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“You Know Me Best”: Perspectives of Adult Siblings with Typical
Abilities and Intellectual/Developmental Disabilities

Kristy Lynn Staniszewski

Submitted in partial completion of the Master of Arts Degree at Sarah Lawrence College

May 2015

Abstract

This thesis explores the lives of adult typical (ADTYP) siblings, their siblings with intellectual/developmental disabilities (I/DD), their unique relationship, and their need for support. Over seventy percent of adults with intellectual and developmental disabilities (I/DD) in the United States currently live at home with their families. In most cases, the parents of an individual with disabilities are assigned the role of primary caregivers. With this role comes great responsibility and, in households with multiple children, the ADTYP sibling gradually assumes the burden of that responsibility and all the joy and heartache that come with it.

By reviewing narratives and conducting oral histories of both ADTYP siblings and siblings with I/DD, I reveal that ADTYP siblings often can provide more insight than parents into the interests of their siblings with I/DD and will often make more appropriate decisions about day-to-day care than those of which their parents are capable. Siblings with I/DD can attest to this better than anyone, and it is therefore equally important to closely examine the ways in which sibling relationships are meaningful to individuals with disabilities.

The first chapter of this thesis explores the creation of sibling support programs and organizations historically, and illustrates how typical siblings benefit from these systems as adults. The second chapter then, discusses literature of the sibling movement and the importance of local support groups for ADTYP siblings. The third chapter brings us to the heart of this work as it introduces the voices of siblings with I/DD, who must constitute an essential component of sibling research.

When siblings with disabilities are provided the opportunity to have their voices heard, they become the spokespersons for their own lives. Some individuals with I/DD can experience significant challenges in communicating, but when both the ADTYP sibling and the sibling with disabilities are part of the same conversation, clarity and understanding of what is most important to those with I/DD can be shared. Through the interviews in this thesis, what becomes evident is that ADTYP siblings provide more than logistical support and caregiving; they give their siblings with I/DD access to independence and create opportunities for them to exceed their disabilities and limitations.

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This thesis is dedicated to my sister, Amy Rose Staniszewski.

Preface

A.M.Y.S.

“A.M.Y.S.” stands for “About my younger sister.” This was my team name a few years back for an Easter Seals benefit walk. Having a creative team name was definitely not the most important element of taking part in this experience, especially for my little team of two, but I remember how much it excited me all the same. Not only was my team name my sister’s actual name (first initial of our last name and all), but the abbreviation was short for a phrase that made sense, and was deeply meaningful. After all, the reason I was part of this benefit walk was all about my younger sister, Amy.

Amy is a thirty-two-year-old adult with intellectual and developmental disabilities (I/DD). She is high functioning, on the autism spectrum, epileptic, and has a mood disorder that is associated with her epilepsy. She is precious to me and I love her dearly, but she also makes my life extremely complicated, and that dichotomy of emotions is a simple but accurate summary of the experience of most siblings with typical abilities. We deal with a mixed bag of emotions on a regular basis: remorse and indignation about the guilt associated with being “the normal one,” anger about our sibling’s getting the so-called “short end of the stick,” or resentment that *we* got the “short end of the stick.” Some experience frustration, depression and anxiety, while also feeling grateful that our siblings with I/DD have taught us acceptance, patience, flexibility, sensitivity and understanding. Overall, most feel that having a sibling with disabilities has made us better people.

Our circumstance and need for support are just as significant as our siblings with I/DD, and there are indeed quite a lot of us. Sibling movement advocates report that at least 4 million

individuals in the United States have siblings with I/DD,¹ and these figures represent only the siblings who have been identified, because despite advances in sibling research, there are still a number of underrepresented sibling constituencies. We are in critical need of support, since most of us are currently or will eventually become caretakers of our siblings. Although the types of caretaking roles we assume will vary, we are all in the same situation of having this rewarding, but challenging life-long commitment.

Those of us who are caretakers become labeled as such because we have now filled the guardian role, taking care of a dependent sibling/family member. However, in the eyes of both siblings, with or without disabilities, we do not see a guardian or dependent, nor typical or disabled; we see our sister or our brother. The sibling relationship is a bond, a history of shared experiences that cannot be replicated with anyone else, and this relationship is best understood when explained from the perspectives of the siblings themselves. This thesis is meant to accomplish just that.

Throughout my life it has been regularly suggested to me that I become a social worker, service coordinator, a group home facilitator, or something involved in the disability service field. It is actually quite common for siblings with typical abilities to pursue careers in “helping professions,” but I have honestly never had an interest in doing so; I feel that I already have a full plate being Amy’s sister. It has been surprising to others, as well as to myself, that I have come around to this field anyway, through academia. This journey can be explained partially by the ways in which my life has been affected by finding support programs and organizations just for adults with siblings with I/DD. I did not discover such systems until I was almost thirty years

¹ Don Meyer and Emily Holl, “So You’re a Sib,” in *The Sibling Survival Guide: Indispensable Information for Brothers and Sisters of Adults with Disabilities*, ed. Don Meyer and Emily Holl (Maryland: Woodbine House Inc., 2014), 1-4.

old. Until then, it never dawned on me that such systems would even exist, or how much I could benefit from them. The fact is, my life has been profoundly changed by finding support systems and organizations for siblings with typical abilities, and I am sure that my arrival to sibling research during my graduate studies has everything to do with this experience.

In addition to finding this support, however, the bond I have with my sister has always been a driving force deep inside of me and a part of every decision I have made in my life. The sisterly and motherly connection I have to her is integral to who I am, and so I suppose coming to this work of exploring the perspectives of siblings with and without disabilities may have been inevitable, echoing my team name once again, that for me, it is indeed all about my younger sister.

Introduction

This thesis explores the lives of adult typical (ADTYP) siblings, their siblings with intellectual/developmental disabilities (I/DD), their unique relationship, and their need for support. Since the inception of the disability-rights movement in the 1960s,¹ more individuals with disabilities have lived their lives as integrated members of society, rather than in institutions, which was the prevalent protocol prior to World War II. As a result, over 70 percent of adults with developmental disabilities in the United States live at home with their families.² In most cases, the parents of an individual with disabilities are assigned the role of primary caregivers. With this role comes great responsibility and, in households with multiple children, the ADTYP sibling gradually assumes the burden of that responsibility and all the joy and heartache that come with it.

The unique circumstance of ADTYP siblings is in need of close examination because, although many have assumed some level of the caregiver role, if not all levels, they are rarely given the tools to properly perform that role. Neglecting siblings, policy makers and professionals involved in disability care consult only with the parents of the individual with I/DD, which consequently leaves ADTYP siblings out of conversations regarding day-to-day care and planning for the future. Compounding the issues of sibling exclusion in disability care policy is the fact that ADTYP siblings do not have the same resources for support that are available to parents. Historically there have been support groups for parents of children with disabilities throughout the United States that allow them the opportunity to meet other parents in

¹ The objective of the 1960s Disability Rights Movement was to improve accessibility, safety, patient rights, and equal opportunity for education, employment and independent living for individuals with disabilities. See Roberta Ann Johnson, "Mobilizing the Disabled," in *Waves of Protest: Social Movements since the Sixties*, ed. Jo Freeman and Victoria Johnson (Lanham, MD: Rowman & Littlefield, 1999), 25-46.

² Don Meyer, "Introduction" In *Thicker than Water: Essays by Adult Siblings of People with Disabilities*, ed. Don Meyer (Bethesda, MD: Woodbine House, 2009), 5.

similar situations, to gather information, to learn coping skills, and to find comfort in knowing that they are not alone.³ Since the early 1990s, ADTYP siblings have been joining forces in an attempt to be recognized as vital participants in the care of their siblings with I/DD.

By reviewing narratives and conducting oral histories of both ADTYP siblings and siblings with I/DD, I reveal that ADTYP siblings often can provide more insight than parents into the interests of their siblings with I/DD and will often make more appropriate decisions about day-to-day care than those of which their parents are capable. Siblings with I/DD can attest to this better than anyone, and it is therefore equally important to closely examine the ways in which sibling relationships are meaningful to individuals with disabilities.

This thesis also demonstrates how gendered caregiving informs the roles of ADTYP siblings, illuminating the fact that ADTYP sibling issues are largely considered women's issues. Sibling research to date shows that female siblings are the family member most likely to take over the caregiver role of an individual with I/DD.⁴ Recurring themes for both mothers and sisters include their roles as mediators, the challenges of personal care, choices regarding education and careers, relationship issues, procreation concerns, anger, depression, resentment, and isolation. Based on their gender alone, mothers and sisters of individuals with I/DD are almost always assigned the role of primary caregiver. There is an expectation that, as women, they possess a natural instinct to be the caretaker; this assumption often leads to little awareness of and support for the caregiver.⁵

³ See Support for Families of Children with Disabilities (www.supportforfamilies.org) for historical information on support systems and current resources for parents of children with disabilities; accessed November 20, 2014.

⁴ Meghan M. Burke, Julie Lounds Taylor, Richard Urbano and Robert M. Hodapp, "Predictors of Future Caregiving by Adult Siblings of Individuals with Intellectual and Developmental Disabilities," *The American Journal on Intellectual and Developmental Disabilities* 117, no. 1 (2012): 33-47.

⁵ The theory of mothers being associated as natural caregivers can be traced back to 1866 when Edward Seguin, M.D., an advocate for educating children with I/DD, asked "who could watch over the tardy coming of these

Awareness about the gendered nature of caregiving increased during the 1980s and '90s through analysis of the experience of mothers with children with I/DD.⁶ This experience is in many ways synonymous with that of ADTYP female siblings. In her book *Disability, the Family and Society: Listening to Mothers* (2000),⁷ psychologist Janet Read presents a series of oral history interviews with mothers of children with disabilities conducted in the United Kingdom between the early 1980s and 1996. The core of Read's work involves the personal testimonies of twelve mothers who explain the various roles they play as women, and how having a child with disabilities has affected their lives. In addition to presenting the oral histories, Read traces the disability rights movement since the 1960s in the U.K. and 1970s in the United States, investigates changes in law and policy, and addresses how these changes have affected her interviewees. She explores theories of motherhood, and how caring for someone with disabilities calls for new theories. Furthermore, Read researches projects that advocate for support of mothers with children with I/DD. Read's intention is to shed light on what it means for a mother to take on the role of caregiver to a child with I/DD. She hopes that other mothers, caregivers, professionals and researchers are left with a clearer understanding of, and insight into, their situation.

The issues that Read identified in her research on mothers in the 1980s and '90s are the same issues that I address with regard to ADTYP siblings today. In the introduction to her book, Read addresses criticism she received for interviewing only mothers of children with I/DD and

functions better than a mother, if she were timely advised by a competent physician?" Edward Seguin, *Idiocy and its Treatment by the Physiological Method* (New York: W. Wood & Company, 1866).

⁶ Alison Stokes Gottlieb, "Single Mothers of Children with Disabilities: The Impact of Multiple Roles," *Family Relations* 46, no. 1 (January 1997): 5-12.

⁷ Janet Read, *Disability, the Family, and Society: Listening to Mothers* (Berkshire, England: Open University Press, 2000).

not other family members. She states that “listening to mothers does not carry with it any assumption that disabled children, their fathers and their brothers and sisters need no voice or that mothers can speak in their stead” and “while it is legitimate to enable mothers to explain why they do the things that they do, I recognize, that research is needed which consults with *all* family members about their experience, needs and circumstances.”⁸ This thesis rests on research whose necessity Read acknowledged fifteen years ago. During childhood, many young typical sisters act as “little mothers” to their siblings with I/DD, and this motherwork tends to continue through adulthood. In addition, this thesis responds to Read’s point regarding the need to include *all* family members through conversations and interviews with ADTYP siblings and siblings with I/DD.

Another academic study of mothers with children with I/DD is psychologist Johanna Shapiro’s “Stress, Depression, and Support Group Participation in Mothers of Developmentally Delayed Children” (1989).⁹ This study includes reports of fifty-six mothers of children with I/DD, thirty-four of whom attend support groups for parents of children with disabilities. Shapiro finds that professionals in the disability field most often recommend support groups to parents with children with I/DD. Results of Shapiro’s study indicate that mothers who participated in support groups showed signs of lowered levels of anxiety and were more apt to share and create informal support systems and relationships outside of these meetings. Mothers who did not participate reported higher rates of depression, confusion, isolation and feeling overwhelmed.

The study notes that support groups just for mothers may not be ideal because the rest of the family cannot always benefit from the positive impact of group support systems, and

⁸ Read, *Disability*, 2-3.

⁹ Johanna Shapiro, “Stress, Depression, and Support Group Participation in Mothers of Developmentally Delayed Children,” *Family Relations* 38, no. 2 (April 1989): 169-173.

suggests that all family members be included when addressing significant challenges that affect the marital relationship and family dynamic as a whole. In addition, Shapiro notes that each mother who participated in this study has at least one other child with typical abilities, and yet the term “sibling” appears only once in the article. In the assessment section, Shapiro states “the groups focused regularly on the impact of the handicapped child on family life with particular emphasis on siblings and the marital relationship”¹⁰ Despite this acknowledgment, siblings do not receive further attention in this article. My thesis goes beyond Shapiro’s discussion of the value of support groups for mothers, and illustrates how ADTYP *siblings* benefit from attending these groups; it also brings to light the lack of appropriate support groups, and the difficulties in accessing information about groups that are in fact available.

Psychologists Maureen O. Marcenko and Judith C. Meyers’s “Mothers of Children with Developmental Disabilities: Who Shares the Burden?” (1991)¹¹ summarizes a study of one hundred mothers of children with I/DD with the purpose of understanding the need for and importance of support. The authors observe that mothers, regardless of marital or employment status, report unmet needs for information about services, help with household chores and caregiving, and emotional support. The support that these mothers do receive comes from a combination of family, friends, service providers, educators, agencies, and so on.

The most significant difference between married mothers and single mothers is the availability of help to married mothers from their husbands and husbands’ families. This manifests itself in a number of ways, such as babysitting, assistance with household duties, transportation to appointments, and emotional support. Female siblings have unmet needs similar

¹⁰ Ibid., 170.

¹¹ Maureen O. Marcenko and Judith C. Meyers, “Mothers of Children with Developmental Disabilities: Who Shares the Burden?” *Family Relations* 40, no. 2 (April 1991): 186-190.

to those of the mothers in this study, but the help from husbands and husbands' families reported by married mothers does not exist for most married ADTYP sisters. The father, grandparents, aunts, uncles and other caregivers of a child with I/DD are much more likely to be emotionally invested than an ADTYP sibling's sisters-in-law. Her husband is less likely to be involved in day-to-day care, and his family is unlikely to involve itself because the biological kinship and accompanying emotional investment are not there.

In sum, the authors report that day-to-day responsibility for the care of the child with I/DD falls to mothers, that those in the workforce have increased demands because they assume the dual role of housekeeper and employee, and that the caregiving burden placed on the mothers surveyed is largely due to the extraordinary, long-term dependency of children with disabilities. The study concludes that, unless the service system keeps pace with family needs, mothers will not be relieved of their burden. My thesis argues that a similar study of ADTYP female siblings also shows that the job of caregiving tends to fall to female siblings with typical abilities and that most female siblings have a triple responsibility of working, taking care of their siblings and taking care of their own families and households. Furthermore, the dependency of siblings with I/DD can last their entire lifetime, and that until the system includes siblings and recognizes their needs, they will bear this burden without assistance.

Over the past decade there has been a gradual increase in the number of sibling-specific research studies. In "When Your 'Problem' Becomes Mine: Adult Female Siblings' Perspectives of Having a Brother with a Disability" (2009)¹² psychologist Michelle Pompeo reports on a study of five ADTYP sisters in their early-to-mid-twenties who recount the challenges they faced

¹² Michelle Pompeo, "When Your 'Problem' Becomes Mine: Adult Female Siblings' Perspectives of Having a Brother with a Disability," *Exceptionality Education International* 19, no. 2 (2009): 50-62.

growing up with a brother with I/DD during the 1980s. At the time of the study, all five women lived at home with their families in Canada, and in all but one family the sibling with I/DD also lived at home. All the interviewees were Caucasian, educated, and middle class.

The interviews covered various themes such as childhood confusion and unhappiness about the sibling's disability, and protectiveness of the sibling and the family. Anger and resentment are common in children with siblings with I/DD and each participant in this study reported having such feelings at various points during childhood. Pompeo observed that having a sibling with I/DD exerted a positive influence on her subjects' adult selves. Desirable attributes such as acceptance, tolerance and patience with those who are different proved common among these women, but each ADTYP sister had a difficult time seeing these attributes in herself. Interest in opportunities for advocacy also proved common, and four out of five of the interviewees chose careers in the "care professions," which frequently attract ADTYP siblings. Alternatively, some ADTYP siblings avoid care positions as they feel they have already devoted enough of their life to caregiving. The findings of Pompeo's study are reiterated throughout this thesis by the voices of other ADTYP siblings.

Pompeo explains that the purpose of her qualitative study was to illuminate the social experiences of typical female siblings with brothers with disabilities. She emphasizes that her findings should not be used to generalize about the larger population of typical siblings and notes that more research should be conducted with a diverse pool of participants and with control groups. Although Pompeo's work is limited, it is beneficial to anyone who seeks to understand the sibling experience. Her work highlights the voices of ADTYP female siblings, points out the need for greater diversity in sibling research, and proposes areas that need attention. As her study shows, moreover, ADTYP siblings who grew up before support systems were available may be

in more need of support than those than those growing up today who had access to sibling supports as children.

One of the largest sibling studies to date is the “Predictors of Future Caregiving by Adult Siblings of Individuals with Intellectual and Developmental Disabilities,”¹³ by psychologist Meghan Burke et al. This study is based on a survey of 757 ADTYP siblings regarding future caregiving for their siblings with I/DD. The survey divided caregiving into five domains: residential arrangements, financial arrangements, legal guardianship, interacting with the service system, and providing companionship and emotional support. Their results show that 30 percent of the siblings surveyed expect to assume total responsibility across all five domains. In addition, 70 to 85 percent anticipate assuming equal levels of future caregiving across each domain. Furthermore, the majority of siblings who expect to take care of their siblings are adult female lone siblings (the only sibling with typical abilities), currently live near the sibling with I/DD, have a close relationship with this sibling, and are consistently active in the sibling’s life. Most of the ADTYP siblings in this group report that their siblings’ current caretakers are their parents, who cannot successfully meet all of the needs of the sibling with disabilities. Burke et al. further discuss the need for support systems for siblings and state that with an understanding of who these future caregiving siblings are, better supports can be provided to them. In addition, by understanding the dynamic that future caregiving entails, the disability service system can better gauge what kind of supports are needed. This study also provides data that exemplify the ways in which caregiving is gendered.

Interviews with ADTYP siblings *and* siblings with I/DD are essential to understanding their perspectives and the uniqueness of their relationships. Only hearing the voices of ADTYP

¹³ Meghan Burke et al. “Predictors of Future Caregiving,” 33.47.

siblings is not sufficient for understanding how valuable their inclusion is to individuals with I/DD. This is particularly true for service providers who work directly with individuals with I/DD and their parents. Service providers are, appropriately, most concerned with understanding the individual with I/DD and hearing what it is that they want, and what is important to them. It is therefore essential that siblings with I/DD be provided a space to discuss their perspective about the importance of their sibling relationship. The more their perspective is revealed, the more likely service providers will be to include ADTYP siblings in conversations.

Two ADTYP siblings and four siblings with I/DD were selected for in-depth interviews in this thesis and are identified by pseudonyms. In addition to interviews, brief conversations with a number of ADTYP siblings transpired and statements were collected, including some with individuals who are professionals in the field of disability services. My research also includes participant observation at conferences that pertained to various topics concerning I/DD. Conference attendance not only provided informative primary resources, but also allowed me the opportunity to network with other ADTYP siblings and with professionals in the disability field.

The first chapter of this thesis explores the creation of sibling support programs and organizations historically, and illustrates how typical siblings benefit from these systems as adults. Furthermore, the ADTYP siblings voice their disappointment that support programs available to children today were not available when they were young. ADTYP siblings feel that they would have not only benefited as children from peer interaction, but also from the knowledge that parents gain about the special needs of their typical children. In addition, the value of disability conference attendance for ADTYP siblings is addressed, and I argue that the inclusion of sibling-specific needs in agendas for disability conferences is paramount to raising

awareness to service providers, family members, and also in providing more support and information for siblings.

The second chapter discusses literature of the sibling movement, most of which includes the personal experience and perspective of ADTYP siblings. Sibling-specific needs have been increasingly addressed in literature since the early 2000s and this thesis focuses in particular on three works: *What About Me?: Growing up with a Developmentally Disabled Sibling* (1994),¹⁴ one of the earlier analyses about how having a sibling with I/DD informs the lives of adult siblings; *Thicker Than Water: Essays by Adult Siblings of People with Disabilities* (2009),¹⁵ the first literature solely focused on the voices of ADTYP siblings through a collection of personal essays; and *The Sibling Survival Guide: Indispensable Information for Brothers and Sisters of Adults with Disabilities* (2014),¹⁶ which is the most recent addition to ADTYP sibling literature. This groundbreaking publication is a how-to guide for ADTYP siblings that addresses concerns over a lifespan. This chapter also illuminates the importance of local support groups for ADTYP siblings, and includes testimonies from ADTYP siblings that echo the issues raised in the literature of the sibling movement.

The third chapter brings us to the heart of this work as it introduces the voices of siblings with I/DD, who must constitute an essential component of sibling research. When siblings with disabilities are provided the opportunity to have their voices heard, they become the spokespersons for their own lives. Some individuals with I/DD can experience significant challenges in communicating, but when both the ADTYP sibling and the sibling with disabilities

¹⁴ Bryna Siegel and Stuart Silverstein, *What About Me?: Growing Up with a Developmentally Disabled Sibling* (New York: Plenum Press, 1994).

¹⁵ Don Meyer, ed., *Thicker than Water: Essays by Adult Siblings of People with Disabilities* (Bethesda, MD: Woodbine House, 2009).

¹⁶ Don Meyer and Emily Holl, ed. *The Sibling Survival Guide: Indispensable Information for Brothers and Sisters of Adults with Disabilities* (Maryland: Woodbine House Inc., 2014).

are part of the same conversation, clarity and understanding of what is most important to those with I/DD can be shared. Furthermore, this chapter demonstrates that the intimate bond between typical adults and their siblings with I/DD generates rich emotional connections that go far beyond the logistics of physical care.

Chapter One

The Sibling Movement: Creating Support Systems & the Commitment to Inclusion

Brothers and sisters deserve respect for the many contributions they make to their families and to the lives of their siblings who have disabilities. They deserve understanding from parents and from service providers who profess to be interested in families, yet manage to overlook their unique concerns. And they deserve opportunities for basic considerations, such as validation and helpful information, for their benefit and to help them support their brothers and sisters.

But most of all, they deserve to know they are not alone.¹

Don Meyer
Director, Sibling Support Project

Don Meyer was first introduced to me as “the father of sibling support,” a title that I quickly learned was perfectly accurate. Director of the Sibling Support Project, the first national program dedicated to supporting brothers and sisters of individuals with disabilities, Meyer is an advocate, educator, mentor, and senior author or editor of seven books. He is most known, however, for his creation of Sibshops, a recreational program for school-aged siblings that offers peer support through rewarding activities and events. He has pioneered a strong and growing movement of support for siblings that has stemmed from the increased awareness of parent support needs, and from his years of working with the generally neglected family members of children with disabilities. Meyer’s leadership has changed the lives of siblings in many ways, most of all, by showing us that we are not alone.

The Seattle-based Sibling Support Project began in 1990 and has continuously expanded over the past twenty-five years. More than 475 of its Sibshop programs are currently running in

¹ Don Meyer, introduction to *Thicker than Water: Essays by Adult Siblings of People with Disabilities*, ed. Don Meyer (Bethesda, MD: Woodbine House, 2009), 5.

most American states and Canadian provinces and in eight other countries.² This success can be largely attributed to the unique curriculum of discussions and activities that are designed to create fun interaction for young siblings with their peers, and also to the Sibshops Standards of Practice.³

Although Sibshops are not officially considered a form of therapy,⁴ they often have a lasting therapeutic effect. In a 2005 survey of Sibshop graduates,⁵ adults who attended Sibshops when they were children, over 90 percent of Sibshop graduates reported that Sibshops had a positive effect on their feelings towards their siblings; two-thirds reported that Sibshops taught them coping strategies; and three-quarters reported that Sibshops had positively affected their adult lives. Additionally, 94 percent said that they would recommend Sibshops to others.⁶ Given these results and the significant expansion of Sibshops since their inception in 1990, it is clear that they are a valuable resource for young siblings and their families.

The Sibshop experience available today was not available for ADTYP siblings who grew up prior to the 1990s. As ADTYP sister and advocate Delilah Picart explains,

Growing up, I didn't have SibShops, so my own conflicted feelings of frustration and anger and sadness were bottled up. I volunteer at a SibShops group, and I see the kids nodding their heads at similar stories shared.⁷

Many ADTYP siblings share Delilah's belief that involvement in something like Sibshops would have not only benefited them as children, but improved their adult lives as well. This is largely

² "About Don Meyer," The Sibling Support Project, accessed April 7, 2015
<http://www.siblingsupport.org/about/about-don-meyer>

³ Don Meyer, "The Sibshop Standards of Practice," *The Sibling Support Project*, accessed February 25, 2015,
<http://www.siblingsupport.org/Sibshops/the-Sibshop-standards-of-practice>.

⁴ *Ibid.*, 2.

⁵ Sally Conway and Donald Meyer, "Developing Support for Siblings of Young People with Disabilities," *Support for Learning* 23, no. 3 (2008): 113-117.

⁶ *Ibid.*, 114-115.

⁷ Delilah Picart, statement submitted to author, New York, April 7, 2015.

due to the fact that Sibshops not only create opportunities for young peer support, but also educate parents and raise awareness about the needs of young siblings. This point is exemplified in the Sibling Support Project's memorandum "What Siblings Would Like Parents and Service Providers to Know,"⁸ which addresses an assortment of themes and communicates strong statements directly to parents. Examples of this include: "parents can help their typically developing children by conveying clear expectations and unconditional support," "parents can help siblings now by helping their children with special needs acquire skills that will allow them to be as independent as possible as adults," and "when brothers and sisters are 'brought into the loop' and given the message early that they have their parents' blessing to pursue their dreams, their future involvement with their sibling will be a choice instead of an obligation. For their own good and for the good of their siblings who have disabilities, brothers and sisters should be afforded the right to their own lives."

Learning about the current support systems and programs available to young siblings can be a complicated process for adult siblings who lacked access to such supports when they were young. One ADTYP sister recalls the first Sibshop she attended as a graduate student studying psychology: "I just felt so great, but then I was like, why didn't I have this? I definitely would have liked to have had something that stuck, that I felt was beneficial."⁹ Another ADTYP sister who teaches special education says, "I'm often asked what parents and service providers can do to help siblings. [I tell them] start a Sibshop... I wish they were available when I was younger."¹⁰

⁸ "What Siblings Would Like Parents and Service Providers to Know," The Sibling Support Project, accessed April 7, 2015, <http://www.siblingsupport.org/publications/what-siblings-would-like-parents-and-service-providers-to-know>.

⁹ ADTYP sibling, interviewed by author, New York, March 24, 2015.

¹⁰ Kay Swanson, "What Was I Thinking" in *Thicker than Water: Essays by Adult Siblings of People with Disabilities*, ed. Don Meyer (Bethesda, MD: Woodbine House, 2009), 29.

Expressing similar feelings, a third ADTYP sister also emphasizes the importance of parents' understanding the needs of young siblings with typical abilities:

I think it would have been wonderful if Sibshops had been around when I was growing up. However, one thing that I find interesting is that even if Sibshops were something that had existed at the time that I was growing up, it would never have occurred to my parents that I might have needed to talk to someone about my disabled sister. Their own denial about the effect she could have had on me and my other "normal" sister would have prevented it. So what I think would be extremely valuable is to somehow educate service providers and others who interact with the parents of disabled children about sibling issues so that they make a point of telling the parent that their "normal" kids are probably also affected by the disabled child--this could be disturbing for a parent to hear, but I think it is essential.¹¹

For many ADTYP siblings, the more aware we become about the types of peer-support opportunities now available to young typical siblings, the more we realize how much we need and can benefit from peer support as adults. Thankfully, in addition to Sibshops, the Sibling Support Project has grown over the years and continuously develops additional forms of support for typical siblings across a lifespan.

In 1996 Don Meyer founded SibNet, the first listserv for ADTYP siblings that enabled them to connect with each other electronically. Two years later SibNet's listserv became an email-based Yahoo group, and in 2009 the SibNet Facebook group was created. These private online groups are accessible only by invitation or request, and the total current memberships are 1,928 in the Yahoo group¹² and 2,324 in the Facebook group.¹³ For many ADTYP siblings, becoming a SibNet member confirmed Meyer's assertion that "we are not alone." ADTYP siblings around the world connected to one another online, sharing their experiences, and what quickly became evident was that, regardless of age, gender, race, class, religion, geographical location, living arrangement, family structure or the kind of disability their sibling has, much of

¹¹ ADTYP sibling, interviewed by author, New York, March 31, 2015.

¹² "Group Information," SibNet Yahoo, accessed May 3, 2015, <https://groups.yahoo.com/neo/groups/SibNet/info>.

¹³ "Members," SibNet Facebook, accessed May 3, 2015, <https://www.facebook.com/groups/SibNet/>.

the experience of ADTYP siblings is universal. For most, it generates a mixed bag of emotions, and since the sibling relationship has the potential to last a lifetime, the online peer support offered by groups like SibNet is essential.

ADTYP siblings who connected online soon desired to bring that connection to the level of in-person support. This was initiated as small local groups formed to share resources and information. As time went on, larger groups emerged, most notably, the Ohio SIBS group. By this time support for younger siblings was already available in Ohio at larger institutions such as the Ohio State University Nisonger Center. Here, under the guidance of Dr. Tom Fish, Director of Family and Employment Services, young siblings attended support groups to meet peers, share concerns and gain information. Through this work, Fish ascertained a need for adult sibling support, recognizing how the needs of siblings change over the course of a life time. Fish then began organizing large adult sibling groups including the first sibling conference in Columbus, Ohio, in November 2001.¹⁴ This conference enabled siblings from multiple states to get together and learn about the various issues, concerns, and needs of ADTYP siblings. Then, in 2006, a few key leaders of sibling groups began holding conference calls to discuss the ways in which more could be done. This led to a national sibling gathering in Washington, D.C., in 2007, and there the Sibling Leadership Network was born.¹⁵

The Sibling Leadership Network (SLN) initially consisted of working groups that focused on three key areas: support and information, research, and policy and advocacy. At the second national conference for siblings in Columbus, Ohio, in 2008, a policy white paper was

¹⁴ “History of Ohio Sibs,” Ohio Sibs, accessed April 4, 2015, http://www.ohiosibs.com/?page_id=6 .

¹⁵ Katie Arnold, e-mail to author, February 18, 2015.

published based off of the recommendations of the three SLN working groups.¹⁶ In 2010, at the International Sibling Conference in Greenwich, Connecticut, the SLN was officially incorporated as a not-for-profit organization.¹⁷ It has since developed a strategic plan and established five committees that support the SLN mission of “providing siblings of individuals with disabilities the information, support and tools to advocate with their brothers and sisters and to promote the issues important to them and to their entire families.”¹⁸

Nineteen state chapters of the SLN have since been developed. Familiar with the relevant state laws and regulations, they provide support and information that is specific to an ADTYP sibling’s needs. As the SLN’s Executive Director Katie Arnold explains:

Chapters are the grassroots of the SLN and where more of the personal contact happens. Each chapter has its own feel and flavor, some of our chapters are incorporated as their own nonprofit and some have an official Board, while others might have one or two people coordinating activities of the group. Some hold an annual conference or bring in speakers; others have social gatherings at local restaurants or people’s homes. It is really up the people of the chapter. To be part of the national SLN, our chapters all agree to the mission and core values of the organization.¹⁹

State chapters can be especially constructive for ADTYP siblings who are looking for information pertaining to state and local laws, policies, and services. In addition, they provide networking opportunities for siblings within a specific locale and serve as “a judgment free zone for siblings to meet each other and share their sibling experiences.”²⁰ Ohio SIBS was the first state organization to become an official SLN sibling chapter, and in 2010 it was chartered as a not-

¹⁶ Tamar Heller et al., *The Sibling Leadership Network: Recommendations for Research, Advocacy, and Supports Relating to Siblings of People with Developmental Disabilities* (September 15, 2008), accessed April 4, 2015, <http://siblingleadership.org/about/the-sln-white-paper/>.

¹⁷ Katie Arnold, e-mail to author, February 18, 2015.

¹⁸ “Our Mission and Core Values,” *Sibling Leadership Network*, accessed April 3, 2015, <http://siblingleadership.org/about/>.

¹⁹ Arnold, e-mail.

²⁰ Erin Sweeney Hutzelman, email to author, March 2, 2015.

for-profit organization Soon Ohio SIBS became a model for other adult sibling groups and organizations across the country.²¹

Ohio SIBS has also illustrated the effectiveness of holding conferences that discuss sibling issues. Since 2001, Ohio SIBS has held an annual sibling conference, most recently in November 2014. This conference covered a wide variety of topics, including estate planning, advocacy, self-advocacy, sibling research results and future needs; and it featured a keynote lecture by Andrew McQuaide on inclusive employment. McQuaide is the Coordinator of Community Development and Planning for the Rhode Island State Department of Developmental Disabilities and is also an ADTYP sibling. He discussed how Rhode Island successfully implemented Employment First,²² a set of policies that promote inclusive employment as the first priority and preferred outcome for people with disabilities. McQuaide emphasized the importance of Employment First but also stressed that it does not mean employment *only*, arguing that there needs to be a balance of quality employment and quality of life for individuals with disabilities. He explained that the task at hand is to have hard conversations with policy makers and service providers about how to expand the Employment First opportunity and discussed how ADTYP siblings are uniquely qualified to take the initiative because they have a lot of experience with hard conversations. He illustrated the point with a story about a time when it seemed his sister with disabilities needed to be hospitalized.

The hard conversation was saying to my parents “I know that you don’t want [my sister] to be in the hospital; I know that you really want to do this from home.” But when [my sister’s] having a really hard time, she can become self-injurious and she can not-purposefully hurt others [...] And so I just said to them, “I know that you want to do this from home, but at what cost? And where is the line? At what point is this not doable?”

²¹ “History of Ohio Sibs,” Ohio Sibs, accessed April 4, 2015, http://www.ohiosibs.com/?page_id=6.

²² Employment First is a set of policies that promote inclusive employment as the first priority and preferred outcome for people with disabilities. “Office of Disability Employment Policy,” United States Department of Labor, accessed February 16, 2015, <http://www.dol.gov/odep/topics/EmploymentFirst.htm>.

And does someone have to get hurt before we are willing to rethink how we are doing some of these things.” I will tell you that I’m not a fan of making my father cry but that was a hard conversation; it was a necessary conversation and my dad cried and said, “No, we’re still committed to doing this from home” [...] So I called my [ADTYP] sister [...] thinking that [she] would just call my parents and talk some sense into them and that would be that. [...] Instead [my ADTYP sister] called my mom and said “Andrew’s really worried” and so she said “I’m going to get my four kids,” (which range from eight months to eight years of age). “We’re going to get in the car and drive up to Rhode Island and spend the next ten days with you to see if we can’t ride this out.” It was that sort of creativity and commitment that I think we as siblings are really kind of good at. When we start having conversations about employment and we start having conversations about how can our siblings be actively engaged in our community, we can think differently than others.

I’ll tell you quite frequently, there is always someone who raises their hand and says, “Well what about that person who?” And then they’ll go through the list: wheel chair bound, feeding tube, behavioral issues, nonverbal, cognitive delays. And the thing that’s really cool is that in my head I’m going “Oh, you’re talking about my sister. Yeah, what about that?”²³

Here McQuaide not only illustrated ADTYP siblings’ unique qualifications, but also provided insight into the common challenges that ADTYP siblings face when having difficult conversations with their parents, especially discussions that question their parents’ caregiving decisions.

As McQuaide’s talk suggests, ADTYP siblings who are professionals within the disability field have the ability to provide exceptionally valuable perspectives regarding the needs of individuals with disabilities. This indispensable perspective was shared with other siblings at the Ohio SIBS conference, but also with parents, grandparents, friends, other family members and professionals in the disability field. Each of these constituencies also had the opportunity to observe how ADTYP siblings in the audience responded to McQuaide, heard their comments, and witnessed the commonality of unique strengths that ADTYP siblings possess.

²³ Andrew McQuaide, conference presentation transcribed by author, November 8, 2014.

The SLN also organizes national conferences just for siblings, and its upcoming conference in Louisville, Kentucky, in May 2015, will include panels and round-tables on sharing sibling experiences, advocacy opportunities, charting a life course, future planning, supporting self-determination, building state sibling chapters, and more.²⁴ Ohio SIBS and the SLN are currently the only organizations that hold sibling-specific conferences, but there are many disability conferences that take place every year in the United States, and they can be just as effective as sibling-focused conferences in raising awareness

However, this requires that disability conferences more consistently address sibling issues. In light of the large scales and high attendance rates of many of these disability conferences, incorporating sibling issues could give these gatherings unparalleled importance in spreading the word. The Young Adult Institute's (YAI)²⁵ annual international conference in New York City is one example of a venue where sibling voices can be heard by an exceptionally large, diverse audience. Over the years YAI has increased the frequency with which its conference program addresses sibling's issues.²⁶ For instance, at the 33rd Annual YAI conference in 2012, the program included a panel of siblings who shared their personal experiences and a lecture by Don Meyer entitled "Brothers and Sisters with Special Needs: Unique Concerns, Unique Opportunities."²⁷ Sibling inclusion in conferences such as YAI's, which are attended by family members, individuals with I/DD and professionals in the field, is an important step forward.

²⁴ "2015 Conference Agenda and Speakers," SLN, accessed April 5, 2015, <http://siblingleadership.org/get-involved/national-sln-conference/2015-sln-conference-agenda-and-speakers/>.

²⁵ YAI is a network of agencies that offer services for individuals with intellectual and developmental disabilities. "YAI: Seeing Beyond Disability," YAI, accessed April 4, 2015, <http://www.yai.org/>.

²⁶ "Brochure Archives," YAI, accessed April 4, 2015, <http://www.yai.org/resources/conferences/yai-conference/brochure-archives.html>.

²⁷ YAI, *The 33rd Annual International YAI Network Conference Program* (April 30, 2012 – May 3, 2012), accessed April 4, 2015, <http://www.yai.org/resources/conferences/yai-conference/brochures/2012-ic-brochure.pdf>.

Another organization that is incorporating sibling needs into its conference programs is the Asperger Syndrome and High Functioning Autism Association (AHA).²⁸ Its fifteenth annual conference in April 2015 included a workshop titled “Family Matters: Enhancing Parent and Sibling Relationships from Adolescence to Adulthood.”²⁹ AHA is a smaller organization than YAI and has a narrower focus, so AHA’s conferences might not be attended by as large or diverse an audience as YAI is, but their inclusion of sibling issues holds equal importance.

Professionals in the disability service field often use the term “parents” to describe family members who are in need of supports and services, but in an effort to be more inclusive, they have gradually shifted towards using the term “family” instead.³⁰ In theory, siblings fall under this rubric, yet sibling issues are often neglected by “family-oriented” conferences, support services, and online resources. The most recent Family Connect Conference sponsored by United Cerebral Palsy (UCP) of New York City exemplifies the pattern. This conference, held in November 2014, addressed topics such as the changing landscape of services for loved ones, accessing services, respite opportunities, planning for the future, insurance issues, maintaining relationships, advocacy, technology, safety concerns, creating a happy and fulfilling life, and more.³¹ Every one of these issues can directly affect siblings, but this “family-focused”

²⁸ AHA is an association whose mission is to increase awareness and knowledge of higher functioning Autism. “About AHA,” AHA, accessed April 4, 2015, <http://www.ahany.org/index.htm>.

²⁹ “Events and Conferences,” AHA, accessed April 4, 2015, http://www.ahany.org/ev_con.htm.

³⁰ This report discussed the changing definition of family and states that “A young person may live in any number of family constructs, including ones in which couples are married, cohabitating, or the same sex, or in single-parent, blended, grandparent-led, foster care or group home. A youth’s family may not always include a mother and father. Rather, a sibling, aunt/uncle, grandparent, neighbor, teacher, peer, or other influential adult may play a guiding role for a young person.” The National Collaborative on Workforce and Disability for Youth, *Tapping into the Power of Families: How Families of Youth with Disabilities Can Assist in Job Search and Retention* (Info Brief Issue 27, April 2011), accessed March 21, 2015, <http://www.ncwd-youth.info/infobrief/tapping-into-the-power-of-families>

³¹ United Cerebral Palsy of New York City, “Family Connect Conference: The World is What You Make It,” accessed May 1, 2015, https://www.kintera.org/site/c.buIWJcNSKnL6G/b.9204597/k.4652/Family_Connect_Conference_2014_The_Worl

conference excluded us from the conversation. I attended this conference, along with more than 550 other individuals, 40 percent of them family members, and in the entire time I was there I did not meet one other sibling.³²

While at the UCP conference I attended a workshop on future planning for families of special need individuals, a critical topic of concern for many ADTYP siblings. The moderator of this workshop wanted to get a sense of who was in the audience, and so before the presentations began, members of the audience were asked to raise their hands when they heard their “role” mentioned. The moderator then called out the following: parent of an infant, toddler, early childhood, young adult, teenager, adult, elderly child, grandparent, service provider, and other professional in the disability field. When I realized that the roll call was over and that no one had asked about siblings, I quickly yelled “SIBLING!” My screeching inspired much laughter, cheers, and a round of applause, and during it all I felt the familiar mixed bag of emotions. On one hand it felt good to be acknowledged, maybe even appreciated, but it also felt wrong and uncomfortable. Why was I receiving applause? Was my presence there amusing to others? Was it pleasing, or surprising? Why would I not be there? Why would my presence there be anything but understood and expected? The reality is that I did not feel understood and I did not feel seen in this so-called “family-focused” environment. If there were in fact any other siblings present that day, they were few and far between. Perhaps that was to be expected, however, since I found this conference from the Parent Talk Listserv, which excludes siblings.

Of the family members who were in attendance at this conference, many of them were mothers of young children with Cerebral Palsy (CP). This illustrates that there are significant

[d_Is_What_You_Make_It/apps/ka/err/error.asp?c=buIWJcNSKnL6G&b=9204597&en=7gJDJOOrH6LMIYPuH5LJJUOEJhIHISpWbKILTNGJqK3F&err=C](https://www.unc.edu/~deidre/err/error.asp?c=buIWJcNSKnL6G&b=9204597&en=7gJDJOOrH6LMIYPuH5LJJUOEJhIHISpWbKILTNGJqK3F&err=C)

³² Deidre Davis, Project Connector Coordinator for UCP of NYC, e-mail to author, April 6, 2015.

concerns in regards to children with CP, but also that the needs of adults are being neglected. Most children with CP live long, full lives and throughout their lifetimes they will require some level of assistance.³³ Who is looking after their needs and addressing their concerns? For many it is probably their parents, and the absence from this conference of the parents of adults with CP does not mean that they do not need support. What is probable is that many of these parents are elderly, and may not be as electronically connected as younger parents, which forms obstacles in being informed about events such as this. Some may also find that accessing events in venues such as this midtown Manhattan location is physically difficult. What is most likely, however, is that these parents are no longer the only ones taking care of their adult child with CP. Chances are they have help, and that help is provided by siblings with typical abilities. This scenario is even more likely for all adults with CP whose parents are no longer alive. Therefore, had UCP's Family Connect conference included and reached out to ADTYP siblings, more adults with CP would be likely to have advocates who are educated about the latest information regarding disability services.

More inclusion of ADTYP siblings is in the best interest of professionals in the disability service field, organizations and groups, disability related conferences, and both siblings with typical abilities and with I/DD. Inclusion provides ADTYP siblings with resources that help in caring for our siblings with I/DD, and also allow us to take better care of ourselves. Our current circumstance of having minimal access to these resources tends to result in one of two extremes: the involved siblings who are overextended, do everything on their own due to lack of resources, and are at risk of burning out; or the siblings who cannot get involved due to the overwhelming

³³ "Life Expectancy," My Child at Cerebral Palsy.org, accessed April 19, 2015, <http://cerebralpalsy.org/about-cerebral-palsy/life-expectancy/>

combination of massive responsibility and little to no resources. It is possible for ADTYP siblings to find balance between these two undesirable options, but this requires our inclusion, access to resources, and to be included in all conversations pertaining to our siblings' care and wellbeing.

Chapter 2

Read About It, Talk About It: Literature and Support Groups for ADTYP Siblings

Literature generated by the sibling movement has grown exponentially over the last two decades. These publications address sibling issues for both children and adults and for siblings with typical abilities and those with intellectual and developmental disabilities. The authors of sibling literature range from movement leaders who write about policy to individuals who share personal stories. No contribution is too big or too small, as long as it raises siblings' awareness that they are not alone and the larger society's awareness that their voices must be heard.

Despite the advances of sibling movement literature, disability literature overall still tends to leave out the needs of siblings. A recent example of this is psychologist Andrew Solomon's *Far From the Tree: Parents, Children and the Search for Identity* (2012), which is a culmination of more than ten years of research, with interviews from more than three hundred families. Solomon claims his research is "family-focused," but neglects to address the needs of siblings, or seek out their perspectives with interviews.¹ Another example of recent literature that excludes siblings is therapist and educator Susan Rosano's *The Parents Notebook* (2014),² which addresses supports and services for families with children with I/DD. In her preface Rosano explains that *The Parent's Notebook* offers opportunities for parents, siblings, caregivers, and others to learn about new ways to manage their challenges. Her mention of siblings suggests that

¹ Andrew Solomon's *Far from the Tree*, neglects to include the sibling's voices. This is particularly evident in Chapter Five which discusses families who are coping with autism. The families that Solomon interviews here clarify that there are siblings with typical abilities present, but the well-being of the sibling with typical abilities is never discussed. Only the perspectives of parents and children with disabilities are addressed. Andrew Solomon, *Far from the Tree: Parents, Children and the Search for Identity*, (New York, NY: Scribner, 2012).

² Susan Rosano, a mother of a child with I/DD, states in *The Parent's Notebook* that, "surprisingly, there are very few books that are specifically written to help parents [...] and [they] should know they are not alone, that others feel similarly, and that there are solutions to the difficult situations we all encounter." This statement is inaccurate due to the fact that there are volumes among volumes of parent focused literature available today. The problem Rosano describes here is still an issue for siblings, not parents. Susan E. Rosano, *The Parent's Notebook: A Support Guide for Parents of Children with Special Needs*, (Vermont: Log Cabin, 2014).

their needs and concerns will be addressed, but unfortunately this is the first and last time siblings are mentioned in this “family-focused” publication.

Of the sibling literature that has been published, most addresses the needs of young typical siblings, leaving a significant gap between the literature and adult siblings. The ADTYP sibling literature that has been published, however, is rich with critical information that addresses a wide range of topics. One of the earliest books to focus on ADTYP siblings is Bryna Siegel and Stuart Silverstein’s book, *What About Me?: Growing up with a Developmentally Disabled Sibling* (1994).³ Siegel and Silverstein analyze how the adult lives of siblings are influenced by the childhood experience of having a sibling with I/DD. They argue that sibling relationships provide models for relationships later in life, and that for an adult who has a sibling with a disability, that model is skewed. Included in their discussion is the ways in which families adjust to a child with I/DD; the cultural, religious, and educational factors that influence the adjustment; and similarities between the coping and defending strategies of ADTYP siblings and adult children of alcoholics. They also identify four categories of behavior among children who have siblings with I/DD: the “parentified child,” the “withdrawn child,” the “acting out child,” and the “superachieving child.” Many ADTYP siblings, particularly sisters, tend to fall into the categories of the parentified and superachieving child.

A parentified child is one who reacts to the sibling with disabilities by assuming a parental role.⁴ The usual trajectory of a child’s parentification begins when the parents adapt to the child with I/DD by drawing closer to that child. The child with typical abilities then fears abandonment by the parents, and draws closer to the sibling as well, in order to form an alliance

³ Bryna Siegel and Stuart Silverstein, *What About Me?: Growing Up with a Developmentally Disabled Sibling* (New York: Plenum Press, 1994).

⁴ *Ibid.*, 113.

with the parents. The parents normally react to this behavior with exaggerated approval and appreciation; they fail to realize that this behavior is potentially harmful and unhealthy for the child with typical abilities. Similarly, the superachieving child gains their parents attention and admiration by trying to be perfect. They believe they are not worthy of being loved without achieving success and have “difficulties developing feelings of intrinsic self-worth outside the achievements that parents can enumerate as proof of their exceptionality.”⁵

According to developmental psychologists such as Jean Piaget and Erik Erikson,⁶ the emotional and psychological development of a child follows a natural trajectory. The early childhood years are an egocentric stage in which children are interested in things directly related to them. They are not in the habit of seeking logical explanations or trying to decipher the intentions of those around them. For children who have siblings with disabilities, however, there tends to be a different set of rules. These children recognize from a very early age that their siblings have special needs. Parents can easily mistake this recognition for an understanding more sophisticated than it really is.⁷ The latency years of childhood, which usually begin around age five and last until the onset of puberty, are a time where a child becomes more capable of learning, creating and acquiring new skills and knowledge, thus developing a sense of purpose.⁸ Many children find that sense of purpose in school projects and neighborhood activities, but for parentified children, the sense of purpose is found at home, where they can help their parents with tasks such as caring for a sibling – a job generally reserved for adolescents, who have a better capacity for judgment. By the time parentified children reach the stage of adolescence,

⁵ Ibid., 175-176.

⁶ Carol Garhart Mooney, “Jean Piaget,” in *Theories of Childhood: An Introduction to Dewey, Montessori, Erikson, Piaget and Vygotsky* (St. Paul, MN: Redleaf Press, 2000), 77-98.

⁷ Siegel and Silverstein, *What About Me?* 113-114

⁸ Mooney, “Eric Erikson,” in *Theories of Childhood*, 53 to 76

when experimentation with different identities occurs, they have already taken on specific adult roles associated with caring for siblings with disabilities.⁹

Most ADTYP siblings do not recognize the impact of their parentification until they reach adulthood, when they have the capability to look back and accurately identify their own parentified conduct. The process of looking back can be very difficult. According to Siegel and Silverstein, if the parentified role is the only thing for which a child receives positive feedback, that individual is likely to seek out caregiving roles in adulthood. Often, this is the only kind of gratification that the parentified ADTYP sibling will look for in a loving relationship. In addition, the ADTYP sibling is likely to realize that the parentified pattern is dysfunctional, which may lead them to their “expending a great deal of mental energy coming to grips with his or her childhood role, and resenting it.”¹⁰

Unlike parentification, most superachieving ADTYP siblings are aware of their behavior throughout their lives, rationalizing their need for perfectionism under the guise of just wanting to be a good parent, spouse, employee, son or daughter, and brother or sister. These ADTYP siblings struggle with letting go, believing that they are the only ones that can get a task done correctly, which leaves them exhausted and stressed. This situation only worsens when their parents continue to have unrealistic expectations of their adult child’s abilities. Superachieving ADTYP siblings are at risk of burning out and therefore need to reassess their goals and their various roles in life. For many superachievers, individual psychotherapy can help them understand the depths of the perfectionist tendencies as it relates to their having a sibling with disabilities, and can then begin to work on finding ways to let go and slow down.

⁹ Siegel and Silverstein, *What About Me?* 113-114

¹⁰ *Ibid.*, 125.

The analysis of the parentified child and the superachieving child in *What About Me?* echoes the personal narratives of many ADTYP siblings. At one point or another, the testimonies in ADTYP sibling literature, interviews with ADTYP siblings, and the conversations that take place when ADTYP siblings come together all touch on this subject of rushed child development and exhaustion from being spread too thin. What becomes evident is that ADTYP siblings who identify themselves as superachieving and/ or parentified children have experienced a loss, because during the years when they were supposed to be looked after and protected, they instead became protectors.

A superachieving ADTYP sibling's realization of their parentification can have significant impact on their perspectives regarding the various types of relationships they have formed in adulthood, sometimes leading to their detaching from these relationships in order to take better care of themselves. What becomes clear, however, is that the one adult relationship that is most often not affected by this realization is the relationship between the ADTYP sibling and the sibling with disabilities. For instance, a thirty-something superachieving, parentified ADTYP sister moved across country over ten years ago to pursue her career, and she has since found much success. During this time she has also become aware of her parentification and through therapy and support from other siblings has significantly decreased her interaction with her parents. However, she is still in regular contact with her sister with I/DD, usually Skyping a few times a week and scheduling cross-country visits a few times a year. According to her sister with I/DD, her ADTYP sister understands her better than anyone and she is "the most important person in [her] life."¹¹

¹¹ Carol, a sibling with I/DD, interviewed by author, New York, April 3, 2015.

The personal stories of siblings offer the most accurate portrayal of what life is like as an ADTYP sibling and a sibling with disabilities. The groundbreaking book, *Thicker Than Water: Essays by Adult Siblings of People with Disabilities* (2009),¹² edited by Don Meyer, is the first publication to collect the personal stories of ADTYP siblings. This collection offers a very diverse, intimate look into the various thoughts, concerns, and experiences of ADTYP siblings, and is intended to raise awareness of sibling issues and needs among professionals in the disability service field. The book is also directed at the many ADTYP siblings who remain unaware that support systems exist, and that they are not alone in their experiences. There is also the hope that these essays will reach parents, inspiring them to think about the ways in which they handle family affairs and to consider the special needs of their children, of any age, with typical abilities. Organized according to each author's age, these essays provide insight into the continuously changing circumstance of ADTYP siblings over the course of a lifetime.

Meyer begins his introduction with a personal anecdote from a forty-something-year-old sibling who has just recently discovered through SibNet that she is not alone in her experiences as an ADTYP sibling. Meyer's analysis here is simple and to the point:

Forty years is a long time to wait for such validation. Services providers would never make parents of a child with special needs wait for forty years to meet other parents who have children with similar disabilities. But for some reason this basic consideration isn't seen as important for brother and sisters.¹³

The situation of ADTYP siblings having to wait years to discover other ADTYP siblings is a problem that has been gradually decreasing since Meyer's implementation of the Sibshop model.

¹² Don Meyer, ed., *Thicker than Water: Essays by Adult Siblings of People with Disabilities* (Bethesda, MD: Woodbine House, 2009).

¹³ Meyer, Introduction to *Thicker than Water*, 5.

For the ADTYP siblings who were unable to attend Sibshops, *Thicker than Water* provides a new opportunity to make that discovery.

The voices of ADTYP siblings in these essays encompass a myriad of emotions and concerns. Some express gratitude for their sibling's influence, such as "he taught me patience... and the value of difference,"¹⁴ and "growing up with [my sister] taught me patience, acceptance, and understanding."¹⁵ Another ADTYP sibling writes about feeling worried: "I have always been very protective... almost to point of paranoia."¹⁶ Stories of feeling helpless are shared by an ADTYP brother who explains, "I ache with frustration and guilt at not being able to help solve [my brother's] inactivity and social isolation."¹⁷ There are also narratives about keeping perspective during moments of guilt. As one ADTYP sister confesses, "although I tell myself that I am doing my best and that being hard on myself won't help, there are days when I feel very guilty about my decreased day-to-day involvement with my sister. At those times I remind myself that my relationship with [my sister] is life-long."¹⁸

Thirty-nine ADTYP sibling contributors in *Thicker than Water* share many emotions and experiences. Through these essays the ADTYP siblings' voices are heard and the complexity of their reality is revealed. This collection has made a significant impact on the lives of other ADTYP siblings and on parents as well. As one parent of a child with I/DD states in her review of *Thicker than Water*, "parents need to know how siblings feel about special needs, now and as adults... [but] it may lead you to feel guilty about mistakes you've already made."¹⁹ Volumes of

¹⁴ Melissa Garrison, "Asked and Answered," in *Thicker than Water*, 5.

¹⁵ Kay Swanson, "What Was I Thinking," in *Thicker than Water*, 29.

¹⁶ Matthew Carpenter, "Katie," in *Thicker than Water*, 11.

¹⁷ Zach Rossetti, "Don't Apologize for Being a Brother" in *Thicker than Water*, 46.

¹⁸ Yona Lunskey, "Aunty Danni" in *Thicker than Water*, 52.

¹⁹ Terri Mauro, "Thicker than Water book review," *About Parenting*, accessed April 7, 2015
<http://specialchildren.about.com/od/booksonfamilyissues/gr/thickerthanwater.htm>

parent-focused disability literature have clearly illustrated that guilt is a commonly felt emotion. Through works such as *Thicker than Water*, what becomes obvious is how closely acquainted ADTYP siblings are with that same emotion.

Frustration is another frequently felt emotion for ADTYP siblings, usually in regards to their own lives, their siblings' limitations, and the behavior and reasoning of their parents. This multi-layered frustration is exemplified in a *Thicker than Water* essay by Nina, ADTYP sister and author of "A Letter to my Brother."²⁰ In this essay, thirty-seven-year-old Nina is writing a letter to her brother Ben, a thirty-six-year-old man with Down syndrome who lives at home with their parents. In this letter, Nina tells Ben about her painful frustration with their parents' choices, especially their refusal to discuss Ben's disability and their insistence that Ben would grow up to be like everyone else.

Nina admits to feeling sad that she has not yet started her own family because she has been so preoccupied with Ben's long-term care. In addition, she acknowledges how frustrated Ben must feel between having a curfew, not having a driver's license, being allowed no privacy, and having to ask permission to go on dates with his girlfriend. She tells him, "This is something you and I have never discussed, because I am afraid it would upset our parents, and they're the ones who have to live with you and take care of you every day."²¹ She also apologizes for not including him in the many meetings she and her parents attended regarding plans for the future, and explains how she would have liked him to be there, but, "our parents absolutely refused to discuss your future with me while you were present."²²

²⁰ Nina C., "A Letter to My Brother" in *Thicker Than Water*, 59-63.

²¹ *Ibid.*, 60.

²² *Ibid.*, 61.

One of the most difficult, but touching parts of Nina's letter is when she tells Ben the reality of his circumstance, feeling that this is her responsibility, since her parents continue to lead Ben to believe he will grow up to be normal. She says:

You will probably never have a regular job like me, at least not without a job coach [...] you will never fulfill your dream of graduating from law school, because your brain does not process information quickly and cannot handle complicated calculations [...] you can do other exciting things but you won't get to practice law.²³

Let me tell you something else. You might get married, I suppose, but you probably won't be able to take care of children on your own. I strongly recommend that you do *not* have children (or get involved with a woman who has children), because I am not willing to help you look after them. In fact, I would be extremely angry with you if you had a child, because that would just create added responsibilities for me, more responsibility that I had not chosen, and that has been the story of my life so far.²⁴

Just to be clear, I am not mad at you because you were born different – I love you just the way you are, with all your strengths and weaknesses. Every time I come back to visit you, I am astonished at your capacity to find humor in everyday situations and to be kind and generous to people who are having a hard time [...] when I am feeling uncertain of my place in the world, your warm hug lets me know that being your sister – being myself – is enough.²⁵

Nina continues to explain to Ben how great his life can be, and what kind of life their parents will be able to provide for him. She asks him, “what more could you want? I know, you've told me repeatedly that you want to live independently [...] certainly this will become necessary at some point, when our parents die.”²⁶ She then goes on to explain the two choices he will have: remaining in his community in Canada and living in a group home, or moving into a group home in New York where she lives. Nina tells him, “now that I think about it, I guess I would prefer

²³ Ibid., 60.

²⁴ Ibid.

²⁵ Ibid., 61.

²⁶ Ibid., 62.

[you moving to New York]. You could be part of my life, meet my friends, and I would get to know your caregivers and your friends as well.”²⁷

Nina’s letter to Ben is honest, brazen, and sad, and Ben will never have the opportunity to read it. Nina begins the letter with, “I’ve decided to write you a letter you will never read. I am going to say all the things I would say if you didn’t have a disability [...] if I didn’t fear that anything I sent to you would be opened [...] by our parents before it reached you.”²⁸ The letter ends with, “how I wish we could actually have this conversation. In the meantime, I suppose we’ll have to keep on pretending that our parents will outlive you so that you’ll never get a chance to live independently. That’s the official story at home, anyway.”²⁹

Although Ben many never read Nina’s letter, many other ADTYP siblings will, possibility other family members of service providers too. This letter is Nina’s essay, her contribution to a collection of perspectives and voices of other ADTYP siblings. In the company of other siblings, Nina has found a safe space to speak her mind, to be truthful about the beauty and the despair of having a sibling with disabilities. Sibling movement literature such as *Thicker than Water* accomplishes two things, then: raising awareness of the ADTYP sibling’s circumstance, and providing ADTYP siblings a cathartic opportunity to speak the truth.

Although *Thicker than Water* was the first book to give voice to many ADTYP siblings, a number of other sibling-related texts have been published since 2000.³⁰ The most recent addition to sibling movement literature is *The Sibling Survival Guide: Indispensable Information for*

²⁷ Ibid., 63.

²⁸ Ibid., 59.

²⁹ Ibid., 63.

³⁰ Additional books about ADTYP siblings published since 2000 include: Jeanne Safer’s *The Normal One: Life with a Difficult or Damaged Sibling* (2002), Mary McHugh’s *Special Siblings: Growing Up with Someone with a Disability* (2003), Rachel Simon’s *Riding the Bus with My Sister* (2003), Lynne Stern Feiges’ *Sibling Stories: Reflections of Life with a Brother or Sister on the Autism Spectrum* (2004), Kate Strohm’s *Being the Other One: Growing Up with a Brother or Sister who has Special Needs* (2005).

Brothers and Sisters of Adults with Disabilities (2014).³¹ Edited by Don Meyer and Emily Holl, this “how-to” guide for siblings with typical abilities addresses our ever-changing needs from childhood to senior years. The voices of ADTYP siblings come across loud and clear through a combination of essays by accomplished sibling contributors and personal testimonies of siblings in an assortment of circumstances. In addition to chapters that discuss marriage, children and other sibling concerns across a lifespan, there are chapters regarding sibling research, self-care and sibling support, managing the service system, advocacy, and planning for the future. This book is accessible to parents, providers, and everyone in between, but it is predominantly meant for siblings, to serve and guide us through all stages of life. *The Sibling Survival Guide (SSG)* can be read from cover to cover, or one can use it as a reference book.

In “Love, Marriage and Baby Carriages”³² social worker and ADTYP sister Emily Holl discusses common concerns associated with relationships and the decision to marry and/or have children because as Holl explains, “for most sibs, the quest for love tends to be a little more pragmatic.”³³ Research shows that ADTYP siblings, particularly sisters, tend to marry and have children later in life than women without a brother or sister with a disability.³⁴ Holl’s essay explains why this occurs. First, there is the sibling “litmus test,”³⁵ which refers to the ways in which ADTYP siblings screen potential partners. This screening process entails carefully observing their behavior around those who are different from them, waiting to see if they make insensitive comments or use disparaging terms such as “retarded,” critically observing their

³¹ Don Meyer and Emily Holl, ed. *The Sibling Survival Guide: Indispensable Information for Brothers and Sisters of Adults with Disabilities* (Maryland: Woodbine House Inc., 2014).

³² Emily Holl, “Love, Marriage and Baby Carriages,” in *The Sibling Survival Guide*, 31-44.

³³ *Ibid.*, 32.

³⁴ Meghan M. Burke, et al. “Predictors of Future Caregiving by Adult Siblings of Individuals with Intellectual and Developmental Disabilities,” *The American Journal on Intellectual and Developmental Disabilities* 117, no. 1 (2012): 33-47.

³⁵ Holl, “Love, Marriage and Baby Carriages,” in *The Sibling Survival Guide*, 32.

reactions when learning about the sibling with I/DD, and later assessing how they interact with the sibling and how they handle stressful situations. One ADTYP sister recalled her “litmus test” when she was in high school,

In my younger years, like high school, I would tend to date outside of our school, because everyone knew everyone. So I would date guys from neighboring schools, and then, once I got to know them and once I got comfortable, if I felt like they could come to my house then they could come to my house. But I had to have a whole speech prepared, the “let me tell you about my brother” speech.³⁶

Second, ADTYP siblings are generally perceived by potential partners as being part of “a package deal,” meaning that those who are considering a long-term committed relationship with an ADTYP sibling are also considering a long-term connection to the sibling with I/DD. For this reason, some ADTYP siblings are considered less desirable, which creates obstacles and challenges in finding a partner. All of this significantly lengthens an ADTYP sibling’s pursuit of romance.

Another significant concern discussed in this chapter is the decision about having children, which for ADTYP siblings is laced with fear that their children will have life-altering disabilities. Some siblings choose to have genetic testing, which requires the sibling with I/DD to be tested as well. Other ADTYP siblings choose adoption, and some choose not to have children at all based on their current and future responsibilities for their siblings with I/DD. The *SSG* respectfully acknowledges that these decisions are highly personal and different for each individual, and provides information for those who are interested in learning how to find a genetic counselor, genetic testing, and prenatal testing, and about the costs involved.

The chapter “Squeezed: The Club Sandwich Generation,” by education consultant and ADTYP sister Kitty Porterfield, discusses the multiple caregiving roles that many ADTYP

³⁶ ADTYP sister, interview with author, New York, March 24, 2015.

siblings eventually take on: looking after children, aging parents, and a sibling with disabilities. Like many in the baby boom generation, they are sandwiched between dependent parents and dependent children, but in this case with the added layer of sibling care. As Porterfield observes, “so many emergencies and so little time.”³⁷ She stresses the importance of learning to triage so internal resources can be used effectively. ADTYP siblings tend to have great stamina, resilience and determination when solving immediate problems, all vital lifelines for the club sandwich generation, but putting time into long-term planning is equally important. Porterfield emphasizes the need for ADTYP siblings to invest in themselves, their own families, friends, and personal development to ensure their own wellbeing.

It is imperative that ADTYP siblings build and maintain their own networks of support, especially those in the club-sandwich generation. Securing plans for the future is an essential way of building up that support, but often this is easier said than done. Conversations between ADTYP siblings and parents about long-term plans are often difficult because many parents are reluctant to discuss the future when a son or daughter with disabilities is involved. Having a plan for the future is a necessity for ADTYP siblings, however, because it will not only ensure that their aging parents and sibling with I/DD are properly supported and cared for, but it will also protect their own and their families’ well-being. Katie Arnold, Tamar Heller and John Kramer provide essential planning information in the chapter, “Planning for the Future: What You Need to Know.”³⁸ Here, information can be found on setting up health-care proxies, obtaining guardianship, creating letters of intent, financial planning and residential planning and an in-depth discussion of ways to make planning less stressful. The type of stress that ADTYP siblings

³⁷ Kitty Porterfield, “Squeezed: The Club Sandwich Generation,” in *The Sibling Survival Guide*, 45-56.

³⁸ Katie Arnold, Tamar Heller and John Kramer, “Future Planning for the Future: What You Need to Know,” in *The Sibling Survival Guide*, 145-175.

endure in relation to planning for the future is exemplified in this testimony from Kara, an ADTYP sister:

My family and I have done some financial planning for the future for my younger brother, who is a person with intellectual disabilities, but I've experienced, as I'm sure many people have, lots of push back from my parents. They don't want to think about the possibility of them not being around for my brother, they don't really want to understand the importance of changing their wills to reflect my brother's Special Needs Trust, and I'm repeatedly told it's "not my business" and that having my brother be cut off from benefits "just won't happen," even if they leave him funds directly and don't leave them to the trust. I've found it hard to get my parents to understand even when I call in my lawyer to explain this to them. I'm sure other sibs have discovered this too - and the frustration that comes after doing so much research to support my brother. Short of taking them to court (which is honestly probably impossible). [I need to know] how to explain these concepts to family members in a way that makes them understand the gravity of the situation.³⁹

This chapter on planning for the future addresses how to handle difficult situations like the one described above with helpful tips when discussing plans with parents. One of many suggestions provided is to find a neutral party to facilitate the conversations when family members cannot agree. This could be a supportive family friend, social worker, therapist or someone from a disability organization.

The challenges addressed in *Thicker Than Water* and the *SSG* are one and the same as the concerns voiced by individual ADTYP siblings. Safe, judgment-free spaces to discuss concerns with other ADTYP siblings who can empathize are found in support group meetings that convene on a regular basis. These meetings provide what large organizations and online services cannot: intimate, face-to-face gatherings of ADTYP sibling peers who all share the same locale. During group sessions, siblings can learn from each other as to how to handle specific, problematic situations, and it is the personal, practical, day-to-day concerns of siblings that often lead to stress and anxiety. As Emily Holl writes:

³⁹ Kara E., statement submitted to author, New York, April, 5 2015.

Local in-person support groups are a tremendously valuable way for siblings of individuals with disabilities to connect and share stories, information and support. Inevitably when you get a bunch of sibs around the table, conversation naturally flows. Common topics include challenges navigating the service system and finding the right supports for brothers and sisters with disabilities, worries about the future and difficulties talking with parents about planning for it, balancing the needs of family members and themselves, finding and maintaining romantic partnerships, genetic concerns about having children, and in general how to support their own quality of life while juggling the needs of others. Connecting with others who can relate to what you're going through is a powerful source of reassurance and support.⁴⁰

Support groups also create an opportunity for siblings to see firsthand that they are not alone in dealing with the emotional roller coaster of being an ADTYP sibling. Brothers and sisters have concerns that are similar to their parents, including isolation, guilt, and the future, but siblings also have unique concerns of their own such as resentment, embarrassment, peer concerns and the pressure to achieve.⁴¹ Considering how much time passes before many ADTYP siblings have the opportunity to meet other adults in similar situations, and given the fact that, until this occurs, most go through life without ever considering the possibility that sibling support systems exist, these discoveries tend to be astonishing and life-changing experiences.

One ADTYP sister was in her early thirties when she attended her first sibling meeting and described her experience as,

Very, very emotional, but almost like a relief too because it was something that I never really realized I needed in my life until I had it. But then I was like – oh wait – this exists? It was never something I thought or wished for, but after it was over I immediately wanted to connect with my brother [with typical abilities]. I called him literally once I stepped a foot out the door and told him about everything and asked him if he ever felt certain ways, or thought certain things. We had never talked about it before and I wanted to know how he felt.⁴²

⁴⁰ Emily Holl, statement submitted to author, May 1, 2015. Emily Holl is an ADTYP sister, social worker, and facilitator of the SibsNY local support group.

⁴¹ Don Meyer and Tom Fish, *Supporting Brothers and Sisters: An Effective Means of Improving Life of People with Disabilities* (September 15, 2008), accessed April 4, 2015, <http://siblingleadership.org/about/the-sln-white-paper/>.

⁴² ADTYP sister, interviewed by author, New York, March 24, 2015.

The connections that are made between ADTYP siblings often lead to long-term, family-like friendships, as illustrated by these ADTYP sisters:

I have attended Sibling support events for close to 20 years, and every year I attend, I leave fulfilled and satisfied. Siblings of people with disabilities are unique individuals who are often compassionate, patient understanding people. I always feel as if I have an extended family with other siblings. I collect resources and pass on information, and laugh so much, at the shared experiences and commonality.⁴³

It's the camaraderie and the sense of family; it's like extended family to me. People who are non-judgmental about the why you feel certain ways about things, and just having that, having other people who understand and have been through things... similar [and] can understand why you feel certain ways.⁴⁴

The types of connections that ADTYP siblings find during support group meetings are invaluable, particularly because of the ways in which we find common themes in each of our stories. One of them is the pressure and guilt generated by the assumptions of their parents that ADTYP siblings will eventually take on the role of primary caregiver for the sibling with I/DD.

As an ADTYP sister explained,

My mother always said “one of you was going to have to take care of her [sister with I/DD]” [...] but its more than one person's full-time job to take care of [my sister], so there is no way I could ever do it. My mother always thought I would do it, and there is a tremendous guilt that we all have about it.⁴⁵

The ways in which ADTYP siblings react to the pressure of future caregiving vary. Some become full-time primary caretakers, while others completely detach themselves from their siblings' lives. Most ADTYP siblings fall somewhere in between, finding a balance between having their own lives and remaining active and involved in the life of their siblings with I/DD.

⁴³ Delilah Picart, statement submitted to author, New York, April 7, 2015.

⁴⁴ ADTYP sister, interview with author, New York, March 24, 2015.

⁴⁵ ADTYP sister, interview with author, New York, March 28, 2015.

One ADTYP sister who addressed this balancing act pointed particularly to her own challenges as a woman, as a mother and as an ADTYP sibling,

I feel like I do my part. I am an advocate when I need to be, [full time care of siblings is] emotionally not easy, and how much can you take? So it's not for me, but I'm active and I'm involved and I'm an advocate. Also, being a working mother, there is already a lot to do, and a lot of it is emotional even just being a mother, working or not working.⁴⁶

The notion that this particular ADTYP sister is doing her part is an understatement. She is the youngest of five siblings, with a family of her own and a full time job. While her ADTYP brothers and sisters do their parts as well, she is the sibling that her sister with I/DD sees the most frequently. This ADTYP sister's reliable presence is intensely meaningful to her sister with I/DD, a fact that was reported to me by the most reliable source possible: the sister with disabilities.

⁴⁶ ADTYP sister, interview with author, New York, March 28, 2015.

Chapter 3

Do You Hear What I Hear? The Voices of Siblings

“My sister helped me when I had my first seizure so that made us very close. We’re *very* close.”¹

Although the voice of ADTYP siblings is gradually becoming more included in conversations about the needs of individuals with I/DD through the sibling movement, the voice of the sibling with I/DD is mostly absent. Including the perspective of siblings with I/DD is crucial to productive sibling research. Their exclusion from ADTYP sibling literature is problematic because it maintains their otherness, which then limits full understanding of the ADTYP siblings’ circumstances. Outsiders, foreign to the daily life of ADTYP siblings and their siblings with I/DD, label these individuals as “normal” and “disabled.” For both siblings themselves, however, otherness does not exist; the label that matters is “brother” or “sister.” By including the voices of siblings with I/DD, we are not only gaining their perspective, but also enhancing our ability to understand the complexity and importance of the sibling relationships as a whole.

Journalist Susan Scarf Merrell’s book, *The Accidental Bond: The Power of Sibling Relationships* (1995)² exemplifies how including both siblings in conversations is beneficial, while also illustrating the ways in which the voices of siblings with I/DD are minimally considered despite this realization. The single chapter in which Merrell discusses sibling relationships and I/DD is “Ginger Farr: ‘If I see a Therapist, Am I Sick Too?’” Here, Merrell interviews Ginger and her brother Bobby, a forty-something-year-old man with I/DD. Merrell explains how her uncertainty about how to talk to Bobby leads her to constantly ask if he

¹ Carol, interview with sibling with I/DD, New York, March 29, 2015

² Susan Scarf Merrell, *The Accidental Bond: The Power Sibling Relationships* (New York, NY: Times Books, 1995), 187-212.

understood her. Luckily, Ginger was there not only to help Bobby communicate, but also to help him feel at ease when talking to this stranger. The brief exchange between Merrell, Bobby and Ginger that follows demonstrates the value of talking to both siblings, together.

Merrell explains that between her ignorance of the extent of Bobby's disabilities and her desire to connect with him, she kept asking him the same questions over and over again: "Tell me a little about your mother, can you do that? Is that okay?" Eventually Bobby replies and says, "Are you sure?" Merrell then explains how she didn't know what Bobby meant, and therefore looked to Ginger for assistance. Ginger then informed Merrell that "He wants to know if that is the question you want him to answer, if you've made up your mind." Bobby immediately replied, "Yeah," and with that Merrell began to feel at ease with her ability to communicate with Bobby, just as he felt more comfortable talking to Merrell, because he knew Ginger was there if he needed assistance.

Despite Merrell's realization that Ginger could assist with communication, Bobby's voice unfortunately remains silenced for most of the remainder of this chapter. Instead of recounting what Bobby told her, Merrell focuses on describing Bobby to the reader; his height, weight, cleanliness, hair color, what he was wearing, and so on. She described that he wore a helmet to protect himself from frequent falls, and that he was wearing new leg braces and was therefore unable to bend his knees. Judging by the way Bobby was sitting, Merrell inferred that the braces caused some discomfort and that he was now challenged with relearning the skill of bending his knees. Rather than describe how Bobby was feeling, Merrell should have asked Bobby how he felt, about his seat, his helmet, his braces, or anything else. Given the fact that Merrell informs the reader early in this chapter how inexperienced she is in interacting with people with I/DD, it is foreseeable that she might find it challenging to ask Bobby these questions. This still could

have been accomplished, however, had Merrell further enlisted the assistance of Ginger. This would have led to a much richer portrayal of Bobby, who he is and how he feels. Instead Merrell portrays what she believes Bobby to be and feel.

The interviews conducted for this thesis reveal the perspectives of individuals with I/DD, at times along with their ADTYP siblings. Some of the same communication challenges that Merrell experienced emerged in these interviews as well, but they are richly informative. In addition, themes of pride and appreciation, accessing adulthood, self-advocacy and cultivating one's own family are addressed. The interviewees include John, Maria, Dee and Carol. John and Maria were each accompanied by an ADTYP sibling, who assisted by providing moral support and information when necessary.

Communication

The ability to communicate, to convey our thoughts and be understood by others, is a basic necessity for all human beings. The verbal and non-verbal ways in which we communicate, and the effectiveness of that communication vary among individuals, and many experience challenges with basic communication every day. For individuals with I/DD, the extent of their struggle with communication varies, but all share the desire to be understood.

John

During preparation for my interview with John, a forty-year-old man with autism, his thirty-six-year-old ADTYP sister Kate informed me that, although John is completely capable of answering questions and sharing his thoughts, he is “not a big talker” and is unlikely to provide substantial information. She explained that, although he is like this with most people, she can get

him to elaborate on his answers, and offered to join us for the interview. Already knowing how much John enjoys opportunities to see his sister, I gladly accepted her offer.

As Kate predicted, John was very quick to answer my questions during our interview, but often his answers were short and provided little to no information. Kate, knowing her brother so well, knew that John had more to say and, when she encouraged him to provide more information, he did so without hesitation. For example, after John told me about various trips he has taken with friends and family, I asked him if there were any places in particular he would like to travel to, and he responded, “I don’t have one in particular.” Kate then said to John, “Oh sure you do,” and then John stated, “I would like to visit Ireland where my ancestors are from.” This information led to conversations about heritage and family, and I learned here how interested John is in history, and how important connection to family is for him.

I later learned from John that he likes to talk to Kate via text message. When I asked him what he likes to talk to Kate about, he said, “I don’t have one.” Kate then asked John, “Well, what do you usually talk to me about?” John replied, “I like to ask you about [your job], and how everyone over there is doing.” This prompted a discussion about Kate’s career of providing respite to children with I/DD, and how in the past she has invited John to accompany her to work. I learned how meaningful these experiences have been to John, and how much he loves to meet and spend time with Kate’s coworkers and friends.

John also explained to me different activities he enjoys, such as bowling. When I asked him if he likes sports he said, “I don’t know.” Kate then asked him, “What sport did you play in school?” John replied, “I was a track runner and cross country in high school.” Kate then explained to me that the great thing about cross country is that the scores are individual, so his performance was never at risk of hurting the team. She added that his team was very supportive,

and that each teammate would finish and then loop back around and finish again with John, cheering him on. This story not only gave me insight into the types of support John has experienced at various stages of his life, but also how affected Kate was by the unsolicited compassion and support of John's teammates.

Towards the end of our interview I asked John if there was anything else that he thought I should know about, something that I neglected to ask, and he said, "Can't think of anything." Kate then said to John, "I think you can think of something." He then added, "I'm just happy with my job and I like to go to Yankee games and Mets games," which segued into a discussion about how important it is for John to be independent, and for others to understand how capable he is.

This ninety-minute interview with John yielded rich information, and was very much facilitated by Kate's presence. She was able to elicit answers from John when I could not. At no time during the interview did Kate answer for John, nor did his answers require that she decipher them. John is a high-functioning, intelligent man, completely capable of communicating his thoughts to others, but his nature is to hold back. He is, as Kate explained, "not a big talker," and only those who intimately know him and with whom he is comfortable, such as his sister, are able to extract his vibrant perspective.

Pride & Appreciation

One of the many benefits to listening to the voices of individuals with I/DD is learning about what is important to them; my research found that most often, it is their family and their independence. Both of these topics elicit an overwhelming sense of pride and appreciation from siblings with I/DD. This is because independence for individuals with I/DD is often linked to the

relationships and interactions they have with their families, particularly with their ADTYP siblings.

Maria

I interviewed Maria, a sixty-year-old woman with I/DD, along with her ADTYP sister, Susan. Like Kate, Susan was able to assist me in obtaining information from and about Maria. Prior to the interview, Susan informed me that Maria might not understand certain questions, such as “what is important to her,” because she might not understand what the question means. Susan reassured me that, once I figured out how to phrase a question so Maria understood, she would provide the answers. Susan’s guidance was very helpful, but what I came to realize during this interview was that Maria was much more apt to provide answers when I asked questions about things that are important to her. The topics that consistently proved to be important included her sister Susan, her other ADTYP siblings, and her independent abilities.

Some of the questions I asked Maria received short “yes” or “no” responses, and many did not receive a response at all. When this occurred, Susan assisted by providing information. During our conversation, Maria provided the most information when asked questions about Susan. For example, when I asked Maria if it makes her happy to see Susan, she answered, “Yes, it’s so nice to see her.” Later I asked Maria if she ever wishes she could see her family more often, and Maria’s response was, “Yes, Susan comes to see me, she calls me up and tells me what day she’s gonna come and pick me up, and then I can’t wait until she comes to get me.” Maria’s instantaneous responses to these questions illustrate the importance and the comfort level Maria finds when talking about her relationship with Susan.

This interview was also very much informed by my observing the ways in which Maria and Susan interacted. Maria ordered pizza, and when it arrived Susan automatically got up and began to cut it for her. While her pizza was being cut, Maria initiated conversation with me for the first time and said, “Yes, that’s good, I love to eat it that way,” and then added, “I won’t get my clothes dirty and won’t have to wash the clothes at home.” I asked Maria if it makes her happy that she has Susan to help her out with this, but before I could finish my question Maria exclaimed “YES!” The unspoken understanding that Susan exhibits here is clearly very meaningful to Maria. She feels seen and understood by Susan, and for this she has much appreciation.

Another topic of importance to Maria is her birthday, and the party that her family plans for her every year. I asked Maria how this event makes her feel and she said,

It’s so nice to see everyone and on my birthday. They take pictures and everybody says “Somebody’s pretty for her birthday” and “Maria looks wonderful pretty for her birthday.” Everybody says it. They give such nice cards and they make a cake. Chocolate cake is so good to eat, I love it. Sometimes Susan’s going to maybe bake a cake for my birthday. She has to know how many, how long the cake has to be for how many people are going to come, to make sure they’re going to have enough cake for everyone, for the people to eat. Susan is going to do it.

Maria’s family makes her feel proud and good about herself, and this is exemplified during events such as her birthday party. Maria also illustrates here how clearly she understands and appreciates what her family does for her, and particularly in this case, the types of detail that are involved in organizing events.

In addition to birthday parties, Susan has facilitated a recreational program for Maria and her friends through connections with Susan’s employer. This rewarding program takes place in a beautiful setting and is run by dedicated volunteers. When I asked Maria about this program she exclaimed, “It’s fun, and one day she [Susan] came to see me! She came to see me!” Susan’s

ability to think outside the box, and her willingness to open up the private world of where she works, creates an opportunity for Maria to have more meaningful activities. In addition, Maria's excitement about Susan's visit during this program is about more than just her being happy to see her sister. There is a sense of pride than Maria feels in relation to her friends having this opportunity because of her sister, and in this instance, Maria was proud to show Susan off.

By the end of our interview, I came to understand that, the more time I spent with Maria, the more comfortable she was with talking to me. Maria has much to say, and finding her voice was at times a challenge, but once it was found, the pride and appreciation of her siblings, particularly Susan, could not be denied.

Access to Adulthood

As individuals, we tend to experience a similar trajectory of growth that involves coming of age, obtaining independence, and becoming self-sufficient. For many individuals with I/DD, however, their limitations lead to their being caught between two worlds; childhood and adulthood. Individuals with I/DD observe their peers' growth, but are often unable to access similar experiences due to their disabilities. For those with I/DD who are aware of the ways in which they ought to be accessing adulthood, but understand how their disabilities make that access difficult to obtain, there may be a continuous struggle to find ways of obtaining independence and autonomy. There are, however, ways in which ADTYP siblings can creatively provide their siblings with I/DD the opportunity to access to adulthood.

Dee

Dee is a twenty-two-year-old woman with I/DD, and has two ADTYP brothers, Mark and Steve. Dee is considerably closer to Mark than Steve, despite the fact that Mark lives far away.

Dee's story is particularly illuminating in terms of accessing adulthood through siblings because she and her brothers are triplets, so they are each reaching the various stages of growth at the same time. During this interview, the connection between Dee's closeness to Mark, and the ways in which he represents adulthood became clear.

Dee stated very early in the interview how she feels about her brothers. When I asked her what's it like sharing her birthday, she replied, "It's ok, but Mark is my favorite." I asked Dee if she could tell me more about Mark, and why he is her favorite, and she replied,

Mark's away at college, maybe that's why I love him, I don't see him that often [...] He was in the [Midwest,] and now he's away at college in upstate [New York]. He's doing something with engineering or something, I'm not sure. He's one of those freaky geniuses; he's like one of those science kids that sit in a book and just study and study [...] He's really nice, smart and good looking. I could actually brag about him for hours. My brother Mark wants to be an astronaut.

I then asked Dee to tell me about Steve, and she informed me that he lives at home with her and their parents, goes to school and works part time. She noted that they do not communicate that often, and that, "He can be a real pain because he's here [at home] 24/7...He's always here; he never leaves."

The ways in which Dee's brothers' current lifestyles differ represent varying degrees of access to adulthood. For Dee, Steve's constant presence in her life represents more than just the annoyance of having to share space with him; it resembles the very predicament she finds herself in - the inability to obtain independence. Mark, alternatively, has traveled, is away at college, and lives on his own, which provides Dee the opportunity not only to vicariously access adulthood through her brother, but also to experience it for herself.

During our interview Dee told me how she looks forward to Mark coming home to visit, and that when he is home they spend much time together talking, watching television, browsing

the Internet, and looking at humorous college-themed skits on YouTube. Dee also informed me that she has visited Mark at college many times over the past three years, and emphasized how much she enjoys her visits. Dee is a comedian and jokester by nature, and when I asked her about visiting Mark, she said,

He has his own apartment, and I'm like "Can I live with you Mark? I can't take mom's cooking anymore, seriously!" It's nice there, I might move there one day. I'm going to go to Mark, show up with suitcases and be like, "Hey I'm here to move in!" [His apartment] could use a woman's touch. [I might] sneak in and start cooking for him, heat up food and leave in fridge, and then I'd sit on the bed while he's sleeping and if he overslept, I'd be there and have my alarm clock all ready, and I'll be like, "GET UP!!!"

I later asked Dee if she thinks Mark will move back home when he finishes school, and she replied, "I'm hoping he does. [If he got his own apartment] I'd come over with chips when him and [his girlfriend] are kissing, and I'll be like, 'Don't mind me I just came over to drop off groceries!' Yeah, that would be pretty cool."

Reading between the lines of these humorous stories makes clear how meaningful these experiences are for Dee. For any young adult who is trying to obtain a sense of independence, peer interaction that excludes parents is a crucial component, and opportunities such as these can be difficult to come by for adults with I/DD. This is largely due to the fact that parents and caregivers require a high level of comfort and trust in the capabilities of anyone with whom their child with I/DD spends time alone. The peer group that is most likely to receive that level of trust is ADTYP siblings. In Dee's case, her brother Mark's lifestyle creates the opportunity for her to access various levels of independence that are associated with adulthood, and this, combined with his willingness to facilitate these opportunities, prompts Dee to identify Mark as her favorite. Throughout our interview, Dee was very clear on how important family is to her, including her other brother Steve.

Self-Advocacy

The phrase “nothing about us, without us” reflects the ideology that individuals with I/DD have a right to be included in all conversations about them and to have a say in all decisions that pertain to their own wellbeing. The ARC for People with Intellectual and Developmental Disabilities has adopted the following position on self-advocacy,

People with I/DD have the right to advocate for themselves. This means they have the right to speak or act on their own behalf or on behalf of other people with disabilities, whether the issue is personal (e.g., housing, work, friends) or related to public policy. Recognizing these rights in a respectful partnership between people with and without disabilities can lead to better outcomes and better lives in the community for everyone. [...] People with I/DD should be provided accommodations or supports in order to have a visible, respected, and meaningful place in meetings, conferences, task forces, or other forums when issues and policies that are important to them are discussed.³

The types of accommodations that The ARC refers to here include adjusting the schedules of meetings, enhancing or finding alternative communication methods, providing transportation and funding; all of which help people with I/DD to have a voice in large settings. For those who seek a voice in more intimate settings, such as with parents, service coordinators, or group home attendants, other types of accommodations may be required. Often, the individuals who can provide such accommodations are ADTYP siblings.

Carol

Carol is a forty-four-year-old woman with I/DD and has a history of medical ailments that have left her physically weak and dependent on the help of others. Despite the challenges she has endured throughout her life, her demeanor remains positive and energetic, which she attributes to her ability to advocate for herself. Carol informed me during our interview that she

³ The ARC for People with Intellectual and Developmental Disabilities, “Self-Advocacy,” accessed April 30, 2015, <http://www.thearc.org/who-we-are/position-statements/rights/self-advocacy>.

lives in a group home, attends a day habilitation program⁴ twice a week, and attends college three days a week, studying psychology. In addition, she spends alternating weekends with her mother and father who are divorced, and is very close to her older sister Jane, who lives on the West Coast.

During our interview, Carol explained that, although she has a good relationship with both of her parents, her father is often “in denial” about the severity of her health conditions and, as a result, does not accept the fact that she requires the use of a walker. Despite her self-advocacy efforts, she has been unable to convince her father that her need for the walker is legitimate. She was, however, able to discuss this with her sister Jane, who continuously advocates for her from afar. I asked Carol how Jane first reacted to the news of her needing a walker, and she replied, “At first when I got it she was like, ‘Ehh you don’t need it,’ and I’m like, ‘Yes I do! Are you kidding? If I fall it’s just going to be another thing.’” Carol then added, “Now she understands, and she’ll go back to [their father] and say, ‘Oh she needs it; she needs everything!’ [Jane] can definitely explain things to him because I can’t do it.”

The persistence and self-advocacy that Carol demonstrated when her sister questioned the need of the walker is in stark contrast to Carol’s lack of response when her father refused to allow her to use the walker *at all* while visiting his home. The reason for this contrast has everything to do with the different dynamics of her relationships with her father and, with Jane. As Carol explained to me, her father’s denial inhibits him from hearing her voice and understanding her perspective. Jane, however, not only acknowledges and listens to Carol’s

⁴ Day habilitation is a person-centered program for individuals with I/DD that focuses on community integration and becoming independent in day-to-day, non-vocational personal skills. New York State Office for People with Developmental Disabilities, “Day Services,” accessed May 1, 2015, http://www.opwdd.ny.gov/opwdd_services_supports/supports_for_independent_and_family_living/day_services.

voice, but also is able to empathize with the challenges Carol faces when communicating with their father. Jane's ability to do so is an inherent attribute of being Carol's sibling, and she alone is capable of conveying Carol's perspective to their father in a successful way. Self-advocacy is a vital instrument for individuals with I/DD, and when they come in contact with resistance, they often rely on their ADTYP siblings to see to it that their voices are heard.

Cultivating One's Own Family

The importance of family is a theme that runs throughout conversations with individuals with I/DD. As siblings with or without disabilities grow up, the common passages of life are likely to take place, particularly, marriage and children. The ability of individuals with I/DD to get married and have children depends on each circumstance, but it is fair to say that a significant portion of the disability community will not experience one or either of these life events. When individuals with I/DD have ADTYP brothers or sisters, however, they are still likely to have pleasurable experiences associated with cultivating their own family.

John

Towards the end of my interview with John and Kate, I asked John what he likes best about his brother Brian. He responded with, "Because I'm the uncle of his kids." I then asked the same question about Kate, and his response was, "I'm an uncle of three dogs and two cats. My niece and nephew and the dogs and the cats are my pride and joys." It is important to note that in an earlier, private interview with Kate, she made very clear that she and her siblings rarely have serious, heart-to-heart conversations. Kate, then, was understandably taken aback by John's response. The silence that followed was filled with a remarkable sense of a precious realization between two siblings. When I began to feel the inevitable need to break this silence, I told John

that I thought it was really great that he is an uncle, and how it is clearly an important thing in his life, and acknowledged how he has this opportunity through his brother and sister – and then, I was cut off by John, who said to me, “of stuff I don’t have.” He then looked to Kate, and repeated himself, “You have things I don’t have.”

John said these words to Kate and me in a joyful tone and with a smile on his face. He was clearly expressing sentiments of thankfulness and appreciation, not envy or regret. John’s intention was to be clear about why his connection to his siblings is so important. He understands that one could not exist without the other, and in his mind, the positive thing about his brother and sister is bigger than them as individuals. They represent the opportunity to be an uncle, and to feel the positive emotions associated with a parental role. This is a meaningful experience that ADTYP siblings can create for their siblings with I/DD, and very few other people can replicate this opportunity.

Dee

Similar themes of cultivating her own family surfaced during my interview with Dee. Dee mentioned how much she enjoys “quality girl time,” and how she attends an all-girls evening group that meets once a week, to talk about “nails, bras, and fun girl things.” Dee is also very close to her mother, and told me that when she feels sad or needs someone to talk to, her mother is the person she reaches out to. When I asked about their relationship, Dee said, “We are so close, we could almost be twins. I don’t have any sisters, so she’s the closest thing I’ve got.” Dee continued then to discuss how being a triplet with two brothers can be challenging and said, “Trust me, if my mom could still have children, if she could give me a sister, that would be amazing. A sister is all I want.” Dee creates her own spaces with women through time with her

mother, friends, in groups at events. Although her mother may no longer be capable of giving her the sister she longs for, she still has the opportunity to gain a female sibling through her ADTYP brothers.

When Dee and I discussed relationships, she made it clear that, although she is currently happy with being single, she desperately wants her brothers to get married. Her brother Mark in particular has a girlfriend whom Dee is quite fond of. She described her as, “very pretty, has red hair, is very nice,” and added, “I just hope he goes on and marries her, I’m like, ‘Come on and marry her, I want to be an aunt already; I’m not getting any younger!’” Echoing John, Dee expresses a desire to become an aunt, but nieces and nephews are not the only new relatives her brothers can potentially provide for her. In the event either one marries a woman, Dee will then gain a sister of her own. Dee informed me about the different visits she has had with Mark and his girlfriend, and when I asked her if it was nice to have another female around that is her age, she repeated, “Yeah, I just hope he marries her.” I then mentioned to Dee how she might get a sister if one of her brothers winds up getting married, to which Dee replied, “Yup, I know!” Dee nodded rapidly in agreement and with a huge smile on her face as she said these words, for she has already figured this out, and is looking forward to it. Dee is not guaranteed a sister because there are ADTYP brothers in her life, but they represent the possibility of something that would otherwise be impossible.

Conclusion

If I have a goal, it would be for a national conversation about the importance of siblings in the life of a person with disabilities. We are the longest relationship they will ever have in their lifetime. We know them as well and better than our parents. And only another sibling knows that.¹

Individuals with I/DD are living longer than ever before due to advances in medical technology and research,² and their needs for supports and services will only increase with age. Currently, the supply of residential services in the United States does not meet the demand of those with I/DD. In June 2011, The Research and Training Center on Community Living reported that an estimated national total of 76,677 individuals with I/DD were on waiting lists for residential services. This report concludes that, in order to meet the required need, states would have to expand their existing residential services by 16.6 percent.³ Considering the budget cuts that have occurred since this report was issued, and the fact that additional cuts are expected, it is implausible that the gap will be closed.

Compounding these issues is the fact that service providers are currently shifting to the model of “Self-Directed Supports” which give individuals and their families the option to control and direct Medicaid funds under an identified budget, provided that the individual with I/DD does not reside in a group home or government-funded residential setting. This results in less support from service providers and more support from families or “natural” (read unpaid) supports.⁴ In families with multiple children, the burden of parents having to provide these

¹ Delilah Picart, statement submitted to author, May 1, 2015

² Don Meyer, introduction to *Thicker than Water: Essays by Adult Siblings of People with Disabilities*, ed. Don Meyer (Bethesda, MD: Woodbine House, 2009), 5.

³ *Residential Services for Persons with I/DD* (Minneapolis, MN: National Residential Information Systems Project, 2011), 44, accessed May 1, 2015, <http://rtc.umn.edu/risp/docs/risp2011.pdf>.

⁴ Don Meyer and Emily Holl, ed. *The Sibling Survival Guide: Indispensable Information for Brothers and Sisters of Adults with Disabilities* (Maryland: Woodbine House Inc., 2014).

supports eventually shifts to the ADTYP siblings, and their burden is likely to last longer than that of their parents.

Disability services reliance on the families of those with I/DD clearly indicates that the unmet needs of support and services for ADTYP siblings must be addressed. This is a problem that is not going to go away; in fact it will only continue to grow. ADTYP siblings need service providers to understand their concerns and needs over a lifetime, provide information, create programs, and include both them and their siblings with I/DD in all conversations pertaining to care and service.

In addition, ADTYP siblings and siblings with I/DD should be included in policy development, program planning and services and supports. Siblings need to be informed about programs such as Partners in Policymaking, a national program of leadership training for individuals with and without disabilities.⁵ Through this program siblings can gain strength by learning the intricacies of advocacy writing policy, and effecting change. This program is also extremely beneficial for siblings with I/DD who learn how to become self-advocates and have their voices heard.

There is a significant need for support for siblings with typical abilities. The support systems and organizations that have been created for siblings and the literature of the sibling movement have made significant contributions to bridging the gap between the amount of caregiver support available to parents on the one hand and siblings on the other. Furthermore, the efforts of sibling advocates like Don Meyer and Tom Fish have opened doors for sibling support opportunities that have been life changing for typical siblings of all ages. ADTYP siblings themselves, those who work in the field, the siblings and others who gather at conferences, in

⁵ New York State Partners in Policymaking, accessed May 2, 2015, <http://www.nyspip.org/>.

support groups, on listservs and so on: all help to create change that enhances support for siblings.

As this thesis demonstrates, however, it is most vital of all to observe and listen to the relationship between siblings. This amplifies the voice of siblings with I/DD, which in turn creates an opportunity to understand more fully what is important to them, what they need, what they feel, and what they have to say about all the things that affect them. The belief behind the motto "nothing about us without us" is most effectively put into practice when siblings are included, together, in conversations. Through the interviews in this thesis, what becomes evident is that ADTYP siblings provide more than logistical support and caregiving; they give their siblings with I/DD access to independence and create opportunities for them to exceed their disabilities and limitations.

At one point during my research I asked my sister Amy to tell me what the best thing is about having a sister. She lovingly replied, "Well, the way I see it, you were born, and Mom and Dad didn't want you to be lonely, so they, ya know...did things, and then you had me! Here I am! Now you're not lonely anymore... Now you're stuck with me." As illustrated here, my sister can be quite the comedian at times, but there is insight in what she says. I wanted her to tell me how having a sister is beneficial to her; instead she explained how it is beneficial to me. The fact of the matter is that our relationship is mutually beneficial, as it is for most siblings who find themselves in the same circumstance. Just as Amy said, I am stuck with her, and I would not have it any other way. I want to be there for her. But I cannot do it alone; we cannot do it alone. Our siblings with I/DD deserve to have everything that the sibling relationship can offer, and this can be accomplished only when siblings with and without disabilities enjoy the opportunity to have their voices heard, together.

Epilogue

Sleepovers

My sister Amy loves to have sleepovers with me, but in recent years this rarely happens because my husband and I have a very small apartment, and I learned the hard way just how difficult it can be for the three of us to share this small space, especially considering how intrusive Amy can be at times. So I decided that we would hold off on sleepovers until we move into a larger home. A few months ago, however, an unusual opportunity presented itself; my husband needed to go away for a few days, and my immediate thought was “Great! Amy can sleep over!” One unfortunate snag in this plan, was that he would be traveling during the week, which then creates all sorts of additional complications. My desire to have Amy sleep over, however, exceeded these concerns, and so we went ahead with the plan.

As I have done during previous sleepovers, at a certain point in the evening I informed Amy that I needed to go to sleep, but told her she was welcome to stay up and watch television, providing the noise was kept to a minimum. One of the benefits for Amy when sleeping over at my apartment is the fact that she does not have parental figures dictating when it’s time for her to go to bed. Although it would be in both of our best interests for her to get a good night’s rest, I will not deny her this rare opportunity for freedom of choice about when she goes to sleep. The instructions to keep quiet were, however, wishful thinking on my part, because my sister is a known night owl, and tends to get into things when she stays over. I should have known that a good night’s rest was not in my foreseeable future.

That night I was woken up by her three times. The first two were unintentional disruptions from the sounds of her cleaning random objects in the apartment; it’s important to

Amy to feel useful when she visits, and this usually takes the form of her cleaning things around my home – whether I would like them cleaned or not. The third time she woke me was, however, intentional. Apparently, while reorganizing my shoes in the hall closet, Amy came across a big clear bin, full of old childhood toys. Shortly after she made this discovery, I was gently woken by her whispering in my ear, “Look, look Kristy; look who’s here.” I opened my eyes and was surrounded by Teddy Ruxpin, Rainbow Brite, Glowworms, Barbie Dolls, and a Cabbage Patch Doll hanging above my head, staring me in the face! It was quite creepy, and also hilarious, and also extremely annoying. Somehow, I was able to remain asleep for the rest of the night, despite being nestled inside a weird time warp of toys from the 1980s, and my very loud snoring sister. Despite these interruptions, I felt a deep sense of appreciation for all the simplicities and complexities of who she is, and happiness to have had this time with her.

The next morning, however, I woke up exhausted and with some mild cold-like symptoms and everything about that next day was difficult. My job was particularly stressful that day, and I had class that evening, so I did not get back home until 9:00pm. By the time I did return home I was exhausted, sick, now with flu-like symptoms, the apartment was a disaster, and I was angry. I was angry about getting sick and being so exhausted, I was angry at myself for asking Amy to sleep over when I could have taken advantage of this rare opportunity to have my home to myself, and I was angry about the reasons *why* she had to sleep over *that* night. And I felt guilty for feeling so angry, and then felt angry about feeling guilty. So when I went to the kitchen sink to start tackling the high pile of dirty dishes, most of which were left over from Amy’s 2:00am surprise refrigerator cleaning, I was completely taken surprise by the post-it note taped to the cabinet above the sink.



Amy had left me this note, very simple; it just said, “I love you Kristy, Amy xoxoxox and Mammy,” which is her interpretation of Mommy.

With reading this post-it note, all my anger and frustration dissipated, and was replaced by the deepest sensation of pure, unconditional love. I felt so much joy and I was so thankful, not just for the love I felt from my sister, but for having the ability to provide this experience for her. In her world, sleepovers with me are more than just having fun sister time; they are opportunities for her to experience a simple thing that I take for granted: the ability to function as an independent adult and come home to peers, rather than parents. Opportunities to experience this kind of freedom are hard for her to come by, because of her disabilities, and I was able to give that to her. My feeling this way was the gift that she gave to me.

Appendix A

Support Organizations for Siblings of Individuals with Intellectual and Developmental Disabilities



<http://siblingleadership.org/>

The mission of the SLN is to provide siblings of individuals with disabilities the information, support, and tools to advocate with their brothers and sisters and to promote the issues important to them and their entire families. The SLN promotes a broad network of siblings who share the experience of disability and people concerned with sibling issues by connecting them to social, emotional, governmental, and provisional supports across the lifespan enabling them to be effective advocates with their brother and sister, and to serve as change agents for themselves and their families. There are nineteen state chapters of the SLN (see appendix B).



<http://www.siblingsupport.org/>

The Sibling Support Project (SSP) is a national organization and center for sibling information. Founded in 1990, the Sibling Support Project is the first national program dedicated to the life-long and ever-changing concerns of millions of brothers and sisters of people with special health, developmental, and mental health concerns. The SSP has published books for and about brothers and sisters, hosted online groups for teen and adult siblings, and presented workshops on sibling issues. However, they are best known for helping local communities start Sibshops, a model for recreational peer support groups for young siblings. The Sibshop model was created by Don Meyer, who also formed sibling focused groups such as SibNet, Sib20, SibTeen, SibKids, and SibParents (see below).



Sibshops are peer support groups for school-age brothers and sisters of kids with special needs. For the adults who run them and for the agencies that sponsor them, Sibshops are evidence of their loving concern for the family member who will have the longest-lasting relationship with a person who has a disability. However, for the kids who attend them, Sibshops are pedal-to-the-metal events where they will meet other sibs (usually for the first time), have fun, laugh, talk about the good and not-so-good parts of having a sib with special needs, play some great games, learn something about the services their brothers and sister receive, and have some more fun.

<http://www.siblingsupport.org/sibshops/index.html>

Appendix A



SibNet is the Internet's first and largest groups for adult brothers and sisters of people with special health, developmental, and emotional needs. SibNet is hosted by the Sibling Support Project and the Sibling Leadership Network. Siblings connect through SibNet via Facebook or the Yahoo group.

<http://www.siblingsupport.org/connect/the-sibnet-listserv>



Sib20 is a Facebook group where twenty-something sibs of people with disabilities connect with others who “get it.” It’s sibling support from a young adult perspective. Sib20 is also a community—a remarkably thoughtful, nonjudgmental community of sisters and brothers who share concerns, challenges, insights, and joys that only other sibs are likely to understand.

https://www.siblingsupport.org/connect-with-others-sibs/meeting_other_sibs_online/sib20



Sibteen is a place where teenage sibs of people with disabilities can connect with others who get it. It’s a fun and thoughtful group where members share unique concerns, joys, frustrations, and information with others who truly understand!

<http://www.siblingsupport.org/connect/sibteen-facebook-group-and-yahogroup>



SibKids is a warm and thoughtful listserv for young brothers and sisters of kids with special needs from all over the world. We talk about our sibs, but we also talk about school, music, sports, and life! SibKids is hosted by the Sibling Support Project.

<http://www.siblingsupport.org/connect/index.html>



SibParent: A place where parents of kids with special needs can talk about their “other” kids. On the Internet, there are hundreds of listservs where parents can talk about their kids who have special needs. But there is only one listserv where parents can go to talk about their “other” kids! SibParent, sponsored by the Sibling Support Project, is a new, innovative listserv where parents can discuss the joys and concerns experienced by their typically developing children.

<http://www.siblingsupport.org/connect/sibparent-a-listserv-just-for-parents>

Appendix B

Sibling Leadership Network State Chapters

State		Chapter Name
Alabama		Alabama Adult Siblings Investing in Our Brothers and Sisters Contact: Karen Driver kdriver@dciservice.com
California		California Sibling Leadership Network sibling@casln.org / Julie Neward (Northern California) /Jaqueline Moreno (Southern California) http://www.casln.org/ , www.facebook.com/californiasln
Colorado		Sibling Tree Contact: Sandra Tucker sandra@siblingtree.org http://www.siblingtree.org/
Georgia		Georgia Sibling Connection Contact: Erin.Hutzelman@rockets.utoledo.edu, SLNChair of Network Development
Illinois		Supporting Illinois Brothers and Sisters – S.I.B.S. Contact: Nora Handler handler55@aol.com http://www.sibsnetwork.org/
Maryland		The Maryland Sibling Network Rebecca Furman rfurma1@gmail.com , www.facebook.com/MarylandSiblingNetwork https://www.facebook.com/groups/MarylandSiblingNetwork/
Massachusetts		Massachusetts Sibling Support Network – MSSN http://www.masiblingsupport.org/
Michigan		Michigan's Supporting and Including Brothers and Sisters –MiSIBS Contact: Jennifer McFarlane jennifer.l.mcfarlane@gmail.com http://www.misibs.org/
Minnesota		North Star Siblings Contact: Jeremy E. Warring Jeremy@warringdosdall.com
New Hampshire		SIBS New Hampshire Contact: Erin.Hutzelman@rockets.utoledo.edu, SLNChair of Network Development

Sibling Leadership Network State Chapters

State	Chapter Name
New Jersey	 <p>Supportive Initiatives for Brothers & Sisters in New Jersey -SIBS NJ Contact: Kara Sellix Kara.sibsnj@gmail.com visit http://www.sibsnj.org/</p>
New York	 <p>Sibs NY Contact: Lindsay Hyland lkennedy28@gmail.com http://sibsnny.org/</p>
Ohio	 <p>Ohio Sibs Special Initiatives by Brothers & Sisters Contact: Sarah Hall sahall@ashland.edu or Linda Martens lmartens@ohiosibs.com http://www.ohiosibs.com/</p>
Pennsylvania	 <p>Pennsylvania Sibling Support Network – PSSN www.passn.org.</p>
Tennessee	 <p>Tennessee Adult Brothers and Sisters – TABS Contact: Emma Shouse emma.shouse@tn.gov http://kc.vanderbilt.edu/tabs</p>
Utah	 <p>Utah Adult Brothers and Sisters – UTABS Contact: Alicia Poore mrs.aliciapoore@gmail.com or Joan Venemajoani_55@hotmail.com</p>
Virginia	 <p>Virginia is for Siblings Dana Yarbrough, Center for Family Involvement, (804) 8280352 dvyarbrough@vcu.edu, Becky King, Arc of Virginia, (804) 6498481 rking@thearcofva.org. www.vasibs.org (Coming April 2015!)</p>
Washing D.C.	 <p>DC SIBS http://dcsibs.snappages.com/</p>
Wisconsin	 <p>Wisconsibs (formerly Fox Valley Sibling Support Network – FVSSN) Contact: info@wisconsibs.org www.wisconsibs.org</p>

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