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Disability and Sibling Identity: An Arts-based Inquiry

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Abstract

This exploration into how sibling disability impacts identity utilizes qualitative, arts-based methodologies to generate data and situates this knowledge in an examination of other text-based and visually-based sibling memoirs. I rely on autoethnographic techniques with photography, assemblage and photo-elicitation using family photographs and medical images to explore my narrative identity and how my sister's impairments and disability have impacted that. Five themes became crystalized as I recursively examined the data, led by the most expansive finding that sibling disability can create an epistemology or unique way of knowing that is different from other examples of embodied knowledge. Qualities of this knowledge include emergent themes of interdependence and how my sibling relationship has worked to construct my identity. I also discovered that my position in space and time has been greatly impacted by sibling disability and that the ways that I occupy the world are related to my specific lived experience as a sibling of a person with impairments. The fifth theme gleaned from this project is the most outward facing, as I expose myths about disability and productivity and attempt to unravel the presumptions about these in my own thinking as well as what popular culture presents as truth.

Key words: Sibling disability, arts-based research, autoethnography, narrative identity

Disability and Sibling Identity: An Arts-based Inquiry

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Chapter 1: Introduction

About my project

In this project, I examine and create texts that interrogate the impact of disability on the identity of non-disabled siblings, via narrative analysis of selected sibling memoirs, artistic works, and autoethnographic exploration of my own identity as a sibling of an individual with disabilities. My research questions are:

- What are the prevalent identity themes in text-based and visually-based memoirs and art works created by siblings of individuals with disabilities and how can they be understood through the lenses of Narrative Identity and Disability Studies?
- What is the impact of a chosen medium on the communication of identity themes in selected memoirs and art works created by siblings of individuals with disabilities?
- How has growing up with a sibling with a disability impacted my own identity, and my understanding and expression of the social and political implications of sibling disability?
- Where is my inquiry situated within the larger body of knowledge about sibling disability?

To explore the context of sibling disability memoir as a genre, I first reviewed selected works sorting them into categories of "text-based sibling disability memoirs" and "visually-based sibling disability memoirs/art works." I have devoted the second chapter of this dissertation to a thematic analysis of the initial list of works using systematic coding of memos collected while reading/viewing the memoirs. Although I was open to identifying themes that seemingly emerged from the texts, I was certainly mindful of several previously pondered ideas that I "read for" in these works. These ideas have grown out of earlier investigations I have done into how a disability studies orientation approaches identity and sibling disability. Then, to home in on the focus of my inquiry, I limited my analysis to issues pertaining to the narrative construction of identity for siblings of individuals with disabilities.

Two chapters follow the thematic analysis chapter, one that focuses on sibling memoirs that I have designated as text-based and one about the sibling memoirs and art works that I have designated as visually-based. Each of these chapters details additional analyses focused on relationships of form and function within the respective sub-groups of works and the media they used. I attend to the narrative devices that authors, filmmakers, and artists use to explore sibling identity formation as well as other practices that shed light on how sibling identity is constructed by cultural forces when disability is a factor. For example, I make note of narrative shape, context, intended audience, contradictions within the text, the presence of personal mythologies and dramatic tension (Clandinin & Connelly, 2000; Ferri, 2011; Kim, 2016; Piepmeier, 2012; Riessman, 2008) in a wide-angle view of each memoir. I also make note of how context is revealed in publication/production features such as book jacket designs, book blurbs, intended audience, shelving categories and titles. Drawing on elements of discourse analysis, my examination helps to position the genre of sibling disability memoir as it relates to published/produced works in general and the body of life-writing and art.

My analyses of text-based and visually-based memoirs provides the context for the autoethnographic aspects of my analysis by providing some initial codes (Kim, 2016) that informed my autoethnographic work (Bochner & Ellis, 2016). My methodology for the autoethnographic portion of the project comprises the fifth chapter of this document and describes how I used both autoethnographic (i.e. written text-based) explorations into sibling identity as well as the visual arts-based research methodologies (Kim, 2016; Lawrence-Lightfoot & Davis,1997; Rolling, 2013) of photo-elicitation and photo essay for my inquiry. This hybridized approach has allowed me to use a variety of modalities and has yielded a more fulsome investigation than a purely text-based or visually-based method.

I base my autoethnographic work on my experiences growing up with an older sister, Annalise, who had neurological impairments from an early age and subsequent disabilities during her life. She passed away in 2010 and so her voice is only present in this inquiry as it is filtered through my perceptions. Still, Annalise's life as I have closely observed it continues to fuel my desire to complete this investigation and share how her lived experience impacted my identity as her sibling.

Narrative Identity and Disability Studies

In this introductory chapter, I will lend some general framing and theoretical background to the project as a whole. My orientation to the material relies on perspectives informed by scholarship in Narrative Identity and Disability Studies as well as specific research methodologies such as autoethnography that I describe in a subsequent chapter. One main tenet that undergirds recent thought about how people develop their identity via narrative is that stories from their past are integrated with anticipated future episodes and in this way, "selves create stories, which in turn create selves" (McAdams & McLean, 2013, p.235). This recursive tendency is a good fit with my autoethnographic research methods and resonates with past work that I have done related to the co-construction of narratives between motherhood and a child with a disability (Franits, 2010). However, much of the research related to narrative processes of identity formation in the field of psychology tends to construct disability in a person's life as a difficulty or challenge that then feeds into a narrative of need for "redemption" or "positive resolution" if the individual has constructed what is perceived by psychology to be a healthy identity (McAdams & McLean, 2013). These dominant tropes are in tension with much of the scholarship in disability studies that disavows the "overcoming narrative" as the expected resolution when disability or impairment are a part of the story.

Narrative identity work that is more in line with a disability studies orientation has been an area of interest and inquiry since the early days (or first wave) of disability studies as a field of scholarly endeavor when it was closely allied with the disability rights movement in the 1980s (Garland-Thomson, 2013). The oft cited "nothing about us without us" was a phrase from that time that activist groups used to claim a positive identity related to disability as well as a reclamation of their agency (Charlton, 1998). Individuals with disabilities should be able to tell their own stories, which often don't follow the narrative arc that has been promulgated by mainstream media, cultural influencers, as well as the still dominant medical model of cure. Thus, in the last twenty-five years new and different stories have been published (Couser, 2005) by individuals who claim a disability identity and are working to dismantle the false yet still dominant ideologies that exist about what living with a disability is like.

The understanding of disability as a social construction became a foundation of most endeavors that contributed to the evolution of disability studies as a discipline and still serves a purpose when failure to enact social justice and guarantee accessibility require that exclusionary practices be revealed and revised. However, these attempts sometimes reduce or essentialize the lived experiences of disability, overlooking the realities and varieties of possible impairments and have been rightly critiqued for doing so (Owens, 2015). As the field has grown, it has embraced a more intentional intersectional approach, and with that has hailed broader and more nuanced versions of disability identity. The move towards critical disability studies led to a consequential mandate to pay attention to how disability is considered in sociopolitical and cultural arenas (Hall, 2019). Thus, my project has been informed by a mix of scholarly approaches from traditional disability studies orientations as well as more focused critical disability studies formulations.

Disability and memoir

I now turn my attention to the topic of sibling disability memoir before delving into the selected sibling narratives in the chapters that follow. Historically, many accounts of living with disability have been narrated by medical and psychiatric professionals, who have most often constructed disability as pathology. (Frank, 2004; Kafer,2013) These deficit-based presentations of the disability experience include common tropes of disability: as tragedy; as in need of cure; as burdensome; and, as coexisting with incompetence (Linton, 1998) to name a few. Fortunately, with the advent of the disability rights movement beginning in the United States in the 1970's and the "epistemological break" (Charlton, 1998) that accompanied the larger civil rights movement, people with disabilities have had greater opportunities to tell their own stories about living with disability. The rise of the first-person account and autobiography or disability memoir has benefitted from this trend and interest in narratives written about living with disability from the emic perspective has grown. These texts represent "those who write [vs] those who are written about" (Couser, 2005, p. 124). In a later article, Couser (2011) posits that the burgeoning genre of life writing and its "inclusiveness means that it is a prime site—perhaps the prime site—for the representation of disability today. And it is thus a prime site for the study of cultural representation of disability" (236). These first-person disability memoirs generally do not align with the reductionistic tropes identified in texts crafted by those outside of a disability experience and can be representative of more authentic experiences. Mintz (2012) points out that "Much contemporary life writing participates in such reclamation projects, making subjects of people whose circumstances or characteristics may have denied them social agency" (435).

Memoirs written by individuals who are unknown to the general populace are only successful, Couser (2009) suggests, if they are about a person's out of the ordinary corporeal experience or if they are "some body"(p.2). While this includes individuals who excel at certain physical expressions such as athletes, this category primarily applies to individuals who tell stories of "odd or anomalous" (Couser, 2009, p.2) bodily experiences, including disability. Couser (2009) also suggests that the rise in popularity of the some body memoir has inadvertently exposed readers to life writing about disability, and, thus, has the potential to increase our "disability literacy" (p.4). This is not to suggest that experiences of all people with disabilities are enjoying the trend towards publication, as it remains that race, class, gender, and other identity categories that intersect with disability are not equally represented in published memoir (Mintz, 2007).

Another category of disability life-writing exists that blurs the boundary between the etic and emic perspectives of living with disability. These are stories written by family members of people with disabilities who are like embedded reporters in the context of disabled life. Mintz (2012) observes that "The cultural spectacle of the disabled body or brain is the specter of the family, the secret to be energetically denied, the error to be explained away or mystically redeemed” (438). Family members who choose to publish their stories are often fueled by a deep and complicated drive to write their family member into existence (Mintz, 2012). Parental memoirs are more prevalent than sibling memoirs, as found in an informal survey I applied to websites of booksellers using the key words “memoir”, “parent” or “sibling”, and “disability”. This review indicated that in the last 25 years, more than 80 parental memoirs about disability have been published vs. 16 sibling memoirs about disability in the family. Most general sibling memoirs surveyed were found to be organized around what most would consider negative life experiences such as poverty, homelessness, war, and abuse. In a sub-genre inhabited by stories of tragedy, stories of disability as tragedy fit right in, although not all sibling stories of disability acquiesce to this commonly expected narrative structure. The tension that exists when multiple identities are claimed (Mintz, 2003) also complicates the narratives that siblings tell about living close to disability, and illustrate the diversity of experiences even within this identity category. There is no single story of sibling disability.

Narratives about disability written from a sibling’s perspective are also represented in volumes of collected essays and interviews edited by health care professionals who are sometimes siblings of people with disabilities themselves (McHugh, M.,2003; Safer, J. 2002; Strohm, K., 2002). These collections may not be considered traditional memoirs, as there is often a self-help orientation to the books with sibling stories used as cases rather than explorations about living with disabilities. They are shelved with parenting/special needs books rather than with memoir or auto/biography and include lists of strategies, resources and support group information for siblings of people with disabilities. Publishers and authors orient these texts to a readership looking for help related to siblinghood that they perceive as being negatively impacted by disability. Although I have read many of these self-help style texts during my review, they do not meet the inclusion criteria for the products I have chosen to analyze as memoirs.

Sibling life histories have been examined in academic writing including research that explores and strives to understand what lived experiences are like for siblings of people with disabilities. In what she calls a case study approach, Davis (2005) investigates how her sister's disability shaped their relationship and uses the novel tactic of sharing excerpts of transcribed conversations she had with her sister, as well photo-elicitation techniques using family snapshots. She intersperses these excerpts with explanatory observations and memos which reveal her research methodology to some extent. Although she admits that the resulting article is less of a collaborative sisterly effort than she had originally intended, she observes the priority that academic writing tends to impose and recognizes how that occurred in her own work (Davis & Salkin, 2005). In a more traditional autoethnographic style, Jones (2013) reviews stories that she had journaled about in the past about her family and the impact that her brother's disability had on their shared lives. She contextualizes those stories in observations from contemporary disability discourse and organizes them by theme. In this self-described generative essay, Jones' stated goal is to change public perception of disability and related stigma rather than stall in simple reflection. However, she observes that the thread that she unravels in her analysis also connects her to others whose family narratives have followed similar trajectories (Jones, 2013). In his desire to examine how disability impacts familial dynamics, Savarese (2010) moderated a virtual roundtable for parents and siblings of people with disabilities and in a question/response format, related their perspectives on how disability impacts lived experience of families. In this unusual example of shared family narratives of disability, Savarese was able to direct the flow of the stories and capture them in a transcript which was then published in an academic journal (Savarese, 2010). Presumably, these lightly edited narratives are left to the reader to interpret, without much contextual discussion and with the likely expectation that an academic audience might bring a critical lens to the text. These examples of research texts are important to mention in this discussion as yet another sub-genre of writing about disability in the family which represents scholarly investigations about the topic. While not as accessible to the general public as memoirs are, these texts are imperative to consider for my project, as they can bring alternate points of view to the discussion. Even though these texts don't meet the inclusion criteria for my chosen sample, the scholarship has certainly informed my overall study.

Searching for sibling disability memoirs

My personal experiences as a sister of a woman with disabilities have undoubtedly driven my scholarly interests, particularly in disability studies, but my lifelong search for other sibling stories that resonate with my experiences has often been thwarted. The texts that I did find often skewed towards deficit-model representations (McHugh, 2003, Safer, 2002, Strohm, 2005) or self-help tomes (Meyer, 2005). However, when I was introduced to and discovered some of the artistic representations and critically written memoirs about siblinghood and disability, I recognized the potential of these works to reveal the knowledge of "disability wise" siblings that I was seeking. As a photographer and an occupational therapist who has used creative arts therapies with individuals with disabilities, I have seen the power of artistic expression to understand lived experience and have gravitated towards art-based research methodologies in my scholarship. I have also been engaged in autoethnographic explorations into my identity as a sibling of a person with a disability for many years (Franits, 2011; Franits, 2019) and my exposure to the work of Bochner and Ellis (2016) about evocative autoethnography instilled a desire to formulate my inquiry using these principles. Thus, I sought to encounter other examples of life-writing, or other artistic expressions that could be models for my own autoethnographic and arts-based exploration.

I compiled a list of potential memoirs via searches in the general search engines Google and Google scholar, catalog searches in academic libraries as well as in journals such as *Life Writing*, *Disability Studies Quarterly*, *Journal of Literary & Cultural Disability Studies,* and the *Journal of Contemporary Ethnography*, using the search terms "siblings with disabilities" and "memoir", "art", "photography", and "film". In addition, some of the works were discovered through informal recommendations from advisors to this project. This is by no means an exhaustive list and is not meant to represent all perspectives of artists who have siblings with disabilities. Rather, the art works that I have surveyed in my literature review have provided a matrix for me to situate my own artistic investigations into sibling identity when disability is present, and in this way, constitute one context for my project. It is more of a curated collection than a comprehensive grouping and I chose them because they fit the criteria of being an artistic product and do not self-identify as primarily helpful or supportive for other siblings of people with disabilities. I excluded self-help kinds of manuals and other texts (McHugh, 2003, Meyer, & Holl, 2014) that tend towards prescriptive and inspirational rather than descriptive and experiential.

A note about language

Throughout my discussion, I will most frequently use “person-first” language, recognizing that it is most inclusive to use the word disability as an attribute that an individual has, versus a complete identity that eclipses other elements of their life. In addition to the inclusivity of this practice, I recall that my sister would describe herself as having impairments and/or disabilities but would not have thought of these as defining her personhood. Thus, to honor her memory in this text, I generally refer to individuals with disabilities as such instead of frontloading the word disabled. There are some exceptions though, where to avoid disruptive grammar I have opted to use phrases such as “disabled sibling(s).” I have weighed the decision to do so in each case ensuring that my language did not communicate disrespect or superimpose an essentialized identity onto an individual but rather simply make my prose more readable.

Chapter 2 Thematic Analysis

Telling a sibling story is an automatic negotiation with identity. Sibling memoirists who acknowledge that they should honor the dictum to not tell another person's story (Charlton, 1998; Couser, 2009; Mintz, 2009) also recognize that the story they tell about their own life is that specific story in part because of their sibling. When disability is part of a sibling story this negotiation can be even trickier, as the cultural narratives about disability often seep into personal identity tales (Mintz, 2009). Being wise (Goffman, 1963) to disability because of a sibling's experiences is different than the embodiment of disability experiences, but because siblings often co-occupy contexts and events the boundary between siblings' stories can be quite permeable. Eakin (2008) posits that we rely on the foundation of memory and narrative to our construct identity, but neither memory nor narrative are static conditions. Thus, there is often a fluidity to identity as it responds to forces such as cultural narratives. Thus, identity as a sibling of an individual with a disability is also informed by the story of the sibling with disability, grand narratives of disability (Goodley, 2017) as well as memories of shared stories enacted in a family.

I have chosen twelve sibling memoirs produced since the turn of the twenty first century to explore these identity issues via a perspective informed by disability studies. My specific inclusion and exclusion criteria for text-based and visually-based sibling disability memoirs are explicated in the two chapters that follow this one that are devoted to those sub-genres. Two graphic novels, *Epileptic* (David B., 2005) and *The Ride Together: A Brother and Sister's Memoir of Autism in the Family* (Karasik & Karasik, 2003), inform my inquiry and are included in this thematic analysis for contextual depth, although they are not included as primary objects of study. There are six book-length memoirs that meet my inclusion criteria for text-based sibling disability memoirs and one short essay that I decided to include in this group as it too meets the inclusion criteria and is similar to the book-length memoirs. The included texts in my sample are: *Hazard: A Sister's Flight from Family and a Broken Boy* (Combs, 2017), *That Went Well: Adventures in Caring for my Sister* (Dougan, 2009), *How to be a Sister: A Love Story with a Twist of Autism* (Garvin, 2010), *Boy Alone: A Brother's Memoir* (Greenfeld, 2009), *Any Day Now* (Hershon, 2010), *Riding the Bus with my Sister: A True Life Journey* (Simon, 2002), and *Divided Minds: Twin Sisters and Their Journey Through Schizophrenia* (Wagner & Spiro, 2005). I have identified five memoirs that meet my inclusion criteria for visually-based memoirs of sibling disability. They are *Monia*, a photo essay, (Cocco, 2016); *Without Apology*, a documentary film, (Hamovitch, 2004); *Bumblebees*, a short film, (Kanell, 2016); *Renny, My Favorite Sister*, a series of paintings, (McIver, 2002) and *Habitus*, a series of photographic prints and surface impressions, (Darian Stahl, 2015).

Method

In keeping with the practices of narrative analysis (Clandinin & Connelly, 2000; Kim, 2016; Riessman, 2008) and qualitative coding (Bogdan & Biklen,2006), I have considered each sibling memoir that I chose for this review as an individual text to analyze and read/watch/observe in an order dictated primarily by their availability to me. I devised a chart to record basic details about each of these memoirs and used it to note any narrative patterns revealed. I have borrowed from Ferri's (2011) recommendations[1] about reading disability life writing with a more critical eye and have incorporated many of these questions into my analysis. I decided to apply the same method to both the text-based and visually-based memoirs for this thematic analysis, as themes should cut across all genres. A more specific investigation of each sub-group of memoirs is described in following chapters that goes into greater detail about how specific characteristics of those genres work to communicate identity narratives. The themes identified in this chapter and the genre-specific narrative devices described in the following chapters will then serve as a model for my original research which is the autoethnographic portion of this project.

Themes

Grand narratives and counternarratives

One of my goals for this project is to interrogate the ways in which sibling stories either support dominant narratives about disability that tend towards reductionism or suggest counternarratives, which can do redemptive work by presenting alternative and more expansive constructions of disability experiences. Mintz (2009) cautions against the seeping of ableist ideals into representations of disability as presented by siblings in their life-writings. She suggests that the narrow versions of disability experiences in popular culture can exert influence on the ways in which siblings represent their disabled counterparts (Mintz, 2009). This is certainly observable in portions of the memoirs that I reviewed for this project, although

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[1] Ferri (2011) lists 19 types of critical reading practices applied to life writing and I have incorporated many of these into my own analysis including the use of metaphor, the impact of temporal contexts, how bodies with disabilities are represented and recognition of the intended audience. See Appendix C for the complete list.

none present a solely reductive, ableist stance. Each sibling memoirist includes some redemptive ideas that establish counternarratives to those dominant ideologies that tend to present disability as tragedy or disability as a barrier to be overcome (Titchkosky, 2003). Frank (2004) suggests that the genre of life-writing can be particularly effective at conveying counternarratives as it “upsets conventional identities assigned” (p.178) by the dominant culture to individuals with disabilities (Frank, 2004).

Siblings have unique opportunities to observe and understand disabilities as situated and contextual, rather than as essentialized definitions of brothers and sisters as constructed by the medical model. Many of the memoirs I selected include a point of reflection where the author realizes that their sibling has a medical diagnosis and tries to reconcile that status with the positive attributes that they observe from their position as wise (Goffman, 1963) companion. Combs (2017) recognizes this when she says, “If I were to believe the experts, I’d have to assume my brother did not have empathy…. Yet he has defied this assumption all of his life” (p. 259). Garvin (2010) also speaks to this issue when she says, “I’m not going to make any sweeping statements about what Margaret is or isn’t capable of. Generally speaking, it appears to me that she is like everybody else I know…And I don’t want to pigeonhole her, because people have been doing that to her since we were children” (p.83). Although she does describe some stereotypically autistic behaviors that her sister exhibits, in the same passage Garvin (2010) makes the point that many non-autistic people engage in far more detrimental practices such as driving while impaired, which although more socially acceptable carry greater risk for harm. Throughout these texts, siblings interrogate definitions of normalcy and question if it is even a desirable state. In her poetic conclusion to her essay about being a sister to a man with

William's syndrome, Hershon (2010) flips the equation when she suggests that her brother is not sad about his diagnosis and thus does not feel confined by it. Rather, it is her own vulnerability and shame about her brother that she identifies as problematic and in need of transformation (Hershon, 2010). The message that resounds in these examples is that the problem of disability does not dwell in siblings with disabilities, but rather in the world's response to those disabilities.

In one of the most overt examples of a disability counternarrative, P. Karasik (2003) devotes a chapter in his memoir to a Superman gangster-like comic book character who takes over Karasik's drawing board and scribbles out the pat storyline that Karasik had originally planned for the chapter. The abandoned storyline, which the reader gets a glimpse of when the comic version of Karasik describes the happy ending he was planning to illustrate, is disregarded by the gangster character who calls it "a hearts-n-flowers alibi" (p.156). The gangster character then goes on to narrate what he presents as the true story about the memoirist's brother and the secret world of his disability. This narrative device suggests an alternative interpretation of the behaviors that his brother exhibits and illustrates them using the gangster's "voiceover," providing alternative text to panels of comics used earlier in the memoir. The perspective shift is most clearly exemplified when the gangster character says that "It ain't splintered inside, it's splintered outside" (P. Karasik, 2003, p.158), which in an efficient way to apply the social model of disability (Oliver, 1990) to this story and offers a powerful counternarrative. Rather than formulate his brother's eccentric behaviors, such as reciting Superman episodes verbatim as examples of pathology, Karasik (2003) in the gangster's voice presents this echolalia as an organizing and stabilizing source of support for his brother. His interior life is not splintered, but quite intact while the chaos actually resides in the outside world.

One long-standing and damaging viewpoint regarding children born with disabilities that is fueled by representations in popular culture is that it would be better for all if children with disabilities were not born to begin with (Kafer, 2013; McBryde Johnson, 2005). This extension of the “disability as tragedy” model identifies the exclusive and unjust treatment that people with disabilities are exposed to in most societies, and seeing this injustice as immutable, declare that it would be kinder if people with disabilities didn’t have to be considered (i.e. if they didn’t exist). For some, resolution of the problem involves ridding the world of disability rather than changing the attitudinal and physical contexts that prevent inclusion of people with disabilities in all of society. Children who cannot be cured of their disabilities are “constructed as a cost, a burden, and at worst a mistake” (Frank, p.184) by medical professionals and other authors of the grand narratives that surround disability (Goodley, 2017). Although there is some evidence of this persistent dogma within the sibling memoirs that I reviewed, there are many more examples of how these storytellers resist that eugenic vortex and rather develop positive counternarratives about disability as experienced by their sibling and family.

Siblings present examples that counteract the idea that life as a person with a disability is “a mistake” as they describe how their families disregarded advice and recommendations from medical professionals and other purported experts about their family member who has disability. When David B. (2005) and his girlfriend discuss having a child of their own, her concern about chances of the child inheriting his brother’s epilepsy result in her proclamation that “if there’s a problem I want to abort immediately” to which he counters “If there’s something wrong with the baby I want it to be cared for…I've seen my parents care for my brother without ever stopping. I want to live up to that" (David B., 2005, p.322). In the short film *Bumblebees* (Kanell, 2015), we hear Vance describe how his abilities to walk, speak and write refute what doctors had predicted about his potential level of function when he was first born. Seen through his sister's eyes, as she wrote and directed the film, Vance's life is presented as a strong counterargument to those who presume incompetence (Biklen, 2005) about people with disabilities (Kanell, 2015). Her claim in the film (2015) and in the TEDx talk (2016) that she gave regarding the film, is that the limits that professionals and many others in society place on an individual with a string of diagnoses like her brother should be upended rather than allowed to direct one's life. The delightful and charismatic young man that she reveals in her film is the most powerful evidence to rebut the dominant ideology that constructs disability as tragic (Goodley, 2017). She shows us that Vance is a charming young comic and not a "mistake" by any means.

Simon (2002) recounts that when her sister was first diagnosed, at a time when children with intellectual disabilities were often institutionalized, her parents proclaimed that they would not place her in an institution. They vowed to always include her as one of the family and not hide her away. Simon's fervor is dampened somewhat when this proclamation is coupled with ramifications for her own future, as she understands her parents to say "Never put her in an institution. Ever ever ever. Make room for her in your own house" (Simon, 2002, p.119). While proud about her parents' then radical decision, she is also anxious about being slated as her sister's eventual caregiver, as many of the conversations that siblings have about parental choices go (Simon, 2002). Dougan's (2009) parents reluctantly visited a state institution in response to a recommendation made by a special education consultant, but upon seeing the conditions of the place decide not to send her sister there. Rather, they took matters into their own hands to establish programming for their daughter and even formed a group with other parents of children with intellectual disabilities that would grow into a local chapter of the Association for Retarded [*sic*] Children (Dougan, 2009). Although seemingly obvious choices in today's climate, these refusals to institutionalize children with intellectual disabilities were radical acts in the 1960's, and they represent an alternative narrative to exclusion and segregation, which were commonplace at the time.

Stories about families who instead chose residential placement of their child with a disability can help their audience understand how parents struggled with their initial decision as well as their ongoing feelings such as guilt about that decision. When told from the sibling's point of view we get a glimpse into how these events impacted parents as well as the family dynamics. By revealing the emotional anguish surrounding these decisions, sibling stories of institutionalization can also do redemptive work. In her documentary about her brother, Hamovitch (2004) attempts to reconstruct the time in her family's life when the decision was made to send her brother to live at Letchworth, an infamous and large state institution in New York. She bemoans the fact that her mother passed away before she could ask pointed questions about what it was like to send her brother away, but does include interviews with her father in her documentary. Although he claimed that placing her brother in Letchworth was the right decision, her father also described it as a sad time in their lives and that they were "devastated" by the decision (Hamovitch, 2004). Hamovitch reminisces about the tense family visits to the institution that she eventually became excused from. She marvels at the loyalty of her parents to this ritual, even though it came at great emotional cost to her mother as she observed a regular “day-after Letchworth syndrome” after each visit (Hamovitch, 2004) when her mother became withdrawn and sad. In their search for an appropriate place for their older son to live, Greenfeld’s (2009) parents only investigate placements that would show care for him, rather than attempted cure and their quest becomes more urgent as what Greenfeld observes as intensifying friction between his parents grows as they become exhausted from caring for his brother (Greenfeld, 2009). Their frustration about their fruitless search for the right kind of living arrangement for their son is summarized in his statement, “Sometimes I feel that our entire purpose as a family is to keep Noah out of an institution. We exist to be a place for Noah. But is that really a justification for a family” (Greenfeld, 2009 p.193)? Greenfeld’s parents finally concede to placing his brother in an institution billed as state-of-the-art, and the heart-rending chapter that describes their drive to the facility is made even more poignant by the following chapter comprised of the single sentence, “A boy sits by himself” (p.223) as Greenfeld describes his parting glance of his brother now institutionalized (Greenfeld, 2009). The emotional toll that it takes to place a child with a disability in an institution is movingly portrayed in these memoirs and stories like these support the redemptive notion that social inclusion on every level is a hallmark of a just society and that the need for inclusive contexts is paramount.

The power and tenacity of the medical model of disability does show up in sibling stories though, as a context that the artists sometimes acquiesce to. Some struggle with the diagnosis of their sibling, as if in naming the impairment their loved one is reduced to a constellation of symptoms, as is typical of medical model thinking. Combs (2017) wonders to the reader what her brother would have been like if he had been “born free of autism” (p.195), as though his autism were not an integral part of his identity, but rather a condition. Garvin (2010) recollects that as a child she had a similar fantasy when she imagined waking up to the revelation that her sister’s life to date had all been an act and that she really had a “normal” sister with the end effect that she would be considered normal too (Garvin, 2010). In her recollection of being the next-of-kin for her hospitalized sister, Spiro (2005) reacts with horror to the psychiatrist’s suggestion that her sister has schizophrenia. As a physician and psychiatrist herself, she thinks, “No way! Schizophrenia happens to other people. Schizophrenia happens to people at City Psycho, not to Pammy” (p.182)! The border between illness, which demands a cure, and uncurable disability isn’t always clearly defined, but in his illustrations of his brother with epilepsy, David B. (2005) draws illness as a ghostly shadow, or looming monster, and much of the book is devoted to stories of finding a cure for his brother. Although his depictions of the myriad of healers the family engaged to help his brother tend to be dark and even frightening, which could be considered a critique of the medical model, the theme of cure is persistent and hardly questioned (David B., 2005). In the same way, Greenfeld (2009) describes the vigilance that he observed in his parents as they shopped around for any remedy that could help his brother be less autistic. He says, “There must be a cure, a therapy, a program for Noah” (p.54) for someone who “excels in autism” (p.338). The fifty-page fictional text inserted into the latter portion of Greenfeld’s (2009) memoir is a fleshed out hypothetical story where his brother slowly emerges from his autism. Written in the same voice and with enough references to the earlier stories to fool the reader, it taps into a familiar narrative with a happy ending that readers are likely quick to believe. However, the section that follows, entitled “Reality” (p. 325), crashes into this story in the form of a medical chart note that reduces his brother to a collection of symptoms and what Greenfeld seems to be saying is his “real” identity (Greenfeld, 2009). The purported happy ending that medicine can eradicate disability from these stories does not exist.

As an alternative to accepting or rejecting a medicalized identity for her sister, Stahl (2018) reframes medical images of her sister by incorporating them into artistic products. In *Habitus,* (Stahl, 2018), the artist reappropriates images from her sister’s MRI scans and melds them with renderings and prints of her own body as she creates work that speaks back to the reductionistic tendencies of the medical lens. Stahl recognizes the value of the technology that allows physicians to make reasoned decisions about their plan of care for her sister but does not allow the collection of diagnostic images to essentialize or define her. Rather, she wrests the narrative from that well-worn groove and remodels it as she creates a “testament to a fulfilling life” (Stahl, 2020) that she observes from her proximity to her sister’s lived experience. The creation of a new narrative, authored by the privilege of a sibling relationship, is one that Stahl celebrates as an “act of embodied caregiving” (2020).

Family as Advocate

It is fairly common for the memoirists I am focusing on to relate stories of advocacy that they have observed in their families as they grew up with a sibling with disabilities and many of them explain how they grew into being advocates themselves. Beyond the more typical standing up for a sibling, the advocate for a sibling with disability is often in the position where they are fighting for the very personhood of their brother or sister (Frank, 2004). Combs (2017) writes about her identity as advocate for her brother as a role that she automatically or even unconsciously adopted. She says “Unknown to me, this was my pattern, a tendency to shield imperfection. For as long as I had been alive, whenever people stared at Roddy as if he were an animal, I had shifted my body in front of him” (Combs, 2017, p.70). The desire to protect their siblings physically and emotionally is a strong thread woven through most of the memoirs I have examined. Sometimes that involved a sorting out of their own friends; others who could be trusted to be wise (Goffman, 1963) about their sibling. J. Karasik (2003) explains, “I would have to know if people liked me before I invited them over to the house, because kids who didn’t could say things about David behind my back after they left, things I didn’t like to imagine but which made me murderously angry when I did. I had to protect him. We all did. We could have only friends who were very, very loyal. Only insiders” (p. 81). The childhood memory of a playground altercation winds up being more about language than physical harm, as Combs (2017) risks maternal punishment when she defends her non-verbal brother. As she hears herself address the leader of a group of boys who were taunting her brother, Combs (2017) says “A fury cracked deep inside me, elbowing its way up my throat. I felt breathless, now that I had my enemy- this big, lunky boy, whom I could slap with my words” (p.64). She recalls, “I’d been waiting months for this boy, for a fleshy bad person, someone who was my brother’s enemy, and mine” (p.64). Although embarrassed by the spanking she received as a result of verbally defending her brother with a forbidden swear word, Combs also points to this episode as a crystallizing moment in her own identity as her brother’s defender.

Interpretating a sibling with disability to others is a form of advocacy, as memoirists describe their desire for others to know who their sibling “really is” and to better understand some of the atypical behaviors that outsiders may observe. Gladly, none in my sample go so far as to claim to be their sibling's voice, but rather act as translators of a language they understand because of the privilege (Goffman, 1963) of their insider knowledge. Hershon (2010) says "Sometimes he stares at strangers and I want to tell them: 'You have no idea how nice this person is. He is staring because he is curious about you. He is staring because he doesn't know not to.' (p.25). A young David B. (2005) pleads with childhood friends to understand his brother's epileptic seizures for what they are and not to think of them as violent acts. He is unsuccessful though and they persist in reading his brother's postures as strangulation attempts. In the end he writes off the friendships as he continues to support his brother (David B, 2005). The frustration that siblings feel directed towards those who persist in avoiding or ignoring their brothers and sisters with disabilities fuels their advocacy to change those misperceptions, rather than try to change the behaviors of their siblings, which is an expression of one of the central tenets of the social model of disability. Garvin (2010) reiterates this point after observing her sister being shunned by a fellow hiker at a public park. She says "…it bugged me that he ignored us. It always has bugged me, being the 'normal' one and watching the adults who decide that the best way to deal with the strangeness in my sister is to pretend she doesn't exist" (Garvin, 2010, p.71). As an adult, and acting as his guardian, Hamovitch (2004) decides to stop medicating her brother with sedatives, which had been prescribed as chemical restraints primarily for the convenience of the staff who had formerly taken care of him (Awe in Autism, 2012). His renewed level of engagement with the world is a direct result of her advocacy in this way and she even discovers the effectiveness of music as a mode of communication for him (Awe in Autism, 2012).

Being Different

The adjective "different" is ostensibly neutral, but when applied to describe a person with a disability or their family it often takes on the meaning of non-normative or abnormal, which have decidedly more negative connotations. Some memoirists present their sibling with disability as the source of their family's abnormality. Combs (2017) writes "…but because of him, we were different" (p.24) and Garvin (2010) uses similar wording when she says, "My sister is different because she is autistic, so I am different, too" (p.236). Like a wheel that is out-of-round, the family where disability is present is described as rolling less smoothly than families who don't have a child with disability, pointing to the sibling with disability as the cause of the bumpy ride. Greenfeld (2009) describes how "We attempt to assemble a normal life around this abnormal center" (p. 48), which points to the central position of the sibling with disability in the family as the hub around which everything else rotates. This perceived distortion of shape can impact how individuals construct their identity outside of the family as well. In Goffman's (1963) definition of "courtesy stigma", those who are associated with one who is stigmatized, in this case by disability, will also be stigmatized. Many of these memoirs recount atypical and embarrassing episodes of being in public with their sibling and how the authors perceived others looking in on their world. Garvin (2020) says "…we were likely to be the center of attention at any public event, and not in a good way" (p.13). The impact that coming from a "different" family made on interpersonal connections is clear in Greenfeld's (2009) summation "At exactly the moment when I desperately want to fit in, to belong, I become acutely aware that I never will" (p.124) and "…just once I want to know what it feels like to be someone who can easily join" (p.240). Most of the sibling memoirists note the permanence of their familial atypicality and its impact on their own identity even after moving away from home. When David B.'s (2005) girlfriend breaks up with him, she says "All that stuff about your brother, it's so heavy. I can't help you…you can't carry that around…" (p. 313, 314). He follows this scene up by drawing an ominous and oversized rendering of his brother with disability, who grabs David B. by the arm and says "See, even though you're not sick you're like me. You're cursed! You're cursed like me!" (David B., 2005, p.314)

Not all presentations of difference in these memoirs are negative, and a version of disability pride (Linton, 1998) is described in some of these sibling accounts. Disability is sometimes presented as eccentricity, or a quirky lifestyle that authors state that they are privileged to be a part of (Mintz, 2009). This is often accompanied by a humorous anecdote, or story intended to engage the reader in a shared delight. Stories are presented as evidence that regardless of, or maybe due to the presence of disability in a family, there is a resilient happiness that results from embracing the idiosyncratic routines executed by the siblings with disabilities. Combs (2017) says "Roddy was someone we couldn't hide, and we didn't try to- he went everywhere with us- but because of him, we were different" (p.24). When interviewed about his photo essay about his sister, Cocco (2015) says, *"*The more I spent time with my sister, the more I felt that being disabled means living in a different world than ours—and not a worse one" (Wehelie, 2015). Dougan (2009) is particularly fond of sharing humorous stories about her sister and identifies with other families with children who have disabilities when she says, "We who have this [disability] in our family tend to be joyous about odd things" (Dougan, 2009, p. 200). Garvin (2010) concurs when she says proudly that disability has given their family a distinguishing feature and that they "revel in the rich bits and pieces that stand out and give us our flavor" (p.233).

One episode that Karasik (2003) narrates via comic strip involves himself as a teenager going to the movie theatre with his slightly older autistic brother. The movie selection being shown that day is one of his brother's obsessions, "The Three Stooges." Karasik illustrates his brother's perseverative exuberance and echolaic speech as they enter the theatre and contrasts it to the depiction of himself as hunched over, almost hiding his face under his turned-up collar with the thought bubble, "Everyone's gonna stare at us!" (p.124). As the scene continues to unfold, his brother becomes more animated, as the artist sinks lower in his seat and makes attempts to quiet his increasingly loud companion. The scene turns when he is the one scolded by an audience member who says that he should allow his brother to enjoy the antics of the Three Stooges and that he should stop his shushing. The comic evolves into a surreal, celebratory mix of film characters interacting with audience members, pies thrown, "stoogisms" proclaimed and at the very end a flirtation between the memoirist and the ticket seller. The point made is that the behaviors that identified his brother and, by association, him as different could actually be seen as desirable in certain contexts (P. Karasik, 2003). This reverse stigma that constructs disability as a benefit is present in varying degrees in sibling accounts.

Second fiddle

Formulating identity as constructed by memory and narrative (Eakin, 2008) requires a dissection of sibling stories that are enfolded (Mintz, 2009) in one another. Can there be an identity narrative that exists outside of a disabled sibling's story (Mintz, 2009) or is identity defined by the negative space that the sibling with disability does not inhabit? It is not accurate to claim that the authors of these memoirs only have stories to tell because of their siblings with disabilities (Couser, 2005; Mintz, 2009) and most of them are established writers in other genres. However, they have each chosen to frame their own identity as impacted by and intersected with their siblings' disability narratives.

Most memoirists in this group described their sibling's story as taking precedence in the family, as dramatic turning point and focus of attention, often to the exclusion of others. Combs (2017) remembers gradually realizing that "…she (mother) was no longer available to me and might never be again" (p. 35) and Garvin (2010) too concludes that she and her non-disabled siblings "were getting the short end of the stick because Margaret's autism took up so much of my parent's time and energy" (p. 140). The spatial metaphors that Greenfeld (2009) uses to describe the priority of his brother's needs are powerful. He says "… I can feel the room tilting toward you whenever you walk in, all the attention and parental love drains into you, never to come back out" (Greenfeld, 2009, p. 10) and "Noah is the family's overriding concern, the axis around which we rotate" (Greenfeld, 2009, p.49). In the documentary *Raising Renee* (Jordan & Ascher, 2011) McIver uses a similar metaphor when she says, "Growing up, everything centered around her. She was a bigger-than-life creature" (Jordan & Ascher, 2011). The centrality of their sibling's story and disability inevitably pushes other family members' stories to the sidelines.

The reader is left to assume that because parents were primarily focused on the child with the disability, that the memoirist felt somewhat neglected. In this way, the sibling without disability develops an identity marked by absence of a characteristic, in this case disability.

What is often constructed as stigmatizing (Goffman, 1968) in society can be perceived as a positive characteristic in a family if it draws parental attention towards the child with the disability. Non-disabled siblings may even have felt a sense of envy towards their brother or sister with disability, desiring their own disabling condition that would turn their parents' attentions towards them. An adolescent Spiro (2005) becomes angry around the attention her sister gets after she fractures her leg and in her recall of this moment says, "I have to bite back my fury at all the attention she gets… I should have broken my leg" (p.49). After a particularly emotionally taxing dream, and in an exhausted state, David B. (2005) wonders what it would be like to induce seizures in himself that he has observed in his brother. He draws himself assuming similar postures that he uses when drawing his brother's evolving seizures and says, "If I push myself I'm sure I could trigger more serious seizures. Then I'd really be sick. I could let myself fall! I'd be taken care of, I'd be nursed" (David B., 2005, p.2007).

The metaphor of the family as characters in a play crops up in a couple of memoirs, with the same observation that the sibling with disability is akin to being the star of the show. While people with disabilities are typically marginalized in society at large, within families they may inhabit a more central position, around which the action happens. For example, Greenfeld (2009) says "I am, by implication, a supporting character, a bit player who provides interesting contrast to his autistic brother…" (p.102) and Wagner (2005) taps into the same comparison when she says "…I am only a supporting actor. She's the main subject, the leading lady" (p. 288). Again, the perception of the child with the disability as being more important than the child without the disability feeds into the narrative, which helps to construct the non-disabled sibling's identity as a supporting actor rather than a star.

Reporter

Siblings of people with disabilities have a privileged point of view within their family where they can be close observers of how the rhythm of the family is impacted by their brother or sister's impairments. Similar to journalists who are embedded in a context in order to experience a news story first-hand, siblings watch their parents, their sibling with disability, and other siblings as they navigate daily life, and in memoirs give an account of what they have seen. While this perspective is valuable, we need to keep in mind that sibling stories are filtered through the memoirists' own points of view, which are invariably informed by grand narratives and memories and thus are not just objective reports of "the news." The fact that each memoirist has chosen to somehow relay what it is "really like" to live with a sibling with disability indicates that they recognize the value of their position to inform those on the outside of what life with disability is like. Greenfeld (2009) realizes that it is after his brother is first diagnosed that he begins to make observations of his family and says, "I now start to watch the family, often from above…. It is while I am sitting there, watching, listening, that I begin to feel that Noah is not like other children. This is the heaviness" (p.36). In this statement, he positions himself above where he can get an inclusive overview of family dynamics but is also in the heart of the family where he can ascertain the emotional climate. In this way, he reveals his identity as an embedded reporter in the context of his brother's disability.

In the memoirs I have included in this project, there is quite a bit of coverage of the maternal role as observed by the non-disabled sibling. Siblings' shared relationship with their mother is a potential alliance as they are both recipients of her care, or lack of care as in some instances. The memoirist reporters can gauge their mother's capacity to love them, as extrapolated from how they see their mother bestow love to their sibling with disability. Many express a sense of awe, as Greenfeld (2009) does “For my mother especially…breaking down her love of Noah was as impossible as trying to divide a prime number. It is just there, in all its indivisible and impractical glory… I swear to you, if you watch her those afternoons, you will marvel at the patience of human beings. …Watching her, I get some idea of what parental love is, of the burden of it, of what it requires, of the demands. I also realize that if she loves Noah that much, then she must also love me” (p.219, 220). David B. (2005) also observes how his mother protects his brother, at the same time that she keeps them all together. He says, “As soon as he’s confronted with a problem, Jean Christophe now seeks refuge behind our mother. She keeps looking for a way to tend to my brother, and the rest of the family as well” (David B., 2005, p. 192). Cocco captions one of his photographs with commentary about his mother, describing her as taking care of his sister “every day and every hour, giving her security and serenity” (Wehelie 2015, slide 6). He echoes the sentiment that others (Greenfeld, 2009; Karasik & Karasik, 2003) share that the sacrifices mothers make for their children with disabilities are both unbidden and praiseworthy.

Observations of mother as stronghold are moderated by other scenarios where the actual or perceived challenges of raising a child with a disability overwhelm and reveal vulnerabilities of mothers to the observant sibling. When Combs’ (2017) brother is first diagnosed with intellectual and social disabilities, her mother is overcome by this news and swoons. Seeing her mother in such a state, lying in her father’s arms, requires Combs (2017) to reconstruct the persona she had built up of her mother. She reflects, “But right then, in my living room, I knew my mother wasn’t a songbird or a beauty queen. She was someone whose legs were dangling and whose high heel was falling to the floor (Combs, 2017, p.7). And again, “Something had broken in her then, and now, I saw she was still broken. …Between here and the end of her days lay the relentless needs of a disabled child, and the fear that maybe she didn’t know how to be a mother or how she would ever help her son” (Combs, 2017, p.39). Fear of inadequacy or being unprepared to parent a child with disability is a theme that shows up in parental memoirs (Bérubé, 1996; Piepmeier, 2012; Savarese, 2010) but when a child sees a parental vulnerability exposed, there is added emotional gravity. Just as recognizing a parent’s strength can give a child confidence in their omnipotence, the realization that mother (or father) are capable of being afraid can have a negative emotional impact on an observing child. When Simon (2002) recalls the first time her sister had a seizure, she notes, “Mommy turns. Her eyes are red, and she looks down at us. And we stand there, just like that, staring up at her, until the scare in her face suddenly turns into something else” (Simon, 2002, p. 52). Although the passage goes on to describe a positive outcome of this particular episode, Simon taking note of the fear in her mother’s face is a powerful realization of her mother’s mortal limitations.

In addition to feeling inadequate, parents (and mothers in particular) can feel responsible for somehow causing their child’s disability. For some, thinking that they passed down a faulty genetic mix to their offspring explains why a disability presented itself in their child. Greenfeld (2009) reports that his mother convinced herself that this was how she failed her son. He says, “To concede to herself that her son is disabled, was, in a sense, to cop to the most colossal failure possible. Her own genetic material had come up short” (Greenfeld, 2009, p.25). Much attention is given to explorations of ancestry in David B.’s (2005) graphic novel, and he reminisces that as a child he deduces that “If my brother’s epileptic, it’s from my mother’s side” (p.174). Genetic mistakes are attributed to immorality in the rural hometown where Combs’ (2017) parents hail from. She says that in the Appalachian Mountains, “The only reason for a ‘retarded’ (sic) child was inbreeding, a condemnable thing relegated to whispers and averted eyes” (Combs, 2017, p.16). In this we see the centuries-old trope of disability as evidence of wrongdoing, with a connection to the idea that children inherit their parents’ sin (Goodley, 2017). Even in the face of expert opinion to the contrary, Hershon’s (2010) mother holds onto the idea that something during her pregnancy caused her son’s disability. As her daughter questions her more deeply about her conviction that her illness during pregnancy caused her son’s disability, she breezily says, “I think they’ll figure out there’s a link” (Hershon, 2010, p.28). It is noteworthy that in all of these examples, disability as inherited is considered to be a negative trait and indicative of something that went wrong, which is congruent with tenets of the dominant medical model of disability. This tenacious ideology has its roots in eugenic dogma and practices that thrived in the early 20th century and are yet present today in the application of the human genome research to disabilities such as Down syndrome and autism (Kafer, 2013). In most of the memoirs that I am investigating, the memoirists spend some time pondering the heritability of their siblings’ disability and factor these musings into their own childbearing decisions (Combs, 2017; Garvin, 2010; Greenfeld, 2009; Hershon, 2010).

Even if families can resist the tendency to see disabilities as inherited mistakes, i.e., nature, there are factors that professionals often readily identify as primary causes of pathological behaviors via nurture. Parents are once again blamed for causing disabilities in their children and non-disabled siblings notice the guilt this can induce. In a phone conversation with her mother, Spiro (2005) asks about her twin sister who is struggling with symptoms of schizophrenia. Her mother says "She's up and down, out of the hospital, at the halfway house. They want me to visit less. I guess I'm part of the problem…I'm overprotective or something. Pammy's too dependent on me" (Wagner & Spiro, 2005, p.142). The patronizing behavior that physicians often exhibit towards mothers is captured in Combs' (2017) recalled scene "…Mama looked down at her pocketbook and Dr. Gibbs tapped on her pillbox hat. *Thump thump thump. If you don't stop babying your boy, he'll never bother to stand up and walk"* (p.4). The idea that children can be "spoiled" by indulgent parents persists in grand narratives about parenting in general and seems to have extra strength when applied to parenting children with disabilities. Observant siblings notice the ramifications within their family rhythms and are likely recipients of modified parenting too.

One of the prevailing myths that took hold during the middle of the twentieth century was that poorly understood disabilities such as autism were caused by emotional distance between a mother and her infant child. The idea of "refrigerator mothers" was used to refer to a type of unaffectionate mothering thought to lead to the communication difficulties that autistic children were observed to have (Bettelheim, 1967; Kanner, 1943; Piepmeier, 2012). Although not substantiated in evidence, medical experts eager for explanations were all too keen to attribute perplexing behaviors observed in children with autism to faulty nurturing. This was in keeping with the trend towards behaviorism in psychology during this time and thus the theory gained strength among educators and other professionals as well as the lay public. Fortunately, some families resisted this explanation as their lived experience did not support the underlying assumptions of the refrigerator mother etiology. Greenfeld (2009) relates the intensive research his parents did into the cure-promising interventions that Bruno Bettelheim was marketing as he skyrocketed to fame, but the premise that Bettelheim built much of his work on just didn't fit what they knew of their family. As their investigation continued, they realized that there was no evidence that his cures worked, and eventually disregarded his practice as well as his premise (Greenfeld, 2009). Similarly, Karasik's (2003) parents are confronted with the popular notion that detached parenting is the primary cause of autism when they take their son David to see a diagnostic specialist. P. Karasik (2003) illustrates his memory of the moments directly following the doctor's visit and includes a rendering of his mother with a downcast face reading from the report she has just been handed. It suggests "possibly emotional causes" for his brother's idiosyncratic language, which Karasik's father immediately counters by saying "You, Joan P. Karasik a 'refrigerator mom'?!" (Karasik, 2003, p.25). She persists by claiming that "They say that early lack of parental warmth can cause emotional stress", to which his father replies in bold, "PLEASE!" (p.25) and then tries to relieve the tension by making a sweet joke (P. Karasik, 2003, p.25). The remaining panels of that comic provide an alternative explanation for Karasik's brother's behavior, as we observe Karasik's father initially becoming angry but then comforting and loving in response to his son's persistent crying. When they realize that his crying had to do with him being thirsty, they have the epiphany in the last panel that David's behaviors are likely because he cannot communicate his needs to them rather than any lack of loving parental engagement (P. Karasik, 2003). Fortunately, this idea has more recently taken hold among parents and professionals alike, who have recognized that many of the behaviors that people with autism exhibit are not related to parenting styles, but rather are responses to difficulties in reciprocal communication (Biklen, 2005). In Hamovitch's (2004) interview with her father about her brother Alan's diagnosis of autism, he reveals that their mother was blamed for this diagnosis and that the doctor declared that she must have been "emotionally cold" (11:07). There is some ambiguity in other interviews about how this theory impacted Hamovitch's mother, but the images accompanying this portion of the narrative display countless loving and affectionate moments between Alan and their mother, captured in home movies. Hamovitch seems to be countering the doctor's proclamation with a wealth of evidence to the contrary.

Of course, observations recorded by these memoirists aren't all about healthy and redemptive family dynamics. There are some parents who are overwhelmed by the needs of their children and lack of societal supports for anyone in the family. In response to the paucity of placements for her daughter, Dougan's mom says "I'm so discouraged, I don't know what to do. Irene doesn't fit in anywhere and I can't cope with her anymore. I don't want to leave her to you to have to deal with. I'm thinking the best solution is to just kill her somehow, and then kill myself" (Dougan, 2009, p.87). While this expression is probably understood as melodrama, and her mother wasn't actually homicidal or suicidal, these statements do reveal a certain desperation that she felt. It is disappointing that Dougan (2009) doesn't really unpack this interaction in her text and with extraordinary parsimony, informs the reader that her mother didn't act on these impulses. Simon (2002) initially paints her mother in a sympathetic light, as a harried single mother with several children including one with an intellectual disability who needed extra attention. But as her mother's need to be married superseded her better judgment, Simon (2002) remembers feeling, "We cannot begin to understand our mother, who seems to have gone off the deep end. … But Mom went along with it all, to the point of almost letting her daughter get killed. …She must be a monster inside" (p.229). Her mother's seeming abandonment of her family and willingness to put her vulnerable and disabled daughter in harm's way is almost unforgiveable to Simon and her other siblings. Although they reconciled years later and Simon (2002) was eventually better able to see her mother's perspective, she chose to include these difficult storylines in her memoir as meaningful formative experiences in her identity as the embedded reporter.

An unnamed role – in between sibling and parent

In most of the texts that I have included in this discussion, the authors describe the liminal space that they occupy related to their sibling with disability and parent(s). There are caregiving roles that are typically associated with parenting that siblings may take on upon a parent's death, but siblings of people with disabilities often "parent" their siblings even before that time, sometimes when they themselves are still children. While there is no one way that they enact this relationship, each memoirist reflects on the unique nature of this in-between state. Garvin (2010) writes "Margaret and I did not choose this role reversal. You could say that her autism assigned it to us," (p.1) which portrays their relationship as a simple switch between older and younger sister, as well as roles imposed upon them by a personified autism. Later in her text, she nuances both of these positions as she describes her caregiving as being "a matter of course" (p.188) rather than an imposition, and as she coins the apt phrase "I was her big little sister" (Garvin, 2010, p.188), which complicates their sibling dynamic into a both/and relationship.

Sibling disability memoirs tend to differ from parental disability memoirs precisely because of this in-between relational state and the idiosyncratic way that it is constructed in each case. Parents of children with disabilities often have to resist narratives assigned to them (Bérubé,1996; Lalvani & Polvere, 2013; Piepmeier, 2012; Savarese, 2010) and work to represent their lived experience via memoirs and other life-writing. Generally, they can rely on readers having a basic understanding of what parenthood entails even when detailing their atypical experiences, but there isn't the same kind of script for siblings who take on parental roles for their siblings with disabilities, and thus sections of their memoirs are devoted to defining this hybrid role as played out in their narratives.

The sampling of memoirs I chose revealed that siblings can feel tension and even resentment about taking on some of the responsibilities of a parent, particularly when the sibling has felt less regarded in the family than their sibling who has a disability. The lateral orientation of a sibling relationship where the siblings are presumably at the same hierarchical level within the family does not go through a recalibration when a child takes on the physical and logistical caregiving tasks for their sister or brother. Sibling caregivers remain in the same position in the family, even as they assume the responsibilities and decision-making more typical of a parent. There is often a subtext of obligation in the acceptance of this hybridized role as Spiro (2005) reveals when she says, "I don't want to take care of Pammy, but I need to know she'll be okay, and right now she has no one else but me" (Wagner & Spiro, 2005, p. 102-103). Combs (2017) echoes this sense of obligation and adds her concern about being emotionally equipped for this role as she queries, "Did I have enough love? My worry was no different than any sibling of an adult with disability. After my parents were gone, caring for my brother would be a full-time, nonstop job, without respite" (Combs, 2017, p. 262). Others are more to the point about falling short of their parents' capacity to give care to their siblings with disability. Greenfeld (2009) proclaims "For a brother does not love as a mother or father" (p. 228) and McIver acknowledges that she "can't be my mom and give Renee the life they've had" (Jordan, Heller & Ascher, 2011). In addition, sibling memoirists may see their future caregiving as being an isolating role, as J. Karasik (2003) forecasts, "I saw myself holding my brother David's hand, leading him through his days, big emptiness all around me" (P. Karasik & J. Karasik, 2003, p.4).

The statements are clear; although these siblings wouldn't choose to parent their disabled kin, they feel that they must accept this in-between role, regardless of the serious ramifications for their own lives and not being able to do the same job that their parents did. There is no stand-in for parental love, regardless of how many parental tasks siblings take on, and these memoirists recognize that they will always fall short of that mark. Of course, all families have the potential to engender obligatory tasks that fall to family members when dynamics shift for some reason, such as death or change in capabilities. But the concerns articulated by these siblings seem to arise from the ramifications of the circumstances to their identity because of disability and what taking on parental tasks for their sibling does to that presentation of self and their sibling relationship.

Narrative arc impacted by sibling story

One clear theme that I identified in each of the memoirs that I reviewed is that being the sibling of someone with a disability impacted the trajectory of their own story way beyond childhood. Although family narratives and memories are thought to construct identity for all (Eakin, 2008), for these authors there appears to be a very clear connection between growing up with a sibling with disability and the way that they experience and make decisions about future relationships with friends, partners, and children of their own.

Combs (2017) most clearly identifies how fears of having a child with disability herself initially prevented her from starting a family. She says "I was speaking from a hardened fear. That I could conceive a child like my brother and that it would break me" (p. 272) and "From all I'd seen, it was best not to have children at all" (p. 100). She digs a bit deeper and identifies a core anger that she recognizes in other siblings of people with disabilities. "I wasn't aware how (anger) existed in me, or that I shared it with other children whose sisters and brothers were afflicted in some way. I hadn't a clue how fiercely it would emerge and drive my life" (Combs, 2017, p. 63). Garvin (2010) also credits her childhood with a sibling with disability as factoring into her decision to not have children, but not for fear that there was a genetic risk that she would have an autistic child. Rather, her inability to effectively teach her sister how to live in the world developed into a lack of confidence about being able to teach anyone, particularly children of her own (Garvin, 2010).

There are positive epiphanies too, in the way that these sibling authors frame being prepared by their experiences with a family member with disability as helping them be more resilient and they are sometimes pleasantly surprised by the different paths that their own relationships forge. Growing up with a sibling with disability becomes a marker or touchstone that lends perspective on their outlook to the future. Garvin (2010) says "I had grown up with the dynamics of autism so I was used to surprises, but I was unaccustomed to the happy ending. I was hardwired for the quirky finale, the crisis, and the climax of the unforeseen and the unmanageable" (p. 174). Greenfeld (2009) recognizes what he missed out on in his own sibling relationship when he observes his daughters and how they interact with each other. He says, "Their relationship…helps reveal the shape of the gaps in my own relationship with Noah" (p.92) and "…they are forming a rich and complex sisterhood that my wife and I can only marvel at…" (p.92). While Greenfeld's experience growing up with a brother with a disability formulated his approach to marriage and having children, observations of his own daughters lend hindsight and clarity as he reflects back on his brotherhood. The mutable nature of memory and the work that it does in constructing identity (Eakin, 2008) works in both directions as narratives are informed by more experience and critical distance. He summarizes it thus: "But I understand that Noah is there, always, on my time horizon, the destination of my journeys as sure as he was the point of embarkation" (Greenfeld, 2009, p. 337).

Clearly all of the memoirists I reviewed used their sibling experiences to inform their art and, in that way, have positively benefitted from this identity. Speaking about a piece of short fiction that she had recently written, Hershon (2010) recognized that her "brother influenced the story, has probably influenced everything I've ever written" (p.29). This consciousness, or self-consciousness about how being a sibling to someone with a disability informs artistic identity is present in various forms in my selection of memoirs. Greenfeld (2009) seems somewhat conflicted by the profit he will make from publishing his sibling disability memoir, in part because his father wrote two successful and, in some ways ground-breaking memoirs about life with Greenfeld's brother and his mother also wrote a novel, inspired by her disabled son's story. He muses on the "cottage industry" (p.79) that his brother's life has become for the family and admits that although he set out to write a guide on autism when he first began the project, it took on a life of its own and became a memoir instead (Greenfeld, 2009). In the epilogue to his illustrated memoir, David B. (2005) writes as an avatar speaking to his brother, "I've often been criticized for the darkness and violence of my stories. I didn't realize I was writing about you" (p.358). There are revelations and epiphanies in the creation of these artistic products, and the recognition of this helps to justify the artists' choices to disclose family stories (Frank, 2004).

The disability narratives that are constructed by popular culture and society often follow a traditional narrative arc, with expected trajectories such as cure, redemption, and overcoming disability as the resolution to the "crisis" of disability (Smith & Sparkes, 2008). Stories with this predictable arc reflect a reductionistic view as made familiar in medical narratives of disabilities. But as Frank (2004), referencing Bakhtin notes, family members who seek to present stories about children with disabilities resist any neat resolution or "last word" (p.185) about the child so that they will not foreclose their future. In what Frank (2004) describes as "respectful practice" (p.185), memoirists should avoid the "tidy ending" (Ferri, 2011) even if it frustrates an audience who has learned to anticipate happy resolutions. Although she adopts the well-worn trope of the journey to describe her life as the sibling of an individual with a disability, Garvin (2010) explicitly identifies her respectful practice of leaving the ending unwritten. At the beginning of her book, she says, "I often feel this about my life: mapless, guideless, as if I am actually hammering the nails into the wood of the bridge I need to walk across one crappy, ramshackle board at a time" (Garvin, 2010, p.13), foreshadowing the stories that she populates her memoir with that take her by surprise. Rather than resolve this anxious state with a storyline of how she found her way or guide to help her navigate through life with her sister, she reveals that “I was waiting for the Disney ending when the Virgin of Lourdes would walk down off the stained-glass window in the church, bless you with holy waters, and call you healed. Then one day I realized that I had been completely wrong about all of it” … “It was just life” (Garvin, 2010, p.248). She emphasizes this perspective shift in the very last lines of her memoir when she says “I know you just wanted to know what came next. So do I” (Garvin, 2010, p.252). Her story and her sister’s story are not over, and we are not privy to even a conjecture about the next chapter. The literary device that Karasik & Karasik (2003) employ to make this same point is their invitation to their brother, David, to review their memoir and to conclude it in the way that he sees fit. P. Karasik illustrates himself sitting next to David as they review the manuscript and when they are done, we see a larger pane that depicts their silent, mutual regard (Karasik & Karasik, 2003, p. 198). Their silence is broken when P. Karasik prompts his brother one final time to contribute to the ending which triggers David’s script recitation from one of his favorite television shows, familiar now to the reader. The last page of the memoir is dutifully rendered by his P. Karasik and is not summative. Rather, the full-page illustration depicts the ordinariness of David’s daily routine as he is supported by the cast of fictional characters that he channels (Karasik & Karasik, 2003, p. 200). The message is again that life goes on and the end of the story is yet to be written. These memoirs that resist the traditional template of the narrative arc broaden our understanding of the diversity of disability narratives.

As this chapter has outlined, some of these larger themes are shared by several of the chosen memoirs and many cut across genres. In the next two chapters, I will zoom in and reflect on how specific genres can impact the communication of an idea related to sibling disability and identity.

Chapter 3 - Sibling memoirs- text-based form

In this chapter, I consider what I describe as text-based memoirs written by siblings of people with disabilities. The inclusion and exclusion criteria I have devised to choose texts for this part of the project are defined below, followed by a brief description of the method I used to analyze these texts, and then I finish this chapter with the analysis itself.

Inclusion/Exclusion criteria

The most traditional forms of life-writing are published, book-length memoirs, and in the sub-genre of sibling memoir, disability figures into many of these narratives (Mintz, 2009). In my initial survey of sibling disability memoirs via academic library and bookseller databases, I developed criteria which I used to decide which memoirs to include in this discussion. These were: date of publication; peer-review; defined disability; and, an orientation that was not intentionally rehabilitative.

First, I considered publication date and place and decided to limit texts that had been published within a sixteen-year span (2002-2018), as this relatively recent temporal context would allow for a comparative experience to my autoethnographic research that comprises the second half of this project. Cultural contexts are critical components to investigations of narrative identity (Clandinin & Connelly, 2000) and although there is no single historical context shared by the texts I have included, they are likely impacted by common cultural markers, external to the stories themselves. Thus, the sixteen-year window includes authors in or close to my generation who have been exposed to similar historical phenomena and are writing about the same time periods that I write about. All of the text-based sibling memoirs chosen are published in English and in the United States, which are not inclusion criteria but rather a function of the types of publications listed in the English language databases I used.

Next, I attended to issues of peer-reviewed texts. In my desire to understand the position of sibling disability memoirs within the larger body of life writing, I decided to choose only those already vetted by a group of peer experts, rather than self-published works. Looking at the chosen texts as representative of what gets published has allowed me to recognize trends of what those in power (i.e. publishers) deem worthy of publication and lends perspective to the contextual forces that impact publication decisions.

Following this, I included any sibling memoir that described its subject as a sibling with "disability," regardless of the type of impairment. This resulted in the exclusion of sibling memoirs written about siblings with stories of substance abuse and/or addictions, terminal illness, victims of violent crimes or parental abandonment/abuse. Although these excluded texts would likely be appropriate to examine from a critical Disability Studies perspective, I decided that they were far enough removed from my own narrative that they were beyond the scope of this study. One sibling memoir that I originally included in my study (Smith, 2007) is written by the sister of a man with autism, but I opted to exclude it as over half of the book is devoted to a story about a local crime that impacted the author's childhood and veered away from the disability narrative.

Finally, I considered the orientation of the memoir. I excluded texts that were overtly "self-help" books, written *for* siblings of people with disabilities, as these tend to be grounded in narrow assumptions about disability as tragedy and the idea that siblings of people with disabilities require instruction in strategies to cope with their sibling's disability. I aimed to include texts that at least had the potential for a critical perspective and the self-help genre tended to foreclose any possibility for a more critical engagement with disability. Some of the self-help texts that overtly supported a deficit model of disability and therefore identify sibling relationships as inherently problematic include *Special siblings: Growing up with someone with a disability* (McHugh, 2003), *Being the other one: Growing up with a brother or sister who has special needs* (Strohm, 2005) and the distastefully titled, *The normal one: Life with a difficult or damaged sibling* (Safer, 2002). I did read these texts when preparing for this project, and although I am not including them in my analysis, they are somewhat present because of my intentional and specific exclusion from this investigation.

To reiterate, I chose six book-length memoirs that meet my inclusion criteria and one short essay that I decided to include in this group as it too meets the inclusion criteria and is similar enough to the book-length text-based memoirs to include. These texts are: *Hazard: A Sister's Flight from Family and a Broken Boy* (Combs, 2017), *That Went Well: Adventures in Caring for my Sister* (Dougan, 2009), *How to be a Sister: A Love Story with a Twist of Autism* (Garvin, 2010), *Boy Alone: A Brother's Memoir* (Greenfeld, 2009), *Any Day Now* (Hershon, 2010), *Riding the Bus with my Sister: A True Life Journey* (Simon, 2002), and *Divided Minds: Twin Sisters and Their Journey Through Schizophrenia* (Wagner & Spiro, 2005).

Method

In addition to reading for content themes in the chosen sibling memoirs discussed in the previous chapter, I examined the texts individually and wrote memos that made note of the style and shape of each as well as extratextual features such as the cover art, title, and reviewer's blurbs. I also paid attention to devices such as metaphor use, chapter titles, temporal organization and stylistic characteristics. The close reading of these texts has revealed additional insights into issues impacting identity formation for siblings of people with disabilities. Contextualizing these stories helps to point out which narratives get told and which narratives are missing from this sub-genre.

Analysis

I examined these seven texts with the goal of discovering how each memoirist uses their writing to interrogate their identity as a sibling of someone with a disability. Using Eakin's (2008) equation of identity as the product of narrative and memory, I identify the narrative devices these memoirists use to present their remembered stories as well as the contexts that help to formulate the narratives that they tap into. Frank (2004) says "People build their own stories on the narrative scaffolding that their local worlds make available, and these scaffoldings constrain the kind of story that can be told, even as they enable the possibility of storytelling" (p.178). The more typical narratives that are constructed around disability as well as the counternarratives to those more common tropes were considered as they do work in these texts.

Narrative shape

The shape of a narrative is influenced by the contexts where it is situated and the type of stories that are at its core. When disability narratives are constructed by outsiders to disability experience, they often follow a traditional narrative arc that necessitates a crisis episode, a climactic scene with a turning point and a resolution. These types of narratives underlie many of the products of popular culture about disability and because they tie up in neat resolutions are typically described as inspirational; that is, if disability can be overcome other challenges can be overcome as well, which can be affirming to consumers of these texts. Of course, this arc is an artificial template that reduces narratives of disability and presents them as event-centered rather than experience-centered (Frank, 2004; Mattingly, 1998). An event-centered narrative (Mattingly, 1998) of disability begins with an event or crisis such as a diagnosis of disability, builds up to a climactic moment of cure or rehabilitation for the individual with the disability and then resolves into a state of lessened or complete absence of disability. This is in keeping with reductionistic, medical model narratives that have cure as the happiest of endings. Experience-centered narratives (Mattingly, 1998) of disability are more focused on thick descriptions (Geertz,1973) of what the experience of disability is like, and don’t presume that there is a crisis that requires resolution. Experience-centered narratives don’t necessarily follow an arc shape and, rather than provide a template for story, Mattingly (1998) suggests that these narratives are created by the experiences of the person and are thus bidirectional. That is, narratives can impact experiences, but those experiences can then write or re-write the narrative. In this way, stories shared about being a sibling of a person with a disability have the potential to construct new narratives, rather than fall in line with predetermined plots. I found examples of both event-based and experience-based narratives in the text-based sibling memoirs I reviewed.

The genre of memoir lends itself to the use of a chronological organization for the text as the retelling of a life easily falls into a narrative arc with a beginning, middle and present, if not an end. So, it is not surprising to note that five out of the seven texts I have chosen for this analysis follow a general chronology to frame the stories that they chose to share. Dougan (2009) is most true to this form and begins her first chapter with the birth story of her sister, as told from her perspective as a young girl waiting for her baby sister to arrive home from the hospital. The chapter heading includes the date of the remembered story although none of the subsequent chapters are dated, signaling the import of the event. The chapter includes a parallel story of a ferocious lightning storm taking place as Dougan and her grandmother await her infant sister's arrival. The assignment of a specific date helps to create an event-based narrative as the tree-toppling weather serves as a strong metaphor for Dougan's (2009) sister who like a bolt of lightning enters their family with force and upheaval. The trajectory is steep though, as the "crisis" of her sister's diagnosis is related in the third chapter when Dougan is in elementary school and by chapter five, enough time has passed for Dougan to leave her sister as she moves out to go to college. The remainder of the text, which is the majority of the book, relates her experiences as an adult with an adult sibling with disability (Dougan, 2009) still relayed chronologically, but fast-forwarded through their childhood and young adulthood. Similarly, Combs (2017) begins her memoir with the event-based narrative of the birth story of her brother but leads the reader at a slower pace as she brings us through her shared childhood with him and their older sister. Her story lingers in these early years and reveals more about her family dynamic from those days, not moving away from her family home until chapter twenty-one, more than half-way through the book. In addition, Combs uses the organizing feature of separating her book into three sections, alliteratively named "Family", "Flight", and "Fortuity" (Combs, 2017). Each section delineation cues the reader to shift perspective, as she brings us from her remembered childhood viewpoint through her emerging young adult viewpoint and on into a more contemporary reflection on her life as a lucky adult sibling of a man with a disability.

Greenfeld (2009) also makes use of chronology as a foundational structure for stories shared about his brother who is autistic. His three-section division like Combs' (2017) presents the text in categories he entitles "A child", "A boy", and "A brother" (Greenfeld, 2009) and these more or less follow his early years, on into his adolescent years and then his young adulthood up until present day. Greenfeld's choice of section titles is a little less clear, particularly the third section "A brother," which would ostensibly apply to his relationship regardless of his age. One way to interpret these sub-titles is as a progression from the more objective categories of child and boy to the more connected and relationally defined brother. The word brother automatically refers to at least two people, and in this case includes the author and the person who is the subject of much of his writing. It could be that in the last third of the book Greenfeld comes to an understanding of what it is to be a brother to Noah.

Greenfeld's *Boy Alone* (2009) seems to follow the event-centered narrative arc that leads from the crisis of early struggles of his brother Noah's diagnosis and many continued crises as they grow into adolescence, with the worst moment being the realization that Noah is likely being physically abused by personnel at the residential school he had been attending. This crystalizing event spurs Greenfeld's parents to take the revolutionary step of setting up a home for their autistic son and staffing it with people who are specifically chosen because of their abilities to be caring companions and teachers for Noah. This seems to be a turning point in the story, as in the following chapter, Greenfeld recounts the amazing turnaround in Noah's life, as he begins to use language, engage with the world and even establishes a romantic relationship with a woman from his past. Stories about Noah's purported "emergence from autism" occupy fifty pages of the memoir and seem to move towards a resolution or "happy ending" as prescribed by the traditional narrative arc. But Greenfeld hijacks that script when he interrupts the story with a chapter entitled "Reality" (2009, p.325). He abruptly switches from the happy narrative to a facsimile of a medical chart that reduces Noah to a diagnosis and list of "Identified Maladaptive Behaviors" (p. 327). The picture that these data construct that Greenfeld identifies as "Reality" (p.325) is very different from the Noah of the previous fifty pages. We realize that the story of Noah's redemption from autism is a short fiction inserted into the memoir and Greenfeld uses this device to make the point that there is no happy ending to the narrative. The shape of this narrative, as dictated by Greenfeld's experiences with Noah is then a disrupted arc communicating in an experience-centered way what life with Noah is like and creating an alternative scaffolding upon which to hang stories. Greenfeld describes his motive for including the fictional tale as a therapeutic exercise as well as an exploration of what he calls the "great question in our family…What if Noah were normal" (p.329)? It seems that Greenfeld both longs for the traditional resolution-based narrative and yet also introduces the unconventional perspective that his family developed (Greenfeld, 2009) as an alternative possibility.

Some sibling memoirists mix an overall chronological orientation with flashbacks and flashforwards inserted to highlight important moments. Simon (2002) organizes her stories around a calendar year and divides and names sub-sections of the book with the months of the year. In part, this structure is dictated by the project that Simon has committed to where she spends the course of a year with her sister Beth, who has an intellectual disability, as she rides city buses every day. Part journalistic assignment and part desire to honor a promise she made to her sister, Simon includes contemporary anecdotes as well as salient flashbacks in each monthly section. There is a sequential and chronological progression to both of the storylines and although they co-exist in the monthly sections, they never overtly interact. This is an effective device as the reader maintains a forward pressing desire to follow the narrative arc of the contemporary story of the adult sisters but is informed and likely fascinated by the backstories of their childhood that are sprinkled evenly throughout the text. It fleshes out the characters in a clever way and helps to draw connections between the sisters' earlier days together and who they are in present day. Although this novel structure creates a slightly different shape than the traditional narrative, each of the storylines, told simultaneously, builds to a climactic turning point and falls to a happy ending. These endings, however, are not oriented around cure, but are relational in nature. The crisis in the flashback narrative occurs when Simon's mother leaves home and basically abandons Beth, exposing her to potential abuse. The turning point involves confrontation, reconciliation and forgiveness between Beth, Simon and their mother, with whom they resolve to develop a healthier relationship with. The contemporary story has a built in ending as the calendar year winds down, but the turning point appears to be just before that as Simon realizes that she has learned enough lessons riding the bus with her sister and this has made her modify her priorities. She contrasts her initial self-description as career-driven with little time for outside relationships with a scene in a chapter in the "December" (p.314) section where she opts to stop working early and joins neighbors in a holiday activity instead. This is topped off a few pages later when she hints at the beginnings of a romantic relationship with a man whom she met through her bus riding trips with Beth. Simon's finding a partner seems to constitute the trope of disability as a redeeming force; that is, Simon learns to prioritize relationships over success and becomes a better person because of her sister. While these narrative resolutions don't eradicate or cure disability, Beth's intellectual impairments seem to be constructed as less tragic if they have enabled Simon to live a more satisfying life. In this way, both story lines follow the traditional event-centered narrative arc.

In the bivocal memoir *Divided Minds* (Wagner & Spiro, 2005) twin sisters narrate their life stories in a generally chronological manner, taking turns and each lending their perspective to the same time periods and sometimes the exact same events. This presentation allows for the individual with the diagnosed disability to present her story alongside her non-disabled sibling and does not privilege one narrative over the other. In this way, it acts as a counternarrative to outsider "expert" texts that attempt to relay a disability story. Although the four "books" or text divisions correlate to life stages (school age, college age, post-college young adulthood, adulthood) the crisis of the narrative is introduced at the very beginning of the book in the prologue, in the voice of Wagner (2005) who is the sister with the disability. This set-up gives the reader foreknowledge of the anxieties and functional issues that Wagner's disability impacts and allows us to proceed to read the backstory with this point in mind. This crisis is described again near the end of the book, midway through the section Book Four (p.260) this time by both sisters, alternating telling portions of the story, each from their own perspective. In the later iteration, the story has more context and thus seems like it might be leading to a turning point and then resolution. In addition, the timing of this crisis event happens around Y2K, which wasn't contrived by the memoirists but serves to emphasize this shape of the narrative and likelihood that it will follow a traditional arced trajectory. However, the events surrounding this dramatic moment do not turn the story. Any expectation of positive changes is unrealized as the sisters reflect on the crisis. The issues that do get resolved are Wagner's (2005) realization that the crisis was hers alone as the rest of the world continued on in its way, and Spiro's (2005) admission to being tired of dealing with her sister's crises. She says, "I hate the uncertainty and the feeling that we're always stumbling from one crisis to another. I hate the false hope, the longing for a cure…" (p.299). This ending to the narrative leaves the reader unsettled and wondering what the future holds for Wagner and her sister. In this way, the memoir veers from the dominant narratives related to disability and cure and presents more of an experience-centered narrative as it resists a happy ending, or any ending at all.

Rather than use chronology to structure her stories, Garvin (2010) employs a thematic organization to her book, introducing each chapter with a salient quotation from the etiquette maven, Emily Post. This device gives the reader a hint of what is to come in the chapter while communicating the standard that would be considered polite or ultra-normative as defined by Ms. Post. These quotations act as the straight line, to which the stories that follow veer from, oppose or even erase. In this way, Garvin's text (2010) messages the reader that she is writing against the dominant narratives that we might be harboring in our expectations. This is emphasized by the thematic categories she uses for each chapter, as an experience-centered narrative, that primarily includes stories from adulthood interspersed with anecdotes from the past in no dictated order. She tells stories from the past in order to make a point and to give examples of the experiential knowledge she wants to share. The challenge in accurately remembering stories is one that memoirists face regardless of how they organize their tales, but few articulate. Garvin (2010) says, “Some of my relationships have become trapped in the amber of my memories and comparing the present with the past can be confusing” (p.53) and “The past isn’t singular, a large block of was or wasn’t, did or didn’t, had or hadn’t. It includes many layers compressed over the years. Memory, ours and others, is accurate and misremembered, abandoned and reclaimed. It is like stone itself. If you cut a cross section, you can read the floods and the droughts, years of famine or plenty. In my own cross section I found marks made by these friends and neighbors I’d almost forgotten. And after all that time, I found some of what hadn’t been said to be what I treasured the most” (p.149). Out of all of the memoirs that I reviewed, Garvin (2010) is perhaps the most overtly reflective about the process of creating her identity from the narrative and remembered stories (Eakin, 2008) and the challenges inherent to this process. It could be argued that within this group of texts, Garvin’s (2010) memoir does the most to resist following a prescribed narrative shape that dominates many cultural expectations about being the sibling of a person with a disability.

Representation

Although these memoirs are ostensibly about the authors themselves, as siblings of people with disabilities, the authors construct their identities as they relate to their siblings’ identities, and thus they are obliged to represent their siblings in some way to the reader. The ethical choices that memoirists make (Frank, 2004) when depicting their family members are usually related to what Mintz (2009) calls responsible representation without co-opting their sibling’s story (Mintz, 2009) or presuming to know exactly what their sibling’s experience is.

Some memoirists use a diagnosis or medical term as a kind of shorthand to introduce their sibling. Of course, a diagnosis doesn't give a full picture of who an individual is, but it sketches out one aspect of the individual's identity that in turn contributes to their non-disabled sibling's identity story. Although none of the authors essentialize their sibling by describing them with a diagnosis alone, the quest to find out "what's wrong" with their sibling is commonly included as an episode or a continual question in their family stories. Hershon (2010) frames her essay around this narrative as she recalls the vagaries of her brother's diagnosis when she was growing up and present-day curiosity fueled by her own pregnancy and concerns about hereditary conditions. She muses on her brother's non-diagnosable constellation of characteristics and behaviors and generates a list that reads like a poem: "He makes heartfelt speeches on special occasions. He'll never be able to drive. He is a natural athlete who will never learn to sustain a game or keep score. He looks great on a ski slope" (Hershon, 2010, p.24). The juxtapositions of the positive, negative, and sometimes contradictory traits in this listing offers an antithesis to the list of criteria for a medical diagnosis and marks her resistance to the reductionist tendencies that accompany that sort of diagnostic identification. And yet, at the heart of the story is the revelation that her mother did know that her son had Williams syndrome but didn't think it important to use the label or identify with other parents whose children had been diagnosed as such. Hershon (2010) is shocked when she hears this and tries to understand why her mother hadn't revealed it previously, but then has the epiphany that her parents' dedication to providing a full life to both of their children surpassed any benefit that a label for her brother may have imparted. She paraphrases their attitude with the sentiment, “It’s just the way it is” (Hershon, 2010, p. 26) and indicates that they did not focus on the syndrome as his identity.

Other memoirists (Combs,2017; Dougan, 2009; Greenfeld,2009) recount stories of the drama surrounding the diagnosis of their brother or sister, but none in my sample consider a medical account as a single defining feature of their sibling. Rather, in each case there seems to be a decided effort to represent their sibling’s identity more holistically, recognizing and respecting their personhood. Garvin (2010) writes “I’m not going to make any sweeping statements about what Margaret is or isn’t capable of. Generally speaking, it appears to me that she is like everybody else I know, that her sense of the world is not static, and that she can learn and adapt to new situations” (p. 83). She then goes on for several pages, recounting stories of some of her sister’s most idiosyncratic behaviors and unpacking the experience of autism via accounts of her sister’s routines. Her presentation though is not just about her sister but about her own relationship with autism because of her close knowledge of her sister’s life. She writes about hearing the word autism, “I feel lonely and familiar at the same time homesick, like someone is talking about a place I used to live. *Autism. Look, I’m showing my scar. My sister has autism”* (Garvin, 2010, p. 84). The close connection between her sister’s identity and her own becomes a hallmark of this text.

Some sibling representations in these memoirs run counter to the emancipatory work that these texts generally tend to do related to disabilities. As if acquiescing to the literary tropes that disability is often associated with (Mitchell & Snyder, 2001), Greenfeld (2009) wonders if others see his brother, Noah as “a freak, a broken human, a sick animal, kept alive by the taxpayers and despite himself” and then admits “I can see him that way, too…” (p.339).

In her often insensitive and parsimonious descriptions, Dougan (2009) uses outdated language and easily falls into clichés. In a fictional letter to her sister Irene, she speaks of other people with disabilities as “yelling and croaking and snorting and drooling” (Dougan, 2009, p.203) and credits her sister with having courage to be among them. She goes on to channel the hero trope and embraces it as a defining feature of her sister’s presence in her life (Dougan, 2009). Infantilization is another common way that many cultural products use to construct disability and it shows up in Simon’s (2002) writing where her sister Beth is described as “four feet ten, with unzipped regal purple coat, buttercup yellow pants, and an oversized orange marmalade Eeyore T-shirt” (p. 15). The attention Simon pays to her Beth’s childish attire echoes the style often utilized by people describing adults with intellectual disabilities. Simon likely chooses to include such descriptions to give the reader a glimpse into Beth’s personality as expressed in her sartorial style. However, it also reinforces the common misrepresentation of adults with intellectual disabilities as being childlike.

Photographs and representation

Of the six book-length memoirs I include in this examination, three of them use family photographs on their covers, (Combs, 2017; Greenfeld, 2009; Wagner & Spiro, 2005) two use stock photographs, (Dougan, 2009; Garvin, 2010) and one uses a graphic illustration of a suburban street scene (Simon, 2002). The photographs used are of particular interest to me because of the autoethnographic methodology I use in the other part of this project that relies on photographs as data. I should acknowledge that authors do not always have complete creative control over the cover art used for their publications and editors and jacket designers often make the final determination as to what the book cover looks like, so I can’t say with certainty how the covers reflect the authors' intent. With that in mind, I will make a few observations about these photographs and sibling identity. All cover photographs depict children so we are made aware that at least some of the stories told within each memoir will be from the author's childhood, which is not the case with all life writing. However, it makes the point that the sibling relationship that inspired the text to begin with is powerful because of its longevity and presence in the author's formative years.

The most contextually inclusive representation is on the cover of Wagner & Spiro's (2005) memoir where the sisters are captured standing and holding hands in an informal pose in front of what looks to be the suburban family home (see Appendix A, Figure A1). Neither girl is looking at the camera, which suggests that the image was made either before or after a more formal pose or as a candid shot. The photographer caught them as they were engaged with each other, not attending to anything else. The identically dressed twin girls look to be in a conversation as they each gaze towards the ground and their pixie haircuts and gingham skirts suggest children's fashions of the middle of the twentieth century. There are no clues in the photo as to which sister has the disability and which sister does not have the disability and that mirrors the text quite well as each sister contributes to the memoir lending her perspective to described events. This black and white photograph does a good job situating the memoir in time and place and also reflects the shared voice of the memoir that both sisters contribute to.

Although the background has been cropped out of the family photograph on the cover of Combs' (2017) memoir her social context is represented in the posed, studio-like portrait of a man, woman, and three children clustered around them (see Appendix A, Figure A2). Her father is positioned at the very center of the photograph, with her mother seated close by, the author and her older sister standing on either side of her father and her little brother, Roddy sitting in their father's lap. All have their eyes focused on a point slightly to the left of the camera except for Roddy who is looking straight at the camera, and thus the reader/viewer as well. His gaze directed so expressly at the viewer is ironic as he is the sibling with autism, and one of the characteristics that Combs describes in the text is his difficulty maintaining eye contact. Because he is sitting on his father's lap, he is the closest child to the center of the photo which aligns with his centrality to Comb's story. They are all positioned in close proximity to one another, suggesting a certain intimacy and all in the photograph are smiling except for Combs' brother Roddy. This hints at both the tight family dynamic as well as Roddy's emotional asynchrony that Combs writes about. Finally, we are reminded that this is Combs' story, by the selective colorization of the photograph. The majority of the image is sepia-toned, which elicits a sense of nostalgia, but Combs' dress is cherry red which makes her stand out from the rest of the family. Her self-described "flight" from the family and from her brother in particular are integral to the title and thus visually reinforced with this pictorial design feature.

The sweet, candid photograph of two seated, smiling, boys, one leaning his upper body and head to rest on the others' shoulder seems to contradict the title of Greenfeld's (2009) memoir *Boy Alone* (see Appendix A, Figure A3). If anything, this photograph communicates connection and togetherness rather than a lone state. Both boys are looking directly at the camera and their broad smiles exude joy. The only context we can glean, aside from their relationship to each other, comes from the twentieth century attire they wear, as all other background has been cropped out. There is no indication which boy is the author and which is his brother, which can be said of the title as well. Which brother is the "boy alone"? The other significant feature of the photo on this book cover is that the image of the boy sitting more upright is cropped in half vertically, so that we only get to see the left side of his face and body which is mostly in shadow anyway. Could this be a metaphor that he is yet unrevealed and that this memoir will allow the reader to see a more complete picture of who he is? Or perhaps it is to reiterate the point that Greenfeld makes throughout the memoir that his brother, Noah gets the majority of his family's attention and thus appropriately claims the central portion of the cover image of this book.

Neither Dougan (2009) nor Garvin (2010) use their own family photos as cover art for their memoirs, although Garvin does use a photograph of herself and her sister on the title page of her book. In each case, the images that are used on these book covers seem to be appropriate for the content inside, and unless the reader checks the photo credits they wouldn't know that these aren't photos from the authors' family archives. Garvin's cover image which takes up about a third of the space depicts two young girls around the same age, swimming underwater in a pool, both looking at the camera which must also be underwater. The girl on the left has all extremities splayed out as she is caught mid-swim, and large air bubbles from her mouth and nose partially occlude a view of her face. She is all kinetic. By contrast, the girl on the right appears to be still, with one set of toes touching the bottom of the pool. Her extremities are held closely to her body, although she does gesture with her right hand towards the camera, and thus the viewer. The background is just the sun-dappled water of the pool and we get no other contextual clues from this image. One is struck by the extreme difference between these girls who seem to share physical characteristics such as hair color and stature but are in two very different states of action. The movement of the girl on the left, with arms and legs akimbo is balanced by the stability of the girl on the right whose extremities are flexed and not moving. Could this indicate the difference between sisters that Garvin describes in her memoir? If so, it is unknown which sister is the mobile, unstable one and which sister is the grounded and connected one.

The slightly out-of-focus candid photograph of a young girl dressed in birthday party attire gives the reader clues about the temporal context of Dougan’s (2009) memoir, as the girl’s dress and the colorization of the photograph evoke the middle of the twentieth century. The girl is caught in a dance-like posture with arms open widely and a broad grin as she looks directly at the camera and viewer. The blurred subject adds to the sense that this snapshot was taken by an amateur so I was surprised to find that it was not a family photo from the author’s collection. The upbeat nature of the child’s gleeful expression is certainly congruent with the light-hearted writing style that Dougan uses within the memoir and although it ostensibly matches the positivity of the title, *That Went Well*, the author’s tendency to use sarcasm within her text leads me to believe that she actually means the opposite. There aren’t any clues if the photograph is supposed to represent the author or her sister, and this cover art is much less revelatory about the memoir or sibling identity explored in the book than the others in my sample and the same can be said about Dougan’s text as well which is rather superficial in the storytelling. Her parsimonious descriptions tend to be more reportage than reflective or insight-driven expressions.

The editorial decision to use a family photo, or an image that looks like it could be a family photo for the cover art of these memoirs is an effective strategy to draw readers to the tale as the snapshot from a family album is easy to relate to. Hirsch (1997) says, “Recognizing an image as familial elicits…a specific kind of readerly or spectatorial look, an affiliative look …through which we adopt the image into our own familial narrative" (p. 93). In this way, authors and publishers hail the reader (Ellsworth, 1997) to engage with the text as one that they will be able to relate to as they are reminded of their own familial narratives. The family photos used in this group of memoirs are all from the past when the authors and their siblings were children, but the choice to use them isn't just an archival exercise. Rather, the use of these specific memories (or in the case of stock photographs, images that resemble specific memories) when considered with salient narratives, yields insights about present-day identity (Eakins, 2008). Kuhn (in Hirsch, 1997) suggests that "Family photographs may affect to show us our past, but what we do with them- how we use them- is really about today, not yesterday" (p.189). The intent and the circumstances surrounding the original creation of these photographs are not as salient as the current meaning that is imbued in these pictures and helps us to understand the exploration into sibling identity when disability is involved.

The only memoir in this sub-group that includes other images in the body of the text is *Divided Minds,* by Wagner & Spiro (2005), which offers the opportunity to consider this assembled album of family photographs as additional visual data to examine. The photographs have been chosen and are displayed together in an intentional sequence to emphasize the narratives called upon within the memoir. The eight-page, glossy insert is placed in the story in the middle of what might be called an identity crisis for Spiro and a medical crisis for Wagner. This placement likely has more to do with production considerations than narrative shape, but it is interesting to note that the last line of the text before the photo section is "Slodown?" (Wagner & Spiro, 2005, p.178). That is exactly the effect this insert has on the reader, to slow down and move away from the narrative for a moment and note some of the selected highlights of the authors' lives. In this chronologically organized curated collection, the first six of the twenty-two black and white photographs are from their childhood, and in the first five of these, the two authors are undifferentiated from each other, as the captions refer to them as "the twins" or "the Spiro children". This is in keeping with both authors' accounts of their early years when they very much functioned as a unit. In the sixth photograph, there is slight movement towards a marked distinction as the caption points out that one of the then fifteen-year-old girls is trying out contact lenses while the other one is wearing glasses. This is revealed in the text as at that time each sister develops interests and habits that are more individualized. In the remaining sixteen photographs, the sisters are not ever in the same shot as their stories diverge. In photos seven through twelve, there appears to be an effort to show an equal number of images of each of the sisters in similar circumstances, at college and graduating from college. The next images in the album are mostly of Spiro and in those photos, she is shown to be engaged with her partner, children or other family members. In all cases she is smiling as she looks into the face of her baby or poses for the camera with a broad grin in the company of loved ones. By contrast, the two images of Wagner on these pages are taken when she is alone, caught unaware, and doesn't engage with the camera (and therefore the viewer) at all. The photographs corroborate descriptions in the text of Spiro's life as connected and focused at the same time that Wagner's life spiraled into chaos related to psychotic episodes. Spiro is situated and surrounded while Wagner appears disconnected and alone. The last page of this insert makes an attempt at resolution as each author is pictured in a single photograph and both are shown smiling in ostensibly happy circumstances. There is still a deep contrast between the two however, as Spiro is pictured in a glamorous ballgown in the midst of a dance with a debonair partner who is gazing intently at her as she makes an elegant dip while Wagner is shown unadorned, wearing a pair of shapeless overalls sitting in an easy chair and snuggling a small kitten. Taken together, one might surmise that each sister's narrative resolved in a happy ending, albeit completely different from each other. But the text belies this point as the story continues to reveal that Wagner's mental illness leads to an increasingly more impaired state where she requires hospitalization to remain safe and winds up with secondary memory problems because of the electroshock therapy she agrees to. Although Spiro winds up in seemingly better circumstances than her sister, the trajectory of her story is not fully conveyed by the sparkly ballroom snapshot either. The photos, in other words, do not represent the entire story.

Each of the photographs in this insert is captioned, although in all but one case, it is unknown who captioned them. The caption on the second photograph which shows a birds-eye view of the sisters as infants, lying on a blanket right next to each other identifies that the sisters' mother wrote on the back of the photo. Her words are included and they indicate that even she cannot be sure of the identity of the twins as they look so similar to each other. This agrees with the stories presented about the sisters' youngest days when their personalities were less distinguishable from one another. The other captions are written in the third person for the most part, but refer to parents as Dad and Mom, indicating that one of the sisters must have written these. Some of the captions merely identify who is in the photograph, but others make some editorial comments such as referring to a "rare visit" that Wagner made, presumably to Spiro's home or the depiction of Spiro's husband and children in "better times".

It brings up a question about whose perspective we are seeing these photos from as the captions direct.

Titles

The titles of these text-based sibling disability memoirs act as captions to the cover art, cueing the reader how to interpret the image (Hirsch,1997). The titles also orient the reader to the perspective and tone that the author uses to convey the stories within the text. The titles of the book-length memoirs all use the convention of a shorter, catchy title followed by a longer, more explanatory subtitle. While two out of the six do use the word sister in the title (Garvin, 2010; Simon,2002) and four mention sister or brother in the subtitle (Combs, 2017; Dougan, 2009; Greenfeld, 2009; Wagner & Spiro, 2005) none of these memoirs names a disability in the title. Two of the memoirs do identify disabilities in their subtitles (Garvin, 2010; Wagner & Spiro, 2005) more as contextual markers than as the main thrust of the texts. None of the titles indicate that the authors are trying to speak for their sibling or tell their story and this is upheld within the texts. All present stories about their own identities as formulated by life with their sibling and in this way support the tenet articulated by disability activists and advocates that we should not claim the story of another (Charlton, 1998; Couser, 2009; Mintz, 2009). While it is true that these specific stories wouldn't be the same if disability were not in the mix, the authors speak about navigating with their siblings as co-travelers rather than the non-disabled sibling being in charge and leading the sibling with disability through the landscape.

The narrative trope of life as a journey shows up in the title of two of my chosen memoirs (Simon, 2002; Wagner & Spiro, 2005), and in both cases the journey is one that siblings are on together. Two other memoirs in this group use the positive descriptors of "adventures" (Dougan, 2009) and "love story" (Garvin, 2010) which call up counternarratives to the disability as tragedy motif. These titles set a positive tone and readers may be enticed to read a story of adventure or love rather than a tale of false inspiration or pity. Garvin (2010) makes it clear that her stories are about her relationship with her sister rather than a case study, and only mentions autism as a modifier; that is, her stories have "a twist" of autism like a garnish on the rim of a cocktail. Garvin's (2010) title invites the reader to consider the sibling relationship first and

On a less positive note, the full title of Dougan's (2009) memoir is both sarcastic and somewhat patronizing. In *That Went Well: Adventures in Caring for my Sister* (Dougan, 2009), the author sets up the expectation that we will hear about the episodes in her life with her sister when things did not go well, almost in the style of a stand-up comedian or humor columnist which the author is. The prologue continues this style by telling an outlandish story that sets up the action in present-day before launching into the flashback chapters which follow. Her subtitle "…Caring for my Sister" (2009) sets up the expectation that Dougan will describe how she has provided care for her sister, Irene, but this is not reflected in the text. Rather, she relates the variety of supervised apartments and group homes that her sister tried out after leaving their family home. She was absolutely involved in her sister's life but was certainly never her caregiver. Of course, Dougan could be using the word caring in a different sense, meaning the loving concern that she felt towards her sister. There is no way to assess this, and it wouldn't really be appropriate to do so, but I will note that most of the stories that she relates have to do with the frustrations of Irene's living situation and some of her anti-social behaviors. There are no passages where she speaks with strong positive emotion about Irene.

Another problematic title is Combs' (2017) *Hazard: A Sister's Flight from Family and a Broken Boy.* Combs uses a play on words in her choice of the word *Hazard* in the title as beyond it's typical use to indicate a dangerous situation it is also the place name of a small town in Kentucky where her parents grew up and where her family returned in her early childhood. This word stands out on the book cover as it is the largest text on the cover and the font color is red. In fact, the only other color on the cover is the same color red that was used to colorize the photograph of the author's dress as previously noted. The double meaning of this word as well as the warning sign print color alerts the reader to expect some looming danger in the pages beyond the cover. The sub-title reveals two important features of the author's perspective; Combs considers her brother Roddy "broken" and she recognizes that when she left home, she was fleeing her family and particularly her brother, whose disability she wanted to leave behind. The reader is left to wonder what kind of hazard she fled and enters into the text with that question framing the subsequent stories. Understanding disability as brokenness or enumerating the hazards of living with disability are not emancipatory counternarratives. Rather they serve to reify the negative dominant ideologies that pervade so much of contemporary culture. However, Combs' text is also beautifully tender at times and exudes a deep affection towards her brother whom she presents as a unique individual worthy of equal opportunities to live and love. As a teenager she overhears a painful conversation between Roddy and their mother where he explains his longing for an authentic friendship such as what he observes in his sister's life. She writes, "The sound of my brother's sob generated a pain I had no words for. It buckled me. I held on to the doorframe, unable to move" (Combs, 2017, p.147).

The ambiguity in the title of Greenfeld's *Boy Alone: A Brother's Memoir* (2009) certainly piques interest in the reader, as we are unsure of which boy, Greenfeld or his brother Noah, is being presented as alone. People with autism are often characterized as people who desire to be by themselves and so at first glance, a reader might assume that the title refers to Noah who is diagnosed with autism. But this characterization is often untrue and reveals more about the assumptions made by the reader than the individual in question. Perhaps the boy alone refers to the author Greenfeld, who in the text presents himself as often unhappy, underachieving and someone who has had difficulty establishing meaningful relationships with people. He says quite clearly in the text that he was often forgotten in the background in his home while his parents used up all of their energy to try to address Noah's needs and he often wound up playing on his own. He does use a repeated phrase at the very beginning of the book and at the beginning of one of the last chapters of the book that emphasizes Noah's state of being alone. He says, "A boy sits by himself on a stained white carpet…" (p.3) and "A middle-aged man sits by himself on brown lawn outside a run-down house…" (p.329). These bookended descriptions certainly support the notion that the title refers to Noah, but it is easily understood that it applies to both brothers, each alone in his own way.

Intended audience

Memoirs are ostensibly written for readers who want to know more about what life is like for a particular author who is situated in a specific context. When an author's social or familial context includes a sibling with a disability, the author's narrative identity is complicated by that. As a writer performs their identity in a sibling memoir text, they automatically include their sibling in that "performance" (Riessman, 2008). How they are included will in part determine who the targeted readership is. For example, some readers will be attracted to work that enumerates the difficulties that can accompany life with a sibling who has a disability. In Dougan's sarcastic *That went well* (2009) and Combs' *…flight from …a broken boy* (2017) the words in their titles communicate the struggles their stories delineate. Other authors tell their readers that they are connected and caring by using words in their titles that are evocative of the relational aspects of their stories; *How to be a sister: A love story…* (Garvin, 2010), *Riding the bus with my sister* (Simon, 2002). When the emotional mood of sibling representation resonates with the reader, they may be drawn to that particular story.

On the other hand, some sibling memoirs are crafted to trouble the grand narratives that are sustained by societal expectations of what living with a sibling with disability is like. Some authors may want to reach those with preconceived notions and misconceptions in order to change their perspective. In her essay, Hershon (2010) writes her unspoken explanation she wants to give to strangers who judge her brother with "You have no idea how nice this person is. He is staring because he is curious about you" (p.25). The written word gives her the opportunity to clarify for the audience who her brother actually is, vs. how he might be read by strangers.

In the case of *Boy Alone* (K. Greenfeld, 2009) the author's tale acts as a follow-up to the memoirs that his father wrote (J. Greenfeld, 1972; J. Greenfeld, 1979; J. Greenfeld, 1987) about life with his autistic son, Karl Greenfeld's brother. The distinct point of view that the younger

Greenfeld introduces in his text allows readers to discern a higher definition image of his brother and himself than the parental memoirs alone are capable of. While Karl Greenfeld, as a brother, does not contradict his father's accounts, he does express a desire to give a fuller picture of life in their family. For as much as the elder Greenfeld's accounts include observations about how Noah's experienced autism seemed to be impacting his brother Karl, it is Karl's memoir that reveals the bigger picture including his observations about each of his parents and the family as a dynamic system. The story that Karl Greenfeld presents in *Boy Alone* (2009) is broader in scope than his father's books and thus may appeal more to readers who are interested in how disability is constructed in families. Readers who are familiar with stories about Noah published in the last century may also be a focused audience for Karl Greenfeld's work. The level of celebrity that being Noah's sibling brought to Karl Greenfeld by his father's work is a point of contention for him (2009) but ironically many readers are likely drawn to his memoir because of name recognition. In a review of the book in the New York Times (2009), Morrice goes as far to say that the "parents of the Noahs of the world are the obvious audience" for Karl Greenfeld's memoir (Morrice, 2009, p.19).

Authors make use of a variety of techniques to draw targeted readers into their text, including impactful prologues and first sentences. They often serve to predict how the rest of the narrative will unfold, and thus have the power to entice the reader to continue reading or not. In all cases, the memoirs that I am focusing on set the stage with markers of context early on in the texts. Readers are invited to come alongside the author and see what they see as they recount a scene that serves to introduce their sibling. Humorous or dramatic anecdotes such as Simon's (2002) sister commanding Simon to wake up in order to get ready for a bus trip and

Dougan’s (2009) sister throwing groceries at her head have the desired effect of inciting curiosity. Greenfeld (2009) chooses to present the more stigmatizing characteristics of his brother as he describes self-stimulating behaviors, which are often associated as hallmarks of autism. The immediacy of these atypical actions presents the sibling in their most dramatic form, which can work to enlist the reader in a continued observation. What will they do next? Both Greenfeld (2009) and Wagner & Spiro (2005) use a screenplay style in these first words that lends an objectivity to the narration as we see “A boy sits by himself…” (Greenfeld, 2009, p.3) and “A middle-aged woman, distraught…” (Wagner & Spiro, 2005, p.1). This technique lends a certain veracity to the storytelling as it appears to be straight description and the reader feels as if they are a participant observer. The screenplay or script style of writing is also familiar and therefore accessible to an audience that is cinematically literate.

Memoirists may employ devices to reach specific readers, but the power of a publishing house to market any book to an audience should also be considered. Decisions about jacket design, blurbs and format are often made by personnel at publishing houses who have an understanding of successful marketing. The “blurbs” or mini reviews that are quoted on book jackets are carefully chosen to reach the target audience and can sway potential readers to make a purchase. Simon’s (2002) book was adapted into a screenplay which led to a successful production of a TV movie version of the memoir (Huston, 2005) with actor Rosie O’Donnell playing the lead role of Simon’s sister. The notoriety of the cast and director as well as the distribution of the film via the Hallmark channel resulted in millions of viewers for this production (Simon, 2016) and although critiqued for being overly sentimental (Lowry, 2005) the broad exposure that the movie gave to the story allowed for the written memoir to be re-

released in 2013, with a blurb from O'Donnell on the top of the back cover. In fact, a review in *Publisher's Weekly* went so far as to say that "a blurb from Rosie O'Donnell and an author tour should pique women readers' interest" (Edelstein, 2002) perhaps referencing O'Donnell's fan base. Employing Simon's fame and recognition as a sibling memoirist, other books have printed blurbs from Simon on their book jackets as well (Garvin, 2010; Dougan, 2009) as if to promote fame by association. Blurbs from noted experts, such as a psychologist (Greenfeld, 2009), other memoir writers (Combs, 2017; Garvin, 2010) and a person living with autism who is said to have inspired the movie *Rain Man* (Dougan, 2009) can lend credibility to the stories encased in the jackets. I note that most of the memoirs of interest have been published by large publication houses which is in keeping with the popularity of the memoir genre in general, and which has benefited sibling disability memoirs as well (Couser, 2009; Mintz, 2009).

Some readers may be swayed to engage with a text after reading a compelling review. Of course, which books get chosen to be reviewed and where the reviews are published indicate to some degree the power of marketing professionals, and how they frame the work for select audiences. The most widely reviewed memoir in my sample was the Greenfeld (2009) book as it was reviewed in the prestigious New York Times Book Review (Morrice, 2009) that has millions of readers, as well as a more specialized academic journal related to Intellectual Disorders. Simon's (2002) book was also reviewed in a publication with a very large readership, and a decided slant towards those interested in issues impacting women (Hewett, 2002). Other works in my sample showed up in more general venues such as Publisher's Weekly and Kirkus reviews (Publisher's Weekly, 2010; Kirkus Reviews, 2008). The Wagner & Spiro memoir (2005) was reviewed in a few medical psychiatry journals, which is likely because of the psychiatric disability highlighted in the book, as well as the profession of Spiro, who is a clinical psychiatrist. Authorial reputation can invite reviews and/or readers alike.

Who are the authors?

The sample of seven works (written by eight authors since one work is co-written) is too small to generalize about the demographics of their authors but I will briefly discuss some of my observations about how the memoirists represent themselves. There is not a lot of diversity represented in this group as seven of the authors identify as women and the one man in this group (Greenfeld, 2009) also happens to be the only one who identifies as mixed race while all others do not mention race at all. Whiteness remains the default identity, although four of the presumably white memoirists reveal their racial identity with family photographs on the front cover. These observations point to the still-true critique that Ferri (2011) made a decade ago, that life-writing about disability "privilege(s) White bodies" (p.2275) and more diverse representation remains lacking in published accounts. The prevalence of female authors may point to the tendency for women to take on caregiving roles particularly in families where a family member has a disability (Kittay, 1999; Rawson, 2009), or that in current times, more published memoir writers in general tend to be women (Budd, 2015). One observation that Garvin (2010) makes when interacting in a sibling support group network is that most of the group members were teenage girls who had become "little adults" (p.95) as caregivers to their siblings with disabilities. She mourns the fact that these young women seemed to have accepted this role as inevitable without questioning the impact it will make on their own narrative arc.

None of the authors discloses having a disability themselves and there is a tendency for them to present this as the most significant contrast with their sibling (Combs, 2017). This is most evident in the dually authored *Divided Minds* (Wagner & Spiro, 2005) when as a young girl, the non-disabled Spiro speaks candidly of her fears that she may be at risk for the troubling symptoms that she notices her twin sister experiencing. With the intensity of empathy that many twins report, a young Spiro wonders after an orthopedic injury, “Pammy’s hurt- what’s going to happen to *me*”? (Wagner & Spiro, 2005, p 48). The relationship between Wagner and Spiro is characterized as competitive by both authors, but at a certain point, Spiro recognizes that being the mentally healthy one is preferable to the troubling symptoms that beset her sister, even though she gets more attention. Her epiphany underscores the irony of her success as a psychiatrist as her sister falls deeper into the role of patient. For as much as any of these authors are strong advocates for inclusion of their siblings, or people with disabilities in general, the line between disability and ability is firmly drawn in their texts and they all land on the side of ability.

The temporal and geographic contexts for these memoirists are similar to each other in that they are all currently middle-aged Americans. This places their childhood, and many of their memoir stories, in the mid-20th century in a post-WWII, pre-disability rights America. The threat of “institutionalization” of the sibling with disability looms in each of the stories, and there is no mention of inclusive education for them either. Dougan’s (2009) family resisted the doctor’s advice to put her sister in an institution but were frustrated by the lack of services for children with intellectual disabilities in their community. Through their search for appropriate supports, her parents became advocates and eventually instrumental in founding the

Association for Retarded (sic) Children in the state of Utah. Dougan is clearly proud of this, but also adopts a point of view that presents her parents and her sister as pioneers and heroes and goes so far as to say that disability makes her sister a better person (2009). This trope often appears in disability narratives in popular culture, and it is disappointing that Dougan reasserts it in her own text and doesn't use the platform she has as one who is "wise" (Goffman, 1963) about disability to present a counternarrative to that. In most of the memoirs in my examination, the parents resisted the medical recommendations at the time to place their children in institutions. And in all cases, the future sibling memoirists followed the trend as young adults to leave home and discover their own path, as opportunities for White, middle-class, able-bodied, college-educated individuals living in America in the middle of the 20th century were plentiful. In all cases, the memoirs were written after the non-disabled sibling returns to and/or considers their family as an adult. This common narrative arc of "Family" "Flight" "Fortuity" as Combs names in her section headings (2017) is in part because of the common time and place that these stories take place.

Although there are only hints at social class within their works, it seems that none of the authors are positioned in a lower socioeconomic level. They have each written and published in other genres, and thus presently have some degree of notoriety and the advantages that accompany that type of success. The realities of financial struggles that many people with disabilities have do not factor into the stories in my sample. Rather, many identify their economic privilege indirectly when including contexts in their anecdotes. Dougan (2009) mentions cruises and trips to Hawaii as well as having a housekeeper when they were growing up. The long list of cure-based therapies that the Greenfelds undertook (2009), which even included moving the family to California to be enrolled in a therapeutic program, were possible because of the economic security that the success of the elder Greenfeld's memoirs (1972; 1979) afforded them. In Combs' (2017) reminiscence about her "complete" (p.ix) family she juxtaposes the ascendence of her father's engineering career and subsequent move to a more beautiful home in a different part of the country with the birth of her brother, who dashes her dreams when his disability is revealed. Combs also references the idea that was passed down from her grandparents that disability, particular intellectual disability was associated with families who lived in poverty, and in some cases due to "inbreeding" in those families. Remembering a visit her family made to the rural town Hazard that inspired the title of the book, (2017), Combs describes how "station of life" was signified if a family "bore too many children, many of them slow, most of them inbred, all of them dirty" (97). As she relates a scene from a childhood visit to a laundromat there, she clues the reader in to the family rhetoric that was disrupted when disability arrived in her own home which met none of those criteria. Some of the authors do introduce the specter of financial hardship for their sibling within the greater concern for their future and the paucity of reliable supports for people with disabilities in the United States. This is often couched in observations about the emotional cost of future planning and the inevitability of the shifted responsibilities from parent to sibling.

Most of the memoirists I am discussing have had children of their own, but none with disclosed disabilities, although some worried about that possibility when they were considering parenthood (Greenfeld, 2009; Hershon, 2010). An informal search reveals that the vast majority of family disability memoirs are written by parents, and their first experience with disability is often when their child is diagnosed. For a writer who has grown up with a sibling with a disability, the terrain is more complicated as they consider their own potential parenthood with greater knowledge of how disability can impact a family. There is an adage about gaining increased understanding of one's parents upon becoming a parent yourself. Greenfeld (2009) emphasizes this by adding that parental love is greater than any other and even though he had the advantage of knowing his brother for his entire life, he would not ever be able to love him as his parents do. In an examination of her choice to not become a mother, Garvin (2010) recognizes that her sister's disability factors into her decision in some way although not based on evidence of any increased risk for disability. Rather, the evidence that surrounds her such as delightful relationships with her young niece and nephew seems to present a counter argument for her decision to remain childless. In the end, she does not solve the "mystery" of the relationship between her sister and her decision to not have children but leaves the reader with the idea that there is one.

Other narrative devices

The examined memoirs can be considered as a group as they all follow a relatively traditional presentation, and all but one is in a book-length format. The authors rely on some narrative devices that are common to the inclusive genre of memoir such as use of the present tense, writing in screenplay-like dialogue, and quoting from artifacts such as diaries. The combined effect is that the reader feels as if they are "with" the author as they relate an experience or re-cast a memory as an observed scene. This bearing witness or "withness" is particularly effective when authoring a sibling memoir which is inherently a narrative about accompaniment. As a disability story, the perspective is as close to that of the person with the disability as can be without being an autobiographical account. To their credit, none of the memoirists in my sample attempts to tell their sibling's story. Rather, each one frames their narrative as a story about themselves in their role as sibling to someone with a disability. The use of self-referential verb clauses in titles, such as *Riding the bus…* (Simon, 2002), *Caring for…* (Dougan, 2009), and *Flight from…* (Combs, 2017) positions the authors in relation to their siblings and clues the reader in to the primary figure of the text. The titles *How to be a sister* (Garvin, 2010) and *Boy alone* (Greenfeld, 2009) are a bit more ambiguous as they could apply to either the sibling with the disability or the sibling writing the memoir, but the texts are clear in their orientation as they primarily tell the stories of the non-disabled siblings as informed by living with a person with disability. Finally, the memoir *Divided minds* (Wagner & Spiro, 2005) is two memoirs in one, where each sister crafts her own narrative about living with schizophrenia; one with the diagnosis and one without, but as close as another human being can be as her identical twin.

The use of metaphor as a storytelling device is typically employed in the memoir genre, and well-represented in my group of selected stories. I have already mentioned the overarching metaphors that give some of these narratives their broad shape, such as a journey (Simon, 2002; Wagner & Spiro, 2005), or a flight (Combs, 2017), but more specific metaphors found within the texts are pertinent to a discussion of disability and sibling identity. Regarding disability in general, Combs (2017) includes the most examples of observations of physical disability with rich and evocative prose. When describing other children she met as she was growing up, she includes a girl with a "head that rolled around like a cantaloupe" (14), a boy whose body was "pretzeled" into a wheelchair (14), a girl whose paralyzed arm was like a "turkey wing" (78) with a "creature hand" (80) that had "fingers like eels" (78) and a boy who reminded her of “a large stork, stick-legged and loose-winged”(98). She uses these non-human, often animalistic metaphors when describing her brother as well, as she calls his stimming hands “two fat-bellied birds” (141) and his utterances like “barks” (141). An episode of his frustration that she watches leads her to say that he was “lurching to and fro as if he were a bucking bronco” (141) like a “feral, wild forest child unleashed from a pen” (141). This representation of people with disabilities as less-than-human is underscored by a young Combs’ question to her mother about her brother having a soul. Having witnessed the deaths of a few pets and animals in the wild, her mother indicates that those animals aren’t in heaven because they have different brains than humans, and therefore no souls. This perplexes the girl as she considers the fate of her brother whom she has understood also has a different type of brain (89) and therefore may not be admitted to heaven either. Greenfeld (2009) also characterizes his brother as an animal but related to the caregiving required of an animal who is a family pet. He says that Noah is like a pet cat who has both “endearing helplessnesses” (91) that insinuate “responsibilities without end” (91) for his family. These sentiments echo the debate that some moral philosophers entertain related to the full personhood of people with disabilities (Lewiecki-Wilson, 2011) with the most notorious of them found in Peter Singer’s rhetoric. The slippery slope of Singer’s argument, that people with multiple disabilities have a lower quality of life than most animals leads to a justification of euthanasia for infants who are deemed disabled at birth (Singer, 2003). To be clear, the use of these metaphors in my sample of memoirs does not ever get to the point of suggesting that siblings with disabilities would be better off had they been euthanized as infants or that they are less than human. Still, this facet of exploration that Combs (2017) and Greenfeld (2009) record is worthy of mention.

Disability metaphors that are more positive emerge in these texts as well, although some veer towards a "supercrip" (Schalk, 2016) orientation where disability induces characteristics worthy of praise. As Schalk (2016) points out, supercrip narratives can have an emancipatory or regressive impact and should not be considered as a single positive or negative stereotype. Rather, as a construction that is impacted by the genre of sibling memoir, the supercrip narrative is sometimes used by authors to thicken their descriptions of their brothers and sisters. In Hershon's essay (2010) she muses on a Bob Dylan song that her adult brother sings and as she scrutinizes the lyrics and finds metaphor within, she has an epiphany about disability and vulnerability. Her initial thoughts about vulnerability and wanting "release" (31) from the weight and shame of it switch from her brother to herself, as she recognizes that her brother is "already there" (31) in an "odd, specific light" (31) while she has more work to do to achieve that state. In this way, she asserts that her brother has achieved a higher level of awareness than she has because of his disability. Combs (2017) echoes this rarified consciousness in her suggestion that her brother has access to higher levels of understanding than non-disabled people do (p. 158). She uses the metaphor of "altered rooms of reality" (p. 158) that others may find by using hallucinogenic substances and posits that her brother may have an "infinite ring of keys" (p. 158) that allow him access to these additional experiences of the world by unlocking rooms that others generally can't find. In turn, this explains some of the non-normative behaviors that her brother exhibits as she presents those oddities as evidence of his position on a higher plane of human experience, rather than as markers of deficiency.

The excavation that sibling memoirists do about their own identity in these works lends itself to the use of metaphor as well. In an adolescent rage directed at a counselor, Greenfeld

(2009) recounts that he was fed up being viewed through the “prism” (p. 128) of his brother’s disability. A prism does not function as a lens, but instead bends and refracts light so that the image seen through it is distorted and fractured. This distortion of perspective is a theme throughout Greenfeld’s (2009) text as he struggles to assert an identity outside of his relationship to his famous autistic brother. In a counseling session about his own behavioral issues, Greenfeld realizes that the psychologist is working on the assumption that all can be explained as outcomes of siblinghood with Noah (Greenfeld, 2009) and Greenfeld bemoans the fact that even his own “fuckups” (p. 128) are attributed to having an autistic brother. Garvin (2010) comes to understand her relationship with her sister who has a disability as a contextual component of her life in the way that “soil or weather” are components that impact a garden (p. 174). She is relieved when she recognizes that the success of her life, like the success of a garden, is not dependent on her work alone as a gardener (p.174) but rather is also impacted by the family that she grew up in and the influence of her sister’s disability on that time (Garvin, 2010). She continues the metaphor as she describes the work of tending a plot of land and being patient for the various seasons of her life to cycle. And just as gardens are often messy and surprising, Garvin (2010) comes to understand that because of her sister’s disability, her life won’t always be a “tidy plot” (p. 174). She contrasts this adult revelation with a dream that she often had when she was younger, where she was in a car going downhill on a treacherous, icy road (p. 181) and when she attempts to use the brake realizes that she is not the driver of the car, but a passenger. This loss of control characterizes many of the anecdotes Garvin relays in the earlier chapters of the book, but midway through the memoir, she uses another metaphor to signify her newly asserted agency. She likens her siblinghood to knotted cords, yet she decides to “untangle the threads of my own life from what I remembered of our dual one” and “wind them onto a new loom…to make sense of who I was and how autism had shaped me” (100). Combs (2017) too recognizes the need to re-script her earlier narrative that caused her to flee from her family. As an adolescent, she recognized a growing anger aimed at her family as an “egged creature, small and contained – quietly growing” (p. 62) that would “fiercely emerge and drive her life” (p. 62). Her anger crescendos as she senses that her familial dynamic makes her different from her peers that she likens to “a door (that) had swung open on invisible hinges and for the first time I saw what was inside” (p. 143). But rather than remain distant from her family, and particularly her brother as she was “straddling two worlds” (p. 246) she eventually comes to a place where she recognizes the inner strength and joy that her family also helped her to develop. This reformatting of her identity is represented by the model airplane, “Little Wing” (p. 267) she had fashioned as a child with her father, once seen as a disappointment but when discovered in adulthood she understood it as a token of being present with her father and connectedness (Combs, 2017).

While these memoirists have made use of metaphors to describe disability and its impact on their narrative identities, have they also used disability itself as a metaphor in their stories? In Mitchell & Snyder’s (2001) work on opportunistic metaphors or what they term “narrative prostheses”, they point out how storytellers make use of disability or a character with disability to further a storyline or introduce a trope with disability as a signifier. Mitchell & Snyder’s definition and application of this principle generally involves works of fiction and cultural products that are found to use disability to achieve a goal beyond sharing a disability experience (Mitchell & Snyder, 2001). Sibling memoirs, by definition, intend to present the story of at least two lives where disability/impairment is real and not a contrivance. Thus, a quick answer might be no; in sibling memoir, disability is just a part of the complete story being told. But of course, these memoirs would likely not exist if disability were not at their core. As Richardson (2012) points out, “disability is the disruption that requires narrative, if not narrative repair, and the family’s response to the disability becomes the plot of the memoir” (p.1). The cultural forces at work that may incite an author of fiction to use disability as a narrative prosthesis can impact memoir writers as well. The pervasive narrative arc of inspirational disability stories in the popular press and cinema demands a resolution that involves cure or resembles normalcy, and it requires hyper-vigilance for a memoirist to not modify their own story to fit that expectation. Although none of the memoirs in my sample proclaim a cure or maintain that their sibling overcomes their disability some chose to follow the expected narrative arc in the story they shared. Simon (2002) ends the first edition of her memoir with a bird’s eye view of her wedding as she attributes the success of her “miraculous” courtship to her journey with her sister. Dougan (2009) leaves disability out of the last chapter of her book almost entirely, and even says that she is shooting for a “happy ending” (p. 206) to present to readers, complete with gentle snowfall, memories of happy Christmases past and the long-awaited gift of a horse. She does reference disability with a metaphor of an old, “wounded willow” tree that has been replaced by a “locust tree, tall and strong and whole” that is “not half as interesting as the wounded willow” (p. 207) but a tree (or situation) that she is grateful for (Dougan, 2009). Thus, Simon (2002) and Dougan (2009) present their redemption stories (Piepmeier, 2012) where disability has served to make them better people, justifying any of the challenges that disability has brought to their families as they seem to imply that the difficulties of growing up with a sibling with disability was worth it if they grew and benefitted in the end.

In an attempt at a counter-narrative to the populist urging for a redemption story, Greenfeld (2009) asserts that the life of a person with autism does not always yield lessons learned for those around them, and that instead he finds comfort when he retreats from his brother. While he recognizes that he can't completely "turn (his) back and walk away" (p. 340) his cynicism about his brother's future as an adult with autism in an unsupportive culture pervades the latter portion of his memoir. He takes a decidedly non-metaphorical stance when he summarizes that autism is a biological occurrence that people do not recover from, and that there are meagre opportunities for adults with the diagnosis (Greenfeld, 2009). Although less cynical in tone, Garvin (2010) and Wagner & Spiro (2005) resist the pull of narrative resolution that some stories use disability to consummate. In the final chapter of her memoir, Garvin (2010) writes directly to her sister cataloguing various moments in their lives that have emotional weight. She has a revelation as she "always wanted to believe that there was some magic to your disability, some deeper meaning" (p. 247) and that her "attempts to overcome it somehow made our lives more important, gave our suffering a spiritual dimension. … Then one day I realized that I had been completely wrong about all of it. Your autism was nothing special. … It was just life" (p. 248). Similarly, Wagner & Spiro (2005) each leave the reader with a sense of inconclusion as they write their ultimate paragraphs. Spiro bemoans the fact that her sister will always be in a kind of "hell" (p. 314) as she dips in and out of psychosis. Wagner contextualizes her experiences with mental illness with a certain detachment that she credits to

Buddhist philosophy, that allows her to “live in the now” (p. 316) as she rides the waves that come her way (Wagner & Spiro, 2005).

My analysis of these text-based sibling memoirs reveals important insights into the interplay between the presentation of the text and the messages within. In the next chapter, I will turn my attention in a similar way to what I am calling visually-based sibling disability memoirs.

Chapter 4 - Sibling memoir – visually-based products

In this chapter, I discuss memoirs created by siblings of people with disabilities, who work in a visual medium rather than in a written text-based mode. It is important to include these visually-based sibling memoirs in my discussion, as the autoethnographic inquiry that will comprise the latter portion of this project is art-based research (Knowles & Cole, 2008, Margolis & Pauwels, 2011, Rolling, 2013) where I will use photographs and assemblages as the visual media of data production. Thus, the memoirs that I have reviewed for this chapter include works that employ visual modalities such as photography, lithography, silkscreen, short film, documentary film, and painting in order to identify how sibling memoirs in visual media investigate disability and identity. It could be argued that I am unwisely mixing different genres in my choice of visually-based memoirs, but this is unavoidable with such a small available sample. There are simply not enough sibling disability stories within any one genre outside of written texts to support a substantial investigation within one category. Thus, I make every effort to employ analytical tools that apply across artistic genres, and when appropriate use genre-specific strategies to explore specific works.

I should clarify that I am superimposing the category title “sibling memoir” onto this group of products, even though none of the works considered for this inquiry self-identify as memoir. Typically reserved for written text-based work, the word memoir may seem ill-fitting for these artistic products that don’t primarily rely on text to convey their message. However, as narrative identity theory undergirds this entire project, I intend to read these artistic products as narrative texts; that is as entry points into sibling identity stories that include disability. If memoir is understood as a record of events based on “personal observation and experience” (Brittanica, 2020) then all of the works I have included qualify.

The inclusion and exclusion criteria I devised to choose works for this part of the project are defined below. A brief description of the methodologies used for my analysis follows and the last portion of this chapter is the analysis itself.

Inclusion/Exclusion criteria

My initial survey of sibling disability memoirs via academic library and bookseller databases, yielded some of the cultural products that I am including in this chapter of visually-based memoirs, and others were recommended to me by advisors to this project. The inclusion and exclusion criteria that I developed for the text-based memoirs reviewed in the previous chapter were used for the visual-based memoirs as well, with some modifications. These include recent date and place of publication, release, production, or display; evaluation by peer-review; identification of sibling as having an impairment, disability, or medical diagnosis; and an orientation that is not intentionally rehabilitative. In addition, as mentioned, these memoirs all use visual media to narrate and/or express their sibling experiences as informed by disability.

First, I considered publication/production date and place. Only works which have been published, released, produced, or displayed within the sixteen-year span of 2002-2018 were considered for this review, in keeping with the inclusion criterion for the text-based memoirs discussed in the previous chapter. This ensures that these works temporally align with the data that I am using or will produce for this project. The series of paintings that McIver assembled as *Renny, My Favorite Sister* includes works that pre-date my inclusion criterion of 2002, however the cataloguing of these canvases as a group occurred within the specified time frame for this project (McIver, personal communication). This group of memoirs all use the English language in any accompanying text, although one of them was originally produced in Italian (Cocco, 2016) so I used an available version that had been translated into English.

I next considered the type of professional reviewing bodies for visually-based memoirs which include traditional publishers, documentary film production companies, film reviewers, art critics, art dealers and gallerists. As described in the previous chapter, an external body that vets creative work before it becomes publicly available brings a level of scrutiny to the work based on the criteria that the peer evaluators have established. Therefore, criteria for publication of exhibition catalogs, distribution of documentary films and gallery display factor into my discussion of these visually-based memoirs. Videos posted on YouTube, other social media platforms and blog posts do not undergo any critical or professional review, so these were not included in the sample.

I also decided to only include products that overtly address disability or impairment of a sibling. Although the word “disability” is not included in any of the titles of the chosen works they all use the word “disability” or another signifier in descriptions of their product. For example, in the text that accompanies his photo essay, Cocco (2016) says that his sister was disabled from birth and McIver responds to an interview question about her sister with “she was born mentally disabled” (Jordan & Ascher, 2011, 0:04:02). When writing about her work, Stahl (2018) references her sister’s chronic illness, and that she is a “woman with disease” (p. 22) and although she resists the reduction of her sister’s identity to a medical image or chart note, she recognizes the impairments that she deals with on a regular basis (Stahl, 2018). In the

TED talk that Kanell gives about her short film and her brother (2016), she informs the audience of the list of diagnoses her brother was given as a child, but also resists the assessment that his personhood can be reduced to this jargon (TED, 2016, 1:43). Similarly, in the first few minutes of the voice-over in her documentary, Hamovitch (2004) uses the passive voice to list what her brother has “been called” (Hamovitch, 2004, 0:01:16) throughout the years by the medical establishment. It is directly after this passage that the title of the documentary flashes on the screen, with its declarative and pro-disability identity message “Without Apology” (Hamovitch, 2004, 0:01:42).

I also considered point of view or orientation of the artist and as I did not find the “self-help” version of sibling memoir within these visually-based products, I did not have to exclude any works based on that criterion as I did in the group of text-based memoirs. There are some artistic products about siblings of individuals with disabilities, such as the photo essay *Sisters, brothers, and disability: A family album* (Gans, 1997) and the documentary film *Raising Renee* (Jordan, Heller & Ascher, 2011), which are informative about sibling stories, however, are not produced by siblings themselves. I have used both products as supporting materials for my inquiry about sibling-produced memoirs.

Stating the obvious, only sibling memoirs that employ a visual medium as their means of expression were considered. As mentioned, this criterion identified memoirs that express themes in ways that will inform my own project that relies on the visual media of photography and assemblage, both produced and archival. Although I initially considered including a poem as a non-traditional sibling memoir (Fraser, 2003), applying the criterion of visual medium has excluded this and has yielded memoirs more salient to my own work because of their visual nature. My reading of Fraser's poem (2003) has informed my perspective even if I do not spend time in analysis of this work.

The exclusion criteria I established for visually-based memoirs narrowed my original sample somewhat. Although I have included two graphic novels in the thematic analysis in chapter 2; *Epileptic* (David B., 2005) and *The Ride Together: A Brother and Sister's Memoir of Autism in the Family* (Karasik & Karasik 2003) as they met many of the inclusion criteria for this project, I have chosen to exclude them and not apply further analysis to these works. The genre of graphic novel differs substantially from the other media in this discussion as they rely much more on text and an overt narrative arc and thus would require a wholly different type of analysis. In fact, the application of critical analysis to graphic novels dealing with disability has evolved into a dedicated practice (Foss, Gray, & Whalen, 2016) that addresses genre-specific perspectives that do not apply to the other included memoirs I am using. Thus, in an effort to use consistent analytical tools for this project, I opted to exclude graphic novels from my final sample group. However, they provide helpful context as background sources.

Therefore, the five sibling memoirs that meet the inclusion criteria for this section of my project are: *Monia*, a photo essay, (Cocco, 2016); *Without Apology*, a documentary film, (Hamovitch, 2004); *Bumblebees*, a short film, (Kanell, 2016); *Renny, My Favorite Sister*, a series of paintings, (McIver, 2011) and *Habitus*, a series of photographic prints and surface impressions, (Stahl, 2015).

Method

The analytical process I applied to these visually-based memoirs included reading, watching or examining each work while writing memos on salient characteristics that I identified in each. In addition to the narrative analysis (Clandinin & Connelly, 2000) and thematic coding (Bogdan & Biklen, 2006) that was included in Chapter 2 on themes throughout my entire sample, I applied principles of visual analysis such as identifying point of view and gaze (Chalfen, 2002; Kim, 2016) and considerations of composition, subject, color, and light (Rose, 2012) to these visually-based memoirs. I have borrowed from the taxonomy of visual rhetoric that Garland Thomson (2001) articulates as applied to popular photography to organize some of my observations. These additional modes of study prepared me for the visual analysis that I applied to my autoethnographic photo-elicitation data. I used a chart to itemize characteristics of the memoirs including several columns to record notes about the visual aspects of my critical examination and that informs the following analysis.

Analysis

Representation/Visual Rhetoric

While visual depiction of a sibling memoir may seem to be less likely to veer into misrepresentation of a person, as many assume that pictures “don’t lie” (Hirsch,1997; Kuhn, 2002), visual artists employ editorial strategies as frequently as writers do, and we should not confuse the realism of an image with a more (or less) authentic representation of a person or relationship (Plantinga, 2018). Garland Thomson (2001) reminds us that images are often rhetorical devices that have the potential to influence viewers and that artists frequently “tap into well-established disability tropes” (p.335) in their work. The visual conventions (Bogdan,

2012) that may have influenced the artists I am considering reflect contemporary trends in fine art, as well photographic and film practices in more mainstream venues such as social media platforms. None of the works I examine here purport to tell an essentialized story of sibling disability or sibling relationship but provide perspective on their family narratives and identity as impacted by disability.

In Kanell's short film, *Bumblebees* (2016), viewers are introduced to the filmmaker's brother Vance by listening to his scripted voiceover while watching him engage in typical adolescent activities such as hitting and throwing a baseball, showing off some goofy dance moves, and worrying aloud about how to act on a date. His chiseled features, friendly smile and athletic build are highlighted in the filmmaker's close-ups of his face, as well as long shots of him trotting around a baseball field after pretending to hit a home run. Aside from slight asymmetry observed when running, and a slightly slow speech cadence, Kanell does not expose markers of Vance's disability but rather contrasts images of his ability with voice-over statements doctors had made about potential significant disability when he was a baby. Viewers see for themselves that the medical experts were wrong in their prognosis as they observe Vance go about his daily life completing ordinary tasks that they can relate to. Garland Thomson (2001) suggests that although a portrayal of disability like this in *Bumblebees* employs realism to communicate a disability experience, the ordinary presented as extraordinary cleaves a divide between the subject of the short film and the viewers. The audience doesn't just see a young man getting ready to go out on a date; rather they have been primed to see this person overcome the scientific odds, and thus witness what is presented as extraordinary.

The filmmaker is clearly proud of this family narrative and her work demands that viewers attend to this positive, albeit limiting representation of her brother.

Although Kanell (2016) showcases how "normal" her brother is in this film, she also includes scenes that indicate a discrepancy between his chronological age and activities generally thought of as appropriate for children rather than adolescents. For example, as Vance's narration explains that his doctors predicted that he would never read, the camera pans over his shoulder as he is seen to be reading aloud. But the book he is reading is a picture book by a children's author. Viewers see that he reads, but wonder if he reads what people his age without disabilities read? In another scene, Vance describes being anxious as he meets up with an acquaintance for a date. The script allows for some humor here as he asks his date what she would like to do, including a trip to Italy. The audience feels relief when she chooses to simply hang out as this lowers expectations, and presumably Vance's anxiety. However, the place she suggests that they visit is the playground and the last scene of the film shows the two teens swinging next to each other at a playground. This choice may be a device to indicate shared interests between the two young people, but it also suggests an infantilizing mindset about teenagers with disabilities.

In the photo essay *Monia* (2016) the photographer Cocco has assembled 21 images that represent his sister, Monia, who is "disabled from birth" as an "act of knowledge and research" (Cocco, 2016). Again, markers of disability are not explicitly portrayed in these pictures, but in the few images where Monia's full face is visible, she is captured doing childlike activities in childlike ways. In the 18th photograph in the series, a frontal portrait of Monia shows her clutching a small bunch of wildflowers in her hand as she gazes at them with delight (see

Appendix A, Figure A4). Her un-self-conscious expression and inelegant handling of the bouquet bring to mind images in popular culture of childhood flower-picking activities. In another photograph (see Appendix A, Figure A5), Monia is seen as the recipient of care, as her elderly mother fastens a garment around her underwear-clad daughter who passively receives this assistance, seemingly unaware of the photographer's lens. The shared vulnerability of this mother/daughter task is remarkable only for the ages of the subjects. This level of caregiving is typically associated with caregivers of infants or toddlers, and when it is observed outside of that temporal context it communicates a childlike dependence often associated with disability (Kittay, 2019). Cocco's choice to include this private moment in his curated collection tends to trigger a feeling of sentimentality and pity (Garland Thomson, 2001), emphasized by the camera's position above the subject looking down on the scene.

However, the majority of works in this photo essay (Cocco, 2016) are remarkable because they do not include recognizable images of Monia but employ other devices to represent her lived experience and relationships to the human and non-human world. Many of the images recall inhabited sensory spaces where the play of light or the buoyancy of water evoke wonder in viewers that is ostensibly shared with Monia. In some images (see Appendix A, Figure A6) we see Monia's hand and arm reaching for and interacting with patches of light in an otherwise darkened space. Other photographs show Monia as a small figure, enveloped in the frigidity of falling snow, or overshadowed in a towering, rustling corn field, or paddling in the deep end of a luminous, turquoise pool. In the text that accompanies the photo essay, Cocco (2016) suggests that Monia "lives in habits, simple gestures and long moments without words or actions" and his work represents this in timeless, sensorily rich compositions. The medium of still photography can communicate sensory contexts as experienced by people who are unhindered by verbal communication and Cocco does this effectively in his work about Monia. The preeminence of text-based communication in contemporary western society is a force that constructs disability because those who do not communicate using standard text-based methods are often deemed “unintelligent” (Biklen, 2005). However, Cocco’s photo essay veers away from this construction as the images draw viewers into an appreciation of Monia’s delight in her lived experience. In her examination of photographer Susan Harbage Page’s series of images of her nephew who has intellectual disability, art historian Ann Millett-Gallant (2017) conjectures that “The viewer is excluded from her imaginative narrative, as the photograph frames the interior world of the subject” (p.22). Perhaps in the same way, Cocco’s representation of Monia’s sensory contexts indicates an idiosyncratic experiential knowledge that is inaccessible to the viewer, yet nonetheless appreciated through her brother’s lens.

In an atextual, but orally produced soundtrack, filmmaker Hamovitch concludes her documentary about her brother Alan, (*Without Apology*, 2004), who has been diagnosed with a variety of intellectual disabilities with his recorded utterances that have been mixed into a jazz composition. Although we hear Alan’s vocalizations throughout the film, they are often juxtaposed with the very clear and content-rich voiceovers that the filmmaker provides. This contrast tends to underscore Alan’s sounds as a marker of disability, as we are distanced from his experience. But as the film concludes, Hamovitch manipulates our perspective as she recontextualizes those same sounds we have interpreted as non-normative and makes them more accessible to us. Documentary films often rely on unscripted recordings of ambient sounds, overheard conversations, and vocalizations to supply context for the narrative from which characters emerge. Hearing Alan's vocalizations as improvisational music brings us closer to his sensory experience and allows us to reconceptualize his utterances as ability rather than hallmarks of disability. In a blog post that Hamovitch wrote about spending time with her brother (2011), she describes his vocalizations as chants, a word commonly used to describe sacred sounds, that leave her with a sense of wonder (Hamovitch, 2011).

Another technique of representation that Hamovitch employs in *Without Apology* (2004), is her use of extreme close-up shots of Alan's face. The opening scene of the documentary is a close, solarized, still shot of Alan (see Appendix A, Figure A7) that "comes to life" as the narrator's voice-over asks a series of questions about her relationship with the subject. After about a minute of seeing segments of Alan's face, the scene shifts to a wider angle that includes a frontal view of Alan's torso and head, and the arms of the narrator, whom the audience now knows is the filmmaker and Alan's sister. Hamovitch's choice to initially use close-up shots of her subject could be a way of drawing the viewer in (Plantinga, 2018), even as the voiceover bemoans the fact that the filmmaker does not know her brother well. As she states her intention to gain deeper understanding, the viewer is invited to join her in this quest with the shared perspective of seeing Alan close-up.

Similarly, in the group of oil paintings that Beverly McIver includes in *Renny, My Favorite Sister* (2011), the artist paints an up-close view of her sister Renee's face in eight of the twenty included canvases. All of these are frontal views, with the subject staring back directly at the viewer as if posing for a photograph. In fact, McIver often works from still photographs (Jordan & Ascher, 2011) and her paintings convey the captured moment of a snapshot. All of the works in this series include figures painted in an expressionistic style that are recognizable as the artist and/or Renee. Her style has also been described as fauvist (Rubenstein, 2011) for the bright palette and powerful brushstrokes she favors which convey emotion, but the portraits generally do not mark Renee's disability in any stereotypical way. It should be noted that in five of the images, (*Dear Renee*, 2005*; Picture 5*, 1993; *Renee*, 2004; *Renee*, 2010; *Renee*, 2011) Renee's left eye is depicted as laterally deviated which may reference some motoric visual issue, and in one of the paintings (*Renee with Handicap Sign*, 2011) McIver's sister is positioned next to a parking sign that includes the iconic blue wheelchair representation. McIver's inclusion of the word "handicap" in the title of this painting could certainly be understood as a marker of her sister's status, particularly since she rarely uses contextual objects in her portraits. No other environmental cue is included in *Renee with Handicap Sign* (2011) and this singularity lends a level of importance to this particular representation.

Two of McIver's canvasses in this collection portray Renee more dynamically, as the figures are painted in such a way that they resemble multiply exposed photographic images. The portrait, *Double Renee* (2011) shows McIver's sister with a sweet smile and gaze directed at the viewer. The distortions created by the "double exposure" seem to only amplify the positive mood, although they could also indicate that "something is off". The emotional state evoked in *Can you Hear my Silent Scream*?, (2004) (see Appendix A, Figure A8) is difficult to pin down, although its high intensity is unquestionable. Renee's mouth, opened to its widest aperture with teeth fully exposed occupies much of the lower third of the canvas and reverberates with multiple renderings of her lips in various orientations. This scream is echoed by the same technique applied to the figure's nose, eyes, and glasses. The effect bounces the viewer's attention between the subject's screaming mouths and the oscillation of her upper face, drawing us into a state of vibrating emotional tension. The text inscribed horizontally across the canvas, bisecting Renee's face, is the title of the painting, *Can you Hear my Silent Scream*? which serves to interject some ambiguity into any interpretation of this work. McIver does describe frequently being on the receiving end of Renee's episodes of rage when they were children, that were presumably caused by her disability (Green, 2012). However, a silent scream as mentioned in the title reveals a certain empathy with a screaming Renee. In a seeming plea for others to listen, McIver's painting amplifies her sister's previously unheard scream and thus advocates for her right to be heard. Presumed incompetence (Biklen, 2006) associated with intellectual disability often disenfranchises people with disabilities even more and the frustrations of not being heard elicit understandably strong emotional responses among those being mis-perceived.

The idea of representation via amplification of a sibling's voice is a strong current in the work of Darian Goldin Stahl, and particularly in her collection entitled *Habitus* (2015). In this group of photographs and lithographs, Goldin Stahl manipulates diagnostic scans of her sister's body, and in some cases combines them with impressions of her own body created with charcoal and paper to achieve figural but unrecognizable images. She chooses to represent her sister's experience as a person with the chronic disease Multiple Sclerosis via abstracted and unidentifiable renderings of figures. Her stated intent (Stahl,2015) is to induce viewers to "feel" or identify with her sister and her fallible body. In the collection, we can recognize corporeal components such as brains, spinal columns, skeletal structures, and even some partial faces. However, the melded and constructed figures do not exhibit typical identifying features such as the exterior facial and external structures we rely on to recognize other individuals. Stahl's sister, and her disabling illness are not made obvious to the viewer, although ironically the images that are incorporated into this work are the very same that physicians used to diagnose that illness. In her work, Stahl pushes back against the dehumanizing and reductionistic practices that medical science fosters (Stahl & Stahl, 2016). By appropriating the MRI scans used to monitor her sister's faulty neurological network, Stahl reveals the interior state that human beings share, as her modifications and manipulations of the images are an attempt to "rehumanize" (Stahl, 2015) the scans. Her mission is for the medical profession and others to see her sister as a complete human being and not just a diagnosis and she works towards that end through the strategic modification, use, and exposure of images more typically seen only by radiologists.

While Stahl vociferously advocates for her sister as being more than a sum of her scans (2018) she also falls into the rhetorical groove of depicting disability as negatively awe-inspiring (Garland-Thomson, 2001). In her musings about the figures that she creates in a piece entitled *Restless* (2014) (see Appendix A, Figure A9), Darian Stahl (2018) relies on words such as "monstrous", "looming" and "daunting" (p.30) to describe the subject which although depicted as a single individual, is constituted of manipulated images of her sister's MRI scans and renderings of her own body via surface impressions. This hybrid figure is intentionally represented as a "grotesque…mass of arms and faces" (p.29) with the goal of inciting a state of anxiety in the viewer in order to elicit empathy about her sister's mental state regarding her diagnosis. Stahl's reliance on images of anomalous bodies as a stand in or "narrative prosthesis" (Mitchell & Snyder, 2001) to express feelings of angst reveals a certain implicit bias about non-normative bodies in the artist's work. Although Stahl presents her work as emancipatory for all who feel dehumanized by the medical model (Stahl, 2015) she clearly interjects her very personal fears and ideas about illness and disability into the pieces included in *Habitus* (2015).

Depictions of the sibling relationship

The presence or absence of the artist-siblings themselves within these alternative genre memoirs is more of an active choice than in the text-based memoirs I have reviewed, as in the text-based memoirs stories retold necessitate a specific cast of characters including the artist-sibling as narrator, while image-based works do not. However, the viewer experiences the presence of the artist-siblings to some degree in the alternative genre memoirs and particularly in those that include more text, such as the documentary *Without Apology* (2004). Not only does Hamovitch supply the majority of the voiceover and real time audio track throughout the film, but she also often appears on the screen, usually interacting with her brother Alan (Hamovitch, 2004). These glimpses of their idiosyncratic but effective communications and Hamovitch's patient interactions even when her brother becomes agitated and makes loud noises in public places display her respect for his unique humanity. Of course, these scenes are intentionally chosen, and viewers don't know what was left on the cutting room floor, but the footage that we do see presents Hamovitch as a devoted advocate for her brother.

In the other film in my sample, *Bumblebees* (2016), filmmaker Kanell is not once heard nor seen. She does, however, exert her presence during the entire short film, as she has written the script that her brother recites in the voiceover and has clearly directed the acted-out scenes. Although viewers do not get to observe Kanell interact with her brother, we can infer some things about their relationship as we listen to the words she has him say and observe the cinematic and editorial decisions she has made. In the film a family cat acts in Kanell's stead giving her brother advice about how to act when on a date. The advice can be understood as what Kanell might actually say to her brother, or the entire film can be read as advice that Kanell would give to her brother about the importance of authenticity in human relationships.

Interpretations of dynamic sibling relationships rely on conjecture more when viewing still images versus film, but in the three still collections I am using for this project I can make some salient observations. The photographs included in Cocco's photo essay *Monia* (2016) do not include any images of the photographer himself, and if we rely solely on this work we can only guess about his relationship with his sister. Monia does not seem to regard the photographer in any of the twenty-one images included in this essay, and her face isn't even included in nine out of the twenty-one photographs. However, the desire of the photographer to try to capture and communicate how Monia experiences the world could indicate a loving regard for her. As a vulnerable subject, Monia does not seem to mind that her brother is with her during intimate moments (see Appendix A, Figure A5), and the images don't come across as voyeuristic. Similarly, fewer than half of the canvasses that make up McIver's series *Renny*, *My Favorite Sister* (2011), include the artist. However, in their snapshot-like composition McIver's sister Renee is generally depicted as very aware of and even posing for the viewer. In the eight canvasses that do include sibling-artist McIver with her sister, the proximity of the figures to each other, facial expressions, and even the titles of the individual paintings convey evidence of their relationship. Earlier works, such as *Me and Renee Up Close* (1997) reference the sisters' relationship before McIver became Renee's legal guardian and caregiver. The artist places herself first in these titles and is the prominent figure in the near foreground of the canvas even though she disguises herself with blackface clown makeup, as was typical for her self-portraits during this time period. Works from a decade later such as *Embrace* (2005) (see Appendix A, figure A12) and *Sisters Touch* (2006) reveal emotionally tender moments between the siblings and neither figure is presented as more dominant than the other. The latest canvas in this grouping, *Renee Moving Away* (2011), is notable for both the title that gives top billing to Renee, but also the composition that portrays a total lack of connection between the figures who are at a distance from each other and a partially rendered Renee who appears to be receding into the background, as the title indicates. McIver depicts herself with a sad and distracted expression, looking off to one side, as Renee gazes directly back at the viewer with a more neutral but not particularly joyful visage. In the documentary film *Raising Renee* (2012) McIver makes it clear that although it was not ideal to have Renee living in her home, she was definitely anxious about Renee moving away into her own place and this tension shows up on the 2011 canvas.

Perhaps the most enmeshed sibling relationship depicted in the works I chose for my sample is that of sibling-artist Darian Goldin Stahl and her sister Devan Stahl in Darian Goldin Stahl's series *Habitus* (2015). The unique media and novel techniques employed by Goldin Stahl result in hybridized figures constituted from Devan Stahl's MRI scans and graphic impressions of Goldin Stahl's body. Viewers cannot discern one sister from the other in any of the works in this series but are rather introduced to a third figure if you will that is an amalgam of images of each sister's body. Goldin Stahl's stated intent is to create a metaphorical figure as a "proxy" for her sister (Stahl & Stahl, 2018, p.34) and to reclaim the interior images created by medical technology by positioning them in external quotidian contexts as in the pieces *Doorway* (2013) and *Hallway* (2014). Goldin Stahl describes her work as a collaboration with her sister who writes about her illness (2018) and many of the images underscore their shared objective to change current reductionistic medical attitudes. The most striking example of this in the *Habitus* (2015) collection is *The Scan and the Mirror* (2013) (see Appendix A, Figure A10) where we see a side view of two faces facing each other, which are fused in the middle of the work revealing a frontal view of an apparently conjoined mouth and nose. The two sets of eyes gaze at each other while the nose and mouth are oriented towards the viewer, poised to make a declaration. Viewers likely feel the combined power of these two brains, visible through cross sectioned skulls, and anticipate the distilled message in its highly concentrated strength delivered through their shared portal.

Titles

The key function of a title for cultural products such as short films as well as documentaries is to hail the viewer (Ellsworth, 1997) so that they take the next step and pay the fee, and/or commit to the time needed to watch the movie. Titles can set up a question in the viewer's mind that persists in the background as the film progresses; how does the title relate to the work? In the short film *Bumblebees* (Kanell, 2016), the filmmaker answers this question early on with the revelation that the seeming impossibility of the physics of bumblebee flight is an apt metaphor for Vance, the subject of the film, who has defied the dire predictions made by the medical experts when he was born. Clearly a proud sibling, Kanell presents that Vance, like a bumblebee, has confounded science and thus is worthy of our attention. This metaphor sets out the singular theme of the piece and is revisited at the end when applied to Vance's love interest, another "bumblebee". The straightforward connection between the title and the theme of overcoming disability is befitting this easily accessed and heavily processed short film.

The title of the documentary *Without Apology* (Hamovitch, 2004) is more cryptic than *Bumblebees* (Kanell, 2016) and is never directly referenced in the film. The phrase implies that there has been some perceived insult or offense that does not warrant justification from the accused. That is, the filmmaker does not apologize for what the viewer is about to see and hear. This title, as a device, piques the interest of the viewer and also allows for multiple interpretations. In the introductory voiceover, as though speaking to her brother Alan, Hamovitch (2004) reveals that she feels like she doesn't know him. As the narrative progresses, viewers learn that Alan was institutionalized at age 8, thus removing him from Hamovitch's daily life. We then learn that she took a further step away from a relationship with him when she opted to no longer go on family visits to the institution where he lived. She stayed away from him for many years and the guilt that she confesses to for this absentia is only overshadowed by the guilt that she suggests that her parents felt for placing Alan in the institution to begin with. And yet, the admission of these regrets does not presume that they were the wrong decisions, as Hamovitch reminds us of the temporal and social contexts that impacted these decisions, and thus no apology is warranted.

It is also possible that Hamovitch (2004) is using her art form to introduce Alan to viewers, even as she is reacquainting herself with her now adult brother, and that she does not apologize for who her brother is. If seen as a product of advocacy, *Without Apology* is an example of "disability documentary as a leading form pushing forward the general agenda of inclusion and exploring what this really means not only for people with impairments but also for a society that is supposedly inclusive" (Brylla & Hughes, 2017, p.7). Hamovitch does not shy away from revealing idiosyncratic, puzzling and perhaps frightening behaviors that her brother displays, and the effect is that by the end of the film they are no longer surprising to viewers. In this way, Hamovitch unapologetically exposes the viewers to some of the sights and sounds that can accompany disability in her quest to promote a more diverse and inclusive society.

When considering sibling memoirs that are not text-based, any title associated with the works tends to impose or orient the viewer towards a particular visual interpretation of the works. In her compelling historical survey about how Western artworks become titled, Yeazell (2015) reminds us that "images are still dependent on a verbal culture" (p.4) and recalls the common contemporary practice of relying on accompanying wall text, inclusive of title, when considering a work of art on display. There is a common assumption that the titles of artwork are assigned by the artists themselves, as clues to interpretation of the works. However, as Yeazell (2015) points out, the practice of assigning titles to works of art has its historical roots in the art marketplace where the title becomes an additional feature that can help to "sell" the artwork and is often composed by "persons other than the artist, after the fact" (p.5). It therefore behooves me to be circumspect in my interpretations of the titles most associated with the artworks I have chosen for my sample.

The simplest example is the photo essay *Monia*, (2015) assembled by Giovanni Cocco and published in a "photobook" in 2016 (Cocco, 2016). The 21 photos were hung together in a few competitive international exhibits, but published catalogs are either unavailable, or were never printed. Thus, the only record of these works as an assembled whole are in the photobook that Cocco self-published and aside from the photo essay title *Monia* the individual photographs are untitled. I have relied on the sequence that Cocco employed in the photobook and when referring to any single photograph have identified it with its numerical place in that sequence. Using his sister's name as the single title is aligned with the artist's stated intent to focus viewers on Monia as "Photographing her story and her life is the first step for one to enter the life of the other, with both the joy and the difficulty of the encounter" (Cocco, 2016).

In contrast, in the series *Habitus* (2015), Stahl arranges 18 images that each bear their own title that the artist has ostensibly given them. The naming conventions are sometimes simply practical, as in the four prints named *Dualism I, Dualism V, Dualism VI and Dualism VII* all from 2015 and created with the same technique. (Presumably there are other prints in this series that are named *Dualism* but did not make the editorial cut to be included in the larger group.) Each of these prints depicts a mostly symmetrical pair of figures or body parts that the sibling-artist has constructed using her sister's body scans as well as her own surface impressions. The duality suggested by the titles could be referencing these two bodies but may also mean other dualities that Stahl writes about in her artist's statement for this series (2015). She discloses that her aim is to "restore fractured identity" particularly related to interior life as depicted in medical scans and the exterior lived experience of having an illness (Stahl, 2015). Other prints in the series are named for the contexts that she depicts such as *Hallway* and *Stairway*, both from 2014. The straightforward naming of these physical spaces aligns with her stated goal to bridge the divide between the clinical deconstruction of a person and their lived reality, and she does so by depicting the scanned figures in home settings emphasizing the point with their simplistic titles (Stahl & Stahl, 2018); the extraordinary within the ordinary.

On the other hand, Stahl uses the more obscure word “habitus” to entitle the assembled group of images yet does not define the term as she uses it nor does she give the viewer any insight about her choice. In the most generic sense, habitus can relate to “body build and constitution especially as related to predisposition to disease” (Merriam Webster, n.d.) and this is a reasonable application to Stahl’s work about her sister’s multiple sclerosis. Her work relies on corporeal depictions and her technique of incorporating medical scans speaks to the constitutional predisposition that Webster includes in their definition. However, sociologist Bourdieu (1990) expanded the meaning of the term to refer to the embodiment of history; that is ideas that have become so internalized by an individual that they don’t even consciously consider them as ideas, but base actions and decisions on them anyway. Although she doesn’t cite Bourdieu, Stahl seems to represent this idea in her writing about the reductionism that she has observed her sister experience in her interactions with the medical community (2018). While grateful for their medical expertise, she is equally frustrated that her sister’s physicians tend to sub-consciously reduce Devan Stahl to merely a “sum of her scans” (Stahl & Stahl, 2018, p.23). If we consider the expanded definition, then Stahl’s series *Habitus* (2015) can be read as a challenge to recognize this implicit reductionistic bias that the powerful medical model imparts to even non-medical people.

The group of paintings that sibling-artist Beverly McIver links together in the group *Renny, My Favorite Sister* (2011) were never exhibited together, and do not include every canvas that McIver has painted of her sister Renee. However, on her website McIver purposely groups these 20 paintings dating from 1993 to 2011 that depict her sister and sometimes herself, and most of the paintings have titles that can be discovered from other sources but are not identified on her website. I decided upon this particular grouping to include in my review because of the artist's intent in making an exclusive collection, even though some of the paintings pre-date my inclusion criteria range. McIver's intentional grouping of these canvases dates to 2011 on her website (McIver, n.d.) and thus the paintings as a unit qualify. Unlike the ambiguity of the series title *Habitus* (2015), the title *Renny, My Favorite Sister* (2002) is more accessible and immediately understood. McIver gives us a glimpse into their sororal bond by using a sweet nickname "Renny", and by referring to her as her "favorite sister." It should be noted that McIver and Renee have another sister who rarely if ever shows up in any of McIver's paintings. This omission and declaration of Renee's favored status seem to indicate that McIver may see Renee as a muse for her art. The titles of individual paintings in this grouping tend to be short and basically descriptive with little need for interpretation (e.g. *Me and Renee Dancing*, 1997; *Renee Drinking Starbucks*, 2011), however a couple of the canvasses have titles that are more enigmatic. The 2004 painting *Can you Hear my Silent Scream?* (see Appendix A, Figure A8) has been discussed earlier and when coupled with the screaming figure, the title evokes many questions about what emotional state is being depicted in the painting. In *Calendar Girl* (2007), Renee is painted with an enigmatic, but not happy expression on her face and the harsh yellow color of her shirt is echoed in several yellow brushstrokes that compose her face. She is not engaged with the viewer at all and her slumped posture indicates a certain malaise. It seems that with this canvas, McIver uses the title as a contradiction to her depiction, as a calendar girl is conventionally understood as a perky young woman with a big smile, dressed in provocative clothing, and gazing at the viewer. It is unclear what McIver intends with this contrast of imagery and title, but refreshingly, she refuses to objectify her sister in her work.

Medium and Intended Audience

The five different genres represented by the visually-based memoirs I am considering each rely on a different medium and have a different target audience as well. In addition to the intentions of the artists, the conventions that surround specific media influence how they are distributed, displayed, and sold. For example, paintings and fine art photographs are traditionally displayed in galleries and museums and often have agents or art dealers to handle any sales. McIver's canvases in the collection *Renny, My Favorite Sister*, (2011) and Cocco's photographs in the photo essay *Monia* (2016) have been hung in exhibits in museums and galleries where the general public has had access to them. In McIver's case, she has never hung a show that was completely comprised of portraits of her sister, but she has included images of Renee in most shows throughout her career. Her intent it seems is to investigate her own identity rather than make any general statement about disability. She says "All of my portraits are self-portraits. I use the faces of others who reflect my most inner being" (Willie, 2005). On the other hand, the photo essay *Monia* (2016) is meant to be viewed in its totality and each photograph is a critical part of the entire exhibit. In this case, Cocco's work is primarily about representation of his sister and her world. He states that "(p)hotographing her is an act of knowledge and research. It is a way to understand her, wondering what she thinks and what she wants. From life. From me." (Wehelie, 2015) He also says, "One day she will be part of my life, she will have to deal with me, every day, with the way I see her and love her. Telling her story and her life is the first step for one to enter the life of the other, with both the joy and the difficulty of the encounter. (Wehelie, 2015)”. Both McIver and Cocco have received accolades for their respective works, and have won awards and scholarships for their art. Neither artist or their representatives have affiliated their work with disability organizations, nor present it as art “about” disability, and thus do not constrain their marketing to a specifically disability-interested populace.

The photographic works included in Cocco’s photo essay *Monia* (2016) and Stahl’s series *Habitus* (2015) are considered artistic products, rather than photojournalism or family photography. This important differentiation allows us to examine them with an aesthetic lens and to contextualize them without requiring strict verisimilitude. That is, the intentions of the artists may be to communicate observations about their sibling relationships and disability, among other ideas, but the audience should not read these works as reportage. This is made particularly clear in Stahl’s series *Habitus* (2015) as she incorporates images copied from her sister’s medical scans, melded with surface impressions that she has made by rolling her own charcoal-coated body over treated paper. The photographic prints that she then makes of these combinations do not bear any resemblance to the two figures involved in the creation of the artwork. This series was assembled with the very specific purpose of “creating empathy” (Stahl, 2015) for individuals who are dealing with chronic illness such as her sister. Although hung in a public gallery space, *Habitus* (2015) also served as Stahl’s final visual presentation in printmaking for her MFA degree at the University of Alberta, thereby imbuing the series with an academic endorsement. Stahl refers to this work as art-based research and her continued work in the field of Health Humanities suggests that her intended audience includes those with greater exposure to the ideas put forth in the scholarship of that field.

Other artists have explored issues related to disability, illness and non-normative bodies incorporating medical scans into their work (Potier, 2011). Contemporary works by Katherine Sherwood and Laura Ferguson rely on diagnostic images of their own non-normative bodies (Stahl, 2018) and Marilène Oliver uses MRI scans of her entire family for her sculptures (Monahon & Jameson, 2020) but the unique contribution that Stahl makes to the sub-genre of “body art” (Potier, 2011) is the sibling relationship explored and constituted in her prints. She describes their work as collaborative and her stated mission is to “give context to (her sister’s) medicalized body” (Stahl, 2018, p.26). In this way, Stahl brings an even higher level of specificity to an already specific sub-genre of artistic expression.

The audiences for short films and documentaries are certainly wider than those for the works already discussed which are generally seen in galleries and museums. The short film *Bumblebees* (Kanell, 2016) is probably the most accessible work in my sample and maybe the most appealing to a contemporary audience used to short videos shared on social media. Stylistically it follows that formula with upbeat instrumentals, rapid scene changes, use of humor, and even the ubiquitous cute cat. The film is available for free as a YouTube or Vimeo stream and was the impetus for a North Carolina-based TEDx talk given by the sibling-filmmaker in 2016, (TEDx, 2016) which is also available on the internet without cost to the viewer. As they are easily shared and don’t require an extended time commitment, these types of films are generally seen by more viewers than longer works but may be forgotten as easily as a TikTok video or other ephemeral piece on social media. Still, Kanell’s film has been viewed over 33,000 times on the streaming platform Vimeo (Kanell, 2015) and was the winner of several awards at different film festivals, including those focusing on disability issues. This high level of visibility is difficult to achieve with other media. Although the internet allows some metrics to be collected easily such as the number of hits a video has received, it is much more difficult to determine who those watchers are. As accessibility to various social media platforms has improved over the years, more individuals with disabilities and siblings of people with disabilities are visible on these platforms and are posting their own stories (Kent, 2019). If one searches for the subject "sibling disability" on YouTube, hundreds of different videos are listed that showcase a variety of approaches to the topic, but these are not peer-reviewed films like *Bumblebees* (2015) and have therefore not been reviewed for this present study.

At the other end of the continuum is the full-length (74 minutes) documentary film *Without Apology* (2004) that sibling- filmmaker Hamovitch originally distributed through a small independent film company that she owns (http://oneeyedcatproductions.com/). Like *Bumblebees*, (Kanell, 2015) for the first year after its release *Without Apology* was screened at several international film festivals as well as some gatherings organized around the topic of disability, and particularly intellectual disability. In addition, Hamovitch has been a speaker at some of these gatherings, including conferences organized by and for siblings of people with disabilities (One-eyed cat productions, 2005). This particular film was also originally released as VHS and DVD recordings available for purchase from Hamovitch's film company, and as of 2021 can be streamed on the Vimeo platform for a more reasonable fee (Hamovitch, 2021). It is again difficult to determine any shared characteristics of the film's internet audience as the anonymity afforded by the streaming platform prevents disclosure of this type of information. However, Hamovitch's confessional tone and revelation of family secrets seek out an empathic ear perhaps most likely found among other siblings of people with intellectual disability or families who have also struggled with their own histories of institutionalization.

The documentary form is popular for filmmakers who wish to explore disability experiences and particularly for those who claim that they want to "make a difference" (Brylla & Hughes, 2017, p.4) in how lived experiences of disability are understood. Unlike historical documentaries about disability, that tend to objectify individuals with disabilities from a medical perspective (Brylla & Hughes, 2017) Hamovitch uses techniques that focus on the singular experience of her brother's daily life. Plantinga (2018) indicates that a typically compelling documentary character type is understood as "conflicted" and "traveling a meaningful journey" (p. 125). However, Hamovitch opens her film with the observation that she doesn't know her brother well, that he may be unknowable, and thus not able to conform to Plantinga's (2018) taxonomy. The only way that viewers can begin to understand Alan is via Hamovitch's lens and editorial eye and ear. Although her brother does not use words to communicate, Hamovitch does let Alan "speak" for himself by showing him in a few different contexts and moods where his repertoire of behaviors is represented. In addition, she does not indicate that it is his disability that makes Alan unknowable, but rather her own absence from his life that has limited her ability to understand him. Unlike Kanell's (2016) obviously staged and scripted short, Hamovitch includes sustained and undirected scenes of her brother going on walks, eating, and spending time with her which makes the film seem less filtered or contrived. Plantinga (2018) describes the documentary form as "an implicit contract between the filmmaker and the audience: the audience takes it to be a film in which the images and sounds, claims and implications are asserted to be veridical—that is, accurate or reliable guides to the film's subject" (p.116). Hamovitch seems to accomplish this in her work that she describes as a "personal documentary" (3conversations in April, n.d.) as there is no other way to direct or modify Alan's behavior. Of course, editorial choices can also impose the director's agenda, but *Without Apology* is a good example of reflexive documentary (Mitchell & Snyder, 2010) where the filmmaker leaves herself open to analysis as a participant observer in the work.

As I keep these lessons in mind, I now turn my attention to how I produced my own data and autoethnographic analysis of that data. In the chapter after that I return to these reviewed memoirs that others have created as I discuss how my own production resonates with these other sibling disability stories.

Chapter 5- Autoethnography, methodology

The purpose of this inquiry is to discover how growing up with a sibling with disability has impacted my identity and how this is expressed in creative manifestations of my identity formation related to my sister who had impairments and disabilities. In this chapter, I explain the qualitative research approach that I have chosen to address these questions, as well as the arts-based methodologies that are most appropriate to produce and analyze my data. I have constructed a rationale for my choices by explaining the warrant for this kind of research, as well as the fit between my approach and methodologies to the questions at hand. After this rationale, my discussion includes a description of the contexts I worked in and the data sources I used. Specific data collection and production procedures are outlined as well as my process for analysis of that data. The usability of a qualitative project such as this is important to articulate and so I speak to issues of credibility and dependability (Denzin & Lincoln, 2000) that add to the value of my project within the body of other research in this area. In my commitment to maintain a critical eye throughout the process I describe potential limitations to my project, as well as what I actively put into place to minimize the impact of those limitations. A summary of salient points at the end of this chapter will serve to reiterate the most important intent of this project.

Rationale for research approach

The paradigm that undergirds the choices I made when designing this study comes out of the discipline of Disability Studies and relies on a social constructivist model of disability (Kafer, 2013; Siebers, 2008) that privileges the first-person perspective in inquiry (Davis, 2017;

Ignagni & Church, 2008). The historical under-representation of stories of people with disabilities as narrated by individuals living with disabilities has spawned a movement within the disability community of scholars to advocate for and support research done by individuals who are living the experience (Linton, 1998; Longmore, 2003; Siebers, 2008). Therefore, I must recognize, as other researchers have noted (Ignagni & Church, 2008; Kafer, 2013) that if I purport to speak for people with disabilities, I am only reiterating and empowering the dominant narrative of the "expert" outsider, as I am not currently disabled myself. Instead, I choose to explore the phenomenon of disability from my own perspective as a sibling of a person with disability. In the words of Clandinin & Connelly, (2000), I am "in the parade" that I "presume to study" (p.81). My interrogation of identity as a sister of a person with a disability does not purport to present her story, but rather my own narrative as impacted by her story with a "sideways glance" (Bahktin, 1984, p.32) at disability. Even from this vantage point, one hopeful result of this project is to suggest a counternarrative which could disrupt oppressive, dominant narratives about disability that abound in popular culture and have been written or represented by outsiders, or people without close knowledge of disability.

A qualitative approach to these questions allows for a deep excavation of lived experience where an epistemology of disability (Carlson, 2010; Garland-Thomson, 2018; Wendell, 1996) has informed the lives of siblings of people with disabilities. That is, growing up with, close observation of, and being privy to the daily ramifications of a sibling's disability brings knowledge to a family in distinct ways, and it is this knowledge as it has informed identity that my project interrogates (Wyatt & Adams, 2014). In the situation of what Goffman (1963) described as being wise, siblings of people with disabilities have access to perspectives that are not accessible to decontextualized experimental studies and are instead best understood using a qualitative orientation to the project (Bogdan & Biklen, 2006; O'Day, 2002). The most effective ways to tap into this experiential level of knowledge are from a qualitative tradition and are focused on discerning the meaning of lived experience over essentialized states of "truth" that are present in other research traditions (Bogdan & Biklen, 2006; Creswell, 2009; Trahar, 2009).

The use of narrative as a methodological mode of inquiry has enabled me to produce narratives as data, and systematically examine these narratives using principles of narrative analysis and synthesizing the results of my analyses guided by principles of narrative reasoning (Clandinin & Connelly, 2000; Kim, 2016; Polkinghorne, 2007; Riessman, 2008; Trahar, 2009). My synthesis is constructed as an attempt to answer my research questions with reflexive acknowledgement of the discourses that have informed this synthesis (Trahar, 2009) and I have examined my contexts throughout as I have interrogated my identity. More specifically, an arts-based narrative inquiry suits this quest as the goal of meaning making can be accessed via narratives and other artistic products that exist primarily to make sense of life (Clandinin & Connelly, 2000; Kim, 2016; Lawrence-Lightfoot & Davis,1997; Rolling, 2013).

My choice of an arts-based narrative approach stemmed from my desire to engage in this study in an unconventional manner (Ignagni & Church, 2008) in order to ferret out meaning from a different direction than what a more traditional research project might do. This novel orientation is an artistic product in and of itself (McNiff, 2008) and establishes a new pathway to understanding lived experience and how that can impact identity. Although there have not been many arts-based or arts-informed inquiries within Disability Studies (Ignagni & Church,

2008) the approach clearly resonates with the tenets of Disability Studies which transcend disciplinary boundaries (Ignagni & Church, 2008) and embrace diverse modes of communication (Couser, 2009; Fries,1997; Kuusisto, 1998). In a discussion of their goals in using arts-informed methods for critical disability inquiry, Ignagni and Church (2008) explain that they “are seeking ways to evoke and provoke moments of epiphany, solidarity, and even frustration” (p. 631) in their scholarship. This decidedly transgressive model seeks to transform the dominant narrative about disability through the chosen methodology as well as the results. In the same way, I have investigated aspects of disability as experienced by wise (Goffman, 1963) siblings, with methods that expand knowledge from a critical standpoint such as those available in arts-based narrative inquiry. While there is no single narrative of identity related to being the sibling of an individual with a disability, it is my hope that by making my reality available, others will have the opportunity to understand my findings within the context of their own storyline and world view (Rolling, 2013).

Other models of disability, such as the powerful medical model (Davis, 2017; Linton, 1998) have made attempts to use art in disability research, but as the positivist tendency is so strong in medicine (Garland -Thomson,1996; Linton,1998), most projects are oriented towards measurement of the therapeutic benefits of art rather than exploring how art can reveal insights about the lived experience of disability (Ignagni & Church, 2008). The relatively recent addition of coursework in narrative medicine (Charon, 2006) to medical curricula has been an important move towards using the pedagogy of art, particularly as it applies to understanding illness and disability (Charon, 2006; Costello, 2011) and although not a research methodology per se, this theoretical slant also informed my choice of methods.

The genres of arts-based narrative inquiry (Kim, 2016) that I used as methodological practices include autoethnography (Bochner & Ellis, 2016; Boylorn & Orbe, 2014; Denzin, 2014; Jones, Adams & Ellis, 2013; Wyatt & Adams, 2014), as applied to photographic narrative or photo-essay (Knowles & Cole, 2008; Rolling, 2013; Rose, 2012) and as applied to archival photo-elicitation (Chaplin, 2011; Harper, 2002; Knowles & Cole, 2008; Prosser, 1998; Rose, 2012). My examination of a select group of narrative products created by other siblings of people with disabilities as described in chapters 2, 3 and 4 of this document has informed my art with organizational themes and provided a counterbalance to the narrative analyses I applied to my own stories (Kim, 2016).

A review of autoethnography

Autoethnography, which is a form of life-writing, is a natural fit for an exploration into identity and disability, as it intends to observe cultural phenomena through the lens of personal narrative (Jones, Adams & Ellis, 2013; Kim, 2016). Ellis (2016) describes the reason that she chose autoethnography for her work because “what was happening extended beyond me and could yield insights about culture, social structure, relationality and communication” (Bochner & Ellis, 2016, p. 197). Autoethnographic products are therefore both interior explorations as well as vehicles for examining a variety of contexts (Kim, 2016). Researchers who use autoethnographic methods are committed to a type of life-writing that incorporates reflexivity based in theoretical constructs which is then well-situated to critique the cultural practices being studied (Boylorn & Orbe, 2014; Chang, 2009; Ellis & Bochner, 2000; Jones, Adams & Ellis, 2013; Kim, 2016). My exploration required that I “zoom in” to my own experience and then turn the lens to “zoom out” to reveal the contexts of my experience, particularly the cultural tropes related to disability where my experience is situated. I have represented both perspectives in my narrative and have elaborated on them in my data analysis.

Disability identity has been explored via autoethnography (Lewis, 2007; Neville-Jan, 2004; Rambo, 2013; Scott, 2013) but little if any autoethnographic scholarship has been published about identity issues for siblings of people with disabilities. Couser (2005) bestows the designation of autoethnography onto Simon's memoir *Riding the Bus With my Sister* (2002), although Simon does not claim this orientation herself. Couser's argument is that Simon's life writing goes beyond memoir as it develops a cogent critique of how disability is constructed in modern society, and thus she employs the inward/outward structure that is a hallmark of autoethnography (Couser, 2005; Jones, Adams & Ellis, 2013). Although methodological explanation and theoretical rationale is missing from the text, Couser (2005) claims that it approximates autoethnography because it is an intentional observation and documentation of a person's experience, and Simon therefore employs many of the same strategies that an autoethnographer would. The paucity of other autoethnographic works about sibling identity and disability reveals a vacancy in the scholarship and provides a strong warrant for me to complete this project using this methodology.

The autoethnographer, Bochner (2016) speaks of epiphanies, or moments in one's life when one is struck by or granted an insight. Identity is among the things that can be understood in these moments (Boylorn & Orbe, 2014) and my interest in sibling identity has indeed been informed by epiphanies. These remembered moments of clarity forms many of my data entries and more were elicited as I intentionally and reflexively recorded my narratives (Bochner & Ellis, 2016; Richardson, 2002). Autoethnography incites researchers to "return to the scenes that tarnished us, the ones hovering in our memories awaiting an opportunity for us to take pen in hand and write ourselves into a moment of transcendence, however fleeting" (Bochner & Ellis, 2016, p. 68). This encouragement from Bochner & Ellis (2016) affirms the choice that I made to use autoethnography to investigate my identity related to my sister.

Autoethnography as applied to photographic narrative

The specific arts-based narrative that I produced and examined using autoethnographic methods is a series of photographs I refer to as photo-essays (Mitchell & Allnutt, 2008; Rose, 2012), that I shot and assembled in response to pre-determined prompts. These prompts are specific to theoretically based issues of identity as the sibling of someone with a disability, but general enough to avoid being prescriptive or reiterative of dominant tropes regarding disability in this culture. That is, I had opportunities as the artist to interpret the prompts in a way that provides a counternarrative to the prevailing narrow construction of disability that is so prevalent in our cultural context (Davis, 2017; Garland-Thomson, 1996; Linton, 1998; Shakespeare, 2006). In more traditional photo-elicitation projects (Harper, 2002; Rose, 2012) participants are given a prompt by the investigator and take photographs based on their interpretation of the prompt (Harper, 2002). My autoethnographic design required that I both determine the prompts and respond to them, so I carefully documented the theoretical justification for the prompts before I took or assembled the photographs in response. My commitment to that temporal sequence ensured a systematic approach to the creation of my arts-based narrative, which is more expansive than text alone (Rose, 2012).

The photographs that I used were edited and/or manipulated using digital or manual technologies, as appropriate. This flexibility allowed me to be intentional about the work as art, rather than as photojournalism. An arts-based approach to my sibling identity story presents an "argument" (Rose, 2012) for an alternative way to understand disability and can be an evocative experience for any who view the photo-essays (Ignagni & Church, 2008; Rolling, 2013; Rose, 2012) that may trouble the same issues for the viewers. In her discussion of photography as research methodology, Rose (2012) stresses the importance of having a "conceptual framework" (p. 323) to undergird a photo-essay. My work is grounded in tenets of identity theory and Disability Studies and thus I developed a "shooting script" (Rose, 2012, p.324) from this perspective that directed my photographic exploration, and which was based on my investigations into Disability Studies and sibling identity, described in other chapters. Although I developed this systematic approach before creating the photo essays, the project was an artistic endeavor and thus I allowed myself to veer from the script as I felt moved to do. I kept a log with my thematic script that serves as field notes (Atkinson, Coffey, & Delamont, 2003; Bogdan & Biklen, 2006; Cresswell, 2009) and I recorded moments where I deviated from the script, as well as any epiphanies or other reflexive thoughts. The way that I produced this narrative is in keeping with the autoethnographic process already described, where I balanced interiority with contextualization (Jones, Adams & Ellis, 2013). The more interiorly focused artistic product can be understood as an inquiry because of the explication of context, which in this case is a collection of cultural tropes that persist about disability and identity.

This context is described more specifically later in this chapter, but it is important to note here that others have advocated using artistic methods to investigate assumptions related to disability (Ignagni & Church, 2008), which supports my rationale for choosing to do so. I did not represent disability in my photo-essays, as it would be inaccurate as an outsider perspective and would only serve to reiterate the dominant and false notion that the onlooker is expert who brings a purported objectivity to an inquiry. Rather, I shot/found photographs that speak to how disability has informed my identity from my position of sibling and embedded reporter. Ignagni & Church (2008) promote arts-based research around disability as they posit, “Drawing on the arts can force us to relate radically to disability in ways not easily available to us in our everyday lives” (p. 631). This confrontation of assumptions can happen because of the medium and to a greater degree than text alone (Ignagni & Church, 2008; Rolling, 2013; Rose, 2012). The ability of art to interrogate dominant ideologies has been a powerful research tool for my inquiry as it can communicate an epistemological counternarrative (Eisner, 2008; Fries, 1997; Garland-Thomson, 1996; Kuusisto, 1998) to how disability is framed.

The tendency for my autoethnographic writing to blur boundaries with memoir or cathartic expressions (Bochner & Ellis, 2016; Boylorn & Orbe, 2014; Denzin, 2014; Jones, Adams & Ellis, 2013) has been diminished by my commitment to narrative organization of and orientation to the data that I created (Jones, Adams & Ellis, 2013; Maynes, Pierce & Laslett, 2008) and I kept focused by using an arts-based approach to create the data (Riessman, 2008; Rolling, 2013). There is no calamity in writing a memoir, but the intent of my project is the use of arts-based narrative as inquiry and not therapy (Ignagni & Church, 2008). The accessibility of visual images (Ignagni & Church, 2008; Kim, 2016) and readable text I produced intentionally interrogates an ideology and roots itself in a research tradition. Any psychic benefit of the art I produced and autoethnographic epiphanies (Bochner & Ellis, 2016) I experienced can be understood as value added to the project but was never my end goal. I specifically make this point as I would like to upend the commonly held assumption that life with and near disability necessitates a therapeutic encounter (Linton, 1998).

Autoethnography as applied to archival photographs

Within the photo-essays that I created in response to theoretically generated prompts, I incorporated a selection of extant family photographs to elicit autoethnographic writing about the issues of disability and sibling identity that I gleaned from my literature review. The use of archival material to provoke insights via focused, reflexive writing provided additional data for my narrative analysis. Found captions of family photographs are understood as potentially valuable data as well (Chalfen, 2002; Kuhn, 2002) and captions already on photographs were included in my reflections. Throughout this process, I documented how I chose themes and photographs, and wrote captions and statements in systematic field notes that were then used for my eventual narrative analysis.

While family photographs are not usually understood as artistic products, or even intentional narratives in and of themselves (Sandbye, 2014), their ability to evoke emotional responses (Bochner & Ellis, 2016; Kuhn, 2002; Sandbye, 2014) make them valuable sources for autoethnographic data (Mitchell & Allnutt, 2008). Traditionally, family photographs have not been considered worthy of much scholarly attention (Chalfen, 2002; Sandbye, 2014), however, some are advocating for the use of family photographs as data sources that can be used in transdisciplinary ways, to discover aspects of cultural history otherwise ignored (Chalfen, 2002; Kuhn, 2002; Mitchell & Allnutt, 2008; Rose, 2012; Sandbye, 2014). To the autoethnographer, using family photographs provides an opportunity for both the interior, evocative reflection (Bochner & Ellis, 2016; Kim, 2016) and the contextual framing (Boylorn & Orbe, 2014; Chang, 2009; Jones, Adams & Ellis, 2013) that historical objects (Mitchell & Allnuttt, 2008; Rose, 2012) can offer.

Photo-elicitation

The method that underlies the autoethnographic writings I did related to the photo essays I created is referred to as photo-elicitation, which is a research method more commonly used with participants other than the self (Harper, 2002; Kim, 2016; Oliffe & Bottorff, 2007; Prosser & Burke, 2008; Rose, 2012; Schwartzenberg, 2005). The rationale to use photo-elicitation in my autoethnography is that it was an apt vehicle that helped me burrow into the interior passages that autoethnography demands (Bochner & Ellis, 2016; Boylorn & Orbe, 2014; Denzin, 2014; Jones, Adams & Ellis, 2013). Traditional photo-elicitation relies on interviews with participants, using photographs (either found or taken by the participants) as points of entry into reflections about the images (Collier & Collier, 1986; Harper, 2002). As I purposively took photographs related to a prompt and purposively collected and captioned images from family photographs, I engaged in an interview of sorts with myself as I relied on the tenets of photo-elicitation to guide me through the process.

Photo-elicitation using family photographs is particularly appropriate to use in a contemporary project about disability, as it presents an insider's view of a disability experience. The scholarship about disability has historically been heavily informed by more positivist methodologies (Fries, 1997; Linton, 1998; Longmore, 2003) which cannot represent the experiential knowledge of living with a disability. To represent disability more authentically, phenomenological methods are the better choice, and photo-elicitation using family photographs has provided this kind of data. The accessibility of my project, using visual images as well as text, is in keeping with recommendations from disability rights advocates who promote universal design in scholarly work (Sauer, 2012) as well as narrative researchers who support the use of plain language in these projects (Kim, 2016).

The archival family photographs I chose and the photographs that I shot for the photo essays signify life with disability from a person-centered point of view, rather than from a medicalized or voyeuristic perspective. The oppressive ideology that has long accompanied photographs of people with disabilities where difference and anomaly is catalogued comes out of medical traditions where textbooks exhibited photographs of anomalous bodies, and the entertainment industry where disability has been read as freakishness (Bogdan, 2012; Fries, 1997; Garland-Thomson,1996; Schwartzenberg, 2005). In these cases, bodies with impairments are objectified, put on display, and ogled for the purported education of or titillation of the viewers. The ordinariness and naturalistic contexts of my family photos and the photos that I took for this project directly resist these historical ways of picturing disability, and they certainly differ aesthetically from the photographs that were staged for medical or entertainment venues. I also wrote a short “curatorial statement” (Mitchell & Allnutt, 2008, p.254) for each photo essay, positioned alongside each, explaining how the images relate to the identified theme.

Research context

On the surface, the context for research using autoethnographic methods appears to be the self, however autoethnography requires that a life story be contextualized and explored using a critical methodology (Bochner & Ellis, 2016; Boylorn & Orbe 2014; Denzin, 2014; Kim, 2016; Maynes, Pierce & Laslett, 2008; Wyatt & Adams, 2014). The setting for my project then, is the cultural landscape that I find myself in as the sibling of a person with a disability. In fact, Jones, Adams & Ellis (2013) laud the method of autoethnography for its ability to investigate a specific context more closely than other methods because of the insider status of the investigator (Jones, Adams, & Ellis, 2013). My review of sibling memoirs has revealed major tropes related to sibling disability and my exploration into identity and sibling disability is situated alongside work done by a community of artists who have examined similar issues via their own media. Community here is used to denote relational interconnectedness via similar experience rather than any physical or geographical location (Leavy, 2012; Springgay, Irwin & Kind, 2008)

I have also considered the ideological context that I have done my work in. Much of what surfaces when applying the search terms “sibling” and “disability” into scholarly databases as well as the Google search engine, are works written by individuals outside of the experience. That is, many researchers and disability service providers publish texts based on their empirical observations and measures of people who are siblings to someone with a disability, rather than first-person accounts from the siblings themselves (Porter & McKenzie, 2000). The limitations of these kinds of inquiries and so-called expert opinions is that they tend to adopt and reinforce the dominant ideological perspectives on disability as medical problem, tragedy, and defect and extrapolate that to predict the impact that disability has on a sibling. This often serves to perpetuate the negative and oppressive points of view about disability as well, and the grand narrative (Kim, 2016) of disability as tragedy gets extended to sibling narratives.

The medical model insists on presenting disability as a condition in need of a cure (Linton, 1998; Longmore, 2003) and if deemed incurable, then overcome via rehabilitative techniques that compensate for the presumed defect (Davis, 2002; Kafer, 2013). In kind, this model perceives siblings of people with disabilities as disabled by association, in that a "normal" sibling relationship is thought impossible to have when disability is present (Goffman, 1963). The response then is to recommend remedial activities such as support groups and workshops for siblings (McHugh, M. 2003; Meyer & Holl, 2014) to compensate for the defective (sic) sibling relationship they were born into. This paradigm is very powerful, and thus the construction of disability as defect pervades popular culture (Ignagni & Church, 2008) as well as positivistic research in the social sciences (Bogdan & Biklen, 2006). This ideological context has informed the expectations that others may have for my identity as a sibling of a person with a disability and pre-formulated the signifiers that I was hailed to accept in terms of what my identity should be, even before I applied a critical lens to my own viewpoint. My current project provides a counternarrative to these toxic ideas and an arts-based project has been the right choice to help me to realize this goal. Ignagni & Church (2008) write "…counter discursive arts and imagery can challenge the multitude of one-dimensional disability portraits that proliferate in mainstream arts and popular culture; disability as evil or innocent, as heroic or pitiful, as asexual or sexually deviant" (p. 629).

Data Sources

The main sources of data for this project are my own autoethnographic productions related to my identity as informed by being the sibling of a person with a disability. This includes autoethnographic writing, photographs that I took, and archival photographs, along with the captions and curatorial statements (Mitchell & Allnutt, 2008) written to accompany the photographs.

As described earlier in this chapter, my data production using the methodology of autoethnography (Bochner & Ellis, 2016; Denzin, 2014; Jones, Adams & Ellis, 2013) consists of texts generated via photo-elicitation (Rose, 2012) which I have used to assemble photo essays (Kim, 2016) including texts I wrote about archival photographs from my collection of family photographs (Mitchell & Allnutt, 2008). The texts that I wrote comprise a large percentage of the data that I examined using procedures practiced in narrative analysis (Clandinin & Connelly, 2000; Kim, 2016). The actual images, which are the photographs that I shot in response to a prompt (Harper, 2002), as well as archival photographs, are other sets of data which I analyzed using codes established in my review of sibling memoirs, and new codes and themes that emerged during the production of and reflexive practices about the data.

This data did not require oversight and approval from an Institutional Review Board, as none of these sources include data from living human subjects. However, I was mindful of the stories that I accessed via these techniques (Bochner & Ellis, 2016) and the human subjects that are represented within any of them. The ethical considerations that I was sure to bear in mind are grounded in the American Education Research Association (AERA) Code of Ethics (2011) as well as the International Visual Studies Association (IVSA) guidelines (Papademas & IVSA, 2009) related to respectful use of images of people. The archival photographs I used includes images of my parents and sister who are all deceased, while the photographs that I produced for this project do not include living human subjects other than myself. I aimed to establish a “sacred space” (Kim, 2016, p. 103) within my narrative inquiry that honors the stories that I accessed via these data. Other people that I referenced in my writing can be considered characters in my stories rather than participants in my research (Bochner & Ellis 2016). A regularized reflexive practice (Kim, 2016; Rose, 2012) during all of my data production was recorded and helped me make decisions related to ethical quandaries that surfaced during my project.

Data Production

Narrative inquiry and particularly autoethnography demands a continuous feedback loop between data production and data analysis (Bochner & Ellis, 2016; Kim, 2016), and so drawing a straight temporal line between the two aspects of the process does not reflect the actual sequence of events I followed, but I did commit to an overall organizational strategy for my work that I describe here in discrete sections. I am using the term “data production” rather than “data collection” as it is a better representation of the active and creative nature of the data generated for this project.

Photo-essays

As I shot each photo-essay in my attempt to interrogate my identity as a sibling of someone with a disability, I relied on principles of photo-elicitation as described by Harper (2002). I used the themes I found in the literature I reviewed as the prompts (Harper, 2002) or guiding ideas for the photographs I took. Each prompt came from reflexive practices while reviewing sibling memoirs and includes a reference to my identity as well as my context. The shooting/assemblage script (Mitchell & Allnutt, 2008) (see table below) that I devised was based on themes from my review of sibling memoirs and relates to how I interpret my identity as a sibling of a person with a disability within the context that those themes describe. My intent was to produce data that would be appropriate for the narrative analysis that autoethnography accomplishes with both life-writing and context represented. As I describe in Chapter 6, I modified the shooting/assemblage script as a response to autoethnographic reflections, thus allowing a recursive trajectory to shape my work, rather than stick to the original list.

Photo-elicitation is most effective when the time period allotted for the photographs is short and specifically articulated and when the number of photographs taken is pre-determined (Harper, 2002). These parameters require that the photographer be focused on the project and goals of the project and therefore explicit in intent when taking the photographs. For this inquiry, I did a majority of the shooting, choosing, modifying, and assembling photographs during a 6–8-week period which is a bit longer than a typical photo-elicitation project (Harper, 2002). This allowed me to take new photographs as well as digitally or manually manipulate them and assemble them into photo essays. I kept field notes about each photograph as I took them and as I veered from the shooting script, I documented why I did so. My field notes include memos (Bogdan & Biklen, 2006) that reflect epiphanies (Bochner & Ellis, 2016) that I came to while taking or manipulating the photographs.

I shot the photographs with a digital, single-lens reflex camera and my cell phone camera and stored them as digital files in a discrete folder on my computer. I digitally manipulated the photographs as needed using basic photo editing software and documented my decisions and reasoning in additional field notes related to any modified photograph. When I took the requisite number of photographs, I saved the final versions and sorted and captioned them (Harper, 2002) keeping field notes about my sorting and captioning process. I combined these with family photographs that were digitally scanned and finally arranged all of the photographs into digital photo-essays. The eventual project yielded five photo-essays of high-resolution photographic prints or assemblages.

Table 1- Original shooting and assemblage script for photo-elicitation

THEMES
Grand narratives and counternarratives Am I a better person because of my sister's disability? People want to be inspired by disability Myths surrounding disability The epistemology of disability
Roles Embedded Reporter Role shifts – Sister, mother, or therapist? Unnamed role between- sib and mom Third sister Second fiddle
Narrative arc Disability does not automatically ruin families- typical and atypical sibling life Who gets to construct disability? Interdependence, reciprocity, and mutuality
Advocacy Positive disability identity and "being wise"
Being different The normality of difference Broken bodies
Voice The ethics of representation/misrepresentation

I initially used the same themes used in my original photo-essay shooting script (Table 1), which I had identified in my review of sibling memoirs to glean extant family photographs from my personal archive. This archive includes both printed photographs and digital photographs, but I scanned any print photographs to digitize them. I originally intended to print hard copies of all of the photographs and assemblages made, but in the end only printed out some of the images as my analysis dictated. As I sifted through the archive of family photographs and medical images, I paid attention to any additional themes or stories that emerged from my exposure to these renderings (Kuhn, 2002) and modified my themes and shooting script accordingly.

During this initial gathering of images, I kept field notes about the process and how I made the decisions about which photographs to use. Using the “systematic sociological introspection” described by Bochner & Ellis (2016, p. 167), I actively recalled the specific circumstances that each photograph represented as well as memories of other people referencing that photograph or stories they told about it. By attending to the primary memory each photograph elicited and taking the time to allow other feelings to surface about it, I was able to tap in to both what the image triggered in my thoughts as well as how the image could be explained or understood within the ideologies represented in my themes.

As I assembled the photo essays, I wrote a “curatorial statement” (Mitchell & Allnutt, 2008, p. 254) to further explain the images and how they relate to the theme. I originally planned each statement to be around 150-200 words, but as they are autoethnographic in nature they emerged from the field notes that I took and were not easily contained in a single paragraph. These essays bridge the data production and data analysis facets of my project as each is a constructed narrative that attempts to answer my original inquiry.

Data Analysis

Sibling memoirs that others have created, including selected artistic endeavors, are best analyzed as narratives (Kim, 2016; Polkinghorne, 2010; Rolling, 2013,) with an intent to discover what kinds of patterns or themes are discernable related to how sibling disability shows up in identity. These "narratives-under-analysis" (Bochner & Ellis, 2016, 187) are represented in my review of sibling memoirs in chapters 2,3 and 4 and point to the themes that I used to structure my own arts-based research. These narratives-under-analysis provided the groundwork for my own inquiry and allow for touchpoints that I returned to frequently as I cycled back to reflect on how my story interacts with stories that others have told.

The data that I produced include field notes on the process of creating the photo essays, captions in the photo essays, and curatorial statements about the photo essays. The photographs were coded as to the visual elements observed such as point of view and gaze (Chalfen, 2002; Kim, 2016) and all of these data were analyzed through identification of the themes that emerged and the story that they told me to write. As the "midwife" (Kim, 2016, p. 119) of this story, I brought it into the world via a text that is both autoethnographic and arts-based. The performative nature of this practice (Smith & Sparkes, 2008; Rolling, 2013) befits my inquiry as my project involves identity, which as Riessman (2008) notes is "situated and accomplished with audience in mind" (p 106).

As the variety of my data has allowed, I used narrative analysis when examining my autoethnographic writing and photographic production. This analytical approach stems from a desire to think narratively (Clandinin & Connelly, 2000; Kim, 2016; Polkinghorne, 2010,) while using the most appropriate tools for the type of data being examined. Data (texts) that I created within autoethnography were examined using narrative analysis (Bochner & Ellis, 2016; Kim, 2016; Polkinghorne, 1995; Rolling, 2013) and creative analytic practice (Richardson, 2002) and yielded a narrative that both positions and critiques my data. I crafted this narrative to "problematize social and cultural norms and practices in light of (my) personal experience" (Kim, 2016, p. 124). The specific social and cultural norms that I have examined were initially identified in my literature review and viewed through the theoretical lens of Disability Studies that is at the core of this inquiry.

In my analysis, I have considered the four distinguishing features of autoethnographic writing that Kim (2016) recommends. In all cases, the narrative that I have created is positioned vis-à-vis other narratives and ideologies. I compare my story to other siblings of people with disabilities who have published texts about their experiences, followed by a comparison of my story to the theoretical conversation about identity issues for siblings of people with disabilities. Later in my project, I recall Kim's (2016) third consideration that orients my discussion as one that will speak to readers who have similar experiential backgrounds and can relate to the story that I present. Hopefully, many readers will feel that my story "desires" them (Kim, 2016, p. 109) and they will bring their own interpretation to the text as they engage with it. Finally, I identify the ways in which the culture that I am a part of shows up in my story (Kim, 2016), marking contextual influences and shapers. This systematic and conscientious use of critical analysis from multiple perspectives marks my text as a research narrative and not simply a work of autobiography.

I continued my reflexive practice throughout my writing process, and I continued to discover more through my writing (Kim, 2016; Richardson, 2002) as I was open to epiphanies (Bochner & Ellis, 2016) as they occurred. The orientation of evocative autoethnography (Bochner & Ellis, 2016) allows for the emotional and intuitive triggers to reveal findings, however I mediated these with contextual guideposts that prevented me from dwelling in catharsis and helped me to contextualize my findings.

The eventual form of my analysis is like a layered account (Bochner & Ellis, 2016; Ronai, 1995) with my texts, photos and reflections on theoretical constructs as well as insights from others' artistic works delivered as an imbricated series of stories that make up the narrative. The interstices between the layers hopefully invite the reader to engage with the narrative in his or her own way, upholding the tenet of effective autoethnography that Kim (2016) identifies where readers connect to the text meaningfully. The intentional juxtaposition of the photographs to different texts is an autoethnographic statement as well (Chaplin, 2011) and the eventual format of my project is an expression of the story.

Issues of trustworthiness

The design of a qualitative research project demands a level of rigor that is specific to data that by its nature cannot be replicated. It is not the intent of this kind of a project to create an experiment to support or refute a hypothesis and so the rigor of a project such as mine is more effectively measured by its dependability and verisimilitude (Kim, 2016) than its repeatability or validity. My work should be judged by criteria suitable for narrative inquiry such as credibility (Rolling, 2013) and authenticity (Clandinin & Connelly, 2000) rather than constructs more applicable to positivist studies, such as validity and reliability. Credibility of my autoethnography is deepened by the study design itself, with multiple data sources yielding multiple opportunities to view the data from differing perspectives. As the researcher, it may seem that I have only one perspective but the purposeful inclusion of texts and photographs from different sources and the reflexive contextualization of these serves to triangulate, or better yet to view these data through the sides of a multi-faceted crystal (Denzin & Lincoln, 2000). I have also striven to be authentic and truthful in my narrative explorations, offering the whole story including what could have been easily left out or ignored (Pathak, 2013). I have been mindful of the ways in which memory shapes stories (Kuhn, 2002) and have identified those stories that have been reiterated throughout my personal history and the impact they have had on my newly crafted narrative.

Good narrative inquiry will stimulate the reader to engage with the story in such a way that new knowledge will be created specific to that reader’s experience with the research (Kim, 2016). My project then is a representation of my local knowledge, made accessible to others for their consumption and own interpretation (Kim, 2016; Rolling, 2013). Arts-based research methods are particularly accessible as imagery and metaphor inherent to these methods can speak to more readers than do projects presented in more traditional research jargon (Kim, 2016). The effectiveness of this accessibility can be influenced by reflexive practices that I have established throughout the research process (Riessman, 2008), ensuring a mindful approach or “wakefulness” (Clandinin & Connelly, 2000, p. 184) where I view my narrative as a moral responsibility (Richardson, 2002) that I present in ways that others can engage with. In this way, I am being mindful of the community that my research speaks to (Pathak, 2013) and the transferability of my results to individuals with similar experiences. While I will not presume to apply my findings to another person's situation, if my work is usable by others in their unique contexts, then the transferability of this project (Lincoln & Guba, 1985) will be acceptable. While not the sole evaluative consideration, the effectiveness of these practices will result in my ability to persuade (Riessman, 2008) or evoke an emotional response in (Bochner & Ellis, 2016) my readers.

Limitations and delimitations

Limitations

The question at the foundation of my inquiry relates to my identity and how my identity has been impacted by my role as the sister of a woman with a disability. The limitation inherent in my question is that I cannot maintain the anonymity of my sister and am therefore telling portions of her story on the way to telling my own. I have done my best to maintain a level of confidentiality, however there is a tension built in to this method between disclosure of private stories for the sake of answering the research question and holding back from a more complete response to the research question in order to protect her privacy. An obvious response to this quandary is to obtain her consent to include her history as I examine my own, but impossible as she passed away several years ago, leaving her stories behind.

This brings up another issue related to my project, which is more definitional in nature. Has my identity shifted since my sister passed away and if so is my project based in retrospection alone, or does it have meaning for the present day? Am I still a sister? I don't know that this is an answerable question but have chosen to proceed as someone who still identifies as a sister of a woman with disability and recognize that the temporal context must be considered in my analysis. I also intend to contextualize my narrative in a way that will make my research salient to others who have had similar experiences.

While my choice of research design is not inherently a limitation, there are some challenges that come along with autoethnographic and narrative methodologies. Rather than enumerate what critics of these methodologies cite, who are often speaking from different philosophical paradigms, I will look to more measured accounts from scholars who actually use these methodologies, and therefore are more likely to have a similar research orientation to my own. In her reflection on the process of creating her autoethnography, Wall (2008) suggests that the dominant ideologies surrounding her area of inquiry still worked their way into her text, regardless of her initial goal to subvert them. The compromises that she made in each iteration of her project to make it more acceptable to those evaluating her work, changed her emphasis somewhat enabling her to move through the academic system, but yielding a diluted final version of her project (Wall, 2008). I suspect that I will also need to justify my design choice to people beyond my committee and recognize that this might mean compromise on my part. In the article about her autoethnographic project, Zibricky (2014) describes the tension she felt when some of her findings did not support her original warrant for the project and one of the themes she identified in her text was disappointment (Zibricky, 2014). The disappointment that she felt rose from her strong desire to produce research that changed dominant ideologies, rather than support them but her choice to honestly report her findings strengthens the trustworthiness of her work, even if the ideological impact is less than she hoped for (Zibricky, 2014).

Delimitations

Unlike qualitative projects where there are other participants, an autoethnographic project cannot rely on strategies such as member checking (Bogdan & Biklen, 2006; Cresswell, 2009) to triangulate data. However, the continual contextualization of my data (Bogdan & Biklen, 2006; Cresswell, 2009; Kvale, 2002; Lincoln, 2002) and regular, systematic reflexive practices (Bogdan & Biklen, 2006; Cresswell, 2009; St. Pierre, 2002) have enabled me to shift my point of view, try on other perspectives and question my own assumptions that have impacted my analysis. In addition, the initial themes that I chose to organize the shooting script (Mitchell & Allnutt, 2008) for my photo-essays have been derived from other sibling narratives that I examined before creating my own texts. These other perspectives have served as points of departure that my own project took off from and they were also zones of consonance and resonance with my reflexive thoughts. The reiterative nature of an autoethnographic project has afforded me the opportunity to revisit what others have discovered and described, which has allowed for deeper and more novel insights to my own work.

Another strategy to delimit shortcomings of this project is related to the arts-based methodologies I have used. As with any artistic endeavor, an organizational plan such as my shooting script can be deviated from as the artistic product emerges. Although an important feature that marks my work as research, the systematic guidelines I originally established had to also be flexible enough to make room for inspiration. I veered from my shooting script as needed and did not squelch ideas that I had not previously entertained. The freedom gained because of the discipline imposed by the inquiry has allowed my project to unfold in an authentic way, and hopefully in a way that is accessible to others because of this authenticity.

Summary of Methodology

This inquiry is focused on the ways in which being a sibling to an individual with a disability impacts identity. The primary methodology of this arts-based research project is autoethnography using narrative methods to produce and analyze data. The artistic narrative methods involve producing photo essays which were created using principles of photo-elicitation.

I used narrative analysis to examine and discover how my identity has been impacted by growing up with my sister who had a disability. Relying heavily on tenets of the field of Disability Studies, I have highlighted my experiences while questioning if not disarming some of the dominant ideologies that circulate about disability and family roles. By contextualizing my narrative within the matrix of current practices and attitudes about disability as well as other sibling narratives, I present a counternarrative that can subvert some of the oppressive results of dominant ideologies.

The reflexive and systematic examination I am committed to has staved off any tendency to write an autobiography, or a biography of my sister. This project has the potential to present a very different perspective on disability and how it can impact families, communities, and policies. Beyond clarification of my own identity formation, my autoethnographic discoveries will be transferable to other siblings of people with disabilities and transformative to ideologies about the importance of disability in society.

Chapter 6 – Findings: Autoethnographic Data and Analysis

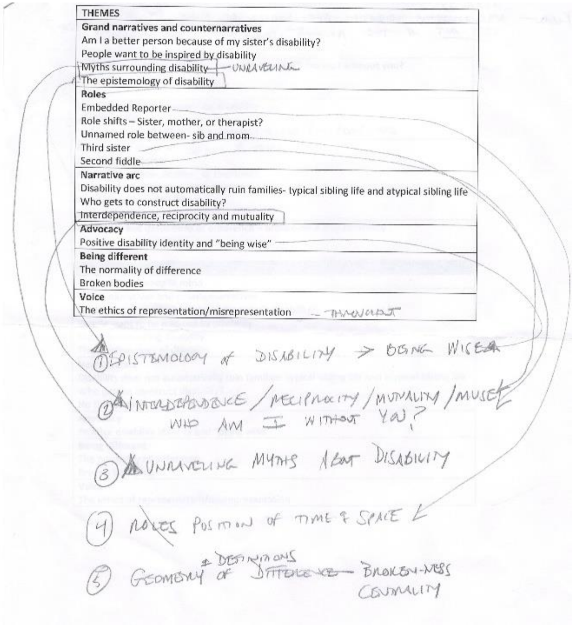
In this chapter I provide a summary of my: data production methods; modifications made during the process; examples of my data; and themes from my data analysis. My data combines text-based and non-text-based methods as I integrated photographs and assemblages with texts that relate to those images. In this way, I can eventually compare my work with the text-based and non-text-based work of the other sibling artists that I reviewed. This chapter answers my third research question, "How has growing up with a sibling with a disability impacted my own identity, and my understanding and expression of the social and political implications of sibling disability"?

Reflections on the process of creating data – photo essays and commentaries

Autoethnographic and arts-based narrative research methods are highly recursive and do not follow a particularly linear trajectory. That is, as a researcher produces data, insights into new or different ideas emerge, which can divert the research into unplanned territory. The original research questions, however, remain intact and the tenets of the overarching methodology are respected, but the reiterative nature of the data production requires a frequent re-visitation to identified themes and expectations. This requires the researcher to be sensitive and open to other considerations and discoveries made during the data production process (Bochner & Ellis, 2016).

For example, the original shooting script (listed in chapter 5) drew from the themes that I had identified in the sibling memoirs I reviewed. As I fleshed out the themes and made notes about sub-themes in each narrative, I was also reviewing collected family photographs and previous autoethnographic assemblages and writing. I paid attention to the sub-themes and some additional themes that became prominent as I delved into these archives and, as a result, I modified the taxonomy of my shooting script with new images to reflect this layer of analysis. One of the modified lists I used as a guide for my data production is depicted in Figure 1.

Figure 1
Shooting script



THEMES
Grand narratives and counternarratives
Am I a better person because of my sister's disability?
People want to be inspired by disability
Myths surrounding disability — UNRAVELING
The epistemology of disability
Roles
Embedded Reporter
Role shifts – Sister, mother, or therapist?
Unnamed role between- sib and mom
Third sister
Second fiddle
Narrative arc
Disability does not automatically ruin families- typical sibling life and atypical sibling life
Who gets to construct disability?
Interdependence, reciprocity and mutuality
Advocacy
Positive disability identity and "being wise"
Being different
The normality of difference
Broken bodies
Voice
The ethics of representation/misrepresentation — THROUGHOUT

① EPISTEMOLOGY of DISABILITY → BEING WISE
② INTERDEPENDENCE / RECIPROCITY / MUTUALITY / MUSE
WHO AM I WITHOUT YOU?
③ UNRAVELING MYTHS ABOUT DISABILITY
④ ~~ROLES~~ POSITION OF TIME & SPACE
⑤ GEOMETRY OF & DEFINITIONS DIFFERENCE — BROKEN-NESS
CENTRALITY

Although I maintained my original plan to use extant photographs as well as new photographs that I shot in response to prompts, I found myself being drawn to family photographs more frequently than newly created images produced for this project. In many cases, I altered both types of images digitally and/or mechanically to express an idea more distinctly resulting in several assemblages in addition to single and unaltered photographic images. As I combed through boxes of archival images, I gravitated to images of my sister and although the focus of this project is on my own identity it is her life's shaping of me that thrums at the heart of this endeavor. And since she is now gone, I cannot include her in any present-day narrations and must rely solely on old snapshots or metaphors that I explore in more recent images. My strong desire to have my sister more present in this project led me to include more family photographs than I had originally anticipated and to use different artistic techniques than planned in the earlier stages of this project.

My use of assemblage, placing photos within photos, and fabricating objects instead of solely relying on single photographic images aligns with my choice to *construct* a narrative rather than issue a photo-journalistic report. Although I use the metaphor of being an embedded reporter in my commentary for the photo essay called *Position in space and time*, I only mean that I had access and proximity to the story, and I do not intend for my work to be seen as news reportage. Rather, I hope that my work is viewed more as a humanistic and philosophical exploration that is contextual yet universal.

The curatorial statements that accompany the photographs in each photo essay are of varying lengths and were written primarily as autoethnographic and explanatory artist's notes. Although I anticipated writing essays of 150-200 words, several of the statements exceed that length. There is a statement associated with each image and by design they should be read while viewing the designated photograph. I wrote these statements as Microsoft Word documents, viewing two pages at a time with the text on the left side of the screen and the image on the right side of the screen as I would envision them if they were to hang in a gallery. When I first shot/chose images I wrote captions for each, modifying them as needed, while writing the commentaries in order to underscore or encapsulate the main idea of each commentary. The parsimony required when writing captions often clarified what the most significant idea was within the coupled image and text. This would in turn sometimes bring me back to edit the text, which is another example of the recursive process that my methodology employed.

I have also entitled each photo essay with what I hope is an evocative phrase. My first draft used the theme as the title of each photo essay, but the words used to describe data are not sufficient to name artistic products. Thus, I gave each photo essay a title more befitting the medium and in my discussion of themes below, I will also discuss the title of each photo essay as it relates to and clarifies the theme it is associated with. In the reiterative and reflexive manner that autoethnographic methods demand, I have modified these titles to better represent the images as my analysis has revealed additional or more focused considerations.

Data and emergent themes

The five themes that developed out of my produced data are distinct yet interrelated. They do not need to be considered in any order, although I think that the theme about the epistemology of disability in some ways encompasses the other themes and so it is helpful to consider it first. The five themes that I will discuss are: 1) An epistemology of disability, 2) Interdependence, 3) Attempts to unravel myths about productivity and disability, 4) Context and dimensions: My position in space and time as a sibling and 5) Siblinghood constructs identity

The themes are associated with photo essays that I compiled as the arts-based responses to the research question “How has growing up with a sibling with a disability impacted my own identity, and my understanding and expression of the social and political implications of sibling disability”? and then elaborated on with autoethnographic writing. The five photo essays have titles as does each image within the photo essays. I have chosen representative images and text excerpts from my data to clarify my analysis of each theme. While I have used my sister's name (Annalise) within my autoethnographic texts, I differentiate my analytical writing by referring to her only as "my sister".

Theme 1: An epistemology of disability

This theme generated a photo essay entitled *Epistemology of an astrocytoma,* which is the specific type of brain tumor that my sister was diagnosed with at the age of 18 months. I must start with the disclaimer that I am not suggesting that a medical diagnosis such as astrocytoma is equivalent to the term disability, which I consider a social construction (Seibers, 2008). However, the named tumor is the starting point for my sister's medical history, resultant impairments, and connection to how she lived in the world as a person with disabilities. The knowledge that I gained from my proximity to this sequence can therefore be traced back to the thing itself, as medical phenomena, a set of physical and cognitive impairments, and disablement; with their blurred boundaries, these became my teachers.

To lend some contextual mooring, here is an excerpt from my autoethnography that accompanies the first image in this photo essay. It is displayed next to a photograph of a cobalt-colored orb (see Appendix B, Figure B1).

> *When my sister Annalise was 18 months old, she was diagnosed with a brain tumor near her cerebellum that was causing her to lose her newly formed skill of walking. She had an unsuccessful surgery to remove that tumor and also received radiation therapy to reduce the size of the growth. The tumor grew back and she underwent another surgery to successfully remove it when she was 6 years old and I was 3. Although that invasive growth was eradicated, the combined impact of the treatments for it led to secondary problems that she dealt with the rest of her life, such as hydrocephalus that required a shunt to be installed in the ventricles of her brain.*

> *Shunts are rather like plumbing fixtures that are prone to clogs and degradations of age and so she had many shunt revision surgeries throughout her lifetime. In addition, the radiation therapy that she was treated with back in the early 1960s used radioactive cobalt which was not particularly refined and likely caused many benign meningiomas to sprout on the outermost layer of her brain. While not malignant like her original tumor, the space that these lesions occupied led to other symptoms caused by compressed tissue and eventually seizures towards the end of her life. The functional impairments that resulted from this persistent medical intervention included walking balance issues, incoordination, and cognitive deficits, such as impaired short-term memory. The radiation she had as a toddler, also caused her mop of honey-colored ringlets to fall out, only to be replaced by mousey thin strands of hair.*
>
> *As I was born into Annalise's medical and disability story, I always knew that health was not guaranteed for anyone and more specifically that her hospitalizations made her body more vulnerable. Although my parents always spoke frankly about her medical history, the observations I made from my front row seat taught me even more about impairment, disability, and care*.
>
> *The title for this photo essay comes from the idea that Annalise's original tumor set in motion a body of knowledge specific to her neurological impairments. A body of knowledge that I benefitted from my close relationship as someone intimately embedded in her experiences. I resist the notion that her health history was somehow pre-destined in order to teach me, our parents, or the world some lessons, but this doesn't take away the reality that there is knowledge that I have because of Annalise's life and my deep exposure to it.*

Yet, let me be clear – I do not claim to know what it is like to live as my sister did. What I do know is what it is like to live as her sister. The knowledge of her embodied experience (Flynn, 2021) informed me about the tenuous nature of health and ability—of my own body and the bodies of those around me (Seibers, 2008). To this day, I am impatient with those who are surprised by the temporary nature of able-bodiedness and because this was an early lesson for me, I assumed that others had this knowledge as well. Presumptions that others have about guaranteed health and ability have seemed as ridiculous to me as any fairy tale. Throughout her life my sister's body seemed to operate with a unique set of rules and no intervention could resolve her many impairments. Although during each neurological bout her acute symptoms could be alleviated with surgical intervention, there was never a chance for cure and her tenure in the world was as a person with lasting impairments and disability. This then became the context where I grew to understand what being different from others meant.

Another concept that resonates with my experience is what Goffman termed being "wise" in his classic yet dated and often problematic (Brune & Garland Thompson, 2014) work *Stigma* (1963). Being wise, in a Goffmanian sense, is having intimate knowledge of a person's lived experience being marginalized and stigmatized, because of some perceived marker such as disability (Cochrane, 2014; Goffman, 1963). This knowledge is indirect, or what Cochrane (2014) terms a vicarious narrative and is unique to those in close proximity to a person with disability. In this sense, my parents and I all became wise because of my sister and her life with disability. This wisdom is an artifact of my sister's lived experience, filtered through my own identity and thus exists in the space between our individual lives. While Goffman (1963) is rightly criticized for emphasizing the binary of "normal" vs. "other" (Brune & Garland Thompson, 2014), the category he defines in his discussion of being wise is a hybrid of sorts and fits my position of being close to, but not identifying as a person with disability. Wisdom befits a deeper state of knowing that is generally associated with accrued life experience that I was privy to in my siblinghood.

An epistemological insight that eventually became clear to me as I grappled with religious teaching and what I observed in my home is the Cartesian falsehood of the mind/body dichotomy. There was a time in my life when I thought that there must be an ideal, "whole" version of my sister somewhere and this thinking likely came in part from the teachings of our family's church, where there were a number of conflicting messages about bodies in general. On the one hand, there was much said about our bodies being like temples – sacred spaces to be revered and kept holy. Biblical passages were cited that focused on how to live a chaste life that "honored" this holy creation. But when a body was somehow compromised by disease, disability, and at the most extreme death, much of the rhetoric surrounding corporeality focused on the body as merely a shell for the soul—a clay vessel or a husk that would one day wither. What really mattered, they said, was what was inside that body, the person's spirit or soul. In this way, bodies that were atypical, or impacted by disease or illness were not to be mourned because they were only temporary dwellings for the eternal soul. This contradiction perplexed me, as somehow my sister's disabled body was deemed unimportant and not the "real her," while mine was to be safeguarded against any invasion or impurity because how I chose to use my body had definite repercussions for my soul. Heaven, I was told, was where my sister would finally have a body that was whole, but how could that person still be my sister? My sister had a V-shaped scar on her neck from an emergency tracheostomy, hair that was permanently wispy from radiation, large and expressive hazel-colored eyes that bulged from residual intracranial pressure. She experienced the world in that body and the world perceived and read her in that body. How could anything else be her authentic self?

The photographs in the essay are chronologically arranged and indicate the ever-presence of the curriculum that my sister's brain tumor designed and used to in/form my identity to a great degree. It may seem unusual that I am giving such agency to a clump of neural tissue, but the point of this photo essay is that that tissue feels like an entity because of the power it wielded. The blue abstract orb image that I use to tie this set of photographs together represents the cobalt radiation that was used to shrink the invading growth in my sister's skull, but instead seemed to give that lesion superpowers. Thus, the radiated tumor became an abstract force in my life and in my parents' lives too. By re-framing the deadly radiated tissue as a teacher, I am smoothing some of its sharp projections, perhaps as an attempt to reduce the pain that it also inflicted. But as I re-present my sister's stories, I must take care not to misrepresent them or elucidate only the areas of positive impact that her history may have had.

One concern that arises in this essay as well as in all of my work is the myriad of ways in which I have used my sister's medical/impairment/disability narratives for my own purposes. My claim that her history made me wise (Goffman, 1963) could be read as me stealing from her plate as the second image in this series suggests, showing me as a three-year-old taking food off of my sister's plate (see Appendix B, Figure B2). I would like to think that learning from my sister's experience has been a way for her to help me (Flynn, 2021). My sister did not necessarily identify as a person with disability and, thus, would not claim a "cripistemology" (Johnson & McRuer, 2014) where she could acknowledge what her lived experience with impairment had taught her. She also would not likely identify with the idea that her disability experience would be a source of knowledge for me. But I think that she *would* claim that one of her jobs as "big sister" was to teach me things.

Although I cannot articulate all of the knowledge my sister's lived experience imparted to me in this first photo essay, leaving the other photo essays to explicate a little more, I do demonstrate in this series some of the relational dynamics where knowledge has been and is conveyed. These include older sister/younger sister, soundtrack composer/listener, monarch/loyal subject, muse/artist scholar, and influencer/devotee. These are not the typical roles that are listed when considering how siblings with or without disability interact. But that's exactly how a new epistemology works in its ability to expand knowledge.

One image from this essay that explores these relationships is entitled *Fanfare* (2009, 2013) (Figure 2) and the accompanying statement includes the following insights:

> *I manipulated this image of Annalise playing her keyboard to include a cobalt "crown" that represents the many small growths occupying space in her head at the time. A crown shape is apropos as she was particularly fond of fancy accessories and because it also bestows upon her a certain authority. Just as a reigning monarch might be held in high esteem, I want to honor Annalise for what she conveyed to me and others through her life with impairment. This is not to elevate her to a facetious "supercrip" status, but rather to recognize the values that she imparted to me, ever her loyal subject, by her example.*
>
> *The crown also includes star elements which reference her original star-shaped tumor as they form a kind of constellation around her head. In medical jargon, individuals are often described as displaying a constellation of symptoms, indicating a list of medical issues that tend to be associated with one another. In my sister's case, this constellation included worsening balance issues while walking, short term memory loss, and grand mal seizures that happened with greater frequency towards the end of her life. Annalise's constellation became an epiphany for me as her impairments illuminated the world as I experienced it. Just as the wise were guided by the celestial map in the Biblical epiphany story, I have become wise in Goffman's sense as I allow Annalise's story to lead me.*
>
> *This snapshot was also manipulated to include what appears to be a musical score resting on the stand of the keyboard. This element was added later and is actually an image that I shot during Annalise's final hospitalization during an EEG study to measure seizure activity. It is essentially a photograph of the EEG monitor screen that shows a series of measures of electrical activity with an inset video still of Annalise's electrode-covered head during the test. When I took the photograph of the EEG screen in her hospital room, I was struck by the picture within a picture format and how it revealed Annalise's face at the same time that her brain activity was being measured. This record of the rhythm of her brain waves with repeated oscillations and ripples over time resembles a multivocal musical score, and thus I digitally placed it on her keyboard when creating the image Fanfare. In some ways her neural wiring wrote the score for the music that she made that is also included on the soundtrack of my life.*

Figure 2
Fanfare

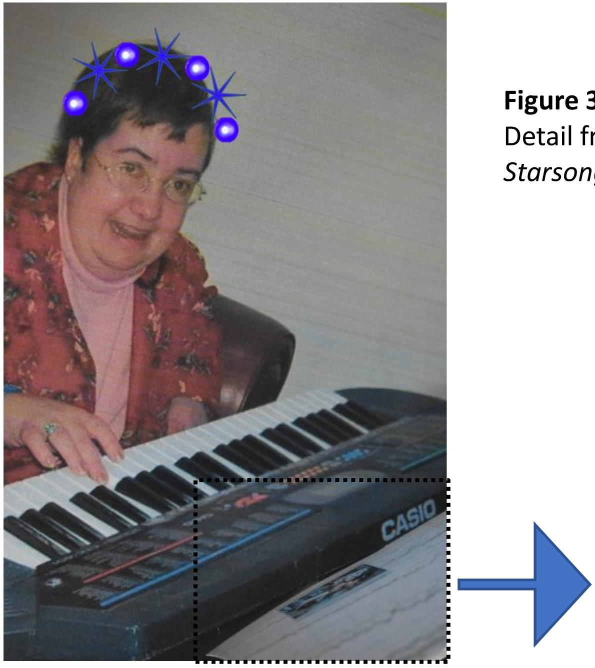
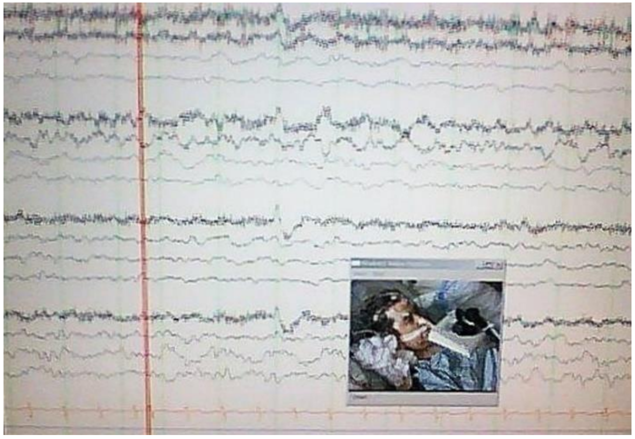


Figure 3
Detail from *Fanfare*, showing EEG image,
Starsong

Figure 4
Starsong



The image that I used as the basis for *Fanfare* (Figure 2) is a simple family snapshot that I took to record an ordinary moment when my sister was engaged in a favorite activity. When I came upon it as I sorted through photographs to use for this project, it automatically elicited memories of that time and place in our lives and the concomitant emotional states associated with those memories. But as I considered the image as an answer to the prompt about my identity as impacted by my sister's impairments and disabilities its meaning expanded and helped to crystallize ideas that up to that point had not been articulated in my thinking. My artistic manipulations such as the digital assemblage of the cobalt orbs and stars as well as the placement of the EEG image (Figure 3 and Figure 4) were the result of these reflections and led to further extrapolations of the celestial metaphors I had already drawn out. Thus, in creating these assemblages, I came to an increased understanding of how my siblinghood carried its own knowledge; an insight that I was unaware of until I tinkered with these photographs and created something new (Richardson & St. Pierre, 2005).

Theme 2: Interdependence

The word disability conjures up many tropes, almost always negative, and almost always associated with the discomforting notion of dependence. In a society that generally values independence above any requirement of support, the onset of a disabling condition is often perceived as being sentenced to the undesirable state of reliance upon others to participate in life activities. However, the continuum of dependence to independence is misleading and scholars such as Piepmeier (2021) and Kittay (2019) eschew this reductionist linear spectrum. Rather, interdependence is a construct that more accurately describes all human relationships, including those in which disability is a facet. Disability historian Paul Longmore wrote in his 2003 work, *Why I Burned My Book and Other Essays on Disability*, "society-at-large prizes self-sufficiency, independence, functional separateness, and physical autonomy" (p.x), which are often impossible states for people with impairments. Belser (2016) says, "When people speak of the ‘indignity’ of disability and lament disability as a condition that cannot be endured, they imagine disability as devastation of human independence, a fate presumed to be worse than death” (p.6). In the United States, we have a tendency to valorize independence. We revere the “self-made” person, the pioneer, the overachiever, and the do-it-yourselfer. Even the 4th of July is officially called Independence Day, rather than naming it “USA day,” in the style of other countries such as Canada or Sweden. Our choice to celebrate being an independent country takes precedence even over a declaration of our unique national identity and the idea of independence is embedded in many ideals of complete American citizenship.

The restrictive binary of dependence vs. independence has been rejected by scholars in Disability Studies who suggest that interdependence is a more accurate term to use to describe the complex and imbricated relationships between human beings. Kittay revolves her philosophical theory of justice as it relates to capabilities, around what she calls the “inevitability of human dependency and the inextricable nature of our interdependency” (2015, p.286). She reminds us, too, that able-bodiedness is a temporary state, and thus dependence is a common experience for all human beings. Kittay suggests that it is not neediness that makes dependence unpalatable, but rather the lack of opportunities and social ease that come along with a state of dependence that are undesirable. She encourages us to see dependence in a new light as an opportunity to enter into interdependent relationships. Kittay says this about dependence:

> We see it not as an impediment to living well, but as a source of value: a source of connection; an occasion for developing our capacities for thought, empathy, sensitivity,

> trust, ingenuity, and creativity; in short, as providing for us the conditions of our distinctive human freedom and dignity (p.290).

What if, instead of a hierarchy of desirable states that places independence at the pinnacle, we consider interdependence as the place where optimal experience happens? Can we reframe our understanding of being in the world together with this epistemology of disability? The idea of interdependency born out of dependency doesn't apply solely to individuals with disabilities but can inform all. My dependence on my sister, most significantly for my identity formation, and her dependence on me for support and care allowed for us to establish a strong system of interdependence and thereby engage in relationships and activities in a richer and more meaningful way.

The photo essay associated with this theme is entitled *Who am I without you*? and refers to the question of my sibling identity formation at the heart of this project and is also meant to signal to my audience the interdependent relationship that I have with my sister, particularly as impacted by her disabilities. It could be argued that all sibling relationships are interdependent in nature, but the level of dependence and the extended timeframe of dependence often inscribed by impairment and disability can result in a more robust interdependent relationship than that between non-disabled siblings. And I mean to point out in this work that it is my need that I have identified. It is not appropriate for me to tell my sister's story of in/dependence, but rather to communicate my own reliance on her lived experience to figure out who I am in the world. The original title for my photo essay sounded more like the title of the theme, using the word "interdependence", but I was struck by a question that Butler (2020) posed in her exploration of identity and grief and thus swapped out my original words for her phrasing.

Photography lends itself particularly well as a medium for this theme, as I use selective focus, and different assemblage techniques to illustrate the interrelatedness of our stories. This work is not autobiographical, nor is it a biography of my sister. It is about the space between us, and how that is moderated by impairment and/or disability. This intersectional space includes our different needs in elemental as well as esoteric ways and is ever present even though my sister died years ago.

Many of the metaphors I rely on in this photo essay are connected to the natural world and the interdependent processes that are inherent to ecosystems. The root systems that support growth around a rock garden, and the infusion of nutrients into the soil that feed neighboring plants are unseen yet critical components to healthy growth. The tenets of rhizomatic philosophy as informed by disability studies (Mercieca & Mercieca, 2010) articulate that the work that goes on horizontally underground connects seemingly disparate ideas in a non-hierarchical fashion and branches out into new fertile ground. Any one of these branches can be an entry point into discovery and previously unknown interconnections are revealed. Thus, the work I have done in this entire project has been like tilling the soil in order to aerate and break up any clods or barriers that would inhibit growth. In preparing the matrix for ideas about sibling identity and disability, I have induced interconnected growth and now see the results in the art that I have made “above ground”. Two of the images in this series rely completely on these horticultural metaphors (see Appendix B, Figures B9 and B10).

The final image in this photo essay entitled *Revisitation*, (Figure 5) also relies on images from nature as I call upon the cyclical rhythm of the sea and the spiral formation of the whelk shell to describe my recursive process of gathering knowledge. Although the photographs in this series are not arranged chronologically, it is befitting that this last image speaks to one of the rituals that I observed after my sister died. The temporality that directs many narratives is not my message here, but I do recognize that when my sister died, I was confronted with questions about my own identity. Butler (2020) says:

> It is not as if an 'I' exists independently over here and then simply loses a 'you' over there, especially if the attachment to 'you' is part of what composes who 'I' am. If I lose you, under these conditions, then I not only mourn the loss, but I become inscrutable to myself. Who 'am' I, without you? When we lose some of these ties by which we are constituted, we do not know who we are or what to do. On one level, I think I have lost 'you' only to discover that 'I' have gone missing as well. At another level, perhaps what I have lost 'in' you, that for which I have no vocabulary, is a relationality that is composed neither exclusively of myself nor you, but is to be conceived as *the tie* by which those terms are differentiated and related. (p. 22)

In her musings about the impact of losing her sister, Leddy (2023) bemoans the fact that there is no word comparable to widow or orphan to describe the sibling who is left behind. She says “I was born a sister. When I entered the world, Kait was already in it. There is no version of me that exists without her imprint” (Leddy, 2023). The interdependence of our identities, or what Butler calls the tie (2020) of our relationality requires that I recognize my sister’s presence even in her absence and the interconnectedness I still know. The text that accompanies this image (Figure 5) says:

> *I do not write about Annalise to work through my grief. It's not that I don't miss her, and I do sometimes cry when giving a presentation that incorporates moments from her life. However, my scholarly interest and perseveration on the topic of sibling disability is driven by a desire to share the wisdom I have come to understand because of my sororal identity. Annalise died in 2010, but I will always be her sister. The narrative shape of my life has been drawn in part by being her sister and is more of a spiral than an arc. That is, I do not anticipate that I will ever achieve resolution or closure around the birth, the death, or the disability of Annalise. The knowledge that has emerged through my proximity to her life is not like a pot of gold at the end of a rainbow. Instead, as I continue to interrogate my memories and express my thoughts in artistic media, I collect small treasures along the way, picking them up and putting them in my pocket as one might do when beachcombing. This path is reiterative and reflexive as I experience cycles of understanding.*
>
> *The beach has long been a context of comfort for me and when Annalise and I were children we spent many summers at Jones Beach, which was only a few miles away from our home. It made sense to me that I should sprinkle some of Annalise's cremated body at this place a few months after she had died. My husband took this photograph of me releasing some of her ashes into the wind at the shoreline and captured the refracted sunlight as it encircled my figure at the moment I opened my palm to the ocean. I then superimposed a photograph of a whelk spiral to represent the cyclical nature of my exploration in its ancient spiral formulation. My footsteps in the sand seem to indicate that I have walked towards the center of the shell's coil where I have paused to release Annalise's corporeal remains. My feet are oriented in a way that suggests that I am at the very beginning of the spiral path about to embark on an ever-widening trajectory.*

Figure 5
Revisitation

Theme 3: Attempts to unravel myths about productivity and disability

This theme speaks to the emancipatory work that I hope my scholarship can do. That is, one of the warrants for my research is to dispel some of the inaccurate discourse around disability, based on my privileged position and observations as a sibling. The photo essay that investigates this theme is entitled *Nevertheless, she persisted* and troubles the ideas of productivity and perseveration as they relate to disability. The photos in this series document the process of making an object and should only be considered together. I also rely on an ancient story about process over product to underscore my point.

In Homer's tale, *The Odyssey*, Penelope displays her loyalty to her husband Odysseus, who has been absent for years, by foiling the plans of would-be suitors with a clever ruse. She promises to acknowledge her widowhood and marry one of these supplicants as soon as she completes a weaving project. She is observed to work at her loom for hours every day, but unbeknownst to those awaiting her eligibility, every evening she reverses her progress by unraveling the fabric she created during the day. In this way, she forestalls any marriage proposals as she awaits the return of her own Odysseus. Eventually, her deception is revealed, and the story moves on to document the journey that Odysseus takes until he is finally reunited with Penelope. But the portion of the story that resonates with my experience is Penelope's weaving and unweaving practice as I use it as a metaphor for questions surrounding productivity and my sister's practice of repeated crocheting and then unraveling her work.

In a society that perpetually measures the worth of an individual in units of productivity, those who are not or cannot be competitively employed are thereby less valued by those in power. This designation is often bestowed on people with disabilities who are not seen as contributors to the wealth stream, but rather as drains on society's reservoir. Indeed, one of the criteria of standard disability classification is if the individual in question can work or be productive (Ellison, 2022). One who is productive can show an end product that is valued by others and is often remunerated for that product. My sister was never "gainfully employed" due to her long history of neurological insults and injuries and although she did go to a sheltered workshop for many years of her adult life, she never accrued more than a few dollars in her weekly paycheck. However, one thing that she loved to do in her non-workshop time was to crochet. She would sit for hours at a time, making a long chain stitch which is the first step in any crochet project. She was successful in making this foundational stitch, falling into a rhythm and even moving into what Csikszentmihalyi (1990) would call a state of "flow" as the chain spilled from her lap onto the floor. At some point, she would pause her needle, examine the chain, find an unacceptable stitch or some other prompt and proceed to rip out or unravel the entire length of work. She would then start anew, without complaint or evident frustration. This is not an unusual practice for needleworkers when finding a mistake (called "frogging"), but they usually have the goal of fixing their mistake and eventually completing the work. Few fiber artists make their stitches without having an end product in mind and even Penelope's weaving was ostensibly to create a burial shroud for her father-in-law.

For my sister this cycle was on repeat, first creating the stitches and then unraveling them. Like Penelope, she never made measurable progress and her work never resulted in any end product. The term often used by medical practitioners for activity that is repeated without an apparent goal is perseveration, and it is a classic marker of neurological dysfunction (Allison, 1966). Perseveration is qualitatively different from its etymological relative perseverance although both terms signify continued activity. The negative connotation of perseveration rises from the aimlessness or non-productive result of the activity versus perseverance which is always goal-directed and often leads to some measurable, often laudable achievement. Thus, the value placed on, and power given to those who persevere is not available to those who perseverate. I challenge this value system related to end products and along with others who have troubled this notion as it relates to people with disabilities (Nussbaum, 2011; Kafer, 2013, Kittay, 2019), suggest a broader understanding of personhood by exposing the myths that surround productivity.

While Homer assigns deep relational significance to Penelope's act of unraveling, I am not really sure why my sister unraveled her work, or why she kept on crocheting to begin with if it never resulted in a functional or beautiful object. As a novice knitter myself, I recognize the sensory pleasures of handling fibers and the repetition of stitching can be meditative. Even unraveling work can feel great as the stitches unloop from one another with a barely audible but palpable pop (Winn, personal communication) as each strand is released and stretches out to its original length. Perhaps this is the kind of joy that the perseverative stitching and unraveling gave to my sister. Taking pleasure in purely sensory activities is a universal feature of the human experience as the increasing popularity of aural exposure to elicit an Autonomous Sensory Meridian Response demonstrates. Using fidget toys is another example of how some use tactile sensory input often in public contexts to achieve a calming or alerting sensation. However, societal expectations around which activities are acceptable for this purpose can place limits on idiosyncratic tastes. Crocheting, in our culture, is supposed to yield a product and to be non-productive in this activity with no tangible goal in mind becomes a marker of strangeness and/or disability. Even needleworkers who have several works-in-progress generally desire to one day bring their work to completion.

To escape the negative connotations of the word perseveration, and to avoid the heroism invoked by the word perseverance, I suggest the more value-neutral word persistence to describe the activity that my sister engaged in when she tangled with her yarn projects. This word also inspired the title of the photo essay associated with this theme, *Nevertheless, she persisted*. As described in the statement that accompanies the photo essay, this phrase is inspired by a values-based decision made by United States Senator Elizabeth Warren, who was critiqued by another senator. The word “persisted” was initially used in a derogatory fashion, but the phrase was then co-opted by the supporters of Senator Warren and allied advocacy movements to instead describe their sustained efforts in a positive way. My purpose in choosing this title for this photo essay is to indicate the strength of my sister’s endurance as well as to pay homage to Senator Warren and her commitment to social justice.

This essay begins with an image, (Figure 6), which was captured by my husband on a low-resolution cell phone camera in 2010 as my sister lay in a neuro ICU bed, shortly before being taken off life support. This was at the end of a long hospitalization that had at one point looked quite hopeful until her body finally could not rebound and a few days after being taken off life support and a few days after this photograph was taken, she died.

Figure 6

Nevertheless, she persisted

I wrote the following about this image:

The quilt that covers her is handmade by friends who each contributed a section conveying messages of love and hope. It became a death shroud. I am standing next to her hospital bed on her right side and although my face isn't visible, my trademark scarf and jewelry are. I have placed my left hand on her forehead in a gesture that is somewhere between a maternal stroke and an ecclesiastical blessing. Although she never opened her eyes or uttered another word again, I continued to speak to her with assurance and love, as did the continual stream of visitors to her bedside. On the day that the staff removed the life supportive technologies from her body, a group of friends and family gathered around her bed and sang a couple of songs, anticipating that she would die moments after the ventilator was disconnected. Nevertheless, she persisted, and it wasn't until a few days later that she finally died. The power of these moments surrounding her demise and death is what inspired me to use this photograph to create other photographic products and the resulting essay.

The title of this work comes from a phrase adopted by activists in 2017, after a member of congress used the phrase in an attempt to stifle Senator Elizabeth Warren as she read from a text calling out civil rights injustices. Advocates reclaimed the words, and they became a battle cry for those fighting for justice, particularly for women and oppressed minorities

After selecting this photograph from my personal archive, I digitally enhanced the file to make the colors more vibrant and to improve its clarity and had the image printed onto fabric as a repeated pattern that I then cut out into long strips. I sewed the short ends of the fabric strips together which resulted in a kind of thick fabric yarn. I then decided to embellish the seams with embroidery using pink cotton thread. Although I initially used the simplest of stitches, I decided to use a different stitch pattern on each seam, and they became more ornamental as I progressed along the fabric strip. The whimsical, decorative stitch patterns and pink thread color are in honor of my sister's tastes and likings, and I really enjoyed this meditative "women's work." The final step in this project was to use the embellished but fraying fabric yarn to "finger crochet" a long chain by starting with a slip knot and then pulling a section of the yarn through the hole. I continued doing this for about three-fourths of the length of the yarn and then stopped. I then pulled on the loose end of the yarn and undid all of the chain stitches. I did this several times, observing how it felt to do and then undo my work. A photograph (Figure 7) illustrates this unfinished chain.

Figure 7
Unfinished chain

This photo essay is unique in my collection because, as I have indicated, it documents a process. Although each image can be understood on its own, the interpretation is most congruent when seen in sequence together. The data creation process that I documented is a good example of the recursive and reflexive nature of autoethnographic arts-based research as I did not know what the process would be until I was in the midst of making the work. Congruent with tenets of arts-based research (Casey & Murray, 2022), the fabric yarn project revealed meanings as I was making it requiring that I modify the steps as a response to what the data was teaching me. Sometimes this was in tension with my desire to make an aesthetically pleasing product. For example, when I was working with the fabric yarn, I noticed the cut edges beginning to fray so I began to sew a decorative blanket stitch on the edges using colorful thread used in an earlier part of the project. But then I recognized that my creation of a neat edge worked against one of the ideas inherent to this project; my identity as a sibling informed by disability is untidy and unfinished. Any attempt to make it more presentable would not be an accurate depiction of my inquiry.

As I used the fabric yarn to finger-crochet a long chain, in the style of my sister's persistent work I had the desire to fasten off the stitches and then sew the chain together to make something further as the final product. Of course, this too would have worked against what was at the core of this theme that productivity should not be the measure of a person's value. My inclination to fabricate a finished product is rooted in my own bent towards valuing productivity and having something to show for my work. It is a measure of the strength of cultural norms around productivity that even in the midst of my attempt to dispel myths about it I was prepared to do the very thing I was warning against.

Homer’s Penelope persisted in her weaving/unweaving practice because she persisted in her hope that her husband would return to her. Her work-in-progress was a burial shroud for her father-in-law, that she did eventually complete. I chose the admittedly low-resolution image of my sister to replicate on the fabric yarn rather than a photograph of her crocheting, because it somehow resonated with Penelope’s story. The photograph shows my sister on her death bed, persisting. She is adorned with a quilt that served as a sort-of burial shroud. My sister’s persistence in her last days, even after all life-support technologies had been removed helped me to realize that it was not up to me, or even the medical staff when her work would be done.

I can see myself as well in Penelope’s story, and my persistent reliance on my sister’s life experience to forward my own scholarly and psychic agendas could be seen by some as perseverative. In the commentary associated with the original image used for the fabric yarn, I point out signifiers of my identity, and include both recognizable features and potential roles that I played in her life. As I observed the physical act of making a chain stitch with the fabric yarn and how the image of my sister kept manifesting itself on each new stitch, I pulled through I once again benefitted from the art revealing what I already knew (Casey & Murray, 2022). My own persistence as well as my productivity relies on my sister’s repeated appearance as she is born again and again in my inquiries. The unraveling I must do to keep on gaining insight into sibling disability should be valued as much as any resultant product from this work.

Theme 4: Context and dimensions: My position in space and time as a sibling

As my scholarship has developed, I have been increasingly convinced of the importance of context for any level of critical investigation. The interdependence that is vital for survival reaches beyond human bonds and requires a recognition of the dimensions of space and time that we occupy and that we are products of. The inclusion criteria that I applied to the sibling memoirs utilized in my literature review noted the importance of both temporal and geographic reference points to ensure that I share some common contextual foundations with them to situate my own memory work more accurately.

Some suggest that the experience of living with a disability lends itself to alternate measures of space and time (Garland-Thomson, 2005; Kafer, 2013; Mairs, 1996) and my proximity to my sister's life as a person with disabilities has induced me to consider this. The title of the photo essay associated with this theme is *Perspectives and Positions* and it explores dimensions that have impacted me in my siblinghood.

Although many of the stories I share about my sister include some reference to her medical history and the dramatic interventions involved, a cure was never the goal and my family understood that my sister's present as well as future would always include impairments and disabilities. In her discussion of temporality, Kafer (2013) contrasts the medical model or "curative time" with the concept of "crip time" (p. 25) as an alternate to mainstream expectations and practices involving time. My sister did take longer to do things due to mobility issues and slower cognitive processing speed, but the more salient crip time feature that she exemplified was her ability to live in the moment. My family understood that the future was not guaranteed to any of us and coupled with my sister's exceedingly short short-term memory, the present moment overshadowed any thoughts of the past or future. This exposure to another way of being in time has benefitted me and my ability to live "in the moment" is well practiced. Admittedly, though, I am limited when it comes to planning beyond my immediate future. The photograph that references time in this collection is a commentary on alternate or even surreal experiences of time that can accompany living with a disability. Of course, the piece is a nod to Dali's work, but I entitled it, *The persistence of **my** memory*, (Figure 8) claiming ownership by inserting a possessive pronoun and switching out a CAT scan image for a melting clock.

Figure 8
*The persistence of **my** memory*

The accompanying text to this image explains:

I knew the word "cerebellum" and understood the fluid physiology of the brain long before I took a neuroanatomy course as when I was growing up I had seen what happened to my sister when these structures periodically malfunctioned. My mother

> *taught me to look for signs that Annalise's intracranial shunt was clogged, and I understood early on that there was a relationship between space-occupying tumors and functions such as balance, coordination, and cognitive functioning. It sometimes felt as though Annalise was a ticking time bomb and we all needed to be vigilant in watching for symptoms lest she "get sick." Unrelenting headaches, extra sleepiness, and the most fearsome eyes bulging out of their orbits would signal that the pressure inside of her skull was increasing and would lead to dire circumstances if not surgically relieved right away.*
>
> *This photograph references Salvador Dali's 1931 surrealist painting Persistence of Memory that is commonly referred to as the painting of melting clocks. The clock motif is a nod to the ticking time bomb metaphor, and I used a printed enlargement of one of Annalise's CAT scan images to stand in as a one of the dripping timepieces. The ovoid shape of the scan reminds me of a clock face and the directional marking "P120" can stand in for the number at the lower edge of a timepiece. This particular image is a transverse slice of Annalise's brain that reveals at least two meningiomas growing on the outer layer of each of her temporal lobes which are visible as threatening bulges at the 4 o'clock and 7 o'clock positions. Although not malignant growths, these kinds of tumors still take up cranial space and compress the neural tissue nearby, causing a variety of symptoms including seizures. Shortly after this CAT scan was interpreted, Annalise was prepped for yet another intracranial surgery to excise these growths.*

Other images in this photo essay speak to my position relative to my sister and the spaces we occupied. Throughout her life, my sister was at the center of our family and her preeminent location was never questioned. Just as the space-occupying tumors that grew in her skull pushed other tissues aside, my sister's needs took up space that left little room for others' concerns. In a sabbatical trip my family made to Sweden when my sister was 6 years old and I was 3, she experienced an exacerbation of neurological symptoms that required surgery to remove the encroaching cerebellar tumor. The narrative that grew around our time in Sweden took the shape of concentric circles, emanating from the hub of my sister's health issues, and broadcast primarily by my mother. Upon our return to the U.S., and for years hence, the stories about our life in Sweden were told and re-told, ever echoing back to the dramatic point where a Swedish neurosurgeon saved my sister's life. My mother's identity as Annalise's primary caregiver, advocate, historian, and protector grew out of this narrative as well, and it became the template upon which future stories were plotted. A panoramic photograph in this series with a picture of my sister in the exact center exemplifies this concept (see Appendix B, Figure B23).

I cannot presume to know what my sister's perspective was from her position, but I do acknowledge that she had a unique point of view that was entirely distinct and deserves to be regarded as such. In an unmodified family photograph in this series, my sister is depicted standing in the backyard of our family home, holding an "instant" camera and looking away from the photographer as she presumably was getting ready to take a photograph of her own (see Appendix B, Figure B22). I took this picture of her when I was a teenager with my upgraded single-lens reflex camera that marked me (I thought) as a "real" photographer. My adolescent hubris that discounted my sister's photographic eye was partially fed by the ableist idea that a person with a disability and particularly an intellectual disability is not capable of a discrete orientation to the world. But I now realize that the viewfinder that my sister peered through to understand the world formulated her standpoint and later her sitpoint (Garland-Thomson, 2005) regardless of her intellectual capabilities. The strong arguments made by Carlson, (2010), Kittay, (2019) and others that intellectual disability does not diminish personhood support the idea that my sister's point of view is worthy of consideration. Although it is not appropriate to posthumously conjecture what her point of view was, nor is it the goal of this inquiry to figure out how she saw the world, I can appreciate the photo archive that she left as a reminder of her distinct perspective. The text that accompanies this photo, entitled *Point of View* elaborates on this idea.

> *I have inherited Annalise's photo albums and collections of loose Polaroid photographs and as I sift through them today, I realize their great value as they reveal her unique perspective. Her literal point of view can be understood as I extrapolate what she saw through the viewfinder of her camera. Most of the photographs she took were of people; friends and family obediently posing upon her direction. Although limited by the medium of low-resolution instant film, many of her snapshots captured broad smiles from her subjects as they gladly communicated with her as photographer. She also tended to caption many of them in a fashion similar to our mother's scrapbook notations from her own young adulthood. This idea that a photo could tell a whole story was not lost on Annalise and reading her inscriptions now yields insights about her perspectives.*
>
> *Many of the Polaroid photographs that Annalise took of me appear to be shot from a lower viewpoint looking up at me. The most obvious reason for this is that she was around 7" shorter than me, but given that, I wonder what it was like to always "look up" when she located me in the viewfinder. This became even more of an issue during the last few years of her life when she regularly used a wheelchair for safer mobility and became "waist-high in the world" (Mairs, 1996).*
>
> *Sadly, Annalise was never quite able to take advantage of contemporary technology and didn't use a personal computer, cell phone, or digital camera. The user-friendliness of digital photography and the ease of printing from a home computer might have opened up other ways for her to express herself in this medium. But I am convinced that there was great value in watching the camera transform her singular point of view into an object that she could hold, inscribe, and place in her collection.*

My proximal position as her sibling and later as my sister's guardian gave me access to her experiences and allowed me to co-experience many of them. As I look to the narratives that were written by her life as a person with disabilities, I need to recognize my place as a character in the stories that I am studying (Clandinin, & Connelly, 2000). Although I use the metaphor of the embedded reporter in this photo essay text, I am committed to the non-journalistic practice of reflecting on how these experiences have formed my own identity and set of narratives. I have been "on assignment" in the neuro ICU, day habilitation program, group home and even in my own home as I made it more accessible for someone with impaired balance. I have acclimated to life in all of these spaces and have acted as guide, interpreter, advocate and support staff as I have built stories to report. In the broader community, I have watched how other people have responded to the impairments and disabilities that my sister showcased and have observed a variety of reactions from pity and disdain to authentic friendship and respect. The value of my position as an insider has allowed for deeper and more connected insights into what it was like for my sister to live in this world, but always from my perspective.

Just as my siblinghood granted me certain access to my sister's lived experience, my status as depicted in a photograph of my hospital visitor ID sticker (see Appendix B, Figure B24) allowed me to be with her in her dying experience. This is yet another space where few are privileged enough to dwell. Once we had made the decision to remove the life-sustaining technology from my sister's body, we set a time for the staff to do so and arranged for a group of friends to surround her bed and sing to her during that moment as we anticipated her immediate demise. But my sister's dying was like her living in that her presence in space and time defied expectations. Instead of a simple narrative arc to this story, the false denouement we had set up with a chorus of loved ones became instead an anti-climax. There was no high drama as she was transferred to another unit in the hospital where it wasn't until a few days later that she quietly took leave in the presence of a solitary napping friend. I had maintained my rhythm of spending time in her hospital room every day and soon became the impatient rather than the inpatient visitor as my nametag declared. When I received the message that she had finally passed away I was relieved as much as I was sad. As I made my way through the abandoned hospital corridors in the wee hours of that morning, I realized that once again I had been granted access to a space only because of my sister, but this time because of her absence instead of her presence.

As I work to understand how my identity has been impacted by my sister's life, I must fight any tendency to essentialize or reduce my sister's experiences or our relationship to the single feature of disability. Because the scope of disability as a construction is as broad and varied as human experience itself, it is ridiculous to even present disability as a sole characteristic. Nor should I reduce my sister's identity to a list of her neurological impairments. And yet the slippery terrain of easy taxonomies and facile explanations surrounds my inquiry. While the shorthand that I have relied on for this project comes from exposure to my disciplinary and scholarly perspectives I need to recognize that a deeper understanding must also include the idiosyncratic way that my family interpreted my sister's embodied experience (Taylor, 2000) and other contextual realities of time and space. Each assertion I make about my sister's life and how it impacted my identity needs to be examined from all angles, to be sure that I have not used any "tricks." That is, I should not construct facades or shallow impressions of my sister and her life in order to serve my purposes. When I represent her to others, I need to respect her full humanity, as far as I understand it. The last image in this photo essay is a trick photograph entitled *Annamorph* (see Appendix B, Figures B25 and B26). An anamorph is an optical illusion where a flat object is rendered in such a way that viewers see it as three-dimensional. My rudimentary skill in this technique resulted in a moderately compelling image of the box that contains my sister's ashes, standing upright on a wooden surface. Although the photograph seems to be of a solid box, it is a photograph of a photograph, so the box I photographed was actually a completely flat object. This technique requires an appreciation of perspective and optics and thus became an effective metaphor for my exploration into how I see my sister as well as how I present her to others. I must be vigilant in recognizing and revealing instances when I haven't considered the depth of my sister's life, while admitting that there are areas that remain illusions to me.

Theme 5: **Siblinghood constructs identity**

Sibling identity is the overarching theme of this project, but the fifth theme that emerged from my art focuses on the construction of identity and the processes by which that occurs. There are many kinds of piecework that art-based research can employ such as collage, mosaic and bricolage and the rich metaphors inherent in these genres are apt for this discussion (Knowles & Cole, 2008; Rolling, 2013). The photo essay associated with this theme is entitled *Broken bodies and piecework* and it explores the process of discovery I continue to observe as I proceed in my investigation.

When I select photographs of my sister to serve as prompts for autoethnographic investigation, I choose pictures that seem to be portals into the themes of disability and/or identity that I feel a need to explore. When I use her image, and particularly when I share images of her, I am mindful of the ethical quagmire surrounding this practice. If her memory allows me to use the narratives borne by her disabled body, I certainly have a responsibility to not willfully misrepresent her. Yet I recognize that in my words or in the images that I choose, I am never quite fully presenting who she was – that would be an impossible task. Rather, I show glimpses of her – facets – aspects – portions that I have teased away from the whole. As I explain in the analysis of Theme 4, it is critical that I illuminate this practice so that no one facet is taken to mean the whole.

Any analysis requires that the investigator break apart the corpus of work being studied, and this photo essay invites analysis most explicitly. The very first image in the set (Figure 9) inspired the theme as I came upon it in an already broken apart state when I was sifting through my family archive. While not exactly family photographs, medical images like this one were familiar objects in my household and were gathered in similar fashion to other memorabilia. Much like a found poem, this image was not altered but was included in my photo essay for its aesthetic and symbolic value.

Figure 9
Mosaic

The x-ray film of my sister's torso depicts her body, but one that is broken into small parts that remain in situ. The effect is one of a mosaic or even stained glass where many components fit together to create a whole picture. My musing about the so-called broken body that is referenced in both deficit-oriented disability literature as well as Christological texts yields several insights into how I perceived my sister's impairments when I was growing up. My nascent observations about the spiritual and/or religious interpretations of disability and impairment and my own identity in that realm are beyond the scope of this project and perhaps deserving of their own inquiry. However, our family's faith tradition is a prominent thread woven through our narrative and has complicated how I have perceived my sister's impaired body (Creamer, 2006) as well as my own corporeal self. I wrote:

> *A church teaching that I am reminded of in this discussion of brokenness and bodies is the communion ritual that most Christian churches practice with some regularity. Considered by many to be the most reverent time of a worship service, congregants are reminded of the crucifixion of Christ and his foretelling of that event during the Last Supper where he gathered with His disciples. Biblical accounts of this gathering report Him as saying "This is my body, broken for you" as he apportions bread and distributes it to the group. This exact phrase is commonly used within the liturgy of communion as communicants partake of the bread. Here we have the concept of corporeal brokenness as the very foundation of Christian salvation. The only way to God, we were taught, was by accepting this body – this broken body, in what is often referred to as the celebration of communion.*
>
> *This muddled my thinking even more as I struggled how to think about my sister and in particular her body. Was it a temple or a shell? Was her body, in its brokenness somehow more Christlike than my own? Had my sister in some way been sacrificed when her body was broken? And was brokenness something to be celebrated just as we celebrated communion?*

Returning to the x-ray image, (Figure 9) I will point out that its utility in this particular photo essay extends beyond setting the stage, as I used it in two other works in this set. It appears as the second piece in the series but exposed to a different light source which yields a very different result. When illuminated from behind as it is designed to be viewed in medical diagnostic settings, the translucent film reveals the interior of my sister's body typically unseen. When the light source is aimed at the front of the x-ray, its opacity blocks any identifying features of a human form and instead we can only see the undulations of the plastic surface, warped by heat and age (see Appendix B, Figure B28). Of course, it remains an image of my sister's skeletal torso but in this second photograph that fact is unknowable to the viewer. The simple re-orientation of the light source I used to photograph this unusual family keepsake has allowed me to control how others see my sister. In the same way, I control the metaphoric light I shed on my sister's life as a woman with disabilities and impairments in my research and can change the way that others perceive her. Once again, I need to be mindful of the power inherent in this endeavor.

The other place where the x-ray image shows up in the photo essay *Broken bodies and piecework* is in the third of a series of collages (Figure 10) where its backlit version is matched with a portrait from years later that reveals my sister's shaved head with a sutured neurosurgery incision. The lower third of the collage is completed with a segment from her pre-school days where her party dress and footwear locate her in the mid-20th century. These collage components were randomly chosen from a group of cut up images that I prepared for this series. Following the practice of surrealist artists who coined the absurdist term "exquisite corpse" for the process, I randomly matched the components, arranged them so that they were visually congruent and then unified them in a single digital rendering. I then used each of these collages as a prompt for autoethnographic writing. The unplanned reverse chronology of the placement of the components can remind viewers that my sister's impairments spanned her entire life.

Figure 10
Exquisite corpse 3

This particular collage (Figure 10) inspired the deepest examination in the series as I was struck by the incongruity of my sister's cheerful smile with the graphic view of her surgical incision. My thoughts dwelt on her vulnerability and how this incites a level of discomfort in viewers. But what if vulnerability could be seen as a universal, inevitable, and even desired state? Kittay's (1999, 2015, 2019) work on interdependence, dependence and vulnerability suggests that people with disabled bodies can teach us to not fear, but rather embrace the lessons of trust and connection that accompany vulnerable states. It is in fact dependence that forges the deepest relationships. Taking a cue from the early 20th century originators of the artists' game "exquisite corpse" who re-imagined reality, perhaps we can begin to re-imagine disability and re-image disabled bodies as exquisite. My text associated with this collage (Figure 10) explains this further.

> *This third image in this series is actually my least favorite. It might be seen as disarming, (not just because we don't see her arms) but the combination of the stitched incision on her shaved head and the X-ray vision of her torso insinuates a trope often relied upon in science fiction or horror stories such as the one about Frankenstein's monster, where bodies or portions of bodies are patched together, radiated, or mutated. The scholarship that examines historical and cultural formulations of disabled bodies as "monstrous" suggests that the centuries-old practice of presenting anomalous bodies as frightening lives on in popular culture of today. Those with ordinary bodies may well fear the extraordinary bodies of those with disabilities.*
>
> *However, it's not just the startling unfamiliarity of a body that looks different from one's own that terrifies. It is also the vulnerability that these images present, that triggers discomfort. Annalise's wide-eyed, unselfconscious grin in the top panel seems naïve. Does she realize that she has this bloody incision on her head? The armless torso in the middle panel is quite defenseless. (For this type of X-ray a child's arms would be positioned straight up, overhead, and restrained that way) The crinolines and bobby socks in the lower panel are markers of childhood and innocence. The literature suggests that vulnerability tends to make us uncomfortable, particularly when paired with disability, as it is often associated with weakness, incapacity or lack of agency.*

My interest in using x-rays for this inquiry led to me use my sister's CAT scans as well and they show up in the piece *The persistence of* ***my*** *memory* in the Theme 4 related photo essay *Perspectives and positions* as well as the piece *Headshot* that I included in the photo essay associated with this fifth theme (see Appendix B, Figure B29). This digital collage was an opportunity to juxtapose photographs of my sister's head with two CAT scans and an x-ray of the same area of her body as contrasting elements. Beyond the exterior/interior questions this piece might pose, the ways that these two types of images construct my sister's agency are also vastly different from each other. Much has been written about the medical gaze (Foucault, 2003) and how medical practices tend to objectify individuals with disabilities, often discounting the expertise that comes from living in a body with impairments. In *Headshot*, (see Appendix B, Figure B29) the x-ray image in the bottom half of the assemblage shows a side view of my sister's skull and torso, as well as the technician's hand. While it is understandable that a medical professional was enlisted to keep my young sister still during this x-ray, the sight of a spectral hand holding her chin is a reminder of the many times she must have been restrained, held, poked, prodded and invaded while her body was examined and measured in the service of an accurate diagnosis. The diagnostic pictures remove any possibility of reciprocal regard, and while I am grateful for the technology that saved my sister's life more than once, I also recognize how often it reduced her to a collection of digitally dissected parts.

My tendency to deconstruct my sister's identity in order to understand my own can be countered by time spent in synthesis, in an attempt to recognize the interplay of signifiers in our two lives. It is also crucial to recognize that identity is not a static state, but rather a "process of positioning…and shifting identifications"" (Hall, 2017, p 37). The narratives that delineate my sister's life and my life related to hers include all of these headshots, curly and shaved, hidden under a kerchief or wig, and exposed in radiographic views. I do not wish to co-opt my sister's stories, yet in the process of my investigation, I hope to present them in a way that gives her some opportunity to "stare back" (Fries, 1997).

The last piece in this series is the assemblage *Unboxing* (Figure 11) and is based on the work of mid-20th century artist Joseph Cornell, particularly the shadow boxes he put together using found objects in his collection. Although Cornell grew up with a disabled sibling it is unclear if he ever investigated his brother's identity or his siblinghood in his work (Solomon, 2015). Still, the idea that a group of seemingly unrelated found objects could be presented together to convey a theme inspired my attempt at this art form in my own investigation into siblinghood. To be fair, most of the objects I used were already in my sister's collection, so my curatorial skills were not challenged, but hopefully my intentional placement and interpretive commentary clarify that this is not a mere showcase of my sister's stuff. Rather, the work is about how I have understood myself in light of the relationship I had with my sister. For example, the element of a closed leopard print container proclaims my sister's right to privacy that my investigation should honor. The fading tulip near the display of her cremated remains are clear markers of the brevity of life, but also speak to my sister's very real embodied existence. Her desire for romantic love was marked in the many Polaroid snapshots she collected of male friends, such as the one included in this assemblage. But its juxtaposition to the chunky, child-like string of beads hanging on the right side of the box speaks to the societal tendency towards infantilization of individuals with cognitive disabilities (Gill, 2015) and the presumed incapability of my sister to enter into a mature love relationship. Although this collection of objects forms an ostensible shrine or retablo to honor my sister's memory, my inclusion of the piece in the photo essay for this project was an attempt to problematize my memories of her as well as my sibling identity narrative. That is, I have to check my own tendencies to reduce her, to compartmentalize her, to box her in, which perpetuates an injustice that often accompanies the label of disability and I want to resist that trend.

Figure 11
Unboxing

Summary

The autoethnographic and artistic products that I created in this inquiry have yielded insights into my identity formation as impacted by my siblinghood with a woman who had impairments and disabilities. I launched into this investigation from the groundwork laid by other sibling memoirists described earlier in this document and whose insights directed my initial explorations. My process of data creation was more recursive than linear and thus the themes that arose in my data are related to but not equivalent to the themes I identified in the other life story products that I reviewed. The next chapter describes how my work is situated in relation to these other products.

Chapter 7 - Discussion

This chapter will situate my work in the larger body of sibling memoir products that I have previously analyzed as well as theoretical perspectives that have informed this inquiry. In this chapter, I will point out new ideas, similarities, as well as themes from other sibling work that did not emerge in my texts and images, and thus answer my 4th research question, "Where is my inquiry situated within the larger body of knowledge about sibling disability?

As I pointed out in Chapter 6, the prompts I originally intended to use to produce my autoethnographic and art-based data came from my analysis of the work that other sibling memoir-makers have done. However, as I began to make art related to these themes and as I perused my extant photo archive, I recognized that my identity work would more naturally fit a slightly different taxonomy and thus the themes that emerged from my data, as outlined in Chapter 6, resonate with, but are not equivalent to the themes I identified in other sibling texts/products. I recognize this as a strength of arts-based and autoethnographic methodologies, as this freedom allows for deeper and less-formulaic conclusions.

New/different ideas that emerged from my work

Epistemology of impairment and/or disability

My initial autoethnographic exploration was directed by the theme of grand narratives and counternarratives about sibling disability that I identified in my sample of sibling products. As I searched for ways to display or portray some of these narratives in my own work, I recognized that in addition to the scholarship I have engaged with about these ideas, I also rely on an interior barometer to gauge how sibling stories feed narratives. This measurement standard has been a significant component of my identity and I came to realize that is derived from the unique knowledge I have because of the proximity I have had to my sister's lived experience with impairments and disabilities. My curiosity about how or even if this kind of knowledge is experienced by other siblings of individuals with disabilities led me to create the photo essay entitled *Epistemology of an astrocytoma*, described in Chapter 6.

None of the other sibling stories that I investigated for this project overtly identified an epistemological foundation generated by their siblinghood, so in that way this finding is distinctive to my inquiry. Others have written about epistemologies that come from lived experience of disability and are identified as components of self-identity (Carlson, 2010; Garland-Thomson, 2018; Wendell, 1996) or parental identity (Kittay, 2019) but few have been associated with the distinct knowledges available to siblings of individuals with disabilities. One recent sibling account (Ikonen, 2022) reveals how a sister discovered the value of probing her autoethnographic texts using "sonic analysis" (2021) as she recognized the particular knowledge that she has access to because of the relational proximity she has to her brother with disability. Ikonen considers the aurally based epistemic formulation that was fostered by being with her brother as instructive to others; to those who are committed to greater understanding of individuals who communicate in atypical ways as well as researchers who may now engage in various listening practices in their inquiries (2022). The identification of a specific knowledge available to Ikonen (2022) because of her siblinghood signals to me that my unique way of knowing because of my own sororal relationship is valid. I consider this theme to be the most impactful finding of my inquiry and deserving of wider and broader future investigations.

Narrative shape: Timelines twist into Möbius strips

One advantage of using photography, photographic assemblage, and photo-elicitation as the media for my investigation is the freedom I have to present my narrative(s) in an achronological fashion. While the text-based sibling products that I reviewed frequently rely on a traditional linear chronology to tell their stories, the visually-based sibling products in my sample tend to not be linked to any timeline. However, because my art is research data that is accompanied by autoethnographic text, temporality could be incorporated into my narratives, even if chronology was not. For example, some of my text explores the anticipated death of my sister and how she seemed to have a schedule of her own that veered from the expectations of her loved ones and the hospital staff. This finding enabled me to then explore the concept of productivity vs. wasting time and I subsequently created a new photo essay entitled *Nevertheless, she persisted* that portrays how dis/ability identity is often constructed around ideas of productivity. In my autoethnographic writings associated with this set of images I came to understand my own relationship with productivity and could better understand my narrative identity as I then re-wrote that story. Time is present in my work, but the timelines I may have originally encoded in my memories become twisted back onto themselves as I experience moments of realization and deeper understanding. In this way, my narrative identity is akin to a Möbius strip (Figure 12) as my self creates stories, which in turn create my self (McAdams & McLean, 2013). This recursive process is another unique finding in the genre of sibling disability memoirs and is likely possible because I coupled visual with text-based data in my work. This speaks to the goodness of fit between my research questions and chosen methodology and could encourage other researchers to use similar pairings.

Figure 12

Mobius strip fashioned from all images in my data

Technical differences: Manipulating family photos vs. taking new ones

As I described in Chapter 6, I modified my original plan to take new photographs to explore my research questions and broadened my techniques to include assemblage and archival family photographs as well as creating new images for this project. I reiterate that these methods are a more congruent fit with my desire to emphasize my sister's presence in this project and my adherence to the narrative nature of my findings vs. engaging in reportage. It is important to note that I changed this plan as a response to the autoethnographic work I allowed myself to dwell on/in and as an example of the recursive nature of arts-based research. For example, in the image entitled *Selfie?* (Figure 13) from the photo essay I created about interdependence, I combine a new photograph with a digital implant of a family photo. My initial attempt at a photographic response to the prompt of "interdependence",

Figure 13

Selfie from the photo essay about interdependence, *Who am I without you?*

included a self-portrait holding some sort of image of my sister. As I thought and wrote about mutuality and the connectedness between my sister and my identity, I considered the concept of the selfie and thus thought to include my cell phone in the image because of its association with taking a selfie. This evolved into a search for an image that I could digitally paste onto the image of my cell phone screen, and I chose a family snapshot of my sister and I when we were very young. Finally, I decided to entitle this assemblage *Selfie* but point out in my accompanying statement that it is not the slightly out-of-focus contemporary image of me that is the selfie, but rather the snapshot depicted on my phone screen that is the true self-portrait of me because it is literally and metaphorically focused on a snapshot that captured my sister and me in mutual regard. My self-portrait is more accurate when it includes the dynamic of my sibling relationship.

The images created by the sibling artists I reviewed for this project include all newly created objects without mixing in family photographs. Although Beverly McIver references photographs to make her oil paintings (Jordan & Ascher, 2011) and Stahl uses a variety of diagnostic film products for her prints (2015) none of the artists mix new and old photographic images. Hamovitch (2004) and some of the text-based memoirists do include still photographs within their work, however there is no intentionally placed assemblage that includes new and old images in their art. My decision to mix contemporary images with family photographs, or to modify family photographs to respond to thematic prompts is a technical hallmark that is uniquely mine in products about sibling disability.

Idiosyncratic metaphors

The sibling memoirs in my sample make use of a wealth of metaphors that I discuss in earlier chapters, and it is not unusual to rely on this type of narrative device for powerful and effective communication. In this project though, my particular choice of metaphorical language may be seen as unusual even within the realm of evocative writing and this is indicative of my distinctive approach to identity work. One of the most well-developed metaphors I use in both text and visual data is the celestial likeness of my sister's original brain tumor. I entitled the first photo essay in my collection *Epistemology of an astrocytoma,* as I reference the specific star-shaped tumor that was the cause of my sister's medical problems and resultant impairments. Just as this star gave rise to my sister's specific lived experience, I refer to the epiphanies it brought me to, as well as the other tumors or celestial spheres that it attracted into our orbit and the lessons that they communicated. My use of astral comparisons extends to the gravitational pull that my sister (and her knowledge) had on all members of my family, and particularly me as I compare myself to the moon that reflects my sister's starlight. The interdependence of this set of metaphors helps to highlight the relationship between my sister's experience and my own and it is in this space between us that allows me to explore sibling identity.

Additional metaphors emerged from my visual data as I created it which is a notable benefit of engaging in arts-based research (Casey & Murray, 2022). For example, as I responded to the prompt of "interdependence" and chose a family photograph of me standing on a beach, releasing my sister's funerary ashes into the wind, I got the idea to digitally superimpose a photograph I took of a whelk shell with its spiral geometry onto the figure. It was not until after I edited this image that I came to the understanding that the cyclical shape of the seashell was an apt representation of the narrative shape of my investigation. The juxtaposition and orientation of my feet in the image seem to indicate the metaphorical path that my inquiry has taken, and my description of beachcombing and picking up small treasures resonates with the process I have adopted for this project. The visual medium alone may not have communicated these ideas, but the autoethnographic texts accompanying the image allowed these concepts to be revealed to me as I wrote. My hybrid methodology is again affirmed by this observation.

The unusual metaphors I use in the piece entitled *Nevertheless, she persisted,* also grew from the process of artmaking as I created photo fabric yarn and crocheted a partial chain with it. This is probably the least accessible work in my collection as it is so far afield from the other sibling works I reviewed in both medium and theme. I dare say that I am the only customer who has ordered fabric with the repeated image of a person on their deathbed from the custom printer and am likely the only sibling memoirist who has used that medium to explore issues of disability and how quality of life is measured in our society. It is because of my sister's singular life that I had to make such a singular work and am amazed by the number of realizations I had throughout the time it took me to craft this piece. Just as there is no one narrative of sibling disability, using a variety of methodologies to investigate identity narratives supports a greater breadth and depth of understanding the impact of sibling disability.

How my work resonates with other sibling memoirs

My findings also resonate with ideas that others have expressed, and many of the themes I identified in other sibling works emerged in my data too. A question might arise about how reading other sibling stories could potentially dictate the themes I find in my own work, and I have already identified that I did in fact use ideas from others' products to prompt my art for this project. However, the unrestricted artistic process and reflexive writing I did resulting in memos and autoethnographic texts brought me insights that veered away from the themes I had already identified in other sibling memoirs and yielded results that I discuss in the preceding section. Still, I recognized some of my experiences in the works of others which may indicate certain tendencies among artists with disabled siblings; I summarize these here.

Counternarratives

By definition, the grand narratives that exist about disability are ubiquitous in cultural products (Mintz, 2009) and although I did identify some of these in the sibling works I reviewed, the presence of counternarratives to popular tropes was more notable and recognizable in their work as well as my own. The most easily recognized is the resistance to and rejection of the medical model of disability as this is at the heart of the social model of disability. In Kannel's short film, *Bumblebees* (2015), the narrator reads his sister's script about his successful life and how he has defied all odds set by medical practitioners when he was born. This declaration that deflates an overblown medical opinion speaks to the expansive view that Kannel (2015) has of her brother and highlights his full humanity rather than minimize and equate him to the itemized list of dysfunctions compiled by doctors. In my photograph entitled *Annamorph*, (see Appendix B, Figure B25), I too explore this counternarrative as I warn against even my own tendencies to reduce my sister to her disabilities or impairments. I created this image with trick photography and used a visual pun about dimensionality that serves as a metaphor for reductionistic vs. expansive thinking about disability.

I also challenge the common narrative of disability as brokenness in my series of images in the photo essay entitled *Broken Bodies and Piecework*. Although the underlying theme to this photo essay is primarily about how my sister's lived experience of disability helped to construct my identity, I also explore how her life had been compartmentalized by the medical processing she went through and the objectification inherent to those practices. In my analysis of this series of photographs and assemblages I decry my own tendency to reduce her to a collection of pieced together characteristics in order to serve my inquiry. Similar to Stahl's reappropriation of her sister's diagnostic MRIs in *Habitus* (Stahl, 2018), I too resituate my sister's medical images to craft a different narrative that does not serve the mechanistic medical tropes about disability. Our respective reinterpretations of images more typically seen in radiologist's offices restores agency to our siblings as we return renderings of their bodies to them via our work.

It is Stahl's (2020) desire for her sister to be understood in her full humanity that drives her artistic products and this trend towards advocacy shows up in many of the memoirs that I reviewed for this project (David B., 2005; Hamovitch, 2004; Hershon, 2010). Our insider sibling perspective has allowed us a more complete understanding of our sisters and brothers and the realization that they have their own point of view, even if not easily communicated to people who don’t know them as well. In my series entitled *Perspectives and Positions* I include an unmodified family photograph that I took of my sister when we were both teenagers. I chose to include this image as it shows my sister readying herself to take a photograph with her instant camera and helps me to observe that she had a unique point of view, worthy of recognition. I again identify my own past failings to see her as someone who also composed and collected pictures. It is because of this self-knowledge that I can strongly resist the common notion that individuals with disabilities, and particularly intellectual disabilities, are not capable of developing a rich and singular perspective of the world they indwell. My sister and others deserve in the least to be understood as complete human beings, with their humanity undiminished by impairment or perceived disability.

Roles and Positions

The imbricated relationships between siblings defy simplistic definitions and of course every sibship has its own specific dynamic as well. But I did recognize some of roles that my sister and I performed when I looked at the sibling stories in my sample that are familiar because of our shared experience of sibling disability.

The most striking of these for me is the term “big little sister”, coined by Garvin (2010) and used to describe the liminal position that a younger sibling may assume as they take on responsibilities to care for their older sibling. I too identify the constancy of my role as little sister while assuming the additional tasks of caregiving and decision making that an older sibling might more typically take on. The photo essay that I assembled about interdependence includes a framed diptych of two family photographs of my sister and myself interacting with each other (see Appendix B, Figure B10). The two snapshots were taken decades apart and the accompanying autoethnographic text explores the idea of the additional role of big little sister that I evolved into, while maintaining my status as little sister. This idea really took hold as I further explored what it means to have an additional relational status with my sibling and went so far as to describe it as being a third sister. This then led to ideas even further afield than Garvin's original terminology (2010) when I embraced the Haudenosaunee story of the Three Sisters (Oneida Indian Nation, 2020) as it informed my role as big little sister and our interdependency. This then led me to adorn the frame around the diptych with seeds from corn, bean, and squash plants which are the metaphors employed in the Haudenosaunee legend. This is a good example of how a sub-theme that I identified in my literature sample directed my initial photographic assemblage, and how my autoethnographic writing and recursive artmaking then responded in an original way.

Another role that I identified with when examining other sibling stories was what I code as "embedded reporter". Just as Greenfeld (2009) describes how he moves between being above the action and being in the thick of it, I examine the variety of positions I am in relative to my sister's life in the photo essay entitled *Perspectives and Positions*. I navigate between the privilege afforded me by my proximity to my sister that allows me to get the "scoop" and playing "second fiddle" to her needs and centralized location in our family. McIver identifies her sister's key position in their family in both verbal (Jordan & Ascher, 2011) and visual media (McIver, 2002) as she generally paints portraits of her sister taking up most of the space in the center of the canvas. Greenfeld's (2009) vivid description of how the "room tilts" (p.10) towards his brother resonates with McIver's statement that everything "centered around" her sister (Jordan & Ascher, 2011). I tap into both of these ideas in my photograph *Front and Center* that uses digital distortion to exhibit a fisheye version of my office space with my sister's image enlarged and in the exact center (see Appendix B, Figure B23). As the viewer falls in to this image, they come face to face with a family photograph displayed on my desktop computer of my sister caught in a moment of joy as I peek out from behind her. This image communicates that even though I report from my embedded position, my sister remains the focal point.

Photographs that I took in my office for this project such as *Front and Center* establish a clear link between my scholarly work and the narratives that surround my sister. In this way she can be understood as my muse or inspiration for my art and my work. I dare say that all sibling artists in my sample could identify with this role as they have all created products that have arisen from their siblinghood. A muse is generally associated with artistic inspiration and can have a broader impact than a strictly objective warrant associated with traditional research. In Millett-Gallant's (2017) discussion of how an individual with intellectual disabilities becomes a muse for his aunt photographer Susan Page, she explains the complicated relationship between artist and muse. She says "…having a muse leads to discoveries that always include the discomfort of becoming lost and the process of painful disillusionment. Sometimes, muses cause the viewer of their images, not just the artist, to become moved, altered, and transformed." (Millett-Gallant, 2017, p.25). This idea is quite congruent with the goals of my project as well as the other sibling artists that I have considered. Unlike a constructed model in service to perpetuate "inspiration porn" (Young, S., 2012), or to be a tool that simply exists for another to use, a sibling with disability can be a muse for an artist willing to be vulnerable as they excavate sometimes uncomfortable truths.

Technical similarities

Autoethnographic texts are a form of life-writing, but they are decidedly not memoir and therefore don't rely on the same narrative techniques such as those used in the text-based sibling products that I reviewed. However, some of the family photographs used on the book covers and included within those memoirs are reminiscent of the family snapshots that I incorporated into my data collections. In all cases, the photographs we used help to contextualize our stories with cultural markers such as fashions and relational cues about other family members. The iconic mid-20th century crinoline-flounced dress that shows up in my image *Exquisite Corpse 3* (see Appendix B, Figure B32) is almost interchangeable with the dress worn by Dougan (2009) on the cover of her book (see Appendix A, Figure A11) and would fit right in with the images on the covers of the memoirs written by Combs (2017) and Wagner & Spiro (2005) (see Appendix A, Figures A2 and A1). This type of shorthand can cue the reader/viewer about the temporal context and set up expectations about the cultural trends that have impacted our stories.

Another technique that I use in my work is to include images of myself within the pieces, either as self-portraits or captured by another photographer. This is particularly salient for this project as I am exploring the relationship between my sister and myself and how her lived experience impacted my identity formation. Other sibling memoirists use this strategy as documentary (Hamovitch, 2004; Wagner & Spiro, 2005) and/or as commentary (McIver, 2002).

The composition that McIver uses in works such as both versions of *Embrace* (2005, 2005), (see Appendix A, Figure A12) and *Me and Renee Dancing* (1997) uses space and physical interaction between the figures (hugs and dancing, respectively) in an intentional way to represent emotional connection. In my piece *Nevertheless, she persisted* (see Appendix B, Figure B14) I too show physical connectedness as I am shown placing my hand on my sister's forehead as she lies in a hospital bed and in the work *Front and Center* (see Appendix B, Figure B23) my hands grasp my sister's shoulders in a hug from behind as I place my head right next to hers. Although I didn't take either of these snapshots, I modified each as I incorporated them into images that answered the research prompt.

I also created a collage that involved more artistic manipulation to emphasize the interdependency between my sister and I entitled *Help!* (Figure 14) which I included in the series called *Who am I Without You?* . This piece incorporates cutout photographs of my sister's head, affixed to cutout photographs of my body, clad in a shapeless hospital gown and posing to mimic a record album cover from our childhood in the 1960s. My decision to use my own body as a stand-in for my sister was dictated by her absence as she had passed away before I created this image. However, it serves a purpose here to communicate even more strongly how my sister and I are interconnected and how our identities each grew around the other. Although quite divergent in technical application, Stahl's artistic combination of renderings of her own body with diagnostic imaging of her sister's body conveys a similar finding about interdependency in her series *Habitus* (2015). Her use of MRI views of the interior of her sister's body in this collection are as unusual and thereby effective as the MRI and x-ray images that I use in works such as the *Exquisite Corpse* pieces (see Appendix B, Figures B30, B31 and B32) as well as the digital collage entitled *Headshot* (see Appendix B, Figure B29). As my intentions for those radiologic views veered towards a different theme I did not include my own body therein but recognize the power in reclaiming medically objectivized images of our respective sisters' bodies and using them for artistic purposes.

Figure 14
Help!, a photo collage from a series about interdependence

My collected work for this project is perhaps most like Stahl's work as she identifies her practice as arts-based research (2018). As research, vs. memoir, picture, or documentary, there is a clear intent to discover truths and to disseminate them as well as methodology that dictates the practice. In this way, Stahl and I both present our work before a scholarly audience and expect a level of scrutiny that is different from that given to other cultural products. My work also resonates with Cocco's photo essay *Monia* (2016) in that we both rely on photographic still shots to communicate deep ideas about our siblings, disability, and our relationship to these. We also both identify our collected works as photo essays which establishes an expectation that the interconnected works will be viewed in relation to each other. This intentional curatorial process adds an additional layer of meaning to the body of work when taken as a whole.

What did I leave out? Omissions

While there are storylines and imagery in the reviewed sibling memoir works that did not emerge in my own inquiry, it is perhaps more salient to point out what I knowingly omitted from my data-making that is present in many of the other sibling stories. In earlier chapters, I discuss how other memoirists (Combs, 2017; Garvin, 2010; Greenfeld, 2009) craft a narrative identity within their products that includes past iterations and future expectations of their family life and how having a sibling with disability has impacted the shape of their family narrative. I too have explored these concepts, but in earlier texts (Franits, 2011; Franits, 2019) where I focus more on my relationship with my mother, her parenting of my sister and my own motherhood and how each of these has been impacted by my sibship. Although clearly a feature of my identity story, perhaps it did not show up in my artistic response to the current research questions because of my previous excavations, thus disqualifying it as newly discovered or generated knowledge. While I don’t deem my previous writings about this as exhaustive, my desire to reiterate those findings is supplanted by the warrant for my current research about other influences.

In addition**,** it is a more ethically fraught process to research a topic that by definition would include revelations about my child and/or my husband if I were to consider the narratives surrounding my own motherhood for this project. Barbour's (2004) observation that the desire to protect the privacy of one's child often supersedes autobiographical curiosity, thus leading to a "scarcity of reflection" (p.74) about familial narrative shape-makers. I do wish to protect my child from the variety of narratives that my disclosures could construct that might impact his identity going forward. It might seem that I have chosen to expose the lived experiences of my sister and other family members more freely because they are no longer around to counter my claims; I cannot fully distance myself from this assertion. However, it is not that I discount deceased family members' right to privacy, nor do I consider that they bequeathed their stories to me. Rather, it is the finite nature of those stories that allows me to use them as sources as there is a built-in limitation. My narrative identity may not be stable (Baglieri, 2019) as it is reshaped each time I retell remembered stories, but those stories have all been written. My parents and sister cannot contribute new material to the collection, although I can continue to reframe these memories as I proceed in my investigation of their impact. The omission of themes about my own motherhood has also allowed me to establish boundaries around this current project in order to keep it a manageable size and see it to completion.

How my work fits in - Temporal contexts

Using moderately broad inclusion criteria, I consider myself a peer of the authors and artists who created sibling works that I reviewed for this project. That is, I am an American who grew up in the late middle 20th century whose sibling was identified as disabled from an early age. This places me in a time span from when the civil rights of individuals with disabilities were marginally recognized through to our current moment when federal legislation theoretically insures equal opportunity for people with disabilities in public education, employment, public facilities and other areas of historical discrimination. Medical technologies such as treatments for the type of tumor that my sister had have also evolved in extraordinary ways although the ubiquitous medical model retains a firm grip on how disability is constructed. Children born today with the same diagnosis and constellation of impairments that my sister had would have a decidedly different experience than what she lived, and any siblings involved would be impacted differently as well.

Most of the themes that arose in my inquiry are contextually bound in space and time although they are still salient for a contemporary dialogue. For example, in my discussion about persistence and productivity, I describe the paucity of competitive employment opportunities for individuals designated as disabled when my sister and I were growing up in the 1960s and 1970s. She wound up working in a so-called sheltered workshop where her work was neither fulfilling nor fairly remunerated. Although around in some form in the US for almost 200 years, sheltered workshops were widely recommended by educators and health professionals in the middle of the 20th century as they were seen as the only viable employment option for individuals with disabilities, regardless of an individual's skill set. These segregated environments kept people with disabilities away from public life and fed the misconception that full personhood could only be achieved by those who were deemed productive or competitively employed. Although the passage of the Americans with Disabilities Act (ADA) in 1990 ostensibly outlawed employment practices that discriminated against people with disabilities, some sheltered workshops still exist (Schwartz & Moore, 2021) and thus we do not yet have a fully integrated workforce in the US. My sister's underemployment history is clearly linked to the time and place of her life and has fueled my desire to continue to work towards increasing higher levels of integration in the work force. Although there remains a frustrating lack of parity for individuals with disabilities, today's employment prospects for people with disabilities are better than they were in pre-ADA times.

My work is also a product of the technology available today, as I have access to digital as well as analogue methods in this genre. Choosing digital photography as an expressive art form has enabled me to modify archival photographs and medical images without destroying the originals as well as combine family photographs with contemporary images in assemblage. I have also been able to access the visually-based memoirs for my review via the internet instead of traveling to view the canvases, photographs and films at a gallery or cinema or attempt to see private collections. While not the optimal way to experience art objects, this convenience has served my inquiry well as I focused on messaging about disability from the sibling artists more than their aesthetic presentation. However, I do hope to one day see these works as they were likely intended to be seen, displayed in a gallery space, museum, or theatre. This leads me to the question of who will view my own work and in what context.

Audience

My audience for this project is potentially quite narrow as its final version will serve as partial fulfillment of an academic degree and thus it is written in an academic style, as per the requirements of the institution that will evaluate its merit. But throughout the research process and particularly in the autoethnographic and arts-based methods I employed to create data, I have sought to create a text that "desires the reader" (Kim, 2016, p.112). That is, through careful application of methodology and a commitment to aesthetic presentation, I hope to capture the essence of my inquiry in a way that is accessible and interesting to any readers.

I would imagine that other individuals doing autoethnographic research would be interested in this work, particularly if investigating the impact of disability on those in its wake. The increased prevalence of using autoethnographic methods for researchers who identify as having a disability (Davies & Hislop, 2023; Kasnitz, 2020; Pryer, Hannum-Swain & Bailey, 2021) has not yet impacted investigations of sibling disability which is generally researched by social scientists without the benefit of this type of first-hand knowledge (Meltzer & Kramer, 2016). In the same way that individuals with disabilities should be primary investigators and/or active participants in research about their experiences, sibling investigations are best led by siblings themselves. Thus, I promote the use of autoethnographic methods for sibling researchers, encourage publication of this genre of scholarly inquiry, and hope that my document can serve as a template for doing so.

Scholars looking to explore issues related to disability and identity formation may find a goodness of fit between arts-based research and their inquiry as the epistemological potential of artistic expression becomes more widely recognized (Eisner, 2008). The prospect of “investigating disability through the arts” (Ignagni & Church, 2008, p.627) opens up methodologies particularly to those who would seek emancipatory types of projects that work to subvert dominant and positivistic disability tropes. I am hopeful that my project may help to make arts-based research more widely known outside of fields such as art education where it has traditionally been more commonly practiced and seen as a viable alternative to other methodologies more typically used in disability studies scholarship.

The accessibility of photography as an art form that is generally appreciated by a wide audience may also engage individuals with my project from a purely aesthetic point of view, but because my project was conceived as a hybridization of autoethnographic texts and images, the written curatorial statements that accompany each image should be available to viewers as well. The challenging logistics and unfeasibility of a display of these complete photo essays limits the prospective audience. Still, I won't foreclose the possibility of one day displaying the art I created for this project with more manageable iterations of the accompanying autoethnographic texts. The potential venue would likely dictate the type of audience my work might attract.

I suspect that the group who might be most interested in this project is other siblings of people with impairments and/or disabilities. The desire to connect with other stories that resonate with our own experiences can drive us to seek out those stories, just like I did when embarking on this inquiry. Although I have been fueled by my own need to communicate how sibling disability has impacted my identity, the recognition of "my" issues in the work of other artists has affirmed my nascent thoughts and has acted as midwife (Kim, 2016, p. 119) for my scholarship to come into the world. One way to measure my success in creating an evocative autoethnography (Bochner & Ellis, 2016) is to determine how transferable my findings are to readers. I sincerely hope that other sibling artists have an opportunity to engage with this project and will work to disseminate it in a way that is particularly accessible to them.

Conclusion and implications for future research

My investigation into sibling disability and how it impacts identity has had an exceedingly but likely necessary long gestation period. Previous iterations of this project employed different methodologies and resulted in false starts. It was not until I accepted the challenge of using a hybrid arts-based and autoethnographic approach that I was able to make progress in my labor and create the data that eventually developed into this text. I saw affirmations of this good fit throughout my data collection and analysis process and am convinced that these methods were the most appropriate way to answer my research questions.

The new knowledge that this project has generated includes the recognition of epistemological territory that is mapped out by sibling disability. That is, there is much that remains uncharted and there is much to explore by those who have lived close to disability experiences as embedded reporters and wise (Goffman, 1963) witnesses. I truly hope that my work can help siblings of individuals with disabilities see the potential to explore the particular knowledge that their lived experience has granted them. The publication of first-person accounts within a research tradition would make inroads and help to re-balance the scholarship that has heretofore been skewed in a more positivist direction (Meltzer & Kramer, 2016). I intend to publish the findings of my project in some form and hope that it reaches others who have grown up near disability so that they too work to expand this knowledge base with their own contributions. Perhaps I will develop a proposal for an edited text similar to those about mothering and disability (Lalvani, 2019; Lewiecki-Wilson & Cellio, 2011) that will give siblings an opportunity to share their particular knowledge in a published format.

I anticipate that any one of the themes that emerged in this project could yield a separate, focused investigation and as I have continued to make art related to several of these topics there is already a body of work being formulated toward that end. The topic of interdependence is of particular interest to me and am confident that I could continue my exploration into this as it has been informed by my siblinghood and other scholarship such as Kittay's (2019) philosophical delve inspired by her own family and proximity to disability. A more narrowly focused project would allow me to do some close readings of other sibling works, including both text-based and visually-based cultural products that deal specifically with the concept of mutuality as I explore connections to disability and impairment. As I have had success with the arts-based and autoethnographic methods used for this project, I will continue to rely on these techniques to create and analyze new data as I excavate deeper into the material.

I am also committed to promoting arts-based and autoethnographic methods particularly for those researching issues surrounding disability and impairment. Aptly stated by Ignagni and Church (2008), "Art can sometimes be used to trouble the embedded and taken-for-granted relations of disability. Drawing on the arts can force us to relate radically to disability in ways not easily available to us in our everyday lives." (p.631). Gaining access through this non-traditional entry-point allowed me to engage with the material for this project from an alternative point of view, resulting in different findings than what a more traditional approach would have engendered. The unexpected epiphanies and unanticipated delight that this project has brought me has thus produced an evangelistic desire to share these techniques with other researchers. Perhaps I could submit an article detailing my methodology to a journal that is focused on research methods or share the same at a conference venue.

Finally, I turn back to view the starting point of this work and see my sister acting as guide, shining a light on an unseen path, lending rhythm to my steps, ever present even in her absence. It is not an exaggeration to say that I am who I am because of her, and it is in celebration of her life that I write these words with gratitude and love.

Figure 15
Starting point

Appendix A

Images from sibling memoirs

This appendix includes selected images from the memoirs that I examine in Chapters 2,3 and 4 of this document. These images may give the reader additional insight into my discussion of sibling identity themes and medium-related expressions of those themes in the products I studied.

Figure A1
Divided Minds cover
Wagner & Spiro (2005)

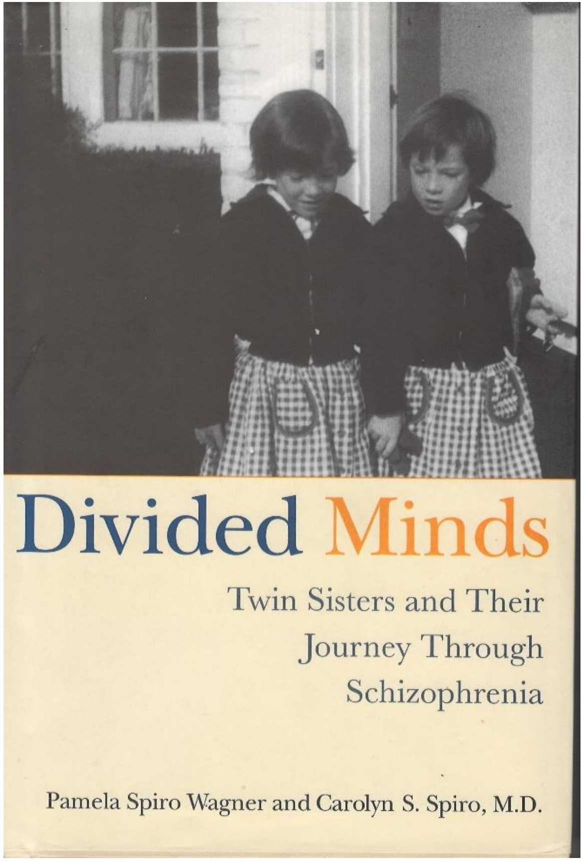
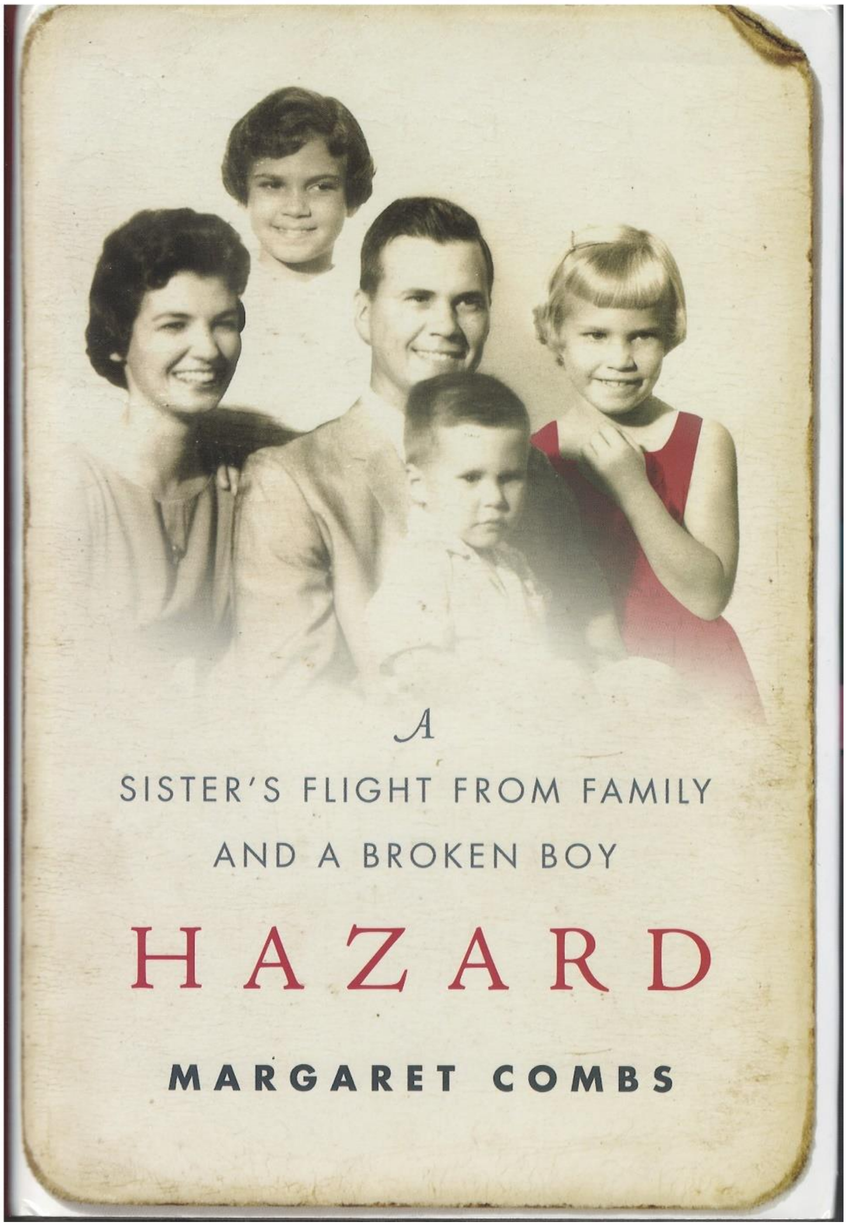


Figure A2
Hazard Cover
Combs (2017)



A
SISTER'S FLIGHT FROM FAMILY
AND A BROKEN BOY

HAZARD

MARGARET COMBS

Figure A3
Boy Alone cover
Greenfeld (2009)

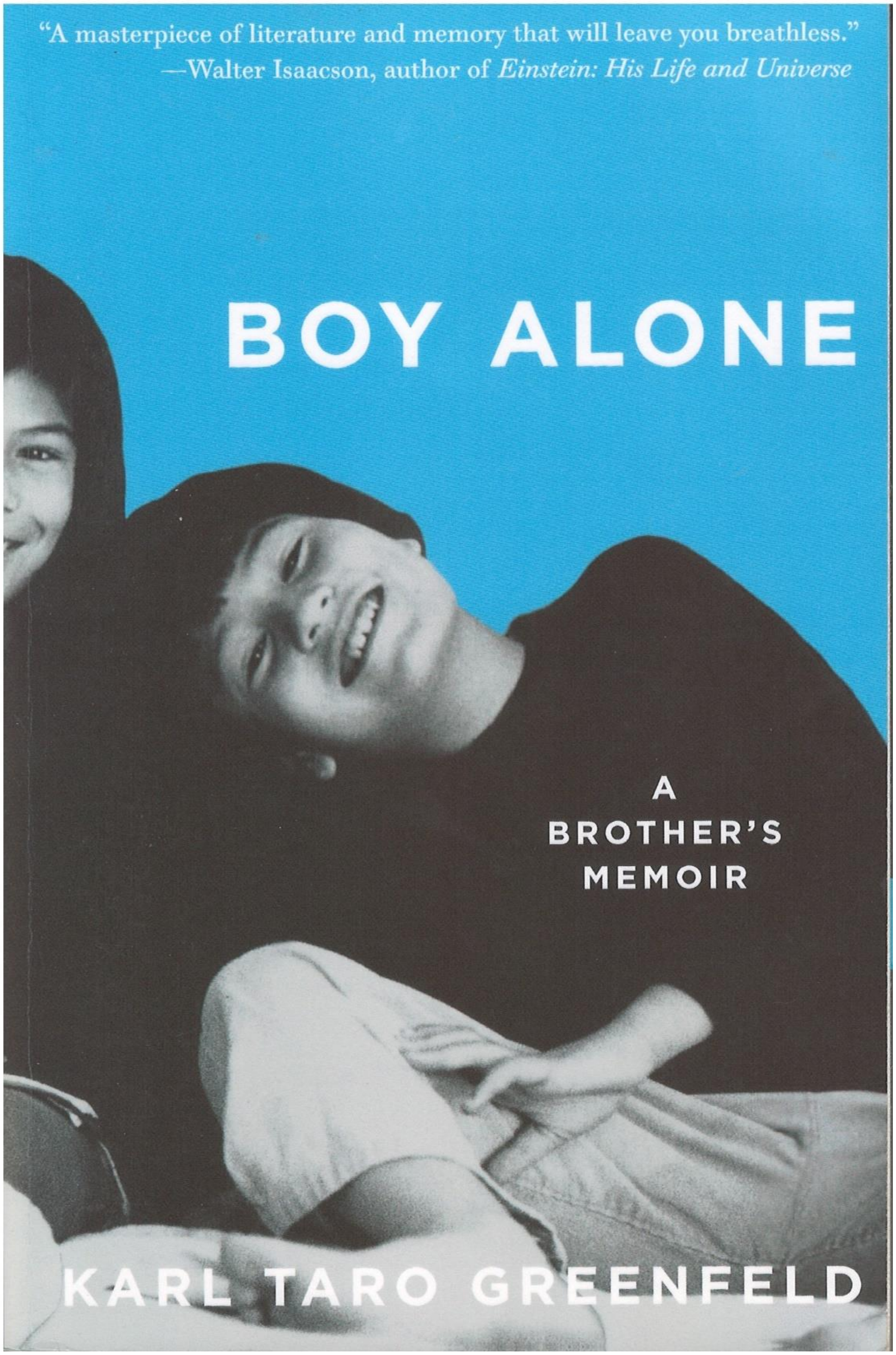


Figure A4
Monia, image 18 from photo essay
Cocco (2016)

Figure A5
Monia, image 13 from photo essay
Cocco (2016)

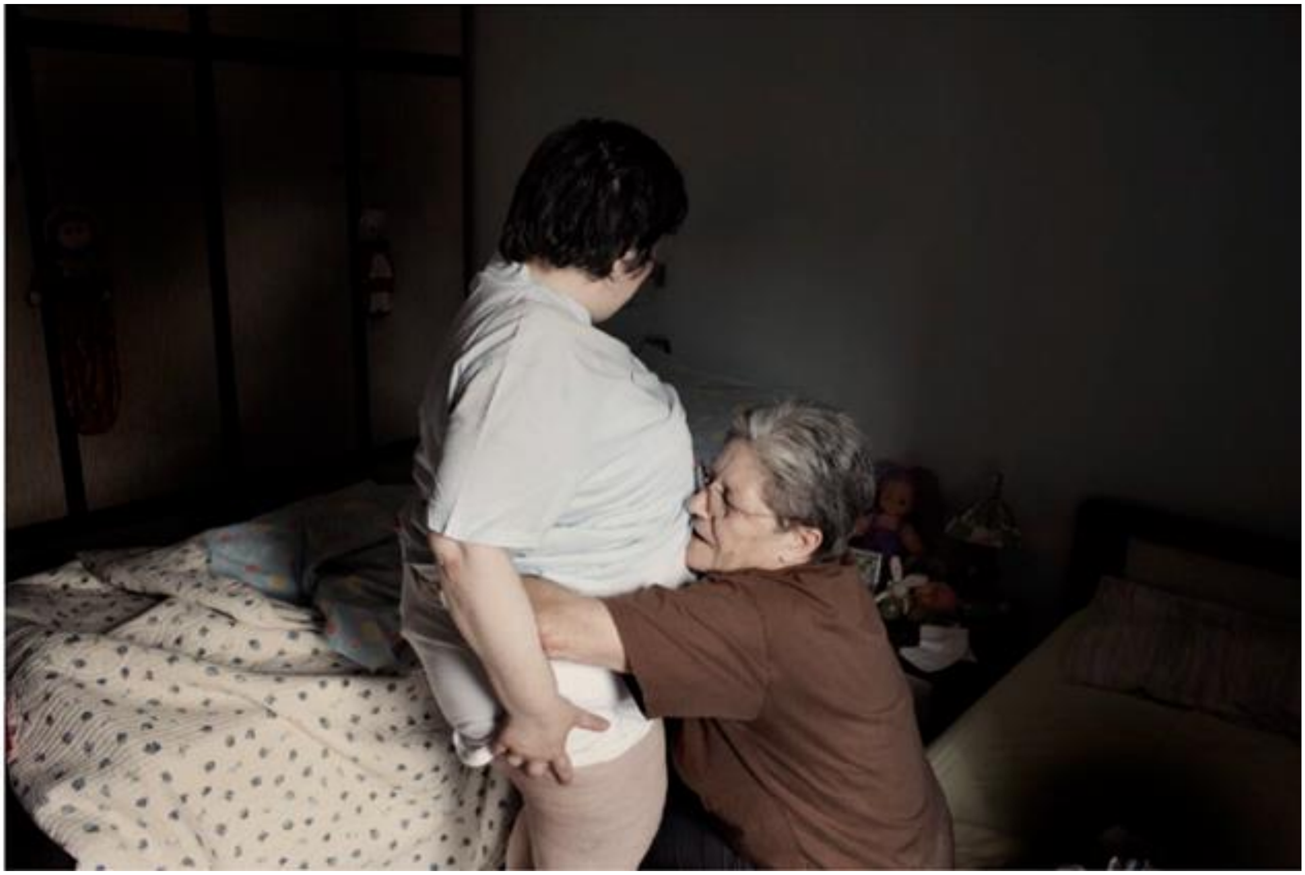


Figure A6
Monia, image 8 in photo essay
Cocco (2016)

Figure A7
still from film, *No Apology*, 1:13:30
Hamovitch (2004)

Figure A8
Can you hear my silent scream?
McIver (2004)
Oil on canvas
38” x 40”

Figure A9
Restless
Stahl (2014)
Archival inkjet on film
98" x 88"

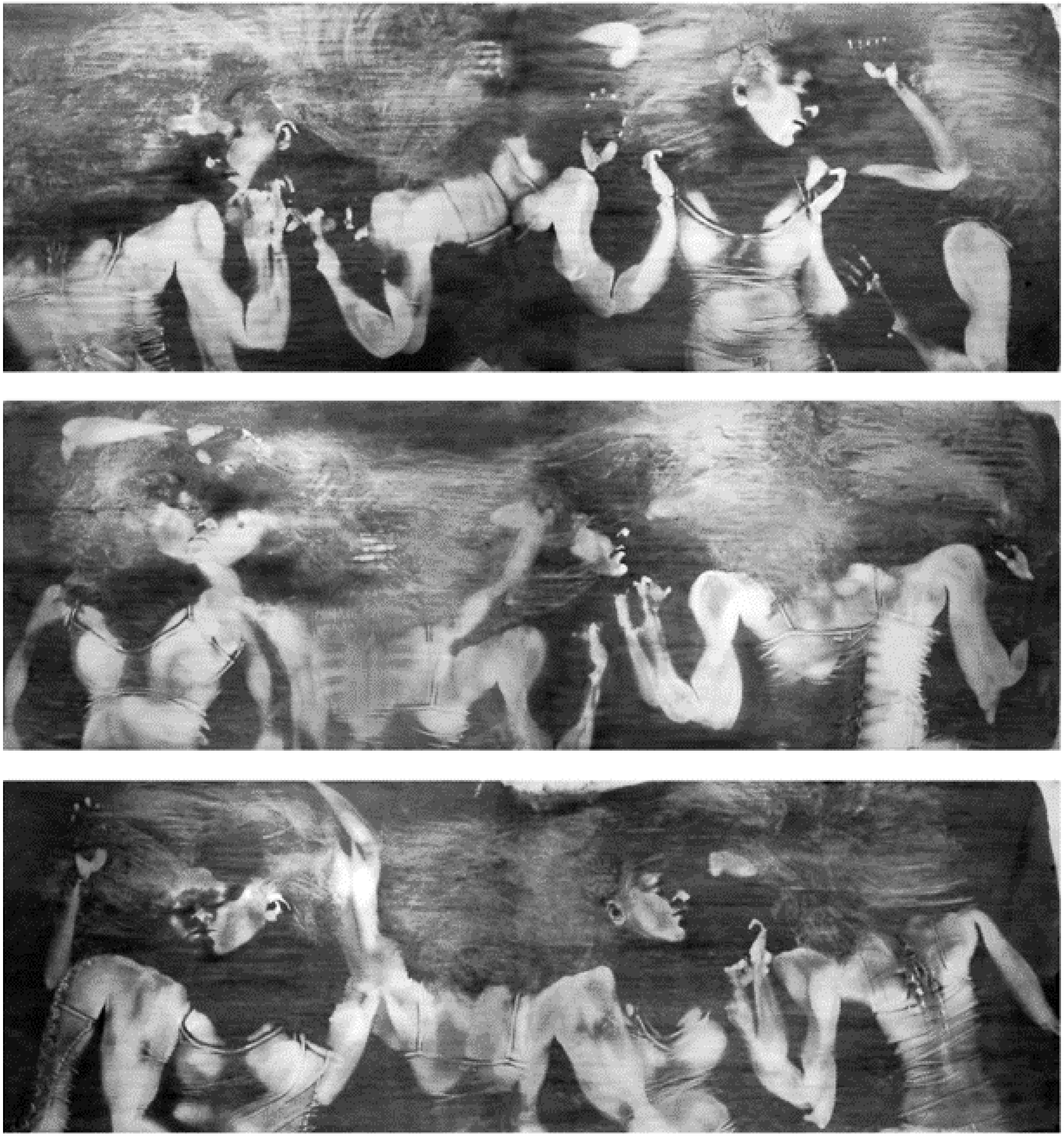


Figure A10
The Scan and the Mirror
Stahl (2013)
Stone lithography and silkscreen
22" x 28"

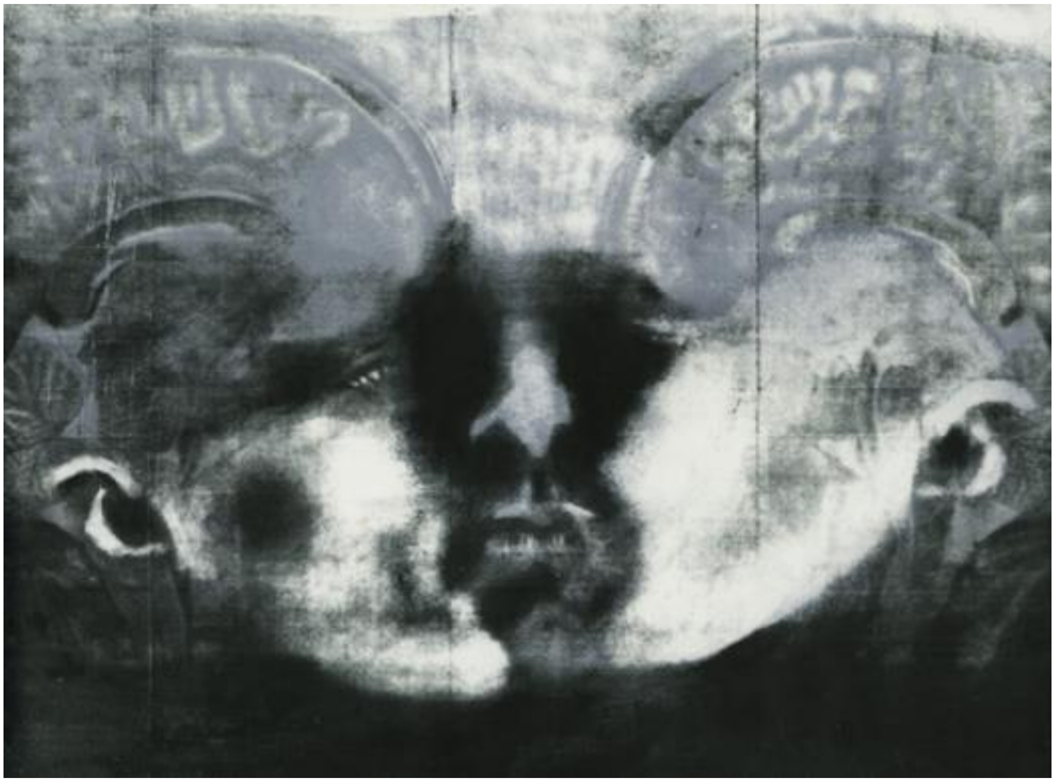


Figure A11
That Went Well cover
Dougan (2009)

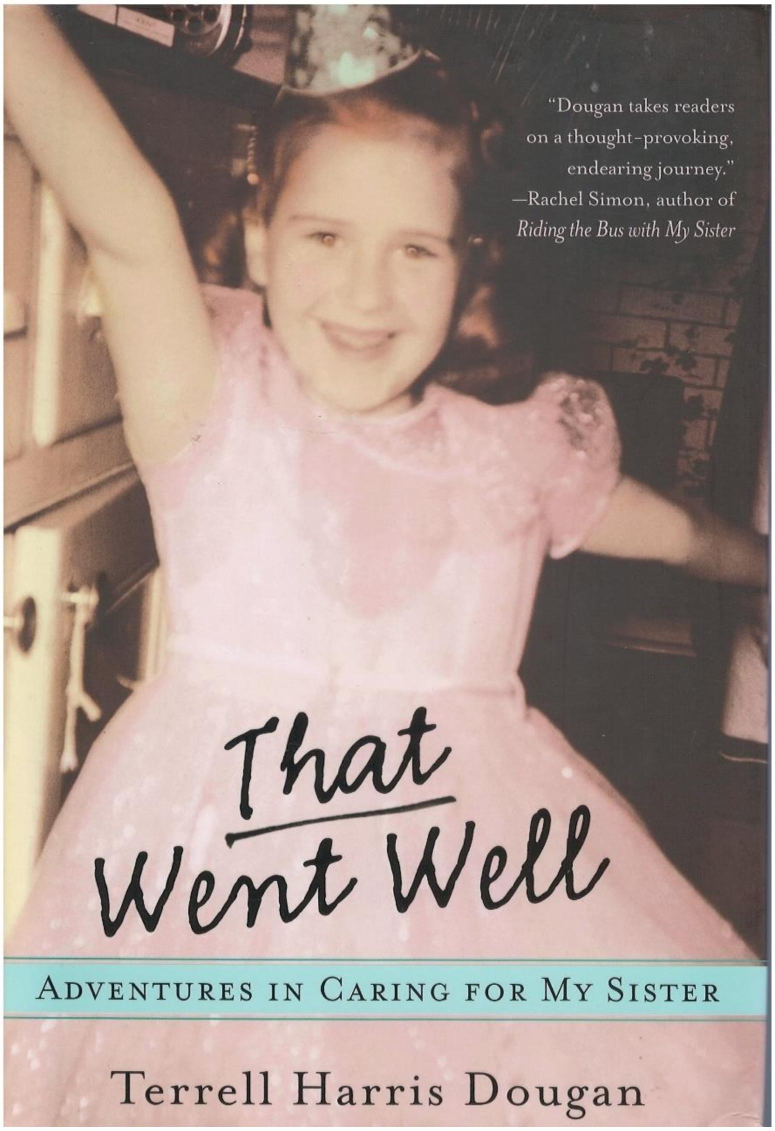


Figure A12
Embrace
McIver (2011)
Oil on canvas
48”x 36”

Appendix B

Images created as data

This appendix contains images of the art products that I created for this project. Unless otherwise noted, the medium is digital photography and I am the photographer. All images are in my personal collection. The images are presented in the order that they were arranged within my original textual autoethnographic data, but autoethnographic text is not included in this appendix.

Figure B1
Cobalt
2019

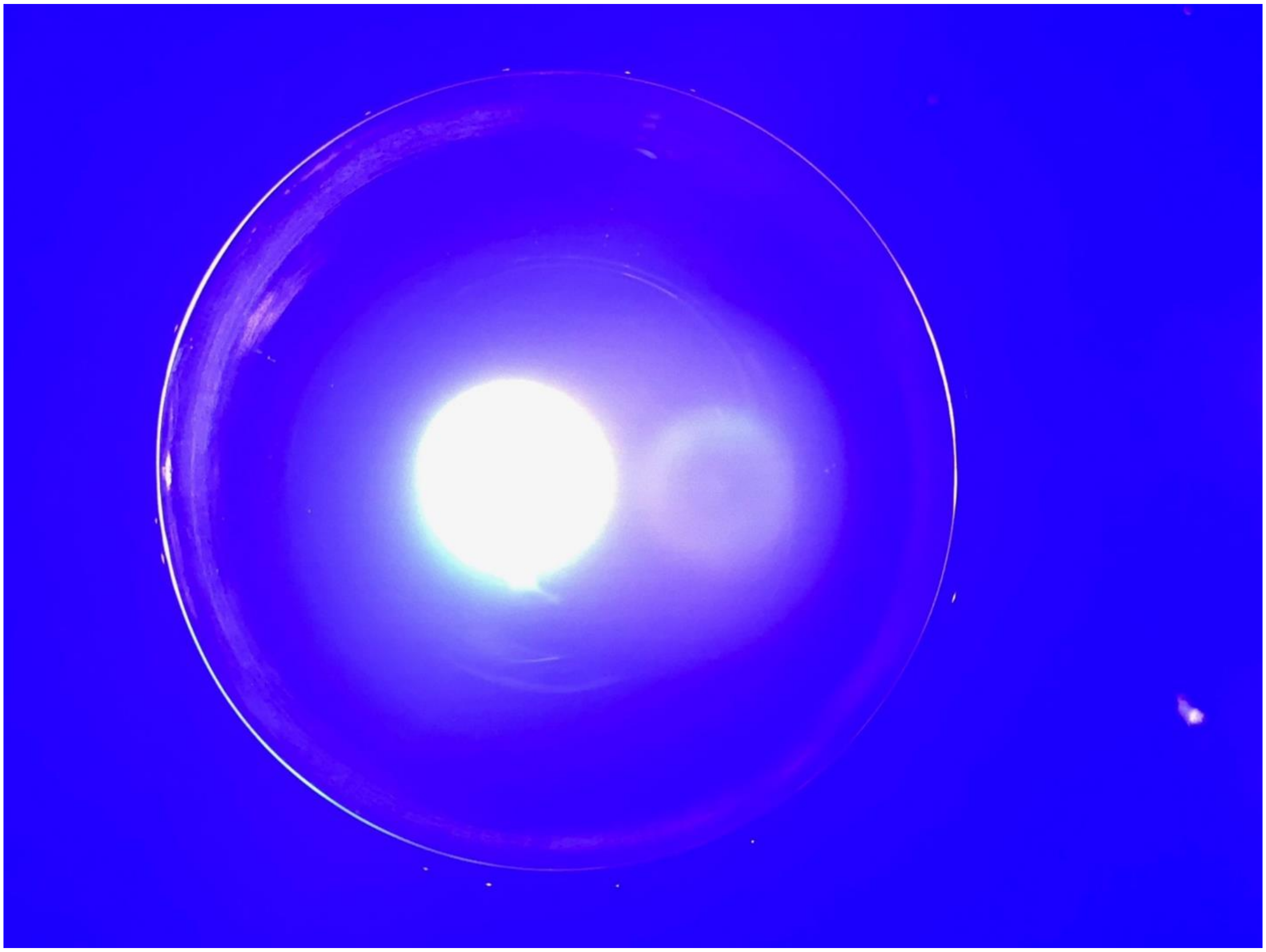


Figure B2
Stealing from my sister's plate
Family photo, black and white photographic print, 1964
Digitally modified, 2023

Figure B3
Ripple
Family photo, black and white photographic print, 1964
Assemblage and digitally modified 2018, 2023

Figure B4
Fanfare
Family photo,2009
Digitally modified, 2023

Figure B5
Starsong
2010

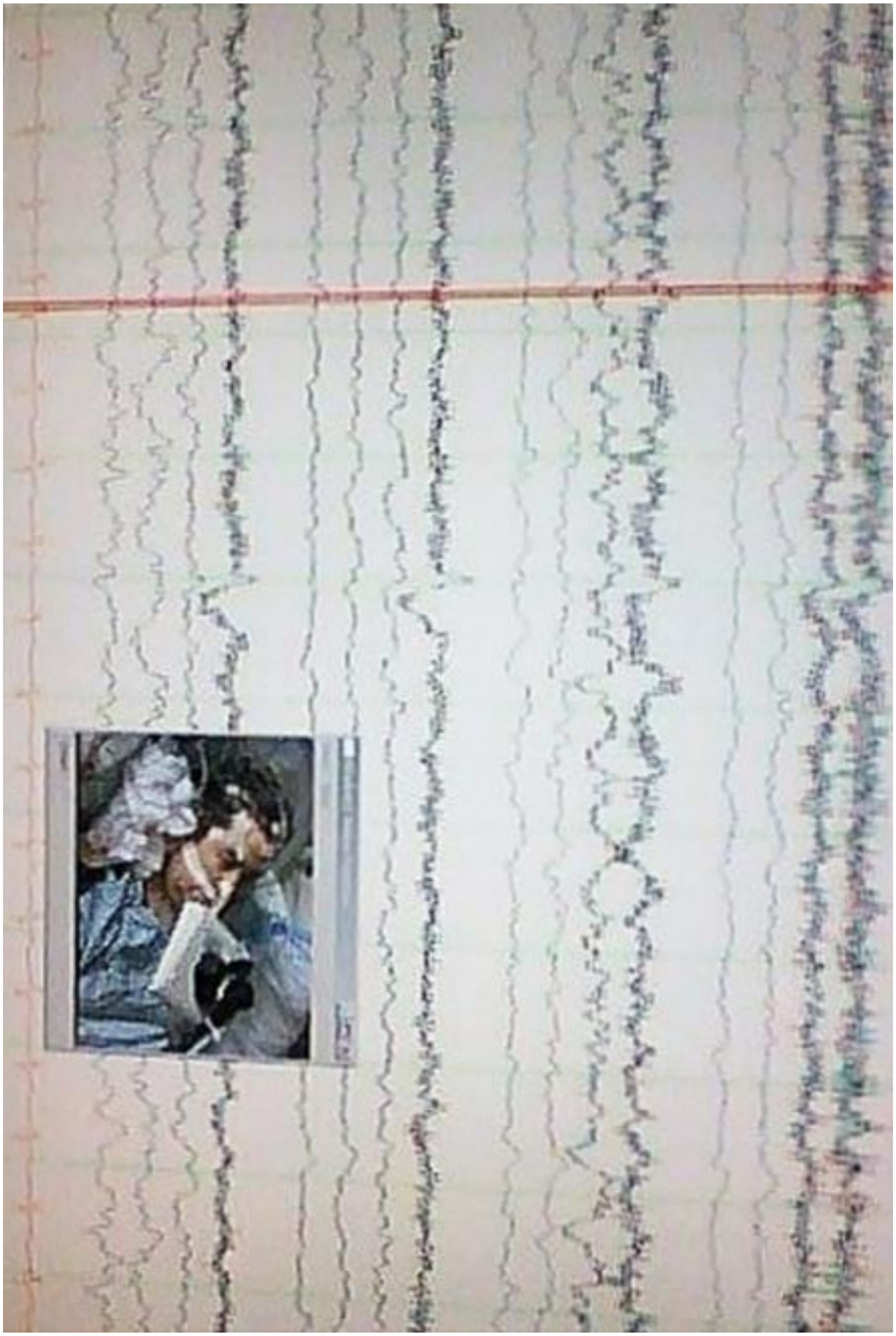


Figure B6
Co-presentation
Digital photo by Mary Ann Janda, 2016
Digitally modified, 2023

Figure B7
Influencers
2019

Figure B8
Selfie?
2023

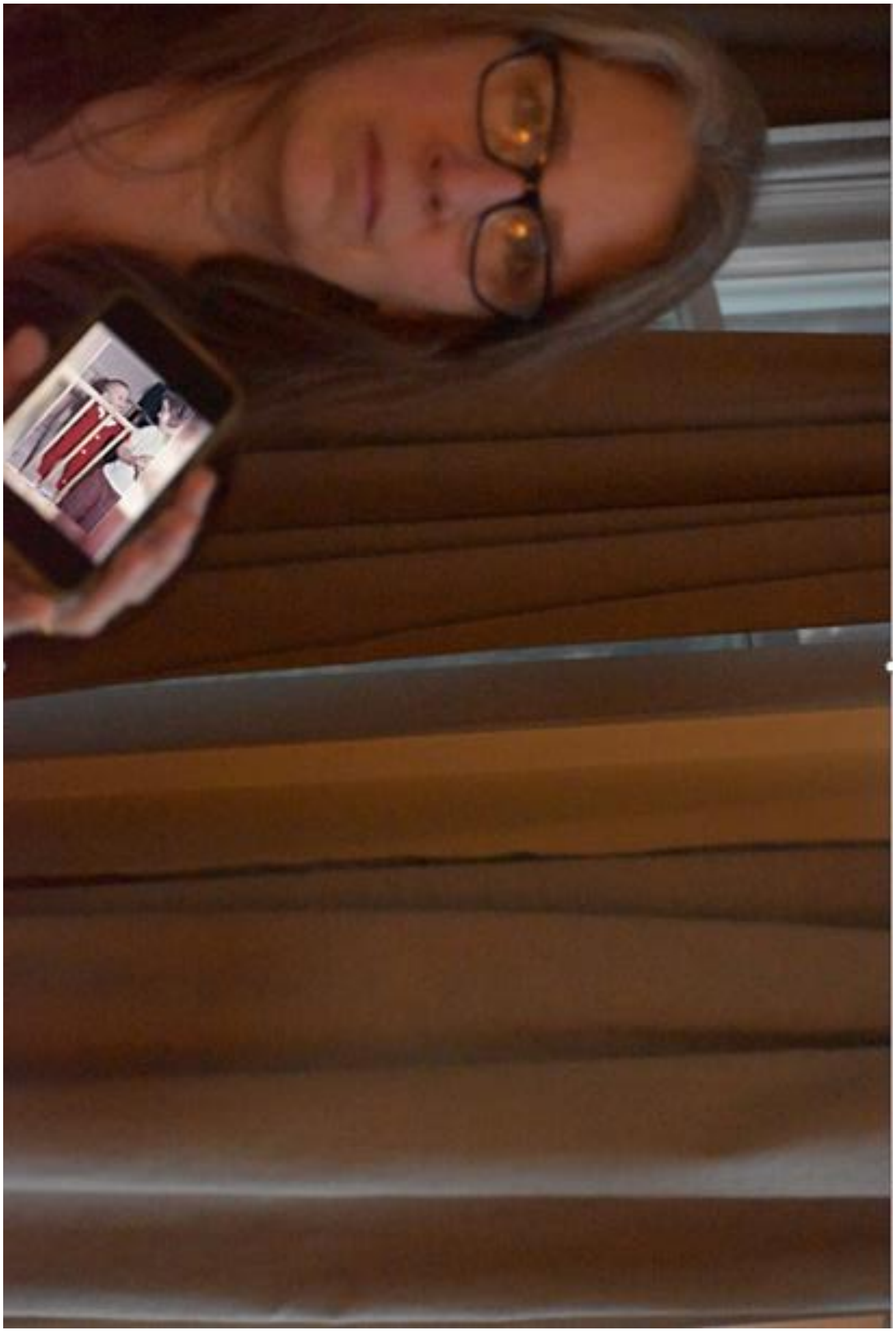


Figure B9

Sister, I Hear You Laugh

2022

Figure B10
Three sisters diptych
Family photos, black and white print, 1963, Kodachrome print, 2001
Assemblage, 2023

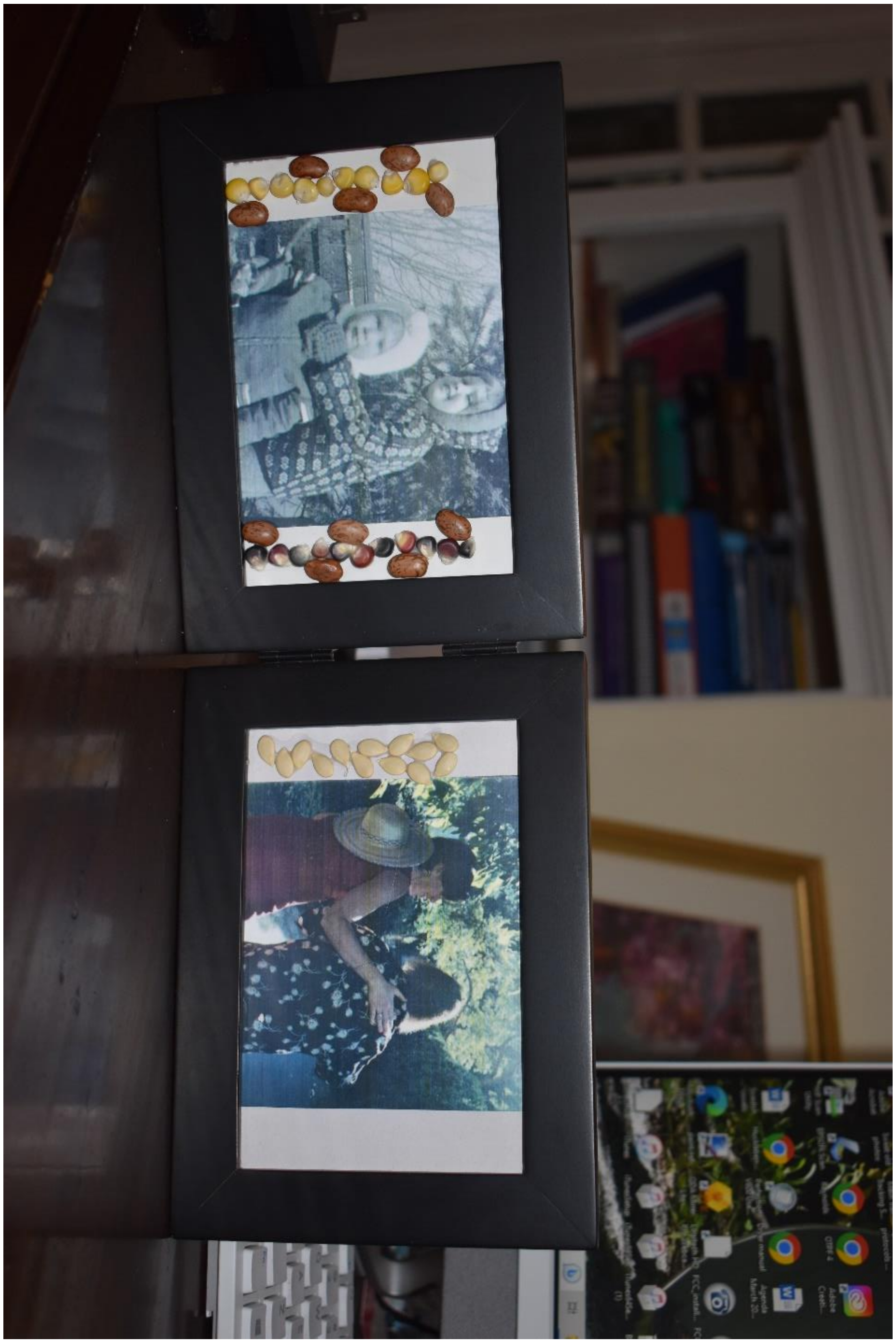


Figure B11
Help!
Collage, 2019

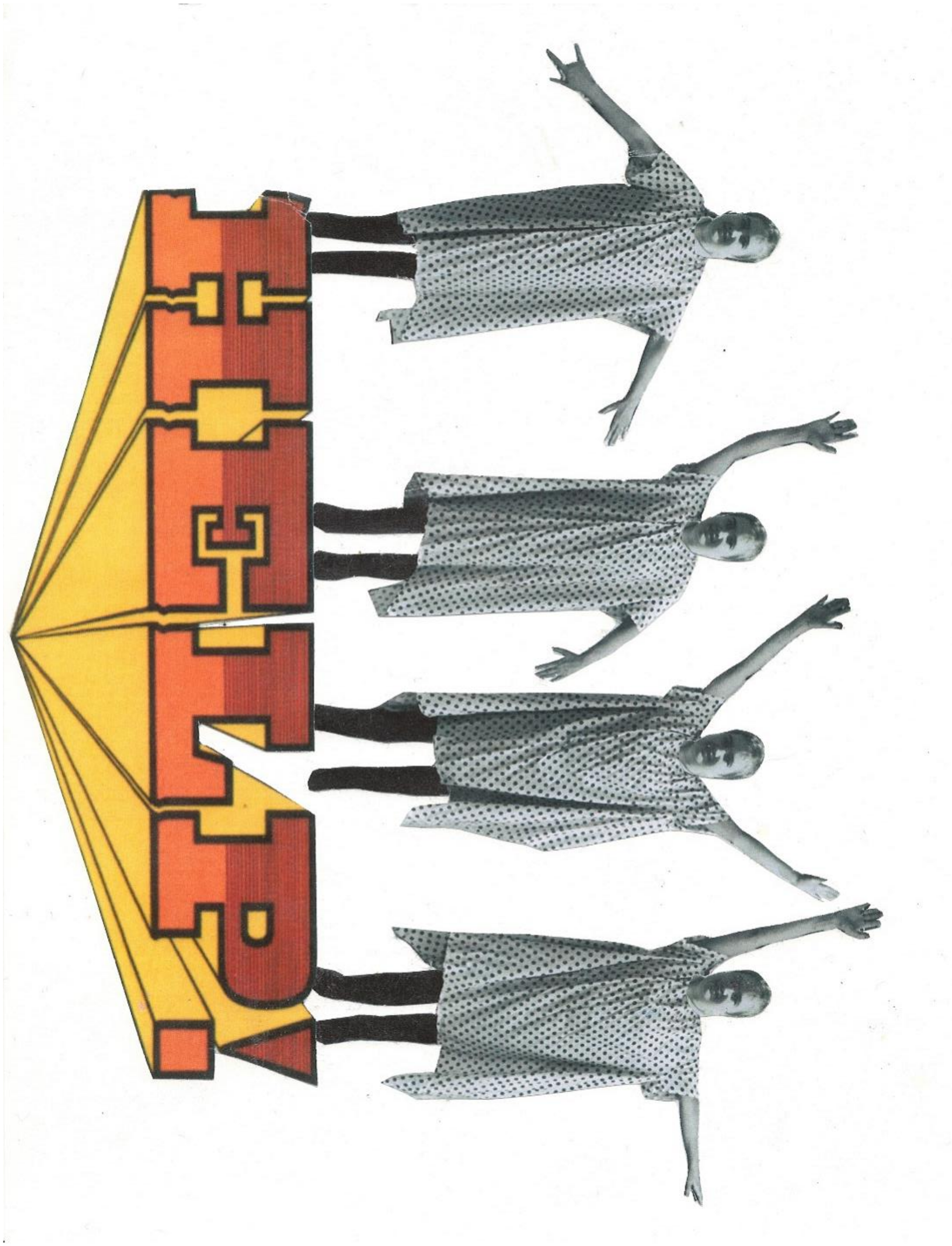


Figure B12
Revisitation
Digital photograph by Wayne Franits, 2011
Digitally modified, 2023

Figure B13
Interdependent Identities
Construction, 2023

Figure B14
Nevertheless, she persisted
2010

Figure B15
Fabric strip printed with photographic image
2023

Figure B16
Fabric strips sewn together
2023

Figure B17
Fabric strips embellished
2023

Figure B18
Fabric strips edged in blanket stitch
2023

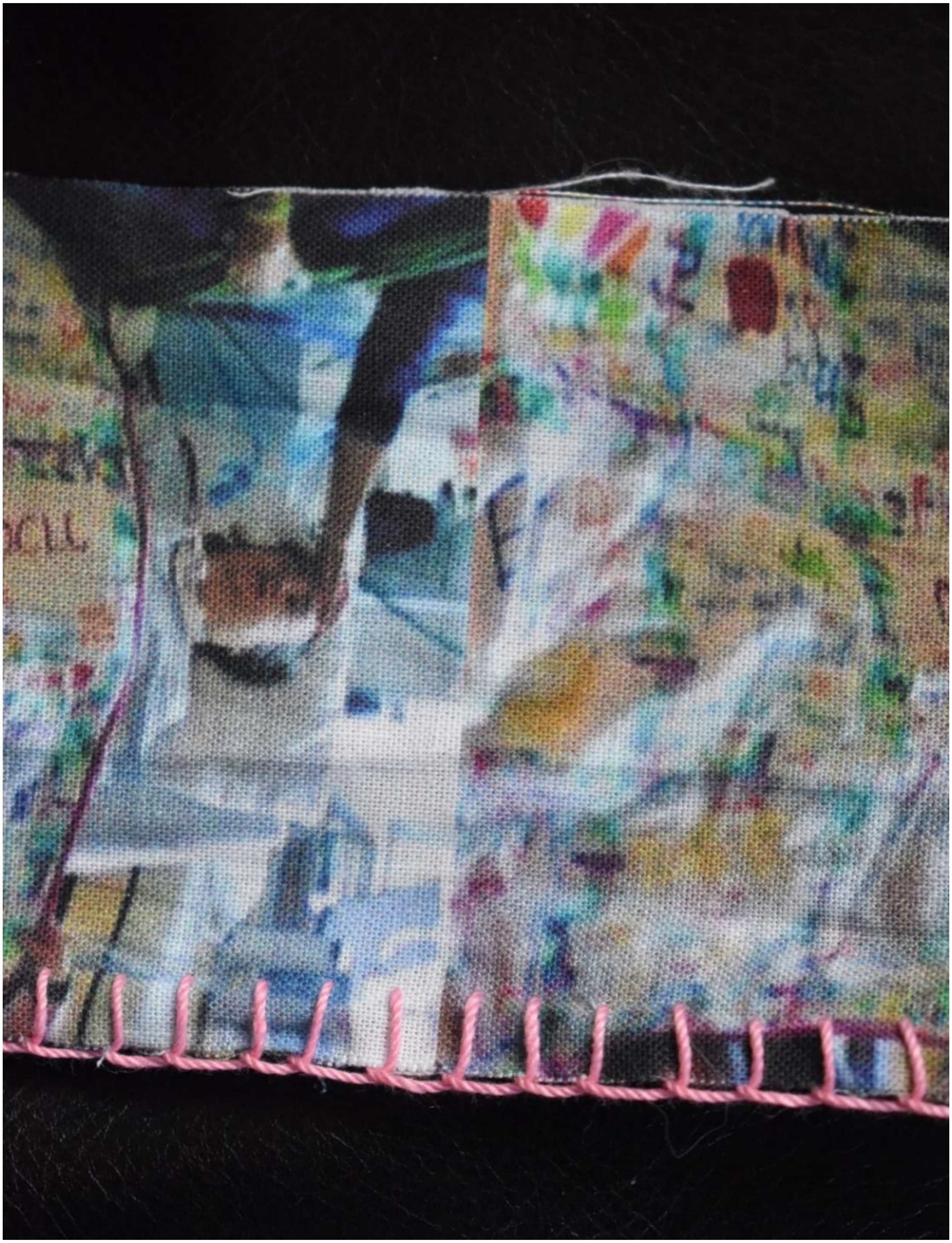


Figure B19
Pulling fabric thread through a crocheted stitch
2023

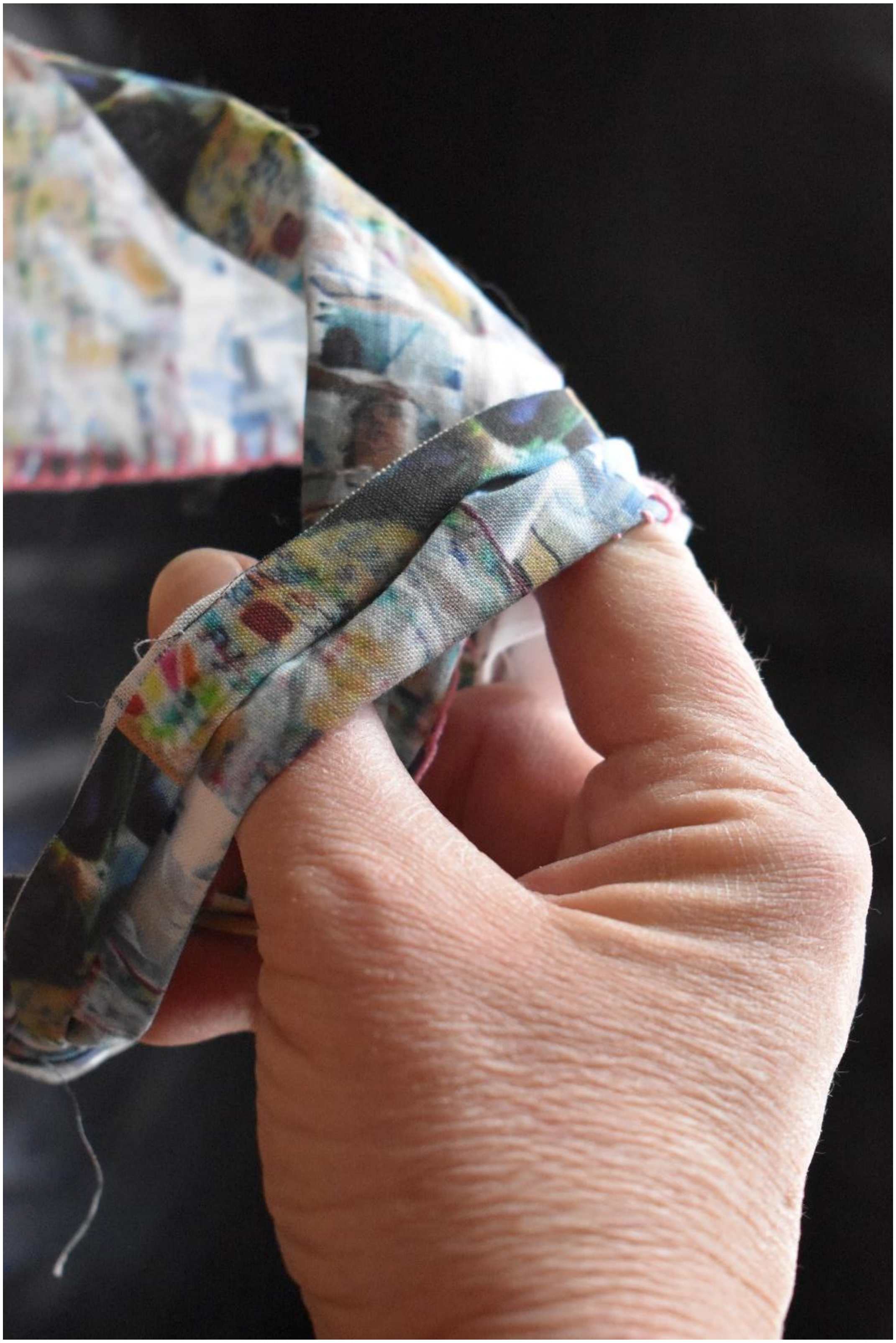


Figure B20
Unfinished chain
2023

Figure B21
The persistence of my memory
2023

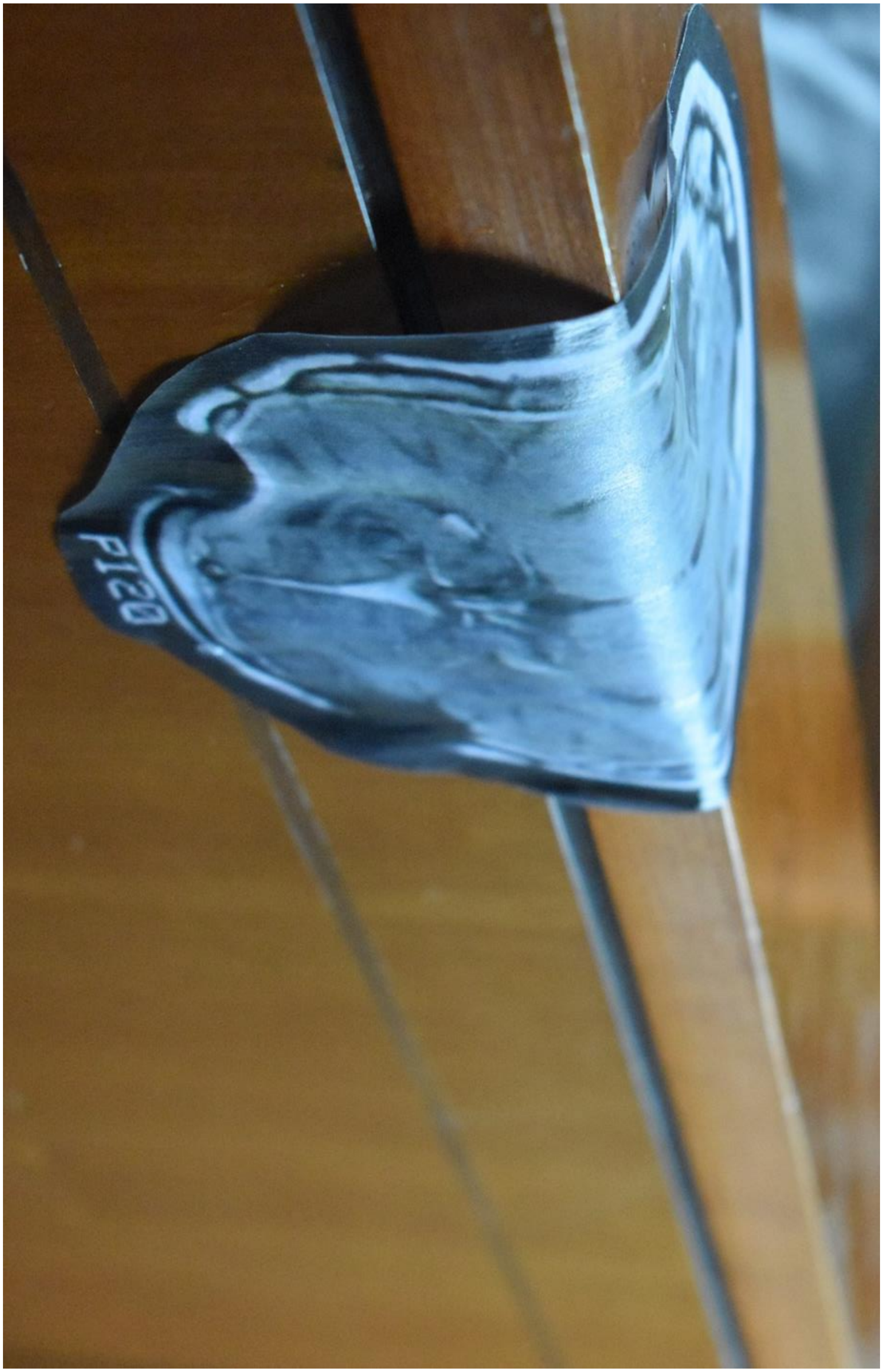


Figure B22

Point of view

Family photograph, Kodachrome print, n.d.

Figure B23

Front and Center

2023

Figure B24
ID
2023

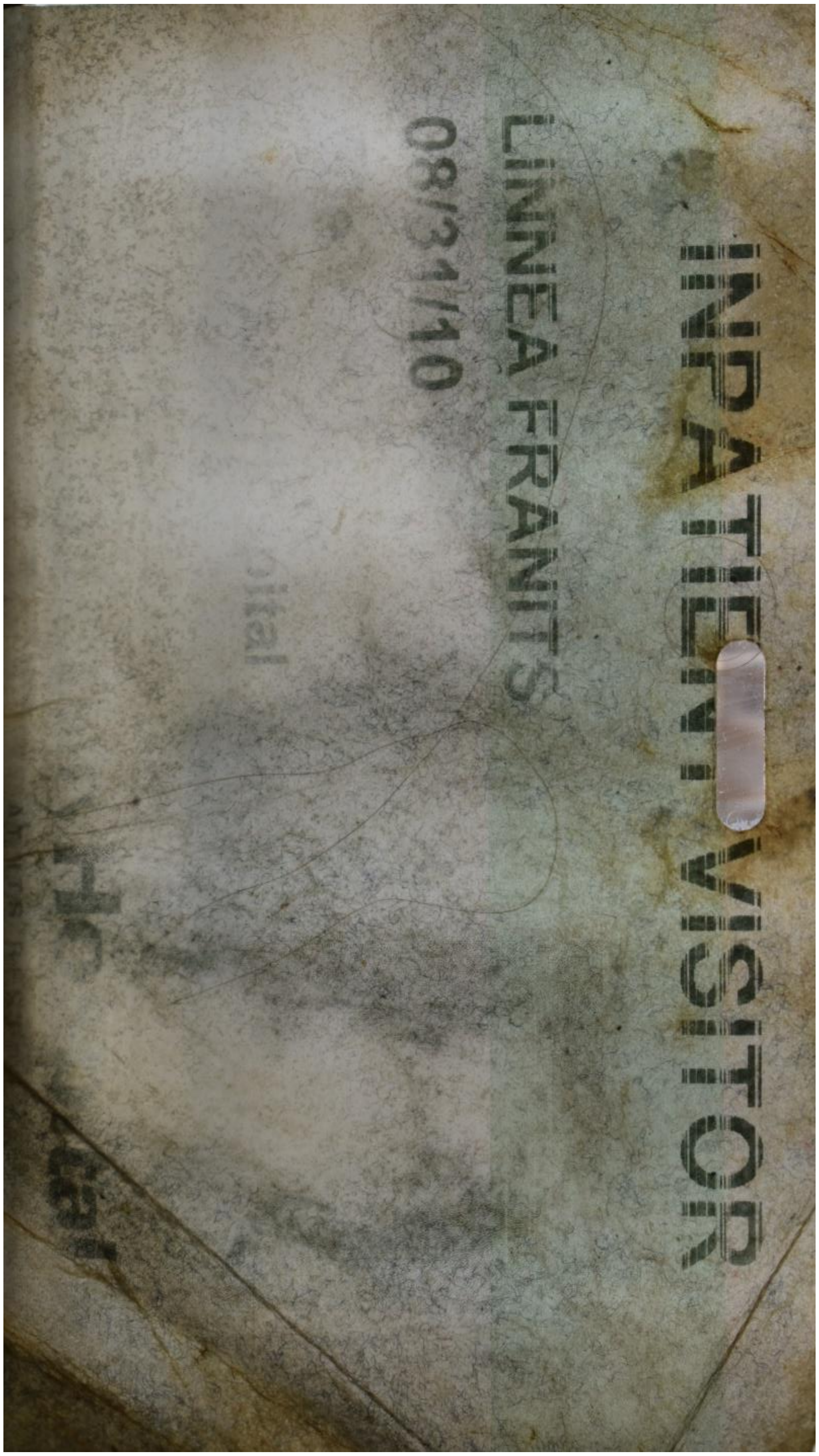


Figure B25

Annamorph

2023

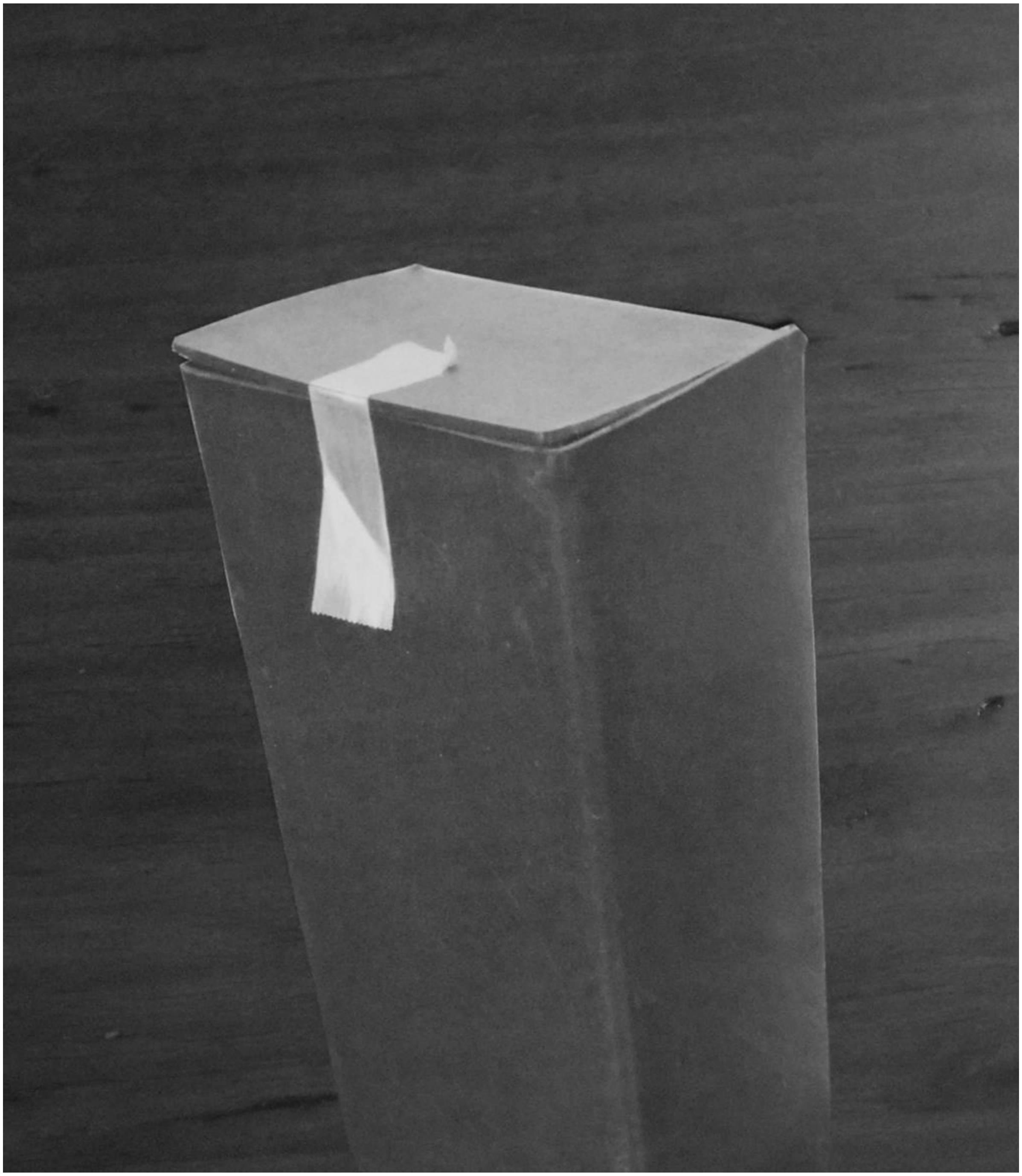


Figure B26
Revealing how I took the photograph *Annamorph*
2023

Figure B27
Mosaic
2021

Figure B28

X-ray of my sister's torso, lit from above

2021

Figure B29
Headshot
Various family photos and medical images in digital collage, assembled 2023

Figure B30

Exquisite corpse 1

Various family photos and medical images in digital collage, assembled 2021

Figure B31

Exquisite corpse 2

Various family photos and medical images in digital collage, assembled 2021

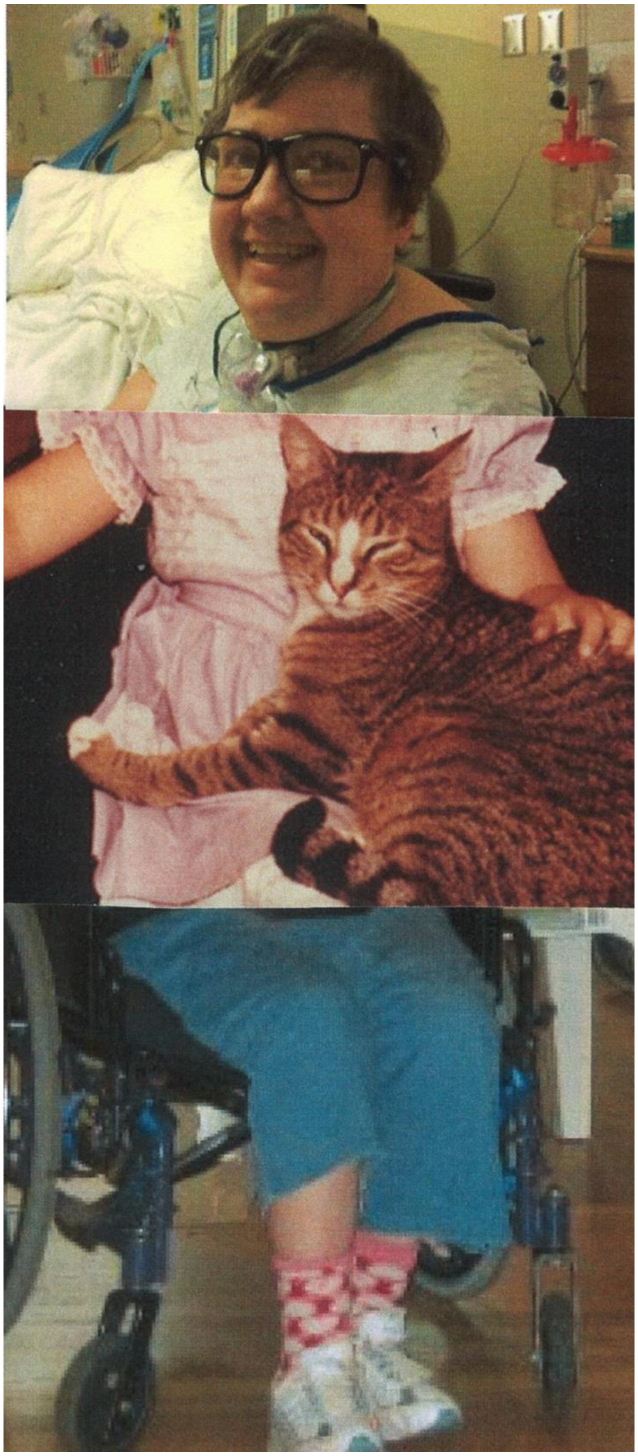


Figure B32

Exquisite corpse 3

Various family photos and medical images in digital collage, assembled 2021

Figure B33

Unboxing

2019

Appendix C
Critical Reading Practices

The following is a list of suggested critical reading practices that Ferri (2011) recommends for readers of disability memoirs. I incorporated many of them into my own readings of sibling memoirs as I developed a protocol for my analysis.

1. How is the story told in terms of time? How does the author order his/her life experiences? How does the text build from beginning to end? If it is a narrative about an acquired or progressive disability, how does dis/ability figure into the plot of the text? What happens before and after the diagnosis?
2. What are the critical incidents that are (and are not) narrated? Are there gaps/years not accounted for? How is space represented? Does the narrative travel—how do the spaces/places in the narrative figure into the text?
3. How is the body conceptualized or represented? How does the text take up embodiment? What is the place of bodily experience and embodied knowing? How does the disabled body serve as an alternative source of knowledge?
4. How does the author negotiate rationality and emotion? What is the relationship between mind/body and reason/emotion in the text?
5. How does the narrative embrace notions of desire, sexuality, and sexual agency? How does the author resist or push back against assumptions of asexuality?
6. How does the author view dependency or interdependency? How does the author push the genre of autobiography (as one person's story) to make spaces for a more interconnected view of self/other?

7. How does the author use humor and for what purposes? What other language and discourse practices are evident in the text?
8. Where are ruptures, gaps, or fractures in the narrative? Where does the narrative resist conceptual tidiness in favor of a more complicated telling?
9. Can you find examples where multiple and/or conflicting voices emerge? Where does the person deviate from the conventional scripts of disability and difference, and where do they take up these scripts?
10. What are the different ways of making meaning of disability, race, class, and gender employed by the author?
11. Do you notice any silences within the text? How do these silences provide clues about the implicit power dynamics at work in the text? What aspects of disabled identity cannot be spoken or told, at least not directly?
12. What meanings arise by attending to the intersections of disability, race, ethnicity, gender, sexuality, and so on? How do race, gender, class, and sexuality complicate how disability is experienced in the narrative (and vice versa)?
13. Who is the imagined audience, and how are we, as readers, positioned and “hailed” by the text? Is the text written with a disabled or nondisabled reader in mind? Does the narrative make assumptions about other identities either shared or not shared?
14. What are the overarching metaphors or common threads that the author uses to make meaning of his or her experiences? What are the metaphors of disability, and how do these metaphors compare to cultural representations of disability?

15. How does the author resist being known? In reading this narrative, how can we embrace an ethic of "unknowing" as we encounter the text? How does the author resist our impulse as readers to "know" the narrator as a finalized, contained, and static self?
16. What is the relationship of the self to others in the narrative? Does the author develop a critical consciousness around disability, race, gender, sexuality? If so, when? How did this come about?
17. How does the person blur the conventional genre of autobiography, and what does this tell us about the limits and possibilities of the genre itself?
18. What are the sources of received knowledge about disability, race, class, gender, and sexuality? What is the personal mythology operating in the text?
19. How does ability or normalcy operate in the text? How does the author position himself or herself in relation to hegemonic notions of normalcy. (p. 2277-2279)

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Linnéa E. Franits, MA, OTR/L
CURRICULUM VITAE
January 2024

Education:

May 2021
Certificate of Advanced Study in Disability Studies
Syracuse University
Syracuse, NY

August 1997
Master of Arts degree in Occupational Therapy- “post-professional”
New York University
New York, NY

May 1982
Bachelor of Science degree in Occupational Therapy
New York University
New York, NY

Professional Experience:

June 2006 – present
Associate Professor of Occupational Therapy
Utica University
Utica, NY

August 1994 – June 2006
Assistant Professor of Occupational Therapy
Utica College of Syracuse University
Utica, NY

August 1992-August 1994
Adjunct Professor of Occupational Therapy
Utica College of Syracuse University
Utica, NY

1991-1996
Injury Prevention consultant, Work Safe (DBA), Syracuse, NY –

1987-1991
Staff Occupational Therapist, St. Camillus Rehabilitation Center, Syracuse, NY –

Licensure and Certification:
License to practice:
State in which license is valid: New York
License type (please underline): [✓ ***OT***] ***OTA Other***
License Number- 3049
Expiration date- 7/25

Professional Membership:
I sustain membership in the following organizations:

- Professional member of the American Occupational Therapy Association (AOTA)
- Member of the AOTA Work Programs Special Interest Section
- Member of the Coalition of Occupational Therapy Advocates for Diversity (COTAD)
- Member of World Federation of Occupational Therapists
- Member of New York State Occupational Therapy Association
- Member of the Society for Disability Studies
- Governing Board member of the Southern Humanities Council
- Governing Board member of the American Association of University Professors, Utica

Professional Activities:
Peer reviewer for *Disability Studies Quarterly* – invited to review submissions related to sibling disability

Professional Publications:

Franits, L.E. (Fall, 2019) Mother is wise: An insider's observations of how disability constructs maternal identity. In P. Lalvani (Ed), *Constructing the (M)other: Narratives of Resistance at the Intersection of Motherhood and the Politics of Normal.*

Franits, L.E. (2011). Stories Mothers Tell. In J. Cellio and C. Lewiecki-Wilson (Eds.), *Disability and Mothering: Liminal Spaces of Embodied Knowledge*. Syracuse, NY: Syracuse University Press.

Halliday, R., Franits, L.,(2006). Teaching Goodness: Moral Development Theory and the Teaching of Ethics. *Teaching Philosophy.*

Franits, L.E. (2005). The issue is: Nothing about us without us; Searching for the narrative of disability. *The American Journal of Occupational Therapy 59*(5). p. 577-579.

Professional Presentations:

February 2024- *Body snatcher: Identity, interdependence, and body as context*
(paper presentation)
Southern Humanities Council, annual conference
Savannah, GA

January 2021 – *The exquisite corpse: Reimag(in)ing my sister, disability, and myself*
(short paper presentation)
Southern Humanities Council, annual conference
(Virtual due to COVID restrictions)

April 2020 – *Getting your hands dirty: A systematic review of the use of creative arts in occupational therapy education*
(2 hour poster presentation)
American Occupational Therapy Association, annual conference
Boston, MA
*****PRESENTATION CANCELED DUE TO COVID-19*

January 2020 – *This is my body, broken for who? Celebration and disability*
(paper presentation)
Southern Humanities Council, annual conference
Baton Rouge, LA

April 2019 – *Listening Wisely: A conversation between academics and clinicians about empathic interventions*
(poster presentation with Professor Colleen Sunderlin)
American Occupational Therapy Association annual conference
New Orleans, LA

January 2019 – *Ripple effect or Epistemology of a brain tumor*
(visual research presentation)
Southern Humanities Council annual conference
Asheville, NC
(peer reviewed)

April 2018 – *The Importance of sibling stories: Family-centered Care and Adults with Disabilities*
(proposed as a session, accepted as a poster presentation)
American Occupational Therapy Association, annual conference
Salt Lake City, UT

January 2018 – *Images of truth, lies, fiction* (visual presentation, co-presented with Professor Steven Specht from the Psychology department)
Southern Humanities Council, annual conference
Savannah Georgia

April 2017 – *The power of story: Teaching narrative analysis to improve clinical reasoning* (proposed as a session, accepted as a poster presentation)
American Occupational Therapy Association, annual conference
Philadelphia, PA

January 2017 – *Interdependence and Flow* (paper presentation)
Southern Humanities Council, annual conference
Louisville, KY
(peer reviewed)

April 2016 – *The Client is at the center: Using qualitative research to inform clinical decisions"* (poster presentation)
American Occupational Therapy Association, annual conference
Chicago, IL
(peer reviewed)

January 2016 – *Privacy Settings: Disability breaks the rules (*paper presentation)
Southern Humanities Council, annual conference
Louisville, KY

January 2015 – *Virtue and vice: Disability as device* (paper presentation)
Southern Humanities Council, annual conference
Athens, GA

April 2014 – *"The view from here: Understanding the experiences of others through photography* (poster presentation)
American Occupational Therapy Association, annual conference
Baltimore, MD

January 2014 - *"Authentic narratives elicited from photographs: History, memory or fantasy?* (paper presentation)
Southern Humanities Council, annual conference
Richmond, VA

October 2013 – *Artifacts and impediments: Searching for the narrative of disability* (paper co-presented with Professor Mary Ann Janda)
New York College English Association, annual conference
New York, NY

April 2013 – *Using photographs to understand occupational deprivation: Enacting caring* (poster presentation) (collaboration with UCOT student group)
American Occupational Therapy Association, annual conference
San Diego, CA

April 2011- *Narratives of resilience and independence* (poster presentation) (co-presented with Professor Colleen Sunderlin)
American Occupational Therapy Association, annual conference
Philadelphia, PA

April 2010- *Narratives of disability* (poster presentation)
American Occupational Therapy Association, annual conference
Orlando, FL

June 2008- *The social model of disability and the construct of independence* (paper presentation)
American Occupational Therapy Association, annual conference
Long Beach, CA

October 2006 – *Occupational Justice – Employment for individuals with autism* (paper presentation)
5th Annual Northeastern U.S. Conference on disABILITY
Scranton, PA

April 2006 – *Stories families tell: Family narratives when disability is present* (poster presentation)
American Occupational Therapy Association, annual conference
Charlotte, NC

March 2005- *Parents' stories: Serving as educational resources and healing tools* (paper co-presented with Professor Melodee Moltman)
Florida Association of Child Life Professionals, Inc. annual conference
Orlando, FL

October 2004 – *Searching for the narrative of disability* (paper co-presented with Professor Mary Ann Janda)
Mid-Atlantic Popular/American Culture Association Conference
Buffalo, NY

May 2004 – *Teaching of evidence based practice using a framework to encourage clinical reasoning* (paper co-presented with Professor Nancy Hollins and Professor Sally Townsend)
American Occupational Therapy Association annual conference
Minneapolis, MN

October 2003 – *Teaching goodness: The effect of an ethics course on students' moral reasoning* (paper co-presented with Professor Robert Halliday)
Association of Schools of Allied Health Professions annual conference Toronto, ON

October 2003 – *"Teaching of evidence based practice using a framework to encourage clinical reasoning* (paper co-presented with Professor Nancy Hollins and Professor Sally Townsend)
New York State Occupational Therapy Association annual conference Fishkill, NY

May 2003 – *"Integrating the circles of evidence based practice (*paper co-presented with Professor Debbie Marr)
Boston University Faculty Summer Institute
Boston, MA

May 2002 – *Older parents/Older children: Recognizing our feelings, dealing with fear and loss* (panel presentation)
"Reaching for the Stars" annual conference sponsored by Exceptional Family Resources
Syracuse, NY

June 2001 – *Using evidence-based practice to improve clinical reasoning* **–** (paper co-presented with Professor Debbie Marr)
Boston University Faculty Summer Institute
Boston, MA

Teaching Activities:
At Utica University, I regularly teach the following courses in the MSOT program:
OCT 505 Theoretical Foundations
OCT 506 Human Occupations
OCT 573, OCT 573W, OCT 574 and OCT 574W– Fundamentals of Occupational Therapy Practice I and II
OCT 571 and OCT 571W– Occupational Performance for adolescents and young adults
OCT 572 and 572W- Occupational Performance for adults and older adults
OCT 549- Research Seminar I
OCT 615- Synthesis: Theory to Practice