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Coping strategies used by families caring for a child or children with special needs: Available intervention services and access to other resources

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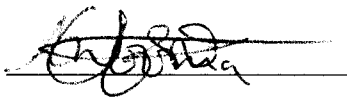
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Antonia N. Ofosu

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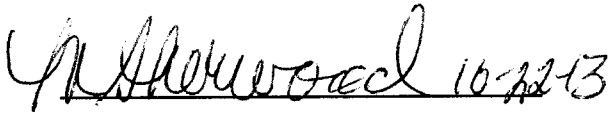
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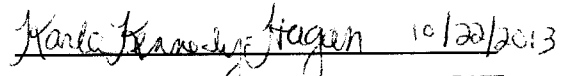
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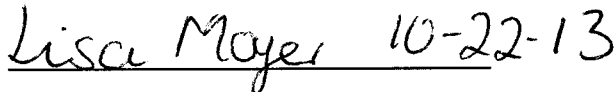
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Running head: COPING STRATEGIES USED BY FAMILIES

Coping Strategies Used by Families Caring for a Child or Children with Special Needs:

Available Intervention Services and Access to other Resources

Antonia N. Ofofu

Abstract

Although caring for a child or children with special needs is a demanding task, families continue to strive to meet their needs while in that unique situation. The purpose of the study was to identify the intervention services and other resources available to families caring for children with special needs, determine whether the resources pertain to the specific needs of those caring for a child or children with special needs, and also to ascertain the extent to which resources influence coping strategies for these families.

Sixteen primary caregivers of a child with special needs participated in the study by filling out a questionnaire developed by the researcher. A descriptive content analysis, constant comparison and hermeneutics were used to analyze the data. The study found that access to intervention services and other resources is dependent on knowledge of where to find resources, the availability of professionals that will provide direction, the ability to search for what is needed and overall eligibility. In determining if families caring for a child or children with special needs have access to the intervention services and other resources that pertain to their specific situation, results indicated that families in this population do have access to general needs for the child, however the severity of the child's need and family dynamics may influence the access they have to specific resources they need.

The last objective, to ascertain the extent to which the intervention services and access to other resources influence family coping strategies, indicated that the family's acceptance and attitude towards care of the child influenced coping. In addition the families that used intervention services and resources that met their needs and showed progress with the child indicated that they were able to cope with stress in a better way.

Key words: child with special needs, disability, coping strategy, resource, intervention, access

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Chapter 1

Introduction

According to Halfon, Houtrow, Larson and Newacheck (2012), “the UN convention on the rights of persons with disabilities led to the development and adaptation of a new definition of disability that is built on the IFC framework”...The definition states that, “persons with disabilities include those who have long term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (p. 15). As research indicates, disability does not denote the inability to function effectively in society; however it shows that it may present some setbacks.

Although families caring for children with disabilities, which may also be referred to as children with special needs, may experience some challenges peculiar to their family structure, some of their experiences with social, emotional and financial struggles are not any different or new as compared to that of families caring for a child or children without special needs. In relation to the changing context of childhood and impacts on health, Halfon et al. (2012) indicate further that “many children live in social environments that limit their full inclusion and participation in the social world” (p. 16). Furthermore research by Singer claims that “earlier assumptions of virtually universal and unvarying negative impacts on families has been displaced by a more complex understanding of family adaptation and of long-term resilience” (as cited in Thurston et al. 2011, p. 264).

Families caring for children with special needs are facing life with all its complications, alongside caring for a child or children that need special attention. Wilkins (2007) indicated that caregivers “also saw their child with special needs as a teacher who showed them resilience,

honesty and an appreciation for the beauty in the world” (p. 43). Consequently families need to be provided with the intervention services and access to resources, to assist them in their efforts, and also help to sustain their achievements with the children.

Growing literature supports the idea that families living with and caring for a child with disabilities tend to go through stressful experiences as a result of their unique situation (Hughes, 1999; Pelchat & Lefebvre, 2004 as cited in Daire, Munyon, Carlson, Kimemia, & Mitcham, 2011). In addition, Lee and Gardner (2010) suggest that the stress of caring for a child with a disability disrupts family structure and has an adverse effect on family functioning. This disruption makes it difficult for family members to adapt and maintain cohesion (p. 471). Existing research also sheds light on the resources these families need and how to make them available. Bruder (2010) found that “the primary task in early childhood intervention is to ensure that specific child and family characteristics unique to those with disabilities and delays are fully and effectively addressed” (p. 351). Families caring for a child with special needs require access to both internal and external resources. This access is of paramount importance to the success of family living, as the strain associated with caring for a child with special needs demands that the family pull together all available resources.

As compared to a family caring for typical children, these families are often unable to function as a whole without taking into consideration the presence of the child with special needs. In other words, a child with special needs may influence family life to a greater extent than a typical child. Unfortunately caring for a child with special needs may result in a crisis situation which tends to affect all members of the family, as well as interactions between the family and society on the whole. This is why focusing on the child with special needs alone would not yield information policy makers and advocates would need in order to better provide appropriate services for families.

Families need to be equipped with the intervention services and access to resources that pertain to their needs, in order to reduce the intensity of crises situations. Price, Price and Mckenry (2010) stated, “ Family systems resources refers to internal attributes of the family unit that protect the family from the impact of stressors and facilitate family adaptation during family stress and or crises” (p. 10). For most families the coping strategies they use, and the effectiveness of those coping mechanisms, make the difference in living standards. The crisis of having a child with special needs is not solvable and hence can only be managed. Families, therefore, may rely on intervention services and access to other resources already in place in order to cope with caring for a child with special needs, while attempting to maintain family cohesion.

According to Reichman and Corman (2008), a child with a disability can produce a series of stressful events for family members; however very little research has been attempted on any demographic or economic effects on families with a child or children with special needs (p. 680). Families and professionals need to identify and address other external factors that contribute to the ongoing distress of such families, and how to manage these factors. Although it demands much of families, others have been able to live like regular families because of their resilience. Thurston et al. (2011) indicated that there are, however, a significant portion of parents most responsible for the child with special needs that are not able to adjust. The focus of studies on children with special needs has mainly focused on the obvious nature of children requiring special needs, and the distress it may cause for parents or families.

According to a study on “Theories In Disability In Health and Research” Oliver (1998) stated that, “Recent research, attempting to combine theories, and scientific measures of the extent of disabling barriers with disabled people's own experiences of the extent and nature of those barriers, involves disabled people in designing, collecting and analysing the data, its

success remains to be seen” (p. 1447). As a result of the complexity in family living and the different family systems into which children with special needs are born, it is essential that professionals and policy makers have the information they need to assist such families in managing daily family life. This study focuses on the resources available to families caring for children with special needs. The researcher seeks to identify whether available resources pertain to the individual needs of the various family structures of those caring for a child with special needs, and examine if family coping strategies are influenced by the available resources.

Statement of the Problem

A number of studies have researched coping strategies used by families caring for children with special needs; however few have studied whether such resources are helpful in meeting specific needs or whether the available intervention services and resources have an influence on family coping. As stated by Halfon et al. (2012) “The dynamics of disability in the child population is one of the areas where there has been a paucity of data” (p. 31). For professionals, such as child advocates and policy makers working with families, an awareness of the variety of needs of various family structures is essential in order to aid in identifying whether the intervention services and access to resources influence their lives in a positive manner.

In the case of families caring for children with special needs, the family dynamics change and the strain on families caused by stress is intensified. According to Halfon et al. (2012) “Children with disabilities tend to have more extensive health care needs, have greater rates of unmet needs for health and related services, and experience social and environmental barriers to full participation in life events” (p. 14). Caregivers of children with special needs are therefore challenged with maintaining family cohesion in spite of these crises. They consequently need the appropriate help in order to cope with stresses that come along with caring for a child with special needs. It is essential to seek information about the intervention services and access to resources

available for these families. This can help professionals to monitor and assess each resource's contribution to family coping strategies and thus increase stability in family living.

Purpose of the Study

The purpose of the study was to identify the intervention services and other resources available to families caring for children with special needs, determine whether the resources pertain to the specific needs of those caring for children with special needs, and ascertain the extent to which resources influence coping strategies for these families.

Research Objectives

The research objectives of this study included:

1. Identify the specific intervention services and other resources, available to families with a child with special needs.
2. Determine if families caring for a child or children with special needs have access to the intervention services and other resources that pertain to their specific situation.
3. Ascertain the extent to which the intervention services and access to other resources influence family coping strategies.

Definition of Terms

Child with special needs - A child with a form of physical, emotional, behavioral or mental disability which requires some form of intervention, services, programs, or monitoring.

Disability - A disability is a "condition or function judged to be significantly impaired relative to the usual standard of an individual or group. The term is used to refer to individual functioning, including physical impairment, sensory impairment, cognitive impairment, intellectual impairment mental illness, and various types of chronic disease" (www.disabled-world.com, 2012, para. 1)

Coping strategies - The “active processes and behaviors that the family actually try to employ to help it to manage, adapt, to or deal with a stressful situation” (Taanila, Syrjala, Kokkonen & Jarvelin, 2002, p. 74)

Resource - “A natural feature or phenomenon that enhances the quality of human life. A source of supply or support: an available means” (www.merriam-webster.com).

Intervention - Any form of action which interferes with a situation to reduce its impact or prevent further harm.

Access - Being able to be within reach of

Summary

Families caring for a child or children with special needs have to employ coping strategies in a complex manner. Intervention services and access to other resources play a role in how families cope. In order to be able to study such families and collect useful data, the researcher would have to identify each family caring for a child with special needs as an individual entity and not as part of a group of families facing the same circumstances. The research objectives have been developed from the purpose of the study. The definitions of terms which have been stated will be used in the context of this particular study. The chapter that follows provides an overview of literature concerning families caring for children with special needs, and will focus on family needs, family coping, intervention services and access to resources.

Chapter 2

Review of Literature

Until recent times, provision was not made available for children requiring special services. Children with special needs were expected to make use of the services that were put in place for the general population of children. Families caring for such children either struggled through this difficulty or avoided any situation which put their child at a disadvantage. Either way, the child with special needs was losing out on intervention and access to other resources that could minimize the challenge for their families. Past research indicates this as a deficit in the life of children with special needs, “Children with disabilities may be restricted in social participation and experience less access to education and other social services” (United Nations Children’s Fund Division of Policy and Practice & University of Wisconsin, 2008, p. 2). This is important to consider given that statistics on child disability indicate that:

Of the 53.9 million school-aged children (aged 5 to 17) in the U.S. civilian noninstitutionalized population, about 2.8 million (5.2 percent) were reported to have a disability in 2010. For many of these children, the kinds of disabilities they experience may require special approaches to providing education or other accommodations.

(Brault, 2011, p.1)

Families living with, and caring for, children with special needs often strive to understand their own challenges, functioning and peculiar needs. Family advocates, professionals and government organizations also seek to effectively plan ways to help manage the family units that find themselves in this situation. Family-centered practitioners are aware that the family unit is a source of strength for a child with a disability. Because the family is primarily responsible for the child, they are also often in the best position to assist the child (Davis & Payne, 2009). Another indication made by research is that theories on disabilities have influenced provision made for

families caring for children with special needs to a great extent. Oliver (1998) stated that “All health care and research are influenced by theories” (p. 1446). However, research concerning individual needs for families based on theories as compared to family context is yet to be addressed.

Families with young children with special needs are confronted with ongoing challenges that can impact various aspects of family life (Davis & Payne, 2009). More attention needs to be focused on the difficulties that often confront families with children with special needs (Reichman, Corman & Noonan, 2008, p. 682). When families are better able to cope with the care of a child with special needs, they are better able to manage the situation in which they find themselves, and, most importantly, the child or the children benefit.

Struggle for Families: Policies, Intervention and Access to Resources

Families caring for children with special needs are constantly trying to make use of the resources to which they have access. Unfortunately, as society evolves so do their challenges and the resources that may have been sufficient in the past tend to be lacking. For instance whereas intervention services and other resources used to be sufficient for families caring for children with special needs, the change in the type of individual needs of each family, and the increased numbers of individuals requiring modified sources of intervention has put a strain on both the families and available resources. Research studies in the past have pointed out this shortfall. Ireys, Grason, & Guyer (1996), stated that “as states implement health system reforms, new problems are emerging in the organization and financing of care for children with disabilities and chronic illnesses. Children with disabilities and chronic illnesses represent the high-cost segment of the childhood population; although few in number, they consume a vastly disproportionate

amount of service dollars” (p.178). As a result of cuts to governmental programs and lack of government money coming in, families caring for children with special needs tend to suffer as they adjust in order to provide the best possible care for their children. As a result of the individual needs of such families, the mere existence of policies, intervention or access to resources alone is not sufficient in reducing their struggle. The families need to comprehend how to use the resources.

In a research project conducted concerning coping strategies used by large versus small families caring for children or a child with special needs, a common issue was identified regarding working and caring for children requiring special care. The families expressed a struggle to maintain the home, go to work and care for the child. A single mother indicated that she had to stay home to be with the child, or secure only part time jobs to make time to be at home. In the process she missed out on a higher salary, which would have gone towards the upkeep of the child. Kagan, Lewis, Heaton and Cranshaw (1999) claim that “The demands and rewards of combining parenthood and employment, and the policies and practices designed to support families has, however, been overwhelmingly based on families with non-disabled. The needs of parents of disabled children are often different and more long- term; they are not confined to the early childhood years” (p. 370).

Another concern for families caring for children with special needs is the ability to focus on that child while also making sure siblings are also receiving the care they need. This is of concern because caring for a child with special needs limits the family to an extent. For instance, siblings without a disability may be subjected to the same patterns as the child with a need. This can be stressful for both parents and siblings because as one child is receiving care the other may be lacking appropriate attention.

Research indicates that,

Over the past 6 years, researchers at CanChild Centre for Childhood Disability Research at McMaster have addressed sibling support groups; they discuss sibling desire to experience social interaction with others, and most especially with other siblings who also have siblings with disabilities. In addition the siblings without disabilities who had access to support groups perceived positive outcomes such as, an increase in self esteem, quality of life, social interaction,, understanding disability issues and most importantly coping strategies within family situation (Naylor & Prescott, 2004, p. 204).

In addition, they indicate that in pursuit for the appropriate care for the child with special needs, families and professionals have to ensure that siblings of these children are not deprived of a typical childhood (p. 205). Research indicates that families caring for children with special needs face physical, social, emotional and financial issues. Although the issues may not be permanently resolved, it is evident that intervention services and access to other resources play a significant role in how families manage additional stress.

Family in Respect to Needs

According to Ahmadi, Khodadadi, Anisi and Abdolmohammadi, (2011), “two major courses of action are taken by societies in order to reduce the problems of the families with disabled children; first, the effort to prevent the disability and developing mental and physical defects, and second, creating the necessary welfare and rehabilitation facilities to serve the disabled individuals and their families” (p. 49). The nature of families in such a situation is either to accept the challenge and have a positive outlook on family functioning or to be overcome by the

personal, social and economic challenges they experience. Either way the goal of families caring for children with special needs is to get through each day having achieved some sense of success.

The choices families make tend to determine the success of their coping strategies. However, most often families may not be aware that they are using coping mechanisms to manage their situation. Margalit, Raviv and Ankonina (1992) found “two main types of coping: the active coping methods which are information seeking and problem solving, and the avoidant coping strategies, which are efforts to deny, minimize or escape the stressful situation”(p. 202). Regardless of which type of coping strategy families decide to use in order to manage the difficulties they go through, they are often unable to cope with stressors without the presence of intervention services and access to other resources.

Whereas families with children who do not require special assistance would find a variety of ways to solve the issues that they face, families caring for a child with special needs tend to focus on coping and coherence as a constant issue in their lives. It is clear that families manage the stress associated with caring for a child with special needs in a variety of ways. In fact, research by Margalit, Raviv & Ankonina (1992) indicates that when individuals experiencing some form of stress take steps to address the issue and attempt to reduce the stressor, they are practicing a form of coping.

Research studies on families living with, or caring for, children with special needs have probed into the different factors that would either make this journey a success or more of a challenge. Access to the right intervention practices and other resources contribute immensely to the outcome of the efforts of these families. Research continues to identify the contributions of these interventions and other resources to families caring for children with special needs. “Given the increasing emphasis on promoting positive outcomes in these families, researchers examine

the contribution of child, family, and support characteristics to the quality of life in families of young children with disabilities”(Davis & Payne, 2009, p. 153).

The provision of services to children with disabilities and their families can be addressed through a family – centered approach to care (Freedman and Boyer, 2000; Law et al., 2005). Family-centered practices recognize that families are unique entities, they are the backbone in the child’s life, and that families therefore should be viewed as specialists in the identification of both their children’s abilities and needs. However families strive to deal with the demands of caring for a child with special needs, regardless of resources available. This is because families need to understand how to make use of intervention opportunities, and access the resources available to them.

Crisis in Families Caring for Children with Special Needs

Families caring for children with special needs tend to experience crisis on a daily basis; this is dissimilar to the experiences of families that care for typically developing children. Research indicates that the management of crises may depend on the resources available to a family. Stewart et al. (2006) conducted a research to evaluate an information kit for parents of children and youth with special needs and part of their results suggested that “parents who received and actively used the parent information KIT experienced significant increases in their perceptions of their ability and self-confidence in getting, giving and using information to assist their child with a disability” (p.498). Resources available to the family include tangible resources, such as money and technology used to make life easier for the children, as well as intangible resources like information, family support, spiritual beliefs or laws and policies put in place to protect families.

Members of both the immediate and extended family such as siblings or grandparents may participate in helping family members faced with the challenge of bringing up a child with special needs. Research by Wilkins (2007) reports on how some families “spoke about their sibling children being strong, caring and educated individuals who with the support of the parents often became drawn to supporting others” (p. 43). Within a social context some communities make community-centered programs and support groups available to assist such families. Wilkins (2007) while focusing on a sense of community, again reports how some families felt, “we gain strength and a sense of belonging from caring members of our community” (p.42). In many cases, churches and their members also make themselves available in different forms to assist families, most often this occurs through faith in a religion.

Policies and Services

The growing population of children with special needs has drawn the attention of policy makers. The government has policies in place to provide resources for families caring for children with special needs. These policies can be considered a resource for families as they attempt to address issues for this growing population. Brault (2011) reports that:

In 1975, Congress enacted the Education for All Handicapped Children Act, which required all public schools that accept federal funds to provide equal access to education for children with physical and mental disabilities. Congress reauthorized the act in 1990, expanded certain programs, and renamed it the Individuals with Disabilities Education Act (IDEA). In 2004, Congress amended the law and further clarified its intended purpose that states provide a free appropriate public education for all students aged 3 to 21, including children with disabilities (p.1).

The Individuals with Disabilities Education Act (IDEA) is one of such laws “Ensuring services to children with disabilities throughout the nation. IDEA governs how states and public agencies provide early intervention, special education and related services to more than 6.5 million eligible infants, toddlers, children and youth with disabilities” (U.S Department of Education, Office of Special Education Programs, 2006, para. 1). The National Dissemination Center for Children with Disabilities is another useful resource funded by the U.S. Office of Special Education Programs (OSEP), the aim of the organization is to provide information to

learn about typical developmental milestones in childhood, specific disabilities and disorders, and the disability categories in our nation’s special education law. ... National Dissemination Center for Children with disabilities can also put you in contact with the wide range organizations, conferences, and resources and resources that are focused on specific disabilities and the disability network at large (Nichcy.org, 2010).

As the years have gone by, the laws, policies and services rendered to families caring for children with special needs have been modified to include this specific and yet growing population. Research by Leiter and Krauss (2004) claims that “One of the most celebrated and controversial components of the Individuals with Disabilities Education Act is the provision for shared decision-making by the parents of the children receiving special education services and school personnel for determining the educational programs and related services children receive” (p. 135).

Even though the primary focus of the act is on education, it covers many areas of concern for parents, some of which include cognitive and social development, hence helping families to deal with one aspect of the issue. Working with families, or the primary caregivers of children

with special needs, results in practical information, which can be used purposely to provide the best care for the child. Aside from the IDEA, other policies have been put in place in the United States to support families caring for children with special needs.

Additional policies for families caring for children with special needs, include No Child Left Behind (NCLB), which has a primary focus of ensuring that disadvantaged children also have equal access to standardized education and educative material, the Americans with Disabilities Act (ADA), which protects the rights of persons with disability in relation to equal access to public locations as well as employment, and the Assistive Technology Act (ATA) which ensures that access to technology makes it possible for persons with disabilities to excel at school work or any societal setting (Nichcy.org). Private organizations, churches and individuals have also contributed to this population to ensure that they are able to manage their situation. Also recent policies and services for children in general struggle to take into consideration different specific needs of children and their families. Bruder (2010), states that “policy makers and service providers are challenged as to how build sustainable, collaborative and effective service structures for all children and families” (p. 350).

A study on disability policy by Turnbull, Beegle & Stowe (2001) required them to define core concepts of research by policy makers, “one key issue became apparent: Who is the primary beneficiary of the policy that we were researching-the child with a disability or the child's family” (p. 134) ... Another issue which was addressed is whether “policy and practice encourage services to be provided to the entire family” (p. 142).

Research is beginning to address the existence of resources for families caring for children with special needs, in addition to those targeted at the specific needs of the child. In light of this

information there is an urgency to investigate the intervention services and other resources to which families have access.

According to Halfon et al. (2012) there is a need to “call on policy makers to strengthen existing data systems to advance understanding of the causes of childhood disabilities and guide the formulation of more strategic, responsive, and effective policies, programs, and interventions” (p. 13). Further research needs to be done in order to better understand how family coping strategies are influenced by intervention services and other resources available.

Intervention Services and other Resources for Families Caring for Children with Special Needs

Although a number of policies have been put in place to address children with special needs, those in the situation seem to be lacking some of the help they need. This may be because family dynamics are different in each home. Resources tend to be designed for the population of children with special needs as a whole and do not address specific issues within each family context. Fortunately for families, both individuals and private organizations have found it necessary to take this issue upon themselves and also provide valuable information to add to what has been made available through public policy. For example the Center for Children with Special Needs and the Seattle Children’s Hospital are known to provide specific resources for families with children with special needs. In addition, Children’s Disability website was created by Allison Martin, who is a part of a family caring for a child with special needs. Finally, Kids Together Incorporated is a non-profit, all-volunteer organization that also provides targeted services to families.

Although research continues to investigate the population of children with special needs, there is a lack of work addressing how effective and useful information has been for families.

Recent literature on the success of the use of various resources has begun to surface. Stewart et al (2006) states that “Over the past 6 years, researchers at CanChild Centre for Childhood Disability Research at McMaster University in Canada have been working together with parents of children with special needs and service providers to develop a Parent Information Kit” (p. 493). The primary purpose of the information Kit is “to help parents use information as a tool to get the best for their child” (p. 494).

A study was conducted to evaluate the Parent Information Kit and results indicated that; parents found that the resources that provided information about services that assisted them in finding support groups, helped them understand how to access resources from both the center and the community at large, and offer specific information such as the assessment of their child were relatively low as compared to other types of family centered services they received. In fact, Stewart et al (2006) also stated that “providing parents with strategies and an organizational tool for managing information can assist them in their day-to-day self management in parenting a child who has a disability” (p. 499).

According to Price, Price and Mckenry (2010), family perception has a role to play in influencing crisis within a family. Thus if policy makers produce interventions and provide resources based on assumptions of need instead of allowing families caring for these children to identify needs, they may continue to yield unsuccessful results. According to Patterson (as cited in Taanila et al, 2010), “The aim of the familial coping procedures is to maintain or restore the balance between the demands and resources” (p. 74). Hence intervention and access to other resources needs to correlate with the demands of families. This is why further studies need to be done on the influence of access to intervention and other resources on coping strategies. A study by Thurston, Paul, Loney, Wong & Browne, 2011, also investigated:

Associations between socio-economic, family and child variables with parental symptoms of psychiatric distress in a multi-diagnosis, 0 – to 19 – year - old group of children with complex disabilities and needs, and second to explore trends in the direct and indirect costs associated with symptoms parental psychiatric distress in these families. (p. 264)

Results from the study indicated that parents caring for a child with special needs experienced mild to severe forms of distress, and that the distress could be attributed to reports of low social support, the impact of the crises on the family, and coming to terms with different forms of parenting styles to name a few. Surprisingly, reports also indicated that the severity of the condition of the child did not seem to influence parent distress (Thurston, Paul, Loney, Wong, & Browne, 2011).

This report shows why investigating existing factors pertaining to families caring for children with special needs should also be given attention. Care providers should better understand that the needs of families caring for children with special needs go beyond providing intervention services and resources for the child alone. Intervention and other resources put in place for the child may not necessarily extend to the parents, or other members of the family caring for the child with special needs. In their discussion Thurston, Paul, Loney, Wong & Browne (2011) expressed concern for parents that are raising a child or children with special needs and suggested that primary care providers should involve parents in their assessments and evaluations for needs in order to lessen family stress. They found that parents are more likely to misjudge their child's needs and provide less quality care, when they are under stress.

Based on results from research studies, policies, intervention services or access to resource that have been developed to assist families and their children need to be used the right way to achieve success. Simply having access to some form of intervention or a variety of resources may not necessarily assist families in managing their circumstances adequately. In a

study about the experiences of parents of disabled children using the internet, Blackburn and Read (2005) indicated that “in addition to cost and access to equipment to access the Internet, lack of skill was a key barrier to using it” (p.519). Families need to be educated on how to utilize the intervention and access to resources they receive. Most importantly families need to know when to utilize resources to achieve the best results.

The study conducted by Blackburn & Reed (2005) in reference to the United Kingdom where the study took place, also states that the then “current government committed itself to introducing a range of new measures to support careers, including parents of disabled children, and emphasized the importance of making improved information available to them in a variety of forms, including online” (p.507). In fact, Blackburn and Reed (2005) also found that parents of children with disabilities used the internet as a medium to receive information regarding issues of significance. Needless to say, care providers working with families should also be given information that can assist them in helping families. If they are not provided the tools and resources that can cater for each families needs they should be able to assist families, in terms of where they can turn to for additional help.

As stated by Strunk (2010), families experience high levels of stress when they are unable to meet the demands of caring for a child with special needs (p. 627). A number of families are lucky enough to detect that their child needs attention or assistance from birth, other families may find out at a later time. The nature of caring for a child, who requires special care, is such that, families may be aware of the child’s challenges, but unsure of the exact issues that will surface when the child begins interaction with other children through an educational setting or social events.

On the other hand according to Taub (2006) children with special needs may not be identified until after they have been in the education system for some time. What's more, unexpected injuries may occur at a later age, resulting in a child developing special needs. Research indicates that early detection results in better care because "Only children who are detected early in life can participate in early intervention programs and services. Thus, the 70 to 80 percent who are not currently being detected before entering school cannot benefit from Early Intervention Programs and Services" (The Center for the Improvement of Child Caring, n.d.). Some of the benefits include the children completing high school, being able to live independently and holding regular jobs.

In addition Guralnick, (2005) pointed out that,

Ensuring the availability of well-coordinated, highly effective early intervention programs in every community, each representing contemporary principles and practices, is held to be a reasonable goal by policy makers, parents, and professionals. It is further thought that the absence of uniformly high-quality early intervention programs can jeopardize the health and optimal development of our nation's vulnerable children and pose increasing challenges to the ability of families to function effectively (p. 1).

The research indicates the need for the identification of special needs in children as soon as possible; this determines effective intervention. Professionals working with children may also serve as a form of intervention screening for families because they can identify when families might need assistance. Research indicates that "Most students with disabilities (around 96 percent) are being educated in regular school buildings, and almost half are in regular classrooms

for most of the day” (U.S. Department of Education, 2005, para. 4). In fact, Bruder (2010) makes claims that interventions, programs and services for families caring for children with special needs continue to grow and advance as a result of the recognition of the need for assistance at the early stages of a child’s life (p. 340)

Although intervention services and other resources may be made available to families caring for a child with special needs, families may not necessarily be making use of these resources. This may be because of late intervention, generalization of concerns specific and peculiar to a child, cultural differences, a lack of knowledge in a primary caregiver, or an overall lack of resources to assist families. Research continues to indicate the need to investigate this population because early intervention has been known to reduce the challenge for families.

Summary

Families caring for children with special needs struggle to cope with daily challenges. The problems they experience are continuous and may vary from one family to the next depending on family context. Whereas one family may struggle with caring for a child with special needs while caring for another sibling, another family may be struggling with combining time spent at work and time spent at home with the child. Often problems are cumulative in nature and one issue can cause another to manifest. The demands of families caring for children with special needs have placed a strain on both families and the resources available to provide support.

Family needs are unique and therefore the intervention services and access to resources would be most effective if they address individual family need. Although this need exists, the intervention and access to resources available to families are not adequate enough to provide for the needs of this growing population. Families are often unable to cope effectively with the stress

associated with caring for children with special needs, because society keeps evolving and with it comes new social, economic, mental or physical challenges. Most families caring for children with special needs rely on coping strategies to get through the day. The unique demands on families with a child with special needs require them to also rely on various intervention services and access to other resources to provide appropriate care. The intervention services and access to other resources play a major role in providing positive results for these families. The intervention services and access to other resources may not necessarily eliminate the problems families experience, however they influence the different components that exist in their lives.

Coping strategies are a major component in the lives of those caring for a child with special needs. They have a key role to play in the management of the situations in which families find themselves. For the most part, the process of using coping strategies may be conscious or unconscious, but the successful coping is what is essential for these families. Intervention services and access to other resources influence the success of coping to a larger extent.

Chapter 3

Methodology

The purpose of this study was to identify intervention services and access to other resources available to families caring for children with special needs, determine whether the resources pertain to the specific needs of those caring for children with special needs, and ascertain the extent to which resources influence coping strategies for these families. This chapter describes the study design, sample procedure, data collection and process for data analyses.

Research Design

The research design used was a mixed methodology self-report approach. The participants were asked to complete one questionnaire. There were 14 questions in total, which included closed-ended questions and open-ended questions and some of which were in tabular form. The closed-ended questions provided demographic information of the participants in the study, such as their age and educational background, while the open-ended questions was used to gather richer data as participants elaborated on earlier closed-ended questions and provided more information regarding their use of resources to address the special needs of the child or children for whom they provide care.

Data was analyzed using a descriptive content analysis and a hermeneutical analysis, which required an in-depth interpretation of the information that was reported. The researcher identified common patterns that emerged from the data, and also identified pertinent information reported by participants on the extent to which intervention services and access to other resources influence coping strategies. The nature of the questions that were posed to participants, were structured in a way not to restrict participant responses. They were given an opportunity to

express their thoughts and emotions if any existed, concerning their intervention and resources that were and may have been available to them.

Sample and Sample Procedure

The participants who received the questionnaire were a purposively selected sample of primary caregivers of a child or children with special needs. The participants had been the primary caregiver from the onset of the child's special need or disability. The participants' age and type of family configuration were not deemed pertinent to the current study. Participants were contacted through three different facilities. The Department of Communication Disorders and Sciences located in the human services center at Eastern Illinois University was the first to be identified to have access to willing participants for the study. The department had a clinic that provided services to children and their families. The children who report to the clinic had various diagnoses ranging from delayed speech, to Autism and Apraxia. The Human Services Director at the clinic identified the individuals that met the criteria for the study and invited them to participate in this research project. The Human Services Director was provided a brief written explanation of the study to verbally share with the potential participants (Appendix A). Each individual that indicated an interest in the study was given a packet of information which included the questionnaire (Appendix B), along with participant instructions (Appendix C), and the consent form (Appendix D) by the professional working with the child during their scheduled appointment.

The Charleston Transitional Facility (CTF) is a non-profit organization which specializes in working with individuals with developmental disabilities. All the participants from CTF who took part in the study had their children in The Autism Program (TAP) under the CTF organization. Family Matters located in Effingham. Family Matters Parent Training and Information Center is an organization that empowers parents and professionals to achieve the

strongest possible outcomes for students with disabilities, and to enhance the quality of life for children and young adults with disabilities.

Instrument

In order to gather as much information as possible, one instrument containing both closed and open-ended questions was used to collect the data for this study. The O-Special Needs Self Report Questionnaire (Appendix B) was developed by the researcher with the sole purpose of identifying intervention and other resources to which participants have access and then exploring each family's use of these resources. The instrument was also designed to identify whether the participants perceive that these resources have influenced their coping strategies. The questionnaire was developed based on the objectives of the study.

A version on the questionnaire was pilot tested with two families both caring for a child with special needs children. Face validity was obtained from the professor in the course for which the instrument was initially developed. The O-Special Needs Self Report Questionnaire provided the researcher with information to identify the intervention services and other resources available to the families caring for a child or children with special needs and if having access to intervention and access other resources pertain to their needs.

The questionnaire was also used to obtain data that would ascertain the extent to which resources influence coping strategies for these families. Overall the intended purpose of the questionnaire was to collect data which reports on intervention services and access to other resources, and also to interpret their report and carry out an in-depth analysis of the extent to which the intervention services and access to other resources influence their coping strategies.

Procedure for Data Collection

The contact with the first nine participants was initiated by the Human Services Director of Health Services on the campus of Eastern Illinois University, on the researcher's behalf. When the primary caregiver of the child or children expressed interest, and agreed to participate in the study, they were presented with a packet of information regarding the study which included and the O-Special Needs Self Report Questionnaire (Appendix B), participant instructions (Appendix C) and paperwork addressing the informed consent (Appendix D).

The researcher's contact information was made available on the consent form, as well as that of the thesis advisor. The participants could contact the researcher by phone or email if they needed clarification regarding any aspect of the study. Participant's receipt of the consent form along with the questionnaire served as acknowledgement and willingness to participate in the study before progressing to complete the questionnaire. The informed consent and questionnaire were placed back in the packet upon completion and returned to the facility to be returned to the researcher. A total of thirty seven packets were handed out to primary caregivers who use the services at the clinic with a return rate of 24% ($n = 9$).

The program coordinator at CTF electronically sent out the participant instructions (Appendix C), the consent form (Appendix D) and the questionnaire (Appendix B) to 100 primary caregivers. Participants were asked to email completed questionnaires by email to the researcher. The project coordinator at Family Matters Parent Training and Information Center electronically sent out the participant instructions (Appendix C), the consent form (Appendix D) and the questionnaire (Appendix B) electronically to 118 primary caregivers in the following counties: Champaign, Clark, Coles, Crawford, Cumberland, Douglas, Edgar, Effingham, Jasper, Moultrie, Piatt, Shelby, and Vermilion. One participant was mailed the instructions, the consent

form and the questionnaire with a return stamp, which she completed and returned to the researcher.

Two participants sent the completed questionnaires back to the researcher by email.

Family Matters sent out 118 the packets electronically with a return rate of 4% ($n = 3$).

Charleston Transitional Facility sent out 100 packets with a return rate of 4% ($n = 4$).

Participants were never identified by name and data was used in the aggregate, which negated the risk of any identification of specific participants. The nature of the topic might have been sensitive to participants; the self-report aspect allowed participants to feel less pressured when asked to reflect on their experiences and opinions. This helped ensure honest and accurate information. This anonymous method of reporting information helped reduce the risk of participants withholding any information that would have significantly contributed to the study.

Data Analysis

Data was analyzed using a descriptive content analysis and a hermeneutical analysis which requires an in-depth interpretation of information. A descriptive content analysis was used to interpret responses of participants and through their responses, understand the context in which they find themselves as related to the research questions for this study. According to Foresight enriched Research Infrastructure Impact Assessment Methodology (n.d.) “descriptive content analysis examines the quantitative and qualitative data collected through methods as e.g. document analysis, interviews or surveys with the aim of summarizing the informational contents of these data with respect to the research question. The informational content is presented in a straight and descriptive summary structured according to the needs of the study” (para. 2.). Statistics were calculated by hand to analyze demographic information; in addition data were “identified and examined using a process called constant comparison, in which each item is checked or compared with the rest of the data to establish analytical categories” (British Medical

Group, 2000, para. 4). Analytical categories were identified as they emerged from the data. When this was achieved, hermeneutics were applied to modify data.

According to Burton (2000), “hermeneutics address issues related to the interpretation of data. “ The aim of hermeneutics is to make clear an object of study or an area of enquiry that is currently unclear and requires further clarification” (p. 22). Research also states that “hermeneutics focuses on the significance that an aspect of reality takes on for the people under study” (Hermeneutic Theory, n. d). According to Paterson and Higgs (2005), “there are three key philosophical assumptions or constructs that inform hermeneutics as a strategy for knowledge creation” (p. 342). The three keys include an understanding and interpretation of what is being studied through language, knowledge acquired through a detailed understanding of the text and research objectives, and a circle that is created between the researcher, parts of the text and the whole text (p. 343).

Summary

The research design was developed to identify intervention and other resources available to families caring for children with special needs, determine whether the resources pertain to the specific needs of those individual families, and ascertain the extent to which resources influence coping strategies for these families. To achieve this, the researcher collected data from primary care givers of a child or children with special needs. Using a mixed methodology self-report approach, participants were asked to complete The O-Special Needs Self Report Questionnaire. The data collected was analyzed using a descriptive content analysis, the constant comparison model and hermeneutical analysis.

Chapter 4

Results

The purpose of this study was to identify the intervention services and other resources available to families caring for a child or children with special needs, determine whether the resources pertain to the specific needs of those caring for a child or children with special needs, and also to ascertain the extent to which intervention services and resources influence coping strategies for these families.

This chapter presents the results obtained after collecting and analyzing data. The research design used for the study allowed the researcher to identify pertinent information about the child with special needs, such as when the need was identified, how the need was identified and when and what intervention services and resources were made available to the child and the child's primary caregiver. In addition participants reported on their access to resources, the kind of information they received concerning their child, as well as the influence their intervention services and access to resources had on their coping.

Participant Demographics

Participants that were identified by the researcher were a purposively selected sample of primary caregivers of a child or children with special needs. The participants had been the primary caregiver from the onset of the child's special need or disability. The participants' age and type of family configuration were not deemed pertinent to the current study. Participants were contacted through three different facilities, the Department of Communication Disorders and Sciences at Eastern Illinois University, the Charleston Transitional Facility and Family

Matters. A contact person at each facility assisted the research by identifying individuals that met the criteria for the study and inviting them to participate in the research project.

The facilities were also provided a brief written explanation of the study to verbally share with the potential participants (Appendix A). Individuals from the university that indicated an interest in the study were given a packet of information which included instructions (Appendix C), the consent form (Appendix D) and the questionnaire (Appendix B) at the facility.

The interested participants from the other two facilities were also sent the questionnaire, participant instructions and the consent form electronically. Only one participant was mailed an envelope with a return stamp, which included the instructions, consent form, and the questionnaire to complete and return to the researcher. Two hundred and twenty- five questionnaires were sent out in total, and 16 were completed and returned to the researcher.

Statistical analysis of participant demographics indicated that the average age of the participants was 36 years. The number of years that the participants had cared for a child with special needs ranged from 1 – 12. The average number of years was 6. The average age of the children of the participants was eight years, and the average age at which they were diagnosed with special needs was about 2 years of age.

Autism was the diagnosis reported the most often by the participants in the study (see Figure 1). There were six (38%) participants who indicated having a child with some form of Autism.

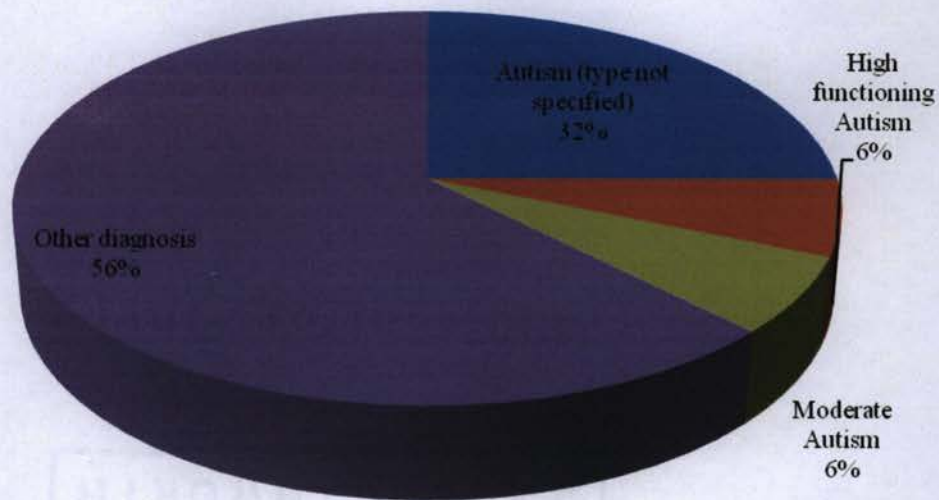


Figure 1
Participants' children's diagnoses ($N = 16$)

Each of the participants lived in the home with their child or children. A majority of the participants (thirteen participants, 81%) indicated that they cared for only one child with special needs and three (19%) cared for two children with special needs. Eleven participants (69%) cared for a sibling without special needs in addition to the child/children related to the scope of the study, while five (31%) participants care only for the child with special needs. One participant

that cared for a sibling without special needs did not do so on a daily basis because the child was a step child and not always in the home.

Participants relied on various caregivers when they were not available. One participant (6%) had an aunt providing care in the child's home during the day. Another participant (6%) had a grandmother of the child who provided care for the child. All other participants provided primary care and depended only on the other parent of the child for assistance. One participant (6%) did not have help from the other parent and was solely responsible for providing care.

Data Collection

A total of 225 questionnaires were sent out to possible participants. Each participant received instructions for completing the questionnaire as well as a copy of the consent form. In total 16 completed questionnaires were returned to the researcher and were used for the study. While this only represented a 7% return rate, this was deemed acceptable given the fact that the study was exploratory in nature. Nine participants from the Department of Communication Disorders and Sciences at Eastern Illinois University returned their completed questionnaires. Four of the participants from Charleston Transitional facility and three participants contacted through Family Matters sent the completed questionnaires back to the researcher by email and mail.

Data Analysis

Data were analyzed using the constant comparative method (Corbin and Strauss, 2008). This method allowed for the analysis of data through the identification of disparity and likenesses within participant responses. Concepts that appeared more than once within the data were identified and constantly reevaluated as new data emerged. If concepts stayed relevant throughout

the process they were then grouped into initial categories, which then led to the emergence and identification of over-riding themes (Appendix E). The process of data analysis was on-going; as reoccurring concepts were identified in the raw data and categories/themes were established, they were checked and double-checked with new data in order to establish relevance. Corbin and Strauss stated that “this type of comparison is essential to all analysis because it allows the researcher to differentiate one category/theme from another and to identify properties and dimensions specific to that category/theme” (p.73).

Data analysis for this study used two steps, open coding and comparative analysis. The researcher employed the use of open coding to determine initial categories by breaking data apart and identifying concepts that were reoccurring (Corbin & Strauss, 2008). At the same time, the researcher qualified concepts in terms of their properties and dimensions (p.195). As concepts continued to remain relevant as more data were analyzed, those concepts morphed into categories.

Comparative analysis was used to further define categories and develop themes. Corbin and Strauss (2008) described the process as “comparing incident against incident for similarities and differences. Incidents that are found to be conceptually similar to previously coded incidents are given the same conceptual label and put under the same code. Each new incident that is coded under a code adds to the general properties and dimensions of that code, elaborating it and bringing in variation” (p. 195). In this manner all data were broken down, labeled and used to identify characteristics that existed for all participants. The researcher began to place data into categories, and did so while taking note of similarities and differences, as well as characteristics that stood out from all the data. Vandyk and Baker (2012) stated that the approach of constant comparison “features the assignment and reassignment of data to units and units to categories,

with every piece of data continuously compared with every other piece of data. This back and forth assessment allows for both refinement of units and categories in an ongoing manner” (p. 351). This process of analysis allowed the researcher to develop core categories.

Identification of core categories. Data analysis led to the development of three core categories. The three core categories which were identified were as follows:

- Core Category # one: Individuals caring for a child or children with special needs identify personal coping strategies which aid in their ability to provide care.
- Core Category # two: Individuals caring for a child with special needs report access to appropriate intervention services and other resources.
- Core Category # three: Individuals caring for a child or children with special needs have different experiences when it comes to intervention services and other resources and therefore they respond differently regarding their perception of the availability, access and use of intervention services and other resources.

Each core category represents a grouping of concepts that reoccurred during data analysis. The following sections of this report will use participant voices to illustrate the nature of each category and subcategory.

Core category # one: Individuals caring for a child or children with special needs identify personal coping strategies which aid in their ability to provide care . Core Category number one was related to the coping strategies used by participants caring for a child with special needs. The researcher found that participants identified various methods that they would use to manage their daily lives, which were termed “coping strategies.” Several sub-categories were identified under this category.

First, the data analysis revealed that participants had the belief that they could only truly rely on themselves for the tools needed to cope with the stress of raising a child with special needs. One participant reported,

Talking to someone with the same situation really helps. Family that helps take care of the child understands but it is hard to talk to anyone else about your situation because they just don't get it. I haven't been offered much support. I don't seek much support for myself though.

While most participants indicated the need to avoid reliance on others, they did so for various reasons. Some felt like they did not need support, and those that would like assistance often gave up because people were unable to understand their situation and help effectively ease their struggle. One participant stated,

Support groups can be depressing and full of angry delusional parents. I stayed as far away from them as I could.

Another participant indicated this concern by stating,

I asked for help with my son for years from professionals, family and friends. Most of these individuals were in denial about the severity of my son's issues or plain arrogant. This led me to seeking support regularly, which was awful for me emotionally and mentally. Also when individuals would offer support, I would end up having to come pick him up or get calls telling me about what difficulty people were having with him. A lot of times it's just easier and less stressful if I just take care of him myself.

Another participant described her struggle with her child's behavior. She stated,

I have been known to hide a candy bar in my room and lock myself away to eat it when I faced a difficult day. During the most difficult years (the pre-school years) we faced fecal smearing and hair pulling and I relied heavily upon prayer and meditation on God's word. There were no volunteers for babysitting due to the unpleasant behaviors and my husband and I were on our own with parents living hours away, unable to help us.

The second subcategory under Core Category #1 was related to the fact that participants recognized the need to stay positive and healthy for their child. For the most part, individuals were concerned about how their well-being would reflect on the child and they were determined to keep any negative atmosphere away from the child. Participants attempted to do so in a variety of ways. For example, many participants indicated that regular exercise helped them take some time for themselves and also reduce stress. Statements such as the following indicate one participant's need to focus on herself in order to better help her child.

Maintaining a positive approach on a daily basis is a must and is very helpful, but sometimes challenging. I take the one day at a time approach, exercising helps immensely and it keeps my depression under control, running helps me relax and remain focused on my son's needs, reading and photography get to be an escape for me. I love taking photos and editing, it relaxes me.

Participants also reported that they had accepted, and came to terms with, having to care for a child with special needs. Participants who expressed success in coping felt that acceptance

of their unique situation gave them the much needed strength to keep going because they were prepared for the challenge.

Acceptance was most helpful; once you accept what your child is dealing with it becomes manageable. I have learned to accept his limitations and that I have to prepare for certain situations.

Participants reported that acceptance of the loss of a typical child and an understanding of the impact of a variety of situations on a child with special needs was crucial. For instance one participant stated,

I try to go to social events I know he can deal with and avoid others.

She had accepted her child's limitations, learned what emotional or physical challenges may exist for this child, and took measures to cope. Another participant stated that telling her son what was going to happen each day in sequential order worked well for her, others felt music helped relax both themselves and their children. Others turned to their faith for support, with one participant stating that church assisted and that it helped to be surrounded by others with a strong faith.

Core category # two: Individuals caring for a child with special needs report access to appropriate intervention services and other resources. This Core Category identified areas of access to appropriate intervention services and other resources. Several subcategories were identified by the researcher.

The first subcategory is related to the use of professional services. All of the participants indicated that they had participated in a professional assessment, and although some were not

pleased with the interventions services and other resources they received, they indicated that they were aware of the diagnosis, and resulting special needs, of their child. One participant stated,

I received information about an early childhood intervention program after I took my child to a birth to three screening.

Another individual stated,

We received early intervention services and a list of service providers, but other than that nothing else. We found the remaining services ourselves.

During analysis the researcher found that the majority of participants found out about the child's special need through a professional, and were then directed to some form of intervention service or other resource. Those who noticed the child's developmental issues themselves and sought help were provided with a screening and an assessment upon contacting a professional. Regardless of where or how participants accessed information, at every point in analyzing data the researcher came across a reference to a professional who helped the family.

The second subcategory addressed the fact that participants reported that they felt the need to turn to sources for information concerning their child in addition to what they received from professionals. They indicated that most of the information they were seeking concerned how to cope with the situation, how to care for the child, and what would make life easier for the child and the family. For example one participant indicated that she did not have much information in terms of financial planning or care for the rest of the family, while another participant clearly stated,

Money, we use to have it, now we don't: His needs have depleted our resources horribly and we have had to forego programs because we cannot afford them.

Another caregiver stated,

We would love to do ABA (Applied Behavior Analysis) but have no resources for it.

Another participant indicated that she received adequate information on medical intervention services following the assessment of the child and it was very helpful, however emotional or psychological information was not given. She had to seek information regarding those topics on her own.

A majority of the participants felt they were aware of the type of support required for both themselves and their child; they had information both from professionals and from the sources they had located on their own, such as resources available in the community. However, not every participant believed that they had access to what was needed for them or their children. For instance, one participant reported of starting a lego social skills group for her child and other children in the community. She felt she was unable to get access to all the intervention services and other resources she needed; therefore, she started her own group. In doing so she was also able to help other parents caring for a child with special needs.

Core category # three: Individuals caring for a child or children with special needs have different experiences when it comes to intervention services and other resources and therefore they respond differently regarding their perception of the availability, access and use of intervention services and other resources. This core category addressed participant

experiences with intervention services and other resources as well as their perception of the experiences.

The first subcategory explored the intervention services or other resources found to be beneficial by the participants in the study. Participants identified resources which were useful, but strenuous at the same time. Participants also indicated a need for access to intervention services and resources available specifically for the need of their child, not generic in nature. For example, one participant felt she did not have access to particular services or resources such as applied behavior analysis, which she felt would help her child. Another participant felt that respite care would have been beneficial, stating

Otherwise parents are on their own.

In addition when a child's behavior is difficult to manage, few people offer to help so respite is difficult to obtain. This leads to little opportunity for relaxation techniques like walking or reading.

The second subcategory described the fact that participants sometimes felt they did not receive adequate information on intervention services and resources. A participant explained the fact that her son became involved with Screening Assessment and Support Services in the last month of the 2012 -2013 school year, and the interventions services and resources were very helpful. However, she felt he could have been diagnosed earlier. He was in the school system for four years and had consistent behavioral issues. Yet, her son's behavior was not addressed until he threatened to commit suicide. She believed if their interventions, and the following resources, had come sooner it would have saved her son and their family a lot of heartache. Another participant also expressed concern about the timing of intervention services and resources, stating

that most children with the same condition as her son have a classroom aide, at least part time, therefore,

If those services were more easily available early on, then children will most likely do so much better.

Other participants felt that others did not understand their needs.

It helps to talk to my sister, but one has to be careful opening up to others. Most people don't understand our situation and instead of listening they may try to "fix it" instead.

The term "fix it" was used to describe how the participant felt about how people make conclusions about her situation. She stated that she did not believe anything was wrong or broken in her son, but rather, would just like to be heard. She also indicated not making use of communication as a resource because of the judgment she receives. Other participants also shared concern about being misunderstood by both family and friends and professionals, because they received help that was insufficient or not beneficial.

We waited ten months and fired nine pediatricians before we were granted an assessment, so during that time we educated ourselves online and at the library about his symptoms.

Identification of themes. Based on the qualitative data analysed for the study, themes were identified and compared with each of the sixteen participant responses for the study (See Appendix E). Participants may have felt, perceived, experienced or were associated with all or a number of the themes that emerged from the analysis of the data. For the purpose of the study however, participants who did not in some way clearly state or make any indication in their

response that could be associated with a particular theme, were not taken into consideration by the researcher during the process. The themes which occurred the most often were as follows:

1. Participants acknowledged the help of professionals or the specific intervention and resources to which they have had access.
2. Participants felt they did not receive adequate information of intervention services and resources.
3. Participants indicated specific actions taken to manage with caring for a child with special needs.
4. Participants felt that they were aware of the type of needs they and the child require.
5. Participants felt that there was room for improvement with availability of intervention and caregiver and child.
6. Participants accepted and had come to terms with caring for a child with special needs.
7. Participants identified intervention services and resources which could increase coping.
8. Participants recognized the need to stay positive and healthy for the child.

The least occurring theme for all sixteen participants was that the participant was hopeful about the availability of intervention services and other resources in the future.

Hermeneutic analysis and results. Hermeneutics was then used to make sense of the data as a whole. According to Burton (2000), “hermeneutics address issues related to the interpretation of data. The aim of hermeneutics is to make clear an object of study or an area of enquiry that is currently unclear and requires further clarification” (p. 22). This analysis was used by the

researcher to make meaning of the data. Participants made mention of how pleased they were with intervention services and other resources they were able to access in the past, what they had currently and their hopes for the future. Other participants expressed disappointment in the information they received and felt hopeless when it came to receiving intervention services and other resources that were pertinent to their needs. Although themes emerged during the analysis process, each participant had a different reality in relation to the themes. The subjective nature of the data influenced the use of hermeneutics.

The demand that intervention services and other resources meet the specific needs of each participant's child, and their perception of the services they received was their basis for their expression of reality. Initially participants seemed to be indicating that intervention services and other resources were not available. However during analysis the researcher identified that participants felt the intervention services and resources were available but not adequate, and could have been more useful if received in a more timely manner or if they met each child's unique needs. Reoccurring statements such as,

.....nothing else, that was all, was not enough, I also had to search, we found information from Google, local newspapers, talking to others and taking walks to support awareness, I asked and looked around.

The following statements were also important and indicated the timely manner participants referred to,

I had to wait till he was three

Not until he was three

Not until he got help from the school system.

Furthermore, the process of hermeneutics required the researcher to analyze participant stories as told through their narratives. In this process the researcher referred to the raw data that was presented, the final themes that emerged and in order to seek clarification of the subject under study, evaluated both sets of information in relation to the research questions that were developed for the study. The analysis process allowed the researcher to understand the experiences of primary caregivers of a child with special needs. The individual texts were used to express the realistic context in which the individual primary caregivers cope. The researcher was able to understand their suggestions, comments, opinions and real life scenarios, when it comes to the availability, access and use of intervention services and other resources.

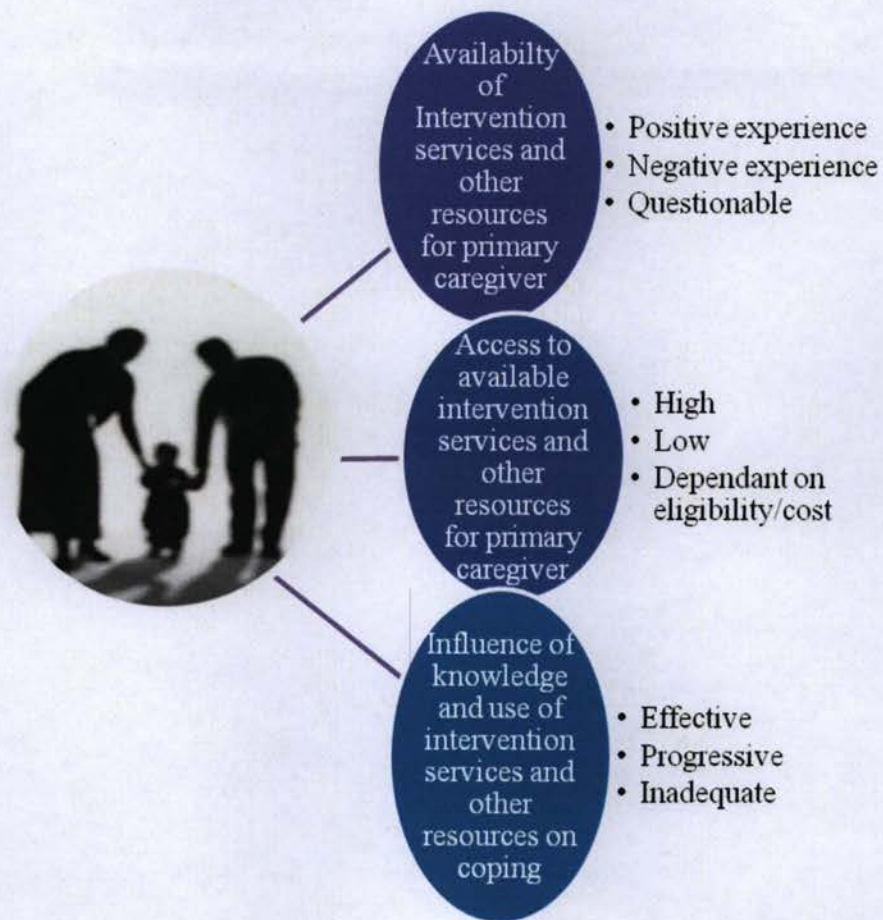


Figure 2. Details of reality for primary caregivers of a child with special needs

Results in relation to the research objectives. On a whole, data analysis gave insight into the research objectives for the study. The research objectives of this study included:

1. Identify the specific intervention, and other resources, available to families with a child with special needs.
2. Determine if families caring for a child or children with special needs have access to the intervention services and other resources that pertain to their specific situation.

3. Ascertain the extent to which the intervention services and access to other resources influence family coping strategies.

The first research objective was to identify the specific intervention services, and other resources, available to families with a child with special needs. A majority of the participants stated that they utilized early intervention services. Other individuals indicated other services, such as SASS (Screening, Assessment and Support Services), TAP (The Autism program of Illinois), IEP (Individualized Education program, the internet, other primary caregivers of children with special needs, community resources, health services, dance and music therapy, speech training and DTT (Discrete Trial Training) that they utilized. The researcher was able to ascertain that a variety of services were available to children with special needs and their families.

The second research objective sought to determine if families caring for children with special needs have access to the intervention services and other resources that pertain to their specific situation. Participants had access to the intervention services and other resources that pertained to the specific needs related to the assessment and evaluation of the child. Some families had access to community resources, but they had to identify these resources by themselves. It is important to note how often participants utilized others for support. For example, family members and life partners provided assistance as did other parents raising children with special needs.

These individuals were invaluable because they knew, and generally understood, the unique aspects of each child's condition. A majority of the participants had access to services such as an Individual Education Plan; this made them feel like provisions were being made for

their child's education, as well as social and psychological development. The public school system also had services, such as special classroom aides, that were helpful to participants in providing individualized care for their child or children.

The internet was used as a source of information. Participants reported that it provided more specialized information on intervention services and resources than they had received from professionals. It also provided alternative ways to approach caring for a child with special needs. Those who did not feel they did not receive much intervention services and other resources, reported that using the internet gave them confidence in knowing more about the child's needs and provided ways to help the child and themselves.

The research concluded that families do have access to services that pertain to the specific needs of their child or children. Some of those individualized services were provided in the schools in the form of classroom aides and IEPs. However, many specialized services had to be identified by families themselves. The internet was identified as a source of a wide variety of information for families.

The final research objective sought to ascertain the extent to which the intervention services and access to other resources influence family coping strategies. The perception of the intervention services and access to other resources which influence family coping strategies was subjective. Participants each had different ways of coping, and the effectiveness of their method was dependent on the individual. One participant decided to take matters into her hands and start a lego support group; this group benefited her child as well as other children with special needs. For example, participants found stories from the internet about families just like themselves,

which provided them comfort. They reported themselves to be better able to cope knowing that others had been in the same position and continued to manage.

Primary caregivers who used strategies such as exercise, listening to music, taking time off, turning to faith or talking to others, indicated that it helped to ease the stress, but they believed that if the intervention services and other resources that assisted them with the child's needs were adequate and tailored to meet their different needs, they would manage better. Affordable or alternative sources of intervention services and resources could help participants cope better while providing care for the child. A number of participants indicated that when they received intervention early, it provided a strong foundation for them to work with the child. Those who had to wait until they were eligible or could afford it, expressed that they believed the child would have made better progress, if intervention had been introduced at an earlier age.

Conclusion

Each participant provided care for a child or children with special needs. On the whole participant experiences were similar, different or completely unique. The participants' family dynamics and the special need of the child gave insight into the availability, access and influence on coping that was experienced. The three core categories identified were focused on the fact that participants identified personal coping strategies that aided in providing care for the child. The participants also reported having had access to professional help. Lastly participants indicated their differences in experiences while providing care for the child with special needs. Participants felt they did not receive adequate information of intervention services and resources. A number of themes that stood out during analysis pointed out that participants indicated specific actions taken to manage with caring for a child with special needs, participants felt that they were aware of the

type of needs they and the child require, participants felt that there was room for improvement with availability of intervention and caregiver and child and participants recognized the need to stay positive and healthy for the child.

Chapter 5

Discussion and Conclusions

This chapter reintroduces the purpose of the study and its relation to the research objectives. Results are discussed and responses of individual participants are also used to support the discussion. Information from the literature review is used to support the discussion throughout the chapter. The limitations of the study are acknowledged and addressed. Recommendations are provided for professionals working with families or primary caregivers of children with special needs. In addition recommendations for future research concerning the purpose of the study will also be made. Finally the chapter ends with a conclusion of the study background, results and implications.

Summary of the Study

A number of studies have researched coping strategies used by families caring for children with special needs; however few have studied whether such resources are helpful in meeting specific needs or whether the available intervention services and resources have an influence on family coping. The research objectives of this study were to, 1) identify the specific intervention services, and other resources, available to families with a child with special needs, 2) determine if families caring for children with special needs have access to the intervention services and other resources that pertain to their specific situation, and 3) ascertain the extent to which the intervention services and access to other resources influence family coping strategies.

Explanation of core categories. The first core category that was identified in the analysis implied that individuals caring for a child or children with special needs identify personal coping strategies which aid in their ability to provide care. There appeared to be several subcategories of useful information in this main category. For example, based on the data collected for the current study it could be inferred that individuals that care for a child with special needs tend to believe

that they can only truly rely on themselves for the tools needed to cope with the stress of their life. For example, one participant in the study mentioned that she stopped seeking support from others. It was mentally and emotionally stressful for her when people offered help. She stated that she was tired of being called to pick up her son because he was too difficult to handle. In her opinion taking care of him by herself was easier to do. She wrote,

A lot of times it is just easier and less stressful if I just care for him myself.

Although the participant felt this way, she still indicated the need to have a break to relax every now and then to relax. In support of this need by primary caregivers, research by Harris (2008) found:

Families need a range of practical support to aid them in caring for their disabled child. Providing a short break can allow carers much-needed time to do other things and reduce the strain of constant caring. This support can come from wider family or friends but can also be provided by respite care in the form of home care, playgroups or short-term residential stays. (p. 360)

It seemed that individuals that care for a child or children with special needs often believe that they are alone in their struggle. Professionals should seek to identify methods to alleviate these feelings of isolation, as this was a common theme throughout the data.

On the other hand, it is positive to note that individuals also see the importance of taking care of themselves in order to better care for their child or children. Individuals caring for a child with special needs have stress in their lives, but they rely on various methods to relieve that stress, such as reading and exercising. It was interesting, that participants chose both mental and physical coping strategies to use to deal with stress. Participants reported that they did not want to create a negative environment for the child; they believed the child will do better if they were also able to manage the situation. One participant wrote,

You have to learn how to adapt for your child and give them good life experiences

Finally, this study found that a major aspect of coping with the stress of raising a child that needs special care is the acceptance of the situation and a willingness to acknowledge limitations and move forward in the most effective manner possible.

The second core category identified by the researcher in the data analysis addressed the availability of services for families; it stated that individuals caring for a child with special needs reported that access to appropriate intervention services and other resources was sometimes difficult. As with the first major core category, several subcategories of information were gleaned from the analysis.

The first subcategory addressed the fact that most of the children with special needs that were identified in the current study were receiving a professional assessment of some type. Although those that care for the children may not always be pleased with the resulting intervention services and other resources they receive, they were aware of the diagnosis, and resulting special needs, of their child.

The second subcategory revealed that individuals caring for a child with special needs overwhelmingly felt the need to turn to other sources for information concerning their child, even after they had received assistance from a professional. Individuals that were raising children with special needs were mostly concerned with information on coping with their specific situation, how to care for the child, and what would make life easier for the child and the family.

The final core category confirmed that individuals caring for a child or children with special needs have different experiences when it comes to intervention services and other resources and therefore they respond differently regarding their perception of the availability,

access and use of intervention services and other resources. This core category addressed participant experiences with intervention services and other resources as well as their perception of the experiences. The first subcategory in this section explored the idea that individuals caring for a child or children with special needs report the need for care that is specific to the diagnosis of the child, not generic in nature. This ties in to the fact that those individuals also reported feeling that they are not given adequate information regarding the services available for the specific needs of their children. Clearly, one must assume diversity when working with families raising children with special needs; one size does not fit all.

Discussion of Research Objectives

Objective one: identify the specific interventions, and other resources, available to families with a child with special needs. Data from this study indicated that those that care for a child or children with special needs are able to access a variety of resources. Individuals often have to be persistent in order to have access to the resources, but many are available. In all, this study found that access to intervention services and other resources is dependent on knowledge of where to find resources, the availability of professionals that will provide direction, the ability to search for what is needed and overall eligibility.

One outstanding issue that emerged from this study was that the use of early intervention services is prevalent. This finding agrees with Carpenter's (2007) earlier work, which found that, "the goal of early childhood intervention remains, as it always has, to meet the developmental needs of the eligible child and the needs of their family related to enhancing the child's development" (p. 666). After the diagnosis of a special need, individuals either tend to be referred to early intervention or the caregivers seek out opportunities. This is crucial to note, because research has always shown that early intervention impacts positive developmental outcomes, especially when a special need is present. Research claims that "many families when reaching out

to professionals during traumatic periods of their lives, have found that the intrinsically supportive process of early childhood intervention (in its appropriate form) has sustained them” (according to Carpenter, as stated in Carpenter 2007).

The average age of the diagnosis of a child with a special need in this study was 1.54 years. For the most part, health professionals either introduced primary caregivers to, or recommended they seek early intervention. This is an indication that early intervention services or programs form the basis for provision of other resources and services. Unfortunately, not everyone who uses early intervention services has access immediately after diagnosis, but at a certain point in time most children do receive some form of early care. As shown from the results of the study, all participants discussed their experience with early intervention and for those who were introduced to it by a professional; it was done after assessment and diagnosis of the child.

The ability to identify, access, and afford early intervention was of crucial importance to the participants in this study. In addition one should note that primary caregivers that have appropriate resources available, have access to these resources, and then utilize them tend to be pleased with the progress they make with their child and feel hopeful about the child’s future. Those who receive intervention early indicate that it helps a great deal. For example, a participant in the study stated,

Since we started with the IEP (Individualized Education Program) so quickly, I was able to start practicing techniques for speech development. The child was monitored closely by early intervention and the developmental or speech evaluators were extremely helpful in guiding us.

Closer examination of the dynamics of the use of early intervention would be of benefit. It appears that early diagnosis of a special need, coupled with immediate intervention, has been

found to be helpful to many. However, individuals also utilize more informal means to gather information about the needs of their child or children.

The researcher found that the participants in this study relied heavily on information obtained from outside of the professional sphere as a resource. Therefore it can be implied that individuals with a child or children with special needs seek help from peers. The researcher also found that individuals use a variety of methods to find information to supplement what they receive from professionals. Individuals that care for a child or children with special needs have options such as support groups and internet networking, but also rely on word-of-mouth and even resort to starting their own enrichment groups if deemed necessary.

Support groups are not a popular option for individuals with a child or children with special needs. Within this study, only a third of participants utilized support groups. The participants were not asked to indicate the reason they chose to avoid participation in such groups, so it can only be speculated whether they were not aware of such groups or that they chose non-participation. One participant of the study stated that support groups could be depressing and full of angry delusional parents, so she stayed as far away from them as she could.

On the other hand, many individuals obtain a large part of their information from other families. One participant stated,

For several years we pieced together information from other parents who had children with special needs. Through this network we discovered equestrian therapy, dance/speech therapy and grants and resources in the community.

It could be inferred that families are very individual in their need for peer support and that they seek out what is needed. Professionals may assist caregivers by helping in the development of tools that provide them with the ability to identify credible information in online source material. In addition, it seems that professionals could help facilitate the peer-sharing that is currently

taking place informally. Once resources are identified, finances play a part in whether they can even be utilized.

A number of participants in this study mentioned the fact that finances impacted availability of resources. It is expensive to maintain the care of a child with special needs. Often, money problems don't occur until the diagnosis of a special need and the on-going cost associated with addressing the need deplete family finances. In addition, children often require enough specialized care that family members cannot work full-time, leaving caregivers the option of working only part-time, if at all. This finding is in line with the work of Sen and Yurtsever (2007), who said that,

The care and treatment of a disabled child also creates difficulties financially for families. While the economic load that every child brings to his or her family is very high, the care, treatment, and education of a disabled child brings an even greater burden to the family. (p. 247)

It is evident that seeking and maintaining care for a child or children with special needs puts a strain on family finances. Being eligible for intervention services and resources is one aspect of the entire picture, having the resources to pay for it when eligible is another. This issue must be addressed because research has shown that those that are able to better support their child financially also have children with better outcomes. According to a study by McGill, Papachristoforou and Cooper (2005), "more articulate middle-class families with financial and psychological resources are more likely to succeed than others" (p. 164). This issue needs to be addressed and factored into the intervention and services provided for families. This way all family types can afford to support their child with special needs, while also caring for other siblings. Caring for a child with special needs is an on-going process, therefore access to

resources also needs to be a process. Progress needs to be monitored, evaluated and reinforced to ensure that the child is always getting the help he or she needs.

Religious resources were one of the least mentioned items in relation to resources available; however they were used by some participants. Religion was identified as a way to gain hope and as a method used to get through tough times. It is interesting to note that one participant in the study used her church to identify other resources.

I stumbled upon the birth to three programs through therapists who attended my church. My pediatrician did not point me towards any resources or therapies.

In conclusion, individuals that care for a child or children with special needs have access to a variety of resources. Two important resources are early intervention and peer support. Professionals that work with families would be wise to address the need for every child to have intervention services as quickly as possible following diagnosis. In addition, professionals could assist with the development of credible peer-sharing options with specific communities. Finances impact availability of resources for many families. This is important, because research has shown that families with a child with a special needs that have better financial resources report better outcomes for their children. Finances should never impact quality of care. Every child deserves to have the same type of care, so equitable distribution of resources is a must. Finally, religion can be a resource for families struggling with the stress of a child or children with special needs. It can provide comfort as well as opportunities to connect with peers.

Objective two: determine if families caring for children with special needs have access to the intervention services and other resources that pertain to their specific situation. It is important to note that for most families caring for a child or children with special needs the severity or nature of the disability influences the dynamics of the family and the availability of intervention services and resources, as well as the ability to access these services. For instance,

families with a child that engage in behaviour that is difficult to manage (i.e. faecal smearing) have more trouble relying on others for respite care. This suggests that, to some extent, general support for families may be needed, and that this support would need to be specific to the behavioral needs of the child. Harris (2008) found the same thing, stating that “understanding the needs of children and families can better enable practitioners to provide appropriate support” (p. 359). It is evident that research supports the idea that professionals and service providers should work with the families caring for the child or children to identify their unique needs and tailor services to meet those needs.

Objective three: ascertain the extent to which the intervention services and access to other resources influence family coping strategies. For the most part participants in this study indicated more concern about the intervention services and other resources available specifically for their child or children than those used to help themselves cope. As to whether participants are aware that such situations require not only intervention for the child but also for primary caregivers, and the extent to which it influences their coping and care giving for the child, the researcher is not aware.

This study found that those that care for a child or children with special needs must have a realistic outlook regarding the situation. A realistic understanding of the limitations and opportunities available to the child is a must. Taanila et al. (2001) found the following:

Parents felt that a realistic outlook of the child’s disability and acceptance of the situation had helped them to cope. They had an optimistic attitude towards their child’s future, which also made it easier for them to accept the situation. They thought that their child would cope in his/her life and that there would be enough supporting systems for him/her to cope even later in life. (p. 80)

While Woolfson (2004) claims that “many parents of disabled children find their own ways of coping and adjusting to their child’s disability and that they subsequently hold views about disability that are different from dominant societal views and promote effective parenting” (p. 11).

Individuals that care for a child or children with special needs utilize a variety of intervention services and other resources. However primary caregivers who have access to, and effectively use, appropriate services and who witness progress by their child also seem to have better coping strategies. Therefore, it can be inferred that families that have access to, and utilize, appropriate services for their child or children are better able to cope with the stress of care giving. It is crucial for professionals to understand that provision of appropriate resources impacts coping skills.

It is also important to note that individuals seem to share a common concern when it comes to the future care of a child with special needs; and report that this concern impact coping. Children with special needs can require care from birth to death. Each child must go through early development, but may also need services during the elementary school years, the high school years (which will include puberty), and while they are adjusting to various adult responsibilities. The individuals caring for children with special needs indicate the need to feel secure that needs will be met at each stage of development. Knowledge of the availability of future resources, allows for a higher level of coping to occur.

Limitations of the Study

One major limitation of this study relates to the research design. Some qualitative methods do not lend themselves for the study results to be generalized, and this is the case for this study. The sample size used for this study was sixteen (16) primary caregivers of children with special

needs, thus the results pertain to only the population used in this research. In a few cases the participant did not seem to understand what was expected of them.

Recommendations for Future Research

This research led to some important areas of insight regarding those that provide care for a child or children with special needs. However, further research needs to be conducted with a larger sample size in order to get a broader and more realistic take on the availability of intervention services and access to resources for families caring for a child or children with special needs. In addition, quantitative methods may be helpful in collecting demographic data on the families and then making comparisons in regards to outcomes. For example, how does ethnicity, financial status, and severity of the child's diagnosis affect availability and access to, and use of, intervention and resources.

Future research needs to be conducted specifically on the types of intervention services and resources being offered by professionals, government agencies, policy makers and the rule of the law, as well as what is available through community resources, churches, the internet, books, friends and family. Further research could address the types of services needed by families, searching for a correlation between services needed and services offered. This may help professionals and families understand the supply and demand relationship that must exist for families and primary caregivers of children with special needs. Research into this topic may also allow for further understanding of the interplay between the diagnosis of a child, the family's access to intervention services, and the family's ability to cope.

Recommendations for Professionals

Families or primary caregivers may not know what they need or where to look in search for help for their child. Therefore professionals should have that information readily available for them. In addition, primary caregivers may not receive the services they need immediately, but it may help to ease their worries if they knew what their alternatives were and possible resources they could make use of in the mean time.

Worry and uncertainty is a lifestyle for most primary caregivers, and in order to reduce or eliminate what may turn into high levels of stress, professionals need to share their past experiences about working with families. In addition, listening to caregivers about their day to day challenges and real life experiences may give professionals a starting point to modify, include or eliminate practices or procedures which are available to families.

Geographical location may be an issue for families, limiting their access to available resources. Therefore the internet is often used as a strong tool to reach such families. A number of primary caregivers mentioned use of the internet in their search for intervention services and resources. It is possible that there is a lack of communication between health care providers and other professionals in the social services field. If the possibility exists for a diagnosis to be matched up with a professional to manage the child and family, and provide them with the appropriate and most efficient help they need, it would eliminate confusion of where to go after having received a diagnosis.

Education has always been a useful tool in any environment. The right learning environment should be provided for families caring for a child with special needs. Primary caregivers need to understand what it takes to cope with a child with special needs and should be

provided relevant, realistic and appropriate coping strategies to use to manage the situation. Service providers should also ensure families make use of whichever intervention service or resource they are provided with.

Conclusions

Little research has been conducted on families caring for children with special needs in relation to their experiences and perception, identification of their individual needs and if their needs are met by the intervention services and resources for which they are eligible and have access. Contemporary research has indicated that although there has been an increase in services for families to support children with disabilities, there has not been much research conducted on the efficient use of the services (Freedman and Boyer, 2000, p.) . Another area of concern for such families is if the services or resources help them to cope with the situation.

The results from this study have provided a better understanding of availability and access to intervention services and other resources for primary caregivers of children with special needs. Primary caregivers also indicated how useful the intervention services and resources were to them and how they pertained to their need. Primary caregivers indicated their perception, concerns and comments on coping strategies and, how or if intervention services and resources influenced them in any way.

It would be in the best interest of primary caregivers of children with special needs if their intervention services and resources were individualized. According to Freedman and Boyer (2000), “ for many people with developmental disabilities, family members, usually parents are the backbone of their community support system, often serving as an alternative to institutionalization” (p. 59). Research therefore supports the idea that families of children with

special needs are an important factor in the success of the access, use and effectiveness of available intervention services and other resources.

Although intervention services and resources exist for families caring for children with special needs. Primary caregivers still have some concerns about how accessible these services are to them and when they are eligible for each type of service. Participants in this study indicated that there were three major ways they identified information. Very few participants had direction from their doctors or from a medical professional after assessment and initial diagnosis of the child; they were only given medical information. In one participants report, she indicated that she only received information about the child's medical conditions, such as gastroenteritis and sinuses. A larger number of the participants got their direction from organizations working with families and children with special needs and thirdly from other professionals working for in the school system.

Families may be stifled if they do not have the appropriate interventions services and resources they need. Providing for a child requiring special needs without efficiency can result in a decline in the child's condition or perhaps lead to a standstill in development. Children build the basis for their cognitive, social and developmental stages in their young years. This is why it is important for primary caregivers of children with special needs, to have the support they need for their childhood years. Families caring for a child with special needs are doing a tremendous job managing the situation and society needs to acknowledge that and provide sufficient support (Carpenter, 2007, p.667).

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Appendix A: Cover letter

I am a graduate student at Eastern Illinois University, enrolled in the Family and Consumer Sciences program. I am currently working on my thesis and would be conducting a study on the coping strategies used by families caring for a child with special needs.

The purpose of this study is to identify the resources and intervention services available to families caring for children with special needs, determine whether the resources pertain to the specific needs of those caring for children with special needs, and ascertain the extent to which resources influence coping strategies for these families. I would be most grateful if you would assist me in identifying families who would be interested in participating in my research study.

The children or child would not be involved in the study. The primary caregiver of the child or children would be the one to answer the questionnaire that would be used in collecting data for the research. I will need 37 interested participants caring for children or a child with special needs that will be willing to participate. Any information they share will be anonymous and kept confidential. If they agree to participate, they would be handed an information packet with a formal consent form and one questionnaire, to be completed and returned two weeks after receiving them.

If there is any information you are concerned about or a question you need to ask about the study, I am more than willing to clarify. You can contact me or my thesis advisor by email.

Researcher:

Antonia Ofosu
aofosu@eiu.edu

Thesis Advisor:

Dr. Michelle Sherwood
mlmeadows@eiu.edu

Appendix B: Instrument

The O-Special Needs Self Report Questionnaire

Thank you for taking the time to fill out my questionnaire. The questionnaire is anonymous and information gathered will be used solely for the purpose of the study. Your participation in this questionnaire is completely voluntary. You may choose to withdraw at any time without penalty or prejudice. Please ask questions for clarification if you are unsure about your participation. My name is Antonia Ofosu. My contact information by email is aofosu@eiu.edu and by telephone at 217-721-7130. You can also contact my thesis advisor Dr. Michelle Sherwood by email mlmeadows@eiu.edu or at 217-581-6349.

Terms/Definitions

Coping strategies- the behaviors or actions taken by a family or individual that help to manage stressful situations.

Intervention – anything that intervenes on your behalf to assist in caring for the child with special needs. The source could be from within the family or from other external sources, such as church or governmental services.

Resource – anything physical, social or mental which can be applied to a situation for improved or satisfying results.

Access- A means to come within reach of and make use of

1. What is the diagnosis of your child?

2. Please indicate adults, if any who share primary care responsibility of the child.

3. Does the caregiver live in the home with the child? Please circle

Yes

No

4. What is their relationship (e.g. Mother, father, grandparent, sibling, friend of family etc)

5. a) If you are caring for more than one child requiring special needs, please indicate how many_____

b) Are you caring for other siblings who are not requiring special needs?

Yes

No

Please indicate how many if applicable_____

6. What is your age? _____

7. Educational background: please circle

High School

College/University

Professional training

None of the above (please specify) _____

8. What age was the child when you realized he or she needed special attention?

_____ and how old are they now? _____

9. Place check what best describes your situation.

_____ Special needs were identified by primary caregiver and followed up by a professional assessment of the child

_____ Identification of special needs were reported to primary caregiver by professional report on the child followed by a professional assessment of the child.

10. Did you receive information on intervention and other resources related to children with special needs after assessment?

_____ Yes

_____ No

a) If Yes please list the type of information you received (specify)

b) If No where did you turn to for information and what information did you find?

11. Below are some sources for intervention and other resources for children with special needs. Please indicate with a check, which you have actually used or if you have heard

12. about it through someone else (professional or not), in a magazine, book, or through media. If not leave space blank.

Intervention and other resources	Used	Heard of
Government laws and policies (e.g. IDEA, IEP)		
Support groups with other primary caregivers of children with special needs		
Religious sources		
Community resources		
Resources from a private organization		
Medical resources		
Internet resources		
School resources (teachers, class settings, curriculum)		
Technology (online information kits/technological aids for child)		

Others not stated above please indicate

13. In your opinion, have you had access to intervention and other resources that have helped significantly in caring for the child?

14. Did the time frame in which you received intervention and other resources influence the care you provided for the child? Why or why not?

15. How would you describe information you received

a) General information for any caregiver of a child with special needs.(Information which can be used by any one caring for a child with special needs and does not tackle the specific needs of your child

b) Information specific to the unique needs of your child

Please describe how you felt about the following coping strategies while using or after using intervention and other resources

Coping Strategies	Perception/Feelings
Talking to someone (friends or family)	
Using relaxation techniques (taking a walk or reading)	
Maintaining positive approach on a daily basis	
Sleeping	
Participating in religion or other form of spirituality	
Exercising	
Writing in a journal	
Listening to music	
Participating in a hobby	

Avoiding any support	
Using activities that will give positive emotions	
Physically and mentally avoiding the stressfully situation	
Acceptance (you have learned to live with it)	
Participation in social events	
Paying attention to only the positives not the negative	
Trust that with the resources you have access to and are using you can manage the situation	
Other (Please describe)	

Appendix C: Participant Instructions

Thank you for your participation in this study. The questionnaire is an important part of the study and is needed to make the study a success. Kindly note the following instructions.

1. Please read questions at least twice before responding
2. Please complete the questionnaire with a pen
3. If you are unclear about any question, do not hesitate to contact me by email at aofosu@eiu.edu or by phone on 217 -721- 7130
- 4. Please ensure that you do not leave any questions blank.**
5. If you get the questionnaire completed before the two week period, you are more than welcome to return it.
6. The consent form is your copy to keep for your acknowledgment and documentation

Appendix D: Consent Form**CONSENT FORM TO PARTICIPATE IN RESEARCH**

*Coping Strategies Used by Families Caring for a Child with Special Needs: Available
Intervention and Access to Other Resources*

You have been asked to participate in this study because you are the primary caregiver for a child or children with special needs. The study seeks to identify the intervention and other resources available to families caring for children with special needs, determine whether the resources pertain to the specific needs of those caring for children with special needs, and ascertain the extent to which resources influence coping strategies for these families.

The study is being conducted by graduate student Antonia Ofosu and Dr. Michelle Meadows, from the School of Family and Consumer Sciences at Eastern Illinois University. Your participation in this study is entirely voluntary and can be halted at any time. Your decision regarding participation in this study in no way impacts the services you are currently receiving at this location.

• PROCEDURES

If you volunteer to participate in this study, you will be asked to:

Read the consent form for participation in the study. The researcher's contact information will be made available on the consent form as well as that of the thesis advisor. You may contact the researcher if any clarification is needed. The questionnaire, instructions and consent form will be given to participants in an envelope. Participants are required to return the envelope with the questionnaire two weeks from when it was received. Participants should keep the copy of the consent form for their records.

- **POTENTIAL RISKS AND DISCOMFORTS**

There are no foreseeable potential risks involved in this study. Any information that is obtained in connection with this study will remain anonymous.

- **POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY**

You will not directly receive information on results from the study. However information from the study will contribute to the body of knowledge regarding the care of children with special needs.

- **PARTICIPATION AND WITHDRAWAL**

Participation in this research study is voluntary and not a requirement or a condition for being the recipient of benefits or services from Eastern Illinois University. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind or loss of benefits or services to which you are otherwise entitled.

- **IDENTIFICATION OF INVESTIGATORS**

If you have any questions or concerns about this research, please contact:

Antonia Ofosu

Dr. Michelle Sherwood

Principal Investigator

Faculty advisor

aofosu@eiu.edu

mlmeadows@eiu.edu

(217)- 217-7130

(217) - 581- 6349

I voluntarily agree to participate in this study. I understand that I am free to withdraw my consent and discontinue my participation at any time, and with no penalty. I have been given a copy of this for.

Appendix E

Summary of Sub Category Themes from Questionnaire

Themes	Participant Numbers															
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
Participant feels the need to rely solely on herself/himself for support	✓	✓										✓				
Participant recognizes the need to stay positive and healthy for the child	✓	✓		✓	✓	✓	✓		✓	✓	✓	✓	✓	✓	✓	
Participant identifies	✓	✓		✓		✓			✓	✓	✓	✓	✓		✓	✓

