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# The Lived Experiences of Adult Siblings of Individuals with ASD

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The Lived Experiences of Adult Siblings of Individuals with ASD

by

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Wilfrid Laurier University, 2014

THESIS

Submitted to the Department of Kinesiology and Physical Education

in partial fulfilment of the requirements for

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## Table of Contents

LITERATURE REVIEW .....	1
METHODOLOGY .....	12
RESULTS .....	21
1. The insights of having a sibling with ASD.....	25
1.1. I realized when.....	25
1.2. Acknowledging the improvement of their siblings' behaviours over time .....	27
1.3. Looking beyond their siblings' ASD.....	28
2. It gets better with time.....	29
2.1. Trials and tribulations: The childhood relationship .....	29
2.2. Appreciation and acceptance: The adulthood relationship.....	30
2.3. The could-haves & the guilt: Reflecting on the past.....	32
3. Taking the good with the bad .....	33
3.1. The hardships associated with having a sibling with ASD .....	33
3.2. The benefits associated with having a sibling with ASD.....	36
4. A glimpse into the future.....	38
4.1. Concerns, concerns, concerns!.....	39
4.2. Will I be a future caregiver? The roles and responsibilities that lie ahead.....	40
4.3. In a perfect world.....	41
5. The voice of the negative case.....	43
5.1. When it all began.....	43
5.2. Frustration with Cody's behaviours & acknowledging his improvements .....	44
5.3. The “non-existent” relationship between Cody and Greg.....	46
5.4. “He took my mother away” .....	48
5.5. “I didn’t want my family to be seen with a disability.” .....	50
5.6. Future.....	51
DISCUSSION .....	52
References .....	60
Appendix A: Typical therapies for ASD .....	63
Appendix B: Relative studies .....	64
Appendix C: Research poster .....	65
Appendix D: Consent letter.....	66
Appendix E: Background questionnaire.....	69
Appendix F: Interview questions.....	76

## LITERATURE REVIEW

### Autism Spectrum Disorders Background Information

Autism Spectrum Disorders (ASD) are the most prevalent neurological and severe developmental disorder affecting 1 in 88 Canadians, reflecting a 78% increase over the last 6 years (Autism Speaks Canada, 2013). ASD is more prevalent in males, with a male to female ratio of four to one (Autism Speaks Canada, 2013).

The term ASD encompasses five different developmental disorders, including: Autistic Disorder, Asperger's Syndrome, Rett's Syndrome, Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS) and Childhood Disintegrative Disorder (DSM-IV-TR, 2000). ASD is commonly characterized by mild to severe impairments in the social, behavioural, cognitive, and physical domains (Ferrailoli & Harris, 2012). The Diagnostic and Statistical Manual of Mental Disorders, IV-TR provides the necessary criteria in diagnosing ASD (DSM-IV-TR, 2000). ASD is typically characterized by social and communication impairments, preoccupation with specific objects, as well as repetitive motor movements such as hand flapping (DSM-IV-TR, 2000). ASD can also be associated with motor deficits, intellectual disabilities, behavioural problems (e.g., aggression) and health concerns (e.g., sleep and gastrointestinal issues) (Autism Speaks Canada, 2013).

Not everyone diagnosed with ASD expresses the same characteristics. As the name states it is a spectrum disorder, meaning that an individual diagnosed with ASD can be anywhere along the continuum (Autism Speaks Canada, 2013; Ferrailoli & Harris, 2012). Although any two children may have the same diagnosis, it is unlikely they will exhibit the same behaviours (Horvat, Kalakian, Croce & Dahlstrom, 2011). Some of the behaviours exhibited by children with ASD may be more or less severe when compared to other children with the same diagnosis.

Unfortunately, there is no cure for autism. However, there are numerous therapies that are available for children with ASD, to promote their overall development and to address any deficits in the physical, communication and behavioural domains (see Appendix A for a brief description of therapies) (Autism Speaks Canada, 2013).

### Impact on Family

ASD is a lifelong disorder which requires a tremendous amount of support and caregiving from family members. The family acts as an important agent for developmental maturation and social, physical and cognitive growth (Seltzer et al., 2005). Undoubtedly, the added responsibility of raising a child with ASD weighs heavily upon the lives of the family members living with this individual. For example, these parents may experience financial burdens as a result of costly therapies for their child (Fleishmann, 2005; Fletcher et al., 2012; Hines et al., 2012; Hodgetts et al., 2013). Additionally, parents may develop health issues as a result of lack of sleep and stress due to their child's irregular sleep patterns (Fleishmann, 2005; Fletcher et al., 2012; Hines et al., 2012; Hodgetts et al., 2013).

### Impact on Siblings

Seltzer, Greenberg, Orsmond, and Lounds (2005) provide a detailed description of the typical sibling relationship:

The sibling relationship constitutes the longest lasting family tie, beginning with the birth of the younger sibling and ending with the death of one member of the sibling pair. Siblings share a common family heritage, both genetically and experientially, and perhaps for this reason, the sibling relationship is normatively characterized as egalitarian, reciprocal, and mutual (p. 354).

However, one might question whether this description is accurate when one sibling has been diagnosed with a developmental disability, such as ASD. In any family system, the relationship between siblings is of great importance, as this relationship is often the child's first relationship

with similarly aged individuals (Seltzer et al., 2005). A series of quantitative and qualitative studies will be presented to review existing research regarding the experiences of individuals of siblings diagnosed with ASD. Both quantitative and qualitative studies are able to contribute research concerning siblings that assists in understanding their experiences.

### Comparative Studies Exploring Siblings of Individuals with ASD

In an attempt to unveil the experience of siblings of individuals with ASD, quantitative researchers have completed comparative studies on the impact of having a sibling with ASD. For example, Macks and Reeve's (2007) examined the different emotional and psychosocial adjustment of children who have a sibling with ASD compared to children who have (a) sibling(s) without disabilities. Fifty-one families with a child with ASD participated. One parent and one child who was typically developing were recruited (21 males, 30 females) from each family. Ages of the siblings with ASD were not disclosed, however researchers did state that 24 of the sibling participants were younger than the sibling with ASD and 27 were older. The sex of the siblings with ASD was also not provided. For the comparison group, 36 families were recruited that did not have children with ASD. One parent and one child (16 male, 20 female) were selected from these families. Additionally, in the comparison group, 18 of the sibling participants were younger than the sibling with ASD and 18 were older, again the sex of the siblings with ASD was not mentioned. The children from each of the groups were aged 7 to 17 years. Sibling participants were asked to complete the Children's Depression Inventory-Short Form (CDI-S) (Kovacs, 1992) and the Piers-Harris Children's Self Concept Scale (Piers, 1984). Participating parents completed a Behaviour Assessment system for Children-Parent Rating Scales (BASC-PRS) with regards to the sibling who is typically developing, as well as a demographic questionnaire. The study concluded that siblings of children with ASD had higher

positive self-concept than did children of non-disabled siblings. The researchers suggested that the reasoning for this may be because they were comparing themselves to their sibling with ASD. This allowed the typical siblings to view themselves in a more favourable light, as they did not have the same impairments as their sibling with ASD. Additionally, researchers emphasized the increased maturity evident in individuals whose siblings had ASD also could have led them to perceive themselves in a more positive light (Macks & Reeve's , 2007). Although researchers did not specify, one may conclude that this increased maturity was a result of the forced independence that typical siblings must acquire and the increased responsibilities they may have.

In another comparative study, Orsmond and Seltzer (2007) examined the relationship of siblings of adults with ASD and siblings of adults with Down Syndrome (DS). Data were obtained from 154 participants, 77 siblings who had a sibling with ASD and 77 siblings who had a sibling with Down Syndrome (DS). The participants were 21 to 56 years of age and 58% of whom were female. The mean age of the siblings with ASD was 35 years old and 73% of whom were male. As for the siblings with DS, the mean age was 32 years and 68% of whom were female. The following information was collected by researchers regarding the demographics of the participants and their sibling with ASD: (1) frequency of sibling contact; (2) positive affect in the sibling relationship; (3) the functional independence in activities of daily life with regards to their sibling with ASD or DS; (4) information specifying the behaviours of the individuals with ASD or DS; (5) areas that the typical siblings' lives had been greatly affected as a result of having a sibling with ASD or DS (e.g. family relationships, career plan and feelings about themselves); (6) the coping mechanisms utilized by the typical siblings; and (7) the typical siblings' concerns regarding their siblings' (ASD or DS) future. Researchers found that siblings of adults with ASD reported less contact and a less positive relationship with their brothers or



sisters during their adult lives than siblings of adults with DS. Researchers postulated that this was the result of their siblings' (with ASD) reduced ability to socialize and communicate. However, it was also found that adult siblings of adults with ASD reported a more positive relationship with their parents while growing up with a brother or sister with ASD, than those who had a sibling with DS (Orsmond & Seltzer, 2007). Unfortunately, details as to why this finding may have occurred were not provided.

Orsmond, Kuo and Seltzer (2009) compared the sibling relationship between adult siblings of individuals with ASD to the sibling relationship of adolescent siblings of individuals with ASD. The adult group consisted of 142 individuals aged 19 to 55 years, 60% of whom were female. The siblings with ASD of these adult participants had a mean age of 29, 71% of whom were male. The adolescent group consisted of 56 individuals aged 12 to 18 years, 64% of whom were female. The siblings with ASD of these adolescent participants had a mean age of 19 years, 71% of whom were male. Adolescent siblings engaged in a phone interview lasting approximately 45 minutes and completed a brief package of questionnaires. Adult siblings completed only the brief package of questionnaires. The reasoning for this methodological difference was not disclosed. The researchers collected data concerning the following: sibling relationship quality; the psychological well-being of the sibling participants; coping strategies that were used when faced with stress due to their siblings with ASD; the social support the sibling participants received with regards to the siblings' diagnosis; and behavioural problems exhibited by the siblings with ASD. Main findings concluded that adolescent participants received more social support from their parents and friends than the adult participants. However, the questionnaires failed to mention spousal support as a means of social support. Had they included this, the results may be very different. It was also confirmed that adult participants

reported less contact and less engagement in shared activities with their sibling with ASD. Despite these findings, it was concluded that adult siblings and adolescent siblings reported the same degree of positive affect in the relationship. This is supported by prior research conducted by the same researchers. They confirmed that a main predictor of the quality of the adult relationship among individuals in which one has a disability is the quality of their adolescent relationship. In terms of coping strategies, adolescent participants relied more on emotion-focused coping strategies (e.g., denial) and used less problem-focused coping strategies (e.g., positive interpretation and growth) when compared to adult siblings. The researchers stated that the different coping mechanisms employed by individuals were a reflection of different age patterns. For both the adult and adolescent siblings, it was revealed that the more troubling the brothers' or sisters' behaviour was, the more negative the sibling relationship. It was likely that typical developing siblings were unwilling to engage in activities when their siblings were exhibiting behavioural problems (Orsmond et al., 2009).

#### The Lived Experiences of Siblings of Individuals with ASD

The experiences of siblings of individuals with ASD has been discussed in past qualitative studies that examined the primary caregivers of individuals with ASD. For example, Fletcher, Markoulakis, and Bryden (2012) examined the costs of caring for a child with ASD. Data was collected from eight primary caregivers through semi-structured, one-on-one interviews. The researchers revealed that the mothers spoke about the challenges that their other children were faced with, as a result of their sibling with ASD. They perceived that their children had increased stress levels due to the lack of parental attention they received and due to the children's increased responsibilities. Participants mentioned that much of their attention was focused on the health needs of their child with ASD, minimizing the attention received by the

typically developing sibling. Further, heightened responsibilities for siblings of children with ASD were reported because often the sibling would assist in providing care to their brother or sister.

These results are further supported by Shaff, Toth-Cohen, Johnson, Outten, and Benevides (2011). The purpose of their qualitative study was to obtain in-depth knowledge regarding the lived experiences of how sensory-related behaviours of children with autism affect family routines. The participants within this study consisted primarily of mothers (n= 5). Data regarding their experiences were collected through semi-structured, one-on-one interviews. The researchers dedicated a section of their findings solely to the impact of children with autism's behaviour on siblings. The concern regarding the lack of parental attention and the increased independence that the typically-developing sibling must acquire was acknowledged by the parent participants.

Both studies concluded that the siblings of individuals with ASD are confronted with countless difficulties. The major concerns that these studies addressed were the increased responsibility, forced independence, and decreased parental attention of siblings. These qualitative studies emphasized the fact that siblings are also affected by living with an individual with ASD, and it is not only the parents that endure the challenges associated with raising a child with this condition.

Moyson and Roeyers (2012) conducted a study examining the quality of life of siblings of individuals diagnosed with ASD. Data were collected from 17 sibling participants (10 female, 7 males, mean age= 10 years) whom had a sibling diagnosed with ASD (all male, 5 to 16 years of age). Each sibling participant engaged in one or more phenomenologically-based interview with the researcher lasting 40 to 70 minutes in length.

Nine major themes emerged from the analysis process. These themes were as follows: (1) *forbearance*: difficulties associated with their brothers' challenging behaviours; (2) *mutual understanding*: the importance of having a brother who was verbal, as they felt that this was important for successful communication; (3) *joint activities*: enjoyment when they had the opportunity to do "normal things" with their brothers, such as playing games that typically-developing siblings are able to play; (4) *private time*: the need to distance themselves from their brothers, as this was a means to cope with their brothers' disorder; (5) *trust in well-being*: extreme concern for their brothers' future with regards to living and working situations; (6) *acceptance*: relief when they were able to accept and understand their brothers' diagnosis; (7) *exchanging experiences*: the importance of speaking to other siblings also in a similar situation; (8) *social support*: the need for further support from parents and friends; (9) *dealing with the outside world*: appreciation that the outside world was not always aware of their brothers' diagnosis due to the invisibility of ASD, but felt frustration when attempting to explain their brothers' diagnosis to others.

This study was able to identify the lived experiences of individuals of siblings diagnosed with ASD by capturing the participants' voices. The results shed light on the difficulties endured by these siblings and their need for further support. The findings that emerged from this study were also consistent with the themes presented in three other qualitative studies that explored the lived experiences of siblings of individuals diagnosed with ASD (aged 5 to 29 years) (Benderix & Siverberg, 2007; Mascha & Boucher, 2006; Petalas et al., 2012), specifically the difficulties associated with their siblings' challenging behaviours, current increased responsibilities, constant worry about their siblings, and feelings of embarrassment (see Appendix B for more information regarding Benderix & Siverberg, 2007, Mascha & Boucher, 2006 and Petalas et al., 2012).

However, it is important that the limitations of these studies are presented. Moyson and Roeyers (2012), Benderix and Sivberg (2007), Masha and Boucher (2006) and Petalas et al. (2012) all interviewed participants that were very young, some as young as six. It was likely that six year olds may have had difficulties accurately telling others about their experiences, which may reduce the credibility of their answers. Additionally, the interviews conducted by Masha and Boucher (2006) and Petalas et al. (2012) were approximately 20 minutes in length, which calls into question whether they were able to capture the experiences of siblings of individuals with ASD in this short period of time.

Huinker (2012) also investigated the experiences of siblings of individuals diagnosed with ASD, but she used strictly an adult population, unlike the previously mentioned qualitative sibling studies. Data were collected from six adults (five females and one male), aged eighteen to thirty-nine years, through semi-structured, one-on-one interviews. The researcher interviewed the sibling participants for 15 to 30 minutes and used the theoretical orientation of grounded theory. Eight themes emerged from the analysis: (1) *quality of relationship*: the majority reported having a high quality relationship with their sibling; (2) *pro-social behaviour*: all agreed that having a sibling diagnosed with ASD allowed them to acquire positive personality traits such as, becoming more patient with others; (3) *self-esteem*: the majority agreed their self-esteem was not affected as a result of having a sibling with ASD. The researcher did not specify if this was in regards to as a child or at the present time; (4) *academic performance*: some felt that having a sibling with ASD had negatively affected their academic performance, while one felt that having a sibling diagnosed with ASD positively influenced his academic performance; (5) *career choice*: majority agreed that having a sibling with ASD influenced their chosen career; (6) *parental treatment*: only two felt that they received unfair treatment from their parents, while the

others felt that there was no difference between the attention their sibling received and the attention they received; (7) *advantages of having a sibling diagnosed with ASD*: they felt that having a sibling with ASD made them more understanding and compassionate toward others; (8) *disadvantages of having a sibling diagnosed with ASD*: spoke about the difficulties of watching their sibling deal with challenges surrounding school and peers, and having to constantly worry about their siblings' well-being.

These findings shed light on the experiences of adult siblings of individuals with ASD by exploring negative and positives aspects. Positive aspects included becoming more patient and compassionate of others. While negative aspects included the difficulties associated with watching or hearing about their siblings getting bullied by peers. However, further research regarding an adult population will determine the accuracy and consistency of these findings as the study has considerable limitations. For example, it is questionable whether Huinker (2012) was able to sufficiently examine the experiences of her sibling participants by gathering data from only 15 to 30 minute interview sessions. Also, only six adults were interviewed and no mention of reaching saturation was discussed within the article. This may have contributed to the lack of detail regarding the emerging themes.

#### Gaps in Current Research and Rationale

The main focus of qualitative research regarding the family members of individuals with ASD has concentrated on parents, primarily mothers. Although this research is able to provide limited information on the difficulties endured by siblings, it does not provide sufficient detail that truly portrays the lived experiences of these siblings. Further, the few qualitative studies that specifically address the lived experiences of siblings of individuals with ASD have considerable limitations, which may affect the credibility of the findings. That said, the limited information

that is provided enables us to understand that this experience is difficult and demands further research.

More research regarding the lived experiences of adult siblings of individuals diagnosed with ASD is essential to understand the dynamics of this sibling relationship. Additionally, adult siblings can reflect on their experiences from when they were children to their present experiences as adults. Further, adult siblings may take on some responsibilities as caregivers in order to assist their parents or when their parents are no longer able to do so. Research that can identify their challenges can act as a framework for developing a necessary support system for these individuals.

The purpose of this study was to examine the lived experiences of adult siblings of individuals with Autism Spectrum Disorders. As such, the specific research questions that were addressed include:

1. How does a sibling without ASD define the relationship they share with their sibling with ASD, reflecting on any changes from the past to the present?
2. How does having a sibling with ASD impact the life of a sibling without ASD?
3. What are the costs of having a sibling with ASD?
4. What are the benefits of having a sibling with ASD?
5. What are the coping mechanisms the sibling without ASD utilizes with regards to their sibling with ASD (if any)?

## **METHODOLOGY**

### Research Design

The purpose of my study was to examine the lived experiences of adult siblings of individuals with ASD. To fulfill this purpose and to answer my research questions, the most appropriate methodology to guide this research was a qualitative methodology. I felt that this methodology could provide me with deeper insights into the sibling experience. More specifically, the theoretical approach used to guide this research was phenomenology.

Phenomenology is the study of the essence of the experience of a particular phenomenon (Patton, 2002). Phenomenology aims to explore “How human beings make sense of experience and transform experience into consciousness, both individually and as shared meaning” (Patton, 2002, p. 104). This was the most suitable approach for the present research study as the aim was to thoroughly understand the lived experiences of siblings of individuals with ASD.

Phenomenology is accomplished by “Carefully and thoroughly capturing and describing how people experience some phenomenon- how they perceive it, describe it, feel about it, judge it, remember it, make sense of it, and talk about it with others” (p. 104). To accurately capture these lived experiences, participants were siblings of those with ASD.

I gave background questionnaires to participants prior to the interviews to provide me with contextual information for the interview. The participants provided information, which helped in leading appropriate discussions and the development of suitable probes for the interviews. The one-on-one semi structured interviews captured the participants’ voices by allowing them to relay their lived experiences regarding their relationship with their sibling diagnosed with ASD. The interviews also provided me with raw data, such as direct quotations, that revealed in-depth emotion, accurately portraying the participants’ experiences (Patton,



2002). To ensure accuracy of the transcribed interviews, member checks were used. By obtaining data from each of the explained methods, the essence of the participants' lived experiences were explored.

### Sampling Strategy and Participants

To accurately portray the lived experiences of adult siblings of individuals with ASD, I asked participants who had experienced this phenomenon firsthand to participate in the study (Patton, 2002). I used purposeful sampling, more specifically criterion sampling and snowball sampling, as well as eliciting the help of key informants.

I recruited participants through word of mouth and by distributing a poster to facilities that serve individuals with developmental disabilities, primarily ASD. To see the research poster, please refer to Appendix C. Potential participants who contacted me were assessed to ensure they met the study criteria and were able to provide information-rich data. The study's criteria included: the participant had to be an adult, aged 18 years of age or older and had to be a non-ASD sibling of an individual who had been formally diagnosed with ASD. In addition to criterion sampling, I also employed snowball sampling. This involved me asking my participants to recommend any individuals known to them who were also suitable for my study (Patton, 2002). A total of 10 participants were recruited. Recruitment ceased once my supervisors and I believed saturation was reached.

### Ethics

Prior to the study, all tools and procedures were approved by the Wilfrid Laurier University Research Ethics Board. Upon receiving ethics approval, participant recruitment ensued. Consent was obtained from each participant prior to partaking in the study. To see the sent consent form, please refer to Appendix D.

## Procedure

The following tools were used to collect data: background questionnaires, semi-structured interviews, field notes, member checks and photos.

### *Background Questionnaire*

I gave a background questionnaire to my participants by email or in person or prior to the interview. The goal of this questionnaire was to gather general information about each participant and his/her sibling with ASD. I used this information to guide the interview, providing context and areas for further discussion. The questionnaire addressed the following areas: (1) demographic information (such as age, sex, education, living situation, employment and marital status); (2) background information regarding the sibling with ASD (such as age, gender, date of diagnosis, and typical behaviours); and (3) information regarding the relationship between the participants and their sibling with ASD (such as questions concerning the closeness of their relationship, the impact the sibling's diagnosis had on their life and how their relationship with their sibling with ASD has changed throughout their life course). To see the background questionnaire, please refer to Appendix E.

### *Interviews*

I conducted a one-on-one semi-structured, face-to-face interview with each participant, in order to capture his/her voice and gain in-depth knowledge regarding his/her lived experiences. These interviews took place at a time and place of convenience for the interviewees. Nine of the participants completed one interview. One participant had a very different experience compared to the other nine participants therefore he was considered a negative case. To develop further knowledge regarding his lived experiences, I conducted a second interview with this participant. All of his results are presented in a different chapter (To see results, please refer to chapter 5).

The interviews with the nine participants ranged from 39 minutes to an hour and 38 minutes, with an average length of an hour and 3 minutes. The first interview conducted with the negative case was 38 minutes and the second interview was 23 minutes in length. For one of the participants meeting in person was not possible, therefore the interview took place over Skype. The rest of the interviews were all completed in person.

The interview consisted of 13 open-ended questions concerning the following areas: how the participant currently viewed their relationship with their sibling; how their relationship with their sibling had changed throughout their life course; the impact the sibling's diagnosis had on the participant's life (e.g. their personality traits, relationships, career choice); the costs and the benefits of having a sibling with ASD; how the perception of their sibling's diagnosis had changed throughout their life course; and any coping mechanisms they have utilized with regards to their sibling's diagnosis. The process of interviewing ended when my supervisors and I believed saturation was reached. Saturation is defined as "Bringing new participants continually into the study until the data set is complete, as indicated by data replication or redundancy" (Bowen, 2008, p.142). Reaching the point of saturation enhanced the trustworthiness and credibility of the study.

I recorded all interviews and they were all transcribed verbatim, for a total of 231 pages of transcripts. To ensure the privacy of my participants, pseudonyms were used rather than the participants' actual names and all other identifying information was removed. To see the interview questions, please refer to Appendix F.

### *Photography*

My participants had the option of providing me with pictures that they felt represented their past and/or present relationship with their sibling (e.g. a picture of a park they often went to

when they were children). The photographs did not have to contain the sibling pair in them, but rather depict a memory of the relationship between the sibling participant and their sibling with ASD. Two participants chose to do so. One participant provided me with the pictures electronically and the other participant brought them to the interview. I did not keep these photos. Harper (2000) states the following: “From the phenomenological perspective, photographs express the artistic, emotional, or experiential intent of the photographer” (p.727). Stzo, Furman and Langer (2005) state that photography is considered a credible data collection method as it provides a direct representation of reality, therefore accurately portraying the participants’ perceived relationship with their sibling. Although the photos prompted the two participants to reflect on their relationship with their sibling with ASD, the photos did not provide me with enough data that described their lived experiences. Overall, the photos did not enhance my understanding of their lived experiences of being a sibling of an individual with ASD and were not used in data analysis.

### *Field Notes*

In order to assist with the analysis of data and to ensure its accuracy. I completed field notes prior to, during and after each interview. As stated by Patton (2002), “Field notes contain the descriptive information that will permit you to return to an observation later during analysis” (p. 303). The field notes described where and when the interview took place, in addition to information pertaining to the interview itself, including: the participant’s reactions, changes in their demeanor, changes in the intensity of their emotions, and any pauses they took while speaking (Patton, 2002). I used the field notes when transcribing and analyzing the data. For example, the field notes would remind me if a participant was using sarcasm or expressing certain emotions such as sadness or happiness.

### *Member Checks*

After the interviews were transcribed verbatim, participants were given the option to complete a member check. The member check provided the interviewee with the opportunity to clarify and/ or elaborate on any areas that may not have been clear during the interview, and to include any details they may have forgotten to mention. This member check also allowed my participants to omit any information from the interview that they no longer felt comfortable disclosing (Lincoln & Guba, 1985), offering some degree of control over what was analyzed. Their member checks were all sent via email, as this seemed to be the preferred method for distribution. After completing their member check, I asked my participants to send the document back to me by email. Of the ten member checks that were sent out, six participants' member checks were returned. Four of the participants stated that they did not need to omit, clarify or elaborate on any of the data. They also provided me with the answers to the questions asked. One participant chose to remove information that she felt might reveal who she and her sibling were, in addition to elaborating on information that she felt was too vague. She also answered all questions included in her member check. Additionally, one individual removed information from his transcript that he no longer felt comfortable sharing. The completion of the member check further contributed to the credibility and trustworthiness of the data, by ensuring that the information provided by the participants was accurately conveyed their thoughts and feelings (Lincoln & Guba, 1985).

### Credibility

Credibility of my study was enhanced through the completion of an extensive literature review and the use of rigorous methods, in addition to my experience and knowledge in ASD populations and qualitative research. Prior to the data collection, I completed a thorough review

of research pertaining to the lived experiences of siblings and caregivers of individuals with ASD. Further, I have completed a qualitative research course at the graduate level, ethics training (TCPS-2) and was a member of a graduate qualitative study group (consisting of graduate students and undergraduate students as well as two experienced researchers) that regularly met to examine and discuss data from ongoing research studies. Also, I have worked extensively with individuals with ASD. For the past three years I have volunteered at camps, fitness/ physical education classes and recreational programs for individuals with disabilities, primarily ASD. Additionally, I tried to build a positive rapport and trust with my participants through the use of consent forms, member checks and consistent communication throughout their involvement in the research. Rather than focusing on sheer sample size, I only addressed information-rich cases (Patton, 2002). Information-rich cases provided in-depth information. As well, both data triangulation and investigator triangulation were employed, this will be discussed below.

### *Triangulation*

To enhance the trustworthiness of my data, two methods of triangulation were used, namely data triangulation and investigator triangulation. Data triangulation involves using multiple sources of data (Patton, 2002). For this study, background questionnaires, semi-structured interviews, field notes, photos and member checks were all used to collect data. The use of multiple data collection sources is recommended by Patton (2002) to strengthen the study. Investigator triangulation is “The use of multiple perspectives to interpret a single set of data” (Patton, 2002, p. 347).” I analyzed the data, with the assistance of my two supervisors. Additionally the data were examined and discussed by the graduate study qualitative group. The use of data and investigator triangulation not only enhanced the credibility of my study, but also assisted in reducing any potential research bias that may have resulted if a single person

collected and analyzed all of the data (Patton, 2002). For example, the themes that emerged from the data analysis process were all agreed upon by myself and my two supervisors.

### Analysis

My analytic process followed the steps recommended by Moustakas (1994). The first step was *époche*, which required that I refrain from judgment by looking at the experience with an open mind, setting aside any preconceived opinions I may have, and acknowledging my personal biases. I accomplished this by taking note of any pre-existing opinions prior, during, and after all interviews. These notes were readily available for my review throughout the entire research study. Further, I refrained from pre-judgments and becoming personally involved with the participants. I accomplished this by providing neutral responses and reactions to all participants throughout the interview process. The second step was *phenomenological reduction*, which involved identifying the data in pure form by recognizing key phrases and statements pertaining to the phenomenon of interest, and then assigning appropriate meanings to these key phrases. This assisted me in identifying the meanings behind the reoccurring themes. The last part of this step was to provide a tentative statement pertaining to the reoccurring themes. The third step was *horizontalization* and *delimitation* which requires examining all data with equal weight, organizing the data into meaningful clusters and removing irrelevant and recurring data. By doing so, significant themes were identified. The fourth step was *textural portrayal*, a description of an experience that does not contain the phenomenon itself, providing content and illustration. The fifth and final step was the *establishment of structural descriptions*, which involved searching for deeper meanings of the representations of the participants' unique experiences. After the completion of all five steps, textural portrayal and the establishment of

structural descriptions were integrated (Moustaka, 1994). Through the completion of these steps, the essences of the lived experiences of individuals of siblings with ASD were unveiled.



## RESULTS

The participants in my study included seven females and three males. My participants ranged from 19 to 28 years of age (mean=23 years). For more detail on participants, please refer to Table 1. Nine participants had only one sibling diagnosed with ASD. The remaining participant had two siblings diagnosed with ASD, specifically both of the siblings had PDD-NOS. Siblings with ASD ranged from 18 to 33 years of age (mean=22 years) and 9 of these individuals were males and 1 was female. In terms of the specific diagnoses of these individuals, six had been diagnosed with autism, three had been diagnosed with Asperger's syndrome and two had been diagnosed with PDD-NOS. Siblings were diagnosed between the ages of 2.5 to 25 years old, with a mean age of 7 years. Two of my participants were not biologically related to their sibling with ASD, and considered them step-siblings. All siblings with ASD lived at home with both parents. For more details regarding the siblings with ASD please refer to Table 2. Five participants currently live with their sibling and five participants did not. More than half of the participants (n=6) reported that their current relationship with their sibling has improved compared to their childhood relationship. The remaining participants stated that their sibling relationship had not changed from their childhood relationship. The majority of my participants reported that having a sibling affected them during childhood and adulthood in areas such as family relationships and emotional health.

**Table 1: Background information on participants**

	<b>P1 “Greg”</b>	<b>P2 “Liz”</b>	<b>P3 “Max”</b>	<b>P4 “Laura”</b>	<b>P5 “Olivia”</b>	<b>P6 “Mya”</b>	<b>P7 “Chloe”</b>	<b>P8 “Ava”</b>	<b>P9 “Liam”</b>	<b>P10 “Lilly”</b>
<b>Sex</b>	Male	Female	Male	Female	Female	Female	Female	Female	Male	Female
<b>Birth date</b>	Feb 11, 1990	Aug 20, 1992	May 5, 1986	July 19, 1993	May 21, 1992	April 17, 1994	Dec 10, 1987	May 7, 1992	Dec 9, 1990	May 5, 1994
<b># of siblings</b>	4	1	2	1	4	3	1	2	2	3
<b>Lives with ASD sibling</b>	No	No	No	Yes	No	Yes	No	Yes	Yes	Yes
<b>Child relationship</b>	Poor	Good	Fair	Good	Good	Excellent	Good	Excellent	Good	Poor
<b>Adult relationship</b>	Poor	Good, but better than before	Good	Good	Excellent	Excellent	Excellent	Excellent	Excellent	Excellent

**Table 2: Background information on siblings (with ASD) of participants**

	S1 "Cody"	S2 "Markus"	S3 "Russ"	S4 "Scott"	S5A "Jack "	S5B "Devon"	S6 "Dustin"	S7 "Ethan"	S8 "Vince"	S9 "Mason"	S10 "Sophie"
<b>Birthdate</b>	July 13 1995	Aug 2, 1996	Aug 2, 1980	Dec 27, 1996	Nov 10, 1990	April, 11, 1994	July 13, 1995	Feb 28, ,1990	Aug 5, 1990	Feb 25, 1993	Nov, 1990
<b>Diagnosis</b>	Autism	Autism	Asperger's Syndrome	Asperger's Syndrome	PDD- NOS	PDD- NOS	ASD	ASD	Asperger's Syndrome	Autism	Autism
<b>Other conditions</b>	None	None	None	M.I.D, global learning disability, generalized anxiety disorder, bilateral hearing loss	None	Epilepsy	Mood disorder	OCD, anxiety disorder, ADHD, sensory processing disorder	Asthma, allergies	None	None
<b>Age of diagnosis</b>	3	5	25	9	5.5	5.5	3	4	10	2/3	3
<b>Primary caregiver</b>	Mother	Parents	Father	None	Parents	Parents	Parents	Parents	None	None	Yes, babysitter

## **Themes**

Analysis of the data revealed four major themes regarding the lived experiences of adult siblings of individuals with ASD. The themes were: (1) The insights of having a sibling with ASD; (2) It gets better with time; (3) Taking the good with the bad; and (4) A glimpse into the future (Table 3). However, the themes mentioned only applied to nine of the ten participants, as they shared very similar experiences. One participant, who was considered to be a negative case, had a unique experience when compared to the other participants. A negative case is defined as representing, “A dimensional extreme or variation on the conceptualization of data” (Corbin & Strauss, p.263). Therefore, his results will be presented separately. Each of the themes will be discussed in turn.

**Table 3: Themes and subthemes**

**Lived Experiences of Adult Siblings of Individuals with ASD**

<b>Themes</b>	<b>Subthemes</b>
1. The insights of having a sibling with ASD	a) I realized when... b) Acknowledging the improvement of their siblings' behaviours over time c) Looking beyond their siblings' ASD
2. It gets better with time	a) Trials and tribulations: The childhood relationship b) Appreciation and acceptance: The adulthood relationship c) The could-haves and the guilt: Reflecting on the past
3. Taking the good with the bad	a) The hardships associated with having a sibling with ASD b) The benefits associated with having a sibling with ASD
4. A glimpse into the future	a) Concerns, concerns, concerns! b) Will I be a future caregiver? The roles and responsibilities that lie ahead c) In a perfect world...

## 1. The insights of having a sibling with ASD

My participants brought up many of their own insights about having a sibling with ASD. Many of these insights were very similar and required that they reflect on vivid memories of their siblings with ASD. This theme was broken down into the following subthemes: (a) I realized when...; (b) Acknowledging the improvement of their siblings' behaviours overtime; and (c) Looking beyond their siblings' ASD.

### 1.1. I realized when...

All of my participants vividly remembered the moment they realized that their sibling was much different from themselves and others. Laura recalled a specific family event at which she began to question her brother's behaviours.

*I remember one Christmas it was really, really loud 'cause there were so many of us. My brother was just four, so he was little. My brother just sat on the stairs and covered his ears. So he just sat and wouldn't come and open presents with everybody, 'cause we were like, everywhere. We had, like, 2 dogs and my grandparents were over, so there [were] a lot of people. So he couldn't take it. So, he just sat and covered his ears. And I was like, "Why isn't he opening presents?" Like, "Why is it so hard for him to open presents with everybody?" ~ Laura*

Several participants detected differences in their sibling's behaviours when they compared them to that of other children.

*I remember when I was in, whatever grade, and he was in kindergarten and we had, like, reading buddies.... Like, I guess I remember seeing him compared to the other kids like, he was **so** quiet and like other kids were, like, reading and stuff. And I was like, "Whoa," and then that is when I realized. And they partnered me with him because he wasn't comfortable with any other kids. So I don't know, I guess that is when I realized like "... he is different." ~Liz*

*He didn't start talking until he was three... he would do this thing with his hands when he got nervous, or he would cover his ears when it got really loud. And I just thought he was nervous. So I was like, "Meh whatever, maybe like, that is just something that he does." Then as I started to get older and he started getting older, it became more obvious as to what he had. So I could kinda point out the different things like, it's weird when he claps his hands because not everyone does that when they get scared. ~Laura*

*I think I could tell that there were certain, um, things that he would do that didn't seem to match up with other kids....Um, he didn't engage in conversation for one. Like, if you asked him a question he'd respond but he [wouldn't] really initiate conversation, unless he [wanted] something, or if he [had] something very specific to say. ~Chloe*

One participant acknowledged that her two brothers with PDD-NOS were different when she noticed that they had not met a number of developmental milestones.

*They weren't, like, with toilet training was, you know, you know when I was three, that is when I was toilet trained. They took a little longer. So when I was toilet trained, Jack, he was the older one, was still in diapers or pull-ups or whatever. So both of them didn't get toilet trained until they were like five and a half or five. ~Olivia*

Ava acknowledged her brother's disability from the reactions of others, in addition to realizing her brother's behaviours were different. These reactions further substantiated her belief that her brother was different from other people.

*But what I think what really, **really**, drew attention of it to me was other kids making fun of him. So a lot of the time I remember in the playground, someone would make fun of him or say something to him. And he would come up to me and be crying because someone would say something. And being a younger sister, it's a little awkward because it was like, "Okay I have to be a little more protective now".... And even my friends growing up would be like "Your brother is different" or like "Your brother is weird."*

Unlike many of the other participants, Ava was able to recall her parents telling her about her brother's diagnosis when she was seven years old. This allowed for her to compare her feelings of her initial memories of her brother's condition prior to diagnosis to when her parents told her about the formal diagnosis.

*I remember when my parents were like, "Okay, this is what your brother has, Asperger's, and here is some information about what he has, and if you have any questions, like, ask us about it, or your brother about it." And I just remember being a lot more emotional about it. I don't know why. Like, I almost felt sad 'cause it's like "Oh my God, he has, actually has something that makes him different, like a doctor says he has something." I, I, I don't know why, I was just a lot more emotional... because when kids came up to me or something like that, I was more defensive and like "No he's not, this is normal" and whatever. But then*

*when, when it comes from your parents, it stirs up a lot more. And it's like, your parents are like, "No, he actually is different than everybody else." And it kind of throws away all the beliefs you had originally. I was definitely a lot more emotional about it when my parents told us that there was an actual diagnosis and he actually does have something...~Ava*

Although many participants recognized their sibling's disability in a different way, they were all able to recall a specific memory in which they became most aware of their sibling's ASD. They were able to describe this memory in great detail as well as the emotions they were feeling at that time.

### *1.2. Acknowledging the improvement of their siblings' behaviours over time*

The impairments exhibited by the siblings of the participants varied greatly; however, all participants acknowledged that their siblings' behaviors had improved substantially over the years. In particular, many participants stated that their sibling no longer exhibited physically "violent" and "aggressive" behaviours.

*Not violent, like he'll now, he is more [verbally]. Like, he will say to my mom "Oh, I hate you" or whatever.... I don't remember the last time that he hit somebody.~ Liz*

*They [behaviors] have **definitely** improved **a lot**...the last time she was, I can't even say violent because it was barely even violent, was a couple years ago. And that was the first time in like, at least five years that I had seen it. ~Lilly*

*If he would get upset, he would smash them [mirror doors] in. I remember one time we were eating dinner and he got upset and he smashed a plate. Um, yah, like uh, hitting sometimes and, just like, the progress that he has made since then is tremendous. He doesn't do any of that stuff now.... Yah, he has made a big improvement. I think the only aggressive thing he does, he bites his hand when he gets upset, which is a big change from smashing plates. ~ Mya*

Participants also conveyed that their siblings had become more independent and self-sufficient in recent years.

*He can kinda do things on his own. Or like, if my sister and I are home we'll be like, "Don't forget to load the dishwasher." ... It's not to the point where he has to ask us constantly to help him with this and with that. Like, he is pretty independent now. ~Laura*



*He's obviously improved because he's learned more tangible, like, more practical things that he can do...as much as he doesn't like it [long pause]. For example, now he'll help clean around the house. ~Liam*

Since Olivia's brothers' behaviours improved, family outings had become a lot easier.

*Things are a lot less frustrating. Especially for my parents because they are a lot more mature....Any family, like, outings, so, if we were going to a restaurant today, we would have no problems with them. But when they were little you would have to, you know, make sure they ordered the right foods.... They would just be a lot more difficult to deal with but now if we go to the restaurant, it's easy.*

All participants spoke about the improvements in their siblings' behaviours. Most commonly, their siblings were less "violent" and "aggressive" than they were as children. Additionally, a few participants conveyed that in more recent years, their siblings were able to complete tasks more independently.

### *1.3. Looking beyond their siblings' ASD*

When participants spoke about their sibling, interestingly they did not use their siblings' ASD to describe them. Instead they placed a strong emphasis on other positive attributes that their sibling possessed or how their sibling influenced the development of specific traits within themselves. For example, the following participants described their siblings as "special" and having a "gentle soul."

*I don't wish that he was different...he's special. It is easier for me to appreciate that in more recent years. He is, like, really progressing and like, he is a really great kid. I wouldn't want him to be any different... ~Liz*

*She has the most gentle soul ever. She is a sweetheart, she's like, oh my goodness, the best. ~Lilly*

Laura stated that her brother enabled her to better understand others. She also discussed that her brother, Scott, was not defined by his Asperger's.

*It made me kinda have an appreciation for those that have this...because I can kinda understand but not relate to them, but understand what it is that they are going through.... Asperger's isn't Scott, Scott is so many different things. Like, that that doesn't define him....There is more to him than just Asperger's.*

Lilly stated that her sibling, Sophie positively affected her family's relationship as a whole.

*Over time I realized that she really is [pause] like, she's even been the reason for our family being so strong too. Because there are so many things that we do together just for Sophie. And that brings us closer.*

It is evident that many participants spoke very highly of their siblings. All participants described their sibling using thoughtful terms and spoke about how their siblings had positively influenced them, as well as their family members.

## **2. It gets better with time**

All of my participants spent a large portion of the interview discussing the relationship they shared with their siblings. All participants conveyed that their relationships with their siblings had improved in recent years. The subthemes within this theme were: (a) Trials and tribulations: The childhood relationship; (b) Appreciation and acceptance: The adulthood relationship; and (c) The could-haves and the guilt: Reflecting on the past.

### *2.1. Trials and tribulations: The childhood relationship*

For the majority of the participants, the childhood relationship they shared with their sibling was associated with many difficulties that prevented them from having a close relationship. In particular, several participants stated that they had negative feelings associated with their sibling such as embarrassment, resentment, helplessness and fear.

*I felt ashamed maybe for him, if that is the right phrase, and embarrassed. And like, I said maybe some resentment towards my brother 'cause he made one of my friends feel awkward. Um, I think helplessness is probably another one, because I knew there was nothing I could do about it. ~Max*

*Growing up, it was a lot more for me. Sometimes [it was] difficult to accept that he was different. Once I kinda figured it out with all the social situations we were in and, part of me was like, [long pause] I guess upset. Because I was scared if people thought he was weird, it meant that I was weird as well, because we were brother and sister.... I can honestly say that there were some instances that I was*

*just embarrassed, because he would be really upset, and would start crying and make a scene, and then I would have to calm him down. ~Ava*

*When I was younger, I was more embarrassed, I guess. And like now I am like “Yah, my brother is autistic.” But when I was younger I would be less inclined to say that. ~Liz*

Another difficulty that a few participants’ experienced as children was trying to comprehend their siblings’ diagnosis. This too served as a barrier that prevented participants from having a close relationship with their siblings.

*When I was a child it was like, more difficult for me to grasp that they are PDD, so they are gonna act in different ways. Like, I would always ask my parents, “Why are they like this?” And my parents would be like, “Just because.” And it was just, you know, frustrating because [long pause]... I had a few friends that have like, older siblings around the same age difference between me and Jack. So it was frustrating to see them and how they interact with their siblings. And how I interacted with Jack and Devon was completely different... because they weren’t interested in the same things as I was, so it was a lot harder to get along. ~Olivia*

Due to the difficulty of understanding their siblings’ diagnoses, this made it challenging to explain their siblings’ ASD to others.

*When I was a kid, I found it difficult to explain autism to other children. Most children did not know about autism, and I also had a hard time figuring out the best way to explain it. I had many questions myself. ~Chloe*

My participants all conveyed that their childhood was associated with difficulties regarding their sibling with ASD. These difficulties subsequently strained their relationships with their siblings at this time. Many of the participants reported a host of negative emotions as a result of the ASD and found it challenging to understand their siblings’ disability itself.

## *2.2. Appreciation and acceptance: The adulthood relationship*

On the contrary, all of my participants conveyed that their current relationships had improved greatly from their childhood relationships. Several participants reported that their increased understanding regarding their sibling’s ASD or of ASD in general, enabled them to become closer to their siblings.

*I guess it has changed since I was younger because when I was younger, I didn't know him that well, or the disorder that much ...I wasn't so interactive with him as I am now, or didn't have the sympathy and protectiveness as I do now....I think we've gotten a lot closer, especially me learning so much from my mom, and just being around him has gotten our relationship a little stronger. ~Mya*

*I think generally our relationship has gotten stronger over the years. Yah, it was never, um, it was never bad or anything like that. But I think, um [long pause] I feel like even the work that I have done in disabilities studies has made me, has sorta changed my perspective on a lot of things. [This] has made me a better sister in some ways. ~Chloe*

*Now I understand that autism is very common, it affects a lot of people worldwide. So that definitely helps, and like I said before, I don't feel so alone in this situation....When I was little like I didn't get that, I just, I was just like "Why do they have to be like this?" And that was pretty much the end of it. ~Olivia*

As well, many of my participants reported that they had become more accepting of the ASD diagnosis itself.

*We have a good working relationship now. And I feel like it's a better relationship than it was, because even I started struggling with, he's different, and now I feel like people are going to judge me because he was different.... But now growing up everyone's a lot more accepting of him, and everyone's a lot more mature. And I think because of that it is a lot easier. ~Ava*

*I am definitely more accepting of them. Like I don't wish that they were normal because I like the way that they are. And I think there is a reason that is the way they are, just to teach, to teach other people about PDD. ~Olivia*

Additionally, the majority of participants stated that they had become more appreciative of their sibling in more recent years.

*I do appreciate um, the sibling relationship more as I [get] older for sure.... Um, I think just getting older and becoming more cognizant of the difficulties that he faced. ~Chloe*

*I think it's because I matured a lot as well. So I stopped egging her on. I again started to appreciate her. I started spending more time with her. Um, and that made me realize, like, I guess the person within her, behind her autism. And um, she's like an inspiration to me, because she just cares so much for everybody else and [pause] she's just filled with love. ~Lilly*

All participants reported that their relationships with their siblings had improved in recent years. This typically resulted from acceptance and increased understanding regarding their siblings and their ASD, in addition to their newfound ability to appreciate their siblings.

### 2.3. *The could-haves & the guilt: Reflecting on the past*

When reflecting on the past, several of my participants revealed that they wished they had acted differently towards their siblings in the past. Additionally, participants realized things now as an adult that never occurred to them as a child. Participants mentioned the guilt they felt when reflecting on the judgment and lack of understanding they exhibited towards their siblings as children.

*I felt guilty in some ways 'cause I knew that I had maybe judged him to be um, you know, different or, or strange....I realized that I should have, I don't know, I shouldn't have been so quick to judge him before. ~Max*

*I feel very close to him. Sometimes, like I'll feel a little guilty about when I was younger and I wasn't quite understanding. You know, I would get upset if he broke things ....Like, even though I would see him in school, I don't think I appreciated to the full extent just how important it was to my parents that he was at the same school. So you know, we would see each other in passing, but I don't know that I made a really strong effort to, like, involve him in my friend group or things like that. Which maybe I could have done... ~Chloe*

Several participants stated that they were now able to better understand the behaviours exhibited by their sibling, compared to when they were children.

*You know what they, say hindsight is 20/20. So I know now why he behaved certain ways. And um, just some things that happened I understand a lot better. Um, but back then I didn't. ~Max*

One participant compared her past feelings to her current feelings towards her sister. As a result, she stated what she felt she should have done as a child.

*I think beforehand when I was little, I don't know how to say it, but I feel like, I felt a little bit different even though it wasn't me, it was my sister. But, um I think I was probably more self-conscious about that. Whereas now, that is something that I would boast about. But like beforehand, I think that was something that I would try and keep more to myself. Um, or if people saw my sister and, um, they*

*would say talk poorly about her, depending on who it was, like if I was friends with them or if I was trying to impress them, it would definitely change things...which obviously shows that I didn't accept her. Um, but I know if I had of listened to her more, and spent more time with her, put some effort into understanding her. Um, then it would have, have a huge impact and I would not be the person I am today. Like with Sophie, as it is now, I'm a totally, completely different person but beforehand, I feel like that would have changed me so much more. Because she can give you so many skills, like patience, and like, she can just teach you to love other things. ~Lilly*

Max's brother did not get diagnosed with Asperger's syndrome until he was 25 years old and Max was 19 years old. As a result, he wished that his past had transpired differently.

*For my older brother with Asperger's, I mean that was difficult to have his own brothers avoid him....Now I, I feel really bad um, I wish that I, we had known, not just me but all, everyone in our, in my family. I wish we known that he had Asperger's, and I wish we had someone that could have walked us through it. ~Max*

While participants reflected on the past, many revealed the guilt they felt regarding the way they had previously treated their siblings. Additionally, participants were able to analyze their feelings and actions as children, which often led the participants to express ways in which they should have (or could have) behaved differently.

### **3. Taking the good with the bad**

All of my participants reported that having a sibling with ASD was not entirely negative, nor was it entirely positive. Having a sibling with ASD presented many hardships, in addition to many benefits. Two subthemes emerged from this theme: (a) The hardships associated with having a sibling with ASD; and (b) The benefits associated with having a sibling with ASD.

#### *3.1. The hardships associated with having a sibling with ASD*

When asked about the costs associated with having a sibling with ASD, all of my participants spoke of the many difficulties that they encountered. In particular, a few participants

mentioned the restrictions they had in terms of family outings. These restrictions applied mostly to when they were children, and no longer existed.

*We didn't really get to do a lot of stuff because Scott would have outbursts and stuff like that....And not be able to sit in a restaurant because it was too loud. And um, not being able to go to the movie theater, because it was too loud. But now we can because he is fine, but when I was little, we didn't do a lot of that stuff.*

**~Laura**

*We wouldn't have been able to participate in activities with the family that were really loud or things like that.* **~Chloe**

A few of my participants also spoke about the frustration they felt regarding the unequal treatment they received by their parents.

*I think it was hard for me to get attention when I was little. Just because Jack and Devon, 'cause of their disability, they needed more attention. So I think that is why I got into, you know, sports. Just so I'd have my own little niche. That is how I got my parents' attention....It was frustrating because it was like "Hey, you have a kid in between." **~Olivia***

*I felt underappreciated when I was younger, and I felt like a lot of resentment and jealousy I guess.* **~Liz**

One participant expressed her current frustration regarding the different treatment her brother received from her parents.

*Now we have our own responsibilities at home. It's kinda, like, it's frustrating in that sense, because everybody else would get in trouble for doing that and he gets in trouble half the time.* **~Laura**

Another common hardship that participants described was hearing about their sibling getting bullied because of her/his ASD.

*That just has to do with the bullying, it makes me sad! Like any kids hearing that, it's hard to hear about your brother.* **~ Laura**

*Bullying was a very large, large component of Vince's life when he was younger. Um, students used to bully him all the time. They used to threaten him...between the ages around, I'm gonna say 8 to about 15 is when he had it the worst....Bullying was definitely a huge component of his life that he went through a lot, and it's really unfortunate.* **~Ava**

One participant mentioned the emotional distress she currently experiences as a result of not being able to have a close relationship with her sibling.

*The other day when I called him to, like, talk and he didn't wanna talk.... I wish we could be closer on that level....It's hard because when I'm here [school], if we are not gonna talk on the phone, then we're not talking at all....Just the fact like we can't talk about certain things and like, so it's like hard and being sad for that.... Less emotional distress and more just like sad, I guess sometimes when stuff like that happens because it does make me sad. ~Liz*

The majority of the hardships associated with having siblings with ASD that participants experienced occurred when they were younger. Many of these difficulties no longer existed, but still remained significant memories for the participants. However, the exceptions were the frustrations associated with the lack of responsibility expected from the sibling with ASD, as well as not being able to have a close relationship with the sibling with ASD currently. In an attempt to manage the hardships associated with having a sibling with ASD, the majority of participants spoke of the different coping mechanisms they utilized with regards to their siblings' ASD. However, some participants felt that there was no need to cope. Of the participants who did utilize coping mechanisms, the most common was humour.

*With my brother and I, just to like kinda ease the tension or whatever, we always joke around. ~Liz*

*I like to laugh a lot...Scott makes me laugh. But like if I, like, just can't be with him for whatever reason, I'll go watch funny movies or sometimes a funny TV show.~ Laura*

In addition to humour, some participants stated that the support of their family and friends also assisted them to cope with their siblings' diagnosis.

*Talking to my parents and my sisters helped. Some of my friends that, you know, that knew my brothers a little bit more, the ones I allowed to come over because they knew my brothers from school. And obviously like humour and things like that. ~Olivia*



Conversely, some participants stated that it was not necessary to use coping mechanisms with regards to their siblings' ASD.

*Now, I don't think I would [use coping mechanisms]. Just because like nothing about Sophie really frustrates me anymore or like, even saddens me. ~Lilly*

*I never felt the need that his diagnosis was going to negatively affect me so much that I would need a coping mechanism or anything of the sort.~ Ava*

Another reason for participants who chose not to use coping mechanisms was that they would rather manage the stressors associated with their siblings as they occurred.

*I guess I've always dealt with it. So if he's doing something, I just deal with it instead of using other things to help. I feel like if he is having a temper tantrum, and I'm taking care of him then obviously I have to deal with it, instead of using a coping mechanism....It's so normal now that I don't need to do something to get my mind off it or, do anything to help me ease or anything. ~Mya*

Of the participants that described using coping mechanisms, the most prevalent coping mechanisms used were humour, as well as talking to family and friends. For the participants who had reported not using coping mechanisms, they stated that they just dealt with issues as soon as they occurred or that they did not experience the frustrations or stress required for coping.

### *3.2. The benefits associated with having a sibling with ASD*

On the bright side, all of my participants discussed the benefits of having a sibling with ASD. Specifically, the majority of the participants reported developing positive attributes, such as patience and compassion as a result of having a sibling with ASD.

*Probably like more like relaxed and patient. Yah, like, because sometimes you're like, "Holy crap, why is it taking him an hour to read this?" Like, but you're like, well he can't. You just gotta sit there and deal with him....Yah I feel like patience and understanding and, like, the ability to just like, take a break and...just do it with him and wait for him to be finished. Because in the end it's him that needs it, not me. ~Laura*

*Patience [laugh] I guess would be one of them because you have to be very patient with them. Because they're not gonna learn something as quickly as a child without autism. ~Mya*

*I've learned a lot more about myself. Be more compassionate hopefully, and caring. Um and uh, hopefully attention to details and being more considerate towards people. ~Liam*

Further, one participant reported that having a sibling with ASD influenced her interest regarding individuals with special needs.

*I'd honestly think that I can say in every single way of my life... I could relate it back to Sophie... Yah, like my job, the reason I'm in it is because... I'm so interested in special needs....I want to help people like Sophie and I want to make them better, and show them that they can be accepted and appreciated. ~Lilly*

Additionally, several of my participants felt that they had developed a stronger understanding and awareness regarding disabilities, in general.

*I think it makes me more aware of just people with disabilities, and like, the struggles that they have. I think I am more sensitive to stuff like that. ~Liz*

*I am more understanding, I feel like people who having not necessarily grown up with it, but haven't been around it a lot don't really know what's it's like.... I don't like say... "Retarded" and I get upset when people say that because, I don't know, it's not that nice....I have more of an appreciation of who they are .... I just feel like, I understand them more, and it's easier knowing that when you grow up with someone like that. ~Laura*

One participant mentioned that her sibling was able to put her in a better mood, in addition to leading her down a future career path.

*A benefit would be that like, I'm always, he can always put me in a good mood because...he is always happy all the time, or most of the time. I don't know if, um, I'm ever in a bad mood and Cody's around, I don't know, he kinda just like brightens my day a little bit.... I think he changed, I think I want to get in areas with kid or kids with disorders, especially with autism. It kinda has intrigued me to go down that path. ~Mya*

When discussing the overall experience of having a sibling with ASD, all participants conveyed that the experience had benefited them in one way or another. Max and Ava perceived that this

experience still involved some difficult times; however they did not overlook the positive aspects.

*It is like an adventure [laughs]. Um, you know there, there [are] definitely parts where it becomes hard and you have to try and deal with certain situations, and not become, I guess dragged down by it... and then there is also um, there [are] also good parts for sure. And um, yah like things I have learned from him... So, so he has taught me a lot about me. ~ Max*

*Overall, I would definitely say it is a positive thing....Growing up is a little more difficult. But now, I think it's overall a very, very positive thing. I have developed a lot of personality traits that will stay with me for the rest of my life, because I've had him as a sibling....I think it definitely resonates in any academic, career or relationship choice that I make as well. ~Ava*

The majority of the benefits reported were the favourable personality traits (e.g. patience, compassion) participants developed as a result of growing up with a sibling with ASD.

Additionally, several of my participants reported having an increased understanding of individuals with special needs. When participants spoke about their overall experiences associated with having a sibling with ASD, it was more positive than it was negative.

However for a few of the participants, it was not until recent years that they were able to realize this. Regardless, my participants all confirmed that there were many benefits associated with having a sibling with ASD.

#### **4. A glimpse into the future**

The theme that all my participants talked about the most was “a glimpse into the future.” When discussing the future, participants conveyed the many concerns they had, as well as the role they would like to assume or felt obligated to assume in caring for their siblings. The subthemes for this theme were: (a) Concerns, concerns, concerns!; (b) Will I be a future caregiver? The roles and responsibilities that lie ahead; and (c) In a perfect world...

#### 4.1. Concerns, concerns, concerns!

Many concerns were brought up regarding the future. Most of these concerns were regarding their involvement in their siblings' future.

*It is particularly hard because there is pressure for the future as well. Like, my mom still works and she probably will for a few more years. But, eventually in 10 or 15 years, they are both going to be nearing 70, and my brother is gonna be like you know, 45 or [46]. And they're probably not going to be able to take care of him that well. Um, so it's something to kinda think about for me, in terms of how much it is my responsibility to try to help as much as I can. Or, at least find someone that could help him....There is some pressure there, and it is stressful. ~Max*

*I know I'll have to look after him when he's older. That kinda worries me, but that's not gonna be for a while. I don't know how that'll play out, maybe a group home. Who knows what will happen in the future. ~Liam*

One participant mentioned her concern for her sibling's well-being in the future.

*I'm scared that, because she's getting older um, her capacity to learn is shortening....It makes things harder on her because she can't do the things she used to. It makes it harder on us because [pause] like, it's just the tiniest things, like we'll tell her to put her coat on... and she just looks at you. We'll continuously repeat it, and she'll just look at you. And that gets really frustrating, because she would have known what to do, like, a week before and now it's like, "Why aren't you doing it?" ~Lilly*

Further, Ava mentioned her concerns surrounding the pre-mature death of her sibling with ASD, as he does not lead a healthy lifestyle. She was also worried about how her brother would react if she were to pass away before he does. However, her main concern was the death of her parents and the effect their deaths would have on her brother and her new role as an immediate family member.

*He doesn't lead a very healthy or active lifestyle, because he isn't that coordinated. So exercise isn't a big thing for him. But like, and he doesn't watch what he eats...but he just does not exercise whatsoever. And it's something that concerns me, that his heart is gonna give out before mine does. It's just another concern. I'm hoping and praying that it doesn't happen anytime soon. But those are my two main concerns. One is that I end up outliving him and the other thing,*

*well, the other thing is what if I go before he does? Because I know that will be devastating for him. My main concern is that we both make it to the future and my parents are gone, now what? ~Ava*

All participants conveyed their concerns for the future with regards to their siblings with ASD.

The concerns participants stated caused them to worry and to question what the future will hold.

#### *4.2. Will I be a future caregiver? The roles and responsibilities that lie ahead*

As siblings of individuals with ASD, my participants reported that they would have to fulfill a caregiving role when their parents were no longer able to do so. However, the role in which each of my participants would assume differed. For Liz, she stated she would want to maintain the relationship her and her brother currently have.

*I mean trying to just maintain what we already have....Say he was living alone in a house, I would definitely, say I went over twice a week and make him dinner.... I mean, I would for sure want to be in his life and have some sort of relationship. It is hard to say. But I would definitely want to take on some sort of responsibility, I guess just to make it easier for him and for my parents.*

In Max's case, he reported that he would provide assistance to his brother as long as it did not affect his own life.

*Ideally I would, I would do as much as I can to help him and my parents to live comfortably, without that affecting what I wanna do.*

In some cases, a few participants described wanting to assume a full-time caregiving role and have their siblings move in with them.

*I remember my parents' idea was that he would have a primary caregiver, or something like that. And that makes me really uncomfortable thinking about something like that. That is the last thing I want. I don't want Vince to be taken care of by a stranger. I don't care if they're trained, I don't, I don't like that. Um, because they don't **know** Vince.... I remember me and my sister sat down and I was like "Well, I don't care if he comes and lives with me"... I know where he is gonna be at all times, and I know he'll be comfortable because he will be with me. And if it means that I have to center all of my relationships around that, whether it be romantic or professional, friendships, whatever then so be it. But at least I know he is safe, and he is somewhere that I can keep my eye on him so nothing bad happens....And I would much rather have him with me, because I know that he is comfortable with me. I know he wouldn't have a problem with it. I know that*

*I would be comfortable with it, and whoever the hell else is living with me at the time will sure as hell be comfortable with it, because if they're not, then they're gone [laughs]. ~Ava*

*I would prefer that he live with me than with, um, in a group home or institution. Um, I have kind of mentioned that to my parents, their sort of fear is "What if you have a job that makes that difficult? Or what if you have a partner that is not okay with that?" So they have raised concerns, but I think it makes them happy that I want to take an active role. ~ Chloe*

*I think that she would be living with me, I'd like that.... But then again she would also probably move around to my brothers.... But I do definitely think that she would be living with me for the majority of it. ~ Lilly*

All participants spoke about the role that they would ideally like to fulfill regarding taking care of their sibling in the future. It was evident that some participants felt a sense of obligation to assume a demanding caregiving role, while others stated they would prefer to assume a 24/7 caregiving role for their sibling.

#### *4.3. In a perfect world*

Several participants conveyed how the "perfect" future situation would unfold for their siblings. In all cases, participants wanted the best for their siblings' future. For example, several participants had hopes that their siblings would be independent, self-sufficient and hold a job.

*So I know he is capable of doing things like that [having a job]....It is just gonna be a slow process, and I hope that one day he will be able to be pretty self-sufficient. ~Liz*

*I just hope that he can get a good job, make money, live on his own, if he chooses to live on his own. ~ Laura*

One participant stated that she would like to see improvements in her step-brother's well-being.

*I'd like to see his moods more stabilized, I guess.... I know it's hard on himself, even taking so much medication... or having side effects from them. Like, for an example, he has lost so much weight just because of the medications. I know the lithium gives him the shakes. So like, in that sense I would like to see him, like, those things kinda calm down, and get to a really normal, steady state, and improve. ~Mya*

Although Chloe's perfect world consisted of an impractical reality, she wished that her brother was a little younger.

*I feel like, when I look at, um, you know, people who are like five years younger than Ethan, sometimes I wish he was five years younger.... Because I feel like there would have been so much more available.*

Even though Ava's parents suggested that her brother live in a group home or with a caregiver in the future, this was not a suitable arrangement for Ava.

*But should we live in the perfect world, and the world happens to be perfect, then that would be ideal, I would rather him living with me than anyone else. ~Ava*

It was evident that participants wanted the best for their siblings' future. Independence and well-being were significant factors in this issue.

All themes and subthemes described the lived experiences of adult sibling of individuals with ASD. All of my participants perceived that they experienced many hardships and many benefits of having a sibling with ASD. It was also conveyed that all participants' current relationships with their siblings had improved substantially over the years. Finally, my participants described their concerns regarding the future, specifically pertaining to their siblings' well-being, as well as the role they were obligated to assume.

## 5. The voice of the negative case

During the process of data analysis, it was evident that Greg's lived experiences of having a sibling with ASD were vastly different than that of the other participants. Greg perceived his lived experiences more negatively, as he described his hardships of having a sibling with ASD outweighed the benefits. As a result, Greg was considered a negative case. A negative case is defined as representing "A dimensional extreme or variation on the conceptualization of data (Corbin & Strauss, p.263)." Therefore, to gain further understanding regarding his lived experiences, a second interview was completed. This interview lasted 23 minutes (the first interview was 38 minutes) and consisted mainly of questions asking him to further explain and clarify his responses during the first interview. After both interviews were completed and transcribed, Greg was sent a member check. He was asked to read over both transcripts and clarify or elaborate on any information, or share new information, as well as omit any information he no longer felt comfortable sharing. Greg did remove information from his transcripts.

### 5.1. *When it all began...*

In 2002 when Greg was 12 years old, he lost his father to brain cancer. Two years later, Greg's mother met her soon to be husband. In 2006, they married. Greg's step-father had a son named Cody, who was diagnosed with low functioning autism. After Greg's mother met his future step-father, Greg experienced many unexpected events, such as having a step-brother who was autistic. When discussing this time period of his life, Greg stated "*So after my dad passed away, two years later this all just came into my life.*" The behaviours that Cody exhibited when Greg first met him caught him off guard. For example, when he described what Cody was like when he first met him, he used terms such as "scattered" and "weird."



*So you know, when he came over uh, I said “Hi” and he didn’t really say anything back. He kinda seemed, like scattered and was all over the place, right? ...He was doing a lot of, you know, weird movements with his hands, his tongue, his face. And you know, it wasn’t like us. So you know, it kinda took me by surprise.*

While reminiscing about this life-changing event, Greg reflected on the mixed-emotions he experienced that day.

*So I guess I didn’t really know if I actually liked it. It was different, right? It’s not what I was used to. And I would have said my life before was the **best thing ever**, right? And now, it’s different obviously. And it takes a while to get into it and used to it. It was different and weird, not anything I was used to. So it took me by surprise a little bit.*

During the second interview with Greg, I asked him if he could elaborate on previously having the “best life ever” and if this changed as a result of Cody becoming his step-brother. Greg conveyed the following:

*No I wouldn’t have said that it is solely because of him, ‘cause of **everything**, and everything that has changed, right? But, he’s obviously a pretty big factor in all of that... because it’s not just another brother that’s, I guess what we would call normal, right? It was someone who wasn’t like we were, it’s harder, right?*

When discussing all the events that took place after Greg’s father passed away and his mother’s second marriage, it was evident that this was a difficult time of transition for Greg. Undoubtedly, Cody was integral to this negative experience for Greg. For example, Cody’s behaviours were not only “surprising”, but it was also challenging for Greg to accept his new brother because he was not “normal.” Finally, Greg contributed majority of the blame on Cody for no longer having “the best life ever.”

## *5.2. Frustration with Cody’s behaviours & acknowledging his improvements*

Similar to the other participants, Greg acknowledged that his step-brother’s behaviours have improved greatly over the years. However unlike the other participants, Greg reported that

the behaviours that Cody exhibited during the time period when they first met as disrupting his life extensively, often causing him to leave his house for the day and night. Additionally, his sleep was affected by Cody's behaviours.

*Oh God screaming, like crazy screaming. Like, screaming fits to the point that I had to leave the house because I [was] going insane.....He [Cody] was always awake by like 6:00am or 7:00am.....So it got agitating because I couldn't sleep in or have quiet time, you know?*

Greg stated that he avoided home because of Cody's challenging behaviours.

*I was never home because of this and other issues. So I was always kinda out of the house more than I was actually home. [Me: What part of Cody kept you away from home? Or was there any part of Cody that made you avoid home?] I guess you could call it stimming, but he has a problem with temper tantrums and stomping. So, what would really get me annoyed is having a long work night at the restaurant, and then [coming] home and [going] to sleep. And it's like 7:00 in the morning and it's like, **stomp, stomp, stomp, stomp**, and you can't sleep, and then you're up at 7:00 in the morning. You're exhausted, you're grumpy, you are arguing and blah, blah and so on and so forth. It just never goes away.*

Fortunately, Cody's behaviours have improved in recent years. Greg illustrated this improvement by providing some examples and highlighting Cody's recent independence.

*Let's say a month ago, since the last time I [had] seen him, he is totally fine. He is a lot better and he is a lot more normal. He is speaking more, he is you know kinda saying "Hi" to me....He can fend for himself, let's put it that way. Like, he can do dishes, he can do dinners.... He is not **always** having fits and screaming, but he still does.*

Greg expressed that the reason that Cody's behaviours had improved was because of the constant care his mother provided Cody. He emphasized that his mother had assumed a full-time job of caregiving for his step-brother.

*So basically my mom is his sole caregiver, and she's taken this as her full-time job....She has gone full spin on this. So yah, from what she has done from when I first met him to now is like, he is probably a thousand times better than what he was.*

Acknowledging the improvement of their siblings' behaviours overtime was a subtheme that emerged from the data analysis of the nine remaining participants. However, it should be noted that the acknowledgment experienced by Greg differed from those of the other nine participants. This was because Greg reported feelings of anger and shock regarding Cody's previous behaviours. He also stated that Cody's behaviours disrupted his life, something that was not mentioned by the other nine participants. Additionally, Greg also reported that the reason why his step-brother's behaviours had improved was solely a result of his mother's constant care and support; something that also was not mentioned by the other participants.

### 5.3. *The “non-existent” relationship between Cody and Greg*

Greg was the only participant that reported both his childhood and current relationship as poor on his background questionnaire. When Greg was asked to speak about the shared relationship between himself and Cody, he defined it as poor and non-existent.

*Truthfully, it is poor. We don't have a relationship.... It's not...a buddy, buddy relationship. It's more like “Hey, how's it going? How are yah doing?” ... I say my peace, and hi, and this and that, and then I leave him alone.*

This was reiterated and confirmed in the second interview with Greg.

*Hm truthfully, probably non-existent. Um, I say “Hi” when I go over to my parents, but that's about it. I don't go over specifically to see him. I don't hang out with him really. It's really [pause] I guess, non-existent.*

Despite the fact that Greg and Cody were traditionally considered to be step-brothers, Greg did not see Cody as his step-brother.

*See, I know he is considered my step-brother. But I don't really think of him as anything. Like if you were to say, “Do you have a brother?” [Long pause] Ah, I'd be like “Yah” only because I know he is through marriage it's my step-brother. But realistically, it's like no.*

Greg was able to provide many reasons why he did not have a relationship with Cody.

Greg's anger and the constant attention Cody required were the strongest factors in this "non-existent" relationship.

*I was always really angry because he was a part of my family, because I never got any attention. Since I was 15 it was always, he was number 1, he was number 1, he was number 1. And it was always like, Cody this, Cody that. It's like that, so we never really had a relationship.*

Further, the 'typical' brother-brother relationship was not a possibility for Greg and Cody because of Cody's ASD. This was specifically because Cody's impaired ability to efficiently communicate and interact with others created barriers for their relationship.

*Just the fact that I know it's not a normal relationship, and it couldn't really be a normal relationship, like a friend relationship or uh, a brother relationship. It's just, totally different.*

Further, he stated that his lack of interest in Cody also played a role in their non-existent sibling relationship.

*See the problem with this, is that I never really took on any interest with this, because of everything else going on in my life. I was depressed about dad and then having two families come together, and him [Cody] being the major priority of everyone's life.*

Although the relationship between Greg and Cody currently and as children was non-existent, this did not mean it would be in the future.

*Once I guess, when I mature a little bit more than what I am now, then maybe I'll open my mind to it a lot more.*

There were many factors that played a role in the non-existent relationship between Greg and Cody. Unfortunately, all of these reasons were negative. The most common reasons were Greg's anger regarding the attention Cody demanded and Cody's ASD that prevented them from ever having a "normal" sibling relationship. When asked if Greg

had any regrets associated with the non-existent relationship between himself and Cody, Greg responded with “*No, I don’t regret any of it.*” This again contrasted with findings that emerged with the other participants. Many participants stated that they wished they behaved differently towards their sibling.

#### 5.4. “*He took my mother away*”

Similar to the other participants, Greg experienced many hardships associated with having a step-sibling with ASD. According to Greg, the greatest hardship and the most frequent topic he discussed was how Cody “stole” his mother from him.

*He took my mom away... because he needed that special care. So it was like, he was first, before anybody.*

For example, the attention that Cody required from Greg’s mother took away from the attention that Greg felt **he** needed from his own mother.

*Let’s say up until a year ago, back from when I was 15, it was always about Cody. It was about Cody. It was about Cody, Cody, Cody. You know, you couldn’t even have a 20 minute conversation with my mom. Because it’s like “Oh, Cody is stimming or screaming” or “I need to go see Cody” or “Greg, hold on I don’t know what Cody is doing, blah, blah, blah.” So it seemed like nothing I said was important, or I didn’t matter or I was just kinda there. And I never got the attention maybe I needed, not so much that I deserved, but I needed.*

Greg explained the emotional strain that resulted from “losing” his mother, after the recent death of his father.

*I guess you go back to the points of losing my mother and feeling like I have nobody.*

Further, Greg vented his frustrations regarding his mother immersing herself too deeply in fulfilling the demanding caregiving role to his step-brother. Not only did he feel that Cody stole his mother from him, but it was also evident that he felt Cody took his mother’s previous identity away.

*I think just when she took it on, this role as a mother to a child with autism, that she never put so much time in for herself.... She's losing friends, she's not around so [many] other people. It's like all she is doing is, Cody, Cody, Cody, Cody. So it's like, that is all she does, you know? And from going on to see what your mom used to be like, always active, always fit, always this, to kinda the opposite. You know, letting herself go a little bit. It bothers me because it is not what I wanted for her since my dad died, right?*

Greg admitted to disagreeing with his mother's heavy involvement with his step-brother. He explained that the four years of the caregiving role his mother provided to his father prior to his death, in addition to the nine years she has been caring for Cody was too much for her.

*Probably because she took care of someone that was dying of cancer for 4 years. And that was like having someone kinda in the same situation, where his brain was not normal for a **long** time. Um, and then she meets someone else, and it's like 12 years. So it's like for the past, more than 12 years, she's dealing with this, these disabilities. When she's doing nothing for herself and, you know what I mean? She's getting older, she's not getting any younger...it doesn't seem like she does anything for herself. It's always everything to do with Cody, Cody, Cody, Cody, Cody, Cody. And it's just, I don't agree with it.*

Greg continued to discuss his feelings regarding his mother's caregiving role to Cody. He stated that he was confused as to why his mother would want to fulfill this role.

*I guess I'm just confused as to why she would even want to do that. She says that it makes her happy and I just go "Okay, sure." I'm sure it does, but I just don't really get it. I guess it's different when it's your own child and you give birth to that child. That's different. But to take on someone else's child like that **forever**. I could never do it. I don't think I would ever want to do it.*

Greg perceived himself as suffering greatly from the loss of his mother to the needs of Cody. This loss was associated with anger, sadness, confusion and stress. Other participants mentioned the frustration they experienced because of the uneven parental attention they received in comparison to their sibling with ASD. However, they did not express the same emotional strain that Greg did, nor did they report feeling like they lost

a parent to the disability of their sibling. When I asked Greg if he still blamed Cody for Cody for “taking” his mother away and for negatively affecting their relationship, he stated “*I could blame him for that, but now do I? Not really, cause’ I’m older and I’m trying to move on from all of that.*” Evidently, losing his mother to Cody is a hardship that Greg is ready to leave in the past.

5.5. “*I didn’t want my family to be seen with a disability.*”

Throughout the two interviews conducted with Greg, a prominent topic discussed was Greg’s yearning to be part of a “normal” family and not wanting his family to be associated with a disability. In fact this desire contributed to the reason why Greg avoided being home.

*I guess you could say what made me happy back then, is friends and their families. And seeing what a normal family without a special needs child is like. And I loved that. So I was never at home, I was always **gone, gone, gone.***

Greg’s resistance to be a part of a family with disabilities is also evident when I asked Greg if he was ever embarrassed of Cody and he stated the following:

*Definitely not now, but before I would maybe a little bit. [Me: why?] I don’t know, maybe it was because I didn’t want my family to be seen with a disability.... But Yah, I just didn’t want my family to be seen with a disability.*

When asked if he wished that the “non-existent” relationship was different, he stated:

*I wouldn’t say I wish, because I don’t wish that, sounds mean, but I didn’t really want **that** kind of stuff part of my life to begin with. And I still really don’t, it’s just, I guess, I don’t know it’s weird. I don’t really, not like I hate people like that. I just don’t want it part of my life, really. And I don’t make the effort to make it part of my life....Just like severe disabilities, ‘cause of everything’s that happened in the past, I guess now it kinda turns me off. Like, I don’t want a part of that.*

He explained that families that do not have disabilities were more ideal than his own family.

*I don't know, I just never want to, uh, to be part of a family that has someone with a severe disability, right? Like it's, just I look at other families and no one has disabilities and everyone's chill and cool. And then you go to my house and it's like the polar opposite. Like whiteboards all over the counters, to-do lists for him, and puzzles and crayons, and little kid shit everywhere. I don't know, I don't like it.*

It was strongly evident that Greg does not want his family to be associated with disabilities, mainly because of the negative experiences that have resulted due to Cody being his step-brother.

### 5.6. Future

Although the future was not commonly discussed by Greg during the two interviews, it further illustrated his feelings toward having a step-sibling with ASD.

When asked if he would assume a caregiving role to Cody in the future, he responded:

*Truthfully probably not, just because of what has happened. And as mean as it is to say, this is also my life and at the very beginning, I never wanted it to be a part of my life. And he has two other siblings that are blood, and you would think that maybe they would step in....If worse, worse, **worse** came to **worse**, then I am sure. But it is not in the future plans, let's put it that way.*

During the second interview, Greg was asked under what circumstances would he provide a care to his step-brother.

*Everyone dying [says jokingly & laughs]. I wouldn't be the first to jump in on it.... I guess like I stated before, I just don't want it part of my life.... I don't have a relationship to where I care **that** much, like my mom would or my sister would, right?*

Greg's response to the mentioned questions concerning his future caregiving role to Cody further solidified his anger regarding his step-sibling with ASD. Additionally, it illustrated the resistance to having Cody in his life and accepting him as a sibling.



## **DISCUSSION**

All findings that emerged from the data analysis described the lived experiences of adult siblings of individuals with ASD. It was an advantage to have an adult population because it allowed participants to reflect retrospectively, hopefully providing a more complete picture of their experiences. Nine of the participants had similar experiences, while the remaining participant discussed more negativity associated with his experiences of having a sibling with ASD. As a result, he was considered a negative case and his data were analyzed and presented separately.

Some of the subthemes that emerged from my study have been supported by other researchers. For example, I found that the childhood relationship between siblings, in which one of the siblings has ASD, is often associated with trials and tribulations. These trials and tribulations served as a barrier that prevented the participants and their siblings from having a close childhood relationship. Some of the difficulties my participants reported regarding their relationships with their siblings were the negative feelings they felt toward their sibling with ASD (e.g. embarrassment, resentment, helplessness, fear). The most commonly described negative emotion was embarrassment. For example, one participant explained that she felt embarrassed when her brother would get upset and start to cry, creating a scene in public. Embarrassment felt by siblings of individuals with ASD is a common finding that has been supported by previous research studies (see for example, Mascha & Boucher, 2006; Petalas et al. 2012). For instance, Petalas et al. (2012) found that siblings of individuals with ASD reported feelings of anger, embarrassment and anxiety, primarily due to the lack of understanding and negative attitudes exhibited by strangers, as well as their own friends.

A few of my participants conveyed the restrictions they experienced in terms of family outings. For example, participants reported that their siblings' ASD (e.g. behaviours like screaming or not being able to tolerate loud noises) made it difficult to go to the movies or out for dinner with their families. This finding is supported by Petalas et al. (2012) who found that siblings of individuals with ASD did not typically get to enjoy the luxury of partaking in recreational family activities, like children without siblings with ASD.

I also found that siblings felt appreciation and acceptance in their current adulthood relationship with their siblings with ASD. As a result of this newfound appreciation and acceptance, my participants reported having closer relationships with their siblings than they did in the past. Moyson and Roeyer (2012) and Petalas et al. (2012) also found that their participants conveyed a sense of acceptance of their siblings with ASD because they had come to understand that their siblings' disabilities were an inseparable part of them.

Similar to a finding discussed by Huinker (2012), my participants conveyed that they believed they have developed positive traits, such as compassion and patience, as a result of having a sibling with ASD. Further, my participants reported enhanced empathy for all individuals with disabilities, and that this experience had influenced their future career paths to work with individuals with ASD. Huinker (2012) also discussed that having a sibling with ASD, allowed her participants to become more understanding and accepting of other peoples' differences, in addition to becoming more patient. Additionally, she stated that her participants were more likely to choose a career based on their experiences of having a sibling with ASD.

Throughout the interview process, my participants often spoke about the concerns they had regarding their future caregiving roles and the well-being of their siblings. This finding has also been supported by previous studies (Benderix & Sivberg, 2007; Moyson & Roeyers, 2011).

These researchers discussed that siblings of individuals with ASD reported concerns regarding their siblings' well-being and the degree of independence their siblings could possess in the future.

Other subthemes that emerged from my study are novel, as they have not been discussed in previous research studies. For instance, all of my participants chose to speak about the time when they first realized that their sibling was different. For the majority of participants, this realization occurred when they compared their siblings' behaviours to that of others. In most cases, they recognized that their siblings' behaviours were "strange" or developmentally delayed, in comparison to other children of similar ages. For example, one participant began to acknowledge that it was "weird" that her brother clapped his hands when he was scared. This finding is important because it emphasizes the reality that children often are aware that something is different about their siblings. This addresses the need for keeping open lines of communication between parents, health professionals and siblings of individuals with ASD.

Another novel finding that emerged from my data was the insights my participants conveyed while reflecting on the past relationships with their siblings. My participants stated that they were not as understanding and appreciative of their siblings when they were children. This led to participants discussing ways they should have or could have treated their siblings better. Specifically, one sibling reported that she wished that she had made a stronger effort to include her brother in her group of friends. This addresses the need to help children of siblings with ASD further understand their siblings' disability. Perhaps, if they understood their siblings' ASD when they were younger, they may not have had the relationships they did, as understanding the ASD might have led them to treat their siblings differently.

My participants all spoke about how their siblings' behaviours had improved greatly over time. The majority of these improvements focused on their siblings' diminished "violent" or "aggressive" tendencies, in addition to their siblings' increased independence in recent years. Interestingly, participants did not use their siblings' autism to define them, when describing them. Instead, they used positive terms such as "gentle soul," "funny" and "special." More specifically, one of my participants reported that her brother's Asperger's did not define him, and that he is much more than his disability. This further emphasizes how the sibling relationship, in which one of the siblings has ASD evolves with time.

All of my participants expected that they would have to fulfill some type of caregiving roles for their siblings in the future. However, the caregiving roles that participants **wanted** to assume varied. For example, one participant stated that he would ideally like to help out, but did not want it to affect his own life. Alternatively, a few participants reported that they would want to assume a full-time caregiving roles by having their siblings live with them. Also, participants spoke about what they had hoped the future would hold for their siblings. Specifically, one participant stated that she would want her sibling to be as independent as possible. Other hopes consisted of their sibling finding a job and that their well-being would improve. This highlights the need for support for siblings of individuals with ASD, assisting them to prepare for future caregiving roles.

### *The Negative Case*

Greg's lived experiences differed from those of the other participants, mainly because his experiences associated with having a sibling with ASD were very negative in nature. Although the other participants reported experiencing difficulties as well, the difficulties mentioned were

not as extreme nor were they accompanied with the same degree of anger and frustration. These difficulties were the primary focus of both the interviews I conducted with Greg.

Overall, Greg did not consider or accept Cody as his brother. This is most likely because Greg perceived that Cody had caused him many issues, such as Cody's challenging behaviours disrupting Greg's life; Cody could not offer Greg the "normal" brother-brother relationship; and because Greg felt Cody "took" his mother away from him. These problems provoked many hostile feelings for Greg such as anger, frustration, sadness, loneliness, and jealousy, feelings primarily directed at his step-sibling.

A few of the negative experiences Greg conveyed regarding having a sibling with ASD have been discussed in previous research studies. For example, researchers found that siblings of individuals with ASD reported not being able to "handle" their siblings' challenging behaviours and referred to them as "disturbing," "annoying" and "aggressive" (Benderix & Sivberg, 2007; Mascsha & Boucher, 2006; Moyson & Roeyers, 2011; Petalas et al., 2012). The participants involved in these studies often coped with their siblings' behaviours through avoidance, as well as by distancing themselves from their sibling, both of which were behaviours described by Greg. Additionally, some researchers have identified the lack of parental involvement that existed when one of the children had ASD, something that frustrated Greg very much. In two research studies that examined the lived experiences of parents of children with autism, participants conveyed that their neurotypical children received less attention than their child with ASD (Fletcher et al. 2012; Shaff et al. 2011). As a result, this was perceived to have increased the stress levels of these siblings and increased their level of responsibility and independence (Fletcher et al. 2012; Shaff et al. 2011). Fortunately, Greg stated that he would like to move past the difficulties that having a sibling with ASD has presented him. However, I assume that for the

relationship between Cody and Greg to be improved, time, forgiveness and acceptance would have to play a major factor.

### *Limitations*

There are limitations within my research despite the measures taken to ensure quality data collection. For example, the sample consisted of more females (n=7) than males (n=3). Therefore, the findings that have emerged from this research study may pertain more so to females. Also, the sample consisted of two individuals that were step-siblings of individuals with ASD, rather than biological siblings. This may have resulted in inconsistencies because step-siblings may perceive a different type of relationship with their siblings, regardless of whether the sibling has or does not have a disability. For example, this sentiment was evident in Greg's experience as step-sibling of an individual with ASD. Additionally, I had intended to use personal photos as a form of data collection by having my participants provide me with pictures that they felt represented their past and/or present relationship with their sibling. Unfortunately, only two participants provided me with photos, thereby limiting the contribution this form of data collection might have towards my understanding of their collective lived experiences. As a result, photography was no longer used as a data collection method. This process could be improved in future research by reminding participants to bring the photographs to the interview, in addition to clearly stating the importance of providing such photographs in the understanding of their experience. Finally, the retrospective nature of the interviews may have affected the accuracy of the retelling of these events.

### *Future research*

To date, the majority of research that has focused on siblings of individuals with ASD has largely focused on female samples. As such, future research that highlights the experiences of

brothers of siblings with ASD would be beneficial. Also, research regarding step-siblings of individuals with ASD is lacking. As a result, research within this area would be helpful in identifying the lived experiences specific to these individuals to determine whether they are indeed unique. Finally, conducting a longitudinal study with siblings of individuals with ASD would provide researchers with the opportunity to identify how the lived experiences of siblings of individuals with ASD change over time, rather than being dependent on participants' recollections.

### *Conclusion*

Having a sibling with ASD undoubtedly has an effect on the neurotypical sibling. Nine of my participants conveyed that their relationships with their siblings with ASD had become stronger in recent years. This was typically the result of their recent ability to appreciate and accept their siblings. Greg's experience was the exception. Additionally, all of my participants discussed their siblings' futures throughout their interview. It was evident that their siblings' futures and the future caregiving roles they felt they would assume for their siblings was important to them. Greg, the 'negative case' had vastly different experiences associated with having a sibling with ASD. This was mainly because Greg described that his hardships of having a sibling with ASD outweighed the benefits, and he consequently developed many resentful and hostile feelings.

My research study builds on previous research regarding siblings of individuals with ASD by providing the unique perspective of adult siblings, something that few research studies have addressed. In doing so, my participants were able to not only reflect on their current experiences as a sibling of an individual with ASD, but also on their experiences as children. It is anticipated that the insights conveyed by all of my participants can provide support for other siblings of individuals with ASD and ensure siblings of individuals with ASD know that they are not alone

in their lived experiences. Further, I intend on developing a list of recommendations for parents who have at least one child with ASD. The objective of these recommendations will be to provide strategies to reduce the negativity experienced by the neurotypical siblings of individuals with ASD, offering suggestions such as those conveyed by my participants. My intent will be to convey these recommendations in both presentations and print, such that the information might reach those who live with and serve individuals with ASD.



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## **Appendix A: Typical therapies for ASD**

### *Applied Behavioural Analysis (ABA):*

During ABA, an assessment of the individual's communication, behavioural, learning and social strength is first completed (Autism Society Canada, 2010). The results are used to assist the individual to acquire new skills, improve and retain others and address any of their challenges. ABA aims in teaching and/or improving functional skills such as attention to social stimuli, imitation skills, language use and comprehension, appropriate play, and social interaction skills. It is suggested the individuals enroll in the ABA prior to the age of 5 and complete 20-40 hours per week (Autism Society Canada, 2010).

### *Pivotal Response Treatment (PRT):*

PRT is derived from ABA and targets to improve "pivotal" areas of a child's development (Autism Speaks Canada, 2013). Some of these areas include controlling reactions to multiple stimuli, initiate socialization, and improve self-management skills. The goal of PRT is to improve communication skills, control disruptive behaviours, and promote positive social behaviours. It is suggested that individuals attend PRT 25 hours or more per week. (Autism Speaks Canada, 2013)

### *Verbal Behaviour Therapy (VBT):*

VBT uses the same principles ABA. The main focus of VBT is to teach the individual to communicate using their words (Autism Speaks Canada, 2013). The program typically begins with the use of many physical and verbal prompts from the teacher, as the individual progresses the use of prompts is reduced. It is recommended that the individual attend minimum 3 hours per week (Autism Speaks Canada, 2013).

## **Appendix B: Relative studies**

Benderix and Sivberg (2007)

- One-on-one, structured interviews for 1 to 2 hours
- 8 males and 6 females, ages 5 to 25

Masha and Boucher (2006)

- One-on-one, structured interviews for 20- 30 minutes
- 10 females and 4males, ages 7 to 20

Petalas et al. (2012)

- One-on-one, structured interviews for 14 to 42 minutes (on average 21 minutes).
- 5 females and 3 males, ages 8 to 17

## **Appendix C: Research poster**

**YOU ARE INVITED TO PARTICIPATE IN RESEARCH REGARDING...**

*The lived experiences of siblings of individuals diagnosed with Autism Spectrum Disorders*

### **Purpose**

The purpose of this research is to understand the lived experiences of individuals of siblings with ASD, specifically by exploring how siblings define the relationship they share with their sibling with ASD by reflecting on any changes from the past to the present, areas of their lives that have been most impacted with regards to having a sibling with ASD, the costs and benefits associated with having a sibling with ASD, and the coping mechanisms they utilize with respect to their sibling's diagnosis.

### **About the Researcher**

The principal researcher is a graduate student at Wilfrid Laurier University who is conducting this research for her master's thesis. The research advisors, Dr. P. Fletcher and Dr. M. Schneider are professors in the Department of Kinesiology and Physical Education.

### **Participants**

Participants must be non- ASD adult siblings (18+) of individuals who have been formally diagnosed with ASD.

### **Procedure**

The background questionnaire and consent form will take approximately 15 to 20 minutes to complete. The one-on-one interview will be scheduled at the participants' convenience and will occur upon completion of the background questionnaire and will be 60 to 120 minutes in length. Prior to this interview, participants will have the choice to provide the researcher with photographs that they feel represent their relationship with their sibling with ASD (photographs do not have to be of the participant and their sibling with ASD but rather photographs which symbolize or portray the relationship e.g., photo of a special place). Photographs can be sent to the researcher via email or mail using a pre-paid postage envelope provided by the researcher. All interviews will be audio taped and then transcribed verbatim. The participants will be asked to review their verbatim transcript (member check) of their interview and return it to the researchers with any added or omitted information or clarification of researcher questions.

### **Interested in Participating?**

If you feel that you are suitable participant for this study, please contact Brianne Redquest at [redq9570@mylaurier.ca](mailto:redq9570@mylaurier.ca), Dr. P. Fletcher at [pfletcher@wlu.ca](mailto:pfletcher@wlu.ca) or (519) 884-0710 ext. 4159, or Dr. M. Schneider at [mschneider@wlu.ca](mailto:mschneider@wlu.ca).

REB tracking number: 3788

## **Appendix D: Consent letter**

### **WILFRID LAURIER UNIVERSITY INFORMED CONSENT LETTER**

Principal Investigators: Brianne Redquest

Advisors: Dr. P. Fletcher, Dr. M. Schneider

You are invited to participate in a research study pertaining to the lived experiences of siblings of individuals with Autism Spectrum Disorders (ASD). The purpose of this research is to understand the lived experiences of individuals of siblings with ASD, specifically by exploring how siblings define the relationship they share with their sibling with ASD by reflecting on any changes from the past to the present, areas of their lives that have been most impacted with regards to having a sibling with ASD, the costs and benefits associated with having a sibling with ASD, and the coping mechanisms they utilize with respect to their sibling's diagnosis.

The principal researcher is a graduate student at Wilfrid Laurier University who is conducting this research for a master's thesis. The research advisors, Dr. P. Fletcher and Dr. M. Schneider are professors in the Department of Kinesiology and Physical Education.

#### **INFORMATION**

Siblings of individuals with ASD will be recruited to participate in this study. Potential participants will be given this consent form and the option to participate. The background questionnaire and consent form will take approximately 15 to 20 minutes to complete. The one-on-one interview will be scheduled at the participants' convenience and will occur upon completion of the background questionnaire and will be 60 to 120 minutes in length. Prior to this interview, participants will have the choice to provide the researcher with photographs that they feel represent their relationship with their sibling with ASD (photographs do not need to be of the participant and their sibling with ASD but rather photographs which symbolize or portray the relationship e.g., photo of a special place). Photographs can be sent to the researcher via email or mail using a pre-paid postage envelope provided by the researcher. All interviews will be audio taped and then transcribed verbatim. The participants will be asked to review their verbatim transcript (member check) of their interview and return it to the researchers with any added or omitted information or clarification of researcher questions. Any added or omitted data should be mailed or e-mailed to one of the principle researchers. The data collected from this research will be locked in the Kinesiology and Physical Education office at Wilfrid Laurier University on 232 King Street for five years.

Participants Initials: \_\_\_\_\_

## **RISKS & BENEFITS**

The participants will be asked to divulge information about experiences which may result in loss of privacy and/or evoke an emotional response. However, this research will contribute to the overall knowledge about being a sibling of an individual with ASD. This will not only increase awareness regarding these siblings but also can assist in developing an appropriate support group for these individuals. Individuals will be told they can refrain from answering any questions with which they feel uncomfortable. As such, the benefits outweigh the risks.

## **CONFIDENTIALITY**

All data and audiotapes will be stripped of identifiers. Each transcript, audiotape and questionnaire will receive a number and the names of participants will not appear on their corresponding information. A master sheet with the names and identification numbers will be kept separate from the data in order to match transcripts with the appropriate data collection tools. The transcripts and audiotapes will only be accessible to the researcher and a graduate qualitative study group that consists of 3 graduate students and two research advisors. All raw data and tapes will be locked securely in a filing cabinet in the Kinesiology and Physical Education Department research space located at 232 King Street. Anonymous quotations within the final report may be used. Documents, records and audiotapes from this study will remain within the possession of the researchers until the study is completed and raw data and tapes will be store securely and kept for five years. Pseudonyms will be used in the reports.

## **COMPENSATION**

There is no compensation for participating in this study.

## **CONTACT**

If you have questions at any time about the study or the procedures, (or you experience adverse effects as a result of participating in this study) you may contact the researcher, Brianne Redquest ([redq9570@mylaurier.ca](mailto:redq9570@mylaurier.ca)) or Dr. P. Fletcher at 519-884-0710 ext. 4159 or Dr. M. Schneider at [mschneider@wlu.ca](mailto:mschneider@wlu.ca). This project has been reviewed and approved by the University Research Ethics Board. If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact Dr. Robert Basso, Chair, University Research Ethics Board, Wilfrid Laurier University, (519) 884-1970, extension 4994 or [rbasso@wlu.ca](mailto:rbasso@wlu.ca).

Participant Initials: \_\_\_\_\_



## **PARTICIPATION**

Your participation in this study is voluntary; you may decline to participate without penalty. If you decide to participate, you may withdraw from the study at any time without penalty and without loss of benefits to which you are otherwise entitled. If you withdraw from the study, your data will be removed from the study and destroyed. You have the right to refrain from answering any question(s) that cause you to feel uncomfortable and you may end the interview at any time.

## **FEEDBACK AND PUBLICATION**

The results from this research will be presented in paper format. The researchers will also submit the results to journals for publication and present their findings at academic conferences. Participants may request an executive summary of the research from the principal researchers when the final results are available in Fall 2014, if so desired.

## **CONSENT**

Check the box beside the statements in which you consent to participate.

- I have read and understand the information above. I have received a copy of the information form and I agree to participate in this study.

Participant's Signature \_\_\_\_\_ Date \_\_\_\_\_

Investigator's Signature \_\_\_\_\_ Date \_\_\_\_\_

- I agree to be audio taped during the face-to-face interview.

Participant's Signature \_\_\_\_\_ Date \_\_\_\_\_

Investigator's Signature \_\_\_\_\_ Date \_\_\_\_\_

- I agree consent to have my direct quotations used in presentations/papers resulting from this study.

Participant's Signature \_\_\_\_\_ Date \_\_\_\_\_

Investigator's Signature \_\_\_\_\_ Date \_\_\_\_\_

## Appendix E: Background questionnaire

### Background Questionnaire

Please complete all the questions by either filling in the blank spaces provided or checking the box with the most appropriate answer.

*Background information about yourself...*

**1. Are you:**

- Female
- Male

**2. Date of Birth (dd/mm/year):**

---

**3. Highest level of education attained:**

- Elementary School
- High School
- College
- University
- Post-Graduate Degree
- Other, *please*

*specify:* \_\_\_\_\_

**4. What is your marital status?**

- Divorced
  - Married or common-law
  - Separated
  - Single
  - Widowed
  - Other, *please specify:*
-

**5. Do you have any formally diagnosed medical conditions illnesses/conditions/impairments? Please list.**

1. \_\_\_\_\_

2. \_\_\_\_\_

3. \_\_\_\_\_

4. \_\_\_\_\_

5. \_\_\_\_\_

*Background information about your sibling(s) with special needs...*

**6. Please provide information about (each of) your sibling(s). Please circle the sibling that you will be speaking about for this research study.**

	<b>Date of Birth (mm/dd/year)</b>	<b>Gender</b>	<b>If your sibling(s) has been formally diagnosed with a special need or condition, please list.</b>
Sibling 1		<input type="checkbox"/> M <input type="checkbox"/> F	
Sibling 2		<input type="checkbox"/> M <input type="checkbox"/> F	
Sibling 3		<input type="checkbox"/> M <input type="checkbox"/> F	
Sibling 4		<input type="checkbox"/> M <input type="checkbox"/> F	
Sibling 5		<input type="checkbox"/> M <input type="checkbox"/> F	

**7. What is your sibling's diagnosis?**

- Autism
  - Autism Spectrum Disorder
  - Asperger's
  - Childhood Disintegrative Disorder
  - Rett's Disorder
  - Pervasive Developmental Disorder – Not otherwise specified
  - Other, *please specify:*
- 

**8. How old was your siblings when (s)he was diagnosed?**

---

**9. In addition to the stated diagnosis, does your sibling have any other conditions? Please list.**

1. \_\_\_\_\_

2. \_\_\_\_\_

3. \_\_\_\_\_

4. \_\_\_\_\_

5. \_\_\_\_\_

**10. Does your sibling currently have a primary caregiver?**

- No
  - Yes, *please specify whom this caregiver is:*
-

*Background information about the relationship between yourself and your sibling...*

**11. Do you currently live with your sibling?**

- Yes
- No

**12. If not, where does your sibling currently reside and with whom?**

---

**13. When you were a child (4-11 yrs old), how would you describe the overall relationship between yourself and your sibling with ASD?**

- Excellent
- Good
- Fair
- Poor

**14. Presently, how would you describe the overall relationship between yourself and your sibling with ASD?**

- Excellent
- Good
- Fair
- Poor

**15. If you feel that having a sibling has impacted your life, please check which of the following areas were impacted when you were a child (4-11 years old) and the areas that are currently impacted.**

<b>Areas that have been impacted (check all that apply)</b>	<b>As a child (4-11 years old)</b>	<b>Currently</b>
Physical health	<input type="checkbox"/>	<input type="checkbox"/>
Mental health	<input type="checkbox"/>	<input type="checkbox"/>
Emotional health	<input type="checkbox"/>	<input type="checkbox"/>
Family relationships	<input type="checkbox"/>	<input type="checkbox"/>
Social relationships	<input type="checkbox"/>	<input type="checkbox"/>
Academics	<input type="checkbox"/>	<input type="checkbox"/>
Career choice	<input type="checkbox"/>	<input type="checkbox"/>
Financial	<input type="checkbox"/>	<input type="checkbox"/>
Participation in activities	<input type="checkbox"/>	<input type="checkbox"/>
Other, <i>please specify:</i>	1. _____ 2. _____ 3. _____ 4. _____ 5. _____	1. _____ 2. _____ 3. _____ 4. _____ 5. _____

**16. Currently, do you use any particular coping mechanisms to help you cope overall?**

- Yes
- No

**If yes, please check those that apply most:**

- Educational services
- Exercise
- Family
- Friends
- Humour
- Journal
- Monetary support (specify type)
- Psychological treatment
- Seeking information
- Support groups
- Spiritual Methods
- Support Organization/Society
- Volunteering
- Other, *please specify:*

1. \_\_\_\_\_

2. \_\_\_\_\_

3. \_\_\_\_\_

4. \_\_\_\_\_

5. \_\_\_\_\_

**\*\*Thank you for completing this questionnaire\*\***



## Appendix F: Interview questions

### Interview Questions

#### *Background information*

- 1) Can you tell me a bit about yourself?
  - School/occupation/ marital status etc.
  - Use background questionnaire for probes
  
- 2) Can you tell me about your sibling in terms of his/her ASD?
  - Use background questionnaire for probes [ focus of living situation, if not living together-how long since you haven't lived with your sibling, how long did you live with your sibling, why do you not currently not live with your sibling?]
  - Can you tell me about his/her diagnosis?
  - What typical behaviours did your sibling exhibit as a child?
  - What typical behaviours does your sibling currently exhibit?
  - Do you feel that the behaviours your sibling currently exhibits are different from when he/she was a child? If so, how?
  - Does he/she have a job?

#### *The sibling relationship*

- 3) How would you currently describe your relationship between you and your sibling?
  - Are you close? Is this consistent over time?
  - Do you partake in any of the same activities?
  - Do you have the same friends?
  - How do you feel about your sibling? Sympathy, appreciation, anger, frustration etc.
  
- 4) Is your current relationship with your sibling different from when you were a child and teenager?
  - Use background questionnaire for probes
  - If yes, why?
  - If yes, what do you feel may have influenced these changes?
  
- 5) What is your responsibility/ role now as a sibling?
  - Do you have a care giving role? And have you always had a care giving role?
  - Does it affect your relationship with your parents?
  - Has your relationship with your parents changed from when you were a child?
  - If so, how?
  - (evolution of relationship)

- 6) Are there any major life events that have impacted your relationship with your sibling?
  - Receiving the diagnosis (if applicable)
  - Progression in specific deficits (behavioural, physical, mental, social)
  
- 7) Are there any costs associated with having a sibling with ASD?
  - Financial, psychological, social, physiological etc.?
  - Embarrassment?
  - Lack of understanding?
  - Distractions?
  - Did these same challenges apply when you were a child? Why or why not?
  
- 8) Are there any benefits associated with having a sibling with ASD?
  - Physical, social, psychological?
  - Acquiring positive attributes?
  - Gained further knowledge with regards to disabilities?
  - Would these same opportunities for growth apply when you were a child? Why or why not?

### ***Concluding questions***

- 9) Have you ever utilized any coping mechanisms overall?
  - If yes, what are they? Escape, find a hobby, friends, talk with others, yoga, support groups, exercise?
  - Who is your strongest support? Mother, father, sibling, extended family, a significant other, professionals (doctor), professor? Is this different from when you were a child?
  
- 10) Ultimately, has having a sibling with ASD has impacted your life?
  - Use background questionnaire to identify the impact on childhood and adulthood, address the differences.
  - If social relationships and family relationships have been affected, ask to specify (e.g. significant others, friends, immediate family, extended family)
  
- 11) Do you have any thoughts with regards to your sibling's future?
  - Living situation?
  - Jobs?
  - What role do you think you will play?

***\*\*look at the picture\*\****

- Can you tell me about the picture(s) you brought in?
- How old were you and your sibling at the time? (If applicable)
- Why did you choose these/this picture(s)?
- What are the feelings you have toward these pictures? Are these feelings relevant today? (Ie. If the picture is of a park, do they still go to this park?)
- What do these/this picture(s) remind you of?
- Is there anything else you would like to mention about these/this picture(s)

***End questions***

12) Do you have anything to add with regards to yourself or your sibling?

13) Do you have any final questions for me?

## Second interview with Greg

- 1) What do you consider your relationship with S1 to be?
  - a. Can you explain your answer?
  - b. Does the fact that he has a disability and is unable to communicate affect your relationship?
  
- 2) Is the relationship with your other step-siblings different?
  - a. Has it always been like this?
  - b. Do you anticipate that this will change in the future?

- 3) In the previous interview you state the following:

*So I guess I didn't really know if I actually liked it, it was different right? It's not what I was used to and I would said my life before was the best [emphatic] thing ever [emphatic] right? And now it's different obviously and it takes a while to get into it and used to it. It was different and weird, not anything I was used to. So it took me by surprise a little bit.*

You refer to previously having the “best life ever”, why did this change? Did S1 play a role?

You use the words “different” and “weird” when describing what it was like when S1 entered your life. Would you still use these words to describe the current situation? If so, can you please elaborate?

- 4) Throughout the interview you often mention that you and your parents do not get along.
  - a. Role mom plays
  - b. Role dad play
  
- 5) It is also mentioned throughout the interview that your mother has assumed a 24/7 365 day caregiving role for S1. What are your current feelings with regards to this?
  - a. Would it be less frustrating if S1 did not demand so much attention and care?
  - b. Are your feelings any different from how you felt regarding this situation as a child?
  
- 6) Do you feel you have ever had a relationship with S1?
  - a. Why or why not?
  - b. Will this ever change?

- 7) You state that you do not have a relationship with S1, do you wish that this were different?
  - a. Why or why not?
  - b. Do you foresee a future relationship with S1?
  - c. Why or why not?
  
- 8) You also stated that your relationship with S1 as a child was poor and it is still poor. Why do you think this is?
  - a. Compare current to childhood
  
- 9) You said as a child, you did not want any part of “it” (S1) p. 7. Do you still feel this way?
  - a. Do you have any regrets?
  
- 10) “I didn’t want my family to seen with a disability”. Can you expand on this
  - a. Do you still feel this way?
  - b. What if it were a less apparent disability?
  
- 11) You state that “if worse came to worse than I am sure” when asked if you would take part in his future. What circumstances would this entail?
  
- 12) Do you have anything else you would like to add?

\*Thank you very much for doing a second interview!