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DOSSIÊ

“I felt alone”: The Importance of Social Support for Early Intervention

“Eu senti-me só”: a importância do apoio social para a intervenção precoce

“Me sentí solo”: la importancia del apoyo social para la atención temprana

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Abstract: When adopting an ecological perspective of Early Intervention (EI), social support became a key concept for understanding families and ways of coping with a child who is at-risk or have been diagnosed with Special Educational Needs. 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 social support and well-being more so than to family Social Economic Status. Social supports play an essential role when planning intervention with young children and their families. This article will provide an evidence based review of the concept and its importance in Early Intervention and it will present a case study to illustrate and operationalize the ideas discussed in the article.

Key Words: Early Intervention, Social support, Formal and Informal support, Ecomap

Resumo: Adotando uma perspectiva ecológica de Intervenção Precoce (IP), o apoio social tornou-se um conceito-chave para entender as famílias e formas de lidar com uma criança em risco ou com Necessidades Educacionais Especiais. Os resultados da investigação demonstram que o apoio social, o bem-estar pessoal, os estilos de interação dos pais e o desenvolvimento infantil estão conceitualmente e empiricamente relacionados, e que as mudanças no desenvolvimento infantil se atribuem mais ao apoio social e ao bem-estar, da família do que ao seu estatuto sócio económico. Os apoios sociais desempenham um papel essencial no planeamento da intervenção com crianças pequenas e suas famílias. Este artigo fornecerá uma revisão baseada em evidências do conceito e sua importância na IP e apresentará um estudo de caso para ilustrar e operacionalizar as ideias discutidas no artigo.

Palavras-Chave: Intervenção Precoce, Apoio Social, Apoio Formal e Informal, Ecomapa

Resumen: Al adoptar una perspectiva ecológica de Atención Temprana (AT), el apoyo social se ha convertido en un concepto clave para comprender a las familias y las formas de tratar con un niño en riesgo o con necesidades educativas especiales. Los resultados de la investigación muestran que el apoyo social, el bienestar personal, los estilos parentales y el desarrollo infantil están relacionados conceptual y empíricamente, y que los cambios en el desarrollo infantil son más atribuibles al apoyo social y al bienestar, de la familia que a su estatus socioeconómico. El apoyo social juega un papel esencial en la planificación de la intervención con niños pequeños y sus familias. Este artículo proporcionará una revisión basada en evidencia del concepto y su importancia en AT y presentará un estudio de caso para ilustrar y poner en práctica las ideas discutidas en el artículo.

Palabra clave: Intervención temprana, Apoyo social, Apoyo formal e informal, Ecomapa



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Introduction

"When my son first got diagnosed, we knew we weren't the first, but we felt alone," shared one Ohio mother during a focus group of parents in 2017. "I felt alone, alone and trapped," added another mother, describing her life after her child was born. A third mother revealed, "Your expectations of what your life was going to be like, the picture that you have . . . that's the thing you give up, the picture of what it was going to be." A mother participating in a Portuguese study admitted, "The future worries me . . . What's he going to do when I die? Who will take care of him?" (Magalhães & Pereira, 2017, p. 244).

Decades of international research have consistently shown that parents of children with disabilities experience stress (Bailey et al., 2006; Bailey et al., 2007; Guralnick, Hammond, Neville & Connor, 2008; Kyzar, Turnbull, Summers & Gómez, 2012; Vanegas; Abdelrahim, 2016). Seligman and Darling (2009) suggest that this stress can be grouped into several themes: (1) Intellectual stress, or the continuous search for information concerning the etiology of their child's delay/disability, the prognosis and what do to; (2) Instrumental stress, or the tasks of caring for their child; (3) Emotional stress, or the myriad of feelings, both positive and negative, that go along with the demands of caring for their child; (4) Interpersonal stress, or the shifts in relationships within the family and between the family and their extended family, friends, neighbors, co-workers, etc.; and (5) Existential stress, or the family's ability to make sense of what's happened to them. A Portuguese mother "It's so difficult and hard . . . later, you blame yourself because you think it's your fault, you didn't do things correctly or, in the past you did something and now, you are being punished. So you ask yourself why? Why was I chosen to have a child with this problem?" (Magalhães & Pereira, 2017, p. 244). "At night I wake up and worry, what will happen if I'm not here," admitted one Ohio parent in 2017. A different Ohio parent revealed: "I felt lonely and isolated . . . constantly going to doctors' appointments, always felt like I was going somewhere, I didn't really have anyone else to relate to, all my friends were getting excited about their child's milestones."

Review of social support concept and its importance for Early Intervention

Singer, Maul, Wang and Ethridge (2017) point out that the stress experienced by families who have a child at risk or with a delay/disability is not just about the child and the child's impact on the family; these families also face the same challenges faced by many families: divorce, physical and mental illness, poverty, social isolation, unsafe neighborhoods, limited resources and limited access to services. "When added to the stress that can be associated with children with disabilities, these stressors can have negative psychological and social consequences for family members" (Singer et al., 2017, p. 795).

Nevertheless, families react to these stressors in diverse ways. Some families continue to struggle while others are able to adapt to the challenges and emerge stronger than before. The term "resilience" has been used to describe those families who are successful in dealing with the ongoing stress, and, according to Patterson (1991), who can "bounce back" from crises and learn from what they are experiencing. Resilient families are characterized by such factors as effective communication and problem-solving; the ability to mobilize needed services and supports; the ability to share both positive and negative feelings and experiences; a sense of optimism; and coping strategies such as positive reframing, prioritizing, and comparison coping (Patterson, 1991; Olsson & Hwang, 2008; Podolski & Nigg, 2001; Singer et al., 2017). The theories behind the concept of "resilience" build on concepts from theories of family stress (e.g., McCubbin; McCubbin, 1993) in that responses to stressful situations are an interaction of shared perceptions among family members, existing coping skills, and the availability of internal and external resources (Singer et al., 2017).

One of the most powerful external resources in responding to stress is that of social support (Singer et al., 2017). Dunst (2017) describes a social systems theory framework that views a family as a social unit, which in turn is surrounded by networks of both informal and formal social supports. In other words, the child and family do not exist in a vacuum, but rather as part of a larger ecological

system (Bronfenbrenner, 1992). In this system social support is understood as a transactional process: what happens outside the family directly and/or indirectly impacts the child, the parents, and the family as a whole (Bronfenbrenner, 1992; Dunst, 2017). Parents have a powerful impact on their child, and the outer levels of support around the child and family have a powerful impact on the parents, and, in turn, the child. Parenting beliefs and behaviors, parent-child interactions, the well-being of the child and family, and available resources and supports are all interrelated:

Whether parents can perform effectively in their child-rearing roles within the family depends on role demands, stress, and supports emanating from other settings... Parents' evaluation 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. (Bronfenbrenner, 1979, p. 7).

In the words of Dunst (2017), "families are complex systems that function within the context of equally complex social systems" (p. 52). Turnbull, Turnbull, Erwin and Soodak (2006) use the metaphor of a mobile to describe how this framework of a family system works: a slight push on one part of the mobile (family) effects one or more parts of the mobile (family), and ultimately changes how the entire mobile (family) moves or functions.

Studies have consistently shown the positive impact of social support on a variety of child and family characteristics: personal and family well-being, family functioning parenting attitudes and behavior, parent perceptions of child functioning, and child behavior and development (Bailey et al., 2007; Dunst, Trivette & Deal, 1988; Guralnick, Hammond, Neville & Connor, 2008; Kyzar et al., 2012; Woodman, 2014). Research has also demonstrated that higher levels of social support correspond with lower levels of parental stress. For example, in one study, mothers' satisfaction with their social support system was related to lower stress levels; furthermore, mother's satisfaction with their social support system affected fathers' stress levels, suggesting that the social support connections of

mothers may indirectly benefit fathers (Woodman, 2014). Social support "appears to play an essential role in family adaptation and personal well-being in general" (Guralnick et al., 2008, p. 1139). In this ecological model, social support is a buffering factor; it serves as a "safety net," a net that can hold families up or keep them from falling (Kyzar et al., 2012; Seligman & Darling, 2009).

What is social support? How is it defined? Social support can be defined in a variety of ways. For example, one of the early definitions of social support was proposed by Cobb (1976, cited in McCubbin et al., 1980). Cobb defined social support:

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 (McCubbin et al., 1980, p. 863).

A decade later, Dunst, Trivette and Deal (1988) defined 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 adaptive manner" (p. 28). More recently, Woodman (2014), using the framework first proposed by Carl Dunst and colleagues, described social support as a "multidimensional" concept that includes such factors as emotional and psychological support, sharing of resources, and physical and instrumental assistance.

What is important to understand about social support and how it works to buffer families from stress and promote their resilience?

1. Families with strong support systems are more effective at handling challenges than families with weaker support systems (Bailey et al., 2007).
2. The impact of social support has been demonstrated in families whose children are developing typically, in families with multiple risk factors, and families of children with delays/disabilities (Dunst, 2017; Guralnick, 2011).

3. Social support is provided through support networks. A family's social support system includes a mix of intrafamily, informal, community and formal support members (Dunst, 2000).
4. Social support can be provided by the family's kinship network (e.g., grandparents, in-laws, extended family members), the family's informal network (e.g., friends, neighbors, co-workers, church members, people who work where the family shops), and the family's formal support network (e.g., early intervention professionals, pediatricians, child care providers, medical specialists) (Dunst, 2017).
5. Quantity and quality are not the same. A large support network with many members is not necessarily more helpful than a smaller support network. Only the family can determine how well their support networks are working for them (McCormick, Stricklin, Rous, Kohner-Coogle & Nowak, 2005).
6. Kinship, informal, and formal networks are all important in helping families adapt to their child's delay/disability, but those networks operate in different ways, with different impacts (Bailey et al., 2007).
7. Kinship/informal supports have a stronger relationship to a variety of outcomes than do formal supports (Dunst; Trivette & Jodry, 1997).
8. Kinship/informal support is characterized by feelings of closeness and mutual support (Dunst et al., 1997).
9. Social support works best when it is individualized, when it is a match for the family's concerns and priorities and their expressed need for assistance (not what the professional thinks the family needs), and when it is offered in a way in which the family, not the professional, is the active agent in seeking and obtaining the support (Affleck et al., 1989; Dunst, 2017; Dunst, Trivette & Deal, 1988).
10. Structural equation modeling has identified the mechanism by which social support impacts a variety of family and child outcomes. Social support directly impacts parental self-efficacy and well-being, and increased self-efficacy also directly impacts well-being. In turn

parent well-being then impacts child development directly and indirectly (mediated through the impact of parent well-being on parent-child interactions) (Trivette, Dunst & Hamby, 2010).

Social support may be especially important for families during the early childhood/early intervention years. Bailey et al., (2007) examined a large longitudinal sample of children and parents who had received early intervention services in order to examine how a variety of factors were related to the families' perceptions about the impacts of early intervention. Their findings demonstrated that (1) the quality of services for the child (e.g., therapies) were viewed as impacting the child but not the family, (2) the quality of family services (supports from professionals) were viewed as having impacted both the child and family, including the family's optimism about the future but not parent ratings of self-confidence; and (3) informal supports (from extended family and the community) were related to both optimism about the future and increased parent self-confidence. The authors suggest that their research demonstrates the important role that informal supports play in how families adapt to disability.

Other longitudinal studies have shown that stress may increase from the early childhood years to middle childhood for parents who have children with delays/disabilities, and not decrease until the child reaches adolescence (Woodman, 2014). "Child-related stressors and family resources [social support] at the time families were receiving early intervention (age 3) had lasting impacts on parental well-being" (p. 50). In other words, the stronger and more resilient the family became during early intervention, the stronger the family remained after leaving early intervention. Bailey et al. (2007) conclude that "professionals should pay more attention to the family consequences of disability and to helping families build and access informal support systems" (p. e1000).

How might the research on the importance and mechanisms of social support and resilience impact how we define and implement early intervention? Thirty years ago early intervention was in its infancy in both Portugal and the United

States, as well as in other countries around the world. Nevertheless, the recognition of family vulnerability and the importance of social support were recognized from the very beginning:

Early intervention by its nature is an intimate service that touches a family's life at a time of double vulnerability. First, there is the normal vulnerability of a family taking on responsibility for a first or additional child. Second, there is the often dramatic vulnerability brought on by the special needs situation. These vulnerabilities may complicate already existing problems, such as low socioeconomic status, unemployment, marital stress, or teenage parenthood. (Healy, Keesee & Smith, 1989, p. 3).

Although the importance of families was recognized, the earliest definitions of early intervention continued to focus on services. For example, in 1989 early intervention was defined as

educational, health, and social services designed to support the development of very young children who, in minor or major ways, have been identified as 'different.' They are also designed to support and strengthen the families that are the primary influence on these children (Healy; Keesee; Smith et al., 1989, p. 1).

The research of Carl Dunst and colleagues on supporting and strengthening families gradually led to a definition of early intervention as "the provision of support and resources to families of young children from members of informal and formal social support networks that both directly and indirectly influence child, parent and family functioning" (Dunst, 2000).

In 2007, a workgroup of researchers and practitioners was convened by the United States Department of Education's Office of Special Education Programs (OSEP) to examine the research and craft an early intervention mission and key principles that reflected the research at the time. This group defined early intervention as a system that *builds upon and provides supports and resources to assist family members and caregivers to enhance children's learning and development through everyday learning opportunities*. One of the group's key principles specifically addressed the theme of social support: *All families, with the*

necessary supports and resources, can enhance their children's learning and development. The workgroup went on to stress that early intervention should be explained to families as a system of supports and services for the family (not only the child), and professionals should spend time exploring with families the formal and informal supports they use and would like to use, which in turn would be incorporated into the plan of intervention (Workgroup on Principles and Practices in Natural Environments, OSEP TA Community of Practice: Part C Settings, 2008, March)

The research on social support continues to shape and re-shape current definitions of early intervention. Dunst and Espe-Sherwindt (2017) define early intervention as:

the different types of parenting supports provided by early childhood practitioners and other social network members that provide parents the time and energy, and knowledge and skills, to engage their children in everyday child learning opportunities that promote and enhance both child and parent confidence and competence (p. 831).

This paradigm of early intervention, which includes supports and resources provided by the family's formal and informal support networks, recognizes the strong impacts that informal network members have on a variety of child and family outcomes, expands the opportunities for "intervention," and strengthens a network that will be available to the family long after they transition out of early intervention and leave those formal supports behind (Dunst, 2017).

But what does this model actually look like in practice? What takes place in order for a parent to describe this model as "no longer feeling like you are alone"? In the next section, we will present a case study from Portugal that illustrates how to implement early intervention through the framework described thus far.

Case study

The case study that will be described is part of data collection for a research study within a dissertation (Serrano, 2003). It is about Joana², a

² The names Joana and Francisco are not the real names

single adolescent mother whose child, Francisco was born with a rare disorder diagnosed as Imperfect Congenital Osteogenesis –Type 2B. The child's disorder makes bone fractures a permanent risk for him. According to the mother her son was born with 36 bone fractures that occurred during the intrauterine developmental period. The mother came from Angola to live in Portugal at a very young age, as her father had a sister living in Portugal and he sent her daughter away to live with her sister for a better future. The mother got pregnant when she was in high school and her aunt did not accept this fact having, since then, a very tense relationship with the mother. The child was referred to the early intervention team by the health services when the child was 3 months old. At this particularly vulnerable moment this mother needed a big of support for caring for her child as she was a teenage mother, living in a country far away from her close family, and needing a place to live as well as continuous support from the medical field.

The EI team started by assessing the mother's needs, concerns and expectations and trying together, to build answers to her immediate needs. They tried to find a daycare for the child, but that proved to be very difficult, due to the medical condition of Francisco. Nobody wanted to take the risk and responsibility to care for him during the day as they were afraid to break Francisco's bones. Then, the answer to this problem was to find financial support for this mother to be able to live alone and care herself for Francisco until he was 3 years old, which became her wish. EI team and the mother were involved with Social Services in the community and they supported financially the renting of a small apartment for Joana and Francisco. She was also receiving Social Welfare monthly, which allowed her to cover her basic needs. Medical expenses were covered by the Portuguese National Health System which provided free and universal accessibility to Francisco and Joana. Thus, the financial support received from formal services gave the mother some stability and decreased her stress over the care responsibilities that she had with Francisco, namely a house to live, money to maintain herself and Francisco every month as she would not be

able to work while taking care of Francisco.

Joana also had a strong emotional support during these years, either from informal and formal support which, accordingly to the mother, made a difference enhancing her well-being and sense of self-efficacy dealing with Francisco and supporting her growth and development. Some of these elements in her close proximity were her best friend whom became Francisco's godmother, and Francisco's grandmother on his father side, both living nearby. Her father (Francisco's grandfather), brothers and sisters were also a strong emotional support even though they were living in Angola, she would call them frequently and reported a strong bond between them that gave her a lot of strength during this period. Joana also mentioned the importance of the support provided by the EI professionals in the team and the medical doctors who followed her at the hospital and private clinic. The obstetrician became very close to her and provided a very close support to her, even after the birth of Francisco.

When Francisco turned 3 years old, the mother and the EI team planned and supported his transition to preschool where he was successfully included for three years until his transition to Primary school when he turned 6 years old. This fact allowed the mother to find a job and became full employed.

Through the above description we can illustrate how powerful the use of families' social support networks can be for EI. A very practical and graphical way to gather information of the social support network of a family can be achieved by using an instrument called ecomap.

The ecomap was developed in 1975 by Ann Hartman to be used in the social work area in her work with environmentally risk families (Jung, 2012). It consists of a graphic representation of a family's connections to the people and social structures of the environment in which they live, drawing their system of social interactions (Agostinho, 2007).

The ecomap can be done by any team member (social worker, nurse, doctor, psychologist) as it is a working tool to be used in the team, but always with the active involvement of the family and its members. It summarizes and represents important information about the family and their environment

in a graphical format that can be easily read by any of the elements involved in the process and illustrates the nature and impact of family relationships with the environment, enabling them to verify whether they are a source of support or not. These aspects allow a better understanding of stressful situations and resources available to respond to needs we identify with the family and provide a consistent information base to plan, with the involvement of the family, intervention decisions (Agostinho, 2007).

In fig 1, you can see a graphic example of the ecomap of Joana and Francisco. We start by identifying who is part of the family and then start identifying significant elements of family support that are part of their network, such as informal support, including extended family, neighbors, friends, working relationships, etc. As well as formal support, such as community services/people, school, health center, financial support institutions or specific institutions such as private clinic etc.

It is also important to identify the types of support provided by the different elements of the network, such as emotional, instrumental, material, companionship support, as well as the intensity of the support and its frequency, how

strong and how often is the support provided.

After identifying the elements of the network, we did look at the type of relationship that links Joana and Francisco to the different elements of their ecomap. Through the information provided we draw lines between the family and each of the squares representing their supports, whose thicknesses represent three levels of support, the thickest one, representing strong and non-stressing relationships, the thin, weak non-stressing relationships, and the one with dots represents fragile and stressful relationship. This procedure helped us understand if that network fits the needs of that specific family. Only the family can evaluate the usefulness of their network. The uniqueness of each family and their characteristics, values, life style and coping will be reflected in the ecomap, so we can find very different ecomaps from family to family. It should also be noted that the number of elements in the network is not necessarily equivalent to quality and only the family can judge on the effectiveness and quality of the support provided by the network. Considering Joana and Francisco, even though it might have seemed a small informal network, she considered that it was perfectly for answering her family needs.

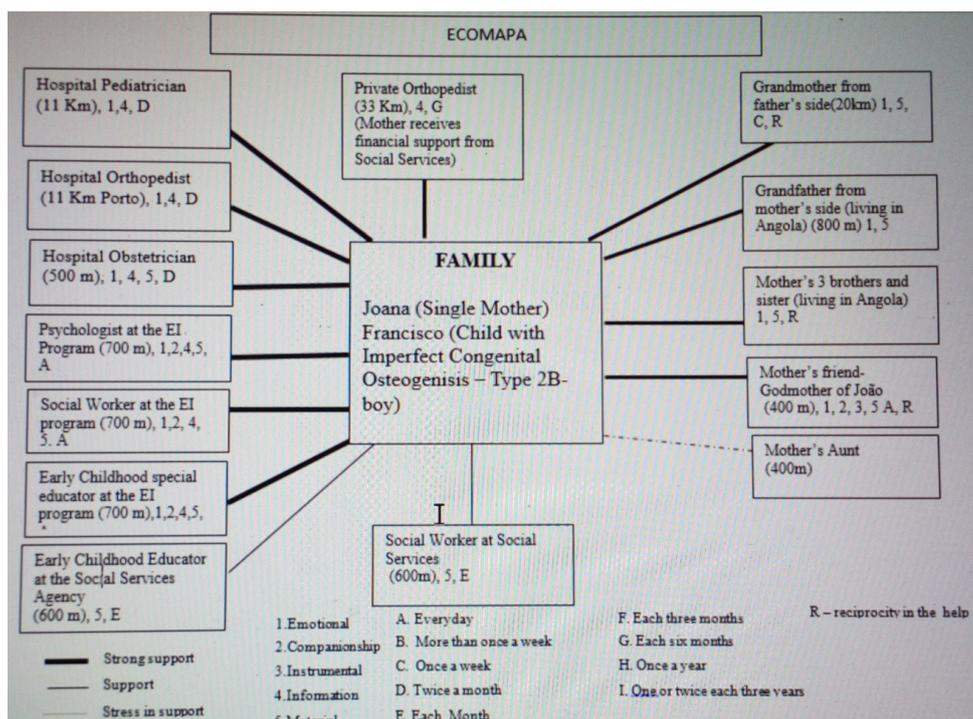


Figure 1 – Ecomap of Joana and Francisco - adapted from Serrano (2003, p. 224)

The ecomap and the problem solving approach that it brings to EI practice for working with families, empirically integrates the perspective, the values and concepts of the Ecological Systemic Theory mentioned above.

When families' basic needs are met, they spend less time on worrying and more time helping their children's development and learning. All families go through difficult times, however, knowing that "I do not feel alone..." makes it easier to deal with the problems they encounter, particularly when their child has a disability.

To conclude, as we mentioned before, parents have a powerful impact on their child, and the outer levels of support around the child and family have a powerful impact on the parents, and, in turn, the child. Joana and Francisco's case study clearly illustrates how support buffered her risk factors and allow her, in turn, to support her child's development. Joana was so skillfull and sensitive towards her child that we would like to leave her testimony exemplifying this. According to the mother her son was born with 36 bone fractures that occurred during the intrauterine developmental period. Despite this severe problem the mother never once broke a bone in her child after birth. But others who had to handle the child for various reasons -- namely, other professionals -- had inadvertently broken his bones. About this the mother says:

Mother: Do you know what the doctors said about me? They said: 'Probably if the mother was another person, she wouldn't have been able to care for this child'. Because my boy had so many fractures. But even though I had to take care of him 24 hours a day, as it happened in the beginning, I never broke anything in him.... I don't know, it's because I'm his mother, I guess (she laughs).

Researcher: See, (laughing with the mother) you've got the "magic touch" -- really, it's the "magic touch". When it is our own child we think with a special care, with a mother's care (Serrano, 2003, p. 270).

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