

5-2018

## How to Best Support Individuals Growing up with a Special Needs Sibling

Lauren McDonell  
*Dominican University of California*

<https://doi.org/10.33015/dominican.edu/2018.edu.02>

**Survey: Let us know how this paper benefits you.**

---

### Recommended Citation

McDonell, Lauren, "How to Best Support Individuals Growing up with a Special Needs Sibling" (2018). *Graduate Master's Theses, Capstones, and Culminating Projects*. 316.  
<https://doi.org/10.33015/dominican.edu/2018.edu.02>

This Master's Thesis is brought to you for free and open access by the Student Scholarship at Dominican Scholar. It has been accepted for inclusion in Graduate Master's Theses, Capstones, and Culminating Projects by an authorized administrator of Dominican Scholar. For more information, please contact [michael.pujals@dominican.edu](mailto:michael.pujals@dominican.edu).

How to Best Support Individuals Growing up with a Special Needs Sibling  
by  
Lauren McDonell

A culminating thesis submitted to the faculty of Dominican University of California  
in partial fulfillment of the requirements for the degree of Master of Science in  
Education

San Rafael, CA  
May 2018

This thesis, written under the direction of the candidate's thesis advisor and approved by the department chair, has been presented to and accepted by the Department of Education in partial fulfillment of the requirements for the degree of Master of Science in Education. The content and research methodologies presented in this work represent the work of the candidate alone.

Lauren McDonell  
Candidate

May 01, 2018

Elizabeth Truesdell, PhD  
Department Chair

May 01, 2018

Jennifer Lucko, PhD  
Thesis Advisor

May 01, 2018

Suresh Appavoo, Ed.D  
Secondary Thesis Advisor

May 01, 2018

Copyright © 2018, by Lauren McDonell

All Rights Reserved.

**Table of Contents**

Abstract.....	v
Acknowledgements .....	vi
Chapter 1 Introduction.....	1
Statement of the Problem.....	1
Statement of Purpose .....	2
Significance of the Study .....	4
Summary of Methods.....	4
Summary of Findings.....	5
Chapter 2 Literature Review .....	7
Sibling Relationships.....	11
Self-Concept and Well-being.....	16
Support Groups.....	18
Chapter 3 Methods.....	24
Research Questions .....	24
Description and Rationale for Research Approach .....	24
Research Design .....	25
Positionality of the Researcher .....	28
Data Analysis Procedures .....	29
Validity & Reliability.....	29
Chapter 4 Findings .....	31
Experiences of the Neurotypical Sibling.....	32
Emotions .....	33
Emotional Support .....	36
Chapter 5 Discussion and Analysis .....	41
Implications for the Literature .....	41
Implications for Practice and Policy.....	43
Limitations of the Study .....	45
Directions for Future Research.....	46
Chapter 6 Conclusion.....	47
References .....	50
Appendix A .....	54

### **Abstract**

The purpose of this study was to understand the emotions of a neurotypically developing sibling. This study also attempted to understand how caregivers can best support the neurotypical sibling in the areas of self-concept and overall well-being. The gap in knowledge is how to better support neurotypical developing siblings specifically in the areas of self-concept and overall well-being. Three participants were interviewed to gain insight about their experiences with their special needs sibling. Participants who participated in a support group for neurotypical developing children with a SNS were surveyed to gain insight about their experiences with the support group. Through the qualitative method approach, it was found that the neurotypical sibling experiences a variety of emotions that include happy, calm, angry, anxiety, worry, and accepting. The survey responses provided evidence that support groups are beneficial and can provide emotional support in the areas of self-concept and overall well-being.

### **Acknowledgements**

I would like to thank Jennifer Lucko for pushing me to continually grow in my writing and the research process. I would like to thank my colleagues Henna Lopez Rahimi, Lauren Clough, and everyone else who gave me a pep talk or struggled through this incredibly challenging journey with me. I would like to thank the participants from this study who took the time to answer my questions and explore some challenging, emotional places that may have not been explored before. I would also like to thank my boyfriend, my friends, and co-workers who listened to me talk about my research, offer me a hug, or provide an encouraging talk. I truly could not have done this without you all. Lastly, I would like to thank my parents for their unconditional support and love through my educational journey.

## **Chapter 1 Introduction**

Growing up with a sibling who has special needs is a unique situation. The “neurotypical” sibling must learn to navigate various emotions that might occur beyond the typical scope of a sibling relationship. I have experienced 25 years of my life growing up with my younger brother who has a speech delay in addition to being intellectually delayed. I was unaware of support groups that would have been beneficial in helping me navigate the emotions that I experienced about my brother while growing up. This thesis will explore the experiences of individuals who have a special needs sibling and how that sibling impacted their lives emotionally.

### **Statement of the Problem**

For the purpose of this study, “special needs” will hold the same definition as “disability.” According to the Center for Disease Control, one in seven individuals has a mental, behavioral, or developmental disorder (Bitsko, Holbrook, Robinson, Kaminski, Ghandour, & Smith, 2016). When you grow up with a sibling, you might feel a sense of “sibling rivalry” or even jealousy of your sibling. Would you believe me if I said that you might feel a pang of embarrassment? That you wouldn’t want to invite your friends over because of your sibling? Or that your self-concept and overall well-being was lower because of your sibling? Individuals who have a sibling with special needs often feel these emotions, however hard it may be to admit that those feelings are present. Many of these individuals may be without a support system to help them navigate these tough feelings. The number of individuals affected by a disability goes beyond the



special needs sibling (SNS). Each of these SNS has an impact on their family and their family members. These neurotypical individuals are often forgotten in terms of needing support.

### **Statement of Purpose**

The special needs population has been on the rise for many years. With certain diagnoses like autism and Down Syndrome steadily increasing, it is important to remember that the diagnosis given to one child is given to the family unit as a whole. Burke and Kinglsey (2005) explain this as a “disability by association.” All of the family members involved with the sibling will feel the effects of the SNS. However, the neurotypical sibling is often not prioritized as needing support.

Neurotypical siblings may perceive their SNS differently based on how others are treating them because of the heightened awareness of the special needs population currently. Due to the growing population and an increase in needed services for those with special needs, there have been many laws that have been passed within the United States that require school systems to provide a free and equal education to all individuals (Yell, 1998; Rogers, 2015; Rogers, 2016). As the special needs population becomes more accepted, individuals who have SNS are also more likely to be accepting of their sibling. There are also more councils that have been formed in Ireland and Great Britain that protect individuals who have special needs (European Agency for Special Needs and Inclusive Education, 2016).

There are often different emotions and feelings beyond a typical sibling relationship that arise when a sibling has special needs (Inam, et. al., 2017; Roberts, et. al., 2015; Loots & Pit-Ten Cate, 2000; Emerson, 2014). Some of these emotions that the neurotypical sibling may experience include isolation, overachievement, embarrassment, anger, resentment, neglect, guilt, and increased care-taking (Naylor & Prescott, 2004; Ali, 2010; McHale, 1989). However, there are limited publications about formalized safe spaces for neurotypical individuals to share their emotions and experiences. In studies done in Pakistan, Pennsylvania, Italy, and Great Britain, individuals who participated in a support group reported a higher acceptance of a SNS, in addition to higher self-concept and higher overall feeling of well-being (Dyson, 1998; Roberts et. al., 2016; Feinberg, 2013).

There are studies that have been done that have examined the sibling dynamic in addition to the success of support groups (Inam, et. al., 2017; Dyson, 1998; Roberts et. al., 2016). However, there is a lack of publicity about access to these support groups for neurotypical siblings. It remains unclear how to best support these individuals who have a SNS. These individuals who have a SNS would benefit from a safe space to share and talk through the emotions that are being experienced.

The purpose of this study was to understand the emotional impact of growing up with a SNS by understanding and exploring the experiences of individuals in relation to their SNS and examining how their SNS played a role in

the neurotypical siblings life. This study also attempted to understand how caregivers can best support the neurotypical sibling emotionally.

### **Significance of the Study**

This study is intended to benefit family units as a whole, with a primary emphasis on neurotypical siblings. This study addresses a group that can arguably be described as an unrecognized and underserved population. This study can be beneficial for parents to become aware that there are different emotions and feelings for their typically developing child compared to their SNS and that there are support groups to help their children develop a better sense of self-concept and overall well-being. This study can also provide insight for educators in providing an awareness of the emotional impact of growing up with a SNS. Due to the diagnosis by association, it's possible that the emotional impact may directly impact the neurotypical sibling's education depending on the severity of emotions being experienced. Additionally, this study can provide insight for caregivers (i.e. parents, educators, grandparents, guardians, etc.) about how to support the neurotypical sibling. This study can lead to developing and or enhancing the support services for neurotypical siblings, and thus can potentially provide relief from daily stress and contribute to the overall well-being of the family unit as a whole.

### **Summary of Methods**

This study inquired into two primary research questions as follows: 1) What are the emotional needs of neurotypically developing siblings? 2) How can caregivers best support the emotional needs of neurotypically developing

siblings? This study used a qualitative approach with the collection of its research. Two different forms of data collection were used. The first was in the form of a survey and the second was in the form of an interview with open ended questions. Three participants who have a SNS were interviewed using open-ended questions in order to gain insight about their personal experiences and feelings regarding their sibling.

A survey that allowed for anonymous responses was also used for a second sample group of participants who have experienced a support group for neurotypical siblings in the Bay Area. The survey allowed for insight about whether they felt the support group that they attended was beneficial in meeting their social/emotional needs. The survey was used in order to gain insight about how the group could have been more beneficial for the participants. An individual who has run support groups within the Bay Area was contacted to gain insight about how the support program is implemented and run. Insight was also gained about the history of how the organization got started in this location.

While statistics and data from previous studies have shown that there is a benefit from providing individuals with support, the purpose of this study is to examine the experiences of impact of a SNS on their neurotypically developing counterparts, specifically regarding self-concept, emotional experience, and overall well-being.

### **Summary of Findings**

This study found that regardless of the different experiences of participants related to background, family life, age, gender, or location of growing

up, all three interview participants experienced parallel emotions. Each interview participant mentioned feeling guilt, responsibility, envy, resentment, embarrassment, and stress in regards to their SNS. Each of the interview participants grew up in a different home life, in a different location, in different generations, have siblings with different diagnoses, and have different experiences of having their SNS living in the same home. Despite all of those differences, all of the interview participants reported experiencing the same emotions as one another.

The survey participants reported that the support group was beneficial in helping them change their views of their SNS. All survey participants agreed that the support group was helpful in navigating their emotions that they have towards their sibling. While not all survey participants felt there was a significant benefit from the support group, all participants reported feeling as though the support group helped to change their views about their sibling and made them feel less alone given their situation. Providing these neurotypical individuals with a support system that allows them to explore these feelings will in turn make them feel better overall and will run over in aspects of their life. Some of these other aspects and outlets could include but are not limited to academically and in relationships outside the scope of their immediate family.

## **Chapter 2 Literature Review**

The Americans with Disabilities Act defines a disabled person as someone who has a 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 (Americans with Disabilities Act, 1991).

Individuals who have special needs or a disability have been present for majority of history, however the concept of special education is a recent phenomenon (Richardson & Powell, 2011). The individual with the diagnosis or the disability is not the only affected by that diagnosis. When there is one member present in the family who has a disability, the whole family has a disability. Burke and Kingsley (2005) describe this as being disabled by association. The family does not literally have a disability, but the diagnosis of the individual who does have a disability affects all members of the family. The disability affects all parties involved and while there are a wide variety of resources available to the family unit as a whole, the siblings of the individual are not often prioritized as needing support to cope with the diagnosis of their sibling.

In what follows, this review of the research literature utilized a broad lens approach to examine the scholarship on the knowledge and awareness of special needs populations in multiple countries where support groups were studied. This knowledge of the history of the awareness of the special needs populations is critical in the context of this study because it provides an understanding of the special needs population and the views that are associated

with this specific population. If the special needs population is more accepted, then it is likely that the neurotypical sibling may be more accepting than in a location where the special needs population is not accepted. In addition, the literature on sibling relationships in different types of sibling relationships was also reviewed in order to understand the experiences of the neurotypical sibling and how their special needs sibling impacted them emotionally. Next, a discussion of self-concept and well-being is provided in order to understand gain insight about the emotional impact and how these specific areas were impacted due to growing up with a special needs sibling. Finally, a discussion of prior support groups was examined to understand the benefit and success of support groups that are in place for neurotypical siblings who have a special needs sibling.

### **History of the Special Needs Population**

For the purpose of this study, a brief history of the countries with prior research in this area will need to be explained. The countries with prior research include Great Britain, Ireland, Pakistan, and the United States. Having this information is relevant as it provides insight about how individuals with special needs are viewed, which in turn may impact how individuals view their siblings. Having perspective and background about the location of prior studies allows further insight to the success of the support groups that are presently in place.

In Great Britain, special education has become more prominent through the years. Under the current law and Education Act of 2002, all individuals at state-funded schools have a right of access to a broad and balanced curriculum that is flexible enough to accommodate different paces and learning styles

(European Agency for Special Needs and Inclusive Education, 2016). Through the years, special education and those with special needs have received increasingly better treatment and there continues to be a push to make sure that all individuals are included in the schools, which in turn exposes more individuals to the special needs population.

In Ireland, there is a council that formed that has a wide range of functions that relate to supporting students with special educational needs. Through this council and various other branches that are more localized to different areas, inclusion is beginning to become more and more prevalent within the education setting (European Agency for Special Needs and Inclusive Education, 2016). Much like with Great Britain, inclusion and the acceptance of those with special needs is becoming more prevalent.

In Lahore, Pakistan, there are a multitude of different school and government agencies that take in children with special needs. When Punjabi established independence, there were only two institutions available that served the hearing impaired and the blind (Special Education Department, 2015). These institutions were nationalized in 1975. Later in 1983-1984, the Special Education of Punjabi was combined with the Education Department. From there, the Special Education Department was founded in 2003 and had 51 institutions that serve 4,265 special needs children. Currently, the Special Education Department now has 273 institutions serving 30,803 special needs children and are currently functioning at every town level (Special Education Department, 2015). As in



Great Britain and Ireland, the special needs prevalence has increased and is reaching more and more individuals as the need increases.

In the United States, there are many different laws that protect individuals who have special needs. Some of the better-known cases include *Mills V. Board of Education of District of Columbia* (1972) and *Pennsylvania Association for Retarded Children V. Commonwealth* (1972) (Rotatori, Bakken, & Obiakor, 2011). In *Mills V. Board of Education of District of Columbia*, children were deprived of an education due to behavioral problems that arose in the classroom. The ruling on this case determined that all students are entitled to a free public education and training appropriate to their learning capacities (Rotari et al., 2011). This was a leading case that led to many court cases that established the foundation for the current special education laws and mandates. In *Pennsylvania Association for Retarded Children V. Commonwealth*, Pennsylvania was also turning away students with severe deficits in their mental ability. The court established that the state would provide accessible, free, and suitable education for all children of school age regardless of disability or impairment and that all parties in the lawsuit would be provided with publicly supported educational programs that were tailored to individual needs (Rotari et al., 2011).

Both of these cases led to the formation of the Education for All Handicapped Children Act of 1974 which led to free public education for all individuals within the United States regardless of disabilities or impairments (Hulett, 2009). The Education of All Handicapped Children Act of 1974 is now known as the Individuals with Disabilities Education Act (IDEA). The IDEA

protects individuals with special needs and requires schools to provide a free and appropriate public education in addition to providing parents with procedural safeguards and rights (Yell, Rogers, & Rogers, 1998). The IDEA protects individuals under 13 different categories: autism, deaf-blindness, deafness, emotional disturbance, hearing impairment, intellectual disability, multiple disabilities, orthopedic impairment, other health impairment (includes dyslexia, dyscalculia, and dysgraphia), speech or language impairment, traumatic brain injury, and visual impairment (including blindness) (Hutell, 2009). Each of these diagnoses has different needs depending on the severity of the disability or impairment. All of these Acts and laws have contributed to the protection and educational rights of individuals with disabilities.

As the special needs population continues to grow and becomes more prevalent in the eye of the law, the general population becomes more and more exposed to the special needs population. Having the knowledge of the various locations of support groups provides insight to the acceptance and understanding of the special needs population. Depending on the views of the special needs population in certain areas, this could impact the way that a neurotypical sibling could view their special needs sibling.

### **Sibling Relationships**

There are many different factors that go into the success or hardships of a sibling relationship. While it can provide a built-in friend, it can also be a tumultuous relationship with different feelings that may arise like the classic sibling rivalry. The sibling relationship is a difficult relationship to navigate on its

own let alone when you have a sibling with special needs in the picture. Siblings often spend more time together than they do with their parents because of mutual grounds like school or sharing a room while growing up (Buhrmester & Furman, 1990). Siblings are often the first introduction to developmental milestones like introducing sharing, the value of patience, and rivalry.

The studies under this theme provide evidence that the sibling relationship is a tumultuous one and also provide evidence that growing up with a sibling with special needs is a different and difficult journey for the neurotypical individual. There are different feelings that arise with growing up with a special needs sibling like rivalry, envy, and resentment (Naylor & Prescott, 2004). Depending on the birth order of the siblings, family size, and other relationships within the family, these feelings may be felt at differing degrees (Breslau, 1982).

**Variables affecting the neurotypical developing sibling.** There are many different variables that affect the typical developing sibling while growing up. Two of these variables include birth order and relationships with others within the family unit. It makes sense that an older sibling's experiences would differ from that of a younger sibling's experiences. Breslau (1982) found that the birth order does have an impact on the way the children perceive themselves in addition to the way that others perceive the sibling. Breslau (1982) also argues that the older sibling had the opportunity to enjoy a "normal" family life prior to their sibling being born, while the younger sibling will have only experienced life with their special needs sibling. It can be argued that knowing a life separate or prior to the special needs sibling being born may be more difficult as the

individual may have become accustomed to a different kind of life, especially if there is a large age difference between the siblings. In a different study that also focused on the birth order and the effects on a sibling relationship, Buhrmester (1990) found that the relationship is typically fully formed by the time the younger sibling turns 12. But this is also dependent on the status of the child within the family and the role that they play within the family unit itself.

Siblings have roles within their own relationship and exude different roles based on their birth order. Younger siblings typically have experienced both the nurturing and the dominance from their sibling while older siblings are the ones who are exuding the roles of the nurturer and the dominator (Buhrmester, 1990). These specific roles will play a large impact on the development of both individuals. These roles that are played will also play a factor in the role that they play within the family unit and can contribute to the type of relationship that is present between the siblings. Buist & Vermande (2014) did a study that focused specifically on three different types of sibling relationships (harmonious, affect-intense, conflictual), but also found that the sibling relationships were also dependent on the relationships that the sibling had with other individuals within the family.

Parents can also play a significant role in simply modeling a healthy relationship. An example of a positive relationship that has healthy boundaries can be modeled if a sibling is close with a parent (Buist & Vermande, 2014). However, if neither parent is close with a child, then there is a lack of a healthy role model and a healthy relationship within the family. Not having a positive

example of a healthy relationship can certainly put a strain on relationships outside of the family in addition to the sibling relationship and dynamic. Having an example of healthy relationships can be traced back to studies done about attachment when parenting. The four types of attachment styles include secure, anxious-preoccupied, dismissive-avoidant and fearful-avoidant (Bartholomew & Horowitz, 1991). These attachment types will affect the relationship between the parents and the children, but also with relationships moving forward that take place beyond the scope of the family.

McHale (1989) studied neurotypical developing individuals who have a sibling with special needs. She found that individuals who have a sibling with special needs did face differences in that they tended to do more family chores and take care of their sibling more than an individual would with another neurotypically developing sibling (McHale, 1989). She did find, however, that the siblings still reported feeling content with their lives despite the higher workload that was expected of them. Siblings also reported feeling content regardless of the rivalry that they would sometimes experience due to having a sibling with special needs who would occupy their parent's time.

The attachment styles will play a large role in the relationships that individuals pursue beyond the family. If a child feels secure in the relationships that they have with their family members, then they are more likely to feel content and secure with exploring other relationships outside of the family (Bartholomew & Horowitz, 1991). If an individual does not feel secure in their relationships, then they are likely to have lower self-concept and be less secure in their relationships

that they explore (Bartholomew & Horowitz, 1991). With this information, it can be determined that the parenting style will also play a role in the sibling relationship and that dynamic. Attitudes towards the sibling with a special need will also likely be a mirror representation of how parents feel about each of their children. McHale (1989) mentions in her study that mothers attempted to compensate for extra time spent with the disabled sibling by also spending more time with the neurotypical sibling. This also led to the conclusion that sibling rivalry may not appear when both children spend a sufficient amount of time with their mother, even though the sibling with special needs will typically spend more time with their mother than the neurotypical developing sibling (McHale, 1989).

**Sibling acceptance.** Ali & Sarullah (2010) found that of the five individuals interviewed in a study about their feelings towards their sibling with special needs, the majority had a positive outlook and acceptance towards their sibling. Individuals reported feeling anger, sadness, guilt, love, pride, empathy, and support when asked about their relationships and views towards their sibling (Ali & Sarullah, 2010). It is noted that these feelings listed might also be experienced by individuals who have a neurotypical developing sibling. The sibling relationship changes as the individuals get older due to maturity and growth. This is true of those who have a sibling with special needs as well. Conway & Meyer (2008) also found that 90% of graduates from the Sibshops support group reported having tools to help them with coping and acceptance of their sibling after participating in the 6-week support group for individuals who have a sibling with special needs.

**Self-Concept and Well-being**

For the purpose of this study, self-concept and well-being will need to be defined. Baumeister (1999) defines self-concept as the individual's beliefs that one holds about him or herself and also includes the individual's attributes. If someone has a low self-concept, then they are not in tune with who they are as individuals and will generally not have a high value of oneself. As it is used in this study, well-being is defined as being comfortable, happy, and healthy. Several studies discuss these terms either together or individually. For the purpose of this study, these terms will be referenced with the given definitions above. Individuals all develop a self-concept and have a level of well-being regardless of their status of having a neurotypical developing sibling or a sibling with special needs. Based on the literature and studies that have been published, the overall well-being and self-concept is often lower in individuals who have a sibling with special needs in comparison to those individuals who have a neurotypical sibling (Inam, Kausar, & Abiodullah, 2017; Emerson & Giallo, 2014).

**Sibling relationship type.** Buist (2014) focused on the conflict and warmth aspects of relationships between neurotypical siblings. There was a direct correlation with the relationship type between the siblings and the level of self-competence and acceptance that was found in the individuals. When a relationship has high levels of warmth, there is more self-competence and acceptance of the sibling than in a relationship with high conflict (Buist, 2014). This could also be applied to sibling relationships where there is a special need present.

In another study that focused on a group of individuals who have siblings with autism, data showed that there was a direct correlation with significantly lower self-concept in these individuals than those with a neurotypical developing sibling (Inam et al., 2017). In addition to the lower self-concept, they were also more likely to experience things like anxiety and depression, resulting in a low overall well-being rating. Emerson (2014) also found that individuals ranging in age from 0-5 who have siblings with special needs reported as having lower overall well-being than those who have neurotypical developing siblings. Social interactions also looked considerably different when compared against the two populations who were researched. Those with a sibling who had autism were significantly shyer and more reserved than those who did not have a sibling with autism (Inam et al, 2017). In a study comparing two populations of individuals, those who have siblings with autism and those who have siblings with Down's Syndrome, both populations reported negative representation of self-concept (Roberts, Ejova, Giallo, Strohm, Lillie, & Fuss, 2015). However, those with a sibling who had autism showed a significantly lower perception of their self-concept (Roberts et al., 2015). Both populations have a sibling with a disability and both reported having lower self-concept.

Neurotypical siblings reported higher levels of stress because they did not have the ability to talk about their feelings in regards to their sibling's future (Loots & Pit-Ten Cate, 2000). Some of the participants also reported feeling a level of embarrassment of their sibling and the reactions of strangers when out in public. This often caused the sibling feelings of annoyance and distress (Loots &



Pit-Ten Cate, 2000). However, Loots & Pit-Ten Cate (2000) also reported that a large majority of the participant group also reported feelings of joy and love towards their sibling. The sibling relationship can be a difficult one to navigate, but there are still positive feelings towards the sibling with special needs present in addition to all of the negative feelings that might occur.

### **Support Groups**

The support groups that have been studied and published about have been in various locations such as Italy, Pennsylvania, Pakistan, Great Britain and Ireland. There is limited content about support groups within the United States. The support groups discussed have been anywhere from a weekend workshop to a 3-month support group that meets weekly for 2 hours.

**Support group models.** In a study done in Pennsylvania that focused on providing support for two neurotypical siblings, findings proved that a support group for all types of siblings would be beneficial, even for those who do not have a special needs sibling present in the family (Feinberg, Sakuma, Hostetler, & McHale, 2013). The support group, All Siblings are Special, was able to help the siblings establish better, healthier relationships with their sibling. This goes back to prove that the sibling relationship is a difficult one to navigate, especially when there is an individual with special needs present. The type of relationship that one has with their sibling is dependent on many factors. A support group can help to provide a platform where individuals are allowed to easily navigate many of these factors in addition to communicating with people about their own personal experiences with their sibling.

Dyson (1998) examined another model that was done in the form a weekend workshop with a multitude of stations for elementary age children to go to. Participants of Sibling Group were provided with a questionnaire that was handed out and all individuals who responded to the questionnaire reported feeling better about their siblings and about themselves by the end of the workshop (Dyson, 1998). This model also provided different resources like books and allowed an opportunity for individuals to make new friends and experience a healthy interaction with like-minded individuals who are going through something similar to them (Dyson, 1998).

Participants of the SibWorks support group who had a sibling with a more severe diagnosis experienced a greater benefit from the support group (Roberts, Ejova, Giallo, Strohm, & Lillie, 2016). It was also found that the emotional and behavioral functioning also increased with the group interventions. SibWorks is based in Australia and follows a six-week model that focuses on individuals between the ages of 8 and 12. SibWorks focuses on a different theme each week and allows for activities in addition to ample opportunities for conversation for the participants (Roberts et al., 2016). Roberts et al. (2016) concluded that the group intervention workshops would be beneficial for individuals who have a sibling with a severe disability and those who have difficulty adjusting to their sibling and their sibling's disability as a whole.

Sibshops is another successful support group for individuals who have a sibling with special needs. Conway (2008) found that the Sibshops model have a variety of different stations geared towards children through the eighth grade. In

the United Kingdom, Sibshops is also examining how to use support groups for individuals who have special needs siblings in the school system (Conway, 2008). Sibshops is looking directly at the graduates of the support group as to how to better support and expand current supports to the school system through the programs within the United Kingdom that are presently in place (Conway, 2008).

**What a support group should target.** Naylor & Prescott (2004) found that when the opportunity is presented, individuals may be hesitant to attend a support group. However, once hesitant individuals do attend a support group, they found the support group to be beneficial for them (Naylor & Prescott, 2004). Based on prior research, they found that the support groups should aim to decrease negative effects that siblings might be experiencing like isolation, overachievement, embarrassment, anger, resentment, neglect, guilt, and increased care-taking (Naylor & Prescott, 2004). The support groups should instead put an emphasis on enhancing the positive effects like social competence, insight, appreciation, compassion, pride, and maturity (Naylor & Prescott, 2004). Naylor and Prescott (2004) found that by focusing on the positive aspects and feelings, they are able to adjust the mindset and potentially reinforce the positive instead of the negative.

Tichon (2005) also found that support groups provided in an online format are becoming more and more beneficial to individuals who have a sibling with special needs. This format could be more accessible as the world becomes more and more geared towards utilizing technology in their day-to-day lives.

Regardless of the format that the support group takes place in, Dodd (2004) found that siblings need the opportunity to share and discuss their personal experiences, feelings of worry, and any concerns that they may have in a safe space with like-minded individuals. It is important for the individuals going through support groups to be aware that they are not alone in their experiences. Dodd (2014) found that there was a strong correlation with the ability to share these experiences and feelings with an increase of self-esteem and a greater ability to handle difficult situations that may arise. When individuals are provided with the correct tools and supports, they in turn feel more secure, have higher self-concept, and report having higher overall well-being.

The literature on this topic provides a clear case that individuals who have siblings with special needs typically have lower overall well-being and lower overall self-concept. There are different variables that determine the self-concept like birth order and the family makeup in addition to the relationships present within the family unit. Another large factor has been the level of support present for the individuals who have siblings with special needs. Support groups that have been put in place have proven to be successful for the participants who attended the support groups whether that be in an online format, a weekend workshop format or an extended 3-month program. The majority of the participants reported having better self-concept, better overall well-being and better acceptance of their sibling who has special needs. Evidence also suggests that there are limited support groups present within the United States. The majority of the support groups that have been successful took place in Ireland,

Australia, Pakistan, and Great Britain. Only one was studied within the United States.

The overall strengths of the literature currently published include the large sample sizes from each study. There have also been support groups that are present worldwide that can reach a large audience. Prior research indicates that support groups are successful in providing individuals with better self-concept and better overall well-being.

A discrepancy present in the literature suggests that individuals who have siblings with special needs actually report having higher self-concept. Another weakness is that there are a very limited number of studies that target support groups within the United States. Having limited research on support groups within the United States limits the research to overseas study groups where culture and population is significantly different than what is practiced within the United States.

The purpose of this research is to examine the impacts of having a sibling with special needs or a disability specifically in the areas of self-concept and overall well-being on the neurotypically developing sibling. There are many support groups that have been found overseas that have been successful with helping these individuals' work on bettering their self-concept, overall well-being and acceptance of their special needs sibling, but there are few publications about these support groups within the United States that offer the same services. The gap in knowledge is whether or not the experiences that individuals endure

result in same emotions experienced by other neurotypical individuals in regards to their sibling.

### **Chapter 3 Methods**

This study examined the emotional impact on neurotypically developing siblings who grow up with a special needs sibling (SNS). In particular, this study examined the impact of SNS's on the self-concept and overall well-being of a sample of neurotypically developing siblings. The study also inquired into how caregivers can best support individuals who have a SNS. The study also examined a support group for neurotypically developing siblings and whether participants found it to be beneficial overall in addition to changing their views of their SNS.

Using a qualitative approach to gather data, researcher utilized surveys and interviews in order to gather the data to answer research questions and to gain insight about the neurotypical siblings emotions and how to best emotionally support them. Both of these forms of data collections were done using open ended questions.

#### **Research Questions**

This examined the questions 1) What emotions does a neurotypically developing sibling develop? and 2) How can caregivers best support the emotional needs of the neurotypical sibling?

#### **Description and Rationale for Research Approach**

This study used a qualitative approach with an emphasis on phenomenological research and narrative research. Narrative research is a “design of inquiry from the humanities in which the researcher studies the lives of individuals and asks one or more individuals to provide stories about their lives”

(Creswell, 2014). Similarly, the phenomenological research is a design of inquiry where “the researcher describes the lived experiences of individuals about a phenomenon as described by participants” (Creswell, 2014). Both of these research approaches are utilized as it focuses on the lived experiences of the interview participants. Participant interviews were used to collect data about the experiences of neurotypically developing individuals who have a SNS. This study also utilized surveys with anonymous responses in order to gather data in a more formal technique. By implementing both of these instruments, the researcher was able to gather more insight through the use of survey research and narrative research. The interview format allowed for more in-depth conversation while the survey allows for a wider population to be reached who have had similar experiences. These instruments complement each other by allowing a wide variety of people to answer questions and therefore have a more diverse data pool. By having questions on the survey that are given different options to select from, there was a limit to what could be said and responses needed to be more refined.

### **Research Design**

The research was conducted in a neutral setting for all interview participants. Research sites, participants, and the sample size were taken in to consideration for this study.

**Research sites.** The researcher met with an advocate in the field of special education who provided contact information for an individual who runs support groups in the Bay Area for individuals who have SNSs. A conversation



was had with this individual who put the researcher in contact with individuals who have gone through the support group.

All research sites were in a neutral setting with the exception of the individuals who have gone through a support group due to limited access to one location of the support group. The interviews took place at a time and location chosen by the individuals being interviewed.

**Participants.** There were three participants who were interviewed for this study. These participants were provided with a pseudonym to preserve their confidentiality. All three participants have a sibling with special needs. Lindsey is 57 years old and has a younger brother with Down's Syndrome. Chelsea is 28 years old with a younger brother who has Down's Syndrome. Michael is 15 years old and has a twin who has Chiari 1 Syndrome and Attention Deficit Disorder (ADD). Each participant signed informed consent forms with or without a proxy (for the minor participant) prior to their participation.

Participants who completed the survey are graduates of a support group for neurotypical siblings between the ages of 5 to 11 who have a SNS. The support group (Sibshops) run by The Sibling Support Project is an international program that began in the United States. The organization was founded in 1990 and became the first international program dedicated to supporting individuals who have SNS. Sibshops began in the United States and has branched out to an international level. Individuals who participate in the group are between the ages of 4 and 12. The support group is three hours per session and lasts from six to eight weeks in length. Weekly meetings are referred to as recreational

workshops that involve high-energy activities with a discussion theme that includes a variety of topics like traveling with siblings and holidays with siblings.

**Participant sample.** The researcher contacted each interview participant via phone to solicit and obtain written informed consent. Since one interview participant is a minor, a letter was sent via email to their guardian in order to obtain written informed consent. Survey participants were recruited through a program coordinator of a support group for neurotypically developing siblings. The researcher contacted potential participants from this group through email directly or through their parents/guardians to obtain written consent for their participation, since participants of the survey were minors. There were a total of three participants in the survey. Two participants were male and one was female. These survey participants ranged in age from seven to fifteen. Race/ethnicity were unknown due to the nature of the anonymous responses.

### **Data Collection Procedures**

Three participants were interviewed for approximately an hour per interview. Each participant opted to do the interview in one sitting rather than break it up in to three sittings. Interviews took place at a location of their choosing. One participant lives out of state and that interview was conducted via FaceTime video. All of these interviews were audio recorded and then transcribed. Each interview participant was asked the same ten questions with a variety of follow up questions depending on clarity and the information that they provided in their response. One of the interview participants had difficulty answering the questions while on FaceTime and asked if she could type answers

to the questions and then email them. She was sent a google document with the interview questions typed out and she answered the questions after taking more time to consider her answers.

Once consent was received for the survey, individuals who participated in the survey received the Google Form via email. This email was provided on the consent form that was filled out and signed by a proxy. The survey was sent via Google Forms and the researcher did not collect emails to ensure that all responses were anonymous and could not be traced back to a participant.

### **Positionality of the Researcher**

The researcher has a sibling with special needs and was able to relate to the participants. The researcher is also a special education teacher who has worked with moderate/severe disabilities and mild/moderate disabilities and therefore inhabits a position of advocacy. While the researcher does not have experience with support groups, the researcher has provided guidance to the neurotypically developing siblings of former students per the request of their parents.

The researcher is also a friend of two of the participants being interviewed. The researcher attended high school and has a personal relationship with one of the interviewed participants. Having prior relationships to these participants enabled a prior level of trust that was already present and did not have to be established prior to or during the interview process.

### **Data Analysis Procedures**

All interviews were audiotape recorded for analytical purposes. Additionally, field notes were recorded during the interview. To preserve confidentiality, each interview participant was assigned a pseudonym. The researcher transcribed the interviews at a later date in order to code data.

Once interviews were transcribed, the researcher coded the interviews using a spreadsheet with key quotes in order to find themes. The themes that appeared during the interviews were noted in a notebook and kept track of using a spreadsheet in order to organize and help see the commonalities between the interview and the survey participants. Codes included words or themes that appeared throughout all of the interviews. Some of the codes may include family dynamic, emotions/feelings, and relationships.

The researcher distributed 5 surveys and had 3 surveys returned. Upon initial formation of the research, the researcher believed there would be more survey participants. Based on 3 surveys, it is not realistic to assume the answers are conclusive of all neurotypical developing siblings who have a SNS. However, the surveys that were distributed were sent and collected at one point and did not consist of longitudinal studies. Surveys were analyzed using themes and patterns of responses based on the participants responses.

### **Validity & Reliability**

Doing qualitative data collection allows for subjective analysis as the research was open for interpretation. The survey data was collected via an anonymous electronic survey. All survey participants received an identical survey

in the same online format. Providing all participants with the same survey allows all participants to answer the same questions. The questions asked did not require the participants to interpret them in a certain way. The researcher triangulated the data from the interviews in order to gain insight about the different experiences.

The research conducted focused on a small population and it cannot be assumed that the same results would be the same in a larger setting or in a different location. All of the interview participants were Caucasian and it cannot be assumed that the findings would be applicable to participants of a different racial or ethnic background.

Validity is increased by identification of the researcher bias because as a member of the group being researched, the researcher has a greater depth of understanding. By stating this bias upfront, the researcher invites the reader into the community. The researcher made an active attempt to not insert herself into the research that was collected and took the data and analyzed it without prior biases. The researcher analyzed with an awareness of the bias that allowed the researcher to be attuned to differences in perspective from her own. While analyzing the data, researcher also kept in mind that this is not a generalization of the entire population of individuals who have a SNS, but a glimpse into that specific population using individual experiences and perspectives about their family situations and experiences involving their SNS.

### **Chapter 4 Findings**

When attending a Special Olympics basketball tournament, there can be anywhere from two to four games going on at one time depending on the venue. One can sit in the stands and look around at all of the faces that are cheering on the individuals on the court. Some of these individuals on the court might have Down's Syndrome, some might have autism, some might have Cerebral Palsy, and some you might look at and wonder what their disability is. Each of these basketball players are a part of a family. This family might include a mother, father, sibling, grandparents, aunts, uncles, etc. Each of these family members is also impacted by that basketball player's diagnosis. Their sibling is impacted in a multitude of ways and may require additional emotional support to help navigate those feelings and experiences.

The findings from this research demonstrate individuals with a special needs sibling (SNS) experience an increase in emotions that may require more emotional support. They encounter a variety of positive and negative emotions towards their sibling because of the unique situation that they find themselves in. There are more difficult emotions that need to be addressed. A support group would be an appropriate, safe place to explore these emotions with like-minded individuals who are in similar situations.

Themes that appeared through the data collection of this research included experiences of the neurotypical individual, emotions that were experienced throughout the neurotypical individuals' lives, and emotional support. After providing context for each of the interview participants and

examining their different family situations and upbringings, the emotions that were mentioned will be examined. This will be followed with the results from the survey that was provided for the support group graduates and participants. This will be concluded by taking a closer look at the emotional supports that the interview participants had growing up.

### **Experiences of the Neurotypical Sibling**

The three interview participants have drastically different backgrounds and different experiences with their sibling and their family life. Michael grew up with a twin brother who has a diagnosis of Chiari 1 Syndrome and Attention Deficit Disorder (ADD). While both Lindsey and Chelsea have younger brothers with Down's Syndrome, Chelsea's brother lived in a group home for most of their childhood while Lindsey's family broke the standard and raised a handicapped child in their own home. Chelsea reports, "he was [at the group home] Monday through Friday and then we had him on the weekends." She reports that the decision to put Daniel in a group home resulted after a family vacation because "my mom couldn't even enjoy herself. He just had such bad behaviors." When looking back at that decision that her mom had made, she commented, "that was probably the best decision that she has ever made because he improved so much because of his behaviors. He was just out of control and we couldn't control him." Even though he was at the group home Monday through Friday, Chelsea still reported feelings of joy and recalled family times together. When asked about her favorite memories from growing up, she reported, "I loved holidays...just going over to my grandparents every Thanksgiving and Christmas

with my mom and brother and just being with family and cousins.” She also reported negative feelings that included “I just didn’t enjoy him. I didn’t like being around him. I would kind of do my own thing on the weekends, too when my mom had him enough though I was young.”

During the time when Lindsey and her brother were growing up, it was the “norm” to put individuals with disabilities in a special home, Lindsey’s parents decided to not do that. She reported, “Most people weren’t raising their handicapped children at home at the time.” Lindsey went on to say, “they went to a house to see if they could put Drew into this Sunshine Children’s Home and I guess they showed my mom...kids like in cages. So...they were determined to raise him at home.”

When asked how he thinks Adam has impacted his life, Michael stated “my parents and I haven’t ever sat down to talk about his future and everything. I think for one, we’re all nervous to do it. I think for two, they’re not quite sure yet...it’s definitely a worry.” When asked to elaborate on this, Michael continued and said “I’ll be sitting doing something and then out of nowhere I’ll get emotional...I’m going to be gone in 4 years and he’ll be at home and it’ll be really sad.”

### **Emotions**

All participants were asked a question regarding the emotions that they have either towards or about their sibling. The survey participants were given a list to choose from and the interview participants were provided the opportunity to answer in an open-ended format.



When asked 'what feelings did you have about/towards your sibling?' all participants mentioned feelings of guilt, embarrassment, regret, jealousy, anger, frustration, protective, and sibling rivalry. Two of the interview participants focused on happier times and associated their siblings with times of joy and happiness. One of the individuals focused on the lack of presence of their SNS. Michael responded to this question with jealousy. He stated, "Back then, he got a lot more attention...so yeah, a little bit of jealousy." Michael also talked about times when he would get frustrated with Adam and how he would "understand that it's this mental thing and Adam can't control it." Michael mentioned the need and desire to be understanding of Adam and his situation frequently throughout the duration of the interview.

When asked the same question about how she felt about her SNS, Lindsey responded with different feelings that she experienced with her younger brother who has Down's Syndrome. She stated, "I became very protective of him. I can remember chasing some kids out of our yard. I...grabbed a broom because Drew was out playing basketball and they came to make fun of him and I went after them." Lindsey also reported feeling "there was a lot of embarrassment...we had this thing that was imperfect." Later in the interview, she mentioned "I feel a sense of obligation and responsibility...I feel a lot of pity." When asked the same question about her younger brother who also Down's Syndrome. Chelsea responded, "I just didn't enjoy him. I didn't like being around him." She proceeded to tell a story from her childhood that stuck out to her. "There was one time he

got so pissed off, my mom got him a Coffee Bean and he chucked it across the room at the mall and I was mortified...I just remember that so vividly.”

The concept and desire to be “normal” came up repeatedly throughout the 3 interviews with each of the participants. Michael reported that he “would treat him like a normal brother...I’ve always kind of treated him normal.” Chelsea stated that she and Daniel “fought like a normal brother and sister would as if he was totally normal.” She later said that because of Daniel, “we couldn’t do a lot of normal things like vacations, going camping, going to the beach for the day, going to Disneyland. It would always be an ordeal that sometimes wasn’t worth the hassle, especially with a single mom.” Lindsey also stated, “I wanted to be normal...we don’t get to be normal...wanting to fit in with the normal white girls, the blondes, [Drew] hindered it.” ‘Normal’ was a word that consistently popped up. There was definitely a heightened awareness of being different.

Each interview participant also brought up the pressure that they feel to become the responsible adult who takes care of their sibling. Michael stated, “I don’t know where the pressure is when parents are gone...I feel like I will have more pressure instead of my older brother to make sure that Alex is okay.” He later stated, “We’ve looked into homes and programs but it’s the type of thing that you’re worried for the day when that comes.” Lindsey also mentioned the future in respect to her brother and what will happen after her mother passes away. She stated, “my older brother is kind of a person who is in denial all the time, which means that I will probably have to, in fact, have already tried to take guardianship of [Drew].” Chelsea reported that her family is looking into moving

to where she currently lives in Tennessee and that Daniel is a large factor in this decision. Chelsea stated, "Daniel is the biggest factor and biggest challenge because California really does offer so much...they always want to be closer to me just for the future." When asked the question about whether or not having a SNS impacted relationships outside of the family, Chelsea stated, "I'm not dating anyone now, but if I get married, Daniel is going to be my responsibility eventually just as my mom gets older and I don't know if he would have to live with us at any point."

### **Emotional Support**

Only one of the participants of the interviews claimed that they had enough emotional while growing up. When asked if he had enough emotional support growing up, he reported "yeah, because my parents are really open...I could ask them a question and they would answer it about him...I'm not afraid to mention that I have a special needs brother." When asked if he would have participated in a support group with other siblings who have a SNS given the opportunity, he stated "It would never get to that level where I would want to go talk to someone about it. I just thought you had to kind of deal with it." He later stated that the interview "was more comfortable than I think a support group would be...I would want to just hang out and talk with one other person."

When Lindsey was the asked the same question about utilizing a support group when she was younger, she responded, "I think if the whole family would have done it, but if it was individualized, then no. We grew up in a family where they thought therapy was for sucks." When asked a follow up question about

whether she thought she would have benefitted from it in hindsight, Lindsey stated, “Oh yeah, absolutely. A lot of my personality was formed by the schism when Drew was born...I probably would have been a stronger, more assertive human being.” Lindsey provided background for her family and the way that they worked together in the situation. “[Drew] was something that we kind of fiercely defended but were secretly ashamed of.”

Chelsea responded in a similar way when she was posed the same question. Her response was “it would have been a good idea. I don’t know if back then I would have said ‘let’s do it!’...but that probably would have been great. If my mom would have put me in it, it would have been good.” She later stated, “They really have that? That’s so cool!” Chelsea also received support in a different setting. She reported, “my mom was part of a mommy group which was 10 other ladies who had kids with disabilities so I was really close with all of them so I felt like I always had someone.”

Despite an awareness that additional support would have been helpful in processing the emotions of having an SNS, all three interview participants reported positive outcomes of having a sibling with special needs. Michael reported, “Overall, I think it’s been fine. I don’t think the negatives outweigh the positives...I like him for who he is.” When asked the follow up question of whether or not he would change anything about his life, he reported that “being more supportive in regards to my parents because it has been a huge toll on them emotionally...just a little bit more support so they could feel like everything is going to be okay.”

Lindsey reported that “the good impact is that I don’t judge people. The bad impact is that I think it crippled me in many ways that I did not understand until just a few years ago when I started trying to find out who I was.” She also had a series of questions that had come up that included “Would I react the same way towards my own [children]? What would it have been like if I was not in the middle of that kind of situation? What would my family have been? Would we have traveled more? Would we have been happier? Would my father have retreated like he did?” She later made a statement that “part of me thinks we would have had a family that included me more had he not come.” When asked if she would have changed her life to not include Drew, she stated “No, no. It’s enriched my life...it’s made me more of a thoughtful person...we have an obligation, we have a duty...I do feel more of a need to reach out than I might have felt.” In the same response, she stated, “I think that whole vent of mine came from a feeling like I got away with something...there’s a lot of guilt in my life. He’ll never drive...he’ll never get married. He doesn’t really know what the hell is going on. There’s a lot of guilt in that I survived that.”

Chelsea reported that Daniel “made me grow up a little faster and I was a lot more independent growing up because of him.” Her career choice was also influence by her brother. She stated, “I got into [occupational therapy] (OT) because of Daniel actually because he grew up and I always saw him going to OT. He’s done that his entire life.” Chelsea had difficulty answering the question when asked in person, so the questions were sent to her via email where she was able to formulate her answers with more thought. She reported, “he has

given me a unique perspective on life than others. Growing up, my life was different than most 'typical' families...I grew up always being around kids with special needs which ultimately led me to the career I have chosen." She later stated in the same response, "he makes me want to be a better person and I just hope that I have made as much of an impact in his life as he has on mine even though I didn't think it back then."

**Survey participants.** Survey participants were asked 'how do you feel about your sibling?' and given a list of possible emotions that included happy, sad, overwhelmed, stressed, jealous, alone, responsible, angry, embarrassed, worried, sensitive, proud, calm, accepting, and other. The survey participants responded with different answers that included positive emotions like happy, calm, and accepting. Some other negative emotions reported included overwhelmed, responsible, and angry. When asked if participating in the Sibshops workshop helped with these feelings, the answer varied. 66% of the participants responded that the support group did help with navigating these feelings, while 33% reported not feeling as though the support group had helped them explore the feelings. There is a contradiction with these findings. The data shows that not all support group participants found the group to be beneficial. However, there was a unanimous result that the support group changed the way that they thought about their sibling. When asked to explain further, a response from an anonymous survey participant included "I'm more understanding and there are other siblings dealing with the same thing I deal with every day." Another anonymous participant reported "We share and discuss all of our

sibling's differences in disabilities, and now I perceive my brother's disability as not the worst." While not all survey participants felt there was a benefit from the support group, all participants reported feeling as though the support group helped to change their views about their sibling and made them feel less alone in their situation.

The support group takes place in a neutral setting with similar aged peers participating and conversing with one another. There are some more preferred activities like games or art mixed with more formal activities that are based on conversation. The researcher asked the survey participants what their favorite part of the group was and 66% responded that meeting new people was their favorite aspect of the group and the other 33% responded that the games were their favorite part of the group. Only one participant responded with not enjoying anything about the support group. Due to the anonymous format, the researcher was unable to follow up to ask why they did not enjoy anything about the group.

All of the data allows for evidence that there is an abundance of emotions that are experienced when growing up with a SNS. The neurotypical siblings must learn to navigate these emotions. Fortunately, there are support groups that are available to those neurotypical individuals to help them navigate these difficult emotions that they may experience.

### **Chapter 5 Discussion and Analysis**

This study found that despite the experiences and the family makeup of the neurotypical individuals, individuals who have a special needs sibling (SNS) experience similar emotional impacts. Participants in the study expressed feeling responsible for their sibling, embarrassed, and a strong desire to be “normal.” There is an abundance of emotions that occur when growing up with a special needs sibling that may require emotional support in order to help process the emotions that these neurotypical individuals are experiencing. Based on the survey results, it was found that participants within the support group found the group to be beneficial, help neurotypical individuals change their view of their SNS and find acceptance within that relationship. The survey established that participants were better able to accept their sibling prior to before participating in the support group while navigating the emotions and feelings that they have towards their sibling.

#### **Implications for the Literature**

This research supported the findings from the literature review in that emotions were a topic that repeatedly came up in the findings. The feelings and emotions that came up in the study included guilt, embarrassment, regret, jealousy, anger, frustration, protective, and sibling rivalry. These support the findings that Naylor & Prescott and Ali & Sarullah found when they examined sibling acceptance. Both of these studies found that neurotypical siblings experiences anger, rivalry, sadness, envy, guilt, love, resentment, pride, empathy, and support. There was also a large emphasis on sibling relationship



and the emotional impact that the SNS brings to that relationship in both the literature review and the findings from this research. The findings from this research also supported the success of support groups for neurotypical individuals. Dyson (1998) found that the weekend workshop, similar to the one examined in this study, led neurotypical siblings to feel better about their SNS and about themselves. The support group model studied in this study offered support for neurotypical siblings who had a SNS with a variety of diagnoses. All survey participants reported feeling better about their sibling by the end of the support group. This finding is in alignment with Roberts et al. (2016) who found that the SibWorks workshops would be beneficial for individuals who have a sibling with a severe or a mild disability.

The study also produced some newer insights that may merit inquiry with a larger population of participants. Even though the interview participants had different family backgrounds, a different family makeup, and differing interactions with regard to their siblings, this study found that all three participants described emotional similarities. Different experiences resulted in the same emotional result of the interview participants. The study also found that the concept of normalcy was frequently expressed. There was a strong desire to treat their SNS normally, to have a normal family, and to do normal things. So much of growing up with a involves doing things that may not be perceived as being normal in a typical family. Some of the interview participants reported that they were unable to do simple things like go to the mall because the behavior of their SNS could be so unexpected. In comparison to their peer group, participants reported feeling that

they were unable to partake in many of the activities or social experiences that their peers were able to do. Two participants even reported avoiding having friends over in fear of either their SNS behavior or what their friends might think. There appeared to be a heightened awareness of being different from their peers.

While there were negative emotions and negative impacts that occurred within the sibling relationship and the sibling dynamic, all interview participants reported their SNS having a positive impact as well. All interview participants reported that there was an influence in career choice, an influence in their character, and an influence in the way that they viewed other people in general.

The findings from this study support the idea that support groups would be beneficial. While the interview participants did not have access to a support group, two of the participants expressed an interest and felt that the support groups would have been beneficial had they known about it and taken advantage of it at a younger age. All of the participants felt that they had support but would have liked to have more support. The youngest interview participant reported that a mentor model would be more appealing than a group model.

### **Implications for Practice and Policy**

This study found that more supports for parents and their neurotypical children should be made available. While there are support groups that are present, parents may argue that they don't have time to take their child to a support group. If a child is receiving emotional support to help them process the emotions that they are experiencing, then it's possible that the sibling relationship

may grow stronger. It's also possible that given these supports, the neurotypical child won't exhibit behaviors in other settings like the school. Given the small sample size of this study, it remains unclear the full extent of the emotional impact of growing up with a SNS. If a neurotypical child is given the resources they need, and a safe space to speak, then it is possible that future problems may be minimized. Both the neurotypical sibling and the SNS have a different set of needs and the needs of both of these parties should be prioritized.

Within a school setting, educators should be aware that their students experience a lot outside of the classroom. There should be steps taken to get to know about the home lives of their students. Not all students may be forthcoming about their SNS and there may need to be a closer relationship established with parents in order to learn about this. A questionnaire about home life that can be sent home at the beginning of the schoolyear for parents to complete including information about special needs siblings may be useful. If students are older, a questionnaire can be given to them in order to gain access and information about their home lives. As a result of growing up with a SNS, it is important to know that there is an emotional impact and unique stresses that can develop and may present themselves in a variety of ways within the classroom for a neurotypical child.

If students are forthcoming with information, it's possible that a club or a group can be founded to establish a safe space for these individuals who have a SNS to come together and share their experiences. Administrators and educators within the school setting should be aware of supports available and

how to find support groups within the area. A special education teacher should also be aware of these supports and should convey this information to parents.

### **Limitations of the Study**

As with every study, there are limitations that come with this study. There were limited surveys that were distributed and returned, which resulted in a smaller data pool to utilize when analyzing the data. If this study could be duplicated with adjustments in the process and the methodology, there would have been more of an emphasis on the surveys and getting more surveys distributed and returned.

This study also only focused on the neurotypical siblings. Getting the parent perspective could have been insightful for understanding the experiences from a different lens and to better understand the sibling relationship from an outside perspective. While the individuals who were interviewed were from three different areas within California, all of the survey participants were from one support group provider within the Bay Area. Having a larger quantity of surveys in addition to surveys from participants from multiple locations could have been beneficial in learning more about the support group success. It could have also been beneficial to have different types of support groups (i.e. online, small group, one to one) to see if participants in those groups found one to be more beneficial than the other.

However, it must be acknowledged that this study is limited to a small area within California and therefore, the results cannot be generalized to a larger area or for a larger population. Still, this study provided a small but insightful glimpse

into a group of neurotypical participants that were impacted by growing up with a SNS.

### **Directions for Future Research**

If this research were to be continued, the school setting would be closely examined to see what level of supports, if any, are currently present within schools. School is often the location where children and young adults spend the majority of their time and it could be beneficial to have a support group model established within the school setting.

Having a parent perspective could also be beneficial as the parents are not directly involved with the sibling relationship and could potentially step back and examine the sibling dynamic through a different lens than the neurotypical sibling. The same could be said about getting the SNS perspective on the relationship with their neurotypical sibling and the role that the neurotypical sibling plays within the relationship through the point of view of the SNS.

### **Chapter 6 Conclusion**

There are a multitude of resources and supports for an individual who has special needs and even their parents and family units as a whole. However, there is limited knowledge of supports that are in place for a neurotypical individual who has a special needs sibling (SNS). There is a large number of support groups on a regional, state, national, and international level that are underutilized due to lack of publication and advertising. This study examined the emotional impact of growing up with a SNS and how caregivers can best support the neurotypical sibling emotionally. Support groups are a large factor that can play a significant role in providing support for the neurotypical sibling.

There is a large emotional impact on the neurotypical sibling regardless of the experiences and of the family life of these individuals. The neurotypical sibling experiences a tremendous emotional burden because of their SNS. Some of the emotional burdens included but are not limited to worries and concerns about what happens when parents pass away (i.e. who is going to take care of their SNS? Where will their SNS live?, etc.), and how the neurotypically developing sibling's actions and dreams (i.e. going to college far away) will impact their SNS. This study also found that there was a significant desire to be "normal" and to do "normal" things. Some of these "normal" activities included going to the mall, going out to dinner, having friends over and going on family vacations. There appeared to be a heightened awareness of being different or growing up in an atypical situation. It is possible that some of the emotions experienced by the neurotypical sibling like resentment could be due to the

inability to be a “normal” family or to do “normal things”. There is certainly a strong desire to fit in and to be normal in comparison to the neurotypically developing sibling’s peers.

There are many emotions that play a role in growing up with a SNS. Some of these emotions included guilt, embarrassment, responsibility, envy, and stress. All of these emotions can be difficult to navigate on their own, let alone with several other difficult emotions. Support groups are helpful in helping neurotypical individuals navigate these emotions and to increase their self-concept and overall well-being by reducing the level of stress that they may experience. The support groups can also be beneficial in helping the neurotypical sibling see their SNS in a more positive way that they might not have had the opportunity to do had they not attended the support group.

There are a lot of emotions and stressors that the neurotypical sibling may experience. This may become apparent in a classroom setting. Administrators and educators should be aware of how to assist the neurotypical sibling in acquiring support whether that be in the schools or in a support group model. In order to gain knowledge about the family life, educators should inquire about home life. It is important to adjust teaching style and to implement a culturally responsive teaching method that allows for the classroom to be a safe space for all individuals. Having a social emotional curriculum embedded within the standards that are taught to would also allow students the opportunity to come forth and share information about their home life.

All emotions can sometimes be difficult and daunting to navigate. Growing up with a sibling can also be difficult as the layer of sibling rivalry can potentially be present. Growing up with a SNS can be even more challenging. The situation adds a layer of difficulty to an already difficult relationship to navigate and understand. Having the use of a support group can be crucial in assisting the navigation of these emotions that the neurotypical sibling might experience.

Neurotypical individuals who have a SNS experience an emotional impact from growing up with a SNS. These emotions and the burden that they may encounter can be addressed in the form of a support group. A support group would be beneficial in changing the way that they view their SNS and to become more accepting of their SNS.



### References

- Ali, M. M., & Sarullah, S. (2010). Typical siblings' acceptance of siblings with special needs. *Procedia - Social and Behavioral Sciences*, 9, 517-521.
- Bartholomew, K., & Horowitz, L. M. (1991). Attachment styles among young adults: Kim Bartholomew Simon Fraser University Burnaby, British Columbia, Canada. *A test of a four-category model. Journal of Personality and Social Psychology*, 61(2), 226-244.
- Baumeister, R. F. (Ed.) (1999). *The self in social psychology*. Philadelphia, PA: Psychology Press (Taylor & Francis).
- Bitsko, R. H., Holbrook, J. R., Robinson, L. R., Kaminski, J. W., Ghandour, R., Smith, C., et al. (2016). Health care, family, and community factors associated with mental, behavioral, and developmental disorders in early childhood — United States, 2011–2012. *MMWR Morbidity and Mortality Weekly Report* 2016; 65:221–226
- Breslau, N. (1982). Siblings of disabled children: Birth order and age-spacing effects. *Journal of Abnormal Child Psychology*, 10(1), 85.
- Buhrmester, Duane, & Furman, Wyndol (1990). Perceptions of sibling relationships during middle childhood and adolescence. *Child Development*, (5), 1387.
- Buist, K. L., & Vermande, M. (2014). Sibling relationship patterns and their associations with child competence and problem behavior. *Journal of Family Psychology*, 28(4), 529-537.

- Burke, Peter & Kingsley, Jessica, (2005). Brothers and sisters of disabled children. *Journal of Applied Research in Intellectual Disabilities*, 18, 93-94.
- Conway, S., & Meyer, D. (2008). Developing support for siblings of young people with disabilities. *Support for Learning*, 23(3), 113-117.
- Creswell, J. W. (2014). Research design qualitative, quantitative, and mixed methods approaches. Los Angeles: SAGE.
- Disability | Definition of disability in English by Oxford Dictionaries. (n.d.). Retrieved January 14, 2018, from <https://en.oxforddictionaries.com/definition/disability>
- Dodd, L. W. (2004). Supporting the siblings of young children with disabilities. *British Journal of Special Education*, 31(1), 41-49.
- Dyson, L. L. (1998). A support program for siblings of children with disabilities: What siblings learn and what they like. *Psychology in the Schools*, 35(1), 57.
- Emerson, E., & Giallo, R. (2014). The well-being of siblings of children with disabilities.
- European Agency for Special Needs and Inclusive Education. (2016, April 20). Retrieved December 05, 2017, from <https://www.european-agency.org/about-us/what-we-do>
- Feinberg, M. E., Sakuma, K., Hostetler, M., & McHale, S. M. (2013). Enhancing sibling relationships to prevent adolescent problem behaviors: Theory, design and feasibility of siblings are special. *Evaluation and Program Planning*, 36, 97-106.

- Hulett, Kurt. *The Legal Aspects of Special Education*. Pearson Prentice Hall, 2009.
- Inam, A., Kausar, R., & Abiodullah, M. (2017). Does having a sibling with autism affect one's self concept? an empirical research. *Isra Medical Journal*, 9(3), 166-170.
- Loots, G.M., Pit-Ten Cate, I.M. (2000). Experiences of siblings of children with physical disabilities: An empirical investigation. *Disability and Rehabilitation*, 22(9), 399-408.
- McHale, S. M., & Others, A. (1989). Sibling relationships and adjustment in children with disabled and nondisabled brothers and sisters.
- Naylor, A., & Prescott, P. (2004). Invisible children? the need for support groups for siblings of disabled children. *British Journal of Special Education*, 31(4), 199-206.
- Richardson, J. G., & Powell, J. W. (2011). *Comparing Special Education : Origins to Contemporary Paradoxes*. Stanford, Calif: Stanford University Press.
- Roberts, R. M., Ejova, A., Giallo, R., Strohm, K., Lillie, M., & Fuss, B. (2015). A controlled trial of the SibworkS group program for siblings of children with special needs. *Research in Developmental Disabilities*, 43-44, 21-31.
- Roberts, R. M., Ejova, A., Giallo, R., Strohm, K., & Lillie, M. E. (2016). Support group programme for siblings of children with special needs: Predictors of improved emotional and behavioural functioning. *Disability & Rehabilitation*, 38(21), 2063-2072.

Rotatori, A. F., Bakken, J. P., & Obiakor, F. E. (2011). History of Special Education. Bingley, UK: Emerald Group Publishing Limited.

Special Education Department. (2015). Retrieved December 05, 2017, from <http://sed.punjab.gov.pk/>

The Americans with Disabilities Act. (1991). Washington, D.C.: U.S. Dept. of Justice, Civil Rights Division, Coordination and Review Section.

Tichon, J. G. (2015). Full length article: Exploring how children express feelings and emotions in an online support group. *Computers in Human Behavior*, 53, 469-474.

Yell, M. L., Rogers, D., & Rogers, E. L. (1998). The legal history of special education: What a long, strange trip it's been! *Remedial and Special Education*, 19(4), 219-28.

Appendix A

APPENDIX B  
IRBPHP SIGNATURE PAGE

SIGNATURE PAGE (8.15)

Select Type of Application: Initial

Applicant Name: Lauren McDonell

Project Title: How to better support the forgotten siblings

Signatures:

I acknowledge that all procedures will meet relevant local, state, and federal regulations regarding use of human participants in research. I am familiar with and agree to adhere to the ethical principles in the conduct of research with human participants as set forth by the Dominican University of California IRBPHP Handbook.

[Redacted Signature]	11/13/17
Signature of Applicant	Date
[Redacted Signature]	11/13/17
Signature of Faculty Advisor*	Date

\*Your signature indicates that you accept responsibility for the research described, including work by students under your supervision. It further attests that you are fully aware of all procedures to be followed, will monitor the research, and will notify the IRBPHP of any significant problems or changes.

\*Category of Review: Determined by faculty advisor or researcher.  
(Note: See IRB Handbook pages 11-13 for category descriptions.)

- Exempt *For Renewal and Modification Applications only.*
- Expedited  Category of Review changed from Initial
- Full Board Review

[Redacted Signature]	11/13/17
Signature of Department Chair	Date

\*\* Review by Dept Chair required for students in some disciplines.

_____	_____
Signature of Dean of School	Date

\*\*\*Review by Dean is required for faculty researchers but not for student investigators unless this is a procedure of the School within which the student is majoring.

Please print and scan this signature page for your file and return electronically to [june.caminiti@dominican.edu](mailto:june.caminiti@dominican.edu) or in person to June Caminiti in Guzman 210.