

5-2024

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Parenting a Child Who Has an Autistic Sibling: Effects on Adjustment and Mental Health

Jess Del Mundo

A Capstone Project for the Bachelor of Science in Human Development and Family Science

Introduction

This capstone project focuses on informing parents about the challenges and needs of siblings of children with autism. Parenting is a profound and meaningful responsibility, and having children with special needs adds to this daunting job. It is imperative for parents to nurture the development and awareness of all of their children, both neurodivergent and neurotypical. This workshop will give parents the tools to navigate this responsibility. I developed a workshop that first informs parents about the positive outcomes for children who have siblings with autism, such as higher levels of empathy and compassion. Second, I will address the challenges for siblings of children with autism. Third, I will discuss how to establish stronger relationships with the siblings of autistic children, which includes developing healthier and more open communication patterns. The workshop will be conducted over Zoom with parents/caregivers of middle-aged ages 30-50 years old who care for typically developing children and children with autism.

Needs Statement

In a 2022 study conducted by Paul et al., it was suggested that the lack of parents openly communicating with their children about their siblings' disabilities leads to confusion, lack of understanding, and even the inability to reflect and manage their own emotions. Siblings of children with autism have reported struggles with personal perceptions (self-esteem) and interpersonal perceptions (social esteem) in relation to the child with autism. This workshop aims to raise awareness and educate parents, caregivers, and anyone who works with children on how important it is to nurture the development and awareness of not only children with autism but also their siblings through scholarly literature. Research has concluded that the adjustment and development of typically developing siblings of children with autism are contingent on many different factors. Studies, surveys, and questionnaires conducted in North America, Latin America, Australia, and Asia indicate that typically developing

siblings may struggle relationally with their siblings with autism and their parents when prosocial interaction is not prioritized between them. This is why support for siblings is critical for parents. Promoting open dialogue, encouraging questions, and fostering a safe environment will help neurotypical siblings form stronger identities and relationships associated with their siblings with autism.

Autism spectrum disorder (ASD) is a neurodevelopmental disorder that “significantly impairs a child's ability to interact and communicate with others. Autism interferes with normal brain development, causing deficits in verbal and non-verbal communication, social interaction, and play (Block et al., 2006).” Autism is characterized by compulsive behaviors such as rocking back and forth or other types of repeated bodily behaviors, repetitive actions, and thoughts (hyperfixations). They value their routine and combat or resist changes to them. Due to these social “abnormalities,” they have difficulty relating to and connecting with others, and others have difficulty relating to and connecting with them. Autism is a spectrum of different behaviors that characterize what it is. Every person with autism displays different behaviors and hyper-fixations, and there is a range of severity. Low-functioning individuals can be characterized by being nonverbal and having a severe inability to control body functions. The repetition of thoughts, questions, and hyperfixations can characterize intermediate-functioning individuals. High-functioning individuals can still somewhat relate to and connect with society, such as being able to learn to drive and get a job; they as well have hyperfixations, social inhibitions, and struggle with social cues and etiquette.

Due to the spectrum of severity and different characteristics that make up autism, there is no one-size-fits-all. Parents not only learn to be parents of a unique individual and raise their children to be functioning and contributing members of society, but they also learn to be the parent of a child with more needs academically, socially, emotionally, and sometimes physically. Research shows that this

adds to higher levels of parental stress compared to parents who do not have children with autism or other neurodevelopmental disabilities. Parents of children with autism are more susceptible to higher levels of stress and strain individually, as a couple, and on the family unit, particularly in mothers who are typically the primary caregivers and bear most of the childrearing responsibilities (Di Renzo et al., 2021). Di Renzo's research strongly advised emotional regulation to be a tool that parents use to balance out any negative emotions they may feel associated with their child with autism. Parents and caregivers must be mindful that their neurotypical children are observing, synthesizing, absorbing, and modeling their parents' behavior.

My project also highlights the benefits of having a sibling with developmental disabilities, such as higher levels of empathy, compassion, and self-concept. In a survey and interviews of siblings of children with autism conducted at the 2021 Special Olympics, participating children attributed their relationship with their autistic siblings to exposing them to empathy, care, altruism, maturity, and responsibility compared to their peers who do not have siblings with autism (Paul et al., 2022). Furthermore, as indicated by the scores on the Piers-Harris self-concept scale, siblings self-reported having a stronger self-concept than those without autistic siblings. Significantly, the Piers-Harris self-concept scale scores reflected stronger levels of confidence and maturity, most likely due to comparing themselves to their sibling with autism socially and academically (Macks et al., 2007). Support groups help siblings remain in touch and honest with their emotions- whether it be confusion or concern for their sibling with autism or less exemplary emotions such as resentment or embarrassment. Studies have also suggested that there are many psychosocial benefits for a sibling of a child with autism. In a self-reported study, typically developing children associated their relationship with their autistic sibling to deepen their empathy and compassion for others versus children without siblings with autism (Orm et al., 2022). Therefore, parents and caregivers providing personal or external

environmental support are essential. Siblings' struggles can be alleviated by providing interventions, classes, and support groups for siblings and the whole family.

Siblings of children with autism can also face struggles socially and developmentally. Because of the social difficulties their autistic siblings face, typically developing siblings may have difficulty relating to their siblings and their peers, and they may struggle with the lack of adequate social interaction at home. This can lead to confusion, frustration, and loneliness. Not only does this cause frustration in siblings, but it also causes many other measurable adjustment difficulties. In a study conducted by Shojaee et al., siblings of children with autism and children without siblings with autism took a Strengths and Difficulties Questionnaire (SDQ). Results proved that there are higher levels of struggles and adjustment difficulties in children with siblings with autism in terms of hyperactivity, emotional problems, anxiety, depression, shame, sadness, loneliness, and anger than in those without siblings with autism. The speculation as to why is due to a lack of parental support and attention and increased responsibilities and expectations on the sibling to be another caretaker for their sibling with autism. The primary communication and social relationship models are the home and the family unit. Further, their siblings' autism often leads to a strained relationship between siblings due to their siblings' inability to communicate and express themselves. Interviews conducted by Chu et al. in 2021 revealed that typically developing siblings often felt embarrassed in public by their siblings or lacked sufficient knowledge on how to communicate with their siblings. Significantly, siblings who have attended therapy with their autistic sibling, such as speech therapy, vastly improved their relationship with their sibling and their understanding of communication.

Parents play a pivotal role in the adjustment of siblings of children with autism. Communication, open dialogue, and parents' attitudes toward their child with autism influence the sibling's attitude toward their sibling. Macks and Reeve (2007) underscored the importance of parents' perceptions. In

Macks and Reeve's study, siblings were given a Piers-Harris self-concept scale to measure social, emotional, and academic struggles relating to having a sibling with autism. Parents were given a Behavior Assessment System for Children-Parent Rating Scales to assess their perception of the child without autism regarding their social, emotional, and academic struggles. Parents of children with developmental disabilities and typically developing children did not accurately view the sibling's social and emotional functioning due to possible projections of frustration and stress onto their typically developing child. In an interview and questionnaire of mothers conducted by Perlman & Howe in 2022, mothers perceived their typically developing child without autism as mature and patient but lacking social interaction at home. The importance of having friends over helped with peer interaction. Finally, a study by Orm et al. (2022) used a Parent-Child Communication Scale - Child Report (PCCS-C). The results emphasized that mother-child communication is essential for the developing child's psychosocial development and mental well-being, and the absence of parental warmth was directly related to higher risk factors of negative adjustment, difficulty communicating, and internalization of feelings. This workshop emphasizes the significance of open parental communication and quality time. They are of utmost importance in supporting the success and adjustment of siblings of children with autism.

In conclusion, this capstone project aims to inform parents about a topic not commonly discussed but that impacts the entire family unit. My workshop's purpose is to explore the many facets of having a sibling with autism and to strengthen awareness of how siblings can be affected by having a sibling with autism. In order to ensure the satisfaction of the family and the self-esteem and prosociality of the siblings of the children with autism, communication is key. This workshop is intended to unlock that door and welcome parents into a safe space to learn how to utilize the theory and research I have developed into my lesson.

Theory

The theory utilized for my workshop is Murray Bowen's Family systems theory. Murray Bowen's *Family Systems Theory* theorizes that in a family unit, each member of the family impacts another member of the family through their direct or indirect behaviors (Prendeville et al., 2019). Family is the first source of relationships for a human being; it is the primary source of emotional connectedness, conflict, love, and a wide range of negative and positive emotions. Bowen's theory focuses on how the family system is woven into a person's individual identity as well as the identity of the family. Some keywords of Bowen's Family Systems Theory are "equilibrium" and "homeostasis (743)." This means that the balance and stability- or the inverse: the imbalance and instability- of an individual family member affects the family's homeostasis or harmony. Stressors in a family, such as a family member with special needs, economic troubles, and marital strife, can all add to the dysregulation of other members of the family, leading to anxiety, conflict, tension, etc. Parents especially have a responsibility for the harmony and equilibrium of their family.

Family Systems Theory applies to my project through parents having responsibility for the harmony and equilibrium of their family and each individual involved. A parent's actions have direct consequences and impacts on their children due to being the primary social and emotional models of behavior. This translates to my project through parents' impact on their children who have siblings with autism. They are responsible for the initial attitude a sibling has towards their sibling with autism. If parents are stressed, disdainful, and have an impatient or negative attitude toward their child with autism, that impacts their neurotypical child. They internalize and model that behavior against their sibling with autism and will develop more negative feelings associated with their sibling with autism. Stress, worry, and anxiety are all natural parts of being human. The added parental stress and responsibility of parenting a child with autism is also natural and inevitable.

Consideration of Diversity

The six participants in my Capstone were middle-aged parents, around 30-50. Four of my participants are immigrants, and one is a first-generation child of immigrants. The ethnicity of five of my participants are of Asian descent, and one is Caucasian. All six of the parents have some sort of college degree. The parents range from middle class, upper middle class, to upper class. The ages of the children of the participants vary. Four of the parents have young adult children with autism and neurotypical children, and two of the parents have a very young child with autism and a young neurotypical developing child. Finally, five of the parents are the biological parents of the autistic child and the neurotypical child, and one is the step-parent. This is an important workshop regardless of whether the parent is biological, a stepparent, or a caregiver (such as a grandparent) because it is for the wellbeing of the entire family.

Cultural consideration played a significant part in my workshop and was something I was very mindful of the entire time I was preparing my workshop. I was a young adult college student and nonparent conducting a workshop for middle-aged parents. As a nonparent, it was imperative that my workshop was not conducted as a lecture on what parents are doing “wrong.” Furthermore, when I reached out through my mother’s network of parents, there were some parents willing to participate; however, they only had a child or children with autism, and they did not have neurotypically developing children. This workshop was conducted exclusively for parents or caregivers of children with not only autism but also a neurotypically developing child or children. Parenting is a profound and meaningful responsibility, and having children with special needs adds to this daunting job. I have so much respect for the time, energy, resources, and pivoting necessary for having a child diagnosed with autism.

Learning Outcomes

My Capstone project focused on informing parents about the positive impacts, inevitable challenges, and developmental needs of siblings of children with autism. The project had the following learning outcomes.

1. Parents will be able to identify three ways that having a sibling with autism positively influences children's prosocial development.
2. Parents will be able to identify three challenges for siblings of children with autism.
3. Parents can list three ways to establish a strong relationship with the sibling(s) of children with autism.

Methods

Location and Participants

The workshop was conducted over Zoom over the course of two days. Using a Google Slides presentation, I conducted the Zoom workshop from Monterey, California, while the parent participants logged in from Southern California and Nevada (see Appendix A). There were five parent participants: two fathers, two mothers, and one stepfather. I recruited my participants through personal association. My mother has a network of parents and families of children with autism who I reached out to since they are family friends. The parents ranged from 40 years old to their late 50s. I chose these individuals due to their diversity of life experience, the range of ages of their children (ages 3-26 years old), and one of the fathers not being the biological father.

Procedures and Materials

I started off the workshop with a pre-implementation icebreaker. I introduced myself and gave context on the purpose of this workshop for my future career goals. As a nonparent, it was important for me to give the parents a chance to share their personal experiences (wins, losses, perceived

shortcomings, and accomplishments in their parenting) since I did not want to appear presumptuous in my lessons. I asked each parent to share their favorite part or memory of being a parent and/or what they learned from parenting both a child with autism and a typically developing child. My workshop was a one-time workshop completed in one sitting through Google slides, and each lesson for my three learning outcomes was given in an hour and a half. I did one workshop for half of the parents on Saturday, March 23, 2024 (two fathers and one mother), and the other lesson on Sunday, March 24, 2024, for the other half of the parents (one mother and one stepfather) who could not make it to the first day.

I put my first two learning outcomes together with a discussion question. The purpose of my discussion questions was to help the parents enrich their connection to my material and their personal lives and to reinforce the ideas to ensure passing scores on the assessment quiz. Learning Outcome 1: “Parents will be able to identify three ways that having a sibling with autism positively influences children's prosocial development” was conducted through a presentation slide of protective factors that are building blocks for siblings’ successes. The most important of these protective factors were open communication and mindfulness. I explained that open communication and mindfulness lead to better Empathy, Care, Altruism, Responsibility, and Self-concept.

Furthermore, I carried this topic onto Learning Outcome 2: Parents will be able to identify three challenges for siblings of children with autism. I presented a slide that broke down that the lack of open communication and mindfulness were risk factors for siblings of children with autism. This can lead to a lack of social learning, competition, exclusion, and resentment. After presenting my lessons for Learning Outcomes 1 and 2, I asked the parents to reflect and discuss when their neurotypically developing child exhibited positive and/or negative behaviors or feelings related to their sibling with autism. On the first day of my workshop, one of the parents rephrased the discussion question to

“challenging” instead of “negative.” I liked the way that they rephrased and I reworded the question for my second day.

Finally, I connected Learning Outcome 3: Parents can list three ways to establish a strong relationship with the sibling(s) of children with autism, with Murray Bowen’s Family Systems Theory. I showed a quick video and had the parents reflect on the first time their child noticed that their sibling acted differently than other children. I asked a follow-up question about how they navigated this in order to reinforce the ideas in their minds for the assessment. Finally, I ended with a summary of my lesson. I also introduced a book recommendation for a book called *How to Be a Sister: A Love Story with a Twist of Autism* (See Appendix C). Finally, I gave my participants the assessment in the form of a multiple choice and short answer 3-question quiz I created on Google Forms.

Results

My Learning Outcomes were assessed through a Google Forms quiz consisting of one multiple-choice question with three answers for Learning Outcome 1 and two SAQs or Short Answer Questions: one for Learning Outcome 2 and one for Learning Outcome 3 (See Appendix B). Each set of parents took the quiz as a unit. Hence, there were five parents in total, but only three official answers were submitted as each parent unit worked in pairs.

Learning Outcome 1 stated, "Parents will be able to identify three ways that having a sibling with autism positively influences children's prosocial development." The multiple-choice selections were *Empathetic, Altruistic, Studious, Athletic, Responsible, Extroverted, and Introverted*. The three correct answers were *Empathetic, Altruistic, and Responsible*. I reviewed all the parents’ answers on the Google form, and 100% of the parents were able to identify the three positive impacts of siblings of children with autism on their’ prosocial development. Therefore, 3/3 answers were correct, and Learning Outcome 1 was fully met.

The second Learning Outcome stated, “Parents will be able to identify three challenges for siblings of children with autism.” The parents were to answer this question with a short answer. Some of these answers included *Exclusion, Resentment, Lack of social learning, and Lack of communication*. I reviewed all the parent’s responses to their short answer questions. Four out of the five parents (80%) identified three challenges that I stated in my presentation, including *Communication between siblings may be limited, Frustration, and Impatience*. Therefore, $\frac{2}{3}$ answers were correct, and Learning Outcome 2 was fully met.

Finally, for Learning Outcome 3, “Parents can list three ways to establish a strong relationship with the sibling(s) of children with autism,” the parents also answered this with a short answer. These answers included *Clear communication, Taking an interest, Exclusive activities, and Quality time*. I reviewed all the parents’ responses to their short answer questions, and 100% of the parents could list three ways to establish a stronger relationship. Therefore, $\frac{3}{3}$ answers were correct, and Learning Outcome 3 was fully met.

Discussion

My Capstone workshop was successful in many ways. All of my Learning Outcomes were fully met. Parents were able to better understand and walk away with tools for communication, perspectives, and developmental impacts for siblings of autistic children. I believe that my workshop was successful as it was an emotional and safe space for expression, sharing, and learning. A very profound part of the workshop was the vulnerability, openness, and willingness each parent provided with their personal experiences of what they have learned while being parents. Parents could take away my lessons and connect them to their personal lives. Although discussion took up most of the workshop, I would not sacrifice this time for sharing as it brought the material closer to the heart of the parent participants and was the strongest part of the workshop.

Certain limitations in my research would be the Assessment. According to the graph, it says that there were only three answers, while I had five parents in total. This is because each set of parents completed the quiz as a unit. There were also several scheduling conflicts as everyone had very busy schedules and would often try to reschedule with me at the last minute. Lastly, although I corresponded with each parent comprehensively, explained my capstone project and its goals, and introduced what I was doing before starting my lessons, one parent didn't fully grasp the concept of my workshop.

For future considerations, I would have roleplaying activities for parents to be able to practice healthy communication as parents and as partners in different scenarios and hypothetical questions their children might have. Secondly, I could have a short questionnaire to help them determine and identify their neurotypically developing child or children's strengths to promote finding extracurriculars for their interests. Furthermore, as stated in my limitations in the research, I would have each parent take the Assessment individually. Moreover, although discussions were one of the strongest parts of my workshop, I may assign breakout rooms or small groups in order to save time. Finally, I would connect parents with further outside resources for families and siblings in pursuance of furthering the conversation of the impact and effects on siblings of autistic children, such as support groups and counseling services. My goal is to one day be able to provide counseling services to families and siblings myself.

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Appendix:

Appendix A

Workshop Slides

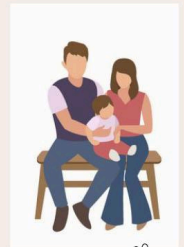
Welcome to “Parenting a Child with an Autistic Sibling” Workshop!

By: Jess Del Mundo



Icebreaker!

What is your favorite part or memory of being a parent?



Mental Health Effects

Positive and negative

Parental Effects

Theory

Family Systems Theory



Negative Impacts vs Positive Impacts



Negative Feelings

- Lack of Social Learning
- Competition
- Exclusion
- Resentment

Vatne, M et al, 2017

Positive Feelings

- Empathy
- Care
- Altruism
- Responsibility
- Self-concept

Discussion Question #1



Can you reflect on a time that your neuro typically developing child exhibited positive and/or negative behaviors or feelings related to their sibling with autism?

PARENTAL EFFECTS & COMMUNICATION

A NEW NORMAL

Communication, communication, communication!!

Communicate openly and answer any questions your child may have

No Communication = Confusion, inability to self regulate

- Paul et al
- Orm et al

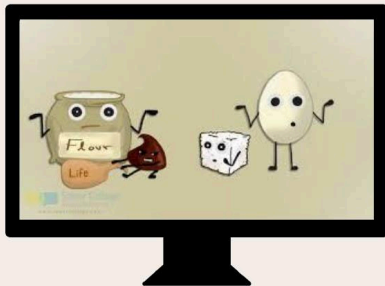


Discussion Question #2

Can you reflect on the first time your child noticed that their sibling acted differently than other children?

Follow up question: How did you navigate this?



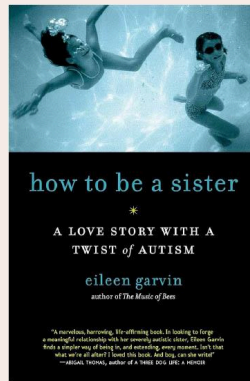


Key Takeaways

- A family is a whole, complex, single system; each member's behaviors can impact another member.
- Key concepts—boundaries, equilibrium, bidirectional, patterns, roles, and functions.

Recap! What Can You Do as Parents

Support	Create a safe, loving environment
Communication	Have a positive learning environment
Quality Time	Do not isolate child
Activities	Activities that foster (individuality, self-efficacy, promoting prosocial interaction -
Keeping in touch w emotions	Take care of yourself as a parent <i>Be a model of behavior! (yourself and child)</i>



<https://www.amazon.com/How-Be-Sister-Story-Autism/dp/1615190163>

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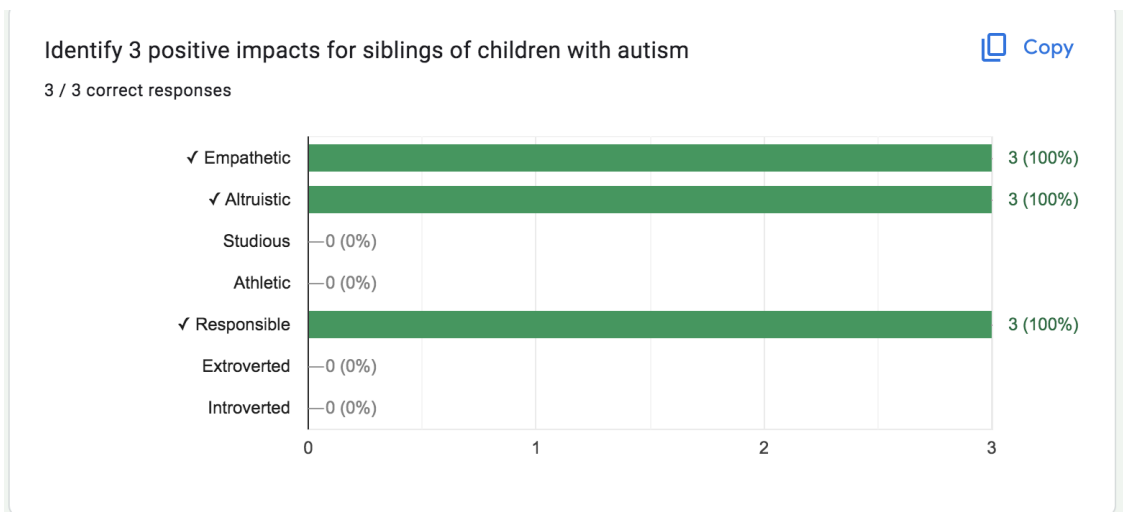
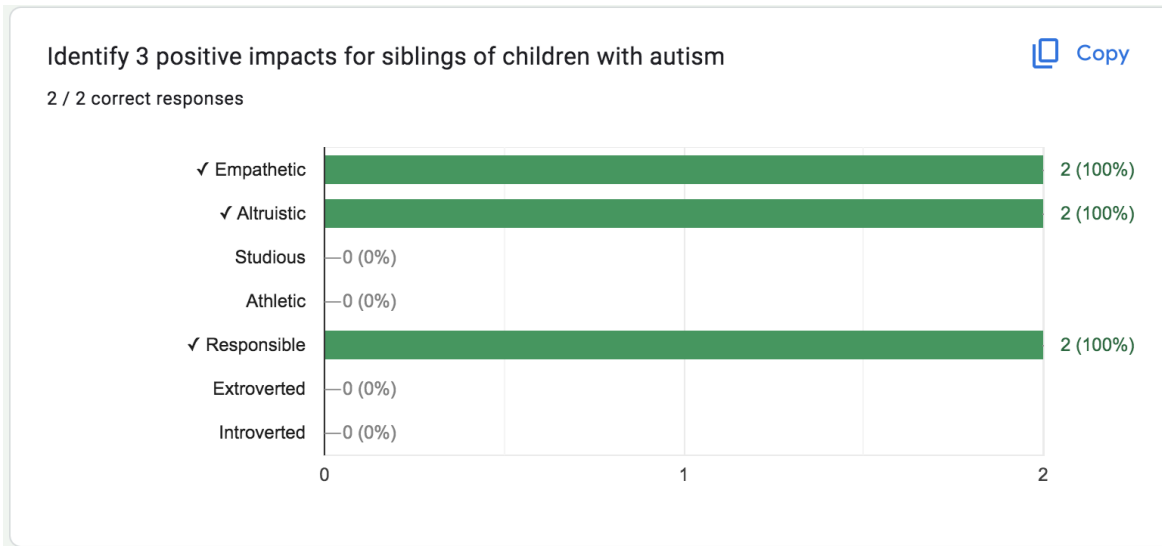
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Appendix B

Google Forms Results



List at least 3 challenges for siblings of children with autism

3 responses

- exclusion, lack of social learning, resentment
- Communication between siblings may be limited, frustration and impatience
- Patience, understanding that's it's a different norm , believing that things will be ok

Appendix C

How to Be a Sister: A Love Story with a Twist of Autism

