BIG/LITTLE SISTER

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Acknowledgments

In J.R.R. Tolkien’s mythology of Middle Earth, three Rings were used by the Elves, the wisest of races, which were more powerful than the Rings given to the Dwarves or to Men. No one in my support system wears any of the Elvish Rings, but I firmly believe they all deserve them.

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Abstract

In this Master's thesis autoethnography, I highlight an often-overlooked intersection between disability studies and family communication by examining key moments in my relationship with my older sister, who has Asperger's Syndrome (the term with which she identifies). I have often taken on the role of protector in our relationship because of her disability, looking out for my sister in spite of being younger than she is. This created a complex big/little sister dynamic between the two of us, shaping how we grew up and sometimes how we still view each other and ourselves to this day. Through memories, artifacts, and both of our voices, I created a performance to dive into what being each other's sister has meant to both of us over the years.

A Note About Disability and Terminology

One project cannot possibly cover the wide range of the word 'disability,' and "since disabled people do not share a single condition, they cannot be—nor should they be represented as a monolithic community" (Couser, 2005, p. 124). While I speak at times about a variety of developmental and learning disabilities, including Down syndrome, cerebral palsy, and intellectual disability (ID), I focus primarily on Autism Spectrum Disorder (ASD). Additionally, at times, I use out-of-date terminology (e.g. mental retardation instead of ID, Asperger's Syndrome in place of ASD). I do this for two reasons. The first is to respect the label with which an individual identifies. For example, when my sister was diagnosed, Asperger's Syndrome was considered to be on the autism spectrum but was still a separate diagnosis from autism. Because of this, she primarily refers to herself as a person with Asperger's, affectionately called an Aspie, rather than an autistic person.[1]

Related to my first reason, my second reason for sometimes using out-of-date terminology is to retain the reality in which individuals have lived. For example, Simon's (2002) sister was diagnosed as mentally retarded in 1961. The reality of that label in that time was very different from the reality of the label ID today. While ID is the current preferred term for the diagnosis and is the terminology that Simon has used in more recent years (Meyer & Holl, 2014), applying it retroactively to Simon's (2002) earlier experiences with her sister Beth would paint a smoother picture of their history and then-current reality than it really was, and in a thesis inspired by a desire to critique the comfort-and-compassion narrative of people with disabilities and their families, I cannot in good faith do that.

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[1] There is division among advocates over whether the person-centered term 'person with autism' or the identity-centered term 'autistic person' is preferable. Both are intended to "emphasize the value and worth of the person" (Brown, 2011, para. 14), and so throughout this thesis, I utilize both terms and a specific one if an individual has indicated a preference for one over the other.

Additionally, I acknowledge that there are many types of families and familial relationships. In a project which is inherently personal by its very nature as an *auto*ethnography, it was natural to narrow my focus in such a way that mimicked my own experiences. Therefore, in this thesis, I am limiting my focus to biological nuclear families. Examples and hypothetical scenarios often focus in on two-child families where one sibling has a disability and the other does not. This is not to dismiss other family situations and experiences; indeed, it highlights how large the research gap is, because there is such a wide variety of situations and experiences which have not been addressed in scholarly literature. I have sacrificed breadth for depth in this case, but I also want to acknowledge the variety of other situations and relationships which I do not address in-depth in this project.

Introduction

Topics in Autism, Second Edition. Siblings of Children with Autism: A Guide for Families. Authored by Sandra L. Harris, Ph.D., and Beth A. Glasberg, Ph.D. (2003), this book was a gift from my parents when I was starting second grade. (If the fact that I was seven years old and reading a book written by two people with doctorate degrees didn't signify a future career in academia, nothing would.) A couple of months earlier, my older sister had been diagnosed with Asperger's Syndrome, finally giving our family a label for her behaviors and traits that had always demarcated her as different. She always stood too close in conversation and moved closer again if you tried to step away. Echoey spaces and fluorescent lights triggered meltdowns, during which she would sob, scream, and suck everyone in the room (and sometimes outside of it) into her world. Every word you said was taken at face value with no consideration for nuances like body language or sarcasm. Everybody always knew that there was *something* going on with her, and her being diagnosed remains to this day "one of the best things that ever happened" to her and to our family "because then there was understanding" (personal communication, March 31, 2020). I was certainly no less happy than the rest of my family to have a clue of what was going on with her all the time, and I became an expert at parroting my parents' explanation: Amelia has Asperger's Syndrome which is a type of autism, and she has trouble understanding body language so you have to be very direct with her, and her mental age is a bit behind her actual age-age so sometimes she acts younger than she really is. That last part was the easiest for me to comprehend. Even though my sister was two and a half when I was born, I had always been the one to be the big sister, and I had always known that when I wasn't helping with her, it was my job to be invisible so our parents wouldn't have to worry about me. My mom and dad had made the effort to find as many books as they could about being the 'normal' sibling, but they could only give me seven.

Thus I learned early the trap of the phrase 'families of people with disabilities.' 'Families' is often used to mean 'parents,' which in turn is used to mean 'mothers' more often than not (Meyer, 2019). As a sibling of a person with a disability (henceforth referred to as a 'sib'), I knew well even as a child that other people didn't get it. Our aunts, uncles, cousins, non-blood family, teachers, principal, friends from church, kids in my class, kids in my sister's class, and more were always asking about and checking on my parents and on Amelia. My identity was always "Amelia's sister" first, with "Tom and Cara's daughter" and "the smart one" tied for second, and no idea what may have come third. And while my sister was my best friend as a kid, sharing fandoms from video games to musicals and so much in between, I pushed her away as I grew more and more bitter over my own invisibility. I was not allowed to complain about Amelia, told so regularly that I didn't understand how hard she was trying that I lost interest in sympathizing with her efforts for years. The rifts that formed in our relationship not only hurt us emotionally, but also hurt our ability to advocate for ourselves and for the importance of our relationship. As the founder of the Sibling Support Project, Don Meyer, often states, “if you’re going to use the f word, you need to be thinking about the family member who will have the longest lasting relationship with the person with the disability” (Goll, 2017). Siblings have the potential for the longest-lasting relationship in the family, and yet the siblings are so often overlooked, forgotten about—invisible. This is true of both the child with the disability and the child without.

Even as an undergraduate, I knew that I wanted to do my Master’s thesis on my identity as a sib and my relationship with my sister, and it only took one foray into performance studies for me to decide that I wanted to do an autoethnography performance. Therefore, to lay the foundation for my thesis, I will first review relevant literature on identity, family communication (specifically storytelling and secrecy, and including a focus on families where one child has a disability when possible), sibs in popular nonfiction—and in particular autoethnographic performance—and autoethnography as a practice. Then I will share the script that I crafted in collaboration with my sister and discuss the live performance of my thesis. Finally, I will conclude by discussing what I discovered, how this thesis contributes to existing work, and new questions that emerged from the performance and the process.

Identity

According to Laing (1969), “‘Identity’ is that whereby one feels one is *the same*, in this place, this time as at that time and at that place, past or future” (p. 86, emphasis in original). Despite its constancy across time and place, though, identity is not formed in isolation. It cannot be wholly separated from what Laing called one’s identity-for-others, a creation made up of one’s identity-for-self, how one sees others, how one thinks others see them, how that impacts the ways in which one sees others, et cetera. In order to form these perceptions and relationships, human beings have to communicate with one another in some manner, such as in a verbal conversation between friends or in a nonverbal message sent by an article of clothing to strangers who walk by on the street. This idea of forming our social worlds via relationship with one another (rather than discovering them as something already out there) is a core concept of Coordinated Management of Meaning (CMM) (Pearce, 1989). In CMM, people simultaneously shape and are shaped by the social realities which are formed via communication. We do this through the stories told, which are how we make sense of the world, and the stories lived, which are how we interact with the world.

As we form our social realities, there are bound to be individuals who have a more significant impact on us than others. Laing (1969) explained complementary identities as "personal relations whereby the other fulfils or completes self. …This function is biologically determined at one level, and a matter of highly individualized choice at the other extreme" (p. 82-83). This is particularly relevant to sibs. In the manner in which I am examining sibs and the sib relationship in this thesis, there is a biological determination factor at play in that the siblings are a part of the same bloodline. The bonds of family are covered more in-depth in a later part of this literature review, but suffice to say for now that these connections run deep. As children grow older, though, it becomes a matter of choice whether or not to remain involved with their family of origin, including involvement with their sibling(s). While most parents would like their children to stay in touch with one another regardless of any child's brain structure, there is often an additional pressure on sibs to remain close to home to look out for their sibling with a disability, particularly if that member of the family requires a lifelong caregiver (Harris &

Glasberg, 2003; Meyer & Holl, 2014; Simon, 2002; Strohm, 2005). Thus while there is a choice to be made, sibs may not feel that they have an equal opportunity to pursue a choice.

In this way, sibs may come to feel like they are only ever ‘allowed’ to be givers—looking out for their sibling and oftentimes for their parent(s) as well (Harris & Glasberg, 2003)—and that being a good sibling means having no needs of their own (Bleach, 2001; Simon, 2002; Strohm, 2005). Because of this, “It may be hard for [the sib] to understand that [they] can have a separate, happy life apart from [their sibling]. Over time, if [they] continue to have trouble separating [themselves] from [their sibling], [they] may grow up to be an adult who cannot lay claim to the basic right to exist as a special, unique person” (Harris & Glassberg, 2003, p. 17). I have absolutely experienced this in my own life, being recognized throughout my childhood and teenaged years primarily as “Amelia’s sister.” For years, I thought that I would redefine myself away from that when I went away to college, and yet throughout my undergraduate career, I found myself constantly highlighting my sister and our relationship in both academic and casual settings. Now, half a country away from home and with no one around me who has ever met my sister before, I continue to emphasize the salience of my sib identity. It is at the core of who I am in every time and place (Laing, 1969). Being a sib has always been and remains more important to my self-perception than other commonly discussed facets of identity such as gender, and although I now claim it as part of what makes me “a special, unique person” (Harris & Glasberg, 2003, p. 17), it has been a long journey for me to get here—a journey I explore throughout this thesis.

This imbalance of give-and-take power between a sibling with a disability and a sib without one is not always only felt by the latter, though. Laing (1969) explained, “A prototype of the other as giver but not receiver, unresponsive or impervious, tends to generate in self a sense of failure. [They] may be successful in different walks of life, but always feels: 'I've got nothing to give really. All I can do is take. Who cares anyway?'" (p. 84). This can lead to the vicious cycle of destruction in phantasy, where eventually the individual "has lost both sense of [their] capacity to give and sense of 'the other's' capacity to receive" (Laing, 1969, p. 84). Again, I have seen this play out in my own family. Regarding the dissonance between our respective identities as the older-little sister and the younger-big sister, particularly when we were kids, my sister stated, "I knew that I couldn't [be the big sister]. But I didn't like that I couldn't" (personal communication, March 31, 2020). This created even more difficulties in our relationship as she grew frustrated with my lack of appreciation for her efforts, driving us still further apart for a number of years.

As both siblings suffer from burnout in their relationship, their relationship may continue deteriorating to a point where they each see each other as 'a bad sibling' (Simon, 2002). Yet even amidst a deteriorating relationship, they may continue to interact closely, simply because they are siblings. Pearce (2005) utilized the concept of logical forces in CMM to explain the ways amidst interactions that people feel they must/should/may/must not respond to the other. There is often an additional layer of logical forces for sibs, aware that there are things which are outside of their sibling's control; these typically feel like subjects which 'should not' be criticized when the reason why they are out of the sibling's control is because of their disability. Additionally, familial bonds in general are a logical force that encourage people to stick together because that is 'what families do' during the good times and during the bad.

Family Communication

As a whole, siblings tend to be overlooked in difficult family situations involving at least one child. Whether the conversation is about mental illness (Flood-Grady & Koenig Kellas, 2019), disability (Canary, 2008a; Featherstone, 1980), or death (Powell & Matthys, 2013; Rossetto, 2015), both popular culture and scholarly works tend to focus on the parent-child relationship at the expense of the relationship between siblings (Greif & Woolley, 2016; Schrodt & Phillips, 2016). Therefore, I will begin more broadly by talking about family storytelling, family secrecy, and the relationship between the two before moving on to discuss the research surrounding siblings. In all of these areas, I include an emphasis whenever possible on families where one person has a disability.

Family Storytelling

Storytelling serves as a means of sharing information and meanings both within and across generations of families. Langellier and Peterson (2004) laid the foundations of "how family storytelling legitimates and critiques particular content to produce 'good family stories,' particular tasks to produce 'good tellings' of family, and particular family definitions to produce 'good families'" (p. 35-36). It is important to note the emphasis on story*telling* rather than simply story; the action of performing a story, not just the text of the story, is what "places issues of meaning and sensibility at the heart of family narrative" (Langellier & Peterson, 2004, p. 40). Family storytelling is conducted through a combination of three methods: ordering content, ordering tasks, and ordering identities (also referred to as group-ordering).

Content-ordering is all about what events become stories based on their tellability and their significance to the family's culture, both in the present moment and for the foreseeable future. These events may become family classics, building the family's identity within itself and to people outside the family as the stories are repeated whether as self-narratives or as stories about another family member (be they parent, child, sibling, or other extended family). In doing so, "they may naturalize family identity as more singular, solid, consensual, and 'clean' than the messiness of family life" (Langellier & Peterson, 2004, p. 56). However, as they continue to be told into the future, the meaning of family classics may be reworked and reinterpreted just as any other stories are. In addition, content-ordering examines the stories which remain untold, a subject which will be covered in more depth later.

Task-ordering is focused on how stories are told, who does the telling, to whom stories are told, and for whom they are told. "Telling family stories is a strategy of cultural survival that requires participation for its success," and task-ordering looks at who participates and in what ways (Langellier & Peterson, 2004, p. 107). Finally, group-ordering examines how families maintain boundaries amidst themselves as well as against outsiders. Langellier and Peterson (2004) describe the family as a "we-relationship [which] is embodied in the intimacy, immediacy, and intensity of family time and family space that structure a reciprocity of perspectives. The 'I' of the person emerges from a familial 'we'" (p. 115). As a result, there may be a singular family member "by dint of character or fate" who defines the entire family's identity (Langellier & Peterson, 2004, p. 120). In a family where a child has a disability, this child often becomes that singular family member.

Families with a child with a disability. Although there has not to my knowledge been any studies regarding how families with a child with a disability conduct family storytelling, there have been studies of how these families disclose information in day-to-day life. Hays and Colaner (2016) studied how families of a child with ASD construct family identity. Using internal discourse techniques (naming, discussing, narrating, and ritualizing) as well as external discourse techniques (labeling, explaining, legitimizing, and defending), parents (and siblings) work to create a cohesive family identity. Creating a shared narrative about the child's diagnosis was something that parents did more for outsiders rather than for the family themselves, and they used rituals and routines to construct a positive "internal identity as a family with normal, structured days" (Hays & Colaner, 2016, p. 152). While every participant expressed a willingness to explain their child's diagnosis, they also noted that doing so could be a burden. However, defending the child with ASD served "as a mark of their loyalty" to their family identity (Hays & Colaner, 2016, p. 153).

On top of constructing a family's identity in conversational discourse, these techniques also highlight how a family with a child with a disability might engage in family storytelling (Langellier & Peterson, 2004). Since a child's diagnosis plays such a large role in family identity, it has a large influence on the family's culture. The story of a child's diagnosis may become one of many family classics specifically tied to the child's disability; therefore, the family engages in content-ordering when they share these stories with each other and with outsiders. Meanwhile, task-ordering and group-ordering arise in Hays and Colaner's (2016) notation that parents' primary reason for creating a shared narrative about a child's diagnosis was for outsiders, while other narratives were constructed for their internal family identity. This answers not only the questions of 'who does the telling' and 'for whom are the stories told,' but also highlights the ways in which families engage in creating and maintaining boundaries, such as defending the child with a disability as a mark of loyalty to the family.

Like many others, Hays and Colaner (2016) only worked with parents, a noteworthy aspect of how researchers have engaged in task-ordering (Langellier & Peterson, 2004)—it is often the parents (and more often than not, the mothers) who do the telling of the family's story. With that said, it is worth emphasizing that other studies have found that, being sibs, "children's identities in their families are situated within sibling relationships" (Canary, 2008b, p. 445; Gordon-Pershey & Hodge, 2017; Steel, Vandevelde, Poppe, & Moyson, 2013) and likely engage in similar behaviors to construct family identity. Additionally, Hays (2016) found that parents of children with ASD benefit from accurate conversations about the diagnosis but suffer from an abundance of them, another finding which can logically be extended to sibs as well. This in turn may lead to how families disclose information about the member with a disability—if in fact they do at all. Although institutionalizing a child with a disability is no longer the common practice that it once was, families may still choose to keep secrets from outsiders or even from members of the family about one member's disability.

Family Secrets

"A family survives by not talking as well as talking" (Langellier & Peterson, 2004, p. 50), and "an untold story gives off at least the illusion of control" (Poulos, 2009, p. 39). Every family works hard to maintain the impression of a 'good family' through their storytelling (Langellier & Peterson, 2004), but managing a family impression is a far more complex task than maintaining the impression of an individual (Poulos, 2009). There are a variety of reasons why families may keep secrets, and there is reasonable justification for many secrets to protect family members and the younger generations. Yet it is true that silences shape family culture just as storytelling does.

Family secrets range from that which is conditionally disclosed, to that which is known but not ever directly addressed, to that which is completely inaccessible for social-historical or psychological reasons (Langellier & Peterson, 2004). For families with a child with a disability, that disability is often a jumping-off point for family secrecy. Parents may conditionally disclose a diagnosis to a child depending on their relationship with one another (Hays, 2016) and/or disclose the diagnosis to sibs slowly in pieces as the sib notices that their sibling is different (Gordon-Pershey & Hodge, 2017). The child may know that something about them is different from their peers (Kelly, O'Malley, & Antonijevic, 2018) yet never receive information about a formal diagnosis (Hays, 2016). Finally, we cannot forget that as recently as the 1970s, parents of children with disabilities were regularly told, "We recommend you put him in an institution and forget he was ever born" (qtd. in Sarris, 2017; Bubenik, Chun-yu, Haas, Hamann, & Utecht, 2019; Calloway, Alexander, Calloway, & Calloway, 2019). This occurred not only in the United States, but around the world (Strohm, 2005). Even now, parents (and sibs) carefully toe the line on what and with whom to share about a child's diagnosis because "their confidants now co-own private diagnostic details regarding a stigmatized diagnosis" (Hays & Butauski, 2018, p. 378). By keeping secrets, families "can protect each other as family groups in a society that is unsupportive and even hostile to their survival" (Langellier & Peterson, 2004, p. 50).

Siblings

The family communication field has tended to focus on the relationships between adult siblings, leaving the study of sibling relationships during childhood and adolescence to other fields such as psychology and sociology. Thus "little is known about how siblings develop, maintain, and negotiate their communication relationships with each other during these formative years" in spite of the fact that "how siblings communicate with each other during adulthood is informed by their childhood and adolescent interactions" (Myers & Kennedy-Lightsey, 2015, p. 229). Myers et al. (1999) made an important distinction between how siblings communicate 'liking' and 'loving' one another. They found that "when siblings establish relational intimacy, they treat each other as equals, establish rapport, engage in self disclosure, and regard each other as friends during their interactions" (p. 346). Liking in particular was influenced by "calm, poised, and relaxed" behaviors, leading siblings who are comfortable together to like one another, while loving was associated with a lack of formality with one another and a deeper commitment beyond that of liking (p. 346). Interestingly, they also found:

> although sibling communication satisfaction was substantially correlated with both liking and loving, the correlation was higher for liking. For siblings, liking may be a more salient concern than loving when it comes to communication satisfaction. Although the sibling relationship is involuntary, the communication behaviors associated with liking may be more voluntary than the behaviors associated with loving. (Myers et al., 1999, p. 347).

This may be influenced by the common encouragement to love one's sibling(s), which may indicate a sense of obligation or necessity to do so (Myers et al., 1999; Rittenour, Myers, & Brann, 2007). In their study of sibling commitment and emotional closeness, Rittenour, Myers, and Brann (2007) found that sibling commitment does not fluctuate too greatly throughout siblings' lifespans. One possible explanation for this is that siblings tend to share a sense of loyalty to the relationship because they have shared a family (whether by blood or not) even if the siblings do not particularly like one another, reminiscent of Myers et al.'s (1999) observation of how loving one's siblings may be seen as an obligation. On the other hand, Rittenour, Myers, and Brann (2007) also found that relational intimacy had a strong influence on sibling commitment as well, returning to Myers et al.'s (1999) idea that liking one another is a voluntary decision which influences the relationship as well.

However, just as in any relationship, siblings often engage in negative behaviors towards one another, too. Interestingly, in their review of the literature around adult sibling relationships, Myers and Kennedy-Lightsey (2015) separated the dark side of jealousy, envy, rivalry, and conflict from verbally aggressive behaviors. However, verbal aggression can be a manifestation of these aspects of the relationship. In their (auto)ethnographic accounts of family bullies, Berry and Adams (2016) shared examples of withdrawal (indicating that a sibling is not wanted), verbal rejection of the familial relationship, and statements of negative affect (indicating dislike for or even hatred of a family member). Each of these types of messages (Myers & Bryant, 2008) were used consistently to bully a family member—two sisters in Berry's ethnographic account and two male cousins in Adams's personal account—creating consistent sources of harmful conflict between the victim and the bully. Moreover, particularly in siblings' youth, there is little chance for escape; as the interviewed sister stated, "I could not run away from my bully, because I lived with her" (Berry & Adams, 2016, p. 57).

Siblings of people with disabilities. For sibs, having a place to get away is even more important (Steel, Vandevelde, Poppe, & Moyson, 2013) as they often feel that their identity within the family is primarily based on their sibling relationship (Canary, 2008b). Similarly to parents, sibs benefit from intervention or support programs, which have a positive correlation with sibs' well-being, coping responses, and relationships with their sibling(s) (Canary, 2008a). During childhood and adolescence, school can potentially be a location of informal support for sibs (Canary, 2008b), particularly if school staff and peers are open to talking about the sibling with a disability but do not demand to do so. However, when teachers utilize the sib as the primary resource to deal with the person with a disability, it has a negative effect on the sib (Steel, Vandevelde, Poppe, & Moyson, 2013). For example, if a student with a disability becomes overwhelmed and has a meltdown during the school day, the school staff will ideally contact the student's parent(s). However, if their sib attends the same school, the sib is easier to access and may be called away from their own schedule to assist with calming their sibling down. In this scenario, the adults in the situation demonstrate to the sib that their primary responsibility is to care for their sibling and that this responsibility takes precedence over the sib's own school experience.

Although Rittenour, Myers, and Brann (2007) found that sibling birth order had a significant impact on sibling commitment for typical siblings, Gordon-Pershey and Hodge (2017) discovered a definitive role asymmetry in sib relationships. No matter whether the child with a disability was older or younger than the sib, the sib took on a more directive role in their relationship, assuming greater communicative responsibility and encouraging their siblings both in play and in matters such as homework. Their parents also observed that the child without a disability frequently exhibited parent-like behaviors towards their sibling regardless of age (Gordon-Pershey & Hodge, 2017).

Thus while "the 'I' of the person emerges from a familial 'we'" in any family (Langellier & Peterson, 2004, p. 115), a child with a disability can often become an even stronger focal point of the entire family's identity, creating complementary identities (Laing, 1969) between that child and the rest of the family. The current sparseness in the communication literature regarding any siblings (Myers & Kennedy-Lightsey, 2015), let alone siblings where one has a disability and one does not (Canary, 2008a), reflects a clear gap to be filled. Yet it has barely been touched upon in the communication discipline. Despite my knowledge that there are sibs besides myself in our field, the sib identity is raised in introductions and dedications rather than being the focus of study itself (Braithwaite & Thompson, 2000; Brennan-Moran, 2020). We certainly do engage in practices of family secrecy (Poulos, 2009) in order to conduct group-ordering and maintain boundaries in our storytelling (Langellier & Peterson, 2004), and as stated previously, there is reasonable justification for many secrets. Nonetheless, although the silence of others has inspired me to work to fill this gap in the literature by sharing my own stories which are not secrets, it can also be disheartening to see my childhood of invisibility reflected back at me in the dearth of academic literature regarding sibs.

Sib Books

To highlight voices other than my own regarding the sib experience, I turned to more popular forms of nonfiction writing: resource books, collections, and memoirs. Of the seven books that my parents were able to find and give to me when my sister was first diagnosed, three are appropriate to discuss here. Written for young sibs, Fiona Bleach's (2001) *Everybody is Different* functions as a resource book rather than a personal account, while Don Meyer's (1997) *Views from Our Shoes: Growing up with a Brother or Sister with Special Needs* is a compilation of short essays written by sibs aged 4 to 18. Finally, Rachel Simon's (2002) *Riding the Bus with My Sister: A True Life Journey* follows a year-long engagement during which Rachel accompanied her sister Beth (who was diagnosed with mild mental retardation) on Beth's daily bus rides around the city. Although my meager collection of sib books has increased slightly in the fourteen years since my sister's diagnosis, I have chosen to focus on these three books because I read all of them for the first time as an elementary student. They were vital to my understanding of what being a sib meant both for me and for others, as well as to my understanding of my family.

Bleach's (2001) book primarily provides resources and answers where possible in a manner that the young sib can understand, using examples like crossing your fingers for good luck to explain why ritualistic behavior can be comforting for people with autism. Amidst her explanations, she resists the idea that the sib must take on a parental role (Harris & Glasberg, 2003; Simon, 2002). Immediately at the beginning of the book, Bleach (2001) states, "[This book] is not about finding ways to make your brother or sister change. Nor is it asking you to help in looking after him or her. There are adults and professional people specially trained to do that" (p. 3). Consistently, Bleach reminds sib readers that they are important, that their feelings matter, and that they are not at fault for any confusing or upsetting behavior that their autistic sibling engages in. As an art therapist at The National Autistic Society's Sybil Elgar School in West London at the time of the book's publication, Bleach had quite a lot of experience working with children with autism and took note of who was being left out: the sibling. For the first several times that I read, reread, and highlighted sentences in Bleach's book, I knew of no one else who had done that. It was another mom from our church, whose autistic son had been in my kindergarten class and whose older son and younger daughter still attended my school, who told my mom about someone else who had seen the invisible kids and decided to do something to make certain that we knew that we were special, too: Don Meyer.

As mentioned earlier, Meyer was the first person to take action to prioritize family members of people with disabilities besides just the mother. In the late 1970s and early 1980s, he was a founder of the program Supporting Extended Family Members (SEFAM) at the University of Washington, the first program in the Northwestern region of the United States to focus specifically on fathers, siblings, and grandparents of people with disabilities. In 1990, he founded the Sibling Support Project, "the first national program dedicated to the life-long and ever-changing concerns of millions of brothers and sisters of people with special health, developmental, and mental health concerns" (Sibling Support Project, 2020). From there, Meyer created Sibshop, events meant specifically for sibs between the ages of 8 and 13 where sibs can meet other sibs, create art, cook, share the good things and the "not-so-good" things about being a sib, play games, and have an opportunity to have something 'just for them' without their sibling(s) who have a disability. Currently, there are over 500 Sibshops in several countries around the world. Additionally, Meyer founded the online communities SibKid, SibTeen, Sib20, and SibNet, and the latter three remain the largest online sib communities in the world (Meyer, 1997; Sibling Support Project, 2020).

Meyer's (1997) compilation of short essays written by sibs covers a wide range of sibs and their families. Writers range from ages four through eighteen; are older, middle, and younger siblings; have only one or have more siblings with disabilities; and have siblings with a large variety of disabilities, including but not limited to autism, cerebral palsy, Down syndrome, hydrocephalus, Fragile X syndrome, and Tourette syndrome. As in all of Meyer's work, sibs are encouraged to share the good and the not-so-good parts of having a sibling with a disability, highlighting many of the way in which having a sibling with a disability shapes an entirely different life experience from families without children with a disability. Seven-year-old Elizabeth wrote about her seventeen-year-old autistic brother, "Sometimes I worry about what will happen to him when he grows up because he might not know how to take care of himself" (Meyer, 1997, p. 10). Other young sibs such as Brandon (age 8) and Derek (age 13) both wrote about how they will take care of their older brother Todd (age 17), who has autism, when they grow up and their parents cannot care for Todd anymore. A sense of isolation also pervaded many of the sibs' writings, as well an awareness that they are often forgotten by professionals and receive less attention from parents and other people, though the majority of writers express sympathy in spite of frustration with parents who devote their attention to the child(ren) in the family with a disability. For example, Allison (age 12) wrote:

> People think of me as "Jacob's Sister," and sometimes I feel like I don't get enough attention from my family. …I think brothers and sisters need to be noticed more. We are special too. My advice to others like me is that you always need to remember that your

> parents love you, no matter how left out you feel. Your special needs sibling needs the special attention at that time. (Meyer, 1997, p. 64)

With the encouragement to open up about the good and the not-so-good parts of their lives, several sibs who sent essays to Meyer expressed relief and gratitude about being able to share their stories in hopes that others would read them and understand a little more about the sibling's perspective. Compiling these stories which frankly discussed various highs and lows of sib life, without an adult's analysis or judgment, allowed Meyer to present a space where it was safe for sibs to be honest with the book's readers. This honesty can relieve guilt for other sibs (both as children and as adults) when they have negative feelings about their sibling with a disability (Simon, 2002; Strohm, 2005); they see that it does not make them a bad person or a bad sibling and that they are not alone in their feelings.

Later, Simon described the day she discovered the Sibling Support Project as "the most momentous shift in my life as a sib" (Meyer & Holl, 2014, p. x) because of the empathy, lack of judgment, and community that SibNet provided, an experience which she and other sibs disclosed they had never previously had. Earlier in her life, though, Simon (2002) was quite used to the overwhelming responsibilities and isolation of being a sib. Throughout their lives, Simon's relationship with her sister Beth was complex. At thirty-nine years old and accompanying her sister on bus trips around the city for a few days every month for a year, Simon still waged war on herself over their relationship. She regularly described the "dark voice" of bad-sister feelings like annoyance and frustration that would arise during interactions with Beth throughout their childhood and in the present. Even in situations where any typical pair of siblings would get annoyed with one another, such as when Beth interrupted Simon's conversation with one of the bus drivers, Simon's primary response to her own frustration was to berate herself for being so hard on her sister: “I wish I were a saint. I wish I were a magnanimous sister who could feel compassion for the way that Beth is re-creating a dysfunctional family environment on the buses. …I don’t want to think, ‘I wish she’d behave a *little* more appropriately today.’ I wish I could *change*” (Simon, 2002, p. 229, emphasis in original). At the same time, Simon recounted multiple instances of pride in her sister, including realizations of Beth’s determination and commitment to finding the bus drivers who are kind and wise, and she recalled fury when others told her that she should be grateful that Beth could function at a level that allowed her to ride the city buses: “I want to shout back, ‘You’re only looking at her disability, not her abilities!’” (Simon, 2002, p. 161). This tension between pride in her sister and frustration with her is normal, but because of Beth’s disability, there is a permanent imbalance in their relationship that consistently reminded Simon to feel guilty every single time that she grew frustrated with Beth. Over the course of their year riding buses together, though, Simon learned a great deal about how Beth had grown since their childhood and came to admire how strong her sister had become. Nonetheless, at the conclusion of their journey when they waited together at the bus stop and Beth chose to board alone, Simon described her reaction as “Too full to move, too empty to think,” (p. 287), caught in contradiction once again but no longer stuck in it. Indeed, on the day of her wedding, Simon credited the year that she spent riding buses with Beth for lowering her own walls and allowing her to find a love for life that she did not have before.

This type of Self-Other reflection, as well as Simon’s participant-observation-esque approach throughout the year with her sister, led Couser (2005) to describe *Riding the Bus with My Sister* as a work which approaches (auto)ethnography. Although it is vague on matters of process and method that professional ethnography would explain in detail, “it was not the organic byproduct of an ongoing relation but rather the result of a deliberate decision on the part of the writer to devote a good deal of her time and energy to sharing, investigating, and documenting an aspect of her sister's life that would otherwise have remained opaque to her" (Couser, 2005, p. 133). Nor did Simon (2002) only talk with her sister about this portion of her life. Throughout the year, she also got to know the bus drivers as well as Beth's support staff and developed a far greater understanding not only of her sister but also of matters such as defining mental retardation and the politics of self-determination. At the same time, much of the book is focused around Simon's own understanding of her sister, their relationship, and the impact of that relationship. It is this deeply personal current which makes *Riding the Bus with My Sister* approach *auto*ethnography specifically.

Autoethnography

Autoethnography is "a critically reflective narrative representing the researcher's personal and political intersections/engagements/negotiations with others in culture/history/society" (Spry, 2011, p. 53). Like the hyphen of Conquergood's (1985) dialogical performance between identity/difference and detachment/commitment, autoethnography exists in a tensive space, "work[ing] to hold self and culture together, albeit not in equilibrium or stasis" but rather "between story and context, writer and reader, crisis and denouement" (Holman Jones, 2005, p. 764). Its commitment to "purposefully commenting on/critiquing…culture and cultural practices" is often noted as a distinguishing feature to separate it from other types of personal work like memoir and mystory (Holman Jones, Adams, & Ellis, 2013, p. 22). However, as Gingrich-Philbrook (2005) noted, other personal methods such as autobiography have long held this commitment as well; instead, he argued, autoethnography is set apart by its work to navigate between "a demand to create knowledge (the epistemic) and a demand to create art (the aesthetic)" (p. 303).

As Holman Jones, Adams, & Ellis (2013) explained, autoethnography began from the intersection of multiple historical trends. As qualitative research became more respected in academia, scholars developed “a greater recognition of and appreciation for narrative, the literary and aesthetic, emotions, and the body” (p. 26). At the same time, identity politics were becoming an important topic of discussion, and the research community became more concerned with the ethics and politics of research. Each of these concerns shaped autoethnography’s development “as a methodological practice that takes seriously the admonitions about what we no longer can do, be, or tolerate as researchers” (Holman Jones, Adams, & Ellis, 2013, p. 31). As the personal turn took hold in performance studies in the mid-1990s (Simmons & Brisini, 2020), both written and performance autoethnography became a staple of the field.

Although the written text is a part of creating a performance autoethnography, performance creates a more immediate and tangible relationship with the audience than a written text. Once a written text is published, it is out there for anyone to read or not read, and you may well never know who reads it when or what it means to them. In contrast, in performance, both the performer and the audience must see each other as human beings rather than just a name on a page or a faceless mass. To me, even if a relationship created with a reader might be strong from the written text, a performance makes it even stronger for that reason. Although the written portion will always be there, re-presenting experiences in an embodied performance autoethnography “privileges immediate experience, the evocative moment when another’s experiences come alive for performers and audience alike” (Denzin, 2018, p. 40). In a thesis all about relationships—the relationship between my sister and me and how that has shaped other relationships in our lives—I wanted to build the strongest relationship that I can. This allowed me to “generate knowledge about the subject matter animating the performance” (Gingrich-

Philbrook, 2005, p. 303), recognizing how my relationship to the audience and vice versa impacts the thesis, including my awareness of what is performed and what silences I maintain. Therefore, in this thesis performance, analysis, and reflection, I have closely examined what was and was not performed (content-ordering and group-ordering: Langellier & Peterson, 2004), how it was performed (task-ordering: Langellier & Peterson, 2004), and how the performance affected my relationship with what is written and who is involved. After all, relationship is a key ingredient of autoethnography (Holman Jones, 2005), particularly performance autoethnography (Holman Jones, Adams, & Ellis, 2013).

Critical autoethnography

While autoethnography as a method can engage in both personal and cultural critique (Boylorn & Orbe, 2014) and one is not mutually exclusive of the other, scholars differ in their starting points. I have dubbed these different starting points of critical autoethnography as the system-centered and the person-centered approach. From the system-centered approach, the researcher begins their work with a focus on systems of power and how they impact groups. Typically, the system-centered approach studies generalized groups (e.g. people of color, people who identify as LGBTQ+, people with disabilities). A performance autoethnography from this approach will still reach an individual level, but it begins with "a commitment to *change*, not just interpret the *world*" (Denzin, 2018, p. 52, emphasis added). For example, Anna Deavere Smith's initial goal for her work was "to have a company that went around and portrayed America" and found a home in academia because of the academy's focus on investigating race and gender in the 1980s rather than beginning with any specific individual (Rose, 2011, p. 440). On the other hand, a researcher operating from the person-centered approach begins with the individual. This researcher's focus is on "articulating how and why and what we think of a *particular* experience in our lives, how we negotiate the various people and situations" (Spry, 2011, p. 54, emphasis added) rather than beginning with a generalized group. It is through a singular person (or perhaps a small number of people) that the researcher comes to the ways that systems of power play out in everyday life. For example, Fox (2010a) began his autoethnography with his relationship with his father rather than beginning with the systemic aspects of Alzheimer's disease and being a caregiver.

It is important to note that the system-centered and person-centered approach are mutually exclusive in terms of their starting points, but only because everything begins somewhere. The performer's initial orientation can easily become blurred during the performance's creation as they scrutinize interactions between Self and Other and the sociocultural context, among other subjects of investigation (Spry, 2011). My distinction between the two is a result of my own struggles with the critical approach, as I have always taken a person-centered approach and continue to wrestle with how much I can claim to take a critical perspective when I offer criticisms of a person who is disadvantaged by systemic issues in the world. There is a great deal of tension in trying to determine how I can consider my work a part of the critical paradigm when critiquing my sister at times. Am I perpetuating ableism which is harmful to her? But the truth of being a sib can be ugly, and the need to normalize that it isn't all sunshine and Santa Claus is one that continues to drive me. Even after completing this project, I don't have the answers, and I don't expect that they will ever come easily. Distinguishing between a critical origin in systems and in individuals helps me to recognize a critical angle on my work, though, and in the end, both the system-centered and the person-centered approach are opposite ends of the same line. As with much else in performance (auto)ethnography, the end result should aim for the hyphen between the two in order to recognize the importance of both the individual and the systems in which the individual lives.

Self and Other can only be understood in relation to one another; likewise, autoethnography cannot be done without at least an acknowledgment of ethnography. As I wove an understanding of myself and my sister in this performance thesis, Conquergood (1985) was always on my mind. I have long seen her Asperger's Syndrome at the core of who we both are, and I had to ask: how do I step back and allow her to interrogate our identities equally as I do? In an ideal world, dialogical performance "resists conclusions, [and instead] it is intensely committed to keeping the dialogue between performer and text open and ongoing" (Conquergood, 1985, p. 9). Finding any answers in this performance and/or this process did not change the fact that my relationship with my sister is ongoing. The lines of communication were and are open between us, and they were opened to a wider audience by the very nature of a public performance on our relationship.

Research Process

As referenced before, I have done a number of projects, presentations, and performances about being a sib. Particularly during my undergraduate career, those were important pieces of my journey to accept my sib identity as a constant across time and place (Laing, 1969) while still "lay[ing] claim to the basic right to exist as a special, unique person" (Harris & Glasberg, 2003, p. 17). However, this thesis was the first time that I was ready to bring my sister's voice into my work, having actively resisted doing so before. I am inclined to describe the reason why as maturity and growth more than anything. I was in elementary school when I proudly told my mom that I would rebel against being a rebellious teenager, and I kept my word throughout high school. To keep up my job of not causing problems for my parents, I could not experience a real rebellious phase until I was out of my childhood home, and while being a straight-laced person remained a part of my personality, my early works about being a sib were definitely a rebellion against my childhood of never being allowed to complain about Amelia. While I was an undergraduate, though, several factors in tandem began to mend my relationship with her. For perhaps the first time in my life, I truly believe that she and I can stand side by side now without losing either of our individuality to the other's black hole.

Therefore, inspired by Pearce (2005), I asked: what are we making together? "That is, what kind of identities, episodes, relationships, and cultures are being constructed by the patterns of communication put together as people interact with each other?" (Pearce, 2005, p. 43). How do my sister and I navigate our complementary identities (Laing, 1969) by our storytelling of our family relationship, including in the secrets that we keep between us and to ourselves (Langellier & Peterson, 2005; Poulos, 2014)?

I wanted to learn how we each recall key moments in our relationship. Did she remember the words? Did I remember the emotions? Moreover, I wanted to examine how we shared them: in private with one another in interviews and in public as we tell our stories in this thesis. There were difficult subjects for us both at times, but of course, there are multiple sides to every story. Like Johnson (2014), my first inclination was always to tell the version that made me look like I was always the innocent one (or at least the most innocent one in the room). However, I am invested in showing that my sister's and my relationship has its ups and downs because of both of us. We are both responsible for making and shaping our realities, and rather than an "accusatory mode of storytelling…and an inability to hear nuances in what the other says" (Pearce, 2005, p. 47-48), I wanted to re-tell our stories in a manner that shows both my sister's and my own agency in creating the situations (Johnson, 2014) which have affected the relationship we share.

One way in which I did this was by including my sister's voice throughout the performance. The inclusion of her voice in this thesis performance has been a key decision on a professional, ethical, and personal level. Professionally, my sister is currently pursuing a career in voice acting and inspires me constantly with her drive, seeking out classes and roles, purchasing equipment and rehearsing to improve the quality of her voice acting, and learning new skills and tricks of the trade. Working her voice into my thesis performance also demanded a higher ethical standard than even doing member checks with her as I wrote the script because she participated in the live performance itself, upholding the standard of "nothing about us without us" as well (Autistic Self-Advocacy Network [ASAN], 2020). Finally, on a personal level, including my sister's voice (literally) was something that I had not done in previous performances. Although I wrote the script, much of her dialogue came directly from our interviews, and I did not direct her performance at all. As a lifelong control freak, including attempts throughout our lives to control my sister (in ways both detrimental and beneficial, i.e. helping her control her emotions to calm down during a meltdown), ceding that control was an uncomfortable thing, especially in a piece that my own "dark voice" complained should only be about me. Discomfort is a necessary ingredient in growth, though, and if I didn't experience any growth whatsoever from doing this thesis, then I would have completely missed the point of everything that I did for this project.

Another method of highlighting both my sister's and my agency in creating our relationship and social realities was to examine a variety of artifacts which have been important to each of our journeys through our relationship. As noted by Fox (2010b), artifacts can provide a jumping-off point in autoethnographic works. While they cannot represent the whole of even one individual's experience, let alone the entire range of experiences which a community may have experienced, "artifacts do, however, say something important and heuristically provocative about the culture from which they were taken" (Fox, 2010b, p. 125). In preparation for the performance, I returned to my old journals, previous performances that I have done about being a sib, the sib books (both fiction and nonfiction) which I own, and the posts that I have made in the SibNet and Sib20 groups on Facebook. The artifacts of my sister's that I examined included the two-page letter given to both sides of our extended family when she was first diagnosed, the letter given to her teachers at the start of every new school year post-diagnosis (specifically, the letter from her senior year of high school), and her drawings of how she thinks of numbers. With the exception of exact words from my journals and my SibNet and Sib20 posts, all of these artifacts found their way into the final performance and will be discussed in more depth later.

Before writing the script, I conducted four semi-structured interviews with my sister about key moments that she remembers from our relationship. These key moments, or "transformative experiences" as Spry (2011, p. 123) refers to them, were the foundation of my performance script alongside the aforementioned artifacts. Armed with those memories from both of our perspectives and artifacts from both of our personal histories, I nonetheless struggled with actually creating the script. One section from my freewriting stands out:

> Why can I not commit words to a page? Because someone might read it. Someone might read it in its raw, unprepared form, and…you don't take a kid whose whole life & identity revolves around "no one must know I am struggling" and face her with the risk of "someone might read this and know."

Considering that I am consistently driven by the desire to normalize talking about the not-so-good as well as the good parts of being a sib, the irony of this struggle does not escape me. As noted by Spry (2011), the autoethnographer "may believe ethically in a part of the text, but still be coming to terms with meaning [they have] made about parts of the experience" (p. 186). In my case, I constantly wrestle with the desire to normalize the reality that sibs don't have an easy life against accusations (both external and internal) of ableism. The person-centered approach to critical scholarship still doesn't feel like enough. I still find it the best way to conceptualize how I might work within the critical paradigm, but can I call this particular project a work within the critical paradigm? My experience with the critical paradigm has often been the paradigm itself doesn't care about the middle-ground. It doesn't matter that my voice has been less powerful than my mom's; all that matters is that it's been more powerful than my sister's. So can I call this part of the critical paradigm when my own voice is a pillar of the piece, even when Amelia's is a pillar, too? Can I really say that I am fighting for my sister just as much as myself when I am critiquing her for things which I know are a result of her Asperger's Syndrome? I don't know that I will ever have an answer to this question. Truthfully, the only healthy solution that I have found to this struggle thus far is therapy, with better results from a therapist who isn't new to me—not really an option when using your university's counseling center since the start of your undergraduate career has meant getting a brand-new therapist every year. Luckily(?), I have been wrestling with this since long before I started therapy, and the combination of insomnia and a truly ridiculous number of miniature Coca-Cola cans to stay awake the following days served me well.

Ultimately, the script came together when I stopped trying to write the whole thing and started putting pieces together. At one time, I had thought that I would reverse who told whose important stories, but Amelia's explanation of remembering emotions rather than details made me realize that doing so would be to cram my words into her mouth and vice versa. This intention remained in a lighthearted moment in the script where we each spoke about our mom's pregnancy with the other, but when it came to the heavy emotional topics, we needed to tell our own stories. Once I accepted that, piecing together the segments that I had in mind became a much smoother process. The final written script did not vary greatly from the first draft at all, and with Amelia's approval, numbers, and voiceover clips, I created the background visuals to accompany the performance and provide a visual grounding for Amelia's voice (see Appendix A).

Walking into the first rehearsal, I had a bird's-eye view on how I wanted the space to be arranged. The symmetry of the stage was never in doubt: two chairs in the middle where the ending would take place, and an area on either side for different stories. That said, my vision was very linear; Dr. Rose, Dr. Schares, and Jake were wholly responsible for the depth added to the piece by the different positionings of platforms up- and downstage and for the idea to place various artifacts on the floor throughout the performance, a decision which I will discuss in more depth later. As I rehearsed, small variations between the written script and the words I spoke began to crop up, as we knew they would. "As you try on the words of the text, your body and the language you created for/from your body will transform one another as you engage the process of becoming the persona, of matching bodies" (Spry, 2011, p. 176). To maintain this aspect of the process, I have adjusted the major changes in the written version of the script (e.g. switching the order of the books referenced in the beginning of the piece) and indicated live, unwritten moments within bolded brackets in the written version of the script included here.

While preparing for the in-person audience, I also worked with Chad to prepare the YouTube livestream to accommodate virtual attendance due to the ongoing COVID-19 pandemic. In addition to opening the performance up to a larger remote audience (including people who could not have attended in person even under non-pandemic circumstances, such as my friends back in Minnesota), this also allowed me to watch the performances afterwards. Although we encountered consistent problems during rehearsals with Amelia's voiceover clips not playing correctly (often skipping the first word or two, or simply not playing at all), they were running smoothly during our audio cue tests before the show began on opening night. My parents, sister, and one of my aunts were among the in-person audience, and with an instrumental of 'Open Up Your Heart and Let the Sunshine In,' the show began.

Script

Instrumental pre-show music
Let the sunshine in
Face it with a grin
Smilers never lose
And frowners never win
So let the sunshine in
Face it with a grin
Open up your heart and let the sunshine in

Lights raise. I am looking around with a soft smile.

The Sunshine Room. That's the nickname for my childhood bedroom. Painted bright yellow, with Tweety Bird wallpaper to this day. It really needs a good cleaning, though.

Amelia:

clap clap clap Okay kids we're gonna be helping out with some—no, no, no, no, Tommy, put that back, that is not a toy. No. *Meanwhile, I'm playing with the curtains* Okay we're gonna be helping out with some housecleaning, we're gonna open up the windows, let the sunshine in. *I push open the back curtains. I find a snack(? Questionable, as proven by Amelia's next words)* and Sarah no, no, no, you can't eat that. No. *I start giggling as I move over to the bookshelf setup* Ryan, would you actually help and stop laughing at me?!

as I'm picking up journals and folders and casually examining them That's my older sister, Amelia. That bit got her to the quarterfinals in a voice acting competition this winter. Her first time competing, and her bit got her through when they cut over 300 other people. How awesome is that?

How to describe our relationship…*I reach for the books* Ah, here's a good start. *The Sibling Slam Book: What It's REALLY Like to Have a Sibling with Special Needs.* I met the editor when I was nine, you know. Don Meyer. Wonderful guy. *open up* "Reader, what should we know about you? / I'm nine years old, and I LOVE to read." *chuckle, look up at audience* That's an understatement.

pick up another Ah, here's a good one to explain Amelia. *The Way I See It*, by Temple Grandin, Ph.D. If you're not familiar with her, you need to be. She's basically the original autistic self-advocate.

pick up another Here's another one. *Siblings of Children with Autism: A Guide for Families.* By Sandra L. Harris, Ph.D, and Beth A. Glasberg, Ph.D. Not one, but *two* Ph.Ds here. You know I was given this book as a seven-year-old?

The image on the screen shifts to a circle split three ways: Amelia's 2007 "1" and 2021 "1" with the indications as such, and the word "ONE" If that didn't signal a career in academia, I don't know what would have.

set books aside But enough of me talking about Amelia. She's perfectly capable of telling you about herself. *return to folder, pull out school letter, reading it as she speaks*

Amelia:

"Hi,
My name is Amelia and I will be in your class this semester/year.
Some of the things I think you should know about me are:
I have Asperger's Syndrome.
I have a hard time understanding body language
I think in pictures
Sometimes I can get really stressed."

Alicia:

Hoo boy can she ever. I mean—*stop, guilty look, clears throat* You've got to remember, this was the mid-2000s. My sister and I were both still children. Elementary schoolers. She was going into fifth grade; I was going into second. I knew what autism was in a vague sort of way—a boy who had been in my kindergarten class is autistic—but Asperger's Syndrome hadn't actually been folded in under Autism Spectrum Disorder yet. And certainly none of my classmates knew what it meant if I said, "my sister is an Aspie." So I memorized a basic explanation complete with examples pretty quickly.

"Amelia has Asperger's Syndrome which is a type of autism. Her mental age is a bit behind her age-age so she acts younger than she really is, and she has trouble understanding body language so sometimes she stands too close when you're talking and only talks about the stuff she likes."

Of course, adults want a bit more information than that. *pull out two-page letter* Our parents wrote this letter to our extended family and friends in 2005 to explain what that meant, **[**and some of it is a little outdated now because of Asperger's Syndrome being folded in under Autism Spectrum Disorder,**]** but the most important part of the letter is really the ending:

"She is what she is and she cannot help it.

Before this diagnosis she was our sweet little Amelia who was very smart, and very sensitive. After this diagnosis, she is still that same sweet little girl.

She is not "fragile" or "mentally unstable" and does not need sympathy. We do need to realize she has different reactions, and must deal accordingly with them. It is okay to help her recognize inappropriate social behavior, but understand that this is not willful misbehavior, and correct with compassion."

look up with a frown **[**Correcting with compassion…**]** Some people are better at that than others.

Image behind shifts to Amelia's "2"s/the word "TWO". I move away from the 'bedroom' setting, while Amelia's voiceover comes in "Asperger's is part of who I am. It's not all of who I am."

I've found that in many ways, my sister's and my brains operate differently. That seems like a 'duh' statement—but I'm not just talking about her Asperger's. At least, I don't think I am. Like, for example, take the way our brains automatically categorize spoken communication. I think in words. *gesture to "TWO" on screen* She thinks in pictures *gesture to 2007 "2"* that change. *gesture to 2021 "2"* **[**I mean, just look at how abstract they were when she was twelve versus how concrete they are now, even if these images are only a partial representation of what she sees in her head.**]**

Is that an Aspie thing for her? I don't know. It seems like most of the people who I ask think in pictures, and many don't even have the "Asperger's personality" that my mom sometimes teases me about having. But Temple Grandin talks about thinking in pictures as a key trait of many autistic people—and like I said, she's basically the original autistic self-advocate, so I'm inclined to trust her.

It's one of those things I don't ever really expect to have an answer for. You get used to those pretty early on when your sister isn't given a diagnosis until she's ten years old.

That's not to say that you don't know that answers are missing, though. All of us knew.

Amelia:

I was never not aware of it, you know? And since I got diagnosed the summer before fifth grade—these were the people that had dealt with me being like this since preschool, kindergarten, first grade… Mom said there were people brought into my class to talk about it, and they didn't come in until the last half hour. She tried to tell them they'd need more time, but they were like "oh no, we know what they're gonna ask, and we cover it." *laughs* They had to hold the buses 'cause my classmates had questions, and they still had to be like "okay, we have to stop now, you have to go on your bus."

Alicia:

laughs Yeah…in a small school where everybody's had everybody else figured out since kindergarten? If you were in the *building*, you knew when my sister had a meltdown, and they were often in the room for the start of it. She could cry and wail and scream with the best (or worst) of them. And her classmates had known her since long before she worked out ways to calm down.

Back then, it didn't really seem to take much to set her off. Big echoey spaces. Too long underneath fluorescent lights. A lack of windows.

pause, look around the blackbox

Well. At least no one's wearing hot pink.

That was a perk to uniforms in elementary school; nobody could wear the colors that set her off except on 'dress down' days. *pick up Amelia's letter again* But there were still a lot of other stressors around.

Amelia:

"Some of the things that make me really stressed are:

Bright colors (especially vivid pink and muddy green)

Fluorescent lights
Loud noises and echoes (like on the bus or in gym class)
When kids are not following rules
When I feel like nobody is listening to me
Working in groups
Bullies
Bugs, especially flying ones (bees, flies, mosquitos, gnats, etc.)
When someone uses the phrase ‘oh my god’”

Nobody likes a stressed-out sibling. I know, typical siblings have a very push-and-pull relationship where they give each other a hard time and get each other worked up—but my sister and I, we’re not like that. We couldn’t be. Because here’s the thing: part of being an Aspie is that my sister is a very literal person. When an old dog of ours was sick and then recovered unexpectedly, our parents teased that to pay for the dog’s continuing vet bills and food, they were going to have to get rid of one of us. I got that it was a joke; Amelia burst into tears.

Seriously. Yeah. We were both in elementary school, but *I* was old enough to get the joke. *She* just—*stop, guilty look, clears throat*

I did what any sister would do. I looked out for her.

And she had her ways of looking out for me, too.

Numbers shift to “3”/“THREE” *I read from The Sibling Slam Book* “Reader, how would you describe your relationship with your sib? Extremely Close.”

Amelia:

For Christmas—I was seven, Alicia was five—and we both got Game Boy Colors. I got Pokémon Silver Version—which is the second generation, the Johto region—and Alicia got Blue Version—a first generation game, set in Kanto. I don't remember what I named my character, but I remember spending ten, fifteen minutes on the rival name, trying to find where those darn question marks were. And I finally found them! And I named him what he *told* me his name was. Question mark, question mark, question mark. And I didn't skip the tutorial that was actually optional, because *I* wanted to know how to play the game!

Alicia:

nervous laughter I thought it was like the show!

Amelia:

She got stuck, and I found out she only had her starter Pokémon: a Venasaur now, fully evolved, and nothing else. So I told her to go to the PokéMart to get some Pokéballs.

*little Alicia voice **[**together**]*** The what?

audible facepalm/forehead smack The building with the blue roof.

Alicia:

laughing for real now She made me go all the way back to Pallet Town—the very beginning of the game—and just throw Pokéballs until I caught a Pidgey. And then walk through all of the towns and routes of the whole game again to build up his level and catch more Pokémon the way I should have been from the start.

[I know that sounds like an obnoxious older sister thing to do, telling me how to play my game, but trust me,] When you're two little kids who are absolutely obsessed with that series, there's no greater way of showing off how cool you are than that.

Numbers transition to "4"/"FOUR"

I hum, as Amelia sings "You teach me, and I'll teach you~ Pokémon! Gotta catch 'em all, gotta catch 'em all! *I join in* Pokémon!"

Alicia:

I have a lot of happy memories like that from being a kid. A lot of them from shared fandoms. Man, it seems like we never liked different things from each other back in those days. *picking up things from superheroes to Pokémon to Doctor Who, smiling and showing them to the audience before placing them on the ground*

[Pokémon, the OG, our first love. That will always hold a special place in our hearts.

Doctor Who, a little more recent. Our first Doctor was Eight, and as any good Whovian knows, you never forget your first Doctor.

Final Fantasy VII. Probably the most current and the biggest reason we need the PS5 to stop selling out before we can buy one.

Another OG, superheroes. Marvel, DC, doesn't matter, we love them all. Though I will say, she's a little more inclined towards Marvel, I'm a little more inclined towards DC. *stage whisper* I'm right.]

*reach *House Rules*. Stops. Holds it up to the audience* I probably shouldn't have read this as a kid. I was in middle school by that point at least, but…yeah, there's definitely some inappropriate content. But it was so rare to find a book that *got it*.

read the back of the book aloud "Jacob Hunt is a teen with Asperger's Syndrome. He's hopeless at reading social cues or expressing himself well to others, though he is brilliant in many ways. But he has a special focus on one subject—forensic analysis. A police scanner in his room clues him in to crime scenes, and he's always showing up and telling the cops what to do. And he's usually right. But when Jacob's small hometown is rocked by a terrible murder, law enforcement comes to him. Jacob's behaviors are hallmark Asperger's, but they look a lot like guilt to the local police. Suddenly the Hunt family, who only want to fit in, are directly in the spotlight. For Jacob's mother, Emma, it's a brutal reminder of the intolerance and misunderstanding that always threaten her family. For his brother, Theo, it's another indication why nothing is normal because of Jacob. And over this small family, the soul-searing question looms: Did Jacob commit murder?"

Amelia:

I had mixed feelings about the book. It's hard not to get agitated by the system being so set against…like I had to take it in small doses, because it's like "he can't help it! Stop it!" And so of course the times that I'm watching him do these things that I've learned how not to do *and* watching the system burn him for it and like, I'm cringing and I'm angry and I'm just, okay, we're done for the night. And having the chapters from the mom's and the younger brother's perspective…I don't like the parallels for you guys, either. I acknowledge that they are accurate, but that doesn't mean that I like that they are. And I don't think that it would have been a good idea for me to have read the book before. Because I would not have been able to leave it as parallels, if I had read it when the two of you did. I was not emotionally capable of saying, “these are the characters, this is my family, they are similar but not the same.”

I think it’s accurate and well-written. But I don’t like it.

Alicia:

silently listens *looks at book again* All of that is valid.

And yet…

starts picking up other books

Riding the Bus With My Sister. Nonfiction, older sister who spends a year with her younger sister, who was diagnosed in the 60s with mild mental retardation.

Wonder. Fiction, some chapters from the perspective of the older sister of the main character, who has facial deformities.

Rules. Fiction, all about a twelve-year-old girl whose younger brother has autism.

gestures to all four These were the only books I had as a kid that told the *story* of being a sib. I had a couple others with mini essays and write-your-own-and-read-others’-answers and explanations and reflections. But these were the four. And all of them are great. But this one…*returns to *House Rules** *opens the book and reads aloud*

“So I run interference. I’m the one who physically drags Jacob away from a conversation when he’s starting to freak people out by being too intense. I’m the one who tells him to stop flapping when he’s nervous on the bus, because it makes him look like a total nutcase. I’m the one who goes to his classes before I go to my own, just to let the teachers know that Jacob had a rough morning because we unexpectedly ran out of soy milk. In other words, I act like the big brother, even though I'm not" (Picoult, 2010, p. 12).

set the book down

This was the only one to understand that being the younger sibling didn't mean being the little one.

Numbers transition to "5"/"FIVE". I move to the other side of the stage, where a single chair is placed on platforms

Amelia:

Do you remember *ElfQuest*? The 'now' of wolf-thought? They didn't think too far in the future or the past, they kinda were in the now. The 'now' of wolf-thought. It's kinda what I try to do, in general. Good things and bad things. Because otherwise I hold onto things too long. Which is why *effects* of things, I keep. But the memory of a specific thing, unless if it was a big event or a funny story, I don't usually keep 'em. If I really try, I can after a while, but I like just holding onto the aftereffects of this improved, this got better, this changed, rather than 'here's what happened that caused these things.' The feelings are kinda part of that…depends on how much I want them to be. There are some feelings that I don't want and some I do. And it's not like I forget that the things ever happened. If someone else talks about the thing, there are good odds that I'll remember the thing. But they go to a different part of my brain that I don't just pull from on my own.

Alicia:

God, I wish I could do that. She remembers how things felt—the pain, the sorrow, the joy—and not necessarily so much about the event that caused the feeling. I remember details—the order of events, who was standing where, whose phone we used—and far, far less about the feelings. But sometimes, I remember enough.

Take for example the day-long Safe Driving course that the two of us took back in 2011 in a classroom with fluorescent lights and no windows. I remember the two instructors—two White dudes, one probably in his fifties, the other maybe in his thirties or forties—starting the day with a video that showed pretty thorough consequences of texting and driving. I remember closing my eyes and telling Amelia to do the same before the video began and to plug her ears, too, because I remembered how upset such videos made her when she took driver's ed. I remember [not plugging my ears,] peeking and [really] wishing I hadn't.

I remember a tight atmosphere while we ate lunch outside by ourselves and knowing a meltdown was coming.

See, when my sister is tense, it radiates from her. But there's a difference in the tension of being upset and teetering on the edge of a meltdown that I think it's safe to say our immediate family knows better than anyone. It's like…if a thunderstorm is coming anywhere around the world, a lot of people get headaches and stuffy noses from the barometric pressure change [and other cool science-y things that I don't know]. But if a thunderstorm is coming in Minnesota, we'll have those things, too, but we'll also *smell* the incoming storm. The shift in the atmosphere, not quite the scent of rain yet…there's an anticipation that we're attuned to.

I guess I don't know if that's specifically a Minnesota thing, but I make people laugh out here when I mention smelling a storm coming.

[And don’t get me wrong.] Nobody’s so insensitive as to laugh when you talk about your sister’s meltdowns, but *God* [when she’s *having* one]—

breathe, settle down, return to story

I remember everyone taking a turn on one of the four driving simulators. If you’ve watched “The Big Bang Theory,” the episode where they try to teach Sheldon to drive and Penny hits him in the face with a pillow to simulate the airbags going off when he crashes? Like that. *sitting in a chair, mimicking driving position* They had audio of a friend in the car and people jaywalking and all kinds of things to make you notice the world breaking the rules without losing focus on your driving.

I remember being tense during my turn, but not like Amelia. My tension was a crack of lightning across the sky—focused, direct, aimed at the dumb little annoyances like the friend refusing to wear a seatbelt and whining about wanting you to call another friend while driving. Amelia’s was the flash of lightning—spilling all over the sky.

One of the rule-breakers in the simulator was a guy running across the crosswalk when you had the green light. And during her turn, Amelia hit him.

Obviously, that’s not a good thing. The simulator played the ambulance sirens, red lights flashing, dude lying there in the crosswalk. Screen goes dark. Then it played a video of a real-live person—a judge—giving the decision of a sentence for the driver for vehicular manslaughter. Screen goes dark again.

Now, I had already been standing next to my sister, watching her just like she had watched me. I was already holding her shoulder, feeling her shake, noticing the tears form and spill down her cheeks.

But the sound of sirens drew a crowd.

My sister and I were the youngest people in that class. And yet these *actual adults* circled around my sister's driving simulator and *watched* the fallout. The *shit-eating* grins on their faces when that clip of the judge played—!

And the instructors? They did nothing.

I chased the rest of the students away from her. Literally chased. I think I was one sentence short of threatening to punch one of them. I took her to another classroom that we had been in earlier that day that [still had fluorescent lights and no windows, but at least] we knew was unlocked. I sat on her lap because a physical weight grounding her helps and reassured her while she wept and called home [from my phone] when she was ready for me to. I put the phone on speaker and explained to our parents because she couldn't get the words out through her tears. I stayed long enough for her meltdown to shift down a notch to only sobbing, and then I asked if I could leave her on the phone with Mom and Dad.

I re-entered the main classroom just long enough to make eye contact with the instructors. *jerk head in a 'come on' motion* People were working on a worksheet, so they both came out into the hallway with me. Then they *finally* asked if Amelia was okay.

"She will be. But you need to tell me right now if there's going to be anything like that again."

[They had never dealt with a meltdown before, so of course] They stumbled over words. No, we were done with the driving simulator. No, there were no more videos. Was I sure she was okay?

"She will be. But we're going to stay in the other room for a bit."

Did we want the worksheets? Was she really okay?

"Sure."

I waited for them to grab the worksheets and bring them to me, along with a couple of pencils. **[**I took the dumb worksheets. Immediately ditched them on another desk near the door.**]** And I went back to cuddle my sister until the day was over and our parents picked us up, at which point **[**my dad drove and**]** I rode shotgun so my mom could sit in the backseat with Amelia.

I would do it all again in a heartbeat if Amelia needed me to. Without question.

The only regret I have about my behavior that day is that I didn't actually punch the one guy who had the nerve to complement his grin with snickering.

Can you imagine some dude in his twenties having to explain that he got punched by a thirteen-year-old girl?

Numbers shift to "6"/"SIX" Can you imagine being a thirteen-year-old who already didn't like the idea of driving, taking an all-day course intended to build on your pre-existing driving skills?

Can you imagine what would have happened if I hadn't been there?

Amelia:

I'm glad you were there. There were times looking back at it where I hated it, but at the time, it was just immense gratitude. And, and like I said, the reason looking back why I hated it was like "ope, there's another example of how I'm a failure as a big sister!"

Alicia:

quiet for a moment, doesn't address Amelia's "failure as a big sister" comment except with a small head-shake My sister needed more. That's just a fact. And so it was my job to need less in turn.

And if you want to know deep-seated my role as 'the easy child' is, I will truthfully tell you: it goes back to the *womb*.

When our mom was pregnant with Amelia? She lost so much weight, because she couldn't keep hardly any food down. Plain yellow potato chips—not even Ruffles! **[**That's a very important detail. She made sure to remind me of it.**]**—they'd stay down for a few hours, and that was about it.

Amelia:

When our mom was pregnant with Alicia, she couldn't get enough food. "WHAT ARE YOU DOING YOU DROVE BY THE MCDONALDS? Ok ok there's a Wendy's coming up aaaaand you passed it. Arby's? Come on, give me something!"

Alicia:

Mom was in labor with Amelia for 30 hours at the hospital. It was that long before our mom, tough lady that she is, whimpered, "Help me." The doctor whispered to the nurse, who perked up. "Super sucker? I can get the super sucker!" They had to suck my sister out of the womb, and **[**she was so ticked off about it that**]** on the way, she broke Mom's pelvis just for good measure.

Amelia:

Mom spent 12 hours at the hospital in labor with Alicia. She and Dad brought calming instrumental CDs, and every doctor and nurse who walked into the room relaxed. “Oh this room is so nice!” She fell asleep between contractions, and Alicia was out of the womb so fast that the doctor tried to slow her down.

Alicia:

And we’ve continued on that way since. Amelia is a homebody; I’m an adventurer. And I don’t think either one of those is a bad thing. It’s just that, when you’re a homebody in a small town and *everybody* knows…

During my formative years—all the way until I went to college **[**and even sometimes then**]**—I was always recognized first as “Amelia’s sister.” And I just *knew* what people meant by that.

You’re associated with failure. With meltdowns. With “spoiled.”

No! *I* am not those things! Separate your negative connotations from me. Separate her from me.

She is more. More than those negative things. More than any of you know. More than any of you.

(She is too much. ***[****But****]*** *She wouldn’t be Amelia if she wasn’t.)*

Numbers shift to “7”/“SEVEN” And nobody could do what she did.

Amelia:

I boycotted math class. I couldn't tell you what specific thing led to it anymore, but the teacher was dismissive, he was rude, he would slam on people's desks…he wouldn't have any regard for my needs. And I finally said "no. I can go to the special needs room. I can do that every hour of this class." I don't remember saying this specifically, but apparently the special needs teacher told me that I wasn't allowed to boycott it, that I had to go to class, and Mom says that I looked at her and said "that's what they said to the ladies who were protesting for the right to vote. They weren't allowed to, but they did it anyway." So, yeah, for a while, I would just go to the special needs room every day for the regular time and then also for that time.

At some point, we had arranged a meeting. Mom said she couldn't go, so then I went and invited Dad, and Mom said "uh, he's on the side of you should be going to class." And apparently, I looked at him and said, "You're uninvited." Well he came anyway, so it didn't work. I'm still glad he did.

Here's the other thing about this teacher; he was a basketball coach. He's a tall guy. So I had the meeting and we worked something out to make it easier because of my needs. And so this guy that's about somewhere around six feet, to this little high school girl: steps up, looms over her, and says, "I am the one in charge of this classroom." According to Mom, if you have to say that to the little high school girl, you're not in charge anymore.

Alicia:

She's right. And that was the proudest I'd ever been of her. That was something I was proud to say "look what my sister did! Look who my sister is!" [I mean, come on. "That's what they said to those ladies who were protesting for the right to vote"? That is up there with "there's no need to call me sir, professor" on the list of top ten clapbacks. She was badass. She was rebellious. She was advocating for her needs.**]**

So naturally, when I had that same teacher for algebra, he never brought it up to me. **[**He was the *only* person to never identify me as "Amelia's sister."**]**

It's probably for the best. I don't think he was as proud of her for it as I was.

But it would have been nice. If someone had seen. If someone outside of our immediate family had reacted with, "Your sister did that? Wow. **[**That's awful that she had to do that, but that's incredible that she's advocating for herself like that.**]** She's incredible."

Numbers shift to "8"/"EIGHT" Because I would have agreed.

I *know* that I would have. Because I know I was proud. God, **[**I mean, I was in middle school at that point and**]** I hated my sister **[**pretty solidly by that point**]** in high school, but I was proud of her for that. I *bragged* about it!

Stop. Wide-eyed. Still

Amelia:

What's wrong?

Alicia:

I…

Nothing.

Amelia:

Are you sure you're okay?

Alicia:

Yeah…yeah, I'm okay.

Numbers shift to "9"/"NINE" *whispers* I have to justify and insist that I was proud of my sister, because if you knew me in those days, you would've doubted that I was telling the truth.

pacing I'm not lying about any of it. I was so proud. And I am fine. I really, truly am.

[That sounds like a lie, doesn't it? But I'm really not lying.**]**

stop How do I explain? **[***looks down at items on the ground* As I always do. With fandoms.**]**

Any "Doctor Who" fans in the house? My family, we're big geeks. I've taken to calling this feeling my Cyberman Mode. See, the Cyberman, they've deleted all emotions. They believe emotion is a hindrance and its elimination is improvement. Progress. And *God damn* if I don't believe them sometimes! Just imagine! No pain. No guilt. No hatred. No feeling guilty because you hated the people you're supposed to love.

…I sound like a psychopath, don't I? Or a sociopath. Or like someone who wants to be one of those. And while I love my BBC Sherlock "I'm not a psychopath, I'm a high-functioning sociopath, do your research" quote, neither one of those is actually a real healthy life goal to have.

But **[**what can I say?**]** I've always been a fan of the bad guys. Draco Malfoy. The Joker. When we went to Universal Studios the summer after fourth grade, Amelia came up to me in one of the shops with the biggest grin on her face and said, "I found your shirt," **[**I was like "what are you talking about, we've never been here before, I'm not wearing any shirt from here—ohhhh, *picking up shirt* oh yeah, you did find my shirt!"**]** and she was right. That shirt reads, "You say villain like it's a bad thing," and **[**as you can see, I still own it and**]** it is in my dresser drawer here in PA as I speak, and I wear it frequently to this day.

For our entire childhood, Amelia and I never played with dolls or action figures. Instead, we played by us. What I mean is, we would act as if we were the characters. We would come up with their lines and their actions, and that was the sign that we were really in deep with a fandom. And for every game we've created over the years, for every fandom, I can only think of one where she took on the antagonist role instead of me—and Jason Todd is an anti-hero, not a villain. In every game, I played the villain, and I relished in it. I always relied on what I had heard about how actors who played bad guys were really the nicest people, because they got all their evilness out through their characters. That was always me.

[I don't think I ever believed I was a great person. I absolutely had to be the villain, because I always am, in my head.**]**

But I really am the villain in my head when I do this. When I talk about the bad things. Even if I am convinced that she is in the wrong, I'm always the villain in the story of the two of us, because it doesn't matter in the end who's wrong and who's right. All that matters is that I'm talking about it and shouldn't, and in doing so, I am always the villain.

And if I'm the Cyberman, then she's the Doctor. Can pass for a human from a distance, until the words and the actions start. One heart overflowing with the emotions that should be spread to two. A few close companions that can keep up. The rest, left behind in the whirlwind wake, aware of this being's presence forevermore.

My sister is the Doctor—too much **[**emotion**]** for a single heart **[**that should be spilling over into the Gallifreyans' two**]**. And I am the Cyberman—removing all emotions from the one heart I have. Forever at odds.

Except…the Doctor had a Cyberman companion. For a while. Well. A Cyberman head. Sort of. Don't overthink it, but his name was Handles, and as far as we know—aside from the TARDIS—Handles was the longest-lasting companion of the Doctor. Three hundred years on Trenzalore.

Together.

[Three hundred years is a long time to ask. I don't know if I could do that with anyone. Let alone with my sister. But it doesn't really matter if I can or not.**]**

Numbers shift to "10"/"TEN" But the show is called "Doctor Who" for a reason, not "The Cybermen." This isn't about me.

Amelia:

If you still want me to record…

Alicia:

suddenly pacing, repeating quietly, almost frenzied This isn't about me.

Amelia:

The thesis is *your* thing.

Alicia:

This isn’t. About. Me.

Amelia:

I don’t want to take it over.

Alicia:

This isn’t about me!

Nothing is. **[**Nothing ever has been; nothing ever will be!**]**

bury head in hands *collapse into chair (next to another)*

silence

Amelia:

I knew that I wasn’t able to be there for you the way you needed me to.

I look up

Both:

And I hated it.

I wipe my eyes and look at the chair next to me

Amelia:

The whole big sister/little sister dynamic has always been weird with us. But I will tell you about the first time that I really felt like I was there for you as a big sister. We were helping Mandy move. I still honestly don't know what was going on. I don't think you ever told me. We were in the truck, and I think Mom and Dad were still inside of her apartment getting stuff ready, and you just started crying, and I didn't know why. So I went over there and I gave you a hug and you leaned on me. And you just cried for a while. And I was, you know, "it's okay, everything's gonna be alright," and I was rubbing your back, and we just did that for about a half an hour. I don't even remember what we did afterwards, I'm sure we did something to cheer up, but that part right there was very important to me. Because I'd just been talking with my therapist around that time too about not feeling like I was the big sister and that I was letting you down. But it's like, "yes!" Not yes, but yes! Because I didn't want you to be sad, but yes, I got to be the big sister! And it felt really good to be there for you then. There's been other times since then, too, but that's the one that was first.

I sniffle. Wipe my eyes. Look at the chair. Look at the audience.

Numbers fade

Alicia:

I feel like I'm supposed to say now that it's all arbitrary anyways. That it's doesn't matter who's the big sister and who's the little sister anymore. That we're just sisters.

But I can't.

Why would I? Why would I take that away from Amelia? Why would I take that away from myself? Big/little sister, those are identities that have burdens and that have joys that have shaped us both from our time in them.

Bet ya thought for a minute there that I wasn't going to say something cheesy about this. Heh. Nope. But you know what? To quote Kate Winslet in "The Holiday," "I like corny. I'm looking for corny in my life."

The truth is, we fluctuate now, and I expect that we will for the rest of our lives. When we went Christmas shopping and our parents' focus on playing Pokémon Go was upsetting Amelia [because yeah, we still play that], I [pulled them aside and was like "hey guys, I get it, Pokémon Go is my life, too, but maybe let's do that another day, yeah?"] asked them to put their phones away. A day [not twenty-four hours] later, when I had an anxiety attack at church, Amelia held my hand for the entirety of Mass and the car ride home, and she brought me her weighted blanket and my teddy bear as soon as we got home.

Amelia:

humming 'Open Up Your Heart and Let the Sunshine In' in the background

Alicia:

And if I'd asked… *I start quietly humming as I gather the artifacts I have scattered across the stage. I hum the song once, and then I start to sing* Let the sun shine in~ Face it with a grin~

Amelia:

Smilers never lose~

Alicia:

And frowners never win~

Amelia:

So let the sun shine in~
Face it with a grin~

Both:

Open up your heart and let the sun, shine, in.

-Finis

Reflection[2]

Like any live show that incorporates technology, opening night naturally had multiple tech problems. Despite the fact that we had run all of the audio cues flawlessly twice before starting the show, there were multiple instances of Amelia's voiceovers not working correctly, and Jake had to reset the entire PowerPoint to try and get it to work, losing the visuals at times as a result, too. My primary warning for this was that I could see the audience's faces, something I couldn't do when the correct images were on the projector, and when Amelia's audio didn't

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[2] The live performances can be found by searching "Big/Little Sister" on YouTube and/or using the following links:
Thursday, March 11, 2021: https://youtu.be/_at2UJHdFdE
Saturday, March 13, 2021: https://youtu.be/EGqxWgddSEQ

come in to say “Asperger’s is a part of who I am, but it’s not all of who I am,” I had about two seconds to make an executive decision. Since those two seconds passed without her voice coming in, I ended up saying the line about her, which was something that I really didn’t want to do. To me, that was a self-advocacy line for her. I want to be clear: while I did adjust some words in writing her dialogue throughout the script (e.g. our actual conversation about *House Rules* was much less linear and involved many tangents and repetitions), that line was directly quoted from one of our interviews. For me to take that line felt like taking her voice out of the picture, because my sister is someone who recognizes that about herself rather than anyone else saying it about her. But ultimately, I would have regretted it more if the words weren’t in the performance at all, because it is so typical to minimize people with disabilities down to their diagnosis, and even though I wanted that moment to belong to my sister, the tech issue meant that I had to deliver it.

Thankfully, the physical aspects of the performance went well on both days. One of my favorite physical aspects of the performance was the layering of artifacts on the floor. All of the fandom artifacts were placed in the middle area of the stage, while my sib books were broken up between the center section (the ‘outer layers’) and the floor next to the ‘bedroom’ platforms with the four books that tell the story of being a sib (the ‘inner layers’). The only item to move from one section to another was *The Sibling Slam Book*, which I set with the outer layers at first and then moved to the inner layer when I introduced the story about the Pokémon games. During the second show, I took this one step further, placing it as the closest item of the inner layer to the audience. This layering allowed me to create my own Hex, to reference the Marvel television show *WandaVision*. Just like sitcoms do in the show for Wanda, fandoms create my idealized world and really my idealized self; they are essential to how I make sense of the world and certainly belong at my core as well, but they are also what is safe to put out there about myself. On the other hand, the books that speak truly about how hard it is to be a sib—those need to stay close to my heart, and my instinct is still to hide that part underneath the fun happy exterior layer. Some things can sneak out to the middle ground, like *The Sibling Slam Book*, where my nine-year-old self wrote short, blunt answers that are sometimes charming and sometimes gut-wrenching. But the ones that reveal the ugly side of being a sib in more depth…those don't fit the idealized lens through which I want to see the world. Yet they are the first layer to any perspective I bring; being a sib is by far the most salient facet of my identity, even more than any fandom with which I identify, and that includes the negative aspects of being a sib.

This was only one of the ways in which the performance was situated not only at the intersection of my relationship with Amelia, but also at the intersection of the modes used to make sense of it. Throughout the performance, the literal inclusion of Amelia's voice allowed for a vocal dialogue between the two of us as distinct people, helping to maintain the balance that I wanted to achieve between her voice and my own. By including the range of artifacts that I did, from DVDs to books to my sister's Game Boy Color, I was able to showcase the most consistent pillar of our friendly relationship throughout our entire lives: fandoms. While it might have come off gimmicky if I had done this strictly as a way to build rapport with the audience, the fact that my sister and I truly do make sense of the world in this way showed that it was also a natural way to make sense of our relationship. At the same time, it was a natural incorporation into an autoethnography performance, a different mode of making sense of our relationship and our lives than the day-to-day use of a variety of fandom lenses.

My use of artifacts in this way is reminiscent of Fox's (2010b) technique of auto-archeology, which he dubbed as such as a reference to Foucault's use of the term 'archeology' to "explain principles of ordering and exclusion in discursive systems…[and] demonstrate how a particular structure of relations constrains and enables identity" (p. 124). In doing so, Fox (2010b) "rel[ied] on organizational documents to make explicit connections between personal history, institutional structures, and communication theory" (p. 140). Using artifacts from his high school days, he examined how his identity as a gay man was performatively rendered in that time and place. Likewise, I used artifacts from my sister's and my lives to examine my identity as a sib and my sister's identity as an Aspie, particularly in those early days. Although I was not positive of the exact time that I received most of the books, I could narrow down all of the documents at least to their specific year. While I had known I would be able to identify the exact dates of journal entries and Facebook posts, I was pleasantly surprised to find that the two letters that I included were still on our home computer with the dates of when the documents were last updated, allowing me to identify their exact date as well. Through the artifacts and through storytelling, my performance drew connections between our family's personal history, institutional structures (e.g. the school system when my sister boycotted math class), and communication theory (e.g. performance autoethnography, family storytelling).

Similarly to the way that Fox's (2010b) perspective as a gay autoethnographer made him "uniquely positioned to interrogate how educational systems constrain and enable young, gay identities" (p. 124), my perspective as a sib autoethnographer placed me in a position to interrogate these works in how they constrain and enable sibs[3]. By showing the limited number of sib books which had an actual impact on me as a kid, I could showcase how sibs are excluded from the conversation, and by pointing out that only one of them addressed being the younger

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[3] It is important to note the fact that I only had one book which talked about being an autistic person, speaking to the exclusion of people with disabilities from the system, but for sake of the 'auto' part of auto-archeology and autoethnography, I am choosing to focus in on the limited number of sib material that I had.

big sibling, I could point out the further constraints on the sib identity as it is presented on the rare occasion that it is at all. These constraints do, however, showcase a clear contribution of my performance not only to the academic literature, but also to the trade literature around families of people with disabilities. In addition, the nature of this thesis as an autoethnography performance is very different from that of a written book. As my mom stated during the talkback portions of both shows, someone will come across this on YouTube (or a future in-person venue) and see themselves for the very first time. Now, I am not one to discredit the power of the written word, but being a different medium, performance holds a different power. As noted by Spry (2011), when moving from scripting to performing, “the researcher [has] to go from the semantic, the language on the page, to the somatic, interpreting that language in and through the body” (p. 183). By layering the words onto the body, the performer creates a sensory and kinesthetic experience that is shared with the audience, and as stated earlier, the immediacy of this relationship was vital to my thesis.

Despite my goal of normalizing talking about the hard parts of being a sib, there was one moment where I feel like I fell into ‘there is never any reason to worry about me,’ and ironically, it came from the story which I have told the most frequently to explain myself as the younger big sister: the safe driving course story. I had a sentence near its beginning stating that I had peeked during the graphic video about texting and driving and that I really wished that I hadn’t, and I emphasized that after Amelia’s meltdown, the instructors only asked about her. However, I don’t think that it was clear enough that I was in fact also not okay from the start of the day because of that video and that me not being okay simply couldn’t matter, because Amelia was more not-okay and one of us needed to pull herself together and it wasn’t going to be her. Related to this, I wish that I had had longer pauses after each of the three “can you imagine” questions as I transitioned into the next section. Both in the moment and after watching both performances back, I feel like it was rushed, when the reality is that that is a huge moment when the weight of being the big sister crashed down on me. Again, I don't think that I properly expressed how not-okay I was on that day, either, but I wish that I would have so it would have made sense to allow more of a moment for the weight of that day to really sink in.

In spite of that, I think I was able to achieve my goal of drawing attention to some of the difficulties of being a sib, especially through the improvisational moments that came from being fully present and fully trusting of the space in which I was performing. Although my eventual outburst in the script read, "It's not about me! Nothing is," I altered the line slightly in both live shows to say, "Nothing ever has been; nothing ever will be!" This allowed me to highlight the ways in which I have completely internalized my invisibility next to my sister. Rather than just this moment and this project not being about me, nothing in my past or future ever has been or will be. Similarly to issues referenced earlier, to dive too deeply into this would cross the line from therapeutic to therapy, but honestly, I am proud of myself for being open to the moment of improvisation and what it meant, because I was actively fighting against slipping into my Cyberman Mode for the entire show. After all, my Cyberman Mode does not only relate to emotions like hatred and guilt. It comes into play when I am afraid, too, and going into the performance on opening night, I was so nervous that I had become numb to the fear. And as stated in the performance, you can't just delete the negative emotions. Everything gets deleted in that process. I couldn't get rid of the thought in the back of my head that going into my Cyberman Mode would shut down any possibility of being open to the discovery of the moment of performance. To experience even brief moments of such was a major victory for me.

Without a doubt, the most impactful of these was during the Saturday show when, while talking about playing the villain in every game with Amelia and the idea that actors who play the bad guys are really the nicest people because they get all their evilness out through their characters, I suddenly stopped using a lighthearted tone and said, “I don’t think I ever believed I was a great person. I absolutely had to be the villain, because I always am, in my head.” Truth be told, I don’t remember saying those words. I wouldn’t have believed that I said them if I didn’t hear them while watching the Saturday performance after the fact. But it was a true moment that occurred naturally in that very second. Spry (2011) described moments such as this as “an expansion of self into the autoethnographic text; it is the threshold into the textualizing body where, body, page, and stage animate one another expanding the epistemological possibilities of performative autoethnography” (p. 168). This is achieved through practiced vulnerability, “a strategic surrendering into a space of risk, of uncomfortability, of uncertainty that one experiences when critically reflecting upon and then embodying one’s own experience” (Spry, 2011, p. 167). By immersing myself fully in the moment in this way, I was able to be open to allowing the words to escape without overthinking them to death (and holding up the performance by doing so).

Importantly, I had to be okay in order for that moment to occur without feeling sloppy, self-indulgent, or uncomfortable for the audience, and this distinction between therapeutic and therapy is an important one. After all, practiced vulnerability is not achieved by overexposing oneself to the point of embarrassment or audience concern for one’s well-being (Spry, 2011). During the Thursday talkback, I was asked why I didn’t include some of the darker subjects in the script, and based on my explanation that they didn’t have a natural place in the script, my mom chimed in to say that including them would have pushed the performance into being therapy rather than therapeutic. She may have been right about the ultimate effect, but that wasn't my reasoning. To remain okay, I needed to protect my own and Amelia's secrets, at least right now. From our interviews, I found that I couldn't talk about the really negative things without feeling like I was justifying my own and others' actions. This inclination towards justification is not unusual, as it would have been an effort to maintain not only a positive impression of myself but also of my family (Langellier & Peterson, 2004; Poulos, 2009). However, every attempt to put them into the script felt too one-sided. I could not figure out how to enter into conversation with my sister about them in the performance when I still struggle to do so in our day-to-day life. With everything going on in our lives and in the world, the timing wasn't right for those conversations, although I hope that we have them someday. For now, these are a perfect example of Langellier and Peterson's (2004) statement, "A family survives by not talking as well as talking" (p. 50). Someday, talking about these things will help our family survive, but at the time of the performance, not talking about them was the way to achieve that goal.

Like the untold stories, the stories that I shared in the performance contained many examples of content-ordering (Langellier & Peterson, 2004). For example, the stories of my mom's pregnancies and giving birth to my sister and me are classics within our family. Although my mom is usually the one telling them as a self-narrative, any one of us can and do share them as stories about each other. By telling these two stories side-by-side, I was able to establish how embedded the identity of 'the easy child' is for me, as well as showing how that role was very much not embedded in my sister. Of course, Amelia and I are both more complex than that, but this content-ordering allowed me to present one aspect that could make our family identity appear "more singular, solid, consensual, and 'clean' than the messiness of family life"

(Langellier & Peterson, 2004, p. 56). At the same time, I reinterpreted the stories differently than how they are normally told by drawing an explicit connection between our mom's easier time being pregnant with me and me being the easier child.[4]

While every decision of which stories were told by whom were ways of engaging in task-ordering (Langellier & Peterson, 2004), so too was the decision of how to conduct the talkback sections after each performance since task-ordering examines who participates in storytelling and in what ways. Although I was the only one onstage after the first show, my family was in the audience and joined the process of our family storytelling by sharing their own ways of understanding the stories. My aunt spoke about how Amelia's voice was there when I was struggling and how that highlighted the ways in which we are always together. My mom talked about the fact that I shared these stories with honesty but not brutal honesty and how she hopes (as I do) that other sibs will find this performance and see themselves in it. My dad didn't say much, but in saying how proud he was of both Amelia and me for going through this and baring our souls, he too participated in legitimizing the performance as a "'good telling' of [our] family" (Langellier & Peterson, 2004, p. 35). The most significant task-ordering outside of the performance itself, though, was the inclusion of my sister in the second talkback. We had agreed that Amelia would not join for the Thursday talkback, both because my family was flying in that day and because that would give her an opportunity to see what the talkback looked like before deciding if she felt comfortable doing it. By joining me onstage for the Saturday talkback, Amelia was able to participate in the storytelling process in a different way than she did in the

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[4] I say this because of my intent to be the one who my parents would never have to worry about, an intention which I upheld particularly strongly during childhood and adolescence. There were definitely times where my unwillingness to let my family worry about me made me the more difficult child.

performance, since she was not hindered by technology problems and had the chance to share stories in a real-time response to people's questions.

Similarly, one example of group-ordering (Langellier & Peterson, 2004) within the performance stood out, and that was the story that Amelia shared of the first time she felt like the big sister. Although I remember the exact details of the buildup to my breakdown, I chose to maintain that boundary throughout this process and keep them to myself to avoid shifting the story into what that moment meant for me rather than what it meant for Amelia. As she stated, the details of who did what aren't what stick in her head, and I didn't want to put them there to make the story into my version of her memory. With that said, I am completely willing to share them now that doing so will not shift the focal point of the story in the moment of first experiencing it, and thus I consider my silence on the matter as maintaining a boundary rather than keeping a secret.

Throughout the performance, I showed many facets of Amelia's and my feelings towards one another. Stories such as our first Pokémon games highlighted times that we communicated liking each other through establishing rapport (e.g. through actually knowing how to play the games) and treating one another as friends. The end of the performance also showed how we now treat each other as equals, fluctuating between the roles as big/little sister to take care of each other as needed and confirming that we do not only love each other, but we also like each other (Myers et al., 1999). Nonetheless, even during the times that I admitted to hating my sister, I emphasized the fact that I still loved her despite not liking her by reminding the audience of the sense of obligation that often exists within sibling relationships (Myers et al., 1999; Rittenour, Myers, & Brann, 2007) and which is even stronger for sibs since defending a family member with ASD is seen as a mark of loyalty to the family (Hays & Colaner, 2016). Even while verbally rejecting our familial relationship by demanding that others separate Amelia from me (Berry & Adams, 2016), I could not let more than a couple of seconds go by before the obligation kicked in (Myers et al., 1999; Rittenour, Myers, & Brann, 2007) and I was defending her by insisting that she is more than any of the negative connotations that people associated with her. Knowing that certain connotations were directly linked to her disability[5], logical forces (Pearce, 2005) dictated that I could not react to them in any way other than defending her. To not defend my sister would have been to betray my entire family (Hays & Colaner, 2016), and I am certain that if I had not defended her, then I would have received a lot more negative feedback from my family regarding brutal honesty in the performance.

As stated by Langellier & Peterson (2004), "the 'I' of the person emerges from the familial 'we'" (p. 115), and as a result, my identity and Amelia's have been complementary for my entire life. While Amelia's Asperger's is indeed not all of who she is, it is inarguable that it has had a massive impact on my identity-for-others and thus my identity-for-self (Laing, 1969). I emphasized this in the performance specifically when I talked about being "Amelia's sister" first and foremost, reiterating the negative connotations that people meant with those words which impacted how I believed people saw both her and me. In addition, experiences such as the safe driving course highlighted how I was only able to be a 'giver,' with my needs always being secondary to Amelia's. In that case, I was also genuinely not okay, but one of us needed to pull herself together, and it wasn't going to be her, so I did it. On the flip side, Amelia was able to articulate the negative impacts of only being allowed to be a 'taker' in our relationship. Through

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[5] The extreme nature of her meltdowns was correctly associated with her Asperger's Syndrome. I only experienced the connotation of "failure" in relation to specific events, but I would wager that there were people who used those events to judge her as a person. She—and our parents—faced judgments of her being "spoiled" by people who refused to recognize that her brain is literally wired differently than the brains of the people to whom they compared her.

sharing the fact that she had had conversations with her therapist about feeling like she never got to be the big sister in our relationship, she showed how the ‘taker’ eventually “has lost both sense of [their] capacity to give and sense of ‘the other’s’ capacity to receive” (Laing, 1969, p. 84). At the same time, by sharing that fact as context for why a moment of being the big sister meant so much to her, she was able to show how the two of us have broken free of that vicious cycle. While we may fall back into it at times, the fact that we have broken free before means it is possible to do so again.

Conclusion

In this thesis, I created an autoethnography performance in which I examined my relationship with my older sister and how her Asperger’s Syndrome has been at the core of both of our identities for our entire lives. In doing so, I have contributed to multiple underrepresented areas of both the academic and the trade literature. Sibling relationships between typical siblings remain understudied, and if a person with a disability is added into that mix, the amount of current research decreases even further. In the occasion that families of people with disabilities are discussed, it is more often about mothers than any other member of the family, including the person with a disability themselves. This is true not only of the academic literature, but the trade literature as well. By creating a performance which is equally held up by the pillars of the academic world and the pop culture world, I have contributed to both. Particularly by sharing the performances on YouTube, I believe that this work will remain accessible to the general public in a way that written works (both academic and trade literature) may not be. They are visible and free to watch at any time, and while I am by no means YouTube-famous, it is extremely easy to go down rabbit holes and end up at videos that you may have never expected; as stated earlier, someone may find these performances that way and see themselves for the first time. While watching the video after the fact does remove a layer of the immediacy that I wanted to prioritize in this piece, any future audience will still be able to see my body language and hear the way my sister and I speak our words, aspects that are missing from written works. The type of in-the-moment discovery that I experienced and shared with the audience during the performance can also not be recreated in written words alone. While the audience may experience such a moment while reading, anything published in an academic journal or in a book has been reviewed and revised multiple times; an author may have experienced it once, but they do not share that experience simultaneously with the audience as a performer does.

With that said, there is still so much work to be done. By its nature as an *auto*ethnography, this project has focused on representing a singular experience: a nuclear family structure with two parents and two daughters, where the older daughter has Asperger's Syndrome and the younger daughter does not. There are so many variations in the details of the sib experience that to try and list them all would fill the length of a dissertation, details which I could not address in this performance. In addition, even within my own family's experience, there were facets of identity which I did not explicitly address in this piece, such as race and gender. While this was a conscious decision in order to emphasize the facet of identity which is so vital to my sister and me and is so rarely discussed by most people, these facets could be explored in future performances. Finally, although other people in our family and social circles were peripheral characters in multiple stories, the focal point of this performance was Amelia's and my relationship. Future performances can add more layers to this by considering the relationships that we each have with our parents, extended family, and other members of our social circles.

I will not say that Amelia and I are just like any other siblings at the end of the day, because we’re not. If we were, then there would be no point to arguing that sibs and people with disabilities need to be able to put our stories out there. With that said, there are aspects of our relationship which mirror that of other siblings, and only the second-most important of those aspects is the fact that we regularly drive each other bananas. I often approach the subject of our relationship with tough love—hard on her and even harder on the people who are mean-spirited in their lack of understanding of her. She often approaches it with tenderness—gentle with me and kinder in the face of cruelty than I will ever be. She is the complement to my identity (Laing, 1969); in fandom terms, she is the Aerith to my Tifa in Final Fantasy VII and the Eliza to my Angelica in “Hamilton.” While our relationship is far from perfect, the complexities and nuances give us both quite the stories to tell. By telling our family story (Langellier & Peterson, 2004) and examining family secrecy (Poulos, 2009) through an embodied performance autoethnography (rather than through written popular literature, which may approach autoethnography but does not quite achieve it: Couser, 2005), my sister and I were able to interrogate our complementary identities (Laing, 1969). In doing so, I have begun the work of filling the gap of sib stories in the Communication field, performing stories of our own lives apart from our siblings and of our relationships with them in order to interrogate the ways that we have shaped one another.

References

Autistic Self-Advocacy Network [ASAN] (2020). About autism. Retrieved from https://autisticadvocacy.org/about-asan/about-autism/

Berry, K., & Adams, T.E. (2016). Family bullies. *Journal of Family Communication, 16*(1), 51-63. https://doi.org/10.1080/15267431.2015.1111217

Boylorn, R.M., & Orbe, M.P. (2017). *Critical autoethnography: Intersecting cultural identities in everyday life.* Routledge.

Briathwaite, D.O., & Thompson, T.L. (Eds.) (2000). *Handbook of communication and people with disabilities: Research and application.* Lawrence Erlbaum Associates.

Brennan-Moran, E. (2020). *Naming the dead: An ethics of memory and metonymy.* (Publication No. 27963086) [Doctoral dissertation, The University of North Carolina at Chapel Hill]. ProQuest Dissertations and Theses Global.

Brown, L. (2011). *Identity-first language.* Autistic Self-Advocacy Network. https://autisticadvocacy.org/about-asan/identity-first-language/

Bubenik, W., Chun-yu, C., Haas, C., Hamann, K., & Utecht, A. (2019, June 22-23). *Sibling panel* [Panel session]. 2019 National Sibling Leadership Network Conference, St. Paul, MN, United States.

Calloway, L., Alexander, L., Calloway, A., & Calloway, L. (2019, June 22-23). *Generations: Sibling journeys, lessons, and triumphs across the years* [Keynote session]. 2019 National Sibling Leadership Network Conference, St. Paul, MN, United States.

Canary, H.E. (2008a). Creating supportive connections: A decade of research on support for families of children with disabilities. *Health Communication, 23,* 413-426. https://doi.org/10.1080/10410230802342085

Canary, H.E. (2008b). Negotiating dis/ability in families: Constructions and contradictions. *Journal of Applied Communication Research, 36*(4), 437-458. https://doi.org/10.1080/00909880802101771

Conquergood, D. (1985). Performing as a moral act: Ethical dimensions of the ethnography of performance. *Literature in Performance, 5*(2), 1-13. https://doi.org/10.1080/10462938509391578

Couser, G.T. (2005). Disability and (auto)ethnography: Riding (and writing) the bus with my sister. *Journal of Contemporary Ethnography, 34*(2), 121-142. https://doi.org/10.1177/0891241604272089

Denzin, N.K. (2018). *Performance autoethnography: Critical pedagogy and the politics of culture* (2nd ed.). Routledge.

Featherstone, H. (1980). *A difference in the family: Living with a disabled child.* Penguin Books.

Flood-Grady, E., & Koenig Kellas, J. (2019). Sense-making, socialization, and stigma: Exploring narratives told in families about mental illness. *Health Communication, 34*(6), 607-617. https://doi.org/10.1080/10410236.2018.1431016

Fox, R. (2010a). Re-membering Daddy: Autoethnographic reflections of my father and Alzheimer's disease. *Text and Performance Quarterly, 30*(1), 3-20. https://doi.org/10.1080/10462930903366969

Fox, R. (2010b). Tales of a fighting bobcat: An "auto-archeology" of gay identity formation and maintenance. *Text and Performance Quarterly, 30*(2), 122-142. https://doi.org/10.1080/10462931003650153

Gingrich-Philbrook, C. (2005). Autoethnography's family values: Easy access to compulsory experiences. *Text and Performance Quarterly, 25*(4), 297-314. https://doi.org/10.1080/10462930500362445

Goll, E. (Host). (2017, November 30). Siblings – Our most important relationship, with Don Meyer (No. 39) [Audio podcast episode]. In *Empowering Ability*. Empowering Ability. https://www.podbean.com/media/share/pb-tazgs-7dd2ac

Gordon-Pershey, M., & Hodge, A. M. (2017). Communicative behaviours of sibling dyads composed of a child with autism and a typically developing child. *Journal of Interactional Research in Communication Disorders, 8*(2), 246-273. https://doi.org/10.1558/jircd.33333

Harris, S.L., & Glasberg, B.A. (2003). *Siblings of children of autism: A guide for families* (2nd ed.). Woodbine House Inc.

Hays, A.H. (2016). An exploratory look at parents' role as information provider in child autism diagnoses: Advancing the theory of motivated information management. *Pennsylvania Communication Annual, 72*(2), 11-33.

Hays, A., & Butauski, M. (2018). Privacy, disability, and family: Exploring the privacy management behaviors of parents with a child with autism. *Western Journal of Communication, 82*(3), 376-391. https://doi.org/10.1080/10570314.2017.1398834

Hays, A., & Colaner, C. (2016). Discursively constructing a family identity after an autism diagnosis: Trials, tribulations, and triumphs. *Journal of Family Communication, 16*(2), 143-159. https://doi.org/10.1080/15267431.2016.1146722

Holman Jones, S. (2005). Autoethnography: Making the personal political. In N.K. Denzin & Y.S. Lincoln (Eds.), *SAGE Handbook of Qualitative Research* (3rd ed., pp. 763-791). SAGE.

Holman Jones, S., Adams, T.E., & Ellis, C. (Eds.) (2013). *Handbook of autoethnography.* Left Coast Press, Inc.

Johnson, A. (2014). Confessions of a video vixen: My autocritography of sexuality, desire, and memory. *Text and Performance Quarterly, 34*(2), 182-200. https://doi.org/10.1080/10462937.2013.879991

Kelly, R., O'Malley, M.-P., & Antonijevic, S. (2018). 'Just trying to talk to people ... It's the hardest': Perspectives of adolescents with high-functioning autism spectrum disorder on their social communication skills. *Child Language Teaching & Therapy, 34*(3), 319-334. https://doi.org/10.1177/0265659018806754

Laing, R.D. (1969). *Self and others.* Tavistock Publications.

Langellier, K.M., & Peterson, E.E. (2004). *Storytelling in daily life: Performing narrative.* Temple University Press.

Meyer, D. (Ed.) (1997). *Views from our shoes: Growing up with a brother or sister with special needs.* Woodbine House, Inc.

Meyer, D. (2019, June 22-23). *Sibs matter! Why everyone must attend to brothers' and sisters' concerns* [Keynote session]. 2019 National Sibling Leadership Network Conference, St. Paul, MN, United States.

Meyer, D., & Holl, E. (Eds.) (2014). *The sibling survival guide: Indispensable information for brothers and sisters of adults with disabilities.* Woodbine House, Inc.

Myers, S.A., Cavanaugh, E.K., Dohmen, L.M., Freeh, J.L., Huang, V.W., Kapler, M.R., Leonatti, A., Malicay, M.M., Schweig, V., Sorensen, H.J., Vang, M.M., & Wise, D.C. (1999). Perceived sibling use of relational communication messages and sibling satisfaction, liking, and loving. *Communication Research Reports, 16*(4), 339-352. https://doi.org/10.1080/08824099909388735

Myers, S.A., & Kennedy-Lightsey, C.D. (2015). Communication in adult sibling relationships. In L.H. Turner & R. West (Eds.), *The SAGE Handbook of Family Communication* (pp. 220-234). SAGE Publications, Inc.

Pearce, W.B. (1989). *Communication and the human condition.* Southern Illinois University Press.

Pearce, W.B. (2005). The Coordinated Management of Meaning (CMM). In W.B. Gudykunst (Ed.), *Theorizing about intercultural communication* (pp. 35-54). SAGE Publications.

Phillips, K.E., & Schrodt, P. (2015). Sibling confirmation as a moderator of rivalries and relational outcomes in sibling relationships. *Journal of Family Communication, 15*, 58-74. https://doi.org/10.1080/15267431.2014.980825

Picoult, J. (2010). *House rules*. Washington Square Press.

Poulos, C.N. (2009). *Accidental ethnography: An inquiry into family secrecy.* Left Coast Press, Inc.

Powell, K.A., & Matthys, A. (2013). Effects of suicide on siblings: Uncertainty and the grief process. *Journal of Family Communication, 13*(4), 321-339. https://doi.org/10.1080/15267431.2013.823431

Rittenour, C.E., Myers, S.A., & Brann, M. (2007). Commitment and emotional closeness in the sibling relationship. *Southern Communication Journal, 72*(2), 169-183. https://doi.org/10.1080/10417940701316682

Rose, H. (2011). A conversation with Anna Deavere Smith. *Text and Performance Quarterly, 31*(4), 440-448. https://doi.org/10.1080/10462937.2011.604969

Rosetto, K.R. (2015). Bereaved parents' strategies and reactions when supporting their surviving children. *Western Journal of Communication, 79*(5), 533-554. https://doi.org/10.1080/10570314.2015.1079332

Sarris, M. (2017, July 10). *Raising children with autism, before the "epidemic."* Interactive Autism Network. https://iancommunity.org/raising-children-autism-before-epidemic

Sibling Support Project (2020). https://www.siblingsupport.org/

Simmons, J. & Brisini, T. (2020). Performance studies in communication. *Text and Performance Quarterly, 40*(1), 1-48. https://doi.org/10.1080/10462937.2020.1725726

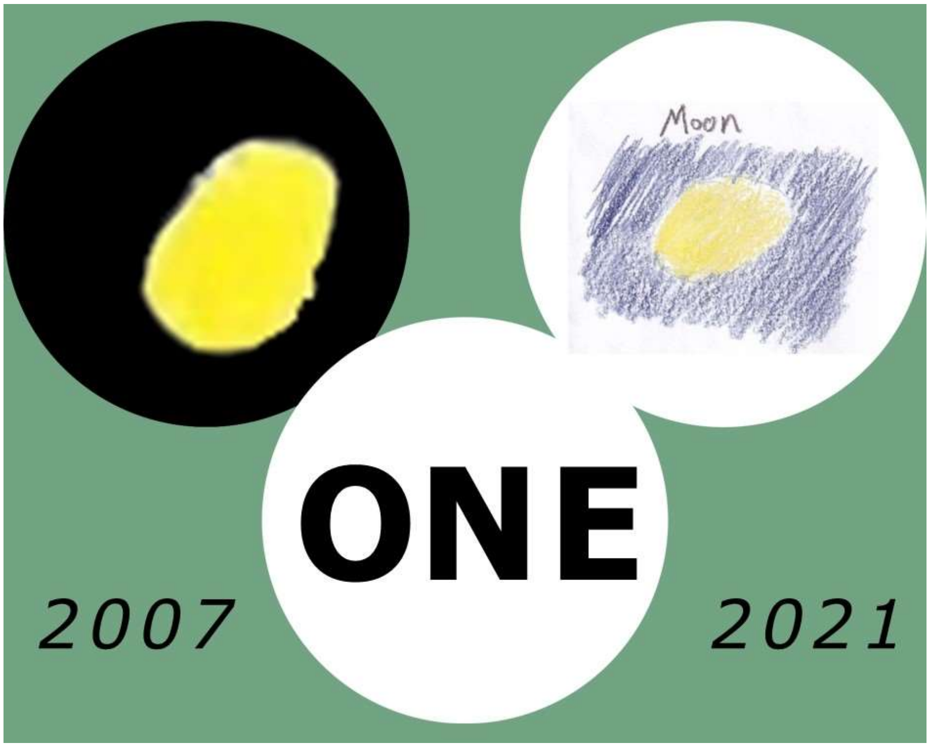
Simon, R. (2002). *Riding the bus with my sister: A true life journey.* Houghton Mifflin Company.

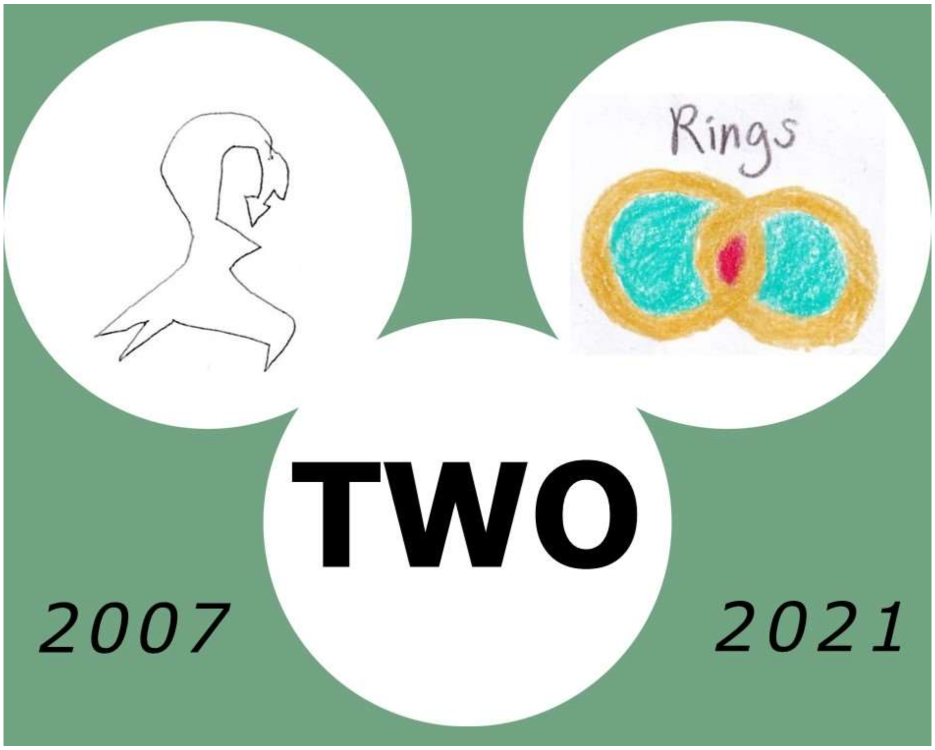
Steel, R., Vandevelde, S., Poppe, L., & Moyson, T. (2013). How to support siblings of children with intellectual disabilities? A brief outline of a longitudinal, multi-perspective study on siblings of children with intellectual disabilities. *Journal of Communications Research*, *5*(1), 81–85.

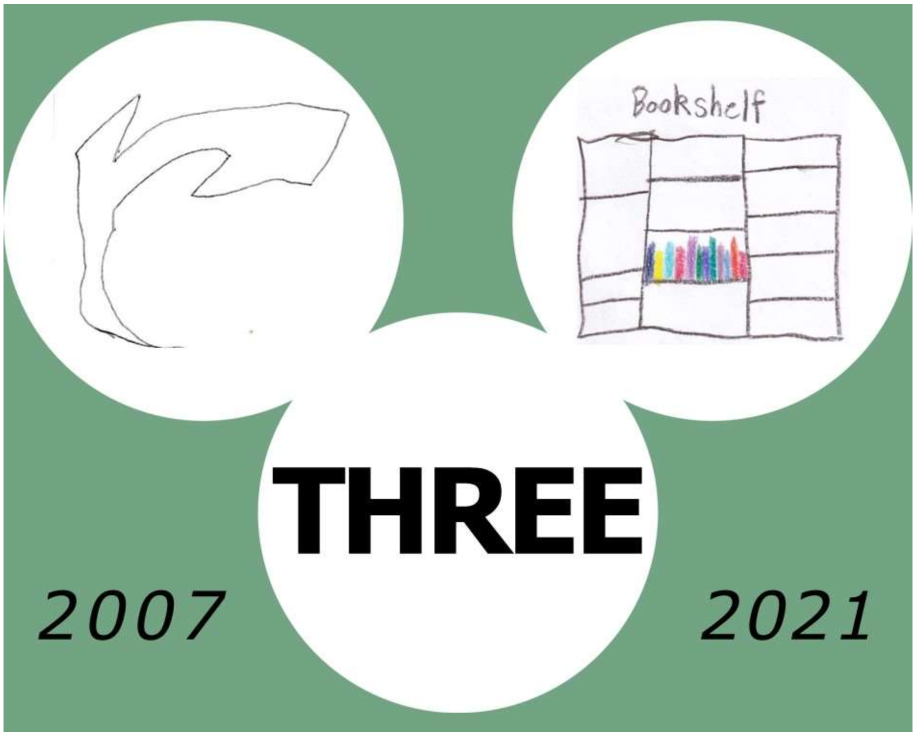
Strohm, K. (2005). *Being the other one: Growing up with a brother or sister who has special needs.* Shambhala Publications, Inc.

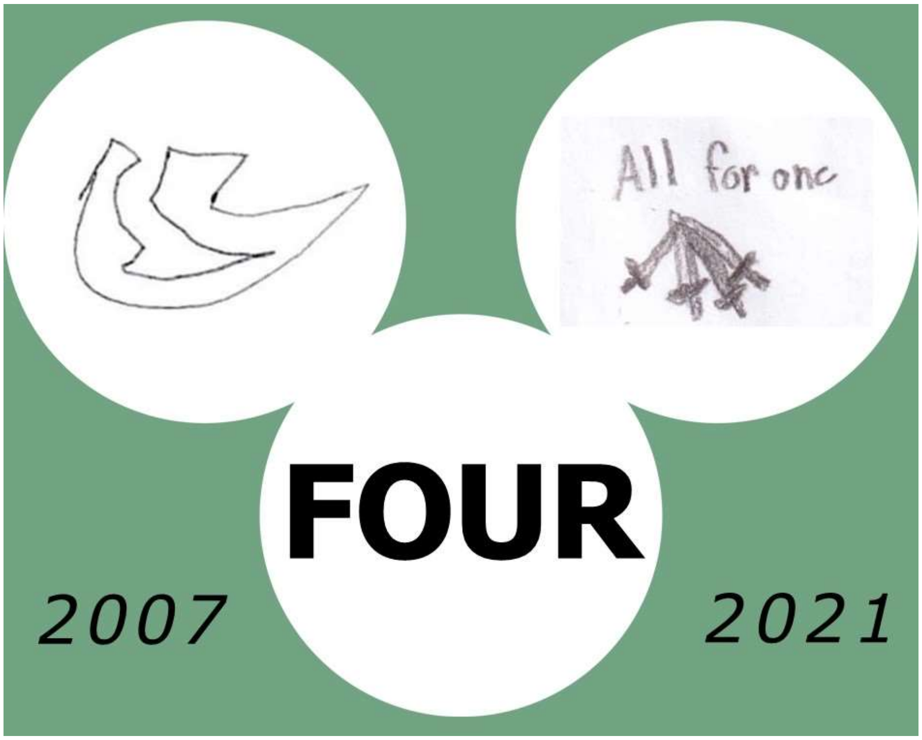
Spry, T. (2011). *Body, paper, stage: Writing and performing autoethnography.* Left Coast Press, Inc.

Appendix A: Background Visuals






Bookshelf
THREE
2007
2021


All for one
FOUR
2007
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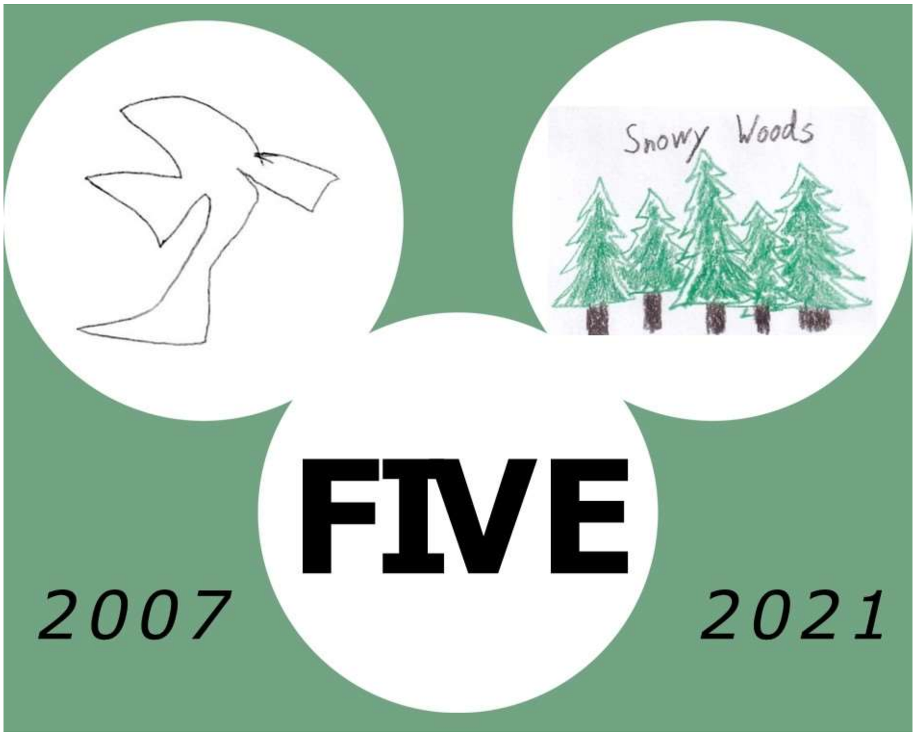
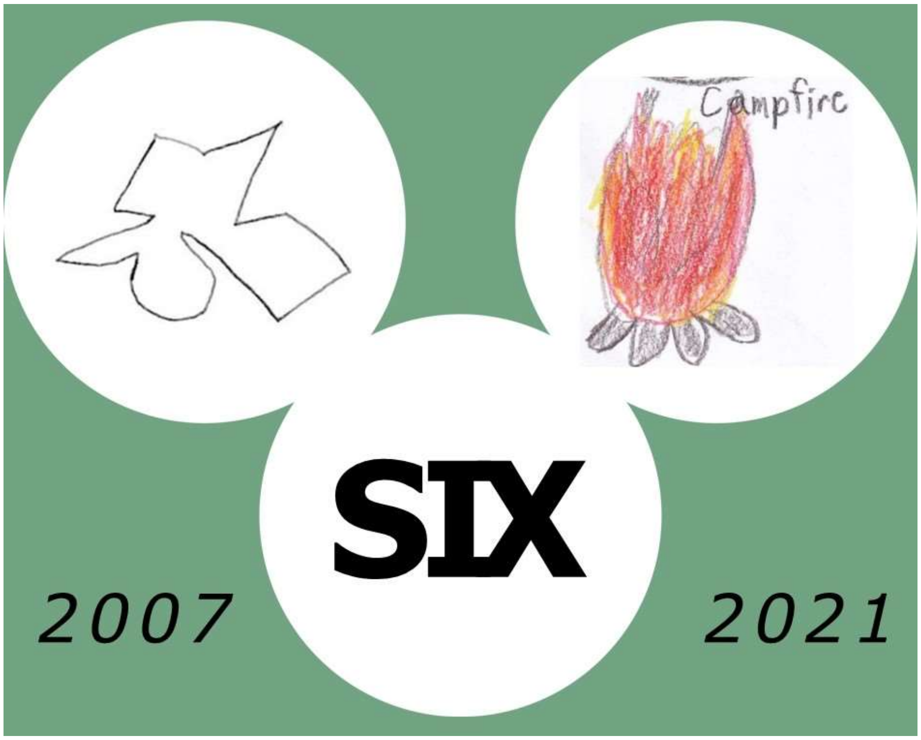

Snowy Woods
FIVE
2007
2021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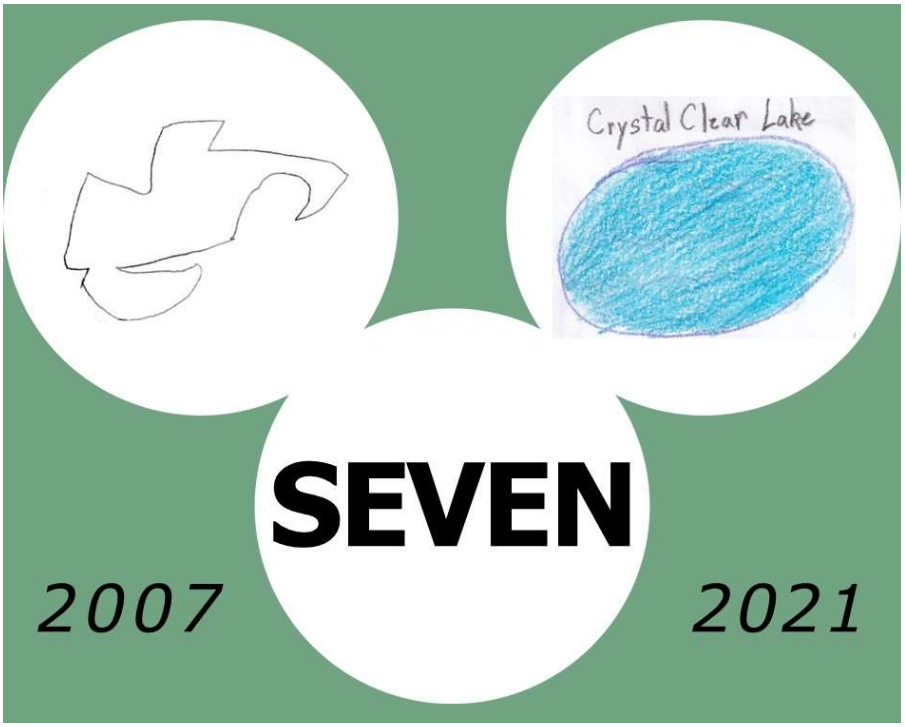
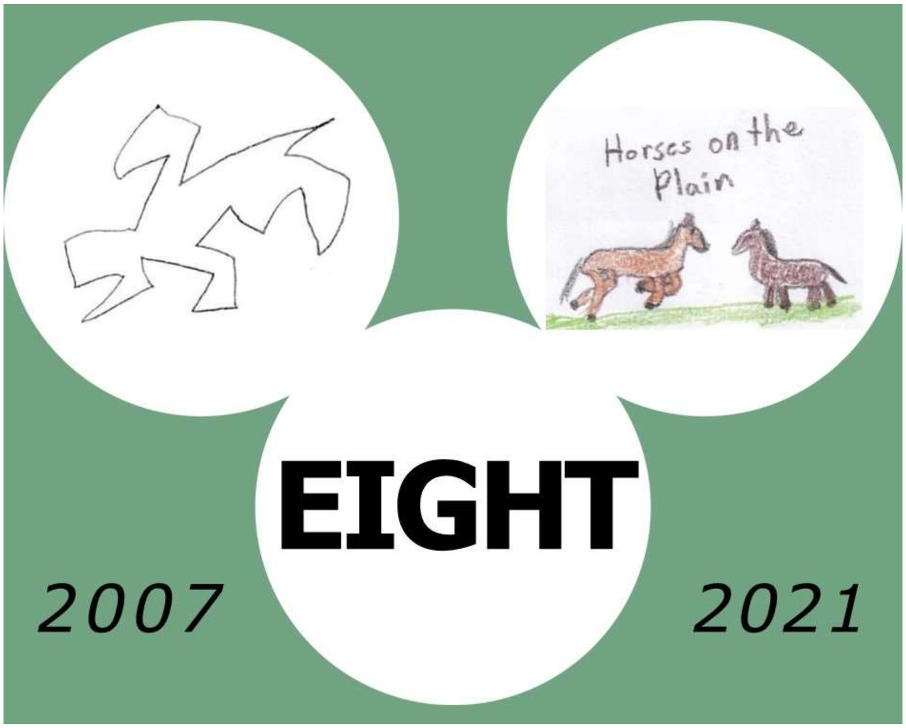
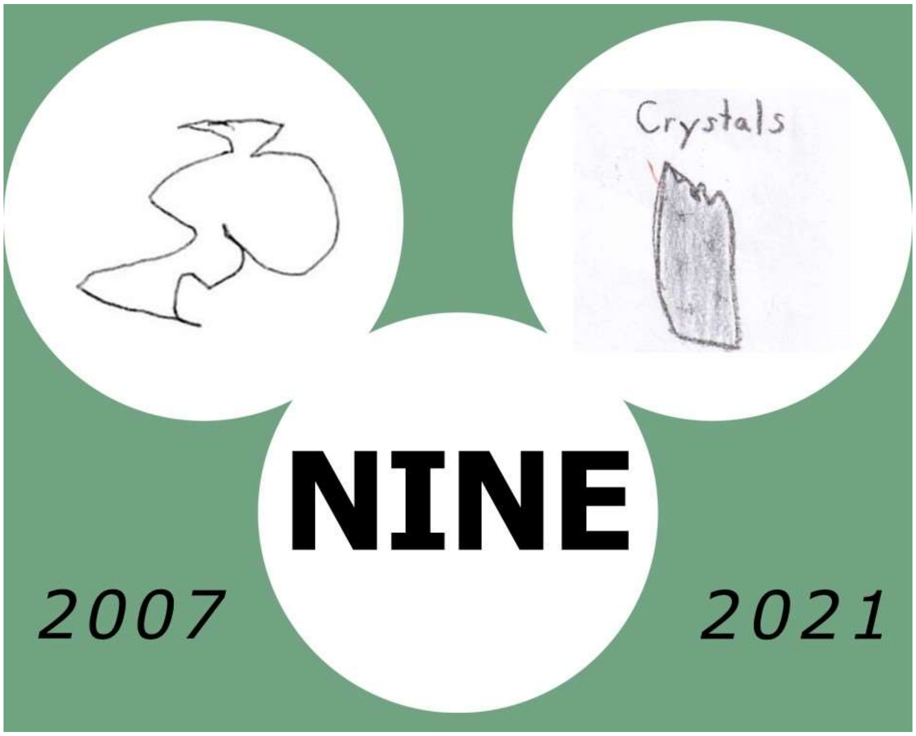
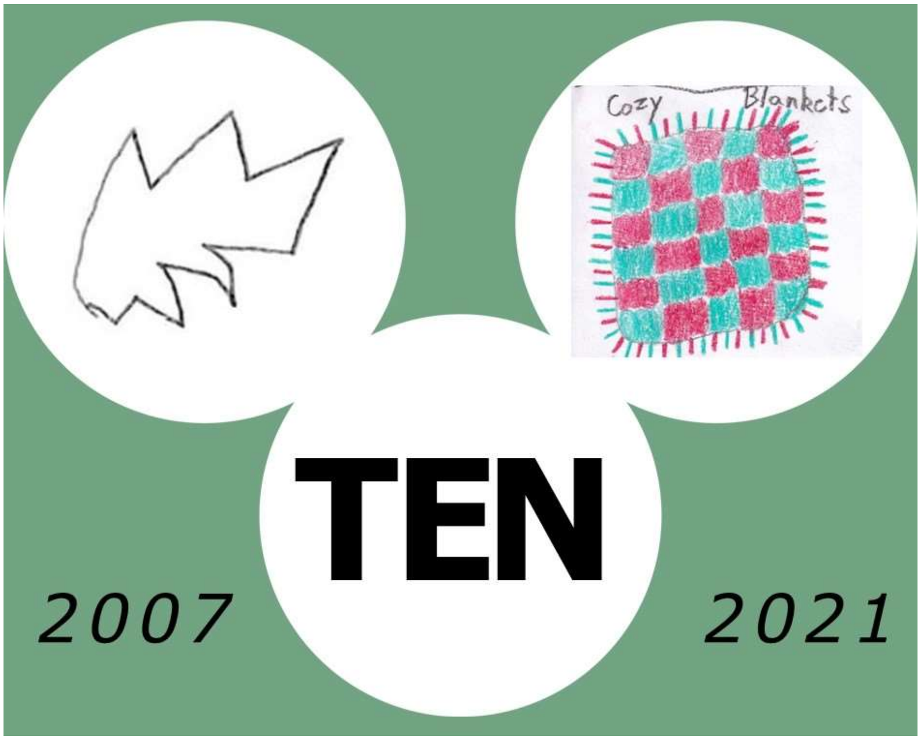
SIX
2007
2021


Crystal Clear Lake
SEVEN
2007
2021


Horses on the Plain
EIGHT
2007
2021


Crystals
NINE
2007
2021


Cozy Blankets
TEN
2007
2021

Appendix B: Performance Poster

BIG/LITTLE SISTER

An Autoethnography
Performance
by Alicia Utecht

SCAN ME

Watch live on YouTube or in the
Communication Department Studio,
Garey Hall

Thursday, March 11 @ 7:00 PM
Saturday, March 13 @ 2:00 PM

Questions? Email autecht@villanova.edu

Appendix C: Performance Program

BIG/LITTLE SISTER

An Autoethnography Performance

by Alicia Utecht

Villanova University
Communication Department Studio
Thursday, March 11 @ 7:00 PM
Saturday, March 13 @ 2:00 PM

Performer: Alicia Utecht
Voiceover: Amelia Utecht

Advisor: Dr. Heidi Rose
Committee: Dr. Shauna MacDonald
& Dr. Sherry Bowen
Lights: Dr. Evan Schares
Onsite Tech: Jacob Metzger
Offsite Tech: Chad Fahs

In this Master's thesis autoethnography performance, I highlight an often-overlooked intersection between disability studies and family communication by examining key moments in my relationship with my older sister, who has Asperger's Syndrome (the term with which she identifies). I have often taken on the role of protector in our relationship because of her disability, looking out for my sister in spite of being younger than she is. This created a complex big/little sister dynamic between the two of us, shaping how we grew up and sometimes how we still view each other and ourselves to this day. Through memories, artifacts, and both of our voices, I dive into what being each other's sister has meant to both of us over the years.

Please note that I will be unmasked during the performance itself. Physical distance will be maintained during this time, and I will be masked for the post-show talkback.

Want to find out more about...

...support for sibs?

Check out the Sibling Support Project (siblingsupport.org) and the Sibling Leadership Network (siblingleadership.org)!

...Autism Spectrum Disorder?

Look up the Autistic Self Advocacy Network (autismadvocacy.org) and works by Temple Grandin (templegrandin.com)!

...Performance Studies?

Take a class (COM 2240 Theories of Performance Studies and COM 3248 Performance Ethnography will be offered in Fall 2021) and/or join the Nova Ensemble (contact Dr. Evan Schares or Dr. Heidi Rose for more info)!

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