

**Caregiving and Commitment:
Stories of Finding Value
Through Raising a Child with
a Disability**

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Undergraduate Honors Thesis in Anthropology

University of Michigan

Winter 2016

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This thesis is dedicated to the parents who shared their stories and to all parents raising a child with a difference whose stories have not been told. I admire the immense care and love you show to your children.

Acknowledgements

First I would like to thank my advisor, Dr. Holly Peters-Golden, for your wonderful support, encouragement, and advice throughout the year. Your medical anthropology class was what inspired me to major in anthropology in the first place, and it is still one of my favorite classes I have taken. Our conversations together helped me to figure out what ideas to explore, and your comments were so thoughtful and helpful as I worked through the writing process.

Thank you to Prof. Mueggler and my entire sociocultural anthropology thesis cohort—Anna, Anika, Katarina, Polina, and Alex. Your ideas were immensely helpful for the formation of my thesis, and talking with all of you every Wednesday helped keep me on track and show me that I could write this, even when it felt like an insurmountable task.

To my family and friends, thank you so much for the loving emotional support and willingness to listen. Your many hugs and motivational messages kept me going throughout the year. To my own parents, thank you so much for all your love and support throughout my college career and willingness to allow me to explore my dreams.

Finally, and most importantly, I want to thank the parents I interviewed for sharing your beautiful stories of raising a child with a disability. Your journeys make up the core of this thesis, and I am forever grateful for the connections I have developed with you and your children as well as the openness you displayed in sharing your stories. Your immense care, passion, and love for your children inspires me for when I become a mother someday, and your stories constantly kept me centered during the writing process.

Table of Contents

Introduction	5
Parenthood and Caregiving	8
Chapter 1. Historical Background and Methodology	13
A History of Education and Raising Children with Disabilities	14
Anthropological Approaches: Comparing the Medical Model with the Social Model.....	17
Disability Terminology Used in this Thesis	22
Methodology.....	25
Chapter 2. Validations of Motherhood Through Caregiving	31
Olivia’s Story.....	35
Finding Meaning Through Identity as a Mother and a Caregiver	48
Chapter 3. Creating a Cohesive Family: Choices of Place and Resource Allocation	52
Michelle and Nick’s Story	55
How Choices of Resources and School Quality Impact Disability Care and Family Functioning	70
Chapter 4. Can Disability Fit into Our Normal?	79
Susan’s Story	84
Accepting Difference, Emphasizing Commonality, and Redefining Normal	98
Conclusion	106
References	114
Appendix: Interview Questions	119

Introduction

To be honest, I wouldn't trade this experience for the world. If somebody came up to me and said they could give me a typical healthy kid instead of my child with Down syndrome, there's just no way I would do that. There's no way that I'd trade Caleb for anything. I feel like we've all just become so much stronger. There are still moments all the time that things are incredibly hard, but I have realized that no matter how hard you think something is going to be, you can do it. – Christina, Caleb's mother

Introduction

Cameron¹ appears nervous as he walks towards me with his bicycle, avoiding my gaze and not saying a word. It is a hot summer day to be outside running after children on a middle school parking lot where a cluster of twenty or so bicycles, trikes, tandem bikes, and hand cycles lie. I work for Program to Educate All Cyclists (PEAC), a nonprofit that puts on a 6-week-long program every summer to teach children with disabilities how to ride different bikes fitting their goals and abilities. 12-year-old Cameron cautiously gets onto the bike before I give him a big push from behind. A few wobbly attempts later, Cameron begins to pedal a two-wheel bike for the first time. I see him smile as he hears cheers from his parents who are right alongside me.

“Cameron, you’re doing so well!” His mom shouts, a huge smile spreading across her face as she runs across the parking lot, video camera in hand to capture a moment she has been waiting for for so long. Meanwhile, his dad stands on the other side of the lot, helping Cameron to focus straight ahead and ride towards him with a kind of concentration that has been quite difficult for Cameron due to his autism. I watch his dad make funny faces and wave his hands in the air, not caring at all about how silly he appears to help Cameron focus.

I recall chatting with Cameron’s dad earlier that day about how he had driven here straight from Cameron’s behavior therapy and that they are heading to see his occupational therapist right after. He appeared stressed and exhausted from driving around to various appointments, but now I see his relief, encouragement, and excitement while helping Cameron ride a bike.

As I run after Cameron, helping him to look straight at his grinning father to stay balanced, I think back to all the other parents who bring their child to this summer program. Rather than dropping their kids off and giving themselves a break, these parents are right there beside their child, cheering them on and looking for ways they can help their child further once they leave for the day and try to ride a bike at home.

I watch Cameron’s parents give him a huge hug and congratulate him for all his hard work, noticing the beaming smiles exuding from all of their faces. I realize that while I love celebrating the children’s accomplishments, the parents deserve to be recognized as well. They are the ones who know their child best and who provide the extra care, support, and love to their children every day.

I first became intrigued by the experience of raising a child with a disability after getting to know parents like Cameron’s through my job with PEAC. Every day of the summer I came to work ready to teach cycling to children who ranged from five years of age to their late twenties

¹ All names in this thesis have been changed to protect the identities of the individuals interviewed and the people present in each narrative.

with different cognitive, mental, and physical disabilities. PEAC's mission is to empower individuals with disabilities through cycling, which helps them gain confidence in their abilities, use cycling as transportation if they cannot drive, and have fun. I loved cheering students on over the summer as they pedaled for the first time, helping them get over that fear of putting on a helmet, and running over to them as fast as I could every time they tipped over a tricycle.

But I realized that while I was able to leave my exhausting job at the end of the day, the parents of the kids I worked with were not able to leave their child's disability behind. Having a child with a disability was an abrupt and unexpected change to all these parents' lives, causing them to reframe their conceptions of parenthood to include caring for a child with additional needs. While I had grown up around kids with disabilities in my inclusive art classes, volunteered at therapies, and been involved in disability activism on my college campus, none of these experiences really captured what it meant to raise a child with a disability. I was fascinated by how they went through this transition and what it meant to accept their new identity as a caregiver.

Throughout the summer, I learned so much through engaging in conversations with these parents about their family's lives. Stories from love to frustration, and laughter to tears echoed throughout the parking lot as I talked with parents at the end of each session. They gave me a new appreciation of the hard work these parents put towards raising their child, motivating me to interview a selection of them to hear more about how they grew to accept and love their caregiving identity.

My purpose in this thesis is to share the individual stories of a select few parents who have a child with a disability. Understanding their personal narratives specifically is invaluable to gaining a holistic perspective on their experience and emotions associated with the journey.

Through these stories, I explore how parents learn to appreciate and find meaning in their caregiving role. By trying to unpack what it means to fully commit oneself to caregiving, I try to expose what these parents value and how they form interpretations of what it means to have a child with a disability. These stories are very individual and personal in nature, but they hint at commonalities important to gaining a greater appreciation for caregiving, illuminating the ideals people have for parenthood in the United States.

Parenthood and Caregiving

Parents are an integral part of raising any child, but the need for care becomes even greater with kids who grow up with a variety of challenges. The caregiving these parents partake in adds considerable stress and restraints on daily life. It consumes time and energy, brings about family and marital conflict, and comes with seemingly unsurmountable barriers and lack of success. But caregiving it is not just a burden (Kleinman 2009). In fact, my conversations with these parents display that it is far from being a burden at all. As Arthur Kleinman says in his essay, “Caregiving: The Odyssey of Becoming More Human,” caregiving “is a practice of empathic imagination, responsibility, witnessing, and solidarity with those in great need. It is a moral practice that makes caregivers, and at times even the care-receivers, more present and thereby fully human” (Kleinman 2009). As Kleinman beautifully illustrates, being a caregiver is a special experience that allows parents to create a unique identity that encompasses their child’s disability and gives their life a greater meaning. This meaning is what I hope to at least begin to explore, understand, and appreciate throughout this thesis – specifically by focusing on the complete narratives I heard during interviews with three of the families I talked with.

Narratives and personal stories have long been a focus of ethnographic anthropology. As Edward Bruner said about the role of an anthropologist, “Our anthropological productions are our stories about their stories; we are interpreting the people as they are interpreting themselves” (Bruner 1986, 10). Essentially, *how* we as people interpret our experiences and reflect their emotions, opinions, and attitudes are more essential to a story than the what the actions of the experience are themselves. Arthur Kleinman further exposes the importance of narrative in anthropology in *The Illness Narratives*, where he emphasizes patients’ stories and the emotional impact of an illness are often more important than the physical disease manifestations themselves. Kleinman shows how studying narratives and sharing people’s stories of illness are essential to give meaning to the illness experience and answer questions of how we experience being human (Kleinman 1988). The clinical disease symptoms are not what usually bring the most suffering or growth; rather, it is “how the person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability” (Kleinman 1988, 3). I hoped to explore raising a child in a similar way – asking questions of how parents create meaning through their experience of raising a child who is viewed to be different and who has significant limitations and care needs.

Listening to parents’ stories and gaining a greater understanding of their experiences raising a child with a disability is integral to our understanding of what it means to be human. These stories shed light on how parents find meaning and compassion through the caregiving relationship with their child. Nurturing a child who needs additional help and who encounters cultural and societal barriers to success gives parents “an opportunity to cultivate virtues such as unconditional love, and an unanticipated but ultimately welcome reorientation of their life’s priorities” (Prussing et al. 2005, 592). Multiple parents I talked with mentioned how raising their

child and advocating for their rights made them feel connected to a cause greater than themselves. This dedication to their children is admirable, especially when parents are faced with stigmatization and negative discourse surrounding disability.

Raising a child in general is associated with a variety of decisions to make, stress to deal with, and parenting techniques to learn. Whether or not their child has a disability, parents feel the pressure to be a great parent and do everything they can for their child despite the intense work (Hays 1998, 91). Motherhood according to child-rearing books should come naturally and be instinctive, but figuring out care for a child with a disability is less instinctive and natural when a child's development is not normal (1998, 57). Andrew Solomon writes about the experience of raising a child who is very different from their parents in his book, *Far from the Tree*, where he shares the stories of parents grappling with how to care for their child who doesn't follow developmental norms (Solomon 2012). Expectations are high for parents, and this becomes even harder when parents cannot base their techniques on their own childhood. In my upcoming chapter on motherhood, I elaborate on the stigmatization parents may face when they have a child with a disability. Mothers have been blamed for causing their child's disability in the past, or they are criticized for not giving their child the proper care. These expectations put considerable stress on parents.

My admiration for these parents dealing with the challenges and satisfaction of raising a child with special needs inspired me to focus on their specific experiences for my thesis. I set out to interview parents from PEAC who have a child with a disability, expecting to hear stories centered around stigmas they had to face and the hardships of raising a child who encounters exclusion from their peers and others in society. While I had seen the love these parents showed through my experiences at PEAC, I still expected their stories to focus on the difficulties and

stigmatization people with disabilities experience, which is what much of the current disability literature highlights. In *Stigma: Notes on the Management of Spoiled Identity*, Ervin Goffman defines stigmatization as the disapproval of a person due to a particular trait that emphasizes how they deviate from social norms, such as having a disability (Goffman 1963). He focuses on how stigma is not solely an attribute, rather it appears due to social relationships that transform this attribute into a discreditable stigma (1963). This negative treatment and social barriers are unfortunately what causes many people with disabilities to suffer the most. Robert Murphy, an anthropologist who uses a wheelchair due to his neurological degeneration, discusses the harsh social and environmental difficulties of having a disability in his book *The Body Silent*. People often assumed he was unable to do things due to his impairment, causing him to be excluded from many events and activities that he would actually have loved to attend (Murphy 1987). Gail Landsman further discusses how stigmatization of disability reflects negatively on raising a disabled child, arguing that this results in a “diminished motherhood” when friends and family have difficulty congratulating parents for having a child who is not normal (Landsman 2009, 75).

But rather than hearing stories focused hardship and social barriers like Murphy’s and Landsman’s did, I encountered stories of optimism and overwhelming love. Yes, there were significant struggles, but that did not define their experiences. I realized that despite negative assumptions about disability and its stigmatization in society, parents find optimism and positivity through the stories they tell surrounding the care of their child.

In this thesis, my primary aim is to create an ethnographic account comprised of individual stories of parents who have a child with a disability. I am interested in seeking possible answers to these questions: Why and how do parents emphasize their hope and

positivity despite the stigmatization of their child's condition? How do they accept their roles as caregivers and find personal meaning through this new identity? And finally, what values have these parents developed for their own parenthood and their own role in raising their child?

While the concept of "disability" often lumps together a wide variety of unique and different conditions, I wanted to see how parents' stories differ and how they navigate their own unique situations. Understanding their stories and experiences is important to gaining a greater appreciation for nuances of caregiving, but it also shows what it means to be a parent. By sharing the hopes and dreams the people I interviewed possess, I hope to gain a greater understanding of what values and ideals parents strive for in the United States. Even though these parents' experience raising a child differently than with children who have no impairments, they still illustrate what they want out of parenthood and why they need to justify their own identity as a parent.

In chapter 1, I begin with a background on some of the legal, educational, and medical obstacles that parents deal with when raising a child with a disability and how anthropology aids in our understanding of disability. Next, I outline my interview methods, which lead into the three individual stories I have chosen to share in my first three chapters. These stories highlight the challenges and benefits of being a caregiver, showing what these parents specifically valued in raising their child. Chapter 2 shares Olivia's story of developing a meaningful identity as a mother, chapter 3 describes Michelle and Nick's difficulty allocating resources to keep the entire family in mind, and chapter 4 centers around Susan's story grappling with the concept of normalcy and helping her child connect with other children. Finally, I conclude this thesis with how these stories shed light on societal constructs of ideal parenthood in America.

Chapter 1.

Historical Background and Methodology

A History of Education and Raising Children with Disabilities

Knowledge of the history of disability treatment and resources available for parents over time is important to understanding parents' experiences today. Before the mid-1900s, parents were encouraged by doctors to institutionalize their children in disability homes since it was thought that the parents would not want them and would not be able to take care of them (Landsman 2009, 4). Deborah, a mother I interviewed, even mentioned how her own parents asked if they had considered institutionalization to be a possibility for Deborah's child with Down syndrome. While she quickly dismissed the idea, Deborah acknowledged that institutionalization was simply the expectation while her older parents were growing up. During this time period up until the 1970s, disability was also seen to be a private problem that should be hidden and confined to families (Frank 2000, 44). Before the 70s, disability advocacy was virtually nonexistent in mainstream American culture and federal measures were not in place to protect the rights of individuals with disabilities.

The first federal programs to introduce early childhood intervention occurred in the late 1960s with allocation of federal funds to identify children with disabilities (Berry 2008, 7). This caused more parents to be aware that their child could have a disability when noticing how their child's behavior compares to expectations as they develop. In the 1970s, activist movements rose for a variety of human rights issues, including rights of individuals with disabilities. One of the first major steps for parents with a disabled child was the Individuals with Disabilities Education Act (IDEA) passed in 1975, which is still widely in effect today. This act ensured that students are entitled to free and appropriate public education regardless of their abilities. Notable features of this act include that parents have the right to be involved in education decision making and that every student has a right to receive his or her education with nondisabled peers to the

maximum extent possible (Berry 2008, 9). IDEA introduced early intervention services for infants that were family-centered and focused on teaching the parents how to care for their child in a developmentally appropriate manner. This empowered parents and increased their caregiving role by encouraging their shared responsibility with experts so that they had control over the progress and implementation of programs for their children (2008, 99). Prior to IDEA, public school programs for kids with disabilities did not focus on the parents' involvement and were not required by all states. As a result, many schools previously denied education to children they deemed unable to be educated. This act helped change disability perspectives by bringing disability out from hiding as a private family issue and making it into a public education issue where parents were at the forefront of collaborating with the education system. After the success of the Individuals with Disabilities Act in the late 1980s, some states closed their disability institutions in favor of increasing care, education, and employment for people with disabilities.

The Individualized Education Program (IEP) is one example of a program designed through IDEA that is still widely used in special education today. The IEP is a written plan that is individualized for each child to outline what the goals are for that student and how services will be provided in conjunction with regular education (E. Martin, R. Martin, and Terman 1996, 33). IEPs are developed in meetings with their IEP team, which may include special education teachers, early education teachers, school administration, therapists, child care providers, and social service providers (Berry 2008, 101). This team gets together to develop a collaborative plan for the child's education utilizing their professional and teacher expertise as well as the parent's knowledge of their own child. Talk about these meetings came up frequently in my interviews, and parents told me how IEP meetings allow them to make many decisions but also are stressful when parents must advocate strongly for what they believe is the best education.

In addition to having a greater role in their child's education through the IEP, parents have more support now because there is less parent blame than there once was. Parents used to be considered the source of a child's disability both genetically and environmentally (Berry 2008, 5). The term "refrigerator mothers" was used to refer to mothers who had a child with autism. This stemmed from the idea that children developed autism because their mothers were cold and unloving towards them (Sousa 2011, 221). The refrigerator mother concept has been widely disproven today, and many disabilities are seen to have unknown causes unrelated to parental caregiving quality. While inattentive child rearing is no longer seen to cause autism and other disabilities, there is still a focus on the connection between parental care after diagnosis and how successfully disabilities are managed.

This shift away from parent-blame has caused a greater emphasis on the value and overwhelming love these parents possess. Due to the additional needs of their child, parents of children with disabilities are most often expected to fulfill the image of a "good mother" and battle relentlessly for resources and care for their child (Sousa 2011). This has caused parents to increasingly be admired for the huge amount of work they put into caring for their child, but it also creates the additional expectation that parents seek out and advocate for every possible resource available to them. Parents are applauded more for their efforts, but they are also held to higher expectations because their child requires more care than a typically developing kid would.

Anthropological Approaches: Comparing the Medical Model and the Social Model

Disability is a relational category, meaning that the term exists in order to distinguish a person as less-able than the culturally-situated normal body (Ginsburg and Rapp 2013). What makes up a “normal body” very much depends on the context and community, and this phrase is often used to refer to features of the majority in that context. Lennard Davis argues that a normal body is that which is productive to society and is not dependent on others to function (Davis 1995). An “abnormal body,” therefore, is one that is impaired, unproductive, or that which needs assistance to function. In this section, I discuss different views of disability that parents must navigate as they both care for their child’s impairment and try to reduce the negative social attitudes surrounding their child’s disability.

Resolving notions in anthropology of the perceived abnormality of disability has focused on the dichotomy between the social model and the medical model, which are conflicting views parents face with their own child’s disability. The medical model considers disability to be an individual abnormality rooted in the body, and it suggests that people should medically intervene to correct anything that deviates from the norm (Theerasilp and Sherer 2014). The social model contrasts this by arguing that disability is not simply an impairment of the body. Rather, the experience of disability is primarily created by social conditions that block full societal participation for a variety of bodies and minds (Ginsburg and Rapp 2013, 54). In this way, individuals are seen to be “disabled” through negative interactions and stigmatization within their social environment.

An example of this is the lack of accessibility for individuals with wheelchairs. Their inability to walk is seen as a physical impairment, but the actual disability is the fact that they cannot participate in many social functions because not all venues are equipped with wheelchair

ramps. As the social model describes, the real suffering in this situation is that the environment is not accommodating or accepting of the individual's needs. Even if buildings have ramps, these are often hidden in the back, forcing people with wheelchairs to feel like they are not included and are therefore, disabled by the infrastructure and attitudes of society.

The social model fundamentally rejects medicalization of disability, illustrating how we should change our attitudes to be more inclusive of individuals with disabilities rather than medically try to change the bodies of disabled persons. The social model is the primary framework in which anthropology and disability studies view the issue, and it is how I have chosen to frame my thesis. By focusing on the social model of disability, it is apparent that barriers preventing access to care and full participation in society severely limit the opportunities for people with disabilities. This also makes it more difficult for parents to help their child feel included and access resources to grow and develop like other children.

However, parents of children with disabilities do not easily come to terms with the social model of disability, especially in the early stages of diagnosis. A medical model suggests that a disability can be cured or corrected, which is an attractive mindset for parents who do not want their child to suffer the limitations and stigmatization of disability (Fisher and Goodley 2007). This mindset is also hard for American parents to escape because of the western biomedical focus on consulting medical help to remove or fix anything abnormal. There is an ideal of "linear progress" developed through the individual-focused and future-oriented thinking of this medical model, which suggests that people should always be progressing forward (Fisher and Goodley 2007, 66). If people are not following this linear progression, then medical intervention should try and make this progress happen. This reduces patients to their specific symptoms of abnormality and assumes all efforts should be taken to progress linearly and achieve normalcy

(Fisher and Goodley 2007, 67). When parents' stories focus on medical problems and developmental delays, they point to a more stressful experience. Missing milestones such as walking and talking are examples of this stress that builds up as their child ages as it becomes unclear whether they will ever develop these abilities. Noticing deviations from the norm further pathologizes the condition and emphasize how something might be wrong.

Parents find the medical model hopeful and attractive when imagining how they can correct each deficiency, but using this model quickly becomes defeating when they later realize that their child will always have some impairments. The linear idea of progress in the medical model may leave these people hopeless once they accept that their desired outcome of a normally-functioning child without limitations is unobtainable (Fisher and Goodley 2007). Their child will always live with a disability and experience stigmatization or assumptions that they are unable to do things like everyone else can. Sadly, this causes some parents feel that they have little ability to nurture the success of their child if their disability limits their future abilities and inclusion (Green 2007, 151).

To avoid this hopelessness, many parents adapt by focusing on the social model and adapting their child's environment to ensure that it has the least disabling and restricting features as possible. Taking on this social model assumes an acceptance of the reality of the child's disability, showing that parents must now move forward to advocate for their child and reduce environmental barriers to their child's success. This helps parents to cope effectively and deal with their own false expectations of parenthood, replacing unmet expectation with simple love for their child. While parents still participate in medical treatment focusing on their child's body and behaviors, they realize how important access to resources and social inclusion are for their child's well-being. They try to set up an accepting environment that has a plethora of resources

for their child to show their genuine care and to validate their own ability to successfully act with their child's best interests in mind.

During my interviews, I listened to stories of parents findings ways to cope with this realization that they cannot cure their child's disability, knowing that it will affect them for the rest of their lives. Accepting the disability as fact is one step, and once parents accept this, they form their own social model of disability. With this mindset, their time is spent struggling to foster an environment that does not put up barriers for their child's inclusion and success. This may include moving to new town, participating in the disability community, or advocating for their child's success in other areas of their lives. Many of my interviewees became passionate advocates for their child within the school system to gain access to resources they believed their child deserved. The lack of resource allocation towards proper and equal special education across school districts is a social barrier that disables some children's learning, resulting in unequal educational opportunities (Kelly 2005). Fighting for a proper education for their children can be exhaustive and expensive, but success is rewarding.

The struggles children with disabilities have in acceptance and social inclusion is inextricably tied to the parents' experience, making it important to study the parents' changing identity and experience. Beyond just finding an environment where their child fits in, parents must find environments where they feel they fit in. Rachel Robinson outlines how mothers are interconnected with their children like an extension to the body, and she refers to these mothers with children who do not fit in as "misfitting mothers" (Robertson 2014). People feel vulnerable when placed in a misfitting environment, so they look for communities where they feel similarities, acceptance, and a good fit (2014). A shift from belonging to misfitting, which may occur when raising a disabled child, catalyzes a period of shifting identity. Identity is relational,

experiential, and context-dependent, so parents' experience in coming to terms with their child's disability also involves a healthy identity transformation where they find their "fit" in society (2014, 596). As mothers learn how the social environment contributes to their child's disability, they look for environments of acceptance in order to diminish feelings of vulnerability and inferiority.

When parents have a child with a disability or any condition that deviates from social normalcy, they try to restore order to their life by reworking their understandings of self, disability, and their social world. This process of rewriting, understanding, and making meaning is what makes studying parents who have children with disabilities so applicable and necessary in the field of anthropology. As anthropologist Gay Becker said, studying "the ways in which people strive to create order out of chaos and thereby render life meaningful have been an enduring focus of anthropological study" (Becker 1997, 5). Rayna Rapp and Faye Ginsburg further specify disability in anthropology by focusing their work on how experiences of having a child with a disability "reverberates into the lives of their families" in ways that reframe kinship, which was previously taken for granted (Rapp and Ginsburg 2011, 380). They describe how families reshape their narratives to incorporate disability and seek resilience in face of lack of services for their child. In the following chapters, I build upon this background and focus on values parents choose to emphasize when they reshape their life narratives.

I argue that while parents experience stress due to their child's medical needs, financial burden, and social misfit, they can find personal growth and positivity through their shifting purpose and identity. Focusing on value gained in the present rather than unrealistic hopes of future progress allows parents to gain a greater appreciation of their child and place less value on the diagnosis and labels (Fisher and Goodley 2007, 68). This prevents hope from being focused

on a concrete, future goal in favor of openness to present experience and unknown sources of meaning and value (2007, 74). Parents feel success and great efficacy when they value the present and acknowledge that they are doing everything they can in the current moment. While the amount of present-value experienced is hard to quantify, it can be understood and shared through telling stories. Storytelling offers a qualitative glimpse into the emotional experience of the parent, which includes the present events and experiences that give parents meaning. In this thesis, I focus on how stories can bring to light positive experiences of parenting a child with a disability by looking at value in caregiving roles, defining a new normalcy, and developing good relationships with others and the community.

Disability Terminology

Through listening to parents stories and my own experiences with the disability community, I have noticed the wide variety of language used to discuss what it means to have a disability. For the purposes of this thesis, it is important for me to clarify my choice of words used as someone who is able-bodied and does not have the authority to side with personal preferences. There are words such as “handicapped” and even “disabled” that are acceptable by some and highly offensive to others. Christina, one of the mothers interviewed, said:

I don't always like the term disability, you know? I like “differently-abled” or anything to try and put a more positive spin on it. To me it's just about finding a new way to look at things. Just because somebody is differently-abled doesn't mean they don't have so many gifts they can give and so much they can bring.

Some people take it farther than Christina to fully reject words that attribute disability to a category of “otherness”. In her article, “Constructing the (M)other,” Priya Lalvani says that many parents reject the word “specialness” because it implies otherness of children and “denies the mothers themselves access to the category of normative motherhood” (2011, 284). This

shows the importance of language in reflecting the parents' experiences and beliefs about their child's impairment as well. But on the other hand, some people use the word "disability" with pride to exaggerate their impairment to other people who may not see their disability or be aware that they have additional needs (Wilkerson 2011).

In my own experience, people feel comfortable using the words "disability" and "special needs," and I also make a point to use person-first language. The "People First" campaign's original goal was to separate the person from the disability, saying that they are a person first and that their disability is just a feature they have (Muredda 2012). Rather than saying "the autistic child" or "my disabled friend," people-first language encourages the phrases "the child with autism" and "my friend who has a disability" to always list their disability second. This use of language came shortly after the passage of the ADA to move away from individuals being labeled as "disabled" to a more descriptive terminology that marks disability as detachable from the people who possess them (Muredda 2012, 2). Throughout my time at PEAC and working with kids with disabilities through Dance Marathon, we have encouraged the use of person-first language and I have consistently used this language ever since.

However, you will notice throughout this thesis that I do not stick to person-first language exclusively. This was a huge topic of debate for me, as it is something I have always used in my speech. Many disability scholars and advocates refrain from using person-first language exclusively in their writing, even though this is seen as the politically correct way to talk about disability.

There are two reasons why I have decided to incorporate both person-first language and descriptors that do not follow this convention such as "disabled person." First, person-first language is often avoided in academic writing due to grammatical awkwardness. Using pre-

modified nouns such as “disabled people” are more concise than post-modified, such as “people with disabilities” (Muredda 2012, 2). This allows for greater clarity of thought. Additionally, there is a discrepancy among disability scholars about whether the phrase “disabled person” is considered to be person-first or not. Conventionally, as Muredda mentions, the term “disabled person” does not situate the person before the impairment. However, in activist Tony Boatright’s article “What Do We Call ‘Em?”, he mentions that from his own experience as a disabled person, “disabled person” is considered to be in the same field as “person-first language” (Boatright 2010) and is a preferred term for people who have disabilities.

The second reason to use “disabled people” as a term not conventionally seen as person-first, is to avoid seeing disability as a negative attribute. In the book *Claiming Disability*, Simi Linton and Michael Bérubé mention that disability rights activist pushed for people-first language in the mid 1970s, but this use shifted in the 1990s so that “disabled people” was increasingly seen as more appropriate by both activists and scholars (Linton and Bérubé 1998). The rationale for this change was to recognize that using the term “disabled” is an identity-marker that disabled people often wish to highlight to show their experience in navigating the world. “Disabled people” is also increasingly being preferred due to the spread of the social model of disabilities, showing how social barriers for people with disabilities “disables” them from full participation in society (Priestley 2001). People-first language may be seen as “politically correct,” but Priestley also argues that it hints at the inherent undesirability of disabilities when suggesting that people want to separate themselves from their impairment.

While personal preferences differ in claiming disability identity or keeping the impairment distinctly separate from a person’s identity, I chose to use person-first language

interchangeably with the term “disabled person” to increase clarity of language and shed light onto the integration of disability in these families’ daily lives.

Methodology

For my ethnographic research, I interviewed parents of eight families who have a child with a disability. These parents are all people living in Saline or Dexter, Michigan, whose children I taught over the summer with PEAC and who responded to my email as being interested in participating. Their children had disabilities that were more physical in nature such as spina bifida, developmental and cognitive in nature such as Down syndrome and chromosomal abnormalities, and emotional or behavioral in nature such as autism. Due to interview logistics and parent preferences, five of these interviews were just with the mother, while the other three were with both the mother and father at the same time. Participants were interviewed at their home or in a local coffee shop, and interviews ranged between 60 and 120 minutes in length. Interviews were audio recorded so that I could engage in conversation rather than being burdened by writing throughout the interview, and then recordings were transcribed verbatim.

I employed a semi-structured interview technique in order to help the parents share their own stories to the extent that they wanted and to tailor interviews to their individual experiences. I entered each interview with a list of questions (see Appendix), but often many of these questions were not asked if they weren’t relevant to the discussion, and others were developed on the spot in response to parents’ individual stories they told. This helped develop a conversational tone and give participants the power to tell their own stories to share what was most meaningful and pertinent to their experiences.

I started each interview asking, “If you and I were meeting for the first time, possibly if I am a new teacher for your child, what would you want me to know about them?” This allowed me to see how they present their child and what aspects they really want to emphasize about them, which often led to further conversations about school and their child’s interactions with others. I then asked them to describe their thought process when they first discovered their child would have a disability, which led into discussions about how their lives changed, leading parents to walk through their life story of caring for their child.

When considering how I would carry out my interviews and approach telling the stories I heard, I was drawn to anthropologist Gelya Frank’s writing in *Venus on Wheels*. Her book is a biography of Diane, a woman with a physical disability whom Frank first met in a college class (2000, 2). Frank talks considerably about her methodology, comparing life histories, life stories, and cultural biography. Frank says, “In listening and responding to a life story, a cultural biographer offers her own experience as a proxy for future readers. When readers engage with the life story and its various interpretations, new meanings are created that will reverberate in the readers own local cultures” (Frank 2000, 23). What Frank emphasized was the influence of her own personal experiences in writing about Diane, showing that as the writer she cannot write someone else’s story without her own perspective and thoughts woven in. Throughout my thesis, I want to acknowledge that although I try to portray these parents’ stories as accurately and true-to-life as possible, my own biases and interpretations will be woven in through my own experiences. While my own biases are often inevitable as I see connections between each parents’ experiences, I aim to share these parents’ stories as narratives that are valued individually, yet related to each other.

Even the parents themselves specifically share their stories with subjective and intentionally thought-out purposes. Their stories told to me may not be verbatim to what they tell their friends or coworkers about what it is like to have a disabled child. They convey a certain feeling or idea behind their experiences. In *Reconstructing Motherhood in the Age of "Perfect" Babies*, Gail Landsman displays how stories help parents construct personhood for their child and develop who they are, especially if the child is unable to speak for themselves (2009, 108). She states that narrators don't tell stories just to express values; rather, they do it to remake their own values and interpretation of experiences each time they tell their stories (2009, 10). How I interact when listening to these parents and what directions I lead the conversation affect the story that unfolds. These interactions between the interviewer and the parent are also avenues to unfold meaning for the parents themselves as they reflect upon their own experiences (Lalvani 2011, 281).

My prior relationships with these parents often gave me more authority than if I had not known them beforehand, especially due to the relationships I had developed with their kids through PEAC. As Landsman discusses, parents often focus their narratives on constructing personhood for their child due to the worry that whoever they are speaking to does not actually understand the great value and personality their child has (2009, 108). I had already established a level of trust with these parents since they were aware that I understood and valued their child's abilities through PEAC. I believe this allowed parents to talk more fully about their own personal experiences since they already knew that I was aware of the fine nuances of the personalities and struggles that their child deals with on a daily basis due to their disability. Many times throughout my interviews, I heard phrases such as "but you know how Noah is when he doesn't want to do something," or "you know how Elizabeth is such a kind and wonderful girl." Not only

did this allow them to trust my judgments, but they also knew my awareness of working with disabled children and knew that I was familiar with many experiences they talked about.

Beyond parents knowing me and being comfortable sharing stories about their lives because I knew their child, these parents also were used to informally telling their story to different audiences. Some parents were part of support groups where they were able to verbally share their stories and experiences with people who could sympathize and relate to their experiences. Others were a part of online communities where they composed written messages to other parents offering and receiving advice as well as typing out their own personal journey for other people to read. When I first sent out emails asking parents if they would be willing to meet with me to share their stories, the parents who replied sent messages saying “we would love to participate” or “we would love to be a part of your research.” Since many people do not understand what it is like to have a kid with a disability and look negatively upon the idea, parents who do have a kid with a disability become comfortable with telling their stories in order to construct personhood for their child and share the reality of the experience (Landsman 2009, 108). Olivia, one of the parents I interviewed, told me how many people get this image in their heads of a bedridden kid, but when she tells them about his personality and shows pictures of a smiling, happy boy, they realize that in many ways he’s like any other child. By becoming used to telling these stories informally to people they know, parents are able to share what their experiences are actually like in a realistic yet positive view.

This enthusiasm in my email responses also hints at a self-selecting group that willingly agreed to participate. Parents who had more negative experiences or who did not feel comfortable sharing likely did not respond to my emails, while parents with more positive experiences were happy to share. Other limitations to my study include that my participants are

all white, middle or upper middle class, married parents. Their hardships are likely significantly different from families who are lower class, are part of other marginalized identities, or are single parents. By having a small set of people to interview, I also was only able to hear stories from a small subset of the population of parent who have children with disabilities. The broad range of disabilities and lack of specific diagnostic groups allowed for a greater variety of experiences, but it also means that experiences of one disability may not be relatable to that of a different disability.

When writing my thesis, my goal was to keep these stories fully in-tact in order to give readers a holistic view of these parents' experiences rather than hearing bits and pieces throughout. Just as Frank wanted to share Diane's comprehensive life history in order to challenge readers to think differently about disability culture and American culture, I want to share these parents' stories in order to encourage people to think differently about what it means to care for a child and what it means to be the parent of a person with a disability. In order to fully relate to these parents, I believe that their stories would be best presented from beginning to end with little theoretical analysis until after readers have understood a parent's full narrative.

Therefore, I did not have a primary theoretical basis or thematic goal in mind before beginning my interviews. I wanted to instead focus on where my conversations led themselves in displaying these parents' experiences. Following the semi-structured interview approach, I looked at each interview after transcription to determine what themes those specific parents focused on or what elements of their story were most pervasive. In the following chapters of my thesis, you will see one specific narratives for each chapter and a theme surrounding those stories. This is to show what we can learn from hearing these individual and what raising a child

with a disability shows about values surrounding caregiving in American culture and ideals of parenthood.

Chapter 2.

Validations of Motherhood through Caregiving

Validations of Motherhood through Caregiving

Becoming a new mother is consistently cited as a significant, defining moment in a woman's life (Callister 2004, 508). For many women, it can signify a successful marriage, passing on family genes and values, fulfilling a caregiving role, or taking on a new identity of motherhood. It brings about a new stage in life of learning how to adapt to this new identity and incorporate a child into the mother's life story.

However, motherhood is not always as predictable, typical, or prescribed as people hope. While mothers do not always expect to have the perfect baby, they do expect and hope to give birth to a "perfectly normal baby" (Landsman 2009, 70). What classifies as normal depends on the culturally-specific expectation people have for a healthy baby. The common assumption is that children with disabilities do not fit into the socially constructed category of "normal" in American society due to the physical, mental, or emotional limitations they experience (Lalvani 2011). I want to explore how parents adjust to taking on this new caregiving role, how they conceptualize having a child who is different, and what this means for their new identity as a parent. Impairment, disability, and limitations are all factors that result in low social expectations for that child's success and the experience of motherhood (Green 2007, 151). Due to these limitations, there are lowered expectations of the degree a mother can ensure tangible development in the child. This consequently reduces the expectation that mothers will have a typical and rewarding motherhood experience. While Gail Landsman regards this experience as "diminished motherhood" due to the differential experience of raising a child with impairments (Landsman 2009), I argue that mothers who embrace their caregiving position as a mother benefit greatly. Finding meaning and value through a caregiving identity helps mothers see the unique role they hold in their child's life.

The historical notion of what makes a good mother has changed over time, but it has largely focused on the quality, dedication, and energy devote to caregiving. Sharon Hay's frequently cited book, *The Cultural Contradictions of Motherhood*, discusses the challenges of defining a "good" mother, as it is largely determined by culturally-conceived stereotypes and expectations (Hays 1998). Hays looks at the primary ideology of "intense mothering," which defines mothers as the ideal, preferred caretakers of children regardless of their employment status. This ideology represents the two conflicting roles mothers ideally choose between: being a traditional stay-at-home-mom or being a working supermom. Regardless of whether the mothers work or not, they still assume a significant caretaking role and responsibility over their child. Intense mothering is guided by experts, emotionally absorbing, and labor intensive: mothers must cease to have their own needs and interest in favor of devotion to the care of others (Hays 1998, 91). While this is not the only model of motherhood, it is the primary model our western culture has endorsed today. Hays admits that although this model steps backward in gender equality, it is the dominant cultural standard we use to evaluate mothering practices, and it is based on the social construction of an ideal family. The mothers in her study emphasized that they *wanted* to take on all the mothering responsibilities they had—they did not feel pressured by their husbands. I am curious about how this plays out for mothers whose disabled children have even more additional care needs that mothers are expected to take on.

Motherhood does not have to be confined to women, although it often is. The defining features of motherhood include being responsible for the relational and logistical work of raising a child and caring for people (Arendell 2000). For the purpose of my research, I look at these caregiving and nurturing aspects of motherhood, but I apply this to both mothers and fathers depending on who is fulfilling the primary caregiving role. While this chapter focuses on

Olivia's identity as a mother, fathers can also take on similar roles when they too emphasize their caregiving nature. Parents often find fulfillment in these caregiving roles, especially when seeing the accomplishments of their children as they grow up into productive adults.

Mothers with a disabled child are continuously evaluated on their mothering behaviors, particularly in their degree of devotion to caregiving, just as all mothers are. However, I argue that people place more scrutiny and expectation upon mothers with a disabled child due to the heightened caregiving needs of the child. Throughout this chapter, I look for answers as to why mothers experience this scrutiny and why they feel the need to justify their motherhood. While there is this increased expectation, I also explore how mothers may experience increased joy and fulfillment when they take on a caregiving role, identity, and job.

Challenges in raising a child with a disability stem from this societal value placed upon having high-achieving children who progress to independent adulthood (Green 2007, 151). Children with disabilities may not progress into adults living independently physically and financially, creating low expectations for a successful outcome in parenting a child with a disability (2007, 151). These low expectations result in the idea of "diminished motherhood," which represents how members of society evaluate motherhood of disabled children (Landsman 2009). Believing that these mothers have a "diminished motherhood" due to the fact that their child is not a typical child with typical care needs creates a system of discrimination. To overcome these social burdens, mothers engage in the rewarding nature of caretaking and validating their position as a mother whose child achieves success and growth. In this section, I share Olivia's story as an example of a woman who invests heavily in her identity as a mother, which is central to how she gains meaning in her life. Using her story, I aim to explore the avenues that allow her to validate her motherhood and find meaning through this newly found

identity. In order to defy the notion of “diminished motherhood” and the notion of lack of success in their children, Olivia and other mothers of children with disabilities embrace their caretaking position and identity as a mother.

Olivia’s Story

I first met Olivia and her child, Noah, at the opening day of summer program through my job at PEAC in the summer of 2014. Noah was a small blonde child who walked up holding both his parents’ hands for support with a huge grin on his face. This is how I saw Noah arrive every day that summer before we would lift him up onto a tricycle and try to help his feet pedal independently. Noah has Smith-Lemli-Opitz, a genetic developmental disorder characterized by learning and behavior disabilities, communication difficulties, and malformations of many internal organs (Kelley and Hennekam 2000, 321). Although he could not communicate through words, I enjoyed getting to know Noah’s smile and big head nods used to express himself. We would sing the happy birthday song – his favorite—while pushing his tricycle around the parking lot, and Olivia would walk beside him every step of the way. I try to get parents personally involved in the bike lessons, and Olivia was one of the most excited to stay by Noah’s side and listen as we made suggestions for improvement. From the start, I noticed how dedicated and watchful Olivia was in taking care of her son and learning how to help him succeed.

Later that fall, I pulled into the driveway of Olivia’s home just as she was getting back from work to sit down and chat for my thesis. Unlike many of my other interviews with parents, her husband was still at work and their child, Noah, was still at school. I instantly felt at home with Olivia’s bubbly and conversational personality that I remembered from PEAC. We talked about her motherhood experiences and what it meant to be Noah’s primary caregiver throughout

his life. Much of our conversation was drawn to how she specifically was affected by her experience as a stay at home mom who adopted much of the caregiving responsibilities for her child.

During Olivia's pregnancy there were no major indications that her child was not progressing normally. Olivia said that there were little things here and there that did not seem quite right, but her amniocentesis results and other tests came back as normal. It was not until after birth that she found out her child Noah had the genetic developmental disorder, Smith-Lemli-Opitz. Olivia and her husband, Joel, felt fortunate to be given a diagnosis right away because they were able to start addressing many of Noah's medical issues. But they acknowledged that many mothers are left without knowing the diagnosis of their child, leading to considerable stress from the unknown. Even in the moment he was born, Noah was whisked away as Olivia was put into recovery while Joel was taken to the NICU and told "a whole laundry list of stuff that was wrong with him, and as a new parent that's not what you want to hear right off the bat."

He was in the NICU² for two and a half weeks, and it was just really hard because I got to go home and he had to stay there. I just cried all the time because of my baby. And of course they figured out what they thought he had, and the first thing they said was "Don't go online." But what do you do? You google it, and so I read about it and was just devastated. Even ten years ago when he was born, they just had this morbid outlook for kids. And maybe it just seemed morbid at the time thinking oh my god he's never going to be able to live independently as an adult, he might have a feeding tube the rest of his life, or he might live in a group home. That's what you read about online, which was really heartbreaking. I don't know how—not that we really got over it—we dealt with it. Joel and I just kind of got together, and when Noah got home you just realize that no matter what he has or who he is or what issues he has, he's still a baby that needs love and family and attention and care. And I don't know how we did it.

² Neonatal Intensive Care Unit

Olivia told me that in those first few moments, it was hard for her to feel like typical mother who is proud to have a new baby when so many things were uncertain and appeared to be wrong with him. During labor and birth, women typically gain a sense of mastery, elation, and accomplishment at the successful completion of bringing a child into the world (Callister 2004, 511). However, a mother whose child has medical challenges experiences a “diminished motherhood” from birth when there is less of a big, congratulatory show when bringing home a newborn with significant medical needs (Landsman 2009, 58). It is more difficult to experience as a complete moment of pride and accomplishment.

From the initial events of diagnosis and birth not going according to plan, mothers begin the process of making and remaking what it means to be a parent (Kelly 2005, 187). Olivia engaged in this as she tried to figure out her meaning and position as a mother when her child has additional needs. Through our conversation, I searched for how she accepted the expectations set for children and grew to love providing the additional care needed for her child.

Even when he was three months old, Noah was tiny, and people would go up and ask how old her cute little baby is. When Olivia mentioned that he was three months old at the time, they responded rather ambivalently or judgmentally, not knowing what to say since this child was not growing as he should. Olivia described how much this bothered her initially because it did not give her that encouragement and love which is characteristic of being a new mother in our culture. Likely these people did not mean to be rude, but they did not know how to conceptualize these differences. Her identity as a proper mother was unknowingly questioned from the start since people did not know how to celebrate her motherhood.

Unfamiliar challenges and confrontation with the unknown can be stressful, as it puts people outside their comfort zones. Olivia expected to have a typical child, and instead she was

presented with a diagnosis that she was unprepared for, but this did not stop her from trying the best to make it work. Beyond the challenges of bringing up Noah and giving him the best opportunities she could, having a child with a disability pervaded every aspect of her life. It brought additional challenges and encounters with experiences that were unfamiliar to her. She quit her job to take care of Noah full time, which was difficult and unfamiliar for her since she previously had been employed since the age of 15. As a career-focused woman, she never anticipated taking on the identity of “stay at home mom.” Olivia and Joel had hopes and dreams for what their life would be like together, so it was challenging to transition into a new and unexpected life course. After realizing that her motherhood did not fit with expectation, it was challenging to figure out how to move forward and accept this transition (Robertson 2014, 593). For her and for many parents, this transition isn’t a choice they have.

That was really hard for me because I've worked since I was 15 years old. It was very challenging, and even now when there are days he is off school or is home for an extended period of time and I think back and wonder how I did that because it's hard to be home with a kid all day. It was hard sometimes for Joel because he'd get home from work and I was just dying to get out of the house. Noah wasn't easy to take places and sometimes it was hard for Joel to understand that when he said, "I just got home from work, don't you want to spend time together as a family?" All I wanted was to get out of here because I was just dying.

Like Olivia, another mother, Susan, told me how difficult the transition was to unexpectedly go from being a working woman to feeling obligated to stay at home and abandon career plans.

It was very hard. I had never not worked. I had always either been a student or working or both. It was very hard and I was very resentful. I was wondering why does my husband get to go out and have a life. I'm saddled with everything. I have 14 medical appointments a week and some lasted six hours. It was a full time job. It was definitely a full time job. It took years to come to terms with this. I was praying about it for years.

Susan loved taking care of her child and being a mother, but she had never planned a life where she wouldn't be able to pursue the career. Ultimately like Olivia, Susan was so glad to be a stay at home mom and learned so much, but it was not what she had planned for.

Staying at home allowed Olivia to take Noah to his numerous doctor's appointments as an infant and care for him rather than paying for a trained caretaker. Once Noah started going to school at age three, Olivia gradually became more comfortable with parenting a child with a disability and went back to work part time a year later. Noah was enrolled at Highpoint, a school that catered to kids with disabilities and who were medically fragile like he was with his tracheostomy tube. At this point in his life, Joel and Olivia were more concerned about his significant medical needs than his developmental delay and difficulty with things other kids his age could do. Since medical conditions put people more at a danger in life or death proportions, Olivia emphasized that safety was number one on their Individualized Education Program (IEP) for Noah, at an even higher priority than his schooling and education. As a now stay-at-home mom, Olivia was terrified to put someone else at school in charge of Noah's care since she finally felt like she was the one used to him and used to taking care of him.

The first three weeks he was there I remember I didn't leave the school. I sat in the teacher's lounge all day and I put together puzzles and I read books. Finally, one day his teacher said, "Why don't you get a cup of coffee or something? Why don't you just go out? He'll be okay." That was the hardest thing—leaving the school, leaving him there, and knowing that he was going to be okay.

The reason Olivia felt so hesitant was not because she didn't think that the teachers were qualified, as she knew they taught kids like her son for their careers. Rather, it gives mothers courage and a sense of hope when they know that they are the only person who knows exactly how to take care of their child and what their child needs (Sousa 2011, 229). The fulfillment that

mothers get from having full responsibility of their child is difficult to give up, as it was for Olivia.

Even once Noah got older and started taking the bus to the local elementary school, Olivia would follow him to the bus stop and make sure he got on the bus and drove away safely before going back home and heading to work. She said, “It was so foreign to me. You spend three years of your life with this kid who needs everything you can offer, and all of a sudden you have time to yourself. I had no idea what to do with myself.” When he was younger, she had learned so much about what it means to care for her kid that she had become an expert, just as all parents learn what their child specifically needs. Adjusting to taking on a caregiving role is typically associated with a period of liminality due to role ambiguity, social changes, uncertainty, and suffering (Gibbons, Ross, and Bevans 2014, 425). At this point, Olivia had adjusted to a caregiving role successfully in her mind.

But now her identity as his primary caregiver and as the one he depended on for all hours of the day had slowly changed, bringing her back into a liminal space of adapting to a *less-intensive* caregiving role. After accepting ownership of Noah as her main job and priority, his dependency on her was the primary thing that gave her life meaning. Some of her most difficult experiences were giving up these responsibilities she felt were integral to her identity, even just to her husband.

I spend the majority of time with Noah. I get him up in the morning and brush his teeth and make him breakfast and all that stuff. I think sometimes Joel feels left out. He's the dad and he's a fantastic father and I felt like, well he works 40 hours a week a full-time job, and I still consider Noah my full-time job. It feels like I'm a robot sometimes. I just do things and I do things and I keep doing them and doing them and Joel's like, "I can do that" because he wants to give me a break. But I'm thinking *no you can't*. Well, yes you can, but I try not to cockeye him and say you're doing it wrong. I try to let him do things his way which might be different from the way I do them. That is something I'm constantly trying to get better at—just letting him do things his way.

While many mothers have difficulty giving up some of their responsibilities as their child grows up, the process of reducing a caregiving role becomes much greater when the caregiving role was significantly heightened to begin with. Noah was not under her care while he was at school. She now had the time to herself that she longed for when she first quit her job, but this idea of doing things for herself was now foreign to her. This was yet another transition period.

After three years at Highpoint the teachers decided Noah was ready to graduate to the normal school, which frightened Olivia again at the thought of decreased care. But Noah loved everything about it – the social interactions, the environment, the teachers, the specials classes. Olivia expressed how this was one of the best decisions they had made for him since Noah felt more connected with his peers, and Olivia began to realize her child’s capabilities in an environment with typically-developing children. The first day Olivia was still incredibly nervous, but with the paraprofessionals and the support staff, she gradually became more and more comfortable as he got older.

It has been important with transitioning to new schools to tell the teachers about Noah. He's very social, very friendly, very outgoing, and very receptive to how you talk to him, treat him, and communicate with him. Even though he can't really communicate back verbally, he can communicate with words and signs and gestures and facial expressions and sounds and stuff like that. I guess that's one of the most important things, you know? And it's important for a lot of people to know that even though he can't sit and have a conversation like what you and I are having right now, he's very aware of everything you say to him. He understands pretty much everything you say to him even though he can't verbally talk back which is very important to know.

Transitions into the unknown process that Olivia was faced with require an incredible amount of support. While talking to Olivia, I saw how her support system created the foundation for loving her child and her caregiving role. While she emphasized how hard it was in the beginning when everything was new, her support system helped ease her transition into the

happy and comfortable mother she is today. Olivia joined the Smith-Lemli-Opitz online support group and eventually became a member of the board after feeling so included and normal in their community. This was a space where everything was not so different and foreign because people all were undergoing similar situations and could bounce ideas and questions off each other. She told me that she made so many of her current friendships from that group, and she valued the ability to connect with people in a similar situation who were going through the same conflicts and questions.

Friendship was an important part of Olivia's experience, and her relationships changed as she continued to meet new people who understood her situation. She never felt neglected or distanced from her friends before she had Noah, but her new friends in the disability community as parents connect with her on such a deeper level. Many of these people are parents of Noah's classmates, mothers in the support group, or even mothers of children with different disabilities in the area. And while many of Olivia's new friends were able to connect with her on this deeper level, they did not let the disability of their child define who they were as friends either. Friendships were good reasons to get out of the house, take a break, and realize that Noah did not require Olivia's attention the whole time. He is his own person, and Olivia can be her own person too.

My girlfriends have been so supportive. We go out and we do things and make plans with my friends, and for me it has been really important to have that outlet and kind of not worry about home for a while. It's so easy to get consumed with your world when you live in this kind of a bubble and forget about what is outside. And it's really important to have a date night or go out with a girlfriend and have a glass of wine or go see a movie. Teach someone how to take care of your kid and go for a walk around the block. It took me a long time to realize that because I was glued to him for years. Joel would try to pry me away and he was like go do something *you*. Because he could see it was becoming ridiculous. He'd come home and see me in my pajamas and I'd be like 'Hi

honey!" and he'd ask if I'd showered today and I'd say I'm just taking care of the baby. Don't forget about yourself.

Through my conversations with Olivia and noticing her caring and invested nature, I saw how she felt the need to be the ultimate, caregiving mother because her child had special needs that required more work and time from her. Olivia tried to go beyond what would be expected of a mother in order to fill that caregiving role of an "intense mother" (Hays 1996), which is so highly regarded in our present society, but she only later realized that it was not sustainable to fully devote her life to her child and not take care of herself and her social needs.

Interactions beyond just friendships and people Olivia knows have helped define the positive view she has grown to accept about her situation. As Noah has gotten older and less medically fragile, he has been able to get out of the house and Olivia will take him to as many places as she possibly can.

Joel's always telling me "you're too social" because I'm always calling people and meeting people and going places and taking Noah everywhere. I don't know, to me it's just so important. I like to meet everyone and have them meet him and then they can put a face with the name and really know who he is as a person. Even when Noah is not with me and people say they feel so bad for me, I say it's okay because he's a happy kid. Or, I'll show them a picture and say oh look here's his picture he's smiling he's a happy kid. I think if you just talk about it they get this vision in their head of this bedridden kid who just can't do anything. And I'm like no, no it's not like that, and it doesn't have to be like that.

When asked if she feels she has been treated differently as a parent, Olivia said she only has when people feel bad for her. In any instance that she has felt different, it has been overwhelmingly positive support of what she does and of how much she seems to care. Mothers feel validation when they get this positive support, showing the importance of community interactions in defining how mothers feel about their own caregiving role. I could hear the

excitement in her voice as she told me that people would come up to her in the supermarket or the bowling alley and say, “you are such a great mom, I can just tell.” She said that even though she was shocked that people would not expect her to take a disabled child to the bowling alley, it made her feel like a meaningful person and a worthy mother every time they said they could just tell she was a great mom. That was what she lived for. This validation gave her the hope and the realization that despite the increased commitment required to her child, everything she has done has been worth it.

Receiving validation is more straightforward for mothers whose child is not disabled. Following the expected rites of passage of bringing a child from birth into full personhood gives mothers satisfaction (Landsman 2009, 59), but expectations are more ambiguous with a child who does not develop normally. Typical mothers go on to cite that satisfaction from their role stems from their child becoming independent and giving back to society (2009, 144), which may not occur when some disabled children are dependent on care for the rest of their lives. This shows the value mothers have in their child growing up into their own independent person. Additionally, mothers stress the importance of creating a family to nurture and develop lasting relationships of mutual care and help (Hays 1998, 109), which becomes unequal when children are dependent into adulthood and cultural ideas of disability skim over the benefits disabled children bring as they become adults.

Olivia’s motherhood was validated further each time she took Noah to watch the Michigan Marching Band practice. Olivia took him because she loves to see how much he loves the music and dances along.

They know us now and say we’re their number one fan. The drum-major comes up and high fives him every time. People see him enjoying the music, and they tell me, “I can tell you’re such a great mom because he loves the music.” That happens pretty

frequently and it's nice to know that other people can see and appreciate us and don't feel weird coming up to me and telling me, "you're such a great mom you're doing a great job."

She contrasted this feeling with being a mother of a typical child, saying that for them it is not every day that someone will come up and say you are a great mom. Why might people feel the desire to congratulate parents for bringing their child out in the community, and why do parents with disabled children value this so much? Parents of typical children do not always need this validation because their success is implicit in the achievements of their child as they grow up and become more independent. However, parents with a disabled child are constantly trying to enable the personhood of their own child and justify their parenting decisions for their child. Other people realize that raising a child with a disability is difficult, so they want to somehow express their relief that their own children are relatively normal. To do this, they show overwhelming support and sympathy when they see mothers in public like Olivia with children who appear to need a lot of care from their parents.

Since Olivia's experiences of motherhood are not typical and are challenging, it is rewarding to know that other parents see how hard she tries to be the best caretaker for her child. Olivia told me how much she loved when parents would see Noah's disability and say their own child has autism, Down syndrome, or any other disability. They would strike up a conversation on the spot. And this is just because they have something in common to connect with. This connection and relief Olivia experiences when meeting other parents with disabled children represents biosociality, which is the connection or kinship people experience due to a specific common biological diagnosis (Whyte 2009, 10). These mothers begin to adopt their child's diagnostic identity as part of their own self, making it so they feel most comfortable around people who understand their experiences. The *lack* of biosociality between parents with a

disabled child and those without can help explain why parents of typical children feel awkward around parents with children who have disabilities. Their statements of praise try to help mediate and make up for this awkwardness they feel. A typical mother would not often experience these overly positive interactions just for bringing their child out in the community.

Talking to Olivia about how comfortable she has become interacting with the public showed me how she has grown to accept her motherhood and take pride in her motherhood identity as she looks back and laughs off any previous off-putting interactions. By the act of verbalizing her comfort, she is also trying to tell herself that she has accepted the situation. When people approach Olivia and Noah in public, usually they ask questions in a positive manner, and Olivia is quite happy to answer and teach them a little bit about his condition. When I asked her about negative interactions, Olivia began to discuss how no one really was that negative, and then finally remembered one she forgot about that affected her greatly at the time. She likely has forgot about this instance because she has reached the stage where she feels like she is a good mother and does receive validation for her efforts, although this was difficult initially.

I nearly forgot about the first time I felt kind of crushed was while he had a feeding tube in his nose for six months. He didn't get his G-tube³ until he was six months old, so he had this feeding tube when we were out and it was taped to his face up his nose. He was so little and I took him to the store one time to pick up a prescription or something. Some guy at the pharmacy went up to me and asked, "Why does he got that hose in his nose," and now I can laugh about it, but at the time I almost started crying right there in the pharmacy.

Beyond just community interactions, hearing about Noah's peer interactions has been encouraging for Olivia. Parents worry about how well their child fits in, and it becomes

³ A Gastrostomy tube (g-tube) delivers nutrition directly to the stomach when children have trouble eating

especially apparent when their child is different from other children. She acknowledges that he cannot talk and he cannot walk independently or run around with the other kids, which unfortunately limits how he makes friends. At school Olivia has noticed that there are a handful of kids who are so encouraging to him and are so positive and make an effort to play with him, which is meaningful to her because she sees that Noah is accepted and valued as a friend and peer. Olivia does not just look for validation in her role as a caregiving mother, but she also looks for validation in her child. One time that he was struggling to walk up the stairs near the gym, the whole class heard him and came out to cheer him on for working so hard to walk up himself. He got so encouraged by that and walked right up the stairs. Moments like this made Olivia feel like her child really was accepted and cherished even though he could not do a lot of things other kids do, which for her showed that her effort pays off. It is common to worry about a mother's child being invisible, isolated, and excluded in peer groups. Women express how it breaks their heart when their child is not invited to parties and feels left out (Lalvani 2011, 286). Despite increased inclusion, it was still hard seeing other kids reach these milestones such as learning to play instruments and playing sports, which she thought he may never be able to do. Over time it hasn't bothered her as much anymore because Olivia and Joel focus more on Noah's own milestones rather than comparing them to others.

My conversation with Olivia stretched on to discussions of finances and interactions during their medical visits, but she always made sure to emphasize that while the experience was hard, she would not have it any differently. She made sure to emphasize Noah as a person and show how much she tries to not let him be defined by his disability.

He's just a lot of fun. And I think when people hear that he has this disability he'll have for the rest of his life and there's no cure, they say, "Oh that's too bad and I'm so sorry to hear that." Initially when he was born that makes you feel worse, but then after they

meet him? They realize in a lot of ways he's like any other kid—he's just happy to be out and be with people and experience life and do things with other kids. So I try not to let him be defined by his disability.

Finding Meaning Through Identity as a Mother and a Caregiver

Olivia's story of her first initial years with Noah exemplifies how mothers find meaning through their caregiving relationship with their child. Decades ago, mothers had been blamed for causing their child's disability or for providing inadequate care and discipline (Sousa 2011). However, in more recent years with considerable evidence that mothering practices do not cause most disabilities, there has been an emphasis on mothers of disabled children being the ultimate, intense mothers (Sousa 2011). This expectation of intense motherhood is comprised of devoting limitless time, resources, and energy to their child's development while shutting down any self-interest that conflicts with the child's needs (Hays 1998).

The idea that mothers of disabled children are expected to be the ultimate, intense mothers has both negative and positive results. On one hand, mothers are chastised if they do not act as the ultimate caregiver for their child since the child has greater needs. When a child does not behave, there is still judgment placed upon the skills of the mother. Additionally, mothers are held responsible when they are not able to provide adequate care due to factors such as finances, available resources, and time (Zibricky 2014, 41), despite the high cost and demands of caring for a disabled child. On the positive side of intense motherhood, however, this expectation shows the increased awareness of the effort and love mothers put towards their children when they have heightened care needs. When children are seen as exceptionally well-behaved and taken care of, mothers are praised for their over-the-top efforts.

Olivia described how people would see her in the store who didn't even know her and say, "Wow, you are such a good mother" simply because they noticed she has a child with a disability. While Olivia initially thought that people expected her experience to be a "diminished motherhood" where she would not experience the joys of having a normal child, she did acknowledge how people noticed the great effort she put into her care. These statements were quite meaningful to her since it pointed to how people realize, appreciate, and acknowledge how much hard work it takes to care for a child with special needs. While she mentioned how bystanders shouldn't expect that mothers keep their disabled children at home all day, she emphasized how glad she was that people believe mothers of disabled children must be doing a good job. They do not know what Olivia's parenting is actually like from seeing her with Noah at the store, but they do expect that she puts a lot of effort into her caregiving, which made Olivia excited that her efforts are acknowledged and appreciated. This allowed her to embrace her caregiving role and find meaning through her identity as an intense mother.

While significant caregiving needs are often cited as a burden and source of stress for mothers, I argue that this sense of purpose and necessity of care brings some mothers great joy. Lioness Ayers cites that caregiving fulfillment results in a careful balance between expectations, explanations, and strategies (Ayers 2000). Stigmatization of disability puts *expectations* for positive motherhood low, but explanations offer justification for the hard work while finding ways to *explain* the mutual benefit caregiving efforts create. Finally, finding *strategies* to be an effective caregiver gives mothers agency and feelings of control over the situation, making them feel like they personally are necessary for their child's development.

As Olivia described, these strategies of effective caregiving are often discovered through direct experience with the child. She became possessive of her care over Noah because she

believed that she knew his needs best, and she valued the fact that she was personally responsible for these caregiving decisions. While it is commonly acknowledged that any mother knows their child best, this becomes intensified with children who have disabilities because there is rarely a single expectation or plan for how the diagnosis will translate into the child's abilities. The primary caregiver of the child, who Hays mentions is often the mother, then learns the specific actions of their child and becomes attuned to their every need. Once mothers realize that they are the only person who knows their child best—often more than any medical professional due to their child's unique behaviors—they gain a newly found courage in their abilities (Sousa 2011, 229). This courage helped Olivia explain the purpose of her caregiving, helping her to find that sense of purpose Ayers describes. Mothers are hesitant to ask their partners or others to do more for their child because they see these other people as less knowledgeable about the right things to do for the child (Hays 1998, 101). Especially since Olivia's position as a stay at home mom put mothering on the forefront of her mind, she embraced the fact that she knew more than her husband about how to take care of Noah. This was seen as *her* responsibility, and she did not want to give this expert knowledge up.

Caregiving, like Olivia experienced, is frequently cited as a source of meaning people find in their life. "Finding meaning" is defined as making sense of one's existence and finding value in that experience (Noonan and Tennstedt 1997, 785). While caregiving, especially when out of necessity, is often cited as a negative stressor in people's lives, it can also be the fundamental way one finds their life-purpose. Finding meaning through caregiving is defined by Anthony Giuliano as "positive beliefs one holds about one's self and one's caregiving experience such that some benefits or gainful outcomes are constructed from it" (Giuliano 1990). As I discussed in the beginning of this chapter, motherhood by definition is closely tied to caregiving,

so this is one avenue any mother can use to create meaning in their life, leading to greater personal satisfaction. Children with disabilities require more care than the typical child, heightening the meaning and purpose mothers can find when taking care of their disabled child. By looking at the experience and necessity of bringing up a child with a disability as a positive caregiving role as Olivia does, mothers can find meaning and positivity.

An advantage of hearing Olivia's caregiving story in full is that we can see how despite the difficulties of adjusting to a new life, she constantly came back and found fulfillment in her caregiving role, which Noah relies on. This narrative does not limit her experience to the challenges and moments that deviate from expectation. By expressing longer life-stories rather than small facts and moments from raising a child with a disability, conversations surrounding mothering switch from mother-blame to heroism (Sousa 2011, 228). The small, seemingly insignificant everyday acts of motherhood are what show how she gained meaning from her caregiving role.

Through Olivia's story, I showed how mothers find positive meaning through enjoying the caregiving relationship they have with their child. Rather than focusing on the burden of the extra work, they find meaning by realizing how important they are personally for their child's development. By consuming their lives with being an intense mother, other people notice how much effort they put in and often commend their efforts, validating their difficult caregiving experience. While it may take over their lives and identity like it did for Olivia, it gives mothers a purpose in their life and love of their role as a mother.

Chapter 3.

Creating a Cohesive Family: Choices of Place and Resource Allocation

Creating a Cohesive Family: Choices of Place and Resource Allocation

Some parents only have one child so they have more time for things, but we have three to keep track of. I stopped going to the support group after a while because we wanted more family time. It's hard seeing how some other parents have appointments all the time and who make a point to use every single resource available to them. But for us, we decided that we will do what we can and what works best for our family. – Kimberly, Steven and Sarah's mom

Choosing how to allocate limited time, money, and attention for an entire family is difficult to do equally, especially when one child requires extra care. For Kimberly, her parenting experience was not just important to get the best care for her disabled children, Steven and Sarah. It was also about making things work for her family.

But keeping the family in mind is difficult when there is the expectation that parents with disabled children will put everything they have towards that child (Landsman 2009). Research has shown that the points of stress for parents do not primarily stem from the impairment itself; rather, they stem from social barriers, perceptions, and access to care (Olsson and Hwang 2008, 1102). These barriers vary greatly depending on the inclusiveness of a family's community, their economic status, and what resources are available to them. Parents may try to reduce this stress by moving to a new community with more inclusion and access to care, or they may put more of their time and money into what they believe will help their child the most. However, these decisions become complicated when parents also have to think about their other children and family members.

In this chapter, I use Nick and Michelle's story to show how parents must figure out how to situate themselves and use their resources in order to benefit not just their disabled child, but also the entire family. I argue that social acceptance and access to resources are largely connected to place, especially with public schools. Therefore, many parents like Nick and

Michelle make the decision to move to a community with a greater access to care if they can afford it and if it will be suitable for their whole family. In fact, three out of the eight families I interviewed reported that they moved to their current community in order to have greater access to a good school system for their child that has a disability. By looking at how parents with children who have additional needs distribute their limited resources and make decisions about access to care, I further show what critical questions and decisions parents face in experiencing what it means to be a family.

Living in wealthy, resource-rich communities is advantageous for people with disabilities if they can afford it. It allows greater access to therapies and resources as well as being surrounded by educated people who are often more aware of disabilities and more conscious about disability equity. These communities are often larger metropolitan areas that have a greater population and need for disability services in general (Thomas et al. 2007, 1907). However, when first settling down before having children, families living in small communities do not expect that they will have a disabled child and need to live somewhere else. It is quite expensive and emotionally taxing to relocate, especially considering that moving may causing dissatisfaction or lesser opportunities for other members of the family even if it brings more resources for their disabled child. This makes for a difficult dynamic that parents must try to balance in order to keep the family intact.

As an important point to note, most families I interviewed for this thesis are upper-middle class—evidenced by the communities they live in, their home environments, and their jobs. A lack of resources is even more devastating and central to families of lower socioeconomic classes since they do not have the funds to make decisions such as relocating that the parents I talked to were able to have. But at the same time, these families have always grown up as a part of the

middle class, so they have middle class goals and aspirations for their family, which they thought they would be able to afford before having a child with a disability. Despite the fact that they are middle class, caring for a child with a disability has significant costs that affect the finances of parents in any situation. Therefore, there are still significant socioeconomic factors at play for the families I discuss that limit their access to resources and create stress on their families.

The following story of Andrew's parents depicts a family who moved to a new city in order to gain greater access to resources, showing how it is a privilege to be able to afford to live in a resource-rich community. These decisions impact not just the child with a disability, but also the entire family, which creates additional stress and factors parents must deal with. Michelle and Nick's story shows how parents deal with these difficult questions of allocating limited resources and keeping in mind the needs and desires of an entire family.

Michelle and Nick's Story

My first impression of Andrew consisted of a rambunctious eight-year-old boy who always came to PEAC with his dad and twin brother. He was small for his age with pale blond hair and freckles that surrounded his smiling face, which I noticed as he walked up to the bikes before beginning our lesson. Andrew's dad was always right there with us, encouraging Andrew and holding onto him as his brother, Brandon, would ride laps around the parking lot on his own bike. Brandon was always encouraging to Andrew, and I could tell he always looked out for his brother even though he does not have autism like Andrew does. From my experiences with Andrew, he was a well-behaved child with limited speech who loved to be silly, such as always calling all the bikes "goats." It provided for many laughs with him and ways for us to use his own personality to help him with his bike riding.

I went to Michelle and Nick's house to chat with both of them about their experience raising Andrew with autism. Their experience was unique in that they had twins—one with autism and one without. This allowed Michelle and Nick to compare how Andrew was developing in relation to his typically-developing brother, but it also created difficulties in proportioning their limited time and resources towards both children.

I chose Michelle and Nick's experience to share in order to show the impact of place and access to resources for parents with a disabled child. Moving gave them to access to a better school system and a community that was more receptive and accepting of disability, but putting a huge portion of their income into Andrew's education took away from the experience of Brandon. Michelle stressed that she wanted to give Andrew the best opportunities she possibly could, and this took a huge toll on their family emotionally because Michelle and Nick both valued having a cohesive family. Their story shows how parents value providing for the entire family, but this becomes complicated when they want to help their child who has a disability and a significant portion of money, time, and resources go to them.

After talking to Nick and Michelle about what Andrew was like before I met him, I realized just how far he had progressed behaviorally. Hearing their story of Andrew's behavioral problems when he was younger showed me just how much he has progressed and how hard Nick and Michelle have worked to get him to where is he today. While Andrew has been able to speak limited sentences and express many of his feelings ever since I have known him, it took a very long time to even say a single word and mitigate his behavioral difficulties in public.

What's so great about our current situation is looking back to when Andrew was really little when it was incredibly hard. Andrew has come so far since then. It was just hard to walk out of the house because he was banging his head into the ground and we were always diving to save his head. And Andrew would also bite. We couldn't go out to eat or to the movies or anywhere due to behaviors like this. And then Brandon was pretty sheltered as well because we just could not get out. Luckily now, Brandon doesn't really

even know or remember that version of Andrew. It was just the hardest thing anyone could imagine because it impacts every area of your life in ways you just couldn't imagine. Just walking the dog, everything is impacted. But because we intervened so early, that Andrew is no more. Now he is just a beautiful, happy, boy. – Michelle

Unlike some of the parents I interviewed, both Nick and Michelle had to continue working while Andrew was an infant to provide for their family and for Andrew's extensive therapies and treatments. Having restrictions such as the economic need for both parents to work contributes to added emotional stress when parents know that they would utilize that time caring for their child if they did not have to work (Olsson and Hwang 2008, 1107). Other parents I talked to who were stay at home moms said they could not imagine how they would ever get everything done if they had to work full time as well, but Nick and Michelle made it work. At 18 months of age, Andrew participated in a caregiving regiment and study at the University of Michigan hospital that involved helping the primary caregiver learn how to care for their child. Due to the nature of the study, it had to be only one caregiver who worked with him for 30 hours per week. Michelle took Andrew for those 30 hours while working, which put considerable stress on her home and work life because she described how she really only had an hour of downtime at home every day. Since Nick was not able to cover any of those 30 hours for her due to the study's restrictions, he also wasn't able to learn as much about how to care for Andrew.

We were trying to make it work while both working full time, and it was incredibly stressful. And on top of that, we were trying to make sure Brandon didn't feel it and know it. We lost friends, we had family who refused to talk to us and didn't understand all we were going through. It was definitely an incredibly hard period of time. –Michelle

Working full time and bringing Andrew to therapy for 30 hours a week made it nearly impossible to give Brandon what they stated to be a "normal childhood." A large amount of their time was spent caring for Andrew, not Brandon, which was painful for Michelle emotionally.

Regardless, she still felt this was worth it for their family in the long run because it would help Andrew's behavior and development.

This intense time spent with therapies also divided her and Nick because Michelle was "learning so much so quickly about how to help Andrew," but she just did not have the time to share with Nick about the best ways to care for him. This caused Michelle to get frustrated when Nick did not know things, but she also acknowledged that there was not much he could do because Nick was not trained extensively as she was.

During this time and throughout Andrew's preschool years, their family lived in a small community 45 minutes from Ann Arbor. This was a considerable distance taking into account that Michelle had to travel to Ann Arbor for 30 hours each week for Andrew's therapy study.

Our schedules just became crazy. We were living in Tecumseh but decided to rent an apartment in Ann Arbor so we could have residency there. They have much better schools for kids with special needs in Ann Arbor so we really wanted Andrew to go to preschool there. With the crazy hours we were working and Michelle having to make up time for being in the study, we basically lived apart from each other for three years. – Nick.

As Nick mentioned, they decided to rent an apartment in Ann Arbor because the school system was so much better there, especially for kids with disabilities. With the passage of IDEA back in 1975, schools are required to offer appropriate education for children of all abilities (Berry 2008). However, this does not mean that all schools offer equivalent education, especially in districts with fewer financial resources. This makes location so important as far as access to resources and care for kids with disabilities.

I think we moved away from Tecumseh because it was difficult to deal with a lot of the teachers and staff there. Obviously we wanted different services as well, but I felt like I was educating the teachers in Tecumseh in the short period of time that I was involved with autism. I thought it was just ridiculous that I was the one educating them and we just didn't have the time to do that. – Michelle

According to Nick and Michelle, Ann Arbor schools offered more therapists and support than most communities, and hiring their own private therapists would be far more expensive than renting an apartment to have access to free resources in the Ann Arbor school system. Ann Arbor schools offered 30 hours of BCBA⁴ therapy per week, while their home schools did not offer BCBA at all. Living in Ann Arbor is expensive, and they were not able to afford a house there at the time, so they rented an apartment until they were able to move when Andrew was five-years-old. Even though it took a huge financial toll, Michelle and Nick were luckily able to afford having a home and an apartment. Many parents with disabled children do not have the option to move to a resource-rich area or gain access to these services at all.

Placing Andrew in an Ann Arbor preschool was so costly that they could not afford a good preschool for Brandon. This was one of the most devastating aspects of their educational decisions because they wanted the best for both children, but they ended up only being able to afford a preschool for Brandon that was far inferior to Andrew's. It was heartbreaking for Nick and Michelle to see that putting Andrew in a preschool with important intervention services for his development mean putting Brandon in a school where he was bullied and left out. It was difficult trying to choose between both kids, but they still knew how important early intervention was for Andrew.

Beyond renting an apartment to get BCBA therapy at school, we were doing all kinds of other things such as private speech therapy, supplements, diet plans for autism, and shots. It was about 2500 dollars a month we didn't have, so we were taking out loans to pay for it. We just could not afford to put Brandon in a good preschool after all that. And Brandon was bullied at the preschool we had to send him to and still remembers that time. I remember sitting at the clubhouse of our apartment we had to renew to keep Andrew in school there, and we couldn't afford it. I didn't know what to do because we knew we were making a decision of keeping Brandon in a preschool we didn't want or

⁴ BCBA stands for Board Certified Behavior Analyst. This therapy is frequently used for young children with autism to help them develop appropriate behaviors using positive reinforcement.

choosing Andrew. And it was devastating. Because as a parent you always have to choose the child who needs you most and it's just always been Andrew. That has killed us. It just killed us. But we thought in the long term that everything was for the benefit of our family and one day we would actually be able to go on vacations together and go out to dinner together because of it. – Michelle

I could hear the devastation and emotion in her voice as Michelle told me about the helplessness she experienced with trying to do the best for both of her children. It was difficult to do the best for Andrew while still trying to give Brandon the best education and life as possible. Eventually they had to sell their house in Tecumseh because it was too expensive to have two places, but this made it even more complicated keeping Brandon in the same school. Currently, they are happy living in their current home with a great school district in Saline, and it is close to Ann Arbor where Andrew gets some of his therapies. But even then, they just moved to their current location last summer when Andrew and Brandon were nine-years-old. It took them nine whole years to have a stable home situation they were happy with.

Throughout both Brandon and Andrew's childhood, it was incredibly difficult to balance allocation of resources for both of them. Michelle and Nick wanted the best for Andrew, but they also wanted Brandon to live a relatively normal childhood. This proved to be almost impossible for them.

We just wanted to be like a normal family and we felt so bad for Brandon. Brandon definitely was sheltered and I think sometimes spoiled because we were constantly trying to overcompensate for the things we couldn't do as a family. We just went on our first family trip this spring break while many of Brandon's peers have been able to go every year. – Michelle

Michelle realized that Brandon felt sheltered in many ways beyond not being able to talk to his friends about their fun spring break vacations. Since Andrew was nonverbal for so long and was not interested in many interactions with Brandon, they did not play together like Michelle and Nick imagined siblings would. Due to Andrew's temperamental behavior, Nick and Michelle

also did not have many kids come over to play or any visitors at all, which impacted Brandon's friendships and interactions.

We felt horrible because Brandon was lacking some basic social skills with his peers. When he started going to an actual preschool that we liked after we moved, his learning greatly improved and we are happy with his experience there. But at that time, he was still just trying to figure out how to talk with other kids because he didn't have that interaction every day. He and Andrew didn't always interact even though they were the same age. – Nick

It was such a difficult balance to maintain since Michelle and Nick constantly emphasized how much they cared about having a cohesive family, but they realized that some sacrifices had to be made for the benefit of everyone. As the children grew older, Brandon developed great compassion for Andrew and loved having him as a brother. Throughout my job at PEAC, I noticed how Brandon looked out for Andrew and always cared about his achievements and his happiness. Brandon would bike alongside Andrew, encouraging him to keep pedaling and congratulating him for even the smallest accomplishment. But despite the immense care Brandon had for Andrew, their parents still stressed how they wanted Brandon to have a normal childhood. They did not want him to feel like he has to look after his brother all the time. It was important for him to develop his own independence and his own life.

It's great to have them in the same school now because Brandon is such a lovable kid. He still actually wants to know what is going on with Andrew like where he's at and what he's doing. But we want him to be able to have a little bit of that independence on his own so he doesn't have to live autism 24/7. Our experience raising Andrew has been incredibly stressful, but on top of that we were trying to make sure Brandon didn't feel and know it. We lost friends and had family refuse to talk to us. But I think we have done a really good job of trying to protect him and shelter him from all that. I think about how he has been impacted by having a brother with autism in a good way. He has a heart of gold because of it. He truly has empathy which isn't something that can be taught. He'll get frustrated still; he's a nine-year-old boy. But he loves his brother, and he just wishes he didn't have autism. – Nick

Despite the significant stress associated with moving and the impact it had on Brandon, Nick and Michelle are still glad they pursued these resources to help Andrew. And they were thankful that Brandon has been able to grow up into a caring and empathetic boy. A significant point of stress for parents with a disabled child is knowing that resources exist to combat their difficulties, but that these resources are not available to them specifically (Beresford 1994, 175). It was hard for Michelle and Nick to know that there are programs and interventions available to kids with autism, but they were not accessible in their original Tecumseh school district. To combat this stress and realization that Andrew would benefit greatly from these resources, they decided to move to Ann Arbor where these resources are available to them.

Michelle and Nick were able to put access to care in their own control by moving to a resource-rich school district and community, which contrasted from their initial community where they felt a lack of control due to an unavailability of resources. Having access to different choices in care and having control over these choices empowers parents (Lazarus 1994, 28). When faced with an illness or disability people had no choice over, seeking access to different choices gives parents more control over their situation, mitigating feelings of helplessness and unpredictability. Despite this lack of control over the diagnosis and prognosis itself, parents look for ways they can take control of the situation because they want the best for their entire family and want options that will help keep everyone in mind.

Feelings of control are situation-specific and point to the relative support one family has compared to others in their community. Michelle and Nick felt helpless in Tecumseh knowing that parents in other communities had greater access to autism therapies and social supports. Even given their ability to move, Nick and Michelle felt severely limited by their finances because they were able to send Andrew to a good school but not Brandon, and they could only

rent an apartment in Ann Arbor because houses were too expensive. Socioeconomic status is a large predictor in access to resources, which significantly impacts how parents experience choices in caregiving (Lazarus 1994, 26). Parents with greater disposable income would find they have more choices in places they could afford to move to and schools both of their children can attend, while people with less disposable income might not be able to afford to move at all. Having accessible choices, therefore, affects parents' feelings of empowerment and stress. Finding ways to assert control helps parents see that resources other families utilize are available to them, and it helps parents feel like they are doing as much as they can for their child. Economic and social privilege give parents greater access to a vast array of support, therapies, and education.

Even though Michelle and Nick put themselves in a situation with more resources and more control, it was still difficult to get Andrew the therapies he needed. Moving to a new school district brought along continuous fighting for more resources for Andrew since people did not know his behaviors and needs as well as Michelle and Nick did.

I'm an overprotective person of people I love anyway, but when it comes to Andrew and autism, I can just get crazy. Occasionally now we still get resistance, but I know the system now and I just don't take it when I know he deserves better. I know part of it is just because of money and that there are only so many resources and so many options and everyone means well. It actually makes me feel bad sometimes knowing if other parents aren't educated about what services are best for their child or if they're still in that denial phase. They might be saying "oh he's fine we don't need anything" if they're in denial and don't know. I think we've just been in this so long and have become so educated that those answers just aren't acceptable to me anymore because he has come so far and I want the world for him. We have run into so many amazing people in this process and just a few bad seeds, but I won't let the bad seeds get their way with him. – Michelle

Although they have learned the school system by now, it was initially very difficult to move and learn about a new system with new people, even if there were more resources

available to them in Ann Arbor. Being able to advocate for these resources is a skill in itself that Michelle had to learn and fight for.

Part of this is that you have to thrust yourself right into it. To be successful with the school districts, you have to become an informed advocate, and Michelle is a tremendous advocate. You have to be able to reach out to get those resources and know where they are at. There was a time while we were learning this process, and our primary speech therapist offered to come to our IEP meeting with us. She sat there across the table and fought for Andrew's education and talked on their language which was Greek to us. – Nick

Michelle and Nick were lucky to have so many people in their community who were willing to help them learn what resources to advocate for and what kind of care and insurance Andrew deserved. However, they admitted that becoming knowledgeable about autism services and what resources are available is not an easy task. It requires a lot of searching and connections that many people do not have access to.

A lot of parents don't know that they qualify and deserve more care within the schools. And they don't know what to ask for or what services are even available so that is really a part of it. I think that there is not enough education about it on what to do, and there are not enough state services. And certainly there is not enough support. – Nick

Navigating this difficult system became much smoother as they established themselves in the community and built connections and friendships with other parents who had kids with autism. While figuring out what services exist and are helpful was still difficult, these friendships helped Michelle and Nick connect through their similarities with other parents and have people with whom they could share advice.

This new community Michelle and Nick found allowed them to find more acceptance through a biosociality of autism because people were aware of their situation and aware of what autism means for a family. Even within the school districts, they had more children with disabilities because they had the support necessary to educate them, which is why Nick and

Michelle moved to the Ann Arbor school district to begin with. Tecumseh simply didn't have as many kids with disabilities since it was such a small community, so it was harder for them to connect, especially through the extensive behavioral challenges autism presents.

I remember many times we would walk down the Ann Arbor preschool hallway and he would just slump down and not move. And it could take ten to thirty minutes to get him moving on his own and doing what he needs to do. People would walk by and see us, but they understood because every child was going to class that way. Everyone understood it and how it's incredibly stressful when you're late to work and something like that happens. So it's nice when your environments are places where people get it. Other people don't understand, and it's so easy for them to judge. – Michelle

Even outside the schools, Michelle and Nick joined a support group and made new friendships with other parents in similar situations who understood their experience. They lost many of their old friends because they had a hard time realizing what their situation was actually like.

I think that commonality with people will draw you in a little bit closer than somebody who doesn't have that. It's such a strong emotional tie when they actually get it, and it's a lot easier to open up to those people. I'm a pretty guarded person in general, and initially when Andrew was diagnosed and thinking about the community we first lived in, we did lose a lot of friends because they didn't understand and I didn't feel comfortable opening up. – Nick

Their new group of friends comes from a support group they joined through the Ann Arbor Preschool called KIAT, which stood for Keeping It All Together. Like the name says, the purpose of KIAT was to focus on keeping *families* together. This was particularly helpful for Michelle and Nick because they saw how hard it was to manage not only a child with Autism, but also how to manage making choices as a couple and keeping Brandon's needs in mind, too.

Nick mentioned how many members of the group had dealt with divorce or conflict with their spouse because of the difficult choices in care for their child.

In your head, you think about how if you get a divorce, you are involved with another person. You're thinking about how one person gets a break from having to deal with this week on and week off, and you're adding an extra income to the process to be able to help afford care for your kid. –Nick

Nick felt bad saying this, but both him and Michelle acknowledged the truth in the statement, saying the consuming nature of autism care “made you think crazy things.” While Michelle and Nick worked hard to stay together because they valued having a cohesive family, they acknowledged how all the parents in KIAT dealt with caregiving decisions affecting—and breaking apart—the entire family. This group helped Nick and Michelle see that they were not alone in experiencing this. Even after the group stopped, they kept their friendships. Nick told me that they recently had a barbeque together, and said, “It was just so nice to be in an environment where everyone gets it. And a lot of them have typical children and a child with autism.” This community sympathizes with their struggle to allocate time and resources between Brandon and Andrew, and it allowed them to bond over similar parenting experiences.

Beyond just access to resources and friendships, interactions with strangers in the community have a significant impact on parents' experiences. Andrew was very difficult to take out for a long time, which was especially an issue when he was younger before they moved to Ann Arbor. At that time, Nick mentioned how he was still adjusting to having a child with a disability, so he took every negative interaction personally and would want to jump on them even though he did realize that they just didn't understand the situation.

Andrew used to have no interest in Halloween back in Tecumseh, and I was pulling him around the neighborhood in a wagon. At the time he had an iPad and he was using it to help with all kinds of things—for fine motor skills, helping with speaking and communication, and helping him learn how to read. If it wasn't for the iPad, we would have never known that he had learned how to read. While I was pulling him around a man came up and said, “It must be nice to have an iPad to play with as a kid.” I was just thinking to myself *it must be nice to have a kid who can talk*. I realize I was being kind of

snappy with him, and now I have a lot more patience and am a lot more willing to explain what is going on. But that time really affected me. – Nick

For Andrew, having an iPad was an integral part of his therapy and communication rather than an expensive toy. It was understandable to Nick why people made different assumptions about why Andrew had this device, but it still frustrated him that people would be so quick to judge.

Positive community interactions are important to parent well-being, and they are especially hard with children who have autism because their disability is not immediately apparent by looking at them. This often makes Andrew's behaviors seem to stem from bad parenting rather than Andrew's inherent autism, especially for people who have not met him before (Sousa 2011). Awareness about Autism Spectrum Disorders can help prevent these stereotypes, but difficulties for parents still arise when out in the community.

Andrew loves going to the grocery store because occasionally I'll buy him a train. But it's good therapy for him because it's not an easy place for him to be at all. There's so much going on, the lights aren't fun, and I don't even like it. Occasionally he loses his mind in the grocery store, and you can see him hooting and hollering throughout the store. He's gritting his teeth and getting angry with me about something, and I have to try to help him through it. It's hard too with Brandon because he gets a little embarrassed in these moments. Our goal is to try and help support Andrew through that, and we've learned ways to help support him through that. Now I don't care what other people say when this happens. If they do say something to me now, I don't have a problem saying something back to them. But overall, my goal is to care for him and I don't care about what other people are saying and doing around him. I think we have chosen the people that love us and accept us and Andrew, so those are the people who are still in our lives. – Michelle

One way to reduce feelings of anxiety in the store is to accept the mindset that they do not care what other people say, which Michelle and Nick were eventually able to develop. And while Michelle and Nick both agree that Ann Arbor had more education and awareness about disability, they also told me how awareness about autism has increased in general.

A lot has changed in nine years since Andrew was born. I mean now you go to a restaurant and people have tablets everywhere. When we were finally able to go out before we would feed him quickly and then get out the iPad so he could watch a movie while we ate. We knew there was a window of time to get through it. We were definitely judged then, but regardless of technology, I think people just don't judge as often now. – Michelle

Apart from personal judgment about their child with autism, Michelle and Nick have seen much more awareness about what autism is in the media and discussions about behaviors in young children.

Prior to Andrew being diagnosed, I never saw a sign for autism. And then 2 years after he was diagnosed there were signs everywhere. You would drive down the expressway and see signs of “1 in 65” or “1 in 112” and just watch the numbers come in about how many kids have it. – Nick

Nick and Michelle are likely more astute about noticing billboards about autism now that it has greatly affected their life, but awareness and diagnosis standards have also changed for children.

When Andrew was an infant, pediatricians were not required to screen for autism and now they are. Insurance wasn't covered either so it was still limited for small businesses. But now there's insurance in Michigan, which we didn't have when he was younger for all those things. So more things are becoming less experimental and more known fact of treatment. – Michelle

After looking at how much more awareness has come to autism and how Michelle and Nick have been able to provide for Andrew, they look back with great appreciation at having had this experience. While it was hard at times and vastly different from the life they anticipated having in Tecumseh, they felt lucky that Andrew was born into a home that was able to make sacrifices and was situated in a community with resources available for his growth. They were glad that Brandon has become such a loving brother to Andrew and that their whole family has been able to help Andrew develop into a wonderful child.

We always think we're lucky and Andrew is lucky because while we maybe we don't have the means, we found a way to make things work. We have the education and the drive to do whatever it took to help him. And I'm so thankful that he was born to us and that we would do that for him. I can't imagine what he would be if someone else hadn't taken those steps to help him. – Michelle

When Michelle and Nick talked about how they were unable to do so many things and progress in their careers as they intended, they always qualified it by saying that raising Andrew was worth it. They found great meaning in their ability to give Andrew a good life because some parents with disabled children are not able to do that. While it was hard, they were grateful they could move to a community with lots of services available and that they could sacrifice their time in order to help Andrew.

Do you want to work and climb that ladder and be working 80 hours a week and never be home with your family? I think about what is important right now and *wow*. It's just such a different mindset. Now I look at what we have accomplished in 9 years with Andrew. It's amazing. That child is absolutely amazing and we had a part of that. That's the reason why we're here—we're a part of that. – Nick

Knowing that they are serving a greater purpose and that their child is better off because of their care gives parents hope (Prussing et al. 2005). They see that their life has meaning because they have been able to help their child in ways that not every family would be able to do.

As we drew our interview to a close, Michelle and Nick emphasized how they were a lucky family and that they were so appreciative about every little thing they experienced with Andrew. They felt that it allowed them to be “far more appreciative than normal people” because things like hearing “I love you” from Andrew and going on vacations were such rare and special things. It made them feel appreciative about their experiences with Andrew and the resources they were able to provide for him.

I think what autism means to me is that it was an opportunity to do something far greater than I will ever accomplish—watching *him* accomplish things. – Nick

How Choices of Resources and School Quality Impact Disability Care and Family Functioning

As shown in Nick and Michelle's account with Andrew, the community that people live in has a significant impact in their access to resources and personal well-being. Being a family involves making decisions about where to live and how to divide time and resources between everyone in the family. The driving factor for inequalities in access to resources for families is the socioeconomic status of the community, which is one of the most important factors in determining well-being of parents with disabled children (Emerson et al. 2006). Socioeconomic status is a complex issue affecting both what resources families can afford and what communities they can afford to live in. Communities with greater access to high-quality health and education are more expensive to live in, perpetuating the concept that money is necessary to properly raise a child with a disability. Nick and Michelle were lucky that they were able to move to a new city to gain more access to resources for Andrew, but many parents do not have that option, resulting in considerable stress knowing that resources are not available to them.

Coming to terms with having a disabled child results in considerable stress, whether it is social, emotional and/or financial. Nick and many of the other parents I interviewed mentioned going through the stages of grief when they discovered the disability diagnosis as a way to deal with the initial stress. There are ways to combat and even prevent this stress, although this is often not in the parents' control. As Bryony Beresford argues, "Vulnerability to the effects of stress is mediated by coping resources. If resources are unavailable, the individual is more vulnerable" (Beresford 1994, 176). These "coping resources" could include support groups, good education for their child, or a supportive family. This means that having low SES⁵ or living in a

⁵ Socioeconomic status

community where there is limited access to resources makes parents much more susceptible to stress. Nick and Michelle experienced this in Tecumseh where the school administration was not very helpful or sympathetic to the difficult decisions they had to make about Andrew's care. Since it was such a small community, Nick and Michelle also did not have support groups or know anyone who had a child with autism, making them feel lost when having to decide what to do for Andrew's care. This suggests that parents who don't have resources that help them cope and adapt have a harder time adjusting to having a child with a disability.

Family itself often acts as a great source of support and can be classified as a "coping resource." This is why it is so important for parents to maintain a family balance and why they value having family cohesion and love to get them through the process of caring for their child with a disability. As one of the other parents I interviewed said, "I think our biggest support has been relying on each other as a couple. We haven't had the time to use support groups, but at least we have had each other to rely on." Therefore, parents value having good spousal support and a good family dynamic when making decisions about their child's care.

Sociologist Sara Green argues that there are two types of burdens associated with raising a child with a disability, which have to do with the nature of parents' stress. The first is emotional distress (subjective burden), which involves the individual emotional burdens associated with the nature of the disability itself. The second type of burden is from socio-cultural constraints (objective burden), which is the stress associated with access to care, resources, and financial stress. This second kind of burden is often what impacts the entire family and causes other family members to experience stress due to the sacrifices they have to make. She shows that after coming to terms with the initial shock of the disability diagnosis and learning how to care for a child, day-to-day care is not necessarily accompanied by severe

emotional distress (Green 2007, 161). Many stressful moments of caring for a child with a disability are similar in nature to caring for any child. In her study, Green found that mothers of children with cerebral palsy, Down syndrome, and spina bifida reported significantly higher levels of objective burden than subjective burden (2007, 154). She showed that parents spend a considerable amount of time, energy, and resources for the care of their child in addition to figuring out the system and learning what services are available and effective. For Nick and Michelle, this consisted of figuring out how to manage 30 hours of therapy while working full time and still giving Brandon a good childhood. This along with the financial stress of affording this care made it difficult for Nick and Michelle to feel like they could function well as a family. Access to resources is a huge component of the objective burden that is one of the most significant factors in determining parents' experiences raising a child with a disability.

Green's research is not alone—many reports discuss how socioeconomic status is the number one factor that determines well-being and burden of having a kid with a disability, even more than the biological impairment of the disability itself (Emerson et al. 2006; Mahoney, O'Sullivan, and Robinson 1992; Olsson and Hwang 2008). The parents in my study were not part of a low socioeconomic class, which I deduced from the communities and houses they lived in, cars they owned, and ability to go on vacations. However, while Nick and Michelle were able to afford treatments absolutely necessary for Andrew, they still experienced significant financial hardships, stress, and lack of resource access. They just wanted to be able to provide him with the best life they could, which is expensive and requires financial sacrifices that significantly limited personal spending and out of pocket, optional therapies for Andrew.

Complementary to the fact that socioeconomic status is burden, it can also be looked at as a safety net for people with greater financial resources. Parents with high socioeconomic status

and high access to resources in their community generally experience less stress and higher personal well-being (Olsson and Hwang 2008, 1102). This is because they have the excess income to be able to afford these treatments without sacrificing as many personal luxuries. It also allows them to live in more expensive, wealthy communities that have a greater share of resources due to the wealth of the community itself. When resources are available in these communities and individual families have access to them, they are less vulnerable to stress (Beresford 1994, 175). However, I would like to question whether it is the wealth itself that provides a safety net, or if it is the agency parents feel when are able to afford a variety of decisions, making them feel less stress.

Socioeconomic status is not the only factor that acts as a safety net for parents while they adapt and cope to fitting care for a child with a disability into their family. Friendships and family support also are important for the emotional wellbeing of families. In a study by Mahoney et. al, they found that the highest levels of stress come from low SES, limited spousal support, or no spouse at all (Mahoney, O'Sullivan, and Robinson 1992, 387). Parents who felt supported by their spouse and had children who appeared to adapt well felt much less stressed and more satisfied with their experience than those who did not. Mahoney et al. also argued that having a child with a disability did not result in deleterious family functioning as once believed. Rather, they state that the degree of satisfaction with family functioning dictated how well parents were able to cope with the stress of additional care and finances for their disabled child (Mahoney, O'Sullivan, and Robinson 1992, 387). These kinship relationships are important. This is a reason why parents like Michelle and Nick really emphasize having a good marriage and cohesive family. Having a satisfying family dynamic significantly reduces other stress.

Nick and Michelle experienced considerable stress through their negative interactions with the Tecumseh school district when they knew that Ann Arbor had more therapists and programs that would benefit their son, which they could only have access to if they moved there. Despite IDEA's focus on all public schools having the appropriate education for students with all abilities, it is widely known that there is significant variation in the quality of special education in public schools (Mason-Williams 2015). Mason-Williams shows how inequalities in education stem from resource-allocation, including which schools have quality teachers and programs. Schools with high rates of poverty and undesirable geographic location make it difficult to attract and retain qualified special education teachers (Mason-Williams 2015, 247). Therefore, they are left with inferior education programs.

In addition to quality of teachers, inequalities in breadth of programs and money put towards disability resources in the schools varies greatly. Funds for these programs come from the state or local levels, causing discrepancies across districts on the amount of money provided for disability services. On the state level, state allocation policies may result in different communities having vastly different financial burdens in times of economic stress for the state as a whole (McManus et al. 2011, 687). Since states get to determine how they allocate resources for schools, inequalities ensue when the state is struggling to fund all education programs and local communities are not advocating for more resources to be given to disability programs in the school. Research shows that affluent districts allocate greater state-funds to special education than poorer school districts, which drastically affects the children living there (McManus et al. 2011, 687). Many communities also have local funds focused on special education programs, which adds an additional benefit for affluent communities while further dividing resource availability in communities where local funds are not established.

The issue is not solely a proportionate lack of funds allocated to smaller, disadvantaged school districts. Rather, it is also an issue of a much lower percentage of funds being allocated to disability services. Maria Berghs argues that this is due to neoliberal governments investing more heavily in productive, able bodies rather than helping people who need the care (Berghs 2015). When finite resources are available for education and health, social inequalities and stigmatized groups receive a smaller share of the resources. As discussed in my first chapter on disability and special education history, the IDEA law attempted to combat these educational inequalities for kids with disabilities by required that appropriate education is provided to all children regardless of their abilities (McManus et al. 2011). However, how school districts define “appropriate education” varies greatly.

What qualifies as good enough to follow IDEA’s mandate of appropriate education varies due to school districts prioritizing their programs differently. In communities with low funds to start with, many schools justify funding programs that help improve their test scores of the general student body rather than increasing support for kids with disabilities (Allbritten, Mainzer, and Ziegler 2004). This is due to increased accountability and pressure for school districts when they do not have a high enough percentage of students performing at grade-level achievement standards in reading and math (Allbritten, Mainzer, and Ziegler 2004). When making resource-allocation decisions, Allbritten et al. argues that “too many school boards, administrators, principals, and teachers continue to devalue the unrealized potential of student with disabilities” (2004, 157). Allocating extra funds to special education is perceived by some districts to be taking resources away from other students, which intensifies negative attitudes toward special education as taking away resources with little quantitative benefit (2004, 158). In times of resource scarcity like with many low-income schools, administrations invest in bodies of

productive power, which discriminates and invalidates other bodies that are not seen as productive for the school district's success (Berghs 2015). Productive power in this case is the students who will be performing at higher levels on achievement tests, which will give the schools a better reputation and more state funds. Since resources for school funding is limited in many districts in general, discrimination is perpetuated by attitudes that students with disabilities do not deserve the funding and equal opportunity for education.

Countering the neoliberal idea of investing in bodies of productive power, the original intent of public education programs is to allow all individuals to succeed regardless of their gender, race, background, or ability. What is considered "equal" for students with disabilities is contested because it is often thought that holding these students to universal standards of education is not practical and unjust (McLaughlin 2010). The *Brown v. Board of Education* case showed that giving the same opportunities to every child was not sufficient to determining equity without considering how that child actually benefitted from the opportunity (2010, 267). Applying this to disability education shows that kids with disabilities often actually require more resources than the typical child in schools to actually look at how they can benefit from the opportunities given to them. This shows why it is especially important for children with disabilities to have good resources in their public schools – because they often benefit from more resources in the first place in order to have equitable education outcomes.

Apart from education quality being impacted by resources available, other structural factors rooted in a community create barriers to care. Parents face physical barriers to resources when they are not located in that community and they have to drive significant distances to receive care (McManus et al. 2011). For Nick and Michelle, this occurred when they had to drive 45 minutes to Ann Arbor every day to receive their early intervention at the University of

Michigan Hospitals, since the study on how to properly care for a child with autism was not available in Tecumseh. Oftentimes programs are available for parents, but I can understand how programs that are far away still provide significant disadvantages to those parents due to the amount of time spent driving. Just because something is available and can be afforded does not mean it is easy to access.

In order to combat structural access to resources, Michelle and Nick decided to relocate to a community with greater resources in the school and greater awareness about disability in general. While still not a perfect solution, it gave them greater access to resources in a more heavily-funded school district. This also reduced Michelle and Nick's feelings of stress by giving them control over the situation and control of resources available to them (Beresford 1994). While moving to a new community is not easy, this control is a coping mechanism that brings families satisfaction that they are helping their child. Having options and choice over care gives parents control, and this control is especially empowering for them in a system where parents often feel lost or helpless (Lazarus 1994). For Nick and Michelle, the access to greater resources in a new school district was worth it.

In concluding this chapter, I want to reiterate how access to resources and an ability to choose between them reduce stress and gives parents a sense of efficacy that they can provide for their child. This becomes complicated when parents must factor in distributing their limited resources to the entire family, showing that parents value a cohesive family but still want to be able to provide for their disabled child. Communities that are more wealthy typically have more substantial programs in quality and quantity for students with disabilities, while lower-income communities often do not have as many programs due to competition for funding and a lack of consistency in what IDEA mandates schools to provide. Nick and Michelle were able to make

the difficult decision to move to a community with greater access to educational programs, which lessened stress by giving them greater access and greater feelings of efficacy in knowing that they were helping Andrew. But it also made them reconsider how they were functioning as a family, showing the difficult balance parents try to maintain when doing the best for their child who has special needs while still valuing the cohesiveness of their family.

Chapter 4.

Can Disability Fit into Our Normal?

Can Disability Fit into Our Normal?

We need only consult our own feelings and thoughts about disability, ... which are gleaned from our culture, to know that disability is a condition of ‘abnormalcy’ that should be removed from both individuals and society; these thoughts and feelings about disability also tell us that if disability cannot be removed, it must be coped with and adjusted to, and that such practices are second-best. – Rod Michalko and Tanya Titchkosky *Rethinking Normalcy: A disability Studies Reader*

This striking quote clearly displays the undesirability of ‘abnormalcy’ and points to disability as a specific deviation from the norm. Parents often have a difficult time adjusting to having a child who is not considered normal due to their unpredictable development, lack of straightforward care, and stigmatization. While parents do not expect or wish to have a baby who is perfect, they do expect and strongly desire to have a “perfectly normal baby” (Landsman 2009).

Normalcy has become a desirable trait since the rise of biopower governance in the 19th century, which Foucault defined to be the governance over bodies to produce productive power by both government administration over bodies and self-regulation (Foucault 2003). Expressed power by the state and induced self-regulation are seen as ways to achieve a normal, homogenous community that has productive bodies capable of benefitting the state and society as a whole. If people do not live up to this norm and are unable to regulate their bodies in a way that is productive to society, they are seen as incapable and are stigmatized. Foucault describes a break in society that puts normal people on one side and abnormal people on the other, establishing categories based on people’s believed productivity. He states that with this model, “the more inferior species die out and the more abnormal individuals are eliminated [...] so the death of the other [...] will make life in general healthier” (Foucault 2003, 255). Foucault initially used this distinction as an explanation for racism and the biological basis for discrimination, but it also applies to the attitudes of those who believe resources should be spent

on helping the most productive people succeed. It is assumed that by being classified as abnormal, disabled bodies are not as productive or effective, so people are set up to have low expectations of the capabilities of disabled people.

Therefore, there are benefits to making efforts to be a part of “the norm,” which individuals try to achieve in two different ways. One way is by self-regulating and changing their own bodies, which is seen to pathologize disability and view it as a correctable medical condition. A second way is by advocating to mold existing normalcy criteria to encompass their own bodily impairments under the classification of normal. This distinction is a key debate within the disability community: either trying to medically “fix” the impairment to become more normal, or establishing disability as a category of normalcy and valuing difference.

Criteria for normalcy are not definitively set; rather, they are specific to different communities with different ideas of what is productive to society (Davis 1995). This is critical to disability scholars and activists because disability is not just a physical impairment; rather, it is a concept that arises due to barriers society creates that prevent people with impairments from participating in their communities. Therefore, if normalcy criteria are adapted to include disabilities and more people are educated about these differences, people would experience less limitation and stigmatization. This is achievable because Foucault’s “normalization society” describes normalcy “as a challenge, as something that can be designed and produced, and as a phenomenon that changes with time” (Waldschmidt 2005, 191). Ervin Goffman also defined the transient, changing conception of normalcy through its varied criteria among different ideologies, saying “the normal and the stigmatized are not persons but rather perspectives” (Goffman 1963, 138). Goffman’s quote points out how people with varying experiences and perspectives define normalcy differently. This shows that normalcy is not a defined state or fact;

rather, it is a perspective that situates normalcy as specific to the context of the interaction and the community.

Parents in a biopolitical society have distinct advantages to raising a child who is considered to be normal. They have greater access to resources such as a school system that favors the average student, and they are celebrated for becoming a new parent whose child has a full capacity to become a productive and successful member of society (Landsman 2009). Discrimination often stems from the perceived inabilities that disabled people have, which translates to the belief that these impairments cause people to be dependent upon others without producing other benefits to the community. While parents can see the good qualities their children have and how they successfully impact the lives of others, this is difficult for other people to see who cannot look past their impairments and inabilities. Usually disabled people are actually quite adept at navigating their own world, or they express their capabilities and value in different ways. Although parents are able to find this value in their child, parents still desire normalcy for their disabled child because they do not want others to see them as a valueless person or social burden (Theerasilp and Sherer 2014). As Michelle, one of the parents I interviewed, said, “We just wanted to be like a normal family.” They worry that their child’s value is tied to the productive things their disability prevents them from being able to do.

This idea of value tied to the norm is parallel to social movements regarding race, gender, sexuality, and other minority categories that are often more focused-on than disability. As deaf scholar Lennard Davis writes, the norm of gender used to be masculine, the norm of race was seen as white, and the norm of class was seen as the bourgeois (Davis 1995, 15). Activist movements have worked towards equality for these groups, which means they should be given the same value and all be seen as normal and equivalent differences in race, gender, and

sexuality. However, little focus has been given to disassociating the value given to the norm of being able-bodied as superior to being disabled.

Therefore, it can be difficult for parents to come to terms with having a child who is devalued and not considered normal when it is out of the parents' control. Biomedicalization of disability increasingly complicates the process because impairments are seen as something that should be fixed, but rarely can medicine change children's bodies to fit up to the standard of normal functioning warranting the label of "disability" to disappear. Parents' struggles become trying to change their child's condition so it fits closer with the norm and trying to convince other people that their disability does not make them an abnormal person. Coming to terms with normalcy and rejecting that their child is abnormal is a journey parents must partake in to help their child feel included and reduce the stigmatization they experience. This ranges from dealing with the initial shock of diagnosis and realizing their child will not likely be considered "normal" to reframing their lives to incorporate their child's disability into a new normal that they are comfortable with.

In this chapter, I use Susan's story to show how some parents grapple with the notion that their child is not normal and why people desire to be normal. This is integral to how parents take on the caregiving identity and find positivity through caring for a disabled child. Susan told me how she dispelled stereotypes that Elizabeth was less capable than she actually was by showing how Elizabeth is often just like any normal kid. Additionally, Susan also showed herself that adapting to a different motherhood of having a child with a disability involved rewriting her ideals of normalcy to incorporate Elizabeth's disability into their daily lives and caregiving duties. To Susan, Elizabeth's disability became part of her family's normal life, which helped Susan become comfortable about being a caregiver and valuing Elizabeth for who she is.

Susan's Story

The first time I met Elizabeth at PEAC, I was greeted with a huge smile and a thoughtful greeting asking how my day was going. She walked over to me every day with her “sticks” as she likes to call them, which are her bright pink forearm crutches that help her to walk. While helping Elizabeth walk the bike or ride on a tandem with me, I would always have great conversations with her about about summer plans and how excited she was to start high school that year. Elizabeth was one of my hardest-working students, always pushing herself to go longer distances and set higher goals. Her mom, Susan, was just as encouraging to Elizabeth, and she always was excited to help set incredibly high goals and cheer her on as she worked towards achieving them. Susan was always at the session to help out, but she also knew when to back away and give Elizabeth that independence. When discussing how some of the goals Elizabeth strives for are very high and almost unrealistic, Susan told me:

We set goals with PEAC and we work hard at it. If we don't accomplish it, that's okay, but that's what we're shooting for. Elizabeth works hard, so it was probably a realistic view that a two-wheel bike wasn't going to happen because Elizabeth cannot walk independently. I have been told as a special needs parent many times that I am in denial. And I think that is an okay place to be. I deny that my child has the limitations that other people put on her, without a doubt. If she wants to accomplish something, she will accomplish that.

I met with Susan at their house to talk about how Elizabeth's diagnosis of spina bifida affected their family. Throughout our conversation, Susan often mentioned how it was hard to recall her initial emotions and hardships when Elizabeth was younger because their family had now adapted to the differences of having a kid with spina bifida. In Susan's words, they had “adapted their normal” to include the differences of having a child with a disability, so it was

sometimes difficult to recall what life was like before they had become comfortable caring for Elizabeth.

Spina bifida is a birth defect caused from imperfect development of the neural tube in the spinal cord, which can cause minor to severe physical disabilities such as difficulty walking, problems going to the bathroom, and loss of feeling in the legs (Kinavey 2007). In Elizabeth's case, spina bifida means she uses crutches to walk, and she also used a walker when she was younger.

Finding out the diagnosis wasn't easy for Susan, but the fact that they found out before Elizabeth was born allowed the family to adjust sooner and be mentally prepared for how their life would change. This mental preparation was the first step in changing their normal and adapting to having a child with a physical disability, but it took a while to come to terms with the reality of having a child with a disability. Elizabeth's diagnosis was first much more severe, and Susan's big emphasis was that the reason it was scary was that it was something she was not familiar with and she had not experienced in her life.

We knew about her diagnosis when I was pregnant, and it was actually very scary because they gave us a grim diagnosis at first. They told us she had something else – trisomy 18 – where kids don't live more than 2 weeks, so we first had to deal with that diagnosis. Then later they told us all the things that would be wrong – blind, deaf, cognitively impaired. So she was going to live *and* she's going to have all these things wrong. So I was thinking at first that we would lose our baby and that's horrifying, but now I'm thinking that we're not going to lose our baby but we're going to have this child with these severe disabilities. And I don't know how to do that. That was scary.

The scary part for parents like Susan is that they learn how to be a parent from observations with their own parents and from their friends and family, but having a kid with a disability or severe medical needs is different. It doesn't often fit in with what they know and what is considered to be normal and expected (Solomon 2012). Therefore, parents experience ambivalence and

uncertainty as they begin to navigate the process of learning how to care for their child, which must be very individualized and specific to their own child's differences (Gibbons, Ross, and Bevans 2014). Transitioning into this new role can be intimidating due to the lack of control over the situation, as Susan did not know initially how to take care of a child with medical needs like Elizabeth.

We went to the doctor and got ultrasounds and tests. The more tests we did, the more we found that their initial prognosis was not accurate. So we had a pretty good picture of who she was before she was born. We were fairly prepared for it, but it still took a while to come to that. You spend a lot of your adult life being in control – you control how much money you make, where you live, who you spend your time with. And here there was absolutely no way to control what was going on. We just had to turn to faith and lift it up and say, “it’s up to you.” And that was actually a relief to just have faith that it was going to be fine.

This attitude was not always easy for Susan, especially when Elizabeth's need for additional care caused Susan to quit her job and change her personal life in ways she did not anticipate. Like the other parents I talked to, Susan came from a privilege position where she was able to control much of her life and career. Control over caregiving shows a sense of mastery, giving parents desired feelings of accomplishment and predictability that is comforting for them (Callister 2003, 511). Disruption to this control was quite jarring for Susan, but her education and monetary stability also allowed her to adapt more smoothly than many people would be able to. Prior to Elizabeth's birth, Susan worked in rehab for people with brain injuries, which is a job she always loved doing, making her devastated to give up on her career. But as a positive note, her extensive knowledge and comfort with health care gave Susan the skills to be the best caregiver for Elizabeth, making it the obvious choice for her to stay home with Elizabeth rather than her husband. Even though this was the right decision for their family, it was still difficult considering that being an employed mother was part of Susan's norm for herself. Having to quit her job due

to Elizabeth's additional care needs also further affirmed that Susan has become different from her other employed friends since having a child with a disability.

I had never not worked. I had always either been a student or working or both. It was very hard and I was very resentful. I was wondering *why does my husband get to go out and have a life?* I'm saddled with everything. I have 14 medical appointments a week and some lasted 6 hours. It was a full time job. It was definitely a full time job. My son who is now 16 was a year and a half when Elizabeth was born, and I had to take him everywhere. Greg, Elizabeth, and I went everywhere. We went to all Elizabeth's appointments, and it was full-time. I don't even remember how many, but maybe 16 or 18 different specialists worked with her. We were just at the U of M ⁶Hospital all the time. So yes, I was resentful about quitting my job at first. It took years; I was praying about it for years.

These appointments included multiple surgeries for Elizabeth to help the movement in her legs and visiting therapists through the schools. She started early intervention therapy at four months of age and currently sees a speech therapist, occupational therapist, and a nurse at her high school. Although Elizabeth's medical needs caused Susan to quit her job, it actually led Susan to a new career in the school system when she returned to work where she learned even more about how to be a good advocate for Elizabeth.

I am a speech therapist in the schools now, so I know the system which helps a lot for getting Elizabeth the best education and therapy. I remember a time when I was still home with Elizabeth where her physical therapist came to the house to see her. She owns a contract company, so she contracts all the services through the school such as occupational therapy, physical therapy, and speech therapy. That day I was just telling her how I need to get out of the house and I need to get out of here. And she said "I need someone one day of the week," and I quickly replied, "I'll take it!" So that's how I ended up working in the schools. It was great timing too because my older daughter had just started kindergarten, so I've been with the schools now the whole time my kids have been as well. And had Elizabeth not been born I would not have made that transition. It just happened to work out because the physical therapist owned this company and got me involved with it so I was able to get that experience.

⁶ University of Michigan

Throughout our conversations, Susan stressed how everyone's life turns out differently than they planned it. At first Susan felt uncomfortable not being employed because it disrupted her normal sense of self, but later she was able to adjust and adapt her life to something she is now used to. We discussed how many times people are not happy about expectation not matching up with reality, but often these life-events cause new avenues to open and new experiences to take shape.

So I'm sure you've heard a lot of sappy stories of how my child just changed our lives but you know it's true, it's all true. They do. They change everything and it's just a matter of how you frame it. I loved my job in rehab and I don't think I'll ever have a job I love more than that but what I have now works for my family. I love my job now but if you were to hand me both jobs with the other circumstances I would take the other one. But this job works and it's perfect for my family.

Rather than focusing on how having a child with a disability prevented her from pursuing some of her dreams, Susan emphasized how having any child changes a parent's life and what opportunities are available to them. The experience of raising a child of any ability level is associated with significant stress and life-changes, which cause any parent to have to adapt their norms to incorporate their new child and the challenges that come with raising children. While Susan's experience raising Elizabeth had many differences to that of her other typical children such as the numerous doctors appointments, procedures, therapies, and experiences of stigmatization, Susan constantly emphasized the experiences that were similar to that of a typical child. The emphasis on the ordinary and similarities of parents who do not have a child with a disability shows how much Susan valued appearing normal. By emphasizing the normality of her everyday life, Susan felt that other parents would place less judgment and see how raising a child with a disability does not have to be significantly different from raising an able-bodied child (Lalvani 2011). Susan told me how many of the adaptations she had to make to her life were what she

would have to make anyway with having a third child due to the increased care needed of having three children versus two.

But many of these changes to Susan's life were not easy to come to terms with, especially considering the significant extra care that Elizabeth needed. It was difficult to accept that Susan needed help and was unable to go through this journey alone.

I learned pretty early on that people want to do stuff and they want to help out. They don't know what to do, though. But whatever they do if you accept it, it's a gift to them. I had a neighbor who would take care of my son so I didn't have to take him to the hospital every time. He was perfectly content going to the hospital every time, but he had more fun at her house too. And she was so kind to do that and it was kind of a gift to both of us. When people offer you something, it's hard at first. It's hard to accept things when you've been independent and self sufficient. It's humbling and it's difficult to accept support, especially from people you don't know well. It was hard and it took a while to learn how to accept that and learn to be helpful and accept that humbly. It takes a while, it's not something people do easily

Even now when people see Elizabeth walking with her sticks, they try to give her things because they feel bad for her. These could be complete strangers who give her candy on the street or people she knows who think Elizabeth deserves special treatment. Usually they do this because they feel bad that she is unable to walk and that some mobile activities are more difficult for her than other kids. This also happened to Noah as discussed in chapter 2, which demonstrated how parents want to help out to minimize their feelings of awkwardness and make up for the fact that they notice a family that appears to have greater struggles than they do. Susan mentioned how people have only been overly positive to them, saying she could not really think of any negative experiences.

I do know that they treat Elizabeth differently. Everywhere we go people want to give her stuff. I'm always thinking what is this; why do people do that. It's kind of toning down a little bit now, but for example, my son is in Cub Scouts and they had an event where you could pitch a tent on the baseball field and they show a movie on the big screen. Jim and I took Elizabeth to go to the bathroom, and we asked this guy where the bathroom was and

when we came back he asked if everything was okay. We told him yeah it's just routine stuff—we've got to take care of her. And he said, "I want to show you something" and he told us we're going to go up to the press box. So I ran and got my other two kids and it was a beautiful view. We got to put the score on the scoreboard and my daughter got to help with the DJ. It's just cool, we get to do things other people don't get to do.

As Susan said, their care for Elizabeth has become "just routine stuff" and she stressed that it was not really something they think about anymore because it has become a normal part of their life. When I asked if people treated her differently as a parent, Susan responded with, "I probably could have answered that with more clarity about ten years ago because it was new. Elizabeth is 14 now and it has been this way for a long time, so I don't know. I don't remember." This shows how Susan has become accustomed to the changes in her life to the point that she hardly remembers her old life, signifying that she has adapted to this new normal for her family.

Their family has also become quite comfortable talking about Elizabeth's disability. Not only does this show that Elizabeth's disability has become normal for their lives, but it also shows that they want to share their beliefs that Elizabeth's differences do not make her abnormal. Luckily, these conversations have been easy for Elizabeth's family, and people have been receptive to learning how they can treat Elizabeth like any other child. Susan reported that people are always so positive, and the only thing they really experience is people asking questions. These are usually little kids, but Elizabeth is very open to talking about her differences and showing kids her crutches she uses to walk.

When Elizabeth was in first grade I went to school and took off her AFOs⁷ and showed the kids that these are just like shoes and they go on her feet. Kids were afraid at that age. They thought she had plastic legs—they didn't know if she was a robot, you know. (laughs) They were a little afraid. So I would take off her AFOs and say she has feet just like you but they just don't work as well as yours. So we did some education with her classmates when they were little. And we'd let people try out her crutches and walker.

⁷ AFO – Ankle Foot Orthosis. This is a brace that supports the foot and ankle extending up the calf to help control movement and support ankles to aid with supporting the body and walking.

When talking with kids in the class, Susan emphasized how even though Elizabeth's feet do not work as well, she has legs just like everyone else. This shows how Susan wants kids to still consider Elizabeth to be a normal human being who is just like her classmates with only a few differences in ability. Rather than focus on Elizabeth's differences, Susan wanted to emphasize the abilities that Elizabeth has to show the kids that they can relate through their similarities. Elizabeth is not solely defined by her differences.

Susan felt that talking to Elizabeth's class was important to help educate other kids about Elizabeth's condition and show them that there is nothing to be afraid of. Many other parents I interviewed also employed similar normalization strategies, saying that it was helpful for them to have question and answer sessions with the class so that they can help dispel any stereotypes and stress that their child is like all of them but just with a few differences. This shows the active role that these parents I talked to had in their children's life and normalization, but it also displays the inherent assumption of "abnormality" for kids with disabilities. Setting up a category of normalcy distinguishes everything that is not normal as deviant or subpar (Davis 1995). Therefore, people with disabilities often either want to focus on the qualities they possess that are similar to everyone else that they can relate to, or they want to dispel the problematic category of normalcy altogether.

Parents of typical children do not have to justify that their child is normal because it is assumed, while parents like Susan have to guide the classroom with how to see Elizabeth as a normal child like her classmates in many regards. Kids were quite receptive to learning how Elizabeth can do many things just like everyone else, which helped to dispel some of the stereotypes both students and teachers had. While people never acted negatively towards

Elizabeth, she did experience stereotypes of people assuming her impairment was more limiting than it actually was. People tried to be too helpful or assumed Elizabeth had cognitive impairments and needed help with things that she was perfectly capable of doing. This is why it was important for Susan to emphasize that she is not that different from her classmates and that she can be treated as a relatively normal kid.

I've battled with the schools frequently to not underestimate her abilities. When Elizabeth was maybe in 3rd grade I had gone up to the high school for something and Elizabeth was walking along with her walker. The young adult teacher from the special education young-adult programs came out and I talked to her for a bit, and I said this is my daughter Elizabeth. Then she said, "Hi Elizabeth I'm going to be your teacher when you get to the high school." And I looked at her and I said, "I hope not." I was just flabbergasted—why on earth would you even assume that? You are pigeonholing her educational capabilities based on the fact that she's walking with a walker. And I just thought *ughhh*. And I'm sure she went back and thought oh my god I'm so stupid. But all the time people make assumptions that she can't do something.

Even people knowledgeable about disability like that teacher have stereotypes of inability, which Susan and Elizabeth work hard at to dispel. These common assumptions that a disability in one bodily category means a person is fully disabled sets up disability as a binary category. People are normal in some regards and different in others, but too often people are labeled as either a "normal" person or a "disabled" person with little discussion of overlap (Davis 1995). Another parent I talked with said, "we're all a little disabled in some regards with things we struggle with." With the assumption that shaky categories of disability and normalcy are all-encompassing, when do people cross the boarder from normalcy to disability? This leads the category of "normalcy" as independent from the category of disability problematic. Someone can have impairments and still have normal qualities, but too often people assume that "disability" is a defining identity that wholly makes up a person. Susan wanted to emphasize how Elizabeth is

not defined by her disability because she has many other admirable qualities that are not in any way impaired, which people often do not realize because they see her disability first.

Compared to years ago, schools have done a much better job at looking past disability as all-encompassing and defining of a person. Susan compared Elizabeth's experience in schools to when she was a child and said that things have changed significantly with children's receptiveness to disabilities in the classroom. It used to be quite abnormal to have a kid with any sort of impairment in a normal classroom. Since kids with disabilities are increasingly put in inclusive classrooms today and are not restricted to special education rooms unless absolutely necessary, typical kids have more peers and exposure to kids who have disabilities. This helps their disability become a normal part of their life, so that these differences are considered "normal" and are just part of normal variation in human populations. There is also increased openness in talking about disabilities, which Susan has experienced by talking with the classes about Elizabeth's disability. And Elizabeth also is comfortable bringing it up and talking about her impairments.

When I was a kid and when you were a kid parents always said, "Don't stare, it's rude to stare." It's not rude to stare anymore. Things have changed. It's just okay to acknowledge differences and ask questions. You know when I was a kid, special needs kids were all at High Point, a school in the area just for kids with disabilities. Probably somewhere around when I was in middle school, they were in our school but they were in a classroom at the end of the hall. When you were a kid, those kids were more in your classroom. So we are desensitizing our population to disabilities and differences, right? So it's not a scary thing we don't have to whisper about it. We just ask, "Hey, what are those crutches for?" and kids do ask. And every once in a while parents do seem mortified you know but Elizabeth's just like "Oh I have spina bifida, want to try them out?" And she'll let little kids walk with her crutches.

Elizabeth has normalized her crutches by making them something cool and special to her, so that she can see them as something that enables her rather than signifies her disability. Physical equipment like crutches are a visible sign someone has a disability, which Goffman calls a

“stigma symbol” (Goffman 1963, 92). People may try to conceal or stop using their “stigma symbol,” or they may show it off as a way to help other people accept their medical device and show that they are not ashamed of it. This helps other people become comfortable with the device so that they can see that it does not make the user any less of a person. Susan told me how Elizabeth does horseback riding with a little girl with Down syndrome who sees her “cool pink crutches” and wants them. After that first encounter, Elizabeth lets the girl borrow them for a few minutes every time. “It’s just a routine,” Susan said, emphasizing how this is normal to them. “It’s good to be relaxed about it.”

More recently, Elizabeth went to her first homecoming dance since coming to high school. Rather than hiding the AFOs on her legs which help her walk, she decorated them. Susan described how Elizabeth and her friends had so much fun “glamming them up” with silver spandex and lots of jewelry. This made Elizabeth feel special, but it also made her AFOs nothing to be ashamed of or nervous that people would see. Dressing up devices that mark a child as having a disability help give them a sense of control over their device, and it makes the AFO something that is less medical and more of a way to display fashion (Happell 2011, 37). This helped Elizabeth see her AFOs as something “cool” rather than something that limited her ability to dress up for the dance. Additionally, homecoming is a meaningful event in many students’ lives, and partaking in this event made her feel included with the other kids. Especially since she is the youngest child, Elizabeth was able to watch her older siblings go to homecoming and realize that she too can have a normal high school experience like them.

Elizabeth’s older brother has also been very supportive by always valuing Elizabeth and never being ashamed to say his sister has a disability.

When Greg was in kindergarten, they were in the same school. As a kindergartener, it was a big deal to stay in line while walking down the hall. Elizabeth would be walking

down with her class and she had her walker, and Greg didn't care, he would get himself in trouble every day because he would jump out of line and give her a hug. The teacher said, "How could I punish that, it's so cute." But he has always looked out for her; he has been a good brother, and he helps me a lot with her too.

Since Greg is so close in age to Elizabeth, it's hard for him to remember having life without a sibling who has a disability. Even as a toddler, Greg was dragged to all of Elizabeth's doctor's appointments and really didn't mind. It had become his normal from such a young age that he always wanted to protect Elizabeth and felt like his life has always been about protecting and valuing her.

But this was not the case for Elizabeth's older sister, Jessica, who is five years older than Elizabeth. Although I did not get the chance to talk to either of Elizabeth's siblings directly, Susan said, "My 19-year-old daughter has spent her entire life feeling ripped off. Her perspective was 'this sucks—this is never about me'." While there are a variety of reasons why siblings might be resentful that their sister has a disability, such as "missing out" on certain experiences, one particular explanation is that they still do not accept their siblings' disability as part of their normal family life. Jessica lived a fairly typical childhood before Elizabeth was born, which was when she had to adjust her life to realize that Elizabeth will require extra caregiving and that their family will be unable to do some things because they want to accommodate what Elizabeth can and cannot do. Research shows that when a disabled sibling is the older child or born shortly after the next sibling, the able-bodied child does not know what life is like without having a brother or sister with a disability. This causes the able-bodied sibling to be more likely to view disability as a simple fact of their family life – essentially, this is what their family norm is (Kriegsman and Palmer 2013). This is one reason why Greg has been so accepting of his sister's disability – he never knew anything else. However, Jessica was significantly older than

Elizabeth, so she felt more distance because of the age gap and because she had experienced life without a disabled sibling.

What families consider to be normal, therefore, depends greatly upon people's expectations of what family life should be like and ability to adapt. Susan felt that she was able to adapt her life to caring for a child with a disability quite well because she had a career in healthcare.

I'm a speech and language pathologist, I have worked with people who have head injuries, and I've worked in health care. All the doctors we needed to know for her I already knew. And I already knew how to be a case manager, so I did know how to do a lot of these things that many parents begin having no idea how to do. I took comfort in my experiences.

While emotional support was quite important, Susan felt like it was fairly easy for her to catch on with how to advocate for Elizabeth and take care of her health. After accepting and becoming comfortable with having a child with a disability emotionally, support groups were not helpful for Susan.

I feel like as far as support groups and things like that I—I don't know how to say this without sounding wrong—I always felt like I was the one providing support. It's because I know stuff and I always felt like I was the one doing the giving and I never felt supported. It's not like I minded that. I'm a teacher for heavens sakes, so I don't mind doing that, but sometimes it's just exhausting. Sometimes I just want to watch TV and relax. So I didn't find that support groups were that helpful for me. We lost a lot of friends over not just this, but you kind of go different directions when you have kids and you wind up making different friends.

Once parents feel like they have established themselves and found the helpful resources and communities for them, they no longer need to seek as much support. Some parents I talked to mentioned support groups as being invaluable, while others consulted only their spouse or friends for emotional support.

Not utilizing support groups also showed me how much Susan did not want disability to define their family. Especially since Elizabeth is now in high school, she has become quite used to the experience and how to care for Elizabeth. Unlike some of the other parents I talked to whose children are still young, Susan feels fully adjusted to having a disabled child. Caring for Elizabeth has become her daily routine.

Elizabeth's disability does not define our family. I think a lot of families are defined by their child's disability. Our normal has changed—I'll say that. Our norm for the way we function has changed, but it would change with any third child. Just the function of having three children to two parents changes everything. I just feel like it doesn't define us. We don't let it. There's a lot that goes on with Elizabeth that is just about her disability but it is just like doing the dishes, you know what I mean. It doesn't affect everything, it's just part of our day. We enjoy Elizabeth, but who wouldn't enjoy Elizabeth.

Elizabeth's personality and loving nature also helped Susan's experience because Elizabeth is so kind and pleasant to be around. At PEAC, I always saw Elizabeth cheering on the other kids and telling them they did such a good job. Since people admire her kindness and enthusiasm, it's hard for people to ever judge her based on her disability. Elizabeth also doesn't let her disability limit her by setting such high expectations for herself and not being afraid to talk about her limitations.

I mean you know Elizabeth, she's just such a good kid. She works hard. I feel like as an educator and as a parent of a special needs child you get what you expect from people. If you expect less you get less in general. People tend to rise to the lowest level of expectation, and if you set your goals and expectations at some remarkably high place you get half way there which is much better than a lot less. I live in denial but am okay with it.

While admitting to be in denial may seem like a bad thing, it allows Susan to emphasize Elizabeth's normalcy and set high expectations for her. She has seen how wonderful an influence

Elizabeth has been on Susan's approach to life. Everything has worked out because Susan has been flexible and trusted that things would be okay.

I have so much advice for other families! I'd just say to be flexible and to not be afraid. That things work out. I have said since Elizabeth was born that if I had been left to plan my own life it wouldn't be this good. Because I was going along a different path and I didn't choose the life that I have for the most part and had I followed the path I had planned for myself, my life would not be this good. You just have to kind of go with it and have faith that life will be just fine.

Accepting Difference, Emphasizing Commonality, and Redefining Normal

Susan is not alone in trying to reshape and redefine conceptions of normal to include her child. In most of my interviews, I heard stories of shock and devastation that the initial diagnosis brought, which led to figuring out how to accept and care for a child that is different. Apart from enhanced medical needs and care, these differences contributed to concern of whether their child will make friends or be accepted by their peers and by other adults. Another parent I interviewed told me, "As siblings, Andrew and Brandon don't interact much. So we always stress on the IEP to foster relationships with peers." Parents worry about how their child would be perceived as different by others and how this affects their sociality, showing a heavy focus on the social perception of disability rather than the physical impairment itself.

This negative perception and alienation due to difference is one of the hardest parts for many parents. People with disabilities are stigmatized because their impairments position them as different from others in a way that is considered to be less capable, weak, or dependent on care (Goffman 1963). As Susan mentioned, the problem is rarely that other people are negative towards Elizabeth due to her disability. In fact, most people are overly positive because they feel sorry and are awkward about how to relate to a person who has an impairment that they do not

know much about (Davis 1995, 1). The real problem often is when people have low expectations for Elizabeth, such as assuming that she cannot cognitively function as well in school just because she is different and disabled in other facets, as well as exclusion based on difference. Parents want their child to be considered normal so that others have high expectations of them, believe in their abilities, and include them with their peers.

In fact, much of the problems parents like Susan face stem from living in a world that focuses so heavily on perfection and normalcy. Our weight, height, scores on exams, cholesterol levels, and earning are all compared to what the average values are, and we are singled out any time we fail to perform at the level of the norm. Even when talking about our own economic status, Americans are far more likely to disproportionately report they are middle class than any other category (Shenker-Osorio 2013). They want to be labeled as average and normal. Gail Landsman discusses how parents may not hope that their child is perfect, but they do at least assume that the child will be “perfectly normal” (Landsman 2009, 70). In “Shut Up about your Perfect Kid,” Gallagher and Konjoian further outline there is a certain absurdity of raising children who are imperfect in a perfection-preoccupied world (Gallagher and Konjoian 2010). Christina, another parent I interviewed whose son has Down syndrome, mentioned that she never got prenatal testing initially because she had no reason to assume that her birth would be anything but normal. Not only do we assume our child will be normal, but we want them to be normal too.

As discussed in the beginning of this chapter, much of the reason we expect to be normal is because biopolitical discourses tailor our population to self-enforce normalcy upon itself. To create a fit and productive national body that other nations admire and respect, individuals must regulate themselves into a uniformity of body and production (Davis 1995, 36). This creates

nationalism for citizens to feel a cultural connection to each other in their similarities and makes it easier for governing bodies to enact their power. Members who deviate from this uniformity are seen as unfit to be successful in their societies, especially when deviations are seen as physical limitations that prevent individuals from fully participating and carrying out productive duties. Parents do not want their child to be unsuccessful, so they hope that they will live up to the standard benchmarks of success.

Being normal has its own advantages since resources are made and distributed with the normal population in mind. For example, it is easier to find shoes at the store if you are a typical size 7 rather than a size 20, and people of average height can drive almost any sized car whereas those under five feet may not always be able to reach the pedals. Looking at these examples, our world is shaped upon providing resources to people who are average because that is what most of the consumers will be. This affects children with disabilities by providing less accessible or widespread education that has their child's disability in mind, which could put them at an academic disadvantage. It also means there are fewer sports teams or extracurricular activities tailored to their abilities, among other opportunities that just are not as readily available for people who are in the minority.

In order to face the fact that able-bodied people are put at an advantage, parents look for ways to reclaim normalcy for their child and their own life and emphasize how their child really is not that different. Disability is a stigmatized condition, so this process of seeking normalcy is simultaneously intertwined with destigmatization. By emphasizing the good qualities of a person and showing how they can relate and connect with others, they are both less stigmatized and seen as more normal and relatable. This furthers people's comfort with the disability and their acceptance.

Susan was the first parent I interviewed for this thesis, and I was first struck by how comfortable she was talking about her experience and how normal it was to her. She clearly emphasized that her family was not defined by disability, and much of her everyday life is the same as if it would be had Elizabeth not had a disability. I, however, naïvely expected Susan to overwhelming report feelings of stigma and oppression. This is not to undermine the stress, emotional burdens, and challenges that accompanied her journey raising Elizabeth, but I did not anticipate how positive Susan's story would be. While research often focuses on the struggles of raising a child with a disability, scholars have found that stress in raising a disabled child is much like raising a child without a health problem or disability. Raising children in general is associated with stress and unpredictability, but this stress simply differs in intensity when raising a disabled child due to the parents' increased responsibilities and unpredictability (Pelchat, Marie-Josée, and Bourgeois-Guérin 2009, 240). If I had interviewed Susan when Elizabeth was much younger and their family was still in the process of adjusting, I likely would have heard Susan talk more about the stress involved. Once the unpredictability calms down and the increased caregiving needs become routine, stress begins to diminish and become more like the normal stress of parenthood, given that parents have the financial and emotional support to handle the increased caregiving needs. Susan does not view Elizabeth's disability as a vast difference anymore, and she instead mentions how much of her day-to-day stress comes from parenting stressors that all parents experience. Stress does not just stem from the disability and its specific care.

In addition to focusing on the similarities in nature of stress, parents focus on the similarities in the joy that their child brings. As someone who knows Elizabeth quite well, I could discuss at length her immediate likeability, consideration for others, and overwhelming

kindness. Susan emphasized that “Elizabeth is the most easygoing person and has a beautiful spirit. She is a beautiful kid. I don’t know if that has anything to do with her disability or if that’s just who she is. She’s a good kid.” Emphasizing the love that Elizabeth brings and the benefits she has brought to Susan’s life is a very helpful way to cope, as it allows Susan to compare Elizabeth with the non-disabled in ways that are correlated with positive social norms (Pelchat, Marie-Josée, and Bourgeois-Guérin 2009, 248). The bond parents establish with their disabled child can be seen as “anchored in normality” due to the joy that they child can bring (240).

Emphasizing their child’s personality and positive qualities help humanize them and show their relatability. Rather than constantly expecting that the disabled person is the receiver of care, this highlights how individuals have many qualities to offer in relationships where both sides gain (Fisher and Goodley 2007, 78). Typically, disability has been seen as a category of difference by emphasizing that disabled people are receivers of care rather than producers, but this separation is rarely the truth. While kids like Elizabeth do require more care due to their disability, they also have numerous beneficial qualities that really add to their relationships with other people and to society as a whole. It may seem cliché to point out, but disability is something Elizabeth *has*, not something she *is*. Adding personality to a child’s characterization helps separate them from their disability, showing that who they are as a person is not related to their impairments.

To further add to the normalcy discourse in their stories, parents will focus on their everyday lives rather than constantly focusing on the unique times of stress. By emphasizing the ordinariness of their lives and everyday jobs, they are able to show that their experience is also comparable to the ordinary stresses of raising a child (Lalvani 2011, 290). As Susan mentioned, having Elizabeth as her third child was stressful because she now has three children, saying,

“who wouldn’t be stressed about having to care for three kids rather than just one or two.”

Parents also like to mention the wide variety of stressors that other parents have, showing that stress in raising a child is variable and that disability is not the only cause of stress. Some parents mentioned kids with drug abuse, smoking, or breaking the law as more stressful and difficult than they could imagine. Those experiences were cited as other difficulties that are normal for parents to experience but incredibly stressful to actually deal with. It is bad to consider a normal versus abnormal dichotomy because all these experiences of being human are different, and these varying differences all make up the variability within our population (Landsman 2009, 206).

Part of accepting variability and rejecting the idea of a detestable “abnormal” category is destigmatization of these differences. Susan helped Elizabeth’s disability become destigmatized by explaining to Elizabeth’s class that Elizabeth can do many things just like the rest of them to show that her disability does not mean that she is not a kid with thoughts and feelings like them. She did this by specifically explaining how Elizabeth’s AFOs help her walk and by allowing other kids to try out her crutches. These items are “stigma symbols” because her use of them visibly shows that she has a disability (Goffman 1963, 92). By explaining how these devices help Elizabeth rather than point out her differences, Elizabeth’s peers were able to see that these devices are not scary and that they help her in a positive way.

In addition to helping others become used to characteristics of disability, parents like Susan undergo a process of remarking their own normal to encompass their child’s impairment. People have a set of ideas about parenthood that are “taken for granted” but must now be revised due to the significant differences in care required to raise a child with a disability (Kelly 2005, 187). By consciously thinking of characteristics of parenthood, parents make and remake their identity to encompass their disabled child and repair disruptions to their embodied self (Kelly

2005, 187). This renegotiation forces parents to think about what they value in a family and what their expectations were for parenthood. Having an openness to renegotiation of parenthood and identity helps parents to redefine their normal and keep their focus on the present, which helps give parents value in their current experience and mitigate thoughts of future uncertainty (Fisher and Goodley 2007, 78). The reason parents have to rework their own ideas of family is because they realize that their current experience does not map well onto preexisting models (Ginsburg and Rapp 2013). As Andrew Solomon discusses in *Far from the Tree*, people grow up with inherent ideals and thoughts about parenting due to how their own parents raised them (2012). When a person is faced with raising a child who is significantly different than them, this presents additional challenges because the parent's model of how to raise a child cannot neatly encompass their new experience. Therefore, they must remake their own identity and kinship experiences to incorporate the additional and specialized care for a child with a disability (Ginsburg and Rapp 2013). This reframing can be seen as a positive practice of adapting one's family life to incorporate caring for a disabled child. As seen with both of Elizabeth's siblings earlier in this chapter, this can be easy for some siblings to reframe if they do not have strong ties to how they were raised, but it can be quite difficult when children are resistant to reframing kinship experiences.

Going through this process of recreating a new normal is part of the liminal stage of becoming a caregiver. Liminality is where people lose one identity and are in the process of constructing a new one. Developing new norms and a new self-concept to come to terms with having a disabled child is associated with ambivalence and uncertainty because parents do not often know how exactly to find these new norms other than exploring the many options available to them (Gibbons, Ross, and Bevans 2014, 423). Parents must also adopt new routines during

this phase of life, which can be tricky before parents become comfortable with the care they must give and how to fit it into their daily routine (Gibbons, Ross, and Bevans 2014).

When I talked to Susan, she was in the post-liminal phase where she had already adjusted her normal to fit into a caregiving role. When telling me about using the bathroom at the baseball event where one of the workers was concerned that Susan had to help Elizabeth in the bathroom, Susan shrugged it off because this sort of care had become a normal part of her life. She also continually pushed Elizabeth to achieve her goals in PEAC and held her to high standards because she has gotten to know Elizabeth's capabilities and when it is appropriate to push her.

Susan's experience shows how disability is a social category that is situated in opposition to the norm. Due to the emphasis on normalcy to be productive in our society, parents who have a child with a disability often want to know how to bring their child closer to the norm. This may be attempted by medical intervention and emphasizing characteristics of their child that make them just like other children. Additionally, parents must recreate their own norm in order to help them come to terms with their child's disability and situate the disability as part of their own normal lives. While Susan often struggled with the stereotypes that other people had about her child and the fact that she had to change her life's normal routine, she was able to successfully accept her new normal. While there is still much to be done to show how we can relate to people with disabilities through our similarities rather than define them by their differences, Susan shows how efforts can be made to teach other people about Elizabeth's impairments and show that having a disability does not mean that people should be defined as abnormal.

Conclusion

Conclusion

Originally, my goal for this thesis was to simply share the stories of parents who have a child with a disability to explore what these parents value and how they find great meaning and satisfaction through their caregiving roles. Despite the fact that people with disabilities make up the largest minority group in the United States (Couser 2005, 602), many people I know have never had a conversation with someone who has a severe disability or seen the care involved in raising a disabled child. I wanted to highlight the value of their parenthood and show what it means to care for a child who is different in the face of a society that seeks perfection and normalcy. This was inspired by my experiences with parents during my summer job at PEAC who were such fierce advocates to help others see the value in their disabled children and to give them the best opportunities they could.

After completing my conversations with these mothers and fathers, I saw that their experience was so much more than just overcoming stigma and dealing with the burdens of care. I was struck by the overwhelming love these parents had for their children and how much their caregiving roles have positively impacted them. The difficult experiences and emotional struggles have all been in efforts to provide the best experience for their child and their family.

Throughout my thesis, I have shown that each parent's experience is both distinctly individual and more broadly collective. Raising a child with a disability is complicated in that no one factor defines a parent's experience, especially considering the vast differences among different disabilities, making for experiences that are incredibly unique and individual. As shown throughout this thesis, Noah's disability created more medical challenges, Elizabeth's impairment was physical in nature, and Andrew's autism made for a range of behavioral issues.

Only by hearing their own stories can we truly understand their individual situations and discover how they find meaning in their caregiving roles.

However, many of the values and motivations displayed by these stories bridge more collectively, answering questions of what parents value and how they redefine their definitions of kinship and parenthood to render life meaningful. Each parent's story that I focused on illuminates a particular value that specific parent found through raising their child, which more broadly applies to values parents must consider when they reframe their conceptions of caregiving and parenthood to include caring for their child. I showed how parents learn to love the enhanced care needed of them because even though it is stressful, it gives them a greater purpose knowing that they know their child best and that their child fully relies on them rather than anyone else for their specialized care. They also must reframe their kinship to incorporate the enhanced care for their child who has a disability, but this must not take over their whole life. Instead, parents value a more equal family dynamic where they try to balance the enhanced care for their child who needs it while still distributing their time and resources fairly to their entire family, knowing that a cohesive family is an important factor in their own well-being. And finally, parents value adjusting to their experience so it becomes a new normal for them as well as helping advocate for their child, so other people can appreciate their child's abilities and uniqueness without seeing them as defined by their differences.

American Ideals of Parenthood

There is a common assumption that raising a child with a disability is fundamentally different than raising a typical child (Landsman 2009), but this is not wholly true. Although these parents experience a different kind of parenthood characterized by enhanced caregiving, their

experiences and aspirations are not so different from people with typical children, which reveals cultural conceptions of ideal parenthood. While the following ideals elicited from these narratives throughout my thesis are not held by all parents, they are widespread cultural norms that the parents I interviewed wished to achieve. Since their parenthood was often seen as different or inferior to others, they emphasized what values and ideals they had for their own parenthood, which reflected commonly held conceptions of parenthood by the people in their communities that they surrounded themselves with.

The goals for being a good, ideal parent involve being an effective caregiver who is able to help their child reach his or her fullest potential. As Olivia showed, the goals Americans have for their motherhood is to be the most effective caregiver for their child, always putting the child before themselves. This “intensive mothering” ideal described by Hays is that mothers must be devoted to the care of their children, and they must cease to have their own needs (Hays 1998, 91). Olivia strived for this ideal by never giving herself a break and always feeling like there was more she could do for Noah. Due to parents’ consumption with caring for their child, their identity as a parent becomes defined by how their child turns out and how “successful” their intense parenting was. Parents who take an all-encompassing, hands-on approach to raising their child feel like their own identity and worth is also improved by their child’s accomplishments. Therefore, parents feel like their own identity is created through how they present their child to the outside world (Kelly 2005, 141). This is what parents of typical children feel since parents feel ashamed and personally responsible when their child does something bad. As Olivia showed by never taking a break for herself and defining her own identity through her role as Noah’s primary caregiver, good parents expect that they must put their child before themselves.

Apart from simply putting their child first, parents strive to be a cohesive family and create a dynamic that allows every family member to succeed without favoritism. This goal is difficult to implement, but rarely do parents want to show favoritism or seem like they are not making efforts to come off as a family without conflicts. Michelle and Nick struggled through choices they had to make for their family that provided a better education for Andrew while putting Brandon in a school where he was bullied and not receiving the education Michelle and Nick wanted for them. Their constant emphasis on providing for Andrew showed the importance in parents helping their child who needs the most care. But also, they showed how parents want to ideally provide for their children equally and only in conditions where they do not have the resources to do so should the child who is most in need receive disproportionately greater care.

While good parents want to make sure that it is known that they put the needs of their child before themselves and value creating a cohesive family, they also ensure that their child is able to relate to other children and is not judged based on their differences or abnormalities. Susan's discussions on normalcy and how she negotiated the value in Elizabeth's abilities showed that parents value having children who fit with society's preconceived notions of what is normal. As Landsman notes, parents do not "seek perfect babies, but they do seek perfectly normal babies" (Landsman 2009, 70). While the criteria for normalcy is fluid and inconsistent, parents want to raise a child that fits in with everyone else and is able to relate to other children. Susan displayed how she showed other children the abilities Elizabeth had that were similar to everyone else, showing that despite her disability, she was not so different from her classmates in her cognitive and relational qualities. Parents value having children that are able to fit in and connect with their peers.

Finally, as I found through discussions with all of the parents, there is the expectation and desire for parents to receive great joy from their child (Pelchat, Levert, and Bourgeois-Guêrin 2009). As I experienced through watching these parents interact with their children at PEAC, people love to cheer on their children and celebrate their accomplishments. Just because their child has a disability does not in any way diminish the joy they feel. In fact, many parents I talked to cited that they experienced even more joy in the small, everyday accomplishments that their child achieved.

We waited almost seven years for Andrew to say I love you, and when he does it is just amazing. We are a pretty lucky family, and we are probably far more appreciative than normal people who get to hear their kid say I love you a million times a day. For every accomplishment we work so hard towards, we appreciate it more than anyone else ever could. And from that aspect we are super lucky, and we cherish and appreciate every moment. – Michelle, Andrew’s mom

By seeing their own child accomplish something that was once very difficult for them specifically, it brings parents great happiness in knowing that they had a role in raising that child and helping them achieve their goals. Parents with disabled children feel relieved of much of their caregiver-stress when they are able to witness their children’s accomplishments and focus on the joy they receive interacting with their child rather than the difficulties (Pelchat, Levert, and Bourgeois-Guêrin 2009, 252).

Before when people would tell me, “I’m sorry that must be really hard,” I would just breakdown and cry. But I think now I look at it and just look at how amazing Andrew is and say you should really meet him. Andrew is so genuine and he just brings that out. When he looks at you and he smiles, it’s amazing. – Nick, Andrew’s dad

Having this positive outlook is not just comforting to parents with disabled children, but it also more generally helps parents celebrate their children’s successes and see that all the time, money, and emotional investment put towards raising their child has been worth it.

Further Directions

The parents in my study make up a very small subset of parents with disabled children. Of the eight families, each of them are middle or upper middle class, white, educated, and are married. Their children are all their own biological children, and they attend public school. For this reason, their stories and experiences more closely apply to parents from similar backgrounds with children who have similar disabilities. While much of the common themes about what they value in their caregiving experience apply universally, their experiences are uniquely their own.

I want to further explore what other parents would have to say cross-culturally and across socioeconomic variation. Families who make up a racial minority likely experience much different stigmatizations that not only cover their child's disability, but also their other identities as well. It would be interesting to further explore how their minority identities come into play and how their different communities affect their experience with disability.

For families with low socioeconomic status, I would expect concerns to center around lack of finances and resources that they have access to for their child. But it is possible that this is not the case. I suggest that interviewing parents on a range of socioeconomic statuses living in different communities with different services available to them would further show the diversity of experiences that parents have. I am curious about what parents say defines their experience when they do not have as much access to care or options available to them. It would be interesting to see if they define their experiences differently and find meaning in different ways.

Final thoughts and reflections

In closing, I hope this thesis has given you a greater understanding of how parents find meaning through their experiences of caregiving when raising a child with a disability. The

parents I interviewed have shown what they value and what hopes all parents express when looking at how to raise their children effectively.

These stories have shown how parents develop the immense love they have for their children despite the great effort involved in caring for their needs. My conversations with parents have shown me how much they have gained from being a caregiver, and they have shown that these experiences do not diminish what it means to be a parent. Even though their experiences were unplanned, these parents have gained patience and compassion, and they have personally felt that becoming a caregiver for their child has changed them for the better. As Kimberly told me about raising her twins, Sarah and Steven, right before ending our conversation:

I've learned so much patience, and I've learned to find the joy in whatever situation there is because it's usually not going to be what you expect it to be. When you find out the diagnosis, you think about your hopes and dreams for what raising a child is going to be and usually having that happen isn't part of it. And obviously there are times you wonder what it would be like if it were different. But you learn to enjoy the process and really find joy in everything. It's all the things that have changed in my heart that are for the better because of caring for them.

References

- Allbritten, Drew, Richard Mainzer, and Deborah Ziegler. 2004. "Will Students with Disabilities Be Scapegoats for School Failures?" *Educational Horizons* 82 (2): 153-60.
- Arendell, Terry. 2000. "Conceiving and investigating motherhood: The decade's scholarship." *Journal of Marriage and Family* 62 (4): 1192-207.
- Ayres, Lioness. 2000. "Narratives of family caregiving: The process of making meaning." *Research in Nursing & Health* 23: 424-34.
- Becker, Gaylene. 1998. *Disrupted Lives: How People Create Meaning in a Chaotic World*. Berkeley: University of California Press.
- Beresford, Bryony A. 1994. "Resources and Strategies: How parents cope with the care of a disabled child." *Journal of Child Psychology and Psychiatry* 35 (1): 171-209.
- Berghs, Maria. 2015. "Disability and displacement in times of conflict: Rethinking migration, flows and boundaries." *Disability and the Global South* 2 (1): 442-59.
- Berry, Judy O. 2008; 2008, c2009. *Lifespan Perspectives on the Family and Disability*. Austin, Tex.: PRO-ED, Inc.
- Boatright, Tony. 2010. "What do we call 'em?" *Paraplegia News*.
- Bruner, Edward. 1986. "Experience and its Expressions." In *The Anthropology of Experience*, eds. Edward Bruner, Victor Turner, 3-30. Chicago: University of Illinois Press.
- Callister, Lynn Clark. 2004. "Making Meaning: Women's Birth Narratives." *Journal of Obstetric, Gynecologic, & Neonatal Nursing* 33 (4): 508-18.
- Couser, Thomas. 2005. "Disability, Life Narrative, and Representation." *Pmla* 120 (2): 602-6.
- Davis, Lennard J. 1995. *Enforcing Normalcy: Disability, Deafness, and the Body*. London: Verso.
- Emerson, E., C. Hatton, G. Llewellyn, J. Blacker, and H. Graham. 2006. "Socio-economic position, household composition, health status and indicators of the well-being of mothers of children with and without intellectual disabilities." *Journal of Intellectual Disability Research* 50 (12): 862-73.
- Fisher, Pamela, and Dan Goodley. 2007. "The Linear Medical Model of Disability: Mothers of disabled babies resist with counter-narratives." *Sociology of Health & Illness* 29 (1): 66-81.

- Foucault, Michel. 2003. "Society must be defended', lectures at the college de France, 1975-76-M. Foucault's lecture on march 17, 1976 (Slovene translation)." *Filozofski Vestnik* 24 (3): 151-69.
- Frank, Gelya. 2000. *Venus on Wheels: Two decades of dialogue on disability, biography, and being female in America*. Berkeley, Calif.: University of California Press.
- Gallagher, Gina, and Patricia Konjoian. 2010. *Shut Up About Your Perfect Kid*. New York: Three Rivers Press.
- Gibbons, Susanne W., Alyson Ross, and Margaret Bevans. 2014. "Liminality as a conceptual frame for understanding the family caregiving rite of passage: An integrative review." *Research in Nursing & Health* 37 (5): 423-36.
- Ginsburg, Faye, and Rayna Rapp. 2013. "Disability worlds." *Annual Review of Anthropology* 42: 53-68.
- Giuliano, Anthony. 1990. *The Meaning in Caregiving Scale: Factorial and Conceptual Dimensions*. Adjustment (psychology). Providence: University of Rhode Island.
- Goffman, Erving. 2009. *Stigma: Notes on the management of spoiled identity*. New York: Simon and Schuster.
- Green, Sara Eleanor. 2007. "'We're tired, not sad': Benefits and burdens of mothering a child with a disability." *Social Science & Medicine* 64 (1) (Jan 2007): 150-63.
- Happell, Brenda. 2011. "No more 'fake it' - it's time to fashion stake it!" *Australian Nursing Journal* 18 (10): 37.
- Hays, Sharon. 1998. *The Cultural Contradictions of Motherhood*. New Haven: Yale University Press.
- Kelley, Richard I., and Raoul C. M. Hennekam. 2000. "The Smith-Lemli-Opitz Syndrome." *Journal of Medical Genetics* 37 (5) (May 01): 321-35.
- Kelly, Susan E. 2005. "'A Different Light': Examining Impairment through Parent Narratives of Childhood Disability." *Journal of Contemporary Ethnography* 34 (2): 180-205.
- Kinavey, Christine. 2007. "Adolescents born with spina bifida: Experiential worlds and biopsychosocial developmental challenges." *Issues in Comprehensive Pediatric Nursing* 30 (4): 147-64.
- Kleinman, Arthur. 2009. "Caregiving: The Odyssey of Becoming More Human." *The Lancet* 373 (9660): 292-3.

- . 1988. *The Illness Narratives: Suffering, healing, and the human condition*. New York: Basic Books.
- Kriegsman, Kay Harris, and Sara Palmer. 2013. *Just One of the Kids: Raising a Resilient Family When One of Your Children has a Physical Disability*. A Johns Hopkins Press health book. Baltimore: Johns Hopkins University Press.
- Lalvani, Priya. 2011. "Constructing the (m)other: Dominant and contested narratives on mothering a child with Down syndrome." *Narrative Inquiry* 21 (2): 276-93.
- Landsman, Gail. 2009. *Reconstructing Motherhood and Disability in the Age of "Perfect" Babies*. New York: Routledge.
- Lazarus, Ellen S. 1994. "What do women want?: Issues of choice, control, and class in pregnancy and childbirth." *Medical Anthropology Quarterly* 8 (1): 25-46.
- Linton, Simi, and Michael Bérubé. 1998. *Claiming Disability: Knowledge and Identity*. New York: New York University Press.
- Mahoney, Gerald, Patricia O'Sullivan, and Cordelia Robinson. 1992. "The family environments of children with disabilities: Diverse but not so different." *Topics in Early Childhood Special Education* 12 (3) (October 01): 386-402.
- Martin, Edwin W., Reed Martin, and Donna L. Terman. 1996. "The legislative and litigation history of special education." *The Future of Children* 6 (1): 25-39.
- Mason-Williams, Loretta. 2015. "Unequal opportunities: A profile of the distribution of special education teachers." *Exceptional Children* 81 (2) (January 01): 247-62.
- McLaughlin, Margaret J. 2010. "Evolving interpretations of educational equity and students with disabilities." *Exceptional Children* 76 (3) (April 01): 265-78.
- McManus, Beth M., Adam C. Carle, Dolores Acevedo-Garcia, Michael Ganz, Penny Hauser-Cram, and Marie C. McCormick. 2011. "Social determinants of state variation in special education participation among preschoolers with developmental delays and disabilities." *Health & Place* 17 (2) (3): 681-90.
- Muredda, Angelo. 2012. "Fixing language: 'People-first' language, taxonomical prescriptivism, and the linguistic location of disability." *The English Languages: History, Diaspora, Culture* 3.
- Murphy, Robert F. 1987. *The Body Silent*. New York: H. Holt.
- Noonan, Anne E., and Sharon L. Tennstedt. 1997. "Meaning in caregiving and its contribution to caregiver well-being." *The Gerontologist* 37 (6) (December 01): 785-94.

- Olsson, M. B., and C. P. Hwang. 2008. "Socioeconomic and psychological variables as risk and protective factors for parental well-being in families of children with intellectual disabilities." *Journal of Intellectual Disability Research* 52 (12): 1102-13.
- Pelchat, Diane, Marie-Josée Levert, and Valérie Bourgeois-Guérin. 2009. "How do mothers and fathers who have a child with a disability describe their adaptation/ transformation process?" *Journal of Child Health Care* 13 (3) (September 01): 239-59.
- Priestley, Mark. 2001. *Disability and the Life Course: Global Perspectives*. Cambridge [England]; New York: Cambridge University Press.
- Prussing, Erica, Elisa J. Sobo, Elizabeth Walker, and Paul S. Kurtin. 2005. "Between 'desperation' and disability rights: A narrative analysis of complementary/alternative medicine use by parents for children with Down syndrome." *Social Science & Medicine* 60 (3) (2): 587-98.
- Robertson, Rachel. 2014. "'Misfitting' mothers: Feminism, disability and mothering." *Hecate* 40 (1): 7-171.
- Shenker-Osorio, Anat. 2013. "Why Americans all believe they are 'middle class'." *The Atlantic*.
- Solomon, Andrew. 2012. *Far from the Tree: Parents, Children and the Search for Identity*. New York: Scribner.
- Sousa, Amy C. 2011. "From refrigerator mothers to warrior-heroes: The cultural identity transformation of mothers raising children with intellectual disabilities." *Symbolic Interaction* 34 (2): 220-43.
- Theerasilp, Ubonpun, and Penchan Sherer. 2014. "Contestation with the bio-power in normalizing process: The life experiences of families with autistic children." *Kasetsart Journal* 35: 497-505.
- Thomas, Kathleen, Alan Ellis, Carolyn McLaurin, Julie Daniels, and Joseph Morrissey. 2007. "Access to care for autism-related services." *Journal of Autism and Developmental Disorders* 37 (10): 1902-12.
- Waldschmidt, Anne. 2005. "Who is normal? who is deviant? 'normality' and 'risk' in genetic diagnostics and counseling." In *Foucault and the government of disability.*, ed. Shelley Tremain, 191-207. Ann Arbor: University of Michigan Press.
- Whyte, Susan Reynolds. 2009. "Health identities and subjectivities." *Medical Anthropology Quarterly* 23 (1): 6-15.
- Wilkerson, Abby. 2011. "Diagnosable." In *Disability and Mothering: Liminal Spaces of Embodied Knowledge.*, eds. Cynthia Lewiecki-Wilson, Jen Cellio. 1st ed. ed., 113. Syracuse: Syracuse University Press.

Zibricky, Dawn. 2014. "New knowledge about motherhood: An autoethnography on raising a disabled child." *Journal of Family Studies* 20 (1) (04/01): 39-47.

Appendix

Sample of Interview Questions

Intro, about your child

- If you and I were meeting for the first time, maybe I am a new teacher for your child, what would you want me to know about your them?
- Tell me about yourself. Tell me about your family.
- How did your family life change when you had a child with a disability? How has your work life changed? How has this affected your whole family?
- Can you walk me through your thoughts when your child was born?
- What was it like when your child started going to school?
- How has your child interacted with his or her peers?
- Has your child ever seemed to realize he/she is different? How do they react in these situations?
- What situations make your child feel comfortable and happy? What brings them joy?
- What do you think has made the biggest difference in your child's life, or what are some things that have made a difference?
- What therapies and activities have benefitted your child the most?
- What concerns do you have for your child's future?
- What does a typical day look like for you and your family?
- Are there times when you felt your child could not do something other children could do? How did you approach these situations?

About your transition personally

- What communities have helped you feel at home personally?
- Have support groups helped you? What role do they play in your life? Has this changed over time?
- What else has offered you the most support in dealing with this? What has helped the most?
- How has having a child with a disability changed your life personally?
- How do you feel it is different for you being the mother rather than the father?
- Did you experience having a child with a disability the way you thought you would? How did it differ?
- Have people treated you different as a parent? How have you felt stigmatizing effects of having a child with a disability

Outside community & family

- What does it feel like when other people sympathize or feel bad for you? Does this happen?

- What do you notice about how other people interact with your child for the first time?
- How did your other children react? What was hard for them?
- What was it like for your extended family?
- What are some major things that changed about your family after having a child with a disability?
- How have hospital visits impacted your family? What is it like going to the doctor?

Advice

- What advice would you give to other families when they discover their child has a disability?
- What kinds of things would you like people to know about what it's like to have a child with a disability? What do you wish you knew before going into it?

What have you learned, and how have you benefitted?

- What things have you found to enjoy about having a child with special needs?
- What is the best thing about your child that the world doesn't see?

What is disability?

- What does the term disability mean to you?
- Why do you think disability is stigmatized?
- Have you felt stigmatized being a parent of a kid with a disability?
- What are some stereotypes you have heard and/or dealt with?
- Is there anything else you would like to share?

Closing reflections about the interview

- Is there anything else you would like to share?
- Is there anything I should have asked that I didn't?
- Is there anything that surprised you that I didn't ask that you expected me to? (What do other people ask that I'm not asking)