

“We Do Love Them Equally:”

Parental Perceptions of Being a Sibling of a Child

with Autistic Spectrum Disorder (ASD)

by

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ABSTRACT

This thesis is a qualitative research study that focuses on siblings of children with Autistic Spectrum Disorder (ASD). Even though it is expected that having a child with ASD in the family will influence the whole family including siblings of the child with ASD, the sibling population is rarely included in research related to children with ASD, and there is only limited services available for them. This exploratory study (n=6) is aimed at better understanding the siblings' lives in their family settings in order to identify the siblings' unmet needs and determine how they have been influenced by the child with ASD. This study is also aimed at identifying the most appropriate support for the siblings to help them cope better. The study followed the Resiliency Model of Family Stress, Adjustment, and Adaptation and a narrative theory approach. An in-depth interview with the parents was conducted for the study, so the findings reflect the parents' perception of the siblings. All the themes emerged into two categories: life in the family setting and supports. The findings indicate that the families are striving for balance between the siblings and the children with ASD, but still tend to focus more on the children with ASD. Also, the families tend to have autonomous personal support systems. The parents tend to perceive that these personal support systems are good enough for the siblings; therefore, the parents do not feel that formal support for the siblings was necessary. As a result of the findings, recommendations are made for the organizations that work with individuals with ASD to provide more appropriate services for the families of children with ASD, including siblings. Also, recommendations are made for future studies to clarify more factors related to the siblings due to the limitation of this study; the siblings' lives were reflected vicariously via the parents.

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Chapter 1

INTRODUCTION

Parents who are dealing with behavioral issues with the autistic child are already in a negative mindset. So, all it takes is for the typical kid to do something that maybe that parent was not expecting. And I say, “why would you do that!” I catch myself all the time, then I’m going back into her room, and saying, “I’m sorry. I was just having a rough time.” She catches that all the time. “I’m sorry. It was hard to deal with your brother.”

Mother of 14 year-old daughter and 6 year-old son with ASD

Only limited literature exists on the siblings of children with Autism Spectrum Disorder (ASD) and most of the research has been focused on the etiology of autism. While the sibling population receives less attention in the research field, they also tend to receive less attention than the children with ASD in their family settings. When considering ASD as a typical chronic condition that needs extra support, some research has been done on the sibling population. Unfortunately, the existing research has traditionally focused on the negative side effects that siblings experience. For example, Williams et al. (2010) reported that in 40 studies, 60% of parents of children with developmental disabilities thought that the siblings are influenced negatively by having a child with disabilities in their family setting. Breslau and Prabucki (1987) and Ross and Cuskelly (2006) also stated that siblings might have emotional and behavioral issues due to ongoing stress by having children with disabilities in their families. However, siblings’ adjustment problems are not only affected by the children with disabilities, but also by partial parental treatment (Bagenholm & Gillberg, 1991; Tsao, Davenport & Schmiede, 2012; Van Rensselaer, 2010). This thesis addresses the parent’s perception of: (1) the

siblings' experiences in their family setting, (2) the impacts of having a brother/sister with ASD, (3) the siblings' unmet needs, and (4) supports for the sibling.

The study will be led by the Resiliency Model of Family Stress, Adjustment, and Adaptation and narrative theory. Based on the Resiliency Model, the study will explore the more efficient and effective ways to support siblings. It is indicated by correlation between family adaptation and four other factors that McCubbin & McCubbin (1993) stated: (1) family demands, (2) strength of the family system, (3) family resources, and (4) family's positive appraisal of the situation. Narrative theory will help the researcher to focus on the parents' stories to glean reflections of the siblings' experiences.

Also, a qualitative research design will be used for this study. This descriptive study explores siblings' experiences created by the presence of children with ASD that influence their lives in many different ways, as seen through the eyes of the parents. In-depth interviews were conducted with the parents in order to present rich narratives that illuminate the siblings' experiences in their family setting. The following are the main research questions leading this study:

- 1) What are parents' perceptions of how are the siblings of children with ASD treated and how do they function in their family setting?
- 2) What are parents' perceptions of how the siblings have been influenced by the children with ASD?
- 3) What are the parents' perceptions of how the siblings cope with their situation?
- 4) What are parents' perceptions of appropriate social supports for the siblings to help them cope more easily and positively?

Chapter 2

LITERATURE REVIEW

Autism Spectrum Disorders (ASD) are a heterogeneous group of developmental disabilities that are defined by significant challenges with social interactions and communication, repetitive behaviors, and narrow interests (Miles, J. H., McCathren, R. B., Stichterand, J. & Shinawi, M., 2010). There are many other manifestations giving evidence to ASD: hyper-/ hypo-sensitivities to sound and touch, food sensitivities, irregular sleep patterns, tantrums, self-injurious and aggressive behaviors, impaired motor development and total disregard for danger (Miles et al., 2010). There is limited information shedding light on the etiologies and biology of ASD (Lord, Cook, Leyenthal, & Amaral, 2000), but it is clear that they typically appear in the first years of life and in some cases may be related to Mental Retardation (American Psychiatric Association, 2000). Nordin and Gillberg (1998) indicated that only fewer than 5% of children with ASD would be able to completely recover.

The Centers for Disease Control and Prevention (CDC) estimated that 1 in 88 American children (11.3 per 1,000) had been identified with an ASD in 2008 compared to 1 in 150 children in 2000 (CDC, 2012). This rapid increase produces a burden on many systems related to ASD, such as healthcare, school, and social support systems because extra support is needed in those fields. For example, Peacock, Amendah, Ouyang, & Grosse (2012) found that the average annual medical expenditures for Medicaid pediatric enrollees with an ASD in 2005 were \$10,709 per child, which was roughly six times higher than the expenditures for children without an ASD, \$1,812. In addition to medical costs, \$40,000 to \$60,000 is spent per child per year for behavioral interventions

(Amendah, Grosse, Peacock, & Mandell, 2011); behavioral intervention is one of the general therapies available for people with ASD in addition to educational intervention (Lord et al., 2000). Unfortunately, people with ASD not only require financial support from the healthcare system, but also physical and emotional support from their primary caregivers. Therefore, supporting people with ASD not only burdens social systems, it also burdens families who have members with ASD. As expected, many researchers have found that having family members with special needs clearly influences the parents and other siblings (Fisman, Wolf, Ellison & Freeman, 2000; Guite, Lobato, Kao & Plante, 2004; Angell, Meadan & Stoner, 2012; Naylor & Prescott, 2004). Most of the studies regarding the impacts on families focused on the parents of the child with special needs, and less were focused on their siblings. Moreover, specific studies that researched the impact of ASD on siblings were even scarcer; therefore, expanding the research to families and siblings of children with ASD would reveal how the unique family dynamics work in those families and within the sibling population.

Effects on Families

ASD is a condition that has implications for the primary caregiver, the parental relationship, family functioning, and of course, the affected child (Hodgkinson, & Lester, 2002). Family functioning is affected by the constant need to adapt to new life styles and roles, with extreme stresses often occurring in families with special needs children (Hodgkinson & Lester, 2002). Research consistently finds that rearing children with special needs is stressful (Mancil & Boyd, 2009). More specifically, extreme stress may accompany the process of accepting the diagnosis; therefore, families manage the stressful situation by changing their roles and responsibilities (Brody & Simmons, 2007).

Generally, when the parents first learn of their children's chronic condition, they react with shock, disbelief, denial, grief, anger, frustration, sadness, confusion, and despair (Canam, 1993; Cohen, 1993; Eakes, 1995). Anxiety, guilt, fear, resentment and depression are also common feelings the parents may experience with the diagnoses (Hodgkinson, & Lester, 2002; Melnyk, Feinstein, Moldenhouer, & Small, 2001). These grief-related emotions are created by uncertainty about the future, sustained uncertainty in decision-making, conflicts over childcare responsibilities, and continuous responsibilities as primary caregiver (Cohen, 1993; Eakes, 1995; Hodgkinson, & Lester, 2002).

Since children with ASD require more financial, physical, and emotional support from the primary caregiver than the children without ASD, parents usually report parenting stress due to multiple and ongoing burdens of caring for the children. Children with ASD impact their families because they may require lifelong care and additional financial, physical, and emotional resources from the families. The parents may have to offer much more intensive care in addition to general care, such as setting a firm daily schedule, providing opportunities to socialize, planning daily activities, arranging further education, and providing friendship for the children (Portway & Johnson, 2005).

Those burdens include financial difficulties due to extra costs, physical strain resulting from taking care of the children, increased social isolation, and marital strain (Canam, 1993; Cohen, 1993; Dyson, 1999; Hutton & Caron, 2005; Scorgie & Sobsey, 2000). Gupta & Singhal (2005) also reported other possible challenges that a family of children with special needs may face in their child-rearing tasks: lower parenting competence, forced family adaptability, and significant levels of never-ending stress and

fatigue. In addition, family conflict, disruption in the quality of family life, family disruption, and parental psychopathology are also difficulties parents may face (Dumas, Wolf, Fisman, & Culligan, 1991). For example, many mothers of children with chronic conditions may fear future pregnancies because they are well aware of the genetic implications regarding the condition (Hodgkinson & Lester, 2002). Furthermore, Hutton & Caron (2005) stated that having little or no time for fun and family vacations, having little free time for self, the necessity to plan ahead, the negative impact on the mother's career, and additional concerns for their child also impact the families. These negative impacts are not only related to the extra supports the children need, but also related to the children's atypical, problematic, or disruptive behaviors. There is a positive correlation between the parental stress and their children's symptom severity related to ASD, and a negative correlation between the stress and adaptive behaviors of their children with ASD (Hall, Neely-Barnes, Graff, Krcek, & Roberts, 2012). The negative impacts are also related to the society. Even in a study that looked for positive impacts of children with special needs on their family, the interview with the parents showed how society sees families and children with chronic conditions (Stainton & Besser, 1998). In the study, a parent stated, "a lot of the families are victimized, and they're not only victimized by their own fears, they're victimized by what society tells them." It is stated that all the families mentioned experiencing negative interactions with professionals who have negative perceptions about disabilities (Stainton & Besser, 1998).

Even though the positive impacts of having children with disabilities or chronic illnesses are often dismissed, and the tendency is to focus only on the negative impacts in the professional articles, there are also positive effects on the families (Behr, 1990;

Stainton & Besser, 1998). First of all, having a child with special needs can help the family members to become more mature and stronger by experiencing all that goes on in a family crisis – the children’s extraordinary demands and atypical behaviors (Scorgie & Sobsey, 2000; Stainton & Besser, 1998). Second, the special needs child can become the source of joy and happiness in the family, thus enriching their lives. For most families, it might be common to be pleased with the achievements of a child without ASD, but the fact that a child with ASD overcame their disadvantages enhances the pleasures of other family members (Grant, Ramcharan, McGrath, Nolan, & Keady, 1998; Mullins, 1987; Stainton & Besser, 1998). Third, it increases the parents’ sense of purpose and priorities in their lives (Abbott & Meredith, 1986; Grant et al., 1998; Mullins, 1987; Stainton & Besser, 1998); it is one of the positive effects that psychosocial stress can have (Trute, Hiebert-Murphy, & Levine, 2007). Fourth, it expands the family’s personal and social networks and community involvement (Scorgie & Sobsey, 2000; Stainton & Besser, 1998); (Trute et al., 2007). These families are usually connected to other families of children with special needs, workers from agencies that serve people with chronic conditions, and health professionals of their children. The families value these relationships, and they think it would have been impossible to have these in-depth relationships had they not had a child with special needs (Scorgie & Sobsey, 2000; Stainton & Besser, 1998; Trute et al., 2007). Fifth, some families report that their spirituality increased due to having children with special needs (Abbott & Meredith, 1986; Scorgie & Sobsey, 2000; Stainton & Besser, 1998). Their strengthened religious faith is often interpreted as the way they cope with or reduce stress, and seems to be more related to an individual’s predisposition than a general impact of having children with chronic

conditions (Stainton & Besser, 1998). Sixth, it helps the families to have stronger family unity and closeness because they share many experiences as a result of dealing with problems they face due to having children with chronic conditions (Abbott & Meredith, 1986; Stainton & Besser, 1998). Seventh, not only do families develop increased tolerance and understanding toward disabilities but also toward general human differences: it is a spread effect that goes beyond disabilities (Stainton & Besser, 1998). The families learn how to be tolerant in the difficult process of accepting the children with special needs (Stainton & Besser, 1998). Lastly, having children with chronic conditions can have a positive impact on others and the community (Stainton & Besser, 1998). The families and children with disabilities can influence people around them with their understanding of general human differences and by revealing the hidden potential that people with disabilities have. They can effect change among classmates and neighborhoods, and thus these people may be able to incrementally accept children with disabilities. (Stainton & Besser, 1998).

Effects on Siblings

While much research has been accomplished on the etiology of autism and the effects on the families of children with chronic conditions, only limited research has been accomplished regarding the effects on the siblings. Interestingly, “family” usually only referred to parents, and siblings are often ignored in studies related to families of children with special needs. Even though there are only limited studies that examine the impact of ASD on non-disabled siblings, it is predictable that caring for children with ASD also has implications on the siblings. Unfortunately, these understudied and underserved siblings have only traditionally been examined with a focus on the negative side effects,

particularly the internalized or externalized behavior problems. Guttmanova, Szanyi, and Cali (2008) defined externalizing behavior problems as “behaviors characterized by an under control of emotions,” which include challenges with interpersonal relationships and compliance, aggression, and violent behaviors. On the contrary, internalizing behavior problems means “an over control of emotions (Guttmanova et al., 2008);” it includes social isolation, depression, anxiety, low self-esteem, and dependency (Guttmanova et al., 2008).

Williams et al. (2010) stated that of the 40 studies done between 1970 and 1995, 60% of parents of children with developmental disabilities considered that the non-ASD siblings are influenced negatively by the presence of disabled children. Breslau and Prabucki (1987) also reported that siblings of children with disabilities might have emotional and behavioral problems because of ongoing stress due to having sisters and brothers with disabilities. In addition, Hodgkinson & Lester (2002) showed the parents’ negative perspective on the impact on the siblings; they were concerned with the influence on the behavior and socialization of children without disabilities. Some problems were described as depressive disorders, which are considered a genetic predisposition (Ross & Cuskelly, 2006). Unfortunately, since all the studies did not have a comparison group of children without chronic conditions, it is unclear whether those problematic behaviors of the siblings are truly created by the influences of the children with special needs or not. Those behaviors may be typical outcomes in any family with more than two children.

Ross and Cuskelly (2006) indicated that siblings of children with ASD are more likely to have internalized behavior problems; however, it is unknown what risk factors

contribute to the internalized behavior problems (Ross & Cuskelly, 2006). In the study, the authors organized the problems that the siblings deal with into five categories: aggressive behaviors of the children with ASD (physical aggression, verbal aggression, destruction of property, disruption), social difficulties of the children with ASD (invasion of privacy, lack of social reciprocity, lack of sharing), syndrome-specific behaviors of the children with ASD (communication impairments, unusual behaviors, inability to cope with change, lack of understanding of agency), concerns for siblings with ASD (e.g., that other children may bully their siblings with ASD, etc.), and others (Ross & Cuskelly, 2006). Most of them are related to the characteristics of ASD or unique family dynamics regarding the children with ASD – especially, the dynamics between the siblings without ASD and the children with ASD. It was clear that the internalized problematic behaviors of the sibling in this article were the result of impacts they received from the children with ASD, and not the result of typical sibling conflicts. It is worthwhile to point out that all of those problems were out of the siblings' control and there was nothing the siblings could change or help about their brother's or sister's problems; since they have to face the problems every day, they may create their own coping strategies. Ross and Cuskelly (2006) detailed with specificity the problems that the siblings deal with in the family environment; however, they did not show how the siblings were influenced by the community they live in. The article only slightly mentioned how the siblings worried for their brother and sister because they may be teased by other children (Ross & Cuskelly, 2006), but it did not mention how other children influenced the siblings in regards to having a brother and sister with ASD.

Williams et al. (2010) categorized both negative manifestations and positive effects in siblings through qualitative research with parents of children with developmental disabilities; those categories emerged from narrative, qualitative information. In the study, the negative manifestations included: upset/anger/resentment, negative behaviors, lonely/sad/depressed, jealous/envious, embarrassment, worry/fear/anxiety, school problems (academic and social), low self-esteem, guilt, overprotection of the ill child, sibling competition, and indifference. In this study, the reasons for the negative manifestations were categorized into three sections: (1) disability-related; (2) siblings' physical or emotional isolation from parents because of less attention on the siblings; and (3) other issues not specifically included in the previous two categories (Williams et al., 2010). Reason (1) includes a lack of understanding about the condition, inevitable role as a caretaker at school, not enough interaction and communication with the child with the disability, and a lack of understanding about the symptoms of the condition. Reason (2) includes lack of one-on-one time with parents and the feeling of getting less attention. Reason (3) includes a forced, huge responsibility as a caregiver, role reversal when the healthy sibling is younger than the child with special needs, and forced sacrifice for the child with special needs (Williams et al., 2010). Bagenholm & Gillberg (1991), Tsao, Davenport & Schmiede (2012), and Van Rensselaer (2010) also showed adjustment problems of children without disabilities are linked to differential parental treatment that generally favors the child with disabilities; the reasons for the negative manifestations in the siblings are not only related to the children with disabilities, but also to their parents. Other studies found siblings experience less social competence (Dyson, 1999), role strain as a caretaker (Dyson, 1999; Rodrigue, Geffken,

& Morgan, 1993), high parental expectations (Dyson, 1999; Gupta & Singhal, 2005), greater social withdrawal (Benderix & Sivberg, 2007; Dyson, 1999), decreased parental attention (Bagenholm & Gillberg, 1991; Dyson, 1999; Gupta & Singhal, 2005; Rodrigue et al., 1993), feeling unsafe and anxious at home (Benderix & Sivberg, 2007), lower self-concept (Dyson, 1999), and guilty feelings for being healthy (Van Rensselaer, 2010) as negative effects. These internalized and externalized behavior problems are relatively well-known because professional articles usually dismissed the positive effects on the siblings and tended to focus on the negative effects with biased expectation— similar to the effects on families (Stainton & Besser, 1998).

However, the children with chronic conditions can also influence the siblings positively. The positive effects included: family closeness, greater sensitivity to children with special needs/caregiving, and personal growth/maturation (Williams et al., 2010). The reasons for these positive effects are usually related to the siblings' personal, social, and cognitive characteristics (Williams et al., 2010). Abbott & Meredith (1986) concluded that having brothers or sisters with disabilities can be beneficial for the siblings because they can have more opportunities to teach, help, and provide care due to their roles as caregivers. However, it is only possible when the parents are competent and supportive. Also, healthy academic and behavioral adjustment (Kaminsky & Dewey, 2002), interpersonal and caretaking skills (Mates, 1990), higher level of empathy and altruism (Bagenholm & Gillberg, 1991; Benderix & Sivberg, 2007), increased tolerance for differences (Bagenholm & Gillberg, 1991; Stainton & Besser, 1998; Stalker & Connors, 2004; Van Rensselaer, 2010), appreciation for life (Van Rensselaer, 2010) and a positive self-concept (Kaminsky & Dewey, 2002; Mates, 1990; Rodrigue et al. 1993)

were stated as positive effects on the sibling. Given these findings, further study is needed to explore the influence of living with a sibling with ASD.

Macks and Reeve (2007) indicated that demographic factors – gender, birth order, socioeconomic status (SES), and number of siblings – influenced the effect of having children with ASD. In their research, the presence of a child with ASD showed positive effects when risk factors were limited, but when risk factors were increased, the effects were negative. The research found that the sibling tended to be influenced more negatively when the siblings are male, older than the child/children with ASD, members of a family with low SES, and/or the only child without ASD (Macks & Reeves, 2007).

Interventions

Since relatively few studies have been conducted on families of children with disabilities/chronic illness, there is only limited information about intervention programs for them. More specifically, there is not enough information about the siblings of children with ASD, and the social resources available for the siblings. Most of the social services related to children who need extra care target the special-needs child or his/her parents. Rizzolo, Hemp, Braddock, and Schindler (2009) found 12 types of services that families of people with intellectual and developmental disabilities may be offered. Nine of them were only for people with disabilities, and only three of them were related to other family members – family usually only referred to parents, and not siblings. The three family support services available are family counseling, family training, and parent support groups (Rizzolo et al., 2009). The family support group is usually a combination of training and parent support group. Thus, the family support group program is the main intervention for the family of children with special needs; however, the parents of

children with ASD worry about the lack of parent support group and parent training (Mancil & Boyd, 2009).

There are three different types of interventions for family members of individuals with disabilities: interventions only for parents, only for the siblings, and for both the parents and the siblings. The main interventions that targeted the parents in the research are usually training programs to help them to be able to support their children with special needs. While parental training is a professional-led educational program, parent support groups are usually self-help programs in which the members motivate and help each other's well-being. In the same manner, the sibling support group is also focused on the sibling's well-being (D'Arcy, Flynn, McCarthy, O'Connor, & Tierney, 2005; Evansm, Jones, & Mansell, 2001; Scelles, Bouteyre, Dayan, & Picon, 2012); the sibling support group is the main intervention that targeted the siblings. The siblings can speak to each other about their experiences and concerns in these support groups, but they are also partially educational to help the siblings to better understand their brother or sister. The sibling support groups also function like self-help programs, but they have adult facilitators who encourage the siblings to express themselves. Often, the siblings were ignored in family interventions; however, if the family intervention also targeted the siblings, the parent's role in the intervention was more likely to be a supporter for the sibling than participant of the intervention. In family-focused interventions, both parents and the siblings take educational sessions, but only the siblings have another session for their well-being (Labato & Kao, 2002; Williams et al., 2003).

All the interventions for the siblings are mainly focused on family, communication, education, and support. For example, Williams, et al. (2003) found that

the full intervention – teaching about the brother or sister’s condition, psychosocial sessions, a 5-day residential summer camp, and two booster sibling/parent sessions – was effective to improve the sibling’s knowledge about the illness, social support, self-esteem, mood, behavioral problems, and negative attitude toward the illness. Other studies about support groups also reported similar results: increased sibling knowledge of chronic illness/developmental disabilities, sibling connectedness, self-esteem, knowledge of their siblings’ needs, involvement with their siblings, and decreased internalizing/externalizing global behavioral problems (D’Arcy et al., 2005; Evansm et al., 2001; Labato & Kao, 2002). A recent study about sibling support suggested some interventional ideas for the future: impartial parenting, communication with parents, support groups, parent training and support, sibling play intervention, and sibling support groups (Tsao, Davenport & Schmiede, 2012).

Chapter 3

THEORETICAL FRAMEWORK

The Resiliency Model of Family Stress, Adjustment, and Adaptation will guide this study. Resiliency is the ability to cope, despite experiencing stress and adversity (Ward, 2003). Resilient people can deal with stressful situations easily, and function well even when they are under difficult situations; therefore, resilience is an important factor to live a happy and healthy life (Ahangar, 2010). Resiliency is not a personal trait as people believe, but it can be developed with proper training (Ahangar, 2010).

The Resiliency Model of Family Stress, Adjustment, and Adaptation was developed to explain the reason behind the differences in adjustment and adaptation to stress, distress, and crises that families showed by examining the family system as a unit (Tak & McCubbin, 2002). According to this model (McCubbin & McCubbin, 1993), families adapt to a life stressor by making changes in family functioning. In this model, it is considered that family adaptation to a stressful event has two phases: adjustment and adaptation (Svavarsdottir, McCubbin, & Kane, 2000). The family needs to make minimal changes in their functioning in the adjustment phase, and the pileup of stressors are managed by resiliency factors in the adaptation phase. There are two levels of functioning in adaptation: individual to family and family to community (Svavarsdottir, McCubbin, & Kane, 2000).

The Resiliency Model of Family Stress, Adjustment, and Adaptation is especially useful for examining familial adaptation in the face of a chronic illness and the resources and coping pattern of the family (Tak & McCubbin, 2002). Therefore, this Resiliency Model has been used in studies that related to families of children with chronic conditions

(Cox, Marshall, Mandleco, & Olsen, 2003; Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004; King et al., 2006; Snethen, Broome, Kelber, & Warady, 2004; Tak & McCubbin, 2002). The main importance of this model is resiliency of families, at both the individual and family level and their ability to recover from stressful events.

The Resiliency Model of Family Stress, Adjustment, and Adaptation would be appropriate for this study because the research focuses on the impacts of having children with ASD in their family. This model provides adequate methods to assess factors that affect family functioning and the coping strategies that are used to help adjustment and adaptation, as well as stressors, family coping, and how the crisis has disrupted the family functioning. Therefore, it would be helpful to see the family dynamics that the siblings are exposed to due to the presence of the children with ASD.

Narrative theory will also be used to guide this research. This theory focuses on an individual's story that reflects his/her experiences in their own perspectives (Marsiglia & Kulis, 2008). According to the narrative theory, the individual's own narrative structures are guideposts for all of their activities and functioning, such as moral choices, thought, and behavior (Marsiglia & Kulis, 2008). This approach would be appropriate for this study because the research focuses on the siblings of children with ASD vicariously through their parents' eyes.

The purpose of the study is to identify possible unmet needs and coping skills of the siblings and potentially beneficial social resources that can help the siblings to cope more positively. Since the researcher will have in-depth interviews with the parents to assess those factors from their perspective, the parents' stories that reflect their experiences would play an important role in this study. Since people are influenced by

their environment, some of the siblings' perspectives – who are living in the same environment as their parent – might be linked to the interviews with the parents. The parents' own stories about the siblings' lives will reflect their unique family dynamics, functioning, and the influence of the children with ASD on the families, which would provide valuable information to figure out what it is like to be a sibling of a child with ASD.

Applying the narrative theory would be the best way to enhance accuracy from the same story because it can lead to reading more information between the lines based on the narrative structure of the interviewees. It can be the best way to glean information from indirect interviews because it can expand the information. However, at the same time, researchers should be careful to avoid too much assumption.

Chapter 4

METHODOLOGY

Overview

This is an exploratory study that uses qualitative methods for data collection and analysis. The purpose of this qualitative study is to explore what it is like to be a sibling of a child with ASD from the parents' perspective. Specifically, it explored possible unmet needs and coping skills of the siblings and analyzed possible beneficial social resources that could help the siblings cope more positively and effectively. Exploratory research is usually used when limited information is known about the research topic; the purpose of exploratory research is to generate an initial understanding of the topic, to identify related variables, and to focus more on findings rather than broad generalizations. (Krysiak & Finn, 2010). Therefore, the present study was conducted as exploratory research due to the limited information about the siblings of children with ASD. For this study, the following research questions were posited: (1) What are parents' perceptions of how are the siblings of children with ASD treated and how do they function in their family setting? (2) What are parents' perceptions of how the siblings have been influenced by the children with ASD? (3) What are the parents' perceptions of how the siblings cope with their situation? (4) What are parents' perceptions of appropriate social supports for the siblings to help them cope more easily and positively?

Participants

The participants in this study included seven parents of children with ASD living in the Phoenix, Arizona metro area. Parents were chosen to be participants rather than the siblings because the researcher considered the parents to be people who make decision

for siblings to participate in social support programs. Because this study aimed at finding possible beneficial social resources for the siblings, it is important to understand parents' recognition of siblings' needs. If the parents are not aware of the siblings' need, then they may not send their children to any future support programs. Five mothers and two fathers, representing six different families, were interviewed; one interview included both parents participating together. The criteria for participation in this study were as follows: (1) must be 18 or older; (2) must be a parent of both children with ASD and without ASD; and (3) must be willing to allow the researcher a face-to-face interview that would take one to two hours. The researcher did not limit the participants based on their family type. Therefore, the study included a variety of types of families: two-parent family, one-parent family, one-parent one-grand parent family, and modified extended family – two-parent family who lives near to their grandparents and relatives for purposes of supporting each other.

Table 1

Information of the Participants' Children

The siblings	The children with ASD
18 (male), 15 (female)	14 (male), mild-moderate
7 (female)	10 (male), moderate
12 (male)	13 (male), Asperger's
10 (female), 1 (female)	10 (male), moderate
10 (female)	15 (male), moderate
14 (female)	6 (male), high-functioning

The majority of the participants were Caucasian/White: six parents were Caucasian/White and one parent was Asian. The age range for the siblings was 7 to 18 years-old and consisted of two males and five females. The age range of the children with

ASD was 8 to 15 years-old and all of them were males. Table 1 provide more information about the children, both the siblings and the children with ASD, in this study.

Interview Guide

An interview guide that consisted of 5 close-ended questions and 10 open-ended questions was developed by the researcher and was utilized for this study (see Appendix A). The interview guide was made up of three parts: (1) family dynamics; (2) information about the siblings; and (3) family functioning. Parents were asked to discuss the ages of each child in the family, the severity of ASD, the parent's discipline style, sibling relationship, sacrifice of the families, and impact of the diagnosis. There were also seven open-ended questions exclusively about the siblings in order to examine how the siblings function in the special environment with respects to coping skills, impacts, stress, sacrifice, labeling, role as a caregiver, and potential social support. Questions were created using discussions with professionals who work with families that have members with ASD.

Procedure

Participants were recruited through the Autism Society of Greater Phoenix via e-mail. The Autism Society of Greater Phoenix contacted potential participants who participated in or applied to participate in other ASD related studies before. Potential participants were directed to the researcher via e-mail and phone if they were interested in participating. Participants were screened by e-mail or through a phone conversation to confirm that they met the requirements of the study. The research protocol was initially submitted to and approved by the Arizona State University's Institutional Review Board (IRB) to make sure participants and their rights were protected. The time and place for

the interviews were chosen by the participants; the placement had to be a public place for maintaining confidentiality. Prior to being interviewed, participants were given an information letter (see Appendix B), which stated the nature of the study, potential risk, benefits, confidentiality, and the right to discontinue their participation at any time. There was no incentive for the participants.

Individual, semi-structured face-to-face interviews were conducted with the seven participants. With the consent of participants, the interviews were audio-recorded. The interview consisted of 5 closed-ended questions and 10 open-ended questions designed to gain insight into what the siblings of children with ASD experienced from their parents' perspective and to explore the impacts of having siblings with ASD, as perceived by the parents. However, when the participants could share their experiences without those questions, the interviewer did not ask all of the questions on the list to the participants during the interview. Each interview took 1-2 hours. The audio-recorded interviews were transcribed and analyzed.

Data Analysis

The current study followed a qualitative design to interview parents of ASD and non-ASD children in the same family. An interview protocol was used using audio-recording that focused on learning about the participants' personal experiences and perception of their children as well as their challenges and needs for social support services for the sibling population (children who have siblings with ASD). Since the information was shared in words, not in numbers, the findings were processed—via transcription, typing up, and editing—to be ready for analysis (Miles & Huberman, 1984).

The analysis was conducted through three simultaneous activities: data reduction, data display, and conclusion drawing and verification (Miles & Huberman, 1984).

Through data reduction, the collected raw data was transformed to final processed data via coding, making clusters, teasing out themes, doing summaries, making partitions, and/or writing memos. Through data display information was organized in different easily accessible and solid formats such as graphs, charts, matrices, and networks. Finally, through conclusion drawing and verification, topics, themes, or categories were identified which in turn lead to the final conclusions. All the processes were not discreet but each of them was a part of the analysis (Miles & Huberman, 1984).

For this study, the data analysis was done manually. The raw data was transcribed, and the researcher added field notes (data log about what researcher observed in the field, such as the participants' gesture, facial expression, and body movement) and descriptions of interviews in addition to the transcript. Data analysis began after the final data (the combination of transcript, field note, and description of interviews) were ready.

The researcher listened to all the recorded audio files two times again before beginning analysis of the data. This process led the researcher to consider the narratives of each participant individually and as a whole. The researcher also checked the parents' comments about what their children like (to do) for both the sibling and the child with ASD to figure out the family dynamics and to explore how both sets of children function within a single family setting. In addition, the researcher counted positive and negative impacts on the siblings of having a brother/sister with ASD that the parents mentioned. This allows for an exploration of the parents' perception of the siblings' lives in their family settings. This information was organized into two tables (Table 3 & 4), and the

process helped prevent the researcher from arriving at biased, hurried, limited, or unproven conclusions, which easily happens with qualitative data due to the data's bulkiness, dispersion, and poor structure (Miles & Huberman, 1984).

The analysis involved the process of coding to bring out outlines in the data based on grounded theory. Grounded theory is an inductive research method that allows researchers to discover theory through the analysis of the data (Martin & Turner, 1986). Unlike the traditional model of research that starts with a hypothesis, grounded theory starts research with data collection. From the collected data that examine the realities, theory is generated while simultaneously grounding the narrative in empirical data (Glaser & Strauss, 1967). Since it did not set any hypothesis, there was no specific topic that the researcher looked for before the final data was coded. After the key points of the data were checked as codes, they were grouped into similar concepts, and then they are classified into categories. The categories are the foundation of a theory (Connelly, 2013). The chronological coding process used in this study is described below through the following stages:

1. The final data were printed out separately for each participant.
2. When reading the hard copies, all relevant statements to the participants' experiences were highlighted manually, and notes were made regarding the topics of the highlighted statements.
3. Highlighted parts were numbered based on the code, and a separate list of the numbers and the related codes were made.
4. General concepts were figured out from the codes if some concepts involved more than three participants (50% of all participants). Numbers that referred to certain codes were

found and colored; concepts are color coded. For example, any statements related to challenge, stress, and complaints [codes] were grouped together as impacts of having a brother/sister with ASD [concept], and all the statements related to this concept are colored with green.

5. A new list of the concepts and referred color were made.
6. The concepts were clustered into categories, such as life in the family setting. The whole process of coding is exemplified in Table 2.
7. The hardcopies were reread to make sure the categories cover all parts of the interview.
8. Each coded section of the final data was collected together and reorganized by concept for use as quotations throughout the paper.
9. The different sections were given appropriate headings.
10. The findings were written down.

Table 2

The Process of Coding

Extract Quote from Interview	Code	Concept	Category
<p>“There’s still stress between two of them. I think <i>S</i> hasn’t quite learned how to communicate with <i>A</i>, see <i>A</i>, knows what <i>A</i> is asking <i>S</i>.”</p>	Stress	Impacts of having a brother/sister with ASD	Life in the family setting

* *S* stands for the sibling, and *A* stands for the child with ASD

Credibility

The study needed credibility – the reliability and validity – that depends on the effort and ability of the researcher in qualitative studies (Bashir, Afzal, & Azeem, 2008).

According to Beck (1993), credibility in a qualitative study depends on the vividness and faithfulness of the description that represent the reality. In the study, the researcher used empirical data in the form of interviews and field notes, and the interview protocol was developed to bring out descriptions of the real world experiences. The participants' experiences on a daily basis are represented through the interview because "all cases bear traces of the universal (Denzin & Lincoln, 1994)."

Triangulation is a general strategy to enhance credibility of the data that is suggested by Webb, Campbell, Schwartz, and Sechrest (1966) and explicated by Denzin (1978). It is defined as "a validity procedure where researchers search for convergence among multiple and different sources of information to form themes or categories in a study" (Creswell & Miller, 2000, p. 126). Triangulation is an important technique to ensure the data's reliability and validity by cross-checking (Delamont, 1992). Two types of triangulation were employed in this study: (1) between method and (2) within method. Between method triangulation required more than one method to gather data. For the study, interviews and participant observation were used. Within method triangulation entailed structured approaches to obtain several types of data within one method. For the study, this was done while analyzing the data; to examine and combine the data, the researcher kept checking the coding and the final data of each participant.

Validity

Validations as action, as communication, and as exploration are three approaches to validity in qualitative research (Kvale, 1989). In such an approach, validity refers to the "credibility" of the evidence and the conclusions drawn in the study (Ryan, Scapens, & Theobald, 2002). It also refers to the fit between the narrative of the experiences and

the interpretation or description drawn by the researcher. The primary focus of a qualitative study is to capture lived experiences of the participants “authentically” and to represent them in “convincing” words (Lukka and Modell, 2010; Ryan et al., 2002).

The concept of internal validity refers to accuracy of the data, which means that extraneous factors are eliminated from the interpretation (Cook & Rumrill, 2005). It reflects the extent to which the researcher can conclude that the independent variable and the dependent variable are in a cause-effect relationship (Reis, & Judd, 2000). There are many sources of threat to internal validity including: selection of participants, history of participants, causal ambiguity, interactions with selection, maturation, testing, instrumentation, regression to the mean, and mortality (Wiersma, 2000). Only the first four factors influence the study because this is a qualitative research that consisted of one time interviews.

Beck (1993) suggested five questions that can be a starting point to assess the validity of a qualitative research: “(1) Did the researcher establish the typicality of the participants and their responses? (2) Did the researcher check for the representativeness of the data as a whole? (3) Did the theoretical sampling result in a range of participants experiencing the phenomenon under study? (4) Was the data made to appear more similar or congruent than they really were? (5) Did the study results fit the data from which they were generated?” (p.265) These questions can mainly be covered by triangulation.

There are some more precautions taken in this study to allow for validity. First, only the overlapped information, shared by more than half of the participants, was classified into codes, themes, and categories by using triangulation. Second, because the actual interviewer analyzed the data, the researcher was able to observe all the

participants' behavior, body language and facial expressions. Last, the study was not supported by any kinds of funds that could lead the researcher or the participants to reach particular conclusions. Instead, all the people who participated in the study volunteered with the pure motive of helping their children.

Reliability

In qualitative studies, reliability means “generating understanding” while it means “purpose of explaining” in quantitative studies (Stenbacka, 2001). Howard (1991) stated that qualitative findings can have reliability – internal consistency or stability – when there is no contradiction in the interpretation. According to Golafshani (2003), analyzing trustworthiness is important to guarantee reliability in qualitative study. Seale (1999) stated “trustworthiness of a research report lies at the heart of issues conventionally discussed as validity and reliability.” (p. 266)

The researcher took several precautions to enhance reliability. First, the participants were not influenced by the perceptions of other people because the interviews were separate, one time interactions in a one-on-one setting. Second, participants had ample opportunity to express their ideas repetitively because the interviews lasted from one to two hours. Third, the consistency of the ideas was checked during coding while the data was coded, and controversial ideas were analyzed only if they were repeated. Finally, the analysis categorized the ideas that emerged more than one time in more than half of the participants, serving as data triangulation.

Chapter 5

FINDINGS

The analysis of the findings produced a set of themes organized under two main categories that provide an insider's view into the siblings' lives in their family settings based on the parents' report. The analysis provided the researcher with a better understanding of the siblings' experiences, currently available support for the siblings, and need for extra support for the siblings that could potentially help design future support services for them. Since all the questions in the interview protocol (see Appendix A) were intended to reflect the different aspects of the siblings' experiences, the themes tend to be interconnected.

Due to the influence of the purpose of this study, which was to gain a better understanding of the sibling's experiences whose brother/sister has ASD and to identify appropriate support programs for the siblings to help them cope better, the findings naturally emerged into two categories: life in the family setting and supports. Life in the family setting includes five themes: (1) family dynamics, (2) parents' perception of the siblings' experiences, (3) parents' concern for the siblings, (4) parents' expectation of the siblings for the future, and (5) impacts of having children with ASD in the family. This category is about the siblings' experiences in their respective family settings, so it represents how they are treated, what the parents' expectations and worries are about them, and how parents perceive the impact of having a sister/brother with ASD. Supports include four themes: (1) siblings' involvement in services, (2) personal support system for the siblings, (3) the parents' perception of needs for sibling support, and (4) the restrictions of sibling support service. This category is about how the siblings are

involved in the services for the children with ASD, how the siblings get extra support from others, and how the parents perceive the needs for sibling support. See Figure 1.

Although the study is about the siblings, interviews for the study were conducted with the parents. Therefore, some of the parents' answers may not actually represent the sibling population. However, parents perform crucial roles in the siblings' lives, and the parents are experiencing the same family dynamics, thus these findings represent some aspects of the siblings' reality that they are facing either directly or indirectly.

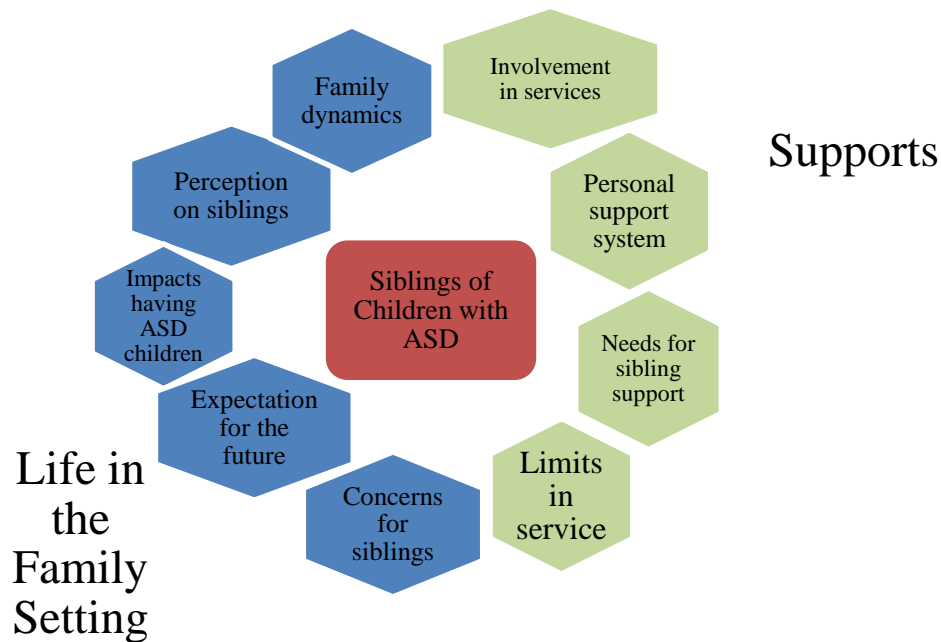


Figure 1. Emerging Categories and Themes

Category One: Life in the Family Setting

This category represents how the siblings are treated and how they function in their family settings. As stated above, the interwoven five themes represent different aspects of the siblings' lives. Since the themes are related to each other, there can be partial overlapping among the contents in some areas. The goal of knowing their lives is

to figure out their unmet needs in their family setting on a daily basis. In the quotations that are found throughout the paper, *S* stands for the siblings, and *A* stands for the children with ASD.

Theme One: Family Dynamics

Despite the focused population of the study being the siblings, the interview protocol included some questions regarding both the siblings and the children with ASD to better understand the family dynamics. The parents stated the kinds of activities their family engaged in on weekends, and it naturally represented how the family functions. The parents stated that they either spent time evenly with both children, or tried to balance the time. To be fair to both children, the parents tended to spend time with both children together, but it became apparent that the children with ASD tended to be the child who would be able to dictate the family situations. Parents were likely to focus on what the children with ASD can do or like to do. Parent #3 represented the phenomenon that focuses on what the child with ASD can or likes to do:

S hasn't complained about time, but that we always have to do what *A* wants. It's little things like that *S* will complain about that. Less now because *A* now eats cheeseburgers. (...) It was more like why do we have to do *A*'s way? (...) *S* would say things like, "I would like to eat this." *S* is a food person. And *S* would ask why we eat pizza all the time. Because *A* likes pizza. I was basically taking *S* and putting *S* in the "A Box". (...) Food is a challenge because they (*A*) know what they want to eat so clearly. It's hard for them (*A*) to branch out.

As the parent mentioned, accepting a limited number of foods is one of the manifestations that give evidence of ASD. It is a typical problem that children with ASD

have, which also influences their families (Cermak, Curtin, & Bandini, 2010; Epstein, et al., 2008; Ernsperger, & Stegen-Hanson, 2004; Fazlioglu & Baran, 2008; Groden, et al., 2001; Kern et al., 2007; Legge, 2002). In this case, even though the parent knew that the sibling is “a food person,” the parent was focused on what the child with ASD wants or likes to eat. Parent #1 expanded the phenomenon to the family level:

We always have pizza Friday night. (...) A was having a very hard time with texture in food issues. (...) Just texture and sensitivity issues that come along with the autism. And umm... A just did not want to eat very much, but one food we can always get A to eat was pizza. And we can try and introduce at times new things on the pizza. (...) It is an easy way to give A something A wouldn't normally eat on the pizza. (...) And I think it worked out so far for S. S has tried some different food. (...) S loves pizza. (...) We were raised that you had to clean your plate, and A had gotten to the point. A was only eating one food, period. Nothing else. And we were forcing A to eat, and it was causing our whole entire dinner time... becoming a nightmare. Nobody wanted to eat. It was stress.

This feeding issue creates stress that affects family meal times. According to Fiese and Schwartz (2008), meal time is very important for families because it is the main activity that families share daily as a group. Therefore, behavior problem of children with ASD during meal times is related to a family's quality of life because it disrupts the daily family climate.

The parents associated the stressful event of eating with siblings' externalized behavior problems during meal times. The parents expressed concern for the siblings'

externalized issues on food when the parents forced the child with ASD to have what he cannot/does not like to eat:

I could tell it affected *S* (female). (...) when *S* (female) was a freshman, *S* (female) stopped eating and I think that has to do with that time because *S* (female) sees food as a thing that, “Oh, it makes me fat.” Part of it has to do with that because we made food an issue when it really wasn’t. (...) It [food] had become an issue, the issue what all the tension would go to. And it caused issues for both my older children (*S*). *S* (male), right now, is trying to build himself up with weight training. (...) “Oh, I am on 4000 calorie diet.” (...) *S* (male) didn’t stop eating.

Although the pizza night was set for the child with ASD at the beginning and it represented that the child with ASD has more input on the family’s activities, it was an inevitable choice that the parents made in order to protect the whole family including the siblings. Therefore, the activity that focused on the capability of the child with ASD actually benefited the siblings too in this case; they could have relaxed mealtimes.

Since the odd behavior around food is a manifestation related to ASD that children with ASD cannot control, limitations related to food can be an inevitable issue that the whole family should deal with together. Like this, family function is affected by rearing children with special needs because the families need to adapt to new life styles constantly for the children (Hodgkinson & Lester, 2002). However, the limitation was not only pertained to food, but also extended to other activities.

Because it [food] is something that they (*S*) can control, and there are so many things that they (*S*) can’t control. (...) Because they (*S*) feel out of control in

other areas, they (*S*) sort of have a tendency on the thing they (*S*) can control, they (*S*) really launch on the things that they (*S*) can control, and control it.

As the parent mentioned, there are many things that the siblings cannot control in their unique environment. Due to the siblings' experiences with their brother with ASD that they do not have many things they can control, it appeared that the siblings can have a tendency to focus on what they can control, and overly control it.

The parents tended to talk about what the children with ASD like to do, but not about what the siblings like to do when discussing activities. Parent #2 presented the activities that the children with ASD like to do:

We try doing things together. I never keep them separate, and that's why *A* does great. *A* goes out. *A* likes to watch a movie. (...) We (parent & *S*) don't take *A* to a café because *A* would be too over stimulated. (...) *A* does like going out to eat things like that.

And parent #4 also stated, "A loves to go to mall. (...) *A* likes Wii, the video game, so *S* plays with *A*."

These quotations are from the answer to the question that asked how they spend time together on the weekend; what the child with ASD likes to do indicates that the family does those activities together on the weekend. The parents mentioned that the siblings participated in activities that the children with ASD like to do. However, they did not mention whether the siblings like to do the same activities or not. Because the parents tended to spend time with both children together, siblings spend more time doing activities that the children with ASD like to do. However, it was not just the siblings who do the activities

together, but the parents, too. As Hutton & Caron (2005) stated, the family members of children with special needs are dealing with having little or no time for fun and having little free time for self in the reality; it has been shown as a typical family dynamic within families that have a member who needs extra support (Hoogsteen & Woodgate, 2013). It was not clear how the siblings perceive the time they spend together with children with ASD because the parents did not talk about this. If the siblings perceived it as a forced sacrifice for the children with ASD, it could cause negative manifestations, such as emotional/behavioral problem, low self-esteem, school problems (academic and social), overprotection of the children with ASD, and sibling competition. The siblings might need help in this area to cope better with their situation.

Even though there was no direct question about what the children liked, the parents naturally talked about it while answering questions pertaining to their weekend activities. To compare both children (the siblings and the children with ASD) in their family setting, the researcher arranged anything or any activities that the children like/enjoy/interested in/love that the parents stated during the interviews, and summarized it on Table 3.

Table 3

What Your Children Like (to Do)?

Sibling (S)	Child with ASD (A)
2 siblings - loves pizza. - likes to cook.	- loves to bake.

<ul style="list-style-type: none"> - really enjoys sports. - likes to listen to music. - likes to watch football. 	
<ul style="list-style-type: none"> - likes the [A's] therapist to come over and interact with S. - likes to go and help in A's therapy when they ask for. - does not like to miss school. likes to learn. 	<ul style="list-style-type: none"> - likes to watch movies. - does like going out to eat things. - likes to draw.
<ul style="list-style-type: none"> - is a food person. 	<ul style="list-style-type: none"> - liked pizza. - likes video games. - likes holding things.
<ul style="list-style-type: none"> - loves it (communicate with A's therapists). - Once S gets attention (of A's therapists), S loves it. - is in love with the baby (other S), enjoying playing with her. loves sports. 	<ul style="list-style-type: none"> - loves to go to the mall. - likes Wii, the video game.
<ul style="list-style-type: none"> - enjoys school. - is really interested in the rules that she didn't care about before. 	<ul style="list-style-type: none"> - enjoys playing on the trampoline. - loves to go to PE (Physical Education).
<ul style="list-style-type: none"> - loves that she has a brother (A). - doesn't like Barbie [but S would play with it when younger children need S's help]. 	<ul style="list-style-type: none"> - likes closed spaces.

Interestingly, the chart shows that the parents tended to state that the siblings liked something related to the children with ASD or that the sibling liked school while the

children with ASD liked simple activities related to their hobbies or daily activities. It represents the parents' perception of both children's roles in the family setting. The parents tended to perceive the siblings as a caregiver or role model for the children with ASD, while the parents were satisfied with the children with ASD when they just enjoyed their hobbies and daily activities without any problems. The parents' answers show that they may have a double standard when it comes to their children and they focus on the limited capability of the children with ASD. According to Williams et al. (2010), one of the reasons for the negative manifestations of having a brother/sister with developmental disabilities is a forced, huge responsibility as a caregiver. The siblings may need help discussing this issue with their parents in order to cope better. Although the families tended to show an unbalanced family dynamic, the parents in the study still tried to be fair to both children. It is parallel to the findings of Hoogsteen & Woodgate (2013) that the parents strive for balance within the family. It is not clear whether the parents and the siblings in the study recognize that their family life revolves around the children with ASD or not, but it is clear that the siblings are living under this kind of family dynamics.

Theme Two: Parents' Perception of the Siblings' Experiences

As compared in Table 3, the parents' perception of the siblings can be considered as different compared to the perception of the children with ASD. The parents tended to perceive/describe the siblings as mature children who understood and accepted their parents and their own situation, and supported the children with ASD. The siblings were also represented as proactive/interactive in communicating with the parents. Most of the parents agreed that the siblings are mature for their ages. Parent #1 stated:

Comparing my two children to others in their own age, Yes, *S* are... in number of ways *S* are more mature than other friends. *S* asked a lot of questions quite often times, “why they do this? Don’t they know such and such and such?” Or, “you know, they’ve been raised a little different than you have. And this hasn’t been a priority of their live, and has been a priority of ours.” We try not to cut, you know, we try not to say because your brother has autism. *S* just have... We [family] have made priorities.

Although the parents tried not to mention that having the children with ASD as a reason for the siblings’ maturity in front of the siblings, the parents recognized the influence of it because the siblings had been raised “a little different” with different priorities for the child with ASD. Parent #4 also recognized the influence of having a child with ASD in the family because the sibling takes on a different role compared to the siblings’ peers:

S is so mature for *S*’s age compare to a lot of peers because *S* is kind of taking motherly roles. *S* knows that. Sometimes, it happens to us, there should be one who takes care of *A* in the future.

However, parents #2 and #6 tended to think that the siblings were naturally mature regardless of having children with ASD or not in their families. Parent #6 stated:

S is very mature. (...) “Hey, you wanna play with Barbie?” *S* doesn’t like Barbie, but when it is with a little girl, *S* got Babies anyway to play with somebody, *S* would play with Barbies. *S* will be a great mom... because you have that and you grew up with.

And parent #2 also stated, “I think *S* is very mature for *S*’s age. That’s why *S* wants to help out. *S* likes to go and help in *A*’s therapy when they ask for.”

According to the data, it seems clear that the siblings were indeed mature, and all the parents accepted it as being helpful. Similarly, maturity has been represented as a positive effect of having children with special needs in much research because the siblings have experienced all that goes on in a family crisis (Scorgie & Sobsey, 2000; Stainton & Besser, 1998; Williams et al., 2010). Maybe because of the maturity, the siblings were described as model children by some parents. Parent #1 stated:

S makes sure that everybody (recognizes *A* as *S*’s brother and takes care of *A*). All of *S*’s friends... it is an example of *S*. Last year, before the end of the year, *S*’s friends found out that *A* was coming to their school. And they all wanted to protect *A* because it’s not fair *A* is autistic and it makes *A* get teased. So, “can you make sure *A* had lunch so we can make sure *A* seat in our table and nobody can’t get mess with *A*?” This is what they asked.

This case represented a positive impact of having children with ASD because the siblings can influence people around them with their understanding of human diversity, including disabilities (Stainton & Besser, 1998). While the sibling of family #1 influenced other people, the other siblings also behaved well in their family and school settings. Parent #3 was satisfied with what the siblings did:

If there’s a rule *A* follows, *S* follows on his own without any complain. Umm... maybe because *A* don’t break the rules. (...) I’ve seen *S* speak that for *A*. Even speak for *A*. (...) *S* is kind of actually doing it [look after *A*]. Not really anything I ever said, “you need to.”

Parent #2 was also satisfied with how the sibling is doing:

S does not like to miss school. (...) *S* likes to learn. *S* is always reading books, looking up stuff, asking questions. (...) We (parent and *S*) are a team to help *A*. (...) I think *S* knows I treat them equally. *S* knows I do stuff that's just for *S*. And then, *A* has stuff that's just for *A*. Because we (parents) educated her early on about it.

The parent considered the sibling as on the same team with the parent to support the child with ASD even though the sibling was 7 years old and younger than the child with ASD. Also, the parent perceived that the sibling could understand the situation and what the parent was trying to do. Likewise, Parent #4 perceived that the sibling (10 years old) knew that the parent was fair to both children. This parent also represented the sibling as a caregiver for the child with ASD at school:

S takes care of *A*. *A* goes to *S*'s class, so *S*'s making sure of *A*'s eating his stuff. *S* is the eyes and ears. (...) *S* doesn't go through many stresses. (...) *S* knows that we spend enough time. *S* understands and realizes that we do love them equally and spend time equally with them.

Interestingly, all the parents' answers represented the siblings' role as caregiver for the children with ASD. Especially, when the parent cannot be around the children with ASD, such as in school, the siblings helped and supported the children with ASD. It is not clear whether the siblings were willing to help, taught to help, or asked to help, but it is clear that they take some responsibilities for the children with ASD. According to what the parents mentioned, the siblings understood and accepted their parents and their situation, and were very supportive of the children with ASD. The parents' positive

perception in this study emphasized a gap between the parents' and the siblings' perceptions. Negative side effects of having a brother/sister with special needs have been explored more than positive impacts in the literature (Breslau & Prabucki, 1987; Hodgkinson & Lester, 2002; Ross & Cuskelly, 2006; Williams et al., 2010). The parents' perceptions in this study seem too ideal compare to the findings of other studies.

The parents also presented ideal images of the siblings with respect to their attitude when it comes to communicating with the parents. The parents describe the siblings as motivated enough to come and talk to them when the siblings need help. Parent #1 stated, "Our two oldest (*S*), [work on homework] sort of on their own. If *S* need help, *S* know they can always come and ask us." Parents #2 and #3 mentioned that the siblings would come and share how they feel/think to them. Parent #2 stated, "*S* never did voice [about stress]. But I think if *S* does have concerns, I think *S* would come and talk with me about it." And parent #3 stated, "If it is now [parents are more focused on *A*], then he would probably now tell me. It was... if he felt that way, he would probably tell me."

Since the siblings were 7, 12, 15, and 18 years-old, most of them were developmentally in the adolescent stage. This stage is well-known for parent-adolescent conflict because the teenagers are developmentally no longer as obedient as they were before (Berger, 2005). According to Steinberg & Morris (2001), there is a natural increase in bickering and squabbling between parents and their teenage children. When the siblings' developmental stage is considered, it shows the parents' tendency to describe the siblings like model children. Yet, if the siblings in the study are proactive/interactive in communicating with the parents as the parents described, it would

be an interesting finding that represents unique family dynamics. If the siblings are not really like model children, but the parents just tend to describe them so, it could reflect the parents' expectations of the siblings to be a good caregiver and role model for the children with ASD.

The parents tended to present different sets of expectations for their children because they clearly knew that the children with ASD have limited capability in some aspects. At the same time, the siblings, who tended to deal with their situation well and were supportive of their families, were considered mature and ideal. Sometimes, the parents were concerned about the siblings' adult-like behavior, but usually considered their maturity to be positive.

Theme Three: Parents' Concern for the Siblings

Maturity of the siblings was considered as positive because it was helpful for the family to function better. However, when the parents feel that the siblings try to act like adults, it became worrisome because that was too much of a load for the siblings. In the study, some parents were concerned about the siblings because they acknowledged that they tended to take too much responsibility for the children with ASD sometimes. Because the parents also hoped the siblings would grow up as children, not adults, they asked the siblings to take a step back from the children with ASD. Parent #4 stated:

S is like... umm... "Is it ok if I sit next to other people?" because I assume *S* sits next to *A* all the time. I say, "Yes, it's fine." *S* kind of feel like, *S* always has to sit next to *A*. "You're a child. We don't want to take away any of your friends or something like that. We don't expect you to be there and watch *A* and protect *A* constantly. (...) Maybe that is what's going on, and the fact that "we know you

love your bro and sister. So you're gonna do that anyway. But A has friends, too."

You know. *S* does feel torn by that, sometimes. *S* does feel torn of that. *S* does get stress probably. You know, we know that *S* does the right thing.

The case shows that the sibling's inner conflict as a child and a caregiver for the children with ASD in a school setting. It was a conflict between what the sibling wanted to do and what the sibling thought she should do. The role of caretaker at school represents an inevitable role of siblings of children with developmental disabilities, and this role can cause negative manifestations in the siblings (Williams et al., 2010). This sibling shows that she could not balance the two roles by herself yet, and looked for the parents' confirmation as if the parents asked the sibling to do so even though the parent mentioned that he never verbally asked the sibling to do so. It is not clear who chose this sibling to be a caretaker for the child with ASD at school. In this case, the sibling acted like a caregiver only for her brother with ASD. On the other hand, Parent #1 shared that the sibling acted like a parent, not just toward the child with ASD, but also toward people in general:

S is also like, *S* says, sort of mother hand-to-hand. *S* noticed something's going on, *S* didn't know how to get out of it. *S* will want to go to Mom. "Mama... this is happening. What do I need to do? I will fix it. Just fix it. I can't do this." "Honey (*S*), you don't have to. Nobody told you to." And that's why I told *S*, "you are not A's parent. It's OK." But here is the concern, *S* wants to be, *S* wants to be a parent for everybody.

In these two cases, the siblings became stressed or overwhelmed because they took too much responsibility for the children with ASD, which they could not handle by

themselves. The parents realized the siblings took too much responsibility when the siblings verbally externalized their stress or anxiety. There are other cases where the parents worried about the siblings' behavior although the siblings did not verbalize their problem. Parent #6 shared his concern for the sibling who chose to overcompensate for the child with ASD:

Well... *A* is not normal. So, *S* feels like *S* has to overcompensate for *A*. Like, *S* has to behave twenty times better than *A* does. "I have to be this pillar child regardless of what's going on in my life and in public." Because *S*'s been acted like an adult for those. So, that's a big load. That really is a big load.

While Parent #6 only focused on the sibling, the sibling's behavior and the impacts on the sibling, there was a parent who worried about both children: the sibling's behavior and the impacts on the child with ASD. This parent realized that the sibling's behavior, which tried to help the child with ASD too much resulted in taking learning opportunities away from the child with ASD. Parent #2 stated:

But sometimes, *S*... it is... actually, now I worry because *S* tries to help *A* too much. (...) If I asked *A* a question, "what did you have at lunch today?" then, *S* is so excited and [tries to answer instead of *A*], "the menu was..." (...) like protective, wants to help *A* out, that kind of stuff. *S* is kind of take on that role. I was talking to *S* about, "I know you're trying to be helpful, but we gotta let *A* learn some of these stuffs."

All the cases indicate that the siblings tried hard to be helpful and supportive of the children with ASD, but the siblings did not recognize or care about their capability. Considering what the study found in the first theme, families' activities tended to rely on

the capability of the children with ASD, it reflects that the parents tended to be less sensitive to the capability of the siblings than the capability of the children with ASD. The parents' concern for the siblings' adult-like behaviors represents the needs for sibling support to help the siblings to balance their roles as children and caregiver. Williams et al. (2010) stated that siblings of children with developmental disabilities consider their caretaker role in school setting as inevitable. Angell et al. (2012) also found that siblings of children with ASD reported themselves as caregivers, helpers, entertainers, and rescuers of children with ASD. In the study of Benderix & Sivberg (2007), some siblings reported that responsibility they experienced was burden. Since siblings deal with many roles, which can be burdensome for them, if the parents cannot help the siblings to find the appropriate balance between different roles, the siblings may need help from outside of the family. However, as the study found in themes one and two, the parents were not always good at balancing their attention on both children. Thus, parents might not fully provide the resources that the siblings need for figuring out the appropriate balance. Yet, the parental role in the family setting is still crucial for the siblings because the parents would be the only one who can acknowledge their problems and listen to them in the family setting.

Theme Four: Parents' Expectation for the Future

Parents of children with disabilities live under conditions of continuous uncertainty (Cohen, 1993). In particular, they worry about the unpredictable and uncontrollable future. In the study, the parents worried about their children's future after they pass away, and all of them expect the siblings to take care of the children with ASD in some ways regardless of what they expect right now. While some parents do not want

the siblings to be responsible for the children with ASD fight now, some parents stated that the siblings are already helping them. The parents tend to show some contradiction in their answers, such as they have not asked the siblings to take care of the children with ASD, but they have raised them to look after other family members. This section is about the parents' answer to the question, "if your child with autism needs care, would you ask your other child/children to help care for them?" Parent #1 only expected the siblings to take care of the children with ASD in the future:

I would say no. We have made that a point. Even now *S* got old enough to, you know, watch *A*. I don't think it's *S*'s price. I really don't... it's tough enough for *S* to grow with the sibling in the house with autism. Have to grow up with *A*, then take care of *A*. (...) We made a comment on to *S* that "you may have to later on. If mom and dad pass away and *A* may needs your help. If we are gone." I mean, it is not the responsibility that *S* has to do right now. That's why we've gotten the HAP worker, that's why we have other people lined up. We don't think it's *S*'s responsibility to do that. I mean, we have talked about, you know, family takes care of family, and if something happen to mom and dad, you may have to step in to be the person that... which is... you know, power of attorney or something like that for *A*. We don't expect *S* to be like taking care *A* at home. (...) that's why... we are trying to work very hard with *A* to be able to work on *A*'s own.

Since the parents know that the burden as caregiver for the children with special needs includes financial, physical, and emotional difficulties (Canam, 1993; Cohen, 1993; Dyson, 1999; Hutton & Caron, 2005; Scorgie & Sobsey, 2000), the parent above tried hard to train the children with ASD to function on their own in order to help the siblings

to have fewer burdens in the future as caregivers. While this parent did not take this topic that emotionally, there was a parent who had a very hard time talking about this topic. This parent appeared scared of talking about the future. The parent refused a group home for the child with ASD because of the possibility of mistreatment: “A can’t express that A has been mistreated. I worry that the most.” Also, the parent was not sure about whether or not the sibling is ready or thinking about taking care of the child. The parent said, “probably not.” with a huge sigh and weeping. The parent represented why parents of children with ASD worry about the time after they die; they cannot trust or find the social services for their children, but at the same time, the parents do not want the sibling to deal with the burden that they are dealing with. Parent #5 said:

Unfortunately, yes. I think so. Just because... I’m not gonna live forever. (...) I’m not going to make S. I’m gonna... hopefully encourage S to not to. (...) I’m not gonna make S have to. I think it would just stress S too much. (...) S is kind of right now jumping on teenager hormones... so I’m not going to stress S out.

This parent recognized the sibling’s developmental stage, and took it into consideration when making decisions for the sibling. Even though the three parents above did not expect the siblings to take care of the children with ASD for now, Benderix & Sivberg (2007) stated that the siblings of children with disabilities feel that they need to take care of the children. Therefore the siblings may already think that the caretaker role is their responsibility not just in the future, but also in the present.

Unlike the three cases above, other parents mentioned that the siblings naturally already took care of the children with ASD and did not consider the siblings’ caretaker

role as a burden for the siblings. They of course expected the siblings to take care of the children with ASD in the future. Parent #2 stated:

Yeah, I would. I mean *S* always wants to help *A*, now. In some ways, I want *S* to know how to help just in case. And I would take it as an urgent. Just in case, one day, *A* does have a little bit of... you know, *S* is the kid who wants to be the one who's caring for *A* even it always happen being selfish and things like that. (...) I would like *S* to know about it. And how it is. (...) Later on, even now. Older or even as adults. *S*'s been helped *A* already. I'm trying to ruin it. So... I think... *S* is not afraid of it. If I felt *A* is in need, it was the only option, I would certainly discuss with *S*. I think I would help with look after *A* because I want to help *A*. I'm *S*'s mother, too. But *S* might felt any, "No! This is my brother, I'm gonna take this on." *S* might think that way. I don't know. With just the way we did it now, I can see *S* thinking like that, but... I don't' ever know.

The parent considered the sibling as "the one who's caring for" the child with ASD who would love to take care of the child in the future. Even though the sibling actually did not mention it, the parent could "see" the siblings thinking like that. Parents #6 shared what the sibling actually said:

If *A* needs care, *S* does, *S* helps *A*. (...) *S* feels that if I pass away, and if *A*'s dad is also out of the picture if something happens to both of us, *S* would help *A*. *S* has always said that. *S* said, "Any man I marry has to understand that I might be needed to take care of *A* if something happens to my parents." (...) *S* is like, "so when the main person goes, they have to have whoever. We can't just let them go out to the society and without connections. And they are Very... umm... *S* said that,

“So vulnerable, mom. *A* is so innocent. The people are just gonna take advantage out of *A*. I’m not gonna let that happen”

Canam (1987) stated that families of chronically ill children deal with anxieties due to the present and future vulnerability of the children, and this sibling actually worried about it. This sibling understood why the child needed the sibling’s help not through education, but through personal experience with the child. Based on the understanding, the sibling hoped to help the child with a plan for the future. Parent #4 also shared what the sibling said:

Initially, you know... we told *S*, “Listen, it’s gonna be your role. It is what you need to do in the future.” So *S* raised in that way, you know. We told *S* that this kind of role... that you need to do. But we didn’t push *S* or make *S*. (...) We’ve not tell *S* to do. We’ve said what’s it gonna be like. And, then *S* said... as I said... *S*’s accepted that. *S*’s... *S*’s... uh... willing and wanted to do that. *S*... as I said... you know. “When I have a boyfriend, I will get married. And I will tell my husband that you know... You gotta understand that I have a brother.” I mean... *S* said that. (...) I like *S* to living *A* around. Just around and help *A*.

As shown above in the parents’ contradictions, the parents were not so sure about whom to ask for help, but tried not to put the responsibilities on the siblings. At the same time, the parents always considered the siblings as one of the options. Since the interview only included the parents’ perceptions, it seems like the parents are the only ones who worry about the children with ASD. However, recent studies found that it was not only parents who worried about the future of the children with special needs, but also the siblings (Angell et al., 2012; Benderix & Sivberg, 2007). The siblings have empathetic

feelings toward the children with ASD when they think about the children's future (Benderix & Sivberg, 2007). However, at the same time, the same study found that siblings hoped the children with special needs would be able to move to a group home because they wanted to be free from the families' burdens as primary caregivers (Benderix & Sivberg, 2007). It is interesting to see the similar contradiction that the parents had also found in the sibling population.

Theme Five: Impacts of Having Children with ASD

There is strong evidence that the siblings are influenced by having a brother/sister with ASD (Fisman, Wolf, Ellison & Freeman, 2000; Guite, Lobato, Kao & Plante, 2004; Angell et al., 2012; Naylor & Prescott, 2004). When the interviewer asked, "How do you think your typical child is affected by having a sibling with autism?" the parents focused more on the positive impact of having a brother/sister with ASD and less on the negative consequences. Also, they focused on the past when speaking about negative impacts or never mentioned any negative consequences. Here are the first answers of the parents.

Parent #1 answered:

I see two things. One, I see that um... *S* is much more tolerant for all people with disabilities.

Parent #2 answered:

I think *S* is little more... like... understanding of it. Just... you know... *S* understands, "ok. All kids can be different."

Parent #3 answered:

You know, honestly, I think it's a bit of benefit for *S* because... I can see a bit more empathy in *S* when *A* acts out with other people.

Parent #5 answered:

I think now *S* sees the world differently and is more open to people who are different, like our neighbor who has a daughter with Autism.

Parent #6 answered:

I think it is positive and negative because *S* loves that she has a brother. *S* is proud that *S* has a brother.

Parent #4 answered:

S felt less and less attention

Except Parent #4, five out of six parents mentioned the positive impact first, which represents that the parents were more focused on the positive impacts than the negative consequences. It is an interesting result because the positive impacts of having a brother/sister with special needs were often dismissed and the tendency was to focus only on the negative impacts in existing professional articles (Behr, 1990; Breslau & Prabucki, 1987; Hodgkinson & Lester, 2002; Stainton & Besser, 1998; Williams et al., 2010).

Table 4

Impacts of having brother/sister with ASD on the siblings

Positive impacts	Negative impacts
Direct answer: <ul style="list-style-type: none">- much more tolerant- does not see difference on special need people compare to other people- more open to differences <diversity>	Answer for other question : <ul style="list-style-type: none">- felt that parents does not fairly treat <i>S</i> (past)- social issues due to <i>A</i>'s behavior (past)- food issues influenced by the child with ASD

<ul style="list-style-type: none"> - intentionally behave in positive way for A and then know how to apply it in daily life - naturally more mature <p>Answer for other question:</p> <ul style="list-style-type: none"> - get benefit from the parents took parenting class for A - parents changed their discipline style after A was diagnosed to be fair to everyone - more open to try new things 	
<p>Direct answer:</p> <ul style="list-style-type: none"> - more understanding of differences - helps her to be a better person (personality) - very mature 	
<p>Direct answer:</p> <ul style="list-style-type: none"> - more empathy for A - less judgmental - more understanding on differences - try to think about other's standpoints - have wider arrangement of being normal 	<p>Direct answer:</p> <ul style="list-style-type: none"> - have a hard time to communicate with A <p>Answer for other question:</p> <ul style="list-style-type: none"> - limit on activities due to A cannot do. (past, "less now")
<p>Direct answer:</p> <ul style="list-style-type: none"> - more mature - accept differences more easily 	<p>Direct answer:</p> <ul style="list-style-type: none"> - less attention (past) - resentment (past) - more responsibility to take care

	<p>of A</p> <ul style="list-style-type: none"> - feel guilty being able to do things that A cannot do
<p>Direct answer:</p> <ul style="list-style-type: none"> - see the world differently and more open to people who are different (diversity) - more accepting of other people with special needs or in other areas - more tolerant <p>Answer for other question:</p> <ul style="list-style-type: none"> - benefit from the benefits for special needs (Line Pass of Disneyland) 	<p>Answer for other question:</p> <ul style="list-style-type: none"> - lack of role-model - embarrassed due to A's act out - sacrifice/deal with limitation of A
<p>Direct answer:</p> <ul style="list-style-type: none"> - love to have a sibling and proud of having one - very mature - naturally take care of 	<p>Answer for other question:</p> <ul style="list-style-type: none"> - having a hard time with A's behavior - getting less attention - need to deal with Parent's stress → no outlet
24 (direct answer: 20)	15 (direct answer: 5)

As shown in Table 4, the parents stated more positive impacts (24 answers) than negative impacts (15 answers). In order to count the number of answers, overlapped answers from different parents were counted separately. The parents provided answers regarding some positive/negative impacts, which were already stated in other studies. Personal growth/maturation (Scorgie & Sobsey, 2000; Stainton & Besser, 1998; Williams et al., 2010), caretaking skills (Mates, 1990), higher level of empathy (Bagenholm &

Gillberg, 1991; Stalker & Connors, 2004), increased tolerance for differences (Bagenholm & Gillberg, 1991; Stainton & Besser, 1998; Stalker & Connors, 2004; Van Rensselaer, 2010), and wider boundary of normalcy (Stalker & Connors, 2004) were positive impacts that were found in both previous studies and in the present study. Embarrassment (Petalas et al., 2009; Williams et al., 2010), role strain as a caretaker (Dyson, 1999; Rodrigue, Geffken, Morga., 1993; Williams et al., 2010), decreased parental attention (Bagenholm & Gillberg, 1991; Dyson, 1999; Gupta & Singhal, 2005; Rodrigue et al., 1993; Williams et al., 2010), guilty feeling for being healthy (Van Rensselaer, 2010; Williams et al., 2010), resentment, lack of interaction/communication with the children with disabilities, and forced sacrifice for the child with special needs (Williams et al., 2010) were negative effects of having a brother/sister with disability that were found in both previous studies and in the present study.

Interestingly, in the study, the parents were likely mention the past when they explained negative impacts, which means the parents perceived that the siblings were dealing with less negative impacts than in the past. It represented that the parents and the siblings had coped with their situation on some level.

Impressively, Parent #2 had a hard time thinking about negative impacts, which may indicate that the parent never thought about the negative impacts before:

It's hard to think of negative. (...) I don't really know any... negatives. Maybe sometimes... I don't know. *S* gets jealous once in a while, or *A* does have screaming and maybe *A* is gonna bother *S*. You know... *S* hasn't shown any.

Even though the interviewer asked about the impacts on the sibling of having a brother/sister with ASD before asking about the siblings' complaints and stresses, the

parents did not mention those negative manifestations until directly asked about them. Therefore, when only counting the direct answers for the question about impacts on the siblings, the parents only mentioned about 20 positive impacts and five negative impacts. The number of the answers only for the direct question more clearly showed the parents' mindset that focused on positive impacts much more than the negative manifestations of having children with ASD in the families.

Category Two: Supports

This category represents how the siblings are presently involved in any type of support system and what the parents' perceptions are regarding the need for supports. As stated above, the four themes represent the siblings' support system in different aspects: involvement in services for the children with ASD, support from others, need for sibling support, and limit on services. The goal of knowing the parents' perception of the support for the siblings and their support system is to figure out the most efficient and appropriate support services for the sibling population to help them cope more easily and positively.

Theme Six: Siblings' Involvement in Services

In the study, it was found that the siblings were not involved in any types of supportive services for having a sibling with ASD. However, some siblings were getting support in a different way: becoming involved in the support for the children with ASD. The parents tended to think that having the siblings communicate/interact with workers for the children with ASD has positive impacts on them. According to Angell et al. (2012), one of the supports that siblings in the study needed was talking with others who understood their situation. One of the participants of the study stated that "Just talking about it, just talking about it makes me feel better." Also, the participants' coping

strategy often involved looking for social support (Angell et al., 2012). This finding explains how the siblings could receive benefit from involvement in the services for the children with ASD.

There were some siblings who are involved in the therapy session for the children with ASD. The case workers did not allow the siblings to participate in every therapy session, but the sibling could participate when it was applicable. Parent # 2 reported that it was beneficial because the siblings could get idea of what the children with ASD do and can have a chance to talk with someone who is familiar about ASD:

A learns taking turns, and things like that. So, she (therapist) will direct *S* to do that kind of stuff. So, she almost kind of including *S* help out in the therapy session when it is needed. (...) *S* is not there for every appointment, but *S* goes and knows what they do. And we see them socially, too. So... it's just different. And I think it's been beneficial.

Parent #4 emphasized the benefit of getting attention:

All the therapists know [*S*]. Because in summer, I take *S* to the sessions. *S* sees. *S* doesn't go in there, but *S* knows... you know.. *S* really comes up with the idea. *S* kind of sees somebody goes in and comes out. And then, our rehabilitation providers come over to our house. (...) they all know *S*. They give *S* gift sometimes for Christmas. They all try to have *S* in therapy every session. (...) They involve *S*, too. It helps because *S* does need to know what they do.

Parent #5 reported that involvement in the services for the children with ASD was beneficial because the sibling could feel she is involved:

S wasn't necessary complaining when *S* was younger. *S* just wanted to join in. "I wanna be a part of this. How can I be a part of this?" So, *S* made her way into the therapy. "I am helping the therapist, mom. Look at me! I'm such a helper" (...) our therapists have always been really cool, and you know, seeing that *A* has a sibling. You know, sometimes they will bring *S* in when it's applicable. (...) When it doesn't interfere too much. They would like to take *S* jump on the trampoline. We always start off every therapy session jumping on the trampoline.

Unfortunately, there was also a sibling who was looking for interaction and communication with the workers for the children with ASD, but had not been able to do so to date. The parent asserted that the siblings felt ignored because they had been treated as if they were invisible by the workers around the children with ASD so far. Parent #6 was sure of the positive impact of interacting with the workers, and hoped the siblings could have a chance to talk with them:

We have *S* in therapy. Therapy social worker. Social worker wants to talk to the parents. And they talk to me and never told *S*. Like they may call and explain things, they talk to me. They never made appointment to talk to *S*, and *S* needs to talk. (...) they would take me to the office, they are not talking to *S*. *S* is like... so, a lot of kids feel eliminated. You know what I mean? "They are gonna hear mom and... mom first, and they are not gonna hear me. Then why do I need to come or anything?"

Even though the siblings were not involved in any support services for themselves, some of them could get a form of support from the workers for the children with ASD. With the chances of participating in the session and communicating with the workers, the

siblings could know what the workers and the children with ASD do separately and get extra attention from the workers. Although it was not direct support for the siblings, the parents thought it was beneficial because they could get some ideas of what was happening around them, and felt that they were also part of the team. As Angell et al. (2012) found, interacting with someone who understands their situation is beneficial for the siblings to cope better. Enderix & Sivberg (2007) also stated that if the siblings can take counseling sessions that encourage them to share how they feel, then the siblings might be able to cope better and easier. Therefore, even though becoming involved in services for the children with ASD was not direct support for the siblings, by allowing them a greater opportunity to communicate with others, it may benefit the siblings.

Theme Seven: Personal Support System for the Siblings

The siblings were also likely to benefit from support outside of the nuclear family, including: friends, mother's friends, extended family, and therapists for the children with ASD. Although the siblings were not involved in any types of formal services, they were involved in a personal support system they created on their own. The system could be the siblings' emotional outlet, role-model, or people who they could ask for help.

In the study of Angell et al. (2012), obtaining support from others was a coping strategy that was identified by sibling participants. There was a sibling in the study who identified support from a friend who has a cousin with ASD. Also, a participant stated that having a friend who is in a similar situation, having a sibling with ASD, helped the sibling to feel connected (Angell et al., 2012).

Likewise, there was a sibling in this study who had a friend in the same situation. The parents were not involved in this support system because it was the sibling's personal

friend; it was a spontaneous support system that the sibling made on her own. They never promised to support each other, but they just naturally shared their experiences and received help from each other. Parent #1 stated, “S’s friend also has an autistic brother. (...) And I think that’s a good friend for her to keep... they can relate to each other and they know how exactly each other feels.” There were some support systems that the parents were also involved in. The sibling got support from the mother’s friend in this case; they got together every Saturday for years. The mother asked the friend to take care of both children if something happens. Parent #5 stated:

We have family get together over. Like every Saturday, we have all our friends over. (...) Every Saturday, we have my friends. It’s 2 friends of 4, and they have.. umm.. an 11 and an 8 year-old, and a 9 and a 2 year-old. So, they will all coming over, and we will have a big dinner and the kids play together. (...) I had been doing it for years. (...) Right now, I have my friend set up. And if something is happen, she’s gonna help out the kids (S & A). And make us along with her. Everything like that. She’s been around a while. A knows her, A follows her direction.

The siblings also got support from extended family. In particular, there was a case that represented Asian American family-oriented cultural values. (Trinh, Rho, Lu, & Sanders, 2009). This Indian American family moved to Arizona specifically to receive family support, so the sibling had extended family near home, including grandparents, an uncle, an aunt, and two cousins. Recently, this family had a new baby to extend their family support system. Parent #4 stated:

We moved to AZ. Support from my family helped that. We were in Orlando. We are from Florida. (...) My parents (grandparents) live here. My brother (uncle) lives here. (...) in our culture, my families are tied. (...) My brother and my sister-in-law know that if something happened to us, my parents are toward for family. They will take care of my kids. That's gonna be you know... their role. If... something happen to my brother right now... you know... my parents will take my nephews and nieces. I mean, they can do it. Or, we will take them. It is how Asian culture, families are family-oriented. In this country, you don't see that. As not as typical.

While this sibling was still involved in the system, there was another sibling who was having a hard time due to the loss of the support system. Parent #6 stated:

That time, it was a four-generation house. (...) I would say that big transition happened after my grandparents (great-grandparents) died. (...) That's the one thing that really changed. My grandparent weren't there anymore, her behaviors were totally changed. (...) because she was well-behaved in all of those manners while they were in the house (...) Maybe S got up to talk to them [great-grandparents' shed]. (...) S just goes out and talks to them. You know, S just... shows to them S's experience and habits. Just go out and talk to them maybe... maybe that would help S.

Although families were resilient, this case shows that some families cannot cope with their situation without social support because they do not have any more family resources to help their families. This parent looked for help both for the siblings and the child with ASD, but could not get social support for either one of them. The parent is

studying social work in order to help other people in similar situations because she has experienced that there are not enough social workers for individuals with ASD and their families. Even though the parent is trying hard to deal with the situation, the sibling still needs support from the family system because the parent's efforts do not benefit the sibling now; it indicates the needs for additional and specialized social support services for the sibling population.

Sometimes, the therapists for the children with ASD function as a support system, too. In one case, the parent tried to get close to the workers around the children with ASD and they became friends. So, both of the children could get support in a personal setting.

Parent #2 stated:

S likes the therapist to come over and interact with her. (...) Now, *A* learns taking turns, and things like that. So, she (therapist) will direct *S* to do that kind of stuff. So, she almost kind of including *S* help out in the therapy session when it is needed. (...) I get close to *A*'s therapist and teacher, we becoming really good friends. And, so... *A* still have all the support around *A* even previous teacher I'm still friends with. (...) I can support... mainly is from me. Or... whoever works with *A*, still talks with *S*, interacts with *S*, things like that. So, because kind of my friend.

Although the siblings were not involved in any type of support services, they were involved in a support system they had created that is outside of the nuclear family dealing with the children with ASD on a daily basis. There was no education or training in this support system, but it functioned mainly as the siblings' emotional outlet.

Ebata & Moos (1994) described two types of coping strategies: emotion-focused

and problem-focused coping strategies. Using emotion-focused coping strategies means that an individual tries to regulate his emotions, whereas when using problem-focused strategies, an individual tries to change the situation or solve problems. Support from others mainly use emotion-focused coping strategies, which help the siblings to regulate their emotions. Although it is hard to solve the problems that the siblings deal with, supporters from outside the nuclear family can be a shield for the siblings who protect the siblings from the children with ASD because they are not deeply connected with the children with ASD like the parents.

Theme Eight: Parents' Perception of Needs for Sibling Support

The parents' perception on needs for support of the sibling population is crucial because they are the ones who would look for the services and decide whether the siblings would participate. However, the parents were likely to think the siblings do not need support services at all, or not for now. The parents tend to be satisfied with the support system they have now, and think that the siblings are doing well. Since the parents perceived the siblings are doing well only with the personal support system that they set up on their own, the parents did not feel the need for support services for the sibling. Parent #4 stated:

Mm... you know... I think... you know... having this other baby [another *S*] will help *S* in the future. If *S* knows that *S* has someone else helping *S* and take care of *A*, looking out for *A*. (Interviewer: So there's always kind of support in family.)

Oh, yeah- I'm stay tight with my nephew and niece. Especially, my niece.

As stated in theme seven, this case indicated the Asian's family-oriented culture. According to Pollard, Carlin, & Fischbacher (2003), Asian Indians tend to not use formal

systems of social support, but rather use informal social support system such as family more often. Asian-Indians' social support seeking behavior has been revealed in studies that they do not seek social support, and the nuclear or extended family takes the responsibility (Ramisetty-Mikler, 1993). Based on the family's cultural values, this family made a decision within the family to expand their family support for both the sibling and the child with ASD by having another baby who would be another sibling. It was the best option for the family in their perspective that does not seek help outside of the family; therefore, the parent perceived the informal family support system as sufficient for the siblings.

Parent #2 perceived that the sibling already received enough support, so did not feel the need for additional sibling support:

I can support... mainly is from me. (...) Basically, we're just S... we always do things with S. (...) There's some difference with mine because S goes... a lot of time, S will go to appointments with us, S usually around the therapists, S... you know, when I do, we do things together and then we have more things just for S, too. So, that is kind of personal support.

Parent #3 asserted that the siblings needed some support before, but not for now because the sibling is doing well now:

For now... I don't. When he was younger, yes. I think it would've been good to go to that kind of sibling group, or something available. By the time we got a diagnosis, there was no... there was hardly even any groups for A, not alone S. (...) And I think... younger, I'd like to have places for S, the sibling, to have his own interaction. But as they get older, they're just so good together. And they have the

same friends. So, I don't really see the need for it anymore. It's gotten to the point where *S*'s cut up for a little bit with that dynamic in interaction. (...) I think in the future, anything *S* will make *S*'s own way.

This parent mentioned that "last year was really hard for everybody." According to the parent, the sibling tested "his boundaries with everybody" and "there was a lot of verbal fighting" last year. However, "it has been a pleasant surprise year" because the children had not shown that much conflict like last year and that was the reason that the parent perceived that the sibling was doing well. It indicated the parent's tendency to focus on externalized behavioral problems, but gave less attention to internalized behavioral problems.

Contrary to the previous case, Parent #5 thought the sibling was too young to participate in social support services. However, at the same time, the parent was interested in a sibling support group and thinking about putting the sibling in it. It indicated that the parent felt the need for support for the sibling at some level. Yet, it was not enough to spur the parent to take action; the parent was hesitating. Somehow, the parent was worried about the sibling when considering social support. Because Parent #5 was interested in a sibling support group, but also afraid to start at the same time, there was a contradiction in the answer:

I'm thinking of putting *S* in it [sibling support group]. Just to show *S* about... other kids in there and there's nothing to be stress about certain things. (...) *S* is too young [10 years old]. It has always been at the back of my mind... till *S* goes older. I'm trying to get my parents to go to... to share stories, strategies, little

anecdotes. (...) I love to start it [sibling support group] younger. You know, like putting *S* in for years. For knowing other people out there like *S*.

In general, the parents tend to not feel the need for the support just for the siblings when they think the siblings are already getting enough support and doing well at the moment. Partially, it was related to the family's cultural background that relies on family members. Still, some of the parents who did not feel the needs were open to earlier or later support service; they just did not feel the need at the moment or hesitated for the time being.

Theme Nine: Restrictions of Sibling Support Services

None of the siblings were involved in any types of formal social support because the parents did not know about any such service or due to the restrictions of existing services. The parents had positive feelings about a sibling support group regardless of whether they knew about it before or not. However, to their knowledge, the siblings could not participate in the group due to age limits on the service. The parents were dissatisfied with the age limit especially Parent #1 and #6 who felt the need for sibling support. Parent #1 who has 15 and 18 year-old siblings stated, "The Sibling workshop started because we kept asking. Jewish Family Services, they're doing as sibling workshop. (...) They won't let *S* come though because they are too old for the services. It's for younger kids." And parent #6 who has 14 year-old sibling stated, "It's for kids' ages 6 to 13. So, there's nothing for *S*." Interestingly, although Parent #2 and #3 did not feel the need for sibling support, they were against the age restrictions. Parents #2 who has 7 year-old sibling stated, "There's grandparent one. Yeah, and I've seen adult sibling,

older like teenager. There's... I've not seen one... Yeah... a lot of youth kids, but none of little kids." And parent #3 who has 12 year-old sibling stated, "The age thing again."

Within very limited resources for the sibling, the sibling support group was the one that the parents heard of the most. However, there was no sibling who actually participated in the group because of the age restriction of the service in the parents' knowledge. It showed that even though the parents look for services and know about the group, it does not always connect to getting the sibling supports because of applicable restrictions.

According to Ryan House (2010) and *Specializing in the Education of Exceptional Kids (SEEK) Arizona* (2013), there are some sibling support groups in the greater Phoenix area that covers 4 to 7 years old, 8 to 10 years old, 8 to 13 years old, and 6 to 13 years old. It means that some of the siblings in this study are eligible for the group. However, those sibling groups are only placed in Phoenix and Mesa, while four out of six participants lived in West Phoenix. Therefore, although the parents never mentioned it, age was not the only restriction of the sibling group, but location of the service could also limit access.

Chapter 6

DISCUSSION

This thesis explores and describes the life narratives of the siblings of children with ASD through their parents' eyes as the research questions guided this study. It explains in detail the existing literature that describes how siblings are influenced by having a brother/sister with special needs (Fisman, Wolf, Ellison & Freeman, 2000; Guite, Lobato, Kao & Plante, 2004; Angell et al., 2012; Naylor & Prescott, 2004). However, while siblings of children with special needs typically have been explored in the literature with a focus on the negative side effects, the participants of the study tended to focus more on the positive effects of having a brother/sister with ASD. This study adds to our understanding of the siblings' experiences, current support for the siblings, and need for extra support for the siblings that could potentially help design future support services for them.

In order to explore and understand the narratives of the participants' perception of the siblings' lives in their family settings, a qualitative research design was chosen as the research methodology. The purpose of choosing this design is to (1) generate an initial understanding of the siblings' lives as told in the participants' stories, (2) identify related factors that influence the siblings' quality of life, and (3) focus more on findings rather than broad generalizations to represent their lives without any prejudice.

The first research question was: how the siblings of children with ASD are treated and function in their family setting? This question attempted to better understand how the siblings live in their family setting. According to the data, while the parents try to treat both the siblings and the children with ASD evenly, the parents have a hard time

balancing their attention between them. The families tend to have strong family unity because they spend more time together for balance. However, the children with ASD are still allowed to have more choice regarding kinds of activities the families do when they spend time together; the parents are likely to focus on what children with ASD can do or like to do. Activities that the siblings like to do do not seem to influence the families' activities, and those were just for the siblings themselves. Also, the parents tend to mention that the siblings like something related to the children with ASD and school, which likely represent the siblings as model children. Based upon these findings, it appears that while the parents respect the limited capability of the children with ASD, they tend to perceive/describe the siblings as able to be role models or caregivers who lead, support, and protect their brother/sister with ASD. A question that arises from this finding is whether the siblings are really like model children, or whether the parents just expect the siblings to be so. Due to this uncertainty, this study rather emphasized the possible difference in parents' and siblings' perceptions even though it aimed to consider the parents as representatives for the siblings.

The Resiliency Model of Family Stress Adjustment and Adaptation theory that led the study helps understand and interpret the parents' positive perceptions about the impact of having a sister/brother with ASD. The theoretical approach helped the researcher to be neutral about the topic. The Resiliency Model emphasizes the families' abilities to cope with their stress and helps identify the differences coping styles (McCubbin, Thompson, & McCubbin, 1996). The researcher began with the idea that the siblings are already coping in their family setting. Therefore, the purpose of the study was not to investigate if the siblings cope, but to understand how they cope. In order to keep

the neutral perspective on the sibling, the researcher tried to make the questions in the interview protocol unbiased to either a positive or negative perspective.

All of the parents think that having children with ASD in their family influence the siblings to be very mature for their age. Due to this maturity, they tend to perceive the siblings as capable of understanding and accepting their situation, and supporting the children with ASD. However, there were some gender differences in the siblings' attitude towards the children with ASD. The parents mentioned some problematic behaviors of the male siblings in the past, while female siblings tended to be more supportive once they understood ASD; one male sibling tried to hide that he had a brother with ASD to his friends and the other one verbally bullied his brother with ASD.

The parents also tend to describe the siblings as proactive/interactive in communication, so they perceive that the siblings would be willing to come and talk to them when they have issues. Interestingly, all the parents show some contradiction when they talk about the siblings' role for the children with ASD. While the parents like that the siblings are supportive and helpful for the children with ASD, they still want the siblings to be children; therefore, the parents worry about the siblings when they try to act like adults. Also, while all the parents expect the siblings to take care of the children with ASD in some ways in the future, they tend to say that the siblings would do so by themselves anyway even though the parents never verbally ask the sibling to do so. This finding also raises a question about whether the siblings are naturally mature or have been raised to be mature in their unique family dynamic. In addition, it is not clear whether the siblings acknowledge the parents' expectation of them to take care of the

children with ASD in the future or whether they do not acknowledge it because the parents never mentioned it verbally.

The second research question was: what are parents' perceptions of how the siblings have been influenced by the children with ASD? This question attempted to better understand how the parents perceive the impacts of having a brother/sister with ASD on the siblings. According to the data, when the parents were asked about the impacts of having a brother/sister with ASD on the siblings, all the parents talked about positive aspects first and talked more about the positive impacts than the negative impacts. The parents directly answered 20 positive impacts, and 24 positive impacts in total including indirect answers. On the other hand, the parents only mentioned about five negative impacts directly, and 15 in total including indirect answers. The parents mention that the siblings are more mature, tolerant, and open to diversity in general. Common negative impacts include social issues due to acting out of the children with ASD in public, getting less attention, and restrictions on activities due to the limited capability of the children with ASD. This finding in part might be explained by the fact that the sample did not include any parents who have a child with severe autism. In this study, the parents tended to mention that their children with ASD are more capable than stereotypical children with ASD or mentioned that it might be different if their child had severe ASD. It appeared that severity of ASD might matter for the impacts on the families. Since the sibling population usually has been represented with negative impacts of having a brother/sister with special needs in the literature, this finding raises a question. Have the siblings in the study really been influenced more positively than siblings in other

previous studies (Breslau, 1987; Hodgkinson & Lester, 2002; Williams et al., 2010), did the parents provide answers in the interview that were contrary to their true thoughts?

The sibling population has been represented with their internalized or externalized behavior problems in existing literatures (Bagenholm & Gillberg, 1991; Dyson, 1999; Gupta & Singhal, 2005; Rodrigue et al., 1993; Ross & Cuskelly, 2006; Van Rensselaer, 2010). However, the parents tended to not mention how their children felt in this study, but only mentioned externalized behavioral problems of their children such as acting out, tantrums, verbal fighting, and so on. The parents perceived that the siblings are doing well or better when they no longer show those externalized issues. Since most of the siblings are in the adolescence stage developmentally, which is a crucial time when they deal with a lot of internal conflicts (Seltenspergera, Milleb, & Guilé, 2012), this study indicated that the siblings may need help bringing up their internalized issues that their parents do not/cannot notice and take care of in their family setting.

The fourth research question was: what are parents' perceptions of what kind of social support is appropriate for the siblings to help them to cope more easily and positively? This question was an attempt to better understand what kind of support the siblings needs to help them cope more easily and positively. While none of the siblings in the study were involved in any type of formal support for siblings exclusively, the findings revealed that the siblings get informal support from outside the nuclear family including: workers for the children with ASD, friend, mother's friend, and extended family. It shows the families' ability to cope against their adversity as the Resiliency Model of Family Stress, Adjustment, and Adaptation emphasizes (McCubbin, Thompson, & McCubbin, 1996).

The parents thought that having the siblings communicate/interact with workers for the children with ASD is helpful for the siblings, and half of the siblings in the study were already involving in the services when it is applicable. The parents tend to count those interactions with the workers for the children with ASD as a part of personal support. Interestingly, the parents in the study tended to consider those interactions with the social workers of the children with ASD as beneficial for the siblings for the following reasons: (1) it helps the siblings to feel involved, (2) the siblings can get attention from more people, and (3) the siblings can have more chances to talk about their experiences/feelings. Interacting with the social workers for the children with ASD is the only support that the families can get out of the families' own resources and the support they get from their personal support system. Otherwise, the siblings get support from friends who are in the same situation, mother's friend as a caregiver, or extended family including grandparents, uncle, aunt, cousins, and great-grandparents. This finding represents that even though the siblings do not get any formal support for themselves, the family or the siblings try to set up their own personal support system to cope with the situation better. However, most of those supports are not just for the siblings, but also for the children with ASD. Therefore, it appears that there is still imbalance in the support system for the sibling.

Unfortunately, even though the siblings do not get any formal support that only focuses on them, the parents tend to not feel the need for sibling support. Half of the parents were not really interested in sibling support program because they perceive that their children are doing well, and they are already satisfied with the sibling support system that they have now. Other parents feel some need, but not enough to actually put

the child into a sibling support program. Ironically, while sibling support groups are the most well-known programs for the siblings among the parents in this study and they were positive about the program, none of the children were able to get into the group in the parents' knowledge due to age restrictions of the program. Some of the siblings should be able to get into the group because the age range of the siblings in the study is 7 years-old to 18 years-old. Therefore, this finding reveals the possibility of limited information or limited access to the information about the sibling support program for the parents.

Limitations of the study

Methodological limitations and weakness are fundamentally inevitable when research is conducted in social settings that the researcher cannot control. Even though the researcher tried to make sure the research was effective and meaningful, there are still limitations of this study. Here is the list of the limitations of this study:

- (1) There is a limit to generalizing the study due to the small sample size and a nonrandom sample. Since all the participants volunteered for the study, there is a strong possibility that there was some self-selection bias and that parents facing very difficult situations at home did not volunteer for the study. However, the study primarily focused on specific findings rather than on making broad generalizations.
- (2) Many parts of the data are unclear because this study tried to figure out the siblings' experiences in their family settings vicariously. Even though the study focuses on the siblings, the researcher interviewed the parents; therefore, the parents' perception might not accurately represent the siblings.
- (3) Question 3 and Question 4 of the interview protocol (see Appendix A) asked, in order to get the answer for the third research question, what are the parents' perceptions of how

the siblings cope with their situation? However, those questions were not appropriate and clear enough to get specific findings in this study. Due to the hidden assumption that the siblings would be older than the children with ASD, more than half of the siblings were not applicable for the questions. Unfortunately, the parent who had the siblings applicable to the questions skipped those two questions because the parent felt uncomfortable answering the previous question about family activities on a typical weekend. Therefore, those two questions actually did not get any direct answer about the siblings' coping skill. Also, due to an assumption that it would be hard to discuss the siblings' coping skill when directly asked, the questions were ambiguous enough for the parents to mention how the siblings cope clearly. Due to the ambiguity of the questions, although some parents answered for the Question 3 and Question 4 of the interview protocol, the parents talked about other things or talking too briefly about coping skills. The parents did mention the siblings' coping skills in their narratives, but not for the two questions of the interview protocol. However, it was too partial to define as coping skills; it was not clear enough to emerge into a theme.

(4) Unexpected minor problems arose (e.g., loud background noise sometimes disrupted the interview while the parent was sharing sensitive issues, and made the data unclear in some parts), however, it was still possible to obtain rich data.

Implications for Social Work Policy and Practice

The stories of parents who have children with ASD and their perceptions of the sibling population can assist in updating social policy and social programs in the field. This qualitative study provides rich details needed for understanding the siblings' experiences in their family setting in the Phoenix, Arizona metro area. Reviewing the

narratives of the parents who are living in the same family setting with the siblings, workers in the social work field can assess the situation and the needs of the siblings, and support them in more efficient ways.

Regarding policy formation, social workers must recognize the burdens of the sibling population caused by their unique situation and come up with ways to help them to cope better. There are eight acts and civil right laws that relate to people with ASD including Developmental Disabilities Assistance and Bill of Rights Act (D.D. Act). While other policies only focus on the individuals with disabilities, D. D. Act also benefits the family with its title II – Family Support. However, as found in the previous literature review, “family” usually only indicates parents, not siblings. Due to the limitation of this study, it rather emphasized the different perceptions of the parents and the siblings in the same family setting. Although parents and siblings are living in the same environment and both are influenced by the children with ASD, their needs are different because they have different roles. Therefore, based on what has been found in this study, it can be suggested to specify the title II of D. D. Act from Family Support to Parents and Sibling Support, in order to strengthen social supports for the sibling population.

With regard to programs in the field of social work, this research found some areas that need to be considered in order to support siblings more efficiently. Due to the varying functioning capabilities of children with ASD, the influences on siblings are also varied. Also, different family demands, strength of the family system, and family resources are the factors that influence the family’s adjustment (McCubbin & McCubbin, 1993). Consequently, one approach to sibling support services is not going to be

sufficient to address all the possible issues related to siblings with a brother/sister with ASD.

There are two interwoven topics that social workers must consider to support the sibling population more efficiently: how best to identify and provide support and the support programs themselves. Social workers need to think more deeply about how to approach the siblings. In the Greater Phoenix area, sibling support groups are the only sibling support programs, which are run by two organizations in Phoenix and Mesa (Autism Society of Greater Phoenix, 2011). Due to the age and location restrictions of the services, many siblings are not eligible for it as shown in the finding. Then, although this research is focused on stand-alone sibling support, social workers should consider different approaches that can benefit the sibling population. The parents mentioned that interacting with the social workers for the children with ASD was beneficial for the siblings. There were some siblings who were involved in therapy session for the children with ASD when applicable, but there was also a sibling who hoped to be involved, but was not allowed by the therapist. Therefore, workers for the siblings in the field can encourage the social workers and psychologists working with children with ASD, to involved the siblings at least for a short time before/after the session, to help the siblings feel involved, get more attention, and have more people to share about their experiences/feelings, which can make the siblings feel much better (Angell et al., 2012). Since a parent's role is very crucial for the siblings in the family setting, social workers also can add some content about siblings, such as their roles and internalized behavior problems, into parent training programs or lead the parents to talk about those topics in parent meetings. As some of the parents in this study did not get the correct information

regarding the availability of a sibling support group, there might be some siblings who are eligible for the program but the parents think they are not eligible due to lack of information. The workers in the field should promote the program more actively or make the information about the program more accessible to the parents to prevent siblings from missing an opportunity to participate in the group. If there is not a support group in the area, workers can group siblings who live in the same area to allow them to share their feelings and experiences in informal settings as needed or explore options for the siblings to access on-line support group resources. Although there would be no formal education in the informal group, interacting with others who understand their situation is beneficial for the siblings as found in the study. Based on the theory that led this study, the Resiliency Model of Family Stress, Adjustment, and Adaptation, more family resources, both formal and informal, would benefit the siblings because family resources and adjustment have a positive correlation (McCubbin & McCubbin, 1993).

In addition, it was found in the study that some parents do not feel the need for sibling support. The parents' perception would limit the siblings' opportunity to get social support because the parents tend to have more influence on family decision making; siblings need the parents' help to participate in any social services (e.g., give the sibling a ride, pay the sibling's membership fee, etc.) Therefore, social workers should consider the parents' perception of need for sibling support and try to figure out how to trigger the parents to recognize the need. For example, the workers may be able to persuade the parents to let the siblings participate in social programs when they assert that the siblings need breaks from the children with ASD. In this study, it was found that the families tend to spend much time together in order to balance the parents' attention on the siblings and

the child with ASD, and taking care of the children with ASD at school was the siblings' responsibility. It indicates that many siblings may not have enough breaks from the children with ASD. Therefore, providing activities only for the siblings that they do not need to think about children with ASD can help the siblings to have a respite from their role as a caregiver.

Implications for Future Research

Due to the limited information about siblings of children with ASD, the current study was designed to interview parents in order to get the big picture of the siblings' experiences. Therefore, this exploratory study could only represent a limited part of the sibling populations' experiences. As expected, this study failed to separate the parents' perception and the siblings' perception due to the limitation. In order to get clear answers to the research questions of the study, further research needs to be directly conducted with siblings. Nevertheless, this study expands upon the existing body of literature by finding impacts on the siblings of having a brother/sister with ASD.

In order to have a different perspective of the sibling of the children with ASD, research also can be conducted with adults with high-functioning ASD in the future. By using their retrospective perspectives, many things that can be revealed: such as (1) interaction between siblings and individuals with ASD and how those interactions changed as they grew up; (2) barriers of interaction with sibling; (3) helpful supports they have experienced; and (4) social support that they hoped to have had but did not have. Since it will rely on the perception of the individuals with ASD, it will contribute a very different viewpoint.

While most of the families in this study developed their own personal support

system and cope on their own way without social support, there was still a family who clearly needed social support due to a lack of family resources. Although the Resiliency Model of Family Stress, Adjustment, and Adaptation emphasized the families' resiliency, it showed that some families need help to increase their resiliency factors through external social support. Further research with families who do not have enough family resources on their own would show the influence of having a member with ASD in their family setting and will help identify more clearly the support that the families need. Furthermore, comparing two groups of families, some who are coping well and others who are not coping well, will help to more clearly elucidate services gaps.

As stated by McHale, Sloan, and Simeonsson (1986), for the siblings of children with disabilities, their adjustment is highly variable. However, only limited variables have been studied for the siblings. While the individual with a disability has been considered as a separate variable in existing literature, parents and siblings used to be considered as the same variable, family; this study also considered the parents as the siblings' representatives. Therefore, while some studies have been done on the interactions between the parents/siblings and the children with special needs, the interactions between the parents and the siblings remain unclear. Future research that address this area, correlation between parents and siblings (e.g., how the parents influence the siblings, how the relationship between parents and siblings related to the siblings' adjustment, how the parents' adaptation degree is related to the siblings' adjustment, and etc.) would be helpful for further understanding of the sibling population's experiences in their families. In addition, while there have been studies that revealed the needs for sibling support (Department of Health, 1991; Naylor & Prescott,

2004), parents' help seeking behavior for the sibling population has been understudied even though parents tend to have more influence when making decision in this area. Further research on the parents' behavior would allow more understating of appropriate approaches to sibling support programs. More research is needed around resiliency and the siblings' gender, severity of ASD, and the parents' marital status in order to strengthen the existing literatures and find the related factors to family resiliency.

In this study, the participants tended to describe the impacts of having a brother or sister with ASD more positively than how it has been described in the existing literature. Since all of the participants were recruited in the Greater Phoenix area in Arizona, it might be related to the culture or atmosphere of where the participants live. Further research conducted in a populous city where people live in a more competitive atmosphere or in rural area may help to make clear that correlation of social environmental factors and the siblings' quality of life. Also, as found in the previous literature review, there is no research about siblings of individuals with disabilities that has a compare group in its design, yet. Therefore, it is not clear whether the stress and challenges the siblings face are related to ASD, or not; they can be general sibling/family issues. In order to confirm the influences of having a brother or sister in a family setting, further research should consider having a compare group in their design.

Chapter 7

CONCLUSION

While much was learned in this exploratory study, there is still more that needs to be studied in order to have a better understanding of the experiences of children who have siblings with ASD. In the parents' perspective, the siblings were mature enough to understand and accept their unique situations, parents' attention to their brother with ASD, and their responsibility as caregiver. Although the parents tried to balance their attention between both children and help the siblings to balance their roles as children and caregivers for the children with ASD, the siblings still tended to be perceived as capable to be caretaker/role model for the children with ASD. It was found that the siblings had some externalized issues related to the children with ASD in the past; however, as they got older, they were doing better with the one with ASD. Since these findings contradict the findings in other recent studies that represented the sibling population as influenced more negatively by having a brother/sister with special needs, this study rather emphasized the possible gaps between the parents' perception and the siblings' perception, which indicate needs for further research in this area. Nevertheless, it was clearly indicated that both parents and siblings were striving for balance.

While the parents have a hard time balancing their attention between the children with ASD and the siblings without ASD, they also tended to strive for balance when forming support systems for their respective children. Due to the limited services for the siblings, families in the study set up their own personal support systems for the siblings, which usually also support the children with ASD. Since the siblings already had access to a support system to help them function better, the parents tended to be satisfied with

the support system they received, and did not feel the need for additional sibling support. The parental role is crucial for the siblings when seeking support, however, only the need for sibling support has been studied, and parental help seeking behavior for siblings has not been the main topic of recent study in this area.

Only limited research has been conducted on siblings of children with ASD so far, so there are many areas that still need to be explored. Most of the studies about siblings of children with special needs are qualitative studies, which indicate that there is not enough information about this population, yet. Due to the characteristics of a qualitative study, most of the studies have small sample sizes from limited areas, which can be the reason for the mixed results. In particular, further study is needed that only focuses on the siblings of individuals with ASD, not general disabilities, because individuals with ASD can show some progress in their function with continuous education, unlike other disabilities. Practically, it would be hard to conduct a large scale quantitative study that covers a wide area in the near future. Continued research is needed in order to gain a better understanding of siblings with the goal of identifying supports that could facilitate the development of positive coping strategies and promote positive adjustment for them. Since ASD is known as the fastest growing developmental disability, further research will be able to benefit a larger population of siblings in the future.

Although there are some limitations of the study, part of the siblings' experiences in their family settings and parents' perceptions of the sibling supports could be reflected in this study. The impacts of having a brother/sister with ASD reflected more positively compare to the existing literatures; however, it still expands the previous studies with the parallel contents. This study also shows the families' resiliency with their personal

support system, how the workers for the children with ASD can benefit the siblings, and how the restrictions of the sibling group limit access of the siblings, which provides ideas for the future sibling supports. It partially showed the parents' help seeking behavior for the siblings, which has rarely been the topic of recent studies. Thus, the findings in the category two show the recent support can implicate for the future social support in practice. Also, this study found, in the existing literature, that "family" usually only indicates parents, not siblings. Therefore, this study also can implicate the existing policy D. D. Act title II– Family Support to specify its target to be parents and siblings. This ensures the siblings can benefit from the policy. This study can benefit the siblings of children with ASD in the practice, especially those who live in the greater Phoenix area, if the findings are considered by workers in the field.

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APPENDIX A
INTERVIEW PROTOCOL

1. How old is the sibling(s)?
2. How old is the child with ASD?
3. When the child with ASD was diagnosed?
4. How old was the sibling(s) when the child with ASD was diagnosed?
5. How severe the ASD that your child has?
6. Tell me about a typical weekend – how do you spend down time with your child with ASD? How do you spend down time with your typical child? How do your children spend time together?
7. Tell me about a typical weekend before your child was diagnosed with Autism. Was there any difference between then and now?
8. Right before diagnosis, how did your typical child manage the problem behaviors of the child with ASD? How about now?
9. Were there changes over time? Why do you think the typical child changed over time?
10. How do you think your typical child is affected by having a sibling with autism?
11. Tell me about the stress your typical child feels because he/she has an autistic sibling?
12. Tell me about the relationships your typical child has with his/her friends?
13. If your child with autism needs care, would you ask your other child/children to help care of them? Why/why not?
14. Do your other children feel somewhat neglected because you spend more time with the child with ASD?
15. What types of services or support systems would help your typical children?

APPENDIX B
IRB APPROVAL LETTER

To: Flavio Marsiglia
UCENT

From: *for* Mark Roosa, Chair *DM*
Soc Beh IRB

Date: 12/06/2012

Committee Action: Exemption Granted

IRB Action Date: 12/06/2012

IRB Protocol #: 1212008591

Study Title: Support for the siblings of children with Autistic Spectrum Disorder (ASD).

The above-referenced protocol is considered exempt after review by the Institutional Review Board pursuant to Federal regulations, 45 CFR Part 46.101(b)(2).

This part of the federal regulations requires that the information be recorded by investigators in such a manner that subjects cannot be identified, directly or through identifiers linked to the subjects. It is necessary that the information obtained not be such that if disclosed outside the research, it could reasonably place the subjects at risk of criminal or civil liability, or be damaging to the subjects' financial standing, employability, or reputation.

You should retain a copy of this letter for your records.

APPENDIX C
INFORMATION LETTER

SUPPORT FOR THE SIBLINGS OF CHILDREN
WITH AUTISTIC SPECTRUM DISORDER (ASD)

Dear Participant:

My Name is Seong Hae Jeong, and I am working with Flavio Marsiglia who is a professor in the School of Social Work at Arizona State University. We are conducting a research study to figure out what it is like to be siblings of children with ASDs through parents' eyes, and find the proper social services that serve their needs to help them to cope positively with life's expectations.

We are inviting your participation, which will involve an hour and a half to two hours for an interview about your experience rearing kids with and without ASDs. I will be recording the interview, if it's OK with you. I will be asking some questions that I hope will inspire you to share your experiences and what you think is important for us to know. The interview will focus on the siblings of the children with ASDs. You don't have to answer any of the questions; you can just tell me you don't want to answer. And, you can tell me to stop at anytime; it's perfectly OK.

Your participation is voluntary and you must be 18 or older to participate in the study. If you choose not to participate or to withdraw from the study at any time, there will be no penalty. If you decide not to participate in the study after you had an interview, then your personal information and recording or transcript will be deleted or shredded at least the day after you announce it to us. And if you wish to participate, but there are questions you do not wish to answer, it is okay, you do not have to respond to any question you are uncomfortable answering.

Although there may be no direct benefits to you, the possible benefits of your participation in the research are that the results of the study may help social services to provide more helpful services for other families who have child/children with ASD and their siblings in the future. There are no foreseeable risks or discomforts to your participation.

All information obtained in this study is strictly confidential. The results of this research study may be used in reports, presentations, and publications, but the researchers

will not identify you. The interview will not be recorded without your permission. Please let me know if you do not want the interview to be taped; you also can change your mind after the interview starts, just let me know. The recordings from the interviews will be assigned a unique number instead of the participants' name. The audio file will be saved in only one desktop computer placed in the Southwestern Interdisciplinary Research Center (SIRC), and will be deleted from the audio recorder right after it is saved on the computer. After the file is transcribed, the audio file will be permanently deleted from the computer as well. Only the researcher has access to the confidential information.

If you have any questions concerning the research study, please contact the research team at: 411 N. Central Avenue, Suite 722, Phoenix, AZ 85004-0689 or sjeong9@asu.edu, 602-496-0700. If you have any questions about your rights as a subject/participant in this research, or if you feel you have been placed at risk, you can contact the Chair of the Human Subjects Institutional Review Board, through the ASU Office of Research Integrity and Assurance, at (480) 965-6788. Please let me know if you wish to be part of the study