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Sibshops: How Effective Are They in Helping Siblings?

By

Amy M. Dailey, LSW

MSW Clinical Research Project

Presented to the Faculty of the
School of Social Work
St. Catherine University and the University of St. Thomas
St. Paul, Minnesota
in Partial fulfillment of the Requirements for the Degree of

Master of Social Work

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The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present the findings of the study. This project is neither a Master's thesis nor a dissertation.

Abstract

Having a brother or sister with special health needs not only impacts parents but siblings as well. Support available for these siblings has been found to be limited in the literature. One particular program designed to provide support to these children is a program called Sibshops. This study completed a program evaluation of Sibshops conducted at a Midwest Children's hospital between 2011- 2012 in order to assess the effectiveness of this program. Qualitative and quantitative data were obtained using parent feedback surveys. Results from the surveys showed that parents felt Sibshops provided their children with a positive experience, allowed them a sense of feeling they were not alone, caused positive attitude changes, increased their child's knowledge about their brother or sister's disability, and allowed for their healthy children to feel recognized in a special way. Additionally, the data also suggested that the five goals in the Sibshop curriculum were being met. While this study would suggest that Sibshops may be effective in providing support to siblings, further research including direct feedback from the children themselves may be beneficial in allowing social workers as well as other professionals working with siblings additional knowledge and insight into the benefits and challenges of having a brother or sister with special health needs.

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Table of Contents

Section	Page
Introduction.....	1
Literature Review.....	3
Prevalence of Children with Special Needs.....	4
Impacts on Families.....	7
Methods to Support Siblings.....	12
Support Group Outcomes.....	14
Curriculum Description.....	16
Methods.....	19
Research Design.....	19
Population and Sample.....	19
Protection of Human Rights.....	21
Data Collection.....	22
Data Analysis.....	23
Strengths and Limitations.....	24
Findings.....	25
Discussion.....	38
References.....	49
Appendices.....	52
Appendix A: Committee Form.....	52
Appendix B: Agency Letter.....	55
Appendix C: Parent Feedback Survey.....	56

Introduction

According to 2008 data referenced in research by DeRigne, one in five households in the United States is raising a child with special health care needs (CSHCN, U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, 2008). Special health needs may consist of things such as chronic or acute illness, mental health crisis, or developmental disabilities (Meyer and Vadasy, 2008). Examples of chronic conditions lasting years or often lifelong are medical conditions such as diabetes, spina bifida, and cystic fibrosis. Other children are diagnosed with acute health conditions such as cancer, seizure disorders, or organ failure which may or may not become chronic conditions. Children with special health needs also include those affected by mental health conditions such as depression or behavioral disorders. Lastly, while this listing of possible special health needs is not exhaustive, it also includes those children with mental retardation, autism spectrum disorder, various genetic and chromosomal disorders such as Down syndrome, Fragile X Syndrome, and Fetal Alcohol Spectrum Disorders. Whatever the special need may be, having a sibling with any one of these particular health needs almost always changes the dynamics within a family.

Having a child with a special health need can affect a family's finances, employment status, and mental and physical health (The National Survey of Children with Special Health Care Needs, 2001). The demands on families may require that parents cut down their work hours or give up a job, at the same time they face burdensome out-of-pocket health care costs. The National Survey for Children with

Special Health Care Needs completed a survey in 2006 that found one in ten parents reported the average time spent providing, arranging, and coordinating care for their child with special health needs was eleven or more hours a week (National Survey CSHCN, 2006). While the child who has been diagnosed often receives special medical attention as well as attention from parents and the community, siblings of these children are often left in the shadows. Forty studies performed between 1970 and 1995 indicated that 60% of parents with children with developmental disabilities reported manifestations of increased risk of negative effects on healthy sibling (Dauz Williams, Piamjariyakul, Graff & Stanton, 2009). Studies such as these have generated awareness of the need not only to address the needs of the child with health concerns but their healthy siblings as well.

Efforts to address the needs of siblings have been evaluated in forums such as family centered care in hospitals or by conducting family team meetings but perhaps the most popular technique seen in the literature has been through the use of sibling support groups (Munsch and Levick, 2010; Levick, Quinn, Holder, Nyberg, Beaumont, and Munch, 2010; Barrera, Fleming, and Khan, 2004; Sloper, 2000; Naylor, and Prescott, 2004; Nolbris, Abrahamsson, Hellstrom, Olofsson, and Enskar, 2010; McCullough, and Simon, 2011). These groups often consist of a social gathering or activities intended to form peer support and opportunities for kids to network with one another. This is the foundation for the sibling support group model titled Sibshops. Sibshops are described by their founder as “opportunities for brothers and sisters of children with special health, mental health, and developmental needs to obtain peer support and education within a recreational context” (Meyer and Vadasy, 2008). These groups are described as fun events that acknowledge that being the brother or sister of a person with special needs is

for some a good thing, for others a not-so-good thing, and for many something in between. These day long gatherings usually consists of games and fun activities intended to form peer support and opportunities for kids to network with one another (Meyer and Vadasy, 2008).

The focus of this qualitative project was to take a closer look at how sibling supports groups, Sibshops in particular, help siblings of children with special health needs. The study asked parents or guardians of siblings how beneficial they perceived the Sibshop experience to be. The perceived benefits were measured by means of a qualitative and quantitative review of parent feedback surveys. This method, in turn, is hoped to provide beneficial feedback that will offer an increased knowledge base to social workers as well as other professionals working with families of children with special health needs. Additionally, the findings may serve as an effective tool for others who may be thinking about implementing or enhancing sibling support groups in their own setting.

Literature Review

Many will know someone in their lifetime that has a child affected with special health needs. In fact, DeRigne's research demonstrates that one in every five families will be directly affected by having at least one child in their household diagnosed with special healthcare needs (Children with Special Health Care Needs; U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, 2008). Literature on the topic of children with special health care needs appears abundant; however information on what is available to help siblings

of these children is not as well documented. The literature researched for this study focuses on four specific themes: the prevalence of children affected with special health needs; the impacts this has on families; efforts to address support for siblings; and positive outcomes seen as a result of these supports.

Prevalence of Children with Special Health Needs

Children with special health needs has been an issue that has received increasing attention in the media and public spotlight over the recent years as the number of children affected with special health needs seems to be on the rise. One group of children that it seems many are becoming particularly aware of is children affected by autism and other similar spectrum disorders. It is estimated that approximately one in every 88 children in the U.S. has autism (Center for Disease Control and Prevention, March 2012) compared to only 1 in 10,000 in 1970. These numbers equate to approximately 1.5 million individuals in the U.S. today who have been diagnosed with autism. Researchers have been looking to find the answers as to why these rates are so alarming. One recent study published in the scientific journal *Nature* found that older men are more likely than young men to father a child who will develop diseases such as autism and schizophrenia. The research study suggests that older men pass on more new DNA mutations- de novo mutations- to their kids than younger dads, putting their children at a higher risk for developmental issues (Calloway, 2012). While this may be just one of many theories being researched, scientists are attempting to find answers about why this medical condition affects so many. The number of children affected with autism and autism spectrum disorders remains concerning.

In addition to autism another medical condition that is prevalent is childhood cancer. Numerous children are given this medical diagnosis each year. For example each year in the United States there are approximately 13,400 children between the ages of birth and 19 years of age who are diagnosed with cancer. About one in 300 boys and one in 333 girls will develop cancer before their twentieth birthday (American Childhood Cancer Organization, 2010-2012). According to the American Cancer Society, about 12,060 children in the United States under the age of 15 were diagnosed with cancer in 2012 (American Cancer Society, 2012).

Perhaps those children with autism and cancer are most widely talked about in newspapers and on television as the prevalence of these children with special health needs are increasing for reasons most scientists don't seem to be able to explain. However there are also numerous other children afflicted with special health needs that have been studied for decades and are just as prevalent. For example, The Centers for Disease Control and Prevention (CDC) and the National Birth Defects Prevention Network have published a study that updates national statistics regarding the prevalence of Down syndrome in the United States (Anderson, Canfield, Collins, Correa, Kirby, Mia, Mason, Meyer, National Birth Defects Prevention Network, Parker, Wang, 2010). The study indicates that there are about 6,000 diagnoses of Down syndrome each year in the United States. One in every 691 babies is born with Down syndrome which is an increase from previous statistics indicating that only one in every 733 babies would be born with the diagnosis. There is some speculation that this increase may in part be due to the fact that women are waiting to have children until later in life. Statistics show that by the age of 35, a woman's risk of conceiving a child with Down syndrome is one in 400.

By age 45, the risk is one in 35 (Mayo Clinic, 1998). While age has been shown to be associated with increased risk for delivering a child with Down syndrome, chromosomal factors make it possible for young mothers to bear a child with the diagnosis of Down syndrome as well. Approximately 51% of babies born with this diagnosis will be born to mothers under the age of thirty.

In addition to those conditions already listed, another special health care need that affects many children is cerebral palsy. Cerebral palsy is not a new disorder, and has probably been around as long as there have been children. Cerebral palsy (CP) is the most common motor disability of childhood. A recent publication from the Autism and Developmental Disability Monitoring (ADDM) CP Network sponsored by the Centers of Disease Control and Prevention (CDC) reported a prevalence of 3.3 per 1000 children in the United States suffer from cerebral palsy (Pakula, VanNaardeen Braun, and Yeargin-Allsopp, 2009). This disorder involves the brain and nervous system functions and can affect things such as movement, learning, hearing, seeing and thinking. Many children affected with this condition will require assistance with their daily routine or cares to some extent for their entire lives.

Yet another condition that affects thousands of children each year is myelomeningocele. Myelomeningocele is a birth defect in which the backbone and spinal canal do not close before birth. According to the A.D.A.M. Medical Encyclopedia this condition is a type of spina bifida. The CDC reports that spina bifida affects nearly 1,500 babies each year. While spina bifida may cause only minor physical symptoms, frequently it can lead to severe physical and mental disabilities (Mayo Clinic, 2011).

Often the term child with special health needs is associated with the physical health of a child but this definition also includes children affected with mental health disorders as well. Such conditions may include things such as an anxiety disorder, depression, hyperactivity disorder, bipolar, and schizophrenia. In recent years, there has been increasing recognition of the prevalence of childhood mental health disorders. One well-regarded study found that one in five children and adolescents in the U.S. exhibit some functional impairment from a mental or behavioral disorder, with one in nine experiencing significant impairment and one in twenty experiencing extreme impairment (Koppleman, 2004).

The literature supports the conclusion that there are a significant number of children affected with special health care needs in the United States but how does having a child affected with one of these disorders impact the family?

Impacts on Families

Studies related to having a child with special health care needs have shown impacts on things such as time spent providing care, parental employment status, family finances, as well as the effects on well siblings (DeRigne, 2012; The National Survey of Children with Special Health Needs, 2001; Daus Williams and Piamjariyakul, 2010.)

With regard to time spent providing care, parents reported that they felt a great deal of their time was spent providing care for their child with special needs. Many families indicated devoting substantial amounts of time to providing health care through tasks such as administering medications and therapies, maintaining equipment, and providing transportation. They also reported spending time arranging and attending medical appointments as well as meeting with other professionals such as teachers,

counselors, and therapists. In a study at the University of Wisconsin-Milwaukee as many as 42.6% of mothers reported during interviews feeling the demands of caring for their child with special needs made it difficult to find time for themselves, while 33.3% also reported that these demands limited the amount of time they could spend with friends and family (McLinden, 1990.) The demands of caring for a child with special health needs not only affects time available, but has also been shown to impact parental employment status as well.

Data from the National Survey of Children with Special Health Needs conducted in California in 2006 indicates that nearly 24 percent of parents report having to stop work or cut back on their hours at work because of their children's needs. This equates to nearly 325,000 children and their families in the state of California. Research has also looked at the type of the child's condition as it relates to parental employment status. Specific research looking at children whose special health needs were diagnosed as mental health-related found that families were more likely to cut work hours or to stop work all together when compared with children without a need for mental health services or when compared with children with a need for other specialty services. (Koppleman, 2004) Kogen et al. (2008) found that children with autism have the greatest parental employment impact when compared with children with other emotional, developmental or behavioral problems. Parental employment status can cause concern with family finances but other causes can be associated with financial burden as well.

Families of children with special needs are often affected by increased out of pocket expenses. Parents are often required to pay out of pocket expenses for health care services not covered by their insurance plans such as therapies, home health care,

prescription drugs, medical equipment and dental services. Families of nearly half of the children with special health care needs reported spending \$250 or more on health care in a year (National Survey with Special Health Care Needs Chart book 2001). Children from low income families are less likely to have expenditures than are children from families of higher incomes perhaps because lower income families may more likely be covered by Medicaid and other state plans. Even though children from low income families have lower out of pocket costs, these children are more than twice as likely as children from higher income families to have conditions that result in financial problems (National Survey of CSHCN, 2001).

While the impacts of having a child with special health needs can affect the families' time, finances, and parental employment status, there is also literature that suggests that there are psychological and emotional effects on the family as well. The demands of parenting and caring for a child with special health needs in particular, can cause considerable stress for parents. In a survey conducted by the NSCH in 2007 parents were asked how often they felt their child was much harder to care for than others of his or her own age, how often the child did things that really bothered them a lot, and how often they felt angry with the child. Parents of 14.8 percent of children reported parental stress-higher than the national rate of 9.6 percent (National Survey of children with special health needs, 2001). Meaden, Halle, and Ebeta (2010) examined the impact that having an autistic child may have on members of family. They concluded that caring for an individual with special needs can have negative impacts on the well-being of members of the immediate and extended family. Specifically, stress was found in the marital subsystem, parental subsystem, and sibling subsystem (Meadan et al., 2010a).

The daily demands and caretaking responsibilities can arouse a family's stress and anxiety levels which may directly affect an individual's physical and psychological well-being (Lee, 2009; Lee et al., 2009; Weiss & Lunsky, 2010, Carrillo, 2012).

Having a child with special health needs not only impacts parental roles but has been shown to impact siblings as well. Siblings often experience changes in family roles, decreased family social activities, loss of parental attention, and increases in family stressors. Some researchers report that the changes experienced within the family unit have been linked to negatively affecting the emotional well-being and functioning of non-disabled siblings (Macks & Reeve, 2007; Orsmond & Seltzer, 2009; Petalas et al., 2009b), while others suggest that typically developing siblings are not at increased risk for adjustment difficulties (Kaminsky & Dewey, 2002; Pilowsky, Yarmiya, Doppelt, Gross-Tsur, Shaley, 2004, Carillo, 2012). Studies have looked at the variety of responses siblings may encounter as a result of having a brother or sister with special health needs. Interviews with 94 siblings of children with cancer, at 6 and 18 months after diagnosis took place to record experiences reported by healthy siblings. Siblings reported feelings of loss associated with loss of attention; loss of their own and their families' usual activities and routines; loss of certainty and security; and loss of companionship of the ill child. In contrast to, and along with the losses, some sibling reported gains were also apparent as a result of the process of coping with their sibling's special health needs. Approximately 60% of siblings reported one or more gains after 6 months and 72% reported this at the time of the second interview conducted at 18 months. Gains reported by well siblings were closer family relationships, feeling increased independence and maturity, and one fifth of the participants indicated actually feeling they had an increase

in family and social activities as a result of families attempting to make the most of life and opportunities (Sloper, 2000). Many siblings report a potpourri of feelings such as anger, guilt, or embarrassment associated with their brother or sister's special needs. In a book written by Mary McHugh titled *Special Siblings* she writes of her personal experiences of having a brother with special needs. She states "I grew up thinking I should never complain, never do anything bad, never cause my parents a minute's worry because they had so much to concern them as it was" (*Special Siblings*, 2003 p. 37).

Siblings of children with special health needs are far more likely to experience guilt than siblings of individuals without special needs. Brothers and sisters may feel that they caused their siblings' disability; they may experience survivor's guilt; they may feel guilty about their own abilities or they may harbor less- than- charitable feelings about their sibling (Meyer & Vadasy, 2008). One sibling writes in the book *Sibshops:*

Workshops for Siblings of Children with Special Needs

"I feel bad when John sees me going off with my friends and wonders why he doesn't have many. He'll be home when I'm out having fun, and it makes my mom feel bad. I feel guilty and don't know how to handle it (Sue, 17, in Binkard et al., 1987, p13).

Shame, where guilt intersects with embarrassment, is a powerful and painful experience for some siblings. Because of the stigma of a disability or illness, siblings can feel that their family is now "marked" and wish they would just fade into the woodwork (Sourkes, 1980). The wide array of emotions and responses recognized in the literature demonstrates a need to address support resources for siblings of children with special needs.

Methods to Support Siblings

Research studies have looked at different ways of helping siblings of children with special health needs cope (Sloper, 2000; Naylor et al., 2004). In one study healthy siblings of cancer patients were asked what resources and strategies they felt helped them cope. Siblings reported the following three areas: relationships, information, and having their own interests and activities. Siblings indicated relationships that allowed them to talk about their situation, and provided comfort and support for their own feelings and a focus outside the illness, were noted as important by eight out of ten siblings. Siblings also vocalized that having information about their siblings illness or diagnosis was helpful in making sense of the situation, understanding why their lives had been disrupted, and feeling involved and still part of the family. Lastly, well siblings reported that having their own interests and activities was helpful for some as it allowed for distractions from worries, helped to maintain normality in their lives, and provided a focus and role outside the family (Sloper, 2000).

While methods such as those talked about by siblings may provide benefit, the primary source of support researched in the literature centers on providing sibling support through the use of support groups or social gatherings. The literature describes several different approaches taken by professionals to provide support experiences for siblings.

Helen DeVos Children's Hospital, in Grand Rapids, Michigan initiated two separate types of sibling support groups for the siblings of their Neonatal Intensive Care Unit (NICU) families (Levick et al., 2010; Munch & Levick., 2001). The first group gathered both siblings and parents to address the needs of siblings. This gathering was done in a format called "Sibling Night" where parents and siblings arrived together but

then were divided by a flexible wall divider. The parents groups followed a format common to NICU support groups, while siblings often used a form of art, such as coloring, or drawing in a book called *My Me Book* as their treatment modality (Munch and Levick, 2001).

The second sibling support group at Helen DeVos Children's Hospital was a group called "Celebrating Siblings Pizza Party". This group gathered monthly for one hour offering siblings age four and older the opportunity to gather for pizza and beverages, while allowing them time to talk with one another. Once the children finished eating they had the opportunity to participate in hands on activities such as coloring, playing with incubators while having their picture taken, decorating a photo frame and/ or engaging in IV teaching with dolls (Levick et al., 2010). This particular group was facilitated by multidisciplinary staff which included social workers as well as nurses.

Another sibling support group evaluated in the literature was a model known as Sibshops. Sibshops are described as "opportunities for brothers and sisters of children with special health, mental health, and developmental needs to obtain peer support and education within a recreational context" (Meyer and Vadasy, 2008). These groups founded by Don Meyer, a pioneer in the sibling movement, currently exist in over 340 locations worldwide. They are generally day long events that consist of games and fun activities intended to form peer support and opportunities for kids to network with one another (Meyer and Vadasy, 2008). The importance of such support groups, in particular Sibshops, was highlighted in an article titled *Feeling Heard: A Support Group for Siblings of Children with Developmental Disabilities*. This article looked to describe and assess models for facilitating support groups for siblings of children with developmental

delays and found Sibshops to be a rich resource for siblings of children with disabilities. (McCullough and Simon, 2011). While support groups are being offered in some settings little research appears to exist on the benefits of such interventions.

Support Group Outcomes

What literature is available suggests that positive outcomes have been reported by siblings who attended support groups. One such study was conducted in Northwest England where siblings of disabled children took part in a quantitative as well as a qualitative study seeking respondent opinions on sibling support groups after they had attended such a group for a five month period. Overall there were positive outcomes reported by the participants that included: increased self-esteem, increased quality of life, increased social interaction, increased coping strategies within the family situation, and increased understanding of disability issues (Naylor and Prescott, 2004).

In another study fifteen siblings ranging in age from eight to nineteen were interviewed by a focus group method, meeting in four groups on three separate occasions to assess their experiences as participants in a sibling support group. Using qualitative data the responses from interviews conducted with the participants were recorded and evaluated revealing three themes: 1) belonging to a group 2) feeling important as a member of the group and 3) therapeutic support helped siblings recall and understand their memories. The findings of this study found that regardless of gender or age, the siblings felt a sense of belonging and comfort by being in a group. (Nolbris, et al., 2010).

While research is somewhat limited on support groups being conducted for siblings of children with special needs, it seems that even less may be known about the outcomes of a model known as Sibshops. One research study in particular was completed

in Cork, Ireland by D'arcy, Flynn, McCarthy, O'Connor, and Teirney (2005) which looked at the effectiveness of this sibling support program. During the study sixteen siblings ranging in age from eight to eleven (11 boys, 5 girls) , were asked to participate in a study in which quantitative interviews as well as parent feedback forms would be utilized to evaluate the effectiveness of sibling support program (Sibshops). Interviews took place with siblings both six weeks prior to the start of Sibshops as well as two months post attendance at Sibshops. Siblings were asked if Sibshops met four goals identified as: 1) meeting other siblings 2) discussing common joys and concerns of having a brother or sister with a disability 3) learn how others handle situations commonly experienced by siblings of children with a disability 4) learn more about the implications of their brothers' and or sisters' special need. Outcomes of this particular study showed that Sibshops were successful in meeting the first three goals. Goal one was clearly met as 81 percent of siblings expressed a wish to meet the siblings again once Sibshops were complete. Goals two and three aimed to provide siblings with opportunities to share common joys and concerns, and ways of handling common experiences were met as 75 percent of children recalled talking about the good and not-so-good aspects of their sibling. Goal four, aimed to provide education and information about their siblings' specific disabilities. This particular goal asked questions that focused on how siblings' lives were different in four aspects that included school, home, play and the future. Answers from the post interview tended to be more specific than those given during the pre-Sibshop interview but did not necessarily display increased knowledge or information. Despite the goals evaluated during interviews, feedback from both parents and siblings revealed that Sibshops were enjoyable experiences. Fourteen of the sixteen

participants indicated having a positive experience and eleven participants thought they were ‘excellent’ or ‘great’ (D’arcy et al., 2005). While outcomes of the study completed appear to be favorable, this appears to have been the only formal study conducted and published thus far on the effectiveness of Sibshops. No studies appear to have been published on the benefits or effectiveness of Sibshops in the United States. The purpose of this study is to complete further analysis of Sibshops in order to achieve a better understanding of their benefits and effectiveness.

Curriculum Description

The Sibshop program was originally founded by Don Meyer and Greg Schell in 1978. Both original founders of Sibshops possess a strong background in the area of assisting siblings of children with special needs. In addition to Sibshops Don Meyer also is the founder of the SEFAM (Supporting Extended Family Members) program at the University of Washington, the senior author and editor of six books, and the founder of SibKids and SibNet, which are no-cost listservs for young and adult brothers and sisters. Greg Schell, MEd, is the parent of a daughter with special needs and has been a teacher, principal, and parent educator for over 30 years.

Don Meyer (now the director of the Sibling Support Project) and Greg Schell (now the director of the Fathers Network) helped pioneer an innovative program for dads of kids with disabilities. The Fathers Program was an effort to provide peer support and information that reflected dads’ interests and concerns. Almost immediately, it became apparent that there were other, traditionally unserved family members who could also benefit from opportunities to discuss their unique joys and concerns with peers who would understand: grandparents and, of course, brothers and sisters.

With the help of the University of Washington, the SEFAM (Supporting Extended Family Members) project was born in late 1981. SEFAM staff further refined the Fathers Program model and developed two new programs: Grandparents Workshop and Sibshops. On October 23rd, 1982 the first Sibshop was held in Seattle, Washington. Recent data from 2012 reports that there are now 340 Sibshops taking place in eight different countries.

Sibshops are described as opportunities for brothers and sisters of children with special health and developmental needs to obtain peer support and education within a recreational context. Sibshops are best described as *events*. They are lively, pedal-to-the-metal celebrations of the many contributions made by brothers and sisters of kids with special needs. The Sibshop model intersperses information and discussion while doing activities such as games, cooking, and crafts. Sibshops are targeted toward youth between the ages of eight-to- 13 years of age, however can be adapted for slightly younger and older children. While originally designed to support siblings of children with developmental disabilities, the Sibshop model is also used with siblings that have other special needs including cancer, hearing impairments, epilepsy, emotional disturbances, as well as a variety of other special health needs. The Sibshop model has been used in various settings and is generally facilitated by service providers (such as social workers, child life specialists, special education teachers, psychologists, nurses) and adult siblings of people with special needs. Sibshops may be offered as frequently as weekly or as infrequently as yearly. They may also be offered in a series (e.g., five Sibshops, meeting once a month, with one registration). The Sibshop being evaluated in this study is affiliated with a Midwestern hospital and is being conducted on a bi-annual basis.

While Sibshops are described as fun events for siblings they are also designed with structured goals in mind. The Sibshop model is comprised of five goals:

Goal 1: Sibshops will provide brothers and sisters of children with special needs an opportunity to meet other siblings in a relaxed, recreational setting.

Goal 2: Sibshops will provide brothers and sisters with opportunities to discuss common joys and concerns with other siblings of children with special needs.

Goal 3: Sibshops will provide siblings with an opportunity to learn how others handle situations commonly experienced by siblings of children with special needs.

Goal 4: Sibshops will provide siblings with an opportunity to learn more about the implications of their sibling's special needs.

Goal 5: Sibshops will provide parents and other professionals with opportunities to learn more about the concerns and opportunities frequently experienced by brothers and sisters of people with special needs.

To assure that when parents send their children to a Sibshop, they are sending them to a program that is true to the spirit and goals of the Sibshop model, sibling programs wishing to call themselves “Sibshops” must register their program. The Sibshop program model being evaluated for this study has been registered and is conducted by trained facilitators. Evaluations of Sibshops are suggested and are currently being conducted by means of parent surveys at the hospital where this programming took place. This survey is designed to assess areas of improvement as well as capture feedback that parents may have received from their child since attending a Sibshop. Currently the data being collected at this site is for internal program evaluation. This study is designed to ask a broader series of questions by means of further evaluating parent survey with an aim of better understanding if siblings felt they met others with whom they could connect, what siblings’ report they most enjoy about Sibshops, and what parent’s perceive their child learned from attending a Sibshop.

The purpose of this study was to analyze secondary data in the form of parent feedback surveys to determine if the goals of Sibshops are being met. I sought to use this feedback in order to better inform and to allow for the opportunity to adjust and improve the program if necessary.

Methods

Research Design

This research project served as a program evaluation of Sibshops which were conducted at a children's hospital in the Midwest examining how well the goals of Sibshops are being met. The study employed a primarily qualitative design with some quantitative aspects. It was conducted by using secondary data in the form of parent feedback surveys.

Population and Sample

The sample for this study represents siblings of children with special health needs who participated in a Sibshop experience between the years of 2011 and 2012 in this setting, for a total of 100 participants. Respondents were parents/guardians of a child with special needs who had at least one or more of their child's siblings participate in a Sibshop event. Diagnoses of siblings' brothers or sisters included but were not limited to: Down syndrome, cerebral palsy, spina bifida, autism, seizure disorders, cancer, diabetes, and other physical and medical health related conditions. On only a few occasions did the participant's brother or sister have a mental health diagnoses.

The population the study looked at was parents of a special needs child who had their sibling(s) attend a Sibshop offering. The surveys asked questions about their perception of the Sibshop program and how they felt it impacted their child/ren who

attended. The demographic data available for each Sibshop was collected by the Sibshop planning committee and is outlined below:

Sibshop #1 (Aug 2011) Location: outdoor camp

Total number of participants: 18 representing 12 families

Males: 8 Females: 10 Age Range: not recorded

Parent feedback surveys mailed: 12 Surveys returned: 7

Sibshop #2 (February 2012) Location: indoor/outdoor nature center

Total number of participants: 30

Males / Females: ratio not recorded Age range: 4 -13 years

Parent feedback surveys mailed: not recorded Surveys returned: 14

Sibshop #3 (Aug 2012) Location: outdoor camp

Total number of participants: 52 participants representing 39 families

Males: 25 Females: 27 Age range: 4-14 years of age

Parent feedback surveys mailed: 39 Surveys returned: 14

Protection of Human Participants

Based on the fact that this is a secondary data analysis, no separate informed consent from participants was required; however, protection of the human participants was achieved in this study by the implementation of several measures. First, this study was reviewed by dual Institutional Review Boards (IRB) to assure that it protected the human rights and welfare of its participants. Separate reviews were done by the University of Saint Thomas IRB as well as the Institutional Review Board for the hospital at which these particular Sibshops were conducted.

Second, all of the parent surveys collected were anonymous and were collated by the Sibshop planning committee prior to the researcher receiving them, thus in no way allowing feedback to be linked directly to participants who attended Sibshops. Results of original parent surveys returned were tabulated by the Sibshop planning committee and presented to the researcher in a collective format therefore eliminating contact with any of the raw data. Original surveys were kept in the possession of the Sibshop planning committee and were not at any time in the possession of the researcher. Copies of tabulated survey results were stored in an envelope in a locked file cabinet at the researcher place of employment and upon completion of this study on May 20th 2013 will be shredded by the researcher.

Third, the Research Coordinator de-identified any parent feedback comments that may have contained names of children provided by parents in their responses. In the event a parent provided their child's name in the feedback portion of the survey the researcher removed this name therefore leaving the space blank in the qualitative statements reported in the findings of this research project.

Fourth, this study did not contain direct contact of any minors but rather used surveys completed by their parents or guardians in an effort to protect the children who participated in these Sibshops. Parents were asked to provide feedback about their child's participation in Sibshops and were given the option of providing their name on feedback surveys in an effort to protect their identity and to allow for anonymous feedback to occur.

Lastly, the name of the hospital at which these Sibshops were conducted was not revealed in the context of this research study in order to further protect the identity of the participants.

Data Collection

The data for this study were obtained from existing responses given in parent feedback surveys following three separate Sibshops offerings. Parent feedback surveys were mailed to parents/guardians of participants approximately one to two weeks after a Sibshop had taken place. These surveys were mailed to parents requesting their feedback on their child's most recent experience at a Sibshop event. Parents were asked to complete and mail back their survey to the Sibshop planning committee in the stamped addressed envelope which was included with the survey. Questions of both quantitative and qualitative nature were asked on the survey. Quantitative items asked parents to rate things such as the meeting time, location, length of the Sibshop, communication of the facilitators, activities/content, and impact on their child's knowledge/feelings toward his or her brother, sister, or other family members. Parents were asked to rate these items on likert scale rated from 1 to 5 with 1 being very dissatisfied to 5 being very satisfied.

Parents were then asked to provide yes/no answers to the following questions as well as offered space below each question to provide additional comments. Questions in this portion of the survey consisted of the following:

- 1) Has your child talked about what has happened during the Sibshop?
- 2) Has your child seemed to enjoy the Sibshop?
- 3) Was there a particular activity that your child seemed to have really enjoyed?
- 4) Has your child seemed upset by anything that was offered at the Sibshop?
- 5) What do you think your child has learned from the Sibshop? How has he or she benefited so far?
- 6) Overall, are you glad your child participated in the Sibshop?

Data Analysis

Data were collected from parent feedback surveys completed between August, 2011, and August, 2012, and were analyzed primarily for qualitative data but also include some quantitative responses that are applicable to the researcher's study question.

Responses to the following satisfaction question were analyzed: impact on your child's knowledge/feelings toward his or her brother or sister or other family members following a Sibshop. In addition to looking at the responses of this particular likert scale question, quantitative data were used to evaluate responses to yes/no questions asked on the parent feedback survey.

Following analysis of the quantitative data, qualitative data found in the comments section of the parent feedback survey were analyzed and coded, looking for themes. These themes were compared to see how consistent they may be with the five identified goals of Sibshops. The validity of this study depends on how accurate parents

were at providing feedback on their child's Sibshop experience. The parental feedback survey is, in some ways, "one step removed," but it comes from a source close to the child and from someone who can observe and reflect on the child's experience in an experience-near way. It also allows for a lower risk of harm approach to gather data for this study.

Strengths and Limitations

There appear to be several strengths within this clinical research study, the first of which is that the study sample tabulates data from more than one Sibshop thus increasing the likelihood of getting a wider sample size across sites. General knowledge indicates the larger the sample size, the more accurate the data is at projecting what the entire population is thinking.

Second, as the researcher for this study I possess a great deal of expertise on the topic. My social work background includes nearly thirteen years of experience working as a hospital social worker with children and families affected with special health care needs. In addition to my experience as a pediatric social worker I am also trained as a Sibshop facilitator, and have had experience both attending and facilitating Sibshops.

An additional strength of this study is the fact that data have already been actively collected on previous Sibshops. This data has thus far served as a valuable tool for the Sibshop planning committee and staff involved to see what general feedback parents have provided. This study can now strengthen the use of this tool so that data can be used to determine if Sibshops are in fact meeting their intended goals.

Lastly, a strength of this study is the fact that the Sibshop program is so widely used. Currently, Sibshops are being offered in eight different countries worldwide at a

total of 340 locations. Such broad use of this program would seem to suggest its potential effectiveness in working with siblings.

Despite the strengths, there may also be some limitations to this study. One limitation may be that due to the time frame during which the study was completed the researcher was unable to collect primary data as another Sibshop was not scheduled to be held within a reasonable time frame of the study. Based on this limitation only secondary analysis was used, thus limiting the survey questions to those already asked. This prevented the researcher in her ability to design a survey tailored specifically toward her specific research question. Next, the study is based on parents' perceptions of their child's experience and not directly on feedback provided by siblings who participated in Sibshops. Another limitation of the study is the fact that the sample represents primarily Midwestern children having parents financially secure enough to afford transportation and registration fees to attend the event. While some scholarship funding was offered this did not represent the majority of participants in this study. Lastly, while the researcher's expertise may lend itself to additional knowledge of the topic, it may also offer biased opinions to be formed based on past experiences with Sibshops. I will be mindful of this in my data analysis.

Findings

During the process of analysis, results from 35 parent feedback surveys were reviewed in an attempt to conduct a program analysis of Sibshops taking place at one Midwestern hospital. Data were analyzed for both quantitative findings and for qualitative themes. Primarily data were analyzed from a qualitative perspective through

evaluation of parent comments found within the parent feedback surveys; however certain quantitative aspects of the survey such as yes/ no answers to parent feedback questions and one particular likert scale item related to children's knowledge and feelings were analyzed as well.

Quantitative Findings

Quantitative questions in the survey took the form of Yes/No questions asked of parents which consisted of things such as: Has your child talked about what has happened during the Sibshop? Did your child seem to enjoy the Sibshops? Has your child been upset by anything that was offered at the Sibshop? Are you glad your child participated in the Sibshop, and are there things we should consider for future Sibshops?

Results from yes/ no data showed strong consistency between parents' responses and positive survey results. When asked the question *has your child talked about what has happened during the Sibshops*, all 35 parent feedback surveys indicated yes. When parents were asked if they felt their child *enjoyed the Sibshop* 33 of the thirty 35 responded yes with only two failing to provide any response and no participants responding no to this question. Parents appeared to provide further evidence of their approval of Sibshops when they responded to the question *are you glad your child participated in the Sibshop*. Thirty four of the 35 parents surveyed responded yes to this question and no parents responded no. One parent opted not to answer this question. Parents were also asked if they felt *their child seemed upset by anything that was offered at the Sibshop*. Thirty four parents responded to this question indicating no they did not feel their child had been upset in any way. One parent did respond yes to this question indicating that their child did not care for an activity that was offered allowing children

the opportunity to touch wilderness animals. Lastly, parents were asked during the Yes/No portion of the survey if they *felt there were things that should be considered for future Sibshops that would make them more enjoyable or informative*. Eleven parents responded yes to this question providing a variety of written responses included in the qualitative portion of the study. Eleven parents indicated no to this question while 13 parents did not provide any response to this particular question.

In addition to evaluating responses to the Yes/No questions the researcher also evaluated responses to a particular likert scale question that was applicable to the study. The question was stated as follows: Rate the Impact of your child's knowledge/feelings toward his or her brother, sister, or other family members. This question asked parents to rate their satisfaction with the following aspects of the group on a scale from one to five with one being very dissatisfied to five being very satisfied. If they had no opinion or the item was applicable parents were instructed to circle N. Results of the likert scale question were as follows:

No parents indicated being very dissatisfied or dissatisfied with this statement. Three parents indicated in their responses being neither satisfied nor dissatisfied. Eight parents indicated feeling satisfied and 21 parents indicated being very satisfied with the impact on their child knowledge/feelings toward his or her brother, sister, or other family member.

Three parents responded by circling N indicating that they either had no opinion or the item was not applicable.

Qualitative Findings

The primary data analysis strategy was qualitative. The researcher analyzed comments found on parent feedback surveys and then proceeded to coding them in an attempt to identify themes. The following themes are those identified during the data analysis process. The first and perhaps most prevalent theme was that respondents felt that their child's experience at Sibshops was positive. Parents also reported that they felt that Sibshops provided opportunities for their children to connect with others children faced with similar challenges. In addition they expressed that Sibshops provided an opportunity for their healthy children to be recognized and acknowledged in a special way. Some parents reported positive changes in their child's attitude and behavior toward their disabled sibling following Sibshops. Several parents reported that they felt their child had gained knowledge about their sibling's disability as well as other disabilities. Lastly, parents and siblings expressed a strong desire to return to future Sibshops and to stay connected with the peers they had met during a Sibshop experience.

The following section will provide a closer look at each of these findings as well as include specific parent comments found in the feedback surveys.

Positive Experience

One of the first themes was that there was an overwhelming consensus among the respondents that Sibshops were viewed by both parents and attendees as positive experiences. Multiple respondents provided feedback statements that would support this finding. Some of these statements included:

"The boys had a really great time and talk about the activities almost daily."

“Both my children talked a lot about the Sibshops when they came home. They loved it!”

“I could not do for _____, as a parent, what being with all the other siblings has done for her!”

“This was our first Sibshop! We absolutely loved it. Terrific experience!”

“My children have enjoyed all the Sibshops they have attended; it is a positive thing they get to do because their brother has special needs.”

While comments from parents on the survey remained mainly positive one parent reflected on their child’s difficulty with feeling homesick during the day long event stating:

“He said he was homesick, but he did say he enjoyed some things.”

In addition to the overwhelming positive feedback from parents another theme that was very prevalent in comments from parents on the survey was how much they felt that Sibshops had offered opportunities for their child(ren) to relate to others.

Relate to Others- Knowing You Are Not Alone

Parents expressed that their children were able to relate to others and that their children articulated feeling that they were not alone. Many parents provided comments in the survey that supported this theme. Some of the comments were things such as:

“He is able to relate to other kids with a chronically ill sibling and to overcome his fears and have this as one of his outlets.”

“She learned that she’s not the only child dealing with a sibling with special needs. It was neat for her to have a fun day and meet other kids. I like that she gets to hear about other families and how they deal with their sibs.”

“I really think it has helped her realize she is not the only one in her situation.”

“They are not the only siblings of “special” children.”

Additional comments from parents supporting this strong theme included:

“He has figured out he is not the only one that has a sibling that is sick or spends a lot of time at the hospital.”

“My children came away knowing they are not alone in the world with two brothers with special needs. We as parents tell them that, but it was reinforced meeting peers who are in the same situation.”

“It was a great experience for her to see that she’s NOT alone. Many of the kids have similar challenges-struggles-joys of having a sibling with disabilities.”

While parents expressed the value of their child being able to meet and spend time with other siblings of special needs children they also expressed how important it was for their “healthy” child to be able to have a day of special recognition.

Special Day of Recognition

A theme that was revealed in the data analysis was that parents found Sibshops as an opportunity for their healthy children to be recognized. Parents provided evidence of this in several comments:

“Gives them something that only they can be part of, makes them feel special too- this is the greatest benefit that I have witnessed with my kids.”

“Finally a day focused on him and not his brother!”

Other parents provide feedback by stating things such as:

“It gave her time to do something without her youngest brother.”

“Made him feel special for a day!”

“ As a parent- I think we forget to acknowledge our “typical kids” ... in their important role as a sibling to their special needs sibling. It’s a challenging role and they often struggle just as parents do. Thanks for the insight and important reminder.”

In addition to the positive experience, networking with others, and the fact that Sibshops offered special recognition of “healthy” siblings, some parents also expressed that they felt attending Sibshops may have contributed to positive changes in attitude as well.

Change in Attitude

Some parents reported feeling that their child's attitude towards their sibling with special needs had changed for the better following a Sibshop workshop. One parent commented:

“Both my girls have more patience with their sibling. They also are more understanding when I have to pay extra attention to their sister.”

Another parent commented:

“They are more tolerant of her actions and needs. They realize now things could be much worse and other families have much more of a challenge than we do.”

While yet another parent commented:

“After what she said about the event & what she said about others she seems to have a good attitude about her sister and how she sees her sister.”

In addition to some parents reporting changes in attitude parents also reported that they felt some of their children had gained an increase in knowledge about disabilities.

Increased Knowledge about Disabilities

Feedback from many parents contained comments suggesting that their child(ren) who attended a Sibshop came away with an increased awareness of their brother or sisters disability or of disabilities in general. Some of the comments provided by parents that would suggest this were:

“_____ talked about that there are so many kinds of disabilities that families live with and adjust to and how much she appreciates her sister.”

“I think _____ gets that there are a lot of other kids-of all ages and from different places – that are like him... I also think he’ll become increasingly more aware of disabilities other than Down Syndrome.”

“_____ has initiated more conversations about her brother’s disabilities/health issues. She is very compassionate about children with illnesses.”

“_____ is very close to her sister with Down Syndrome- we have always focused on what they have in common-and this was a positive way for her to talk about how _____ is also different-and to appreciate her differences.”

Comments such as these would seem to support evidence of an increase in knowledge and awareness of disabilities following Sibshops. In addition to this increase in knowledge and the other themes already identified, one theme that seemed to resonate throughout parents’ comments was the desire to have their child return to a future Sibshop.

Desire to Participate in Future Sibshops

Over and over parent feedback comments spoke about the desire for their children to be able to participate in a Sibshop experience again. Comments supporting this were found in an array of parent statements such as:

“We look forward to other sib classes!”

“We will sign up every time!”

“ _____ told me to be sure to sign up early for the next class so it doesn't get full before she gets in. Please continue this amazing program!”

More parents went on to say things such as:

“Both of my children enjoyed the Sibshop and would like to do it again in the future.”

“He absolutely loved his experience and hopes to do it again when the next one comes around. He always has a positive time with others.”

Comments by parents seemed to strongly express the desire for their children to be able to return to Sibshops, but some parents also provided suggestions of how to perhaps bring siblings together to maintain their newfound relationships between Sibshops as well.

Some of these suggestions included:

“I wonder if kids might benefit from an online facebook-type page and or short session via Skype.”

Another parent suggested:

“an email/phone list to keep in touch with new friends.”

Yet another parent agreed with this by saying:

“Maybe, for the older kids at least offering or suggesting that they may want to exchange contact info with each other so that they can remain in contact with someone who they know understands what they are going through.”

While much of the feedback provided from parents expressed positive feedback it should be noted that there were also some comments that provided suggestions for how better to

enhance these offerings for siblings as well. Some of these suggestions entailed comments such as:

“Maybe help assist the child to find ways to share their new found “thoughts, feelings” with parents. We went for a walk right away & found it seemed to open up sharing.”

Another parent commented:

“I think it would be good to ask the kids at the Sibshop what they like/don’t like and what they would like to do at meetings.”

Other parent comments included suggestions about separating children by age to better suite their different needs.

Comments included:

“I do think that Sibshops split by age might serve some of the older kids better. I noticed fewer older boys attended this time.”

“as they get larger, I think it is important to group kids by similar ages (for discussions) as kids 6-7 may deal with things differently than 8-10, 11-13, etc.”

In addition to the themes identified another aspect of the findings is the comparison of how effective these particular Sibshops were in meeting the five identified goals of Sibshops.

5 Goals of Sibshops

The study found that all five of these goals were achieved. For example, Goal 1 references that Sibshops should provide brothers and sisters of children with special needs an opportunity to meet other siblings in a relaxed and recreational setting. This was

strongly evidenced in the findings as many participants provided feedback referencing both recreational and relaxing activities. Examples of some of these comments included:

“Loved making the blanket, also designing the outside of her bag. She was also thrilled about receiving the book! WOW. So many great things. The T-shirt was a hit to!”

“Facebook talking with the staff, coming home with useful “prizes” (book.blanket): blanket tying was calming, relaxing, fun and you could talk with the other kids.”

“He loved the Zipline, and the fire where they burned their “worries.”

Goal number 2 also was met during these particular Sibshops as parent feedback surveys provide evidence of opportunities for their children to discuss common joys and concerns related to having a brother or sister with special needs. One example of this is a parent who commented:

“She learned that her feelings about having a sibling with a disability are not bad, but probably normal and okay.”

This was just one of the many comments made by parents on the parent feedback survey indicating that parents felt that their child had been given the opportunity to talk with other peers about their experiences in having a brother or sister with a special need.

Further findings would suggest that Goal 3 of Sibshops was met as well. Parents provided feedback on surveys indicating that they felt their child had been given the opportunity to learn how others handle situations commonly experienced by siblings of

children with special needs. One parent wrote the following comment in support of this goal:

“She has learned that she is not the only child dealing with a sibling with special needs. It was neat for her to have a fun day and meet other kids. I like that she got to hear about other families and how they deal with their sibs.”

In addition to the first three goals being met the findings would also suggest that Goal 4 of Sibshops was met. Parents indicated in the feedback provided that they felt their child (ren) had been provided an opportunity to learn more about the implications of their siblings’ special need as a result of attending Sibshops. This theme was strongly evidenced by parent comments provided many of which were listed in comments from parents in the section of the paper titled Increased Knowledge about Disabilities.

Lastly, Goal 5 of Sibshops states that these offerings should provide parents and other professionals with opportunities to learn more about the concerns and opportunities frequently experienced by brothers and sisters of people with special needs. This particular goal was perhaps the most challenging to conclude as the data collection for this study did not necessarily address this question; however in the additional comments section of the feedback survey some parents did provide evidence that Sibshops had offered them opportunities for learning as well. One parent wrote:

“As a parent- I think we tend to forget to acknowledge our “typical kids”.... in their important role as a sibling to their special needs sibling. It’s a challenging role and they often struggle just as parents do.”

Another parent wrote:

“Thanks for the insight and important reminder”

Summary

In summary this study would suggest that the program evaluation of these Sibshops concluded that the five goals of Sibshops had been met. In addition the study also found that six themes emerged from qualitative analysis including positive experiences, relating to others and knowing you are not alone, special recognition, change in attitude, increased knowledge of disabilities, and desire to participate in future Sibshops. Lastly, quantitative data suggest that parents articulated favorable outcomes when asked about their child’s experiences in Sibshops.

The next section will include further discussion comparing the findings to previous literature and research as well as discussing implications for learning and future practice.

Discussion

This study looked at how siblings support groups; Sibshops in particular, may help siblings of children with special health needs. The study included a program evaluation of Sibshops conducted at one Midwestern hospital by which insight about effectiveness and benefits was gained by looking at parent feedback surveys. This discussion includes sections to highlight this study’s findings, implications for social work practice, strengths and limitations for this study, and implications for future research.

Summary of Findings

Positive Experiences

Participant responses suggested that parents consistently felt their children had a positive experience while at Sibshops. None of the parents surveyed indicated that they felt their child had not enjoyed their Sibshop experience. Parents provided numerous written responses supporting that their child had voiced having a positive experience while in attendance at a Sibshop. Parents not only indicated that they felt their son or daughter had a positive experience but that they felt positive about the experience as well. Of the 35 parents who completed surveys all agreed that they were glad their child had participated in a Sibshop.

The results of this study are very comparable to that of previous research done on Sibshops by D'arcy, Flynn, McCarthy, O'Connor, and Teirney in 2005. They found that 14 of the 16 parents and siblings surveyed indicated having a positive experience while at Sibshops while eleven participants thought they were "excellent" or "great" (D'arcy et al., 2005). Reasons for these positive experiences may be related to some of the other themes identified such as the opportunity to relate to others.

Relate to Others- Knowing You Are Not Alone

Many parents indicated that they felt that their children came away from Sibshops with a sense of knowing that they were not alone. Parents provided numerous quotes such as "*My children came away knowing they are not alone in the world with two brothers with special needs*" and "*It was a great experience for her to see that she's NOT alone*" supporting that this sense of belonging and togetherness had been achieved.

These findings appear consistent with the findings of Nolbris, Abrahamsson, Hellstrom, Oleffson, and Enskar's (2010) study in which siblings reported they felt that following a sibling support gathering they had a sense of belonging. Additionally similar findings were discovered in the research done by D'arcy, Flynn, McCarthy, O'Connor, and Teirney (2005) which found that participants reported that attending a Sibshop allowed them the ability to meet others faced with similar circumstances and to discuss the common joys and concerns of having a brother or sister with a disability. In addition to forming a sense of belonging, many parents also recognized that Sibshops allowed their healthy children a day to be recognized in a special way.

Special Day of Recognition

Parents reported that Sibshops allowed their healthy children the opportunities to not only come together but to be recognized as well. Much of the literature would suggest that having a child in the home with special needs often distracts not only time but attention away from the healthy siblings (DeRigne, 2012; The National Survey of Children with Special Health Needs, 2001; Dauz, et. al., 2010).

Literature indicates that parents often feel they must devote a substantial amount of time to providing for the special needs of their disabled or ill child which can often result in a loss of parental attention for their healthy children as well as a decrease in family social activities. These feelings of guilt and responsibility could have perhaps contributed to why parents found Sibshops beneficial as they allowed them the opportunities to recognize their healthy child in ways that can so often be neglected. One parent even wrote: *"As a parent- I think we forget to acknowledge our "typical kids... Thanks for the insight and important reminder."* Not only did parents seem to appreciate having a

special day for their healthy child but many also reported seeing a positive change in their child's attitudes towards their special needs siblings after attending a Sibshop as well.

Change in Attitude

Parents identified that their children came home with a new sense of gratitude and understanding of their sibling with special health needs. Many parents indicated that their child appeared more patient and tolerable of their siblings. While this theme was not suggested in previous literature this research study appeared to find sufficient evidence to support this finding.

In addition to some parents reporting changes in attitude parents also reported that they felt some of their children had gained an increase in knowledge about their sibling's disabilities.

Increased Knowledge about Disabilities

Increased knowledge gained by participation in sibling support groups would appear not only to be a finding of this study but of previous research and literature as well. Several studies reference the fact that such support gatherings enhance opportunities for brothers and sisters to gain knowledge about their special needs sibling (Munch & Levick, 2001; Naylor & Prescott, 2004.; D'arcy et al., 2005). Parents in past studies as well as this study indicated that their son or daughter was able to better understand the special needs of their siblings as well as the disabilities of other children after having attended a support gathering.

Many parents in this study indicated that they felt their son or daughter had gained knowledge about their sibling's disability. Parents felt that attending a Sibshop had initiated more conversations about the siblings' disability/health issues, therefore

allowing a deeper sense of compassion. One parent indicated that they had always focused with their children on what they had in common but felt that Sibshops had allowed an opportunity for them to talk about the differences that existed between their healthy and disabled child and to appreciate those differences.

In addition to what it was that parents felt their child gained from Sibshops, the study seemed to suggest that parents had a strong desire for their children to be able to come back and participate in another Sibshop.

Desire to Participate in Future Sibshops

Survey results in this study suggested that parents desire for their child(ren) to be able to participate in future Sibshop opportunities was strong. While the survey did not specifically ask parents to express if they would be interested in having their child attend a future Sibshop numerous parents wrote responses supporting their desire to have their son or daughter return to future offerings. Comments provided by parents supporting feedback were things such as “*We will sign up every time!*” and “*We look forward to other sib classes!*”

Previous research looking specifically at this question was addressed in the research done by D’arcy and his companions in Ireland following Sibshop opportunities offered to siblings at their organization. Of those surveyed in that study 81% of the participants expressed a desire to again meet with siblings once the Sibshops were complete.

Favorable feedback in this study suggests that the intended goals of Sibshops appear to have been met in this study.

5 Goals of Sibshops

As suggested by the founders of Sibshops, Don Meyer and Greg Schell, the foundation for a successful and purposeful Sibshop should be centered around the accomplishment of the following five goals:

Goal 1 Sibshops will provide brothers and sisters of children with special needs an opportunity to meet other siblings in a relaxed, recreational setting.

Goal 2: Sibshops will provide brothers and sisters with opportunities to discuss common joys and concerns with other siblings of children with special needs.

Goal 3: Sibshops will provide siblings with an opportunity to learn how others handle situations commonly experienced by siblings of children with special needs.

Goal 4: Sibshops will provide siblings with an opportunity to learn more about the implications of their sibling's special needs.

Goal 5: Sibshops will provide parents and other professionals with opportunities to learn more about the concerns and opportunities frequently experienced by brothers and sisters of people with special needs.

This study supported that all five of these goals had been met during the Sibshop offerings studied in this research study.

Participants often talked about the fact that they felt their children had been allowed the opportunity to meet others who shared similar joys and concerns, to learn about the experiences of others, to enhance their knowledge about disabilities and to learn how to handle situations commonly experienced by siblings of children with special needs all while doing so in a fun and recreational setting. The one goal that was perhaps most difficult for this study to evaluate was the fifth and final goal which looks at the ability for Sibshops to offer opportunities for professionals as well as parents to learn more about the concerns and opportunities frequently experienced by brothers and sisters of people with special needs. While the study presented the opportunity for parents to

provide feedback the study does not allow for insight into what professionals may have learned. This is perhaps an implication for future research.

Implications for Social Work Practice

Many parents expressed a desire for their children to be able to return to future Sibshops in the feedback received. However the current structure of registration for Sibshops at the facility studied does not guarantee past participants priority in being able to return to subsequent Sibshop offerings. In fact it often places them behind other children who may have attempted to sign up for a previous Sibshops but were denied based on limited registration spaces. While having the appropriate number of staff to child ratio is important in ensuring a quality experience for participants, denying them the ability to return to a group in which they have found a sense of belonging and connectedness may hold implications as well. A potential practice implication for social workers who may be apart of organizing and facilitating Sibshops may be to organize a system that allow sufficient numbers of offerings to accommodate all interested participants. Suggestions for accomplishing this may be to offer several shorter sessions or more frequent sessions throughout the year.

In addition to attending Sibshops parents also indicated that their children had expressed a desire to connect with individuals whom they had met outside of Sibshops. Parents provided suggestions such as social networking sites like Skype, Facebook, or shared internet websites. Additionally other parents suggested things such as exchanging phone numbers or email addresses as a means of staying connected. These suggestions would all be possible practice implications for social workers who may be considering options of support for siblings of special needs children. It should be noted however that

confidentiality and the need to protect siblings on social media sites would require special consideration.

The last practice implication is also based on direct suggestions from parent survey results which relates to having children grouped by age. Parents observed that their child may have received greater benefit from attending a Sibshop if they were allowed to be with others who may have been more similar in age. This suggestion would allow for social workers in the practice to reflect on both the benefits and challenges of having participants who vary in age either combined or separated. For sibling groups this may present some challenges as younger siblings may be reluctant to be separated from their older siblings. With that said having a twelve year old in a group with several very young children may also present its challenges as the spread of developmental range varies. Arranging participants by age is certainly an implication that deserves consideration for social workers who may be thinking about providing such offerings. One must think through both the strengths as well as limitations and perhaps offer opportunities throughout Sibshops that offer both combined and separated experiences.

Strengths and Limitations of the study

There are several strengths of this study. First, the information gathered provides additional information for social workers and professionals who are considering providing support for siblings of children who have special health needs. Because there has thus far only been one previously published study on Sibshops this study offers another source of data on the benefits and areas for consideration for those interested in Sibshops. A second strength of the study is that the survey used to gather data for this study was designed by the founders of Sibshops and designed to highlight the

achievement of the five designated goals of Sibshops. By using such a reliable tool for gathering feedback it is felt that the results of this study exceed those that may have been obtained by using some other type of survey.

While the study had strengths it also was found to have some limitations as well. One of these limitations included the fact that because surveys were anonymous to the researcher there was no way of knowing if the same parent may have provided feedback after several different Sibshop offerings. Surveys were mailed to parents each time their child attended a Sibshop regardless of whether or not they may have already filled out a previous feedback survey. Because of this it is possible that one parent may have been allowed to over represent their opinion on several surveys results. Also, because the identities of the individuals completing the survey were unknown to the researcher it was not possible to know if factors such gender, race, or economic status may have had any implications into the findings of this study. Lastly, perhaps one of the largest limitations of this study was the fact that results of feedback questions were based on parents perceived experiences of their children and not from the voices of the children directly. This may have allowed for misrepresentation of the actual children who participated in Sibshops. This limitation however may also provide insight into possible implications for future research as well as ways of expanding research which may include eventually seeking direct input from the children who have attended Sibshops.

Implications for future research

In addition to this study providing results that can enhance the body of knowledge on this topic, there are implications for future research. This study was done on a relatively small sample and may benefit from being done with several other Sibshops

being conducted in other parts of the United States as well as around the world. This broad base of feedback may allow for further insight into the effectiveness of Sibshops in other settings.

Another suggestion may be to further focus on Goal 5 of Sibshops to further evaluate what professionals may be learning from Sibshops about the concerns and opportunities frequently experienced by brothers and sisters. Thus far this particular goal of Sibshops seems to be vastly understudied. The collection of this data may offer further growth and enhancement in opportunities that professionals are able to provide to siblings and families of children with special health needs.

Additionally, another suggestion may include the addition of a check box on surveys allowing for the individuals to indicate if they have attended before or if they have completed parent surveys in the past. This may reduce the likelihood of one individual over representing data in the sample allowing for more accurate data collection.

Lastly, perhaps one of the most beneficial suggestions for future research may be to gather data directly from the children who have participated in Sibshop offerings. While parents and professionals may be able to speculate about the perceived benefits children are receiving no one can provide that data better than the children themselves.

Conclusion

In summary, while having a brother or sister with a special health needs may cause challenges for both parents and siblings, it appears that research would suggest that opportunities such as Sibshops provide siblings with a source of positive support. This study would suggest that Sibshops offer children the opportunity to connect with other siblings, to share common joys and concerns and to gain knowledge about their brother

or sister's disability all in the context of a fun and relaxing setting. While future research about the effectiveness of Sibshops is still needed, the results of this study would suggest that Sibshops are successful in providing brothers and sisters of special health needs children with a positive experience and thus meeting its goals.

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APPENDIX A

SUBMIT TO: MSW Program Manager (SCB 201)

DUE: September 28, 2012

**St. Catherine University and the University of St. Thomas School of Social Work
MSW Program**

Request for Establishing MSW Clinical Research Committee

STUDENT NAME: _____ **Student UST**

ID# _____

I have discussed my research with and request that the following comprise my research committee

CHAIR: _____

Faculty Chair Signature Date

COMMITTEE MEMBERS:

By signing below, committee members acknowledge their responsibility to, at minimum, meet as a committee once each semester, to read and comment on student's written work, to offer support and guidance throughout the research process and to attend the public presentation of the paper in May.

1. COMMITTEE MEMBER:

_____ Name

(PLEASE PRINT) Signature

_____ Date

_____ Institution/Agency

_____ Email address to send Final Program and other communication – PLEASE PRINT clearly

2. COMMITTEE MEMBER:

_____ Name

(PLEASE PRINT) Signature

_____ Date

_____ Institution/Agency

_____ Email address to send Final Program and other communication – PLEASE PRINT clearly

APPENDIX B
AGENCY LETTER OF SUPPORT

Date: November, 2012

University of St Thomas
2115 Summit Avenue
St. Paul, MN 55105

Dear Institutional Review Board Committee:

As the director of _____, I am writing to give permission to Amy Dailey, Graduate Student in the school of social work program at the University of St. Thomas permission to conduct a research study on Sibshops which were conducted by _____ staff between the years of 2011-2012. I have met with Amy and received details on her purposed research project and am supportive of her program evaluation for purposes of her graduate research project. I am aware that during the process of her research she will be analyzing secondary data in the form of parent feedback surveys for both quantitative and qualitative portions of her study. She has provided me with details on measures that will be taken to protect the identity of the institution as well as our patients and families and I agree with her use of this secondary data in her study.

I understand that Amy will not proceed with her research until she has obtained the approval of her clinical research committee as well as the Institutional Review Boards at the University of St. Thomas and _____. I also understand that the research project is part of her clinical research paper which will be published and presented in a public forum.

I do not anticipate any direct benefit or risk to our organization however; I would encourage Amy to provide the results of her research study to our staff as well as our Sibshop planning committee in an effort to provide ongoing and continuous improvement within our agency.

I would like to take this opportunity to restate my support of this project and to wish Amy well as she begins to embark on this portion of her graduate studies.

Sincerely,

APPENDIX C



Parent Feedback Form

Please take some time to answer the following questions about your child's participation in the Sibshops.

Date:

Meeting time and location:

Your name (optional):

Rate your satisfaction with the following aspects of the group on a scale from 1 (very dissatisfied) to 5 (very satisfied). If you have no opinion or the item is not applicable, circle N.

Meeting time	1	2	3
4 5			

Location	1	2	3
4 5			

Length of Sibshop	1	2	3
4 5			

Communication and contact with Sibshop facilitators	1	2	3
4 5			

Sibshop activities/content	1	2	3
4 5			

Impact on your child's knowledge/feelings toward his or her brother, sister, or other family members	1	2	3
4 5			

Has your child talked about what has happened during the Sibshop? Yes_____

No_____

Comments:

Has your child seemed to enjoy the Sibshop?

Yes _____

No _____

Comments:

Was there a particular activity that your child seemed to have really enjoyed?

Yes _____ No

Comments:

Has your child seemed upset by anything that was offered at the Sibshop?

Yes _____ No

Comments:

What do you think your child has learned from the Sibshop? How has he or she benefited so far?

Comments: -

Overall, are you glad your child participated in the Sibshop?

Yes _____

No _____

Comments:

Is there anything we should consider for future Sibshops to make them more enjoyable or informative? Yes ____ No ____

Comments

Any other comments?

Please return this questionnaire by....