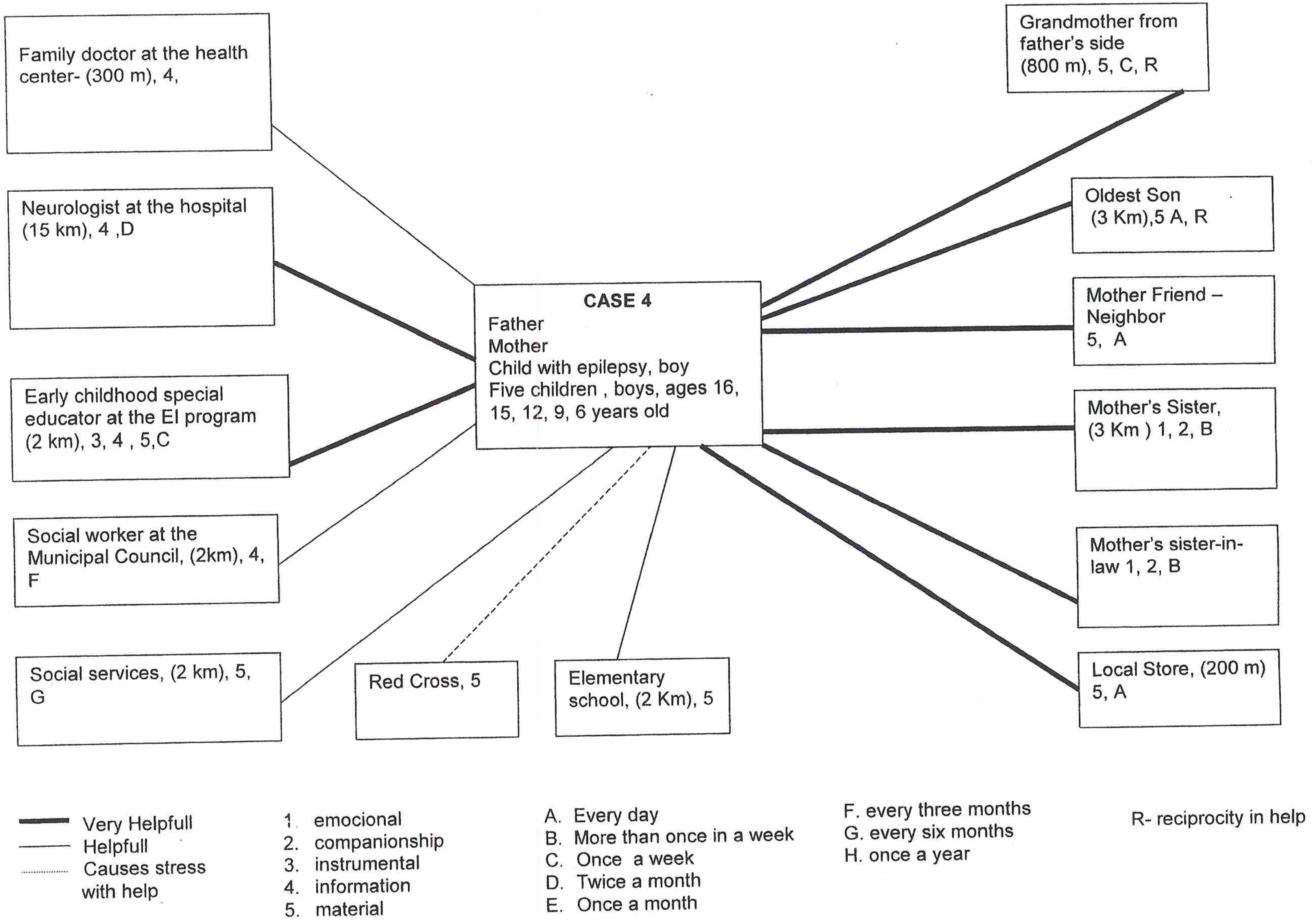
FAMILY NETWORK MAPPING



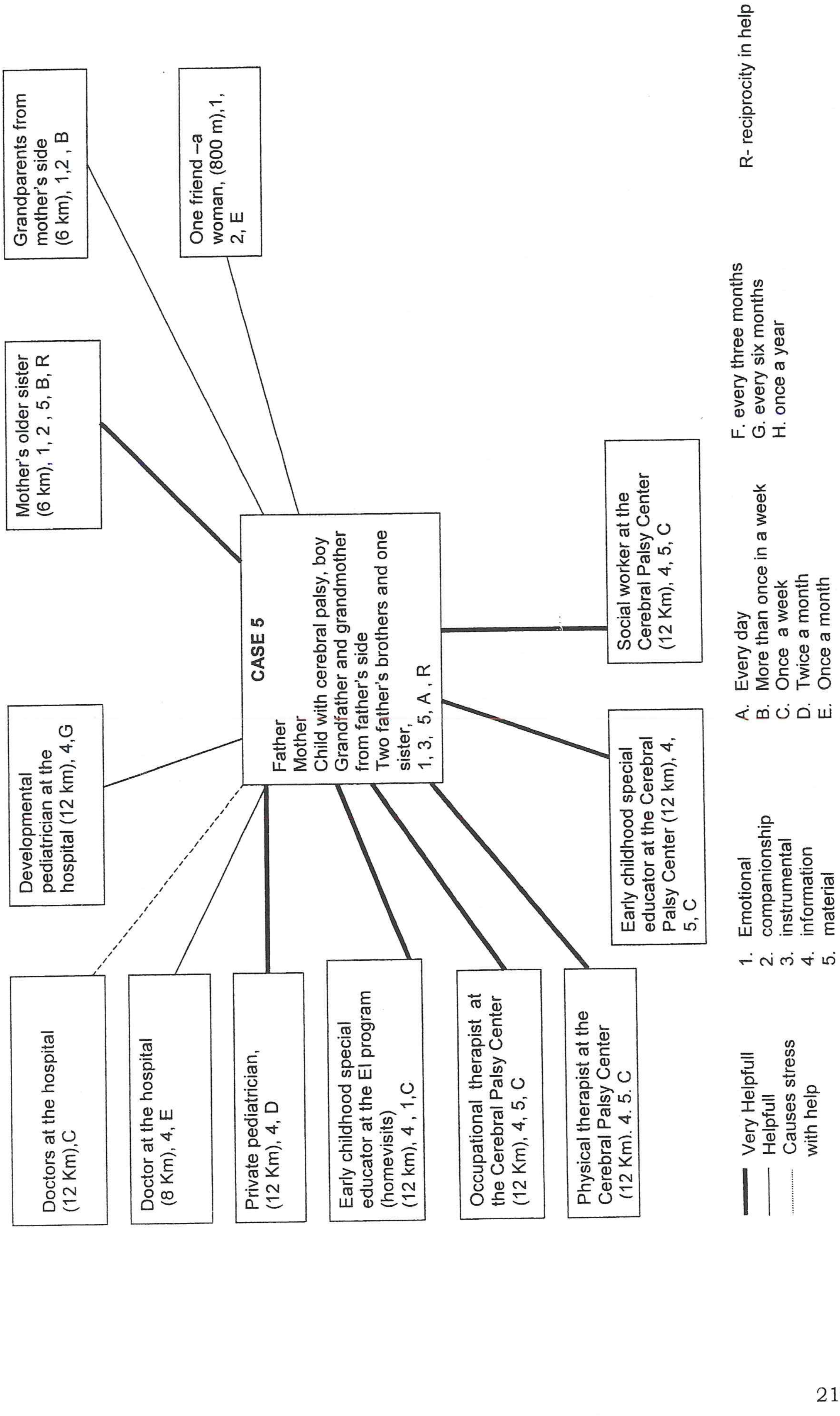
FAMILY NETWORK MAPPING



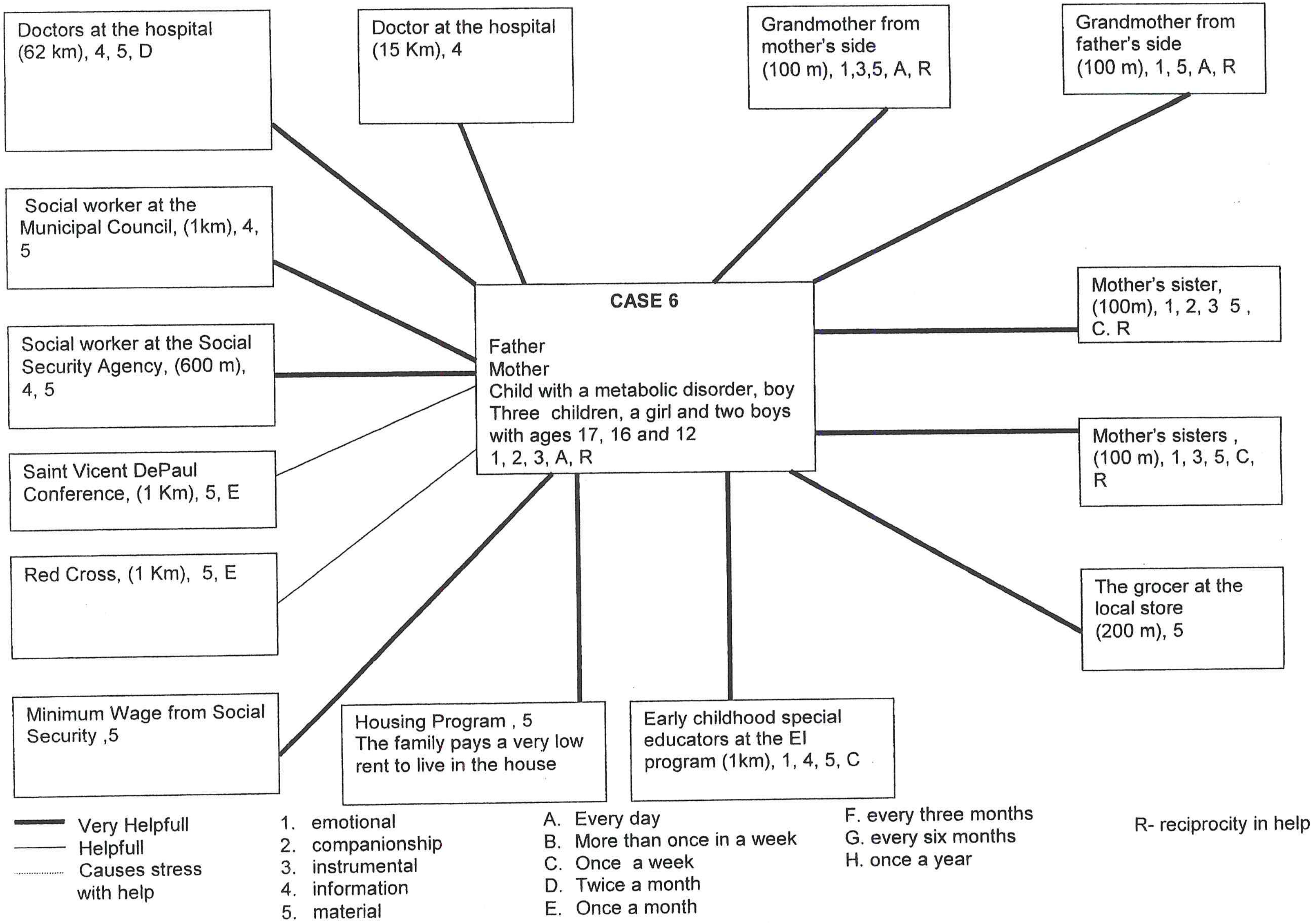
FAMILY NETWORK MAPPING



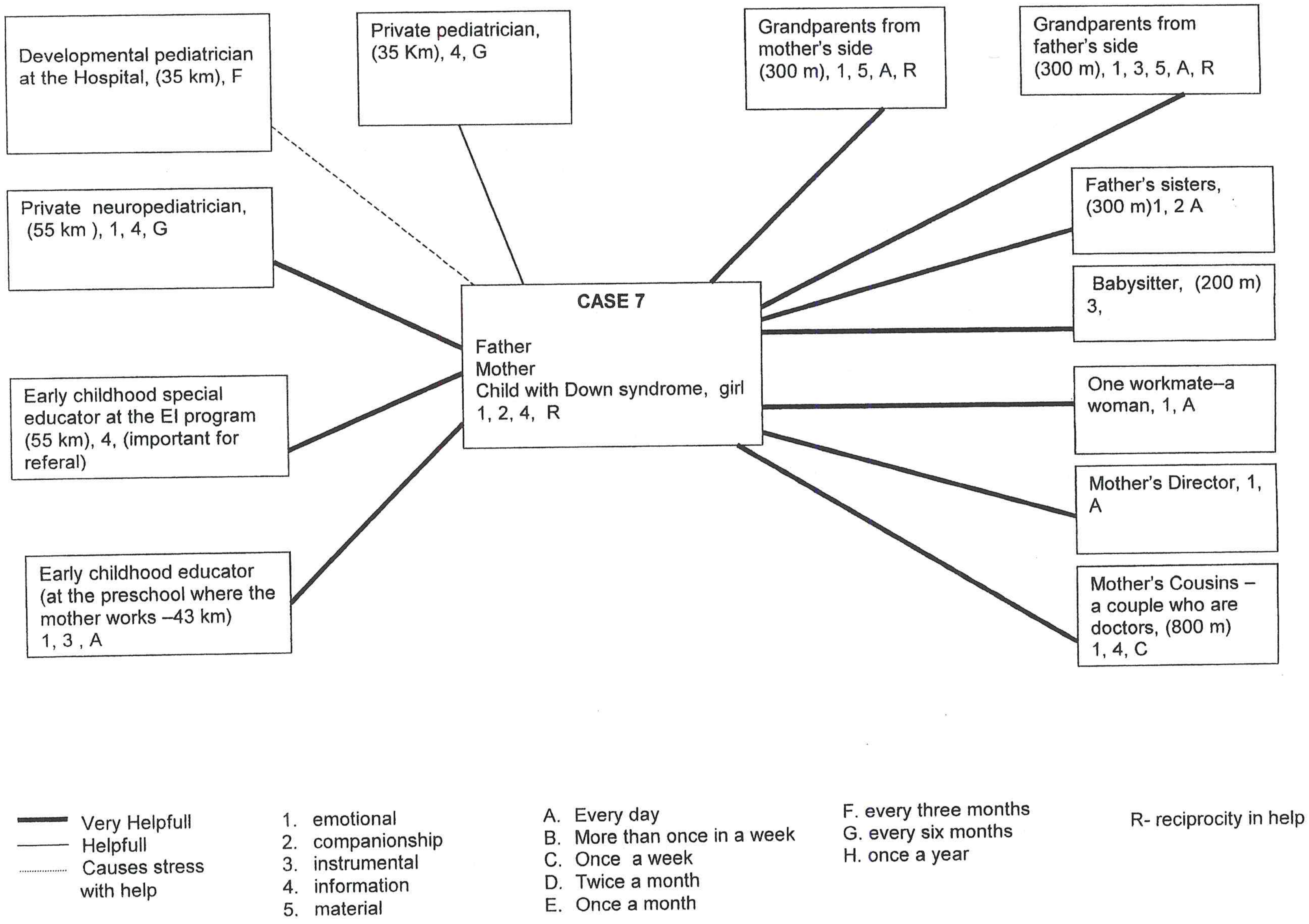
FAMILY NETWORK MAPPING



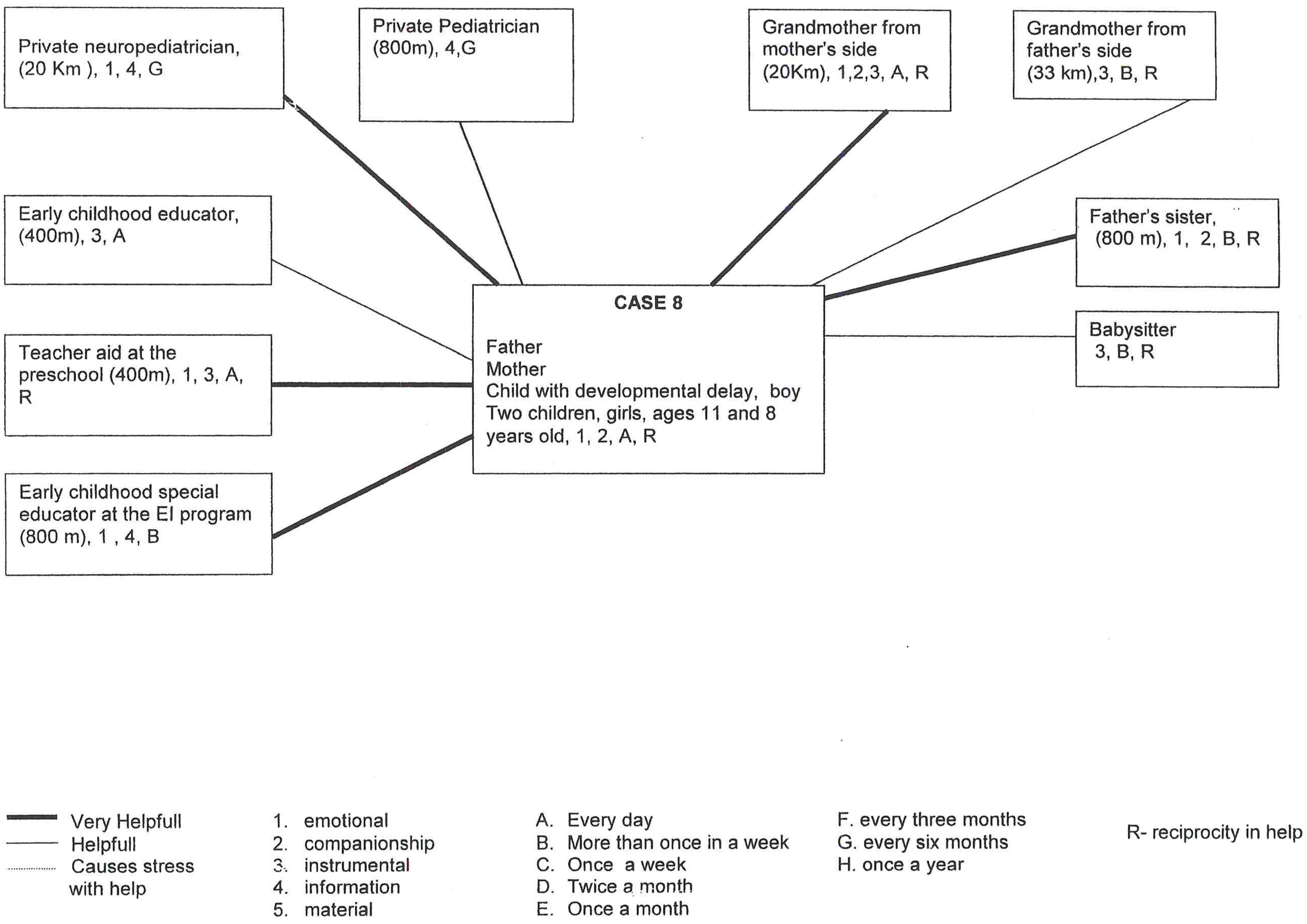
FAMILY NETWORK MAPPING



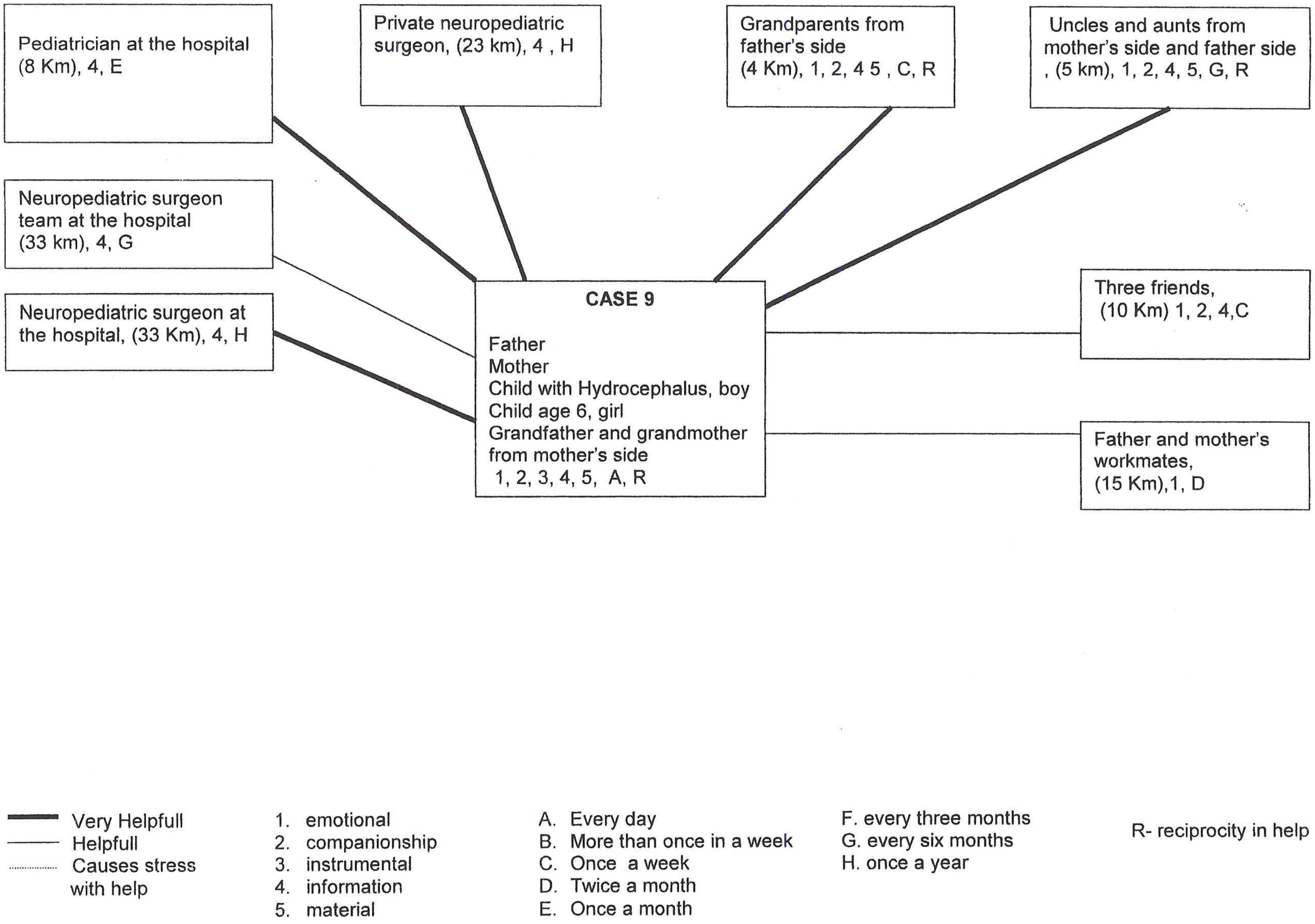
FAMILY NETWORK MAPPING



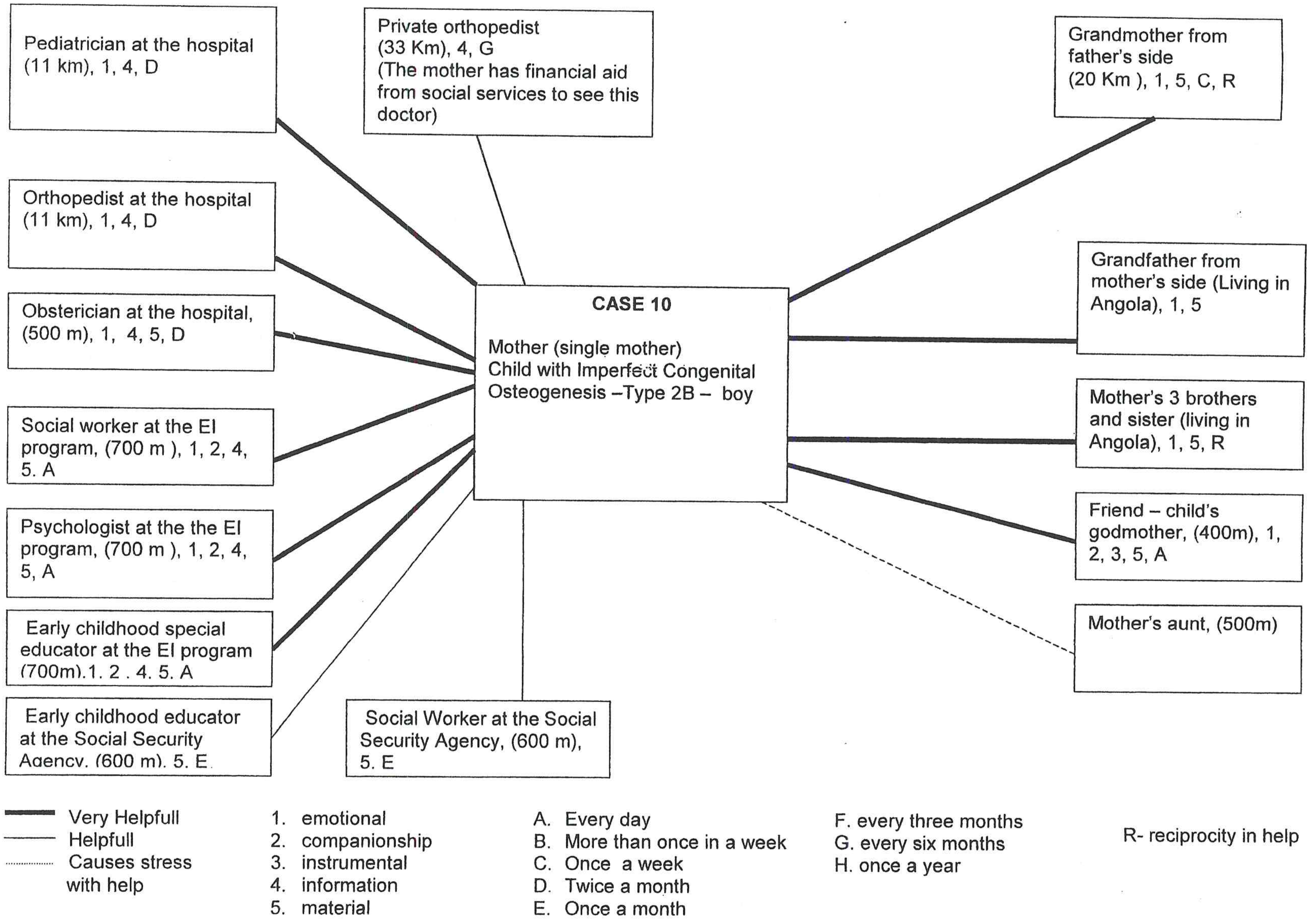
FAMILY NETWORK MAPPING



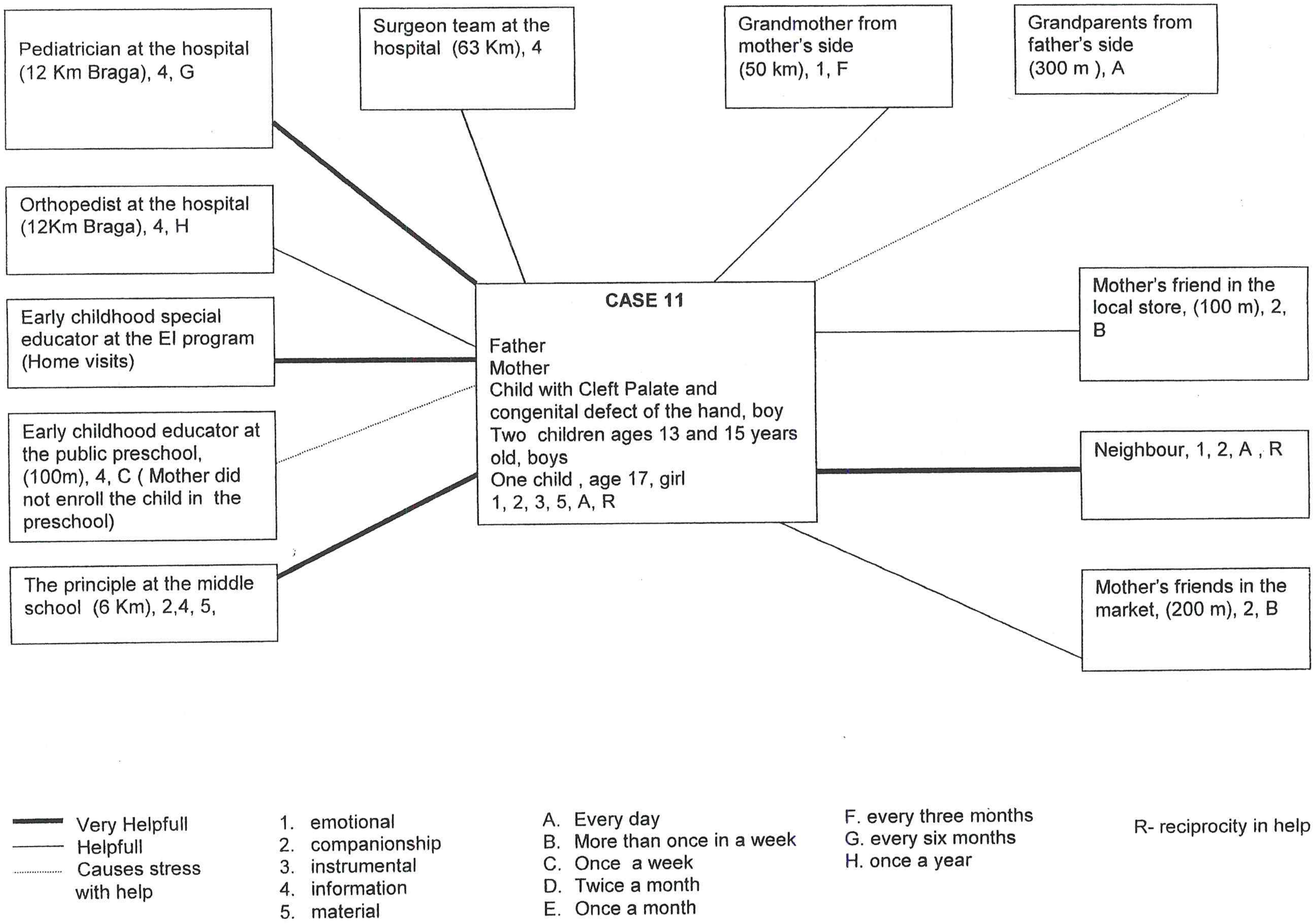
FAMILY NETWORK MAPPING



FAMILY NETWORK MAPPING



FAMILY NETWORK MAPPING



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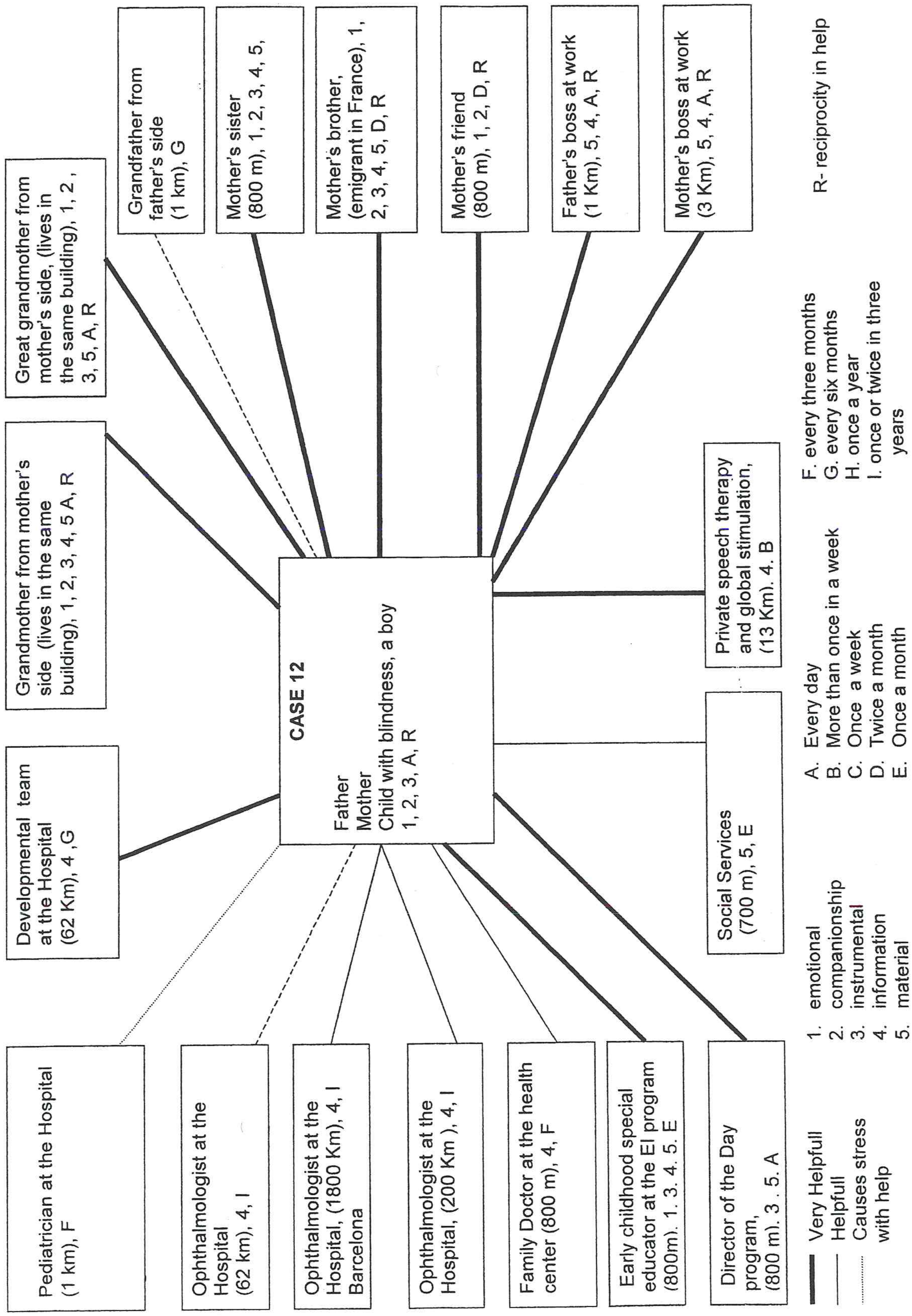

FAMILY NETWORK MAPPING

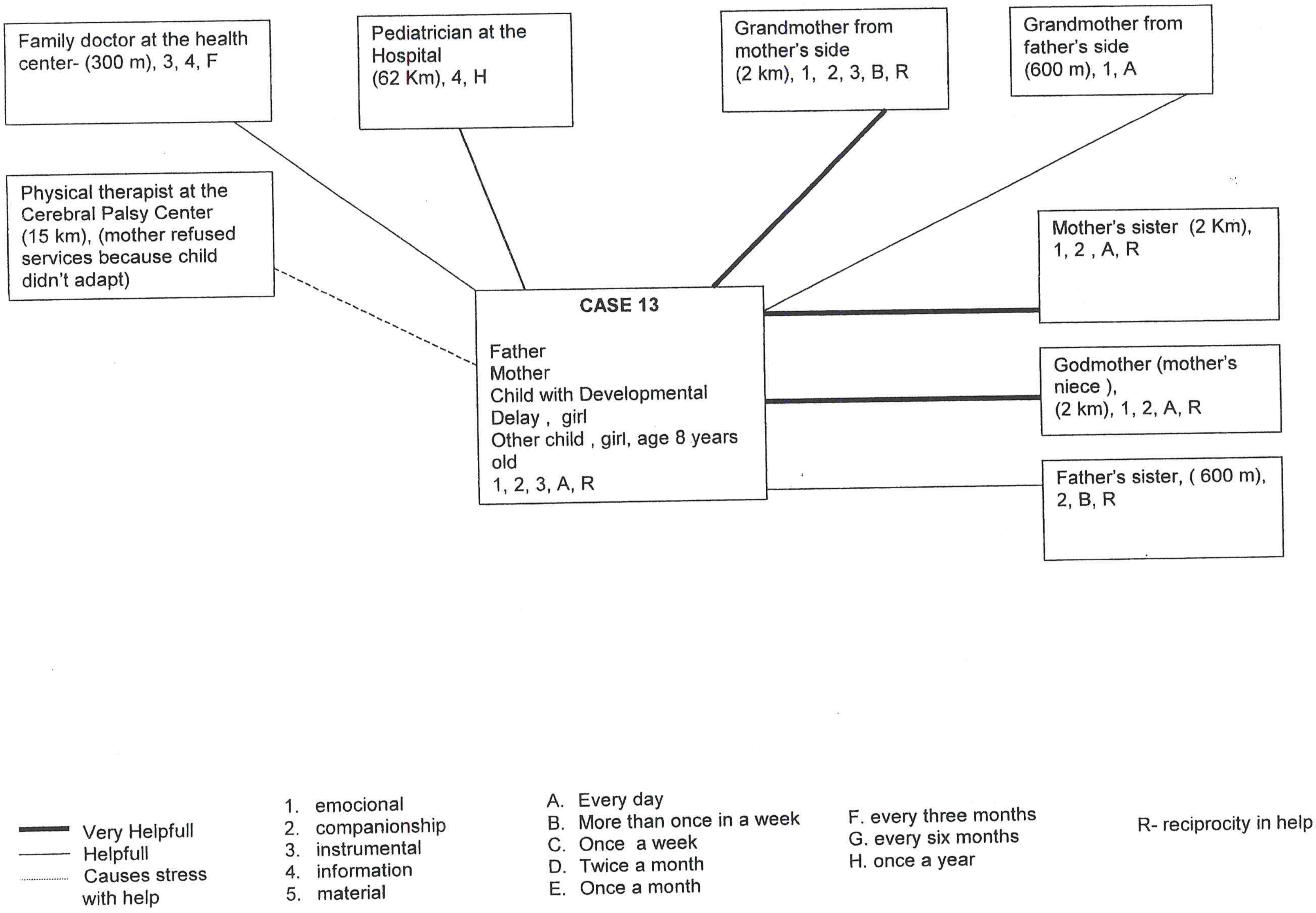

Table 17 - Inventory of social support – Carol M. Trivette & Carl J. Dunst (1988)

Which persons or groups listed to the right provide you help or assistance with each of the following:	Myself	Spouse or partner	My children	My parents	Spouse or partner's parents	Sister /brother	Spouse or partner's Sister /brother	Other relatives	Friends	Neighbors	Church Members/ Minister	Co-workers	Baby Sitter, Daycare, or School	Private Therapist for Child	Child / Family Doctors	Early Childhood Intervention Program	Health Center	Social Service Dept.
1. Who do you go for help or to talk with?	4	1; 2; 3; 4; 78; 9; 12; 13	4	1; 6; 7; 8; 9; 12; 13	7	4; 6; 9; 12; 13	1; 4; 8; 13		1; 10			7; 9			7; 13	4; 5; 8		
2. Who helps take care of your children?	4; 9	1; 2; 3; 78; 9; 13	2; 4; 6; 8	1; 2; 7; 8; 9; 12; 13	1; 5; 13	13	13		1; 10				7; 8; 12			10		
3. Who do you talk to when you have questions about raising your child?	4	2; 3; 8; 9		2; 8; 9; 13		13	8		9			7		1; 3; 12	1; 3; 4; 79; 10; 13	4; 5		10
4. Who loans you money when you need it?		2; 8		7; 12; 13	5				10	4								
5. Who encourages or keep you going when things get hard?	3	1; 5 ; 7; 8; 9; 12; 13	2	1; 2; 7; 8; 9; 12; 13	8	6; 12; 13	1; 8	7; 9; 10	1; 9; 1012			1	8		7			
6. Who accepts your child regardless of how (s)he behaves or acts?	1; 2; 4; 67; 8; 9	1; 2; 4; 7; 89; 12; 13	2; 4; 8	1; 2; 3; 45; 7; 8; 912 ; 13	1; 3; 5; 7; 8; 9; 12	1; 2; 5; 912; 13	1; 2; 7; 8	1; 2; 8; 9	1; 2; 3; 910	1; 2; 4; 9		1; 3	3; 8; 12	1; 2	1; 4; 7	4; 8; 10	1; 4	1; 2; 4
7. Who helps you with house hold chores?	4; 6; 10	1; 2; 3; 7; 8; 13	2; 6; 8	7; 8; 12	5	12							1; 8					
8. Who do you do things to have fun, just relax, or joke around?		1; 2; 3; 5; 7; 8; 9; 12; 13	2; 3; 4; 8	2; 3; 6; 89	3	2; 5; 8	2; 8	2; 6; 9	1; 2; 3; 89; 10; 12	2		1; 12						
9. Who takes the time to do things with your child?	2; 3; 6; 89; 1012	1; 2; 3; 7; 8; 9; 13	2; 8	1; 2; 7; 8; 9; 12; 13	1; 5	2; 5; 9; 12; 13	1; 2; 13	2	1; 2; 10	1			8			8		
10. Who takes you and your child places when you need transportation?	1; 2; 5; 67; 8; 912	1; 2; 3; 5; 7; 8; 9; 12; 13	4	2; 13		6; 13				10								
11. Who hassles with agencies and individuals when you feel you can't get what you need or want?	1; 3; 4; 56; 7; 8; 912	1; 2; 3; 5; 7; 9; 12																10
12. Who helps you learn about services for your child and family?	1; 4; 6; 9	1; 2; 7; 9					8		1			7		3; 12	3; 7; 13	4; 5; 8	5	4

- Families from low SES group (Cases 4, 5, 6, 10, 11) tend to rely more on the formal support network for help, i.e. for these families the formal supports are larger than the informal supports;
- To secure more specialized medical services families had to travel an average distance of 32 Km. This average was for all the families in the study including those living in urban centers or rural areas;
- All families in this study had access to free medical services either through Local Public Health Centers or the main hospitals;
- The type of help given to families is considered most helpful when it happens within a family's informal support networks (Cases 2, 3, 4, 7, 12, and 13). For cases 1, 5, 6, 9, 10, 11 support judged most helpful, appeared within their formal support networks. The consistent factors among these six cases were their lower SES situation and/or the moderate/severe involvement of their children. Case 8 is an exception, despite the fact that this family is within the high SES group and the mild involvement of their child, the child does not have a clear diagnose. So the mother is not willing to share her child's problem with family and friends yet, which might be the reason why this family relies more often in formal support services;
- The type of support provided by the informal networks is different from that provided by the formal networks. Information and material support typically comprises a family's formal support network. Emotional companionship and instrumental support from extended family, neighbors, friends and community organizations appears most often within family's informal support networks. There were

situations however where mothers reported some crossover supports. For example, emotional supports, most frequently a part of their informal support network, was sometimes provided by individuals from the formal support network. These crossover data were reported as emotional support from professionals by mothers in Cases 1, 7, 8, 10 and 12;

- For the majority of families the frequency of contacts among individuals comprising a family's informal network is higher than among the professionals that embodied the formal support network;
- The families report stress more frequently with help from the formal support services than the help they received within their informal support network. However, stress within informal support network was reported in Cases 10, 11, and 12. The stress that they reported was more related with people's attitudes and behaviors than service organization overall;
- For the majority of the families in this study, extended family, particularly grandparents play an important role on family support;
- For the families in this study, reciprocity in helping behavior happens only within informal support network;
- The mean number of formal support services for families with children with moderate/severe problems is eight. This number of professionals and their associated agencies appears to be a vector for stress for these families;
- The network map of Case 10, a single mother, has a profile that demonstrates a larger formal support network compared with her

informal support network. Two possible explanations for this might have to do with the fact that she is an immigrant from the ex-colonies who came to Portugal to live with an aunt, and that she is a single mother. Her recent immigration and her status as a single mother combine to mitigate against her having an established connection with her community or having access to a robust circle of family and friends, helps to understand why she is more reliant on the formal support system;

- Within the informal support network, geographical proximity to grandparents (See table 17) remains a reality for the majority of these families in this study. Access to this critical support system from their immediate family makes life easier for theses families. Complimenting the supports families receive from grandparents is the support provided by the extended family such as uncles and aunts (Cases 2, 4, 5, 6, 7, 8, 9, 12 and 13). Yet another source for support surfaced with Case 12 where the great-grandparent was listed as an important support. Friends are also an important category for support within a family's informal support system. In cases where friends were reported as an important support factor, the families also reported they lived close to the family.

For purposes of better understanding of the different types of support provided by the support networks of these families, and by whom they were provided, I asked families to answer the second part of an instrument developed by Trivette & Dunst (1988) called *Social Support Inventory* (for a description see pages 175).

The responses to the Inventory by each of the families can be seen on page 228, Table 17. Each number represents a family case. Their responses to the Inventory follow each case number.

An overall qualitative analysis of the responses to the inventory discloses interesting data concerning the types of social support functions provided by the different elements of formal and informal social network. On the left column in the matrix there are 12 items that, according to the authors, represent different types of support functions provided to families. Such functions are emotional support, e.g., someone to talk to about a difficulty or concern, items 1, 5, and 6; instrumental support, e.g., babysitting or child care, items 2, 7, and 10; informational support, e.g., child rearing advice, items 3, and 12; material support (borrowing money or other needs, item 4; companionship, e.g., someone with whom to enjoy social activities, items 8 and 9; and obtain services, e.g. get the needs you want, item11. On the top of the matrix graph are 18 different people and groups who are asked help or assistance. The majority of the answers fall on the informal support groups. Support within the family, particularly the support from spouse or partners had the most number of responses and for almost every type of support. Grandparents come next and followed by uncles and aunts. Children, other relatives and friends are also important in the informal support system. Neighbors and co-workers, while part of a family's informal support system, were groups that received the fewest number of responses from the families.

Overall we can say that the informal support network provides these families with emotional and instrumental support, companionship and material needs. A family's formal supports include a rich array of services including those from the following sectors, medical, educational, therapeutic, religious and social. These services were part of the support for families, which concerns information, items 3 and 12, and item 6, accepting the child regardless of how she behaves or acts. Interestingly the strong catholic religious traditions that entangle the cultural patterns of this region of Portugal, the church does not seem to play much of a role in providing support for these families. Case 6 is an exception. The mother stated that she received support from a church institution, Saint Vincent DePaul Conference. The primary mission of this organizational arm of the church is charged with providing basic needs for poor families. Responses from this instrument revealed that very few families received emotional support from professionals. However, there were some references made to the emotional supports some families received from their child/family doctor and the EI program.

These results are congruent with the results that were reported from responses to the interviews that answered research question 1; the rationale for effective formal and informal support. As reported, providing information and offering needed referrals to needed services were the most frequently reported categories of assistance by families and considered as effective forms of formal support. Emotional and financial support were the least referenced formal support categories among families. Families reported emotional, material and instrumental support as rationale effective informal supports. Basically, the types of support founded studying these families, whether they are categorized as formal or informal and the individuals or agencies that provide them were identical when we analyzed both the interviews and the responses to the Inventory of Social Support.

Finally, important data that were collected during the interviews concern the rationale families presented for effectiveness of informal support. Results can be seen in Figure 18.

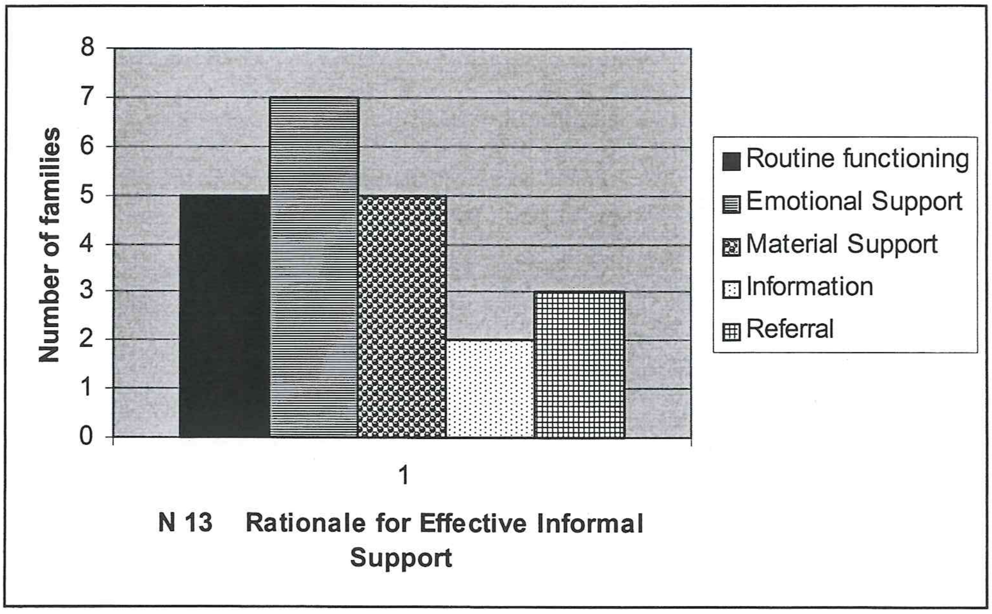

Figure 18

When asked why they would consider the type of informal support helpful, families reported five primary reasons; it helped them with routine functioning on a daily basis, gave them emotional support, material support, information and help them referring their children and themselves to services. More families (7 Cases) reported emotional support as the reason for the efficacy of informal support. These results are coincident with results obtained in the Inventory of Social Support regarding the type of support provided by the informal networks, i.e., the functions provided by the informal network in the Inventory were basically the same described as rationale for effectiveness of help provided to the families. Extracts of the interviews concerning these rationales are:

The mother of a child with Down syndrome of Case 2 said about significant people in her informal support network and why they were important to her :

> The best support was my husband,...and next my children... my boy was 13 years old, and he clearly perceived the situation and he is one of the persons who is the most supportive and gratifies me the most, at the moment is him, but each one on its own way...

Another mother, (Case 4) acknowledge a neighbor who helped her:

> There is a neighbor, who lives behind me and she often times, sees me sad and of course I am sad because my child cries for food, that very often he doesn't have, and she comes over and brings sugar, rice, pasta, milk...she always give me things.

4. Results of the forth research question: What are the needs of the families with children with SN (birth to three) in the District of Braga?

When families were asked to prioritize their needs, they respond with an array of needs, services, and concerns. A content analysis of their responses revealed the following categories:

- Financial;
- Information;
- Child Care;
- Health Needs;
- Help with Household tasks;
- Minimum Housing conditions;
- Housing space;

- Child development;
- Social/ Emotional;
- Concerns with transition;
- Concerns with the adulthood of their children with SN;
- Therapy;
- Specialized educators.

Figure 19 shows an analysis of the needs data using SES as the independent variable.

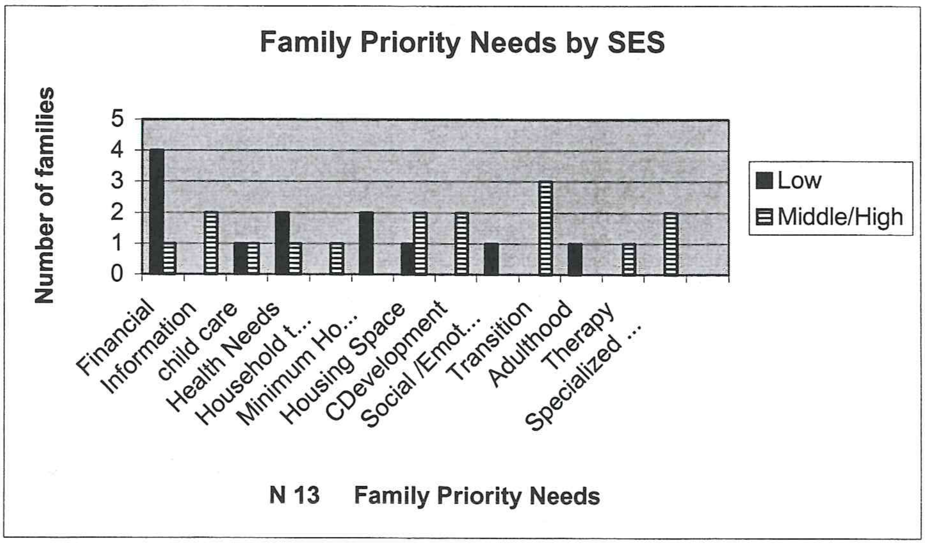

Figure 19

Overall the data reveal SES differences among families. Low SES families appear to struggle with more basic needs, such as finances, healthcare, and minimum housing conditions. Those families from middle/high SES families are more concerned with issues of child development, information, transition, and availability of specialized educators.

The following is a representative quote from Case 3 and indicates one of the needs of Middle /High SES families. The father and mother were interviwed together and mentioned their need for help with the household tasks:

> F: Now, that problem is more on her side...I don't know...the thing that she most needs now is someone to help, we need a person for example to...
> M: ...to help with household tasks, I am feeling that, at least with my oldest son, that he needs more support from us. My youngest son (the child with SN) ...shall we say is the center of the attention, because he needs it. And one thing that I feel I need is turning away from the housework and spend more time with them (her children). Because we work on this time schedule 9 to 12.30 am and 2 to 5.30 pm. Get the children, buy this here, buy this there, and when I get home I go to the kitchen, get dinner ready, doing the dishes, taking care of the clothes, put one in bed, put the other in bed, and shall we say... that availability... is in the air. I think that our oldest child, is, is starting to miss that.

The following quotes from two families for the Middle/High SES refer to their child development concerns, as a priority need. The mother of Case 2 said:

> At this moment there is something that I strongly wish, that she (her daughter with Down syndrome) starts walking, which is one of the things that I worried the most.

While the mother of Case 9 said:

> Related to him? It is always checking... be attentive to everything that could come up and than... I want medical appointments. Every month I am careful about taking him to a pediatrician, to make sure that everything is fine with him, so what really concerns me deep inside is his (her son with hydrocephalus) development. Our concern deep inside is his development right?

The mother from Case 6 details another priority need. This mother from the of Low SES group describes her financial needs as follows:

> What worries me the most is, very often, when I need money for my children, to give them food and I don't have. Is more that. Very often, when the minimum income arrives, and when I check, everything goes to the cooperative (the grocery store), because they sell me everything on credit.

A quote from a single mother from Case 10 refers to her emotional needs as follows:

> I think that now I don't have as many needs, I don't know if that is because I went trough so much problems. Since I start working I have been putting my things little by little, I got used to live with my child alone right? I got used to be everything in that house, and that is the way it is. So sometimes I feel like a little lonely. Yes, with my child I feel a little lonely... sometimes is more difficult to support him or facilitate something right?

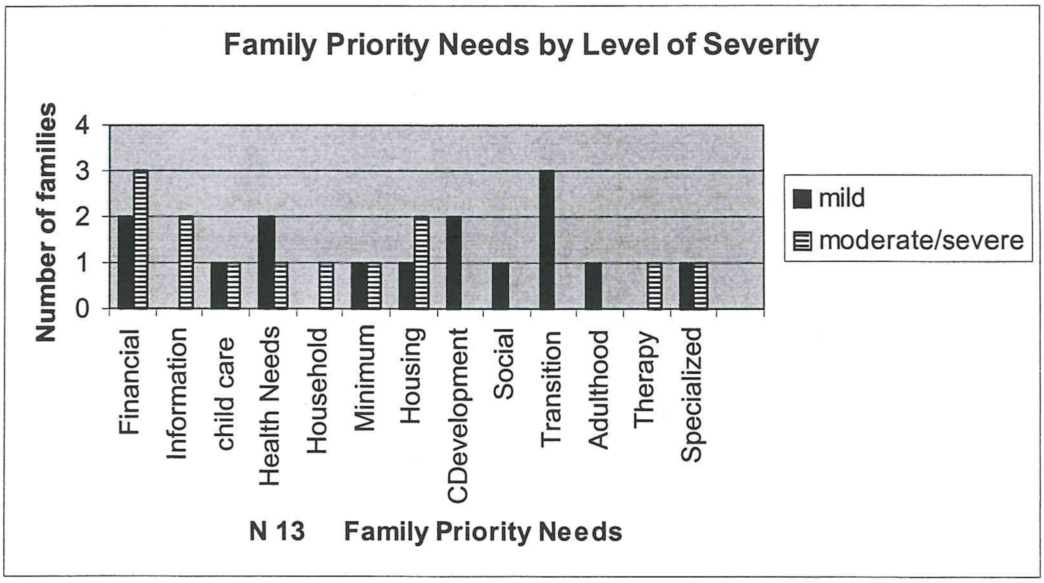

Figure 20

Figure 20 compares the independent variable of the child's disability or level of severity with the priority needs of families. There is evidence that families who have children with moderate/severe disabilities were more apt to mention needs related to finances, general information, help with house hold tasks, housing issues, e.g. space and therapy needs for children. Families whose children were diagnosed with mild disabilities more frequently mentioned concerns with needing supports in areas that include social/emotional, health, child development, transition and adulthood needs than families with children with moderate/severe problems. From these data it appears that the severity of the child's disability change the priority needs of families. As severity increased more general needs and concerns like general child development, transition and adulthood become secondary to concerns more oriented to basic survival needs of the family.

The division of needs based on level of severity is reflected by the two following quotes. Case 8 is a mother of a child who is diagnosed with mild disabilities. She refers to her concerns about transitions for her child:

> It worries me his future, right now he is in the private preschool, but then? After completing the pre-school he goes to the elementary school, and now I don't know where he is should go. That worries me a lot. I don't know who is going to attend him, I don't know what type of school, because this school where he is now is private and has no support from special education, I don't know and that really worries me.

While the mother of Case 12 whose child has more severe disabilities is concerned with more specialized educational supports for her child:

> Needs? What I really need instead of stop working, because we all need to work right? ... and because my child's vision problem, I would like to have someone specialized to teach him to know the things using more of his hands. Even though the others and we teach, I teach what I can, but I would like to have someone more specialized, a support that would help.

These quotes reflect the range of responses and issues that arose when considering the needs of these families. It is clear that both SES and the level of severity of the child's problem are important variables that must be considered because they challenge the resources and increase the needs of these families.

Finally, and regarding needs, we analyzed the answers of the families to the Family Needs Survey (Bailey & Simeonsson, Revision, 1990b), an instrument previously described in the methodology chapter (see page 175). The following are the results for both families from both the low SES and Middle/High SES groups. Each number in the columns of the survey correspond to the case numbers of the families who responded to each prompt, e.g. the answers of Case 1 are represented by number 1, Case 2 are represented by number 2 and so on. Two families (Case 6 and Case 11) did not return the Family Needs Survey.

The analysis compares the Low SES families with Medium/High SES families. While there is a greater concentration of answers on the informational need category for the Medium/High SES group of families compared to the low SES families, the answers to the Survey are scattered across all categories of the scale.

When comparing the answers to the Survey from families with children with mild conditions (N=6) and the families with children with moderate/severe conditions (N=5), the first group of families had 108 NO answers and 65 YES answers and these 65 were spread over the different needs categories in the survey. The category of needs most represented in this group was information with 22 YES answers.

The group of families with children with moderate to severe conditions had 108 NO answers and 39 YES answers, also in this group the needs category that had more answers was the information with 16 YES answers followed by the family and social support category with 8 YES answers.

The results of the survey yield slightly different data concerning needs of these different groups of families then the interviews. This fact might be related to the nature of the information asked to the families. In the interview they were asked which priority needs they would list. Or, what worried them the most. In the Survey they had a written list of statements and they were asked to say Yes, No or Not Sure about each statement that represented a need.

Summary

In this chapter I explored the findings from the study that address the initial four research questions proposed for this study. So the chapter is organized with the results that address each of the research questions.

Table 18 – FAMILY NEEDS SURVEY – Bailey & Simeonsson (Revision, 1990b)

Answers from Low SES Families

	Would you like to discuss this topic with a staff person from our program?		
Topics	**No**	**Not sure**	**Yes**
Information 1. How children grow and develop	5; 10		4
2. How to play or talk with my child	10		4; 5
3. How to hold my child	5; 10		4
4. How to handle my child behavior	10	5	4
5. Information about any condition or disability my child might have			4; 5; 10
6. Information about services that are presently available for my child	10		4; 5
7. Information about the services that my child might receive in the future			4; 5; 10
Family & Social Support 1. Talking with someone in my family about concerns	4; 5	10	
2. Having friends to talk to	4	5	10
3. Finding more time for myself		5	4
4. Helping my spouse accepting any condition our child might have	4; 5; 10		
5. Helping our family discuss problems and reach solutions	10		5
6. Helping our family support each other during difficult times	4		5; 10
7. Deciding who will do household chores, child care, and other family tasks	10	5	4
8. Deciding on and doing family recreational activities	4	5; 10	
Financial 1. Paying for expenses such as food, housing, medical care, clothing, or transportation	5; 10		4
2. Getting any special equipment my child needs			5; 10
3. Paying for therapy, day care or other services my child needs	5		4; 10
4. Counseling or help in getting a job	4; 5		10
5. Paying for babysitting	4; 5		10
6. Paying for toys that my child needs	5		4; 10
Explaining to others 1. Explaining my child's condition to my parents or my spouse's parents	5; 10		4
2. Explaining my child's condition to his or her siblings	5		4; 10
3. Explaining my child's condition to other children			4; 5; 10
4. How to handle my child behavior		5; 10	4
5. Finding reading material about other families who have a child like mine		10	5
Child Care 1. Locating babysitters who are willing and able to care for my child	4; 5; 10		
2. Locating a day care program or preschool for my child	4		5; 10
3. Getting appropriate care for child in a church during religious services	4; 5; 10		
Community Services 1. Meeting and talking with other parents who have a child like mine		4; 10	5
2. Locating a doctor who understands me and my child's needs	4		5; 10
3. Locating a dentist who will see my child	4	5	10

Table 19 – FAMILY NEEDS SURVEY – Bailey & Simeonsson (Revision, 1990b)

Answers from Medium/High SES Families

	Would you like to discuss this topic with a staff person from our program?		
Topics	**No**	**Not sure**	**Yes**
Information 1. How children grow and develop	1; 2; 8; 9; 12		3; 7; 13
2. How to play or talk with my child	1; 2; 3; 7; 8; 9; 12		13
3. How to hold my child	1; 2; 3; 7; 8; 9; 12		
4. How to handle my child behavior	1; 9		2; 3; 7; 8; 12; 13
5. Information about any condition or disability my child might have	1; 3	9	2; 7; 8; 12; 13
6. Information about services that are presently available for my child	1; 3; 9; 13		2; 7; 8; 12
7. Information about the services that my child might receive in the future		9	1; 2; 3; 7; 8; 12; 13
Family & Social Support 1. Talking with someone in my family about concerns	1; 2; 3; 9; 12	8	13
2. Having friends to talk to	1; 2; 3; 7; 8; 9 12		13
3. Finding more time for myself	1; 2; 3; 8; 9; 12		7; 13
4. Helping my spouse accepting any condition our child might have	1; 2; 3; 7; 8; 9; 12		13
5. Helping our family discuss problems and reach solutions	1; 3; 8; 9; 12		2; 7; 13
6. Helping our family support each other during difficult times	1; 2; 3; 8; 9; 12		7; 13
7. Deciding who will do household chores, child care, and other family tasks	1; 2; 3; 7; 8; 9 12; 13		
8. Deciding on and doing family recreational activities	1; 2; 9; 12; 13	8	3; 7
Financial 1. Paying for expenses such as food, housing, medical care, clothing, or transportation	1; 2; 3; 8; 9; 12; 13		
2. Getting any special equipment my child needs	1; 3; 7; 9; 13	8	2; 12
3. Paying for therapy, day care or other services my child needs	1; 2; 3; 7; 9		8; 12; 13
4. Counseling or help in getting a job	1; 2; 3; 7; 8; 9 12; 13		
5. Paying for babysitting	1; 2; 3; 7; 8; 9 12; 13		
6. Paying for toys that my child needs	1; 2; 3; 7; 8; 9 12; 13		
Explaining to others 1. Explaining my child's condition to my parents or my spouse's parents	1; 2; 3; 7; 9; 13	8	
2. Explaining my child's condition to his or her siblings	1; 2; 3; 7; 9; 13		8
3. Explaining my child's condition to other children	1; 2; 7; 8; 9; 13		
4. How to handle my child behavior	1; 9; 13		2; 3; 7; 8
5. Finding reading material about other families who have a child like mine	3; 7; 9; 13		1; 2; 8
Child Care 1. Locating babysitters who are willing and able to care for my child	1; 2; 3; 7; 8; 9 13		
2. Locating a day care program or preschool for my child	1; 3; 7; 8; 9		2; 13
3. Getting appropriate care for child in a church during religious services	1; 2; 3; 7; 8; 9 13		
Community Services 1. Meeting and talking with other parents who have a child like mine	1; 3; 7	9	2; 8; 13
2. Locating a doctor who understands me and my child's needs	1; 2; 3; 9; 13		7; 8
3. Locating a dentist who will see my child	2; 3; 9; 13		1; 7; 8

Table 20 – FAMILY NEEDS SURVEY – Bailey & Simeonsson (Revision, 1990b)

Answers from families with children with mild conditions

	Would you like to discuss this topic with a staff person from our program?		
Topics	**No**	**Not sure**	**Yes**
Information			
1. How children grow and develop	2; 8; 9; 10		4; 13
2. How to play or talk with my child	2; 8; 9; 10		4; 13
3. How to hold my child	2; 8; 9; 10		4
4. How to handle my child behavior	9; 10		2; 4; 8; 13
5. Information about any condition or disability my child might have		9	2; 4; 8; 10; 13
6. Information about services that are presently available for my child	9; 10; 13		2; 4; 8;
7. Information about the services that my child might receive in the future		9	2; 4; 8; 10; 13
Family & Social Support			
1. Talking with someone in my family about concerns	2; 4; 9	8; 10	13
2. Having friends to talk to	2; 4; 8; 9		10; 13
3. Finding more time for myself	2; 8; 9		4; 13
4. Helping my spouse accepting any condition our child might have	2; 4; 8; 9; 10		13
5. Helping our family discuss problems and reach solutions	8; 9; 10		2; 13
6. Helping our family support each other during difficult times	2; 4; 9; 8		10; 13
7. Deciding who will do household chores, child care, and other family tasks	2; 8; 9; 10; 13		4
8. Deciding on and doing family recreational activities	2; 4; 9; 13	8; 10	
Financial			
1. Paying for expenses such as food, housing, medical care, clothing, or transportation	2; 8; 9; 10; 13		4
2. Getting any special equipment my child needs	9; 13	8	2; 10
3. Paying for therapy, day care or other services my child needs	2; 9		4; 8; 10; 13
4. Counseling or help in getting a job	2; 4; 8; 9; 13		10
5. Paying for babysitting	2; 4; 8; 9; 13		10
6. Paying for toys that my child needs	2; 8; 9; 13		4; 10
Explaining to others			
1. Explaining my child's condition to my parents or my spouse's parents	2; 9; 10; 13	8	4
2. Explaining my child's condition to his or her siblings	2; 9; 13		4; 8; 10
3. Explaining my child's condition to other children	2; 8; 9; 13		4; 10
4. How to handle my child behavior	9; 13	10	2; 4; 8
5. Finding reading material about other families who have a child like mine	9; 13	10	2; 8
Child Care			
1. Locating babysitters who are willing and able to care for my child	2; 4; 8; 9; 10; 13		
2. Locating a day care program or preschool for my child	4; 8; 9		2; 10; 13
3. Getting appropriate care for child in a church during religious services	2; 4; 8; 9; 10; 13		
Community Services			
1. Meeting and talking with other parents who have a child like mine		4; 9; 10	2; 8; 13
2. Locating a doctor who understands me and my child's needs	2; 4; 9; 13		8; 10
3. Locating a dentist who will see my child	2; 9; 13		8; 10

Table 21 – FAMILY NEEDS SURVEY – Bailey & Simeonsson (Revision, 1990b)

Answers from families with children with moderate/severe conditions

	Would you like to discuss this topic with a staff person from our program?		
Topics	**No**	**Not sure**	**Yes**
Information			
1. How children grow and develop	1; 5; 12		3; 7
2. How to play or talk with my child	1; 3; 7; 12		5
3. How to hold my child	1; 3; 5; 7; 12		
4. How to handle my child behavior	1	5	3; 7; 12
5. Information about any condition or disability my child might have	1; 3		5; 7; 12
6. Information about services that are presently available for my child	1; 3		5; 7; 12
7. Information about the services that my child might receive in the future	1		3; 5; 7; 12
Family & Social Support			
1. Talking with someone in my family about concerns	1; 3; 5; 12		
2. Having friends to talk to	1; 3; 7; 12	5	
3. Finding more time for myself	1; 3; 12	5	7
4. Helping my spouse accepting any condition our child might have	1; 3; 5; 7; 12		
5. Helping our family discuss problems and reach solutions	1; 3; 12		5; 7
6. Helping our family support each other during difficult times	1; 3; 12		5; 7
7. Deciding who will do household chores, child care, and other family tasks	3; 7; 12	5	1
8. Deciding on and doing family recreational activities	1; 12	5	3; 7
Financial			
1. Paying for expenses such as food, housing, medical care, clothing, or transportation	1; 3; 5; 7; 12		
2. Getting any special equipment my child needs	1; 3; 5; 7		12
3. Paying for therapy, day care or other services my child needs	1; 3; 5; 7		12
4. Counseling or help in getting a job	1; 3; 5; 7; 12		
5. Paying for babysitting	1; 3; 5; 7; 12		
6. Paying for toys that my child needs	1; 3; 5; 7; 12		
Explaining to others			
1. Explaining my child's condition to my parents or my spouse's parents	1; 3; 5; 7; 12		
2. Explaining my child's condition to his or her siblings	1; 3; 5; 7; 12		
3. Explaining my child's condition to other children	1; 3; 7; 12		5
4. How to handle my child behavior	1; 12	5	3; 7
5. Finding reading material about other families who have a child like mine	3; 7		1; 5; 12
Child Care			
1. Locating babysitters who are willing and able to care for my child	1; 3; 5; 7; 12		
2. Locating a day care program or preschool for my child	1; 7; 12		5
3. Getting appropriate care for child in a church during religious services	1; 5; 7; 12		
Community Services			
1. Meeting and talking with other parents who have a child like mine	1; 7		5; 12
2. Locating a doctor who understands me and my child's needs	1; 12		5; 7
3. Locating a dentist who will see my child	12	5	1; 7

CHAPTER V

Discussion and Conclusion

1. DISCUSSION

In this final chapter I would like to discuss relevant data that emerged from this study, and contextualize the results within the extensive research within the domain of family support networks and family needs.

Concerning the results of the formal support networks of these families it is important to note that all families who participated in the study, like all families in Portugal, had free access to the medical and health services. Medical services, despite the fact that some families complained about negative relational aspects with professionals, were available when needed. Although all families in the study had to travel to secure specialized services for their child, transportation was assured, even for the poorest families. The health policy that makes universal medical services available is an important foundation onto which EI services for target populations is constructed. Medical services often function as a first platform for families to access other needed services such as educational, family support programs, and therapeutic services. The results of this study also demonstrated that formal support services function as a primary referral support for families access additional services. Service availability and general access constitutes a strength of the Portuguese system that can be used when planning coordinated EI programs and policies.

Sontag & Schacht (1993) surveyed 536 families who were receiving EI services in the Southwest of the United States. This study conclude that access to services was strongly related to family economic status, for example among those families surveyed poor children who did not receive medical assistance were the least likely to receive any support services. Other factors were also identified in their study as contributing to an uneven distribution of services including; parental awareness of available services, geographical location of the families, e.g., rural and inner city, and child's age. The United States does not have a National Health System, which helps to create an imbalance among its population in accessing medical services. Instead of universal access, in the United States medical service availability is often determined by one of the several variables including; SES of the family, the general availability of the services, and the location of the family's home. Thus, if a family is geographically isolated, and/or they are poor they may have very little or no access to continuing medical services. When one compares these two countries, the positive aspects of the Portuguese universal access medical services policy can be appreciated. Given the country's goal of universal access, the national medical services can be utilized as a foundation to improve both the quality of EI services and to extend their availability to all eligible families and children in Portugal. It is obvious that this is not a factor "per si" that would change things. A number of other variables have to be accounted for if we want the quality and availability of EI services in Portugal to be altered. Some of these variables will be discussed in this chapter.

In spite of the results of this study there remains a question concerning general access to EI programs for families in Portugal. The results may not generalize because the sample was gathered from existing EI programs, and all but three of the families in the sample did not had children enrolled in an EI program. Thus there is little participation from families who were not already active participants in the EI system. Nevertheless, the study suggests that rural areas in the country remain underserved. For these rural populations EI programs are less available and future planning for increasing EI services should begin with these underserved locations.

Beyond the formal support system, one has to also consider the informal supports that families use. For example this study reveals that geographical proximity between these families and their own parents, e.g. grandparents, were an important source of informal support. Cochran & Brassard (1979) assert that a family's informal support network is heavily influenced by geographical proximity to network members, because it increases the probability of regular and frequent contacts between child and/or parent and family network members. In short, proximity to those making up the informal support network, increases the chances for frequent and regular contacts necessary to strengthen primary and supportive relationships, especially for the child.

Over the last four decades Portugal has experienced internal migration among its citizens, which has dramatically changed its demography. Across time, these demographic shifts have seen migration from villages and cities to the large metropolitan areas of Lisbon and Oporto (Barreto & Preto, 1996). Despite the countrywide phenomenon, within the sample of this study, mobility is not a major factor affecting these families. One possible explanation for the low mobility among these families is the fact that the Braga region has a high demographic density (253 inhabitants /km2).

Like in Portugal, High mobility characterizes families with young children in the United States. According to the National Research Council and Institute of Medicine (2000), "...nearly one-fourth of young children ages 1 to 5 move to a new home during the course of a year, with moves only slightly more common among black and Hispanic than among white young children" (p.331). Given their transience, data from families in the United States find that grandparents are not usually available to families as an artifact of their mobility and geographic distances. Instead of grandparents, family friends and neighbors often replace family members as informal supports for families. For example, data from an urban population in America's mid-west reported that non-family friends and neighbors were the primary support for families with young children diagnosed with SN (Gallagher, Serrano & Espe-Sherwindt, 2002). This latter study represents only a small population of families and we should be careful about generalizing the results.

For the population in Portugal, neighbors appeared as an informal support network for participants from the low SES group. A possible explanation for this to happen is that for the majority of the other families there is a strong involvement of extended family members and friends in their informal networks when compared with these two families (see family network mapping of Cases 4 and 11). A related study by Ecknrode (1983) that addresses support mobilization conclude that,

> People with relatively low SES or occupying a minority status may in fact be triply disadvantage in this respect, because, in addition to having more hardships and fewer coping resources (internal and external), effective coping resources (in this case support mobilization) seem less related to internal coping resources and levels of potential support than for persons of higher SES or belonging to a majority group (p.524).

The evidence in the research literature that relates class differences and support mobilization is validated in the diminished informal support network for these two low SES families (Cases 4 and 11). In comparison to families who are more stable and affluent, the informal support network for these two families is smaller. Dunst & Trivette (1988a) examined various aspects of personal social networks of families, using the Inventory of Social Support. Consistent with the above reported results they found that neighbors were among the five least-used sources of support. In a study by García-Preto (1982) of Puerto Rican families that included a family member diagnosed with SN, found that extended family members had a strong feeling of commitment and service to the family. Families said that the informal network became their primary source of support in their struggle for balance. Overall the informal support networks among the 13 Portuguese families we studied confirm the results of the above study.

Another facet that emerged in the natural support systems for some families in this study was the role played by the local storeowner. This figure was also an important figure reported in studies that examined the natural support systems of Puerto Ricans and Latino communities (Delgado & Humm-Delgado, 1982; Delgado & Rivera, 1997). Storeowners play an important role providing credit to the families when necessary while assuring that basic food needs of the poorer families were being met.

Another important source of support for five families (Cases 3, 5, 7 and 12) was the support they received from their work-place. Beyond the interpersonal support that these families received, Portugal has legislated measures to provide parents to meet family and professionals requirements namely:

- Maternity leaving;
- Breast feeding protection;
- Leave to assist sick children (less than 18 years old) and family. By law this type of assistance is equivalent to worker's sick leave entitlements;
- Flexible time, parents are allowed to regulate their working hours to ensure protection of their children;
- Special leave to assist children with disability and chronically ill. The father or the mother are eligible to periods of six months leave up to a maximum of four years, to provide assistance to biological or adopted child with disability or chronically ill during the first 12 years of the child's life (Law 18/98, of 28 April);
- Time spent by the worker in school activities or meetings during working hours is rightfully justified as absence from work.

Despite the existence of these legislative norms, in reality, many employers do not allow workers to exercise these rights. Coutinho (1996) interviewed 62 parents in the region of Lisbon. Among the parents interviewed 18.3% reported that they needed flexible working hours flexibility in order to accompany their children to necessary appointments. In the present study four families referred that they had support from their work place and this support appeared to be dependent on the individual characteristics of the employers and their sensitivity towards the parent's problems, rather then fulfilling the requisites of the law. Nevertheless, the support parents receive from the work place is an important factor to assure that basic care of their children with disabilities are met. This workplace support among those parents who receive them helps to diminish the stress they feel in meeting their daily routines. Considering the importance of these rights in assisting families it is important that professionals understand the legislation and be knowledgeable when providing parents information. It is a recommendation that information on the rights that families enjoy on this subject, should be brought to the forefront of the training agendas in the implementation of family centered services.

The formal services system plays an important but varying role in supporting families. The following are some ways this system functioned for the families and how they view the services they were provided.

Case 10, a single mother, used the formal support network extensively and she reported a general satisfaction with the formal services she received. One of the explanations for reliance on the formal support network could be that she is an immigrant from Angola and she no longer has the extended family support previously available to her while living in her native country. Unger, Jones, Park & Patricia (2001) examined the involvement of low-income single mothers in urban EI programs. Like this mother, they found that difficulties in family functioning, e.g. lack of informal supports and lower levels of child development knowledge were directly related to caregiver/program involvement. Caregivers who lack responsive and appropriate parenting behaviors were more likely to be involved with their children's programs when they are also experiencing parenting stress. As such it is not surprising that this mother would seek out supports from the formal system to provide needed services for her child. A study done by Affleck, Tennen, Rowe, Rosher & Walker (1989), about the effects of formal support on mother's adaptation to the hospital-to-home transition of high-risk infants, can help us understand the importance of formal services for mothers needing a high level of support. This study concludes that mother's preintervention need for support, as opposed to the severity of infants' medical problems, was a critical variable in moderating the effects of the program. And it was more frequently correlated with mothers' positive coping strategies and variables measured during the intervention program.

In general families report that reciprocity is a key component of satisfaction with help they are provided within their informal support network. It is not enough that they receive needed supports from others, but they also need to feel as if they are important providers of social support to others within their networks. Weiss (1974) identified this characteristic of relationships, which he referred to as the "opportunity for nurturance". Therefore, formal services have to consider this aspect of reciprocity in their exchanges with clients if they want to see satisfaction with services improve. Utilizing principles of family centered care in service delivery to families is a good foundation to address this issue of reciprocity within formal networks. Hall, Roter, & Katz (1988) propose that service utilization is significantly influenced by reciprocal interactional patterns between consumers and providers. For providers they consider two domains of behavior; task behaviors, e.g., information giving, competence, and social emotional behavior, e.g., social conversation, partnership building, interpersonal competence. Given the results of this study I will add another important factor, respect. For consumers I would suggest task behaviors include trust and partnership, while social emotional behaviors include satisfaction with services, feelings of empowerment, and how capable and valued the services were.

Results of this study demonstrated that insensitive relationships by formal support networks were among the categories that families described as a rational for judging formal supports as them as being ineffective. This is a weak aspect that these families identified in our service delivery system and if we want to improve consumer satisfaction, along with the quality of services the system needs to attend to the level of sensitivity to its clients before they will be judged consistently positive. Research suggests that parents are more likely to become involved in family support and early intervention when programs are perceived as helpful, positive places that are responsive to the needs of the family (DeBerry, Ristau & Galland, 1984; Dinnebeli, Hale, & Rule, 1999; Powell, 1989; Simeonsson, Bailey, Huntington & Comfort, 1986; Unger & Wandersman, 1988 cited by Unger, Jones, Park & Patricia, 2001). A study completed by Pharis and Levin (1991) with 30 women who had been identified as at extremely high risk for disorders of parenting. The women were given intensive intervention services as part of The Clinical Infant Development Program of the National Institute of Mental Health. It was found that these mothers valued the abstract relational aspect of the services they received more highly than concrete services themselves. Despite their ready acceptance of meaningful and defined services such as assistance with transportation, housing and money management, the authors conclude "...the concrete services need to be supplemented, mediated and delivered by people who have firm, consistent, and caring emotional relationships with those who need" (p. 319). Another study, conclude that individual professionals' behaviors were often directly linked to families' positive impression of early intervention services (McWilliam, Lang, Vandiviere, Angell, Collins & Underdown, 1995). Like the findings of this study, providing adequate services is only part of the equation. Consumer satisfaction is also influenced by the level of how they are treated by those who provide the services. Consistent with the research mentioned, these data provide a clear picture of the importance of the professionals' behaviors toward families. This is another important factor that needs to be included in the curriculum for preparing personnel for early intervention programs.

Another aspect that emerged from this study was the extreme importance that informal support networks play in helping families cope.

This notion is confirmed when examining the family network maps, as well as the responses they provided to the Inventory of Social Support. The results of the Inventory in the present study were similar to the ones found by Dunst & Trivette (1988a). In their study, among the five most commonly used sources of support for families of preschool children with disabilities were the spouse or partner, the respondent's parents, friends, and respondent's brothers and sisters. Among the 13 families in this study, these were also the most-used sources of support cited. Alternatively, the five least-used sources of support found in Dunst & Trivette (1988a) study were the formal support services that included the private therapist for the child, and child/family doctor. One can conclude from the Dunst & Trivette study that families were more inclined to use their informal support system than their formal support system. It is important to remember certain differences when comparing data from the United States with data from Portugal. In spite of Portugal's universal access to medical services, the informal support system, i.e. extended family and friends, are more available given the size of the country and relative stability of the population. In the United States because the population is more mobile and the size of the country, a family's informal network is likely to be less available. As such, they derive their supports more from the formal services network when the services are available.

Another aspect of notice in the present study is the number of the support functions that the informal support system provides. Among the families who participated in this study the support functions provided by the informal system are bigger and more robust than the functions provided by the formal support. The informal support network provides families instrumental, emotional, material, and companionship supports, while the formal system provides basic information, basic medical and intervention services and some emotional support. Another research study using an instrument developed by Dunst *et al.* (1988) denominated Family Social Support Scale, identified support networks of families with children with SN. Consistent with earlier research was found that informal supports were of greater importance than formal supports (Thompson, L., Lobb, C., Elling, R., Herman, S., Jurkiewicz, T., & Hulleza, C.,1997). Confirming earlier findings and the results of this present study. Dunst, *et al.* (1988) states,

> "there is one major and consistent finding from available social support research regardless of the population being studied. Informal support from personal network members has powerful stress-buffering and health-promoting influences. The effects of informal support are generally greater than that attributable to formal support services. In our own research, the effects of informal support are so great that these influences cannot be ignored as a major form of intervention" (p.32).

Despite the fact that in the present study we did not evaluate the stress-buffering or health promoting influence of the networks, we can, infer from the results that the effects of informal support were greater than those attributable to formal support services. Four reasons justified this conclusion; 1) satisfaction with help as described by families happened more often among informal support network members, 2) frequency of contacts was greater among informal support network members, 3) the number of functions served by informal support members was greater than the number of functions provided by formal support members, 4) and reciprocity in helping behavior happened more often within informal support network. Exceptions have to be made for those families classified as low SES who are experiencing extreme stress, because they tend to have smaller informal networks, as we described above.

The density of the network is another structural variable which has received some attention in the literature. In the current study families with children with moderate severe problems had dense formal support networks. Hirsh (1979)cited by Stokes (1983) found the enigmatic result that denser networks furnished greater quantities of support but individuals in the denser networks were less satisfied with support they received. Belle (1981), cited by Crnic & Stormshak (1997), similarly suggested that social support often has costs as well as benefits, because it requires that individuals engage in mutual relationships that place demands on them whether those demands are timely or required. This applies to support networks generally speaking but if we consider formal support networks it may paradoxically place more demands on families as formal services often required families to accommodate to rigid schedules that are time consuming and ultimately increase their stress. For formal supports to be more effective this aspect of stress should be taken into consideration whenever planning services for children and families.

Finally, concerning the needs evaluation for the 13 families in the current study using the Family Needs Survey (Bailey & Simeonsson, 1990b) the most prevalent needs was their desire for more information. This result is similar to several other studies completed in the United States using the same instrument (Bailey, Blasco & Simeonsson, 1992) as well as in Portugal (Pereira, 1998; Morgado & Beja, 2000).

The results of the interviews concerning family priority needs indicated: a) financial, health and minimum housing conditions are the most prevalent expressed needs among low SES families; b) information on child development, and transition are among the most prevalent expressed needs of middle/high SES families, but are not mentioned by low SES families; c) families with children with moderate/severe disabilities more often expressed desire for financial assistance, general information, help with the household tasks, improved housing space and therapy needs. However, other needs such as information on child development, transition and adulthood were not mentioned by these families. These results clearly show that families who struggle with their most basic needs will not invest time and energy to carry out professionally prescribed, child-level educational and therapeutic interventions. A study by Dunst, Leet & Trivette (1988) similarly conclude that to the extent to which non-child related needs are unmet, the likelihood of parents making a commitment to child-level interventions is diminished. This finding has implications on the role EI professionals have when they shift their professional role from child educators or therapists to family interventionists. The results of a study completed by Bailey, Blasco & Simeonsson (1992), also found that among low income mothers meeting basic financial needs was essential before the other needs could be met. It also demonstrated that the disability type of the children had a statistically significant effect on needs expressed by mothers. Nevertheless the above cited authors considered the clinical relevance of this finding limited, because they conceive that the expression of family needs cannot be predicted on the basis of broad child or family categories but, rather there are unique factors to individual families that must be considered. Another study completed by Sandow, Clark, Cox & Stewart (1981), described how the severity of the child's disability can influence parent's perception of family need. Portuguese studies (Pereira, 1998; Morgado & Beja, 2000) demonstrated similar relationships between a family's financial needs and their low SES.

Overall the results of this study demonstrate the importance members of informal support networks play in helping the families caring on their daily routine and developmental tasks. It is also apparent from these results that there are a number of available formal resources (e.g., family health centers, hospitals, IPSSs (Private Institutions of Social Solidarity), social services, church organizations, and child care programs) within the communities that are important to families. These resources can be incorporated to serve as broad-based resources and supports required to meet the needs of the families in future EI programs.

2. CONCLUSION AND RECOMMENDATIONS

In this study I have addressed the social support networks of families with children with or at-risk for disabilities of the district of Braga. The results have raised several issues that may direct future implementation and planning of EI services for these families.

Based on the conceptual model of EI proposed by Dunst (2000), as well as the results of this study I would like to articulate some recommendations for planning EI services in Portugal.

I will start by describing Dunst's (2000) conceptual model, or as he described the *third generation* model of EI, in order to clarify some of the premises underlying the recommendations I will present. This model according to the author, emerges for two basic reasons. First, to eliminate doubts about the intervention targets of family service intervention and, second, to include further advances made in research about other aspects of environmental influences and interventions (Dunst, 2000). The parent-child and child features should be explicitly incorporate in any useful model to avoid confusion about the targets of family service intervention in a family systems approach, i.e., the family as a whole as well as the individual members, including the child as the focus of entering into EI) (Dunst, 2000). The other recent feature of the model includes the research based foundation for understanding the contextual and sociocultural foundations of child's learning and development. Using this context we can better understand parenting and child rearing roles and styles that are most conducive to promoting child competence (Bornstein, 1991;

Bronfenbrenner, 1999; Göncü, 1999, Lancy, 1996; Rogoff, Mistry, Göncü, & Mosier, 1993, cited by Dunst , 2000). As described by Dunst (2000), the conceptualization of EI in the third generation model includes children's learning opportunities (Dunst & Bruder , 1999), parenting supports (Cowan, Powell & Cowan, 1998), and family/community supports (Trivette, Dunst & Deal, 1997) provided in a family centered manner (Trivette & Dunst, 1998). These components of the model are respectively:

> Development-enhancing child learning opportunities are ones that are interesting, engaging, and competency producing and result in a child's sense of mastery about his or her capacities. Parenting supports include the information, advice, and guidance that both strengthen existing parenting knowledge and skills and promote acquisition of new competencies necessary to carry out childrearing responsibilities and provide development-enhancing learning opportunities. Family and community supports include any number and type of intrafamily, informal, community, and formal resources needed by parents to have the time and energy to engage in parenting and childrearing activities. Family centered practices place families in central and pivotal roles in decisions and actions involving child, parent and family priorities and preferences (Dunst, 2000, p.101).

Another aspect crucial to understand recent perspectives of EI is the concept of resource-based versus service-based approach to EI. Contemporary EI practices are to a large degree based on specific services to meet child and family needs (Trivette, Dunst & Deal, 1997). This way of conceiving EI is both limited and limiting because it fails to value other sources of support apart from formal professional support, and at the same time funds to provide all the services that children and families need might never be enough if we keep these professional based solutions to meet the needs (Trivette *et al.*, 1997).

Conversely, what characterizes resource based EI services is the importance and emphasis placed on community support. According to Trivette *et al.* (1997), the concept of community here has to be understood in a broader context than the family's neighborhood. Given this larger view resource-based approach scrutinizes a variety of community people and organizations as sources for support with important resources for meeting child and family needs. Consequently, a resource-based approach to intervention does not rely on a single type of professional help or assistance but rather utilizes and mobilizes multiple sources of informal and formal community resources. The term community resources, according to Trivette *et al.* (1997), means personal social networks, organizations, associations groups, community programs and professionals, specialized professional services. These combined supports can be used by families of young children to provide both the children and the parents the opportunities and experiences that have a positive impact on the child, parent, and family alike.

Having explained the main premises underlying the recommendations, I will mentioning some major points, based on the results of the study, that should be taking into account when planning EI services in this region.

The context for resource based intervention will depend on, and differ according to the community make-up, e.g. groups, organizations, programs. These communities provide learning opportunities and experiences for children and their families who participate in EI (Trivette *et al.*, 1997). Following this line of thought, this study, despite the fact that it took place before the EI Portuguese legislation was enacted, provides important factors necessary to implement a resource-based approach to EI in the District of Braga. These included:

- Major community people, organizations, programs and specific services were identified as important supports to these 13 families, e.g., family health centers, hospitals, IPSSs, social services, church organizations, child care programs, informal support members;
- Informal support networks, e.g. support provided by the extended family network, proved to be critical in reducing the effects of stress and empower families;
- EI programs need to be more actively and explicitly engaged and value informal supports when helping children and families. This may change the role of providers and service coordinators, in that they will increase their assistance to help families identify and engage latent supports in their social networks;
- Family identified priority needs are an important step for providing quality services and increased consumer satisfaction with EI services for children and families;
- More sensitivity is needed from professionals when dealing with children and families. Concrete services should be furnished by providers who show genuine care and concern to families. Theory and research on human development gives robust support to the resulting

generalization that helping people to develop healthy relationships counts for more than things do;

- Service coordination is needed when planning EI programs, to help families deal with the myriad of different services and providers;
- The shift from a service-based approach to a resource based approach implies a shift in how professionals view their roles and responsibilities, i.e., professionals should view their ability as means of creating opportunities and experiences that promote child and family development;
- Personnel preparation on family centered principles and practices is also a major concern for Portuguese EI professionals as EI legislation and family centered EI concepts are relatively recent concepts in Portugal.

Concluding we can infer based on this study, that Portugal has the resources needed to meet child and family needs using a resource-based approach to EI. Nevertheless, the provision of those resources has to be carefully planned to match family priority needs and provider resources to furnish services to children and families in a family centered manner. This approach will require many substantive changes in how our EI programs are delivered in Portugal, e.g. from a professional and services centered perspective. It is not only *what* services to provide families but *how* we provide those services that makes the difference if we want to help families in ways that both empowers and enables them (Karuza & Rabinowitz, 1986, cited in Dunst, 1997). The information given by the vignettes of the family interviews in this study are illustrative of this basic EI premise.

Another aspect that is important to consider when providing services to families is the belief that professionals have about families, especially those pertaining to parenting capabilities and competencies. To illustrate, parenting capabilities I would like to leave the testimony of a single mother who participated in this study, the mother in Case 10, who has a child with a rare disorder designated by Imperfect Congenital Osteogenisis –Type 2B. The child's problem makes bone fractures a permanent risk for him. According to the mother he was born with 36 bone fractures, which occurred during the intrauterine developmental period. Despite this problem his mother has never broken a single bone to her child. But, she recounted that other people including professionals who had handled him for different reasons were responsible for additional bone damaged. About this situation the mother said:

> M: ... related to S. that is what the doctors say to me: "probably if the mother was another person, she would not had been able to care for this child", right? Because S had had many fractures and even though I had to deal with him 24 hours, as it happened in the beginning, I never broke him anything...I don't know it is... mother (she laughs).
>
> I: See, (laughing with the mother) it is the "magic touch", really it is the "magic touch". Then when it is our own child we think with a special care, the mother's care.

Finally, I would like to conclude this Dissertation with a Nigerian proverb that conveys popular and scientific information but is most often transmitted in complex and obscure ways. However, it can be distilled into simple eloquence,

"It takes a whole village to raise a child"

Summary

This chapter presents the discussion of the findings from this study, contrasting with the results form other studies and then provides some conclusions and recommendations for future practices in the field of EI.

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APPENDIX A

Concept operationalization

1. Families Social Economic Status

The concept of social class cannot be confounded with social professional categories. Nevertheless these categories had been used as an indicator of social class, in sociological research practices (Diogo, 1996). The typology used for this research project is the one developed by Diogo (1996) described on table 1. The author adapted this typology from other typologies developed by Almeida, Costa & Machado (1988), and Bourdieu (1979, cited in Accardo & Corcuff, 1989).

Table 1
Correspondence between class, subclass and social-professional categories

Class	**Subclass**	**Social-professional categories**
Bourgeoisie	Entrepreneurial and Proprietary Bourgeoisie (EPB)	Entrepreneur (with 10 or more employees)
	Professional Bourgeoisie (PB)	Liberal professions (independents and with college degree) Directors (employees)
Small Bourgeoisie	Small Framing Bourgeoisie (SFB)	Intellectual and scientific professions (employees) Technical Intermediate professions (employees)
	Proprietary Small Bourgeoisie (PSB)	Small entrepreneurs (employers with less then 10 employees, in any activity and independents)
	Small Bourgeoisie of Execution (SBE)	Administrative employees
Proletariat	Agricultural Proletariat (AP)	Independent farmers Primary sector employees
	Industrial Proletariat (IP)	Industrial worker (employees)
	Services Proletariat (SP)	Non qualified employees

Source: Translated and adapted from Diogo, A. (1996). Representações parentais da escolarização, relação com a escola primária, classe social e dinâmica familiar. Dissertação de Mestrado, Lisboa, Faculdade de Ciências Sociais e Humanas, Universidade Nova.

To obtain the individual class status we used the typology described above and to determine the family class the researcher crossed each individual class and determine the class adopting the criteria described by Almeida *et al.* (1988, p.16). For the cases that had different class status we adopted the highest position as being the family position, independently of being masculine or feminine. When they were equivalent we retain the man's position to determine family class. Table 2 shows the results of this process for the 13 cases of this research project.

Table 2

	Father subclass	Mother Subclass	Family Subclass	Family Class
Case 1	SFB	SFB	SFB	Small bourgeoisie
Case 2	SFB	*	SFB	Small bourgeoisie
Case 3	SBE	SBE	SBE	Small bourgeoisie
Case 4	SP	*	SP	Proletariat
Case 5	IP	Unemployed	IP	Proletariat
Case 6	SP	*		Proletariat
Case 7	SBE	SFB	SFB	Small bourgeoisie
Case 8	PB	*	PB	Bourgeoisie
Case 9	SFB	SFB	SFB	Small bourgeoisie
Case 10		SP (single mother)	SP	Proletariat
Case 11	PSB	*	PSB	Small bourgeoisie
Case 12	PSB	PSB	PSB	Small bourgeoisie
Case 13	SBE	SFB	SFB	Small bourgeoisie

*Mother work at home

To facilitate language use I replaced the term bourgeoisie for high SES, small bourgeoisie for medium SES and proletariat for low SES as these terms are commonly used in the American English.

2. Level of severity

The level of severity was determined considering general descriptive aspects such as:

Mild – Children who had mild developmental delays, without serious medical implications and motor involvement

Medium/Severe – Children who present serious delays usually associated with motor involvement, requiring medical care and are non-ambulatory.

APPENDIX B

CONSENTIMENTO

O estudo levado a cabo pela docente /investigadora da Universidade do Minho, Ana Maria da Silva Pereira Henriques Serrano, tem como objectivo identificar os recursos formais e informais das famílias com crianças de risco (0 aos 3 anos) do Distrito de Braga. A recolha de dados será feita através de entrevistas à família, em dois ou três encontros que serão gravadas em audio. A análise e apresentação dos resultados do estudo será feita por forma a garantir a confidencialidade e anonimato dos participantes. No final do estudo os participantes poderão consultar o documento final caso estejam interessados.

Atendendo ás condições acima descritas aceito participar no referido estudo.

CONSENTMENT

The study done by the teacher/ researcher from the University of Minho, Ana Maria da Silva Pereira Henriques Serrano, has the aim of identifying formal and informal resources of families with children at-risk (0 to 3 years old) living in the District of Braga. Data collection will be done through family interviews, during two or three encounters, and they will be taped in audio. Data analysis and the display of the study results will be done in ways that will protect confidentiality and anonymous of the participants. At the end of the study participants are allowed to consult the final document if they whish to do so.

Considering the conditions described above I accept to participate in the referenced study.

APPENDIX C

RESUMO DO CONTACTO

Nome do participante: [redacted] (Mãe do [redacted]) Local do contacto [redacted] Data 18/01/99

1 - Quais os principais aspectos ou temas que o surpreenderam durante o contacto ?

O facto de ser uma mãe bastante jovem, muito simpática, afável no trato e demonstrando um grande desembaraço no lidar das situações diárias. A interacção positiva e afectiva que estabelece com o [redacted]. O nível de desenvolvimento de linguagem que o [redacted] apresenta para a idade que tem.

2- Resumo da informação obtida (ou não obtida) durante o contacto

Mãe solteira, com um filho que tem um problema ósseo congénito. Problema que torna muito complicado lidar com o [redacted] uma vez que este corre o risco de fazer fracturas muito facilmente. Teve o apoio dos médicos, da Segurança Social e de [redacted].

3- Que outro aspecto o surpreendeu como saliente, importante ou criativo durante o contacto ?

A coragem desta mãe solteira com uma criança que tem uma doença congénita óssea complicada e que apesar de tudo quis assumir a gravidez contra algumas vezes namorado/da tia com quem vivia e difícil se separou por esta questão.

Viveu com enormes dificuldades, quase sozinha mas enfrentando todos os problemas para poder dar ao filho uma vida equilibrada. Tem tido muito apoio da [redacted] onde agora desempenha funções de monitora. Trabalha desde os 14 anos e teve o filho aos 19.

4 - Que outras questões (ou questões que ficaram por responder) terá que considerar no seu próximo contacto ? A sua família vive em Angola (pai e irmãos uma vez que a mãe já faleceu).

APPENDIX D

FAMILY NEEDS SURVEY – Bailey & Simeonsson (Revision, 1990b)

	Would you like to discuss this topic with a staff person from our program?		
Topics	**No**	**Not sure**	**Yes**
Information 1. How children grow and develop			
2. How to play or talk with my child			
3. How to hold my child			
4. How to handle my child behavior			
5. Information about any condition or disability my child might have			
6. Information about services that are presently available for my child			
7. Information about the services that my child might receive in the future			
Family & Social Support 1. Talking with someone in my family about concerns			
2. Having friends to talk to			
3. Finding more time for myself			
4. Helping my spouse accepting any condition our child might have			
5. Helping our family discuss problems and reach solutions			
6. Helping our family support each other during difficult times			
7. Deciding who will do household chores, child care, and other family tasks			
8. Deciding on and doing family recreational activities			
Financial 1. Paying for expenses such as food, housing, medical care, clothing, or transportation			
2. Getting any special equipment my child needs			
3. Paying for therapy, day care or other services my child needs			
4. Counseling or help in getting a job			
5. Paying for babysitting			
6. Paying for toys that my child needs			
Explaining to others 1. Explaining my child's condition to my parents or my spouse's parents			
2. Explaining my child's condition to his or her siblings			
3. Explaining my child's condition to other children			
4. How to handle my child behavior			
5. Finding reading material about other families who have a child like mine			
Child Care 1. Locating babysitters who are willing and able to care for my child			
2. Locating a day care program or preschool for my child			
3. Getting appropriate care for child in a church during religious services			
Community Services 1. Meeting and talking with other parents who have a child like mine			
2. Locating a doctor who understands me and my child's needs			
3. Locating a dentist who will see my child			

APPENDIX E

Inventory of social

Which persons or groups listed to the right provide you help or assistance with each of the following:	Child / Family Doctors	Early Childhood Intervention Program	Health Center	Social Service Dept.
1. Who do you go for help or to talk with?				
2. Who helps take care your children?				
3. Who do you talk to whe you have questions abo raising your child?				
4. Who loans you mone when you need it?				
5. Who encourages or kee you going when things g hard?				
1. Who accepts your chil regardless of how (s)h behaves or acts?				
2. Who helps you with house hold chores?				
3. Who do you do things to have fun, just relax, or joke around?				
4. Who takes the time to d things with your child?				
5. Who takes you and your child places when you need transportation?				
11.Who hassels with agencies and indiviudals when you feel you can't get what you need or want?				
12. Who helps you learn about services for your child and family?				

INTERVIEW GUIDE

Interview N°

Interview date::

Father:____**Age:**
Mother:____Age:
Child:______________________________________**Birth Date**:

Family characteristcs
Number of persons in the family:

Child Characteristics

Father's occupation:____________Level of education:__________
Mother's occupation:____________Level of education:__________

Since when did you find out of your child's problem
Were you or are you receiving a specific type of support for her problem ?
If yes, since when did you receive this support ? Or in which period did you receive it ?

1- When you identified your child's problem who or whom were the persons that you considered that gave you more support or were more effective in giving support and why ?
And who or whom you consider not to be supportive and why ?

2- Which needs do you and your family consider to be a priority? What worries you the most within your family and what do you need to solve those problems?

3- What are the resources available to meet those needs ? The supports that you have match those concerns and needs ? (Are they congruent with your needs)

4 – List all people that you contact regularly in your community or neighborhood (regardless of your feelings toward the people).

From these people list the ones you feel close too and can trust (regardless of how often you contact the person).

List all the social groups and institutions that you interact with on a regular basis

5- Beside each element put the support in terms of :

A-Frequency of contacts
B- Geographical Proximity
C-Reciprocity
(see at the end of the page the rating scale that I gave families to objectively determine these dimensions)

6 – Evaluate the efficacy of the support received in a scale from:

0 –Causes stress with help
1 - Helpful
2 – Very helpful

7 – Describe the types of support received from the different people or services according to the following list .

8 – Whom was or were the persons who helped you in a more efficient way and why?

9-Whom was or were the persons who helped you in a less efficient way and why?

Type of support

1. Emotional (someone that you trust to share your problems with)

2. Companionship (someone with whom you can have fun and spend time together)

3. Instrumental (Take care of your children, pick up you child from school, etc.)

4. Information (child development, child's condition, nutrition, etc.)

1. Material (borrowing toys, other material needs or money)

RATING SCALE FOR THE FREQUENCY OF CONTACTS

A. Everyday basis

B . More than once a week

C . Once a week

D . Twice a month

E . Once a month

F . Every three months

G . Every six months

H . Once a year

APPENDIX G

EXAMPLES OF CODES TAKEN FROM THE FAMILY INTERVIEWS

A number corresponding to the category to which the code belongs in the system categories and the code label precedes each example. The case number of the quotation, and the number of the unit of analysis to which corresponds the citation are presented in round parenthesis after each example.

Code 1 and its subcategories concern the demographic data of the case studies. Code 2 and its subcategories concern the different types of formal support that each family received or was receiving at the time of the interview.

3	**Effective support**	
3.1	Formal	
3.1.1	Rational	
3.1.1.1	Emotional Support	And from that point in time I had a big support, since I took that medication to kill myself I had a big support from the obstetrician that was following me, ...so she gave me all the support, she was concerned if I was feeling well or not well. The psychologist at the hospital was great with me too. ...she [the obstetrician] even asked me if I wanted to live with her, and I said: "No, no it is not necessary, I can handle it" . And so I felt a big support from that side. (Case 10, 124)
3.1.1.2	Information	We start finding out which doctors would be indicated to care for these babies that we had right? A baby with Down Syndrome. So we start getting information and going to Dr. M, to Dr.C. to an otorhinolaryngologist , to Dr. D. a dentist for the tooth device. Who else?...Ah! the developmental follow-up medical appointment at the Hospital of S.João. We always go, always go.(Case 2, 43)
3.1.1.3	Availability	She uses a phrase that I found very funny at that time and nobody had told me beforl: "Do not bother for bothering me". (Case 3, 315)
3.1.1.4	Referral	I asked help to Doctor A and she helped me in everything. She talked with the social worker of the hospital, and then she in turn contacted the social worker here.(Case 6, 363-367)

3.1.1.5	Positive Interaction	[Referring to the social worker at the social service agency]. She talked really nice with me, very well, she treated me well, she talked in a gentle way, and I...(Case 4, 226)
3.1.1.6	Financial Support	Now for example I had always and for a long time, for many years the support of the people from Saint Vincent DePaul Conference, in this case ...they paid me water, electricity, rent and often times they would give me food supplies. (Case 6, 345-351)
3.1.1.7	Schedule Flexibility	... we let him come here (the EI program)because it happens at a later time and at that time he had already eaten, if it wasn't at this time he could not come...that is the reason why he is not going to any child care. He cannot go because someone could give him a cookie or something and that is bad for him.(Case 6, 403-407)
3.1.1.8	Public/Private Collaboration	I: And the pediatrician is a private one? M: Yes, but he also works at the hospital. But at the hospital he only works at the emergencies. I: So were does he has his private practice? M: In Guimarães, here. And the fact that he works in the hospital there is always an access, it is convenient to have a good doctor that works there just in case some problem arrives, we can be safeguarded.(Case 7, 253-256)
3.2	**Informal Support**	
3.2.1	Rationale	
3.2.1.1	Routine functioning	M: The persons that I can really count on...and she I can count, is my mother, she is also an elementary teacher , she is retired, in fact she retired, because I started school when she (her child)was born. My mother is always ready only if she is sick she can't right? Because she is at home. (Case 13,155-157)
3.2.1.2	Emotional support	The best support was my husband,...and next my children... my boy was 13 years old, and he clearly perceived the situation and he is one of the persons who is the most supportive and gratifies me the most, at the moment is him, but each one on its own way...(Case 2, 84)

3.2.1.3	Material support	There is a neighbor, who lives behind me and she often times, sees me sad and of course I am sad because my child cries for food, that very often he doesn't have, and she comes over and brings sugar, rice, pasta, milk...she always give me things. (Case 4, 153)
3.2.1.4	Information	I did not ask anything yet. But he is only four years old and I still have the next year to talk about it and so...but I know that my sister –in-law .talked with Dr.A. and she said that the boy was going to be integrated in a regular school, the public school and that he will have the support of a special education But the only thing that I could find out was :"Hey girl see if you can find out something. When it is going to happen? Does he have someone to support him?", and she said:"Don't worry yet.".(Case 8, 218)
3.2.1.5	Referral	M: ..we went to Coimbra , we went to Oporto right, we went almost everywhere. My husband's boss knows a lot of people and he called us when he found out, not through us, what we knew was done through our effort right? I: Right! M: He called us and he said that he was going to help us, and so he also schedule a doctor appointment in Barcelona. (Case 12, 45)

4	**Ineffective Support**	
4.1	**Formal Support**	
4.1.1	Rationale	
4.1.1.1	Non sensible relationship	Some doctors particularly the doctor at the Santo António Hospital [in OPorto], I felt really sad when we went there, because we parents, we parents became desperate and so we do not look for one doctor, even when they tell us that there is no solution to our child's problem, and yet if it is your first child, being the first time, I couldn't believe when he [the doctor] said...this is a lie it can't happen, my child probably has something but it shouldn't be so serious. He is probably wrong...and so we went to several doctors and they all really said the same thing. My husband' boss schedule us to go to Barcelona [to a famous eye clinic], and we went to Barcelona. When I arrived I was honest with the doctor and I told him: "Doctor, you probably have all the reason, you were honest with us, but I did not believe in what you told us". He started smiling, and he looked like... he didn't laugh, no, but...he smiled like he was deriving pleasure from this. And the doctor that was with him a colleague said: You need to go abroad to know. Here we have ...we have... what did he say... specialists, we have specialists and specialties as good as outside. And I said: "You are right but we parents became so concerned to a point where we don't believe, it is a wrong way of reacting from our side, but we don't believe and so we try to find a solution". And the doctor said: "You did well, you did well". And then I said: "You had schedule an exam for my child that I signed because it had to be done under general anesthesia, are you still doing it to my child?" "Yes I will do it but not for now only when I can." And so I felt with this that he was offended. (Case 12, 147-153)

4.1.1.2	Giving opinions without knowing the family	No, because she got here without knowing the family, and without knowing the first thing she said was that the baby should be with a nanny. "The baby should be with a nanny. These babies need to be with other kids, they should be with a nanny". ... I don't want her to be away from school, no way I am going to prevent her from playing with other children, inversely I want this for my child, but I think that each thing has its own time. If my other children, that are normal children, went to preschool at the age of 3 years, why shouldn't this one go too?(Case 2, 96)
4.1.1.3	Ignore the request for eligibility in a program	F: Saying that the process was sent to Hospital S.João because the institution had nothing to do with it. M: Did not have capacity. F: And mean while we were in this impasse I: Yes F: He basically didn't have any, any M: Any, support. (Case 3, 142-147)
4.1.1.4	Bad Management	F: They don't do it, they don't do it because we took P. to Social Security and there were children who simply drop out of the center but on the other hand the center was still receiving money for their frequency, that was on a bank account and was approximately 60.000 contos, and that money should be...... M:60.000 contos F: That should be used to treat those children, because it is for that reason that the state gives the money. (Case 3, 235-237)
4.1.1.5	Non existence of specialized educational support	M: And so P. is here in the preschool and nobody ever said anything to us, nobody ever asked anything and I know that he does not have the support that in fact, he has the right to have. (Case 3, 394)

4.1.1.6	Discrimination	M: They gave us support the social worker, and now nothing, the Red Cross too nothing. APIP1: No they don't have APIP2: There is a discrimination here APIP1: We are taking care of that. APIP2: Last week we went to talk about that and that will change. This if we realize that they are very discriminated against when they get there to get the food that are entitled of right? And they get there and or they don't have, or it ended the week before or they are closed or because...(Case 4, 193-197)
4.1.1.7	Medical Negligence	Inserted text unit : I: On our way home were the interview took place, the mother told the problem with F. happened due to fetal suffering and anoxia related to medical negligence during labor in the Hospital of S. Marcos , in Braga. Labor had to be instigated but only after many hours and the baby was already suffering. They never told her anything about F.'s problem and she only signed a paper to authorize the baby transference to Hospital s. João in Oporto.(Case 5, 282)
4.1.1.8	Not Adequate Information	He has no problem, his sight is normal, lady you would like that your baby was born walking and talking .His sight is ok and everything is normal.(Case 6, 20)
4.1.1.9	Dishonesty	M: Well, I think that the doctor, the obstetrician should had talked with me, to explain me everything, and I think that he was a person that, from the beginning... I: You felt that he was someone that wasn't honest with you? M: No, he wasn't, he wasn't. And it's funny that some time ago I heard an interview with a mother that had a child with a serious problem and she felt exactly the same about this same doctor as I did.(Case 7, 383-387)
4.1.1.10	Personal Incompatibility	M: No , no, it wasn't that, I went straight to the preschool to deliver the doctor's declaration so that he could be enrolled in the program. I: Oh! Ok!Ok! OK! Now I understand. M: And she said that I was doing things on her back. And she talked like a...she didn't look like an early childhood educator she looked like a quarrelsome rude woman.(Case 11, 160-163)

4.1.1.11	Program drop out	M: The sessions that I went , and I did three or four times...were just for adaptation. I: And that was in the Cerebral Palasy M: Yes, in Guimarães, yes but it didn't work out , and then I talked with the physiotherapist and I told her that the child cried for an hour, she only cried, and cried, and cried, and I was very nervous. I: Yes M:I gave up, I gave up, I went there only four times, but she couldn't do anything. (Caso 13, 27-31)
4.2	**Informal**	
4.2.1	Rationale	
4.2.1.1	Moving away	M.: One or another couple of friends that we noticed a seclusion right? I don't know if that happened because maybe they didn't know how to cope with the situation. And I think that is more often the reason that made them to...they don't know what to do right? And so they seclude themselves gradually. But as I told you we are a very united family the five of us and that makes it difficult for outsiders to come in do you understand what I mean? The ones that come inside are the real friends, and so there wasn't one person or other, no, no I did not have, on the contrary. Even from my husband family, my brothers, mainly men, but they were a strong support..(Case 2, 90)
4.2.1.2	Advising the mother to abort	M: She had a food take away and she was well known here, and while I was there and as I did everything to her she was good to me but when this happened (get pregnant) I had to leave because she wanted be to make an abortion, and I did not want to do an abortion, so at that time I hadto decide and leave her. (Case 10, 148)
4.3	**No negative experiences to report**	M: Sincerely, I can't think of anyone, any person or specific group that had rejected us or start by rejecting us or that wouldn't try to comfort us. I don't have any particular complains (case 1, 60)

5.	**Family Priority Needs**	
5.1	Financial	What worries me the most is, very often, when I need money for my children, to give them food and I don't have. Is more that. Very often, when the minimum income arrives, and when I check, everything goes to the cooperative (the grocery store), because they sell me everything on credit.(Case 6, 458)
5.2	Information	I: Of specific information about... M: Yes there is a big difficulty. For instance, there is a father or a mother that has a child with a problem and there is no one to explain the type of problem and what are the ways to this or that. If the mother or father aren't really concerned... (Case, 7, 533-534)
5.3	Childcare	M: At the moment it's above all a matter of organization because one needs to do this or that and while a normal child can stay with a neighbor or with a friend, J. has demands with other type of people who know how to care for him (Case 1, 69)
5.4	Health Needs	M: Hum! Hum! Related to him right? Ok! Is to be always alert to everything that can come up. To be followed up by doctor's appointments, every month I have the care of taking him to the pediatrician and see if everything is going well with him so deep inside what concerns me the most is his development. (Case 9, 254)

5.5	Household	F: Now, that problem is more on her side...I don't know...the thing that she most needs now is someone to help, we need a person for example to... M: ...to help with household tasks, I am feeling that, at least with my oldest son, that he needs more support from us. My youngest son (the child with SN) ...shall we say is the center of the attention, because he needs it. And one thing that I feel I need is turning away from the housework and spend more time with them (her children). Because we work on this time schedule 9 to 12.30 am and 2 to 5.30 pm. Get the children, buy this here, buy this there, and when I get home I go to the kitchen, get dinner ready, doing the dishes, taking care of the clothes, put one in bed, put the other in bed, and shall we say... that availability... is in the air. I think that our oldest child, is, is starting to miss that. (Case 3, 426-454)
5.6	Minimum Habitat Conditions	M: And now I also need a heater. I: Right! M: Because of my child I: Of course. M: Because of the cold, the house is too cold and that is something they said that they are going to try to get me (Case 6, 429-433)
5.7	Housing Space	M: My needs are a house. I: Hum, hum. M: Well, we are living with my mother-in-law as I told you. I: Hum, hum. M: We are living here but my brother –in-law is sleeping outside. (Case 5, 309-313)
5.8	Child Development	Related to him? It is always checking... be attentive to everything that could come up and than... I want medical appointments. Every month I am careful about taking him to a pediatrician, to make sure that everything is fine with him, so what really concerns me deep inside is his (her son with hydrocephalus) development. Our concern deep inside is his development right? (Case 9, 254-264)

5.9	Transition	It worries me his future, right now he is in the private preschool, but then? After completing the pre-school he goes to the elementary school, and now I don't know where he is should go. That worries me a lot. I don't know who is going to attend him, I don't know what type of school, because this school where he is now is private and has no support from special education, I don't know and that really worries me.(Case 8, 176-178)
5.10	Social/Emotional support	I think that now I don't have as many needs, I don't know if that is because I went trough so much problems. Since I start working I have been putting my things little by little, I got used to live with my child alone right? I got used to be everything in that house, and that is the way it is. So sometimes I feel like a little lonely. Yes, with my child I feel a little lonely... sometimes is more difficult to support him or facilitate something right?(Case 10, 179-181)
5.11	Adulthood	M: My concern is with my children I want them to study, that they become professionals otherwise they wion't make it. (Case 11, 183)
5.12	Therapy	M: Well what I really need, if I could instead of stop working, because we need to work, is to have the speech therapy nearer and the global stimulation that he does nearer.(Case 12, 185)
5.13	Specialized Educator	Needs? What I really need and because my child's vision problem, I would like to have someone specialized to teach him to know the things using more of his hands. Even though the others and we teach, I teach what I can, but I would like to have someone more specialized, a support that would help.(Case 12, 186-188)