

6-2015

Utilization of Specialized Camp Services among Parents of a Child with a Disability

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UTILIZATION OF SPECIALIZED CAMP SERVICES AMONG
PARENTS OF A CHILD WITH A DISABILITY

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

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

by
Heather Ann Wroten

June 2015

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Approved by:

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ABSTRACT

The purpose of this study was to explore the utilization of specialized camp services among parents of a child with a disability. This study sought to investigate specialized camp services as respite for families. The data was gathered utilizing a mixed method survey approach. The surveys were distributed to primary caregivers of a child with a disability who have attended Camp Paivika within the past three years. The sample size of this study was 69 respondents. The results show that the family unit benefits by way of de-isolation. The camper increases social skills, confidence, and independence. The caregivers experience emotional stress relief along with an increased ability to connect with other family members. The siblings of the child with a disability experience a relief of responsibilities associated with having a sibling with a disability as well as an ability to partake in family activities they may not otherwise be able to do. In conclusion, this research indicates positive familial benefits to out-of-home recreational respite services, such as a specialized camp services. Future research on the benefits will give the field of social work greater insight into the importance of out-of-home recreational respite.

ACKNOWLEDGEMENTS

I would like to acknowledge the faculty who supported me through my two years at CSUSB every step of the way. A special thank you to Rachel Strydom, Shyra Harris, Cory Dennis, and Allan Rawland for believing in me and helping me grow as a student and a professional. I would also like to thank Dr. Thomas Davis for overseeing this project.

I would like to thank Riverside County Department of Mental Health and their GIFT program. Thank you for the amazing learning opportunities you have presented to me and your unwavering support the past two years. Thank you Sheree Summers for being a guiding light throughout this process.

Lastly I would like to acknowledge my wonderful cohort members for being fantastic. A special thank you to Amanda Lucero and Sophia Morelli for helping me maintain my sanity. I wouldn't have made it through without your love, support, and constant shenanigans when times were tough.

DEDICATION

First, I want to thank my amazing parents for all of their support. You've never stopped believing in me and have always encouraged me to chase my dreams- even when they lead me to distant lands. You have taught me so much, the meaning of true and unconditional love being the most important. You have supported me through so many trials, tribulations, and crazy adventures; I cannot thank you enough. Your love means the world to me and I cherish you both. I think 20 years of schooling is enough... for now 😊

To my brother, who taught me from afar how to persevere and that it is never too late to get things done. I draw inspiration from you and everything you have accomplished thus far. Thank you for being you and being a great big brother.

To my Granny, one of my closest confidants. Thank you for the cards, letters, and weekly phone calls. It is hard being so far away, but each time I hear from you the world doesn't seem like such a big place. I love you.

To my boyfriend Matt who has been by my side every step of this long journey: from finishing my undergraduate degree, to studying in South America, and moving to California. I could not have made it through this without your unwavering love and support each and every day. Thank you for all of the guidance and constant technical support 😊.

To Kelly Kunsek and all of the amazing individuals at Camp Paivika: you have forever changed my life. I have become a better person because of all of

you. I am inspired everyday by the lessons I learned my first summer at camp and every summer since then. You are the inspiration behind this thesis and the inspiration that makes me want to be a better person each and every day.

“The best and most beautiful things in the world cannot be seen or even touched - they must be felt with the heart.”

-Helen Keller

“What lies behind us and what lies before us are tiny matters compared to what lies within us”

-Ralph Waldo Emerson

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CHAPTER ONE

INTRODUCTION

The purpose of this study is to explore the benefits of specialized camp services among parents of children with a disability. This study seeks to understand the benefits of utilizing specialized camp services for the identified child and family. This study will evaluate information from the parent or caregiver's perspective. For the purpose of this study, the terms "parent" and "caregiver" may be used interchangeably.

Problem Statement

According to the Americans with Disabilities Act website a disability is defined as: "physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment" (ADA, n.d.).

The U.S. Census Bureau conducted research in 2010 and found that there were 2.8 million children between the ages of five and seventeen who are identified as having a disability in the United States. When broken down further the data states that approximately 9.6% of children in California have been identified as having a disability (Bureau, 2011). In 2010 the U.S. Census Bureau found that 4.1% of school-aged children in the Riverside, San Bernardino, and Ontario area were identified as having a disability. Also, according to the data

collected, 4.0% of children in the stated area enrolled in the public school system have a disability (Bureau, 2011). The numbers presented are approximate and only pertain to children who are ages five to seventeen meaning that those children under the age of five and individuals over the age of seventeen are not included. One can assume from the above data that the number of families impacted is even larger than the numbers presented here.

The purpose of this study is to investigate the benefits of a specialized camp setting among parents of a child with a disability. The areas which will be studied include respite, individual growth, and social gains as they pertain to family respite. This will include the potential benefits for the individual attending camp and the family unit as a whole. Respite includes any temporary relief for caregivers, including parents, who are responsible for the care and safety of those individuals with disabilities, chronic or terminal illnesses, or the elderly (Shelton, 2011). Respite can also be defined as any relief from caregiving responsibilities or help with daily caregiving duties (San Filippo Di Matteo, 2005). Identifying opportunities for respite is important as it has been linked to improvements in familial relationships, a way to alleviate the pressure of having a child with a disability, and improved self-esteem (Shelton, 2011). The research will also look at what roles social workers can play in the context of a camp setting.

Studies on respite have produced mixed results. The difference for specialized camp settings is that the aim is also to teach the campers skills which

will hopefully produce long-term changes. Specialized camp services can be considered camp settings in which they are equipped to deal with specialized needs such as physical disability, cognitive disability, mental health concerns, and/or medical issues which would otherwise predicate an individual from participating. This is an alternative way to approach respite; camp is not meant to benefit only the caregiver, but also the care receiver. The benefits of having an individual attend a specialized camp is an area that has not frequently been studied. Individuals who have a disability may have difficulties with social skills, physical activities, relating to same-age peers, and/or gaining independence (Goodwin & Staples, 2005). A specialized camp setting is a place where, whether intentional or not, an individual can improve on the above skill sets. When services are offered and utilized, there is potential for improvement.

Camp Paivika, the camp from which study participants will be recruited, has set forth desired program outcomes which include social development and increased confidence for campers who attend. Some ways that these outcomes are indicated or measured is by discovering whether or not a camper made friends, tried a new activity, learned a new skill, had a successful stay away from home, etc. The desired impact on the families includes providing respite and that increased social skills and independence for the camper will have a positive impact on the family. This can be measured by looking at families self-report of the impact on the overall family health, optimism within the family when campers are successful at camp or gain new skills, and whether campers appear better

adapted to particular social situations. This study will be able to explore whether or not these areas of life have been impacted after a child has attended Camp.

Purpose of the Study

The purpose of this study is to investigate the benefits of specialized camp services among parents of children with a disability. This study will examine Camp Paivika, a summer camp for both adults and children with a disability. Camp Paivika opened in 1947 and is located in the San Bernardino National Forest. This study will provide data to illustrate the benefits of attending Camp Paivika for campers and explore the concept of respite for caregivers. The study will investigate benefits received by the family unit from the parents' perspective. The study will not, however, cover those individuals which are receiving care from a group home or assisted living setting. This study will focus on parents or caregivers who care for a child between the ages of six and twenty-four. The specific areas that will be explored include:

- 1) How does a camper benefit from attending Camp Paivika?
- 2) How does the family entity benefit from being able to utilize Camp Paivika as a means of respite?

The hypothesis regarding these research questions is that campers will benefit by increasing independence and social skills. The family will benefit by being able to reconnect with family, friends and provide an opportunity for the family to rest in order to continue providing quality care to the child. The above mentioned benefits have the potential to increase protective factors within the

family and decrease risk factors. Risk factors can include concerns such as caregiver burnout, tense or distant familial relationships, and mental health concerns such as depression. The protective factors can include, but are not limited to, time for rest and relaxation, reconnecting with family, friends, and peers, and relief from emotional stress.

Understanding the impact on the family unit has the potential to secure additional funding in the future as an option for overnight respite care. One of the barriers to accessing Camp Paivika is cost to families. Although there are some camp scholarships (Camperships) available, not all families will qualify or receive them. According to Shelton (2011), there is federal and state funding available for respite via Medicaid, however, “there is very little research on the potential respite benefits of therapeutic camps” (pg. 18). Further research on respite provided by specialized camps could impact funding and policy regarding camps as potential respite providers. By examining the benefits in terms of protective and risk factors associated with respite, specialized camp settings can more clearly be defined as respite. If respite funding can be accessed, camps may be able to receive funding for their programs or expand the services offered.

Historically, the camp setting has been an important arena for social workers. Unfortunately research and implementation regarding camps as therapeutic group settings has not been largely utilized since the 1970's (Mishna, Michalski, & Cummings, 2002). According to Mishna et al. utilizing a camp setting provides a unique learning possibility for students who wish to study psychology,

social work, and related fields (2002). By investigating the benefits of specialized camp services and their impact on the family unit, social workers may be able to reconnect to their historical roots of utilizing camp settings for services.

CHAPTER TWO

LITERATURE REVIEW

Introduction

This researcher explored and reviewed articles on the topics of camp services for individuals with disabilities, social work involvement with individuals with disabilities, and respite. According to the literature on specialized camp services, there are very few studies that focus on the parent's perceptions of the benefits of specialized camp services among parents of children with a disability. Many of the studies focus on the child's view of the benefits. There has also been very little consideration regarding overnight camp's as potential for family respite and social work involvement in camping programs in the last half century.

History

Social worker's involvement in settings where a person with a disability would receive services dates back to the early 1900's or earlier. According to Kerson and McCoyd, social workers have been "on the frontline" in hospitals, public health settings, mental health organizations, and the community (Kerson & McCoyd, 2013). Although this article primarily focuses on involvement in the health care system, it discusses briefly that social workers had early contact with individuals with disabilities. It must be noted, however, that roles social workers have played in regards to persons with a disability has drastically changed in the past fifty years.

In the 1960's and 1970's the face of disabilities began to change as individuals came together to petition, protest, and fight for the rights of individuals with a disability. While this movement was largely led by individuals who had a disability, many social workers acted as advocates in assisting this movement. In the early 1970's groups worked together to pass the Rehabilitation Act under President Nixon, which was vetoed twice (Patterson, 2012). This movement helped change the climate for more activists in the 1970's and 1980's.

Current studies and efforts seek to explain the complex needs of a family caring for a child with a disability or other health needs. Respite care has been identified as one of the largest unmet needs by families. In one study, parents identified people from many disciplines as providing support including health professionals and social workers (Whiting, 2014).

The idea of supporting caregivers and families within their home rather than removing and institutionalizing individuals with a disability is a relatively new concept. The de-institutionalization movement took place throughout the 1970's and 1980's which prefaced the appearance of the Americans with Disabilities Act (ADA) in the 1990's. Therefore, the roles in which we see social workers today in regards to families raising individuals with a disability began primarily in the 1970's to 1990's and continues to evolve today.

Benefits for Campers

There appears to be very little social work research regarding camps for adults or children with disabilities. According to Mishna, Michalski, & Cummings

(2014) in general there is little literature regarding camp and recreation programs in the social work field for any population. However, among the existing literature “there is an agreement on their value as effective social work interventions and on the current lack of appreciation for their worth” (pg. 5). This article primarily focuses on utilizing camp settings as group work interventions. While Camp Paivika is not designed specifically for social work interventions, it has the potential to have some of the same impact as these early social work interventions. The article cites that the greatest impact of the group camping experience is increased self-esteem, improved relationships with peers and adults, greater ability to assume responsibility, and improved coordination and physical skills (Mishna et al., 2014)

In the *Therapeutic Recreation Journal*, McCormick (1992) studied the perceptions of benefits of summer camp for campers with developmental delays. This article studied the parents’ perceptions of the benefits of sending their child to camp. This study utilized scaling questions to evaluate the parents’ perceptions of the most important to the least important benefits of camp. This study broke down the perceived benefits in the areas of social skill development, physical competence, social competence, cognitive development, respite care, and expressive development (McCormick, 1992). While parents recognized respite as being one benefit of camp, it was not the most important benefit. This study found that parents valued factors such as social skill development and cognitive development of the child more so than the respite benefits it provided

for the caregivers (McCormick, 1992). Social skills and cognitive development are two important aspects of camp; gains are made when children are able to have experiences that they normally would not be able to access.

Specialized camp services provide an opportunity for a child with a disability to have an experience that would not otherwise be attainable. The idea of summer camp is out of reach for many children with a disability due to their complex needs. These perceptions lead to both social and structural barriers for these children. These barriers contribute to individual's self-stigma: the internalization of stigma (Ali, Hassiotis, Strydom, & King, 2012). Summer camp provides a safe place for individuals who are generally marginalized in society for a variety of reasons, whether they be physical, cognitive, or medical. When children are able to share in their feelings of fear, anger, or loneliness; a type of self-help can occur when children who can relate to one another are given an opportunity to explore their identity (Goodwin & Staples, 2005).

In a study designed to explore the experiences of children with a disability at a summer camp, three important themes emerged. First, children with a disability were able to connect with other children who have a disability. Although the children had others in their school with a disability, they cited few chances to interact and build a relationship with other individuals (Goodwin & Staples, 2005).

Second, the individuals identified feelings of independence while they were away from their families (Goodwin & Staples, 2005). Children with a disability have few opportunities to spend time away from their families and test

their independence. Many times individuals with a disability have experiences such as “being denied the right to make choices or having over-protective families” (Ali et al., 2012, pg 2124).

Finally, the youth at summer camp identified a chance to discover their abilities and face their fears or doubts. One camper stated that “his ability to function within the limits of his disability were higher than he previously believed” (Goodwin & Staples, 2005, pg. 172). As demonstrated by the above study, specialized camp settings give youth the opportunity for self-discovery and autonomy. These opportunities support the desired outcomes for increased self-esteem, increased autonomy, and independence.

Respite

Respite has been widely considered in literature in terms of caring for the elderly or in caring for an individual with a terminal illness. The focus is often centered on caregiver stress, burden, social support, and coping (Blieszner & Roberto, 2010). While studies do not often focus specifically on parents care for an individual with a disability, studies often focus on the impact of caring for someone who has complex needs. With this focus in mind, studies based on protective and risk factors associated with respite can be applied to caregivers of children with a disability, as children with a disability require more complex care than their typically developing peers.

A cross-sectional study was done on the challenges caregivers face when they have a child with an impairment. The study found that there are barriers for

families which limit their access to child care, health care, and an unmet need for respite. This study stated that “caregivers of children with chronic health conditions and disabilities are more likely to experience various physical and psychological problems” (Baillargeon, Bernier, & Normand, 2011, p. 618). Due to the increased demand on the families and caregivers, caregivers for children with a disability are at higher risk for encountering adverse situations. There are risk factors associated with the complex care often required for child who has a disability. According to many studies children with a disability or behavior issue are at higher risk of abuse and/or neglect (Popple & Leighninger, 2011). When demands and stress are high for the family and there is little to no access to desired respite, children with a disability have the potential to be at higher risk for adverse situations such as maltreatment or abuse.

Although not all families will utilize respite services, it may not be due to a lack of need. When respite services are not utilized it may reflect a lack of services rather than a lack of desire (Mac Donald, Fitzsimons, & Walsh, 2007). When respite services are utilized, families report that they are able to reconnect with other family members, attend more family activities, and recharge their emotional-self in order to enhance the relationship between the caregiver and the child for which they are caring (Mac Donald et al., 2007).

Camp LIFE in Texas conducted research which primarily focused on respite for the families. This study found that while the child with a disability was at camp parents were able to relax and recharge (Shelton, 2011). The parents

reported doing activities such as spending time as a couple, reconnecting with friends, and spending time with their other children (Shelton, 2011). This respite has the potential to have a positive impact on the family unit as they have time to reconnect and experience relief from caregiving roles.

Another reason that a family may not accept or utilize respite, even when necessary, is guilt. Some families experience guilt regarding the child's diagnosis, while others will experience guilt when they feel as though they cannot care for their child one-hundred percent of the time (Keeler, 1993). Both of these reactions are very complex; more research considerations must be given to this element of respite.

As studies suggest (Green, 2007), caring for an individual with complex needs takes a toll on the mental and physical state of the caregiver at times. It is important to increase awareness of other aspects of caregiving and respite as well. As noted in the article, "We're tired, not sad," many families have positive experiences in the caregiver role. One mother stated "While there have been many emotional highs and lows since that day, and the complexity of her care can often seem overwhelming, the experience of raising my daughter has been both positive and powerful" (Green, 2007, pg. 152). Respite, therefore, should not simply be considered a temporary relief of burden as not all families consider the additional responsibilities as such. Respite is largely an opportunity for rest and relaxation for family members and utilization should be considered a strength of the family.

Mental Health

The mental health and well-being of families is of paramount importance when considering risk and protective factors. While depression is prevalent in the general population, estimates show that 40-70% of caregivers have clinically significant depressive symptoms and “approximately 50% are estimated to meet criteria for major depressive disorder (MDD) at some point during their time providing care” (Blanco & Rohde, 2013). There are a number of factors which have been associated with depressive symptoms in caregivers.

Studies have shown a connection between caregiver’s perceived difficulty of life or psychological distressed as measured by evaluating how often mothers feel: nervous, hopeless, fidgety, worthless, “everything was an effort,” and “felt so sad that nothing could cheer them up.”(Dillon-Wallace, McDonagh, & Fordham, 2013). There are also increased reports of isolation from others such as friends and family members as well as an inability to partake in activities outside of caregiving duties (Mac Donald et al., 2007). These experiences are consistent with symptoms and indicators of depression as defined in the Diagnostic and Statistics Manual 5th edition (DSM 5). According to the DSM 5, depression symptoms include: depressed mood, diminished interest in activities, increase or decrease in appetite, fatigue or loss of energy, feelings of worthlessness or excessive guilt, inability to concentrate, and thoughts of death or suicide (Diagnostic and Statistical Manual of Mental Disorders, 5th Edition, 2013). It is

important to keep these factors in mind when working with families navigating this experience.

Stigma is also a concern for both the individual with a disability and the family unit. “The findings indicate that both individuals and family carers experience stigma and that it may have a negative impact on psychological wellbeing” (Ali, Hassiotis, Strydom, & King, 2012, pg. 2122). Stigma reduction has become a major component of mental health practice; stigma also has a negative impact on families who have a child with a disability. Stigma is any instance or even by which a particular group of people, such as those with a disability, are marginalized by society due to their differences from the dominant group (Ali et al., 2012). Specialized camp settings seek to reduce stigma and work toward inclusion for both campers and their families.

Theories Guiding Research

Systems theory is one of the primary theories guiding the analysis of respite and the impact on families. Systems theory posits that families form an interdependent network in which each member has roles and functions. When there is a disruption in the system, the family unit will work to preserve homeostasis and return to equilibrium (Hepworth, Rooney, Rooney, & Strom-Gottfried, 2013). When there is a child with a disability born into or diagnosed within a family, this event disrupts the established equilibrium and therefore impacts all networks and systems within the family. The family must then learn to cope and find a place of homeostasis and way of functioning.

When the caregiver's energy is primarily focused on caring for the child with an impairment, the rest of the family members must take on new roles and perform new functions. At times this can cause stress and tension within the family. The family may be or appear to be in a state of entropy at any given time. When respite services can be utilized it allows the family to reset and regain their sense of balance and homeostasis.

Another important theory guiding this research is the labeling theory. While certain aspects of labeling theory are controversial, in this context the label of a disability can be extremely limiting. By utilizing specialized camps, children with a disability can be supported in taking part in activities from which they have previously been restricted or excluded. People living with a disability are often told what they can or cannot do, or who they can or cannot be. A specialized camp environment allows them to break free of the label, or diagnosis, they have been given and be seen as an individual who is capable. This setting may be one of the only places where a child with a disability will feel as though they fit-in and are not limited by their diagnosis.

The Strength's Perspective is also an important theory when considering this research. Families who have a child with a disability face adversity throughout each stage of the child's life. Each family and individual presents different strengths that can be highlighted in the camp setting. The use of respite can also be considered a strength of the family as it has been linked to increased social support. It is important to demonstrate the utilization of respite services

does not signify a weakness within the family, but rather the strength to reach out to others.

CHAPTER THREE

METHODS

Introduction

Chapter three will review the purpose of this study, benefits of utilizing a specialized camp among parents of a child with a disability. It will provide information regarding the participants, the selection process, and the methods by which the data was gathered. It will also outline the instrument that was utilized.

Study Design

The purpose of this study was to explore the benefits of utilizing specialized camp services among parents of children with a disability. The study looked at perceived benefits of utilizing an overnight camp setting for both the family and the child with a disability. The participants responded to a survey which employed the mix methods approach. This allowed the researcher to show both the impact of respite on the family, the benefits the caregivers see for the camper, and testimony from the families where appropriate. A brief survey allowed parents and/or guardians to express their view while simultaneously respecting their time as a primary caregiver.

A survey was chosen for this because it permitted this study to explore a population that is spread throughout central and southern California. It also had the capacity to explore the opinions of both parents caring for a child when applicable and it will include qualitative and quantitative questions. The survey

was distributed online in an attempt to get the highest response rate since many of the parents caring for children with a disability have very little spare time. This decision was made in collaboration with the director of Camp Paivika as being the best option to receive to most responses. It should also be noted that Camp Paivika currently utilizes online feedback methods, therefore the parents are accustomed to this type of information gathering.

The limitations of this method include the self-report aspect of the survey. Parents may over report or under report certain beliefs or behaviors regarding camp. Another limitation is not being able to reach certain families since the survey was sent via email; some families may not have regular access to a computer or internet and therefore may not be given the opportunity respond. Given that many questions are asked using a scaling system, parents will not be able to clarify answers if they wished to include more information.

Sampling

The type of sampling used for this study was purposive sample. This study surveyed parents of children who have utilized Camp Paivika. The criterion for being included in this study included: having a child between the ages of five and twenty-four who has attended Camp Paivika at least one time from 2012-2014. This criterion maximized the number of parents able to take the survey while also ensuring that the data is based on current experiences. Parents, legal guardians, or primary caregivers were included in this study as it seeks to understand a

parental perspective of the impact on the family unit. Those children who are receiving care in a group home or out-of-home placement were not included.

Data Collection and Instruments

Data was collected regarding the benefits of utilizing a specialized camp setting for respite. The survey included elements about the child, parents, and family unit; it was gathered from the parents' perspective. Demographic information was collected within this survey including: age of the child, gender of the child, what the child's diagnosis encompasses, parent's age, household income, parents' level of education, and number of other children in the home. Scaling questions explored aspects of respite, benefits to the child and family, and satisfaction with Camp Paivika.

The instrument was designed based on influences within the research; however, many of the questions on the instrument have been adapted from other surveys which gauge respite care benefits. The questions have been modified to address Camp Paivika more specifically. It also included modified elements from Camp Paivika's parent satisfaction survey.

Procedures

The researcher already had a professional relationship with the director of Camp Paivika; the director was contacted and she granted permission for research to be conducted within this agency. An online survey was distributed via

a list provided by the camp director utilizing a Survey Monkey online survey. The collection and analysis of data lasted approximately three months.

Protection of Human Subjects

The purpose of the study was explained to the participants. All surveys were anonymous. Based on the predetermined criteria, emails for the survey were distributed to families who qualified. No identifying information was requested. Each participant was provided with an informed consent that explained their right to confidentiality and the benefits and/or risks of completing the survey. All participants were given information regarding persons to contact should they have any questions or concerns upon completion of survey form.

Data Analysis

The researcher entered all quantitative data from surveys collected into the SPSS system for analyzing. This study explored the benefits of utilizing a specialized camp setting by examining frequencies, correlations, chi-squares, and partial correlates using SPSS for the quantitative aspects of the survey. This study will also explore the people, places, things, and ideas as revealed in thematic qualitative clusters throughout the qualitative aspects of the survey. This will all need to be addressed because of an absence of statistical tools.

Summary

Chapter three addressed the purpose of this study in exploring the benefits of utilizing specialized camp services among parents of a child with a disability. It explored aspects of respite for the families utilizing a mix methods approach. The information was based on the parent, legal guardian, or primary caregiver's perspective. The data was analyzed to find any correlations or connections among different demographic information and benefits identified. Also discussed in this section was the instrument utilized.

CHAPTER FOUR

RESULTS

Introduction

Chapter four will review the results of this study aimed at exploring the benefits of utilizing specialized camp services among parents of a child with a disability. This was an exploratory study. First, it discusses the number of respondents and the criteria utilized to select valid surveys. Next, this chapter explains the statistical analysis used to analyze the data followed by the results obtained.

Presentation of the Findings

The researcher sent the survey link via email to individuals who met the criteria outlined in Chapter Three. Approximately 290 surveys were dispersed and 79 surveys were received. Two surveys were discarded due to child being cared for by group home facility. Eight surveys were discarded due to being incomplete. The total number of valid surveys was 69.

Demographics

Table 1. Caregiver's Age Range

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid 25-34	1	1.4	1.4	1.4
35-44	17	24.6	24.6	26.1
45-54	28	40.6	40.6	66.7
55-64	21	30.4	30.4	97.1
65-74	2	2.9	2.9	100.0
Total	69	100.0	100.0	

Of the participants surveyed, the minimum age of parents was between 25-34 years old. The maximum age reported was between 64-74 years old. The mode age reported was 45-54 years old.

Table 2. Highest Level of Caregiver's Education Completed

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid High School Graduate	3	4.3	4.3	4.3
1 year of college	7	10.1	10.1	14.5
2 years of college	8	11.6	11.6	26.1
3 years of college	6	8.7	8.7	34.8
College Graduate	17	24.6	24.6	59.4
some graduate school	6	8.7	8.7	68.1
Post Graduate	22	31.9	31.9	100.0
Total	69	100.0	100.0	

Frequencies demonstrated above show the participants' highest level of education achieved. As noted above 31.9% of the sample have obtained a graduate degree making it the most frequent response. 25.6% reported that they graduated from college.

Table 3. Average Household Income

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid \$0-\$24,999	3	4.3	4.3	4.3
\$25,00-\$49,999	8	11.6	11.6	15.9
\$50,000-\$74,999	11	15.9	15.9	31.9
\$75,000- \$99,000	8	11.6	11.6	43.5
\$100,000- \$124,999	11	15.9	15.9	59.4
\$125,000- \$149,999	2	2.9	2.9	62.3
\$150,000- \$174,999	5	7.2	7.2	69.6
\$175,000- \$199,999	3	4.3	4.3	73.9
\$200,00 and up	18	26.1	26.1	100.0
Total	69	100.0	100.0	

In response to education levels, frequencies were run on the samples household income. 26.1% reported that their average household income was \$200,000 or more a year; the mode of the sample. The mean response regarding income was \$100,000-\$124,999. This is demonstrated in the table above.

73.9% (n=51) of respondents identified as the child's mother, 14.5% (n=10) identified as the child's father, 2.9% (n=2) identified as the child's step-father, 7.2% (n=5) identified as the child's grandmother, and 1.4% (n=1)

identified themselves as another relationship not specified. The above demographics represent the respondents, or caregivers, in this study. The following demographics describe the children, or care receivers, represented in this study.

Table 4. Child's Age Range

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid 9-12	8	11.6	11.6	11.6
13-15	19	27.5	27.5	39.1
16-18	4	5.8	5.8	44.9
19-20	14	20.3	20.3	65.2
21-24	24	34.8	34.8	100.0
Total	69	100.0	100.0	

According to Table 4, the youngest children were 9-12 years old and the oldest were 21-24 years old. The mode of this sample is ages 21-24 at 34.8% (n=24) and the mean is 16-18 years old.

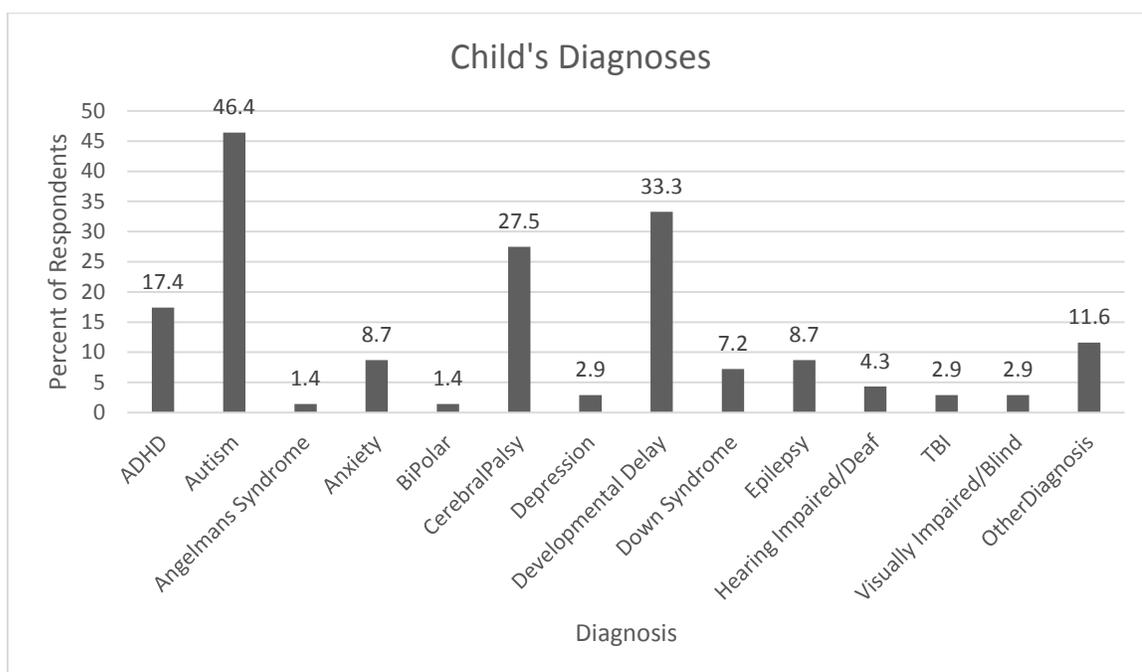


Figure 1. Child's Diagnoses

Frequencies were also run on the diagnoses identified. 46.4% (n=32) reported that their child had Autism, 33.3% (n= 23) reported that their child has a developmental delay, 27.5% (n= 19) reported that their child has Cerebral Palsy, and 17.4% (n= 12) reported that their child has ADHD. It must be noted that percentages will not add up to 100% as some children have multiple diagnoses.

Results

Table 5. Correlations Caregiver Respite Sum and Level of Care

		Level of Care
Spearman's rho	Caregiver Respite	Correlation
	Sum	Coefficient
		Sig. (2-tailed)
		N

Table 5 explores a correlation between reported emotional stress relief and the level of care the child requires. In order to quantify the level of care required for each child, a positive response from each care variable (diabetic care, G-tube, tracheotomy, breathing treatments, bathing, feeding, dressing, toileting, catheter care, medication management, and behavior management.) was given a value of 1. Each participant's responses were summed in order to create a level of care scale from 1-11, 1 being the lowest level of care and 11 being the highest. The level of care variable was then correlated with the participant's report of total care benefits. The caregiver respite sum was quantified by combining all aspects of reported caregiver respite including:

emotional stress relief, time to complete household tasks, opportunity to reconnect with spouse/partner, time for entertainment and socialization, opportunity to spend time with other members of the family, ability to take a vacation, and ability to catch up on rest and sleep. The responses were recorded on a 1-5 Likert scale where 1 indicates “strongly disagree” and 5 indicates “strongly agree.” The responses were summed on a scale from 7-35 with 7 signifying low levels of respite benefit and 35 signifying a significant amount of respite benefits.

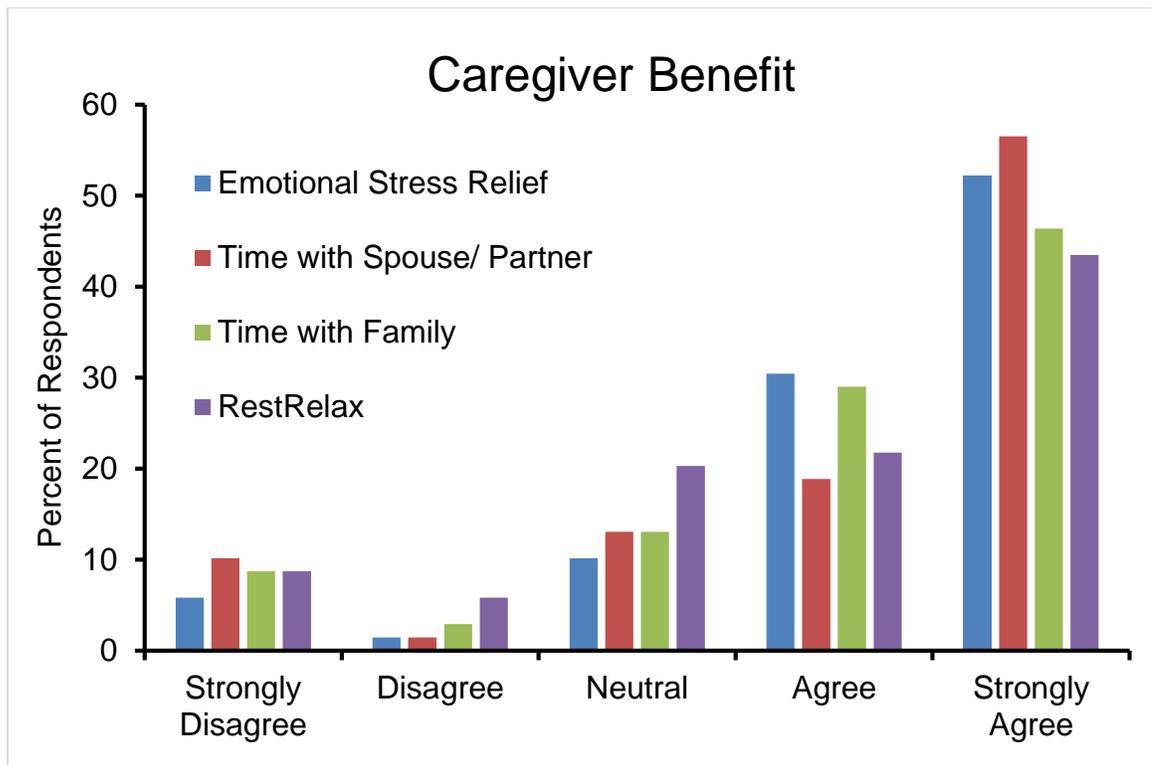


Figure 2. Caregiver Benefits

Frequencies were run on caregiver's response to the benefits they receive while the child is at camp. "Strongly disagree" indicates that the caregiver did not identify with the above benefits. Conversely, "strongly agree" indicates a strong connection to each of the benefits listed above.

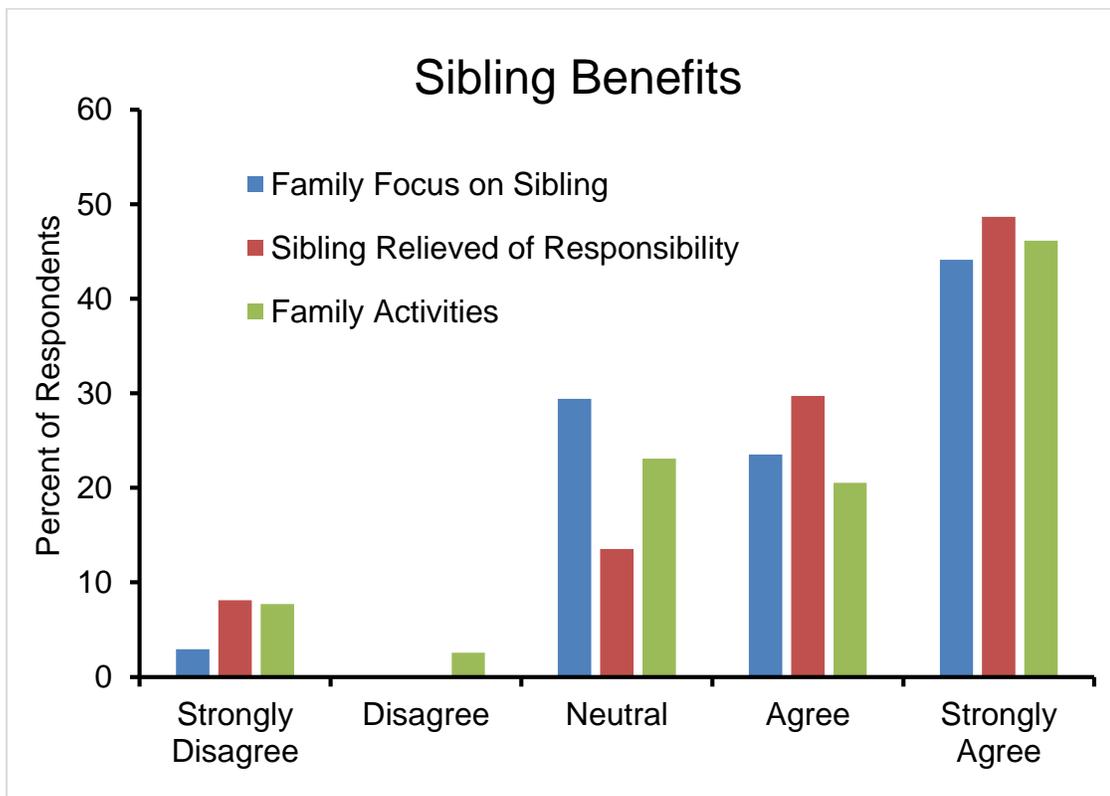


Figure 3. Sibling Benefits

Frequencies were run on caregiver's response to the benefits the siblings receive while the child with a disability is at camp. The above plot includes only

responses from those who reported having additional children in the home (n= 37). “Strongly disagree” indicates that the caregiver did not identify the above benefits with the child’s siblings. Conversely, “strongly agree” indicates a strong connection to each of the benefits listed above. While there is some variation in responses, “strongly agree” was the most frequent response for each area that was explored.

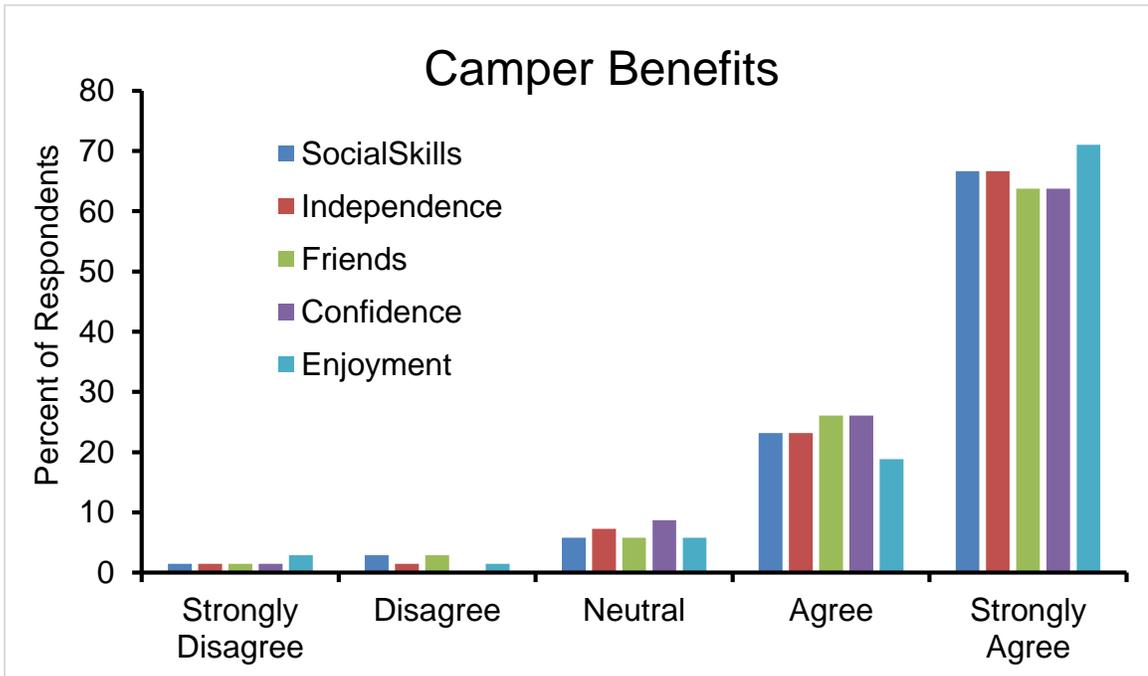


Figure 4. Camper Benefit

Frequencies were run on caregiver’s response to the benefits the camper receives while he/she is at camp. “Strongly disagree” indicates that the caregiver

did not identify the above benefits with the child. Conversely, “strongly agree” indicates a strong connection to each of the benefits listed above. According to the data above the mode of this section was “strongly agree” for all areas investigated.

In the qualitative section of the survey which asked respondents to identify the most important aspect of Camp Paivika, the most common responses revolved around the benefits, such as enjoyment and independence, for the child attending camp. Examples include, “My son LOVES Camp Paivika and looks forward to it every year,” and “it provides a safe environment for my child to enjoy independence.” Another theme included respite for the caregivers and siblings. Examples of this include “My husband and I are able to spend quality time together...” or “it gives us separation which is needed for us both in order to maintain our daily activities all year long.” Another statement included, “the ability to do things the rest of the family likes to do but my special needs child may not like or be able to do.”

CHAPTER FIVE

DISCUSSION

Introduction

This chapter outlines the discussion of the results, limitations to the study, implications, and recommendations for future research. Chapter Five will discuss five key findings of this study. First, it evaluates the previously stated hypotheses and discusses any significant findings in the study. Next, this chapter explains the limitations to the current study. Last, it reviews implications and recommendations for future research.

Discussion

This study explored the utilization of specialized camp services among parents of a child with a disability. The hypothesis regarding this research is that campers will benefit by increasing independence and social skills. The family will benefit by being able to reconnect with other family members, friends and provide an opportunity for the family to rest in order to continue providing quality care to the child. The above mentioned benefits have the potential to increase protective factors within the family and decrease risk factors. Risk factors can include concerns such as caregiver burnout, tense or distant familial relationships, and mental health concerns such as depression. The protective factors can include, but are not limited to, time for rest and relaxation, reconnecting with family, friends, and peers, and relief from emotional stress.

First, camper benefits were explored. In this study camper benefits can be interpreted as increasing self-efficacy as evidenced by an increase in independence and confidence. Both independence and confidence can be identified as protective factors as identified in the hypothesis. Individuals with disabilities have limited opportunities for autonomy and self-discovery; camp provides this opportunity for the child. The child's ability to make self-discoveries might have an impact on their independent functioning when they return home. The change can be noted by the caregiver and is reflected in the data above. The changes and increase in self-efficacy increases the child and caregiver's ability to sustain care requirements in the long-term.

Camper benefits might mean that the children attending camp acquire skills for improved social functioning. The data demonstrates a high report of campers making friends while attending camp in addition to an increase in social skills (see Figure 4). Social isolation can be debilitating to individuals with a disability; camp provides a safe place for children to branch out and create friendships in ways they may not otherwise have the opportunity. As Goodwin and Stables (2005) indicated, children with a disability may have limited opportunities to connect with other children with a disability. Camp provides an arena for children with a disability to connect with each other and build a friendship. The ability to create friendships and improve social skills is a protective factor for the child's mental health and overall well-being.

Compounding the above mentioned benefits, camper benefits can be interpreted as a future trend for improved functioning in general. As campers increase their confidence and learn independence, it will have an impact on their ability to partake in their own activities of daily living. Activities of daily living include: bathing, showering, eating, toileting, dressing, etc. Campers may find that they are able to accomplish more than they previously believed. This was indicated in the study conducted by Ali et al (2012) as they discussed individuals with disabilities being denied the ability to make choices for themselves due to family members being highly protective. A specialized camp setting provides a safe environment in which an individual with a disability can test their own limits socially, emotionally, and at times physically. As individuals learn skills associated with independence, they are better able to adapt to social situations and make their needs known, thus getting needs met.

Second, the sibling benefits were evaluated. Siblings of a child with a disability benefits might mean that other children living in the home have the opportunity to enhance their relationship with their parents. Siblings are able to re-establish uninterrupted contact with their caregivers, thus enhancing the parent-child relationship. This is evidenced by the ability to the caregivers to delegate more time and attention to other children in the home which would otherwise be spent caring for the child with a disability. One participant commented on their “ability to spend time with our other child without demands of caring for a disabled sibling” (study participant). Allowing the child to reconnect

with parents may augment the sibling's ability to cope with daily stressors. A strong connection between parent and child may lead to increased protective factors that have not been identified in the current study. Theory suggests that the parent-child relationship is imperative to family health and functioning; giving the child and caregiver the opportunity to reconnect is one way to improve this relationship.

Another sibling benefit might indicate the augmentation of the circle of family activities as caregiver's reported being able to partake in activities they would not otherwise be able to do. The data in this study suggested that families are able to partake in activities that would otherwise be limited. One participant commented the following as the most important aspect of their child attending camp: "The ability to do things the rest of the family likes to do but my special needs child may not like or be able to do. It is a time that the other members of the family are able to really relax." While the child is at camp the family is able to expand their familial activities and experiences.

Sibling benefits might also be interpreted, in this study, as a level of freedom. Siblings are able to rest and relax from any responsibilities they maintain due to having a child with a disability in the home. The caregiver's reported that siblings experience a high rate of relief from responsibilities associated with having a sibling with disability. Responsibilities does not necessarily indicate the requirement to provide care; it may indicate an ability to

engage in activities or relationships in a way that differs from when the child with a disability is present.

Third, the caregiver benefits were analyzed. Caregiver benefits can be interpreted as the ability to re-establish and enhance a connection with their spouse, partner, or other family members. Aside from emotional stress relief and relaxation, caregivers indicated they are able to reconnect with other family members and their spouse or partner. While the other children are able to connect with the caregiver, the caregiver in turn is able to re-connect with their familial support system. In addition to connecting with family, caregiver benefits might mean an ability to re-connect with their social support system.

Caregiver benefits may indicate enhanced self-care as evidenced by taking time to relax, partaking in social and entertainment activities and reconnecting with family. These are all important influences in a person's life and may improve the caregiver's overall mental health. Participating in enjoyable and preferred activities have a positive impact on mood and decrease depressive symptoms, such as isolation or caregiver burnout. Increased self-care, even if temporary, by caregivers enables them to maintain the arduous schedule of caring for a child with a disability year round.

In addition to the direct caregiver benefits, there may also be indirect benefits such as feeling as though their child has an opportunity to attend a summer camp in a manner that helps the child feel more "normal." Previous studies have found that, while parents appreciate the respite benefit, they value

the benefits for the child more. This was evident in the current study as well.

When caregiver's were asked to comment on the most important aspect of Camp Paivika, a common theme centered on the child's benefit. An example of a comment from this study includes: "a safe environment for my child to get the same experience as a 'normal' child & I don't have to worry about him" (survey participant). As mentioned in the literature review, access to summer camps is often out of reach for a child with complex needs as they may not have the staff or resources to attend to their needs. Specialized camp settings are able to break down the barriers to provide what many kids and their families see as increased accessibility to summer camp where kids can be kids.

When looking at camper, sibling, and caregiver benefit there is one common theme identified. There appears to be a de-isolation process and an expansion of family connectivity to individuals and activities outside of their daily routine. According to MacDonald et al. (2007), isolation from others as well as an inability to opt in activities aside from caregiving duties is a challenge that families face. During the time the child is at camp he/she expands their social opportunity, the siblings and family are able to expand familial activities. In addition, the caregiver is able to expand their social and familial support. This can be interpreted as respite; providing the opportunity for the family to de-isolate and create positive expansion. These act as protective factors for the family's overall mental health and daily functioning.

The hypothesis appears to be strongly supported by the data collected in that attending camp has significant reported benefit for both the child and the family. The data supports that providing respite, aimed at benefiting the individual with a disability as well as other family members, increases protective factors and decreases risk factors for the family unit. The data showed that regardless of income or level of care required, caregivers are reporting high levels of respite benefits for the family unit while the child attends camps. This indicates that every family can benefit from having their child with complex care needs attend a specialized camp.

Limitations and Future Research

While the results were not statistically significant, a preliminary test on the correlation between level of care and the camper benefit appeared to have a negative correlation. While it was evident that there was a positive correlation between level of care and caregiver benefit, it appears that the opposite may be true in terms of camper benefit. Explanations for this may include the increase in level of care may indicate a more complex disability in which the individual may not have the capability of progressing past a certain level of functioning. For example, some campers are non-verbal and wheelchair bound due to paraplegia or quadriplegia. These campers may not experience an increase in independence or a visible increase in social skills or confidence due to the extremity of their physical limitations. This does not indicate, however, that the camper does not benefit from the respite; the benefits may not be as easy to

perceive and therefore are underreported by caregivers. The caregiver benefit in this instance would be reported at a much higher rate due to the intensity of daily care required. Further research which includes a larger sample size might indicate a negative correlation as these preliminary results suggest and offer further explanation regarding this phenomenon.

According to the data in this study, there appears to be a slight correlation between the number of years campers have attended camp and camper benefits. Although it was not statistically significant, further research should be done to identify the increase in self-efficacy in ongoing years and in relation to number of years child has access to out-of-home recreational respite such as specialized camp services. This researcher's hypothesis is that campers increase confidence, social skills, and independence each year. Each of these compounds and expands every year that the camper attends and the benefits become more apparent from the caregiver's perspective. The growth could also be linked to the child aging and maturing allowing the camper to gain more from the camp setting and opportunities it presents.

The data showed no significant correlations between income and respite benefits for the family. This indicates that utilizing specialized camp services is beneficial to all families to a similar degree for those who can access it. While income may impact whether or not a family has access to specialized camp services, once that barrier is overcome, the benefits received appear to be comparable across the board.

The limitations of this study include that it only evaluated one out-of-home respite service, camp services. Further, in terms of camp services this study looks at one camp. Future research can expand on different out-of-home respite settings and different camp locations in order to further the data on efficacy of specialized camp services as a means of respite.

Another limitation includes utilizing an online modality as a means of data collection. The demographics of this study clearly indicate a larger response from those families in high socioeconomic status; this may not be representative of the overall demographic breakdown of the families that utilize Camp Paivika. This might indicate that those families with a lower socioeconomic status who are utilizing camp are not being represented in this study due to a variety of reasons. Some ways in which these families may have been limited include: ability to access internet and email, time and resources to respond to the survey, or not feeling as though their opinion is valued.

Recommendations for Social Work Practice, Policy, and Research

Based on the data collected in this study, there are several recommendations to consider to further the development of social work practice, policy, and research. First, it is imperative that social workers seek specialized training to gain more insight into working with families who have a child with a disability. Further insight into the systemic challenges of providing care and receiving services varies greatly and will thus impact the family's total

functioning. Education on the protective factors associated with respite services is extremely important to working with families who have a child with a disability and addressing any mental health concerns that may arise.

Policy improvements can be amended to existing respite services where the focus of respite reaches beyond the caregiver and seeks to improve functioning within the family unit. Ensuring that respite services seek to improve the overall functioning of the individual with a disability will ensure that respite services will have greater long-term impact on the families' overall well-being.

Social workers are currently involved with families who have a child with a disability in a variety of settings including: schools, mental health settings, case management, behavioral interventions, child protective services, and more. Re-introducing social workers back to their roots of alternative interventions, as suggested by Mishna et al., such as group camp settings will open a new arena for interventions with children who have a disability. There has been research conducted which has shown that utilizing camp settings as social work interventions has been effective on increasing self-esteem, improved peer relationships, greater ability to assume responsibility, and improved relationships with adults (Mishna et al., 2014). With this information having been obtained in addition to the data presented here, social workers have the opportunity to expand services into specialized camp settings as a means of intervening with families.

As research continues to expand the data that supports specialized camp settings, more funding may become available. An increase in funding would allow services to expand and reach more families. Specialized camp settings tend to be cost prohibitive for low-income families unless they have access to financial aid, whether it is through scholarships, regional center funding, or Medicaid. Advocating for policies which provide respite funding to specialized camp settings should be considered.

This research will have an impact on social work practice because it will bring awareness to a current service that many do not know about. Camp Paivika is widely unknown and unrepresented in the social work field, primarily because people are unaware of it and the services Camp Paivika has to offer. Increased knowledge and visibility of Camp Paivika has the potential to open more opportunities for children with disabilities in southern California.

Another significant implication for social workers is that historically agencies and case managers were the primary source of referrals. In the case of Camp Paivika, there does not appear to be a clear connection between important agencies and camp referrals. An important agency in the Inland Empire that could be a source of referrals is the Inland Regional Center, which works with adults and children with a disability. This research will bring awareness of Camp Paivika to current and future social workers who will be able to make important referrals for services.

Further research needs to be done on the benefits of out-of-home vs. in-home respite services. The data supports a strong benefit for all family members in out-of-home respite, such as specialized camp services. Currently out-of-home respite is offered in residential facilities which may not foster the same benefits for the individual with a disability as a recreational out-of-home respite service, such as a specialized camp setting.

The current research on the utilization of specialized camp services is very limited at this time. Current research is primarily conducted by individuals in therapeutic recreation rather than social work. Further exploration on how to integrate recreational services into respite services and integrating social work into this field will promote the social work profession.

Conclusions

The utilization of specialized camp services appear to have a strong positive impact on children with a disability and their families. Providing specialized camp services as a means of out-of-home respite increases protective factors for the entire family unit. An increase in protective factors include increasing child's confidence, independence, and social skills; it also includes giving caregivers and siblings an opportunity for rest and relaxation while re-connecting with each other and their support systems.

APPENDIX A
CAMP PAIVIKA APPROVAL LETTER



October 29, 2014

To the California State University School of Social Work:

Heather Wroten has our permission to conduct research at our agency, AbilityFirst, including the collection of data or the conducting of interviews. We look forward to working with her on this project. Please feel free to contact me should you require further information or verification.

Sincerely,

A handwritten signature in black ink that reads "Kelly Kunsek". The signature is written in a cursive style with a long horizontal stroke at the end.

Kelly Kunsek
Director
AbilityFirst Camp Paivika

APPENDIX B
INFORMED CONSENT

Informed Consent

You are invited to participate in a study on the utilization of specialized camp services for children with a disability. The study is being conducted by a Masters of Social Work (MSW) student from California State University, San Bernardino (CSUSB) under the supervision of Dr. Thomas Davis at CSUSB. The study has been approved by the School of Social Work Sub-Committee of the CSUSB Institutional Review Board.

PURPOSE: The purpose of this study is to understand the parent/ guardian's perception of the utilization of specialized camp services for child with a disability.

DESCRIPTION: If you take part in this study, you will be asked a series of questions in survey format about the experiences of having your child partake in specialized camp services and the risks and benefits of this experience. Your participation in this survey will be brief. The survey will take approximately 15-20 minutes.

PARTICIPATION: Your participation is completely voluntary and you do not have to answer any questions you do not wish to answer. You may skip or not answer any questions and can freely withdraw from participation at any time without penalty. Participation or non-participation in this study will not affect the services you receive from Ability First's Camp Paivika. There are no foreseeable risks to participating in this study.

BENEFITS: Participation in this study will contribute to social work research, educate others about camp services, and create insight into the benefits of utilizing a specialized camp setting for children with a disability and their family.

CONFIDENTIALITY: The information you share will remain confidential. No record will be made or kept of your name or any identifying information. The information will only be review by the researcher as well as the research adviser.

If you have any questions or concerns about this study you may contact Dr. Thomas Davis, Professor of Social Work at (909)-537-3839, or tomdavis@csusb.edu

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APPENDIX C
DEBRIEFING STATEMENT

Debriefing Statement

Thank you for your participation.

The study you have just participated in was designed by Heather Wroten to examine the benefits of utilizing a specialized camp setting for children with a disability. In this study you were asked to participate in a survey, lasting approximately 15 minutes.

If you have any questions about this study, please feel free to contact Dr. Thomas Davis, Professor of Social Work, at (909) 537-3839, or tomdavis@csusb.edu.

If you would like to obtain a copy of the study, please refer to the California State University, San Bernardino, John M. Pflau Library after the summer of 2015 or contact Kelly Kunsek at kkunsek@abilityfirst.org

If you find that the study has caused some emotional discomfort that you had not anticipated, or for any reason would like to speak to someone further regarding the study topic, please contact either the San Bernardino County Crisis Centre at (909) 421-9233 or Dr. Thomas Davis, Professor of Social Work, at (909) 537-3839

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Done

APPENDIX D
SURVEY EMAIL COMMUNICATION

Email sent with Survey:

Hello,

My name is Heather Wroten and I have worked at Camp Paivika for the past three summers. I am a Masters of Social Work student at California State University, San Bernardino and I am excited to be doing my thesis research on families' experiences with Camp Paivika. My goal with this research is to educate others about camp services and create insight into the benefits of utilizing a specialized camp setting for children with a disability and their family.

You are invited to participate in an anonymous study about camp services with a focus on Camp Paivika.

The link below will take you to a survey that is anticipated to last approximately 15 minutes.

(If you have multiple children that attend Camp Paivika, you may take the survey more than once or choose one child to be represented in the study).

Thank you,

Heather Wroten

APPENDIX E
INSTRUMENT

* 1. What is your child's gender?

Female

Male

* 2. Age

9-12

13-15

16-18

19-20

21-24

* 3. Are there other children living in the home?

Yes

No

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4. How many children, by age, currently live in your household?

Less than 1 year old

1 year old

2 years old

3 years old

4 years old

5 years old

6 years old

7 years old

8 years old

9 years old

10 years old

11 years old

12 years old

13 years old

14 years old

15 years old

16 years old

17 years old

18 years old or older

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Developed by Heather Wroten

* 5. What is your relationship to your child?

- Mother
- Father
- Step-mother
- Step-father
- Grandmother
- Grandfather
- Aunt
- Uncle
- Foster Parent
- Other (please specify)

* 6. What is your age?

- 18 to 24
- 25 to 34
- 35 to 44
- 45 to 54
- 55 to 64
- 65 to 74
- 75 or older

* 7. What is the highest level of education you have completed?

Developed by Heather Wroten

* 8. What is your approximate average household income?

- \$0-\$24,999
- \$25,000-\$49,999
- \$50,000-\$74,999
- \$75,000-\$99,999
- \$100,000-\$124,999
- \$125,000-\$149,999
- \$150,000-\$174,999
- \$175,000-\$199,999
- \$200,000 and up

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* 9. How many summers has your child attended Camp Paivika?

10. Please indicate how your child's most recent camp experience was funded. (Check all that apply)

- Family
- Campership provided through Ability First
- Regional Center
- Other (please specify)

* 11. Which sessions have you/ your child attended? (Please check all that apply)

- 3 night summer session
- 5 night summer session
- 7 night summer session
- 9 night summer session
- Youth Weekend Respite
- Adult Weekend Respite
- Mom's retreat

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* 12. What is your child's diagnosis? (Check all that apply)

- ADHD or ADD
- Autism
- Angelman's Syndrome
- Anxiety
- Bi-Polar
- Cerebral Palsy
- Depression
- Developmental Delay
- Down's Syndrome
- Epilepsy
- Hearing Impairment/ Deaf
- Muscular Dystrophy
- Spina Bifida
- Traumatic Brain Injury
- Visual Impairment/ Blind
- Other (please specify)

Developed by Heather Wroten

* 13. What does your child's illness or disability involve? (Check all that apply).

- Medication management
- Diabetic Care
- Catheter/ Ostomy care
- G-tube feedings
- Trache care
- Breathing treatments
- Behavior management
- Bathing
- Toileting
- Dressing
- Feeding
- Other (please specify)

* 14. Who helps with the care of your child? (Check all that apply)

- Spouse/ Partner
- Family members
- Home nursing
- Babysitter
- Specialized daycare
- Regular daycare
- Ability First day program
- Another day program
- I have no extra help with my child's care
- Other (please specify)

Developed by Heather Wroten

* 15. How many hours per month does your child receive the following services:

	Hours
Occupational Therapy	<input type="text"/>
Physical Therapy	<input type="text"/>
Speech/ language	<input type="text"/>
Respite Care	<input type="text"/>
Behavioral Intervention program	<input type="text"/>

Other (please specify)

* 16. What kind of adaptive equipment does your child require?

- Wheelchair
- Walker
- Cane
- Braces
- Communication Device
- My child does not use adaptive equipment
- Other (please specify)

Developed by Heather Wroten

* 17. How do you, as a caregiver/ parent, benefit from Camp Paivika?

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
It provides a time of relief from emotional stress	<input type="radio"/>				
It provides me with time to complete household tasks	<input type="radio"/>				
It provides me an opportunity to spend time with my spouse/partner	<input type="radio"/>				
It provides me time for entertainment and socialization	<input type="radio"/>				
It provides an opportunity to spend time with other members of the family	<input type="radio"/>				
I am able to take a vacation	<input type="radio"/>				
I can catch up on rest and sleep	<input type="radio"/>				

Other (please specify)

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Developed by Heather Wroten

* 18. How does your child benefit from attending Camp Paivika?

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
My child gains social skills while at Camp Paivika	<input type="radio"/>				
My child gains independence while at Camp Paivika	<input type="radio"/>				
My child tries new things at Camp	<input type="radio"/>				
My child meets new friends	<input type="radio"/>				
My child's time at camp increases my child's confidence	<input type="radio"/>				
My child is able to be independent away from home	<input type="radio"/>				
My child participates in activities at Camp that they would not otherwise be able to do	<input type="radio"/>				
Camp Paivika is a place where my child fits in	<input type="radio"/>				
My child enjoys his/her time at Camp Paivika	<input type="radio"/>				

Other (please specify)

Developed by Heather Wroten

* 19. How do other children in the home benefit from their sibling attending Camp?

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	N/A
Allows the child to be the focus	<input type="radio"/>					
Provides respite from the responsibilities of having a disabled sibling	<input type="radio"/>					
Allows the family to partake in activities that they would not otherwise be able to do	<input type="radio"/>					

Other (please specify)



* 20. How likely is it that you would recommend Camp Paivika to a friend or colleague?

Not at all likely										Extremely likely
0	1	2	3	4	5	6	7	8	9	10
<input type="radio"/>										

* 21. Will your child attend Camp Paivika again?

- Yes
- No
- Unsure

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22. Please specify why you would not utilize Camp Paivika in the future (Check all that apply)

- I was not satisfied with the experience
- I no longer need the service
- I found it was too hard to be away from my child
- My child found it was too hard to be away from me
- The cost of Camp was too much
- Other (please specify)

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* 23. What is the most important aspect of Camp Paivika for your family?

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REFERENCES

- ADA. (n.d.). Introduction to the ADA. Retrieved October 05, 2014, from http://www.ada.gov/ada_intro.htm
- Baillargeon, R. (2011). The challenges faced by caregivers of children with impairments of psychological functions: a population-based cross-sectional study. *Canadian Journal of Psychiatry, 56*(10). Retrieved from <http://europepmc.org/abstract/MED/22014694>
- Bureau, U. S. C. (2011). School-Aged Children With Disabilities in U . S . Metropolitan Statistical Areas : 2010, 1401(November).
- Hepworth, D. H., Rooney, R. H., Rooney, G. D., & Strom-Gottfriend, K. (2013). *Direct Social Work Practice* (9th ed.). Belmont: Brooks/Cole.
- Keeler, M. D. (1993). *Guilt and Use of Respite Care by Mothers of Young Developmentally Disabled Children*. California State University- Long Beach.
- Kerson, T. S., & McCoyd, J. L. M. (2013). In Response to Need: An Analysis of Social Work Roles over Time. *Social Work, 58*(4), 333–343. Retrieved from <http://sw.oxfordjournals.org/cgi/doi/10.1093/sw/swt035>
- Mac Donald, E., Fitzsimons, E., & Walsh, P. N. (2007). Use of respite care and coping strategies among Irish families of children with intellectual disabilities. *British Journal of Learning Disabilities, 35*(1), 62–68. Retrieved from <http://doi.wiley.com/10.1111/j.1468-3156.2006.00399.x>
- McCormick, B. (1992). Parents' Perceptions of Benefits of Summer Camp for Campers with Mental Retardation. *Therapeutic Recreation Journal, 26*(3), 27–37.
- Mishna, F., Michalski, J., & Cummings, R. (2002). Camps as social work interventions: Returning to our roots. *Social Work with Groups, 24*(3-4), 153–171. Retrieved from http://www.tandfonline.com/doi/abs/10.1300/J009v24n03_11
- Mishna, F., Michalski, J., & Cummings, R. (2014). Social Work with Groups Camps as Social Work Interventions : Returning to Our Roots Camps as Social Work Interventions : Returning to Our Roots, (September), 37–41.
- Patterson, L. (2012). Points of Access: Rehabilitation Centers, Summer Camps, and Student Life in the Making of Disability Activism, 1960-1973. *Journal of*

Social History, 46(2), 473–499. Retrieved from <http://jsh.oxfordjournals.org/cgi/doi/10.1093/jsh/shs099>

Poppo, P. R., & Leighninger, L. (2011). *Social Work, Social Welfare, and American Society* (8th ed.). Boston: Pearson Education Inc.

San Filippo Di Matteo, L. (2005). *A Study of the Effects of Short-term Respite Care of Caregivers and the Relationships Between Respite Satisfaction and Social Support*. California State University San Bernardino.

Shelton, K. J. (2011). Therapeutic Camps as Respite Care Providers: Benefits for families of Children with Disabilities. *Therapeutic Recreation Journal*, 45(1), 17–31.

Whiting, M. (2014). Support requirements of parents caring for a child with disability and complex health needs. *Nursing Children and Young People*, 26(4), 24–7. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/24805033>