

May 2023

Experiences and Support Needs of Typically Developing Siblings of Children with Autism Spectrum Disorders

Keely Hamilton
Dominican University of California

<https://doi.org/10.33015/dominican.edu/2023.EDU.09>

IRB Number: 11069

Survey: Let us know how this paper benefits you.

Recommended Citation

Hamilton, Keely, "Experiences and Support Needs of Typically Developing Siblings of Children with Autism Spectrum Disorders" (2023). *Master of Science in Education | Master's Theses*. 72.

<https://doi.org/10.33015/dominican.edu/2023.EDU.09>

This Master's Thesis is brought to you for free and open access by the Liberal Arts and Education | Graduate Student Scholarship at Dominican Scholar. It has been accepted for inclusion in Master of Science in Education | Master's Theses by an authorized administrator of Dominican Scholar. For more information, please contact michael.pujals@dominican.edu.



This thesis, written under the direction of the candidate's thesis advisor and approved by the program chair, has been presented to and accepted by the Department of Education in partial fulfillment of the requirements for the degree of Master of Science in Education.

Keely Hamilton
Candidate

Jennifer Lucko, PhD
Program Chair

Katherine Lewis, PhD
First Reader

Zoe Bartholomew, EdD
Second Reader

**Experiences and Support Needs of Typically Developing Siblings of
Children with Autism Spectrum Disorders**

By

Keely Hamilton

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

Dominican University of California

San Rafael, CA

2023

Copyright © Keely Hamilton 2023. All rights reserved.

Abstract

Children living with an autistic sibling face unique challenges and are in need of support (Angell et al., 2012; Marquis et al., 2019; Molinaro et al., 2020). The purpose of this qualitative study was to understand what the experience of having a sibling with autism spectrum disorders (ASD) is like for a typically developing child during middle childhood or preadolescence, the impacts this experience has, and what types of support they feel they need. Five participants were interviewed for this study; all were in middle childhood or preadolescence, live in Marin County, California, and are in a family with a sibling with ASD. There were four male and one female participants whose ages ranged from 7 to 10 years, and their siblings with ASD ranged in age from 4 to 12 years (three males and two females). Data was analyzed using an open coding process to identify themes. The findings show that siblings of children with ASD need support in many areas, including age-appropriate information about ASD, tools for emotional regulation, coping strategies, and a community of peers that understand their unique experience. Many siblings feel social isolation, embarrassment, and bear the responsibility of educating others about their siblings with ASD. This study contributes to the literature by addressing the lack of existing research on the experiences of having a sibling with ASD for children in middle childhood and preadolescence, which are prime ages for support interventions. Implications for the field of education are that schools have a role to play in providing families with information about the importance of sibling support programs and available resources, and in directly providing (for all students) social emotional learning, disability and neurodiversity awareness, and making disability part of school wide diversity, equity, and inclusion initiatives.

Acknowledgements

This project and Master's program was a labor of love for my phenomenal sons. I never would have taken on any of this were it not for both of them. Gus Fiorentini inspired me to attend graduate school, something I never thought that I would do. West Fiorentini inspired this project, helped me refine interview questions and let me practice my interviewing skills with him.

Thank you to my family and friends for your support throughout this program, especially my husband Mario Fiorentini. Monique Jorgensen has gotten me through every single year of my entire education with her belief, encouragement, and motivational pep talks- thanks mom. To the indomitable mama bears of Dedication to Special Education, thank you for being my village. I am inspired by the work we have done and will do for students, educators and families; it is some of the most important work of my life and I am proud to serve alongside you. Colleen Arnold changed the direction of my thesis topic and the course of my career over one lunch, thank you for your stellar mentorship and honest advice. My Dominican community of professors and classmates have challenged, cheered and changed me; it has been an incredible time and I am grateful for you all.

A special thank you to a few people who were involved in this project at every stage- offering feedback, emotional support, and much needed perspective- Marissa Schow and Isabel Yates. For all of the above plus her amazing guidance, and for reading every draft with an editor's keen eye and an open heart, profound thanks to Katie Lewis- this project would not have been possible without you.

Table of Contents

Abstract.....	iii
Acknowledgements.....	iv
List of Tables	vii
Introduction	1
Statement of Purpose.....	2
Overview of the Research Design.....	3
Significance of the Study.....	4
Literature Review.....	6
The Challenges Typically Developing Siblings Face are Varied and Complex	7
Sibling Support.....	9
Ecological and Systems Thinking Approach for Sibling Support.....	13
Conclusion	15
Purpose.....	16
Methods.....	18
Research Questions.....	18
Description and Rationale for Research Approach	19
Research Design.....	20
Findings	27
Navigating Sibling Relationships - In Their Own Words	28
Sibling Experiences at Home	34
Sibling Experiences in the Outside World	35
Siblings are Thinking Deeply About Autism.....	38

Suggestions for Sibling Support	42
Conclusion	44
Discussion	47
Implications for the Literature	48
Implications for Practice and Policy	50
Limitations of the Study	53
Conclusion	55
References	57
Appendix A Copy of IRB Acceptance Letter	64
Appendix B Interview Questions	66
Appendix C Autism Spectrum Elementary Book List	69

List of Tables

Table 1 Participant demographics	29
Table 2 Autism Spectrum (ASD) Elementary Book List for Grades K-2	70
Table 3 Autism Spectrum (ASD) Elementary Book List for Grades 3-5.....	71

Introduction

The longest lasting relationship most people will ever have is with their siblings. When one sibling has autism spectrum disorders (ASD) that ongoing sibling relationship is much more complicated. As the parent of both a typically developing child and a child with ASD, I have witnessed in my own home the need for support and resources for siblings. While there are resources for myself as a parent and caregiver, resources and interventions for my son with ASD, and support for myself and my child with ASD together, there is little to nothing in terms of information or support available for his sibling living with and growing up alongside a person with ASD. In the course of this project I became a certified facilitator of the Sibshops program to help address the lack of sibling support available in the area. My parental instincts are borne out in the research; siblings of people with disabilities need support, and most particularly siblings of people with ASD, as they face additional unique challenges.

The nature and demographics of disability are changing in this country, but our notions about disability awareness and family support services have not kept pace with these changes. Between 2001 and 2011, the prevalence of childhood disability increased by 15.6%, while in the same 10-year period, disability due to neuro-developmental or mental health conditions, including ASD, increased by 20.9%, while disabilities due to a physical health condition declined by 11.8% (Houtrow et. al., 2014). According to Maenner et al., as many as 1 in 54 children in the United States have ASD (2020), and most of them have at least one sibling. Furthermore, in adulthood, siblings become the primary caregiver of their sibling with ASD after the death of their parents in 73% of cases (Glidden & Schoolcraft, 2007). In order for these relationships

to be successful for the person with ASD and their siblings, support is needed throughout their development, and not just as adult caregivers.

Statement of Purpose

Previous research has focused on the unique challenges for siblings of people with ASD (herein termed “siblings”) compared to navigating a relationship with a sibling with other disability types; the research also addresses the efficacy of sibling support and systemic barriers in providing and accessing sibling support. In living with a person with ASD, siblings contend with unexpected behaviors, emotional dysregulation, aggression aimed at them or their belongings, parents with the highest rates of stress and caregiver burden, social isolation, premature maturity, interrupted sleep, as well as increased empathy and lower levels of sibling rivalry (Angell et al., 2012; Benderix & Sivberg, 2007; Fishbein, 2010; Hayden et al., 2019; Hesse et al., 2013; Kramer et al., 2021; Marquis et al., 2019; Molinaro et al. 2020; Petalas et al., 2009). Sibling support has lasting benefits, is among the best predictors of positive sibling adjustment, and could ameliorate many of the negative outcomes reported by adult siblings, which were due to insufficient support (Giallo & Gavidia-Payne, 2006; Hanvey et al., 2022; Roberts et al., 2015). The wider availability of sibling support is limited due to not being recognized as a distinct social service category within the disability/health/social care realm and the not-for-profit/charity sector and also to not being funded appropriately (Kramer et al., 2021; Meltzer, 2021). An over reliance on volunteers limits the availability of support for siblings and the diversity of providers by excluding people who cannot afford to volunteer or to be underpaid for their time and work (Meltzer, 2021).

While a large body of qualitative and quantitative research has identified the complex challenges for siblings, and the benefits and efficacy of support interventions, there is limited phenomenological research conducted with participants in middle childhood and preadolescence, despite this being prime ages for interventions. The purpose of this study is to give voice to siblings currently in middle childhood and preadolescence about their sibling relationship experiences, impacts on them, their support needs, and to identify potential barriers to receiving support.

Overview of the Research Design

Owing to the localized nature of support services, this study focused on siblings living in Marin or neighboring counties. To understand the meaning they are making of their sibling experience, in depth, semi-structured, phenomenological interviews were conducted with five participants currently in middle childhood or preadolescence living with a brother or sister with ASD. There were four male and one female participants ranging in age from 7 to 10 years, and their siblings with ASD ranged in age from four to 12 years, and were three males and two females. Interviews took place in participants' homes, though they were also provided with the option of meeting in a neutral location.

Participants were recruited through two parent groups I am part of as a parent of a child with special needs, through purposeful and snowball sampling, by directly reaching out to families I know who met the research criteria. A qualitative approach was used in examining data which included interview recordings, verbatim transcripts of interviews, and analytic memos. This research study had three questions it sought to answer: (1) What is the experience of having a sibling with ASD like for a typically

developing child and how do they perceive that it impacts them? (2) What type of support do siblings of children with ASD perceive they need? (3) How do siblings of children with ASD perceive or account for changes in their sibling relationship?

Significance of the Study

Whether they are speaking to anyone about it or not, siblings in middle childhood and preadolescence are thinking deeply about ASD. They are navigating complex relationship dynamics within their families, with friends and peers, and in interactions with people in the wider community, all owing to their identity and role as siblings of children with ASD. Siblings recognize and are able to articulate their own needs for support. They would like for that support to occur across multiple environments- at home through open communication with their parents about ASD, in organized peer support programs where they can meet and share coping strategies with other siblings and know they are not alone in their experiences, and in their schools where they would like to see their families considered and their sibling identity reflected.

Rather than falling in the gap between social service categories and being left out of the supports that exist for children with disabilities in schools, which also includes educational opportunities for their parents and/or caregivers, sibling support needs to become a responsibility and be provided in all of these spheres. First, siblings must have their identity and its unique challenges recognized in the classrooms and schools they attend. Families of all sorts, including those with disabilities, need to be considered in the planning of school wide events, and the communications about these events to feel welcome. Disability awareness needs to extend beyond outdated notions

of only disabilities that are apparent at a glance, like people with Down Syndrome or wheelchair users, and encompass less visible and invisible disabilities like ASD, mental health challenges, and neurodiversity. Disability awareness and ableism bias are a social justice issue. We marginalize not only children with disabilities when we segregate and silo special education, but also their families. Siblings are students too, and though they may attend a different school than their sibling with ASD, they are shouldering an unfair burden of educating peers and people in the community about their sibling with ASD. To truly advance educational equity disability awareness- including neurodiversity, less visible, and invisible disabilities- should be included in schools' Diversity, Equity and Inclusion (DEI) initiatives as well as its curriculum, regardless of whether there is an inclusive or segregated model of special education happening on campus.

Literature Review

Sibling relationships are the longest lasting relationship in most people's lives. This literature review seeks to understand the impact that living with a brother or sister with autism spectrum disorders (ASD) has on their typically developing siblings (herein termed "siblings"). Research has identified that siblings of people with disabilities need support in many common areas, and that ASD presents unique additional challenges for siblings not usually experienced among other kinds of disabilities; namely, aggression and/or violence directed toward them by their sibling with ASD. There are many successful program models for supporting siblings (Conway & Meyer, 2008; Hayden et al., 2019) and receiving sibling support has lasting benefits (Roberts et al., 2015). However, there are structural barriers that limit the wider availability of sibling support owing to how it falls somewhere between service categories of support for people with disabilities and support for caregivers; additionally, lack of funding and infrastructure limit who is able to deliver and receive such services (Meltzer, 2021).

This review explores the lived experiences and broader societal influences that cause siblings of children with ASD to need support, systemic barriers to receiving support, and how utilizing ecological and systems thinking frameworks in research can help broaden understanding beyond individual siblings and family systems and extend research into practice.

The following review of literature is organized into three broad themes. First, the complex challenges typically developing siblings experience living with siblings with disabilities will be explored, including what makes autism uniquely challenging for sibling relationships, and other cultural considerations. Next, sibling support will be

examined, starting with existing models, their efficacy and lasting effects for participants, and resources and access to support services. Finally, I turn to a consideration of an ecological and systems thinking approach for sibling support research, including its uses in other fields and broader outcomes.

The Challenges Typically Developing Siblings Face are Varied and Complex

Mixed Results and Non-Consensus

There is no consensus as to whether the experience of having a sibling with a disability is overall positive, negative, or mixed. Siblings experience social isolation and stigma for having a sibling with intellectual and developmental disabilities (IDD) (Marquis et al., 2019). While recognizing their need for support, Angell et al. (2012) also found that less sibling rivalry and high levels of family cohesion were positive effects of having a sibling with a disability. Kramer et al. (2021) found a complex mix of internalizing and externalizing behaviors, feelings of isolation, guilt, stress, responsibility, and anger, as well as increased compassion for others, tolerance, and patience. Premature maturity of siblings has been recognized as something that is both beneficial and detrimental (Kramer et al., 2021; Molinaro et al. 2020). It is clear that siblings are affected by having a sibling with a disability, but it is not clear whether the experience is beneficial, detrimental, or a combination of both.

Autism is Different

The American Psychological Association (2022) defines autism spectrum disorders (ASD), also called autistic spectrum disorder, as “any one of a group of disorders with an onset typically occurring during the preschool years and characterized by varying but often marked difficulties in communication and social

interaction.” The complex nature of ASD, where challenges are commonly experienced with communication, antisocial behavior, and emotional regulation and expression, make it particularly stressful for families to manage (Gray, 2006). Hesse et al. (2013) found that parental stress is a determining factor in the adjustment of typically developing siblings, and that parental stress is higher among mothers of children with autism than mothers of children with other developmental delays and mothers of children without disabilities. Hayes and Watson (2012) found that parents of children with autism had greater amounts of stress compared to parents of children with other types of disabilities. In studying the burden of care and quality of life for caregivers of children and adolescents with ASD, Patel et al. (2022) found that caregivers suffered a high burden of care and an impaired quality of life.

In addition to the effects of parental stress and caregiving burdens, siblings and their belongings are often the target of aggression from their brother or sister with ASD, leading to feelings of anxiety for the sibling (Angell et al., 2012); experience of violence also negatively impacts siblings' psychological well-being (Benderix & Sivberg, 2007). The particular experiences of exposure to challenging behaviors and violence related to their brother or sister's ASD are difficult for siblings (Fishbein, 2010; Petalas et al., 2009). Molinaro et al. (2020) found that there were stark differences for siblings living with a child with ASD including being the target of aggression, less time spent with parents, and increased maturity. Compared to other types of IDD, siblings of children with ASD have greater adjustment and psychological problems (Marquis et al., 2019). Having a sibling with ASD negatively affects self-concept and is a significant predictor of poor scholastic status, happiness, satisfaction, popularity, and behavioral mal-

adjustment (Inam et al., 2017). Specifically, in the school setting, siblings of people with ASD experience a lower sense of perceived relatedness and competence (Gregory et al., 2020).

Cultural Considerations

Culture and cultural context are often not accounted for in research on sibling support; however, they should be. Real differences have emerged in the experiences of Latino/a/x siblings who often take on greater parent-like caregiving roles for their sibling with ASD, and report that caregiving is part of their identity (Long et al., 2022). Kao et al. (2012) also found that among Latino/a/x families, the caregiving roles of siblings were important in these families in ways that may differ from other ethnic groups. According to Lobato et al. (2011), Latino/a/x siblings of children with IDD reported significantly poorer awareness of and reluctance to express emotions, experienced more internalizing, emotional symptoms, problems with parents, and problems with personal adjustment.

Siblings face their own challenges by growing up alongside a brother or sister impacted by a disability; when that disability is autism spectrum disorder, there are additional unique challenges. This becomes more complex when you introduce cultural aspects to the expectations and caregiving responsibilities of siblings. These siblings could benefit greatly from additional support outside of their family unit.

Sibling Support

Models of Support

There are several existing models of effective sibling support, which include an element of peer support. Sibshops was founded in 1990 with a wellness approach and

seeks to provide peer-support in a fun and recreational context; it has since been adapted and implemented throughout the U.S. and around the world (Meyer & Vadasy, 2015). Sunsibs, as part of the Sunfield School in the United Kingdom, reaches out to siblings at the same time they reach out to parents during the initial intake process and involves siblings throughout their organization (Conway & Meyer, 2008). SibworkS in Australia is a 6-week, manual-based, support group that allows for standardization and quantitative study (Roberts et al., 2015).

Sibs Talk, a one-to-one intervention delivered by staff in schools, has shown that teachers have a role to play in supporting typically developing siblings of children with a disability, serious long-term condition, or receiving special education services (Hayden et al., 2019); Sibs Talk recognizes that siblings are students too. Sibs Talk was developed by the Sibs organization, a long standing group in the United Kingdom that realized that support for siblings in schools may only be offered after there are concerns (Sibs, 2022), and that siblings were an identifiable group of students facing barriers to their learning by virtue of their situation, “including disrupted sleep, anxiety about their brother or sister’s health, and less parental support with homework due to the demands of care” (Hayden et al., 2019, p. 406). Though delivered differently, all of these models recognize that the support siblings need includes the opportunity to talk about their experiences, ask questions, learn coping strategies, and know that they are not alone.

Efficacy and Lasting Effects

The effects of sibling support interventions are long lasting. A quantitative study of the 6-week SibworkS support group shows statistically significant large benefit in

emotional and behavioral functioning, and that the benefit remained large three-months post treatment. Medium sized benefits were reported in the areas of improved self-esteem and less coping by externalizing (Roberts et al., 2015). Adult siblings have reported that there were aspects of their own experience as siblings growing up that they had not been able to understand or process and that they would have benefited from a support intervention (Hanvey et al., 2022). Giallo and Gavidia-Payne (2006) found that past attendance in a sibling support group was among the most significant predictors of sibling adjustment. In thinking about the long term care needs of people with disabilities, it is important to recognize that siblings have a role to play and that “if typically developing siblings receive support and information as they grow up, there is a higher likelihood that they will elect to remain lovingly involved in the lives of their brothers and sisters with disabilities when their parents no longer can” (Conway & Meyer, 2008, p.115). Furthermore, in studying adult siblings of people with a disability or chronic illness and asking them to reflect on their experiences as siblings during childhood and adolescence, Hanvey et al. (2022) found that “many of the negative outcomes reported by siblings are not, in fact, the direct result of their brothers’ or sisters’ conditions, but rather the consequences of this insufficient understanding and support” (p. 946).

Resources and Access to Support

Historically, the Industrial Revolution brought about a shift from people with disabilities living at home, and working in family businesses or on family farms when possible (Wehmeyer, 2015), to people with disabilities being sent to live in institutions as a means of managing the stigma of disability. Further justification for

institutionalizing children with disabilities was to remove the burden of care from the family and allow the remaining siblings to thrive; younger siblings often knew nothing about their brother or sister living in an institution (Kramer et. al, 2021). Shifting attitudes over time brought about change and in 1975, the U.S. Congress passed Public Law 94-142, called the Education for All Handicapped Children Act (EHA), which established the right to receive a public education for children with disabilities, and has since been continually reauthorized under the name Individuals with Disabilities Education Act (IDEA) (U.S. Department of Education, 2022). The field of sibling disability research was born during the end of widespread institutionalization practices and focused on psychological adjustment to the presence of disability in the family unit and the impacts to family functioning. In response, the practice of sibling support emerged in the late 1970s and early 1980s in a piecemeal fashion by various disability, health, and social work practitioners and has remained an add-on rather than a central social service offering (Kramer et al., 2021). Though people with disabilities returned to their communities and are now likely to be living in their family homes and are able to attend public schools, much of the stigma surrounding disability and having a family member with a disability remains. This stigma, coupled with the unique challenges of having a sibling with a disability, affects siblings in their lives at home, at school, and in the community. Reducing the stigma of disability in any context, but especially school, benefits students with disabilities and their siblings who are also students. Allowing for this sibling identity to be recognized, acknowledged and supported in the school context, both for the impacts it may have on academic

achievement and personal wellbeing, can have ripple effects across other contexts. Likewise, support in other venues may have positive effects on school life.

Wider availability of sibling support programs is hampered by lack of recognition and legitimacy as a distinct social service type within the disability/health/social care realm and the not-for-profit/charity sector. Sibling support providers mostly operate with minimal funding and staffing and rely heavily on volunteers and people with a personal passion for the work. Diversity among providers is limited by excluding those that cannot afford to do unfunded work. This is true across the sector, in multiple countries, and not due to the fault of any single provider or organization (Meltzer, 2021). Where support exists, siblings in need often cannot be accommodated without delay, sometimes spending months on a waitlist (Roberts et al., 2015).

Ecological and Systems Thinking Approach for Sibling Support

Elements of Ecological and Systems Thinking Model

This model builds off of Bronfenbrenner's ecological systems theory, which views child development as a complex system of relationships affected by the surrounding environment. The environment is broken into five systems-the microsystem, the mesosystem, the exosystem, the macrosystem, and the chronosystem; we must look not only at the child and their immediate environment, but also at the interaction of the larger environment (Bronfenbrenner, 1979). Systems thinking is a method used to understand, anticipate, and change the functioning of systems, as well as the elements, actors, and internal structures within systems (Abercrombie et al., 2015). Elements of systems thinking used in this method are feedback loops, defined by Kim (1999) as "interconnected set[s] of circular

relationships” (p. 5), where one element or actor influences a particular response from the other actor or element. Feedback loops can have positive or negative effects, and both intended and unintended consequences (Sterman, 2000). Another element of systems thinking are levers. A lever is a place in the system where an actor can break the feedback loop and spark change in the system's functioning by implementing an intervention (Maani & Cavana, 2007). This model was applied to sibling support research in a case study by Meltzer and Muir (2021) by taking the responses from a single participant in a prior study and mapping those responses onto a model of ecological systems thinking.

Uses in Other Fields

Saxena and Adamsons (2013) as well as Kovshoff et al. (2017) have used ecological theory in other sibling research. Eriksson et al. (2018) have held that Bronfenbrenner’s ecological theory is consistent with frameworks used recently in public health research. Systems thinking is currently employed in studying public health research and practice (Carey et al., 2015).

Broader Outcomes

This model shifts the focus of sibling research away from the experiences of individual siblings to “how practice and its actors can make change in siblings’ lives” (Meltzer & Muir, 2021, p. 6). This model has the potential to bridge theory and practice by engaging in sibling research that is theoretically driven and establishing interventions that are theory informed (Kovshoff et al., 2017). Lack of theory use has limited the potential for policymakers and practitioners to create empirically based sibling supports (Saxena & Adamsons, 2013). Lack of theory also contributes to the

lack of recognition and legitimacy for sibling support within the health, disability, social care realm, and the non-profit, charity sectors around the world which hampers funding, access, and opportunity (Meltzer, 2021).

Conclusion

Strengths and Contributions of the Reviewed Literature

Research has chronicled the unique challenges and stresses of families living with a child with ASD, which impact the daily lives of their siblings. Among these challenges are dealing with communication, emotional regulation and expression limitations of the sibling with ASD, being the target of aggression and/or violence, reduced parental time and attention due to caregiving responsibilities, disrupted sleep, and experiencing social stigma. Experiences of adolescent and adult siblings have been recorded and common areas of need for support have been identified, which include validating the feelings of siblings about their experiences, feeling seen rather than invisible, coping strategies, problem solving, receiving information and the ability to ask questions about their sibling's diagnosis. Benefits of sibling support, particularly peer support as a protective moderating factor, have been established. Structural, leadership, funding sources, and business processes of sibling support providers have been investigated and found to be hampered by a lack of legitimacy as a distinct social service type, limiting funding opportunities and wider access (Meltzer, 2021).

Overall Weaknesses and Literature Gap

Research on sibling support has been largely a-theoretical with only some integration of Bronfenbrenner's ecological systems model (Shivers et al., 2019). Families that participate in studies tend to already be connected to support services, if

not sibling support services, and tend to be samples of convenience. There is little academic research that takes cultural context into account, though it is emerging that the experiences of Latino/a/x siblings have particular challenges in need of further exploration. Most research has been focused on the individual typically developing sibling and does not take into account the sibling with ASD and their perspective of the sibling relationship, or wider societal influences on the sibling relationship (Meltzer & Muir, 2021). Longitudinal studies of siblings with and without ASD are also scarce. More research is needed about siblings' experiences at school and educational outcomes.

Currently, there is a specific gap in knowledge around the experiences of typically developing siblings of children with ASD during middle childhood and preadolescence (Angell et al., 2012). Another specific gap in the reviewed literature is the lack of use of theory to bridge research and practice (Kovshoff et al., 2017; Meltzer & Muir, 2021; Saxena & Adamsons, 2013). There is some use of family systems theory as an alternative in sibling disability research (Angell et al., 2012; Wright & Benigno, 2019).

Purpose

The purpose of this study is to talk with siblings during middle childhood or preadolescence about their experience of having a brother or sister with ASD, to gauge their understanding of autism, how it impacts them, and how they perceive their own needs for support. I seek to extend the work of Meltzer and Muir (2021) by viewing responses through an ecological and systems thinking framework, to identify potential levers for sibling support, and deepen understanding of possibilities for extending and

enriching sibling support as it is necessary to broaden beyond individual siblings to systems and societal influences that can benefit sibling relationships for both the typically developing sibling and the sibling with ASD.

Methods

Children living with an autistic sibling face unique challenges compared to living with a sibling with other types of disability; these children are in need of support (Angell et al., 2012; Marquis et al., 2019; Molinaro et al. 2020). Currently, there is a lack of existing research that studies the experiences of having a sibling with autism spectrum disorders (ASD) during middle childhood and preadolescence. Furthermore, much of the research on sibling support has been a-theoretical. More data is needed on the experiences of siblings during this period of their lives and their perceptions of their own support needs. I designed these methods to give voice to these sibling experiences and by examining their responses through a framework of ecological and systems thinking (Meltzer & Muir, 2021), I also address a lack of theory-driven research. This framework also served to broaden beyond individuals to recognize and encompass societal influences on siblings and systems that can be altered to the benefits of siblings.

Research Questions

This study focused on in-depth semi-structured interviews with typically developing siblings about their experiences having a brother or sister with ASD. To this end, interview questions were developed based on the following central questions:

- What is the experience of having a sibling with ASD like for a typically developing child and how do they perceive that it impacts them?
- What type of support do siblings of children with ASD perceive they need?
- How do siblings of children with ASD perceive or account for changes in their sibling relationship?

Description and Rationale for Research Approach

In seeking to understand the experiences of typically developing siblings of children with ASD during middle childhood and preadolescence, I conducted a study with a constructivist worldview employing phenomenological interviewing. My research is constructivist in the sense that it seeks to interpret the meaning that participants make of their own experiences (Creswell, 2018). Due to my personal connection to this topic, as the parent of both a typically developing child and a child with autism spectrum disorder, I acknowledge that I am a part of the disability and caregiving community I am studying; and I bring my personal values— that these sibling experiences are worthy of examination and elevation— to this research. According to Creswell (2018), constructivist researchers recognize their interpretations are shaped by their backgrounds and experiences and center themselves in the research they conduct.

This study explores a gap in the research, namely, the experiences of siblings during the particular age ranges of middle childhood and preadolescence. A qualitative, inductive, phenomenological approach was chosen. In utilizing a phenomenological approach it is best to be as chronologically close to the phenomena under study as possible (Seidman, 2013). Since a sibling relationship is ongoing and lifelong, I conducted semi-structured, open-ended, in-depth interviews of typically developing siblings currently in middle childhood or preadolescence, about their experiences with their sibling with ASD. Even as this yielded less sophisticated interpretations than other studies which have had adolescent or adult siblings reflect back on their own experiences when younger, it is reflective of participants' understanding and the

meaning they are making of these experiences as a person currently in middle childhood or preadolescence and adds to this field of study as a comparison to reflections of older participants in other studies.

Phenomenological interviewing also pays close attention to the particular language participants use, taking word choice seriously, and requires following up on participants' choice of words when appropriate to do so (Seidman, 2013). I wanted to understand what these siblings experienced and how they understood it for themselves. Given the subject matter of ASD and their relatively young age, particular attention to word choice in their interpretation was also illustrative of whether these participants had terminology related to ASD in their vocabulary; if so, what was their facility with using that vocabulary? If not, how have they chosen to describe those phenomena in other terms?

Research Design

Research Site and Entry Into the Field

There was not one specific research site identified for this project. Rather, participants were interviewed in a place of their choosing based on where they felt more comfortable, either in their own home or at a neutral location, the Tech Resource Center. I had pre-existing relationships with parents of some of the participants as a fellow parent of a child with ASD. I also had connections to community groups serving families of children with disabilities where I found other participants due to my involvement as a fellow parent. The study focused on families living in Marin and neighboring counties.

Participants and Sampling Procedure

Purposeful sampling was used to identify potential participants currently in middle childhood, who are themselves neurotypical and have a sibling with ASD. Participants were five typically developing siblings aged 7-10 years, living with a brother or sister with ASD. Due to the localized nature of support service offerings, the sample focused on families living in Marin or neighboring counties. Purposeful sampling, particularly snowball sampling, was used and participants were recruited through their parents using multiple methods. Direct email requests were sent to parents whose families I knew to meet the criteria under study. I then used the snowball method of sampling in which I asked parents of participants to recommend anyone they knew that met the criteria and may want to participate in the study (Creswell, 2013). Finally, a letter of introduction outlining my role and the project and asking people interested in volunteering to contact me was sent out by email, newsletter, posted to social media and on group forums through two different special education groups I am affiliated with as a fellow parent participant (I.e. Dedication to Special Education and Square Peg Union). Relatively few participants were needed for in-depth phenomenological interviewing (Seidman, 2013). Parents provided written proxy consent for their minor child to participate in the study by signing a proxy consent form that outlined the study's purpose, provided methodology and risk information, and detailed how data would be collected and protected. Child participants were given an assent form with age-appropriate information. Before asking them to sign, I went over it with them verbally, asked if they understood, answered any questions about what they are agreeing to do, reminded them that they could skip any question or opt out of the

study at any time, and only then asked them sign their name indicating their assent to participate in the study.

Methods

Prior to any interviews taking place, parents had the opportunity to ask questions about the project and give written consent for their child's participation in the study. Minor participants gave verbal and written assent after an introduction where the Children's Assent Form, which was written to be age appropriate, was read aloud to them, understanding was confirmed, any questions were answered, and reminders were given that they can skip any questions or opt out of the study at any time. I then shared some additional information about myself with each participant. To build rapport with and show respect for participants I shared with them the following personal information:

In addition to being a researcher, I am a mom. I have two boys. One of my sons has autism, the other does not. I know some things about living with someone with autism, but I don't know what it's like to have a sibling with autism, and that's why I'm talking to you.

I conducted one-on-one semi-structured interviews with each of the five participants. There were ten questions I asked all of the participants and various follow up questions based on their responses (see Appendix B: Interview Questions). Interview questions were designed to address the three central research questions.

At the completion of the interview, I thanked each participant for helping me in my research and reminded them that no one else will hear the recording of our conversation but me, that I will protect their confidentiality, and that when I write about this, I will use a pseudonym (fake name) for them and their sibling.

All interviews were audio recorded on my password protected cell phone. For

the comfort of participants, no notes were taken during the interview; instead I wrote my observations and impressions immediately after the completion of the interview out of the presence of the participant. I transcribed each interview recording verbatim and upon transcription of the audio recordings changed all actual names to pseudonyms. Actual names were never recorded in written notes, materials or transcripts.

Data Analysis

I collected data through qualitative semi-structured interviews. Each interview was audio recorded using my cellphone. Immediately following each interview I wrote analytic memos capturing my observations of the participant, general impressions of the interview, ideas, phrases, and points that stood out to me during the conversation.

I used all three strategies for qualitative data analysis outlined by Maxwell (2013): writing analytic memos, categorizing strategies through coding and thematic analysis, and connecting strategies through matrices and narrative analysis. Where applicable, I also took the additional step of mapping feedback loops, actors, and levers of potential interventions using the ecological and systems thinking model demonstrated by Meltzer and Muir (2021); for a full discussion of this model, see Chapter 2. Throughout the data analysis process, I wrote memos because “memos not only capture your analytic thinking about your data, but also *facilitate* such thinking, stimulating analytic insights” (Maxwell, 2013, p.105).

Before I conducted interviews, I made a list of expected codes which might apply to participants' responses; these included: challenge, conflict, coping strategy, feedback loop, intervention, and wish. For each interview that was completed, I listened to the recording in its entirety once before transcribing it verbatim. I read each

transcript multiple times to explore and get a general sense of the data, before I began writing memos in the margins of the datasets.

Then I began to code all the datasets. First, I used open coding as an inductive process to see what emerged from the data. Next, I used focused coding to condense and organize codes, removing overlap or redundancy, and clearly defining codes that would then be applied to the complete dataset (Creswell, 2002). I also engaged in peer coding and peer concept mapping as a validity check. I compared these final codes to my list of expected codes and noted unexpected or surprising codes that emerged.

I did an additional review of transcript responses about experiences through a systems thinking lens with the goal of identifying and mapping feedback loops (Kim, 1999; Sterman, 2000) in sibling interactions and applying the Ecological Systems Theory model of systems levels (Bronfenbrenner, 1979). I then took choice moments from interviews where a discreet scenario or challenge could be mapped onto Meltzer and Muir's ecological and systems thinking model framework (2021) and described these in their terms.

Finally, I used connecting strategies. I listed all codes into a data analysis matrix, with supporting language from the interviews, and used this to write my narrative analysis connecting the themes which emerged. Through this process I was able to see what elements of the sibling experience were common amongst participants.

Validity

I am the parent of two sons in middle childhood, one is typically developing and the other has ASD. I am an active part of the disability community in Marin County and

participate in a variety of activities with my children, many of them for children with disabilities and their families. This may have influenced data collection because I am personally invested in sibling support programs being more widely available because I believe they will benefit my own children. Participants may know me or my children from community activities, and I may know them, their parents or siblings. I openly shared with participants about my two sons and my reasons for conducting this project before beginning the interview.

In conducting research with children, it is especially important to consider reactivity. Following are the ways I considered participant reactivity and sought to address it in my research design. First, child participants may downplay or not accurately reflect their true feelings about their experiences out of concern for their parent's or sibling's feelings. I made sure that interviews were conducted one-on-one and out of the earshot or sightline of parents or siblings, and repeatedly expressed my commitment to maintaining their confidentiality. Next, participants may seek to please the researcher. I asked mostly open-ended questions and refrained from taking any notes during the interview. In addition to mostly open-ended questions, I asked a series of yes or no questions about existing interventions, to lessen the pressure to come up with a response in order to please the researcher.

Qualitative data was collected through in-depth semi structured interviews with children which were audio recorded and transcribed. Being aware of my bias and potential influence, I implemented the following strategies to address these validity threats. First, I utilized rich data by making verbatim transcriptions of the interviews I conducted (Maxwell, 2013). These verbatim transcriptions served as the data set for

coding and analysis with the only change being the use of pseudonyms in place of any actual names to preserve confidentiality. Finally, I employed member checks as a means of respondent validation. In addition to helping identify my own biases and any misinterpretations, respondent validation is the “single most important way of ruling out the possibility of misinterpreting the meaning of what participants say and do and the perspective they have on what is going on” (Maxwell, 2013, p.126-127). By soliciting feedback through member checks, I was able to validate that my conclusions were in line with participants' perceptions.

Findings

This qualitative research project provided a platform for the voices of children growing up alongside a sibling with autism spectrum disorders (ASD) to be heard, and sought to answer the following questions: (1) What is the experience of having a sibling with ASD like for a typically developing child and how do they perceive that it impacts them? (2) What type of support do siblings of children with ASD perceive they need? (3) How do siblings of children with ASD perceive or account for changes in their sibling relationship? Most siblings experience emotional dysregulation and unexpected challenging behaviors from their sibling with ASD along with their own big feelings, including embarrassment and social isolation; therefore, they need support in the areas of emotional regulation, age-appropriate information about ASD, coping strategies, and a community that understands their unique experience.

To honor their voices and show how children in middle childhood and preadolescence make meaning of their own sibling experience in all its complexity, we will first look at how participants describe their relationship with their sibling with ASD in their own words through vignettes. While each sibling relationship is unique, after analyzing interview transcripts and analytic memos, four themes emerged that will also be explored. The first theme is about navigating experiences at home within the family unit, including unexpected behaviors, big emotions, and relationships with their parents. Then, siblings described their experiences in the outside world with friends, school, and the wider community. Next, participants demonstrated the ways they are thinking deeply about autism, whether or not they are talking about it with anyone. Finally, suggestions for sibling support based on what has helped sibling participants

previously and interventions they feel they need are shared. The findings of this study give voice to the experiences, perceptions, and insights of these siblings during middle childhood and preadolescence.

To address a gap in the existing literature, which has relied primarily on adults and adolescents reflecting back on their experiences during this time of their lives, children were interviewed for this study to capture their current perceptions and experiences. Five participants were interviewed, all were in middle childhood or preadolescence, live in Marin County, California, and are living with a sibling with ASD. There were four male and one female participants ranging in age from 7 to 10 years, and their siblings with ASD ranged in age from 4 to 12 years, and were three males and two females. While it was not a requirement for selection, all participants and their siblings attend Marin County public schools, and only have one sibling. Pseudonyms have been used for all participants, their siblings and any names or locations mentioned throughout the interviews, to protect confidentiality. Further demographic details about participants and their siblings with ASD are outlined in Table 1.

Navigating Sibling Relationships - In Their Own Words

These sibling relationships are complicated, and for participants, the feelings around them are often mixed. The following relationship dynamics are presented mostly in participants' own words and organized by individual participants, beginning with Orlando.

Orlando

Orlando smiled throughout our conversation and described his relationship with older brother Destin like this:

Table 1*Participant Demographics*

Participant Pseudonym	Participant Sex	Participant Age	Participant Grade	Sibling with ASD Pseudonym	Sibling with ASD Sex	Sibling with ASD Age	Sibling with ASD Grade
Dallas	Male	10 years	4th	Austin	Male	4 years	Preschool
Chandler	Male	8 years	3rd	Phoenix	Male	12 years	7th
Orlando	Male	7 years	2nd	Destin	Male	9 years	3rd
Denver	Male	10 years	4th	Aspen	Female	8 years	2nd
Savannah	Female	10 years	4th	Charlotte	Female	12 years	6th

Oh, it feels like happy. It feels like I'm in space with a happy autism kid. Yeah, with cute happy autism kid. He's really cute even though he's really big...I share Legos with him...my mom told me that she is going to teach my brother how to play video games. I just play video games. I just like being with him because I just like to be with my brother. Because if I didn't have a brother, I would just sit there. Going like this [lays head on the couch]. Boring. And it's now that I have a brother, I'm like, yeah, this is fun. But yeah, I really would like having a sister with autism or normal sister could talk. Either way.

In comparison to other people's relationships with their siblings, Orlando notes the characteristics of his brother's ASD presentation as the differences, noting:

He doesn't know how to talk...He shows me like when he screams and takes my hands off Legos, that means he doesn't want to share...Cuz I mean, it's just...curious. Extreme. Saying how he gets mad. And how he's sad. Also, how he's happy...I didn't really understand him. When he screams, he hurts my ear, sometimes.

He has learned to deal with his brother's extreme behaviors by covering his ears or walking away.

Orlando is curious about his brother and generous. He wants people to understand Destin better and offered, "You can come back if you're wanting to learn more when I discover...I want to discover more about Destin...You can come back whenever you want so you can learn more about Destin."

Dallas

Very early in the interview, when given the prompt: Describe your relationship with Austin, what's it like to be his brother? Dallas responded:

Austin is really fun to be brothers with. I feel like he's a really good brother that I could have. They also a lot of the times get annoyed because these past couple nights he's been really annoying. ...he will just throw a tantrum and not do much stuff. He'll just sit there and wait till we pick him up. But otherwise, I think that he's really fun to be brothers with.

The dichotomy of really fun and annoying exist side by side, and the annoying aspect of his sibling is emotional dysregulation, which he calls a tantrum. In comparing his relationship with Austin to his peers' relationships with their siblings Dallas said,

I usually play a lot more with Austin than other friends with their siblings, and stuff. So, I think that that makes me kind of liking Austin more than other kids like their siblings, because I think that they always think that they're a little bit more annoying. Which yes, I do think Austin sometimes is annoying. But he's annoying in a good way. So, like, I never actually get mad at him like a lot of other people do...But I think that I just have a stronger relation with Austin.

In describing the best part of being a brother to Austin, ASD was still part of the mix:

Austin, that he's autistic, it means that a lot of the times he can be super crazy. But when he's like tired and chill, he'll try to get in my lap and make me get a blanket to snuggle with him. So, when he's tired and like, he's in a really good mood. He just wants to be with us and snuggle. So that's my favorite part about being brothers with him.

Dallas has an understanding of his brother's needs for routine and predictability but struggles with what to do when his brother is having a hard time, describing:

He is just used to that happening and he doesn't expect any changes, so like, that's when he mostly has tantrums.... I try to cheer him up.... Well, a lot of times I just like, try to help him by bringing his favorite things in. But that usually doesn't work. And so, there are not that many ways that I know how to solve it...Like I'm doing something wrong...Then I just feel like I realized again that he's autistic. And I also feel like I'm doing something wrong.

Savannah

Savannah describes her relationship with her older sister Charlotte this way:

It kinda feels normal. And we played together, we're not the sibling who fight all the time. But we do a couple times a week get into arguments and fight. She has anger issues.... Yeah, one time she pushed me so hard. She got mad at me because she thought I was shouting at her. But I wasn't. And so, she pushed me...It really hurt and I don't like it when she does that, so I start crying...She wants to play with me sometimes but she's getting older. So, she's actually saying no to playing with me now. But she used to play with me a lot. We used to play together all the time.

In comparison to friends, she notices both the typicality of fighting with a sibling and how it is different because her sister has ASD:

They get in fights sometimes, but not, but I don't know. It's kind of normal because more sisters get in fights. But like, you know, it's a little different for them, they're both, like their minds work like normally...I already kind of figured out I can't get too mad at her anymore. Even if she's annoying me or being rude. Kind of annoying because I want to. She's annoying.

Denver

Denver had the most to say out of all the participants. He has clearly thought a lot about his sister and is able to articulate his understanding of her needs. In describing his younger sister Aspen, he said:

She can be really kind, and a good sibling. With like, lots of hugs. And she really likes to play...But also lots of times the reason she screams a lot is she wants me to keep playing with her. So, when I play with her, it's really fun for her. And she likes lots of hugs a lot. And when I, like, kind of want to leave the room sometimes she gets sad. She wants to play. Like sometimes she cries a little because she wants to keep playing. I feel kind of sad because we were having fun. But I do want to get to do [other things]. And Aspen needs to, like, get that a little more. She has trouble understanding, like what other people feel about playing still. She wants to keep playing, but some people don't want to...And Aspen really likes to play with blocks. And, like lots of times, she gets startled by loud noises or...she'll scream a lot because she's really excited...Sometimes I've had a really long day and I just can't take it, and I get mad at Aspen and yell. But then after I feel kind of bad because then no. Well, I don't know if I really feel that bad after. I'm just really annoyed because, like, it's a lot to take your sibling screaming all day.

Denver feels that he has a special understanding of his sister, even more than his parents, because of his sibling role; he said:

I also understand Aspen a lot, too. Yeah. I grew up with Aspen. I'm used to living with Aspen. So, it's like, easier to feel that she's feeling. Because like, if you're a parent of someone, you can really understand them. But if you're a sibling, and you grew up with them, you can understand it more. Because you feel growing up with that person most of your life instead of being with that person for a part of your life.

Denver also demonstrated his deep understanding of Aspen and her needs:

She can't really feel getting hurt as much as we do. So, she doesn't really realize that people are being hurt and she doesn't really stop when we're like Aspen that hurts, stop it, please. So, she doesn't really, like, get it as much. So, you gotta be really careful with her. And like, make sure you tell her what you're doing. And a lot of times, she wants people to sit down in a chair, when we're, like eating or something, because she wants to be able to predict what we're gonna do. Because when we're standing up, Aspen wants us to sit because we're able to do more things that are unpredictable when we're standing and when we're sitting, we're not as much.

In reflecting on the downsides of his relationship with Aspen he shared:

You have to share a lot more. That's kind of one of the downsides. Oh, it makes you more flexible with transitions when you have an autistic member because you need to be able to make transitions with them. Because it's harder for them to make transitions. So, you have to kind of go with them a lot sometimes. Like if Aspen wants you to sit you have to sit.

Chandler

Not all presentations of ASD include loud outbursts and aggression; some people with ASD appear aloof or disinterested in others. In describing his relationship with his older brother, Chandler said, "It's pretty chill to be Phoenix's brother." In comparing his relationship with friends', he noted that his friends are more similar to their brothers with more common interests: "I'm more sporty and Phoenix's more like TVish." He also mentioned several times that friends' siblings annoy them much more than Phoenix does. He went on to describe this

They like, fight and tackle each other. We used to. Don't anymore. One, we just don't really get in fights. I don't know. We just don't get mad at each other. Like I said earlier he's not annoying. He doesn't care. Like he doesn't care if my friends are over so like, he just, like, stays inside and does TV.

Phoenix's desire to control the environment was mentioned as a difficult part of living with him- "whenever I'm reading in my room, and he's like, trying to go to bed. He tries to shut off the light...I just turn it back on. And close the door."

Sibling Experiences at Home

Siblings experienced unexpected behaviors and big emotions from their siblings with ASD, including physical aggression, outsized reactions, tantrums, prolonged screaming, and crying. Siblings have also all found ways to deal with their own emotions. The most common coping strategy mentioned by participants was taking space or removing themselves from the situation, doing something else and trying not to focus on it.

Navigating Relationships With Parents

There are additional elements in navigating the relationships with their parents when accounting for the different needs of their siblings with ASD. Though not directly asked, three participants shared challenges they have with their parents and how they respond to those challenges. All three participants commented on the amount of attention they receive from their parents.

Dallas described feeling responsible for his brother's dysregulation- "a lot of the time my parents are going to think it's my fault, I'm not making it better. So, I just feel like they're always gonna get me in trouble for not making him feel better." Dallas is aware of having to think about his brother's feelings, his parents' feelings while reacting to his brother's feelings, and his own feelings in these heightened situations. When asked what helps him handle those difficult situations, he responded, "just knowing that after Austin's all better that I could explain to them, which usually isn't the easiest for me, but umm, it's just good to let them know when they're not as stressed." Along with additional responsibility including having to do more chores, Dallas is also aware of his parents consciously trying to balance the attention he and his brother receive- "I think

that makes them pay a lot of attention to me out of their day, so that they pay attention to both of us a lot...because then everyone gets like the same amount of attention.”

Denver also expressed struggling with parental attention:

She [Aspen] really wants you to, like, leave cuz she wants more attention from mom or dad. ...And that's why it's really hard because you want to hang out too. And when Aspen kind of pushes you away like that, it's really annoying, and you can easily get mad. But one way you can, like, deal with it is take a few deep breaths and you can let Aspen have some attention. And then maybe later when Aspen is not around you can hang out with them. Or you can ask nicely.

In her first response of the interview when given the prompt “tell me about you and your family,” Savannah said, “So I have an older sister named Charlotte. And she has autism. And sometimes I feel a little bit, like, sad because they pay attention to her more.” When asked later in the interview about some of the difficult parts of being Charlotte’s sister, Savannah responded with how she feels her parents treat the two siblings differently and unfairly; she said, specifically, “my dad, he sometimes only believes my sister, and I'm pretty sure because she has autism....I don't know, they're not trying to be mean even though they are.” Charlotte also describes her mom intervening on her behalf to remind her dad that there are two sides to every story. When asked if that makes her feel better, she said, “a little bit, not really though.”

Sibling Experiences in the Outside World

Navigating Relationships With Friends

Embarrassment and social isolation due to their sibling’s ASD were themes that came up throughout many of the interviews. Participants compare themselves to their friends and compare their sibling relationships with their friends' relationships to siblings. Participants also have the additional responsibility of educating their friends

and peers about their siblings' ASD, whether they name it or not. Opportunities for socializing with peers were diminished; Orlando shared, "it feels like just trapped. It's just like, I just am in this house feeling normal with a brother that has autism." Dallas echoed the feeling of being stuck at home- "usually I'm just kind of bored because having Austin, that means I can't really do as much stuff as a couple of my other friends can do." Austin was also aware of his isolation in comparison to others- "it's kind of weird when I see other kids and their siblings and like their other sibling just act so much more like kids that you'd see today... I feel like they kind of always are with more friends." Denver compared his experience to his friend's experience with their siblings this way- "another difference is you can't talk to them, and you kind of wish that you could play with them a lot more, without having to go through like the thing [difficult transitions, behaviors, dysregulation]."

Having friends come over to their house brings the potential for unexpected behaviors and embarrassment, but it can be hard to predict how their sibling will respond. Though his brother is mostly uninterested, and usually leaves him and his friends alone, Chandler did say that, "sometimes when my friends are over, he, like, pulls down his pants." Dallas shared:

I feel like it's kind of weird when my friends come over, because then it just seems kind of embarrassing. Because I used to be really good friends with my neighbor. And they used to always come over and my brother used to act super weird with her.

Denver described navigating relationships with friends in this way:

When there's people over, she's not very good with, like, containing herself, like she'll scream a lot...and she didn't really let us do fun things that much...she gets more jumpy, because she's excited that we have friends over, and it's more harder for her to contain like, her like behavior. And lots of times like she wants to get what she wants...she'll keep

bugging people for it for a while. And when she doesn't get it, she'll get mad and like, scream or yell. Other times she's fine with it. It, like, just depends on what mood she's in.

Chandler also described how he works to translate his brother's behavior for other children to facilitate interactions between his brother and his friends:

When my friends are over here, he can't, like, interact with them, because he kind of wants to. But he kinda doesn't really know how to. So, I tell my friends when he asks us to do something, we actually do it. So, then he can actually feel included.

Navigating Relationships with School and Society

For the participants that attend the same school with their sibling, or have in the past, they all reported that they liked seeing their sibling at school. Orlando beamed and sweetly said, "he always smiles at me when I smile at him." Denver keeps tabs on his sister at school, noticing that she does better with transitions at school than anywhere else and is proud of her; he shared "it's just cool to see, like, the progress she's making." He also takes on the responsibility of looking out for his sister at school; he is both watchful and protective- "I get to see, to make sure she's actually like working on [things] like lots of people in the special eds room need to work with Aspen more. Because I see her in a chair a lot [doing nothing] when she's in school. And it makes me kinda mad."

Much in the way that exhibiting behaviors in front of friends causes embarrassment, the ever-present possibility of behaviors and dysregulation in public with the potential for embarrassment looms large in the life of siblings. Transitioning away from a preferred activity or location is a known challenge for many people with ASD. When these struggles happen while out in the community they bring unwanted attention, and siblings are aware and affected. Denver had a lot to share about the

variety and unpredictability in the ways his sister handles transitions in public and this serves to highlight how unavoidable a part of his life in the community this is:

Times when she's really tired, like after parties and stuff, she's fine with going home. And then other times, she gets really mad and really wants to stay and starts crying and [screams] and stuff... Because it's hard for her to transition from, like, one thing to another. Like if we were at Target, she wouldn't want to leave.... So, it's hard for her to make transitions. Like, if we're at a fast-food place, and we're having lots of fun and eating, she would not want to go home. Or that happens sometimes. And other times, she's like, just fine with going home.

Savannah described how doing something that ordinarily would just be annoying to someone, singing a song that they really don't like, caused her sister to have a large reaction in public- "I made my sister cry at the park cuz I did that. That's it. She hates it when I do that. She started crying."

Siblings are Thinking Deeply About Autism

"Their Mind Works Differently" - Sibling Definitions of ASD

Siblings' knowledge of ASD varied but all expressed an understanding that autistic minds and brains work differently in some way, and have come up with definitions of their own that describe the behaviors their sibling exhibits. Savannah said, "I think a lot of time autism people might have some anger issues." Chandler focused on the differences he notices most between him and his brother- "they can't do things like the same as other kids. Like they can't do a lot of the same sports. Um, sometimes they have a hard time talking." Orlando shared:

I know that when someone screams really loud, it actually, it hurts his ears....When some people that have autism, when they cry, sometimes when I cry my brother cries [inaudible] like he's copycatting me....When I cry, if he doesn't want noise for that long he goes up to my face and wipes the tears out.

Dallas recognizes that there are different types of autism that he doesn't know about and that not all autistic people are the same:

It affects your thinking a lot of the times and it too's, like, kinda weird for your behavior, because you have more needs, and things that you'd like. And I don't know much about it, because I usually just explain what my brother does. But I don't know much about the other types of autism. But also, the way that he throws a fit and has his tantrums and can't control his anger.

Denver is trying to grapple with the mechanics of the behaviors he observes and consistently tries to put himself in his sister's shoes:

Your brain is, I think, like, a little slower and doesn't process the same as others. So, they have more trouble with transitions because their brain can't like, you know how, like when you're transitioning when [plans change] and you ended up staying at home, you'd still get mad, but you'd be okay. More okay with it. But if you're autistic, you would throw a tantrum, and you would be really sad, and annoyed.

Whether or not they have expressly been taught about ASD and what it is, they all have meaning attached to the term *autism* as it relates to their siblings. They recognize that the atypical behaviors they see from their brother or sister are somehow connected to having ASD even if the mechanisms of the causal relationship are only vaguely understood.

“I Feel Like I'm Always Getting Caught Wondering” - Questions They Have

The questions siblings have about autism in general, or about their particular sibling with ASD, all demonstrate care and concern. Orlando asks his questions directly to his older brother who is non-verbal- “I like asking him, why does he, like, scream so much? But yeah, he never answers because he has autism. So, he has to respond something I don't understand.” Chandler exhibits maturity beyond his years and worries about there being a good placement for his older brother- “What's middle

school like in his classroom, with just, like, a bunch of autism people?...And like, what if the next grade doesn't have autism classes? Or the next school?"

Slightly older participants have more sophisticated questions that they have seemingly given a lot of thought to, even if they have not necessarily posed them to anyone. Dallas wonders, "What really makes him different besides the way that he acts and, like, throws a fit? But also, how he gets it [autism]? Which I know that doesn't have an answer, but I just always wonder." Denver has a lot of questions and seeks to understand his sister's experience from her perspective:

I kind of want to know what it's like to have an autistic minds? Like, do you have more of an imagination? Do you like, have troubled understanding words and stuff? Or I know that autistic people do have trouble understanding words. But like, in your mind, what's going on? Like, are you thinking of the words but your mouth isn't like really working the same way that you want it to? Because your brain isn't processing the words enough? Or like, do you think a lot like a normal mind where you have lots of thoughts? Or like, is it pictures in your thoughts or like, is it words? Umm, are you, like, really smart with your minds and stuff? And it's hard to tell autistic people's emotions because their brain doesn't show you. Like their brain doesn't process it the same, so when it gives them the controls to the body, like you have no idea. Like, what's actually going on?

"Nobody Asked" - Their Advice to Other Siblings

When asked directly what would help them in dealing with their sibling with ASD, participants did not have any ideas. However, when asked if they have advice for other kids that have a sibling with autism, most of them had a lot to say. Dallas showed concern for the feelings of typically developing siblings, and an understanding of the struggle for parents, offering the advice- "know that you might not get as much attention, and it's not that your parents don't care, but it's that your sibling just needs bigger needs than you." Savannah's advice shows the conflicting feelings that exist in

these more complicated sibling relationships, especially when dealing with challenging behaviors directed at them:

Well, don't get mad at them or else they're gonna kinda maybe push you or be mean or, like, hit you or kick you or something.... So just, like, be careful because they have a lot of strength. Be careful, but they are nicer to you than normal siblings. Yeah, so that's good. You should be lucky to have a autism person, a autism sibling because they're nicer to you, and usually siblings are pretty mean to you.

Chandler and Denver offer advice that emphasizes the responsibility they feel toward their sibling with ASD and the role they play in their sibling's life. Chandler advises that to make your sibling feel good, you should let them tell you things that you may already know, but act surprised and encourage them to share—"what they say, even if it's not true, just kind of act like you're excited, happy, or like you're saying it's the right answer." Denver recognizes that he's a role model for his sister and is helping to model behavior for her, while also offering coping strategies:

You gotta forgive them more because they don't understand as much ... if they're a younger sibling with autism, they wanna follow you on your steps. So, if you don't forgive them, they're not going to be more forgiving to you, and they're gonna scream more. But if you teach them, like, to be more nicer and to transition and share, then they will probably do more of that. [long pause] and if they're like being unkind, and it doesn't really work, you gotta take a break from it and try later. And, after you take your break, when you try again later, you gotta be nicer. You got to think about, like, what they're going through. And you can also ask your parents for help if your sibling is really not being nice at all. ...And you should always, like, help your sibling if they need help or something.

"I'm a Little Bit Different From the Other Kids" - Perceptions of How it Has Changed Them and Their Life

Two 10-year-old participants articulated how they feel having a younger sibling with ASD has shaped them. Dallas shared:

I feel like I'm a little bit more sensitive, because I usually don't have to talk to as many more people, and I don't really hang out with that much kids. So I feel like I might be a little bit more shy or just like, wanting to be kind of more alone, except for when I'm with my really close friends....I'm just like, wanting to be more alone or just with like, my family, because I feel like I just sometimes need a little bit extra more me-time.

Denver credits his experience with his sister for his increased empathy and perspective taking, something that came up many times throughout our interview. He said, “you can’t understand Aspen as much with words, but you can put yourself in your sibling’s shoes more than you can when you don’t have an autistic sibling.... And like, put yourself in other people’s shoes way more.”

Savannah, also 10, shared how she feels her life is different for having an older sister with ASD:

Cuz I don't get the chance to know what it feels like to have a normal sibling and I'd like to know that. I wish I had one normal sibling. I also want Charlotte though, to know what it feels like to have both.

The two youngest participants, ages 7 and 8, did not connect their experiences with their older brothers having ASD as making them or their lives different expressly other than reporting behaviors they observe and contend with. These differences all speak to the second piece of Research Question 1, in how typically developing siblings perceive having a sibling with ASD impacts them.

Suggestions for Sibling Support

Sibling participants have their own ideas about the types of support interventions they feel they need and would like to have. They are also able to articulate support they have received and how they have benefitted from it. All siblings expressed a desire for support beyond their family unit.

Do You Wish Your Parents Talked to You More About It?

Sibling participants were divided on whether they wished their parents talked to them more about autism into two distinct camps. Those who have older siblings with ASD wished their parents talked to them more about it and expressed a desire to know more about autism in order to help them navigate their relationship with their sibling. Savannah shared, “my parents don't really tell me, like, anything about it. Or I don't really know anything about autism that much.” Those who have younger siblings with ASD reported that their parents had talked to them a lot about autism and felt that it helped them. Dallas said confidently, “I read a couple articles about it with [my mom] ...they already talked to me about it a lot. So, I kind of know a lot about it” while Denver echoed that same sentiment- “my parents already talked to me about it a lot. So, I really understand it.” There were not any participants who did not identify their parents talking with them about ASD as a positive or desired support, which relates to Research Question 2 as a support that all participants perceived they need, or needed in the past and received. For further discussion, see Chapter 5.

Meeting Other Siblings

All of the siblings interviewed expressed that they would like to meet other children that have siblings with ASD, and that it would be helpful for them. This speaks to Research Question 2, as a type of support siblings perceive they need. Orlando said enthusiastically, “I want to learn more.” Chandler echoed a desire to learn more about autism, “and I also want to learn new strategies.” Dallas expressed, “I'd like to see how other kids react to it, so I think that would be kind of helpful.” Savannah seemed wistful

when she said, "I don't really know anyone else." While Denver desires both knowledge and community:

I'm kind of curious about other siblings that have different kinds of autism and stuff. Like it'd be nice to know that I have friends that are going through the same thing, because it's really hard to have an autistic sibling, but there's downsides and upsides. So, you gotta roll with it. And it's really nice to know that you have another sibling growing up with the same problem.

In School

Only one participant mentioned school as a place where he had learned or heard about autism. It made a big impression on him, as Chandler described the event to me two years later- "at an assembly, they turned on the TV and, like, shared what autism was. And it was like this giant [video] clip." Chandler also reported that when his friends are over at his house, they are more willing to include his brother in play when prompted, perhaps because this priming and frame of reference from school provided a base level of familiarity.

Conclusion

Existing literature has studied the experiences and support needs of siblings of people with disabilities during middle childhood or preadolescence by asking adolescents or adults to reflect back on that period of their life and identify what helped or would have helped them. This study asked children currently in middle childhood or preadolescence about their sibling experiences now as they are living them and make sense of them at this stage of their development. Furthermore, this study asked what support they feel would help them while there is still time to give them the support they seek during these crucial years, which are a prime target for interventions.

The first research question asked, *what is the experience of having a sibling with ASD like for a typically developing child and how do they perceive that it impacts them?* The findings show that while it is their normal reality, these siblings are dealing with a lot. They experience unexpected behaviors, emotional dysregulation, and are the target of aggression at times. They experience embarrassment, diminished opportunities for socializing with peers, limited attention from parents, and their own sometimes big emotions dealing with heightened situations. They care greatly for their sibling with ASD and often feel responsibility and worry for them whether their sibling is younger or older, and that it has made them more sensitive and empathetic.

The second research question asked, *what type of support do siblings of children with ASD perceive they need?* The findings revealed a need for open dialogue about ASD with their parents, the ability to ask questions, and to have age-appropriate information about ASD in general including the terms and language they overhear and about their siblings in particular. Siblings also need to know that they are not alone and that there are other children who also have similar family circumstances who understand their unique experience and with whom they can relate and share coping strategies. Siblings need to see their family life considered and reflected in their school life, and for their sibling identity to be recognized. They need their schools to raise awareness about disabilities, both visible and invisible, including neurodiversity and autism spectrum disorders, so they are not solely bearing the responsibility of educating friends about their siblings with ASD.

The third research question asked, *how do siblings of children with ASD perceive or account for changes in their sibling relationship?* Evidence did not directly

answer this question, but provided something different. Siblings notice changes in their relationship, but often without a direct awareness of what caused the change to occur when asked directly. However, in a few instances which will be explored further in Chapter 5, participants provided anecdotal evidence for the cause of changes in their sibling relationship based on a support intervention in response to other lines of inquiry.

The findings of this study reveal that children in middle childhood and preadolescence are thinking deeply about autism and the experience of having a sibling with ASD. They have a lot of insight to offer if only asked. These siblings all expressed a desire for a community of support and they deserve to have it while they are still in this stage of their life.

Discussion

The findings of this study were consistent with many of the themes outlined in the Chapter 2 literature review. There is near complete overlap between the challenges experienced by siblings of people with autism spectrum disorders (ASD) identified in the existing research and by the participants of this study, despite their young age. In particular, findings from this research indicate that siblings in middle childhood and preadolescence are already experiencing social isolation and social stigma (Marquis et al., 2019), premature maturity (Kramer et al., 2021; Molinaro et al. 2020), effects of increased parental stress and decreased attention from parents (Hayes & Watson, 2012; Hesse et al., 2013; Patel et al., 2022), exposure to challenging behaviors from their sibling with ASD (Fishbein, 2010; Petalas et al., 2009), and aggression and violence aimed at them or their belongings (Angell et al., 2012; Fishbein, 2010; Petalas et al., 2009). On a more positive note, the study participants also experience increased compassion for others, tolerance, and patience (Kramer et al., 2021), less sibling rivalry, and high levels of family cohesion (Angell et al., 2012).

Participants of this study self-identified needing support in several of the key areas described in the literature review. Siblings desire information, the opportunity to talk about their experiences and ask questions, learn coping skills, and connect with other siblings in similar circumstances (Conway & Meyer, 2008; Hayden et al., 2019; Meyer & Vadasy, 2015; Roberts et al., 2015). Participants recognized the importance of support that extends beyond the home environment (Meltzer & Muir, 2021), and were not currently involved in an organized sibling support program due to lack of availability and systemic barriers (Meltzer, 2021).

Implications for the Literature

A review of the existing literature revealed the extraordinary challenges for siblings of people with ASD, the importance and impact of support, and the systemic barriers both in providing and receiving sibling support services. There was limited research about the experiences and support needs of siblings during middle childhood and preadolescence, and available research was conducted with adult or adolescent participants reflecting back on their younger selves. This study aimed to address that gap specifically by interviewing participants currently in middle childhood and preadolescence about their experiences and support needs.

Based on the literature review, I anticipated that participants may not be able to answer Research Question 3: *How do siblings of children with ASD perceive or account for changes in their sibling relationship?* Although they could not answer this question directly, they do notice changes and are often proud of their siblings' development or improvement without understanding a cause for it. However, anecdotally, they provided examples of interventions that changed their sibling relationship in answering other questions. In these anecdotes I found two examples of interventions that could be mapped onto the ecological and systems thinking model outlined by Meltzer and Muir (2021) with clear levers that disrupted a feedback loop.

In the case of Denver and his sister Aspen a feedback loop of conflict existed when Aspen wanted people around her to be seated. Their mother provided the lever which disrupted the feedback loop by thoroughly explaining to Denver why his sister was reacting so strongly in these situations and what it meant for her- unpredictability of people's movements causing her stress and anxiety. Once Denver understood his

sister's needs he was able to respond differently in the situations and feel differently about them- that he was being kind and helping his sister rather than being controlled by her. This intervention, though it took place entirely within the microsystem of the family unit, has implications in the mesosystem since Denver is able to clearly advocate for his sister in similar situations and clearly explain it to others just as he explained it to me. He understands and has internalized this need of hers so that is no longer a source of conflict.

In the case of Chandler, an intervention (lever) from the mesosystem, a school assembly on the topic of autism, created changes in both the microsystem and mesosystem. Seeing this assembly at school prompted conversations with his family about his brother, and led to information he had not known prior. Additionally, of all participants Chandler reported the most acceptance of his sibling with ASD by his friends who are fellow students at the school and also viewed the assembly.

Findings of this study illustrate the extent to which siblings are already experiencing challenges and social stigma across environments. They are thinking deeply about ASD, and about their sibling relationships particularly in comparison to peers even at these young ages. They are able to articulate their needs for support, and have suggestions for how they would like to be supported. As stated in Chapter 4, these siblings have advice and insight to offer peers if given the opportunity, and would benefit from a community of support. Together, this demonstrates that this age group has much to contribute to the area of study, and the reasons for excluding them, that they lack the perspective on their experiences, does not necessarily apply.

This study further revealed an additional gap in the research. The role of disability awareness in school, or lack thereof, was a factor for these elementary school participants. This sort of broader school wide intervention was not addressed in the literature review as a potential mitigating factor for siblings, as a way to combat the social stigma of disability experienced by siblings, or relieve the burden on siblings of educating others about their sibling with ASD.

Implications for Practice and Policy

Based on previous research examined in the literature review as well as the findings of this project, there is a need for looking at disability awareness as a social justice issue that is addressed in schools. In order to improve wellbeing and scholastic outcomes for students who are siblings of children with ASD, direct and indirect support for siblings of children with ASD is needed and ought to be addressed in elementary schools and beyond.

Schools have a responsibility to consider diversity in their curriculum and have students' lives and cultures be reflected and represented at school. This ought to extend to disability and neurodiversity as well. Children's literature is a powerful tool in raising awareness and increasing empathy. Having books which include characters with disabilities and feature sibling experiences available in classrooms and libraries is a way to offer support by allowing siblings to see their sibling identity reflected at school. It also allows others to stumble upon or seek out books that provide a window into understanding children with differences in a deeper way. For a list of books about ASD appropriate for elementary school audiences see Appendix C. Increasing empathy and awareness reduces stigma.

Three of five participants interviewed attend a different public school than their sibling due to their sibling's special education needs and not grade level difference, so classroom teachers have a role to play in sibling relationships as well. Many elementary school teachers send home intake questionnaires at the beginning of the school year, have student intake conferences with parents, or both. Teachers should be empowered to ask about siblings, or if there is any information parents would like for the teacher to know to better understand their student's life, such as if anyone in the household has a disability or receives special education services. Teachers can support siblings by examining their own assumptions around home life and expectations of parental involvement in homework. My typically developing son had a vastly different experience from his peers with distance learning during the COVID-19 lockdown because he had a sibling with ASD at home disrupting his learning environment and requiring greater parental attention. On the flipside, many special day classes (SDCs) are isolated and segregated on campuses. Due to the understandable needs of their students for routine and structure, many SDCs do not have the same opportunities for families to visit and participate in the classroom the way that many general education classes do. It is worth considering allowing opportunities for families- including siblings, and not just parents- to occasionally visit with preparation and prompting, so that siblings can picture their brother or sisters' life at school and remove some of the mystery of what happens behind the closed doors of the special education classroom.

Disability awareness- including neurodiversity, less visible, and invisible disabilities- should be included not only in school curriculum but in Diversity, Equity and

Inclusion (DEI) initiatives as well. Kentfield school district in Marin County includes disability in its DEI initiatives, equity mission statement, and has even gone so far to change the name to Diversity, Equity, Inclusion and Belonging (DEIB). This extends to parent groups on campus like PTAs, PTOs, and parent clubs as well, to consider disability of students and family members, ableism, and sensory needs in the planning of school wide events and the communications about them.

Schools act as a central organizing point, and much as they distribute information and resources to parents during the Individualized Education Program (IEP) process, they could be utilized to provide information and resources for siblings in the same way. Siblings of children with ASD are an identifiable group, and it is worth asking parents if they feel that their typically developing children may be in need of support, and to offer resources that families may not know about. Parents should be encouraged to speak with their typically developing children directly about ASD, and to share age-appropriate information, explain terms, services and therapies they are likely hearing about, and to maintain an open dialogue around ASD.

Parent education, perhaps at the Special Education Local Plan Area (SELPA) level, aimed toward parents of students receiving special education services, could include topics concerning siblings and sibling interactions. It could include topics around how and what information to share with family members about your child's disability, ASD specific information, behavior management and support in the home, or could be expanded to include sibling education events more directly. Parent education aimed at the wider school community ought to include disability awareness, examining biases including ableism, and talking to your own children about people with disabilities

in the community. We can not only look to the members of marginalized groups to educate the rest of us about them; it is an unfair burden borne heavily by siblings and parents of children with disabilities, especially ones less visible at a glance, and we all have a responsibility and role to play. Direct sibling support interventions could be provided in schools through a staff delivered one-to-one model like Sibs Talk or in hosting a program like Sibshops that involves peer support in a recreational setting. In other parts of the country, Sibshops have been provided in schools as an afterschool program delivered in a series of short regular meetings or as stand-alone half day programs on a weekend. School sites could also partner with other community groups or organizations to provide school space for a Sibshops or similar program to take place, as that is often a cost prohibitive barrier to sibling support programs being more widely available.

Limitations of the Study

There were several limitations to this study. I only spoke with typically developing siblings, and including their siblings with ASD, their parents, and teachers would provide a fuller view across environments. Though it was not part of the research design, all of the participants only had one sibling; interviewing families where there are multiple siblings with different sibling relationships might yield additional insights. The perspectives presented are limited in that no participants would be considered socioeconomically disadvantaged and did not include any English language learners, though one participant was bilingual. Participants were not engaged in a sibling support program at the time of interviews. The majority of Marin County public schools do not operate with an inclusion model for special education, and there may be

differences in experiences for siblings in areas where students with disabilities are more widely included in mainstream classrooms.

My background in recreation and as a preschool teacher allowed me to develop rapport with child participants quickly and communicate comfortably in a semi-structured way. My positionality as a parent of a typically developing child and a child with ASD affected my findings in a few ways. I shared my parent identity with participants as my reason for conducting this study, and when appropriate, used examples from my own family to help clarify their responses or to validate what they had shared with me by acknowledging a connection. Due to my own experiences as a parent, feeling that the worst thing I share about my son with ASD is all that is recorded by professionals, I felt strongly that I needed to reflect findings in the participants' own words with their complexity of feelings as much as possible. This led to the unusual structure of using both vignettes and themes in reporting my findings in Chapter 4.

Directions For Future Research

Looking at both perspectives of the sibling relationship, including children with ASD and their typically developing siblings, and exploring possible support interventions for siblings together such as conflict resolution skills would be useful data. A longitudinal study of siblings with and without ASD over time would encompass larger societal, environmental, and systems level challenges and opportunities including support interventions. The effects of DEI initiatives and disability awareness in schools on siblings' interactions with peers and in the community is an area yet to be explored.

Conclusion

Siblings of people with disabilities are an identifiable and important group that is overlooked and under supported. This is particularly detrimental for siblings of people with ASD as they face additional unique challenges including being the target of unexpected behaviors from siblings and the highest levels of parental stress and caregiver fatigue of any disability type. Research has shown that many of the negative outcomes experienced by siblings are due to insufficient support and understanding, rather than direct results of their sibling's condition (Hanvey et al., 2022). By not identifying, acknowledging and supporting their important role, these typically developing siblings are left seeing their experience as singular and isolated to their particular family, rather than as experts with unique and beneficial skills others may seek and value beyond their family. By supporting siblings, we may also be empowering future professionals to recognize and capitalize on skills developed in empathy, communication, and flexible thinking, if we frame their sibling experience in that light. Sibling support is crucial for maintaining and improving sibling's wellbeing and academic performance, and bolstering future caring relationships between siblings. The barriers to wider sibling support are systemic and yet the benefits to wider sibling support and disability awareness are societal. Sibling relationships are often the longest lasting relationships in the lives of individuals with disabilities, and siblings deserve to be supported as individuals and not just future carers. Wider availability and greater accessibility of sibling support has been hampered by not falling neatly into any existing category of support services which exist for people with disabilities, recipients of special education services, caregivers of people with disabilities, and parents of

special education students. However, this research indicates that sibling support should be the responsibility of all areas instead of none, and that schools have both a role to play and an obligation to the unique needs of their students that are siblings to brothers and sisters with ASD and other disabilities.

References

- American Psychological Association. (2022). *APA Dictionary of Psychology*. American Psychological Association. Retrieved November 28, 2022, from https://dictionary.apa.org/autism-spectrum-disorder?_ga=2.35776233.830441222.1668984126-554571346.1668984126
- Abercrombie, R., Harries, E., & Wharton, R. (2015). *Systems change: A guide to what it is and how to do it*. NPC Publications.
- Angell, M. E., Meadan, H., & Stoner, J. B. (2012). Experiences of siblings of individuals with autism spectrum disorders. *Autism Research and Treatment, 2012*, 1–11. <https://doi.org/10.1155/2012/949586>
- Benderix, Y., & Sivberg, B. (2007). Siblings' experiences of having a brother or sister with autism and mental retardation: A case study of 14 siblings from five families. *Journal of Pediatric Nursing, 22*(5), 410-418. <https://doi.org/10.1016/j.pedn.2007.08.013>
- Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Harvard University Press.
- Carey, G., Malbon, E., Carey, N., Joyce, A., Crammond, B., & Carey, A. (2015). Systems science and systems thinking for public health: A systematic review of the field. *British Medical Journal Open, 5*(12). <https://doi.org/10.1136/bmjopen-2015-009002>
- Conway, S., & Meyer, D. (2008). Developing support for siblings of young people with disabilities. *Support for Learning, 23*(3), 113-117. <https://doi.org/10.1111/j.1467-9604.2008.00381.x>

- Creswell, J. W. (2002). *Educational research: Planning, conducting, and evaluating quantitative* (Vol. 7). Prentice Hall Upper Saddle River, NJ.
- Creswell, J. W. (2013). Designing a qualitative study. In *Qualitative inquiry and research design: Choosing among five approaches*. essay, Sage Publications.
- Creswell, J. W., & Creswell, J. D. (2018). *Research design: Qualitative, quantitative, and mixed methods approaches* (5th ed.). SAGE.
- Eriksson, M., Ghazinour, M., & Hammarström, A. (2018). Different uses of Bronfenbrenner's ecological theory in public mental health research: What is their value for Guiding Public Mental Health Policy and practice? *Social Theory & Health*, 16(4), 414–433. <https://doi.org/10.1057/s41285-018-0065-6>
- Fishbein, L. B. (2010). *Examining caregiving and household responsibility in typically developing siblings of children with an autism spectrum disorder*. [Masters thesis, State University of New York at Binghamton] ProQuest Dissertations Publishing
- Giallo, R., & Gavidia-Payne, S. (2006). Child, parent and family factors as predictors of adjustment for siblings of children with a disability. *Journal of Intellectual Disability Research*, 50(12), 937–948. <https://doi.org/10.1111/j.1365-2788.2006.00928.x>
- Glidden, L. M., & Schoolcraft, S. A. (2007). Family Assessment and Social Support. In *Handbook of Intellectual and Developmental Disabilities* (pp. 391–422). chapter, Scholars Portal.

- Gray, D. E. (2006). Coping over time: the parents of children with autism. *Journal of Intellectual Disability Research*, 50(12), 970-976. <https://doi.org/10.1111/j.1365-2788.2006.00933.x>
- Gregory, A., Hastings, R. P., & Kovshoff, H. (2020). Academic self-concept and sense of school belonging of adolescent siblings of autistic children. *Research in Developmental Disabilities*, 96 <https://doi.org/10.1016/j.ridd.2019.103519>
- Hanvey, I., Malovic, A., & Ntontis, E. (2022). Glass children: The lived experiences of siblings of people with a disability or chronic illness. *Journal of Community & Applied Social Psychology*, 32(5), 936-948. <https://doi.org/10.1002/casp.2602>
- Hayden, N. K., McCaffrey, M., Fraser-Lim, C., & Hastings, R. P. (2019). Supporting siblings of children with a special educational need or disability: An evaluation of Sibs Talk, a one-to-one intervention delivered by staff in mainstream schools. *Support for Learning*, 34(4), 404-420. <https://doi.org/10.1111/1467-9604.12275>
- Hayes, S. A., & Watson, S. L. (2012). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 43, 629-642.
- Hesse, T. L., Danko, C. M., & Budd, K. S. (2013). Siblings of children with autism: Predictors of adjustment. *Research in Autism Spectrum Disorders*, 7(11), 1323-1331. <https://doi.org/10.1016/j.rasd.2013.07.024>
- Houtrow, A. J., Larson, K., Olson, L. M., Newacheck, P. W., & Halfon, N. (2014). Changing trends of childhood disability, 2001–2011. *Pediatrics*, 134(3), 530–538. <https://doi.org/10.1542/peds.2014-0594>

- Inam, A., Kausar, R., & Abiodullah, M. (2017). Does having a sibling with autism affect one's self concept? An empirical research. *Isra Medical Journal*, 9(3), 166-170.
- Kao, B., Romero-Bosch, L., Plante, W., & Lobato, D. (2012). The experiences of Latino siblings of children with developmental disabilities. *Child: Care, Health & Development*, 38(4), 545-552. <https://doi.org/10.1111/j.1365-2214.2011.01266.x>
- Kim, D. H. (1999). *Introduction to Systems Thinking*. Pegasus Communications: Berwyn.
- Kovshoff, H., Cebula, K., Tsai, H.-W. J., & Hastings, R. P. (2017). Siblings of children with autism: The siblings embedded systems framework. *Current Developmental Disorders Reports*, 4(2), 37–45. <https://doi.org/10.1007/s40474-017-0110-5>
- Kramer, J., Meltzer, A., & Strohm, K. (2021). Social support when a sibling has a disability. *Brothers and Sisters*, 257–276. https://doi.org/10.1007/978-3-030-55985-4_15
- Lobato, D., Kao, B., Plante, W., Seifer, R., Grullon, E., Cheas, L., & Canino, G. (2011). Psychological and school functioning of Latino siblings of children with intellectual disability. *Journal of Child Psychology & Psychiatry*, 52(6), 696-703. <https://doi.org/10.1111/j.1469-7610.2010.02357.x>
- Long, K. A., Chevalier, L., Chu, A., Guthrie, K. M., Kao, B., Plante, W., & Lobato, D. (2022). Cultural influences on sibling relationships, roles, and self-concept in the context of autism: Perspectives of Latino/a/x and non-Latino/a/x siblings. *Journal of Autism & Developmental Disorders*, 52(9), 4100-4113. <https://doi.org/10.1007/s10803-021-05287-z>

- Maani, K. E., & Cavana, R. Y. (2007). *Systems Thinking, Systems Dynamics: Managing Change and Complexity*. Pearson Education: North Shore.
- Maenner, M. J., Shaw, K. A., Baio, J., EdS1, Washington, A., Patrick, M., DiRienzo, M., Christensen, D. L., Wiggins, L. D., Pettygrove, S., Andrews, J. G., Lopez, M., Hudson, A., Baroud, T., Schwenk, Y., White, T., Rosenberg, C. R., Lee, L. C., Harrington, R. A., Huston, M., ... Dietz, P. M. (2020). Prevalence of autism spectrum disorder among children aged 8 years - Autism and developmental disabilities monitoring network, 11 sites, United States, 2016. *Morbidity and mortality weekly report. Surveillance summaries (Washington, D.C.: 2002)*, 69(4), 1–12. <https://doi.org/10.15585/mmwr.ss6904a1>
- Marquis, S., Hayes, M. V., & McGrail, K. (2019). Factors that may affect the health of siblings of children who have an intellectual/developmental disability. *Journal of Policy & Practice in Intellectual Disabilities*, 16(4), 273-286. <https://doi.org/10.1111/jppi.12309>
- Maxwell, J. A. (2013). *Qualitative research design: An interactive approach* (3rd ed.). SAGE.
- Meltzer, A. (2021). The operation of the social support sector serving siblings of people with disabilities: A cross-country analysis. *Social Policy & Administration*, 56(3), 423-437. <https://doi.org/10.1111/spol.12775>
- Meltzer, A., & Muir, K. (2021). An ecological and systems thinking approach for support to siblings with and without disabilities. *Social Theory & Health*. <https://doi.org/10.1057/s41285-020-00158-6>

- Meyer, D., & Vadasy, P. (2015). *Sibshops workshops for siblings of children with special needs*. Paul H. Brookes Publishing.
- Molinaro, M. L., Rollo, L. E., Fletcher, P. C., & Schneider, M. A. (2020). Having a sibling with ASD: Perspectives of siblings and their parents. *Comprehensive Child And Adolescent Nursing*, 43(1), 35-47.
<https://doi.org/10.1080/24694193.2018.1559256>
- Patel, A. D., Arya, A., Agarwal, V., Gupta, P. K., & Agarwal, M. (2022). Burden of care and quality of life in caregivers of children and adolescents with autism spectrum disorder. *Asian Journal of Psychiatry*, 70, 103030.
<https://doi.org/10.1016/j.ajp.2022.103030>
- Petalas, M. A., Hastings, R. P., Nash, S., Lloyd, T. & Dowey, A. (2009). Emotional and behavioral adjustment in siblings of children with intellectual disability with and without autism. *Autism*. 13, 471-483.
- Roberts, R. M., Ejova, A., Giallo, R., Strohm, K., Lillie, M., & Fuss, B. (2015). A controlled trial of the SibworkS group program for siblings of children with special needs. *Research in Developmental Disabilities*, 43-44, 21-31.
<https://doi.org/10.1016/j.ridd.2015.06.002>
- Saxena, M., & Adamsons, K. (2013). Siblings of individuals with disabilities: Reframing the literature through a bioecological lens. *Journal of Family Theory & Review*, 5(4), 300–316. <https://doi.org/10.1111/jftr.12021>
- Seidman, I. (2013). *Interviewing as qualitative research: A guide for researchers in education and the Social Sciences* (4th ed.). Teachers College.

Shivers, C. M. (2019). Empathy and perceptions of their brother or sister among adolescent siblings of individuals with and without autism spectrum disorder. *Research in Developmental Disabilities, 92*, 103451.

<https://doi.org/10.1016/j.ridd.2019.103451>

Sibs talk supports siblings of children with SEND in primary schools. Sibs. (2022, June 15). Retrieved November 29, 2022, from <https://www.sibs.org.uk/supporting-young-siblings/siblings-schools-project/sibs-talk/>

Sterman, J. (2000). *Business Dynamics: Systems Thinking and Modeling for a Complex World*. McGraw Hill.

U.S. Department of Education. (2022, November 18). *A history of the individuals with disabilities education act*. Individuals with Disabilities Education Act. Retrieved December 1, 2022, from <https://sites.ed.gov/idea/IDEA-History#Pre-EHA-IDEA>

Wehmeyer, M. L. (2015). *The Oxford Handbook of Positive Psychology and Disability*. Oxford University Press.

Wright, B. M., & Benigno, J. P. (2019). Autism spectrum disorder and sibling relationships: Exploring implications for intervention using a family systems framework. *American Journal of Speech-Language Pathology, 28*(2), 759-767.

https://doi.org/10.1044/2018_AJSLP-18-0088

Appendix A Copy of IRB Acceptance Letter



Nov 28, 2022

Keely Hamilton
50 Acacia Ave.
San Rafael, CA 94901

Dear Keely,

On behalf of the Dominican University of California Institutional Review Board for the Protection of Human Participants, I am pleased to approve your proposal entitled *Experiences and Support Needs of Typically Developing Siblings of Children with Autism Spectrum Disorder: An Ecological and Systems Thinking Approach* (IRBPHP Initial IRB Application #[11069]).

In your final report or paper please indicate that your project was approved by the IRBPHP and indicate the identification number.

I wish you well in your very interesting research effort.

Sincerely,

Michaela George, Ph.D.
Chair, IRBPHP

Cc: Katie Lewis

Institutional Review Board for the Protection of Human Participants

Office of Academic Affairs • 50 Acacia Avenue, San Rafael, California 95901-2298 • 415-257-1310 www.dominican.edu

Appendix B Interview Questions

Questions for all participants

- Tell me about you and your family (ages, grades, schools)
- Describe your relationship with (*name of sibling with ASD*)
 - What's it like to be (*name of sibling with ASD*)'s brother/sister?
- What types of things do you do with (*name of sibling with ASD*)
- What kinds of feelings do siblings of children on the autism spectrum usually feel?
 - What is an example of a time that you felt [emotion that was identified]?
- How is your relationship with (*name of sibling with ASD*) similar or different from your peers' relationships with their siblings?
- What is the best part of being a sibling to (*name of sibling with ASD*)
- What are some difficult parts of being a sibling to (*name of sibling with ASD*)
- What helps you handle the difficult parts/situations
- Can you think of other things that may help you?
 - If answers yes: Tell me about them
- What do you know about autism?
 - Where did you learn that?
- Do you think that knowing more about autism and understanding it would help you with your sibling?
 - If answers yes: Do you wish your parents talked to you more about it?
- Do you think that knowing or talking to other siblings is something that you would like to do or that you think would be helpful?
- Do you have any advice for other kids that have a sibling with autism?
 - How/where did you learn that?

Additional potential questions

- Can you think of a time when your relationship with your sibling was different or changed? Got better or got worse?
 - Was anything else different during that time?
- In what ways do you think that you are different or your life is different because your (brother or sister) has autism?
 - How do you feel about that?
- Do you think it has changed you and how you are by having a sibling like (*name of sibling with ASD*)?
 - What about you is different?
- Is there something that happens over and over again with your (*name of sibling with ASD*)?
 - Tell me about that...
 - How does that affect you? / How do you feel about that?
 - So what do you do when that happens?
 - How does your sibling react?
- What are some questions you have about autism or your sibling?

Appendix C Autism Spectrum Elementary Book List

Table 2*Autism Spectrum (ASD) Elementary Book List for Grades K-2*

Title	Author(s)
A Friend Like Simon	Kate Gaynot
All About My Brother	Sarah Peralta
All My Stripes	Shaina Rudolph, Danielle Royer & Jennifer Zivojn
Ben Has Autism, Ben Is Awesome	Meredith Zolty & Rebecca Rivard
Chicken Boy: The Amazing Adventures of a Super Hero with Autism	Gregory Allen & Dennis Culver
Different Like Me	Jennifer Elder
Friend For Henry, A	Jenn Bailey & Mika Song
Ian's Walk: A Story about Autism	Laurie Lears
Isaac and His Amazing Asperger Superpowers!	Melanie Walsh
Leah's Voice	Lori DeMonia
Looking After Louis	Lesly Ely
Me and My Sister	Rose Robbins
Mi amigo tiene autismo	Amanda Tourville
My Brother Charlie	Holly Robinson Peete & Ryan Elizabeth Peete
Sometimes My Brother	Angie Greenlaw
The Girl Who Thought in Pictures: The Story of Dr. Temple Grandin	Julia Finley Mosca
To Be Me	Rebecca Etlinger
What About Me?	Brennan and Mandy Farmer

Table 3*Autism Spectrum (ASD) Elementary Book List for Grades 3-5*

Title	Author(s)
A Friend Like Simon	Kate Gaynot
Al Capone Does My Shirts	Gennifer Choldenko
All About My Brother	Sarah Peralta
Autism	Richard Spilsbury
Bat and the End of Everything	Elana K. Arnold & Charles Santoso
Bat and the Waiting Game	Elana K. Arnold & Charles Santoso
Ben Has Autism, Ben Is Awesome	Meredith Zolty & Rebecca Rivard
Boy Called Bat, A	Elana K. Arnold & Charles Santoso
Chester and Gus	Cammie McGovern
Different Like Me	Jennifer Elder
Get a Grip, Vivy Cohen	Sarah Kapit
Hello, My Name Is Max and I Have Autism	Max Miller
Ian's Walk: A Story about Autism	Laurie Lears
Just My Luck	Cammie McGovern
Leah's Voice	Lori DeMonia
Looking After Louis	Lesly Ely
My Brother Charlie	Holly Robinson Peete & Ryan Elizabeth Peete
Rain Reign	Ann M. Martin
Rules	Cynthia Lord
Sam and Me	Dorothy Potash
Slug Days	Sara Leach & Rebecca Bender
Sometimes My Brother	Angie Greenlaw
The Girl Who Thought in Pictures: The Story of Dr.	Julia Finley Mosca

Title	Author(s)
Temple Grandin	
To Be Me	Rebecca Etlinger
Understanding Autism Spectrum Disorder	Holly Duhig
What About Me?	Brennan and Mandy Farmer