Parents' perceptions of effective coping strategies for raising a child with autism

Dee Thigpen

Follow this and additional works at: https://scholarworks.lib.csusb.edu/etd-project

Part of the Social Work Commons

Recommended Citation
https://scholarworks.lib.csusb.edu/etd-project/3365

This Project is brought to you for free and open access by the John M. Pfau Library at CSUSB ScholarWorks. It has been accepted for inclusion in Theses Digitization Project by an authorized administrator of CSUSB ScholarWorks. For more information, please contact scholarworks@csusb.edu.
PARENTS' PERCEPTIONS OF EFFECTIVE COPING STRATEGIES
FOR RAISING A CHILD WITH AUTISM

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Social Work

by
Dee Thigpen
June 2008
PARENTS' PERCEPTIONS OF EFFECTIVE COPING STRATEGIES
FOR RAISING A CHILD WITH AUTISM

A Project
Presented to the
Faculty of
California State University,
San Bernardino

by
Dee Thigpen
June 2008

Approved by:

Dr. Janet Chang, Faculty Supervisor
Social Work

Dr. Rosemary McCaslin, Proposal
Supervisor Social Work

Dr. Janet Chang,
M.S.W. Research Coordinator

Date 6/2/08
ABSTRACT

This study examined parents’ perceptions of positive coping strategies used when raising an autistic child. Ten parents were interviewed in this study and identified personal positive coping strategies such as relying on faith, prayer or reading the bible. The parents in the study also included activities away from their autistic son/daughter such as having a hobby, exercising, support groups and socializing with friends as positive coping strategies that have helped to relieve stress. Parents in this study identified outside services/resources/organizations that helped them cope better such as the IRC, therapists, child’s teachers, and respite care. The parents in this study identified informal support systems as family, friends and neighbors as helpful in dealing with stress.

This study implied that many positive coping strategies are used when raising autistic children. As a result, social workers should not rely on a few strategies to offer their clients, but a host of strategies should be presented as each family’s problems and challenges are different.
ACKNOWLEDGMENTS

I would like to thank all of the parents who made this research project possible. I would also like to thank Dr. Fairly, Buela Tolliver, Tammy Hunt, Toni Mosely, and Elizabeth Atkins for their words of encouragement and support. I would like to give special thanks to Dwight Mathews for his patience, support, encouragement and love throughout this the MSW program.

Finally, I gratefully acknowledge Dr. Chang, Dr. McCaslin and Katharine Peake for their guidance throughout this project.
DEDICATION

The researcher, Dee Thigpen, would like to give all honor and praise to my heavenly Father for giving me the strength and perseverance that has carried me through this entire program.

To my grandmother, Mattie, “Granny”, Burch, who has been my biggest fan throughout my life. To my mother and father Martha and James Ditto, who have gone to be with the Lord, thank you for believing in me. To my children DeVol and Clarence and my precious grandchildren Joseph, DeNavien and Tristalyn. I hope this thesis inspires you to achieve great and wonderful things in your lives. Thank you for your patience and understanding.
TABLE OF CONTENTS

ABSTRACT ........................................................................ iii
ACKNOWLEDGMENTS ................................................ iv

CHAPTER ONE: INTRODUCTION

Problem Statement ......................................................... 1
Purpose of the Study ..................................................... 8
Significance of the Project for Social Work ............ 9

CHAPTER TWO: LITERATURE REVIEW

Introduction ................................................................. 13
Prevalence ................................................................. 13
Policy ................................................................. 14
Theories Guiding Conceptualization ......................... 16
Family Adjustment to Autistic Children ................. 20
Challenges Raising Autistic Children ....................... 22
Proposed Study .......................................................... 25
Summary ................................................................. 26

CHAPTER THREE: METHODS

Introduction ................................................................. 27
Study Design ............................................................... 27
Sampling ................................................................. 28
Data Collection and Instruments ............................... 29
Procedures ............................................................... 30
Protection of Human Subjects ................................. 31
Data Analysis ........................................................... 32
<table>
<thead>
<tr>
<th>Chapter</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chapter Four</td>
<td>Results</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Introduction</td>
<td>34</td>
</tr>
<tr>
<td></td>
<td>Presentation of Findings</td>
<td>34</td>
</tr>
<tr>
<td></td>
<td>Open-Ended Questions</td>
<td>35</td>
</tr>
<tr>
<td></td>
<td>Summary</td>
<td>50</td>
</tr>
<tr>
<td>Chapter Five</td>
<td>Discussion</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Introduction</td>
<td>52</td>
</tr>
<tr>
<td></td>
<td>Discussion</td>
<td>52</td>
</tr>
<tr>
<td></td>
<td>Limitations</td>
<td>58</td>
</tr>
<tr>
<td></td>
<td>Recommendations of Social Work Practice,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Policy and Research</td>
<td>59</td>
</tr>
<tr>
<td></td>
<td>Conclusion</td>
<td>61</td>
</tr>
<tr>
<td>Appendix A</td>
<td>Flyer</td>
<td>63</td>
</tr>
<tr>
<td>Appendix B</td>
<td>Questionnaire</td>
<td>69</td>
</tr>
<tr>
<td>Appendix C</td>
<td>Informed Consent</td>
<td>71</td>
</tr>
<tr>
<td>Appendix D</td>
<td>Debriefing Statement</td>
<td>73</td>
</tr>
<tr>
<td>References</td>
<td></td>
<td>75</td>
</tr>
</tbody>
</table>
CHAPTER ONE

INTRODUCTION

Problem Statement

Autism spectrum disorder (ASD) is becoming the most rapidly increasing disability affecting development (Hann, 2007). "Among childhood disorders ASD has become more widespread than Down syndrome, diabetes and spina bifida" (National Institute of Mental Health, [NIMH] 2007, para. 1).

ASD causes lifelong developmental disabilities and each symptom can range from mild to severe. All children with ASD show deficits in social interaction; verbal and non-verbal communication and recurring behaviors or interest, (Ming, Brimacombe, & Wagner, 2007). Normally developing infants will show social interactions within the first year by watching people, turning their heads toward the sound of voices, gripping a finger or even smiling. But most children with ASD have a great deal of difficulty understanding the social exchange process of daily interactions. Parents who look forward to the pleasure of hugging, training and playing with their
child may be hurt by the emotionless feelings they may experience from their autistic child (NIMH, 2007).

Children with ASD are also unable to understand social cues. To a child who does not understand these cues, a simple statement could mean the same thing, regardless if the parent is displaying feelings of happiness, sadness or anger. The autistic child cannot decipher the difference in tone or expression. Autistic children have the tendency to cry out loud in a classroom setting or have sudden occurrences of talking loudly for no apparent reason. These behaviors could take place everyday or several times a week (NIMH, 2007). Autistic children often lose self-control when their environment changes. They will often get irritated and frustrated when they are not familiar with their surroundings. In their frustration, they can become very aggressive, attack others, throw and break items or bang or bite themselves (NIMH, 2007).

Verbal and non-verbal communication problems are another symptom in autistic children. Autistic children’s verbal communication could range from a few words to an extensive vocabulary. Some may began to speak, and suddenly stop. Others may have repetitive speech or
remain mute for their entire life. Autistic children may be developmentally delayed by as much as two to six years. Their tone of voice is usually neutral and lacks feelings and their facial expression usually does not match what they are trying to say (NIMH, 2007). Often, when autistic children grow older, they become more and more aware of how they are misunderstood and how they lack the mental capacity to understand others. This pattern leads to a lack of socialization in autistic adolescents and adults and could cause depression or anxiety (NIMH, 2007).

In addition, repetitive behaviors often set autistic children apart from other children. They often spend a great deal of time "walking on their toes, flapping their arms or suddenly standing still in place" (NIHM, 2007, para. 15). Autistic children may spend hours lining up toys in a certain way; if someone moves one of the toys, they can become very upset. Therefore, autistic children must have consistency in their environment. A minor change in their daily routine can be troubling. Order and sameness minimize confusion and provide stability to autistic children (NIHM, 2007).
Other “problems that may accompany ASD” are sensory problems, mental retardation and Fragile X syndrome (NIMH, 2007, para. 18). In ASD, the brain is unable to balance the senses correctly; therefore, ASD children can be insensitive to intense cold or pain. An ASD child may fall and break a leg, or bang his/her head on a wall and not flinch or cry, but a light or soft touch on the hand may send the autistic child hollering and screaming. Many autistic children are painfully sensitive to sounds like a lawn mower, ringing telephone or the sound of water. Such noises could cause these children to immediately cover their ears with their hands and start yelling. Because autistic children’s senses are faulty, certain textures, food taste and odors can also be very painful (NIHM, 2007).

Seizures are another common problem with children with ASD. Seizures usually start in the early years of development or during adolescence. About one out of four children with ASD are prone to having seizures. Seizures can cause some children to faint. This is caused by “abnormal electrical activity in the brain” (NIHM, 2007, para. 21).
Among all childhood developmental disorders, autism ranks as the most stressful for parents. This has been a challenge for many caregivers and families (Twoy, Connolly, & Novak, 2006). Caring for a child with ASD can be difficult and painfully demanding in many ways (Twoy et al., 2006). Parents are faced with many stressors everyday. Parental stressors stem from not being able to handle their child’s unstable behavior, lack of assistance and services to help meet the child’s needs, lack of emotional support from friends and family, and understanding that ASD has no cure. Parents who are not able to adapt to the challenges of raising an autistic child will not be able to survive the many demands that will be placed upon them. Coping strategies are one of the most vital tools needed in order to reduce the stress that families may experience when raising a child with ASD (Twoy et al., 2006).

Because of the variety and severity of problems manifested by ASD children, mothers of children with autism must develop adequate coping skills in order to adapt to their child’s lack of socialization, communication, and reoccurring behaviors (NIMH, 2007). Most parents would like to share their opinions and
feelings with their children or have parent-child conversations; mothers of autistic children are deprived of these parental privileges. Parents of autistic children report that they have given up much more of their lives to meet the needs of their child than they could have ever anticipated (American Academy of Pediatrics, 2007). Parents who do not implement proper coping strategies may find themselves highly stressed and with poor mental health problems such as depression and anxiety (American Academy of Pediatrics, 2007).

Parents who have inadequate coping skills will find these situations very stressful and overwhelming and often blame themselves for their child’s disability. Parents use avoidance as a way to cope with stress. Avoidance, which is usually short-term, can lead to poor mental health. Finding the right coping technique will help ease the pain as well as bring pleasure to a parent who is raising an autistic child (American Academy of Pediatrics, 2007).

Bagenholm and Gillberg (as cited in Ross, 2006) found that siblings of autistic children compared to siblings of non-autistic children had more trouble in relationships. Siblings in the study experienced some of
the same emotional symptoms as their autistic sibling. The symptoms included the inability to seek and respond to emotional cues from adults. Parents are not only faced with the challenges of raising an autistic child, they are also faced with the emotional and psychological effects this may have on the other siblings.

However, parents who receive early diagnosis can start intervention strategies to help assist with their disabled child (American Academy of Pediatrics, 2007). Parents who are able to prepare ahead of time can develop appropriate coping skills. Due to the number of rising cases of ASD, the American Academy of Pediatrics (AAP) put together a panel of experts to help pediatric providers achieve early diagnosis of ASD, this allow parents to start prompt and intense interventions in a timely manner. The AAP adopted the acronym A.L.A.R.M. “autism is prevalent; listen to the parents; act early; refer; and monitor” to make pediatricians aware of ASD and to assist them in making prompt referrals (AAP, 2007, para. 1).
Purpose of the Study

The purpose of this study is to identify the main stressors that parents experience when raising an autistic child and parents’ perceptions of what can help them to cope better.

It is important that parenting stressors and coping strategies are identified as they relate to the age of the child with autism. This study may identify many coping strategies that have been successful in helping parents survive the day to day routines of caring for a disabled child.

Families employ a variety of coping mechanisms to deal with stress. A study to examine what forms of coping strategies are used may offer the most positive outcomes that would be helpful and meaningful for parents with children who have ASD. Coping strategies can be active or avoidant. Coping strategies are behaviors or cognitions that parents use to cushion the effects of raising an autistic child. Active coping methods are intended to help people change the way they think about the stressor. Whether the active coping method is behavioral or emotional, active coping is thought to be the better way to deal with stressful situations. Avoidance coping
methods usually stop a person from directly handling stressful situations. Avoidance coping methods usually have unfavorable outcomes and psychological risk factors such as depression or withdrawal (Twoy et al., 2006).

Parents' perceptions of what helps them better cope with a child with autism has become vital. Autistic children live well into adulthood, which means many parents are faced with the continued challenges of caring for their autistic child. Parents’ perceptions of coping strategies for a young child versus those for an adolescent or adult could change. How parents are able to cope, what strategies they use, what support systems and community resources are available all play a major part in a family’s ability to live and enjoy life.

Significance of the Project for Social Work

Social workers have a crucial role in the lives of disabled children. Many parents with disabled children will need the help of social workers to find social support networks, and advocate and mediate for services due to the parents’ lack of knowledge and resources (Hepworth, Rooney, Rooney, Gottfried, & Larson, 2006). Parents of disabled children may have sought out many
services that have not been helpful. Therefore, social workers who have a data bank of resources that can be readily accessed could lessen additional stress on a family.

Child welfare social workers must understand family dynamics including the stressors and lack of coping mechanisms that parents of ASD children may encounter. Social workers must be culturally sensitive to the current coping mechanisms that a family may have employed to actively cope with their child’s disability (Kirst-Ashman & Hull, 2006).

It is also important that social workers undergo necessary training so they are able to identify subtle behaviors for early detection. Social workers, case managers, client advocates and brokers are all in system linkage roles that play a crucial part in the lives of parents receiving services needed to maintain family unity and sanity (Hepworth et al., 2006). Parental stress may be exacerbated in families of low socioeconomic status. The limited resources of government agencies for families often limit the number of services a family with a disabled child may receive. It is important, therefore, that the services recommended by the social workers are
beneficial and meet the needs of the family at the time of assessment.

In the generalist model, social workers follow seven steps: engagement, assessment, planning, implementing, evaluating, terminating and follow-up (Kirst-Ashman & Hull, 2006) when working with micro, mezzo and macro client bases. Social workers who follow the seven steps of the generalist model will ensure that a family will be greeted or engaged with professionalism and assessed to meet the needs of the family at the present time. Social workers must develop a plan to help meet families' needs in a timely manner. The plan must be implemented and evaluated for effectiveness. In some cases not all plans will be doable or not all goals will be met. In this case, social workers along with the family will develop a new plan/goals (Kirst-Ashman & Hull, 2006). When the goals are met, social workers will terminate services, and set a follow-up appointment, usually within two months.

Social workers working with low socioeconomic families may want to follow up more frequently. Frequent follow-ups over a longer period of time will ensure that
added family stressors have not prevented these families from moving forward with their plan.

This study may be used as a guide by social workers for assessing the clients' needs and planning goals when working with families who have children with disabilities. The study may aid social workers to offer families effective coping strategies that have been proven to work for other families. This study hopes to give its readers an overview of autism, its prevalence, symptoms and most importantly, how to cope with the stressors that are brought on by raising a child with autism.
CHAPTER TWO

LITERATURE REVIEW

Introduction

This chapter presents the literature review on ASD, its prevalence and theories guiding conceptualization: social support theory, the resiliency model of family stress and ecological theory. This chapter also discusses a 10 year longitudinal study addressing family adjustment to autistic children and challenges raising autistic children.

Prevalence

Autism can affect any family, regardless of their race or socioeconomic status (Centers for Disease Control and Prevention [CDC], 2007). The CDC, (2007) states that autism in America affects 1 in every 150 children and is four times more frequent in boys than girls. The Autism Society of America (ASA) estimates that 1.5 million Americans and their families are now affected by ASD. The U.S. Department of Education states that autism is growing at a rate of 10-17 percent each year (ASA, 2006). At this rate the ASA estimates that the prevalence of autism could reach four million Americans in the next 10
years. Therefore, autism has become a national health crisis, with an estimated annual cost to Americans of approximately $35 billion dollars.

Policy

The Lanterman Act of 1969 is a California Law that specifies services and support to people with developmental disabilities and their families. The definitions of a developmental disability in the Act is a disability that occurs before the age of 18 and lasts a lifetime. As a result of The Lanterman Act, The Inland Regional Center (IRC) was opened locally in December 1971, to provide comprehensive case management services to people with developmental disabilities (IRC, 2005). The IRC helps coordinate services needed because of a developmental disability.

Case managers assist families in arranging services by locating the services and providing ways to help families get to the service locations. The services provided by the Inland Regional Center include: "counseling, lifelong individualized planning and service coordination, outreach, assessment and diagnosis, information and referrals and research development" (IRC,
2005, para. 1). Social workers take on the role of case managers to help clients meet specific needs.

Laws such as the Lanterman Act to protect individuals with disabilities have been established, along with many services and community resources. However, when a family is at home in crisis, without social workers, therapists, doctors and a social support network, positive coping strategies become crucial in caring for a child with autism. This study may be used as a tool to provide methods of coping strategies that have proven to be effective when social workers are working with parents of children with autism. To identify parents' perceptions of what can help them cope in stressful situations when raising an autistic child this study will use a qualitative convenience sample research methodology. A qualitative method will allow the researcher to identify commonalities among many participants. The data collected hopefully will give parents different coping strategies to utilize. Studies have shown that through support groups, parents who have prior experience with working with autistic children can provide hope, comfort and peace to parents of newly diagnosed children with autism. Therefore, this study
asks what coping strategies work best with parents who are raising a child with ASD.

Theories Guiding Conceptualization

Social support theory will guide this study to determine how a strong social support network can be a positive coping strategy. Also, with a strong social support network, families may reduce stress and/or handle stress more effectively. Social support can be formally defined as "the interpersonal interactions and relationships that provide us with assistance or feeling of attachment to persons we perceive as caring." (Hutchinson, 2000, p. 205). Social support can be material support, such as food or clothing, or emotional support, such as support received from a counselor, intimate friend or family member. Support can also involve instrumental support, such as services received from the pharmacist, grocery store or beauty and barbershops. Social network includes social support as well as anyone who interacts with and/or exchanges dialogue and ideas. Personal support helps guide individuals when they are experiencing stress. Stress can result in cognitive disfunctioning, impaired judgment,
planning, perceptions and/or the inability to focus attention on relevant information. Our social support network, will compensate for these inadequacies by providing guidance and/or respite care to ensure adequate rest. (Hutchinson, 2000, p. 206-207).

Formal or informal social support has proven to be a highly effective adaptive problem-solving coping strategy used to cushion parental stressors. Families who frequently use relatives, friends or neighbors as informal social support, or the services from the IRC as formal support are more likely to have positive relationships among siblings. (Hutchinson, 2000, p. 208). Brothers and sisters who have an autistic sibling are able to enjoy activities together and are overall happier about having an autistic sibling (Ross & Cuskelly, 2006).

The resiliency model guides by suggesting the importance of all family members coming together to meet the demands of their special needs child (Twoy et al., 2006). The resiliency model of family stress, adjustment, and adaptation focuses on two levels of interaction: the approach a family uses internally to handle adversities between family members, and the approach a family uses externally to handle adversities between family and the
According to the resiliency model, (Twoy et al., 2006) in order for a family to adapt successfully, the use of internal and external family-coping strategies must be implemented. Internal family strategies are influenced by relationships and how well families are able to communicate together (Twoy et al., 2006). In other words, the family must become more cohesive and able to rely on one another. External family coping strategies come from resources outside of the family such as the community, organizations, agencies, social networks, and spiritual support all which help to guide the family’s coping strategy.

The ecological approach will guide this study by addressing the importance of how the environment can help families cope with stressful situations. Many parents look for outside sources like religion for a positive coping mechanism. The ecological approach looks at the family as “nested in its environment” (Coulthard & Fitzgerald, 1999, p. 20) and takes into account the diverse systems that encroach upon it. “Organized religion and personal beliefs dwell within these nested systems” (Coulthard & Fitzgerald, 1999, p. 20). They have recognized the contribution that organized religion and
personal beliefs have made to family life. Organized religion can take on many roles for family members. It can provide emotional support, education and sometimes financial and material help. Personal beliefs can help parents meet daily demands and have a positive outlook towards their disabled child. Through parents’ personal beliefs, they may see themselves chosen for this life challenge and they will be given the power to endure this challenge (Copeland, 1988, as cited in Ross, & Cuskelly, 2006). Copeland also found that parents need to be able to change their values, beliefs and their previous way of life in order to cope with or lessen the impact of the struggles the family will have from caring for their disabled child. Hepple (1988, as cited in Ross & Cuskelly, 2006) found that despite their many stressors, most families had set personal beliefs that helped them to adjust to their child’s handicap, allowing them to turn a negative situation into a positive one.

Ross and Cuskelly (2006) found that prayer was used as one type of resource and as a coping strategy. Although prayer can take on many forms for different people, praying to a higher being was the most common. Praying allows the caregiver to calm down or relax; as a
result, prayer temporarily takes the focus off of their immediate problems. The caregivers in this study used prayer as a cushion in time of stress. Prayer appears to be an ongoing source of hope for many participants. Good health proved to be directly related to personal beliefs along with the comfort that comes from prayer. Overall, this study showed that parents’ ability to cope in stressful situations, as in raising an autistic child, depended a great deal on their personal belief systems. Parents ultimately perform better when they feel a sense of hope or peace that they can adequately meet the needs of their autistic child (Coulthard & Fitzgerald, 1999).

Family Adjustment to Autistic Children

A 10 year longitudinal study of families of children with autism conducted by Gray (2002) examined the effects of autism on the family at specific points in time. The study showed that most parents have experienced improvements in terms of their own psychological well-being, the social experiences of their immediate family members and their relationships with members of their extended family. The study also reported changes to
families stressful situations and their strategies for coping with them (Gray, 2002).

The beginning years of autism are a stressful and exhausting time for parents, as they are uncertain that they have received the proper diagnosis and treatment. After parents are confident they have received the correct diagnosis, the child can be placed in the appropriate treatment facility and educational program. During the next couple of years, parents may have problems adjusting to the child’s school or treatment interventions. However, most families find this to be a rather good period in their lives. One contributor to this good report is that the child is learning social skills, emotional and impulse control and his/her attention span has become manageable. As a result, the family stability is achieved (Gray, 2002).

Gray’s (2002) study addresses five areas of concern that have been identified as very stressful areas for parents who are raising children with autism: sibling adjustment, extended family, social experiences, stigma or rejection and concerns for longterm care.

At the start of Gray’s (2002) study a large majority of parents expressed significant concerns for their other
children, because of the family's inability to participate in social activities. At the conclusion of his research, sibling adjustment was still a concern, but parents seemed less worried about the siblings. One reason for this was that the siblings were now teenagers or adults and had developed a solid network system and good relationships outside of the family.

Parents also found that relationships with grandparents had improved. In the early study, grandparents were very critical of the parenting skills used by the parents. They also refused to believe that their grandchild had a disability. Gray's (2002) later study reported better relationships with the child's grandparents; this was mostly due to the grandparents' gradual acknowledgement of the child's disability. In the cases where extended family situations were not resolved, parents became more secure in their abilities to parent and their child's diagnosis (Gray, 2002).

Challenges Raising Autistic Children

In Gray's study the participants were asked to describe the most difficult problems they experienced and how they coped with them. The most difficult problems
that parents mentioned were “poor language skills, inappropriate and embarrassing public behavior, disruption and destruction in the home, violence and aggression, inappropriate sexual expression and obsessions with eating or toileting” (Gray, 2002, p. 219). Earlier results showed a shift in the significance of these problems. In particular, communication was improved by their child or the parents ability to understand their child became better. Parents had lowered their expectations about their child’s communication and had developed creative ways of successfully dealing with their child’s restricted communication capabilities. These changes helped parents to cope better. Later results showed a decline in the “importance of obsessions, poor public behavior and toileting as coping problems” (Gray, 2002, p. 219).

Social rejection or stigma was often experienced by parents. The earlier study showed that parents experienced severe social problems and frequent social rejection. Later results showed that the majority of parents still experience stigma. Parents also reported in the later study Gray (2002), that this now mattered less to them. Some reasons for this were that the child was
able to perform better in public places, and the family had restricted their social activities. Yet, in many cases, parents seemed to have become less sensitive to the reactions of outsiders. Parents also found stigmatizing behaviors less threatening when they were able to find friends who understood their child’s disabilities.

Parents with an autistic child whose problems were severe, showing significant problems with aggression and obsession over time, seem to have the most difficulty. One area of concern was what will happen to their adult disabled children when they are no longer able to provide care for them. Placement for these children in a residential facility is very unlikely, as only the wealthiest people can afford the cost. Also single parents who must work to provide for their autistic child were concerned about placement as their child gets older and no longer qualifies for day programs. Parents must be aware and start early preparation for an autistic child who has been diagnosed as severe. It is always helpful when parents have the tools that will allow them to look ahead. The longitudinal study was intended to give parents hope that today’s stressors may not be of concern
later in life. It also showed parents that planning ahead may be needed for the severely autistic child, as a residential care facility may be inevitable as parents age and are no longer able to care for their autistic child.

**Proposed Study**

This research differs from prior research as it gives an overview on autism, its prevalence, symptoms, limitations, parents’ expectations and coping strategies. This information may prove to be valuable to social workers or any one in the helping profession. For parents, it combines research findings that address stressors and coping strategies that have proved to be reliable and effective. This study integrates several studies to give guidance as well as hope to parents raising an autistic child. The aim here is to look at different coping strategies to find out which would better work for different family structures. The theories that guided this study were the social support theory, ecological theory and empowerment theory. Parents support networks, internal or external, how well a family can cope in its environment and the availability of resources

25
are being used to guide this study. The measures parents take to empower themselves when coping in stressfull situations will determine how well a family will adapt and how successful they will be when raising a child with autism.

The limitation to this study is that autism is on a spectrum, it would take a very broad study to narrow down what coping strategy worked for each child depending on his level of autism and accompanying factors of autism. The child’s developmental age may certainly play a role in his or her development. The parents age, health and finances would also need to be considered.

Summary

A child with autism may have mild or severe symptoms. In either case, this can be a very stressful time for parents. In times of crisis families must pull together, and be resilient in order to meet the demands of the crisis. Raising a child with autism is no different. Families who can adapt and maintain resilience, by relying on a personal belief, religion and/or social support network will be able to better cope during these stressful times.
CHAPTER THREE

METHODS

Introduction

This chapter provides an overview of the research methods utilized in the study of parents' perceptions of what helps them cope better with a child with autism. This section supplies a foundation for how the collected data was analyzed and gives information on how participants' anonymity was protected. Also, described in this section are the study's design, sampling criteria, data collection, instruments, and procedures that were employed.

Study Design

The study examined the effective coping strategies that are utilized by parents of autistic children.

The questionnaire administered to parents of ASD children included demographics to obtain other pertinent variables such as the parent's gender, ethnicity, income, marital status, age, number of children in the home, the autistic child's medical diagnosis, age and gender.

The hypothesis is that the family's ability to cope with their autistic child's behaviors would depend
greatly on their positive social support network and the effective services they have received in the past or are currently receiving. More specifically, parents who are faced with stressful situations, such as raising children with autism, are able to cope better with positive support systems. This study hoped to identify similar effective coping strategies used among the participants.

A methodological concern with this study was children with autism are on a spectrum that could range from mild to severe. This may indicate that coping strategies of parents would vary tremendously depending on the level of the autism. Another concern was the age of the child. This study incorporated parents with children of many ages or of the same age range. However, this study identified coping strategies that were effective for all parents, regardless of the age of the autistic child.

Sampling

Participants were recruited using a snowball sample from the researcher’s social circle. The participants were identified from flyers and/or word of mouth in San Bernardino County. Each participant was asked to give two
names of other parents who have children with autism that might have been interested in participating in the study. Participants were allowed to set the time and location that was convenient for each participant (See Appendix A).

Data Collection and Instruments

The purpose of this study was to look at positive parental strategies and to determine which strategies were used most often. Parental coping strategies were examined using a qualitative interview guide.

Each participant completed a demographic survey, which included the parent's information: gender, ethnicity, marital status, age, number of children in the home and annual income. The autistic child's information included age, gender and medical diagnosis. Also included was a 12-item questionnaire (See Appendix B). Each participant responded briefly to each question as it pertained to his or her child or family. These questions were designed to address a variety of coping behaviors that individuals may use in time of stress or crisis.

The questionnaire had 12 open ended questions addressing the problems the caregivers had or had
experienced, and how they were able to resolve these problems. These questions were designed to find the best coping strategies used by the caregiver, family, and siblings living in the home. Many questions asked, “Have these challenges/problems been resolved? Yes / No Please explain.” These questions were asked to clearly address what measures were taken to resolve each problem(s) in a positive way.

Procedures

The researcher conducted face-to-face interviews with 10 participants. Participants were contacted by the researcher or participants contacted the researcher from information that was received by flyer or word of mouth. Each participant first was given a consent form to read, date and sign by placing an “X” in the box. The researcher informed each participant that his or her participation was completely voluntary and he or she could end the interview process at any time. The researcher then gave each participant the demographic survey information to complete. Next, the researcher asked each participant to respond to each of the 12 questions as it relates to him or her or his or her
family. The researcher hand wrote each response on the appropriate line of the questionnaire. After completing the questionnaire, the researcher read the debriefing statement and left a copy with each participant. The researcher ended the interview by giving each participant a $5.00 Wal-Mart gift card as a token of appreciation for his or her time. The complete interview process ranged from 30 minutes to 1.5 hour. The consent form, demographic survey and questionnaire were collected by the researcher and placed in a sealed envelope to protect privacy and confidentiality.

Protection of Human Subjects

Identifying information, for example name or addresses, was not collected on the demographics questionnaire nor the open-ended questionnaire forms. Instead, a number was placed on the top right side of each form to keep track of the number of the participants interviewed. In an effort to protect the parents' confidentiality as few individuals as possible were allowed to access the raw data. Persons identified to have access to the data included the researcher's supervisor and the researcher. The researcher gave an
informed consent to each participant that explained the purpose of the study, potential risks, length of study, and the researcher's contact information (See Appendix C). A debriefing statement was read to each participant that informed participants of the nature of the study, data collection and where and when the results would be available (See Appendix D).

Data Analysis
The analysis included the total number of participants, and the caregiver’s mean age, income, gender, marital status, and number of children in the home. Also included were the mean age, gender and medical diagnosis of the autistic child. This data was cross-referenced to identify commonalities among the participants. The responses were color coded in order to analyze the data. Coding the data allowed the researcher to identify similarities and differences in the findings. Each answer was coded and categorized. The categorization included, single words, partial or complete sentences. The researcher then identified similarities within the categories and refined or reorganized the coding process until all major themes were identified.
Summary

This chapter provided an overview of the research methods utilized in the study of parents' perceptions of what helped them cope better with a child with autism. This section also supplied a foundation for how the collected data was analyzed and gives information on how participants' anonymity was protected. Also, described in this section was the study's design, sampling criteria, data collection, instruments, and procedures that were employed.
CHAPTER FOUR
RESULTS

Introduction

This chapter presents the findings of parents' perceptions of positive coping strategies used when raising an autistic child. Also presented in this section is the demographic information, which includes ethnicity, age, marital status, and household income.

Presentation of Findings

There were a total of ten parents in the study. Six participants were female and four were males. The mean age of parents was 37 years. The age range of the sample was 29 to 57 years old. Four were African-American; four were Caucasian; one was Hispanic; and one was identified as other. Eight were married; two were single. Three of the parents reported a yearly income below $20,000; one between $20,0001 to 35,0000; two between $35,001-45,000; two between $45,001 -$55,000, and two over $55,001.

Seven of the children were male and three were female. Children ranged in age from 1 to 20 years. Five were between the ages of 4 to 6 years old; four were between the ages of 7 to 11 years old, and one was twenty
years old. The children’s medical diagnoses consisted of: 2 autism, 2 autism-mild, 4 autism moderate-severe, 1 autism-high functioning, and 1 autism-aspergers.

Open-Ended Questions

Question #1: When your child was first diagnosed with autism what/who helped you to understand this diagnosis?

The children in this study were diagnosed between the ages of 2 and 4 years. Six of the parents reported that the IRC diagnosed their child; three parents reported Kaiser Permanente diagnosed their child, and one reported her child was diagnosed by their child’s Head Start program. The parents who had insurance other than Kaiser Permanente were referred to the IRC through their child’s Head Start program, with the exception of one parent who received help from the Head Start program and a preschool for children with disabilities.

Some parents indicated that some warning signs were that their child was displaying behaviors of repetition, loss of language, water obsession and sensitivity to sounds. One mother reported that she cried, blamed herself, and was confused and angry upon hearing the diagnosis. Three mothers reported they were in shock. One
father reported that it took him two years to accept the diagnosis. Some of the parents reported that positive strategies they used to cope with the diagnosis were: reading information on autism until completely understanding the diagnosis, getting help from other parents who have a child with a disability, and locating and talking to healthcare professionals. One parent reported that she received the most help from her child’s speech therapist.

Question #2: At what age of your child’s disability was the most difficult to deal with? Please explain.

All parents responded to this question. The comments made were individual as well as collective. Some parents reported that their child’s non-verbal period was the most difficult. One parent reported that the age of 2 to 5 years was difficult because of potty training and learning the basics such as eating with a fork and spoon. One parent indicated that 3 to 5 years was hard to handle because the child had a busy schedule, including therapy four times a week. One parent reported that parental stress was severe because the constant changing of schools was difficult. This made the child’s behavior worsen. One parent reported that her child at age 11
caused problems because he became rebellious. One parent indicated that the age of 2.5 to 4 years was difficult because the child became very sassy and would talk back saying such things as, "I hate you," or "I will put soap in my eyes." One parent reported that 2.5 years was difficult to deal with because the child was energetic, couldn’t sleep, and couldn’t tolerate sound.

Parents in this study reported that the communication problems were resolved when the child began to speak or when straws were put into one child’s ears to help with speech. Some parents reported that as the children got older they were able to learn the basics such as using utensils and going to the bathroom. Other parents reported that talking to the child repeatedly and minimizing change and appointment scheduling lessened inappropriate behaviors.

Question #3: What was/is your biggest challenge/problems in raising your autistic child?

All ten parents in this study made the following comments about their biggest challenges with their child. These comments fall into the following categories:

1) Children’s behavior, e.g., being destructive with toys; misbehaving in class; having no
sense of danger; having a bad temper; and transitioning.

2) Parents’ own stress, e.g., frustration at not knowing what to do; mainstreaming the child before the parent thought the child was ready; and physically draining having to work on the same thing over and over again.

3) Family issues, e.g., having a large family size; discipline among siblings; and family members, lack of acceptance.

4) Public perceptions, e.g., other people’s stares and comments; and going into public places.

5) Other, e.g., no support for low-income parents.

Children’s behaviors reported by parents consisted of their children having no sense of danger. One parent reported that the child started fires in his bedroom. One parent responded that her son would constantly throw and break his toys. Another parent reported that his daughter loved to sing and would not stop singing in her classroom.

Parental stress reported by one parent in this study included the frustration of not knowing what to do to stop or correct their autistic son’s aggressive
behaviors. One parent reported that it was physically draining for her to work on the same behaviors over and over again, not knowing if her son was able to change his behavior.

Parents also identified some family issues related to challenges in raising autistic children: family members did not understand autism and/or the family members thought that the parents did not have good parenting skills and that is why the child was uncontrollable. One father stated that his daughter’s grandmother, at one time provided support for him, by taking the autistic daughter shopping and spending time with her. But his daughter’s aggressive behavior scared the grandmother and she no longer felt comfortable alone with his autistic daughter.

Public perception was also reported as one of the challenges parents encountered: One parent reported that people constantly stared or stopped and looked at them because of her son’s behavior, which made the entire family uncomfortable in public places.

Other concerns reported by some parents were that there were not enough local support groups for low-income families. One father reported that being low-
income, having a large family and having one car made it difficult for them to access resources.

Most of the parents in the study have resolved many of these challenges by being patient with their child as they worked through challenges and relied on outside support systems such as the IRC, therapists and teachers.

Question #4: What challenges/problems have your autistic child’s siblings encountered?

Nine parents responded in the following categories:

1) Sibling perception, e.g., embarrassed by autistic child’s behavior; felt that the autistic child’s behavior punished them by restricting them from outside activities; felt left out; were over protective of autistic child; felt that parents show favoritism; and siblings felt autistic child did not know when to stop playing and insisted on playing what he/she wanted to play.

2) Autistic child’s behavior toward siblings, e.g., screamed at siblings; and gave younger siblings inappropriate things to eat.

3) Sibling behavior toward autistic child, e.g., liked to tease the autistic child.
Parents in this study reported positive coping strategies utilized were continuing to talk to siblings about autism and how their brother’s or sister’s behavior was a result of autism. Parents reported that as the siblings understood autism they were less embarrassed when they are in public places.

Parents responded by setting aside time whenever possible to spend alone with the other siblings. Mothers stated that their daughters provided much support in helping with the autistic child and tried really hard to understand autism. Mothers tried to spend time alone with their daughters by going shopping and having girl time together. Parents also reported that redirecting the autistic child during playtime gave the other siblings a break so that they could be alone or enjoy each other without constant interruptions from the autistic child.

Question #5: What challenges/problems have you encountered when taking your autistic child into social settings (park, grocery store, doctor, etc)?

All ten parents shared in one or more of the responses that fall into the following categories:
1) Parent’s frustration, e.g., constantly attending to the child at all times; and educating people on autism.

2) Child’s behavior, e.g., would take off at anytime; wouldn’t get out of the car; temper tantrums in the store; being afraid of the doctor’s white smock; and sensitivity to sound.

Parents in this study identified positive coping strategies utilized such as getting help from outside organizations such as the IRC to work on behaviors; restructuring, such as going shopping when the child was in school; avoiding places that were noisy or crowded; redirecting and prompting, such as leaving the store immediately and going home when the behavior first started; talking to the child prior to taking him/her into public places; and/or giving the child a treat before going into public places.

Question #6: How do you cope with the daily stress of caring for your autistic child (what helps you get through the day?)

All ten parents in this study made comments on how they cope with stress in the following categories:
1) Reliance on faith, e.g., God; daily prayer; and reading the bible.

2) Activities away from the autistic child, e.g., walking; chatting on line; moms' night out/support groups; poetry; showering; watching television/movies; hanging with friends; reading; time alone to unwind; photography or other hobbies and exercising.

3) Working positively with the autistic child, e.g., keeping child on a schedule; and ignoring attention-seeking behaviors.

4) Venting, e.g., crying to relieve stress.

Question #7: Who has been the most helpful for your family in coping with your autistic child?

Nine parents in the study made comments about who was most helpful for their family in coping with their child's autism: These comments included grandparents, neighbors, extended family members, siblings, spouse and best friends.

Most parents had informal support to help with their child. Some informal support was people who were able to take the child for a weekend and/or relieved parents so they could enjoy an evening out. These people had a good
relationship with the autistic child and the child respected and responded well to them.

Question #8: What resources/services/organizations have helped you better care for your autistic child? Please explain:

All ten parents in the study made comments about services that had helped with the care of their child.

Parents in the study reported that the IRC, therapists, schools and respite care helped them the most. Seminars, the internet, church, books/magazines, and doctors also provided information to help them better care for their child. Social security was listed as financial support received to help with expenses incurred for care for their child.

One parent reported that the IRC gave a fashion show for all developmentally disabled children and their son participated, which made them feel really good. They also stated that the IRC offers services for the siblings, "siblings are special too." One mother stated that the IRC funded weekend trips for parents to get away. Most parents seemed to be very pleased with the services that were offered by the IRC. However, one parent stated he did not like government programs, and another parent had
never received services from the IRC. The behavior therapists were referred by the IRC to educate parents and provide services to reduce inappropriate behaviors by implementing new techniques and strategies for parents and the autistic child. Many parents reported that they found this service helpful and helped to reduce their stress and their child's inappropriate behaviors decreased.

Question #9: Does religion/spirituality/prayers contribute to your emotional well-being in raising your autistic child?

All ten parents in this study made comments that religion/spirituality/prayers contributed to their well being in raising their autistic child.

All parents relied on a higher power to help them get through each day. Parents reported that prayer everyday was very important to them. Seven parents reported that they attended church services every week or as often as they could. All parents reported that they usually attended church services alone. One parent reported that the entire family would go when they could. Reading the bible was also part of most parents' routine.
One father stated that his prayers shifted from, "give me strength to thank you and gratitude."

Question #10: What activity (exercising, reading, cooking, etc.) has been the most helpful in relieving stress in raising your autistic child?

All ten parents in the study made the following comments about what they found helpful in relieving stress in the following categories:

1) Home relaxation, e.g., cooking/baking/barbequing; washing dishes; getting in the pool; taking a bath; reading/romance novels; listening to music; watching movies; puzzles; working on home computers; and writing.

2) Outside activities, e.g., exercising and fishing. Parents stated that the activities they chose were relaxing and helped them to temporarily take their minds off their problems.

Question #11: Do you have any health concerns as a result of raising your autistic child? Please explain.

Six parents in the study made comments in the following categories:
1) Health of other family members, e.g., one parent expressed concern was for her other children who reported having migraine headaches; one parent stated that she was concerned about her husband’s health because he had diabetes; one parent had another sibling who had been diagnosed with Pervasive Development Disorder (PDD).

2) Parents’ own health, e.g., one parent was concerned about her weight because she gained 30 pounds the first three years her autistic child was born; another parent was concerned because she had a tendency to eat when she was stressed; one parent stated that she was afraid that the amount of stress she was experiencing now might affect her later; another parent stated that she was concerned about her health but was not sure if her autistic child was a contributor; and one parent stated that his smoking had increased.

3) Future health concerns, e.g., the married couples had concerns of how they would care for
their autistic child in the event that something were to happen to their spouse.

Question #12 Please list in order of what you feel was the most helpful positive coping strategies used to care for your autistic child.

Parents in this study identified the following categories as the most helpful positive strategies:

1) Parents’ own behaviors, e.g., patience; acceptance; staying calm; prayer; knowledge; spirituality; keeping busy; talking with people/parents; educating yourself; having faith, accepting diagnosis; learning how to manage routines; time alone; and setting time limits.

2) Support system, e.g., teachers; spousal support; family support; IRC; and support groups.

3) Autistic child’s behavior, e.g., seeing child make progress; time alone with child; negotiating with child; and watching the child’s diet.

4) Outside activities, e.g., hobbies; cruises; and exercising.
Most parents in this study adapted to having to change their current behaviors and employ positive behaviors in order to meet the needs of their child. Support systems, formal or informal, were vital and helped to relieve stress for many parents. Many parents felt that it was crucial to understand their autistic child’s behavior; therefore they implemented different strategies such as spending time alone and watching their child’s reaction to different foods and how the food might affect their child’s mood. Lastly, all parents found that having a hobby or having something to look forward to was an excellent positive coping strategy they used to reduce stress.

Parents in the study were asked to list any comments they felt would be helpful for other parents who are raising an autistic child.

Support groups were recommended to allow parents to learn and share ideas among each other. Support groups also gave parents a break from home and the family. Working with the child’s teacher/school district was an important factor for parents. Parents who sought anger management counseling for their child were better able to control their child’s aggressive behavior. One parent
recommended that when punishing the child, parents should keep in mind to punish according to the behavior of the child. Another parent said that when parents are faced with stressful situations, they should try deep breathing to help deescalate the stressful situation. Treating the autistic child as normal helps with the other siblings. Learning how to accept the child for who he/she is, accepting what they could do and learning how to overlook certain behaviors can reduce unnecessary stress. Parents should keep strong, never give up and keep hope.

Summary

This study set out to identify positive coping strategies used by parents who have autistic children. The findings of the ten interviews conveyed the following results: single and married parents interviewed have identified coping strategies to relieve stressful situations that result from parenting. The parents' personal positive strategies included: relying on faith such as God, prayer or reading the bible and having activities away from the autistic child, such as hobbies, support groups or socializing with friends. Outside services/resources/organizations included: the IRC,
therapists, child's teacher/school and respite care.

Informal support included family, friends and neighbors.
CHAPTER FIVE

DISCUSSION

Introduction

This chapter discusses the results of the study as it relates to the information that was provided in the literature review. This chapter also gives recommendations for social work practice, policy and research.

Discussion

This study set out to identify positive coping strategies used by parents who have autistic children. The findings of the ten interviews conveyed the following results: single and married parents interviewed have identified coping strategies to relieve stressful situations that result from parenting. The parents’ personal positive strategies included: relying on faith such as God, prayer or reading the bible; and having activities away from the autistic child, such as hobbies, support groups or socializing with friends. Outside services/resources/organizations included the IRC, therapists, child’s teacher/school and respite care. Informal support included family, friends and neighbors.
According to (Twoy et al., 2006) active coping methods are intended to help people change the way they think about the stressor, and is thought to be the better way to deal with stressful situations. Avoidance coping methods usually stop a person from directly handling stressful situations but have unfavorable outcomes. The results of the current study are consistent with Twoy's findings in that some parents initially took on an avoidant approach to coping with the disability, hoping that the disability would be temporary and the child would get better or perhaps the problem would go away. Most parents were shocked and blamed themselves for their child's disability when they first received the diagnosis. Understanding autism, accepting that your child's ability in some areas will be limited, and that there is no cure for autism, appeared to be the biggest challenges for parents to overcome. The primary caregivers, mostly mothers of the married participants were able to accept the diagnosis sooner than their spouses. Upon acceptance, parents started dedicating as much time as possible to find information and resources that would help their child function to the best of his or her ability.
Reading, watching television shows about autism, talking to other parents, teachers, counselors, and therapists who worked with their child helped the family to function better. Parents reported that each day presented a different problem. One parent responded that when she thought she had an inappropriate behavior or problem solved, something new arose, or the same behavior again resurfaced. Also added to the equation were other siblings in the family. Parenting can be even more stressful unless the siblings are older and patient with the disabled child.

According to the resiliency model (Twoy et al., 2006), the use of internal and external family-coping strategies must be implemented in order for a family to adapt successfully. Families in this study appeared to work well together and were able to identify potential family stressors such as how to handle the autistic child in public or finding time to spend alone with the autistic child as well as the other siblings. Educating the family members, siblings and extended family over time had a positive impact on the family.

Ross and Cuskelley (2006) found that prayer was used as one type of external resource and as a coping
strategy. Consisted with Ross and Cuskelley’s (2006) findings, all participants in the study, no matter what their religious beliefs, also reported that prayer helped them to get through each day. This study does not identify that the participants prayed less prior to the birth of their autistic child, or prayed more as a result of their autistic child. However, prayer was an important part of each participant’s life. Prayer was used to keep parents thankful and grateful and give parents peace of mind. Prayer also presented hope for parents that they could handle the challenges that arose from caring for their autistic child.

Parents in this study felt that their child’s disability was among the worst of all children’s diagnoses. However, they often found themselves appreciative for the milestones that their child was able to achieve or the stumbling blocks they were able to overcome. Parents often developed a sense of humor among themselves that helped them to cope better when their son/daughter communicated or displayed certain behaviors at home. Parents in this study raising autistic children were resilient; they learned patience, advocacy, skills and an unconditional love for their autistic child.
According to Hutchinson (2000), our formal and informal network provides guidance and support. Consistent with Hutchinson (2000), eighty percent of the participants in this study identified the IRC as their formal network by providing resources through referrals. The IRC provided an accurate diagnosis, speech and behavioral therapists, counseling, financial services, support services and respite care for most parents in the study. Parents identified that their child’s teachers were also among their formal network and working with the teachers was an important factor toward the progression on their child’s learning or behavioral plan. Working parents found this partnership tremendously helpful in reducing stress when working on weekly homework assignments. Hutchinson (2002), also discussed informal support as consisting of family, friends and/or neighbors. Participants’ responses concurred with Hutchinson’s (2000) findings that friends, family and neighbors indeed provide informal support.

Gray’s (2002) study addressed five areas of concern that were identified as very stressful areas for parents who are raising children with autism: sibling adjustment,
extended family, social experiences, stigma or rejection, and concerns for longterm care.

The participants in this study found that sibling adjustment was a stressful factor and varied for each member of the family. The girls appeared to be the most helpful and understanding but received less needed attention from their mother. Mothers identified the concern and addressed it by spending time together with their daughters. Some parents reported that their older and/or younger siblings were a big help to them and the autistic child responded well to the siblings. This appeared to be one of the challenges as well as benefits to having a large family.

Some parents shared that it took awhile for extended family members to understand and accept their child’s diagnosis. Others reported that their family members did not want to be bothered or were uncomfortable with their child’s presence. The absence of close family members can put a strain on any family, especially the caretaker of a disabled child. However, these families did not let this rejection stop them from moving forward in acquiring other pertinent relationships that benefited their family.
Social experiences, stigma and rejection have been very difficult for all participants in this study. However, over time each parent dealt with this reality in their own way. Some were blatant, some ignored, some tried to educate, or some learned to prepare their son/daughter by talking about the event before the event happened. Each parent adopted coping strategies that allowed them to persevere in many difficult situations. Parents came to realize that people who do not have a child with a disability cannot possibly understand what they were facing.

Concerning long-term care, some parents reported they worry about being faced with the decision of who would take care of their adult son/daughter if something were to happen to the caregivers. This problem was not resolved in any of the families who were concerned.

Limitations

This research project identified several limitations. First, because of the small sample size, the answers cannot be generalized for a larger population. Another limitation was the interviews were conducted in San Bernardino County, which may not provide the full
range of services that are available elsewhere to parents of children with autism. Lastly, the children’s ages were broad, which limits a true representation of which coping strategies, used to reduce parents’ stress, might best serve parents of children with a distinct age range. Further research in this area using a larger sample and demographic area may prove to be beneficial in identifying uniformity among parents’ perception of positive coping strategies used.

Recommendations of Social Work Practice, Policy and Research

The American Society of Autism (ASA) (2006) estimates that 1.5 million Americans and their families are now affected by ASD. This alarming number indicates that the social worker profession must be trained in the area of developmental disabilities. It is imperative that social workers have an understanding of autism, cerebral palsy, mental retardation, Down syndrome and other related disorders. Social workers must know the basics of these disabilities in order to provide services to families. Support groups are an excellent resource for families; however, not all groups provide support for all
developmental disabilities. Support groups can be very specific or general. It is important for social workers to know which type of support group will benefit the family they are serving. A support group for a child with cerebral palsy may not meet the needs of a child with autism. However, a support group for autism may meet the needs of a child with mental retardation.

Families with disabled children must have access to goods and services. Doctors, dentist appointments, grocery store lines, pharmaceuticals, bill paying, banking, all require parents to leave their home to take care of these necessary chores. Social workers might consider advocating the suggestion of one parent that caregivers of children with disabilities be allowed to have priority services. The reason this parent advocated for this privilege is that many parents find that their disabled child cannot tolerate the long lines in the grocery stores or the waiting time at the dentist or doctor. Rather the parents can wear an item on their clothing, such as a pin to identify them as having a child with a developmental disability.

The social support theory guides families with developmentally disabled children as well as the social
work profession. Social workers ability to work well with families will be determined by their level of understanding of this population. Social workers, who have an understanding of the Inland Regional Centers and the services they provide, will be able to work effectively with their clients. In representing this population, social workers need to be better educated on resources, services and program availability.

This study examined many issues and challenges that parents of developmentally disabled children encounter within a small sample size. Further research into the issues raised in this study might be appropriate and helpful for social workers that work with this population.

Conclusion

This study examined parents’ perceptions of positive coping strategies used when raising an autistic child. Ten parents were interviewed in this study and identified personal positive coping strategies such as relying on faith, prayer or reading the bible. The parents in the study also included activities away from their autistic son/daughter such as having a hobby, exercising, support
groups and socializing with friends as positive coping strategies that have helped to relieve stress. Parents in this study identified outside services/resources/organizations that helped them cope better such as the IRC, therapists, child’s teachers, and respite care. The parents in this study identified informal support systems as family, friends and neighbors as helpful in dealing with stress.

This study implied that many positive coping strategies are used when raising autistic children. As a result, social workers should not rely on a few strategies to offer their clients, but a host of strategies should be presented as each family’s problems and challenges are different.
APPENDIX A

FLYER
Demographic Information
(Please mark the appropriate answer)

Your Information:

1. Gender: 1. Male ___ 2. Female ___

   4. Hispanic ___ 5. Other ___

   7. Other ___

4. Age: __________

5. Number of children in the home: _________ (including child with autism)

6. Annual Income: 0-20,000 ___ 20,001-35,000 ___
   35,001-45,000 ___ 45,001-55,000 ___
   55,001+ ___

Child with autism information:

7. Age of child with disability __________

8. Gender: 1. Male ______ 2. Female ______

9. Medical Diagnosis ____________________________
QUESTIONNAIRE

This study aims to identify the coping strategies that are most utilized by families who have autistic children. The results of this study will be beneficial for families with children who have autism and other developmental disabilities. The results will also benefit the professionals who work with these families.

Directions

Please answer each question that apply to you or your family.

1. When your child was first diagnosed with autism what / who helped you to understand this diagnosis?

2. At what age of your child’s disability was the most difficult to deal with? Please explain:

2a. Has these challenges/problems been addressed? Yes / No Please explain:

3. What was / is your biggest challenges/problems in raising your autistic child?
3a. Has these challenges/problems been addressed? Yes / No Please explain:


4. What challenges/problems have your autistic child’s siblings encountered?


4a. Has these challenges/problems been addressed? Yes / No Please explain:


5. What challenges/problems have you encountered when taking your autistic child into social settings? (park, grocery store, doctor, etc.)


5a. Has these challenges/problems been addressed? Yes / No Please explain:


7a. How has this person been helpful to your family?


8. What resources/services/organizations have helped you better care for your autistic child? Please explain:

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

9. If applicable, do religion/ spirituality / prayers contribute to your emotional well-being in raising your autistic child? (help to reduce stress)

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

10. What activity (exercising, reading, cooking, etc.) has been most helpful in relieving stress in raising your autistic child?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

11. Do you have any health concerns as a result of raising your autistic child? Please explain:

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

12. Please list in order of what you feel was the most helpful positive coping strategies used to care for your autistic child.

1. __________________ 2. __________________ 3. __________________

4. __________________ 5. __________________ 6. __________________
Other - Please list any comments you feel would be helpful for other parents who are raising an autistic child.
APPENDIX B

QUESTIONNAIRE
Informed Consent

The study in which you are being asked to participate is designed to explore parental coping strategies for families with autistic children. Dee Thigpen, MSW student is conducting this study under the supervision of Dr. Janet Chang, Associate Professor of Social Work at California State University, San Bernardino. This study has been approved by the Department of Social Work Subcommittee of the Institutional Review Board, California State University, San Bernardino.

In this study, you will be asked to answer questions about the problem solving strategies that you have used to reduce stress, and complete a demographic questionnaire. This should take about 20 minutes to complete. All of your responses will be held in the strictest of confidence by the researcher. Your name will not be reported with your responses. Please do not put your name anywhere on the questionnaire. You may receive the results of this study upon completion after September 2008 at the Pfau Library at California State University, San Bernardino.

Your participation in this study is totally voluntary. There are no foreseeable risks to participating in the study. You are free not to answer any questions and withdraw at any time during this study without coercion or penalty.

If you have any questions or concerns about this study, please feel free to contact, Janet Chang, at (909) 537-5184.

By placing a check mark in the box, I acknowledge that I have been informed of, and that I understand, the nature and purpose of this study, and I freely consent to participate. I also acknowledge that I am at least 18 years of age.

Place a check mark here  

Today’s Date: ___________________
APPENDIX C

INFORMED CONSENT
Debriefing Statement

Thank you for participating in this study conducted by Dee Thigpen, MSW student. The purpose of this study is to examine the most effective coping strategies that are most utilized by parents of autistic children. It is hoped that the results of this study will contribute to a better understanding of children with autism and strategies parents have used to reduce stress.

The research data will be collected through the questionnaires you have completed. All data collected will be kept confidential and anonymous. The results of this study will be available in the California State University, San Bernardino Pfau Library by September of 2008. If you have any questions or concerns regarding this research project you may contact my faculty supervisor, Dr. Janet Chang at the CSUSB Department of Social Work at (909) 537-5184.

Thank you again for your participation in this research project.
APPENDIX D

DEBRIEFING STATEMENT
Autism Study

My name is Dee Thigpen. I am a California State University, San Bernardino graduate student looking for parents who are raising autistic children. I would like to interview you on positive coping strategies that you have found helpful while raising your autistic child.

The interview can take place at a time and location that is convenient for you. The interview will take approximately 30 minutes.

Upon completion of the interview a $5.00 gift certificate will be issued to you in appreciation for your time.

If you are interested please call Dee Thigpen @ (909) 851-7004 or email: thigpend@csusb.edu
REFERENCES


*Brain & Development, 29*(9), 565-570.

