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Beyond the Door: Disability and the Sibling Experience

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by

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ABSTRACT

This thesis explores the experiences of adult siblings of individuals with impairments. It expands on the existing literature by exploring the complexity of the sibling experience of disability while moving beyond the concepts of burden and maladjustment that have characterized much of the previous literature. In addition, it expands upon and extends to the sibling experience an emerging view of disability by examining the ways in which themes identified in sibling narratives cross lines between the Medical and Social Models of Disability. Building on work by Mark Priestly and Tom Shakespeare, I call this emerging view the Interactional Model of Disability. Using in-depth interviews, four key themes have been identified: encountering bodily difference, the importance of social relationships, the mediating effects of resources, and complex emotions within the sibling experience. Findings indicate that variations within the sibling disability experience depend largely on whether impairment is appropriately acknowledged and accepted by the larger community, accessibility of resources, and the strength of social support. The use of informal caregiving was also an important factor in terms of the emotions experienced by siblings. Those participants whose families relied exclusively on informal caregiving experienced greater concerns about long term care arrangements than those participants whose families utilized some aspect of formalized caregiving such in home supports or assisted living arrangements.

CHAPTER ONE: INTRODUCTION

The purpose of this study is to explore the disability experiences of adult able-bodied individuals who have a sibling with impairment. To accomplish this goal, I use data collected in extensive life-course interviews with ten adult siblings of individuals with impairments. I ground my work in the Social Model of disability and in recent revisions and expansions of this model which suggest that the disability experience involves complex interactions among four components: the body, social structure, culture and identity. My work adds to this emerging discourse by expanding upon and extending the Interactional Model of disability (generally applied only to individuals with impairments) to the wider social circle - in this case siblings and sibling experiences.

As the sibling of a person with a developmental impairment, I have come to know the never-ending intricacies that are associated with such a relationship - intricacies that include and extend beyond the social world and into the physical - a disability experience that social scientists have not yet fully explored. The day my younger brother was diagnosed with Autism, I recall a doctor taking him beyond a door to a place where I could not follow. That door has been the metaphor for my life and my relationship with my brother. It is also the impetus for this research. The relatively small body of literature that examines the experiences of non-impaired siblings of individuals with impairments has taken an individualistic approach focusing primarily on the adjustment and psychological problems experienced by these individuals, while largely failing to discuss the social aspects of the sibling experience.

Before discussing perceptions and experiences within these sibling relationships, it is important to distinguish between biological impairment and social disability. In this study, impairment will be used to denote the biological difference (whether physical, cognitive, psychological or behavioral). Disability on the other hand will initially be used in the Social Model context to indicate social problems brought about by social processes (Priestley 2003). This distinction will be explored further in the study as I utilize an Interactional Model of disability to explore how the experience of disability affects both individuals with impairments and the siblings with whom they share bonds.

Understanding sibling experiences in families in which one member has an impairment is important and timely. In the United States alone over 56.7 million people live with impairments (Census Bureau 2010). In this thesis, I argue that disability affects an even larger number of people than these figures suggest. The effects of disability can be thought of as concentric circles. The strongest experience of both physical limits and social oppression can be felt at the epicenter, by the person with the impairment, but these experiences can also extend outward - with each larger ring representing various social bonds both private and public.

Goffman argues that these concentric circles exist because non-impaired siblings occupy a position known as "the Wise" (Goffman 1963). Because of their closeness (often in both cohort and proximity), they are accorded "a measure of courtesy membership in the clan" (Goffman 1963:28). Goffman believed there were two types of "the Wise": those working in an establishment catering to the stigmatized group and those related through social structures (Goffman 1963). This research is interested primarily in the second kind of "Wise" person, namely the sibling of an individual with

impairment.   Due to the social structures through which these individuals are related (in this case family ties) theirs is "a relationship that leads the wider society to treat both individuals in some respects as one" (Goffman 1963:29). The result in the case of siblings, who are included in this second type of "Wise" group, is that often they share to a lesser extent the experience of their siblings' impairments. As a result, they do not belong fully to either the world of the impaired or to the world of the "normal" (Goffman 1963).

As members of the "Wise" category, non-impaired siblings occupy a unique position becoming intimate witnesses to their siblings' disability experience which in turn allows them to become witnesses to the experience themselves (Frank 1995). Becoming a witness to the struggles that accompany impairment means becoming a witness to social barriers and what's more - a witness to the embodiment of disability (Frank 1995). Thus, I argue that the disability experience extends beyond individuals with impairments to their close family members - including siblings. Exploring the experiences of these individuals is important to our understanding of the disability experience.

To this end, this thesis intends to explore the following research question: what are the disability experiences of adult non-impaired siblings who have a sibling with impairment? Utilizing ten in-depth interviews, this research will add to the existing literature by exploring the complexity of the disability experience from the point of view of adult siblings while moving beyond the concepts of burden and maladjustment that have characterized much previous literature and identifying themes in the sibling experience that cross physical and social lines.

CHAPTER 2: THEORETICAL FOUNDATIONS

In this chapter, I discuss the dominant paradigms found within disability studies (in particular the Individual and Social Models of disability) and the historic and emerging discourses surrounding these models.

The Individual Model: Disability as an Individual Dysfunction

Historically, medical, psychological and even social research has been based on the Individual Model of disability. Rather than focusing on a broader social context, the Individual Model views disability and impairment as the same concept. Within this paradigm, the challenges faced by individuals with impairments are believed to be "an individual problem caused by impairment" (Priestley 2003: 12) rather than structural or cultural barriers - the onus then is always on the individual. We can trace this way of thinking back to Parsons (1951) and his views of health and functionalism. If health and functional capacity are considered necessary to be productive, and productivity is measured by the number of roles the individual is able to fill (such as employee or handyman), individuals with impairments are at a loss. As a result, the Individual Model views disability as a dysfunction, making it difficult for individuals to complete activities of daily living and creating larger problems for them in the world when they can no longer fulfill their roles in life.

Consistent with the Individual Model of bodily differences, individuals with illnesses and impairments learned to tell their own stories in medical terms. Frank (1995) referred to this medicalized narrative of the illness/impairment experience the restitution

plot. This narrative, much like Parsons' (1951) "sick role", focused predominantly on health and the journey toward re-attaining it. Individuals would "go to paid professionals who [reinterpreted] their pains as symptoms" (Frank 1995: 5) and in doing so would change the way in which they told their narratives. By adhering to the restitution plot, these individuals "not only [agreed] to follow physical regiments that [were] prescribed; [they] also [agreed] tacitly…to tell [their story] in medical terms" (Frank 1995:6) resulting in what Frank (1995) called "narrative surrender" - that is, the conversion of their own stories of illness to a medicalized narrative consistent with the restitution plot. This requirement of "narrative surrender" shifts the focus from the experiences of individuals with impairment to diagnoses, and requires stories to be "contextualized within a secondhand medical report" (Frank 1995:6).

The Individual Model of Disability and the medicalized restitution plot are both interested primarily in the curing of impairment and the negative effects that impairments, when they go uncured, have on individuals. Similarly, the focus on the cure or becoming "good as new" (Frank 1995), is the ultimate goal of the restitution plot with the intended result that once cured, the individual can again become a functioning member of society. There are, however, several limitations to this Individual Model. It fails to take into account institutional barriers such as access to healthcare, cultural barriers such as stigma as well as the fact that some impairments cannot be cured. In order to compensate for these deficiencies, a Social Model was conceptualized which became the predominant model of the post-modern era.

The Social Model: Disability as a Socially Constructed Concept

Unlike the Individual Model which views impairment and disability as the same concept, the Social Model argues that the disadvantages often faced by individuals with impairments are socially constructed (not the result of impairments themselves) "but rather the way in which societies fail to accommodate natural aspects of difference between people" (Priestley 2003:13). Separating impairment and disability allows us to acknowledge bodily impairments while "[pointing] out that disability is something different, 'imposed on top'" (Priestley 2003:14) of these physical attributes. Within this paradigm, disability can be thought of as the oppression created by a society's institutions, expectations, and social processes. These expectations often create barriers in the lives of individuals which keep them from fulfilling valuable roles within our society.

For the purposes of this research, structural barriers will refer to the set of conditions and processes that are affected by institutions such as marriage, education, the medical care delivery system, and the government. These structural barriers may take the form of carework arrangements, living arrangements, financial resources, medical-care access, and social support (of family, friends, and community). Structural barriers are often created through social and economic stratification of individuals. Impairment can require equipment and treatments that are expensive, and individuals with impairments and their families may be discriminated against in the workplace. The net result is that these barriers can often alter experiences of disability based on the individual's socio-economic position within our society.

Cultural barriers, on the other hand, will be used to refer to both individual and socio-cultural perceptions of impairment (what bodies are and are not supposed to be and do) as well as perceived stigma. Stigma denotes discomfort with impairment, often leading to behaviors such as "guarded references, the common everyday words suddenly made taboo, the fixed stare elsewhere, the artificial levity, the compulsive loquaciousness, the awkward solemnity" (Goffman 1963:19) performed by other people. While non-impaired siblings do not experience stigma directly, due to the intimate nature of their social relationship, other people often treat them as part of the stigmatized group. The result is that non-impaired siblings often share to a lesser extent the stigma associated with their sibling's impairment, and as a result do not belong to either the world of the impaired or to the world of the "normal"; it was this shared stigma experience that became referred to as "courtesy stigma" (Goffman 1963). These attitudinal barriers are constructed and maintained (both directly and indirectly) through every day interactions and affect the disability experience differently according to visibility and severity of impairment.

Just as the medicalized restitution plot evolved in concert with the Individual Model of Disability in the modern era, narratives arising in the post-modern era alongside the Social Model were stories told *by* people with impairments rather than *for* them (Frank 1995). Narratives such as the quest plot in which individuals gain something from the experience of having impairments allowed space for the idea that the challenges faced by individuals with impairments were not located inside the body, which had provided them a sense of insight, but with their surrounding social environment (Frank 1995).

Emerging Critiques of the Social Model

While the Social Model has created a greater awareness of both individuality and a need for social reform, it has also unintentionally created a disembodied disability experience. In turn, this disembodied disability experience has created the potential for several political implications that could hinder the ability of individuals with disabilities to get their needs met. In his critique of the Social Model, Shakespeare (2005) argues that if we conceptualize the disability experience without including impairments, we run into several limitations not only in understanding the experience itself but also in terms of policy. If the Social Model in the present form were to remain unaltered, the unintended consequences could potentially be the rejection of medical services and the creation of unmet needs of individuals with impairments (Shakespeare 2005).

By equating the disability experience exclusively with social barriers and ignoring the bodily experience of impairment, we run the risk of creating a society in which "attempts to mitigate or cure medical problems [would] be regarded with intense suspicion" (Shakespeare 2005:31). This suspicion may be linked to fear of a returning medical model, emphasizing the need to relinquish control, or it may be the belief that medical services make impairment synonymous with illness. In addition to the suspicion of medical services, another limitation of the Social Model is that if disability were to be thought of solely as social oppression, the needs of individuals with impairments would no longer need to be surveyed and their needs would be unmet within society.

Besides possible political implications, the limitations of the Social Model extend to the sharing of experiences themselves. Including impairment in the disability experience allows for individuals to talk about their experiences without relying on the

medical model for the nature and meaning of impairment (Shakespeare 2005). If the goal is to limit the impact that impairment has on individual lives, then the Social Model must also be expanded in order to limit the complications stemming from impairments themselves. Impairments are a central part of the disability experience which has largely been ignored by the Social Model. By re-embodying the disability experience, we can explore not just societal barriers, but the way in which those barriers create and exacerbate impairments (Shakespeare 2005).

The Interactional Model of Disability Experience

Several authors (see Priestley, 2003 and Shakespeare, 2005) have suggested that rather than being located entirely in the body or entirely in social and structural oppression, disability experience involves four major aspects: (1) body, (2) social structure, (3) culture, and (4) identity.
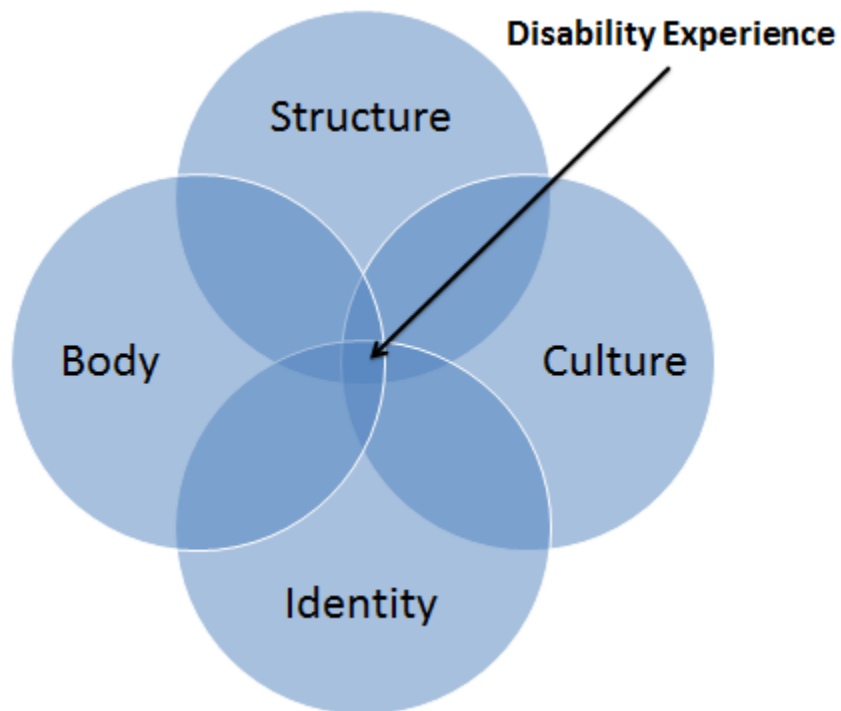
Figure 1. Graphic Depiction of Priestley's Model of the Complexity of Disability.

Priestley (2003) suggests that the best way to understand the complex phenomenon of the disability experience is to view this model as overlapping areas of concern rather than as separate areas defined by either the individual or Social Model. By utilizing this framework the complexities become more apparent, allowing us to conceptualize the ways in which various aspects of the disability experience impact each other rather than viewing them as separate entities (Priestley 2003). In addition, this framework allows us to think about disability in the context of the life course and how these four aspects change and impact each other throughout one's lifetime (Priestley 2003).

As both a critique and contribution to Priestley's (2003) proposed model, Shakespeare (2005) suggests that impairment can be thought of as a predicament in and of itself and that when added in, social oppression interacts with this impairment to create the disadvantage that we must work to remove. In terms of the disability experience, interaction is "the relationship between intrinsic factors (impairment, etc.) and extrinsic factors (environments, support systems, oppression, etc.)" (Shakespeare 2005: 57). By taking into account this interaction between individual and structural factors, we can broaden the definition of disability while also acknowledging the psycho-emotional and personal attitudes of the disabled (Shakespeare 2005). These individual factors may account for the variations within the disability experience (Shakespeare 2005). I use the term Interactional Model of Disability to denote a combination of Priestley and Shakespeare's approaches.

Figure 2. Graphic Depiction of an Interactional Model of Disability.

By combining these two proposed models, my current study will extend what Priestley (2003) and Shakespeare (2005) have suggested by doing the following: (1) expanding on their models to include an emotional aspect and (2) examining whether their proposed models can be extended to those who share intimate social relationships with people with impairments - in my case, siblings. I argue that the term "disability experience' should be used as an umbrella term to cover any combination of the five aspects of disability (structural, cultural, identity, emotional, and bodily aspects).

Because the term impairment can cover a wide variety of bodily differences, it is important not to limit this model to any specific kind of impairment. When we imagine the disability experience using the Interactional Model, for example, a person does not need to have a visible impairment to feel disabled. The Interactional Model refers to the

combined effects of any of the components of disability (body/mind, structure, culture, identity, emotions). In the case of someone with a cognitive impairment, for example, there may not be physical pain nor constraints such as a lack of access to buildings, and yet there may still be cultural constraints and issues of identity (including courtesy stigma) which interact together to create a disability experience. With this in mind, this research is interested in extending the Interactional Model to the disability experiences of siblings.

CHAPTER THREE: LITERATURE REVIEW

To date, the relatively small body of work on the sibling experience in families of individuals with impairments has taken the Individual Model approach, with research focusing on psychological maladjustment of siblings. Most studies in this area use parental reports of the sibling experience. The voices of siblings themselves are under-represented. Where adult siblings have been interviewed, the research has tended to focus on the burden of care and factors associated with such burden. In addition, many previous studies define disability very narrowly - focusing on single diagnostic categories. The general consensus of this prior research has cast impairment as a largely negative experience for individuals and their families. Although researchers have begun exploring possible reasons for sibling maladjustment, few have considered either the positive aspects of sibling experiences or the structural and cultural barriers that might hamper the development of positive relationships between siblings with and without disabilities. By using the Individual Model of disability, previous researchers have spoken to negative adjustment of non-impaired siblings both behaviorally and psychologically without considering the possible physical and social factors that may contribute to the adjustment or non-adjustment of non-impaired siblings. In the sections that follow the literature on siblings of individuals with impairments will be discussed, in four sections: (1) sibling adjustment, (2) differences in adolescent and adult sibling outcomes, (3) care-work and burden and (4) diagnosis-specific sibling experiences.

Sibling Adjustment

Research on sibling adjustment has often focused on the damage done by having an impaired sibling and the factors that may mitigate this damage (Lardieri, Blacher & Swanson 2000; Fishman, Wolf, Ellison, Gillis, Freeman & Szatmari 1996; Pilowsky, Yirmiya, Doppelt, Gross-Tsur & Shalev 2004; Lobato, Kao & Plante 2005). Lardiere, Blacher & Swanson (2000), for example, examined factors related to sibling maladjustment. They found that the presence of behavioral problems in addition to an impairment resulted in siblings exhibiting more conflict, feeling less satisfaction within their sibling relationship, and feeling more worried about potential difficulties their sibling would encounter in the future (Lardieri et al. 2000). Negative sibling adjustment, according to these findings, is influenced by the presence of behavioral problems in the sibling with the impairment, rather than the presence of impairments alone.

Previous literature (Lobato et al. 2005, Aksoy and Yildirim 2008) has also assessed the impact of knowledge about a child's impairment on sibling adjustment. Findings indicate that the more children to know about their sibling's impairment, the more likely their parents were to report difficulty in the sibling's adjustment (Lobato et al., 2005). In addition to sibling knowledge, social environment was found to influence the quality and formation of the sibling bond - in particular those households in which a sibling's impairment does not serve as a barrier (Aksoy and Yildirim 2008). Children in minority families, in particular Latino children, were also more likely to be described as "internalizing problems" (Lobato et al., 2005).

In summary, while the literature concerning sibling adjustment in cases where one sibling has a disability is largely focused on the potential negative outcomes for non-

impaired siblings, such negative outcomes were not necessarily found to be a direct result of the presence of the disability. Environmental factors have been found to play a part in the quality and formation of sibling relationships. In particular, level of knowledge and awareness of their sibling's impairment, behavioral problems, age, and family size appear to have more to do with descriptions of negative adjustment than a sibling's impairment (Lobato et al. 2005, Lardieri et al. 2000, Pilowsky et al. 2004, Fisman et al. 1996).

Differences in Adolescent and Adult Sibling Outcomes

A number of studies focus on the relationships between adolescent siblings with and without impairments in order to examine the impact in adjustment that growing up with a disabled sibling makes (Begum and Blacher 2011; Huang, Ososkie, and Hsu 2011; Mulroy, Robertson, Aiberti, Leonard, and Bower 2008). These studies are often based on parental reports of adjustment.

Studies have found that among adolescents with siblings who have intellectual impairments, there was more warmth in the sibling relationship when siblings were of the same sex (Begum and Blacher 2011). These findings indicate that gender may be a factor in the formation of sibling relationships. In addition to gender, age may also be a factor in the formation of sibling relationships. Studies examining the impact of sibling impairment on non-impaired siblings have found that younger siblings without impairments complained of feelings of partiality from parents while older siblings without impairments never complained of feelings of partiality from parents (Huang et al, 2011). This may be a result of changes in perception as the participants age.

Adolescent sibling adjustment was also discussed in terms of sibling educational outcomes - discussions which often became more complex with no clear positive or

negative answers. In the case of the educational outcomes of their children, parents

reported mixed results in achievement and non-achievement outcomes. Gottfried and

McGene (2013) found that having a sibling with a disability was positively related with

standardized achievement. However, in terms of non-achievement outcomes (things such

as attendance and behavior) there was no significance.

Burton and Parks (2004) examine adult outcomes for siblings including work-

related outcomes. Using a quasi-experimental field study, Burton and Parks (1990)

compared the perceptions of 30 college-aged siblings of individuals with impairment and

30 college-aged siblings of individuals without impairment; using a four-part

questionnaire they studied differences in self-esteem, locus of control, and career

aspirations among these two groups. Their findings indicated that adult siblings of

individuals with disabilities have looked back on the sibling relationship as a primarily

positive experience (Burton and Parks 1994). While adult siblings spoke of feelings such

as embarrassment, guilt, isolation, and concern for the future, they also spoke of being

more responsible, more tolerant, and better able to see the good in other people (Burton

and Parks 1994). For adult siblings, self-esteem was higher depending on visibility - the

more visible their sibling's disability was, the higher the participant's self-esteem; in

addition, "the higher their self-esteem, the lower adult siblings' developed feelings of

guilt and concerns about the future" (Burton and Parks 1994:183). In terms of career

aspirations, adult siblings were no more or less likely to enter the helping professions

compared to their counterparts without a sibling with disability (Burton and Parks 1994).

Of those who did enter helping professions, there were gender differences. Those adult

siblings who had brothers with disabilities were more likely to enter helping professions than those siblings who had sisters with disabilities (Burton and Parks 1994).

In summary, while the majority of studies focus on potential negative perceptions of having a sibling with a disability (from embarrassment and anger to guilt and concerns for the future), findings of these studies suggest that the sibling relationship in many ways retains positive effects on the lives of adult siblings. The literature concerning adolescent sibling relationships (Begum and Blacher 2011; Huang, Ososkie, and Hsu 2011) indicates that in addition to age and gender other factors such as perceived attitudes of parents are also a cultural factor which can account for differences in quality of sibling relationship.

Care-Work and Burden

Previous literature on adult sibling involvement in caring for their siblings has found that ethnic differences have an impact on the amount of care-work performed and feelings of perceived burden. Combined with gender and age these external stimuli appear to impact the sibling relationship between non-impaired siblings and their siblings with a disability (Horwitz and Reinhard 1995).

Gender is a continuing theme throughout the literature concerning care-work, not only in matters of whom is involved in caregiving, but who faces the most subjective burden. When gender interacts with levels of education it can impact feelings of subjective burden which in turn impact the formation and maintenance of the sibling relationship (Greenberg et al. 1997). Gender also shapes the way in which people feel they can communicate their narratives - with women being more likely to minimize the personal sacrifices that accompany caregiving (McGraw and Walker 2007). In the cases

where they were caring for siblings with impairments, women in particular sometimes described their role as more of a parental role than that of a typical sibling - indicating that gender interacts with informal caregiving to create a variation in the sibling caregiving experience.

Diagnosis Specific Sibling Experiences

Research that has examined the experiences of adult siblings has often focused on siblings of individuals with specific types of impairment. These experiences are examined using an Individual Model lens with the foci of the articles centered on issues of adjustment. The Social Model on the other hand has rarely been applied to the sibling experience. Where a Social Model approach has been used, many articles are also interested in examining the experiences of siblings of individuals with specific impairments. Research conducted by Degeneffe and Olney (2009) for example explores how the lives of adult siblings are affected by persons with traumatic brain injuries. In this particular article, three overarching themes were identified including the family impact of traumatic brain injuries, caring both for and about the family member with a traumatic brain injury, as well as how siblings made sense of the experience (Degeneffe and Olney 2009). While some sub-themes, such as sibling concerns about caregiving arrangements and the effect of timing of the traumatic brain injury on sibling development were well-supported by previous research, other sub-themes were not as consistent with the literature (Degeneffe and Olney 2009). Of particular interest were their findings regarding how the sibling experience impacted sibling relationships; their data indicated the sibling experience brought some siblings closer together while driving other siblings apart, and these reactions were often extreme (Degeneffee and Olney

2009). These findings indicate that there are many variations in the sibling disability experience warranting more research. Because their data was mostly quantitative and the focus on siblings of individuals with impairments is relatively new, a more in-depth approach is needed to understand the variations in these relationships and the sibling experiences which create them.

According to the literature on traumatic brain injuries, research (McGraw and Walker 2007) arising from a more Social Model approach has analyzed how discourse has shaped nondisabled women's understandings of themselves and their siblings with impairments as well as how women conform and resist these discourses. The result of analyzing their ten interviews was that women conformed to the dominant discourses by normalizing siblings, emphasizing opportunities for moral enhancement, and minimalizing personal consequences (McGraw and Walker 2007). Because interviewees consisted of only white middle-class women, a more gender inclusive approach is needed in order to understand how this experience extends to siblings of either sex. In addition, it is important to note that these women had siblings who had multiple disabilities, an experience which may have confounded the effects.

In addition, literature (Pompeo 2009) has taken a retrospective look at female siblings' childhood experiences within the educational and public domains. Her findings indicated several emotional impacts including fear of bullying and courtesy stigma, anger and resentment of perceived advantages given to the sibling with the impairment, and positive impacts such as enhanced acceptance (Pompeo 2009). This study is based on interviews with five Caucasian female siblings all of whom had some sort of higher education; while this study relies on a small convenience sample it contributes to the

literature by indicating the importance of emotions in the sibling experience, furthering the argument that an expansion of the Interactional Model to include an emotional aspect is necessary.

In summary, the previous literature has illustrated that the sibling experience of disability is one full of complexity. The use of the Individual Model in previous literature has led to a focus on potential negative impacts of having a sibling with an impairment in many areas of life, including education, career choices, emotions, identity, and internalizing versus externalizing behaviors. Findings suggest, however, that the results are not always negative. Positive outcomes for siblings have also been noted (even when unexpected. The majority of the previous literature, however, has not explored what created the variations in these experiences themselves and how interactions between physical impairment and social aspects contribute to the sibling disability experience.

With the previous literature in mind, this project will use the proposed Interactional Model of disability in order to explore the following questions: (1) What are the disability experiences of adult non-impaired siblings who have a sibling with impairment? (2) How do the five aspects of the disability experience interact to create variations in these experiences? and (3) What role do emotions play in the sibling disability experience? This research will add to the existing literature by: exploring the complexity of the disability experience from the point of view of adult siblings, moving beyond the concepts of burden and maladjustment that has characterized much previous literature, and identifying themes in the sibling experience that cross diagnostic lines.

CHAPTER FOUR: METHODS

Participants

The participants for this research were ten non-impaired adult siblings of eight individuals with life-long disabilities (Appendix A). Minimum requirements to join the study were that each respondent have at least one disabled sibling and were over the age of eighteen. Because much of the prior research has focused on children and adolescents, examining the current experiences and retrospective memories of adult siblings fills a gap in the literature. I limited the study further to those whose siblings were impaired either from birth or early childhood. Timing of the impairment is important for questions involving the structural, cultural and emotional aspects of the disability experience - if a sibling becomes impaired as an adult this is much less likely to impact issues of identity, relationship formation, or the quality of sibling experiences than if a sibling has been impaired since birth or early childhood. In the case where a sibling has developed an impairment as an adult, the sibling relationship is pre-existing - participants recall a time when their sibling did not have a disability. Impairment in these relationships introduces a new element to their relationships but does not necessarily define them. For these siblings, the likelihood that they will be impacted by impairment consistently on a day to day basis is less and therefore may affect their likelihood to feel certain emotions such as resentment or guilt in conjunction with impairment. In the case where a sibling has acquired an impairment from early childhood, however, relationship formation is affected from the beginning, with impairment playing a role in their day to day interactions growing up.

Recruitment of adult siblings of individuals with impairments is challenging. They are a hidden population. Unless they have taken on the role of primary caregivers, siblings are generally not easy to access through the traditional sources through which individuals with impairments and their parents are often recruited (schools, clinics and other programs that provide services to individuals with disabilities). It is possible to recruit through sibling support groups, but the siblings who participate in these groups may be different in many ways from those who do not - importantly, they may be more likely to have experienced problems that lead to them to seek out support. My research, therefore, relied on a non-probability snowball sample. Initial participants were found through my faculty sponsor's natural contacts in the community of families of young adults with disabilities, with subsequent participants found through my committee members' contacts. Adult siblings of their acquaintance were asked if they would be willing to participate. If so, they were given my email address. They contacted me if they were interested in participating. After conducting each interview, I asked participants if they knew other siblings who might be interested in participating. If they did, I asked participants to give my contact information to these potential contacts who contacted me if they had an interest in participating in the study. When they contacted me, the study was described and an appointment was made for the interview. The consent form was summarized and signed at the time of the interview. In the cases where geographic distance prevented in-person interviews, the study was described through e-mail and a scanned consent form along with the interview questions were included. These forms were signed and explained via e-mail before the interview. These procedures have been reviewed and approved by the University of South Florida

Institutional Review Board (IRB Pro00001544). As I had no prior knowledge of the

participants including their names, their identities are kept confidential - thus protecting

their privacy.

Of my ten participants, three were male and seven were female. Their ages varied

from early twenties to mid-sixties. Seven of my participants identified as Caucasian,

with the exception of two who identified as Italian-American, and a third who identified

as Jamaican-American. The majority of my participants grew up with relatively

privileged backgrounds, and all of them identified their siblings as having at least one

disability (see Appendix A).

Simon is a married, Caucasian upper-middle class man in his sixties, who grew up

with his sibling Robin in the rural South. Privileged with both a tight-knit community

and resources, Simon discovered early that his sister who suffered from seizures as a

child had cognitive impairments. Years later when his parents passed away it fell to

Simon for a time to take care of his younger sister, bringing her to live with him and his

wife, before she ultimately moved into an independent living facility.

Angela is a married, Caucasian woman in her early sixties, who grew up in a large

Italian-American family with her younger sister Monica. At the age of one, Monica

suffered from a high fever and convulsions which ended in brain damage. With her

father deceased and her mother severely infirmed, Angela and her siblings have formed

sub-committees to care for both her ailing mother and her adult impaired sibling.

Mary is a divorced, Caucasian woman in her mid-fifties, who is a sister to Angela,

Monica, and Emma. Like her siblings, she continues to maintain a close relationship

with Monica despite the geographical distance between them. Mary is also mother to an adult son with Autism.

Angela and Mary's sister, Emma, is a divorced, Caucasian woman in her early fifties. Emma is Monica's legal guardian and assisted Monica in buying a house, where Monica currently resides with live-in assistance. In addition to helping provide Monica with a home, Emma is also in charge of helping Monica with her finances and Medicaid.

Karl is a Caucasian male in his mid-forties whose older brother, Mark, had autism. From the age of eighteen Mark has been living in a group home semi-independently from his family. Karl is in graduate school pursuing research related to disabilities. Together with their mother, Karl and Mark go on yearly RV trips around the country but for the most part do not see each other due to geographic distance.

Elle is a Caucasian, upper-middle class woman in her early thirties whose older sister Shana is blind and had a developmental impairment. Shana resides in a group home setting where she is assisted in completing activities of daily living such as bathing, dressing, and feeding herself. As a result of her sister's impairment, Elle chose a career which allows her to aid individuals with impairments through the law.

Tara is a Caucasian female in her mid-thirties whose younger sister Roxy was diagnosed with a rare genetic disorder as an infant which impaired her coordination and communication skills. In her particular case, Tara was a witness to her sister's health decline and with it, her sister's inability to walk and communicate.

Mike is a Caucasian male in his late twenties with a much younger sibling, Charlie. Despite the age difference, both Mike and Charlie grew up in the same town in the rural South. Although Mike moved away for graduate school, of his two other

siblings, Mike has committed himself to taking over the role of caregiving for Charlie in the event that his mother is unable to continue.

Judith is a Caucasian woman in her early twenties attending a college in the south. Her relationship with her older sister, Alice, is a strained one due to Alice's behavioral and social impairments. In addition, Alice has had Autism all her life which required Judith to take on a caregiving role early on in their relationship.

And lastly there is Farah, a young Jamaican-American woman in her mid-twenties who attends a graduate school in the north. Like several participants in my study, Farah's younger sister Lisa also had autism. While Farah went away to school, Lisa continued to live with her parents in the South.

While the sample was far too small to allow for valid comparisons across age, gender, race/ethic or impairment categories, I sought a group of participants in which variety along these dimensions were present. Seeking a varied group of adult research participants (in terms of age, gender, race, ethnicity and disability) helped to reduce biased generalizations and also increased the richness of the data obtained.

Research Methods

In order to explore the sibling disability experience, I conducted 10 semi-structured, in-depth interviews; five of these interviews were conducted in person, and five were conducted through e-mail. The interview guide (Appendix B) contained thirty-seven questions including probes designed to stimulate conversation about past and current experiences, as well as to collect demographic information. While I did use preformed interview questions, topics not included in the pre-set interview guide, but presented by the participant, were discussed during the interview.

Each participant was allowed to choose the medium in which they wished to be interviewed (a meeting or e-mail). In-person interviews were encouraged where geographic distance was not an issue. After selecting the method of conducting the interview, each participant was required to sign a consent form indicating that they were voluntary participants and understood that they could withdraw from the study at any time. In-person interviews were recorded with a digital voice recorder for later transcription. Email interviews were printed out. Each file will be kept for a period of no less than five years as indicated by the IRB. All interviewees were assigned a pseudonym for the purposes of anonymity and to further protect their identity, files on participants using their pseudonym were kept in a separate firebox from the consent forms.

After I completed the transcriptions, I used the grounded theory approach to coding proposed by Charmaz (2006). An initial interview was first coded, during which I singled out questions which appeared relevant to the participant. During the initial coding stage I went over the data line-by-line listing short, simple codes to indicate common experiences or meanings. This initial stage was followed by a more focused coding, in which I began combining similar codes and used the most frequently used codes to map out and identify key themes that related to larger segments of the data (Charmaz 2006). More specifically, during my secondary coding I found multiple codes contained the same thematic premise and so I collapsed these into four overarching themes which I then analyzed drawing on the Interactional Model proposed by Priestley (2003) and Shakespeare (2005).

CHAPTER FIVE: ANALYSIS

Although a good deal of variation exists in the experiences reported by the siblings who participated in my study, four overarching themes were evident in the narrative accounts participants gave during the interviews. Themes that were woven throughout the sibling experiences included encountering bodily difference, the importance of social relationships, the mediating effects of resources, and complex emotions. Using the expanded Interactional Model of the disability experience, I will explore the ways in which the five aspects (structure, culture, identity, emotions, and body) apply to each of these overarching themes in order to understand how they interact and create variations in the sibling experience.

Encountering Bodily Difference

In terms of the larger Interactional Model, this overarching theme of encountering bodily difference encapsulates three of the four aspects of the disability experience: structure, culture, and body. As seen in Figure 2, these three aspects exist not only as individual contributors to the disability experience, but are components of the disability experience that interact with each other and often exacerbate each other in the experiences of individuals and families. When participants encountered bodily difference in their everyday lives, larger structures such as the medical community and cultural expectations regarding what the body should be capable of doing often interacted with the actual capabilities of bodies with impairments.
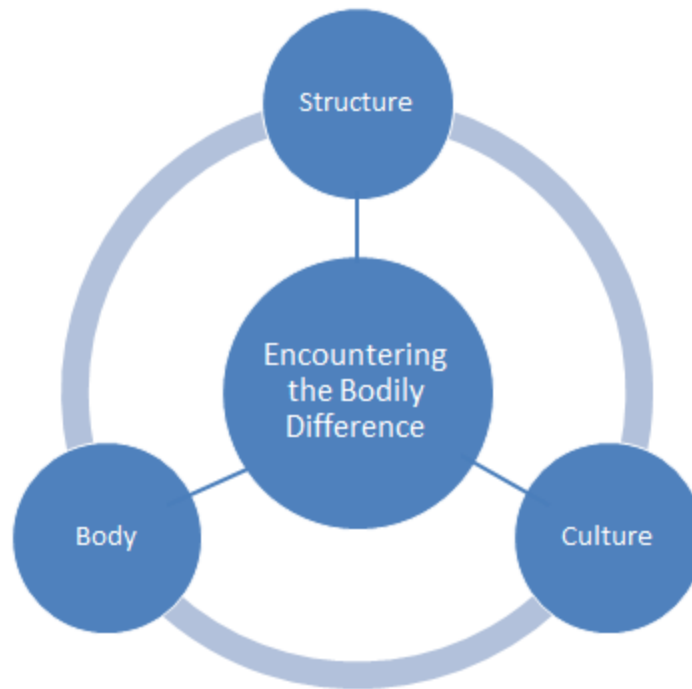
Figure 3: Encounters with Bodily Difference

Recognizing the Difference. One such example of how these aspects of disability experience interacted was the initial understanding of bodily difference and how it differed from cultural expectations. In some cases the first disability experiences were the acknowledgement of behavior that differed from the norm. Recognition that siblings were not meeting developmental benchmarks (cultural expectations about how the body and mind "should" function at various stages in a typical life course), was often the first indication participants had that their siblings had impairments. While parents of children with disabilities often talk about "knowing" their children were different before the diagnosis (Green, Darling & Wilbers, forthcoming), parents may not communicate their suspicions to siblings. In some cases, participants felt they were the first to notice and acknowledge impairment. Mike (who is much older than his sibling), for example,

reports that he was the first in his family to notice his younger brother Charlie had not met those benchmarks.

> And so things you know gradually started, when he did start talking I couldn't understand a damn word he said, which was problematic. And then I was like "mom, there's something, he's in his own little world, he acts a little—kind of different, he just acts different". (Mike, interview transcript, p. 5)

This excerpt illustrates two important concepts. First, that Mike, a single male with no children of his own, understands implicitly that there are developmental benchmarks that all children should meet. Secondly, this excerpt illustrates that when children do not meet these benchmarks it is immediately considered "problematic" as well as "different". In other words, the difference is a difference with social and cultural significance. The everyday knowledge used here to differentiate between what is typical in a child and what is a deviation from the expected behaviors is largely cultural - or based on the perceptions of how the body should act and develop during different periods in time.

This recognition of bodily difference often led participants to assist their siblings even in cases where there was no direct communication of impairment from parent to child. An example of this is an excerpt from Emma, an Italian-American woman in her early 50s. Emma's sister, Monica had brain damage which left her with a cognitive impairment. While this impairment was never discussed with either Emma or her other eight non-impaired siblings, there was an understanding that Monica was not meeting typical benchmarks. Emma explained:

I don't remember mom and dad having any sort of conversation with us…Monica was slow, but mom and dad didn't say that she was mentally retarded. We understood that we needed to help Monica in school if needed. She was slow, but a beautiful child. (Emma, interview transcript, p. 1)

This excerpt demonstrates that although she was aware of her sibling's bodily differences, Emma's relationship with her sister was not negatively affected by it, contrary to previous research which found greater awareness would lead to issues of negative adjustment (Lobato et al. 2005). For participants whose siblings were older, the learning experience of their sibling's impairment was presented as equally insignificant. An example of how older siblings learned of their siblings' impairment can be seen in an excerpt from my interview with Judith, a college student. Judith had never known her sister Alice without an impairment being present and so there was never a singular moment where she learned of her sister's impairment. In these cases impairment, rather than creating a sense of grief for what once was, was considered "normal" or predictable (Frank 1995). Judith says:

I don't know that I ever "found out" she had a disability; it just always was that way as far as I remember. My sister [Alice] is two years older than me and autistic. She is functioning but will always need to be under supervision and has no verbal skills. (Judith, interview transcript, p. 1)

Judith's excerpt indicates that she had no explicit knowledge of her sibling's impairment; as a younger sibling there was no recognizable moment when cultural expectations collided with bodily impairment. This lack of prior knowledge does not appear to be a problem for Judith, in that impairment has always been a part of her

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reality; in fact, the knowledge that her sister will always need to be under supervision is taken for granted and creates no visible emotional stress. For Judith, her sister's impairment is just a fact.

For participants, birth order did not change the recognition of bodily difference in their siblings; however, it did create variation in the interaction between impairment and cultural expectations. Participants who were older than their siblings with impairment were more likely to discuss knowing their sibling was "different", an indication of bodily difference coming into contact with cultural expectations such as developmental benchmarks. This was untrue of participants who were younger than their siblings with impairment. Those participants who were younger were initially unaware of the cultural expectations from which their sibling's body differed. While the majority of the sibling experiences regarding the recognition of bodily difference were perceived neither positively nor negatively, obtaining a diagnosis for this difference often brought siblings into contact with the medical institution (structure). This experience highlighted the ways in which siblings' bodies differed from the cultural expectations of physicians.

Obtaining a Diagnosis for the Difference. An example of how structure and culture interacted with the body was in the obtainment of a diagnosis for siblings. Because access to services often requires a diagnosis, participants were in some cases made aware of the way their sibling's impairment did not conform with developmental benchmarks early on. When participants discussed their sibling's diagnosis in the interviews, these conversations often included negative reactions to physicians. While the diagnosis was not for themselves, several participants both experienced and resisted pressure from physicians to surrender their narratives (their own understanding and ways

of describing their experiences and their sibling's bodily difference). An example of this resistance came from Simon, a man in his 60s whose sister Robin was cognitively impaired, when discussing the role of doctors in the diagnosis, Simon said:

> …we always knew…part of her slowness and everything was…I don't want to use the word blamed…but was related to…*supposedly* related to epilepsy. Which really I don't think it was but you know doctors.
>
> (Simon, interview transcript, p. 2)

In this excerpt Simon encounters bodily difference, and the physician's narrative which in this case is that Robin's cognitive impairment was a result of the epilepsy she had as a child. Simon uses the words "blamed" and "*supposedly* related" when describing the situation, indicating that he resists surrendering his narrative (Robin's impairment wasn't due to epilepsy) in favor of the physician's narrative. In addition, this excerpt indicates that, while feeling the pressure to surrender his narrative, he resists doing so. Simon does not necessarily accept the word of doctors at face value. When he says "but you know doctors" he is giving another example of resistance this time to the construction of physicians as "all-knowing" (Frank 1995).

Misgivings about physicians' diagnoses were fairly common. Because part of the requirement to "getting better" included families adopting the medical narratives of physicians (Frank 1995), these misgivings often went unspoken. While in the past the term narrative surrender (Frank 1995) has included only the experiences of individuals with impairments, my findings show that the expectation of narrative surrender extended beyond the individuals with impairments to their family members, including siblings. This held especially true in the cases where there was a large age gap between siblings, or

where siblings were old enough to recall the initial diagnosis. For Tara, an older sibling with over a decade between herself and the birth of her sibling, this memory of doctors ignoring the possibility of impairment stuck out in her mind:

> Well, we knew, we always knew…And my mom would be taking her to the
> doctor and saying "something's wrong" and they'd tell her "no, no, she's just a
> little bit slower". They really didn't have any idea.
>
> (Tara, Interview Transcript, p. 2)

In this excerpt Tara describes the often mentioned sense of "knowing" there was a bodily difference, but also the misgivings she feels looking back at the way the family was treated by doctors. Her experience and subsequent comment that the doctor "didn't have any idea" indicates misgivings about bodily difference in which the knowledge of doctors is unquestionable. In this way, receiving the initial diagnosis is often an interaction between the body experiencing impairments, cultural aspects which dictate the way a body "should" function throughout the life course, and structural aspects which require that the medical community, in particular doctors, must be involved to receive a diagnosis and subsequently services.

Emphasizing Ability. The cultural aspect of the disability experience was extremely involved in the way in which participants came to terms with the difference between cultural expectations of the body throughout the life course and the actual capabilities of their siblings' bodies. Participants often responded to the interaction of these two aspects of the disability experience by either overemphasizing their siblings' capabilities or infantilizing. In line with the Social Model of disability, and similar to previous studies (McGraw and Walker 2007), several participants at one point or another

emphasized the abilities of their siblings rather than discussing challenges presented by the body.

Because this emphasis differed depending on the visibility of the sibling's impairment, it is my belief that this emphasis was the result of the participants' awareness of stigmatizing societal perceptions of impairment. For those individuals whose impairments were hidden, or what Goffman (1963) referred to as discreditable identities, the emphasis was often placed on the way in which the individuals were able to participate in typical activities while suppressing their impairment. An example of this awareness was given by Simon, who placed emphasis on his sister Robin's observation of traditional social cues:

> You could be in a room with ten people and she'd have a good conversation and you would never know that there was an issue…Logically strong, she knew how to respond and anticipate what the question might have been - loving, caring, [she] wanted to do what she could do to help people.
>
> (Simon, Interview Transcript p. 3)

This excerpt illustrates the primary focus on culture, both through Robin's ability to communicate well with others and also to fulfill traditional feminine traits. The emphasis placed on not knowing about Robin's impairment suggests that Simon acknowledges the broader unspoken perceptions about individuals with cognitive impairments. By highlighting Robin's ability to communicate with her peers and respond appropriately, Simon is in effect resisting the perceptions that individuals with cognitive impairments cannot socialize properly. This excerpt also demonstrates the emphasis placed on normative feminine traits. The emphasis placed on Robin's desire to help

others, to show love, to be caring accentuate traits associated traditionally with females. In this way, the aspect of culture is interacting with the bodily aspect, when participants attempt to discuss their siblings with impairments meeting traditional developmental benchmarks.

For other participants, particularly those whose siblings were struggling with communication, participants acted as a cooperative voice—acknowledging the need for them to act as interpreters in a society which in many ways equates one's intelligence with one's ability to communicate effectively. In this interpretive capacity, the participants acknowledged their siblings social limitations but only by first emphasizing their intelligence. For Mike, a much older sibling in his late 20s whose 5 year-old brother Charlie has autism, emphasizing ability took the form of reporting reading and typing abilities that were above what would be expected at an early age:

> He's always displayed this big aptitude for language. He was like around three or so, we could flip on the guide on the channel, you know we could hit the guide button on the cable or whatever, and he would um, he could read the names of the of the TV shows…And then he got to where he would go to the computer, turn it on, and then navigate to Microsoft Word and open it up and start typing.
> (Mike, Interview Transcript, p. 3)

Despite the fact that Charlie has a developmental disability that affects social skills, and in his particular case has trouble communicating in direct sentences, this emphasis on language is indicative of a broader social perception that individuals who appear to be unable to communicate lack intelligence. This excerpt highlights Charlie's intelligence. Mike implies that in some ways Charlie may even have more intelligence

than the average child, given his ability to read and utilize technology at three years old. Again we see the cultural aspects of the disability (developmental benchmarks) clashing with the actual capabilities of the body.

This desire to emphasize ability did not appear to be influenced by birth order, although birth order did create variations in what siblings emphasized. In cases where the siblings with impairments were older than participants, this emphasis on ability was sometimes the result of participants growing up with the sibling's impairment. In this way the impairment became what was predictable or normal (Frank 1995). An example of how impairment could be thought of as normal was provided in an excerpt by Farah:

> I also never saw her as being disabled until just the last couple of years. It's hard
> to explain. I guess part of it was because I kind of denied that anything was
> different and part of it was because I understood her and she seemed so "normal"
> to me'. (Farah, E-mail Transcript, p. 2)

In Farah's case, the impairment was all she had ever known, leading to the denial of her sister's impairment for most of their shared childhood. Because she had grown up with impairment and understood her sister, Farah's perceptions of impairment were different than the perceptions of participants who were older than their siblings with impairments. Here the developmental benchmarks which I have associated with cultural aspects of the disability experience had been altered from the beginning, reducing the conflict between cultural and bodily aspects of impairment. There were cases, however, where the interaction of these two experiences led to unrealistic expectations in participants.

Importance of Realistic Expectations. Well after the initial encounters with bodily difference, bodily impairment and getting a diagnosis, some participants reported struggling to develop realistic expectations regarding their siblings' capabilities. Looking back on their experiences, participants often remarked on the way in which their own perceptions of their sibling's capability affected sibling relationship formation and maintenance. It is important to note that these perceptions, whether participants considered them to be realistic or unrealistic later in life, were often not related to actual impairment but to participants' perceptions of their sibling's impairment. Here again we see the importance of culture (in this case as perceptions of impairment) interacting with the actual capabilities of the body.

An example of cultural expectations of bodily functions is illustrated by Angela, an Italian-American woman in her early sixties who was also a sister to Monica who had a cognitive impairment. When asked whether she thought her sister's disability affected the way their sibling relationship changed over time, Angela replied:

> Oh I definitely think there's been an impact on the relationship between she and I. I mean, I think I have had to overcome my own biases on what she can do, and what she can't do, and how to approach her on things. And, I've really been learning a lot from watching how my sister deals with her. My sister, Danielle, is very direct with Monica and makes her be accountable for things whereas I tend to be more, I baby her more I guess. (Angela, Interview Transcript, p.7)

This excerpt illustrates that Angela is acknowledging both a cultural expectation of what her sibling should be able to do, while also acknowledging her own expectations and biases. When participants perceived their siblings as being incapable of handling

situations, siblings sometimes stepped into the role of pseudo-parent. This seemed especially true as participants grew older and faced either the loss of a parent or a parent's inability to manage their sibling's care. Often this role change of sibling to pseudo-parent led to a stronger sibling bond, but for one respondent, Tara, a nurse in her early 30s, it did blur the boundaries of her relationship with her sister, Roxy. When asked whether Roxy's disability had affected their sibling relationship, Tara responded:

> Yes, yeah, because you definitely, I never felt as close with her as I did with my other sister because, you know, that talking thing. I took care of her, but that's a different relationship than being a sibling and hanging out.
>
> (Tara, Interview Transcript, p. 7)

This excerpt illustrates two points concerning the importance of realistic expectations. First, that the cultural aspects of the disability experience, specifically the expectations of what the sibling role entails, is often blurred in these atypical sibling relationships and frequently overlaps with that of the parental role. Secondly, that the blurring of roles (and taking on a pseudo-parent role) resulted in variations within the sibling experience. This blurring of the lines between a typical sibling relationship and that of pseudo-parent often brought up a mixture of emotions in participants, but for the majority, while there may have been sadness, there was no negativity. The body, which for the purpose of this research also encompasses the mind, plays a direct part in what would otherwise be considered a cultural aspect of the disability experience. Because the body and mind function differently, in many cases slower, than what is considered typical by society, certain perceptions begin to form about the body's able-ness.

As their relationships with their siblings developed over time, participants were able to look back and reflect on the need to treat their siblings as adults that were capable of maintaining certain expectations. This often required the respondent to reflect on both the actual capabilities of the body, and their own perceptions of cultural expectations about their sibling's impairment. An example of this can be found in an excerpt by Angela, during which she reflects on her approaches to her sibling's impairment:

I can remember just being with her…if we went to the drugstore to pick up something. She'd get her little checkbook out and she writes her check and it takes a long time and people are very…I mean most people are very patient, yet I would be like eh, you know, it's taking so long. I just wanted to do it for her. I really had to take a step back and analyze how I am approaching her about things, and try to treat her as an adult, and that's hard to me. So I would say that's a major way that I had to work on relating to her.

(Angela, Interview Transcript, p. 7)

This excerpt illustrates three key points in the development of realistic expectations. First, it illustrates Angela's recognition that her desire to baby her sister was in part due to her own impatience. Second, this impatience was related to Angela's perceptions of how others around her would react to Monica taking longer to write a check - which I would argue are perceptions of stigma. Last, these perceptions both of what it means to be an adult as well as how others perceive differences are what make creating realistic expectations challenging - not a lack of physical or mental ability.

In some cases, determining the difference between a realistic expectation and an unrealistic expectation in the case of a sibling with a disability was not always an easy

one. This was especially true in these cases where impairment began at birth. An example of this comes from Farah, a 25 year old graduate student, with a younger sister, Lisa. Farah reflected on how the cultural emphasis on ability conflicted with the role of the impaired body, and how this created what she perceived to be unrealistic expectations:

> I regret how I may have handled the reality of her disability. I think for too long I have not accepted her disability as a true disability. And while there is good to that (I don't let it change how I treat her as less than human or something) there is also bad because I have expected things from her or maybe put unrealistic expectations on her, not recognizing that she is at where she is at and it may take her a little time for her to get to where I want her to be.
>
> (Farah, E-mail Transcript, p. 2)

Here several points emerge concerning the determination between realistic and unrealistic goals. Farah is the first to mention an emotional aspect, regret, when discussing the unrealistic expectations she had for her sister. While acknowledging the positive aspects of having unrealistic expectations (namely that she treats her sister equal to others without impairment), Farah also acknowledges that these expectations were creating conflict by failing to acknowledge the capabilities of her sister's body.

In short, participants' experiences with bodily difference often involved three main aspects; interactions between the bodily aspects of the disability experience, often in the form of perceived capabilities versus actual capabilities, the structural aspects, such as involvement with the medical institution which is required for diagnosis, and the cultural aspects, both in the form of developmental benchmarks and individual

perceptions of disability. Variations in participants' experiences could often be attributed to the acknowledgment of their sibling's impairment. In cases where the sibling's impairment was denied, either by medical professionals, participants' families, or themselves, the challenges created by bodily difference was often exacerbated. In cases where impairment was acknowledged, however, encounters with bodily difference and the challenges that sometimes accompany them were alleviated.

The Importance of Social Relationships

Social relationships played a large part in the disability experiences of siblings, and much like their experiences of encountering bodily difference, it encapsulated three of the four aspects of disability experience: structure, culture, and body. Within this theme the cultural aspects of the disability experience take into account two factors: broader cultural perceptions of impairment and the immediate social environment. For siblings, the immediate social environment, and either the support or stigmatization resulting from broader perceptions of impairment, often formed interactions. In and of themselves relationships within these social environments play a large part in the cultural aspect of disability whether they are relationships with spouses, siblings, parents or people located outside the home.

As seen in Figure 4, however, the importance of social relationships is not purely a cultural aspect of the disability experience but one that interacts and is sometimes exacerbated or alleviated by both the body and structure. Because non-impaired siblings often take on the role of pseudo-parent, and thus the bodily needs of their siblings with impairments, strong social support often serves to either alleviate challenges faced by the body. Stigma, on the other hand, can exacerbate them. Likewise, structural aspects such

as financial resources and access to outside care workers interact with social relationships

within the immediate environment the family home.
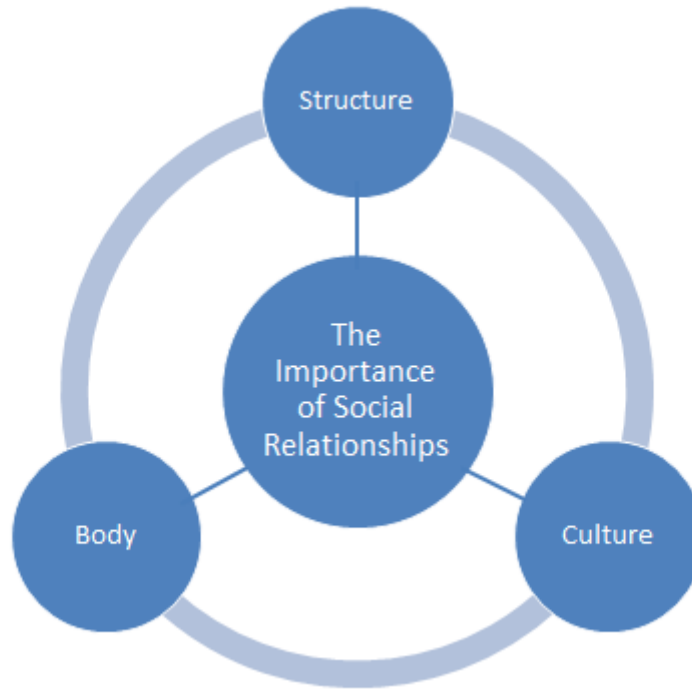
Figure 4: Importance of Social Relationships

Strong Social Support. Discussions of positive disability experiences were almost

always accompanied by inclusion of the sibling with impairment within participants'

broader social networks as well as the existence of strong social support. These strong

social support systems were often found among friends, family, and members of the

wider community not comprised. More often than not, the participants chose to align

themselves with individuals whose perceptions of impairment were supportive and

accepting. As a result, these feelings of inclusion and strong social support often created

a safe space for both participants and their siblings. This social support began in the

immediate social environment - the home - among family members and friends. Simon provided an example of this strong social support within his own home:

> Everything we've ever had, every party we've ever had, [Robin] was always a part of it. She was always accepted. There was never "oh that's Robin", there was never anything like that. (Simon, Interview Transcript, p. 4)

In this case, the cultural aspects of the disability experience were largely positive. Simon did not accept the courtesy stigma sometimes associated with having a sibling with an impairment. Rather, he actively created strong social support within his immediate social environment by including his sister in his social networks. Despite not being directly affected by courtesy stigma, it is important to note that Simon and other participants indicate that they were aware of the possibility of being stigmatized by describing the steps they took to locate and/or create supportive environments. Without prior knowledge of the concept or use of the terms stigma, participants indicated that they were aware of the negative cultural and social ramifications of having a sibling with an impairment. An example of this awareness is in an excerpt from Farah, concerning her social support network:

> I have been blessed with great friends and support. I don't think they have treated me differently, better or worse, because of her disability. If anything they have listened and encouraged me when I have been feeling discouraged or uncertain about how to relate with her. (Farah, E-Mail Transcript, p. 3)

In this excerpt we also see a cultural aspect of disability - in this case the acknowledgment of a broader cultural perception of impairment which Farah understands could result in the negative attitudes and reactions that Goffman calls courtesy stigma.

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While Farah acknowledges that she has not been treated differently because of her sister's disability, her excerpt is especially important because it highlights the unspoken understanding that broader social perceptions of impairment and resulting stigma might extend to those closest to individuals with impairment. In addition, Farah's acknowledgement that she is fortunate to have strong social support indicates that it has alleviated some of the challenges associated with having a sibling with an impairment. Strong social support can be thought of as a positive cultural aspect of disability. In some cases, however, the immediate social environment clashes with broader cultural perceptions of impairment, creating challenges for siblings who are juggling other personal relationships and sibling relationships.

Juggling Relationships. In a family where a child is born with an impairment, both parents have a mutual responsibility to ensure the well-being of their child. While there may be tension in the relationship due to unequal caregiving or other issues related to decision-making, the expectation that time devoted to a family member with impairments is just as important as time spent with others is common. In the context of sibling experiences, however, there were cases where the participants' marital satisfaction was impacted by the amount of time devoted to a sibling with a disability. When asked at the end of the interview whether there was anything important she felt hadn't been covered, Angela mentioned:

> I think one [disadvantage] I could mention that might be significant is that it can
>
> place a strain on, you know, your own relationship when you always have
>
> someone with a disability um calling, you know, needing you. And that has, that
>
> has occurred with my husband, as good as he is, when she calls four times during

a Rays game to tell me someone got a hit you know he's like, "there she is again".

But you know I don't want to discourage that with her, because I think it would

hurt her if I said "uh don't call me back" so I always say "just call me when you

see a homerun" or whatever. But it can be a little bit wearing on your own

relationship at times. (Angela, Interview Transcript, p. 10)

Because siblings occupy a transitional role between playmate and primary

caregiver it stands to reason that there may be some tension in relationships shared with

persons outside what Goffman referred to as the "Wise" group (Goffman 1963).

Angela's excerpt demonstrates how bodily aspects of disability (in this case her sister's

need to call often) interacts with cultural aspects of disability (in this case her husband's

impatience with Monica and his perception of the inappropriateness of her behavior).

This holds especially true in cases where siblings with a disabilities are living in their

non-impaired siblings' homes. In cases where non-impaired siblings have strong ties to

their family or consider family a priority, this may mean putting caregiving first—to the

detriment of their other relationship:

At one point, we kind of had that disagreement about my priorities, you know, I

told him—husbands come and husbands go, my family is always here for me,

don't make me choose because you won't like it.

(Angela, Interview Transcript, p. 2)

Here again we see the needs of the body/mind in conflict with the broader cultural

perception (in this case expectations about priorities). In the US, the culture is largely

informed by individualism and has shaped ideas of the life course, such that typically

siblings are not expected to be caregivers for their other siblings. In this case, because

Monica's emotional needs resulted in Angela juggling relationships, there was a disagreement about the nature of priorities - her sibling relationship versus her romantic relationship. This was especially evident in large families. For Emma, Angela's sister and sibling to eight others, this commitment to family meant the end a fifteen year relationship with her partner - a relationship that was also affected by her close bond with her sister Monica.

> [Her disability] affected my relationship with my partner because of the time
>
> spent with Monica and with my family. My partner really didn't understand and
>
> was from a small family, so a lot of various issues there.
>
> (Emma, E-mail Transcript, p. 2)

When it came to sibling impact on romantic relationships, not all cases were the same. The impact of siblings on romantic relationships differed depending on structural aspects of the disability experience - namely the living arrangements of those siblings. Some non-impaired siblings within the study chose to delegate responsibility to outside sources in order to alleviate some of the tensions created by becoming a primary caregiver. When asked whether his sister's disability impacted his ability to socialize as an adult, Simon responded:

> Well I jokingly say to my UPARC friends that UPARC saved our marriage
>
> because we were all living, all of us, in the same house. My sister is older than my
>
> wife, and my wife is working, and we'd come home and my sister might have
>
> rearranged some of the furniture. Did whatever she did, I don't care how much
>
> you love her [he laughs] there are times… (Simon, Interview Transcript, p. 8)

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This excerpt illustrates an interesting point about the structural aspects of juggling relationships. Structural aspects of the disability experience such as access to resources create a chain reaction in the lives of siblings. Access to resources allows for the use of paid caregivers and group homes, which ease the challenges presented by the body/mind aspects of living with a sibling with an impairment. This in turn alleviates some of the strain on relationships. Overall this interaction between body and structure, allows for positive cultural aspects such as greater social support. Without those structural resources, juggling relationships may become more difficult resulting in an impact in relationship satisfaction or in more extreme cases lead to courtesy stigma.

Courtesy Stigma. For some participants obtaining social support, whether within friendships or families, was also challenging due to their experiences with courtesy stigma (Goffman 1963). This was especially true in cases where siblings had a visible impairment. In these cases, the discredited identities of siblings with impairments were transferred onto the participants (Goffman 1963). An example of the courtesy stigma experienced outside the home was offered by Elle, whose sister Shana was both blind and developmentally delayed. For Elle forming friendships was difficult due to some children's fear of, and aversion to, bodily impairment:

> [Her disability] did affect my ability to socialize in the sense that some kids were afraid of her and didn't want to come over because of their fear of Shana. They were just afraid of her because she was different. She is the most loving person you would ever meet and would not hurt anyone, but kids don't understand that. They just would see her and that she looked different and acted different and would be afraid of her. (Elle, E-mail Transcript, p. 3)

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This excerpt demonstrates a different interaction between culture and bodily impairment than seen previously. Here the broader cultural perceptions of bodily impairment led not only to the stigmatization of Shana, who has the impairment, but also of Elle. This instance is also a demonstration of the way in which having a sibling with an impairment alters the perceptions of individuals - creating a unique sibling disability experience in which bodily impairment is the norm. While this courtesy stigma weakened some of Elle's potential social support, it did not appear to impact their sibling relationship in the long-term.

While courtesy stigma is often conceptualized in terms of friendships, it is important to note that it is not limited to those relationships. Extended families were also sources of courtesy stigma. In cases where there was no official diagnosis, or where extended families did not acknowledge the diagnosis (and as a result the bodily difference), individuals with impairments and by extension their siblings were treated as being defective. For Judith, her extended family's repudiation of the diagnosis resulted in their associating challenges presented by the body with bad behavior and thus led to blame.

> They didn't know how to handle her fits when she was little so I think they just
> attributed it to bad behavior instead of the Autism and enforced punishments.
> Certain family members didn't show up to her important events like a Christening
> or birthday parties. All these stories were instances that upset both my parents a
> great deal. (Judith, E-Mail Transcript, p. 2)

This excerpt serves to illustrate how the interaction between broader cultural perceptions of impairment and the body can sometimes result in negatively perceived

reactions, namely courtesy stigma, and how these reactions are also occurring within families. While stigma was attached primarily to her sibling, this courtesy stigma ultimately resulted in a severance of ties between Judith and extended family members, a loss that was most strongly felt during the holidays. Whereas families are often a source of social support in cases where a child has an impairment, Judith's extended family chose to physically isolate themselves. According to Judith:

All my holidays have been spent right at home with my parents and sister. I

haven't actually ever travelled anywhere for a holiday, and no one's ever come to

see us. (Judith, E-mail Transcript, p. 2)

This isolation during a period when most families in the United States come together, serves as a physical and social representation of the distancing that takes place as a result of courtesy stigma.

In short, while the theme of social relationships was largely comprised of the same three aspects as the previous theme (culture, body, and structure), these aspects interacted differently - with culture serving as an integral part of the sibling disability experience. In cases where people in the social environment acknowledged bodily difference, and there was an abundance of social support, sibling experiences were often perceived in positive ways. Social support, whether from family or friends, served as a means of alleviating challenges associated with impairment allowing participants to both communicate their narratives to others and to find alternative ways to relate to their sibling.

In cases where people within the social environment did not acknowledge bodily differences, however, and as a result social support was lacking, sibling experiences were

often riddled with conflict. Participants without social support found the challenges of impairment exacerbated. Often challenges both resulted in and from the varying degrees of courtesy stigma to which they were subjected by friends and family. The importance of social support, and the interaction of the cultural and bodily aspect of the disability experience, was especially prominent in this theme - suggesting that social relationships play a large part in the experiences of siblings.

The Mediating Effects of Resources

The mediating effects of resources (similar to previous themes) represents three of the four aspects of the disability experience: structure, culture, and body. It is important to note however, that while these three aspects contribute to the experience (both individually and as interactions), this theme is largely dominated by structure. Structural aspects of the disability experience in this case can refer to income or time, either (or both) of which can dramatically affect access to other types of resources such as outside caregivers or assisted living arrangements. For siblings who are primary caregivers, structural aspects such as income often interacted with and affected cultural aspects, such as their ability to maintain strong social support and juggle relationships.
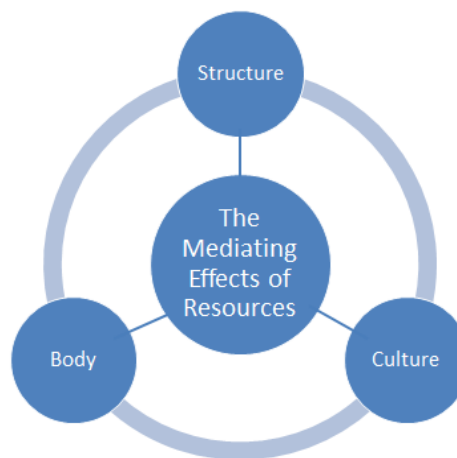
Figure 5: Mediating Effects of Resources

Access to Resources. Within the study the structural aspects of the disability experience most often took the form of access to key resources. Various kinds of resources were mentioned including: where the participants lived; financial resources that allowed them to participate in extracurricular activities; power in the form of social capital; and the ability to afford alternative living arrangements for family members with impairments. Most of the participants came from middle and upper middle class backgrounds which afforded them access to these key resources. When looking at social class, key resources such as income had an important impact on all other aspects of the disability experience.

For several participants, these key resources in some ways provided the ability for siblings to move beyond challenges faced in the home. It is important to note, however, that these resources alone did not take precedence over the importance of inclusion and strong social support in the narratives of sibling experiences. Karl, a graduate student from the North East, acknowledged that while these resources were available, in his case they were expected socially and were not an acceptable substitute for strong social ties.

> My parents really weren't I guess nurturing to the children or anything. We were just kinda there; my mom not so much, but my dad especially, he just seemed to do what was requested, what society required him to do for his children in his kinda status, and how much money he made; so pretty much he was required to pay for us to go to college, and do that kind of thing.
>
> (Karl, Interview Transcript, p. 8)

This excerpt illustrates the intersection between structure and culture. Structurally, Karl's parents had the resources to send multiple children to college and to

pay for alternative caregiving arrangements. Access to resources created a different

social environment for all the siblings in the household and created a wide array of

options in terms of housing and paid carework for individuals with impairments.

Because Karl did not provide carework for his sibling, this may have had an impact on

their relationship.

Financial assets were often linked to other structural resources that created

smoother transitions in the life courses of individuals with impairments and their siblings.

These resources were not limited to the home of the individual with impairment, but

could be found in broader social networks as well. For Simon, who grew up in the 1950s,

it was his grandfather's involvement in politics that paved the way for greater access to

resources such as developmental classes for his sibling, Robin.

> My grandfather was very involved in politics um state level um very, very strong
>
> and he was able to get her, maybe we could have gotten it without him—I don't
>
> have a clue, it was much easier and she went there for classes and other things.
>
> (Simon, Interview Transcript, p. 2)

This excerpt illustrates the importance of both structural aspects and cultural

aspects, and how the support networks created in privileged families often mean the

difference between having outside forces catering to the needs of the individual with

impairment and having to cater to those needs within the home. In many cases, the more

access to outside resources there were, the less structural and cultural strain on the

individual. This was particularly true in the case of living arrangements. For those who

were able to afford them, group homes provided a safe place for individuals with

impairments, giving families a respite from the challenges that often accompany bodily

difference. Group homes also satisfy the need for individuals to be considered

independent, an image of great importance in capitalist societies (Oliver 1990). For Karl,

this meant that from the time his brother reached adulthood, he was no longer living in

the home, an important cultural expectation for both individuals and their families:

> He lives in a group home, he's lived in a group home since about 19…I guess
>
> when he got out of whatever would be considered school age. I guess when he
>
> became an adult, 18, that's when things changed where he had to be somewhere
>
> else besides school or that kind of environment.
>
> (Karl, Interview Transcript, p. 11)

In this excerpt, access to resources meant that Karl's brother, Mark, was able to

move out of the house at the age of eighteen - satisfying a normative life-course goal -

and achieving some form of independence. As a result, neither Karl nor his mother has

been required to provide informal carework for Mark. Therefore, in this particular

family, structural aspects have alleviated the accompanying stress and worry that often

permeates these atypical sibling experiences due to bodily impairment. Overall, access to

resources often led to an improvement in the formation and maintenance of sibling

relationships. In addition, learning to navigate these resources throughout the life course

in some cases led to a greater desire to advocate for those who could not manage on their

own

Caregiving. Beyond both coming to terms with bodily difference and with their

own perceptions of how those bodies functioned, participants were sometimes faced with

the needs of their siblings' bodies being imposed on their own - this was often expressed

in the caregiving aspect of their sibling experience. Caregiving often took the form of

either physical or intellectual help and was not limited by age of respondent. Caregiving

often occurred during childhood as well as adulthood with the responsibilities shifting

over the course of their sibling relationship. An example of childhood caregiving comes

from Tara; the caregiving she provided was in a limited but regular capacity with a

specific time component.

> [When] mom would try to take a nap or something…I would like watch my sister
>
> a little bit. When she was much younger we would walk around the neighborhood
>
> or out back or whatever. But when she was more sick, when my mom was home,
>
> I would take care of her. (Tara, Interview Transcript, p. 5)

In this excerpt we see the interaction of body, structural, and cultural aspects of

the disability experience. While she was not expected to provide caregiving in an

unsupervised environment, Tara did provide caregiving in terms of both physical

activities ("walking around the neighborhood") as well as time - creating both bodily and

structural aspects of her experience. Culture is also exhibited in this excerpt in terms of

gendered caregiving and the expectation that Tara would watch over her sister. The lack

of respite care within the home, and the reliance on informal caregiving, indicates a

strong structural component to this particular sibling experience.

Caregiving in the form of time was often mentioned in the interviews. Although

participants did not have impairments themselves, their experiences were molded by the

needs and capacities of their siblings. These disability experiences were often

exacerbated when carework was left to informal caregivers - creating a strong structural

aspect to these particular impairment experiences. An example of the benefits of

structural support, and the ramifications for siblings when it is missing, is the example

given by Judith. In Judith's case, her sister Alice who had both Autism and further behavioral problems previously had structural support, but after moving to Florida, the structural support was no longer available.

> When we moved to Florida is when I took care of her the most. My sole
> responsibility was mostly to be home when she was and my parents were not.
> This was mostly because when we moved here she didn't have those services
> anymore so all she had was school. Her bus was typically later than mine, fingers
> crossed, so I'd get home first and wait out and watch for her bus to pull up. I'd
> make her a snack, and that was about the extent of it until my parents got home.
> (Judith, E-mail Transcript, p. 4)

This excerpt illustrates an experience occurring in families that lack structural support. For Judith, a lack of structural support translated into her caregiving role extending beyond providing the occasional respite to her parents and into a pseudo-parent role with increased responsibility not usually associated with typical sibling relationships. In this excerpt we also see examples of the bodily aspect of the disability experience. While Alice was able to do most of her daily activities on her own, Judith was responsible for feeding and safely escorting Alice from the bus stop to their home - something that she was unable to do herself given her developmental impairment.

Depending on severity of the impairment, participants also were responsible for helping their siblings accomplish activities of daily living. This increase in both responsibility for their sibling's physical body and time transferred in a lesser way the challenges of the impaired body onto the sibling experience. In the case of Elle, whose

sister Shana is blind as well as developmentally impaired, this experience is likely to last throughout her life-course:

> As long as I can remember I have helped take care of Shana. From a young age I would help her get to the bathroom and make sure she washed her hands. I have also helped her bath, brush her teeth, get dressed, and help her eat. I have also helped her get to bed and get around places because she needs lots of guidance when she is out of the house because she is blind in addition to being developmentally delayed. As we have gotten older I also have helped out taking her to doctor's visits. (Elle, Interview Transcript, p. 2)

This excerpt also illustrates bodily and structural aspects of the disability experience, but unlike previous examples Elle's role consisted more heavily of the bodily component. In this excerpt we see how Shana's bodily needs (feeding, bathing, going to the bathroom) were imposed on Elle's body at a young age. Without Elle's body to help her accomplish tasks, Shana would have been unable to do everyday activities that are often taken for granted. Here too we see structural aspects of the disability experience. A result of not having paid caregivers in the home was Elle's increased role in providing informal caregiving not often seen in typical sibling relationships.

In addition to driving siblings to doctor's visits, individuals with impairments also require a certain amount of advocacy and financial assistance in order to gain some kind of independence. For Emma, trying to provide a sustainable way of life for her sister Monica is very much related to financial resources. Because her mother is unable to continue supporting Monica due to her own health conditions and impairments, Emma has taken on the role of advocate for her youngest sister:

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I never had to [take care of her] growing up because my parents were primary for

Monica. Now as an adult I am Monica's advocate and oversee her care and am

involved with the agencies provided supported living and coaching services to

keep her independent in the community and in her home. Monica and I purchased

a house together that she lives in with assistance. I help her with her finances and

with the recent Medicaid cuts. (Emma, E-mail Transcript, p. 2)

This excerpt demonstrates two points important to the idea of caregiving within

the sibling relationship. First, that caregiving in the case of siblings with impairments is

not always primarily physical. While Emma experiences less of a bodily component of

disability, the way in which she provides caregiving is largely structural. Secondly,

because Emma has the resources to purchase a home for Monica, and has located and

enlisted formal support structures, she has demonstrated the ability of formal support

structures to alleviate the challenges created by bodily impairment. The use of formal

support structures may account for some variation in the bodily aspects of caregiving.

Bodily impairments are intricately tied to the challenges faced by both individuals

with impairments and their families. For siblings, these impairments themselves and the

process through which siblings come to terms with these impairments create a foundation

for the disability experience. The challenges of bodily impairment are often exacerbated

by our perceptions of individuals with impairments. These perceptions extend beyond

the bodily impairment and to cultural expectations of the body's capabilities. In this way

the bodily and cultural aspects of disability are in constant interaction.

Taking on the Advocacy Role. Often considered a part of caregiving, advocacy

for the impaired was a structural experience that stretched across sibling narratives of the

disability experience. For some, this involvement in advocacy shaped personal lives. For others, it resulted in the shaping of careers. Participants who spoke of advocacy often spoke of it as an empowering experience that allowed them to help others in vulnerable situations similar to those of their own siblings. An example of the sibling experience creating a desire for greater advocacy was obtained from Angela:

> I think it's just kind of made all of us um just want to learn more about the circumstances around her and, you know, even more lately than before, the system how to work and advocate for her in the system so that she has the best quality of life. So we're becoming more informed and active in terms of that system whereas before my parents were her advocates and now we're stepping into that role so that's really been the major thing because we want her to have every advantage that she can and high quality of life as she can.
>
> (Angela, Interview Transcript, p. 2)

For Angela, her sibling experience created a larger desire to learn about the structural aspects of the disability experience (namely the system through which her sister received assistance) in effort to provide the best possible life for Monica. Interestingly, it is important to consider what structural resources lead up to the ability to advocate for a sibling. In order to become an advocate several structural factors normally have to be in place: the ability to find time to research advocacy issues, financial resources, and often knowledge about the rights and needs of individuals with impairments.

Angela's sister, Emma, also learned more about the system but her sibling experience impacted her desire for advocacy more broadly. As a result of her experience with the system as an adult, Emma's personal goals evolved into a desire to enrich the

lives of those individuals who had a developmental impairment like Monica. In many instances this desire for greater advocacy and structural support required participants to dedicate time in order to learn how to best understand the system and how it could best serve those who have impairments. When discussing what she has learned from her disability experience, Emma mentions:

> I have also learned a great deal about the "system" and vow to become an even better advocate for Monica in the future. As I slow my career down in the future, part of my time will be devoted to causes to help enrich the lives for the developmentally disabled community in St Petersburg. There is still so much I need to learn about the system. (Emma, E-mail Transcript, p. 4)

This excerpt demonstrates again the multiple parts that make up the structural aspect of the disability experience, and how one part (in this case, time) can impact other parts of the same aspect (advocacy). Because Emma is in a position to dedicate more time in the future, she will be able to take a greater role in advocacy not just for her sibling but for other individuals with impairments, creating another variation in the disability experience. In some cases the desire for greater advocacy shaped not only personal lives but professional lives as well. In Elle's case her career as an attorney has become shaped by the desire to help others who have been disabled by structural and financial barriers. Much of her clientele in these cases consist of those who are impaired themselves rather than assisting family members.

> My career revolves around workers' compensation and social security disability. I chose to go into this field because I wanted to do things to help other people.

Many of my clients have physical, emotional, and some even have developmental

delays. (Elle, E-mail Transcript, p. 1)

In this excerpt, we can see how cultural aspects of the disability experience (in

this case perception) interact with structural aspects (work) as well as bodily aspects

(clients with impairments). Using her career, Elle is in a unique position to help

individuals with impairments obtain compensation which can alleviate some of the

challenges of bodily difference while allowing for independence. While advocating for

individuals with impairments was mentioned by several participants, one respondent in

particular mentioned the need for advocacy to extend beyond those individuals to include

their families:

For medical professionals, especially as I am a nurse, I think there needs to be

more information out there about disabilities and supportive stuff for family

members. Like how to handle those sorts of things because don't really tell you

much, they tell you there is a medical problem, eventually, and you have to jump

through a lot of hoops. You have to see a lot of people and there's a whole

process to being diagnosed with anything too.

(Tara, Interview Transcript, p. 10-11)

This excerpt demonstrates not only the importance of structural aspects such as

advocacy in the lives of siblings, but also the implications of extending current models of

the disability experience to family members. By extending the current Interactional

Model beyond individuals with impairments to family members and those with whom

they share intimate social connections, there is a possibility that there could be greater

advocacy for families. For Tara, who works within the medical profession, her desire for

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advocacy also contains one of the most fundamental critiques of Parson's (1963) "sick role" and the failings of the Individual Model: the use of jargon and the requirement of narrative surrender to medical professionals (Frank 1995).

As a theme, the mediating effects of resources consisted of the same aspects of the disability experience (structure, body, culture) as previous themes, but with a strong emphasis on the structural aspect. Access to both concrete and abstract resources (financial stability and time) alleviated some of the challenges of having impairment. When their families had access to these resources the sibling experience of disability included less of a bodily component - meaning that the needs of the sibling with impairment were less likely to impact the lives of participants or to be enacted through their bodies.

In cases where there was a lack of structural support, however, there was often a large bodily component to the sibling experience, often in the form of carework. Participants whose families did not utilize formalized careworkers were more likely to discuss spending time watching their sibling, or helping them complete daily activities of living such as eating or dressing. Furthermore, reliance on informal carework increased the chances of a role shift from typical sibling to pseudo-parent, a shift which often led to complex emotions about the sibling disability experience.

Complex Emotions and Sibling Experiences

While the Priestley's approach (2003) includes the aspect of identity within the disability experience, based on the interviews and experiences of siblings within this sample, there is a need for expansion of the current model to include another category: complex emotions. Similar to other aspects of the disability experience, emotions are

tied to the socio-historical culture in which we develop; in this way there is an interaction between the cultural aspect and the emotional aspect of the disability experience.

The emotions expressed by individuals with impairments, and in many cases their families, are often the result of cultural expectations - otherwise known as "feeling rules" (Hochschild 1983). These feeling rules dictate what we can feel and when. Within the disability experience then, complex emotions can be thought of as being beyond physiological and instead consist of how participants "define, interpret, and endow perceptions of internal states with meaning" (Karp 2007: 101). Because individuals imbue emotions with certain meanings (Karp 2007), adding an emotional component to the current model could help to account for some variation in disability experiences. Often we see this conceptualization of emotions as being determined by social factors, which prescribe which emotions we can express and how (Stearns and Stearns 1985; Hochschild 1983), reflected in the use of culturally approved narratives such as the restitution or quest narratives (Frank 1995).
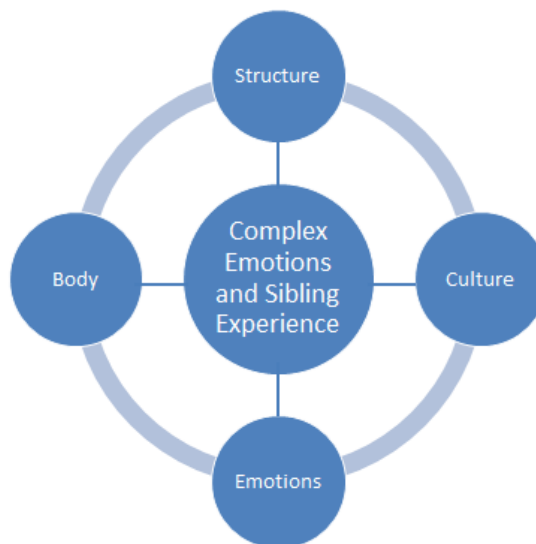

Figure 6: Complex Emotions and Sibling Experiences

It is through narratives that we begin to understand not only the individual disability experience but also the feeling rules that exist within our society and the emotion management that goes on when we seek to resist or conform to them (Hochschild 1983). In situating their emotions within the disability experience, individuals may either embrace or resist such feeling rules and larger cultural narratives, such as the restitution or quest plot (Frank 1995), but either choice impacts their greater disability experience. While a full exploration of the feeling rules associated with the sibling experience is beyond the scope of this thesis, complex emotions definitely played an important role in the narratives participants constructed during the interviews. Empathy, pride, regret and concern for the future were particular common themes.

The Advantage of Empathy. Several emotional advantages to having siblings with impairments were discussed, but there were two advantages in particular that seemed to resonate with all of the participants: a keener ability to empathize, and pride in a sibling's accomplishments. These advantages were often seen as enhancing the participant's identity and were presented as things that had been learned from the disability experience, similar to the quest narrative and consistent with the Social Model (Frank 1995). These advantages were discussed at all stages of the interview and were common across ages and cohorts. In particular, a keener ability to empathize with others was mentioned as an advantage to having a sibling with a disability by the majority of participants. This empathy extended beyond just their own sibling to others with disabilities, their family, as well as those without disabilities. When asked about positive experiences as a sibling to an individual with impairment, Farah mentioned:

I think it has helped me to be understanding of others in similar situations, whether that be a disabled person or a relative of a disabled person, and that is positive…I have learned compassion and patience! I have learned that relationships take time and need to go at the pace that is needed for the relationship. I have also learned to be understanding with others, taking time to see where they are coming from. (Farah, E-mail Transcript, p. 2-3)

In this excerpt, there is an interaction between the cultural aspect, the emotional aspect, and the bodily aspect. Here we see the cultural aspect in terms of perceptions of ability, the bodily aspect in terms of actual abilities, as well as the emotional aspect in terms of learned emotions such as compassion and the ability to empathize. Empathy for those who were also experiencing a disability and for members of their families was a common theme among participants. Many, such as Tara, mentioned that having a sibling with a disability taught them to be more considerate of persons with disabilities and less likely to stigmatize:

Well, it gives you more empathy toward other kids that are handicapped and gives you a better understanding of what they're going through. And it also I think makes you appreciate all the things that you have because people don't realize that we're very lucky we can walk, talk, do things, take care of ourselves, have a functioning life, and do all the things we want to do. When you're handicapped, especially if you can't walk or talk, you're not going to be, like going to the beach, doing sports, like those are things you're not going to be able to do. So every day that you have, that you think was crappy, it's not as crappy as somebody else's. (Tara, Interview Transcript, p. 10)

This excerpt demonstrates a variation in the interaction between the cultural and emotional aspect of the disability experience. Tara has not only experienced emotional growth (increased empathy), but also has adopted the quest narrative in the telling of her disability experience (Frank 1995). This can be thought of in this case as the incorporation of cultural feeling rules. Tara's usage of the quest narrative when describing her disability experience is evident in the way that she describes appreciation for her own able-bodiedness and her sense of luck.

Feelings of Pride. A second emotional benefit mentioned by participants was the sense of pride participants felt in their siblings' accomplishments. Accomplishments in this case seemed to involve achieving more than the cultural expectation or perceived capability of participants (for example, a sibling with Autism learning to form social relationships). Though not always directly involved in these accomplishments, participants still felt a sense of pride which they reported as a benefit to having a sibling with a disability. When discussing what he was most proud of, Simon mentions his sister Robin's move for independence and work ethic:

> We were both very proud of and pleased, and blessed, the day she said she was moving out; she was moving to UPARC group home, you know…Her work ethic, she was on disability but she would catch the bus and do two changes to get to the beach to work in the kitchen at the Holiday Inn.
>
> (Simon, Interview Transcript, p. 9)

This excerpt demonstrates a variation in the interactions between emotional, bodily, cultural, and structural aspects of the disability experience. Feelings of pride were in many cases related to a sibling's accomplishments in spite of bodily difference.

Often the accomplishments mentioned by participants involved what are considered typical milestones in the life course - both structural and cultural expectations that individuals will work and achieve independence. Simon's pride involved his sister's ability to become a semi-independent person with her own home and a strong work ethic. In the case of Farah, similar accomplishments were mentioned, but with a stronger focus on relationships.

> She is really wonderful. I am proud of her and how far she has come: graduating high school, making friends, being social and coming out into the world a lot more. (Farah, E-mail Transcript, p. 2)

For Farah, the cultural expectation that individuals socialize and form relationships was much more important when looking at the interactions among her emotional, bodily, and cultural aspects of disability experience. For many participants, watching their siblings rise above and beyond their expectations was a positive emotional experience. The majority of participants expressed an interest in watching their siblings grow and become productive members of society. While enhanced empathy and pride were consistently mentioned among participants, often as an advantage to having a sibling with an impairment, the disability experience of siblings is one filled with complexity especially when discussing emotional aspects. For many participants, along with enhanced empathy and pride, there were feelings of regret and concerns for the future of their sibling.

Feelings of Regret. Aside from the conflict between cultural expectations of independence and marital relationships almost every respondent described a sense of regret over their inability to balance spending time with their sibling and managing their

own lives. When asked about possible disadvantages or perceived negative experiences associated with having a sibling with an impairment, participants often brought up the way in which they wrestled with a sense of regret. Karl, a former member of the navy and non-traditional graduate student, identified the source of regret immediately:

> That's easy, that's the thing where I could have gone and gotten him and brought him into my house a lot more. You know, just cause, you know how you get busy, you're really not as busy as you think you are. You know, you think every minute is taken up, but it's really not if you really look at the situation. I could've yeah gotten him more than I did, I do really regret that, because I know how much he loves that. (Karl, Interview Transcript, p. 13)

Karl's excerpt demonstrates how emotional aspects such as regret, structural aspects such as time, and cultural aspects such as the expectation of boundaries between siblings' lives interact. In his example, Karl is able to define and interpret the reason behind his feeling of regret - the conflict between the structural and cultural aspects of his disability experience. Other participants had a harder time identifying what they regretted most. While most participants acknowledged it would have been possible to spend more time with their siblings, others wondered whether there was more that they could have done with or for their sibling. When Simon discussed the idea of regret he came to the conclusion that:

> I think every day we regret. Could I have taken her on one more trip, could I have done this, could I have done that? There is always those kinds of things was there something we should have done that we knew about that we should have? No, I

don't think so. Could we have done something better? Well we could always do

something better. (Simon, Interview Transcript, p. 9)

Simon is able to express a regret that is not only woven throughout the narratives

of the other participants but one that is unique to this atypical sibling experience. Within

this excerpt we can see the importance of structural resources, specifically in the form of

time, even on emotional aspects of the disability experience. For Simon, despite having

access to financial resources that alleviated some of the challenges created by his sister's

bodily difference, he interprets his feelings of regret as being a result of possibly not

utilizing structural aspects to the best of his ability. For many siblings, this uncertainty

and regret were also discussed in terms of "not enough":

> I feel like I could have spent more time with her but I didn't. But then I try to tell
>
> myself, I could've possibly spent more time with my family when I was younger
>
> too, I dunno I just feel like it's never enough, like I should've done a little bit
>
> more. Or you know, a little bit more time. So you know that was my regret.
>
> (Tara, Interview Transcript, p. 10)

This excerpt also highlights the importance of structural resources such as time on

emotions of regret. Tara describes this experience as feeling like it's "never enough". In

the case of typical sibling experiences it is not uncommon to spend time with siblings

infrequently, but in cases where one sibling has an impairment, the cultural expectations

are different. For Tara, much like other participants, the expectation is of constant giving

- of time, attention, and in some cases resources. These regrets and concerns were often

mentioned as the relationship began to change and participants began to transition from

the role of sibling to pseudo-parent.

Future Concerns. In addition to impacting the formation and maintenance of sibling relationships, the participants' perception of sibling capability and (as a result their additional role as a pseudo-parent) also impacted the participants' concerns about long-term care arrangements. Participants voiced concerns about who would take care of siblings when their parents were no longer capable of doing so, and concerns about making sure that siblings were able to lead safe, productive lives. When expressed, concerns about the future were often complex and intermingled with sadness and worry about long-term care arrangements. When asked about her experience having a sibling with a disability Farah mentioned:

> I think that if I think into it too much, I can be sad about it. Wondering about her future, how will she do? Will she get married or have kids? What happens when my parents pass on? Can she take care of herself? Will I have to take care of her? These are just some questions I think about. (Farah, E-mail Transcript, p. 2)

This excerpt illustrates the interaction between emotional aspects, structural aspects, and cultural aspects. For Farah there are feelings of worry and concern when contemplating the structural aspects that will come into play when her parents pass away. Because informal carework is often used, sometimes as the result of cultural expectations, siblings of individuals with impairments are often faced with questions about long-term care arrangements. Usually these siblings lack formal support structures and become primary caregivers with little knowledge about larger structures which could alleviate some of the challenges presented by bodily difference. These questions about the future and concerns about long-term care arrangements were expressed across ages and cohorts.

For older participants, there was an added concern - that of preparing a third generation for the responsibility of caregiving. Angela in particular expressed a worry about her sister Monica's possible future should neither she nor her siblings be able to provide care in the future:

> I think you always worry, you know that she's the youngest. What happens if we're, what happens if we're, she has to suffer through seeing, not that there's any guarantee but you know she sees us go, and who's going to care for her, and making sure someone in the next generation is equipped to do that. You know, just wanting her to be always in a good place, and comfortable, and taken care of. (Angela, Interview Transcript, p. 9)

Similar to previous excerpts, we see the interaction between the emotional aspects, the cultural aspects, and the structural aspects of the disability experience here. While Angela and her siblings do employ the help of formalized caregiving structures, there are still feelings of worry and concern for Monica's future well-being, and a cultural expectation that this well-being will be looked after by family. These concerns about the future were sometimes exacerbated depending on the types of disability and on whether multiple disabilities were present. Where individuals had developmental or cognitive delays, the concerns for the future went beyond where the sibling would live, and to whether or not they would be taken advantage of by the able-bodied society around them. For Elle whose sister Shana was both blind and developmentally delayed, these concerns were combined with feelings of guilt and fear. These feelings are thought of as unique to this type of sibling experience, where one party is considered vulnerable.

I always worry about Shana because she really isn't able to care for herself. I

have tremendous feelings of guilt when I don't see her as often as I would like to.

It is VERY scary to have someone in your life that can't take care of themselves

and is incredibly vulnerable. I constantly worry that people are going to hurt

Shana or take advantage of her because of her…because she can't defend herself

in any of those situations. It adds a tremendous amount of stress to life that

people who don't have a sibling like Shana could not even relate to.

(Elle, E-mail Transcript, p. 3)

For Elle, the emotional aspects of her disability experience, namely the feelings of

worry and guilt, interacted more strongly with the bodily aspects than seen in interviews

with other participants. The focus in this excerpt rather than emphasizing cultural

milestones such as marriage, or structural aspects such as long-term living arrangements,

was on bodily harm as a result of having impairments. In the end, these future concerns

were a sub-theme that ran through all ten interviews. Many participants were still

searching for answers to alleviate their concerns about the future, but there were several

that saw the responsibility of caring for their sibling as already incorporated into their

role. While parents worry about the future in terms of what will happen to their children

once they have passed away, siblings often worry about the future in terms of choices

they will have to make. Many have already decided to step into the role of caregiver - a

role that they will likely play long after their own parents have gone. For Mike, for

example, this decision has already been made and he reassures his parents that he will

step in when needed:

He seems to be doing fairly well, [but] we worry about the future: what it is going to be like for him when he gets older and goes through puberty, you know, is he going to be able to take care of himself or live by himself or go to college or you know all these things. And my mom is so worried about "well what if we get in a car accident tomorrow, who's going to take care of him". And I'm like "you don't need to worry about that, I can handle it." It would be difficult but it would get done… it's kind of interesting because in some ways I see him more as like part of my child than I do as a sibling. (Mike, Interview Transcript, p. 4)

This excerpt demonstrates the interaction between emotional, bodily, cultural and structural aspects. While Mike expresses feelings of concern about the future and whether his brother Charlie will accomplish some of the cultural milestones (such as going to college or achieving independence) his decision to become the next primary caregiver has already been made. Recognizing that it may be hard in terms of structural aspects, Mike's decision to become the next primary caregiver is an acknowledgment of Charlie's bodily difference and the importance of strong social support in families with children with impairments.

In summary, the complex emotions associated with the sibling disability experience were often associated with the unique responsibility participants felt both as siblings and as pseudo-parents. Discussions of these complex emotions often followed a set of "feeling rules" as illustrated in the use of common narratives such as the "quest plot" (Frank 1995). While the quest narrative is often used to describe the belief that something was to be gained through the experience of illness (Frank 1995), siblings also employed the quest narrative while describing the emotional aspect of their experience.

In particular, when participants discussed the development of enhanced empathy, they did so in a way that suggested it was the experience of having a sibling with an impairment that allowed for this development.

Other emotions such as pride were also governed by cultural expectations—specifically those expectations based on developmental benchmarks. Participants often felt pride when their sibling accomplished typical milestones such as graduating from high school, living semi-independently, and forming social relationships. Emotions such as regret and concern, however, were also an important part of participants' experiences as they transitioned into a pseudo-parent role. For these participants, the role of siblings was not as clearly defined as in typical sibling relationships. The fluid nature between roles often led to feelings of regret and concern with regret occurring when participants were unable to determine whether what they gave to their sibling was "enough" and concern when they considered their future role as a pseudo-parent to their sibling.

CHAPTER SIX: DISCUSSION

It is important to note that my research design has several obvious limitations. First, the sample size is small and based on recruitment of participants through snow ball sampling beginning with individuals known to my committee members. Findings will, therefore, not be generalizable to all siblings. This type of exploratory, qualitative study is, however, appropriate when little is known about the topic (Neuman 2011). Future directions would include expanding the number of interviews conducted, including more racial/ethnic diversity, a broader range of age groups, and a larger sample of male participants. Further research is needed examining the experiences of racial and ethnic minorities in order to understand how race interacts with impairment, structural aspects such as resources, the cultural aspects of caregiving, and emotional feeling rules. By gathering interviews from a broader range of age groups future research could explore the emotional turning points in the sibling experience, the experience of shifting roles from sibling to primary caregiver, as well as the impact of the sibling disability experience on marital relationships. In addition, a greater number of male participants are needed in future research to examine how gender impacts the sibling disability experience in terms of structural resources such as time and income, as well as more bodily and cultural aspects such as caregiving. Despite these limitations, however, this project has added to our understanding of the sibling experience in several important ways.

Findings support the idea that the disability experience is not limited to individuals with impairment. As Goffman suggests, members of "the Wise" category are

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privy to the experience of disability - at least vicariously. The experiences described

throughout the narratives constructed during the interviews indicate that the sibling

disability experience is complex, varied, and includes all components of the Interactive

Model of Disability. Participants of this study emphasized the interactions between

intrinsic factors (such as emotions) and extrinsic factors (such cultural expectations and

resources). Frequent encounters with bodily difference allowed siblings to experience the

interaction between impairment and social structures. Appropriate acknowledgment and

acceptance of bodily difference by friends, family, and medical professionals, for

example, allowed some of the challenges associated with bodily impairment to become

alleviated; lack of acceptance or appropriate acknowledgement lead to experiences of

courtesy stigma and a lack of social support.

Access to resources also created variations in the sibling disability experience.

Where resources were scarce and there was a lack of formalized caregiving in the home,

challenges associated with impairment were exacerbated. Siblings were more likely to

become informal caregivers within the home, often beginning during adolescence.

Where resources were plentiful, formalized structures were more likely to be used such as

paid careworkers and assisted living facilities, allowing siblings to better navigate

relationships with siblings, the acquisition (or planned acquisition) of the pseudo-parent

role as well as their outside relationships.

Navigating through this experience was often complex emotionally as well as

socially. Participants felt a unique responsibility not often associated with typical sibling

relationships. In some cases, this sense of responsibility led to feelings of concern about

the future, particularly when discussing long-term care arrangements. The vast majority

of sibling narratives indicated that the sibling disability experience was one which allowed for the development of enhanced empathy and feelings of pride. These complex emotions were varied depending on the interaction of emotions with cultural expectations as well as the types of bodily impairment.

The findings of this study have several important practical implications including: (1) the need for greater inclusion of extended family members in the lives of individuals with disabilities and their siblings; (2) the importance of community support programs; (3) the positive potential of formal caregiving on sibling experiences; and (4) the need for greater inclusion of siblings in discussions of long-term care arrangements. Discussions concerning social support indicate that it plays a large part in the variations of the sibling disability experience. The first implication then of this research is the need for greater involvement of extended family members in the lives of siblings. This research has shown that in cases where extended family provided siblings social support, siblings perceived their disability experience in a positive way compared with siblings who were the recipients of courtesy stigma from extended family members. The inclusion of extended family members may also provide siblings with a safe space in which they can discuss their experiences and gain support for the development of their sibling relationship. Because not all siblings will have access to strong support from extended family members, it is also important that sibling support programs address issues like how to resist and counter courtesy stigma, how to juggle relationships and how to find, maintain and actively create supportive environments.

Outside of the extended family, this research has certain implications for communities - namely that these disability experiences indicate the need for community

support programs in which siblings of individuals with impairments can come together with similar individuals. Many of the variations in the sibling disability experience were the result of cultural components such as social support and courtesy stigma, structural components such as resources, and emotional components such as concerns about the future. The problem then is in understanding how we can extend these positive perceptions of impairment in cases where siblings do not have these support systems in place. Community support programs could provide several benefits to siblings of individuals with impairments - specifically by focusing on programs which create a safe space for siblings to discuss their disability experiences with other siblings as well as workshops that could help them understand and function in their changing role in the family. Because these roles change over time it is important that siblings receive training that is age appropriate, culminating in the knowledge of how best to advocate for their sibling with impairment, especially if they are to take on any sort of caregiving role.

In addition to the increased need for social support, this study has important implications regarding paid versus informal caregiving. Use of formalized caregiving arrangements, whether assisted living or in-home care, has in the majority of cases resulted in positive disability experiences amongst siblings. If the goal is to alleviate challenges associated with impairment, then it is crucial to understand how structures can provide positive impacts on the lives of siblings. Further research is needed to clarify whether the use of formalized caregiving arrangements has alleviated some of the challenges, or whether other structural aspects such as income, have resulted in these positive perceptions. Because many families rely on siblings to provide some type of

informal caregiving, another important implication is the need for inclusion of siblings in discussions of long-term care arrangements.

The processes of shifting between the sibling and pseudo-parent role were most often discussed by participants in terms of emotional developments - specifically concern about caregiving arrangements once parents were no longer able to serve as primary caregivers. These concerns may be the result of a lack of communication between parents and siblings about the disability experience and the responsibilities that come with being siblings. These discussions are especially important in cases where parents lack structured support as siblings will be thrown into the advocate role with little help once their parents require care themselves. Previous studies (Heller and Kramer 2009) have suggested that only 32 percent of families have identified a future caregiver for their impaired child. This means that 68 percent of families have no plan in place once the primary caregiver is gone - if siblings are unprepared to take on this role they may face greater challenges than if discussions about long-term care arrangements had taken place. While participants often discussed the emotional aspect of caring for their sibling, few mentioned structural aspects such as income and how informal caregiving would impact their lives should they become the primary caregiver. The implication is that families should include siblings in these conversations about the future in order to alleviate some of the challenges that accompany impairment. In light of these results, it stands to reason that future research into the familial process of choosing long-term caregiving arrangements is needed.

My findings contribute to both the literature on families of individuals with impairments as well as to the discourse on the emerging view of disability as an

interaction (Priestly 2003; Shakespeare 2005). While this Interactional Model was originally meant to frame the experiences of individuals encountering disability, this model is not solely limited to these individuals but rather, like concentric circles, can be used to express the varying degrees of disability experience that all who possess intimate social relationships with individuals with impairments share.

During the course of this study, I began to reflect on the complexity of my own sibling experience. While I fully recognize the interactional nature of my sibling disability experience, there were several points in time where I was unfamiliar with the experiences of my participants. Many of the emotional aspects - such as the sense of pride and regret - I found eerily familiar. However, in terms of structure (specifically the use of formal caregiving) and cultural perceptions of impairment (specifically courtesy stigma), I have come to the realization that my experiences do not line up precisely with those of my participants.

While my participants and their families largely utilized formal structures such as paid caregivers, my family has relied on informal caregiving from the beginning. Because my parents were determined never to leave Jimmy alone with people they considered strangers, they rearranged their work schedules so that one parent would be home during the day and the other at night. Their choice to utilize informal caregiving resulted in my sibling disability experience involving lots of interaction between the bodily, structural, and cultural aspects. Growing up I often helped my brother complete daily activities of living (such as feeding himself) and occasionally stepped into the role of pseudo-parent when my parents weren't home. This reliance on informal caregiving may have some basis in cultural expectations related to ethnicity - something future

researchers should consider when trying to understand factors that create variations in the sibling disability experience.

Other differences I noticed between my experience and that of my participants, was the amount of courtesy stigma I encountered over the years. While the majority of my participants had lots of social support, and rarely discussed instances of courtesy stigma, I experienced courtesy stigma in multiple facets of my community. Whether it was parishioners staring during the children's mass at church, or when the barber told us never to bring my brother back to the salon, I was consistently aware of how people reacted to my brother's impairment and the isolation it created. These experiences of courtesy stigma occurred less often when our family moved, indicating that geographical place may have some impact on experiences of courtesy stigma - another area for future research to address.

This research has expanded the application of the Interactional Model to include a branch of those considered "the Wise" (Goffman 1963) - allowing for a greater understanding of factors that contribute to the variations in the sibling disability experience. It stands to reason that there are variations of the sibling disability experience that I was unable to cover through this research design. These variations of the disability experience will require future exploration if we are to fully understand the experiences of siblings. Continuing to expand this model in the future to include other branches of "the Wise" (including parents, spouses, and paid caregivers) will contribute to further discussions regarding how aspects of the disability experience interact. It is my hope that this research leads to further discussions regarding these interactions and how best to help families move beyond challenges posed by them.

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APPENDIX A

Participant Name	Age	Race/ Ethnicity	Sex	Sibling Name	Sibling Disability	Interview Medium
Mike	20s	White	Male	Charlie	Mild Autism	In-Person
Angela	62	Italian	Female	Monica	Brain Damage	In-Person
Mary	54	White	Female			E-Mail
Emma	52	Italian	Female			E-mail
Simon	60s	White	Male	Robin	Cognitive Impairment	In-Person
Farah	28	Jamaican/ Black	Female	Lisa	Autism	E-mail
Elle	30	White	Female	Shana	Blind, Developmental Delays	E-mail
Judith	22	White	Female	Alice	Autism, Behavioral Issues	E-mail
Karl	40s	White	Male	Mark	Severe Autism	In-Person
Tara	30s	White	Female	Roxy	Brain damage	In-Person

APPENDIX B

Personal Interview Guide

Note that this is a guide and that interview participants will be allowed to discuss other issues if they choose to do so.

Background:
1. Tell me a little bit about yourself.
    a. Do you mind sharing with me what you do for a living?
    b. Has having a sibling with a disability affected your choice of career and/or personal interests?
2. Tell me a little bit about your family
    a. Were your parents married or divorced?
    b. What was your neighborhood like when you were growing up?
    c. Did you have any friends in the neighborhood?
3. Tell me a little bit about your sibling with a disability.
    a. How did you find out that your sibling had a disability? How did you feel?

Childhood:
4. Tell me a little bit about your family when you were growing up.
5. What are your most vivid memories growing up of your sibling?
6. Continuing to think back; how would you characterize your relationship with your parents at the time your sibling was young?
    a. How would you characterize your disabled sibling's relationship with your parents when they were young?
7. Back then, had your sibling's disability affected the way you were treated in by family?
8. Can you walk me through what a typical holiday or family gathering was like back then?
9. Can you describe for me what a typical school day was like back then?
10. Was there ever a time when you helped take care of your sibling? If yes, in what ways did you help take care of your sibling?
11. In the past, did you think having a disabled sibling affected your ability to socialize outside the home when you were growing up?
12. What did you most enjoy doing with your sibling when you were growing up?
13. Can you think of a specific outing you shared with your sibling?

Adulthood:
14. Can you tell me what year you were born in?

15. Can you share with me what your family is like at this time?
16. Has having a sibling with a disability affected the way your sibling relationship has changed over time?
17. Has your sibling's disability affected the way you are treated by your family? Can you tell me about that?
18. Can you walk me through a typical holiday or family gathering?
19. Did having a sibling with a disability affect your ability to socialize outside the home?
20. Has your sibling's disability affected the way you have been treated by others?
21. Can you tell me about some the things that you and your sibling have done together as adults? What have you most enjoyed doing with your sibling?
22. When you think about your relationship with your sibling, what are you most proud of? What do you most regret?
23. How has having a disabled sibling been a positive experience for you?
24. How has having a disabled sibling been a negative experience for you?
25. Did having a sibling with a disability affect your feelings about having children of your own?
26. How do you think having a sibling with a disability has altered the way you react to other people with disabilities?
27. What do you think you've learned from your experiences as the brother/sister of a sibling with a disability?

Demographics
1. Race/Ethnicity
2. Sex
3. Sibling's Impairment