2008

The impact on the self of growing up with a sibling with autism spectrum : an exploratory study

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Recommended Citation

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Growing up with a Sibling on
the Autism Spectrum: An
Exploratory Study

ABSTRACT

This study explores the structure of the self in people who grew up with a sibling with an autism spectrum disorder (ASD). This research utilized a quantitative survey to assess their representations of self. D.W. Winnicott's theory of True and False Self guided this investigation. The study utilized self-report to explore participants' identification with True and False Self characteristics. Questions were phrased in past and present tense as a means of assessing how participants' representations of self have changed over time. At the end of the survey, participants were asked two open-ended questions which generated qualitative data and resulted in a mixed-method study.

The sample (N=33) was gathered from an online group called SibNet, defined as "the internet's first listserv for adult brothers and sisters of people with special health, developmental, and emotional needs." Inclusion criteria for research participants were that they must be 18 years of age or older and have at least one brother or sister with an autism spectrum disorder (ASD).

Findings showed higher scores on False Self measures than True Self measures. The change in responses from "past" to "present" in both the True and False Self measures was statistically significant—suggesting that siblings' representations of self have an evolving quality about them. Furthermore, the change was larger for True Self than False Self. Participants' narratives contained strong associations with False Self

characteristics, as well as themes such as gaining an improved ability to relate to others,

and choosing a career in a helping profession.

THE IMPACT ON THE SELF OF GROWING UP WITH A SIBLING ON THE

AUTISM SPECTRUM: AN EXPLORATORY STUDY

A project based upon an independent investigation,
submitted in partial fulfillment of the requirements
for the degree of Master of Social Work.

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2008

ACKNOWLEDGEMENTS

Thank you to all members of SibNet who were so instrumental in helping me believe in myself. I am forever indebted to you for your willingness to jump in and share your personal thoughts, ideas, and experiences. You were my inspiration in moving forward at all stages of this project. I dedicate this to all the siblings who participated in this research, as well as all of the other siblings out there whom I was not able to hear from.

To Bruce, my thesis advisor…we've made it! Thank you for your dedication and your continued patience in helping me transform my abstract ideas into a viable research project.

To my parents and grandmother, your confidence in me seems to be forever unwavering, even when I have lost hold of it within myself. I have felt you with me on all of my journeys within the thesis process and the Smith experience as a whole. To my beloved siblings, may we continue to grow together and gain strength from overcoming obstacles.

Jamie, Laura, Jenny, and Michelle: I have felt your support even from miles away, and want to thank you for so graciously enduring my constant groaning and reassuring me that this project would, in fact, reach completion.

Thank you Sara, Sabrina, Arden, and Ericka for helping me stay just sane enough in Boston to twiddle away at this, and for always being willing to lend a listening ear and share a cold beverage when I needed it!

Finally, to all my Smith friends, I can't thank you enough. I have special love in my heart for those that have braved dorm living with me for the past three summers. You have seen me at my best and my worst and still stayed by my side (with a funny anecdote, words of encouragement, and a bottle of wine in hand). Kathy and Nicole, I will always remember with fondness your friendship and mentorship in Los Angeles and beyond.

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CHAPTER I

INTRODUCTION

The focus of this research is to examine the structure of the self in people who grew up with a sibling with an autism spectrum disorder (ASD). In this study, people who have a sibling with autism will be referred to simply as *siblings*. Siblings are a population with a history of being overlooked in both scholarly studies and the mass media. Much attention has been paid to the needs and struggles of individuals with autism themselves, as well as on those of their parents. Siblings may be a silent, at-risk population due to their perceived tendencies to be compliant and eager to please (Safer, 2002). Though they may be useful and adaptive, these characteristics can put them at risk, since their emotional needs can go unnoticed, even by themselves.

Autism is a developmental disorder classified under the umbrella term of autism spectrum disorders (ASDs), also sometimes referred to as Pervasive Developmental Disorders. This spectrum includes Autism, Asperger Syndrome, Rett Syndrome, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder – Not Otherwise Specified. Although no two people with autism are exactly alike, common characteristics include "serious impairments with social, emotional, and communication skills. They might repeat certain behaviors over and over again or have trouble changing their daily routine" (http://www.cdc.gov/ncbddd/autism/faq.htm). At times, their

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difficulties relating to others, low levels of eye contact, preference for solitary play, and impaired abilities to express themselves and show affection can complicate the sibling relationship.

With recent rises in autism diagnoses, this issue is especially important. Clinicians, schools, and parents need to be made aware of the specialized needs, not only of autistic individuals themselves, but of their siblings as well. According to the Centers for Disease Control and Prevention (CDC), the prevalence of autism was thought to be 4 or 5 in 10,000 children for decades. New data, however, gathered by the CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network, indicates that the rates are about 1 in 150—an increase of almost 7 percent (http://www.cdc.gov/ncbddd/autism/faq.htm). It is difficult to pinpoint the exact rise in prevalence, but one indicator has been the increased number of children identified by their schools as having autism. Between 1994-2004, the number of children in public special education programs classified as having an autism spectrum disorder rose from 22,664 to 193,637 (http://www.cdc.gov/ncbddd/ autism/faq.htm).

Siblings are masters at maintaining a positive, or at least neutral, stance (Safer, 2002). For this reason, this study will examine D.W. Winnicott's theory of the True and False Self in relation to siblings (Winnicott, 1965). Regarding their role in the family system, many siblings talk about their role as "the good one." They may deny negative feelings towards their autistic sibling and frustration with their parents out of shame and guilt (Rodger & Tooth, 2004; Safer, 2002). As they move through adolescence and into adulthood, they may be unable to explore their identity fully, possibly because of an adoption of False Self characteristics.

Most of the research on siblings has been done either on young siblings (Kaminsky & Dewey, 2001; Marciano & Scheuer, 2005; Ross & Cuskelly, 2006) or on others' perceptions of sibling functioning such as parents and teachers (Kaminsky & Dewey, 2001, 2002; Rodger & Tooth, 2004). The problem inherent in researching young siblings is that they are not developmentally equipped to have a complete understanding of their experience. They are still too dependent upon and entangled within their family system to be able to recognize highly conflictive emotions.

This study examines how siblings' perceptions of themselves change over time. With time, siblings may become more aware of previously unacceptable, negative emotions—and therefore, more in touch with their "True Selves." The method is self-report—half of the questions are phrased in the present tense, while the remaining questions ask participants to reflect on how they felt or behaved in the past—beginning with phrases such as "As a child…" and "Growing up…"

This research utilizes an online quantitative survey to assess adult siblings' representations of self. D.W. Winnicott's theory of True and False Self guides this investigation. The study explores participants' identification of False Self and True Self characteristics, both in the present and as they perceive their characteristics to have been in the past. The questions have been formulated to address seven variables of True and False Self gathered from the literature review. The seven categories are: feeling "real" (True Self), devaluation of the self (False Self), feeling "seen" (True Self), having a sense of self apart from the family role (True Self), "wearing a mask" (False Self), compliance (False Self), and creativity (True Self). The goal is not to label people as having either a True or False Self, but to assess whether participants' self-reports contain more True Self

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or False Self characteristics. The relationship of True and False Self to other variables—age, race, gender, severity of the sibling(s)' ASD, and birth order—was also examined in this study.

CHAPTER II

LITERATURE REVIEW

This literature review is a brief introduction to research done on people who have a sibling with a disability (including narratives written about the experience of being a sibling), Winnicott's theory about the Self, and finally, Winnicott's theory of the Self in relation to siblings of people with a disability. The literature review also highlights some viewpoints offering explanations for the large discrepancies within siblings' reported feelings and experiences.

Siblings of an Individual with a Disability

Research on siblings of people with a disability has been inconclusive (Kaminsky & Dewey, 2002; Rivers & Stoneman, 2003; Ross & Cuskelly, 2006). Findings do not seem to be consistent, but all researchers seem to agree that the population is understudied and in need of further assessment. Siblings are often overlooked, as Riebschleger (1991) states, "siblings of chronically mentally ill people are an especially ignored component of underused family systems…Little attention has focused on siblings of adult chronically mentally ill persons, and siblings, particularly as adults, often become caretakers of the identified client." (p. 94).

Kaminsky and Dewey (2002) did a study surveying parents about their child's psychosocial adjustment in regards to having a sibling with autism. Based on parents'

reports, they found that siblings of children with autism were "not at inflated risk for adjustment difficulties or loneliness" (p. 231). Fisman, Wolf, Ellison, and Freeman (2000) also did a study about sibling adjustment, but found complicated results within their study. They did a 3-year longitudinal study surveying parents and teachers, asking them to evaluate the functioning of siblings of people with a Pervasive Developmental Disorder (PDD), siblings of people with Down Syndrome, and siblings of normally functioning children. The term they use, Pervasive Developmental Disorder (PDD), is the category, or "umbrella term," under which autism and related disorders can be found in the *DSM-IV* (http://www.autism-society.org/site/PageServer?pagename=about_ whatis_PDD). In this particular study, the parent group and the teacher group both identified the greatest difficulties within siblings of individuals with PDD. The parents, however, identified increased difficulty with "externalizing problems," and the teachers identified increased difficulty with "internalizing problems" (though the study does not specify the difference between externalizing and internalizing). The researchers add, "Since teachers' scores are generally a stronger predictor of siblings' later functioning than are parental scores, and in this case persisted over 3 years, internalizing difficulties must be seriously considered in assessing the impact of PDD on siblings" (p. 373).

Other researchers have found definitive difficulties among siblings of people with a disability. Marciano and Scheuer (2005) found that the quality of life for siblings of a person with autism is impaired. Compared to siblings of people with a speech disorder, the quality of life of siblings of autistic individuals was worse. In the conclusion, the researchers state:

It becomes crystal clear the need of attention and help to the siblings of autistic

children. Further studies should focus on the understanding of the factors which

may contribute for the better adaptation of these siblings, for the role of the family

in this context and for the development of preventive interventions for this

population (p. 69).

Ross and Cuskelly (2006) found that siblings of children with an autism spectrum

disorder (ASD) are at an increased risk of developing internalizing behavior problems,

"referring to problems such as depression and anxiety" (p. 79).

Siblings of people with a developmental disability are often an overlooked

population. Jeanne Safer (2002) writes that "Many parents allow the abnormal one to

deplete the oxygen of family life by imagining—and communicating—that the normal

one is low maintenance. Not only do healthy children get less care; they are assumed to

need less" (p. 62). She maintains a stance that "normal siblings" are neglected due to the

inordinate amount of attention required for the child with a disability. She believes the

lives of these "'normal ones'…[are] far more complex than the sentimental image

presented by the media and even by their own families" (p. xvi). Safer emphasizes the

complexity of growing up with a brother or sister who has a disability. She identifies the

sibling experience as the "Caliban Syndrome," consisting of premature maturity, survivor

guilt, compulsion to achieve, and fear of contagion (pp. xvi-xvii). She also talks about

the process of identity formation in people who have a brother or sister with a disability:

Splitting character traits between siblings is common in damaged families, and it

is only a superficial advantage for the one who is assigned the positive

characteristics. A person who defines herself in opposition to another can never develop an independent identity and is always warding off the dark side the other represents (p. 51).

Jeanne Safer has a brother with a mental illness, and interweaves her own narrative in her writing about siblings. She writes in great detail about her perception of her role in the family. She discusses her perfectionism and desire to please her parents:

With a child's logic, I figured out he was ostracized because he was bad. This made the consequences of being anything like him dangerously real. What if I lost my temper once too often, got a less than stellar grade, gained too much weight—failed at anything?...What saved me is that I knew how to make my parents happy (pp. 12-13).

Clea Simon, author of *Mad House: Growing up in the Shadow of Mentally Ill Siblings* (1998) shares a similar perspective: "Many of us [siblings] have shared the frantic desire to overcompensate, to somehow make up to our parents for the ill child's feelings" (p. 9). Safer, Simon, and many others make it clear how affected they have been by having a brother or sister who has a disability. Another theme that comes out of the literature is the evolving nature of siblings' perspective over time—of themselves, their brother or sister with a disability, and their family as a whole.

Additionally, it is important to include the strengths siblings report gaining from having a brother or sister with a disability. Rodger & Tooth (2004) suggest there is a movement away from portraying overly negative effects of having a sibling with a disability and towards an acknowledgement of positive influences. The authors state, "It

is recognized that families with a child with a disability offer siblings unusual opportunities for growth and maturation and development of qualities, such as sensitivity, nonjudgmental attitudes, and awareness of individual differences" (p. 54). They highlight coping skills such as humor, identification of personal growth experiences, achieving fulfillment, and having pride in the child with a disability. Safer (2002) adds that siblings' "self-knowledge is often deeper, their sensitivity to suffering heightened, and their appreciation of the human condition more profound than people who have had easier lives" (p. 187). "Contact a Family," a website geared towards families with disabled children, offers an optimistic view of the overall experience of siblings: "Most siblings cope very well with their childhood experiences and sometimes feel strengthened by them" (http://www.cafamily.org.uk/siblings).

Though the strength and resilience of the sibling population abound, Safer's premise that siblings glamorize their lives with disabled siblings in order to defend against dark emotions offers another view. She compares this defensive stance to an "invisible fence," like the ones which shock dogs when they reach the edge of a yard until eventually the dogs learn where the borders are intuitively. "In the psyches of healthy siblings, the all-too-human anxiety and hostility disappear like the natural canine impulse to chase cars" (2002, p. 64). This suggests that repression of negative emotions may be a common theme in many families who have a child with a disability. Just like siblings, parents also have difficulty expressing these emotions: One sibling shares, "My parents never admitted that they were depressed or angry, so my anger was strangled too" (p. 63).

Safer (2002) discusses parents' unconscious role in teaching the sibling without a disability to repress dangerous emotions. Parents can project their own defended emotions pertaining to their child who has a disability onto their other children: "What parents cannot allow themselves to feel, they cannot allow their normal children to feel either. Any uncensored emotional outburst would hold up a mirror to what they struggle to excise in themselves" (p. 58). It may be possible that parents have unconscious motives to ward off emotions like anger and resentment towards their child. This use of defenses would allow them to maintain empathy and love towards a child who elicits such immense challenges. Safer suggests that parents might "implicitly pressure them [siblings] never to express—or even to recognize—rage, terror, or resentment" (p. 63). The experience of these emotions would just be too threatening.

Often, siblings feel shame about having these emotions at all—let alone expressing them. Safer (2002) asks, "How can hurt feelings or a skinned knee ever take precedence over the trials of a sibling who is paraplegic or paranoid? Normal children—even preferred ones—never come first in a crisis and must stifle the impulse to object" (p. 61). The concerns of typically developing children and adolescents pale in comparison to their siblings' catastrophes (p. 94).

Winnicott's Theory of the Self

D.W. Winnicott (1965) defines the False Self as being "built up on a basis of compliance" (p. 133). The development of a False Self occurs when a person is so focused on other people's needs that he or she loses track of his or her own. For whatever reason, the person feels the need to mold aspects of his or her personality to

accommodate others. Upon discussing Winnicott's theory, Anderson & Winer (2003) state that a False Self develops when "people respond primarily to their caretakers rather than being responded to: a False Self adaptation is one of compliance" (p. 80). Berzoff et al. (1996) provide a similar definition:

> The True Self cannot emerge if the child feels she must be exclusively attuned to the needs of others in the family system and if she needs to be a certain way in order to be recognized and connected. The highly individualized True Self will not emerge when the environment fails to be genuinely attuned to the child's uniqueness (Berzoff, et al., 1996, p.140).

Winnicott proposes that a person must have the capacity to express the core of her/his personality. In their research on adolescents, Harter et al. (1996) use the term "False self behavior," which they define as "the extent to which one is acting in ways that do not reflect one's true self as a person or the 'real me'" (p. 360).

D.W. Winnicott originally developed the theory of True and False Self, and many theorists and scholars have revisited it and expanded on it through the years. Though Winnicott's theory can often seem dichotomous, contemporary theorists tend to think of the concept as a continuum of behaviors. Winnicott himself touches upon the idea of True and False Self states as existing along a range:

> If the description of these two extremes and their aetiology is accepted it is not difficult for us to allow in our clinical work for the existence of a low or a high degree of the False Self defence, ranging from the healthy polite aspect of the self

to the truly split-off compliant False Self which is mistaken for the whole child"

(1965, p. 150).

Furthermore, Winnicott (1965) explains, "Naturally in individual life there are all degrees of this state of affairs so that commonly the true self is protected but has some life and the false self is the social attitude" (p. 133). True and False Selves, therefore, can be looked at as a spectrum—a range of behaviors and characteristics, with a True Self being on one end of the spectrum and a False Self being on the other.

Compliance is at the heart of the distinction between True and False Self. Winnicott (1965) explains, "The true self must never be affected by external reality, must never comply" (p. 133). The False Self, on the other hand, is overly compliant—to the point where the individual loses touch with his or her sense of self. In connection with the tendency to be compliant, people who are exhibiting a False Self also appear to wear "social masks." In her paper, "Hunt the Slipper," Richards (1996) states that "Winnicott traces the False Self to its final position. Here, it is little more or less than an essential social mask" (p. 25). Other writers have echoed this notion: "False self behaviors are considered to be motivated by attempts to present the self in a manner that will impress or win the acceptance of others" (Harter et al., 1996, p. 361). At some point, the intersection of a conscious choice to wear a mask/act in compliance and a loss of one's sense of self becomes unclear.

These social masks and tendencies towards compliance stem from an individual's devaluation of him or herself. When a person feels like he or she is not good enough, this is also a False Self characteristic. To put it another way, "to the extent that one's true self

is devalued, one would be expected to go to greater lengths to avoid expressions of this core self" (Harter et al., 1996, p. 362). In a more contemporary perspective on the True and False Self, Wilkin (2006) states, "While the construction of a False Self enables the person to survive life and even, on the surface, appear to be functioning well, there is always a sense of 'not good enough'…that causes the person to present for therapy" (p. 14). Some have also tied in a lack of self-awareness with the adoption of False Self characteristics. Harter et al. (1996) discuss less False Self behaviors in those that have "knowledge of their true selves, namely, the extent to which they report knowing who they really are" (p. 363).

The opposites of these traits of compliance and devaluation of the self would be a move towards the True Self. Standing up for one's self and believing that one's core self is good, for example, would be True Self characteristics. A person also must develop a sense of self apart from his or her interpersonal roles. When people comply only to what others what them to be, they end up defining themselves solely by the roles they play around others. Harter et al. (1996) identify False Self behavior as consisting of "different role-related selves," such as self with parents, self with siblings, self with friends, self with a romantic partner, etc. (p. 360). They say that "each of these selves typically contains attributes that appear to contradict the attributes of other selves" (p. 360). Winnicott (1965) also writes about the implications of conforming to certain prescribed roles: "There are those who can be completely themselves and who also can act, whereas there are those who can only act, and who are completely at a loss when not in a role" (p. 150).

"Only the true self can feel real…when the false self becomes exploited and treated as real there is a growing sense in the individual of futility and despair" (Winnicott, 1965, p. 133). Feeling real is an essential component to experiencing a True Self. "Those who live according to the False Self feel hollow and unreal, as if they were just going through the motions" (Anderson & Winer, 2003, p. 80). This feeling of being unreal can have dangerous consequences. Harter et al. (1996) explain that "false self phenomena are linked to alienation from any sense of a real or validated core self" (p. 361). Winnicott cautions that those who have adopted a False Self persona are "completely at a loss…when not being appreciated or applauded (acknowledged as existing)" (Winnicott, 1965, p. 150). They need constant validation from others to feel alive. "Just as those struggling for breath are aware of breathing, and only those who feel 'unreal' long to feel 'real,' so it is those who feel themselves, or are seen to have, a False Self who dream of an imagined True Self" (Richards, 1996, p. 24).

In his "Mirror-Role" paper in 1967, Winnicott makes the central statement, "I am seen, so I exist" (Cameron, 1996, p. 41). People need validation from others in order to become in touch with their True Selves. When "the Self has experienced a *resonance* of itself in the Other, or has felt *recognized* in some important way by the Other," the development of the sense of Self is nourished and enhanced (Wright, 1996, pp. 72-73). In order for a True Self to emerge, those characteristics that are unique to the individual must be recognized, or attuned to, by primary caregivers. Wright (1996) explains, "attuned responses fit the (True) Self and are confirmatory of it... 'Someone out there is responding to me—therefore I am'" (p. 79). People that exhibit True Self characteristics enjoy spontaneity, creativity, and feel inspired in their lives. They feel their life has

deeper meaning. Anderson & Winer (2003) state that "People who act out of the True

Self feel alive, invigorated, and inspired" (p. 80).

Winnicott's Theory of the Self in Relation to Siblings of People with a Disability

Often times, individuals who have a disability require a lot of care and attention

from their caregiver(s). Siblings are often encouraged—directly or indirectly—to be

more independent. They may experience what Winnicott calls psychological

misattunement. On the other hand, siblings are also typically very involved with their

families. Safer (2002) calls them 'family vice-presidents' with responsibilities but no

authority" (p. 60). They are exposed to a variety of distressing, and sometimes even

physically threatening situations. According to Winnicott's belief about the formation of

the self (1965), siblings of people with a developmental disability are in a double bind;

they are expected to be autonomous, yet connected.

In the midst of a family struggling with everyday tasks, the children who do not

suffer from a disability face unique struggles. Through their efforts to accommodate their

families, they often become detached and dissociated from their own wants and needs.

"Many healthy siblings grow up with a hunger for attention that is never satisfied and that

seems wrong to feel. Their needs, so consistently ignored, become invisible to

themselves" (Safer, 2002, p. 94). It is often too difficult for siblings to hold onto feelings

of anger or other negative emotions they feel towards their brother or sister with a

disability because of their own shame and guilt. Their repression and denial of feelings

can show up in other forms such as depression and anxiety. In addition, the transition for

siblings when they leave the family environment can be overwhelming and leave them

feeling like they have lost their identity. This is related to their development of a "False Self" during childhood (Safer, 2002).

Their main source of identity becomes that of "sibling" and they have difficulty being seen as a unique person. Speaking about her life with her brother tying into her identity, one sibling said, "Once a sibling, always a sibling" (Safer, 2002, p. 70). Other siblings adopt their brother or sister's disability directly into their own senses of self: "I share the disability of our family…Our family *was* a disability" (p. 99). The literature shows that siblings often fantasize about their sibling's death or institutionalization (Safer, 2002). "To finally have your home, your parents, or your life to yourself when a sibling is institutionalized or dies is another dreadful victory" (p. 121). These fantasies allude to siblings' often hidden and unconscious desires to find an identity separate from being a sibling to someone with a disability.

As an attempt to make up for the demands of their brother or sister with a disability, siblings often overachieve and strive for perfection. One sibling shares, "I had to be perfect…They [her parents] put all their hopes on me. It didn't matter who I was; I had to be more. I carried the weight of having to be normal and functioning and achieving—I never had the right to be immature in any way, to act out or stomp my foot" (Safer, 2002, pp. 99-100). This woman's story exemplifies what Winnicott would call the development of a "False Self." Jeanne Safer (2002) defines this concept as "preeminence," with similar implications: "Preeminence, which requires children to mold their personalities to their parents' specifications, is perverse because it distorts the self" (p. 100).

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Often times, siblings of individuals with a disability are exalted as heroes in the family. They become overly compliant and adopt a "False Self" to be given the attention they so desperately crave. Part of their motivation is also to differentiate themselves from their brother or sister with the disability. Safer (2002) talks a lot about siblings' "fear of contagion" and compulsion to prove (mostly to themselves) how different they are. They can end up seeming quite successful, but there is sometimes a guarded and/or hollow quality to their happiness. "It is human nature to want to be the star, but nobody who is related to a friendless outcast [a sibling with a disability] enjoys her popularity unambivalently" (p. 111).

Every person, at some point or another, behaves in ways that can feel inauthentic to his or her True Self. Even if people with an autistic sibling possess characteristics of a False Self, they should not be assumed to have a False Self in a broader sense. In her chapter in the book *The Person Who is Me: Contemporary Perspectives on the True and False Self* (1996), Val Richards goes so far as to say that labeling people with a False Self can be "potentially damaging" (p. 31). She states, "The False Self, especially when functioning as a more or less healthy social mask, is not so much a consistent attribute as, like other psychic states, more a fluid to-ing and fro-ing" (p. 28).

Repercussions

If, in fact, people who grow up with a sibling with autism are at risk for adopting False Self characteristics, they are actually at risk for extremely harmful outcomes. Wilkin (2006) explains that "self-harming defences and suicidal gestures are not uncommon and often serve to prove the person's existence in a non-compliant (but

pathological) representation of the True Self" (p. 14). She takes it even further by asserting that the person can suffer from "intractable depression and disabling anxieties: all driven by the frustrations and hopelessness of a life without genuine purpose" (p. 14). Winnicott himself cautions that "at the extreme of abnormality the false self can easily get itself mistaken for real, so that the real self is under threat of annihilation; suicide can then be a reassertion of the true self" (1965, p. 133).

Although siblings' adjustment appears challenging, there appears to be definite hope. Safer (2002) proposes that "Normal siblings have two life tasks: to recognize the enormous impact a damaged sibling has on them, and to forge an identity in which that sibling is peripheral. The first makes the second possible" (p. 67). Siblings often move away from the family as a concrete step in individuating. "Geographic solutions…are common; having the sibling out of sight puts him at least temporarily out of mind, and the person can feel freer to find herself without having to witness his resentment" (p. 117). Safer (2002) holds that geographic relocation, however, is not a guaranteed solution: "Of course, since the sibling's image is still carried within, real and lasting separation occurs only when the control that the image exerts diminishes" (p. 117). So, it seems important that an emotional separation take place.

Even when a person gains his or her own sense of self, it seems possible that False Self characteristics and behaviors can resurface given the right triggers. False Self representations in siblings, therefore, can be pervasive and rigid or can be intermittent (and in their own way adaptive). It is the pervasive and rigid False Self representations that may lead to negative outcomes such as self injurious behaviors and other negative outcomes.

Summary

Although the current literature on siblings demonstrates vast discrepancies about their experiences, it is obvious that siblings are an understudied population. In a sense, one could argue that siblings are ignored by researchers in the same way they are overlooked by their families. When they do receive attention (in the literature or otherwise), it might only be directed towards their "False Selves"—the pathological outer shells of perfection they have created around them. Some research focuses solely on the resiliency of this population and the positive traits they gain from being a sibling. Most of the research is either extremely optimistic or overly pathological. The question remains, with such limited amounts of research, what *really* are typical representations of self in siblings of people with a disability such as an autism spectrum disorder?

CHAPTER III

METHODOLOGY

The only general consensus about research on siblings of individuals with a disability is that it has been limited and inconsistent. Most of the personal narratives of siblings and studies which survey siblings themselves show that siblings do in fact struggle with having a sibling who has a disability. Some literature identifies a risk of depression in siblings, problematic coping mechanisms, anxiety, and internalizing anger associated with their autistic sibling(s). There is very little research on the self and identity development, and no research was found on D.W. Winnicott's True and False Self as it relates to this issue. Despite most of the narratives written by people who have a sibling with a disability—almost all of these involving discussion of their need to "wear masks" and to reassess the sibling experience over time—research on these types of issues is difficult to find.

The purpose of this study was to find out more about the experiences of adults who have grown up with a sibling with autism. Do they indicate characteristics of a False Self (high levels of compliance, devaluation of the self, etc.) within their present and/or past representations of themselves? This question was examined using a quantitative, descriptive study with an online survey instrument. A quantitative research design was chosen to make it possible to analyze the impact of several variables and to make the obtained data as generalizable as possible. It allowed for a much larger sample

and, therefore, enriched the findings. In addition, the instrument includes two qualitative questions which allow participants to supplement the narrowed focus of the quantitative portion.

Sample

The sample was gathered from an online support group called SibNet. SibNet was started by a man named Don Meyer, the director of the Sibling Support Project. It is defined on the website (http://www.siblingsupport.org/connect/the-sibnet-listserv) as: "the internet's first listserv for adult brothers and sisters of people with special health, developmental, and emotional needs." Inclusion criteria for research participants were that they must be 18 years of age or older and have at least one brother or sister with an autism spectrum disorder (ASD). Originally, this sample group was intended to be compared to a sample of siblings who are also clinical social workers. The intention behind this was to study a population that 1) may have higher levels of self-awareness (due to their being encouraged to explore their representations of themselves both in the educational context and through participating in therapy) and 2) may have different characteristics than those who have sought out a support group for the issue. Unfortunately, the plan to survey a sub-sample of clinical social workers was not feasible.

This study uses a nonprobability sample because survey respondents were expected to participate on a voluntary basis. The sample was also purposive, as the study was advertised to users of SibNet. An obvious bias of this sample was that these siblings felt their experiences of having a brother or sister with special needs were significant

enough for them to seek out this very specific form of support. All of the topics discussed on SibNet involve sibling-related issues, and much of it pertains to emotional support.

Ethics and Safeguards

Ethics within this study was monitored by the Smith College School for Social Work's Human Subjects Review Committee. Participants were given an Informed Consent Form, which described the parameters of the study. Participation in the study was completely voluntary. Participants were asked to take an anonymous internet survey over www.surveymonkey.com. Participants were guaranteed anonymity because they were not asked for any identifiable information and because the survey includes encryption techniques to keep their answers private. They were given a chance to insert additional information in two open-ended questions if they chose, but otherwise none of the information obtained will be personally identifiable. In addition, the data collected was numerically coded to protect any personally identifiable information and the data will be stored in a locked file for a minimum of three years.

Data Collection

A link was posted on SibNet's forum inviting people to participate in the study. Individuals either clicked on the link which led them directly to the online survey or indicated their desire to participate via e-mail. Those who met the selection criteria were sent the Survey Monkey link which they could use to take the electronic survey. Everyone who completed the survey met the selection criteria. The Informed Consent

Form was presented on Survey Monkey to all participants before they began the survey (see Appendix A).

Data was collected using an online quantitative survey (Appendix B) which was designed to assess adult siblings' representations of the self. The questions explore participants' identification of both True and False Self characteristics—both now and in the past. The True and False Self characteristics were measured using a Likert scale. Participants were asked to rate themselves both on how they feel and behave presently as well as how they remember feeling and behaving in the past. Some questions were asked in present tense and others were preceded by phrases such as "As a child…" and "Growing up…" The instrument relies on self-report to obtain data on whether participants perceive that their representations of self have changed over time.

A defined list of characteristics of True and False selves does not exist. For the purpose of this study, seven characteristics have been developed from the literature review. False Self characteristics include being overly compliant, wearing social masks, and devaluing the self. True Self characteristics will be defined as having a sense of self apart from the family role, feeling "real," feeling seen and recognized, and feeling creative/inspired. The degree to which these True and False Self characteristics were present was calculated by scoring the instrument.

As stated above, participants also had an opportunity to elaborate on how they feel they have been impacted by having an autistic sibling using the two open-ended questions. Before beginning the Likert scale questions, participants were asked for demographic data. The demographic data included age, race/ethnicity, gender, severity of sibling(s)' ASD, and birth order.

The questions measuring True and False Self constructs were adapted from instruments included in Goldberg's (2007) *International Personality Item Pool* (http://ipip.ori.org/). The International Personality Item Pool (IPIP) is an internet database of various standardized measures available for public use. It is defined on the website as "a scientific collaboratory for the development of advanced measures of personality and other individual differences" (Goldberg, 2007). The IPIP includes questions from many different personality inventories compiled on one page and separated into 204 different categories (Goldberg, 2007). The categories range from everything to "Achievement Striving" to "Zest/Vitality/Enthusiasm" (http://ipip.ori.org/newIndexofScaleLabels.htm).

Existing questions within the IPIP were used as much as possible to increase validity. Some of the questions were used but modified to be more relevant to the topic and the population being surveyed in this study. In addition, the IPIP provides instructions on how to score questions (http://ipip.ori.org/newScoringInstructions.htm). Scores from each of the characteristics of True and False Self (creativity, sense of self apart from role, etc.) will be tallied using the IPIP instructions. For the purpose of this study, a participant who scores positively for compliance, for example, will be presumed to have a positive correlation with that False Self characteristic. Based on the data, the study assessed the degree of self-reported True/False Self characteristics in the present and the past. A copy of the survey and information about how the questions were scored can be found in Appendix B.

The study's validity and reliability have been enhanced by the anonymity of the online survey. The questions may feel very personal for the participants and the

anonymity of being in front of a computer rather than in front of an interviewer hopefully allowed them to be more honest. It is difficult to assess face and content validity, as some of the questions have been altered from their original form in the IPIP scales, and additional questions have been added. The questions, however, do come from an extensive literature review and have undergone critiques from numerous Smith College faculty and numerous revisions. They stand as a preliminary attempt at uncovering siblings' experiences and assessing whether or not they have experienced characteristics of a False Self in relation to their family system and in current functioning.

Data Analysis

Data was coded and converted to SPSS, allowing for the analysis of frequencies and descriptive statistics. The data is primarily nominal and ordinal, so nonparametric tests were utilized. The degree of self-report of True and False Self characteristics among people who have a sibling with an autism spectrum disorder is the focus of the study.

Discussion

Based on the literature, it was expected that siblings describe their experiences to be more positive than negative. It was anticipated that they may feel guilty answering more pejorative sounding questions and feel protective of their families. Even though the quantitative instrument assessed False Self characteristics directly, some of the questions were phrased in a positive way and then reverse scored so that not all of the questions would sound so pejorative. Additionally, the numerical responses to the quantitative

questions may have felt more anonymous than the open-ended qualitative responses, which may have felt more personally identifiable. It was expected, therefore, that the quantitative measure would allow people to feel less guarded and lend itself to a more accurate assessment of False Self characteristics than the open-ended questions would.

Regarding change over time, it was expected that scores for True Self characteristics would increase with time and that scores for False Self characteristics would decrease with time. A large degree of variance between younger people (younger than 26) and people older than 40 was also expected. Therefore, age as well as other demographic variables were examined for associations.

One of the limitations of the study was that it utilized participants from an online support group for siblings of people with a disability. It is likely that they sought the group out for a reason. It is difficult to say whether these people's experiences are necessarily more difficult than others who aren't part of the group, or if they simply have more ability to talk about the difficulties openly. Also, there is a bias in the resources needed to participate in the study, since respondents must have access to a computer, know how to operate it, be able to read, and have a certain level of skills in order to both be a part of the online support group and to take the survey.

A major source of research bias was that the researcher herself has two siblings with autism. Part of the reason for doing the study was the researcher's own curiosity about other people's perceptions about their similar experiences. The other motivation for the study was to draw clinical attention to siblings of autistic individuals—something that this researcher has found personally insufficient. On the other hand, this researcher's

personal experience provides inside knowledge of some of the issues, which has been

helpful in conceptualizing the study and generating the survey questions.

CHAPTER IV

FINDINGS

The major questions that were addressed in this research project were: Do siblings

indicate higher levels of False Self characteristics than True Self characteristics? Do

participants respond differently when asked to rank past versus present characteristics? Is

there a relationship between True and False Self representations and any of the

demographic data—age, race/ethnicity, gender, severity of sibling(s)' ASD symptoms,

and birth order? The focus of this study was intended to be on the quantitative findings

generated from the True and False Self Likert scale questions in the survey. It was

expected that participants' representations of self would be more clearly explored by the

quantitative instrument than in the open-ended questions at the end of the survey.

Although there were only two open-ended questions in the survey, participants wrote

more than what was expected. Their answers to these questions were arguably more

revealing about their representations of self. The narrative, qualitative data gained from

the open-ended questions was so rich that it warranted its own section in both Chapters

IV and V.

The number of participants is technically 34, but one respondent exited the survey

without answering any of the questions, so for the purpose of this study, n=33.

Participants' ages range from 18-64. There are 3 people who did not provide their age,

but of the remaining 31 participants, the mean age is 33.87, the median age is 30, and the

mode is 24-years-old.

TABLE 1 — Age of Participants:

Mean	33.87
Median	30.00
Standard Deviation	13.099
Variance	171.583
Minimum	18
Maximum	64

The majority of participants are white and female. 88.2% of participants identify

solely as white. Two participants identify as Asian and one participant identifies as

White/Latina. In terms of gender, out of the 33 people who responded, 30 are female

(90.9%) and 3 are male (9.1%).

Participants were also asked to provide their birth order position in their family of

origin in relationship to their sibling(s) on the autism spectrum. The majority of

participants who responded are younger than their sibling(s) with autism (48.5%). The

next most common group is siblings who are older (39.4%). Four participants are in

between two siblings with an autism spectrum disorder (12.1%).

TABLE 2 — Birth Order of Participants:

	Frequency	Valid Percent	Cumulative Percent
Oldest	13	39.4	39.4
In the Middle	4	12.1	51.5
Younger	16	48.5	100
Total	33	100	

Siblings were asked to rate the severity of symptoms in their autistic sibling(s).

Most of the participants describe their sibling(s)' autism as "severe" (27.3%). Closely

following, however, are those who describe their sibling(s)' autism as "moderate" (24.2%), "mild" (21.2%), or "very severe" (18.2%). The remaining three respondents identify their sibling(s)' autism as "very mild" (9.1%).

TABLE 3 — Severity of ASD Symptoms in Participants' Siblings:

	Frequency	Valid Percent	Cumulative Percent
Very Severe	6	18.2	18.2
Severe	9	27.3	45.5
Moderate	8	24.2	69.7
Mild	7	21.2	90.9
Very Mild	3	9.1	100
Total	33	100	

Quantitative Data

Questions were combined into four measures: False Self Past, False Self Present, True Self Past, and True Self Present. The scores for each measure were calculated by taking a mean of the relevant questions, with responses being reverse scored as required by the instrument. The resulting scores maintain the 1 to 5 range of the original questions, with a higher score indicating a stronger association. High scores on False Self measures have different implications than high scores on True Self measures.

Cronbachs alphas were run for all four measures to test internal reliability, looking at how well this particular group of questions "fit together" as a measure. The internal reliability is considered adequate or better when it has an alpha above 0.60. Based on the Cronbachs alphas (below), the questions in the True Self measures seemed to fit together better than the ones in the False Self measures.

TABLE 4 — Cronbachs Alphas for Measures:

	Alpha	N	N of Items
False Self Past	0.707	34	6
False Self Present	0.669	34	6
True Self Past	0.798	34	8
True Self Present	0.665	34	8

Comparison of Siblings' Total Scores on True and False Self Representations

Overall, participants rated themselves above neutral on measures of False Self. Out of the maximum score of 1980 on the False Self measure, the sum of participants' scores was 1312 or 66.3% of the highest score possible. As a whole, if participants had answered neutrally (marking "Neither Inaccurate nor Accurate" every time), they would have scored 60.0% (due to the use of a 5-point scale). This means that participants' identification with False Self characteristics was 6.3 percentage points into the "moderately accurate" range. Overall, results show that participants also rated themselves into the "moderately accurate" range on measures of True Self. Out of the maximum score of 2640, the sum of participants' scores was 1658, or 62.8%. Though they did test positively, they scored only 2.8 percentage points into the "moderately accurate" range for having True Self characteristics. When compared to scores for False Self characteristics, participants scored 3.5% lower on True Self characteristics. In general, therefore, participants scored positively for both True and False Self characteristics, but their scores were higher for False Self characteristics.

TABLE 5 — Total True and False Self Scores:

	SCORE	MAX	%
False Self Total	1312	1980	66.3
True Self Total	1658	2640	62.8

Out of a 5-point scale, the mean score for False Self characteristics was roughly 3.3. The mean score for True Self characteristics was approximately 3.2. The median for False Self was 4, whereas the median for True Self was 3. There is also a modal difference between the two categories—the mode for False Self characteristics being 5 and a mode for True Self characteristics of 4.

TABLE 6 — True and False Self Statistics:

	MEAN	MEDIAN	MODE	ST DEV
False Self	3.338422	4	5	1.370228
True Self	3.152091	3	4	1.313543

Change in True and False Self Characteristics Over Time

In order to determine if there was a change in "False Self" from "past" to "present," a paired t-test was run. There was a significant difference in the "False self" measures: $t(32)=-2.371$, $p=.029$, 2-tailed. The mean in the past was higher (3.4898) than in the present (3.1878). In order to determine if there was a change in "True Self" from "past" to "present" a paired t-test was run. There was a significant difference in the "True self" measures: $t(32)=3.707$, $p=.001$, 2-tailed. Respondents had a higher mean score in the present (m=3.3612) than in the past (m=2.9430).

In addition to the t-tests, other differences in reported past representations of self and present representations of self were found:

<div align="center">TABLE 7 — Comparison of False Self Data from Past to Present:</div>

	SUM	%	MEAN	MEDIAN	MODE	ST DEV
False Self Past	684	69.1	3.489796	4	5	1.394089
False Self Present	628	63.4	3.187817	3	4	1.33258
False Self Total	1312	66.3	3.338422	4	5	1.370228
Change	**-56**	**-5.7%**				

<div align="center">TABLE 8 — Comparison of True Self Data from Past to Present:</div>

	SUM	%	MEAN	MEDIAN	MODE	ST DEV
True Self Past	774	58.6	2.942966	3	2	1.350918
True Self Present	884	67	3.361217	4	4	1.242818
True Self Total	1658	62.8	3.152091	3	4	1.313543
Change	**+110**	**+8.4%**				

In general, participants tended to report *fewer* False self characteristics presently than they reported possessing in the past. Furthermore, participants reported having *more* True Self characteristics presently than they reported having in the past. The increase in True Self characteristics (8.4%) was more dramatic than the decrease in False Self characteristics (5.7%).

The lowest aggregate score showed up on the questions addressing participants' report of True Self characteristics in the *past* (X = 2.9 with a score of 58.6%). This measure was the only one in which the mean was below 3, making the total score below 60%. Additionally, the measure of participants' True Self *past* characteristics was the category with the lowest mode, which was 2.

Likewise, participants' highest aggregate score was on False Self characteristics in the *past*. This data corresponds with the above data that participants scored low on True Self characteristics in the past. The mean for past False Self characteristics was 3.5 and the score was 69.1%. The mode in this category was 5, and the median was 4.

Individual False Self Characteristics

TABLE 9 — Compliance:

	SUM	MAX	%	MEAN	MEDIAN	MODE	ST DEV
Compliance Past	246	330	74.5	3.72727	4	5	1.30732
Compliance Present	249	330	75.5	3.83077	4	5	1.112
Compliance Total	495	660	75	3.77863	4	5	1.21079
Compliance Change	**+3**		**+0.9%**				

TABLE 10 — Devaluation of the Self:

	SUM	MAX	%	MEAN	MEDIAN	MODE	ST DEV
Devaluation Past	205	330	62.1	3.15385	3	4	1.42775
Devaluation Present	152	330	46.1	2.30303	2	2	1.26454
Devaluation Total	357	660	54.1	2.72519	2	2	1.40906
Devaluation Change	**-53**		**-16.1%**				

TABLE 11 — Wearing a Mask:

	SUM	MAX	%	MEAN	MEDIAN	MODE	ST DEV
Mask Past	233	330	70.6	3.58462	4	5	1.40192
Mask Present	227	330	68.8	3.43939	4	4	1.12494
Mask Total	460	660	69.7	3.51145	4	4	1.26714
Mask Change	**-6**		**-1.8%**				

Compliance was the only one of the False Self categories to increase from past to present, according to participants' reports. This trend would indicate that, in this study, siblings actually became slightly more compliant with time. The change from past to present was minimal—only a 0.9% increase. The change from past to present was also minimal in the questions designed to measure the degree to which siblings "wear a mask" (a 1.8% decrease from past to present). On the other hand, the change in scores from past to present was more noteworthy in the questions regarding participants' devaluation of

the self. Participants scored somewhat high on devaluation of the self in the past

(62.1%), but scored lower on present devaluation of the self (46.1%). Siblings' report of

devaluation of the self dropped 16.1% from past to present, the mean changing from 3.2

to 2.3, and the mode from 4 to 2. Compliance had the highest scores in all sections—

past, present, and total scores. It was closely followed by siblings' scores on "wearing a

mask."

Individual True Self Characteristics

TABLE 12 — Sense of Self Apart from Role as a Sibling:

	SUM	MAX	%	MEAN	MEDIAN	MODE	ST DEV
Sense of Self Past	211	330	63.9	3.24615	3	2	1.41455
Sense of Self Present	207	330	62.7	3.13636	3	2	1.34606
Sense of Self Total	418	660	63.3	3.19084	3	2	1.37625
Sense of Self Change	**-4**		**-1.2%**				

TABLE 13 — Creativity:

	SUM	MAX	%	MEAN	MEDIAN	MODE	ST DEV
Creativity Past	198	330	60	3	3	2	1.15025
Creativity Present	232	330	70.3	3.56923	4	4	1.23705
Creativity Total	430	660	65.2	3.28244	3	4	1.22333
Creativity Change	**+34**		**+10.3%**				

TABLE 14 — Feeling Seen:

	SUM	MAX	%	MEAN	MEDIAN	MODE	ST DEV
Feeling Seen Past	171	330	51.8	2.59091	2	1	1.33563
Feeling Seen Present	210	330	63.6	3.18182	3	2	1.2638
Feeling Seen Total	381	660	57.7	2.88636	3	2	1.32876
Feeling Seen Change	**+39**		**+11.8%**				

<div align="center">TABLE 15 — Feeling Real:</div>

	SUM	MAX	%	MEAN	MEDIAN	MODE	ST DEV
Feeling Real Past	194	330	58.8	2.93939	2	2	1.43451
Feeling Real Present	235	330	71.2	3.56061	4	4	1.06884
Feeling Real Total	429	660	65	3.25	4	4	1.29812
Feeling Real Change	**+41**		**+12.4%**				

Two of the measures developed to represent a True Self—"Feeling Seen" and "Feeling Real"—contained scores below the 60% marker, or below a mean of 3. The combined scores of past and present were still below 60% in one of the categories, which was feeling seen (score was 57.7% and X = 2.9). Past reports of feeling seen and feeling real were the two categories that were the lowest (feeling seen was 51.8% with X = 2.6 and feeling real was 58.8% with X = 2.9). The most common response for questions intended to determine whether participants felt seen when they were children was 1 ("Very inaccurate"). Furthermore, the scores for creativity were exactly 60% (neutral), and the mean for creativity was exactly 3. The scores for having a sense of self in the past was 63.9%—only 3.9 percent above neutral—with a mean of 3.2. Three out of the four categories developed to represent a True Self went up from participants' reports of past to present, all within 10-13%. The only category to go down, however, was the characteristic of a sense of self apart from the role of sibling.

Relationship of Scores to Demographic Variables

No significant differences were found for any of the demographic data. For birth order, a Oneway Anova was run to determine if there was a difference in participants' mean scores on any of the 4 measures. No significant differences were found. A t-test

was run to determine if there was a difference in participants' mean scores on any of the measures by race or gender—again with no significance found.

In order to assess the relationship between True and False Self characteristics and the severity of their sibling with ASD's symptoms, Spearman rho correlations were run and no significant correlations were found. In attempt to assess change in True and False Self over the lifespan, the variable of age was re-coded into three categories: 18-25, 26-39, and 40 or older. Then, in order to determine if there was a difference in any of the measures by age category, Oneway Anovas were run. No significant differences were found in any of the measures.

Narrative Data from the Open-Ended Questions

Although the concentration of the study was intended to be on the structured questions and quantitative data collection, the responses to the two open-ended questions were very extensive. Upon reading through the narratives, they were so rich that they needed a section of their own. It was surprising to see how much time and effort participants put into writing these responses. The responses reflect a great variance in experiences and the impact of having a sibling with ASD on the formation of the self. The following sections are made up of direct quotes from participants' combined responses to the open-ended questions in the survey (Question 1: How has having a sibling with Autism shaped who you are?; Question 2: Would you like to share anything else about your experience as a sibling to make this study more representative of your experience?). They have been coded into "False Self Themes," "True Self Themes," "Changes in Self Over Time," and "Other Themes." See Appendix C for a listing of full

responses to each question. None of the responses have been altered in any way (aside from bracketed text), so they may contain spelling and/or grammatical errors.

False Self Themes

<u>Struggle with Sense of Self Apart from Family Role (9 responses):</u>

I have also had to do a lot of teaching/restructuring interactions so my sibling could participate with the rest of the family.

My brother with autism is a lifelong commitment for me.

Having kids was difficult. I've been worried about every aspect of their development becuase I already have the responsibility for one person in the future I hope I don't have it completely for my kids as well.

I find it hard not to 'mother' him these days. I want to help him, do things with and for him, but he resents this. I don't know how else to be with him. To some extent I use him now to shape my own identity. I tell people about him, almost to make me appear more interesting.

I had no role, other than the caretaker of my youngest sib.

There are also a lot of frustrations... my brother relies on me for advice, especially when he is depressed. He ruminates about things which upset me, and I have to spend hours on end trying to console him and point out how he is viewing things in a maladaptive way, but because of his ASD and rigidity and black and white thinking, sometimes this goes nowhere. It's very draining on me... especially because it is so one-sided. It's not like I can go to him for advice or for consolation when I'm feeling down. On the other hand, he has taught me so much, even unintentionally, and I have benefited so much from his presence in my life... so in the difficult times, I keep reminding myself of that.

I have always planned to be a part of overseeing my youngest sister's care, but its increasingly looking to fall to me, and my mom is even speaking of it in those terms now… I love my sister, but I chose not to have children, and may now find that this very decision will lead to my becoming the 'parent' to my youngest sister, for the rest of my life. I think there were a lot of possible impacts in earlier life, and that's all huge, but this looming responsibility, which will likely be for the rest of my life, is what really seems to be impacting me the most right now.

I feel very responsible for my brother.

The experience of having a brother with autism is fundamental to who I am now. The way I interact with people, the way I respond to problems, and my sense of self are related to that experience.

<div align="center">Not Feeling Seen (7 responses):</div>

Having him with us in our home…devoured our family's energy in coping with him.

As a child I felt left out, ignored and as if I had no power…I grew up feeling 'invisible'. I never learnt how to get attention in a positive way. I developed an eating disorder and depression probably as a result of my brother. I craved attention but didn't get it…I was jealous of the time and attention he got from my parents, professionals and friends of the family.

No-one listened to how I felt. No-one supported me in coping with him…I want people to feel sorry for me, to understand how hard it was.

I feel invisible.

As for the 'attention' questions, I think I always secretly wanted it, yet whenever I actually had it I felt very uncomfortable. Still do!

I truly was the 'forgotten child.'

My two siblings with disabilities…were seen by my mother and other siblings as needing care, but all other sibs were supposed to be "independent" – I…was ignored by [my] older brothers.

<div align="center">Devaluation of the Self / Not Feeling Good Enough (5 responses):</div>

My brother had no qualms about talking to anyone and everyone, but I couldn't join in. I felt less interesting than him.

I want them to see me as being the good, caring sister. I get annoyed that sometimes he can appear really friendly and charming, and people see this and think that is who he is. They don't see the other side of him, all the challenges and daily frustrations.

I also struggle with survivor guilt.

I often feel like my parents care more about my sibling than me. I feel…that I am not as important as my sibling is.

I feel that not only did parents cater to emergencies of my disabled sibs, but so did my other sibs…this affected me, for I never felt I belonged in my family.

<u>Wearing a Mask (5 responses):</u>

It also, unfortunately, made me unable to share my feelings well with others.

I'm way too stoic, not showing my feelings except to those who I'm close to.

My parents viewed me as being really good with him, the caring big sister, but I didn't feel it. I felt frustrated. I wanted to hurt him, hit him, tell him off, but I couldn't.

It was a very isolating experience—a big secret that no one talked about because it was too painful.

My needs were never as great, so I never wanted to be a problem to my parents.

<u>Compliance (3 responses):</u>

When I was younger I copied what my big brother did. I think I try to hard to appease people, and sticking up for myself often goes the wrong way.

[I] learned how to put others needs over my own… I still tend to go along with what everyone else wants instead of what I want…Also tend to be non-confrontational, I'll give in to what others want to avoid conflict.

I... am sometimes too much of a people-pleaser.

<u>Not Feeling Real (3 responses):</u>

I don't really feel like I know how to relax and 'just be' in any kind of relationship, because that wasn't a part of my childhood.

It's very draining on me... especially because it is so one-sided. It's not like I can go to him for advice or for consolation when I'm feeling down.

I'm very mentally engaged when I'm with other people, to the point that I allow myself to become deeply exhausted and then need to spend extended periods alone in order to recuperate.

<u>Lack of Creativity/Spontaneity (1 response):</u>

I have trouble communicating my thoughts and ideas.

Feeling Seen (2 responses):

Coming from a family of 4 kids we were all part of the mix and so I never felt like my parents didn't pay enough attention to me. If anything I wished for more alone time! But I think that my family has been really instrumental in creating an inclusive environment.

My parents strived to treat all of us equally whenever possible. To me it was "normal" to grow up with someone with autism because that is all I have known.

Sense of Self Apart from Family Role (2 responses):

Once I left home, it was much easier to keep from taking my sister's behavior personally, and I feel like this skill separates me from my parents and my other siblings who haven't lived far away for an extended period. This distance makes me useful to my family in some ways, but I think they resent me for it.

There are many factors in my childhood that have contributed to my experience and the shaping of me as a person.

Valuing the Self (2 responses):

It was (and still is) difficult, but it has made me into a very strong and good person. I am proud of the person I turned out to be.

I think of myself as the family member who is the most unscathed. I sort of always knew that was how it would be...I remember having bad dreams as a child that my house was on fire and I was getting out, but I was sad and afraid because I knew I would be the only survivor.

Creativity/Spontaneity (1 response):

I'm generally the one in my family to generate new ideas and maintain a forward thinking approach.

Feeling Real (1 response):

I am more eager about living life to the fullest and appreciate what I have.

Not Wearing a Mask/Ability to Express One's Self — 0 responses

Noncompliance/Assertiveness — 0 responses

Changes in Self Over Time

I think is has had a bigger impact that I previously thought. Looking back on things, I realize how much it has shaped who I am for the good and bad.

As I grow older, though, I am coming to understand more of the roots for this behavior, and thus to be somewhat more compassionate, or at least understanding.

Although there are parts of my past relationship with my brother I would love to forget, with regards to his aggression towards me, his accomplishments have been a true inspiration to me. We have a very positive relationship now.

It seems that [it has shaped who I am] more than I thought, a fact that I have recently found out by meeting other siblings and joining sibnet.

I didn't think much at all of having a sibling with autism until I was a teenager, but once I did, I thought about it a LOT.

Once I left home, it was much easier to keep from taking my sister's behavior personally.

My therapists and friends say it's a miracle I'm as functional as I am, and that my story is a triumph of survival and tenacity. Fortunately, I've come to believe them.

Other themes in the Open-ended Responses

<u>Improved Ability to Relate to Others (18 responses):</u>

I think that I have a much better understanding of people's differences.

As I have got older I realise I am more tolerant of people with differneces.

[I am] more compassionate about less fortunate and those who 'fall through the cracks' in life.

I think I have an increased capacity for empathy.

I think I am more compassionate and empathic to different people.

I have so much patience, tolerance for others' differences, and empathy because of my brother

I also feel like I can be more patient and understanding than most people.

[I am] more patient and understanding.

Having a sibling with autism has made me care much more for people with disabilities than it may have had I had typically developing siblings.

I am a special needs preschool teacher thus I relate to the kids families much better than I would without.

It has made me feel sympathy towards those who have a disability and it has made me more aware of how I treat others.

Having my brother has taught me to be compassionate, and interested in those who are different than I am.

It opened my eyes to something that most of the world does not understand and has made me appreciate more just the overall idea of being different, as compared to what I think I would have been.

It has inspired me to be more open-minded about life.

I am good at reading people which I think reflects on the issues around communication my brother has.

I feel like I spend a lot of time compensating for people who have problems communicating because I can usually tell what they mean even if they can't figure out how to say it.

In my adult life, I felt that my feeling misunderstood enabled me to guess at some of my youngest brother's difficulty, so I began to help him

The experience has given me an invaluable gift for seeing potential in others, hidden or not, as well as wanting to cultivate that potential.

Career Choice (13 Responses):

It's helped me…to discover my passion for working and learning with people with various disabilities.

I currently work with children with autism as a special educator.

I am a special needs preschool teacher thus I relate to the kids families much better than I would without.

I have become a psychologist and I work with children with autism, entirely inspired by my brother.

I am training as a clinical psychologist and my experiences with my brother have definitely influenced my choice of career.

I am working in the field of Developmental Disabilities and I feel that working with my brother growing up gave me direction on a career.

I also have chosen my career path partially based on having the experience of being a sibling (I am in school for Occupational Therapy).

I think it's…probably pointed me towards my current profession (nursing).

Influenced the work that I've gone into, both in part time jobs and my current full time job.

It drove my career choice.

It has affected my career choice.

I feel that when I graduate with my BASW, having had my brother in my life will have benifitted not only myslef, but those whose lives I will touch in my profession.

It is because of my brother with autism that I have chosen to be an Advocate for individuals with developmental disabilities…He is the reason many others have chosen to be in the field of special education.

Having a Sibling with ASD Made Me Who I Am Today (8 responses):

It was the pivotal molder of me as a person, I'm sure. I could write a book.

Made me who I am today.

It's a big part of who I am.

The experience of having a brother with autism is fundamental to who I am now. The way I interact with people, the way I respond to problems, and my sense of self are related to that experience. I can't be certain how my life would be different without a brother with autism, but I suspect I would be a less patient, less kind, and less mature person…My brother's autism was severe and his disability completely defined my childhood.

It has shaped me in so many ways.

I am proud of the person I turned out to be, and I owe a great part of it to my experience as a sibling.

I have found my purpose in life because of what he has taught me through the years.

It's had a huge impact on me.

<u>Complications due to Additional Family Stressors (7 responses):</u>

I think my family's reaction to it shaped me more than he did. My mother in particular was overwhelmed, self medicated, and often treated me as though I was autistic too.

Much depends on how parents deal with the experience of having a child with autism. My mother has untreated depression, which has been more difficult for me to deal with than my brother's autism.

My experience was compounded by the larger family dynamic - 7 children, wide age spans between oldest and youngest; alcohol of both parents but in social climbing ways. My two siblings with disabilities, older sister with athsma then mental illness, and youngest brother with Brain Injury and communication disorder - were seen by mother and other siblings as needing care, but all other sibs were supposed to be 'independent' - I had no role, other than the caretaker of my youngest sib, and was ignored by older brothers. I feel that not only did parents cater to emergencies of my disabled sibs, but so did my other sibs - there were big age differences, so I had nothing to do with my older brothers - this affected me, for I never felt I belonged in my family - I sought support from a neighbor - who was from a different culture - British - and doing this was seen by my family as rejecting them, so we really developed major impasses.

I consider my family very emotionally unhealthy.

No adult--whether in my family or in the special education profession--wanted to believe that my sibling was dangerously violent and needed to be placed in a specialized facility instead of being allowed to terrorize my entire household. They preferred the mythos that All People with Disabilities Are Sweet and Good and Kind, and called me a liar and selfish when I tried to seek help as a child. I paid the price. I can't be around my sibling and my remaining family has disowned me for "not doing my fair share" as caregiver even though at least one of the immediate family members knows the truth. Quite frankly, I got nothing positive out of having a sibling on the autism spectrum, and a lifelong legacy of psychological trauma as a result. I'm an outlier on the spectrum, but I feel my voice needs to be heard to help those other sibs who experienced violence at home. If my sib had not been disabled, I would have had functioning parents who loved me instead of depressed and in one case mentally ill alcoholics who destroyed the family in their insistence that everything had to be, as Don Meyer puts it, revolving around 'The United States of Johnny' even though my sibling

was dangerous to everyone in the household and most especially me, the youngest and most vulnerable.

I would be curious if some of the things we've seen in our family are common to others in which one member has a disability: alcohol use by father, eating disorder in sibling, incidences of depression in each sibling. I've read there may be a genetic component that links each of these, but it might also be a result of the family environment that developed in the wake of having a child with a profound disabiity.

Hopefully younger sibs are not experiencing what I did. When my brother was born, there was no early intervention, no educational opportunities for him, no support groups for parents or sibs...we were pioneers in having him with us in our home and not institutionalized. That was a brave decision, but devoured our family's energy in coping with him.

Concerns about Having Children (4 responses):

I'm also scared to death of having a child with ASD. This is a huge reason why I still don't have children yet even though I've been married for 6 years.

I only have one child - when my son was born I was grateful to have a "normal" kid, that I didn't want to take the chance that a second child would be autistic.

Having kids was difficult. I've been worried about every aspect of their development becuase I already have the responsibility for one person in the future I hope I don't have it completely for my kids as well. My 3 year old daughter appears to be fine. My son is only 10 months and appears to be fine too. I split up the vaccines on both of my children out of fear and not knowing what to belive.

The fact that most worries me is my incapacity to start my own family, which I am not sure it is related to my brother's existance."

Early Maturity (4 responses):

It made me mature very quickly and feel a level of responsibility that is less common for siblings of normally developing individuals.

I am much more aware of the realities of society and not as idealistic as many of my peers.

It made me much more responsible and aware of "the world" and other people's feelings from a very young age.

I'm often thought of as seeming older than my age (both because of my perspective and my professional position).

I'm scared about what will happen in the future when my parents are no longer around to watch over my brother.

I already have the responsibility for one person in the future.

I find it hard not to 'mother' him these days. I want to help him, do things with and for him, but he resents this. I don't know how else to be with him.

Look at the longer-term aspects of this: the transition from parental care to sibling care, and the supports, expectations of that. This is what I am facing now, and for all I know, it could completely change the course of life for me and my husband. If there is no residential placement for her, will she need to live with one of her siblings? My brother was never expected to share in her care (another possible survey topic, gender differences in the experience), and since he and my other sister have small children, I expect my husband and I will need to take on the majority of her care. One of my sister's children has Down Syndrome, so she has her own plate full. I have always planned to be a part of overseeing my youngest sister's care, but its increasingly looking to fall to me, and my mom is even speaking of it in those terms now. One big aspect: Is there a group home for her? Is it safe and suitable? Will she need to come live with us? That was not the choice of my parents, and it isn't mine, but if she doesn't have anywhere to live, then that might be our only real choice. I love my sister, but I chose not to have children, and may now find that this very decision will lead to my becoming the "parent" to my youngest sister, for the rest of my life. I think there were a lot of possible impacts in earlier life, and that's all huge, but this looming responsibility, which will likely be for the rest of my life, is what really seems to be impacting me the most right now.

Violence/Aggression of Sibling with ASD (3 responses)

My much older sibling with autism was violent and abusive on a daily basis when I was a child. He repeatedly tried to sexually molest me and kill me. I have PTSD as a result.

There are parts of my past relationship with my brother I would love to forget, with regards to his aggression towards me.

What's hardest for me to deal with is the anger and cruelty. Disability in and of itself is fine with me, it's meanness I have trouble with.

CHAPTER V

DISCUSSION

Quantitative Data

Comparison of Siblings' Total Scores of True and False Self Representations

In looking at whether siblings in this study reported more False Self characteristics than True Self characteristics, the answer was yes (but only slightly). In the aggregate, participants scored 3.5% higher on False Self characteristics than True Self characteristics. The higher scores on False Self characteristics may indicate that people who have a sibling on the Autism Spectrum more often act in ways to accommodate others rather than satisfying their own wants and needs. The demands of having a brother or sister with ASD may make it difficult for a sibling to behave according to his or her True Self "if the child feels she must be exclusively attuned to the needs of others in the family system and if she needs to be a certain way in order to be recognized and connected" (Berzoff, et al., 1996, p.140). Although there was some difference, the aggregate data in this study do not suggest a significant predominance of False Self characteristics over True Self characteristics in siblings. The lack of any control or comparison group in this study limits the strength of this data even more.

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Changes in Self Over Time

The results show that the difference in responses based on time ("present" versus "past") was statistically significant for *both* True Self and False Self measures. Participants' False Self scores went down over time and their True Self scores went up. This data indicates that siblings may move toward a more "healthy" representation of the self as they age. This relationship between time and siblings' representations of self, however, needs further investigation. In this study, for example, when the age of participants was analyzed (using Oneway Anovas), no statistical significance was found. The subjective method used to measure time as a variable in this study (phrasing some questions in a past tense and some in a present tense) results in confusion about how to explain these findings. Does the change in siblings' representations of self plateau after a certain age? Or, do they continue to connect with more aspects of their True Self and shed remnants of a False Self throughout the lifespan? This may be related to siblings' individual differential development, the amount of environmental support, or some combination of the two—which were not examined in this study.

The appearance of the lowest scores on the "True Self Past" measures further supports the idea that people who grow up with a sibling with ASD may perceive that True Self characteristics are stronger in the present than in the past. Again, this prompts the question, how much older? Correspondingly, participants' highest scores were on the "False Self Past" measures. Based on this data, siblings may need to rely on False Self characteristics while growing up with their sibling with ASD. Both of these findings, however, require more data to draw any conclusions. Also constraining the strength of the findings was the lack of any other sample group with which to compare with the

SibNet sample group. The changes in the True and False Self measures from past to present could reflect a normative developmental process. Because the data is based on self-assessments, there may be some degree of social desirability and acquiescence in the responses.

Interestingly, the degree of change in False Self characteristics was actually less (a 5.7% decrease) than the change in True Self characteristics (an 8.4% increase). One might wonder what accounts for the differences in change between True and False Self characteristics. Participants' more noteworthy change (and increase) in scores from True Self characteristics in the past to True Self characteristics in the present may relate to what Heinz Hartmann (1958) calls "change of function:"

> The conception of change of function is familiar in psychoanalysis: a behavior-form which originated in a certain realm of life may, in the course of development, appear in an entirely different realm and role. An attitude which arose originally in the service of defense against an instinctual drive may, in the course of time, become an independent structure, in which case the instinctual drive merely triggers this automatized apparatus (more about this later on), but, as long as the automatization is not controverted, does not determine the details of its action. Such an apparatus may, as a relatively independent structure, come to serve other functions (pp. 25-26).

For example, some participants indicated that they grew up with siblings who were aggressive or had severe behavior problems. In order to defend against instincts to retaliate, they may have employed defenses such as denial (of anger toward their sibling with ASD) or Anna Freud's (1938) "identification with the aggressor." The difficulties that siblings may defend against early on may change into different, even adaptive, functions, such as empathy, as they differentiate from their siblings (and families) and gain more insight about their own development. Empathy was a major theme in the

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open-ended responses—empathy for individuals with special needs and for people in general. Many of the siblings praise their siblings with ASD and have even chosen to enter a helping profession—some specifically working with individuals on the Autism spectrum.

The minimal change in False Self scores from past to present could be explained by Hartmann's idea of "change of function" as well. Perhaps the False Self characteristics are not necessarily a fixed element in siblings' senses of self, but can be triggered when siblings are reintroduced to unresolved conflict in their families of origin. Although siblings become more rooted in their True Selves over time, their False Self characteristics may still be a part of them—vulnerable to resurface when presented with "the perfect storm" of circumstances. Safer's (2002) "geographic solutions" may be an example of siblings' attempt to connect with their True Selves. When they return home for a visit, however, some of their False Self characteristics and behavior patterns may reemerge. This may result in self-reports that are not able to disavow False Self characteristics in the present—even when general functioning is predominantly in the True Self range. This concept was not examined in this study.

Although the changes in the True and False Self measures from past to present were statistically significant, they were overall minimal. One explanation for the minimal change is that siblings' structure of self is indeed quite fixed from an early age, reflecting both True and False Self characteristics. It could also reflect the subjectivity of the measurement. In addition to the factors discussed earlier, the measure also relies on participants' self-report. It may have been difficult for participants to remember with accuracy how they felt or behaved in the "past"—a task which is inherently vague and

embedded with complicating factors, such as his/her current age, degree of differentiation from family, insight, and what stage of life he or she reflected upon when answering the question. A third possibility is that the survey may have some validity issues, which will be explored further in a later section.

Trends within Individual False Self Characteristics

"Compliance" was the only one of the False Self categories to *increase* from past to present, according to participants' reports. This trend would indicate that, in this study, siblings actually became slightly more compliant with time. Though the increase was small (only 0.9%), it sticks out as the only of the False Self constructs to not decrease with time. Perhaps one's degree of compliance is a more fixed element of the self. Out of the three constructs designated to represent False Self, compliance contained the highest scores in both the past and present measures. It is also possible, therefore, that the trait of compliance highly correlates with the experience of growing up with a sibling with ASD. This finding would support Jeanne Safer's (2002) aforementioned concept of "preeminence, which requires children to mold their personalities to their parents' specifications" (p. 100). She links preeminence to a distortion of the self in siblings of people with ASD, and explains that the demands placed on siblings are "double—they must simultaneously fulfill parental aspirations and compensate for their sibling's failure to do so" (p. 100). The high scores on compliance also support Winnicott's emphasis on compliance when defining the False Self (1965). This finding may also suggest that compliance is not necessarily a negative trait. Siblings may report an increase in compliance—intuitively knowing that it can have adaptive as well as

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defensive properties (particularly with age and insight). Compliance scores were closely followed by siblings' scores on the measure for "wearing a mask," which has similar implications.

In contrast to "compliance" (which increased slightly from past to present) and "wearing a mask," (which decreased slightly from past to present) the change in scores from "past" to "present" was more significant in the questions regarding participants' devaluation of the self. Scores for "devaluation of the self" dropped 16.1% from past to present. Participants scored somewhat high on devaluation of the self in the past (62.1%), but scored lower on present devaluation of the self (46.1%). This dramatic decrease may indicate that siblings come to value themselves more with the passage of time. Further research is needed to determine if this is consistently true and to explore what accounts for that change. It could be related to the trait of perfectionism Safer (2002) identifies as common in siblings (pp. 99-100). Additionally, maturity and insight might result in more self-esteem, self-empathy and appreciation of just how challenging self-development is for those that have a sibling with ASD.

Trends within Individual True Self Characteristics

Within the True Self measures, "Feeling Seen" had the lowest aggregate scores. The most common response for statements about feeling "seen" as a child was a 1 ("Very Inaccurate"). This data indicates that siblings may struggle with feeling "seen" in their younger years. Winnicott himself emphasizes the importance of feeling "seen" in his "Mirror-Role" paper in 1967 by stating, "I am seen, so I exist" (Cameron, 1996, p. 41). It

is also possible that "feeling seen" was a more complex (academic) concept, and that it eluded some of the participants.

In regards to changing over time, the scores in three out of the four measures of True Self increased from "past" to "present"—all by 10-13%. The only category to decrease was the characteristic of having a sense of self apart from one's role as sibling. Though the decrease was only 1.2%, further exploration is needed to determine why this is the case. It could possibly be related to the ongoing needs of people with ASD across the lifespan, thereby extending their siblings' responsibilities beyond those of typically developed adults. This explanation is supported by the literature: "Little attention has focused on siblings of adult chronically mentally ill persons, and siblings, particularly as adults, often become caretakers of the identified client." (Riebschleger, 1991, p. 94).

Relationship of Scores to Demographic Variables

Although no significant differences in the True and False Self measures were found for any of the demographic data, the small sample size limits the reliability of these findings. Regarding the variable of birth order, for example, only 4 out of 33 participants were "in the middle" of their siblings with ASD. It is unclear, therefore, whether the lack of statistical significance has to do more with the variable of birth order itself or with the small sample size. The variables of race and gender had similar constraints. The majority of participants were white and female. Because of these small numbers, an analysis of gender and race as they pertain to the sibling experience could not be properly assessed by this study. Perhaps a larger and more diverse sample size would reveal more statistical difference in these areas.

Though ages ranged from 18-64, the majority of people were below 40-years-old. Only 8 participants were above 40. It would be interesting to have a more equal comparison between middle-aged and young siblings to see whether significant differences emerge. This issue seems especially salient given the significant difference found within participants' report of change in True and False Self characteristics from past to present.

Given the diversity in this study regarding the severity of symptoms of ASD in participants' siblings, it was surprising that there was no association between severity of symptoms and the True and False Self measures. Since the umbrella of autism spectrum disorders is so broad, and since ASD can present so differently in each individual, this was an interesting finding.

Validity of Quantitative Data

The issue of validity of this study is a complex one. The operational and conceptual definition of True and False Self was informed by the literature review, but the pieces were put together in a new way. A formal definition and defined characteristics of this phenomenon do not exist. The questions used in the survey were taken from several different measures. Face validity, defined by Anastas (1999), is "whether the manifest content of a data collection instrument or question actually seems to address the concept used to label it" (p. 321). In this study, the face validity of the instrument comes into question because, although the questions were derived from existing instruments, they were extracted from their original context and even altered in some cases (to relate more specifically to the topic).

The Cronbachs Alpha showed that questions in the measures fit together adequately, but was not able to determine how well the questions actually measure True and False Self. Additionally, there was no group with which to compare the sample of siblings recruited from SibNet. Therefore, this study is meant to be viewed as an exploration rather than a declaration of universal experiences.

Content validity—that the whole measure's "constituent items taken together adequately sample or cover all of the content relevant to the area being assessed" (Anastas, 1999, p. 322)—also is an issue inherent in this study. This examination of True and False Self within a sample of people who have a sibling with ASD was designed to measure a limited facet of the whole experience. As demonstrated by the lengthy explanations and addendums participants added in the open-ended questions, the issue of being a sibling is far more complex.

In summary, the validity of this study comes into question because True and False Self is a theoretical construct that has not been operationally defined in ways that support empirical measurement. The choice of characteristics used to measure True and False Self (compliance, creativity, etc.) were based not only on the literature, but on trying to identify constructs that would be quantitatively measurable. It is possible that the chosen set of constructs resulted in False Self being more measurable than True Self. If this is so, it may help explain some of the variation between the True and False Self measures regarding the change from "past" to "present." Aside the significant difference between the "past" and "present" measures, the quantitative data did not result in many significant statistical findings.

Qualitative/Narrative Data

The following is a discussion based on participants' answers to two open-ended questions: 1) How has having a sibling with Autism shaped who you are?; 2) Would you like to share anything else about your experience as a sibling to make this study more representative of your experience? As mentioned in the findings section, the richness of the responses was surprising. The poignancy and eloquence with which siblings described their experience drove the decision to move towards a mixed method focus—incorporating both the quantitative data from True/False Self measures and the qualitative data gained from narrative responses.

In contrast to what was expected, participants more often identified False Self characteristics within their narratives than they did within the quantitative instrument. Given the pejorative nature of False Self principles—a tendency to wear a mask, a desire to please—this was a surprising finding. One might assume siblings would be hesitant to share their conflictive emotions based on a desire (conscious or not) to protect their families. What emerged from this study was an openness and honesty about the difficulty of the sibling experience. Participants expressed a wide range of thoughts, feelings, and experiences pertaining to the subject. Since the concepts of True and False Self guided this study, the responses were coded into the True and False Self constructs utilized throughout this investigation. In addition, other common themes were identified—which may or may not tie into the concepts of True and False Self. These include an improved ability to relate to others, career choice to enter helping professions, complications due to additional family stressors, the notion that having a sibling with ASD made them who they are, concerns about having children, early maturity, the

transfer of sibling caretaking responsibilities from their parents to themselves, and
violence/aggression of their sibling with ASD.

False Self Themes

In contrast to the quantitative measure, in which the construct of "compliance"
was most strongly identified by participants, the struggle with finding a sense of self
apart from the role of sibling was the most commonly mentioned False Self theme in the
qualitative portion of the survey. Nine people described what seemed like an experience
of having an inadequate "sense of self separate from their role" in the family. This
finding is consistent with the literature which points to the importance of forming a sense
of self which is defined by more than just the roles one occupies in his or her life. As
discussed previously, Harter et al. (1996) identify having "different role-related selves"
as indicative of False Self behaviors (p. 360). Winnicott (1965) connects "those who can
only act, and who are completely at a loss when not in a role" with potentially developing
a False Self.

Regarding the self being too closely intertwined with the family role, many
siblings become parentified—speaking to what Safer (2002) calls "family vice
presidents" (p. 60). Several participants alluded to this phenomenon. One participant
states, for example, "I had no role, other than the caretaker of my youngest sib." Others
spoke about the increased demands (present or impending) that arise once parents can no
longer care for their sibling with ASD. For instance:

> I have always planned to be a part of overseeing my youngest sister's care, but its
> increasingly looking to fall to me, and my mom is even speaking of it in those
> terms now… I love my sister, but I chose not to have children, and may now find

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that this very decision will lead to my becoming the 'parent' to my youngest
sister, for the rest of my life. I think there were a lot of possible impacts in earlier
life, and that's all huge, but this looming responsibility, which will likely be for
the rest of my life, is what really seems to be impacting me the most right now.

Others spoke more broadly about the strong impact of having a sibling with ASD on their sense of self. One participant says, "To some extent I use him now to shape my own identity. I tell people about him, almost to make me appear more interesting." Another states, "The experience of having a brother with autism is fundamental to who I am now. The way I interact with people, the way I respond to problems, and my sense of self are related to that experience." So, it seems having a sibling with ASD can shape a person's sense of self in a variety of ways. In order to balance one's role as sibling with one's ability to express a True sense of Self, Safer's (2002) perspective is that: "Normal siblings have two life tasks: to recognize the enormous impact a damaged sibling has on them, and to forge an identity in which that sibling is peripheral. The first makes the second possible" (p. 67). Perhaps, then, participants' self-awareness about the challenges of growing up with a sibling with ASD actually indicates a more secure sense of self.

Several participants mentioned feeling "invisible"—a contradictory concept to the True Self characteristic of "feeling seen." One participant calls herself "the forgotten child." Participants' deficits in "feeling seen" by primary caregivers is consistent with a lack of validation which perpetuates a False Self representation. Wright (1996) emphasizes the importance of feeling *recognized* in some important way by the Other" (Wright, 1996, pp. 72-73). Siblings adapt by learning to be independent, which can lead to a variety of strengths. At some point, however, when a person's universal need to be "seen" goes unfulfilled, it can lead to problematic consequences. For example, one

participant in this study linked her feeling of invisibility to the development of an eating

disorder and depression, stating that she "never learnt how to get attention in a positive

way." This finding supports Ross and Cuskelly's (2006) finding that siblings of children

with an autism spectrum disorder (ASD) are at an increased risk of developing

depression. So, on the one hand, siblings may crave attention, yet once they receive it

they may not know how to respond. A participant of the study exemplifies this concept:

"I think I always secretly wanted it [attention], yet whenever I actually had it I felt very

uncomfortable." This ambivalence is congruent with Safer's (2002) statement, "Many

healthy siblings grow up with a hunger for attention that is never satisfied and that seems

wrong to feel. Their needs, so consistently ignored, become invisible to themselves" (p.

94). One explanation for the discomfort could be a sense of guilt about not being

deserving enough for that attention.

One participant expresses this concept of not feeling deserving enough by stating

that she "struggle[s] with survivor guilt." Other participants expressed similar

sentiments, identifying feelings of inferiority within the family system: "I often feel like

my parents care more about my sibling than me. I feel…that I am not as important as my

sibling is." Another states, "I never felt I belonged in my family." These statements

exemplify the construct of "devaluation of the self," which is identified as problematic

not only by siblings themselves, but in the literature as well. Harter et al. (1996) claim

that "to the extent that one's true self is devalued, one would be expected to go to greater

lengths to avoid expressions of this core self" (p. 362). One participant voiced evidence

of self-restraint, stating, "My brother had no qualms about talking to anyone and

everyone, but I couldn't join in. I felt less interesting than him." It is this silence and

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censorship, stemming from "devaluation of the self," that leads to the feeling of wearing a mask.

Approximately five participants conveyed the theme of feeling like they are "wearing a mask" in their narratives. Several of them specifically mentioned difficulty with showing their feelings. One stated, "My parents viewed me as being really good with him, the caring big sister, but I didn't feel it. I felt frustrated. I wanted to hurt him, hit him, tell him off, but I couldn't." Regarding the related construct of "compliance," several participants made reference to this characteristic. When talking about the sibling experience, one sibling stated, "I still tend to go along with what everyone else wants instead of what I want." Another states, "I think I try to hard to appease people." As mentioned earlier, the trait of compliance was more of a theme in the quantitative measure than the qualitative measure. It could be possible that the participants do not connect their compliant tendencies with their experience of being a sibling.

Regarding "feeling real," three people identified possible examples of this characteristic. As stated earlier, Anderson and Winer (2003) state that "Those who live according to the False Self feel hollow and unreal, as if they were just going through the motions" (p. 80). One participant, for example, shares: "It's very draining on me... especially because it is so one-sided. It's not like I can go to him for advice or for consolation when I'm feeling down." Another participant tied in the finding from Harter et al. (1996) that "false self phenomena are linked to alienation from any sense of a real or validated core self" (p. 361): "I'm very mentally engaged when I'm with other people, to the point that I allow myself to become deeply exhausted and then need to spend extended periods alone in order to recuperate."

True Self Themes

The True Self themes were much more difficult to find within the narratives, but not because siblings did not indicate positive effects of being a sibling. Many of the frequent themes were indeed positive—such as a heightened level of empathy and an increased ability to accept others' differences. This part of the discussion will focus only on the threads of the designated True Self constructs utilized in the quantitative instrument—"feeling seen," having a "sense of self apart from family role," "creativity/spontaneity," "valuing the self," and "feeling real." No examples could be found of an ability to express one's self (not "wearing a mask") or asserting one's needs (not being overly "compliant"). The lack of findings in these two areas may accentuate the struggle that siblings really *do* have in expressing their true feelings and acting in accordance to what they want rather than what others want. Overall, the findings for True Self themes in the narratives were limited—with only eight examples (versus 33 examples of False Self themes).

"Feeling seen," "sense of self apart from family role," and "valuing the self" all had two examples. Considering the importance of all of these constructs according to the literature for the development of a True Self (Berzoff, 1996; Cameron, 1996; Harter et al., 1996; Safer, 2002; Winnicott, 1965; Wright, 1996), it would be expected to have a higher number of examples from these constructs. In both examples of "feeling seen," the participants mentioned their families' responses as an influential factor. One shares, "Coming from a family of 4 kids we were all part of the mix and so I never felt like my parents didn't pay enough attention to me. If anything I wished for more alone time!" Regarding having a "sense of self apart from family role," one participant alluded to the

multiple factors that have influenced her sense of self rather than just the one factor of having a sibling with ASD: "There are many factors in my childhood that have contributed to my experience and the shaping of me as a person." The other emphasizes how her sense of self was strengthened once she "left home." Two of the siblings wrote powerful messages about the value they have for themselves. For example, one sibling states, "It has made me into a very strong and good person. I am proud of the person I turned out to be."

The constructs of "creativity/spontaneity" and "feeling real" each seemed to have been represented by one response each. One participant says, "I'm generally the one in my family to generate new ideas and maintain a forward thinking approach." This participant elaborated by discussing how this has made her driven professionally. It seems she has been able to use the defense of sublimation in channeling her experience into something positive. The other states simply, "I am more eager about living life to the fullest and appreciate what I have." These statements align with what Anderson & Winer (2003) say about a True Self—that "People who act out of the True Self feel alive, invigorated, and inspired" (p. 80).

Changes in Self Over Time

Most people identified that having a sibling with ASD has impacted them, and some provided descriptive language about *how* they have been impacted. Given the developmental process and various changes in circumstances, one might assume the impact has a fluid quality to it. To assess how siblings' representations of self have changed over time is difficult because it is unclear whether people who describe

themselves as having a certain trait (e.g. patience) always had that characteristic or developed it along the way. Some people, however, did provide specific examples of changes they noticed within themselves over time.

Three participants identified a change in their perception of how having sibling with ASD has impacted their senses of self. All three realized they were more impacted than they previously thought. These statements may point to the process of connecting with one's True sense of self and uncovering emotions that became hidden under a False Self. It could be explained by an increase in self-awareness, as exemplified by the research done by Harter et al. (1996) which found less False Self behaviors in those that demonstrate higher degrees self-knowledge. Another participant expresses a more dramatic change over time in her representation of self: "My therapists and friends say it's a miracle I'm as functional as I am, and that my story is a triumph of survival and tenacity. Fortunately, I've come to believe them." Because of the extreme trauma this participant experienced within her family—both related to her sibling with autism and other factors—she describes herself as "an outlier on the spectrum." Even so, her story depicts someone whose sense of self has changed greatly over time, perhaps now for the first time feeling "seen" and therefore more in touch with her True Self.

The other participants who identified changes over time reported changes in their perception of their sibling with ASD. One participant highlights the change in her relationship with her sibling:

> Although there are parts of my past relationship with my brother I would love to forget, with regards to his aggression towards me, his accomplishments have been a true inspiration to me. We have a very positive relationship now.

Two people mentioned a change in how they perceive the *behaviors* of their sibling with ASD—one learning not to take her "sister's behavior personally" and one "coming to understand the roots for this [her brother with ASD's] behavior, and thus to be somewhat more compassionate, or at least understanding." Most likely, these changes in the sibling relationship have impacted the siblings' representations of self. It is unclear, however, how their senses of self have been impacted precisely.

Other themes in the Open-ended Responses

The other themes that emerged from the open-ended questions are included here to provide a broader sense of the sibling experience and to incorporate multiple perspectives. These eight other themes may or may not relate to the True and False Self phenomenon. This section will explore whether each theme has any possible relationship to True and False Self as they are defined within this study.

The most common theme was that participants felt having a sibling with ASD resulted in an improved ability to relate to others. Eighteen participants mentioned that they gained these positive interpersonal traits—traits such as empathy, tolerance, patience, understanding, and compassion. This theme does not seem to tie into either True or False Self directly. Its explanation would tie more into Hartmann's "change of function" idea—as was discussed previously. To correlate these traits with a True Self seems to deviate too far from Winnicott's (1965) theory, and to connect them with a False Self would suggest they contain an element of pathology.

In a similar way, the abundance of participants in the helping professions is also difficult to associate with True and False Self. Their desire could relate to Harter et al.

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(1996)'s concept of "different role-related selves" or Winnicott's notion of being "at a loss when not in a role." Perhaps a deficiency in one's sense of self apart from the role as sibling carries over into future professional endeavors. This concept would support the quantitative findings of this study which showed that participants' senses of self apart from their family role was the only True Self construct to decline over time (only slightly). An attachment to a "helper" role may drive siblings to seek out helping professions. More research is needed to examine this phenomenon. This also relates to the theme that emerged of participants struggling with taking on the primary caretaking responsibilities of their sibling once their parent(s) is/are no longer able.

Also related to siblings' senses of self were the numerous responses about how having a sibling on the autism spectrum has defined who they are as a person. Throughout the responses, participants repeatedly made statements such as having a sibling with ASD "made me who I am today." These comments do not definitively indicate a False Self, however. This study can only identify the frequency with which this theme emerges—the limitations of the study and its exploratory nature prevent it from making any definitive interpretations.

Four people mentioned feeling like having a sibling with ASD made them "more responsible" and/or "mature." This trend of maturity is consistent with the findings of Rodger & Tooth (2004). Three specified that this maturity took place at a young age. This trend could relate to the higher levels of False Self behaviors that participants reported having in the past. It could correspond with several of the constructs—wearing a mask, not feeling real, compliance, struggle with sense of self, etc.

The additional themes that emerged from the narratives reiterate the complexity of this experience. Seven people mentioned additional family stressors that influenced their experience of being a sibling. Three people even talked about experiencing violence and aggression from their sibling with ASD. These additional factors point to the need for other methods of studying this population or additional research in this subject area.

Validity of Qualitative Data

Since the study included only two open-ended questions, the conclusions that could be drawn from these responses are limited. The questions were purposefully meant to be vague and generated a large variety of responses. The coding of this data, therefore, was more subjective than it might have been had the entire instrument been qualitative or the two questions more specific. Additionally, the qualitative section contains the same limitations regarding how True and False Self have been conceptualized within this study that were identified for the quantitative instrument.

Strengths and Limitations of the Study

One major limitation of the study was the extremely narrowed focus. As evidenced by the additional themes that emerged from the responses to the open-ended question, the theory of True and False Self cannot represent the sibling experience as a whole. The resiliency and strength of the participants that stood out from the narratives challenged the limitations of this binary construct. The theory of True and False self is only one perspective from which to learn about siblings' representation of self and the impact of growing up with a sibling on the autism spectrum.

Additionally, the sample size was less than intended and decreased reliability of the findings. Although there were no significant correlations with between survey responses and the demographic data (the severity of symptoms of the ASD, the birth order, gender, race, or age) trends within these (or other) factors may emerge with a bigger sample size. The lack of control group also limited the impact of the study.

As evidenced by the amount of data generated from the two qualitative questions, the quantitative focus of study might also be considered a limitation. As discussed previously, the validity of the instrument is questionable due to the scarcity of previous research on this topic. The instrument was also limited by the self-report methodology.

The mixed method results that were generated from the instrument served to strengthen the implications of this study. The quantitative portion assessed True and False self in a more precise way, and the qualitative portion allowed participants to identify what they personally found to be most salient.

Implications for Future Research

Given the significant change in the "past" to "present" questions, further research should investigate how and why siblings' representations of self change over time. A longitudinal study would be helpful for this objective and would eliminate the need to rely on recollection of how participants remember themselves in the past.

Further research is needed on what drives such large numbers of siblings of individuals with ASD into the helping profession. Thirteen out of 33 participants identified their career choice as being mainly influenced by growing up with a sibling with ASD. Many people even chose to work specifically with people on the Autism

Spectrum. Furthermore, with the increase in prevalence of autism spectrum disorders, more research needs to be done on the effects of having a sibling with ASD across the lifespan. With the transfer of caretaking responsibilities for one's sibling with ASD from their parents to themselves, siblings' risks of depression, anxiety, or other effects could become heightened during this stage of life. Further research should focus on the concerns and needs of siblings facing these challenges.

Implications for Clinical Practice

The notion of "change of function" (Hartmann, 1958) suggested by the findings of this study may be important for clinicians to keep in mind while working with people who have a sibling with ASD. It may be a helpful way to make meaning out of the sibling experience, particularly in the way that "change of function" suggests that some siblings may be particularly vulnerable to regression in stressful situations that evoke old issues related to the False Self "defense."

Summary

Overall, participants scored higher on False Self characteristics than True Self characteristics. The change from "past" to "present" in both True and False self was statistically significant—suggesting that siblings' representations of self have an evolving quality to them. Furthermore, the change was larger for True Self constructs than False Self constructs. This finding might indicate that, although False Self characteristics become expressed less frequently, they may not disappear completely. Furthermore, this study suggests adult siblings may have a continued desire to feel "seen" and validated by

others. These two statements extracted from the narrative data exemplify siblings'

viewpoints about this issue: "Families and providers should not forget the feelings and

needs for the siblings;" "[I want] more of this [sibling research], so that we can be more

heard!"

The siblings of individuals with ASD in this study demonstrated immense

strength and resiliency. Although their narratives contained more False Self themes than

True Self themes, their gains from being a sibling seemed to equal (if not surpass) their

struggles. The number of siblings in this study who are employed in a helping profession

speaks to their tenacity and empathic qualities.

The complexity of this study's findings in some ways seem to parallel the

intricacies of the sibling experience. In the end, many siblings are still trying to figure it

out themselves—left only with the many questions to grapple with over their lifetimes:

> I sometimes wonder who I would be if I hadn't grown up with him. I can't answer
> that. Would I be more self confident? Would I have developed so many mental
> health issues? Would there be another sibling in his place? And what would that
> mean? I don't regret having him as a brother. He has taught me so much, made me
> who I am. But I do wish he could communicate more easily and we could be
> closer. I care for him so much, but I never know if he cares at all for me.

Clinicians should be mindful of the emotional nuances within the sibling relationship

when one sibling has an autism spectrum disorder or other disability. The complexities

inherent in these relationships may leave the individual with vulnerability in accessing

and maintaining the True Self. More research is needed into the nature of these

relationships over the lifespan, particularly for those that end up in a caretaking role for

their sibling with a disability. Despite all the variations within sibling relationships, they

are usually the longest relationships in a person's life. Very often, siblings have a unique

and special bond connected by their histories, their present lives, and their future. The

sibling relationship is quite possibly one of the most formative in shaping a person's

sense of self and one of the most influential relationships in a person's life.

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Appendix A
Informed Consent Form

Dear Participant,

My name is Margaret Dickey. I am conducting a study of adults who have grown up with a brother or sister who has a disorder on the autism spectrum. I am curious to know more about how they have been impacted by this experience. The study is being conducted in partial fulfillment of the requirements for the master of social work degree at Smith College School for Social Work and for possible presentation and publication.

You are being asked to participate in this study if (a) you are over 18, and (b) you have a brother or sister with an autism spectrum disorder. As a subject in this study you will be asked to complete a brief online survey. Questions will focus on how you define yourself both within the context of your sibling(s) with autism and in your life in general. The questionnaire will take approximately 15 minutes to complete.

Your participation is voluntary. You will receive no financial benefit for your participation in this study. However, you may benefit from knowing that you have contributed to the knowledge about experiences of siblings of people with autism and other related disorders. It is my hope that this study will help clinicians have a better understanding of siblings, since they are often overlooked. You may also benefit from being able to tell your story and educating people about your experience.   With the consistent increase in diagnoses of autism, addressing this issue is extremely timely and important.

The potential risks of participating in this study are the possibility that you might feel strong or uncomfortable emotions while talking about your experiences. In case you feel the need for additional support after participating in this study, I suggest you visit the SibNet website (www.siblingsupport.org). SibNet offers a listserv in which siblings of individuals with disabilities can join and get support from other siblings. If you experience any feelings of discomfort that you would like to explore with a mental health professional, please contact Mental Health America (www.mentalhealthamerica.net) to find a mental health professional in your area. If you feel you need more specialized support regarding the experience of having a sibling with an autism spectrum disorder, you may visit the Sibling Support Project's website at http://www.siblingsupport.org.
 From there, you can connect with other siblings or locate a "sibshop" in your area (http://www.siblingsupport.org/about/sibshops/find-a-sibshop). This information will also be available upon completion of the online survey.

Strict confidentiality will be maintained, as consistent with federal regulations and the mandates of the social work profession. Confidentiality will be protected by coding the information and storing the data in a locked file for a minimum of 3 years. Your identity will be protected, as you will not be asked for your name. The data may be used in other educational activities or publications as well as in the preparation for my master's thesis, with the exclusion of any identifying information.

This study is completely voluntary. You are free to refuse to answer specific questions and to withdraw from the study at any time. If you decide to withdraw, all data pertaining to you will be immediately destroyed.

By completing and submitting the survey, you indicate that you have read and understood the above material and that you have had the opportunity to ask questions about the study, your participation, and your rights and that you agree to participate in the study. If you have any questions, concerns, or wish to withdraw your consent, please contact Margaret Dickey. You may also contact the Chair of Human Subjects Review at (413) 585-7974. Thank you in advance for your contribution to this research.

1) What is your age (in years)? (will develop the categories after data is collected)
2) Race/ethnicity with which you identify? White, Latino/a, Asian, African American, Asian Pacific Islander, South Asian, Native American/Alaskan Native, Middle Eastern, Biracial or Multiracial (please specify), Race or Ethnicity Not Listed Above (please specify)
3) Gender with which you identify: Male, Female, Transgender, Gender Not Listed Above (please specify)
4) In your family of origin, where do you rank in birth order in relation to your sibling(s) with autism? Older, In the Middle, Same Age, Younger
5) In general, how would you describe the autistic symptoms of your sibling(s)? (This is an oversimplified question, but to help you answer, think of how impaired your sibling is as compared to other people with autism you have seen. If you have more than one sibling on the autistic spectrum, rate according to the one whose autism seems the most severe) Very Severe, Severe, Moderate, Mild, Very Mild

Instructions: For the remaining questions, you will see phrases describing people's behaviors and feelings. Please use the rating scale below to describe how accurately each statement describes *you*. Describe yourself as you generally are now, not as you wish to be in the future. Some of the questions ask you to remember back to your childhood and you should answer accordingly. You may experience guilt, embarrassment, or shame while answering the questions, but please answer as honestly as possible. So that you can describe yourself in an honest manner, your responses will be kept in confidence. Please read each statement carefully, and then rate it according to the following scale.

Very Inaccurate	Moderately Inaccurate	Neither Inaccurate nor Accurate	Moderately Accurate	Very Accurate
1	2	3	4	5

6) I worry a lot about what other people think of me.
7) Overall, I feel comfortable with myself and who I have become.
8) Growing up, I never really gave much thought to how having my sibling(s) with autism around was affecting me.
9) When I was a child, I usually did the opposite of what I was told to do.
10) Growing up, I felt like I could be "me" around my family.
11) I typically tell people the truth about how I feel no matter how I think they will react.
12) I take the time to get in touch with my inner thoughts and feelings (through therapy, journaling, talking with others, prayer, quiet reflection, art, support groups, etc.).
13) As a child, I was always good at putting forth new and interesting ideas.
14) I felt like, when I was younger, I was one person around my autistic sibling(s) and a completely different person around other people.
15) Other people see me for who I really am.

16) Most of the time, I feel like I am just going through the motions—meaning I feel a sense of disconnectedness and/or meaninglessness in my daily life.
17) I secretly wished for more attention when I was growing up.
18) When I was growing up, I often wore a mask of happiness so that I wouldn't burden others with my problems.
19) I felt really good about myself as a child.
20) I constantly find myself sacrificing what I need in order to fulfill my role as brother or sister to my autistic sibling.
21) I never care what others think.
22) I feel fulfilled and inspired in my life right now.
23) As a child, I did whatever it took to be accepted by others.
24) I often felt like an imposter when I was a kid.
25) When I was a child, I paid a lot of attention to my feelings.
26) I often feel invisible.
27) I am the same person around my sibling with autism as I am around anyone else.
28) I was the type of child who went along with the ideas other people came up with.
29) When I was a child, expressing my feelings (frustration, anger, sadness etc.) was easy for me.
30) I rarely notice my emotional reactions to things.
31) I don't feel satisfied with who I am.
32) As a child, I never felt like I was good enough.
33) When I was a child, I felt free to be the "real me" wherever I went.
34) Nowadays, I feel like I can be the "real me" in my life.
35) I typically hide my pain from others.
36) Finding ways to be creative is difficult for me.
37) As a child, I felt like I was seen and appreciated.

Instructions: The last two questions are open-ended, so please feel free to share as much or as little as you want.

38) How has having a sibling with Autism shaped who you are? (open box)
39) Would you like to share anything else about your experience as a sibling to make this study more representative of your experience? (open box)

Scoring:

1) Demographics (no scoring)
2) Demographics (no scoring)
3) Demographics (no scoring)
4) Demographics (no scoring)
5) Demographics (no scoring)

How to score IPIP scales (http://ipip.ori.org/newScoringInstructions.htm):

For (+) keyed items, the response "Very Inaccurate" is assigned a value of 1, "Moderately Inaccurate" a value of 2, "Neither Inaccurate nor Accurate" a 3, "Moderately Accurate" a 4, and "Very Accurate" a value of 5.

For (-) keyed items, the response "Very Inaccurate" is assigned a value of 5, "Moderately Inaccurate" a value of 4, "Neither Inaccurate nor Accurate" a 3, "Moderately Accurate" a 2, and "Very Accurate" a value of 1.

6) Compliance – False Self Present (+)
7) Devaluation of the Self – False Self Present (-)
8) Self-Awareness – Past (-)
9) Compliance – False Self Past (-)
10) Sense of Self Apart from Role – True Self Past (+)
11) Wearing a Mask – False Self Present (-)
12) Self-Awareness – Present (+)
13) Creativity – True Self Past (+)
14) Sense of Self Apart from Role – True Self Past (-)
15) Feeling Seen – True Self Present (+)
16) Feeling Real – True Self Present (-)
17) Feeling Seen – True Self Past (-)
18) Wearing a Mask – False Self Past (+)
19) Devaluation of the Self – False Self Past (-)
20) Sense of Self Apart from Role – True Self Present (-)
21) Compliance – False Self Present (-)
22) Creativity – True Self Present (+)
23) Compliance – False Self Past (+)
24) Feeling Real – True Self Past (-)
25) Self-Awareness – Past (+)
26) Feeling Seen – True Self Present (-)
27) Sense of Self Apart from Role – True Self Present (+)
28) Creativity – True Self Past (-)
29) Wearing a Mask – False Self Past (-)
30) Self-Awareness – Present (-)
31) Devaluation of the Self – False Self Present (+)
32) Devaluation of the Self – False Self Past (+)
33) Feeling Real – True Self Past (+)
34) Feeling Real – True Self Present (+)
35) Wearing a Mask – False Self Present (+)
36) Creativity – True Self Present (-)
37) Feeling Seen – True Self Past (+)
38) Open-ended Question (no scoring)
39) Open-ended Question (no scoring)

How has having a sibling on the autism spectrum shaped who you are?

I think my family's reaction to it shaped me more than he did. My mother in particular was overwhelmed, self medicated, and often treated me as though I was autistic too.

It is because of my brother with autism that I have chosen to be an Advocate for individuals with developmental disabilities. I have found my purpose in life because of what he has taught me through the years.

I think that I have a much better understanding of people's differences. I have also had to do a lot of teaching/restructuring interactions so my sibling could participate with the rest of the family. I also have chosen my career path partially based on having the experience of being a sibling (I am in school for Occupational Therapy). I am good at reading people which I think reflects on the issues around communication my brother has.

I think I have an increased capacity for empathy, but I also believe that empathy isn't usually supernatural -- just well-developed powers of observation plus the ability to interpret what one sees. I feel like I spend a lot of time compensating for people who have problems communicating because I can usually tell what they mean even if they can't figure out how to say it. I don't really feel like I know how to relax and "just be" in any kind of relationship, because that wasn't a part of my childhood...I'm very mentally engaged when I'm with other people, to the point that I allow myself to become deeply exhausted and then need to spend extended periods alone in order to recuperate.

I think is has had a bigger impact that I previously thought. Looking back on things, I realize how much it has shaped who I am for the good and bad. I am currently in school to be an occupational therapist, so having a sibling with autism has made me care much more for people with disabilities than it may have had I had typically developing siblings. It also, unfortunately, made me unable to share my feelings well with others. I believe this is partially by example (when I was younger I copied what my big brother did), and partially because my needs were never as great, so I never wanted to be a problem to my parents. I think I try to hard to appease people, and sticking up for myself often goes the wrong way.

It's helped me connect with others who have had similar experiences, and also to discover my passion for working and learning with people with various disabilities.

It seems that more than I thought, a fact that I have recently found out by meeting other siblings and joining sibnet. Some characteristics of our personalities are very similar, especially along older sisters. The fact that most worries me is my incapacity to start my own family, which I am not sure it is related to my brother's existance.

Learned how to put others needs over my own. More compassionate about less fortunate and those who 'fall through the cracks' in life. I'm way too stoic, not showing my feelings except to those who I'm close too. I still tend to go along with what everyone else wants instead of what I want. I have trouble communicating my thoughts and ideas. Also tend to be non-confrontational, I'll give in to what others want to avoid conflict.

It drove my career choice. It drove how I raised my own children. It drove/drives my relationship with my parents as they age - very difficult relationship. In short, it was the pivotal molder of me as a person, I'm sure. I could write a book...

I currently work with chldren with autism as a special educator. I also feel like I can be more patient and understanding than most people.

Made me who I am today. Influenced the work that I've gone into, both in part time jobs and my current full time job.

Yes it has. I am a special needs preschool teacher thus I relate to the kids families much better than I would without. I love writing and talking about sibling issues. It's a big part of who I am.

It's had a huge impact on me. As a child I felt left out, ignored and as if I had no power. I always used to say I had the worst of two worlds - I had a younger brother who I had to look after, put up with, experience difficulties with, but I didn't have the benefits of having a sibling, such as having someone to talk to, play with, share fun times with. I grew up feeling 'invisible'. I never learnt how to get attention in a positive way. I developed an eating disorder and depression probably as a result of my brother. I craved attention but didn't get it. My brother had no qualms about talking to anyone and everyone, but I couldn't join in. I felt less interesting than him. I was jealous of the time and attention he got from my parents, professionals and friends of the family. My parents viewed me as being really good with him, the caring big sister, but I didn't feel it. I felt frustrated. I wanted to hurt him, hit him, tell him off, but I couldn't. No-one listened to how I felt. No-one supported me in coping with him. As I have got older I realise I am more tolerant of people with differneces. I am training as a clinical psychologist and my experiences with my brother have definitely influenced my choice of career. I would love to be closer to my brother but his ASD makes this difficult. I want him to love me, talk to me, share nice times with me, but he finds this hard. It makes me feel sad. I long for the brother I never had. He too has grown up and is more independent. I find it hard not to 'mother' him these days. I want to help him, do things with and for him, but he resents this. I don't know how else to be with him. To some extent I use him now to shape my own identity. I tell people about him, almost to make me appear more interesting. I want people to feel sorry for me, to understand how hard it was. I want them to see me as being the good, caring sister. I get annoyed that sometimes he can appear really friendly and charming, and people see this and think that is who he is. They don't see the other side of him, all the challenges and daily frustrations. I sometimes wonder who I would be if I hadn't grown up with him. I can't answer that. Would I be more self confident? Would

I have developed so many mental health issues? Would there be another sibling in his place? And what would that mean? I don't regret having him as a brother. He has taught me so much, made me who I am. But I do wish he could communicate more easily and we could be closer. I care for him so much, but I never know if he cares at all for me.

I am an activist and go for the underdog. I also struggle with survivor guilt and am sometime too much of a people-pleaser.

It has made me feel sympathy towards those who have a disability and it has made me more aware of how I treat others.

I think I am more compassionate and empathic to different people. I also have a child with Down Syndrome and feel very comfortable with who he is and don't fret about his diagnosis or his future. I know how valuable he is because I know how much my sister brings to life, in spite of the difficulties and challenges in caring for her.

More patient and understanding

I only have one child - when my son was born I was grateful to have a "normal" kid, that I didn't want to take the chance that a second child would be autistic -- this runs in my family on my mother's side and I think both my parents were "on the spectrum"

The experience of having a brother with autism is fundamental to who I am now. The way I interact with people, the way I respond to problems, and my sense of self are related to that experience. I can't be certain how my life would be different without a brother with autism, but I suspect I would be a less patient, less kind, and less mature person.

Absolutely

I am much more aware of the realities of society and not as idealistic as many of my peers. I am always the responsible and practical one and I'm generally the one in my family to generate new ideas and maintain a forward thinking approach. This has made me very driven and successful professionally, but I'm often thought of as seeming older than my age (both because of my perspective and my professional position). While I feel very responsible for my brother, my parents have given me every opportunity to do what I wanted/needed for myself. The only area where things have been restricted is in what we've been able to do as a family (i.e. where we can go, when and how).

My experience was compounded by the larger family dynamic - 7 children, wide age spans between oldest and youngest; alcohol of both parents but in social climbing ways. My two siblings with disabilities, older sister with athsma then mental illness, and youngest brother with Brain Injury and communication disorder - were seen by mother and other siblings as needing care, but all other sibs were supposed to be "independent" - I had no role, other than the caretaker of my youngest sib, and was ignored by older

brothers. I feel that not only did parents cater to emergencies of my disabled sibs, but so did my other sibs - there were big age differences, so I had nothing to do with my older brothers - this affected me, for I never felt I belonged in my family - I sought support from a neighbor - who was from a different culture - British - and doing this was seen by my family as rejecting them, so we really developed major impasses.

It has shaped me in so many ways. I have become a psychologist and I work with children with autism, entirely inspired by my brother. I have so much patience, tolerance for others' differences, and empathy because of my brother.

I think it's made me more accepting of others, more patient, and probably pointed me towards my current profession (nursing)

Having an older brother in the Autism spectrum has had an impact on me. I am working in the field of Developmental Disabilities and I feel that working with my brother growing up gave me direction on a career.

It has affected my career choice and my social interactions.

While I truly was the "forgotten child," having my brother has taught me to be compassionate, and interested in those who are different than I am. The experience has given me an invaluable gift for seeing potential in others, hidden or not, as well as wanting to cultivate that potential. I feel that when I graduate with my BASW, having had my brother in my life will have benifitted not only myslef, but those whose lives I will touch in my profession.

It has inspired me to be more open-minded about life. I am more eager about living life to the fullest and appreciate what I have.

It made me much more responsible and aware of "the world" and other people's feelings from a very young age. It made me mature very quickly and feel a level of responsibility that is less common for siblings of normally developing individuals.

My much older sibling with autism was violent and abusive on a daily basis when I was a child. He repeatedly tried to sexually molest me and kill me. I have PTSD as a result. No adult--whether in my family or in the special education profession--wanted to believe that my sibling was dangerously violent and needed to be placed in a specialized facility instead of being allowed to terrorize my entire household. They preferred the mythos that All People with Disabilities Are Sweet and Good and Kind, and called me a liar and selfish when I tried to seek help as a child. I paid the price. I can't be around my sibling and my remaining family has disowned me for "not doing my fair share" as caregiver even though at least one of the immediate family members knows the truth. Quite frankly, I got nothing positive out of having a sibling on the autism spectrum, and a lifelong legacy of psychological trauma as a result. I'm an outlier on the spectrum, but I feel my voice needs to be heard to help those other sibs who experienced violence at

home. If my sib had not been disabled, I would have had functioning parents who loved me instead of depressed and in one case mentally ill alcoholics who destroyed the family in their insistence that everything had to be, as Don Meyer puts it, revolving around "The United States of Johnny" even though my sibling was dangerous to everyone in the household and most especially me, the youngest and most vulnerable. I would have learned to be tolerant and compassionate without having to fear for my life every day and having the first time my sibling tried to kill me being when I was six years old. I would have learned to help others without learning to keep silent about my sibling's attempt to incestuously molest me. I would have been a much happier and more stable person if my sibling had been institutionalized quickly to protect me. My therapists and friends say it's a miracle I'm as functional as I am, and that my story is a triumph of survival and tenacity. Fortunately, I've come to believe them.

It opened my eyes to something that most of the world does not understand and has made me appreciate more just the overall idea of being different, as compared to what I think I would have been. I also loathe use of the word "retarded." I'd rather hear the f-word!

Would you like to share anything else about your experience as a sibling to make this study more representative of your experience?

My brother died of renal failure when he was 26 and I was 23.

Although there were many challenges growing up, my parents strived to treat all of us equally whenever possible. To me it was "normal" to grow up with someone with autism because that is all I have known. Although there are parts of my past relationship with my brother I would love to forget, with regards to his aggression towards me, his accomplishments have been a true inspiration to me. We have a very positive relationship now. He is a perfect example of someone that was able to overcome some very negative situations. He is the reason I have chosen the road of being an Advocate for individuals with developmental disabilities. He is the reason many others have chosen to be in the field of special education. He is an inspiration!!!!

Coming from a family of 4 kids we were all a part of the mix and so I never felt like my parents didn't pay enough attention to me. If anything I wished for more alone time! But I think that my family has been really instrumental in creating an inclusive environment.

Once I left home, it was much easier to keep from taking my sister's behavior personally, and I feel like this skill separates me from my parents and my other siblings who haven't lived far away for an extended period. This distance makes me useful to my family in some ways, but I think they resent me for it. I consider my family very emotionally unhealthy, and I think of myself as the family member who is the most unscathed. I sort of always knew that was how it would be...I remember having bad dreams as a child that

my house was on fire and I was getting out, but I was sad and afraid because I knew I would be the only survivor.

I feel that many, if not most, of my brother's difficulties come from his OCD and depression, not simply his Asperger's. What's hardest for me to deal with is the anger and cruelty. Disability in and of itself is fine with me, it's meanness I have trouble with. As I grow older, though, I am coming to understand more of the roots for this behavior, and thus to be somewhat more compassionate, or at least understanding.

Perhaps it is important to remark that my bro has Down Syndrome and that we were raised in South America, where unfortunately the available resources are not the same as in North America.

Hopefully younger sibs are not experiencing what I did. When my brother was born, there was no early intervention, no educational opportunities for him, no support groups for parents or sibs...we were pioneers in having him with us in our home and not institutionalized. That was a brave decision, but devoured our family's energy in coping with him.

I'm scared about what will happen in the future when my parents are no longer around to watch over my brother. I'm also scared to death of having a child with ASD. This is a huge reason why I still don't have children yet even though I've been married for 6 years.

My brother with autism is a lifelong commitment for me.

Having kids was difficult. I've been worried about every aspect of their development becuase I already have the responsibility for one person in the future I hope I don't have it completely for my kids as well. My 3 year old daughter appears to be fine. My son is only 10 months and appears to be fine too. I split up the vaccines on both of my children out of fear and not knowing what to belive.

Much depends on how parents deal with the experience of having a child with autism. My mother has untreated depression, which has been more difficult for me to deal with than my brother's autism.

I often feel like my parents care more about my sibling than me. I feel invisible and that I am not as important as my sibling is.

Look at the longer-term aspects of this: the transition from parental care to sibling care, and the supports, expectations of that. This is what I am facing now, and for all I know, it could completely change the course of life for me and my husband. If there is no residential placement for her, will she need to live with one of her siblings? My brother was never expected to share in her care (another possible survey topic, gender differences in the experience), and since he and my other sister have small children, I expect my husband and I will need to take on the majority of her care. One of my sister's children

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has Down Syndrome, so she has her own plate full. I have always planned to be a part of overseeing my youngest sister's care, but its increasingly looking to fall to me, and my mom is even speaking of it in those terms now. One big aspect: Is there a group home for her? Is it safe and suitable? Will she need to come live with us? That was not the choice of my parents, and it isn't mine, but if she doesn't have anywhere to live, then that might be our only real choice. I love my sister, but I chose not to have children, and may now find that this very decision will lead to my becoming the "parent" to my youngest sister, for the rest of my life. I think there were a lot of possible impacts in earlier life, and that's all huge, but this looming responsibility, which will likely be for the rest of my life, is what really seems to be impacting me the most right now. Also, I would be curious if some of the things we've seen in our family are common to others in which one member has a disability: alcohol use by father, eating disorder in sibling, incidences of depression in each sibling. I've read there may be a genetic component that links each of these, but it might also be a result of the family environment that developed in the wake of having a child with a profound disabiity.

The autism spectrum is incredibly broad. I would suspect that depending on the severity of autism, siblings react in different ways. My brother's autism was severe and his disability completely defined my childhood. I wonder if the same can be said for siblings of those with mild autism?

Just that it was a very isolating experience- a big secret that no one talked about because it was too painful

In my adult life, I felt that my feeling misunderstood enabled me to guess at some of my youngest brother's difficulty, so I began to help him, when he was 24 and had so many seizures and had no way to leave home for adult world. I found it fascinating to watch him learn and appreciate me for helping him - I learned that the service system misinterpreted him a lot - his explosive communication was part of Brain Injury - and a perceptual disability related to seeing and acting with physical things in his surroundings - Dyspraxia, or Developmental Coordination Disorder. But professionals had not learned of this difficulty, it was not added to the DSM IV until the mid 90s, so they only saw his explosive communication, and kept focusing on consequences and behavior for explosive communication or group programs just left him out, and he would eventually drop out. Without insight about his Learning Style needs and communication issues - he was misread. I got him into Mental Retardation programs because he needed the slow and structured learning, but socially, he needed individual help that he never got. They did not see his day to day struggles and eagerness to learn, with simplified, clear steps that he needed to be able to practise. Only in the last several years, was he finally diagnosed, but by then he had begun to fall a lot. Rescuing him from the severe consequences of being seen as a violent,strong young man with explosive communication - I learned to set him up with simplified physical cues, and tie him to local community routines. This worked very well, for he has been eager to fit in, contribute, participate, but doesn't know what to ask for, or how to plan for himself. I'm glad I've helped, and am proud of the innovative work I did - it takes Occupational Therapist kinds of skills, and that's what I learned

mostly - and communication patience, so he trusts me, as I have stood by him and made sure he got consequences or lessons at his pace - but my informal work for him separates me from so many who look at broad based issues, not developmental ones - and even from my other family members. I feel good that I have learned to identify what has gone on, but am lost in the face of bureaucracy, as I try to set up a small plan to take care of myself as well as him, into the future. He lives in a boarding home, 4 hours away, and that's an OK arrangement, but I need to get some supplement to my income, in order to visit him the 4 - 5 times a year that I'd like to do.

There are also a lot of frustrations... my brother relies on me for advice, especially when he is depressed. He ruminates about things which upset me, and I have to spend hours on end trying to console him and point out how he is viewing things in a maladaptive way, but because of his ASD and rigidity and black and white thinking, sometimes this goes nowhere. It's very draining on me... especially because it is so one-sided. It's not like I can go to him for advice or for consolation when I'm feeling down. On the other hand, he has taught me so much, even unintentionally, and I have benefited so much from his presence in my life... so in the difficult times, I keep reminding myself of that.

"Growing up" is a relative term. I didn't think much at all of having a sibling with autism until I was a teenager, but once I did, I thought about it a LOT. As for the "attention" questions, I think I always secretly wanted it, yet whenever I actually had it I felt very uncomfortable. Still do! Good luck with the survey!

Families and providers should not forget the feelings and needs for the siblings.

First, it is important to note that my brother is also profoundly retarded and brain damaged. Second, there are many factors in my childhood that have contributed to my experience and the shaping of me as a person. I have done my best to answer as appropriately as possible to this one, single factor. Thirdly, while I choose to accentuate the positive, there were many difficulties attributable to having an autistic sibling.

It was (and still is) difficult, but it has made me into a very strong and good person. I am proud of the person I turned out to be, and I owe a great part of it to my experience as a sibling.

Yes, please! More of this, so that we can be more heard!

Appendix D
Human Subjects Committee Approval Letter

March 17, 2008

Margaret Dickey

Your revised materials have been reviewed. You have done an excellent job of clarifying your study and of making the other needed amendments. Everything is now in order and we are glad to give final approval to your project.
Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain signed consent documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.
Good luck with this useful and interesting study.

Sincerely,

Ann Hartman, D.S.W.
Chair, Human Subjects Review Committee

CC: Bruce Thompson, Research Advisor

Appendix E
Recruitment Letter

Dear members of SibNet:

  Have you noticed that with the increasing attention paid to autism these days that siblings often get left out of the buzz? That is largely due to the absence of siblings in the research and literature. Now is your chance to let your perspective be heard! My name is Margaret Dickey and I am researching how people are impacted by having a sibling with autism for my Master's thesis at Smith College School for Social Work. I have created a brief survey of 39 questions geared toward finding out more about your experience and how it has affected you. The survey should only take approximately 15 minutes of your time.
  With the identified spectrum of autism disorders on the rise, this research could not be more timely. This is an opportunity for you to contribute to research on an understudied population. All but 2 of the questions will simply ask you to rate how accurate a statement is for you on a scale of 1-7. You will be given an opportunity to share more about your experience on 2 open-ended questions, but please feel free to share as much or as little as you want.
  If you have any questions or concerns, please contact me. If you are ready to get started, simply reply to this e-mail and say you are interested. I will e-mail you back with a link to the online survey. All you have to do is click on it, and it will take you directly to the survey. All of your answers will be completely confidential and before you take the survey you will receive a more detailed explanation about how that works.
  Thank you in advance for your cooperation and support of this research!

        Sincerely,
        Margaret Dickey