

INTERPRETATIONS OF NORMAL: EXPLORING FAMILY LIFE OF CHILDREN
WITH DIVERSE ABILITIES

by

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DISSERTATION ABSTRACT

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This qualitative work provides insight into the lives of children with diverse abilities and their families as they negotiate social mandates of family life. Through interviews of various family members, from siblings to grandparents, I have found families attempting to interpret perceived prescriptions of normality with a family member stigmatized by medical, cognitive, and/or behavioral deviations. Through this work, I reveal that although the term normal eludes definition, it is constructed and re-constructed as each family member makes sense of specific life experiences. The families depict what they believe to be “normal” family life as they understand it from past experiences and their surrounding culture. However, family members continue to play with the term in defining experiences that fall outside of or transcend what they believe to be typical interactions. As the families in this study define themselves as a unit, “normal” appears to be a baseline by which they interpret their lived experiences of family life and childhood resulting in a creation of a new normal or belief in their “beyond normal” characteristics. The unintended consequences of adhering to mythical constructions of family life, creating a new normal, and beyond normal perceptions are also explored. Analyzing the ways in which families portray their daily interactions will contribute to the fields of

childhood studies and special education by providing a nuanced view of childhood, family life, and parental involvement.

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Never Lose Hope

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Introduction: “A Twist on the Typical”

As I made my way through the crowded middle school lobby, through the sea of proud family members and giggling girls in tutus, I wondered, “How did I get here?” I am researching families and their support systems, not dance recitals. I nervously clutched my iPad and made my way through the lobby. I glanced ahead of me to see Bethany twirling in delight as her grandparents proudly smiled at her then at each other. She wore a plush white robe to cover her sparkly sequined costume and her smiling face displayed gobs of makeup. She sashayed through the audience like the star of the show. Tonight, this wasn’t a middle school; it was a performing arts stage for Miss Kitty’s School of Dance. The crowded auditorium was buzzing with familial anxiety and joy. The show finally began and the crowd fell silent. I looked around at family members on the edge of their seats. I grumbled, alone in my misery. Even the first act was torture. Judging from the applause, I surmised the dancers were wonderful, but I would have felt more comfortable playing superheroes. I sat slumped in my seat for what seemed like fifty dance numbers watching young women, ages five to eighteen, perform for their elated family members. Finally, Bethany’s class entered. I sat up. I couldn’t take my eyes off of the troupe. I was amazed by the choreography, the dancers completely aligned with each other, dutifully responding to the beat. They were wonderful! Like superheroes valiantly saving the day! Although about five years older than the eight and nine year olds in her class, Bethany was physically identical. She proudly swayed, bounced, shook, and tapped along to the music. This, her mother confided, is what she loves to do. This is their family’s life: a life devoted to dance practice and recitals for two daughters. Despite Bethany’s diagnosis of a rare disorder, the cognitive delays, the medical complications,

and a life expectancy of her early twenties, their life, Mom assured me, is, “pretty typical with a different twist on the typical.” During my first interview, this phrase resounded in my ears. As I listened more closely to Bethany’s family and to other families who had a family member with complex medical, cognitive, and behavioral needs, I realized that typical/normal/average was a consistent theme across every family that I interviewed. Although one family member may have deviated from a medical or behavioral norm, the families repeatedly tried to convince me that their lives were much more than their child’s diagnosis.

Over the course of a year, I researched thirteen families in a rural New England area. Each of their life stories encouraged me to re-evaluate my understanding of what it means to be a special education teacher. As I met the families with children whose diagnoses ranged from autism to rare genetic disorders, I realized that it was more important to tell the story of their everyday lives than it was to recount their plight in accessing services and involvement in educational planning. Their families indicated that their lives were as full of joy as Bethany’s. In interviewing multiple family members, I heard stories that stressed the strength, fun, and individuality of each member of the family and the extraordinary strengths of their child with special needs. I was introduced to family life as it is influenced by disability, specific historical characteristics of family, and of the rural communities in which the families lived. Sitting at kitchen tables, following guardians throughout their hectic day, and engaging with children in school and in extracurricular activities, I saw a different side of family life; one that I often overlooked as an educator. Most importantly, I learned that the families are more than their child’s special education. Life, for them, extends well beyond the classroom.

Even though the family members with whom I interacted knew this project focused on special education, they rarely discussed school or their involvement with school without being explicitly questioned. Time and again, the families highlighted the “normal” lives that they lived. The families recounted their “typical” everyday interactions and their “ordinary” routines. I was intrigued by the continual invocation of the word “normal” when they described their lives. Negotiating the socially constructed model of traditional family life, the families in this study sought to construct their own conception of what ordinary *is* and *is not* in their lives. Sometimes they expressed how they enacted average family life: comparing their busy lives to more traditional conceptions of family. However, they also evaluated the ways in which their family situated itself amidst classifications of normal as they recounted lived experiences that deviated from or exceeded typical family life and childhood. Therefore, through this study, I shed light on the ways that families construct ideals of a typical family life, create their own normal, and view their family and family member with behavioral, medical, and cognitive needs as “beyond normal.” By viewing families as a unit, as prescribed by family systems theory (FST) and reacting as socially stigmatized individuals, I present the ways in which families engage with conceptions of normal. I will also detail the unintended consequences that may result from such a focus on the term “normal” as it plays out in their interactions with each other and their community. Families, I argue, do not adhere to a normal or an abnormal category; rather, their lives can be viewed along a continuum. As I describe in “Spectrum of Normality,” families’ interpretations of normal are not formalized over the life span, nor do they follow a linear trajectory; instead, the families continually define and re-define what normal means to them as situations dictate.

This story presents the ways in which families grapple with the term “normal,” despite their child’s classification of falling outside a medical, behavioral, or cognitive norm.

What is normal?

After interviewing twenty individuals across thirteen different families, I have found that perceptions of normality permeate how each family defines itself. As the families spoke to this nebulous concept of what family entails, I eagerly sought to answer, “What is normal family life?” However, as the current study demonstrates, “normal,” though an active force in the families’ portrayal of themselves, eludes definition. Cooper (2014) argues that, “the concept of normalcy is so pervasive in Anglo-American culture and yet so abstract, so difficult to characterize and yet so hegemonic” (p. 136). The families in this study speak to this powerful abstraction as they try to achieve what they believe is typical family life and re-work their understanding of how normality plays out in their lives. The pervasive forces of normality have affected children and their families as professionals determine who is and is not reaching specific behavioral and developmental milestones. According to Halpern (1998), the monitoring of children and their families through standardized norms expanded during the late 19th century as social interest in children’s development gave rise to the field of pediatrics. Sydney Halpern’s *American Pediatrics: Professionalism: The Social Dynamics of Professionalism 1880-1980* reveals the interplay between society and medicine as she chronicles the birth of pediatrics. Halpern contends that this branch of medicine evolved from social forces that necessitated its inception, arguing that pediatrics developed amidst, “changing notions of childhood and social movements promoting child welfare” (p. 9). Similar to Richardson’s (1989) claim in *The Century of the Child: The Mental Hygiene Movement and Social*

Policy in the United States and Canada that the mental hygiene movement attempted to monitor the lives of children and encouraged categories of normal and abnormal, Halpern asserts that pediatrics worked to perpetuate the monitoring of the “normal” child. Halpern argues that regular well visits lend to the constant monitoring of both child and family allowing the pediatrician to advance normative practices of hygiene and child rearing, while monitoring developmental milestones and parental performance. Further illustrating the historical trajectory of the normal/abnormal dichotomy, Harriet Cooper (2013) argues that, “during the early twentieth century, the figure of the ‘abnormal child’ came to replace the figure of the ‘sick child’ in the childcare manual” (p. 142). Employing the work of Foucault, Cooper illuminates the historical trajectory of creating notions of normality in children through parenting manuals. Therefore, a child’s medical condition stigmatized both the child and the mother for not falling into normal classification.

Furthermore, at a time when visions of normality were being ingrained into professional and social arenas, IQ tests allowed for another level of child categorization, one based in “scientific truth.” Emotionally inspired by the Progressive era’s child saving, scientifically motivated by Child Study’s promotion of discrete developmental stages, and following G. Stanley Hall’s study of adolescence, the IQ testing movement took flight.¹ The advent of the American intelligence testing movement brought educators and psychologists together in an attempt to cure both educational and social problems. In “Schools as Sorters” Paul Davis Chapman (1988) describes the effort of professionals to cure social ills through weeding out the unintelligent. The intelligence test provided a

¹ Halpern’s “American Pediatrics” writes, “Childhood became a focus of normative and social reform in America during the first half of the nineteenth century” (p. 37).

“scientific” guideline in which administrators and educators could siphon out the undesirables, the children who could not conform to the behavioral and academic standards of the classroom. Special classes could then be created for these “abnormal” students. However, the original purpose of the test, as advanced by its French creator, Alfred Binet, was never to classify students. Rather it was a method of aiding children already presenting an academic disability. Stephen Jay Gould (1996), in “The Mismeasure of Man” contends that, “American psychologists perverted Binet’s intention and invented the hereditarian theory of IQ” (p. 157). The tests, as designed by Binet, were to provide education to children whose disabilities would have precluded learning in a traditional environment. Gould writes that Binet had cautioned those applying his test, “Intelligence, in any meaningful sense of the word, can be augmented by good education; it is not a fixed and inborn quantity” (p. 154). Unfortunately, Lewis M. Terman and H.H. Goddard who brought the IQ test to American schools, failed to heed Binet’s advice. Instead, Terman and Goddard sought to apply the intelligence tests broadly and in a manner that reinforced racial and socio-economic biases reflective of the era. To Terman and Goddard, the tests confirmed the absence or presence of intelligence among different groups of people resulting in a broad classification of who was and was not worthy.

The families depicted in this study continue to face the perversion of Binet’s IQ tests through the stigma felt as they enact family life with a person whose developmental tests deem them “abnormal.” Although their child may deviate from specific developmental or behavioral milestones, family members assured me that it is only *one* aspect of their lives. Stigmatized by this one deviation of average, “normal” became a central focus in our interviews. Reaching for the elusive norm revealed itself as the

family informants referred to the ways in which their families adhered to their perceived conceptions of normality. Scrutinized by professionals, family, and friends, the caregivers of the child who deviates from prescribed milestones of cognitive, medical, or behavioral functioning must bear the stigma of disability. In an attempt to counter their purported flawed identities, I found families speaking to how they, as a unit, enacted “normal.” Disability researchers have found that family members, particularly mothers, engage in discourses of normality. For example, Landsman (2009) referring to the words, “normal” and “perfect” proposes that her informants, “do use these terms; they also react to them, negotiate with them, rework them, and often come to reject them” (p. 11). The families presented here did not reject the term “normal.” Instead, they negotiated the concept in their own way. A specific deviation may classify one aspect of their life as abnormal, but they have constructed this abnormality to fit into their ordinary family functioning, re-configured what it means to be normal, or saw their new normal as something beneficial. Reacting to the one marker of abnormality, the families attempted to normalize the other layers of family life. Maul and Singer (2009) report similar findings, arguing that families try to “make family life as ‘normal as possible’ through parental division of responsibility where mother takes on the role as primary caregiver and father as worker.” The authors continue, asserting that families find themselves “insisting on normalcy” (p. 164). By relating their child and their family to normal, the families continually define and re-define themselves and their child. Clearly, the impact of hegemonic constructions of normality permeate the children’s lives, relegating not only their physical and/or neurological condition as abnormal in relation to that of their peers, but also influencing how their family sees them and their family unit. Despite the lack of a concrete

definition of normal, the families continually work with the term in making sense of their own lives. In employing the term, the families attempt to counter stigma, to speak to ways that they make comfortable their uneasy situation, and reveal the worth of their unit and their child.

Enacting Normal

The families in this study are well aware of the categories of normal and abnormal. Although medical professionals classify their child as abnormal for failing to meet a standardized norm of behavior, health, or cognitive aptitude, as a family unit they feel they are meeting the criteria for what they believe to be normal family functioning. In Davis' (2013) work, *The End of Normal: Identity in a Biocultural Era*, he explains his prior assertion in *Enforcing Normalcy: Disability, Deafness, and the Body* that, "normalcy was a category that had been and is enforced in our culture" (p. 1). As if countering the stigma associated with their child's measured normal, the families repeatedly offered ways in which they could be classified as a "normal" family. Each member directed me away from their child's measured differences and revealed multi-dimensional layers of family experience. Through their descriptions of family life, family members illustrated the ways in which their family observed traditional family practices such as spending time together during meals, caring for each other, and enjoying family activities. As the family members shared their stories, the ways in which they stressed their normality was striking. They had no reason to highlight their "normal" lives. I was studying their child's *special* education. Yet, time and again, the families described themselves through personal constructions of family life. Whether they were describing the ways that their family adheres to what they perceived to be typical family interactions

or through creating their new normal from the physical needs and routines to which they must abide, the families in this study repeatedly spoke in relation to norms. Always mindful of their classification as abnormal, the families employed the term even when referring to situations that found them outside of typical family interactions. When families described experiences that they were unable to classify as normal, they reassessed their interactions in a way that demonstrated a new normal, embracing the unique contribution that their family member adds to the situation. Of particular interest, for example, were the families' descriptions of hospital trips as a comforting experience; one that led to visiting with old friends and people who were like family. Families presented themselves to me in ways that depicted their functioning as a unit, rather than as people reacting to disability. Each member added a different dimension to the family as a whole by reacting and negotiating to their personal conceptions of childhood and family life. Each member brought to the family conceptions of family life as influenced by their past, location, or individual interests. For example, to Bethany's family, who introduced this chapter, dance was a typical family activity to which all members had to adapt. Dance not only affected their family's schedule, but also influenced the activities that other members of the family found important. This encouraged a family focus on dancing and the inclusion of Bethany into a dance class, even if it meant dancing with a younger troupe.

Although researchers describe the literature as finding families in a state of negotiating the effects of their family member's disability (Boyras & Sayger, 2010; Gavida-Payne & Stoneman, 1997; Jackson, Traub, & Turnbull 2008), my informants emphasized activities that conveyed their emotional and recreational normality; thus,

revealing that it was not their family member's disability to which they were reacting but the stigma associated with disability.² For example, as a warm up in the interviews, I would ask family members to describe their family. The following adjectives were chosen: *Close, loving, and caring* (Papa, Javon's grandfather); *Active, energetic, and close* (Gilly, Javon's 13 year old aunt); *Strong, brave, and humble* (Connor's mom, Hillary); *committed, fun, and outdoorsy* (Patrick's mom, Dori); and the most endearing was 7 year old Eric, Javon's brother, who wrote *nice, helpful, and kind*. The adjectives continued along these lines, each representing family unity: their relationships with each other, the activities they enjoy, and the ways they interact. There were no descriptors that would suggest that the family was "abnormal" or "different." Additionally, there were no adjectives employed that would highlight their family member's disability. This, I argue, results from family members seeing themselves as a unit not defined by disability. Rather, as a group of people, each with their own personalities, who work toward living what they conceive to be a "normal" and worthy life. This is a story about the people who choose to care for a child with complex needs and the sense they make of their lives as they interact with the world of disability. I found that families negotiate normality with their stories and experiences along a spectrum. This spectrum allows me to reveal their lives and specific interactions that they perceive to be normal, their own normal, or even as beyond normal.

² As disability scholars move toward ethnographic research of family life, narrative accounts address the lived experiences of families leading to a more multi-dimensional understanding of family life. Researchers counter the causal nature of disability and stress, happiness, marital discord, sibling adjustment, etc. (Stoneman, 2005; Kelly, 2005).

Conceptual Framework: Spectrum of Normality

Over the course of my research, I questioned, “Why are the families using the term “normal” so frequently in our conversations?” What is normal to them? This resulted in more questions than answers. Normal, I have found, is a term applied as a way for families to make sense of their daily experiences. It is individually defined by the units, determined by unique situations, and used as a baseline to illuminate qualities that outsiders may fail to see. By using the conceptual framework of a spectrum, I explore how families work with “normal” and re-frame specific experiences to depict multi-layered forms of what normal means to them. Normal, therefore, is not clearly defined. Instead, the families’ interactions with the term are displayed across a spectrum, thus demonstrating the equivocal nature of the concept. As I analyzed my interviews with family members, wrote about their interactions with conceptions of normality, and spoke with my committee members, it became apparent that the families were not classifying themselves as normal or abnormal. Corker and French (1998) applying the work of Linton (1998) assert that the binary of abnormal and normal, “avoids concrete discussion of the ways in which [people] actually differ” (p. 31). My informants defied the rigid classification of one or the other; rather their descriptions led me to view their relationship to normal as functioning on a spectrum. While theorists see families trapped by either normal or abnormal (Davis, 1995); searching for the elusive normal (Bridgens, 2009), creating and re-defining normal (Landsman, 2009), or engaging in what some scholars see as a “transformative process” (Singer, 2002, citing Barry & Singer, 2001; Turnbull, Patterson, Behr, & Murphy, 1993), I see the interplay with normality, on a

spectrum constantly being negotiated depending on the moment, the activity, and the audience.

Analyzing experiences across a spectrum provides an opportunity for defining different aspects of the families' lives as normal (enacting traditional conceptions of family life), their own normal (departing from convention), or beyond normal (exceeding traditional expectations). First of all, I identify their conceptions of normality as their center, to which many of their examples allude. They depicted their normality through sharing examples of what they considered traditional family interactions constructed through their past, the settings where they lived, and in comparison to members of their extended family (chapter 2). Sometimes, the families admitted that certain interactions, like frequent trips to the hospital or re-configuring family life might deviate from center. So, I placed these interactions to the far left on the spectrum. However, this pull from normal resulted in their creation of their own normal (chapter 3). Lastly, even though they found themselves slipping from community notions of ordinary, they also found times in which they and their family member with complex medical, behavioral, and cognitive needs were "beyond normal"; these situations involved unique characteristics of their child, or their dedication to their child (chapter 4). The spectrum of normality allowed me to view family interactions as they interpreted normal for their lives. Instead of focusing on the ways in which deviations from cognitive, behavioral, and medical expectations disabled family life, the spectrum of normality provided a platform for revealing the lived experiences of the families as they enacted family life amidst the stigma of disability.

Conceptual Background

The impetus for this work stems from my background in FST and childhood studies (CS). In an attempt to understand the multiple lives of families and children as influenced by their unique experiences, I focused on children with disabilities. This focus led to conversations situated in theories of stigma and disabled childhood studies (DCS). CS and DCS encouraged the understanding of the lived experiences of children and their families as influenced by their time and place. FST allowed me to view the family as a unit, the starting point through which I began my analysis. Stigma theory revealed the factors influencing the ways family members acted and reacted within their unit and with their community. Using this framework in analyzing the families, I pictured a sand and water wheel beach toy with multiple moving parts. The toy served as the family unit with individual components making up one system of functioning. The toy, however, sits upon the sand, a loosely defined platform moved easily by outside forces. This represents the nebulous concept of “normality.” Water being poured through the funnel symbolizes stigma, an outside force affecting individual family members differently as they move in their unit. Together, the theories provide a structure for examining the ways in which families function as a unit and create their identity based on stigma and their interpretations of normal.

Family Systems Theory

Martha Morrison Dore (2008) traces the development of FST citing its inception with General Systems Theorist Ludwig von Bertalanffy (1968).³ As Dore explains, the system’s theory evolved across Comte and Durkheim, Parson’s divisions of labor, social

³ “a biologist who was concerned with understanding the totality of an organism as more than a sum of its individual parts and processes” (p. 435).

exchange theory, symbolic interactionism, and resulting in its current iteration advanced by seminal family system's theorist, Murray Bowen, a psychiatrist. Bowen worked with Nathan Ackerman who "advocated seeing all family members together in treating a child with emotional or behavioral problems" (p. 437). Since its inception, FST has been employed in fields like psychology (Davies & Cicchetti, 2004; Hopper, 2007; Minuchin, 1985; Wang & Crane, 2001), special education, and palliative care (Mehta, Cohen, & Chean, 2009), as both an approach to treatment and a research tool. As a special educator, I was most inspired by the work of Ann and Rudd Turnbull, whose application of FST added to the field of special education by shedding new light on parental involvement and the ways families interact with each other and their community, Turnbull, Turnbull, Erwin, Soodak, and Sherwin (2015) assert that, "professionals have recognized that every member of a family differs from every other member (as the shapes hanging from a mobile do) and any action related primarily to one member will rearrange the relationship of that person to all of the other family members" (p. 31). In honoring family systems, I sought the perspective of various family members of children who had complex medical, cognitive, and behavioral needs. Each member contributed their unique understanding of family and community relationships as they reacted to prescriptions of normality. FST has guided my work as a special educator and as a researcher. As a practitioner, I made it a point to consider the many voices of the family. For example, as a teacher I encouraged grandparents to attend more community events with their families; helped siblings advocate for and interact with their sibling with autism; and established supportive and empathetic relationships with parents that included them in their child's education and assisted in finding play dates for their child. Incorporating the individuals that comprised

the unit allowed me to better meet the needs of my students. I was not just my students' teacher; I played a role in many of their extended families. The family, I learned, is my greatest ally. As a researcher, FST guided this work as it informed who I interviewed and how I interpreted the interviews. The original plan was to understand how people accessed services; however, as each member of the family brought his or her own perspective, it became clear that their functioning encompassed much more than special education services. By looking to each member of the family, I was able to understand the ways in which each family member assisted in defining who they were as a unit.

This work seeks to expose the ways in which families are indeed interdependent, a key feature in FST. What affects one, affects all. To understand the individual, family systems theorists advise a contextual understanding of family members: one that sees the person as an active member in a circular system (Minuchin, 1985, p. 290) and through an examination of all members of the family unit (Davies & Cicchetti, 2004). For example, Dore (2008) explains the functioning family unit: "if one family members feels stress, they all feel it; if one member is affected by an event outside the family system, whether positively or negatively, they are all affected" (p. 448). The families in this story are affected by the perceived stigma of having a family member who deviates from traditionally imposed cognitive, medical, or behavioral expectations. My informants revealed their interconnectedness by emphasizing how their conceptions of normality influenced their relationships with each other and their community. Each family member stressed their relation to the various norms, which affected their participation in specific activities with their family member with a disability. Gilly, a teenaged aunt of a young boy with autism, succinctly illuminated the ways in which her family's emotions are

influenced by a member's actions. Gilly described her nephews, "If Javon is not paying attention or Eric is not listening, it gets stressful. But after everything, it gets better; we all get happy. Javon just makes us laugh and things get better" (Gilly age 13). Gilly reacts to Javon and Eric's deviation from normal expectations of listening or paying attention and explains how these deviations cause the entire family stress; yet, all is ameliorated once the children are acting according to behavioral norms. By focusing on the family's interconnectedness, FST elucidates the effect of each member on the functioning of the unit. The following section identifies the specific components of FST that have guided my thinking throughout the writing of this work.

Components of FST

I used certain features of FST in examining the families in this study. FST concepts such as boundaries, cohesion, adaptability, and homeostasis played an integral role in making sense of the families' relationships with each other. First of all, family systems theorists suggest that fluid "boundaries" create relationships and emotional connectedness that result in stronger family units. Several families in the study drew upon fluid boundaries to create and re-create new familial ties and to adhere to new roles. As the families reflected on the horrors of abandonment, poverty, and abuse, they revealed the ways in which their family evolved into their current family constellation. The families that resulted were strong family units that determined who would remain in their system and those who were unworthy. Together, the members created a whole functioning unit. This is also consistent with the emergent childhood disability literature that stresses the importance families place on their lives as a group. For example, Canary (2008) found that "family activities, interactions, and values were revealed as important

aspects of how members saw themselves and others within their families. This feature of identity narratives did not highlight aspects of ability and disability at all; rather members focused on global features of their families that are part of who they are and what they do” (p. 447). The families in my study confirm the interconnectedness espoused in FST in that they see themselves as individuals mutually affecting each other. Their fluid boundaries allowed them to create and re-create family life to meet the needs of their specific unit. Instead of a focus on individual characteristics like the disability of one member or the career of another, the families revealed their commitment to their unit by dealing with daily stressors and finding happiness as a group.

Secondly, family systems theorists have defined the ways in which family members function together as “cohesion.” Turnbull et al (2015) define cohesion as, “family members’ close emotional bonding with each other and to the level of independence they feel within the family system” (p. 447). The families presented in this study exposed their cohesion through the ways in which they re-defined their roles in the family, worked together toward specific goals, and sought to highlight the positive qualities of each of their members. As independent agents, they bring to the unit their understanding of traditional family activities. These understandings affect their interactions with each other and their community. Without these close bonds, families disbanded and friends were discarded. The ways in which close family bonding maintains or forces the creation of new family life is explored in chapter 3. Additionally, family systems theorists have referred to the ability of families to work together to meet their unit’s needs as “adaptability.” Turnbull et al (2015), citing Olson (1988), describe adaptability as the “family’s ability to change in response to situational and

developmental stress” (p. 440). This work highlights the various ways that families adapt to their situations. Families make myriad modifications to adjust to their circumstances, from physically altering homes for wheelchair access, changing careers, to providing extra assistance while fishing or baking cookies. The family members in this study demonstrate their continuous adaptability thus substantiating FST’s claims regarding family functioning.

Lastly, this study illustrates FST’s tenet of homeostasis, or “familiar equilibrium” (Minuchin, 1985, p. 290). As described by Turnbull et al (2015), “homeostasis represents the family’s ideal state when the energy expended by the system is perfectly balanced by the energy coming into the system from the environment” (p. 439). The families revealed their balance by eagerly exposing the benefits of being in their family and the sources of support that their friends and service providers added to their system. Homeostasis, for the families in this study, is not the resolution of one stressful situation; rather, it is the way they balance their lives to adapt to their “life rhythm” (Gills and Wells, 2000). The ways in which they maintain balance becomes, as Dore argues, their “customary structures and ways of doing things” (Dore, 2008, p. 450). Viewing the families’ explanation of life experiences along the spectrum of normality reveals how they balance normal, less than normal, and beyond normal family interactions. They have learned to move with their life rhythm. Even though they may be visiting the hospital, it feels comfortable to them. Even though their husbands were unable to meet their child’s needs, they discovered different ways to cope and occasionally found new partners. Even though children were subjected to abuse, grandparents stepped in to help. The homeostasis for these families lies along a spectrum, their lives balanced by their reactions to and

negotiations of “normal.” This balance follows not a straight trajectory, but is a constant balancing act, causing the families to work and re-work their functioning, their community involvement, and their relationships with family and friends. The families in this study, moving with their life rhythm, attempt to counter stigma by appreciating what their child has to offer, acknowledging their own creativity, and recognizing the importance of exceptional service providers. Reaching homeostasis allows the families to relish in the positive that is unique to their own system and take pride in the many qualities that norm-focused observers may overlook. Homeostasis for my participants is not adhering to community notions of normal, but interpreting experiences along a continuum of “normal.”

Following FST, I have found that the family units are influenced by individual members’ perceptions of normality. I argue that it is not disability alone that affects the families’ interactions with each other; rather it is social mandates of normality that influence their relationship within the family and the wider community (neighbors, extended family, and friends). For example, there is a young aunt who lives with her nephew with autism; she takes on the role of behaviorist. Grandparents, similarly, understand the role of engaging in normal activities and seek to provide situations such as motorcycle riding and Easter egg hunts for their granddaughter with complex medical needs. Parents speak to ideals of family life in which they highlight their family dinners and old-fashioned values. Confirming family functioning as advanced by FST, I portray the lived experiences of family members as they contribute to their family unit. Of particular importance are the ways in which these interactions are related to managing the stigmatized label of disability.

Stigma

Stigma theory influenced this work as I observed each family member, in advancing the “normality” of his/her family, was reacting to the stigma of disability. As explained by Goffman (1977), stigma results as we define and categorize people with whom we come in contact. Upon seeing someone, we assign a social identity based on preconceived judgments. For example, seeing a young boy with platinum blonde hair on the beach may result in referring to him as a surfer. If the person being judged possesses a trait that we find abnormal, the person is “thus reduced in our minds from a whole and usual person to a tainted, discounted one. Such an attribute is a stigma, especially when its discrediting effect is very extensive; sometimes it is called a failing, a shortcoming, a handicap” (p. 204). The social identity above differs from that of a person others find abnormal. A person in a wheelchair, for example, may also be considered intellectually flawed as they have been reduced to that of only their physical difference. The children of interest in this study have been judged based on behavioral, medical, and cognitive deviations from their peers. Failing to adhere to standard expectations, the child is thus stigmatized. Researchers have studied the stigma associated with medical, behavioral, and cognitive digressions related to people with disabilities and their families. (Ali, Hassiotis, Strydom, and King, 2012). To name a few of these groups: people with emotional behavioral disorders (EBD) (Kauffman, Mock, & Simpson, 2007; Molloy & Vasil, 2002) people with epilepsy (Jacoby, 2002), people with AIDS (Herek, 1994), and people with autism (Gray, 1993; 1997).

Stigma researchers indicate that disability stigmatizes the individual and their family members. First of all, the children in this study who are medically, cognitively, or

behaviorally deviant, receive the stigmatized label of disability (Little, 2010 citing Anspach, 1979; Putnam, 2005; Goffman, 1977). The label of disability bears a history of oppressive and unjust acts (Baglieri, Valle, Connor, and Gallagher, 2010) perpetuated by media images that portray disability as a form of suffering, and as determining an unworthy life (Little, 2010). Furthermore, Green et al (2005), citing Link and Phelan (2001), explain that “labeling is the recognition of differences and the assignment of social salience to those differences. In the context of disability, it is the recognition that a certain biological trait differs from the norm in ways that have social significance” (Green et al, 2005). The children of interest in this study are acknowledged as different from their peers thus affecting their interactions within their families and their communities. These digressions from expected developmental standards result in being labeled disabled, thus resulting in stigma.

This stigma falls also on the family members. According to Goffman (1963) family members are the “wise” or possess a “courtesy stigma.” He explains that the “wise” are “persons who are normal but whose special situation has made them intimately privy to the secret life of the stigmatized individual and sympathetic with it, and who find themselves accorded a measure of courtesy membership in the clan” (p. 28). He continues discussing persons who are “wise,” stating that, “all are obliged to share some of the discredit of the stigmatized person to whom they are related” (p. 30). Furthermore, in contemporary analysis of the effects of stigma on family members of a child with disabilities, Gray (1993) finds parents of children with disabilities to be stigmatized and Landsman (2009) paraphrasing McMahon (1995), writes, “In an era in which mothers’ social worth resides in their association with valued children, the woman who gives birth

to a disabled child may be less than a full mother” (p. 169). Drawing from these studies, I argue that each of the family members in this work is a stigmatized individual, exposing their normality as a way to react to perceived stigma.

As the family members discussed family life with me, they negotiated how their family related to standard expectations of health, intelligence, and behavior. These expectations permeate their daily lives. As Goffman (1963) writes, “The general identity values of a society may be fully entrenched nowhere, and yet they can cast some kind of shadow on the encounters encountered everywhere in daily living” (p. 129). Living in the shadow of normality, the families in this study are constantly reminded of how their family member with disabilities fails to live up to perceived standards of normalcy, thus stigmatizing their child and their family. By viewing themselves through a lens of normality, the families presented their lives to me in ways that would validate their ordinary family functioning. Therefore, each chapter reflects the ways in which family members employ typical family life to combat stigma. In chapter two, family members provide detailed accounts of their “normal” lives by enacting rituals, routines, and activities that they have constructed as a part of normal family life. In chapter three, they avoid stigma by showing that even though they do deviate, their deviations have led to a new normal or regular life. Finally, they prove their child’s worth and their own worth by showing how exceptional they truly are in chapter four.

Each family member in my study acknowledged conceptions of normal family and childhood experiences and sought to explain ways in which their family exemplifies traditional family life. By employing FST, I was able to gauge the ways in which multiple members in particular families reacted to stigma. Coleman (1997) corroborates

the benefits of obtaining multiple perspectives arguing that, “Viewing stigma from multiple perspectives exposes its intricate nature and helps us to disentangle its web of complexities and paradoxes. Stigma represents a view of life; a set of personal and social constructs; a set of social relations and social relationships; a form of social reality” (p. 216). In providing a forum in which family members could discuss their daily interactions within their family as it pertained to their family member with complex needs, I was able to see the ways in which the stigma led to specific constructions of family life.

As we continued our conversations, the families not only depicted a private life that they felt included normal family functioning, they also described and sought to participate in activities outside the home that they believed were part of the normal childhood experience. Family members focused on providing what they considered typical family activities, such as trips to museums, library story times, and outdoor play, thereby revealing to the greater community that they could indeed be active participants in society. Family members reacted to stigma by conveying to me the many activities in which their family member can engage, the acceptance they receive from their small community, and the myriad ways that their child is experiencing a childhood that they deserved. Javon’s 13-year-old aunt and Bethany’s 16-year-old sister speak to the stigma that they feel surrounds their family member with complex needs. Gilly declared that people with autism are, “like normal people. You can’t treat them differently. They deserve to have a normal life” (Javon’s aunt, Gilly). Gilly grappled with the stigma that she knows will follow her nephew. She wants him to be treated like everyone else since he is normal, well, “like normal.” Regardless of their stigmatized label, Gilly believes

people with autism deserve the same quality of life as everyone else. Kirstyn also speaks to the stigma that could be associated with someone who has complex cognitive or developmental needs. She concluded our interview with advice for other siblings:

Um, just like don't expect them to act like you did when they are your age because they're not the same person for one. But also, they don't have the same mental and physical capabilities. So they're going to grow at different rates and have a different personality than you would normally think they would (Kirstyn).

Addressing people who may consider her sister as “less than,” Kirstyn wants to educate others on developmental differences. She believes that awareness of these differences could potentially lead to a de-stigmatization of people with cognitive or behavioral needs. Kirstyn realizes the norm and hopes to convey to others that deviating from this norm is reasonable; one should not expect everyone to adhere to specific developmental ideals. Gilly and Kirstyn’s comments can be looked at in relation to Canary’s (2008) research in which she found that “participant’s identity stories include constructions of ability, disability, individuality, and relationships...these constructions often involve the negotiation of contradictions inherent in their everyday lives” (p. 452). Gilly and Kirstyn’s contradiction is the fact that their family member is normal to them, yet defies traditional conceptions of what a child their age should act like. This theme also presented itself in parent, sibling, and grandparent narratives. As the families situate themselves through regular everyday interactions and activities, they also have to contend with cognitively, behaviorally, and medically complex situations that would render them abnormal in the greater society.

To examine the ways in which families related to their everyday experiences, I considered the “frames” that families employ to detail their lives. As described by Little (2000) citing Goffman (1974), frames are “a schemata of interpretation that enables

individuals to locate, perceive, identify, and label occurrences within their life space and world” (p. 4). I draw upon “frames” to understand how the families made meaning of their lives. Furthermore, Little (2000) goes on to explain that, “frame transformation processes take activities, events and biographies that are already meaningful within one primary frame and redefine them in terms of another frame” (p. 4). As families describe their digressions, moving along the spectrum of normality, they transform their frame of deviance into one that is their own normal, a situation that is not as bad as one may think, a situation that may even be comfortable. As families seek to portray their worthiness and avoid stigma, their conversations with me allowed them to reframe their experiences. These new frames lead to a nuanced understanding of the daily lives of people with disabilities. As families reframe their experience, they add to the understanding of the multiple lives led by families and children.

Childhood and Disability Studies

The nascent field of disabled childhood studies (DCS), borne of the melding of childhood studies (CS) and disability studies (DS), seeks to portray the multi-dimensional lives of children, representing them and their families as beyond disability. DCS ceases to pathologize people with disabilities and instead examines the richness that is their life. The lives of families have been studied in multiple ways. For example, previous research has attempted to situate families of children with disabilities in either the medical or social model. The medical model places the problems associated with deviations from the norm within the person, while the social model sees the interaction of physical problems coupled with social barriers (Green, 2007; Leiter, 2007; Skinner & Weisner, 2007; Landsman, 2005; Jenks, 2005). Although individuals with health, behavioral, and

intellectual deviations can only receive services in our current system through a medical label, researchers contest the solitary use of such a method of classification. Michalko (2002) argues that, “There is a hegemonic finality that comes with the biomedical model of disability. It advocates the primacy of the ‘natural body’ for the human condition and promotes disability as an unnatural biological condition” (p. 31). DS therefore sees an individual as more than a medical category; social barriers also affect them. However, the social model has not been without critique, with scholars arguing that by claiming people to be disabled by their environments, they have disregarded the experiences of people with impairments (Connors and Stalker, 2003; Curran, 2010; Molloy & Vasil, 2002). Colver (2006) succinctly describes the difference between impairment and disability writing that, “a normal newborn baby has many impairments compared with an independent adult—he or she is incontinent, cannot speak, cannot move about etc.... a baby has impairments but is not disabled because society and the environment adjust to meet his needs” (p. 502). Therefore, scholars like Molloy and Vasil (2002) support the “second wave of writing” in which theorists like Corker and French (1999) argue for the de-marginalization of those with impairments. Whereas the first round of DS made the distinction between disability and impairment, suggesting the focus on disability, Molloy and Vasil cite Goodley (2001), who calls for a “re-socialization of impairment that allows for accounts of both the lived experience of impairment and the ways that impairment is discursively embodied” (p. 663). DS, as it moves forward from its incipient stages of emphasis on social barriers, seeks to highlight the many ways people experience physical, intellectual, and behavioral deviations from expected norms. When considering

the lives of children with disabilities, the focus on the diversity of their experiences blends nicely with that of CS.

CS, as advanced by James and James (2012) in Key Concepts in Childhood Studies, details the history of childhood and its implications for research with children. Rather than seeing children through a developmental lens or as passive members of society, CS researchers posit the importance of seeing children as independent agentic actors who affect their environments and relationships. CS scholars seek to gain the child's voice in research, thus adding to the understanding of varied childhoods. James and James advise that a CS contribution to research has been to "assert the diversity of childhoods based on all those influences (e.g. culture, history, geography, politics, economics) that comprise the social context in which children are born and in which they grow up" (p. 41). Throughout CS work, scholars depict the ways in which childhood is "socially constructed," influenced by a person's location, time, and socio-political context (James & Prout, 1990). This knowledge of children provides invaluable information on the diversity of lived experiences and the ways in which children affect their own lives. Seeing children in this light allows a more thorough understanding of the ways in which children are marginalized, especially when considered in relation to socio-economic standing, ethnicity, and ability.

Listening to children and resisting analysis through a universal trajectory of development can result in a more nuanced understanding of children's lives. For example, childhood researchers have broadened the field's knowledge of how children's lives are experienced by gender (Thorne, 1992); context (Thorne, 2005); race (Ferguson, 2001; Lewis, 2003); and income (Lareau, 2011). The field of CS has engendered a re-

examination of the lives of children leading to a new understanding of multiple childhoods, one in which scholars re-think such topics as what it means to be a working child (Burr, 2006; Kenny, 2008) or even a child soldier (Rosen, 2005). Rather than seeing children as affected by their environment, the children that these researchers have presented are active players in their social lives (Lanclos, 2003) contesting universal prescriptions for childhood and re-creating images of what it means to be a child. Most notable, Myra Bluebond-Langner provided the foundation for CS researchers by emphasizing the importance of the child's voice. In her seminal work, The Private World's of Dying Children, Bluebond-Langner (1978) listened to terminally ill children discovering that they know much more about their illnesses than their parents realized. Contextually viewing children and examining children of various abilities has led to the most recent emphasis on children with disabilities in the field of DCS.

DCS calls researchers to focus on children with disabilities by illuminating their diverse lives, experienced through various abilities, social barriers, and ideological forces. Like the field of CS that warns against developmental approaches, Curran and Runswick-Cole (2013) make a point of noting that "concepts of child development and impairment that are applied to disabled children are not studies of their childhood" (p. 127). Childhood, as examined through DCS, reveals the many layers of experiences that children encounter, not only their digressions from expected milestones. For example, in discussing the experiences growing up with a disability, Haraldsdóttir (2013) laments that she and her family "were constantly being reminded of abnormality, negativity, defects and helplessness. There was rarely any consciousness of what we were like, our talents, progress or ability...And that not to be normal was awful" (p. 16). By focusing on ways

in which people deviated from typical development, practitioners and researchers lose sight of the many abilities that people with disabilities have to offer. DCS does not limit their work to the child; it also focuses on the family (Abbott, 2013; Runswick-Cole, 2013). Grech (2013) confirms the family focus by asserting that disability is “lived as a family affair” (Grech, p. 100). Current research has found that families negotiate their lives as influenced by the medical model and social model, while negotiating standards of normality as they journey through the world of disability. DS scholars, like Davis, seek to portray the diversity that is disability, but he argues we will be unable to accomplish this until we acknowledge the influence of conceptions of normality on our understanding of disability. Davis (1995) argues for the critical examination of normality and states, “[o]ne of the tasks for developing consciousness of disability issues is the attempt, then to reverse the hegemony of the normal and to institute alternative ways of thinking about the abnormal” (p. 1008). To understand the diversity that is disability, Davis asserts that researchers must first address overarching prescriptions of normality so that one can view the disabled through standards of humanness. To understand families, researchers argue that a multi-layered examination of families must be conducted. Halfon and colleagues (2012) write, “instead of a simple dichotomy, disability is understood as a dynamic continuum influenced by biology, social factors, environmental conditions, health services, and personal preferences” (p. 16). Additionally, Landsman (2005) and Leiter (2007) find that mothers’ lived experiences espouse the medical and social models. The mother participants in Landsman’s research are foundationally entrenched in the medical model. As they begin their journey, mothers subscribed to medical understanding of disability yet awareness of barriers and social judgments aroused sentiments in

accordance with the social model. My informant, Susan, shared ideas that corroborate Landsman's and Leiter's findings. Susan described, "Initially, as a parent it was – you know – the hope for the prognosis, because you're always – when you are pregnant there's almost no, no thought that 'oh my kid could have special needs.' You are supposed to have this normal, happy, healthy baby. And that wasn't the case and you know, coming to terms with that in and of itself was itself challenging" (Bethany's mom). Susan struggled with a disconnection between her expectations and real life. A few seconds later, Susan conveyed that she had indeed come to terms with her daughter's disability and focused on providing her with the skills necessary to survive in an obstructive environment. Susan exclaimed, "No, I want as few accommodations for her because at some point she's going to have to accommodate to the world. What happens when she grows up becoming used to these accommodations? Where does this leave her as an adult?" She continued, "I want her to be as normal as possible, as few accommodations as possible." Here, Susan's comment echoes the work of disability scholars by illustrating the influences of both the medical and social models in her life as she attempts to support a "normal" and worthy life for her daughter. Susan's daughter has a medical condition that will most likely prevent her from living independently; yet, Susan also realizes that social barriers also could potentially restrict Bethany's opportunities. Therefore, Susan seeks to teach Bethany the skills to navigate social barriers.

In applying DCS, I shed light on the lived experiences of families of children who have diagnoses that render them different than their peers. I acknowledge the ways in which families make sense of this purported difference and create their own sense of a

normal life through this difference. Using the medical and social models as backdrops to understanding the cultures in which families identify themselves, this study seeks to reveal the interplay between genetic factors and society contributing to the emerging field of DCS. The children in this study have been medically diagnosed with severe medical conditions or as having intense behavioral needs due to Autism Spectrum Disorder (ASD). At no time did any of the family members question the diagnosis or the fact that their child would be transformed if only social barriers were broken. Therefore, I argue, that it was their medical condition, situated within a society that has specific beliefs regarding what constitutes a good childhood that influenced the focus on “normal” in our interviews.

Through this work, I bear witness for the families who attempt to reveal their “normal” to me. By depicting the varied family lives that the families created, I present another aspect of childhood. As CS researchers seek to portray multiple childhoods influenced by racial, ethnic, gendered, and socio-economic backgrounds, I add to the scholarship by exposing childhood as shaped by the interplay of disability and conceptions of normality. By capturing the voice of different family members, I caught a glimpse of the lived experiences of children with disabilities. This preliminary investigation provides a lens through which other researchers can understand the lives that families attempt to create for people with disabilities. By questioning what it means to have a normal childhood, I argue my contribution to the field of CS is demonstrating that my informants prove normal occurs in diverse ways despite hegemonic beliefs of what normal should be.

My Label

As discussed above, the history of disability is replete with varying and evolving terms to describe people with disabilities. As I wrote the stories of the families, I had a difficult time assigning a term that both illuminated the unique person and respected the history and struggle that accompanies their complex medical, behavioral, and cognitive lives. As often as possible, I tried to refer to the child of interest by his/her name; however, this precluded the creation of a collective identity for the families. Although as Grech (2013) argues, “Homogenizing the experience of disability and childhood is an impossibility” (p. 98), I still had to find a common ground for the families that I interviewed. As the stories will demonstrate, their experience of disability may vary, but their negotiations of normality reveal similar themes.

When consulting the literature, I found that most DS, DCS, and British disability scholars employ the term “disabled child.” Colver (2006) argues that her preferred term is “disabled child” as the child is “disabled by their environment” rather than possessing the disability.

I felt that researchers should place the person first, as the word preceding person may draw attention away from other attributes. I wondered why we couldn’t say the *child with the disabled environment*. Although Landsman (2009) cites the importance of people-first language, she utilizes the term “disabled child.” She asserts, “The use of ‘disabled’ as an adjective has indeed become common as a marker of pride in the disability rights movement... a marker of identity” (Landsman, 2009, p. 12). Although I am quite supportive of the Disability Rights Movement and do hope to advance an appreciation of people with disabilities, none of my families claimed this as marker of identity. As a

matter of fact, none of the families employed *disabled child*; instead they used person-first language utilizing terms like “kid with special needs” and at times “children with differing abilities.” I have toyed with *person with differing abilities*, a common term employed locally by educators and people in the families’ communities. Yet this term still implied a difference, a deviation from something normal.

Since the families did not utilize a consistent label, I have chosen to use *person with diverse abilities*. I feel this highlights the unique abilities that the family member with disabilities has to offer their family and their community and focuses on the strengths of the child and that which they have to offer. As the reader will find, each of the children in this study has unique personality traits, with diverse abilities. For example, Bethany, as cited in the beginning, is a wonderful dancer. Connor can locate where he is by scratching; Alice is a life-changer; Richie is an inspiration. Children have been described by their family as having more than just a rare disorder or autism. They have many abilities that make them who they are.

Chapter Descriptions

The families in this study have been given specific situations and have to negotiate various familial shifts, professional interactions, and institutions to create a life that feels normal. Because many of the children have rare medical conditions, medical professionals cannot adequately guide the families in this story; they are working in virtually unknown territory. Even the most well respected specialist has little to offer these families. Addressing the needs of their children is trial and error in all of their stories. They create a new sense of normal that includes different friends, excludes certain family members, and may even incorporate unexpected relationships. Daly (2003) finds that families, “create impressions about who they are as a family that either support or challenge dominant notions of family stability or normalcy” (p. 774). The construction of family life plays a particularly important role in my informants’ lives as they combat stigmatized beliefs about what it means to have a child with disabilities. The following provides an overview of each chapter recounting the ways in which families react to stigma through constructing their own normality.

Chapter 1 details the starting point of this journey. As I introduce the families and discuss my use of qualitative methodology, I explore the conversations and situations that led to the focus on “normal.” Additionally, I reflect on both the giving nature of people related to the field of special education and the social capital that I developed through this study. This chapter acknowledges the importance of illustrating the families’ lives but warns that these experiences may be specific only to their individual units.

In chapter 2, I will discuss the ways in which families construct their vision of family life and how they enact this vision through their lived experiences. The families in

this study were influenced by a romanticized conception of childhood that they created through their past experiences and comparisons to contemporary models of what families and children should be. Pahl, Ray, and Spencer (2003) argue that, “The mantra-like repetition of the term ‘traditional family’ in much contemporary sociological analysis has become a substitute for critical thinking.” (p. 14). Therefore, I analyze the ways in which families have constructed their own definitions of traditional family life as it relates to their past, rural community, and middle class ideals of typical family activities. The informants in my study are well aware of the dichotomy of normal/abnormal, understanding that they can be viewed as abnormal to some. However, I argue that the families situate themselves not as one or the other (either normal or abnormal), but along a spectrum. The families highlight their engagement with everyday childhood activities; the success that they have had in “training” their child to be normal; and the ways in which they espouse traditional family values. While talking to me, the families took the opportunity to define and illustrate the ways in which their family meets societal and community expectations of normality. This is consistent with family systems theories in that each family member is influenced by prescriptions of normality thus affecting their relationship with each other and their family. As the families describe their own normality, however, this may distance them from families who do not adhere to the same constructions of family life.

In chapter 3, I highlight the ways in which family members address their departure from ordinary. The families acknowledge their deviations from the norm, but illustrate the ways in which their adaptations result in a new experience of normal. My findings are consistent with Levine’s (2005) work that argues families of children on

ventilators redefine normal. Also consistent with Kelly's (2005) findings in which she posits that, "Achieving a societal view of normality was rarely the goal; rather, parents sought to fully enact a parenting identity within the constraints and with the possibilities presented" (p. 199-200). Although the families seek to place themselves in the realm of traditional family life, they are also presented with situations that preclude them from maintaining traditional normal status. Therefore, with the circumstance in which they find themselves families create their new normal. In the creation of their own normal, they develop new roles, construct new families, and new situations that feel like home. By embracing their new ideal, they may find themselves acting in capacities that push their levels of comfort; for instance acting as a nurse or therapist or taking help from strangers (when they were raised to believe in their own self-sufficiency). Or, as one family indicated, they may even find themselves being helped by drug-dealers. Therefore, this chapter explores what happens when the family's "normal" significantly departs from their constructed ideals of family life and how the term plays out in such scenarios.

Chapter 4 provides a space for family members to not only speak to the creation of normal, but to embrace the positive qualities that their family member with diverse abilities has to offer. Responding to the lament of Singer (2002) who argues that, "the little that is known about families who perceive their children with disabilities as positive contributors to their families provides few clues about how to support positive cognitive adaptation" (p. 150). This chapter allows the reader to see the child with diverse abilities for the abilities that he/she possess that truly are diverse: from little inspirations to life changers, the family members in this chapter illuminate the "amazing" qualities that their child has to offer. Of course, this spotlight is not without incident. As the family members

illuminate how wonderful their child is, they may inadvertently negate the unique characteristics of other children who have a stigmatized label, thus perpetuating the stigmatization of the very group of people of which they are a part. Not only are there unintended consequences of seeing their child, themselves, and their community as “beyond normal,” the chapter highlights the ways in which family members must prove their child’s worth based on parental expectations of performance and standards of worth.

This work’s concluding chapter summarizes the theoretical and practical implications of this study while suggesting future research possibilities. Most importantly, chapter 5 lists suggestions recommended by family members. The advice given by family members illustrates the importance of listening to families as a way to sincerely involve them in their child’s education and to enhance the services provided to families and their children. By simply asking families to “tell me your story,” educators may discover new opportunities for engaging families as they negotiate their “normal.”

Conclusion

As I continued to hear the normal mantra, I realized that as a DCS researcher, as an advocate for children who are diversely abled, and as a voice for these families who welcomed me and sought to help me in any way possible, I needed to explore their “normal” daily lives. I needed to tell the story of not how they differed, not the oft-cited deficit understanding of the role of disability, but to provide another layer of understanding of childhood. If I did not add to the understanding of these families’ “normal,” I would do a disservice to my field, the children, and the families who believe in their sense of ordinary and family dignity. By looking at families as a unit and exploring the ways in which they counter stigma, this work brings the reader through the multiple ways in which the families use the word “normal” to understand their specific experiences.

Chapter 1: Methods

The Path: “Changing my view of involvement”

After a discussion with Carl and Isabel about the dilemmas they faced regarding medications, feeding tubes, and special diets, I learned that, for them, quality of life was much more important than quantity. In a memo to myself on July 18, I wrote: “The decisions that these families have to make is so far beyond the choice of whether or not their child is included or if he has specials instead of Math.⁴ It is amazing what involvement means to these families. Changing my view of involvement!”

My process of discovery is not unique, but is similar to the journey present in other qualitative works. I started down a path, but quickly realized that what I believed was important was not relevant in the lives of the families with whom I spoke. The day I sat in a family’s kitchen staring at an illegally procured bottle of medical marijuana for an 8-year-old boy, I knew that my study was taking on a life of its own. Going into this research, I believed I could help families by understanding how they accessed special education services and how they involved themselves in their child’s education, but I quickly found that their lives needed to be understood through a more multifaceted lens. Had I continued questioning them about institutional involvement, I would have neglected the everyday stories that the families desperately sought to share with me. The lives that they depicted involve so much more than attending meetings or chaperoning class trips.

As I stared in disbelief at a small bottle filled with cannabinoid oil in the kitchen of a home in a middle class neighborhood in a rural New England town, I understood that I had no idea what life entailed with a child with complex medical, cognitive, and

⁴ “Included” is a term used in special education to refer to the placement of a child with disabilities in a class with his/her non-disabled peers. Specials are ancillary education class such as: Physical Education, Art, Computer, and Library.

behavioral needs. I was in new territory! I left the classroom; I broke free of the constraints of trying to encourage families to become involved in their child's life. The families *were* involved. It didn't matter whether Dad attended meetings or Mom packed a healthy lunch. I saw that involvement was something that I needed to understand differently. Listening as Isabel described the method of heating the oil and determining the right dose, I knew that families had a different story to tell than the one I had envisioned. I sat in the family's kitchen, surrounded by pharmaceuticals and feeding devices, I felt like an investigative journalist, being drawn into unfathomable topics that were the everyday reality for this family: a reality that subverts national authorities to accomplish what needs to be done for their child.⁵ Not only were we discussing the use of medical marijuana for an 8-year-old, we were discussing the community support that offered to find marijuana for them—the community support that helped deliver it. The small jar contained a possible method of providing peace through his illness.⁶ I stared at the bottle hearing about the simple way that this item could be purchased if laws didn't stand in the way. I sat in awe, flooded with so many questions yet having none to ask. I drove home that night and processed the situation for about two hours. I have continued to process what normal family life is to this day.

I believe there is no better way to understand the lives of the families of this rural state than to sit and chat with them in their homes; to see their cluttered kitchens overflowing with dishes and knick knacks; and most importantly, to experience the feeling of being home. My most significant interactions took place in the families'

⁵ "Marijuana is currently categorized as a Schedule I drug under the Controlled Substances Act (CSA), Title 21 U.S.C. § 801, et seq." (<http://www.dea.gov/docs/dangers-consequences-marijuana-abuse.pdf>)

⁶As it turns out, the medical marijuana did not work for this child but the family believes it could work for others considering prescribed medications have also failed their son.

kitchens or around their dining room tables. It was there that we laughed and cried, became angry at governmental failings, and developed friendships that helped me both academically and personally. It was in the kitchen where I watched Bethany's bear of a grandfather cry over his granddaughters' accomplishments; where Javon's grandfather expressed his belief in the intellectual capacity of his non-vocal grandson; and where I viewed for the first time, cannabinoid oil. Although hearing people's stories is touted as an efficient qualitative method, I could not have captured the authentic nature and delved so deeply into these people's lives had I not been sitting and speaking with them. To people who value dinners together and random visits of family and neighbors, sharing stories in this way is their normal.

Confidentiality

Considering the delicate nature of the above information and the responsibility that I have as a researcher to protect the confidentiality of my informants, I chose to maintain anonymity to the strictest degree. I employ pseudonyms for all participants, towns, and I decided not to refer to the state by its name. One parent expressed concern over her confidentiality. I wrote in my journal after her visit, “Jess came to my office after work. She seemed energized and ready to talk. However, before she began, she questioned the confidentiality component to ensure that her name, her school’s name, and town would not be used. She expressed, “It is a small state and I know teachers all over the state!” I assured her that I would not use people’s real names and hoped that I could avoid using the name of the state. I also had to speak with my participants of the possibility of identification since many of their children’s disorders are quite rare and they live in a small state. For example, one parent, whose child is one of four diagnosed with a rare disorders in the country, realized the impossibility of keeping their identity secret; however, as a researcher I feel that it is my duty to protect their anonymity to the greatest extent possible, therefore most often the child’s specific disorder is not mentioned.⁷

⁷ The mom assured me that she is an “open book” and gladly shares her story.

Their Stories

I try to go to meetings where people are or try to read books but - you know. I read a lot of books about autism and most of the time they're done by psychiatrists and people like that and I'm thinking you have no clue unless you have done this yourself. We can do all these observations and not only that, every autistic is different (Patty).

At no time did I need to wait longer than a week to meet with families. As soon as I explained my topic to them, people eagerly invited me to their homes or offered to meet with me. Families, I found, had an intense desire to tell their stories. Often, family members would mention that they were accustomed to telling their story; that they hoped that the telling of their story would benefit others; and many wanted to provide an antidote to textbooks that purport to understand what family life is like for families with a child with diverse abilities. As the quote above from Javon's grandmother reveals, their lives are so much more complex than a "how to" manual will allow. Patty and I discussed her desire to write a book once everything has settled down a bit; she even allowed me to copy a journal that she has kept over the last year to detail her grandson's progress. Other parents also commented about their desire to log their story; their joy in recounting how far their child has progressed; or the struggle that they have endured to create a quality life for their child. One woman, Jenny, who I met by happenstance via an incorrectly typed email address, wrote an extensive and encouraging letter to me. First, she explained that I had the wrong contact information. Then, she revealed that she was a special educator out west. Jenny briefly described her encounters with families and the problems associated with special education. What was most intriguing was her willingness to help me, a complete stranger, who incorrectly typed an email address. With Jenny's permission, I have included the complete correspondence in Appendix B but I offer one

quote of hers to summarize: “Good luck with your study. I don't mean to be presumptuous, but please let me know if I can help supply you with contacts in any way. I know several families with special needs who might be willing to be part of the study.” I am amazed at the willingness of strangers to share their lives with me. I am grateful that people are eager to assist in my education; yet, I wonder if their willingness results from a desperate need to portray their lives to people who are unfamiliar with the world of disability. Perhaps the families share in an effort to shed light on both their struggles and the ways in which they maintain typical family functioning.

Although many of the families scoffed at the local support group, all were willing to support other families in their journeys: they all hoped that perhaps I would be the one to accurately convey who they are, where they struggle, and how they are succeeding. By neglecting my own research goal of understanding families’ access to services and involvement in schools, I have made the first step in telling a story other than my own. I just hope that I can do justice to the stories that the families hoped I would tell.

It is equally important to remember that the stories that were presented to me happened at a time when the families felt they were ready to talk and able to reflect on the struggles and the triumphs that they experienced in their lives. Furthermore, the stories that the families told were the stories that they specifically chose to convey about their family’s identity. Researchers like Applequist (2009) find a similar communication of family information. Employing Goffman’s (1974) concept of “frames”, Applequist describes that; “Frame analysis involves the study of key experiences individuals describe to others that represent the greater schema of experience. Goffman suggests that individuals select specific strips to convey their frames to others and the presentation is

matched to the intended audience” (p. 4). The strips, frames, presented in this study portray snippets of family life that detail the ways in which families see themselves compared to others in their community. The stories that they share define how they attempt to live up to socially constructed ideals of family life and childhood. The stories describe how they negotiate normality in their daily lives. Jesse, Alice’s mom, exclaimed, “I got hundreds of stories. I like telling stories!” This journey showed me how desperate families are to share their story both for their own processing, but also to raise awareness about the lives they are living.

As the families made sense of their identities and their family life, they navigated the world of memory which, as other ethnographers have found, are not factual pieces of information waiting to be expressed, rather they include the time, place, and emotion in which they occurred (Biklen, 2007 citing Rubin, 1996). Furthermore, as Biklen has found in her research with youth, “Our memories are related to our race, class, gender, and generational positions; that is, to powerful identity markers; they are both personal and cultural” (p. 258). The families in this study are not only influenced by the criteria that Biklen provides, they are also influenced by geographic location and experiences of disability. The memories that the families share have been constructed as they move through their rural communities and understand the support that it entails. As the families negotiate disability, their current state of progress and support surely plays into how they remember past experiences with aggressive behaviors and late night trips to the hospital. I would think that if I interviewed a family member while they waited anxiously for the doctor to report on the latest seizure or CAT scan, our conversation would not include reflections on normal family functioning or the comforting feeling they receive at the

hospital (as is discussed in Chapters 2 and 3). As the parents make sense of how disability informs who they are in relation to conceptions of normality, they create an identity informed by socially constructed memories.

Furthermore, as Emerson, Fretz, and Shaw (1995) advise, “Ethnographers do not take a member’s story as a factual account but rather as an expression of the speaker’s experience and views at a particular moment in time, to a specific audience, in order to accomplish particular purposes” (p. 116). To understand this advice in light of my study, I see the families’ stories as a way in which they choose to present themselves to me, their audience. Strength and normality play a significant role in the stories that the families tell. All of the families focused on specific events that revealed the strength of their unit. Examples such as Leila’s mom who speaks of providing full-time nursing care to her daughter who is medically fragile and Diane, who speaks in oft-heard support group expressions like “one day at a time,” directed my attention to particular events that displayed strength. Not only did the families seek to convey strength, however, they also wanted me to see their child as more than caseworkers, educators, and doctors see them; I was their chance to break free from the deficit laden descriptors that they must employ to find help and secure services. The stories that they were able to tell to me, a researcher interested in their narrative, were those of family-life and life outside the school and the hospital. To this end, families could also advance their own agenda of finding services, help, and recreational activities that were unrelated to school. Many of the families recommended different programs that they wished to create or stressed the need for quality service providers. In the case of Bethany’s grandparents, they used some of their

time with me to question post-secondary options for their granddaughter.⁸ Other agendas that parents may have possibly been advancing are the national legalization of medical marijuana and the creation of a rare genetic database to assist in diagnosing children at an earlier age, both issues in which three of the parents lobbied at the federal and state levels. Regardless of their agenda, the families shared a significant amount of time with me, welcomed me into their homes, and shared deeply emotional experiences, and for that, I am truly grateful. I plan to help advocate for the causes that the parents, either covertly or overtly, asked me to support.

Meeting the Families

At the time of our conversations, my informants had strong family units that worked together with fixed supportive roles. Despite the organized roles that the families embraced, they were still quite busy. I found many guardians multi-tasking so they could accomplish many tasks and meet the needs of many people at once. For example, two mothers came to my office and they both ate their lunch as they spoke with me. They welcomed the day out of their house yet had to fit in eating and meeting with me into their busy schedules. Similarly, I followed one mother while she walked around the perimeter of her wooded yard as her son bounced from sitting in the car, running through the woods, and standing on picnic tables. Bethany's parents were also constantly engaged: her mother walked around prepping lunch and caring for two "daycare kids." During Dad's interview, he made a full dinner of shrimp and sausage jambalaya while we spoke. Even the special educator had me on many adventures in a van moving between

⁸ Although Bethany is only 14 years old and high school extends until the person is 21, families of children with diverse abilities must begin thinking about transitioning from high school so that they may have a plan in place by the time the person is 16 years old.

two different schools and through multiple classrooms as we chatted. They all fit me into their busy lives to share their story.

The families' stories transcend disability, speaking of their family as a unit working toward their "common good." For example, Tori, a mother of two children with Attention Deficit Hyperactivity Disorder (ADHD) and one with both Post Traumatic Stress Disorder (PTSD) and Tourette Syndrome, and a husband with PTSD and a Traumatic Brain Injury (TBI), jokingly comments on their family life, "Interesting is the fact that we have all these labels yet we're able to function as a family" (Tori).⁹ Often the families alluded to their classifications as an explanation for me to see the struggle, but they quickly reflected back on their lives as a unit, not as a category of disability. The families often described themselves through strong familial relationships. For example, Javon's grandmother, Patty, described Javon's relationship with Papa: "Them two (Papa and Javon) have quite the relationship. I'm the one who does everything but those two got the relationship (laughing) because my husband raises hell with him all the time." Also, Patty discusses Javon and his thirteen-year-old Aunt Gilly: "He is waking her up by jumping into bed with Gilly and covering her up. They got their little ritual going on. Even at night time they do their own little thing and he listens to her." Similarly, Javon's grandfather comments on the strength of their family, "This is family. This is who we are and what we do." The families reveal their appreciation for each other through our interviews. Each family has an idea of what family life should be and they continually strive to accomplish that within their daily experiences. The following describes this study's three most cited families providing a snapshot view of their lives. These are the

⁹ Her husband sustained his TBI serving in the Iraq War. Tori explained that her child's PTSD resulted from missing years with his father and watching his change upon returning from war.

families that I came to know more deeply than the others, as we related personally, spent significant time together, or connected on an emotional level.

Bethany: her parents (Susan and Craig), sister (Kirstyn), and grandparents (Nanny and Poppy)

Bethany's mom was my first interview. Although I would expect this to be a daunting experience, I was more nervous navigating the town roads, fractured from frost heaves left by the icy winter. I drove through the quaint New England town bearing the marks of an old factory area. A grassy courtyard surrounded by a white fence ran the length of the town with a clock tower sitting to the north end of the park. Old, dark buildings and a few mom and pop stores lined the street. Dollar General, a Subway, and a Dunkin Donuts mark the ends of the town, capturing more business than the stores owned by local families. After the two block-long town, I turned into a neighborhood of small ranch, mobile homes. I crossed over the tracks to find Bethany's house. The house is a doublewide ranch home, big enough to comfortably house the four members and operate as a day care for a few children.

Susan, a 40 year-old woman with shoulder length brown hair, greeted me on this cold morning with a look of bewilderment and possibly fear. She skeptically looked me up and down. I reminded her of our meeting and she quickly invited me in and accepted the coffee I brought. Laundry was piled on the couch waiting to be folded, dishes sat waiting to be cleaned ("Ahh, I'm at home!" I wrote in my notes). We sat in the kitchen, the table half-full of papers, the other side ready for hungry family members.

I enjoyed speaking with Susan. She was an easy first interview. We laughed and commiserated on the struggles of having children. She provided advice on parenting,

revealing the knowledge of raising children until their teen years. She laughed easily and was comfortable speaking with me. Susan spoke highly of her parents and in-laws, sharing with me the advice that they provided as she began her journey with a daughter with diverse abilities. Although she exuded a calm confidence when speaking of her daughter, she also described herself as a “Mama Bear” when it came to her two daughters, especially when seeking services for Bethany. Susan had a difficult life, revealing the struggles of a working-class family in this small New England town. Despite the hardships, she maintained an air of optimism and approached each day as it came, often referring to the motto of “One day at a time.” She was frequently interrupted by her daycare charges who were eager for her attention. We talked while she made lunch, fed the children, and directed them to prepare for leaving. She is a busy woman, but eager to share her story to help others and to speak of her daughter, her challenges, and most importantly how amazing Bethany is.

Bethany, a fourteen year-old girl, is as unique as her medical condition. Possessing a rare genetic disorder that less than 100 people in the world have, Bethany was not expected to live past puberty. Exhibiting cognitive, physical, and social challenges, she has been perplexing her doctors since birth. One doctor had to consult his medical school textbook to understand the disorder; unfortunately the one paragraph that the text provided was insufficient in helping the family. The doctor said that he would get back to the family once he knew more. Mom jokes that fourteen years later, she is still waiting! The family takes each new manifestation of the disorder in stride, treating specific symptoms as well as they can, providing medicine, and following dietary guidelines. Despite the myriad challenges Bethany faces, according to her family, she is a

one-of-a-kind personality, charming people wherever she goes and marching to the beat of her own drum. Mom recounted a story where she demanded to wear cowboy boots to Physical Education class so she could teach the class to country line dance. Bethany is a cute young girl, about four feet tall with brown eyes that show years beyond her numerical age. Academically and socially, Bethany behaves as a kindergartener, struggling to read and eagerly seeking the family's attention. At one point during my visit with her dad and sister, she came out in a bathing suit (about three months too early!). From my interactions with her, her family, and watching her during a dance recital, one can easily see the joy she receives from dancing and entertaining others. Her grandmother also describes her as exceptionally compassionate, seeking resources to help students in her class who are struggling more than she is. Even though Bethany is a fun young woman who seems as easy to get along with as her mom, she has very few friends. Bethany's dad, Craig, explains, "No one ever calls and asks if she wants to sleep over... She used to be invited to birthday parties, but now she's not even invited to birthday parties anymore. When she was younger she was." As disheartening as Dad's comment was, it illuminates the advocacy efforts that Dad undertakes for his daughter. Several times during the interview, when I asked if he had anything else to add, he would mention services that would benefit his daughter: a friendship club with sleep overs and a local Special Olympics cheerleading team.

Craig's ideas for his daughter took into consideration her interests and what she may need socially. Although Craig, a middle aged man, strong in physicality and demeanor, is dedicated to his daughter, meeting with him was not as easy going as with Mom. When I arrived in the home for our interview, he was busily moving around in the

kitchen while Mom sat at the kitchen table. Kirstyn, their other daughter sat in the living room completing homework, while Bethany wandered around the house, at times completing homework, other times looking for an activity to occupy herself. I stood for a long time awkwardly waiting to be asked to sit or to begin conversation. I stood silently for about five minutes trying to engage the daughters or Mom. No one seemed to know who should make the first move. Kirstyn continued doing her homework avoiding any eye contact with me (“Uh oh, her interview is next!” went through my head!). I finally sat down; Craig joined me a few minutes later. He then started leafing through a catalog. Mom corrected him and he put it down. We were ready to talk! The conversation did not flow as well as it did with Susan, but she did sit next to him the whole time, often looking as if she wanted to interrupt. A few times Susan corrected him and suggested he add a few things during the interview. Craig warmed up a little when I brought up the fact that my father was also in a bowling league that met Thursday nights. We had a pretty formal interview with me following my interview protocol, and Craig dutifully responding. Craig described his role in the family as provider and cook while leaving Bethany’s school and medicine care to his wife. Halfway through the interview, Craig stopped to finish the dinner he had been cooking. He handed each family member a bowl, then, looking at me, proclaimed, “You’re here for dinner; you eat with us!” Although there is limited research regarding successful interviewing protocol in people’s homes, Abbott applies the advice of Davies (2008) who recommends that one must follow the “conventions in the place in which they have been invited” (p. 43) so, when Bethany’s father offered jambalaya, I gladly sat and ate jambalaya! As I finished the delicious

dinner, Craig responded to a few more questions anxiously waiting to be finished and to offer the suggestions that he felt would help Bethany.

Kirstyn, a junior in high school, was next. She really had little interest in speaking with me, but did seem slightly more comfortable as our conversation progressed. Mom also sat next to Kirstyn during the interview. I felt badly that I couldn't offer the family members more privacy, but it seems that they are accustomed to this. Kirstyn made it clear that she did not mind Mom being there and she didn't hesitate to embarrass or correct Mom when she felt it was necessary. Kirstyn's lack of inhibitions can be seen in the following exchange among the three of us when I responded to Kirstyn's insinuation that she could claim Mom's money for her own:

Me: I appreciate your honesty with your mom here. That's awesome! I was afraid you were going to hold back. Unless that was holding back?

Mom: Holding back doesn't really quite fall into Kirstyn's category - at all!

K: No not really! (We all laugh)

Kirstyn lightened up a bit while speaking with me, but still remained pretty guarded. During our interview, she and Bethany had a disagreement because Bethany kept pestering Kirstyn by making fun of her. They even were physically engaged with Bethany pulling Kirstyn's hair. Kirstyn made a few comments about Bethany's breath. The situation subsided eventually with all of the adults laughing with the girls. The relationship between the girls appeared to have many layers, with Kirstyn often agitated by her sister's behavior; yet she was also protective and supportive of her sister. Bethany looks to her sister as a role model. Bethany became a dancer just like her sister and is eager to hang out with Kirstyn's friends, even if Kirstyn would prefer if she didn't. Overall, Kirstyn describes her family-life positively, stating, "We always help each other.

If someone is upset, we're always respectful. Like if they're tired and they've been busy, we don't really ask them to do a lot." The respect and help that the family has for each other extends from their grandparents who work toward maintaining their belief in family and fun.

Nanny and Poppy, Bethany's maternal grandparents, are native New Englanders, both raised in big farming families. Nanny, with beautiful, gray short hair, is a fit woman in her late-sixties. Poppy, the quintessential New England grandfather, has a full head of gray hair, a bushy, gray beard, and wore a flannel shirt. Surrounded by mountains, their home is a log cabin type house that sits high on a hill, looking out onto acres of forest behind their home. Their neighborhood is home to about five houses along a stretch of two miles of road. They claim to know all of their neighbors and will talk to them daily as they ride to and from work. They are dedicated to their children, offering babysitting services that account for about four of their weekdays. They host holiday parties that offer large Easter egg hunts, big family dinners with food that will please all five of their grandchildren, and a warm hospitality that kept me glued to my seat for about three hours. In our conversation, I found them to be warm, yet not too close. They described themselves as "kids at heart" happy to have the time and the health to devote to their family. Nanny and Poppy work toward providing Bethany a life full of family activities that range from cutting down Christmas trees to baking cookies. They are proud to know her, to be this "charming little lady's" grandparents, and proud of her many accomplishments. Their love and commitment to family encouraged me to embrace the same dedication in my own family. Our conversation and what I witnessed in their home

left me inspired to make creative additions to our family get-togethers. I wore a contented smile the whole drive home.

Javon: his custodial grandparents (Patty and Pa/Sam), 8 year old biological brother (Evan), and 13 year old aunt (Gilly)

Anyways, we went to [a southern state] and got custody of the boys on April 16th. We had to borrow a car to get there and it took every cent we had to make the trip, but we didn't want the kids in foster care or maybe even Javon put back in an institution (Patty's 5/2/13 entry from the journal she allowed me to copy).

Patty called me the same day that she received the recruitment letter. She was eager to talk and assured me that they had a unique story to share. The directions to their home did not include a numerical address rather Patty directed: “go over twin bridges, past flat pasture, and you’ll see a big white building, with a big porch, and a red big barn.” Sure enough, tucked away from the Main Street of their small town, behind horse farms, and backing up to a forest, sat their home upon acres of green yet muddy fields. It was an older home in need of a fresh coat of paint with a yard filled with farm machinery, a trampoline, two broken trucks, and a garden. Two big dogs barked as I walked to the kitchen door. Patty, a middle aged woman with red soft curls lining her pale face that wore years of cigarette smoking, warmly welcomed me in to her kitchen that housed old appliances, a round table in the middle, a dark tiled floor, and beautiful chimes outside of the door. This certainly was not a home from “Better Homes and Gardens”, but the feeling of happiness and hominess quickly made me feel like I was in the best house ever. The walls were lined with knick-knacks, country art-work (like flattened spoons on a piece of wood) and catchy plaques that said:

If keys missing, I've gone fishing

Life without horses, I don't think so

Kindness Begins at Home

I smiled as I took in what felt to me as quintessential rural surroundings. I asked Patty if she wanted me to ask questions or if she just wanted to share her story.

Patty quickly went into her story, speaking as if she had told it many times before. This dramatic story began only one year ago. Patty's stepdaughter had three sons and moved south with them. Two sons, unfortunately, were neglected and taken into state custody as their mom enjoyed a drug bender. As Patty recounted in her journal above, she and Sam were willing to do anything to rescue their grandchildren from the state and an abusive mother. Patty also explained in the journal that they had to start teaching six-year-old Javon "things that a one-year-old should know." She continued explaining the situation between Javon and his mother, "Pa was totally shocked that the doctor was so candid with him and he was pretty upset with what she said about Javon and his mom. No father wants to hear what a fuck-up their daughter is." Patty confided to me that Javon's mother neglected him, believing that he was "retarded" and therefore locked him in a room whenever he was home. If Javon required any care, his eight-year-old brother Evan, would provide it. In her journal, Patty describes the twenty-hour car ride home from the south:

Javon was terrible on that ride back. He tried to climb out the window. He tore apart the ceiling in the back seat of the car. He kept going after his brother, hitting and scratching and biting him...It looked like Javon was pissed off at the world and he acted like a caged animal. He always had a scowl on his face he never laughed or anything.

Unfamiliar with autism and the effects that three years of neglect and over-medication has on a child, Patty and Sam were unaware of how their lives would change. However, they each have taken a role in helping Javon and have succeeded in teaching him

appropriate behaviors and how to enjoy a family. Also included in Patty's journal is a "Then and Now" list that highlights the progress that Javon has made this year. Of particular importance are accomplishments in: communication, emotional connectedness, personal care, and most importantly, Javon is no longer abusive to his family members.

I had the privilege of meeting Javon on my second visit to their home. He is a handsome, energetic, and sweet six-year -old boy, who is about four feet tall, with dark brown skin, and short black hair. He and I had an instant connection over television and I was able to interact for extended periods of time with him.¹⁰ Although he still has limited vocal communication, he clearly explains what he wants. I enjoyed watching him bounce on a yoga ball while watching television, run from room to room trying to engage his brother and aunt, and truly appreciated his use of "pa pa pa pease" to request that I give him popcorn. As I watched him in the home, it was hard to believe that this young man was neglected and had the potential for aggressive behavior. I could see how easy it was to fall in love with him. As Patty wrote in her journal after less than a month of caring for him: "Javon is getting wicked attached to me and I am to him. He is also getting attached to Sam."

Javon's grandfather, Sam, a middle-aged man, who reflects years of physical work and cigarette smoke, made an immediate connection with Javon and was much easier to converse with than Bethany's father. Sam eagerly responded to my questions, frequently sought ways to present Javon in a positive light, and spoke highly of his immediate family. He claims that, without Patty, he would have pulled his hair out and

¹⁰ Somehow, I connected with Javon. Patty explains to someone over the phone: "My grandson-he's autistic- and we've got a lady here and he keeps bringing her in the other room, [laughter] which is very unusual 'cause usually he's got trust issues."

would be “sitting in a room talking to myself!” Sam, a native New Englander, reveals the importance of family, spending time together, and pulling together to help a family member in need. He believes that his work at a summer camp for people with diverse abilities gave him a better understanding of how to interact with Javon, but for the most part, it was a good friend who has a son with autism, his youngest daughter, step-daughter, and Patty that really helped Javon progress. Sam also highlighted the role that Evan, Javon’s eight-year-old brother played in the transition. Sam explained, “And his—his brother understands a lot of the things that we don't, you know? Growing up next to him, he knows what he wanted and kind of helped us along the way.” Although Evan is still adjusting to his new life and having to share attention with a brother that he could once ignore, Sam pointed out the many positive qualities that he has.

When I met Evan, he really did not want to interact with me. According to Patty, he despises talking to adults and won’t even interact with his therapist. The move has been difficult but he is finally making friends and enjoying school. Evan, about six inches taller than his brother, is thin with short black hair, dark skin, and deep brown eyes that seem to look past you. He and I spoke briefly. I gave him the opportunity to respond to questions or draw, however he only drew one picture, wrote down three words to describe his family, and responded to most questions by shrugging his shoulders and responding with as few words as possible. Even when I tried playing video games with him, he still appeared skeptical and yearned to be away from me. Evan commented that he does not care for his Aunt Gilly, but likes playing with his brother, watching SpongeBob, and could easily name Javon’s favorite foods. I found it interesting that even though Evan seemed to resent speaking to me and was purportedly having trouble

adjusting, he still accepts his role in the family and provides assistance when other family members need to understand what Javon wants.

Continuing the theme of helpful family members, I found Aunt Gilly to be an especially helpful young woman. She is a beautiful girl with soft white skin and long brown hair. She spoke easily with adults and appreciated her close family relationships. At thirteen years of age, her life as a partially only child (her sister is away at college) dramatically changed; yet, she seems to embrace her role in helping Javon and takes pride in his many accomplishments. Gilly commented that she is “proud that he doesn’t abuse anyone.” She explained, “When he first came we were all black and blue and he head butted me a couple of times. I was bruised everywhere. But he’s gotten a lot better. I am very proud of him for it.” Here, Gilly reveals the challenge of having two new housemates, and struggling with one who was also physically aggressive, but the hard work that she described has certainly paid off. Gilly appears to enjoy her family members and their bonding to help Javon and each other. She said, “everyone is pretty much always in a happy mood unless it’s been a stressful day but usually everyone is pretty happy! So, we always have a lot of energy and we like to improve Javon’s behavior and improve on the family.” It was relaxing speaking with Gilly and I enjoyed hearing her suggestions for helping Javon and her genuine appreciation of her parents, her sister, and her nephews – at least appreciation of Javon – she and Evan are working on their relationship.

Richie and his parents, Isabel and Carl

I met Richie’s mom at a local conference through a mutual friend, and from that meeting, it only took an email to create a relationship that would lead to connections with

the majority of my informants. Isabel and I are both in our thirties with a shared vision for children with diverse abilities, education, and child-rearing. We spoke easily, laughed often, and bonded over anger at the current system of insurance funding, medical responses to rare genetic disorders, and special education services. Our first interview occurred in my office, yet we had several encounters over meals, at her home, at local support-group meetings, and driving long distances together. Isabel is a caring mom and helpful friend. She has mentored several parents who are new to the world of cognitive, medical, and behavioral needs. Isabel gives of herself to many and in turn has many people that support her, her son, and her husband. Although she recently left her job as an EMT to take care of Richie full time, she still has little time for herself as evidenced by her joy to leave the house to meet with me and eat a sandwich. She sat in my office, happily chatting about her son and their journey. She has a soft young face and speaks with thoughtfulness and care. We easily engaged in conversation for two hours; she only left because her respite care provider had limited hours to offer. Isabel and her husband agreed that she would handle Richie's daytime care and insurance payments, which has turned into a full time job since Richie has regressed over the past year. She must carefully manage her son, his feeding tube, and his seizures, while negotiating the complicated world of insurance. Between that and Richie's multiple therapies, Isabel says they are a very busy family!

Richie, an adorable eight year old with big brown eyes, and a personality that shines through despite his lack of vocal communication, is one of seven people in the United States and one of twenty people in the world who have his particular genetic

disorder.¹¹ Isabel explains that it is a degenerative disease that will continue to diminish his functioning. At one time he had the ability to walk, talk, and eat by mouth, however these abilities have since disappeared.¹² Richie completed two years of preschool, and one year each of kindergarten and first grade spending the full day at school. However, now, a second grader, he must receive educational services at home since he does not possess the immune system to fight childhood sicknesses. He does communicate with his peers, who he has known since preschool, via Skype. The students enjoy reading to him and showing him the work they've been completing in school. He, in turn, participates by sending holiday cards and attending the occasional field trip. Richie is an easygoing boy who enjoys watching cartoons. He moves very little but has a way of drawing people to him. When I met him, I held on to Richie's hand for a few minutes, enjoying the soft connection; ignoring the fact that it probably is awkward to hold an eight year-old's hand! No one said anything as I sat on one side holding his hand and dad, Carl, sat on the other, snuggling into his son. Carl seemed lost in the moment as I did, both slowly realizing that we had a conversation to resume.

Carl is a sweet man, also in his thirties with a soft boyish face. He works several jobs to support his family and works as a volunteer firefighter to support his community. Carl has deep roots in the town, having attended the local Pre-K-12 school that his son attends. His sister and parents live close to him. He speaks of self-reliance but also knows he could not provide as much for his son if it were not for the generous financial and emotional support of his community. He spoke slowly and hesitantly seeming as if he

¹¹ There could be more cases; however, there are currently no databases that include symptoms of rare genetic disorders. This is something that Isabel and other mothers in my study have lobbied for in Washington D.C. Richie didn't receive his diagnosis until he was seven years old.

¹² He started walking again this month but the doctors are not hopeful that this will continue since there were not treatments that led to it; it just started happening.

didn't want to give me the wrong answer. The first part of our interview was pretty formal. I asked questions, he cautiously responded with short answers. We ended the interview with the basics answered and then Isabel entered the room and questioned a few responses; this jarred Carl's memory and we began a second interview, this time slightly more relaxed. This happened one more time (I was now late for dinner at my own home). When finished, I retrieved my jacket, and slowly said goodbye as Isabel received a package from the local pharmacy containing one of Richie's five seizure medications.¹³ Somehow, the conversation began for the fourth time, this time much more relaxed, around the breakfast bar and as discussed in the beginning of this chapter, around a small bottle of cannabinoid oil. Oddly enough, this is when the conversation became very relaxed. Carl questioned me, "You're more or less studying the schooling, right?" I responded:

Well, I was. I am (I say without conviction). That's the joy of this study (I say with regained composure), wherever the interest lies of the family that's the road I am going to go down!

Carl and Isabel consulted with each other in whispered voices and then the conversation began relaxed, informal, and full of information about medical marijuana, community support, and having to choose between quality and quantity of life for their young son. It was as if the idea of discussing schooling frightened Carl since he was only minimally involved; however, once we began speaking about medical, physical, and even illegal issues, Carl relaxed. He was discussing an area that he knew best: his son's physical well-being and the great lengths that he goes to provide a quality life for him. I left that night, well past dinner, about 9pm. I drove down the mountainous windy road looking out over

¹³ According to his father, Richie has a seizure "every second of his life."

the valley below, wondering and trying to process. As I said above, I knew then that I was embarking on a different journey.

The Families

As a researcher in the field of Childhood Studies (CS), I grappled with not including the voice of the child with diverse abilities; however, my work in special education, which employs FST, permitted me to break free from the constraints of only looking to the child. My time spent with the families, watching their interactions with each other, and observing their child in school yielded a preliminary understanding of the child and their interactions with their world. In the future, I hope to continue my relationships with the families and begin to build relationships with the child of interest. There are a few voices of young people present in this study but for the most part, it includes the voices of parents, grandparents, and professionals who care for a child with complex behavioral, medical, and cognitive needs. The children in this study varied in intensity of need: yet most of the children were non-vocal and at the time of the study were not consistently using any type of augmentative communication device. As a special educator who has gotten to know and understand children without vocal communication, I know, that with time, it is possible to capture their voices. Yet this study focuses on a foundational understanding of the families, an understanding of family life from those with vocal communication. Once this work is complete and I have an understanding of the every day lives of families and the concerns that family members have for their family members with diverse abilities, I will return to the work to try to capture the voice, the feelings, and the interactions of the child with diverse abilities. Until then, the reader must realize that this work shares the thoughts, feelings, and aspirations of family

members of a child with diverse abilities. At times family members speak for themselves, at times they speak for their child, and at all times they are representing one input of a family unit whose functioning depends on each of its component parts.

Whether it is to achieve a particular agenda, share a troubling story, or even the power to share their family's accomplishments, through interviews, virtual focus groups, analysis of an Individualized Education Program (IEP), a personal journal, family observations, class visits, attendance at local support group meetings, and attending a dance recital, these stories led me on a journey through the lives (or at least the snapshot of lives) of some amazing families. In total, I interviewed twenty members across thirteen different families. I interviewed every mother except in Javon's family (as noted above, he lives with his grandparents). The following, categorized by children's names (with ages in parentheses), details the participants that were interviewed in each family and the familial support they receive. The service providers are listed by their names.

Bethany (14): Mom, dad, sister, and grandparents. Parents are married with paternal and maternal grandparents living close.

Javon (6): Custodial grandparents, thirteen-year-old aunt, and eight-year-old brother.

Javon's Aunt who is in college did not want to be interviewed but she plays a supportive role in the children's lives. She often babysits for Javon and takes him on long runs.

Alice (12): Only interviewed mom, Jesse. Though her aunt offered an interview, a meeting was never established. Alice's 2 female siblings were not asked since the family does not discuss the fact that Alice has Autism. Dad did not want to be interviewed as he has a severe distrust in school personnel.

Connor (7): Interviewed mom, Hillary. She and Dad had recently divorced. Although the divorce was amicable, and I met Mom at Dad's home, I was unable to connect with him. Connor passed away nine months after our interview. The lives he touched were evident by the many people who attended his service.

Kam (9): Interviewed mom and had a few comments from grandmom who sat in the other room watching her three grandchildren. They have a very large supportive family all within 10 miles of their home.

Leila (2): Interviewed mom, Heidi. She and dad had divorced before Leila was a year old. Heidi's mother and grandparents live about an hour away. Mom has a boyfriend who has been supportive especially in her quest to nationally legalize medical marijuana.

Patrick (9): Interviewed mom, Dori; dad was not interested. The parents are married and the father's sister and parents live close and are very supportive. As a matter of fact, Patrick's aunt worked as a special educator in his school.

Richie (8): Interviewed mom and dad. Dad's family lives in the same town and provides support through fundraising and providing brief babysitting services. Richie's paternal grandparents do not feel comfortable babysitting for long periods of time.

Deker and Elijah (19 & 21): Interviewed their biological mother, Rachel. I attempted to interview Rachel's wife, Sandy, but we were unable to connect before they adopted their new baby. Rachel explained that her ex-husband was involved in the children's lives as well but did not offer to connect me with him. Sandy's family has been especially supportive of Deker and Elijah. Rachel's family lives in the mid-west.

Derek and Devon (15 & 17): Interviewed Derek and Devon's mom, Tori. Their father has a TBI and PTSD from military service; he was not interviewed.

Sharon and Phil (14 & 17): Interviewed their mother, Diane, who has no biological family in the area. Her husband was arrested and she did not indicate where he was currently.

Service Providers: Ms. Alman and Dorothy. Ms. Alman taught Javon and Bethany in a local public school. Dorothy works as a parent advocate in the community. She knew many of the families that I interviewed. They both use their experience as parents of children with diverse abilities to inform their practice of helping other families.

The Study

Recruitment

Convenience sampling and snowball sampling allowed me to connect with families in the area who were involved in special education. Convenience Sampling as described by Morse (2007) connects the researcher with “available” (p. 235) participants through soliciting informants through advertising or from organizations. Snowball Sampling, then, uses the initial contacts as a way to meet other people involved in the same area of interest (Morse, 2007). Being new to the area but working in the field of special education, I first reached out to the only connections that I had: acquaintances of colleagues, two teachers at the local school district, and one woman at a local family organization. Of the five families that my colleagues recommended, only 1 responded. I asked that the teachers send a recruitment letter home with their students (See Appendix A). One teacher felt uneasy asking families to participate; however, the two families that responded from the other teacher called the same day that they received the letter.¹⁴ We set up meetings immediately; I was to go to their homes the following week. The most important connection, Richie’s mom, Isabel, I met at a conference for local families and providers; we were introduced by a mutual friend, Rosalind (Rosalind is my son’s classmate’s mother). The remaining informants responded to pleas from Isabel on Facebook and via text. As my study focused on relationships within special education, I chose not to single out a specific label of disability; rather, I sought any child who had an

¹⁴ The low response rate is consistent with previous studies that have attempted to recruit families of children with disabilities through schools (Canary, 2008, citing Connors & Stalker, 2003, p. 442).

IEP.¹⁵ However since Isabel, one of my first connections, has a child with significant medical and cognitive needs, many of her friends' children fell into that category. There were a few children who faced less intense social and academic challenges but the majority of the family participants in this study have children with significant medical, cognitive, and behavioral needs. When I realized that my informants were mostly parents of children with more significant challenges, I sought out informants that were related to a child with complex medical, cognitive, and behavioral needs. Morse advises that, "Participants must be experts in the experience or the phenomena under investigation" (p. 231). Experts in this case, then, were parents who had children with rare genetic disorders, were chronically ill, and/or had significant behavioral challenges. Reflective of the homogenous racial profile of this small New England State, every participant in the story is white, except for Evan and Javon who are black.¹⁶ The families varied little in socioeconomic status; most were working class, some closely bordering middle class while others, like Diane and Leila's moms, lived at the poverty line.

The Interviews

We cannot observe how people have organized the world and the meanings they attach to what goes on in the world. We have to ask people questions about those things. The purpose of interviewing then is to allow us to enter into the other person's perspective (Patton, 2002, p. 341).

To understand the ways in which families negotiated the world of disability, I chose qualitative in-depth interviewing: "conversations with a purpose" (Marshall & Rossman, 1999). Participants were given the opportunity at the beginning of the

¹⁵ A child can receive an IEP if they meet 3 criteria: they have one of thirteen classified disabilities; their disability affects their educational performance; and they would benefit from special education services. A team of professionals and parents create an educational program that will help the child progress socially and academically.

¹⁶ According to 2011 data, New England white residents make up 95.3% of the population (<http://www.nebhe.org/thejournal/trends-indicators-demography/>).

interview to tell their stories or to respond to questions. Some went right into their stories while others needed a few questions to prompt responses. The 2 fathers, 2 grandfathers, teenaged aunt, and 2 siblings that I interviewed felt more comfortable being asked questions (see Appendix C). The mothers and grandmothers that I interviewed only seemed to need a few questions to begin and then their stories took off winding around a narrative of family, school, friends, failures, and triumphs. Rarely were there long pauses or moments of awkward silence. If we ever hit a lull, I would ask another question. Also, one parent was particularly concerned with me completing all the questions that I had, even though she really was only given 3 of the 20 questions in our three-hour conversation! Although we engaged in emotional conversations and I had a difficult time processing many of the struggles that the families faced, I enjoyed the time that I spent with every family member.

Researchers in the field of disability have chosen qualitative methods as a way to capture the experiences of families with a disability to more accurately reflect the complexities of family life. For example, Green (2006), a mother of a child with Cerebral Palsy, recognizes the contemporary view of researchers that suggests that raising a child with a disability is either black or white; she however argues that her “personal experience is much more nuanced and complex than the current body of literature would suggest” (p. 152). Therefore Green employs a mixed method approach, utilizing data from a survey and interviewing family members with a child with diverse abilities. McKeever and Miller (2004) also sought to capture the voice of the family through the use of unstructured narrative accounts, structured interviews, and observations to address how maternal care givers interact with their community.

Qualitative methods allow for a more nuanced understanding of family life, one that does not include causal relationships of disability on family interactions. Studies that try to examine the role of medical and social conceptions of disability like Landsman (2005) and Leiter (2007) and Skinner and Wisner (2007) will lead to a more detailed understanding of family life, thus allowing us to, like Solomon (2012) advises in Far from The Tree: “expand our definitions of the human family” (p. 6). In interviewing families, I discovered the need to address this socially prescribed definition of family life since the data that emerged from this study reveals that families’ conceptions of normality influence their interactions with each other and their community causing them to enact what they perceive to be normal activities, to create their own normal, and to judge how their child transcends normality.

Location, Location, Location

When I started my study, I was grateful to conduct my research relatively close to my new home in a small New England state. Location proved not only beneficial to my ability to conduct interviews, it also proved a salient feature in family life. Most of the families have deep roots in the state, which is highly prized among these native New Englanders. The families believed that their upbringing in this area contributed to their understanding of people with diverse abilities. One set of grandparents, for example, explained that “farm families and communities” encouraged them to accept people for who they are and allow them to embrace the lives that were given to them. Nanny described growing up on a farm, “it was a lot of hard work but a lot of fun, simple things. You don’t need expensive things to do and have fun and relate.” I then asked, “So, do you think working on the farm prepared you?” Poppy responds, “yes” while Nanny adds,

“for life’s challenges.” Life’s challenges whether they are financial, personal, or medical are always present; farm life prepared these grandparents to work with any situation. In his analysis of rural communities, Bruce Mallory (1995) explains the difference between rural families and those in urban and suburban areas, “families with a history of dealing with difficult circumstances, such as those living in poverty, are more likely to take the presence of disability in stride and make the necessary accommodations, compared to middle class families whose lives have been relatively protected, comfortable, and predictable” (p. 15). The families in this study knew many hardships in life from losing their life savings to losing friends at young ages; disability was simply another life challenge to which they adjusted. Although their rural background was only one aspect of their multi-dimensional lives, adhering to perceptions of rural principles such as dedication to family, valuing community, and hard work, proved a guiding force in many of their lives.

Not only did caregivers feel prepared to raise children through living a rural life, they also felt that the natural surroundings and small town benefited their child. The one family that I interviewed who were new to the area also appreciated the benefits of living in a small rural town. In our virtual forum, she commented:

*My daughter loves the outdoors. She loves the flora and fauna and the huge amount of open space in [our state]. I do not believe that she would be happy in an urban concrete laden world. She loves the serenity where we live. She likes to hike and skip stones. This relaxed environment is very beneficial for her. I believe that it also beneficial for my son, as he does not feel the pressure of a more populated state. He enjoys the peace and quiet that he has in our neighborhood... Additionally, because [our state] is more relaxed, it is not as competitive as some of the bigger states. This is good for both of my children. They are accepted just as they are and appreciated as the children that they are.
(Diane).*

The families in this study recounted similar experiences as Diane, embracing the warmth of community and nature that living in their rural towns provided. They feel that they are accepted and can better serve their child through living a life where you can “skip stones” on a lake and talk to your neighbor. This sense of community, according to Flora and Flora (2013) involves “a shared sense of place.” They continue, “This sense of place involves relationships with the people, cultures, and environments, both natural and built” (p. 9). The families in this rural area believe that their natural surroundings benefit their children as hiking, snow activities, and acres of land occupy their children from day until night. Even the children who are currently too sick to partake in outdoor activities were at one time encouraged to spend many hours outside. Additionally, the families speak highly of the strong community of family and/or friends that they have created in their towns. As Diane reveals above, the area provides an atmosphere of acceptance and appreciation for who they are. According to Howley and Howley (2014) these relationships stem from the community’s focus on the “common good.” They explain, “the social priority in community is interdependence whereas the social priority in society is unilateral independence” (p. 36). Although self-reliance may be a prized goal in rural communities, community members are willing to support each other as they work toward that shared goal. Families in this study have benefited tremendously from the sharing and generosity of community members who care. The values and sense of community upon which the families believe rural areas are built evidences itself throughout the stories as families negotiate their role in a world governed by norms. In the following chapters, I will examine the influence of rural community on the families’ lives while demonstrating

the challenges of the rural idyll as well as the disparities found in the support received by families with a child with medical needs as compared to a child with behavioral needs.

Social Capital

Reiterating the theme of the “common good,” Carl, Richie’s dad, described the relationships in their local public school that serves students from Pre-School to 12th grade: “Yep it’s a big family. It’s 300 something odd family members! Everybody takes care of their own and that’s impressive too.” Not only is this illustrative of Carl’s rural mind set, it speaks to Putnam’s description of New England’s high social capital. Social capital has been described as a community resource based on social trust and social networks (Putnam, 2001). To determine social capital by state, Putnam drew from a multi-disciplinary array of research to gauge: membership in organizations, participation in civic duties, volunteering, time with friends, and the amount of trust one has for others. From this, Putnam found that all of New England ranked high on its social capital index. Considering Putnam’s study is now 14 years old, it amazed me that social capital still remains high and is enacted so readily in this rural community. As I will discuss in the following chapters, Carl, an active community member, reaps the benefits of his “300 member family” as they often provide moral, financial, and at times “medical” support. Although I was eager to explore Putnam’s findings as they related to accessing special education services, I quickly discovered that *my* burgeoning social capital would play a greater role in this study than it appeared to play for my participants. Leaving an area where I had high social capital among families with children with diverse abilities, I was

worried that meeting new families would pose a problem to my study.¹⁷ How would I find people to interview? Would people be willing to share their stories with me, knowing that I was not affiliated with a school district? Would I be welcomed into the families' lives as a flatlander?¹⁸ However, it only took one conversation to realize that the work I was doing was considered among these rural people as the "common good"; therefore, the community of families tended to assist me in any way possible. I wrote the following memo in my journal after a text conversation with Richie's mother, Isabel, in which she notified me that she had placed a post on Facebook about my study and had heard from 8 people within 3 days: "People are just so willing to help. Is this about my social networks or theirs? Would this be happening if I were in another profession?"

My Identity Outsider/Insider

Increasing my social capital through this journey has introduced me to a different culture of family life, one where lives must be lived day to day, where death and sickness are a very real presence. Although I, too, am a parent and have been involved in the world of special education for twelve years now as a teacher, an advocate, and a friend; the world in which I have immersed myself for this research was foreign to me. Not only am I an outsider as a flatlander, I am an outsider mother, and an outsider to what it means to be involved in school. As a flatlander, I was unaware of the social support that the families expect and have been raised to embrace. I also learned quickly the benefits and disadvantages of living in a small state. All but one of the families was native to the area

¹⁷ I had just left a state where I had worked as a special educator for 8 years and had truly immersed myself in the culture.

¹⁸ According to urban dictionary: A flatlander is a "term used in the mountains to describe people from lower elevations" (<http://www.urbandictionary.com/define.php?term=flatlander>). I have heard this term several times since moving to New England in both convivial and slanderous tones to describe people from non-mountainous states.

and had strong networks of support. It wasn't until I began researching rural communities, that I was fully able to appreciate the sense of community and family that is part of these families' everyday lives. My outsider status however did have its benefits since many of the families wanted to share with me the joy of their rural lifestyle and the successes they achieved. And of course, the one participant, Diane, who was from New York, viewed my status as an outsider with compassion. Both of us bonded over our outsider statuses knowing that we would never be considered true members of the state no matter how long we lived here. Although we are accepted as we are, our relationships with people who are native to the state may always be distanced.

Having spent twelve years working with children and parents involved in special education and befriending many of the families, I have learned how to develop relationships that respect the family and highlight the ability of the child. One mother that I have known for 8 years adamantly advises, "Never tell a parent with children with disabilities that *you know* what they are going through!" I have applied this to my work as a teacher and a researcher and I try to listen with empathy and without judgment. As a mother, I could relate on many parenting aspects yet behavioral and medical concerns eluded me. And at times I felt like just another person gawking at the family and the ways in which they proceeded through their lives. For the most part, the conversations flowed easily and I feel as if I developed lasting relationships with many of the families. There were, however, moments of discomfort and silence especially when we discussed children dying or life after high school when life options are limited for people with cognitive, medical, and behavioral needs. I found interviewing the siblings to be the most challenging aspect, especially with Evan. To him, I was another person talking about his

brother, trying to elicit information about their personal lives. Kirstyn, though polite, also seemed disinterested in my questioning. To the siblings, I was certainly an outsider, too old to understand their feelings and too removed to understand their family. Being raised to respect their elders and politely respond to them definitely benefitted my study as they dutifully responded to my questions and provided insight into their lives. Overall, the study helped me to examine who I was professionally and personally. I feel as if I learned as much about my life philosophy, my relationship with community, and my relationship with family as I did about my informants' lives.

Reflexivity

As I mentioned above, I felt most connected with Bethany, Javon, and Richie's families. With Bethany's family, their easygoing nature, welcoming dispositions, and eagerness to help Bethany led to many conversations and opportunities for engagement with multiple family members. Similarly, Javon's family was so intent on seeing him succeed that they were willing to speak with anyone. They often sought answers to perplexing questions and hoped to have their story heard. Richie's parents, also advocates for their son, are active in telling his story whether to a class of college students, at community events, or at conferences. They are well versed in their story. This helped begin our conversation however their easy going personality and our shared parenting beliefs and love of the ocean added to the connection that we had with each other. We have maintained our friendship throughout this writing and I believe we will continue after the project has ended. It is this friendship and my reflection on my work that has me continuously asking myself, "Is this the story that the families intended to be told?" To uphold my duty to the families, I analyzed and re-analyzed conversations, memos,

journals, notes, and the completed drafts of this work, compared them to the growth that I have experienced and the biases that I may have as a parent and an educator.

As an educator, I believe in reflexive practices, calling for a reflection at the end of each day to better enhance my lectures. I preach to future educators the importance of understanding our biases before entering a classroom, and being mindful of these biases in our interactions with children. In an attempt to bring reflexive practices into my research, I continually stepped back from my work and questioned, whose agenda am I advancing? As a mother, I have a heightened sense of what is and is not perceived as normal; perhaps my own beliefs of how people react to my children, my parenting, my “stay at home dad” husband have somehow influenced me to focus on how other families are interacting with social conceptions of normality. By reflecting on my biases, the themes that emerged, and other researchers who have found similar trends, I have made an effort at maintaining the perspective of the families.

The Data

Every interview was audio-recorded. I wrote down a few notes during our conversations but mostly listened. Within two months of interviewing the families, I transcribed the interviews. For one interview, I used a private transcription service, however financial constraints precluded me from continuing with the service. Although transcribing the interviews proved a time-consuming process, I felt more involved and closer to my informants after listening to our interviews. After transcribing, I coded for themes using “track changes” in which I highlighted specific sections for themes that I had intended to find and ones that I hadn’t considered but continually manifested. According to Emerson, Fretz, and Shaw, I employed both open and focused coding. First,

I went through the transcriptions noting, “any and all ideas, themes, or issues they suggest, no matter how varied and disparate” (p. 143). From that initial coding, I re-read the transcriptions looking for specific themes like: description, involvement, support, family, friends, nature, normal, advocacy, Tao, personnel, and suggestions.¹⁹

After transcribing the interviews, when I understood what themes were the most relevant, I invited my participants to join a virtual forum in which I asked them questions to support my findings. As of this writing, only two families responded. This small rate of participation is consistent with what other researchers have found when working with families with children with diverse abilities. Abbott (2013) writes, “in practice, families were generally willing to give up one chunk of time to take part in the research, but reluctant to offer more” (p. 43). The families that did respond however, really believed in the idea of normal. When asked the question:

QUESTION 1: Although I set out to explore special education, I found that your lives were so much more than just about school. Many times people highlighted their normal family lives. Am I correct in this? Do you want to add anything?

Diane responded: Absolutely correct. Although living with children with varying abilities has its challenges, providing them with the most “normal” home life is what I work toward. Helping my children be happy in whatever they accomplish is my goal.

While Tori answered: Most Definitely! Our children are our life! This goes well beyond education. For example, last weekend we attended the Vermont Winter Special Olympics and Derek skied and received 2 silver and one bronze medal and Devon snowboarded (first year) and received three Gold medals! They had excused absence from school for this!! Doing things as a family and being involved with others in our situation is a wonderful thing!

I also kept a journal in which I recorded field notes to provide space for, “active processes of interpretation and sense-making” (Emerson, Fretz, and Shaw 1995, p. 8). I

¹⁹ The theme of Tao resulted from a belief that my families possess a Taoist philosophy to life and disability. In February 2015, I gave a presentation in which I compared family interactions with Benjamin Hoff’s “Tao of Pooh.”

usually recorded the field notes in my car, using Google docs so that I could access from my computer, phone, or iPad. I never waited longer than a few hours to record my thoughts on an experience with the families. I also kept field notes of my meeting attendance, conference attendance, and recreational activities with the families. One family shared an IEP with me, another their personal journal. To manage different themes that surfaced throughout the interviews, recreational activities, and analysis of paper work, I used memos.

The memos allowed me to connect with theoretical constructs that helped me position my findings among those from other scholars thus providing a starting point of analysis for the themes that I found. This grounded theory approach allowed me to “discover” (Emerson, Fretz, & Shaw, 1995) alternative theories than those that I had originally proposed. Although I came to the work with a foundation in CS and FST, I realized that theories regarding rural community, stigma, and disability studies were integral in understanding the lives of the families with whom I spoke. Being guided by the themes that the families presented allowed me to thoroughly examine the nature of their stories and the ways in which their interactions with their families, friends, and community may be influenced. Grounded theory allows researchers to be guided by the themes that their informants present. Originally posited by Glaser and Strauss in 1967, grounded theories, as described by Strauss and Corbin (1998) “are likely to offer insight, enhance understanding, and provide a meaningful guide to action” (p. 12). By viewing the families not only as a system but also through the lens of stigma and DCS while remembering their roots in rural community, I felt adequately prepared to address the themes that had emerged in my data.

Validity

Although finding the truth in any story may be a fool's errand, the information that I present in this study are from the stories that the families chose to tell so that they could define themselves and their families. In an attempt to triangulate my sources, hoping to reveal a common interpretation of family life, I tried to observe the families in different settings, analyze paper work, and discuss their lives with multiple family members and service providers. Even though my online forum only yielded two respondents, the two that did respond, confirmed my findings. Additionally, when I discuss my findings with other families of children with diverse abilities or with people who are navigating what normal means to them, the themes that I have found resonate with them. One mother, for example, commented that, "we need work like this to tell us that we are not alone." After my presentation comparing The Tao of Pooh to these families and their "normal lives," two men thanked me for discussing what normal is. They had been influenced by conceptions of normal all their lives: one grew up as a Jehovah's Witness; the other grew up as a female. They asked that I continue discussing these topics so that more people would understand. And finally, one sister who also heard the presentation told me that this was exactly what her family found as they raised her brother with Down Syndrome.

Generalizability

The families in this study were chosen because they were interested in sharing their stories, which certainly limits the generalizability of my study. Furthermore due to the limited range of participants and unique locations (in terms of racial composition and remarkably high social capital) I do not propose that this study will be generalizable to

the broader population. However, it provides an in depth view of how families of a particular location negotiate conceptions of normality. Examining the ways in which family members interact with each other also provides a nuanced view of family interactions with disability. Since all families are unique in their relationships with each other, I do not purport that this study will be generalizable to all families. However, since conceptions of normality pervade various aspects of family life, this study may resonate with more people than I had originally intended. The following chapters outline the ways in which families define themselves through conceptions of normality, create their own normal, and view themselves as beyond normal when considering the abilities of their family member with diverse abilities.

Chapter 2: What's Normal? Countering Stigma by Adhering to Constructed Images of Family Life

Being Normal

Nanny: We have a motorcycle in the garage and Bethany has her own helmet that we bought for her in her favorite color, yellow. She takes that and her little white trim jacket and because she tremors, Poppy puts a seat belt on her to help her settle down...She absolutely loves it when Poppy goes to school to pick her up!

Me: Wow that is cool. That is really cool! (I say looking into Poppy's crystal blue eyes.)

Poppy: (A pensive man, saying very little, lights up) I go up one step every time I do that!

As I sat in Bethany's grandparents' home, I could feel the warmth of family surrounding me. The sun shone in the back sliding glass door, giving the home more light than one would expect from the wooded walls, ceiling beams, and floor that surrounded the kitchen. The pictures of children and grandchildren covered the wall in front of me. To my left, I noticed a door looking out onto the mountains; behind me, a large kitchen; and to my right, a wall donning signs about family and happiness. I felt instantly comfortable with Nanny and Poppy, even though they seemed unclear about why I was interested in speaking with them. I tried to explain my study as well as I could but just asked them to talk about their roles, the support they provided, and stories of Bethany. Nanny, a slender woman in her late sixties with short gray hair, spoke most of the time, using my name often, which made me feel like I knew her much longer than a few hours. Poppy's puffy white beard and full head of white hair epitomized a New England farming grandfather with sun kissed skin and an easy smile. He said very little; but when he did speak, his slow, carefully chosen words in his deep New England accent revealed a

strong love for his family. Nanny and Poppy started our conversation explaining that they love all their grandchildren the same and provided assistance through babysitting and attending to the interests of their two children and five grandchildren. When they spoke of Bethany, they highlighted the many activities that they enjoy doing with her. Bethany, they often reminded me, engages in the same activities as their four other grandchildren. Even though they may provide extra assistance to Bethany, she is required to partake in all family interactions.

This theme of participation manifested itself through my interviews with other families. Guardians, siblings, and extended family members highlighted the ways in which their child, considered abnormal by standardized educational and/or medical lens, engaged in what they considered to be typical childhood experiences. For example, Javon's aunt animatedly detailed times that she and her friends brought Javon on four wheeling adventures; the moms of Richie and Patrick eagerly listed class field trips as one of their child's favorite outings; and Tori, Derek and Devon's mom, fondly described her sons' comfort in the woods, fishing and building forts with their father. My informants attempted to convey to me that their families did indeed fit into "normal" family functioning despite their stigmatized label. From private engagement in family activities like sewing, eating dinner, or enjoying television together to public participation in community events, outdoor activities, or trips to museums, family members carefully presented their family life to me. They explained that they were more than their child's disability. The families were able to engage in the same activities as surrounding families. They too, they asserted, valued the same family time as their local culture. Interpreting the families' depictions on a spectrum of normality, this chapter

underlines the ways in which the families described what normal means to them: how they've constructed what typical family life should be, how they applied that to their own family, and what this may mean for their children.

Throughout our conversations, families continually highlighted the daily activities in which they engaged to create what they considered to be “normal” family interactions. From grandparents to siblings, the families constructed visions of a typical childhood based on their own upbringing, their location, and middle class ideals. Their memories of family time as well as the perceived interactions of neighbors and extended family members influenced how the families illustrated their experiences to me. Ideals about childhood permeated the families' lives in such a way that my informants felt it necessary to share with me the ways in which their families adhered to a particular standard of family life. The families have been ruled by expectations of normality as they negotiate their family members' diverse abilities.

Challenging the stigma associated with complex medical, cognitive, and behavioral needs, the families in this study defined themselves through daily interactions that highlighted their strength as a unit and illuminated what they conceived to be “normal” family activities. Citing Goffman (1963), Gray (1997) argues that, “behavioural assumptions about what the family was, were translated into normative assumptions about what the family should do” (p. 1097). Ever mindful of what other families are doing and how their family may differ, the participants in this study attempted to prove how their families could adhere to perceived typical family activities like story time at the library. By revealing the ways in which families have constructed their images of typical family life, I shed light on the ways in which the families created and engaged with

normative assumptions of what they should do as a family. As families described their familial and social interactions to me, they attempted to combat negative images of children with disabilities and their families by presenting stories of nightly family dinners around a kitchen table, visits to a museum, and large holiday gatherings. The ways in which each family defines normal are unique to that family, formed from memories of their family life and their surrounding culture.

During my journey, the families' pleas for me to understand their lives as "normal" were too loud not to be acknowledged. Scholars attribute invocations of normalcy as a way for families to redefine themselves amidst derogations of disability. For example, McKeever and Miller (2004) found that mothers discussed the typical interactions of their children as a way to "ascribe a lifeworld of emotional, intentionality, dignity, and value to their children- in essence, a habitus worth loving and supporting" (p. 1187). Not only were the family members detailing their child in ways that spoke of the child's strength, they also highlighted their family's dignity by adhering to specific family roles. Researchers in family studies outside of disability studies discuss similar trends. For example, Karen Pyke (2000) in her research on Korean and Vietnamese immigrants finds that her informants "critically juxtaposed themselves to the ideal of the American family" (p. 78). Although I concur with McKeever and Miller and Pyke's findings in that families strive toward an ideal family life, this chapter illustrates the ways in which the ideal is personally constructed.

Through our discussions, families situated themselves in the realm of what they felt was traditional family functioning. This striving for regularity aligns with Goffman's (1963) work in which he argues, "society establishes the means of categorizing persons

and the complement of attributes felt to be ordinary and natural for members of each of these categories”(p. 2). The child’s stigmatized label leads to a classification of the child and their family as different, unable to participate in specific activities or to achieve a normal childhood or family life. The child is assumed to be naturally deficient, unable to engage in the same activities as his or her typically developing peers. Although the families are well aware of their child’s deviations from what are ordinary medical, cognitive, and behavioral characteristics, they were insistent that I comprehend how they created what they believed was a normal family life. As if following a parental script of how to raise a child, the parents engaged their child in enrichment activities, ritualized mealtime, and forced family dinners in an attempt to perform their role as dutiful parent creating the perfect childhood. As families struggle to define themselves and childhood, they depict what Gray Cross (2004) argues is the “modern parents rehearsing again and again the same frustrations as they endlessly shift between permissiveness in search of the self-actualizing youngster and control in an effort to mold the superchild” (p. 2451). Despite the absence of a universally experienced childhood, parents continue to muddle through their beliefs of what childhood should be. The families fail to recognize there is no “normal” yet they continue to internalize, perform, and renegotiate pervasive conceptions of normality as they define their family unit.

The families’ definitions of normal family life reflect the influence of past and present constructions of family and childhood. According to family studies theorist, Kerry Daly (2003), “[mainstream] accounts of family reality are often divorced from space and place” and this scholar advocates “a closer examination of the roles of setting and context in shaping family life” (p. 782). Furthermore, DCS scholars advise on

providing the narrative, the daily experiences of families, and seeking a socio-cultural understanding of the ways families live (Abbott, 2013; Runswick-Cole, 2013; Skinner & Weisner, 2007, Grenn, 2007) and define themselves (Jenks, 2005; Landsman, 2005; McLaughlin and Goodley, 2008). Mirroring the work of CS scholars that implicate history (Graff, 1995), place (Holloway & Valentine, 2000), and social location (Jenks, James & Prout, 1998) in the construction of childhood, this chapter addresses the definitions of family life that my informants constructed through their “space and place.” Their descriptions upon which they derive their understanding of “normal” reveals the problematic nature of such a term as it is drawn from their memories and beliefs of what is culturally expected. Therefore, the following presents “normal” as defined by the families’ past experiences, membership in a rural community, and comparison to contemporary middle-class prescriptions of how children should be raised. However, as the families define normal, those who do not cleave to their constructed image of normality may be excluded.

Old School Family Life

We eat dinner every night and we sit at the table and try to have conversations like an old fashioned family would, instead of running hither, tither, and yon. So I've tried to keep the values that my mom and my dad instilled in me versus that driving through McDonalds and we all eat in the car (Diane).

Diane demonstrates FST by bringing to her system values from her childhood thus affecting how each member interacts with their family unit: the children are expected to sit at the table with their mother, eat her home-cooked meal, and converse about their day. These interactions have been constructed by Diane's memories of her past experiences in a family. With their homemaker mother and the family enjoying time together, Diane feels that the unit adhered to socially prescribed norms of family interaction. These normative expectations of family life spring from ideals of what historian Stephanie Coontz (1992) refers to as the "nostalgia trap," our longing for a better time. This feeling of what family should be may not even be real, it may be a creation based on television shows and repressed memories of difficult times. Our memory may fail to recognize the hardship in the family, the social inequality, and the fact that Diane's children may have been institutionalized rather than spending time around the kitchen table. Diane raises her two children espousing beliefs that were informed by her past. Her created vision of what family life should entail leads to family engagement in a specific dinnertime routine. As she avoids stigma by negotiating her position through traditional family interactions, she reveals one layer of what normality means to her family. Diane reaches into her memory to establish a worthy family life for her children.

Seeking to de-stigmatize their families, especially their family member with diverse abilities, caregivers found multiple ways of constructing an image of family life that they felt proved it as ordinary. Drawing from their own experiences as children-or the childhood that nostalgia created -the families used their conversations with me to present themselves as traditional as possible. As my informants detailed their lives within the home, they described themselves as engaging in what they believed were typical family activities. Within the first five minutes of our conversation, Diane, with her carefully chosen words and soft voice, described that “old-fashioned values” were important to her. Before launching into the devastating effects of her husband’s incarceration and failed attempts to help her daughter with autism, she sat across from me, speaking of values that were important such as: caring for each other, spending time together, and as she says, “that whole: you have to get together for holidays. We’re a family unit.” Diane has created an image of what normal family functioning should be based on her own experience as a child yet it fails to incorporate her family’s current constellation. In her historical analysis of families, Coontz (1992) states that, “nostalgia for traditional families, and myths about their strengths, prevent us from drawing useful lessons from the past and making effective innovations for our families’ futures” (p. 281). The families in this study are holding on to a romanticized standard of family life that, first of all, may never have happened but if it did, it most likely did not include family members with significant cognitive, behavioral, or medical needs. Clinging to an ideal of family life may prevent families from constructing family activities that more effectively engage all members.

The attempts to prove that they adhered to traditional family interactions also resounded through our conversation when I sat with Javon's thirteen-year-old aunt, Gilly, in their old farmhouse. Surrounded by rustic décor, Gilly, an award-winning equestrian with long brown hair and innocent brown eyes, happily described her family's enactment of "traditional" family values:

That's just how my parents are. They're kind of old school and they like to have dinner together and see how everyone's feeling and everything. I think that's what brings us together... My dad is really into the manners and everything. He thinks that's a life skill that you need at this age. So we had it very young and he's [Javon] going to have it very young" (Gilly).

Organizing a family dinner can be a daunting task especially when one tries to incorporate various members and their activity filled schedules. However, as Gilly explained, Javon's family makes a concerted effort to have dinner together every night and through conversation, the grandparents try to discern how the children are feeling. Gilly sees her family as "old school" representing a time when manners and family time were important and validated the family's worth. This mythical referent influences the activities that the families perform and to them conveys an image of typical family functioning. When viewed through a FST lens, Javon's family demonstrates cohesion in that their relationships with each other provide support through which they can enact their belief in specific family values thus allowing them to combat the stigma associated with Javon's behavioral deviations. This cohesion creates a familial tie that lends itself to establishing a dinner- time routine and for them proves that their family does not truly deviate from the old school values with which the grandparents themselves were raised. The family, as a unit, works hard to instill in Javon the manners necessary to fit in to the community and also to provide him with the traditional values that they believe are an

integral part of familial life. Javon's grandparents believe that this skill will not only benefit him in the family but also in society. However, as family members deal with the unique characteristics of the individuals present in their unit, their motives and functioning may differ. Many factors are at play as families construct their identity as a unit. Javon's family believes that they are "old school" yet once the ideal is observed through a contemporary lens, one can see that the impetus for "old school" values takes on a new meaning. The families may believe they are enacting values from a better time yet the impetus for such an emphasis may differ in 2015.²⁰ These behaviors are important for the families to ensure that they are feeling successful in creating a good childhood yet crediting it to the past certainly muddies the waters for a contemporary life. As revealed in Javon and Sharon and Phil's families, there is tension between living the life they believe they should be living and their lived reality. The families engage in a considerable amount of effort to achieve their desired outcomes, working hard to create a life for their child that extends beyond his or her disability.

Goffman's understanding of stigma is relevant to making sense of these families' practices. Goffman (1963) argues, "the stigmatized individual can also attempt to correct his condition indirectly by devoting much private effort to the mastery of areas of activity ordinarily felt to be closed on incidental and physical grounds to one with his shortcoming" (p. 10). The literature also implicates behavioral deviations as having a significant impact on how families feel others perceive their child and their family (Gray,

²⁰ In contemporary society, young black men are closely monitored and are unjustly punished for their actions (Ferguson, 2001). At the time of this writing, the United States saw an increase in the murder of young black men by police officers for minor legal infractions. This has engendered the Black Lives Matter movement that seeks to bring awareness and justice to the thoughtless killings of young black men and combat the injustice of institutionalized racism in the USA.

1993). The families have struggled with their loved ones' "inappropriate" behaviors and have been the target of the condemnation from outsiders: they are well aware of the stigma that accompanies deviations from normal behavioral expectations. Diane, Gilly, and Tori each condemned the ignorance of others. Gilly explained that her knowledge of Javon's progress helped her deal with strangers. She commented, "I don't really get embarrassed by him. I mean a little but when he is like screaming in the stores or something I'll be like, 'shhhh!'...If somebody has something to say about him I don't really listen because I know how far he has come and I don't really care what other people think." Javon's family's hard work within the home and the progress Javon has made in engaging in family activities proved that they are privately working toward correcting his stigmatized behaviors. Furthermore, Diane lamented that, "the community doesn't understand" and Tori explained, "It's just frustrating that a lot of people out there don't get different things if you're not the norm." The family members see their private practices like dinnertime routines as ways to combat the community members that condemn their child's digressions from expected social behaviors. These families felt the import of sharing how their family can engage in activities that were so highly esteemed in their youth. In her quest to define family time, Daly finds that families, "felt obligation that they honor their parent's traditions through the manufacture of their own traditions for their children...it was the nostalgic mood or the memory itself that seemed paramount— for it seemed to anchor them to a secure past" (p. 288).

As the families work together in their respective units – the guardians trying to preserve a particular image of family life — they revealed the ways in which memories of their childhood influenced how they defined themselves as a normal family. Daly's

(2003) research also finds that families have a tendency to “hold onto an image of past family life that is romanticized and idealized” (p. 778). She argues further that this has been neglected by family studies theorists and warns that researchers must be cognizant of the double lives of families. Citing Gillis (1996), Daly claims that “everyone lives in two families: one they live with (in everyday reality) and one they *live by*. The families that we live by are imagined families drawn from the past and constituted through myth and ritual” (p. 778). As the families detailed the values that they maintained through dinnertime routines and manners, they demonstrated the lives they “live by,” a belief in what their family should be. However, their everyday reality revealed a more complicated picture. For example, Diane, a single mother of two children with autism, is still committed to old-fashioned values even though her son has difficulty with social understanding and her daughter’s aggressive behaviors have resulted in periodic removal from the home and placements in foster care and residential treatment centers. Diane described her challenging relationship with her daughter, at one point she even questioned institutionalization to provide a better life for her son. Despite the chaos that surrounded her family, such as her battles with service providers and the constant fear that living in poverty created, Diane tried to convey the picture of a traditional family through their dinnertime routine. The every day to which Diane speaks, has been constructed from her memory of her childhood. Although Diane grew up in a home with siblings and parents who were not disabled, she maintained this understanding of familial expectations for her own children. Therefore, cooking meals and eating at the table every night was an important part of normal family functioning to her. To her, dinnertime was a way in which she created normality in the midst of chaos. Diane’s concluding remarks

reveal the tension between the life that she wants to lead and the one that she has. She pensively comments, “I have my days and I have my moments and don’t let anyone tell you that I don’t resent my kids because there are days when I do. As fast as I say, ‘I wish I never had them’ as the words are coming out of my mouth, I regret it. It’s just. It’s hard. Its not an easy road but I love it.” Perhaps her resentment results from the failed attempts at family dinner or the belief that life would be easier if they could only sit down together and talk over a meal. Holding on to a particular image of family life may be more of a disadvantage than an advantage for her family.

Similarly, tension between traditional family beliefs and the life that families are actually leading appeared in the ways in which Javon’s family conveyed their compliance with their old fashioned values. For Javon’s family, engaging in their dinnertime ritual took considerable dedication and teaching to ensure that Javon would comply. Dinner-time appeared to be a monumental undertaking, as Javon could not sit for longer than 2 minutes and had limited vocal communication. The family worked hard and continues to work hard to teach Javon how to engage in their family dinners. Additionally, Javon’s family confesses that it was just recently that he learned to use a fork. Javon’s family, insistent that he perform the dinnertime routine, spent countless hours training him to eat with a fork, to sit at the table, and to expand his menu. Further reflecting their commitment to assisting Javon in engaging in family activities, Gilly explained that family activities are “harder than they used to be but we’ve gotten used to it. And we worked with him so much that it’s just like going out with just everyone like we used to.” Despite Javon’s complex behavioral and communicative needs, his family believes that he must engage in family activities and possess perfect manners. Javon’s grandparents’

pasts dictate that manners and dinner together are integral parts of “old school” values; therefore, they go to great lengths to teach this to their children and grandchildren. Although the complex behavioral modifications that are necessary for Javon, Sharon and Phil, to engage in a dinner routine are quite cumbersome, the families focus their attention on engaging in what they consider to be quintessential normal family practices. As my informants negotiated the stigma of disability, they connected to learned ideas of family life, attempting to promote their normality. The next section continues the conversation of how families define themselves as normal by examining the influence of geographic location in the construction of family life.

Outside versus Inside

Any kid shouldn't be (pause) any healthy kid shouldn't be sitting in front of the TV all day long. They should be outdoors being active and so forth. That's the way I was brought up. It's painful to see Richie unable to enjoy it more (Carl, Richie's Dad).

Carl not only revealed the influence of his memories of family life, his rural community also played a significant role in defining what normal was for him. During our interview, Carl discussed the joys of teenage parties in the woods and hiding from the police down by the quarry, playing outside until dark, and the importance of outside playtime for children. It was easy to imagine Carl as a young boy, with his soft skinned round face and easy laugh running through the woods or joking with his friends about the local police by the quarry (the same woods and quarry that I passed driving to current home). We laughed at the fun he described and as we laughed we both turned our attention to Richie who sat about three feet away from us. The laughter quickly turned to uneasiness. I sat pursing my lips wanting desperately to take a deep breath but fearful that it would convey my discomfort. Dispirited, with his gaze suddenly turned from me to the floor, Carl mentioned how Richie, at one time, also enjoyed playing outside. Richie, laying almost flat on his recliner staring at a cartoon through his thick glasses, did not acknowledge his father's lament that children shouldn't watch television all day. At that moment, I cursed this rural area where we lived, angry that people could run around in the same woods, continue to drink by the quarry, while Richie, at eight years old, was relegated to childish cartoons, a feeding tube, and a recliner. Yet, this lifestyle that I condemned in this meeting was the same one I embraced for other children whose

guardians were convinced that their children needed the outdoor space to expend the limitless energy that their autism provides.

Reiterating the oft-heard ideal of the rural utopia, families often spoke of the importance of nature and community. Although I maintained my skeptical suburban roots, I have also personally witnessed the value placed on nature and community in this New England area. Children are expected to spend time outside and community members often interact with the children. Having two young children, I quickly realized the importance of outside playtime: children are sent outside for recess with their big coats, hats, gloves, and snow pants regardless of snow or temperature (they only stay in if the temperatures are in the teens or if there are high winds). At community events, children are encouraged to be outdoors, playing unsupervised with children who range in age from toddler to teen. Not only are children expected to be outside for extended periods of time, children are embraced by and participate in the community. The local farmer's market, for example, evidences the appreciation of children in the community. My partner and I allow our children, ages four and six, to wander – with us at a distance – through the large crowded concrete market. The children enjoy the freedom and we appreciate knowing that even if we lose sight of them for a while, we feel they are safe. We have stumbled upon farmers offering the children free veggies, local artists engaging the children in conversation, and merchants using my children's purchasing power as a math lesson. Children in this New England community are expected to play and participate.

According to my informants, their children love to be outside. Their child's participation in outdoor play validated their compliance with typical childhood behaviors as influenced by their rural location. Carl's conception of childhood includes experiences

outside, playing, or working on automotive tasks. Carl expanded upon these conceptions of what he considered to be a normal childhood as a way to demonstrate that Richie enjoyed what other children do and should enjoy: time outside not watching television. Carl explained further, “When the weather’s nicer he’s outside with me. He’s an outdoors kid. When he was healthier – oh my gosh – it was a real fight to get him back indoors. He just loves the outdoors!” When I questioned what activities Richie prefers, Carl responded, “he likes the ball games over there...He likes to always have something in his hand just tinkering seeing how things go. He likes to roll the ball.”

Richie loved the outdoors; therefore, he adhered to what Carl believed exemplified normal childhood. Outdoor play centers the family on the spectrum of normality, proving their child’s dignity and observation of what Dad perceives to be typical rural childhood. Carl asserted that Richie engages and desires to engage in the same behaviors that typical children in their rural community experience. It is only because his medical condition impedes him from participating that he sits in front of the television.

Also employing outdoor time to illustrate conformance to normal rural childhood behavior, Patty, Javon’s grandmother, highlighted Javon’s appreciation of outdoor activities, “He loves to go hiking; he loves to go for walks.” Gilly added to the description of Javon’s outdoor play seeing it as a time where she can play with Javon and her friends:

We teach him how to play basketball and run around but most of the time we go outside with him and we go on four wheeler rides...It’s really fun and in the winter we went sliding with him. It was fun.

Again, influenced by their rural location, outside play manifested itself as a way through which families conveyed that their child engaged in the childhood that families believed

one should have. Javon's family loves to be outdoors, from ice fishing to hiking, and Patty explains that Javon also enjoys participating in these activities. Gilly, too, believed that the outdoor activities are representative of what children should be doing. She discussed the opportunities that her family provides for Javon hoping that these opportunities result in a better childhood, a "normal" childhood. Gilly explained, "Whenever I work with him, I treat him like a regular kid because I don't want him to think he's different. I want him to think that he's like everyone else...so I just gave him opportunities to be a normal kid." Gilly's desire for Javon and the hard work that she puts into helping him are consistent with McLaughlin and Goodley's (2008) findings. The authors describe one of their parent participants: "her choices about how much to shape Jack's behavior against the norms of society are guided by social recognition of the costs of difference" (p. 324). As mentioned above, Gilly is quite aware of the social stigma associated with disability and seeks to transform Javon's behavior through hard work and through multiple opportunities that she believes "normal" children in their rural area have. It is important to note that Gilly described her time with Javon as *working* with him. Affected by constructions of normality and the stigma associated with departures from the norm, Javon's family can be understood through FST, in that as one member is affected by stigma, they all are. Therefore, they *all* work toward improving Javon's behavior in the hope of minimizing or entirely depleting the stigma surrounding his behavioral deviation.

I observed Javon running from one outdoor activity to the next, his endless flow of energy pouring out around the big yard that surrounded the family's home. He ran along the tree-lined trail behind their home, or bounced for extended periods of time on

their trampoline. I saw him enjoying what his rural surroundings offered, his family happy that he was not hitting or throwing a tantrum, but rather running outside, as they believed children should.

Similarly, when I observed Patrick, a young boy with autism, I felt firsthand what Javon's family must feel; the contrast between outside and inside was dramatic. Dori met me outside claiming that her son really wanted to wander around. While we talked, we followed Patrick, around the yard, running between trees, hiding in a wooded area, and at one point, losing his shoe. He was happy. His mom was watchful but appeared relaxed. The moment we entered the home, the situation changed from freedom to confinement, and Patrick's mom seemed unable to please him. She would ask him repeatedly what he wanted. He would play a video game on the iPad, take her phone, get up, wander around, and look for food. We spoke very little as we tried to find an activity that would bring contentment for Patrick. We eventually returned outside where Patrick continued his exploration and Dori and I finished our conversation. Nature was integral to experiencing a normal life for Dori and Patrick. Running around outside, enjoying the rural idyllic childhood was not a myth for Javon and Patrick's families, it was how they enacted "normal." In his study of rural families in the UK, Valentine (1997) finds that restricted property and traffic concerns preclude children from enjoying the natural freedom that they should be afforded living in a rural area. He writes, "parents argued that their children are being robbed of the idyllic rural childhood represented in popular culture, sometimes highlighting the perceived loss with anecdotal accounts of their own idealized rural childhoods" (p. 143). In contrast, the families in my study believed that nature was

the key to their child experiencing a normal life. As disheartened as Carl may have been acknowledging this, there was a time, he assured me, that Richie did love to play outside.

Rural literature paints contrasting images of what it means to grow up in a rural area. For example, Theobald and Wood (2010) argue that social media and school textbooks create a stigma associated with rural life as “a past condition that we left behind” (p. 27). Other scholars have found rural life described by informants as defined by lack of services (Applequist, 2009, Vaughn & Saul, 2013; Spring, 2013; Tickamyer & Henderson, 2010). On the other hand, Flora and Flora (2013) argue that there is a “rural myth;” Brown and Schafft (2010) refer to the “rural mystique.” These exaggerated conceptions of rural life purport that childhood is running through tall grass until dark, valuing time spent with family and friends, and a strong devotion to family and community. The myths preclude people from seeing the failed farming fields, the poverty, or as in Carl’s case, the child who cannot sit down by the quarry or run outside for all hours of the day. Brown and Swanson (2003) argue that, “the American public tends to see its rural population as a repository of almost sacred values and a stable anchor during times of rapid social change” (p. i) and specifically related to this study is Holloway and Valentine’s (2001) study of the “rural childhood idyll.” The families in my study, although they sometimes sacrificed quality services (see chapter 4) adhered to the mythical properties of childhood in rural areas, even if their own children were excluded from rural opportunities. Their stories also align with the work of rural scholars like Flora & Flora, (2013); Schafft and Youngblood Jackson (2010); Moctovish & Salomon (2003); and Mallory (1995) who posit that rural people are multi-dimensional encompassing varied identities. When examining rural families and childhood, they are not only the

embodiment of running through woods nor are they solely their farming heritage, they are people composed of many identities influenced by many factors like gender, age, familial relationships, race, and ability.

The field of CS encourages geographers to examine the lives of children in rural places. This research, mostly from Europe, also presents conflicting perceptions of growing up in rural locations. Researchers have found children to both appreciate and resent their natural upbringing (Smith & Barker, 2001). For example, Giddings and Yarwood (2005) find that children appreciate their natural surroundings as it provides “secret hideaways...away from the adult gaze” (p. 108). However they continue that, “As children grew older, the frustrations caused by the lack of facilities and conflicts over space obliged them to look beyond the village and towards the wider range of social possibilities” (p. 109). Similarly Glendinning, Nuttall, Hendry, Kloep, and Wood (2003) describe children’s contrasting perceptions of rural life revealing mostly positive sentiments yet their findings reiterate the lack of services. The authors also posit that background factors such as gender, social class, etc. affect “experiences of rural life and ambitions for the future” (p. 153). However, they fail to mention how disability may influence one’s identity in a rural setting. All of the families in my study interacted with place through disability and their stories contribute another dimension to understanding how people of varied identities embrace their rural setting. The children and families in this study extend beyond identities of rural and disabled but are also: sibling, aunt, middle class, poverty-stricken, dancer, welder, computer wizard, and nature enthusiast.

Rural areas are also noted for their strong community, their sense of “we-ness” as described by Brown & Schafft (2011, p. 35). Additionally, Spring’s (2013) qualitative

work in Canada finds a participant defining rural through “social interaction where a rural place spawns familiarity, inclusiveness and togetherness, a safe place in which to live and teach” (p. 31). Flora and Flora, exposing the uniqueness of each community in rural areas, distinguish communities by their natural, cultural, human, social, political, financial, and built capital. Analyzing the capital by community rather than by individual, Flora and Flora present interesting insight that is relevant to considering the families in my study because it is not so much the individuals in these cases but the communities in which they are a part that help them to define themselves. Even if they are influenced by external ideals of meritocracy (like Carl wishing not to take handouts) they still rely heavily on their community to embrace them.

This sense of community not only provides support to families, it once again provides their child with that rural idyll childhood. Their worthiness is manifested through their interactions with the community. To counter the stigma associated with their family members’ disability, my informants stress the many activities in which their child was successful and appreciated by the community. For example, Bethany’s Nana described BINGO night at the local church where everyone “loves” Bethany. Similarly, Connor’s mom, Hillary, felt the kindness from children in Connor’s school. She happily detailed an outing with her son encountering students from his school, “All the kids love him! I’ll go for runs with him in his chair and a kid will be like I know him! He goes to my school. I’m like, ‘aww ok.’” The families reveal their appreciation of community members who embrace their child and their family. From depicting their child participating in purported normal childhood activities to appreciation from community members who respect and “love” their family member, the families in this study go to

great lengths to de-stigmatize themselves and their child with complex needs. The families' definitions of normal family life and childhood result not only from their past and their surroundings, their child's worthiness is also predicated on their acceptance within the community. While obeying rural conceptions of childhood, the family can therefore be recognized as valued members of the community. This supports Goffman's (1963) argument in which he explains, "persons with a courtesy stigma provide a model of 'normalization' showing how far normals could go in treating the stigmatized person as if he didn't have a stigma" (p. 31). Also feeling the stigma of disability, family members seek to prove the worthiness of their child and their family by portraying experiences that demonstrate that they are indeed a typical family. Their family member with diverse abilities can engage in traditional family activities and can uphold family values of care and good manners. Engaging in the activities that the families have constructed through their perceptions of normal childhood centers them on the spectrum of normality. By engaging in activities that are symbolic of what the family member believes to be a normal childhood, they can define their family interactions as worthy and acceptable. The following section will detail the ways families construct their definition of normal childhood for their family member with diverse abilities, as influenced by contemporary middle class conceptions of childhood.

Busy and Boring

We do everything we possibly can to enrich her life. We've taken her to the aquarium... We've taken her to museums. We've taken her to the puppet circus. We still try to give her that sense that she can do anything that other kids can do... We walk her. We've taken her to story times (Leila's mom, Heidi).

Although Heidi described her daughter Leila as “empty” or in a “vegetative state,” she continued to try to provide “normal” experiences for her. During the first ninety minutes of our conversation, Leila slept two feet from us in a pack and play. She is a pudgy two year old, with soft, round rosy cheeks and a plump belly. She looked like a child from a magazine with the face of an angel, sleeping soundly next to her young mom who frantically completed college work and made time to be interviewed. As we chatted, the Occupational Therapist entered and began working with Leila. They worked for thirty minutes, the therapist rubbed her arms, asked her to touch buttons, and played with her hair. Leila never woke. The therapist acted in response to Leila's mom's intentions that they would continue to provide services even if she appeared unresponsive. Although Heidi is unsure of Leila's awareness of that which she is experiencing, she provides daily exposure to activities that she believes are important for a child to have. Heidi perceives that these normal experiences are a way to provide her daughter with a quality of life that she feels she deserves. Despite severely disabling medical classifications, the families described the array of community experiences that they provided for their child. In an attempt to reveal that they are not different from other children, the families highlighted activities in which they felt children should participate as part of typical childhood experience.

These experiences respond to middle class expectations for childhood activities as supported by the work of Annette Lareau (2011). Lareau in *Unequal Childhoods: Class, Race, and Family Life*, seeks to prove that social class influences children's lives especially when they are navigating social institutions. Lareau contends that child-rearing philosophies vary among the classes. She proposes that child-rearing methods employed by middle class parents differ dramatically from those of working class and poor families. Lareau defines the child rearing strategies employed by the families in her book as: "concerted cultivation" (CC) and "accomplishment of natural growth" (ANG). Lareau contends that CC allows an interactive parent-child relationship in which the parents encourage development of linguistic skills through word play and negotiations, seek to develop skills through various extra-curricular activities, provide a highly structured schedule, and take an authoritative role when dealing with institutions like health care and school. Alternately, ANG, provides a strict division of parent-child interaction in which the parent provides the child's needs yet grants more freedom of schedule, substitutes directives for negotiations, and exemplifies a "sense of powerlessness and frustration" when dealing with institutions (Lareau, 2011, p. 30). Although Bourdieu may deem Heidi as falling short of middle class classification as she is a single mother, with only a high school degree, and whose only income is Social Security since she had to stop working as a bus aide to care for her daughter. However, Heidi, as indicated in the opening quote, is well aware of middle class conceptions for normal childhood and attempts to provide Leila with a particular quality of life through engaging in these activities. Surrounded by middle class neighbors and aware of various opportunities in her community to participate in activities that encourage parent-child interaction and

varied extracurricular activities, Heidi attempts to provide these opportunities to Leila. Solomon (2012) also finds parents of children with diverse abilities engaging in activities that promote intellectual and physical growth comparing this engagement to Pascal's Wager.²¹ Although unsure that the child would benefit from the experiences, the parents continued to engage their child just in case there was indeed an understanding buried deep beneath their child's surface.

Similarly, Richie's father, Carl, strives for middle class conceptions of normal childhood when discussing Richie's schedule. Carl explained:

I know people are busy taking kids to sports and dance. That's their routine. Our routine is going to doctors and hospitals so forth and therapies and whatever. That's Isabell's sports mom type person (Carl).

Carl, influenced by his middle class surroundings, realized that all families are busy with their children's activities. Carl reiterated the literature of both middle class suburban and rural families. First of all, as explained above, Lareau's CC acknowledges that, "children's activities determined the schedule for the entire family" (p. 37). Similarly, MocTovish and Salomon (2003) citing Doherty (1997) find as "formerly agrarian communities become suburbanized, priorities attached to a suburban lifestyle such as child enrichment activities have emerged to dominate the rural family schedule. Small town and rural youth, like their suburban counterparts, are now overscheduled with music lessons, dance lessons, skill classes, competitive sports, or other activities" (p. 85). Surrounded by families whose lives adhere to this prescription of family life, Carl embraced their busy lives as one embraces the many activities in which their children

²¹ Pascal's Wager named for Blaise Pascal's argument for the belief in God. If you believe and God does exist, you have lost nothing. However, if you don't believe and God does exist, you have much to lose (<http://plato.stanford.edu/entries/pascal-wager/>).

engage. Carl acknowledged that his family is just as busy as other families – busy being the norm – but he knows that this busyness is the extent of their normality when compared to their peers. While others are running from one recreational activity to the next, his family bounces from appointment to appointment.

Some families, also informed by their surroundings, defined themselves as normal, by both constant movement and how they enjoyed their free time. Bethany’s mother, for example, stressed the ways in which their family engages in “normal” activities.

Bethany’s mom described their life:

*Mainly, we all have our own things that we’re into. And we all bring our own things. This is what it is for the most part. We are a pretty close family, busy. Our down time is usually vegging on the couch watching TV or a movie. Busy. Other than Bethany’s needs you know which can be pretty intense at times. The **average** family day-to-day stuff. **Day in and day out.** Some things get added into the mix. And then there are other days when it’s like, “Oh I don’t have to do anything.” **Average busy family in a different order of everybody else**” (Susan).*

As I sat with Susan drinking coffee at their dining room table, listening to her story, I was struck by the multiple expressions of normal that she used to describe her family’s life.

Words like “average” and “day-to-day stuff” seem to convey an almost mundane existence. Phrases like, “different order” or “other than Bethany’s needs” are included more as an after-thought than as an integral focus of their family’s life. Bethany has a rare genetic disorder that impacts her physically and intellectually. As a freshman in high school, Mom confided, she needs someone to attend to her hygiene needs. Something that outsiders would label as a significant impact on family life received only a nod from Mom. As Susan tried to explain her family life, she employed descriptions that would not

find her deviating too far from the norm. We are normal, she asserted to those who may be interrogating how disability has impacted her family's life.

I believe that Susan used our conversation as a way to portray her family as functioning normally to contest the stigma associated with having a child with disabilities. Susan's discourse falls in accord with Goffman's (1959) assertion that, "when the individual presents himself before others, his performance will tend to incorporate and exemplify the officially accredited values of the society, more so, in fact, than does his behavior as a whole" (p. 35). Seeing time together around the television, or reiterating Carl's description of being busy as normal, Susan took the opportunity with me to paint a picture of their family as engaged in typical family interactions despite the needs that may arise moment-to-moment in caring for Bethany. Susan alluded to knowledge of the customary family life by mentioning that their family *is* average but "in a different order." Susan spoke to her notions of normality being busy yet relaxing with each other by accentuating their family interactions as within these parameters. Comparably, Diane uses sitting around and relaxing with the family as a taste of their family's normality. She explained, "We have pajama days, we eat popcorn, and watch movies." Neurotypical families, as researchers have pointed out, describe their family time just as Susan and Diane did. For example, Daly (2001) argues that families in her study defined family time by, "'Not having to do anything,' was what any of these parents and children craved. Their pursuit of family time was not with a particular activity in mind, but rather, was characterized by a desire to strip away all activity" (p. 289). According to Susan and Diane, despite having children with "intense" needs, their families still follow average functioning routines and daily interactions. Through their time together sitting around a

television, they enact the same familial interactions that other families around them experience or for which families desire in their assessment of family time. In her response, Susan's comments make sense when viewed through FST. She explained that the individuals in the family, though engaged in unique undertakings, contributed to their close family functioning. The family, whether as bowlers, dancers, or students, all add their personal qualities to the family unit and they come together to engage in what Susan perceives to be a typical family activity of "vegging out and watching TV." To define their families to me, Susan and Diane highlighted the qualities that they believed society values: a close family sharing time together around the television.

The families also sought to expose their normality through describing family activities within the home and the community. Even though the child may not be engaging as one would typically expect, the families perceived specific behaviors and activities to be valued by society, and therefore they offer these experiences to their children. By engaging in the same activities that they believe others are, the families attempt to fit into the cultural image that surrounds them. Pugh (2009) refers to this as the "economy of dignity" children prove through experiences and consumer goods that they are "worthy of belonging." Using their voice to prove that their child does indeed fit in, parents sought to prove to me that their child and their family is "worthy of belonging." Although Pugh's families did not include children with diverse abilities, it appears that the same forces are at play when parents define how they as a unit mirror cultural standards. Pugh argues, "parents were motivated not just by the prospect of the child's difference from others, but also by their own emotional memories – often their anxious recall – of their experiences of being different as a child" (p.9). In an attempt to avoid

stigma, to prove that their child and their family are not different from those around them, the families described experiences with each other that they felt conveyed the image of typical American family, hanging out together. Viewing the families on a spectrum of normality, I have argued in the above sections that families construct their definition of normal family life through past experiences, their rural community, and present conceptions of middle class childhood rendering them centered on the spectrum. However, I question, the implications for constructing these self-regulatory guidelines. What forms of exclusion result from such parameters of normal?

Implications

Although the families revealed their engagement with customary activities and relationships among friends and family members, engaging in these tasks is not an easy undertaking. For example, according to Leila's mom, Heidi, navigating a large aquarium in a wheel chair, is a daunting task as one maneuvers through tight spaces, encounters uncooperative employees, and squeezes into limited elevator space. Or as Bethany's grandparents pointed out, one must find accommodations for fishing and cooking with a young woman whose tremors impede the grasp necessary for holding standard equipment. Furthermore, the outdoors provide a space for childhood fun yet one must be ever mindful of the tantrum that may conclude the trip or the seizure that may occur while playing in the backyard. Although each family member gladly accommodated their family member with diverse abilities, reaching their ideal is not without struggle. Most poignant was the devastation on Carl's face when he realized that the childhood he described eluded his son, Richie, immobilized in front of a television rather than roaming free through the woods. Family members created a normal life for their child through enacting what they believed to be conventional practices of family life. Whose narrative is being advanced through these constructions of childhood? This story isn't articulated by the child, rather it is one written by the parent. The story depicts a childhood the parent believes that their child should be having.

Additionally, all of the families have an image of what normal family life and childhood should be. Whether it is going outside or sitting around the television together, the families indicated that this is indeed what normal families do. Bridgens (2009) argues, "The definition of the normal life will often change, but the desire to reach it will remain

an unchanging certainty” (p. 755). Are families marginalizing their child further by placing them in their personally constructed idyll of childhood? Rather than finding innovative ways to achieve ordinary family functioning for their specific family, the families maintain the boundaries of normality determining who may partake and who will be excluded. Working within their unit, each member brings forth their own conceptions of average family life to find ways to combat the stigmatizing effects of disability. However, as the families negotiate social prescriptions of normality, one must question, whose normal are these families employing and what then is *not* normal? As the families define themselves as a unit, justify their typical functioning, and convey life beyond disability, the term becomes even more abstract. Even among the families themselves the definition is unclear. What does normal entail? Diane condemned families for not eating around the dining room table. In this way, she asserted that her life without a busy schedule exudes more traditional values than perhaps a busy sports family. On the other hand, Carl asserted that their busy life is like that of a sports family. Some families found sitting around the television as the norm while other families felt that children should be outside, not watching television all day. Is one family more “normal” than the other? Should a child “veg” out in front of the television and then go outside to be considered normal? By dictating standard expectations of family life, the families may perpetuate the creation of limited borders of normalcy. With the varying descriptions that the families provide, the notion of normality remains elusive yet so very present in their lives.

Conclusion

Influenced by their past, rural community, and middle class ideals, each family member in this study brought to the family unit a conception of what normal childhood and family life entails. The experiences that the families portrayed had nothing to do with their child's special education; however, it was important for them to introduce their child and their family to me. Throughout this study, I found that the fear of falling outside the norm has led parents to repeatedly prove that their lives involve so much more than their stigmatized label. Working together as a family unit, each member tried to achieve what they considered to be normal family functioning. Each family accentuated the ways in which their family, the child of focus in particular, experienced lives that they believed are indicative of normal family life: a life that includes more than therapists, special education classes, and doctors. This chapter exposes the normality that the families feel they embrace in their everyday lives. As researchers portray the lived experiences of diverse families, this work will add to the scholarly understanding of how families with a child with a disability enact "normal." Davis' (2013) work sees diversity as the new normal, however he reminds the reader that diversity has yet to incorporate people with disabilities. It is my hope that this study sheds light on the pervasive feelings of enacting normal to avoid stigma while illustrating the diverse experiences of families with a child with complex medical, cognitive, and behavioral needs. Unlike Davis, I believe that even if disability is considered among the diversities of family life, each family constructs "normal" from their own experience. "Normal" plays out differently as the families avoid stigma and reframe their experiences within the confines of their current situation. Therefore, each family's interactions and relationships fall along a continuum.

Sometimes, as described above, they were centered on the spectrum in what they believe are normal family interactions. The next chapter details the ways in which families negotiate interactions that fall to the left of the spectrum creating a “new normal” for their family.

Chapter 3: Creating a New Normal

This is Our Normal

*It's just the life we lead; the hand we're dealt. Wouldn't change it for the world. No sense in being jealous of other families who have healthy children or what not. We'd like to have that too but **this is our normal life** we know no better. So instead of going to basketball games and soccer games, we go to hospitals and doctor visits (chuckles). Richie doesn't know what healthy means. He thinks **normal** and healthy is this and what he lives and breathes every day (Carl).*

Carl and Richie snuggled on the couch together as Carl recounted different experiences and situations that defined who they were as a family. With his arm around his son in a safe and warm embrace, Richie continued staring at his favorite cartoons while Carl detailed the ways in which their family was “normal.” Even though Carl was aware of the ways in which families around them enacted family life, the ways in which his family created childhood and family life for their son was unique to them. Although Carl purports to embrace his new lifestyle, perceptions of a particular type of childhood and family activities influence his perception of his own family. His family cannot adhere to or reach this ideal and must create a normal of its own. Influenced by the hegemony of typical family life, the families in this study continually create and re-create how “normal” plays out in their families and in their relationships with others. This chapter exposes how families employ the term “normal” to make sense of their new lifestyles, ones that may not fit into their constructed images of family life. Despite failing to mirror those around them, the families still cling to “normal,” ensuring me that their lifestyles indeed are normal for them.

This feature of recreated family life aligns with the work of Kelly (2005) and McLaughlin and Goodley (2008) who identify the complexity of the family narrative for

people with disabilities. The negative and the positive seem to overlap, creating something that defies categorization of either positive or negative. For example, Kelly (2005) finds that “parents sought to fully enact a parenting identity within the constraints and with the possibilities presented” (p.199-200). The families’ definitions and understanding of who they are develops as they relate to each other and their community. Michalko (2002) explains that “disability provides a ‘now that’” perspective (p. 19). “Now that” the families must frequently visit the hospital, juggle therapists, and/or find a vehicle that can accommodate a wheelchair, they immerse themselves in their new lives, in their new roles. The families conveyed contentment with their new lives, enjoying the comfort that their created routines provided. Throughout our interviews, family members repeatedly referenced normality: the ways in which their family was average, and the ways in which they had created versions of normal—particular to their distinct circumstances. In chapter 2, I found the families placing their lives within the confines of what they perceived to be standard such as comparing sporting events to doctor visits. However, their new normal is not so readily accepted within their families or within the community. Their new normal causes them to re-think family relationships and draws them into situations that they may have never dreamed possible.

The families’ deviations from standard ideals do not render them abnormal, rather through these interactions they create a different sense of normal. This chapter elicits the ways in which families continue to apply the term “normal” to their lives despite straying from the constructed image that they have of childhood and family life. This chapter displays the re-creation and improvisation of what normal means to them. Through our conversations, the families revealed that they have come to embrace and be comforted by

their recreations. The families' new normal consisted of accepting their particular path, re-defining family, working with non-standard familial roles, and engaging community in distinct ways. Consistent with disability research, the families in this study re-work their family life to meet their needs. Bernheimer and Weisner (2007) explain that families are continually responding to their situation (citing the work of Bernheimer, Gallimore, & Weisner, 1990; Gallimore, Weisner, Kaufman, & Bernheimer, 1989; Weisner, 2002). Like Carl indicates above, this *is* their normal. Although the families in this study continued to strive toward societal expectations of what family life should entail, they also created new visions of normal for their families. As Carl demonstrates in the opening comment, the life that they are living is the only one they know. They have familiarized themselves with doctors and therapists rather than coaches and sporting events.

FST recognizes that families adapt to different events throughout the life cycle, with each member influencing the family system. As families adjust to their life cycle events, they rearrange family roles, change family constellation, and establish new community relationships. Dore (2008) describes FST noting that members “rework their relationships with their families of origin as well as their friendship networks. The couple must begin to develop the family structure including the rules that govern the roles and responsibilities of each partner, that will characterize the new family system” (p. 441). Turnbull and Turnbull’s analysis of FST is relevant in understanding the families who participated in this study. Many commented about their re-working of relationships within their families of origin and with their communities. Despite the comfort that families take in their routines and within their families, members choose who stays and who leaves, who needs to work, and who can stay home. Functioning within their system

leads to new roles like changing relationship dynamics with relatives. In the community, the families face the best and worst of people: inappropriate treatment from uninformed individuals and overly eager “helpers.” The families grappled with their own situations shadowed by traditional expectations of what they believe family and childhood should be.

Embracing Our Normal

There's a lot of highlights- simple things- like when she has a milestone, even if you get that little glimmer of a smile from her. The simple things like the cat falling asleep on her lap. Or just watching family hold her. She coos at you. Every once in awhile she'll coo. You know she's happy. Like the little things like falling asleep in my arms to just those things that you can appreciate after all the hell you go through (Leila's mom).

As Leila's mom detailed, she learned to accept her life for what it offered. Leila has multiple seizures a day, rarely escaping a night's sleep without one, and has failed to meet the prescribed milestones of walking and babbling. However, Mom embraced the small rewards that Leila offered such as: contentment with a coo-ing baby, joy in seeing her child loved and held by family, and peace knowing that she is resting easy. As the families grappled with the meaning of their everyday lives, they also expressed the ways in which they created routines and constancy from the life that disability engenders. The families, through details about milestones, hospital visits, and new routines, revealed that this life that they are living, though deviating from what others may perceive as normal, works for them. Larson's (1998) ethnographic work of mothers caring for children with complex medical needs discovers similar negotiations of disability. Larson argues that for mothers "the embrace of paradox was the management of the internal tension of opposing forces between dealing with the incurability while pursuing solutions, and between maintaining hopefulness for the child's future while being given negative information and battling their own fears" (p. 11). The families in this story repeatedly balance various forces in their lives. The families revealed the tension resulting from the difference between their everyday lives and the family life standards they attempted to meet. Although families tried to cleave to what they perceived as traditional constructions of family life and childhood, they do acknowledge their difference. This difference, they

still refer to as normal, since it is their standard, the life that they know. While families of neurotypical children may continue to chase the dream of the ideal childhood, the families in this study seek solace in their new routines no matter how significantly they deviate from their expected trajectory. Whether they utilize this as a coping device or they appreciate creating a routine during hectic life situations, the families attempt to prove that their “normal” is just as worthy as the lives of the families that surround them. The negotiation of socially prescribed standards occurs moment to moment. Families’ interactions with conceptions of normality transform as they come to terms with their specific situation. Thus, they re-define what normal means for them.

For example, Richie’s dad, Carl, and Connor’s mom, Hillary, revealed the paradox of frightening trips to the hospital that resulted in relief and comfort. Although frequent visits to the hospital may be considered a deviation from average family experiences, some of the families in this study found their hospital stays as a time of solace much like returning home. Carl described the trips to their hospital that is three hours away. Although a daunting experience each time, this family created their own extended family and a community of support. Carl disclosed:

*Its kinda nice too because now we’ve been going down [to the hospital] so much that when Isabel goes down she has a **network**. There’s people down there that if Isabel goes down there by herself or if we’re down there they’ll come and spend an hour or so in the hospital just to visit. Or for outpatient, we’ll spend an hour with and go visit. There’s a little boy around Richie’s age that when he’s down there outpatient they come up once or twice a week and do little adventures: day type things. Yeah it’s **nice**. I think there’s 5-6 of them that are **like family members** to us because we’ve spent so much time that they know Richie. They know the good and the bad. It’s just **comforting** that once you are there it will be better and the anxiety will go down. It’s like **family**. You’re like **a family member**.*

Connor’s mom, Hillary, also finds comfort in going to the hospital. She explained:

*It's really sad but Cam and I feel like it's our **second home** because we spend so much time there. It's just **like going home**.*

Both Carl and Hillary discussed the ways in which their lives deviate from most families in that they need to make many trips to the hospital, sometimes for extended periods of time. However, despite the stress related to admitting their child into the hospital and the anxiety that precedes the trip, once they arrive, the families situate themselves into their network of friends who are like family: one that provides a network of supportive and caring relationships. The participants in this study assumed their new identity as a member of a hospital family, comforted by their new friends. As the families created and recreated what typical family life meant to them, I found these occurrences not as abnormal family interactions but rather a new place on the spectrum of normality in their created normal. Embracing their lifestyle for what it has given them, Carl and Hillary appreciate the comfort that they feel in the hospital, surrounded by people who understand them more than their family of origin and friends. These hospital stays are undoubtedly not a positive experience; however, the new normal that manifests itself through these occasions provide relief to families who are in need of support and a good friend. It is not that disability afforded them a more positive or more negative experience; rather, it introduced them to a new way of living. This way of living encompasses both anxiety and friendship.

Similarly, in Javon's family, their new normal provides not only comfort but also encouragement to live a longer and healthier life. For example, Javon's grandfather, Papa quit smoking for Javon. He described, "It's just – like I said, he taught me how it was gonna be...I want to be around longer with him, you know. I'd like to see him grow

up...When he's come so far" (Papa). Papa appreciates the new life that Javon has brought to his family. Although their family underwent a major transformation in the year that Javon has lived with them, it has created a new normal that may be difficult, may be led by Javon, but inspires a sense of purpose to live longer. Papa, who already raised 3 children, sees promise in his grandson who has made great strides since living with them. Even though Javon was abusive and uncontrollable for the first 6 months, the family's hard work and love paid off. Papa understands that their life deviates from his idea of the family norm, that Javon may control the family, but he appreciates Javon's presence so much that he is willing to give up smoking in an effort to spend more time with him. Even though Papa appeared to me as a man who would not be controlled by many, he allowed his grandson to tell him how it was going to be. Not only was Javon changing their family dynamic, he also seemed to be changing his grandfather. Could Papa's new normal be one of a soft willed non-smoker dominated by a child? As the individual units of the family change, so does the unit as a whole.

Illustrative of the FST perspective, the families in this study revealed the ways in which individual members contribute to the functioning of the whole family. It is apparent that the creation of their new normal depends on family members' willingness to embrace their new lifestyle and change to meet the needs of the family. As the families adjust to their routines, relationships change and new roles within the family are created. In FST, this is referred to as "adaptability." Turnbull et al (2015) define adaptability as the "family's ability to change in response to situational and developmental stress" (citing Olson, 1988, p. 49). Reflecting their adaptability through their strong family, Javon's Aunt Gilly describes the ways in which her family adjusts to their new lifestyle.

According to Gilly, their everyday life involves a close family that is working together to improve Javon's behavior. She reported, "Javon has brought us really close to each other because we have all worked to improve on his behavior and everything. It just helps to have close family when you're trying to do that." Javon's move to live with his grandparents provided him a cohesive family, one where each member contributed individual strengths to the system. As Gilly noted, each member worked hard to improve Javon's behavior. Throughout the interviews with Javon's family members, I found that each contributed in specific ways: the grandparents provide a consistent routine, Gilly takes pride in her work on behavioral training for Javon, Evan knows Javon's likes and dislikes, and Gilly's older sister provides Gilly with female bonding time, and takes Javon on long runs in the woods. In addition to his humorous and adventurous personality, Javon also adds to the group by being the force that unites them. The grandparents and their two daughters quickly adapted to their two new family members by embracing their cohesiveness and focusing on the great lengths they would go to help one another. Even if demanding at times, Javon's family has created their own normal as they manage specific behavioral needs.

The families' "adaptability" aligns with the work of Skinner and Weisner (2007) who, through their study of families with children with Intellectual Disabilities, find that "families become involved in a process of 'renorming the normal,' a recalibration based on an idiosyncratic state of health that cannot be averaged because it is based on a population of one, their own child" (p. 305). The norm in Javon's family includes behavioral work and extensive periods of exercise to allow him to expend his energy. Adapting to their new normal, Javon's family places great importance on training him to

behave appropriately and function within their family system. Javon's family values each members' contribution especially those that Javon has taught them and encouraged them to accomplish. Like Javon's family, the other families in this study have adapted to their new routines, to "renorm the normal." Carl and Hillary have embraced hospital stays as time spent reconnecting with friends and taking comfort in their safe haven. Although Carl and Hillary must involve themselves in complex medical procedures and emergency visits to tend to their children who are medically fragile, they have found a place where they are accepted, cared for, and supported. The families in this story had to make choices, learn a different set of routines, build support networks, and recreate new roles within their families so that they may create a new normal. Grinker (2007) explains, "in a family with autism, there are different expectations, different meanings, and even different kinds of happiness" (p. 296). Despite the varying labels of disability that the children in this story possess and the different realities that these labels presented, their families evoked a similar sentiment by embracing the life that they are living. The families certainly found themselves negatively reacting to situations, however the families chose to focus on experiences that revealed the ways in which they adjusted to these negative situations and adapted to their lives. More ethnographic work into the lives of families will reveal the varied accommodations that manifest in familial life. As argued by Family Systems Theorists, adaptability is a "process" that runs along a "continuum" (Gargiulo & Kilgo, citing Turnbull et al., 2011 and Olson et al., 1989). Following this thought, families evolve, as the circumstances require. They continually transform to meet the new needs that arise within their system. The continuum of adaptability ranges from rigid and unchanging to changing abruptly. The children in this

study have experienced times in which their families were unable to adapt to their medical or behavioral needs. Families who were rigid in their beliefs as to what family life should entail failed to see the new “normal” that could result from their current situation; unwilling to accept their new routines some families disbanded.

Creating new families

I'm disappointed. I'm disappointed in my family. You know, you can choose some of your own family. I consider my girlfriend of 40 years to be my sister rather than my siblings. You don't really need to be related by blood. You can be related by commonality and understanding and just by a lifetime of ups and downs (Diane).

Diane's response to the question, "How has your family helped you?" speaks to the re-creation of family. Diane created her own family when her biological family dismantled. By not functioning like she had expected, by not giving her the support that she had thought they would, Diane felt it better to create a new family. Her new family is one of her choosing: a close friend who has provided her the attention and support that Diane had thought her birth family should provide her. Diane's changing family life echoes Weston's (1991) seminal work in queer kinship literature that researches the experiences of gay informants in San Francisco who chose friends as family when their biological families rejected them. Weston defines these relationships as "family of choice." She explains, "A degree of choice always enters into the decision to count (or discount) someone as a relative." She continues citing Schneider (1968) "Knowingly or unknowingly, individuals set about editing their family trees by arranging relatives along a continuum defined by poles of closeness and distance" (Weston, 1991, p. 73). Even though her friend was not biologically related to her, Diane recognized that her unconditional support epitomizes family. A single mom of two children with autism, Diane had to choose "family" that would support her through positive and negative experiences. As a matter of fact, Diane's friend encouraged her to relocate in order to attend a specific school for children with autism. The friend provided emotional support,

shelter, and real estate advice as Diane transitioned from a Southern state to a Northern one. Family reconfiguration also resonated with other participants in this study.

Bethany's mom, Susan, also chose to "edit her family tree." She explained the choice to remove themselves from extended family members who proved unsupportive of their children. When a family member questioned Bethany's appearance, Susan willingly severed ties with her. Susan recounted the story of a family birthday party, where one aunt commented on Bethany's skin, saying that she would not "bring her into public looking like that!" Susan promptly responded by gathering the children and leaving.

Indignantly Susan confided:

We don't need 'em if this is what they want to do. And judge! I'm not raising her to be self-conscious and superficial. She has to be comfortable in her own skin good or bad this is what her skin is. I packed my girls up and I left. You wanna know what? We don't need them!

True to her words, Bethany's family has not raised her to be self-conscious. Although Bethany is much shorter in stature and appears years younger than fourteen, she and her family take great pride in her adorable appearance. When I first met Bethany, she sauntered out of her bedroom, like a New York City fashion model, swaying along the runway in a bikini. At her dance recital, she walked around the crowd, proudly revealing her sequined outfit. Susan will gladly dismiss any family member that negates her efforts of building her daughter's self-esteem. As Susan and Diane come to terms with their new normal, they expect their family members to act in specific ways. When their families failed them, they, without hesitation, severed the relationships. Conceptions of how a family should behave and support each other influence their relationships with their extended family members, encouraging them to retreat into their system of family functioning that behaves according to their visions and intentions. Similar to the queer

kinship literature, my families are choosing their own families. Unlike the queer kinship literature, the families in this study are the ones making choices as to who will stay and who will not. Weston (1992) explains that as gay families of choice result from an “emergence from a specific history of categorical exclusion from participation in kinship relations, an exclusion associated with claiming a lesbian or gay identity” (Weston, 1992, p. 135). In the case of these participants, exclusion occurred on both ends. Although many family members and friends rejected the families and child with diverse abilities, my participants were also the ones actively excluding those members who failed to see beyond average interactions, intellect, behavioral dispositions, or physical appearances.

Other families recounted the need to re-evaluate who supported them and who failed to live up to their expectations. For example, Leila’s mom, Heidi, had to make the decision to leave her husband when she determined that he was not dedicated to their daughter’s care. The last straw was when her husband refused to learn CPR for their daughter. She told him, “If you’re not going to be a reliable parent of a kid that has all these needs, then you just don’t need to be one.” From that decision, Heidi became a single mom, caring alone for a child with complex medical and cognitive needs.

Although Heidi feels that parenting Leila sometimes can be more like a nurse providing twenty-four hour care, she does not regret leaving her husband. Heidi has also found another partner, Kenny, who she believes has provided more than Leila’s biological father. In describing Kenny, she stated, “He helped me raise her since she was a year and a half. He’s really good to her. He really stood up to be a dad. He’s big at advocating for her, finding resources, and doing research. He’s better at the computer than I am. He’s really good.” Decker and Elijah’s mom, Rachel, also noted the lack of commitment from

her first spouse. Trying to care for two children with diverse abilities, she described her relationship with her ex-husband, “Even in my previous marriage, I was doing it alone.” She then continued telling me about her wife, Sandy’s dedication to the family. Rachel, with a sense of peace and love, commented:

When she showed up it was the first time I had an actual partner. It took me two years to realize how in it she really was. She’d only been living with us a few months. So, Decker was sick one morning and she said she would take the day off. ‘You’re kidding me!’ I said, ‘You’re going to stay at home with a throwing up child?’ She said, ‘you don’t like throw up anyway!’ (Rachel pauses, then breathes in contentedly) They are her kids. She has taken them on.

The new lives that these families are creating afford little room for members that are not adapting to different forms of functioning. The families are steadfast in their “we don’t need ‘em” sentiment affording little forgiveness for the members that are unwilling to accept their new normal. In Heidi and Rachel’s cases, they were fortunate that they were able to easily disconnect with their unreliable spouses and find people who were dedicated to them and their children. Twenty years following Thorne’s (1992a) critique of the word “family,” the mothers in this story lend credence to Thorne’s argument that, “the family’ implies a firm, unchanging entity, always similar in shape and content. Feminists have long challenged this imagery, which resides in functionalist theories of the family, for falsifying the actual variety of household forms and for perpetuating male dominance” (p. 6).²² When their spouses or family members failed to support them, they countered traditional expectations of family life for breaking free from the person and establishing new ties with someone that would conform to who they were as a family unit.

²² Questioning family continues into the twenty-first research of families. Pahl, Ray, and Spencer (2003) find that the terms traditional family and family of choice have significant limitations, barring researchers from the varied connections that span biological and platonic relationships.

The mothers in this section highlight the varied forms and dimensions of family life, bringing forth new life into what it means to be a family and to care for a child.

Re-defining family comes not only from mothers but also from extended family members that care deeply for the children in their family. Sometimes, the mother isn't the champion. An extreme and very unfortunate case of a mother not adapting nor performing appropriately is Javon's mother. Javon's family life also was recreated when his mother abused him. After 2 years of being locked in a bedroom during his time at home, Child Protective Services contacted his biological grandfather, Papa and Patty, his step-grandmother, to travel 14 hours to gain custody of him and his older brother. Papa and Patty restructured their lives and the life of their thirteen year-old daughter to create a new family life for Javon and his brother, Evan. Their lives over the past year had been fraught with abuse from Javon, a struggle to connect with an emotional Evan, and many hard hours of teaching Javon how to be a member of a family. Their work is far from over but the "normal" that they created has provided a new life for Javon, one with the initial stages of communication, and one where he no longer physically aggresses toward his family. The families are constantly adjusting and readjusting to a new form of normal. Sometimes the families must separate themselves from family members who are not providing them the lives or the support that they believe will encourage a functional system. The families are employing their conceptions of normal and what families should be to decide who in their family stays and who leaves. As the families create their new lives, they also negotiate the roles that the family members must adopt to create a functional family system.

Role Changes

Usually Susan deals with them [school] more than I do. Like right now, I usually help her, like right now she has her menstrual cycle and she can't really take her pad off so I have to change her pad. And if I notice it hasn't gotten changed in a while, I'll let her [Susan] know and she'll deal with it and she'll send them an e-mail saying, 'keep an eye on her pad and change it more' (Bethany's Dad, Craig).

When I interviewed Craig, he had returned from work at 3pm and started cooking jambalaya around 4pm. Our meeting started awkwardly as he moved between the stove and the kitchen table where I waited for him with his wife, Susan. Susan finally instructed him to begin our interview. As I sat listening to his experiences concerning his daughter's special education, I did not anticipate hearing the myriad ways he involved himself in her life. Although Susan tends to both school and medical concerns, Craig is deeply involved in Bethany's life: tending to her hygiene needs as well as providing her with emotional support and searching for ways to enhance her social life. According to FST, roles within a family change to create a functional family system to meet the needs of the system as a whole. Although the roles change according to the present need, at the time of this study, the families had created fairly consistent roles, ones that each member confidently and proudly performed. The families in this study embraced their new roles within the family, adopting a "divide and conquer" mantra in which the families took on responsibilities to support the functioning of the whole family. Disability theorists, Maul and Singer (2009), who apply Bernheimer et al.'s eco-cultural niche theory, define this family-work as "accommodations." Accommodation, they posit, "has to do with problem solving, with redesigning familial roles and relationships, and with marshaling whatever financial, social, and emotional resources a family might have to adjust to the challenge of raising a child with a disability" (p. 155). Rather than approaching family from a

pathological focus on disability, the authors argue that observing these accommodations will benefit researchers and practitioners. This section views the roles that families adopt to accommodate the varied needs of their families. Many of the guardians, for example, determined that the financially wise decision would focus on the male guardian's career allowing the mother to stay at home to work as caregiver. In a few cases, mothers also took on the role of political lobbyist seeking drug reform and a database for rare genetic disorders. I argue that each member of the family, from the youngest cousin to the oldest grandparent, found themselves with a new identity.

Although the scholarship speaks to encouraging father participation in IEP meetings (Mueller & Buckley, 2014), the fathers in this study demonstrated a different type of involvement, one that complicates the question of paternal participation. From Craig's quote above, he could appear uninvolved in school, with Susan sending the emails about tending to Bethany's hygiene needs, however, he is behind the scenes, parenting his daughter. This is something that I have found is often overlooked when educational researchers question the participation of fathers in IEP meetings. Teachers also neglect the behind the scenes participation of parents if they are not present in meetings and class parties. As scholars consider the involvement and roles of family members, the role of parenting a child with complex medical needs must be more fully analyzed lest the intense involvement that occurs at other levels be ignored. For example, Ly and Goldberg (2013) recommend delving deeper into paternal perceptions and reasons, which preclude them from participating in school activities. Ly and Goldberg argue that researchers must note the complex factors, like meetings scheduled during work hours that may prohibit inclusion in meetings. Our current knowledge of fathers and their

relationships and roles within the home are quite limited. In researching the lived experiences of parents with children with disabilities, Kelly (2005) finds that “an understood and relatively taken for granted sense of what it is to ‘parent’ becomes the subject of conscious making, unmaking, and remaking” (p. 187). Attesting to these findings, the family members in this study re-define their roles as parents, advocates, educational participants, behavioral interventionists, and medical providers, to enhance the functioning of their family system. Maul and Singer (2009) report similar findings, stating that families, “reassigned traditional roles in ways that both accommodated the need of their disabled children and allowed the family to function more smoothly” (p. 165). These roles may differ from what is expected at the institutional level, but their participation is crucial at their family system level. The families in this study have arranged and re-arranged their families to meet the needs of all involved. Each member plays an integral role in their family’s functioning, leading the families to define the roles that they play in assisting each other to achieve their normal. The key players, at times, extend beyond guardians. Through this study, I have discovered families evolving to include grandparents, same sex partners, life-long friends, siblings, and extended family, attesting to the importance of fluid boundaries in a family system. The following details the roles of these various family members as they involve themselves in their child’s life.

The male guardians in this study played a role in caring for their children; one that I feel is often overlooked in the educational literature. As noted above, Craig took on the cooking as well as the hygiene needs of his daughter. Papa tries as much as possible to be present and enjoy his grandson, claiming that he even wants to live longer because of him. A third male guardian, though busy with many forms of employment, both paid and

volunteer, plays an active role in his son's recreational and medical life. The lived experiences of these families reveal a different type of involvement, one that researchers do not clearly see when they tie involvement to institutional relationships. For example, when I questioned Javon's grandfather, and Bethany and Richie's fathers about their participation in IEP meetings, they deferred to the female caregivers blaming time constraints on lack of participation. A superficial portrayal of the males conveys uninvolved participants. However, as I questioned further, I realized that their involvement extends well beyond the IEP meetings and class parties. Their involvement includes a more intimate participation than sitting around a table in a school and commenting on current goals and objectives. The males in this study participate through medical and behavioral interventions that are overlooked when simply questioned about involvement at the institutional level. Like Bethany's father, Craig, quoted above, may not be able to attend IEP meetings but his involvement with his daughter manifests itself on a more personal level.

The women in this study also found themselves enmeshed in activities that strayed far from their original life plans. While maintaining their individual dreams and aspirations, the family members, as they create their new normal, bring to their system an individual role that contributes to the whole system's functioning. Singer (2002) found that "some parents may, during the process of identification and labeling of their child, be inducted into a new social niche and a new identity" (p. 151). Many of the female guardians, for example, had to commit to full time care of their child with disabilities. This is consistent with much of the literature that finds mothers taking on responsibility of the children while the father works (Grinker, 2007; Ly & Goldberg, 2013). As mom

works as the primary caregiver, she knows many of the teachers and therapists, allowing the father to work and play a behind the scenes role in the activities that operate during the traditional 8-5 workday. The women in this story complained only of the financial difficulties of forgoing their employment to stay at home with their child. Perhaps, limited career prospects aided in their adjustment or maybe they were happy to care for their child and felt a sense of accomplishment when figuring out a new insurance loophole or success at an IEP meeting. Hillary even commented that her advocacy efforts are, “how I stay sane!” In the relationships within the family, it appears that the mothers control many of the household operations as well as the medical care.

As they performed their new occupation of caretaker, the women also illustrated the accompanying roles of advocate, lobbyist, school aficionado, and insurance combatant. Each member of the family has specific roles to which they adhere. Although some of the female caregivers work, the women who stay home seem to use their role as caregiver to take charge of the family. Their role provides them intimate knowledge of their child’s complex educational and medical needs. Sometimes, the fathers are on a need to know basis. Richie’s father explains, “Isabel does most of Richie’s doctor’s visits and therapies and so forth and I’m at work, so I’m behind the scenes on a lot of it... God forbid anything ever happened to Isabel.” The roles that disability created may provide the women with a profession that may have been more than what their small town could have offered to a woman with only a high school degree. The mothers’ new roles inspired new careers. One mother found the motivation to take college courses, aspiring to become a Special Education Teacher. Another female guardian plans to write a book

since the books that she read were insufficient in explaining the daily struggles that caretakers face in raising a child with autism.

In this study, the defining and re-defining of roles is not limited to that of guardian; each member, sibling, aunt, young cousins, and grandparents reveal the ways in which they contribute to the functioning of their specific family system. Gills and Wells' (2000) study examining siblings of people who had a Traumatic Brain Injury (TBI) found that families re-arrange their individual activities to meet the needs of the whole family. Gills and Wells employ the phrase: "doing what it takes" (p. 50). The families realize the need to do what it takes, each member adding to the functioning of the system. Young family members take an active role in providing help to their family member with special needs. Kirstyn, Bethany's sister, discussed her role in the family:

I do my chores, and like I help out my sister like if she's not on task with what she needs to be doing during the day. Sometimes I have to pick up for her chores so she can keep going through the day. I help out with keeping Bethany on task when Mom is doing other stuff or if my Dad is busy.

To maintain the flow of the day, to accomplish the chores that need to be finished, Kirstyn will help her sister, recognizing that some days are harder than others. She also understands that her parents, at times, are unable to help so she must play the role of assistant or teacher, keeping her sister "on task." Although Bethany's mother mentioned that she tries to remind Kirstyn that she is not the parent, this role sometimes still falls to her. Contributing to the functioning of the family, Kirstyn knows what must be done and willingly participates, as she feels necessary. Continuing the theme of helping out, Bethany's grandfather, Poppy explains that the cousins also assist as needed. Poppy explains, "while her cousins all recognize her needs, they also accept her as needing help and pitch in to help her." Bethany's diverse abilities did not limit her participation in

routine family activities. She is still required to complete her chores and function within the extended family; however, if she does need assistance, her family members provide it. A similar theme manifested itself in Connor's family. Even though Connor's cousins are younger than him, they are still mindful of his needs and tasks that must be accomplished during the day. Hillary recounted the story of her 3 young nephews who are under 5 years old: "It's so funny. They crack me up. When Connor is crying they try to comfort him. They are very in tune with what is going on with him. They won't take their eyes off of him." Hillary also explains a time when a two-year-old cousin was grunting and pointing to the physical therapist since the therapist had forgotten part of Connor's typical therapy routine. Although very young, Connor's cousins are well aware of the ways in which their family functions and step in to help.

Extending beyond providing assistance, Gilly, Javon's thirteen-year-old aunt, dedicates herself to Javon's behavioral and academic improvement. Inspired by her parents' adherence to routine and devotion to appropriate behavior, Gilly explained how she interacts with Javon, especially when he is not behaving according to the family's expectations. Gilly noted,

I came up with my own ideas. Sometimes when he throws a fit they [her parents] kinda rely on me because he'll listen to me. All I have to do is use a firm voice and he'll get up and listen and he's very good about it. I came up with this myself because I kind of saw my mom doing things. It's -I don't know- it's the way I kind of taught myself how to deal with him. He seems to listen and he doesn't seem to mind.

Gilly has taken on the role of behavioral interventionist, taking pride in her ability to change Javon's inappropriate behaviors. Throughout our interview, she discussed the ways in which she "works" with her nephew, trying to teach him to interact "normally." Although Gilly mentions the difficulty that babysitting poses to her social life, she seems

eager to teach Javon manners and behavior. She even speaks of a “playpen” idea that she has for “training” him to play outside by himself. Over the past year, Gilly’s family has devoted themselves to correcting Javon’s inappropriate behaviors. Gilly gladly performs her role in this system and proudly lists the accomplishments that the family has made in teaching Javon. Whether it is tending to a crying cousin or teaching manners, the members of these families have created new roles within their systems conveying the importance that individual family members play in creating the family’s new normal.

The New Normal: Does it Conflict with Who We Are?

*I lost quite a lot of friends because I can't – I've changed a lot – my friends always want me to go out and I can't. They don't understand so you know. They get mad at me because I can't do things that they can do. So it's really challenging to maintain friendships let alone relationships you know other things like that. So, I lost a lot of friendships. I guess when you have a child with special needs you get to evaluate who your real friends are. I've had a few who have stuck around but they don't really come around, I think it's because they don't really understand. They're just so busy. I mean they don't make the effort to offer to help
(Leila's mom).*

As Leila's mom mentioned above, relationships changed as she created her new normal. Having to provide round the clock care for her daughter leaves little time for socializing which many of her friends don't understand. Although the families embraced their new normal, the roles that the family members espouse may affect their relationships with friends and family. Other parents, like Dori, mentioned the benefit of Facebook in maintaining friendships since she cannot bring her son on typical play-dates. As families struggled with maintaining certain friendships, other community members unexpectedly revealed immense amount of support. In this study, the families of children with medical needs reported the most generous of human kind: people throwing benefits for their child, offers to babysit, and even strangers sending money regularly to their home. Many people tried to show their support for the families. For example, after a benefit raising thousands of dollars, Richie's aunt presented his parents with a photo album inscribed, "*You don't walk alone, we walk with you every step of the way.*" Community members seem to be stressing to the families that they are aware of their needs and are available to help in any way possible. As Richie and Connor's families reflected on the generosity of their community and the support given to their children,

they also lamented how outpouring of help feels awkward. Richie's father, Carl, explained, "We don't go with our hands out looking for help, you know. I'm a private person...So, but, I appreciate everything everybody does when they do do it. It just feels weird." Similarly, Connor's mom, Hillary, described her relationship with the community, "A lot of people do really nice things for Connor and it's really humbling as a person to watch strangers or people that don't even know Connor, who just know us, to do stuff for him. ...It's humbling watching your kid get something that brings him so much joy and know that you couldn't provide it." Influenced by the perception that traditional families should be able to do for themselves, Carl and Hillary spoke of the humbling experience of receiving donations and how they would rather help themselves, but they have to take it for their children. Influenced by conceptions of "normal" family functioning in the 21st century U.S., parents embraced ideas of keeping to one's self and going it alone. Hegemonic discourses of individualism and privacy have convinced these families, even those with the most challenging medical conditions, that they should be able to handle this on their own. Yet, according to Coontz (1992), this has not been how families have traditionally functioned. Coontz argues that, "depending on support beyond the family has been the rule rather than the exception in American history, despite recurring myths about individual achievement and family enterprise" (p. 69). Raising a child, even those without complex medical or behavioral needs, poses myriad challenges; yet, families believe that they should be exiled to their own homes to fight their battles alone.

As families enter their new normal, new friendships develop, old ones sometimes disappear, friendships take on new meaning, and people begin helping in unimaginable ways. In this study, the families' new normal involves receiving help from outsiders,

though it may be unsolicited or even illegal. The help provides the family a way of functioning that may have been impossible had the community members not been involved. No matter how reclusive people may be or how hard they try to “keep it in the family” it is impossible for the families of children with complex medical needs not to receive help or offers of help. The scholarship on families with children with disabilities finds families relocating for better services (Silverman, 2012), and engaging in alternative healthcare treatments (Silverman, 2012; Wong & Smith, 2006).

The families’ engagement with community members reveals the same commitment to thinking outside of the box to help their child. The most curious incident, one that runs contrary to any inclination of normality, occurred for Carl and Isabel and involved the use of medical marijuana for their son, Richie. Desperate to try anything that might relieve Richie of his daily seizures, the family had hoped to try medical marijuana.

Although medical marijuana is legal in their state, Charlotte’s Web, the specific strain that they needed was not available. To obtain Charlotte’s Web, the family would need to break federal law to bring the cannabis oil from Colorado to their home. Although Carl, Isabel, and their doctors were eager to know the effects for Richie, no one was willing to commit a felony. Then, a community member stepped in to help. Isabel confided:

We knew what was coming. We knew it [cannabis oil] wasn’t being shipped directly to our house because the sender doesn’t want to be traced. And he’s afraid that people may be watching our house like what packages are coming and going. He knew people in the area so he got them to say, “yes” they would deliver it. One Saturday morning at 8 o’ clock I was in the shower and the phone rang. So I answered it and I’m like, “hello?” And the guy says, “I’m in your driveway and I’m like um I just got out of the shower it’s going to be a couple of minutes. I gotta get dressed and then I’m like “crap!” I still had shampoo in my hair (laughing, Carl saying, “yep!”)

So I had to hurry up and like I don’t know this guy. So I called in the meantime, I called my mother- in- law and I said, “Just so you know, there’s this guy here if I

don't call you back in 20 minutes please come to my house." Like I wasn't really scared but I wanted somebody to know what was going on!

As Richie, Isabel, and Carl create their own normal and try to achieve a better sense of health through alternative medicine, they are confronted with a situation that slaps any sense of normality they have in the face. Not only did they receive an illegal substance in their driveway at 8:00 am on a Saturday morning, they also were offered various forms of marijuana from local high school students, an ER nurse, and pizza place employees. Although their pleas on a local news station for the federal legalization of marijuana does not espouse traditional conceptions of normal family functioning, the resulting offers of help go beyond any semblance of standardized community interaction. As if community members saw themselves as the Robin Hoods of the marijuana world, people from all over sought to help, because everyone knew where they could find some pot! This begs the question, why do people want to offer this form of help, especially one that is still illegal in this northeastern state? Had I more time, I would have interviewed the people who offered to help as a way to understand their underlying motives. Are we just aching to return to a more social organization of family life, one where we all care for the children? Is it the sickest children that make others realize that we are all in this together, that this sick child could be yours? Perhaps the fear of losing a child is enough to realize that it does take social cooperation and communal childrearing to successfully care for the family.

Although each guardian of children with complex medical needs mentioned the uncomfortable feelings of having others do for them, they all recognized that the gifts were quite necessary in providing their child with the equipment, toys, and medicine that

they needed. As I heard the stories of generous community members, my thoughts turned to the other children in my study, particularly Javon, Sharon, Phil, and Patrick, who did not suffer from medical complications but from behavioral differences. Their guardians did not mention any benefits or offers to help. They couldn't even find quality *paid* babysitters. Yet, when one assesses the easier child to babysit, surely a child who runs fast would be easier to tend to than a child who needed to be catherized and fed through a feeding tube. Could the imminence of death encourage community to provide support while they can? Perhaps, medically compromised children are considered deserving of care (because the children didn't cause their own problems) while children with behavioral problems are often blamed for their behavior. Or the history of parental blame continues to plague the families of children with behavioral digressions rendering them unworthy of help. I still find myself uncomfortable thinking about the disparity between those who receive a fundraiser (or multiple fundraisers) and those who do not.

Further illustrating the disparate receipt of kindness and outpouring of money and support, family members of children with behavioral needs mentioned that professionals revealed less acceptance of the family's new normal, reminding the families that their family life is normal only to them. Although family members may confidently embrace their role as teacher, professionals in the community may fail to see the progress or the potential that family members see in their child. Some professionals, like school principals, are unaware of how to help children who deviate from the behavioral norm. Javon's grandmother told a discouraging story about the local principal who was unable to handle Javon's meltdown during a school visit. Patty recounted the story:

She was very rude, very disrespectful. She said he couldn't be doing this [having a tantrum] in the hallway because it was a public place. So needless to say, the

way she said it, all it did was make me cry. It made me feel I was second rate... she kept saying you need to get him out of here and she picked him up...she literally picked up and put him in my truck.

Despite the family's hard work in teaching him manners and appropriate dinnertime behaviors, people unfamiliar with Javon were unable to appreciate his progress. As he continues to display inappropriate behaviors in new situations, even professionals may be unaware of how to handle the situation or they may reject the child, thus reminding the family that the normal they have created, their roles as teacher and behavioral interventionists, are not understood outside of their family.

Although this study is limited in that it did not capture the voices and experiences of the children with diverse abilities, it does consider other family members as they take on multi-faceted roles. Even though family members dedicate their time to helping their family members succeed, they are still required to accept multiple identities. No matter how much family members embrace their new normal, they are still charged with being a behaviorist or a medical provider even when they may just want to be a parent. Patrick's mom, Dori, explains that she doesn't want to learn the principles of Applied Behavior Analysis (ABA) or "work" with her son.²³ She says, "We're tired and to do that [teach specific behaviors] on top of it, sometimes it's nice to come home and relax...sometimes I just need to do the dishes not *teach* him [Patrick] to do the dishes." ABA is touted as an effective, evidence-based practice in decreasing behaviors associated with autism. Yet, the scholarship reveals similar sentiments among parents of children with autism.

Researchers have cited the difficulty in implementing the principles of ABA in one's

²³ "Over the past 40 years, interventions based on the science of Applied Behavior Analysis (ABA) have been highly effective in mitigating some of the challenges and developing adaptive behaviors in many populations and are now internationally recognized as the most effective basis for treatment with ASD" (Dillenburger, et al p. 112, citing Maurice, Green, & Luce, 1996 and Larsson, 2005, and Perry & Condillac, 2003).

home since it is time consuming (Dillenbruger et al, 2004), exhausting (Makintosh, Goin-Kochel, and Myers, 2012 ; Steiner, Koegel, Koegel, and Ence, 2012) and challenging to have parents as therapists (Granger, des Rivières-Pigeon, Sabourin, and Forget, 2012).²⁴ Furthermore, writing as an anthropologist and parent of a daughter with autism, Grinker (2007) explains the tedium associated with ABA, “In the flow of everyday life, you simply cannot always act as a therapist” (p. 185). As Dori lamented having to choose between parenting and teaching her child, she revealed the choice that family members are required to make to add to their family system. As families create their new normal, they embrace new roles; yet, sometimes these roles feel more like a medical provider, as in Leila’s mom’s situation, or sometimes it’s a tiring job that requires too much of a work-weary parent.²⁵

On the other hand, sometimes a young relative who eagerly wants to help adopts the role of interventionist. Yet what are the implications for the family relationship when the family member is required to be more than just a relative? Gilly, for example, constantly referred to *working with* Javon to help him achieve normalcy. Despite the fun they may have together, their relationship is shadowed by conceptions of normalcy that lead to interactions in which Gilly can teach Javon so that he may achieve a “normal life.” This work toward normality may have negative effects on the nephew-aunt relationship or even the sibling-sibling relationship as discussed by Bethany’s sister, Kirstyn. Even though the helpful family member seeks to ensure a comfortable existence for their

²⁴ Parents, especially mothers, are continually recommended as service providers to their child with autism. Steiner, Koegel, Koegel, and Ence write, “The notion of the utility of parents as interventionists has spanned over four decades” (p. 1218). However, the time, resources, and skills necessary to adhere to treatment procedures are not available to all families.

²⁵ Parents as interventionists play a particularly integral role in the literature on Early Intervention for children with autism. Using parents as teachers, according to Silverman (2012) has its roots in ABA especially resulting from Lovaas’ research in the 1980s.

family unit, their role may lead to a power dynamic that relegates the person with diverse abilities to a position of patient or client rather than that of nephew, sister, or child. It is important to note that, at the time of the interviews, none of the younger family members complained of helping their relatives. These questions have also not been answered in current research, since researchers provide conflicting evidence on the influence of disability in a family: finding both positive and negative associations of disability (Stoneman, 2005). At times, the young relatives wished for a more typical relationship with their family member with disabilities but overall, all family members took pride in their accomplishments and accepted their role in the functioning family system.

The families may also find tension with the greater community even as family members embrace and take pride in their new normal. For example, when families are reminded that their life is not as “normal” as they would like, it can be stressful. Isabel discussed her son’s neuro-typical peers:

It sounds horrible but sometimes, I sometimes have a hard time when they post [on Facebook] ‘my kid got their green belt in karate’ or oh look ‘he’s playing hockey’ and it just bothers me. I shouldn’t be bothered but I think it’s a normal kind of feeling. It’s just yeah (speaking softly) I don’t know. I’m excited for them but at the same time I’m heartbroken. Yeah. (Isabel).

Isabel and Carl have been Richie’s biggest advocates, devoting their lives to his care, advocating for his medical needs, and guiding other families who have children with rare genetic disorders. Their lives revolve around his care and supporting families with children with complex needs. Their normal has been created through him. However, they too struggle when they are reminded that the life that they are living may differ from their peers. Families appreciate their new normal and the relationships that have developed from its creation but they continue to grapple with the fact that no matter how much

they've embraced this lifestyle, their family member still falls short of social expectations of normality. I see the families in this study sliding along the spectrum of normality: at times, they are fully centered, adhering to socially constructed visions of family life. Other times, they are managing transgressions of normality, involved in creating their own type of everyday existence.

Conclusion

After hearing the experiences of these families, I have found that having a child with a disability didn't make the family whole or add stress; it was the families' relationships with one another, the way they or their extended family interacted with them and with disability that led to a "new normal."²⁶ As seen in the above section, Javon's family, the ones who chose to make a difference, quickly realigned to work toward a common goal. This chapter illustrates the ways families re-configure to meet their needs. The families in this study adapted to their lives and created new families — ones that they felt would enhance the functioning of their system. Families had to sever relationships with their family members: sometimes it meant divorce, sometimes it meant cutting ties with extended family members that didn't understand their new normal, and in the extreme case, it meant denying custody to an abusive parent. As the families negotiated their child's diverse abilities, they chose the accommodation that would suit the needs of their family and their child. Grinker (2007) explains how families' lives are affected by autism: "Change is forced upon us, and we embrace it, often without realizing how much we're doing...Autism shatters many lives, and it changes everyone. But many turn the hardship of raising a child with a disability into something positive, even if it means their futures are different from what they expected, or from what their families and cultures wanted" (Grinker, 2007, p. 198). Although the term "shattering" may be a little harsh, the change is evident in the families' responses.

Reflecting the principles of FST, the families in this study reconstruct family relationships and adopt new roles to enhance the functioning of their family system. The

²⁶ Researchers have spent extensive periods of time finding the positive and especially negative correlations of disability on family life (Stoneman, 2005).

families create a new normal for the family, reconfiguring relationships within their family and their community. When families are allowed to be who they are- to accept that disability affects their lives in many ways- we see the many dimensions of family life, childhood, and disability. Coontz argues that, “Many ‘maps’ of modern family patterns accentuate one or another feature at the cost of distorting the total panorama of reproductive and marital change. One of the worst things about distorted maps is that when people reach dead ends, they are falsely blamed for ‘losing their way’” (p. 206). The families in this section are creating a new “map” for themselves: a new guideline. Not only have they travelled down the traditional routes of family life, they have also forged new roads, placing their families on the map. In the next chapter, I will demonstrate that as families slide along the spectrum of normality, they also find a new destination, one that celebrates their journey through unknown territory, a destination that is “beyond normal.”²⁷

²⁷ The destination motif of disability is not new to this study. For a beautiful metaphor comparing disability to destination see Emily Perl Kingsley’s poem, “Welcome to Holland.”

Chapter 4: Beyond Normal

Better than Normal

Maybe my kids are not going to be super stars but they'll love me forever, in a very pure and uncomplicated way (Diane).

Diane, in her slow hushed voice recounted the many hardships that befell her during her child rearing years. She lost her husband to incarceration, she has two children with autism, one whose aggressive behaviors has led to temporary placement in residential facilities and foster homes; yet, through the difficulties at home and the “war” she must wage to secure educational services, Diane still maintained that her children possessed a quality that made them more special than others. Diane detailed the love that her two children with autism provide her. As the families in this study negotiated the concept of normality, they not only sought to be considered normal and embrace their new normal, they also illustrated the ways in which their child is “beyond normal.” The families explained that their child possesses certain characteristics that render them to be almost magical by inspiring others and changing people’s lives. Although many of the families are constantly reminded of traditional expectations for childhood, they also enjoy the difference that is their lives. The families can step back from aggressive behaviors and chaotic schedules and appreciate their child’s unique contribution to the family. Solomon (2012) finds a similar trend in the families that he interviewed. He writes, “myriad families learn to tolerate, accept and finally celebrate children who are not what they originally had in mind” (p. 5). In his work, Solomon presents families who have had to adjust to a child who was unlike them, a child with what he calls, a “horizontal identity.” The child’s identity, Solomon describes, is unlike their parents’ identity and

fails to meet the expected standard of what the parents had envisioned for their child. Solomon finds that children's identities rather than growing up to meet their parent's expectations, move horizontally in an unexpected fashion. Whether their child had diverse abilities, different sexual orientation, or different conceptions of right and wrong, the parents in Solomon's story negotiated life with a child who was not what they had expected. Regardless of the difference, Solomon finds that parents struggle as they react to this diverse identity in their lives. Some of Solomon's families chose not to accept their child while others, like he mentions in the quote above, were able to embrace and eventually rejoice in their child's difference. Solomon's work highlights the parents that reacted positively and negatively, ending in an embrace of or a denial of their child. My work, however, examines multiple family members as they situate themselves on a spectrum of normality: continually re-defining themselves in relation to their conceptions of family life. This, I argue, happens moment-to-moment as behaviors change and families interact with each other and their community. Solomon's story accounts for the acceptance and the rejection that parents encounter as they come to understand their unique child. The stories in this work, on the other hand, find families in a complicated on-going process of defining experiences within the confines of socially prescribed norms. The families are continually negotiating the ways in which their child fits into a narrative of normality, sometimes meeting the standard, other times deviating and forming their own normal, and, as described in this chapter, also seeing their child as more than expected.

As the family members in this study reflected on their daily lives, they revealed their acceptance and appreciation of that which each member of their family and

community adds to their system. The roles that family members espouse have been a significant theme throughout this work: parents, grandparents, aunts, siblings, and other family members took on roles that contributed to the functioning of the family. This chapter describes the families' perceptions of the contribution that the child with diverse abilities provides to the family unit by highlighting the "beyond normal" qualities of the child, family, and service providers. The families' descriptions speak to the need for their child and their families to be seen as more than their disability. Continuing along the spectrum of normality, the families, as seen in chapter 2 are centered, enacting what they believe to be traditionally constructed practices of family life; in chapter 3, the families acknowledge their deviations yet create their own normal; in this chapter, they move from normal to better than normal. The families provided examples of their child as beyond ordinary, exuding an amazing air or having abilities that have yet to be realized. The families conveyed the inner beauty of the child and the potential ability, if only one could uncover their veiled intellect. These descriptions, as beautiful and inspiring as they may be, come at a cost. By acknowledging the exceptional abilities, love, and character of their own child and their own family, the families are relegating others into an abnormal position. The identity work involved in making one's own child extraordinary means defining that child in relation to an "Other."

The "beyond normal" descriptions continued as family members detailed their creative functioning and the exceptional care of service providers that added to their success as a unit. The families were grateful to those who helped them, however their high expectations of care may preclude them from seeing the benefits of other service providers who may have technical abilities yet lack the personal touch or time to establish

personal relationships with them. At times, this may affect other families with children with diverse abilities who attend support groups but whose interactions or diagnoses may differ from the participants in this study. It may even affect their relationships with neurotypical children whose behaviors may be described in a negative light. As the families portray their child as beyond normal and adding to their family, children in other families may be unintentionally excluded.

Tapping Into our Amazing Being

I always say we're lucky. When you meet her, you will get it. She's a life changer. ...She teaches us to see the world because she sees it differently. I believe she changed my life and I believe that she has the ability to change people's lives ridiculously! (Jesse)

Jesse, a mom who explained that she loves to tell her success story, eagerly disclosed Alice's positive attributes that are beyond those of her two sisters. Jesse felt that Alice embodies special qualities that enable her to relate to the world differently thus teaching her family a new way of interacting with each other and their community. For example, Alice's passion for her school projects resulted in changing the family's lifestyle, meeting others, and changing their lives. Alice's first independent study led her to train for a 5K. This commitment to fitness inspired her mother to re-evaluate her own lifestyle choices. Had Alice not "insisted on running," Jesse confessed, "I don't know where my health would be... I was really headed on a not good path. And I just kept gaining and gaining [weight] and I was not in a good way." Now, aunts, uncles, and friends enjoy annual runs together. Another school project found Alice dog training. The family now has their own puppy and Alice has established a strong relationship with her dog training classmates, who are twenty to thirty years her senior. One couple, Jesse explained, were reinvigorated when Alice joined the class. After training for twenty years,

they said watching the way Alice developed the skills encouraged them to continue with their class. Not only does her dedication to specific activities inspire others, Jesse believes that Alice possesses a mystical quality that changes people's lives. Jesse goes on to explain that she, her sister, and her best friend attribute life changes to Alice's birth. If it weren't for Alice's birth, Jesse explained, she, her sister, and friend would have moved away from their small town. Because they stayed, Jesse married her husband, her sister met her husband, and Jesse commented that her friend said that Alice's birth was "when everything fell into place for me." Although Alice may rely heavily on routines and often cannot be left alone because Jesse feels that she needs to translate for her, Jesse acknowledged the many positive experiences they have together such as singing in the car loudly or running 5Ks. She is more than a person enslaved by routine; she has a messianic quality about her, transforming the lives of those around her. This child, Jesse purports, is special!

During my interviews with the families, they assessed their family dynamic and relationships with each other and their community. Through this assessment, they provided images in which they reacted to conceptions of normality. As they detailed their experiences they embraced the many positive qualities that their child offers. In a "Zen-like" (Solomon, 2012) acceptance of family life, the families in this study appreciated the contribution that their family member with diverse abilities adds to their lives. Family member participants echoed the sentiments of Grinker (2007) as he describes his daughter Isabel. He writes,

Isabel has taught me that the unexpected, even the beautiful, can emerge even from the undesirable, like a lotus growing out of the mud, its beauty and purity unsullied by its origin. That beauty can be found in a single person, inside of

whom there is something – no, not something ‘normal’ but a brilliant light or an inner truth struggling to blossom (p. 35).

At a time when the families can sit with an outsider and reflect on their family’s relationships and experiences, they portrayed that their family member with diverse abilities adds to their family unit, to their community, and possibly to the world. Furthermore, like Grinker, the families believed that their child can be so much more if only people could tap in to their child’s potential: that there is a locked genius hidden deep within.

Employing the work of Davies (1997) and Ezzy (2000), Fisher and Goodley (2007) emphasize in their work the “philosophy of the present.” Fisher and Goodley explain that families possess “a liberation from a need to fight for the future, thereby freeing a person to enjoy the present for what it is” (p. 74). Unlike the families in Fisher and Goodley’s work, the families in this study still feel the need to battle for the future, ensuring appropriate educational and social outcomes for their family member, yet they readily embrace day- to- day living, take pride in their child’s accomplishments, and see them in a unique light. Despite the difficult situations in which many of these families find themselves- frequent trips to the hospital, endless doctor’s visits, around the clock nursing care, or aggressive behaviors, the families still see their family member in a glorified light. Not only are they looking at positive qualities, they find *exceptional* qualities in their family member with complex needs. For example, Carl speaks of Richie as being “a little inspiration” to his classmates. I have seen evidence of this “inspiration” as I know many students and teachers from Richie’s school. One student in particular from Richie’s school claims that she has devoted her life to special education because of Richie. She plans on becoming a speech language pathologist, fundraises for Richie’s

family and Special Olympics, and volunteers in community events for people with diverse abilities. Furthermore, at a community event where Carl, Isabel, and Richie told their story, I found their two sessions filled to capacity, college aged students listening intently to their stories. At the end of the event, people repeated the word “inspiration” and “amazing” when describing Richie. Many community members know him either personally or through Facebook and they speak of how “inspiring” he is to them. Recently, Richie walked after 8 months of sitting in his wheel chair. The community response was overwhelming! Facebook fans, first of all, commented endlessly about the happiness they felt for the family. Not only that, but people were discussing the great news in public spaces and classrooms. This child has encouraged people from marathon runners to high school seniors. With close to 2,000 followers, Richie’s Facebook page is a testament to the spectrum of people that he inspires. One man who has never met him runs marathons dedicated to Richie. Richie has also received a few medals from the man who runs for him. Richie’s family members view community reaction to him positively thus causing them to describe their son as an inspiration.

Bethany’s family also sees her as an important asset to the community and as possessing an ideal outlook on life. Bethany’s grandmother, Nanny, for example, disclosed that BINGO patrons at the local church consider Bethany as a “good luck charm.” Nanny confessed that many elderly patrons ask that the petite yet self confident Bethany sit next to them so that they can win the next round of BINGO. Nanny proudly demonstrated that not only is Bethany accepted by the community, she is valued as something magical, something beyond normal. Even Bethany’s sister, Kirstyn, a high school junior who spent most of the time complaining that Bethany was “annoying” or

could be “up their butts,” still pointed to the positive qualities and the outlook on life that her sister had that was better than the average person. After observing Bethany “annoying” her sister by mimicking her, contradicting her, and pulling her hair, I asked Kirstyn what she was most proud of for her sister. I expected very little after watching the two sisters argue but she responded, “Just that she doesn’t care. Like she cares what people think, like she’ll get upset by it, but it won’t affect her very long. So…” Mom then adds, “Five minutes upset then we’re good...I’ve often thought if everybody in the world could see the ways kids with special needs do, then the world would be perfect.”

Although Kirstyn perceived Bethany to be annoying, she can still observe the positive attributes that her sister possesses. Kirstyn perceives these qualities as better than those of other people her age who may hold a grudge or become overly concerned about what others think. Butlas and Pohlman (2014) refer to these shining positive characteristics as “silver linings.” From grandparents to teenaged siblings, the families see their family member with differing abilities as not only an asset to their unit but potentially as a benefit to the community and the world. Despite deviating from perceived cognitive, medical, and/or social norms, the family members welcome the influence that their child has on their family and their community. In another attempt to avoid the stigma of disability, the families continued to play with the term “normal.” But this time they were proving that they were better than even what they believed ordinary had to offer. As I attempted to interpret the parents’ and grandparents’ presentations of “normal,” I witnessed them trying to justify both their child’s worth and their family’s worth. However, in Bethany’s case, it was as if her sibling, Kirstyn’s evaluation of her sister not only proved her worth, in a sense, it could be something of which others could be envious.

Like Kirstyn was saying, “she is a lucky teenager because she doesn’t care what others think!” The families want others to see the value that their child adds to the family and to their community. Grasping to reach expectations of normality, creating family life around that which others may perceive to be abnormal, the families conveyed that their child was not only worthy but more worthy than others.

As the families accentuated the ways in which their family member with diverse abilities exceeded expectations of normality through the magic that is their child’s personality, they also tried to convey their child’s intellectual capabilities. The families argued that if people took the time to get to know their child or if they could tap into their true potential, one would discover their intellect. Researchers have found that families highlight their family member’s abilities as a way to deconstruct social perceptions of disability, to combat the theft of personhood that plagues people with differing abilities. The dominant discourse surrounding people with disabilities fails to acknowledge their humanness; rather, it highlights their deficits and their negative influence on family life. Kelly (2005) referring to Thomas (1999) discusses the plight of one mother in portraying her daughter’s humanity, “opposing those narratives became the daily activities and struggles of sustaining and reproducing personhood within profound impairment through her daughter as a social being endowed with rights” (p. 188). Also stressing their family member’s personhood and the value that their child adds, Landsman’s (2009) work with mothers of babies with disabilities finds that as mothers react to social prescriptions of what babies should offer, they learn to accentuate positive aspects to combat negative images of children with disabilities. She writes, “if a woman later defines her child neither as a product in the commodity market nor as a gift from God but rather as a giver

of gifts, she raises the value of her child beyond that of the ‘perfect’ child she had once anticipated and strived to obtain” (Landsman, 2009, p. 146). By highlighting their child’s positive attributes, the beauty that hides within them or the magical qualities to which others are attracted, the families positioned their child in a new light, one that exceeds conventional conceptions of normality.

The families in this study struggled against dominant expectations of childhood and intelligence by emphasizing the ways in which their family member could meet or exceed standards. Families sought to expose their child’s intellect that may be overlooked since they lack vocal communication or engage in disruptive behaviors. Connor’s mom, Hillary, for example, expresses the importance of observation to see how people with diverse abilities learn. Hillary described that even though others may be unaware of what Connor is doing, he connects with the world in ways that elude neurotypical understanding. Hillary explained:

He is very smart. He may not express it. But if you watch him like he’s always scratching he’s very tactile, is always scratching. Cam figured it out. Connor will get on a new surface and won’t know where he is. So he’ll scratch a lot until he knows where he is (Hillary demonstrates by scratching quickly across the sofa). He totally knows. Cam caught onto that. It was always constant then (slows scratching down).

Hillary explains that her son, who is blind and cognitively impaired, understands where he is by scratching at a surface. After constant observation, Connor’s father determined that Connor learns about his position and place through scratching. This skill, Hillary believed, developed through an intellect that may be discounted due to his diagnosed disabilities yet he learns in a way that most people would not even understand.

Similarly, Javon’s grandfather discussed the untapped potential that outsiders fail to see when interacting with people of diverse abilities, particularly people diagnosed

with autism. Javon's grandfather commented, "They [people with autism] know a lot more than we know and they don't have no way to express it to us because we don't know what they're thinking...He might know the cure to cancer...If not him somebody of his caliber or whatever, you know? Look at Einstein." Comparing Javon to Einstein, Javon's grandfather, Papa, masks the extensive behavioral interventions necessary to prevent Javon from aggressive behaviors. Not only that, but searching for what Javon could be, may preclude him from recognizing the intensive academic preparation needed for Javon to vocally communicate. Papa wants others to see the potential that hides within his grandson. Seeing only behavioral deviations prevents others from finding Javon's hidden genius. Papa believes by harnessing Javon's potential and providing a way to communicate, one would discover his amazing intellect. I have seen this first hand as a teacher. There are children who, at first glance, appear disconnected from their world and their language, and these children possess an unbelievable intellect or an adorable personality. For example, I met a student with Autism and Down Syndrome who could not express himself in English but knew three languages when sitting in front of a computer. I met a young man with Cerebral Palsy and Cognitive Delays who loved playing tennis, racing, and being a prankster even though few people ever played with him. Every family wanted me to know that there is more to their child than meets the eye. Jesse's mom also adds to this, saying, "I think she [Alice] has the capability of helping others in the long run. I think she has a lot to offer, we just have to figure out how to get it from her to where it can be helpful for people." It is our fault as viewers then if we do not see the potential of their child. Conventional expressions of intellect obscure the child's true potential. Our busy schedules and our focus on standard expectations prohibit

us from seeing that which these “beyond normal” children offer. If only we stopped pathologizing and began searching for the masked ability, we too would see what these family members recognized. Each of the families saw amazing abilities within their family member and used me as a vehicle for exposing the life changer, the inspiration, the genius, the person too often overlooked when we look through a standardized lens. Seeing the member for the qualities they add to their family and what they could potentially be in the greater society allows families to look toward the future for their child, something that may be missing as other families search for colleges or watch their child excel in sporting events. They have a family member that may be overlooked and even stigmatized based on what he/she cannot do. The families, by seeing their child as more than tests and milestones dictate, provide a new hope for their own family, their child’s future, and for themselves as parents, grandparents, siblings, and aunts.

Beyond Normal for the Child

We don't need a box

And to deal with that [Javon's behavior] every day it takes a strong – a really strong — person. And it takes a lot of network of people for support (Javon's Grandfather).

As Javon's grandfather indicated above, caring for Javon's needs is a challenging job that requires both individual strength and the support of a caring community. As demonstrated in chapter 3, when Javon moved in with his grandparents and young Aunt Gilly last year, their family life was completely re-arranged. As Javon's family adjusted to the demands of his high energy, disruptive behaviors, and lack of vocal communication, they acknowledged that their work was exceptional and must be handled by strong people and supported by others. The families in this study not only described their family member as exceptional, they conveyed familial and professional interactions that exceeded traditionally expected levels of attention. Every family member that I interviewed chronicled the extraordinary care that they provide to their family member with needs. The families described caring for their loved one through acting beyond conventional thinking, situating themselves "outside of the box." As a unit, the families expressed their ability to handle challenging medical and behavioral issues by using their creativity and facilitating interactions with extended family members and friends. Researchers analyzing mother's of children with disabilities have found that positive perceptions of their family member result despite the amount of work involved (Butlas & Pohlman, 2014; Green, 2007; Kelly, 2005). Kelly, Green, and Butlas and Pohlman find that the family's work exceeds normal expectations of care and may pose specific

challenges, yet the family member willingly assumes his/her role and sees it as a valuable contribution to someone who adds tremendous value to the lives of all family members.

The families in this study were willing to go the extra mile for their family member and expected the same level of creative thinking and dedication from the professionals who supported their child. Corroborating the work of Kelly, Green, and Butlas and Pohlman, Bethany and Decker's family members explained how they have trained themselves to think imaginatively about their family member with needs. For example, Bethany's grandparents discuss how they helped Bethany engage in family activities. Nana commented, "It's adapting to her needs. You have to remember with kids with special needs – or any kids anyway – you don't need to stay in defined traditional roles to make things work for them. I think that's the way we tend to support: is thinking outside of the box type of mentality." Bethany's grandparents believe in engaging Bethany in all of their family activities and work to achieve that through adapting to her needs. Their ingenuity permits Bethany to go fishing, bake cookies, ride on a motorcycle, and enjoy Easter Egg hunting with her neurotypical cousins and sister. Bethany's grandparents gladly shared the ways in which they individualized their family egg hunts for each of the grandchildren. The older grandchildren are sent seeking through the woods, across acres of property while the younger children are kept close with color coded eggs. Bethany's hunt is not as far as the older children's, but she is still sent around the yard, close enough so she doesn't tire but farther than her younger cousins. Each child must find their colored egg, read the clue, perform a series of actions, and continue until they find the last clue that leads to their reward. Nanny and Poppy confessed that the egg hunt now takes two hours to prepare but they are happy to provide the fun for the

grandchildren. Poppy reiterates Nanny's belief in "thinking outside of the box" by asserting, "That's the way it has to be. If it can't work the traditional way, find some way that does make it work!"

Rachel and her wife, Sandy, also think creatively when functioning as a family unit with their sons with autism. Rachel described her family as, "Creative, very creative, considerate, and appreciative of each other and ...We don't believe in a box." Rachel and Sandy spent a considerable amount of time thinking of their children's needs and the unique ways of accommodating them so that their sons could express their abilities. For example, once they provided Deker with a speech to text computer application named, "Dragon Speak Naturally," he was able to write stories that went from "two sentences to two pages." Pacing back and forth in the living room while speaking his stories has resulted in what Rachel described as "creative writing stories that are fabulous!" Also, Rachel detailed, for Elijah, "who always collected things, we had made in the attic of the garage his creative space. He would take soda cans. He would cut soda cans into shapes and cut them up with scissors or whatever he had." This, Rachel boasted, probably resulted in his attendance in and completion of a welding school. For Rachel and Sandy, their sons benefitted both artistically and academically from their creative thinking. The families not only see their family member as beyond normal; they also see themselves as thinking beyond normal boundaries of family engagement. Although their family member may need additional help or more space than their other children, Bethany's grandparents and Deker's moms are willing to think outside of the confines of normal family interactions. Likewise, the families expect the same level of care and devotion from service providers.

Beyond Normal Professionals

Supporting the families in this study goes beyond the dissemination of information and provision of services and medicine. The families emphasized the importance of personal interactions and care that transcends the office and the classroom. The literature on families of children with disabilities explains that families feel that personal interactions with service providers are tantamount to best practices. For example, in their study of families of children with special needs, Nelson, Summers, and Turnbull (2004) found that “professionals who go above and beyond are perceived as having a genuine interest in the child and family as persons” (p. 161). They argue that some participants “appeared to welcome the idea of developing friendships and family-like relationships with professionals serving their children” (p. 162). The families in this study certainly welcomed friendly interactions with their medical and educational staff.

Richie’s dad, for example talks about the nurses in a large city hospital:

It’s a huge hospital. You walk into the cafeteria that holds 1000 people and you can count 20 people that know our name or Richie’s name. We haven’t seen them in six months or a year or what not. And when we walked into the emergency room this last time there’s nurses that all know Richie’s name and they came to see if everything was alright. They knew we were going to be there for a while so they tried to set up events or activities for Richie throughout our stay. It’s kind of neat!

Richie’s family felt comforted knowing that even in a large city hospital there are people who remember them by name and appear to be truly interested in their child’s wellbeing. Additionally, the nurses arrange outings for the family when they stay for extended periods of time. Richie’s parents mentioned trips to the zoo and baseball games arranged by the nursing staff. Nurses have also offered Isabel and Carl an opportunity to escape for a date night. Although they did not feel comfortable leaving Richie, they appreciated the

offers to leave the hospital for the evening. Richie's family spoke little of the medical knowledge of the professionals in the hospital but could rate each one on his or her personality, good humor, and willingness to establish a friendly rapport with them. Similarly, Sharon and Phil's mom, Diane also favored personal involvement from her service providers. She speaks about the extra steps that her case manager has taken saying, "he cares about the family as a family. It's not just Sharon and Phil. He'll call me up and ask how are YOU doing... I am not concerned about Sharon right now. I am really concerned about how YOU are today." Diane's school case manager not only provides the necessary educational resources to her two children but offers a personal connection with the entire family. By taking time to see how Diane is feeling, the case manager establishes a relationship based on trust that makes him more than an educational resource. Diane feels truly supported and believes that her case manager will provide the best educational options for her children. Having never met and lacking the ability to assess the nurses and case managers' performances, I cannot conclude whether they are truly skilled at their professions; however, the families are quite satisfied with their services. The personal relationship between families and service providers also manifested as a salient feature in family/teacher relationships.

In this study, I found that service providers take on roles that far exceeded their "normal" job description. From medical providers to teachers, parents appreciated when their service providers provided ancillary care. According to the participants in this study, the role of the special education teacher often involved much more than educating children according to state standards. The admired special education staff provides after-hours counseling to the parents and may also offer babysitting services. Although I heard

horror stories of teachers who were unresponsive, did not follow the child's IEP, or were unable to provide an appropriate education, the families could all name a teacher who was able to provide their child *and* their family with the support they needed. Hillary explained how she developed a strong relationship with her Early Intervention providers, creating a team of people on whom she continued to rely for years after. Hillary described a time when she was really upset about insurance funding, "I contacted the people [Early Intervention team] and they calmed me down. It was so nice that I could still have a relationship with those guys and they could make me feel instantly better just hearing their voices." To Hillary, the Early Intervention team was like a family member or a good friend on whom she could depend when she was troubled. Even if the team was unable to correct the insurance problem, they were able to ease her mind and provide her with the emotional support to continue the struggle for funding.

Another relationship that transcended the boundaries of educational services was that of Ms. Alman and her staff who taught both Javon and Bethany.²⁸ Bethany's mom, Susan, commented, "Ms. Alman has been great! She checks her email at night. She checks her email on the weekends. Things like that. And you know, realizes that it's not just a 9-5." Susan also described times when she was frustrated with her daughter and complained to Ms. Alman. Ms. Alman provides the support and encouragement that Susan needs. Susan appreciates that her daughter's teacher is available beyond school hours for academic and personal matters. According to Susan, Ms. Alman is the best teacher that Bethany has ever had. Ms. Alman's support extends beyond emotional care of children and their families. As a matter of fact, Mrs. Alman told me that she

²⁸ Ms. Alman taught mainly middle school students ages 10-14 yet Javon had such difficulty in other classrooms that Ms. Alman's self-contained classroom was the only option for him.

understands that parents need a break and welcomes students into her class even when they are sick to provide parents with respite care. Some parents were even able to obtain full time employment because the children were in her class. Javon's grandmother corroborated Susan's comments and spoke to the assistance that Ms. Alman and her staff provided that went above-and-beyond. First of all, Ms. Alman came to their home to meet Javon before he entered her classroom. Not only did Ms. Alman establish a relationship with Javon, she provided his family with strategies that facilitated the transition from his mother's home to his grandparents' home and helped his grandparents understand how to live with a child with autism. Javon's grandmother exclaimed, "the school has been absolutely amazing with him and again I can't say enough!" Many times she attributed Javon's success to the school. Patty explained that not only do the teachers help during the school day, they also provide assistance at home. When she needed to go out-of-state to attend an event with her daughter, the para-educators at Javon's school stepped in as childcare providers during a school vacation. Patty recounted, "The girls in the school down there when I needed someone for him, they did my [childcare] so my husband could go to work. They took him from 8 am to 5 o'clock at night...They did that for him. They worked their schedule for him." The parents in this study were grateful for the relationships that their child's educators created. It is important to note that there was no information provided about technical aspects of the special educator's job, like knowledge of curriculum, application of evidenced based practices, or adherence to state standards, rather the families were grateful to teachers who established relationships of support and encouragement. The families truly appreciate the "beyond normal" relationships with medical and educational professionals. But what happens when a

service provider can only provide minimal assistance or a child is not an inspiration? What are the consequences of beyond normal expectations for children and the people that help them? In contemporary society, where the values and salaries of teachers are hotly debated, I wonder how we can ensure such a level of commitment when teachers are both criticized and already complaining of the poor pay for the amount of work they do. Buried under a sea of paperwork, threatened job performance based on test scores, teachers have a difficult time managing their work in the classroom let alone developing relationships that place them in a counseling, babysitting, and afterhours support group position. As politicians seek to enhance the United States educational system, perhaps discussions of relationships and work beyond the school day should factor into both the teacher's job description and their annual salary.

My Child is Better than That

Let me tell you something, I'd rather have my kids than have the sass of their kids any day of the week (Diane).

Diane's comment above and the one that opened this chapter reflect her perception of her children's beyond normal qualities. She feels that her children's personality traits are superior to neurotypical children for they "love unconditionally" and they show greater respect toward others. Here, Diane's comments reveal that her neurotypical nieces and nephews have personalities that she would prefer to avoid. Her nieces and nephews failed to see the abilities that her children had referring to Sharon and Phil as "handicapped" and "retarded." She would prefer to have her own children, whose communication styles differed from the norm, than hearing the "sass" and hurtful words of her nieces and nephews. Additionally, their uncle described Sharon and Phil as "better mannered" than his own children. Diane chooses Autism over their disrespectful attitudes. She places neurotypical children in the abnormal preferring to keep her children as they are, without the "sass," lack of manners, and poor word choice. Diane perpetuates the stigma between one group of people over the other by placing her children as exceeding normal while stigmatizing those who may not possess the same manners or respectful dispositions as her children. Comparing her children to other children, Diane confided, "They're not jaded. Life has a tendency to callous. I think that's where I might be fortunate." The families in this study continually negotiate the hegemony of normality: trying to place themselves within normal, creating their own normal, and exposing how their lives are beyond normal. Yet, these negotiations among the families may relegate others to a less than normal category, one that is less preferable than their children's beyond normal traits. While the families described their child's amazing qualities, children lacking a diagnosis

and possessing specific labels, or parents who lacked motivation became the culprits of abnormality. As Davis (1995) argues “our construction of the normal world is based on a radical repression of disability, and that given certain power structures, a society of people with disabilities can and does easily survive and render ‘normal’ people outsiders” (p. 558). Davis asserts that you cannot have normal without abnormal. In defining themselves along the spectrum of normality, other families and other children may become “outsiders.” Discussions in which the family members imbue superhuman qualities upon their family member with a disability creates another deviation from typical, one that classifies other children as atypical or, at the minimum, lacking in character if they cannot provide the same magical, inspirational, or life changing experiences that their peer with a specific medical or behavioral condition offers.

In a time when parental culpability for their child’s deviations from the norm runs rampant, situating oneself within traditional family life, or even within family life that exceeds expectations, benefits both children *and* parents. Judith Warner’s (2005) work that details the anxiety ridden mothers of Washington D.C. notes that, “turn of the millennium parenthood is all about performance. Our performance and our kids’ performance” (p. 197). This performance, Warner argues, determines the successful from the unsuccessful mothers. She asserts, “What’s really unique about maternal anxiety today is our belief that if something goes wrong with or for our children, it’s a reflection on us as mothers” (Warner, 2005, p. 191). Concerned with maternal image, image of children, and the reflection of this image on families, parents go to great lengths to convey their child’s unique contributions to the family and community. Although the literature focuses heavily on mother’s work in creating an image of worth for themselves

and their child, I have found that all members that I interviewed – parents, grandparents, siblings, and aunts – illuminated the worth of their families and their child with diverse abilities. Each member sought to counter flawed perceptions of family life by highlighting their work, their child’s work, and their family’s unique traits. As families work to create their own image of family and daily life, they may be neglecting the value of other families. Other disability studies researchers have supported this claim. For example, in her auto-ethnography, Zibricky (2014), discussing her role as a mother of a child with disabilities, disputes Erma Brombeck’s “The Special Mother” article that asserts that God specifically chooses mothers of children with disabilities. Zibricky posits that this “divides mothers, creates stigma, discrimination and inequalities within motherhood” (p. 43). If family members are seen as special because they are related to someone with diverse abilities, this, as Davis also warns, will once again separate the normal into the abnormal; thus leading to a stigmatization of people without disabilities or people with different labels of disabilities. Motherhood is hence divided into the specially chosen; or the ones, as depicted in Warner’s interviews, who are trying to clean up the “mess” of creating perfection; or the families that have yet to embrace positive qualities that their child offers.

Stigma also surrounds the use of specific categories of disability creating, as Jesse evidenced, divisions among children whose labels are and are not acceptable. The following demonstrates Jesse’s choice for her daughter of Autism over Emotional Disturbance (ED), thus classifying children with the label of ED as abnormal, something to be avoided. Jesse disclosed the struggle she faced against the ED diagnosis:

And one of the things I had to fight with them [school district] and fight and fight was her primary disability to be not emotionally disturbed...my kid is emotionally

disturbed because of her high levels of anxiety and because she is AUTISTIC (yells the word autistic) Sorry didn't mean to yell, I was so angry...I don't want my kid labeled as Emotionally Disturbed! That is a huge label to slap on somebody. Yeah so is Autism. It [ED label] just doesn't seem as invasive as Autism. She does have high levels of anxiety, clinical levels of anxiety, like through the roof.

Jesse considered the label of autism less stigmatizing than that of ED. Here, she decides how the school will describe her daughter. Although both diagnoses lack a known cause, the ED label is fraught with a history of ethnic bias (Mandell, Davis, Bevans, & Guevara, 2008), parental stigma (Crawford & Simonoff, 2003; Moses, 2010), and misidentification (Kauffman, Mock, & Simpson, 2007). The label of ED has been implicated in more restrictive educational placements (Praisner, 2003) and students with ED have been found to be less accepted by their peers (Moses, 2010) and treated differently by school personnel (Praisner, 2003; Moses, 2010).²⁹ Choosing a child's label is not specific to Jesse nor is it a problem of the twenty first century. Historically, parents have been known to prefer one diagnosis over another as to not implicate themselves in the child's disability. Social standing, for example, was (and still is) a parental motivator in labeling children with specific diagnoses. Prescott argues that, "upper-class parents found a diagnosis of SLD [Specific Learning Disability] more favorable than alternative explanations of school failure, which blamed poor academic performance on emotional conflicts, bad parenting, and low intelligence" (p. 57). The reputation of the parent played an integral role in the application of different categories of disability. If a child's label implied poor parenting, a medical diagnosis relieving a parent from blame would be preferable to the parent.

²⁹ The defining characteristics of Emotional Behavioral Disorder (originally named Serious Emotional Disturbance and Emotional Disturbance) are imprecise as they result from subjective measures of behavior (Kavale, Forness, and Mostert, 2005). For a detailed description see Clough's (2005) Handbook of Emotional and Behavioural Difficulties.

Prescott reiterates the importance of parental reputation stating that, “having a delinquent child was a sign that the parents had failed to cultivate middle class standards of child nurture and parental conduct” (p. 90). This issue of reputation is particularly salient when considering rates of autism diagnoses. The use of disability classification as a way to enhance social standing has also been applied in debates over the increase of autism rates. Silverman asserts that “others have argued that introducing autism as a category in special education records in the United States and the social stigma of mental retardation led parents to push for autism diagnoses and doctors to accede to parents’ wishes, encouraging the false perception of a real increase in autism” (p. 48). Furthermore, Shattuck (2006) found that “shifting identification” from Learning Disabled (LD) and Mental Retardation (MR) to Autism led to an increase in autism rates rather than an actual autism epidemic. Parents, at times, have taken classifications of disability and applied it to meet their personal aspirations. Classifications are interpreted through broader cultural lenses of race, power, and gender. Whatever the motivation for one disability label over the other, children continue to be stigmatized based on disability classification. As evidenced by Jesse’s determination in relieving her daughter from the ED classification, even the families that are fighting against their own stigmatized label denigrate specific labels of disabilities.

Avoiding stigmatized labels meant that parents could be opting for a more medically involved diagnosis rather than admitting that one’s child may just have a behavior problem. Franklin also questions the role and motivations of parents. He describes that, “By explaining the school failure of their children as learning disabilities, suburban parents were able to rescue from imminent collapse the dreams that they held

for their children and for which they had sacrificed their financial resources and emotional well being...Post-World War II suburbanization certainly could have created the social conditions that spawned the learning disabilities movement” (p. 72). As noted above, parents seek to remove personal guilt for having a child that fails to live up to academic, behavioral, or medical standards. They look to labels and categories to make sense of their role in the disability as well as a way to perhaps de-stigmatize their child or themselves. Although Jesse was the only parent in this study who blatantly denied one category of identification over another, many of the other families celebrated in finally receiving a label for their child’s observed deviations from conventional expectations of behavior and development. Rachel, for example, joyously recounted the day that she and her wife received the Autism Spectrum Disorder (ASD) diagnosis for her nine-year-old son who had been displaying delays in toilet training, inappropriate social interaction, and sensory integration difficulties. Rachel explained, “Some people are totally devastated when they get the diagnosis. We practically celebrated (speaking in a relieved voice) Oh, that’s what it is! Is that all...ahhh (she giddily says, laughing).” It was as if all the difficulties and deviations from expected milestones and behavior could be explained by one label. Although there are no cures and no medications to specifically treat ASD, Rachel and Sandy were relieved that their son’s behaviors finally had an explanation. Indeed, it was not their parenting or Rachel’s divorce; it was ASD.

Even the parents whose children have rare genetic disorders were relieved to finally have a name for their child’s differences in behavior, cognitive, and/or physical regressions. The mothers of Leila, Richie, and Connor, despite receiving news that their child’s illness was terminal and had no known cure, were elated to finally name the

disorder. These three moms even advocate at the local and national level for the creation of a rare genetic disorder database so that other families can more readily label their child's disorder through the input of symptoms. Being able to name the disability may provide some respite from the confusing aspects of disability but none of the labels provided much guidance. The guardians whose child has autism continue to "muddle" through "trials and errors" and the children with medical labels continue to baffle medical professionals and family members. The families treat symptoms as they arise but at least they have a name for their child's differences. For the behaviorally deviant, the diagnosis provides a reason why their child is not progressing or behaving like his/her peers. It is neither the child nor the parent's fault; they have medical evidence that their child's misbehavior is not a family or child flaw. The families, upon finding a medical diagnosis, first of all felt relieved that they had a name to which they could focus their efforts toward a cure. Secondly, the named diagnosis validated the parental concerns. No longer the mother who was overly worried about a little gas (Leila's mom) or a parent overly concerned about a small seizure, they had a diagnosis that verified that they were not exaggerating their child's complications. Though stigma accompanies disability, the families could avoid the stigma of being overprotective, hypochondriacs, and/or ineffective guardians.

Furthermore, it is not only the child's label that separates one family from another. While the families in this story told of their child and their family's feats of beyond-normal interactions, some families who may have been struggling were dismissed as inferior. If families of other children with diverse abilities did not live up to expectations, the families who participated in this study relegated them to classifications of "less than."

When discussing support groups, all but two of the families disputed their benefits. Guardian responses to support groups exemplified the problems that may arise when families focus on beyond ordinary characteristics of their child or themselves. Jesse explained why she did not attend the local support group, “I get a feeling that a lot of people there were just treading water and maybe they were. Their life stories are probably totally different than mine but I didn’t feel like they had the same expectations for their kid as I did for mine.” As Jesse navigated the world of special education and provided for her child, she separated herself from the families that she perceived as not holding their child to the same high expectations that she held for Alice. Since the families in the support group had yet to acknowledge the untapped potential of their child or failed to see their child as a life-changer or a source of inspiration, my participants generally felt that they diminished the worth of the support group. Rachel reiterated the anti-support group sentiments claiming that she felt the attending families were too negative. For example, Rachel discussed how she and her wife ceased support group attendance because their outlook conflicted with other families. She explained,

We felt that we were sort of the positive voice. There was a lot of kid bashing and a lot of negativity and a focus on the weaknesses. And it was kind of draining for us because we were already fighting against the school. We were fighting... It was already hard. We didn’t need to go to another place that felt hard. Even though it was called a support group it felt like we were kind of supporting other people.

Although Rachel mentioned that she would willingly support others, she could not attend another support group meeting since other families’ negative perceptions conflicted with her families’ focus on the positive. Her family embraced the unique, beyond normal qualities of their two sons with diverse abilities. While avoiding their own stigma, families may inadvertently stigmatize children and families who are also muddling

through conceptions of normality. As evidenced above in Diane's quote about her children loving her forever and Rachel's focus on their family's acceptance of diverse abilities, stigma avoidance may inadvertently enable some to devalue other families.

Even though support groups were intended to support families as they navigate through the world of disability, many of the families in this study found it difficult to attend. As noted above, both Rachel and Jesse found the parents and guardians of children with disabilities to be negative and to hold their children to lower expectations. A common theme that also surfaced was that of "whining" group members. Isabel commented that, "they can drive me nutty in there." As the families grapple with their normality, creating their own normal, and finding themselves in the midst of beyond normal children, family, and community, they failed to see the worth in groups specifically designed to meet their needs. The stigmatized becomes the one who stigmatizes: the families find themselves bothered by the actions of the other parents in the group, parents whom themselves are trying to find their way through the maze of disability resources and conceptions of normality. In discussing the relationship to other stigmatized persons, Goffman (1963) argues that "whether closely allied with his own kind or not, the stigmatized individual may exhibit ambivalence when he obtains a close sight of his own kind behaving in a stereotyped way, flamboyantly or pitifully acting out the negative attributes impute to them. The sight may repel him, since after all he supports the norms of the wider society" (p. 107-108). The families in this study choose to adhere to conceptions of normality, forming their own beliefs of what constitutes a successful support group. They are "repelled" by families who may manifest behaviors and perceptions that they have worked diligently to avoid. As they seek acceptance by the

wider community, they may be distancing themselves from people who “degrade” their efforts at normalization. Seeing their families in a glorified light may perpetuate the stigma of disability for families who have yet to achieve this understanding. Overall, the families find that the local support group provided little to accommodate them. Whether their families differed in ability, age, expectations, or personality, all of the families but Leila’s mom and one mother who works supporting families agreed that they did not prefer to attend the local support group.³⁰ Sadly, the support groups in this small rural area failed to meet the specific needs of the family. The majority of support comes from family, friends, and service providers that provide exceptional attention and care to the family. The judgment of who is and who is not worthy presents itself even among the families that are themselves trying to avoid stigmatization. Although Jesse and Rachel accepted their children for who they were and held them to high expectations, they were unable to appreciate the struggles of families who did not interpret their children and families in a similar way. The families thus contributed to the stigmatizing of worthy and unworthy family life. The families in this study have invested in their child and in their child’s future; however, some families are not as fortunate to have the time, the money, or the intellectual capacity to accommodate their child with needs. To complicate further, the hard work that is referenced also comes at a price: the families often mentioned the absence of quality respite care providers. What happens when service providers fail to meet the beyond normal expectations that families hold for them? Unfortunately, beyond normal care leads to the belief that others pale in comparison.

³⁰ It is important to note that Heidi, Leila’s mom, had the youngest child, a two year old, and her town did not have a support group. She was in the process of organizing one. Some research points to the age of children as a factor in determining support group membership but in this case, many of the families ceased attendance when their children were toddlers preferring online support instead.

Workers

Freaks of nature who can't get a job anywhere else because the only job they can get where they're making decent money as a punching bag and collect a decent salary (Diane speaking of respite care providers in her area).

As Diane indicates above, finding quality respite care providers is a daunting task. She was the most outspoken of the family members seeking quality care but the theme also surfaced throughout many of the interviews. Diane's comments speak both to her feeling of resentment toward the unqualified personnel hired to help her two children with autism and to the work that the personnel must complete. The term "freaks of nature" indicates a lack of respect for the people coming in to her home. She has had some pretty unfortunate interactions with people hired to assist her. Furthermore, seeing the respite care provider as a "punching bag" reveals that they are hired only to maintain a specific behavior than to encourage appropriate means of communication and interaction. Although the state provides sufficient funds for respite care providers, families found personnel to be less than willing to do anything more than just sit with the child. I silently wondered, "What would one accept as payment for serving as a punching bag?" As the families recognized that they were "beyond normal" and began to meet service providers that provided exceptional care to their entire family, other service providers were found to be lacking if they did not establish the same relationships with the family. Even Javon's teenaged aunt, Gilly, discussed the incompetent childcare providers, "you can't sit on your phone and babysit him because some of his babysitters did that...and I feel that they should be active and we just need to find a good babysitter for him." After experiencing school personnel and community members that go above and beyond for

them, the families have high expectations for other service providers; thus, leaving the families with very little personnel from which to choose when seeking respite care.³¹

Teachers and service providers are also cognizant of the problems that arise when professionals do not go above and beyond for children with diverse abilities. Ms. Alman discusses her fears of sending her students to the high school, acknowledging that the high school staff does not create the same warm atmosphere that she and her staff had created. Ms. Alman lamented,

We're sending some of our babies to the high school and we don't know if they're going to take care of them the way we had. And we really had battles with the high school. You know, you really have to develop a rapport and relationships with these parents. You know these parents have to trust you. I am not so worried about the transition of the kids, I'm worried about the transition of the parents.

Ms. Alman is well aware of the problems that arise when teachers fail to develop relationships with parents. Ms. Alman discussed ways that she could improve the transition but she felt that the staff at the high school was unwilling to go above and beyond for the parents. The parents have been accustomed to a teacher, a friend, a counselor, and a child-care provider. After the transition of their child to high school, they will be left to fend for themselves, engaging in another battle to secure services that will lead to successful academic and social outcomes for their child. Although forming strong relationships with students and families will undoubtedly lead to more comfortable working relationships, the question remains, what is the role of the educator especially as the students move into high school? Is it possible to teach both higher-level academic material while maintaining the relationship needs of the parent and the student? Or should relationships be the focal point of the student-teacher dyad? Should teachers be

³¹ The lack of training for school personnel has also been documented in the literature. See Giangreco & Boer (2005); Giangreco (2003).

expected to be everything to the parents, the family, and the child and if so, where can one fit in material dictated by the Common Core State Standards? Even though I advocate for and have witnessed the benefits of creating strong relationships with students and their families, the immense amount of servicing that special educators must provide can be overwhelming. Perhaps special educators are providing a disservice to families by continually holding their hands; the special treatment may further alienate students with diverse abilities. Meeting the diverse needs of students, guardians, and curriculum undoubtedly requires a beyond traditional balancing act.

Conclusion

Through this chapter, I sought to highlight the many positive attributes of the family system of children with diverse abilities. The child, the family, and the professionals that serve them each contribute to the functioning of the system. Davis (1995) questions why we only see people with disabilities as their disabilities, using the example of Helen Keller and her neglected political beliefs³² or in the case of successful people with disabilities, they “have their disability erased by their success” (p. 335). By promoting the beyond normal qualities of the child, the outside of the box thinking of family members, and exceptional care provided by certain professionals, it is my hope that families of diverse abilities are seen not through their disabilities but through the positive attributes that arise when the family unit interacts with each other and their community. However, it is also important to keep in mind that while we promote the exceptional qualities of some families, we should be aware of the implications to families and providers who are not able to function as productively. We should be aware of the complexity involved in labeling and take caution as stigma avoidance may relegate others to positions of “less than.”

³² “She was a socialist and believed in free love” (p. 301/3515).

Chapter 5: Practical Implications for Honoring Varying Degrees of “Normal”

The families in this study graciously opened their homes to me, dedicated time to help in completing my study, and eagerly shared stories of loved ones that may go unnoticed when observed through an educational lens. By expanding beyond my focus of educational services, I found stories that needed to be told. Families conveyed to me that they intentionally created a family life that encompassed more than their child’s special education. These stories implicate conceptions of normality in families’ navigation of childhood and family life. In an attempt to avoid stigma, family members engaged in what they believed to be traditional childhood activities, created their own sense of normal everyday life, and exposed how their child, their family, and their community were “beyond normal.” The emerging field of DCS allows for children to be seen beyond universal prescriptions of development, thus advancing an understanding of the every day lives of children and their families. Numerous researchers, who purport that families’ lives are much more than disability, have encouraged this nuanced view of family life (Green, 2007; McLaughlin and Goodley, 2008; Jenks, 2005). Landsman (2005) calls for research to highlight “the everyday experience of interdependency...to reexamine the identity of disability and create a more inclusive world” (p. 139). By examining stigmatized families through a FST lens, I provide new examples of everyday family interactions to expose diverse childhood experiences. It is my hope that the portrayal of varied types of normal, new normal, and beyond normal qualities discussed by the families lead to social acceptance of family’s diverse lived experiences. The following sections describe the theoretical and practical implications of this work as well as suggestions from my informants and future research recommendations.

Theoretical Importance

This work adds to the burgeoning field of DCS by providing an analysis of normality, adding to the ever-growing definition of family life, and encouraging the examination of parental involvement through a family focused lens. Thus, this work heeds the call of scholars who urge researchers to continue molding of the field of DCS through new frameworks to analyze the lives of children (Watson, 2012). First of all, by rejecting binaries of normal and abnormal, I found that families define their “normal” along a continuum; this led to my analysis of their interactions through the conceptual framework of a “spectrum of normality.” They do not perceive their lives through the rigid classification of normal or abnormal and their daily experiences do not adhere to a linear trajectory. I argue that families’ narratives about everyday life fall along a spectrum of normality as individual members analyze and negotiate encounters on a moment-to-moment basis. Through listening to families, we learn that their lives manifest in relation to community norms of the ordinary, their own version of typical, or through “beyond normal” behaviors and interactions. Thus, researchers can provide a venue through which families and scholars challenge assumptions of normality. For example, Haraldsdóttir (2013), advancing the theoretical importance of DCS, posits that “[i]t is important to challenge these disabling reactions, both so parents have the courage to stand up for their children and so disabled children will not be violated the right to be human beings – not impairments. Simply children” (p. 21). By examining the ways in which family members reacted to prescriptions of normal, I have provided a framework in which both researchers and families can interrogate how conceptions of typical childhood influence families to construct their own visions of family life.

Secondly, this work adds another dimension to the definition of family. As indicated by Solomon (2012) stories must continue to be told so other scholars may appreciate the varied lived experiences, multiple constellations, and interactions of families. As noted by the myriad family constellations, roles, and relationships present among my respondents, families in this study undoubtedly shed new light on definitions of the family. My participants create and recreate their family structure and its members to meet the needs of their unit. Families were fluid and membership shifted over time. Rooted in queer kinship scholarship, Weston (1991) speaks to the importance of recognizing different familial configurations by acknowledging the varied interactions and commitments that lead to the “families we choose.” The families in this study extended beyond the immediate family with many players actively participating in the creation of ordinary family life experiences. Not only do individual members enter and leave the unit, their roles transform to meet their many needs. White argues for a contemporary understanding of family life, rather than the historically founded myths that we employ to engage in family time. The author asserts that, “Traditions must be constantly renegotiated if they are to be effective” (p. 9). By acknowledging the families’ traditions, their creation of new traditions, and their perceptions of beyond normal children, family, and community, this work provides a nuanced view of childhood as it is experienced through the family unit thus expanding the definition of childhood and family life. Contributing to FST, this work expands the boundaries of how scholars view families. My study views families not only as a system but a system whose members actively contribute to the creation and re-creation of a functioning unit. Therefore, each member is an active force in the family’s evolving identity.

Adding to the field of CS, this work provides another dimension of the multiple lives that children lead. The childhoods that families attempt to create for their child with complex medical, behavioral, and cognitive needs are influenced by typical constructions of childhood. Every member of the family brought to their unit the ideal of childhood engendered by their past, their rural location, and/or the middle class communities in which they lived. However, their everyday experiences of disruptive behaviors, illness, or cognitive delays resulted in the creation of a new normal. By portraying their new normal, this work affirms the diversity of lives that children and families lead. Childhood, I argue, is influenced by when, where, and how the child and the family engage with each other and their community. Although the needs of the child may preclude what outsiders perceive as typical engagement with family and community, this work highlights the ways in which diverse abilities contribute the creation of a “new normal” for families.

Lastly, delving into the lived experiences of the families allowed for a more thorough understanding of what involvement actually means. Rather than considering involvement from a strictly educational standpoint, one that views parents as involved or uninvolved based on their attendance at IEP meetings, this study considered the contributions family members made relating to health, hygiene, and recreational activities. As seen in chapter three, fathers engaged in activities within in the home like Bethany’s father who tends to her hygiene needs or Richie’s dad who sees himself as a “behind the scenes” player. These fathers know the medical needs of their child yet have limited involvement with the school. As advocated by Turnbull and Turnbull (1982), if we want to involve parents we need to provide more individualized ways for them to become involved. Examining the individual roles that family members espouse will allow

educational researchers to look beyond the field trip and IEP meeting participation and see involvement as the whole family experience. In respecting the lives of children with complex medical, intellectual, and behavioral needs, researchers and practitioners would benefit from viewing involvement as extending beyond the classroom.

Practical Implications

As a special educator, I originally feared that by telling these stories, I wouldn't add anything to the field. Why focus on something as theoretical as normal when there are interventions to implement, children to teach, families to help? However, as I wrote and considered what was important to the families, I felt that this work's practical implications exceeded any intervention that I could have performed. Although we cannot apply these findings to all families, the stories give insight into the unique needs of particular families. By encouraging families to tell their stories, to understand how they enact and negotiate normal, practitioners can determine what strategies will be the most useful. Disability scholarship advances the use of narrative as a way to successfully work with families. For example, medical professionals, teachers, social workers, and other service providers can embrace the "unique personhood" of the family member with disabilities as a way to enhance empathy (Larson, 1998). Additionally, researchers advocate the use of asking parents to tell their story as a method for creating interventions by providing positive models of adjustment (Sundler, Hallström, Hammarlund, & Bjork, 2013; Woodgate & Degner, 2003), intervening in medical settings (Butlas and Pohlman, 2014), and providing assistance within the home (Bernheimer & Weisner, 2007). Therefore, the story of families and the portrayal of their everyday lives provide a guideline for ways in which practitioners can help families. Furthermore, Jackson, Traub, and Turnbull (2008) argue that families' personal stories result in practitioners developing educational interventions specific to their family of focus. And Landsman (2009) quoting Wayman, Lynch, and Hanson (1990, p. 68), asserts that "understanding a

family's response to their child's disability is important because it affects the kinds of support and services that can be offered" (p.13).

By acknowledging what families need in their daily lives, practitioners can provide services and interventions to promote the family's activities not the activities that the practitioner feels are important. Take Javon's family, for example: they love ice fishing as a family, perhaps their intervention would involve helping them to engage in this activity together. By understanding the families daily "accommodations" service providers can better serve the families with whom they work. Furthermore, such an understanding of families will find practitioners embracing the unique family constellation and roles of the family they are serving rather than trying to fit them into a preconceived ideal of what family is and how they should function. Although school is only a small part of a child's day, educators often feel that it is the only activity to which children and families must attend. This "school-centric" attitude precludes educators from seeing the child as part of a larger system. The lives of children, as detailed in this work, extends well beyond homework and class trips. By acknowledging the myriad involvement of the parents, the knowledge that they have of their child, and the various ways families construct their identity, educators and teacher educators will recognize the important contributions that families can make to their child's education. Before the first day of school, family interviews in which educators simply say, "tell me your story" can both develop relationships and enhance our understanding of families. By knowing the families more intimately, educators can move beyond the child's favorite toy and honor who the family is, engage in active perspective taking, and create relationships that value the child and family for each of their unique characteristics. As described below, my

participants have many suggestions that could potentially benefit their lives and the lives of people with disabilities.

Suggestions from Families

In an attempt to thank the families that shared their time and their stories with me, I have compiled a list of suggestions that they made throughout our interviews. I have also attempted to heed some of their advice like starting a community cheerleading group for people with diverse abilities, professionally acknowledging life beyond the classroom, and advocating for genetic databases and the legalization of medical marijuana. I will continue to try to make an impact in my community from the suggestions that the families provided. But, I do hope that the reader also sees these suggestions and applies them to their local communities. DCS recognizes the importance of listening to children with disabilities. Runsiwick-Cole advises, “Disabled children’s childhood studies are about what disabled children want, and the reflexive research processes used to illuminate the connections between disabled children’s lives and services” (p. 129). Although this work sought the voice of family members, their suggestions may benefit researchers and practitioners as we move forward in serving people with diverse abilities. The following suggestions are not listed in any particular order:

- Bethany’s father and Sharon and Phil’s mom recommended more recreational opportunities for their children. Diane lamented, “There aren’t the supports for my kids to have the same fun as other kids.” Javon’s aunt Gilly also advocated for Javon’s recreational experiences; she wanted to provide him with “opportunities to be a normal kid.” Acknowledging the dearth of social interactions, families recommended organized social opportunities: like a buddy system to pair students for lunch or academic

activities, a sleep over for children who aren't regularly invited to sleepovers, or a Special Olympics' cheerleading team.

- Every participant mentioned the lack of quality personnel. Patrick's mom suggested having more alternative service providers like music therapists and the need for summer time care. Javon's grandmother recommended more training for people who provide respite services.
- Leila's mom and Javon's grandfather both questioned what it means to be handicapped accessible. Heidi complained about the playgrounds that may purport to be handicapped accessible but really aren't. Accessible varies according to the person: Javon really dislikes the noise of hand driers in public restrooms while Leila has poor head control and would need head support on a playground swing. Families advocated for a more nuanced application of accessibility.
- All of the guardians utilized the Internet. Many "Googled" their child's symptoms and rare genetic disorders to arm themselves for doctor's visits or to find other families in the same situation. Parents recommended the use of online support groups for families who were newly diagnosed and those seeking more information. Other guardians used Facebook for online support groups and as a social tool when full time care of their child precluded face-to-face interaction with friends. Many guardians, weary from endless late night research, pleaded for a centralized database of information. To achieve this, there were several suggestions:

- Derek and Devon’s mom, Tori, advised, “when you receive a diagnosis families should receive a list of websites and books to help.”
- Connor’s mom suggested an online index where you input child’s symptoms, needs, etc., and it can direct you to a specific website and online information.
- The guardians of children with rare genetic disorders are actively lobbying local and national politicians for a database in which doctors could input symptoms to diagnose a rare genetic disorder more efficiently and promptly.
- “Parents should learn more, advocate, and make time for self care” (Tori). Ms. Alman reiterated the importance of parents taking care of themselves by advising parents to, “accept offers for help.”
- The parents of Richie, Connor, and Leila advocated for the national legalization of medical marijuana to promote the use and trial of Charlotte’s Web.
- To prepare for hospital stays, especially when staying in a hospital’s family housing, Richie’s parents recommended having a bag prepared that includes the following items (Richie’s parents have made care packages for the families in their hospital):
 - A list of local places to eat, rolls of quarters for laundry, phone numbers of doctors, shampoo, soap, and toiletries (many of these they saved from hotel visits).

- Although this may not be possible for all children and their academic needs may differ, Alice's mom claims that Alice benefitted by being in a small school and learning through Project Based Learning.
- The service providers who were also parents recommended building working relationships with teachers. Ms. Alman advised, "Be an advocate, without being an adversary."
- Rachel and I discussed a child-rearing utopia where family and community provided support to children. While discussing the need to support all parents, not only those who have a child with medical, behavioral, or cognitive needs, Rachel excitedly asserted, "We're tribal people...Nobody can do this alone. We weren't meant to do this alone!" If everyone looked out for the safety and well-being of children and their families, there would be less hurt, Rachel argues.

Whether the suggestions stemmed from dreams of social change, like Rachel suggests or practical recommendations to meet the social, medical, or academic needs of the child, the families in this study brought forth suggestions that could potentially enhance the lives of not only their child, but many children with diverse abilities thus confirming the advice of researchers who believe in the power of families' stories to aide in interventions. Every family had an idea to help. Perhaps the simple act of listening will aid in both educational and social reform for children with diverse abilities.

Future Research

Born of DS and CS, DCS provides a framework for encouraging child and family research. This study provides only one layer in understanding the lived experiences of a child with diverse abilities and his/her families. Following the DCS model, listening to the child will be the next step in this research. However, without their families' input, I would be neglecting the unit that mediates daily life and care for children with such complex needs. It is my hope that future research extends the families' understanding of ability and closely analyzes the ways that negotiations play out in the lives of children with complex medical, behavioral, and cognitive needs. As most of the children in this study were non-vocal, the studies will be time-consuming. Researchers must first learn the nuanced ways that the children communicate, but must also include careful observation, and continual conversation with the family members to confirm findings and beliefs as to what is occurring. Furthermore, I would like to focus on providing the stories of mothers of varying socio-economic statuses. As Sousa (2011) asserts in her work, memoirs permit "a uniform intention to seek out new cultural awareness and normative practices that allow families to engage in cultural conversations about parenting in ways previously unavailable to mothers of children with intellectual disabilities" (p. 231). Hearing an array of parenting stories, not only ones that conform to standardized expectations of family life, provides insight into diverse childhood experiences; however, memoirs may only be available to mothers who have the time and resources both financial and intellectual to write a memoir. I hope that my future work, as well as the work of other researchers, provides a range of guardians, representing varied economic,

racial, and ethnic backgrounds, the opportunity to share their stories so they may add to the conversation of diverse parenting and childhood.

Final Remarks

I am grateful that I had the opportunity to meet the families that I described throughout this work. Not only have I met truly tremendous children, parents, grandparents, and aunts, I reflected on my own family and my own understanding of mothering and expectations for my children. As my family and I construct what family life is for us, I extend my appreciation to the families that taught me to strive to adhere to a life that I feel is fun and loving, to embrace the difference that is unique to our family, and to see my children for their beyond normal characteristics. I look forward to future work with families, especially considering the voice of the child. I even welcome the opportunity to attend more dance recitals! To conclude this work, I would like to end with sentiments from Bethany's great grandfather. A man, who at 87, fourteen years ago, embraced the world of disability more than many educated people in 2015. I should have known after hearing this during my first interview that my original topic of accessing services would change. Sitting at their kitchen table, Susan recounted the day that her great grandfather met the newborn Bethany in the hospital:

He just looked at her and said, 'She can go to the moon! Just let her define what her issues are... You can't let her be defined by what the books say; let her define the books.'

Appendices

Appendix A: Recruitment Letter

Dear Parents and Guardians:

I am a Professor at Castleton State College working on my PhD in Childhood Studies through Rutgers University. I am conducting a study on families who have a child with special needs and I am looking for people to interview.

My study seeks to understand the social relationships that lead families to advocate for and involve themselves in special education. I would also like to know about the people who provide you with the knowledge about innovations in special education services and technology.

I am hoping to interview guardians and siblings of a child with special needs.

If you are interested in the study or would like to learn more, please contact me:

Leigh-Ann L. Brown
Office phone: 802-468-1356
Cell phone: 609-317-3659
Email: leigh-ann.brown@castleton.edu
Thank you,

Leigh-Ann L. Brown

Appendix B: Correspondence from “Jenny”

I believe you have the wrong Jenny Charmane. I often get the other one's emails. We must have similar email addresses through gmail. I've received hair salon appointment confirmations for her in the past in the Boston area. I live out West, so it was obvious there was another Jenny with a very similar email. Try forwarding this to her but without the dot between the first and last name maybe? I imagine you are trying to get ahold of the same Jenny because one of your phone numbers looks like its a Boston number. I have an aunt that lives out there, so I think I recognize it. Good luck getting in touch with the other Jenny. I actually work with special needs students myself in an Elementary setting. I would be interested in learning the results of your findings. We have encountered some special problems this year as I work in a private school with little funding for special needs, yet many parents find private education as a last resort for their child who has either been kicked out of every other school they've attended for "bad behavior" or parents who are looking to mask their child's autism or hide it altogether by escaping the system that would label them with IEP's, testing, and diagnoses. Its an especially difficult situation for both teachers and students alike. Even though we are not trained in special needs, we as teachers are faced with teaching them because the school is in such dire need of tuition since the recession of 2008. Luckily, this year the school is closing and has opened up a state charter school in it's place. Hopefully we will have the state and federal funding these children so badly need and deserve as special needs students.

Good luck with your study. I don't mean to be presumptuous, but please let me know if I can help supply you with contacts in any way. I know several families with special needs who might be willing to be part of the study.

Appendix C: Interview Items

Interview Questions for Guardians

Introductory comments
<p>Welcome and thank you for taking the time to participate in this study. As you are now aware, the purpose of this study is to gain a better understanding of how families use their social supports to access, advocate for, and involve themselves in special educational opportunities for their child with special needs . I will be asking you some questions that may not be easy to answer. I encourage you to answer to the best of your ability. There are no wrong answers. If at any point you become distressed, we can stop the interview.</p>
<p>Statement of Confidentiality: We will be recording this session in effort to maintain the integrity of your dialogue. However, your identity will remain anonymous and only the researchers will have access to this recording. This discussion is confidential and any information will be solely used for research purposes.</p>
Opening question
<p>At this time, could you please describe yourself and your family.</p>
General Question
<p>Tell me about your experiences having a child with special needs</p> <p>Who is your greatest support?</p> <p>How does your immediate family support each other?</p> <p>Why?</p> <p>Who else do you rely on for help?</p>

Can you tell me about babysitters/family/friends.

Would you mind describing your relationship with the school.

Can you describe your relationship with the community?

Guided domain question

Can we discuss areas of social support? Please tell me about your friends- who are they?

Do they understand special education? Do they provide support? What out of the house activities do you feel the most comfortable engaging in?

Aside from friends and family do you find other areas of social support? (I am thinking of support groups, other families with children with disabilities, teachers, neighbors).

How easy is it to find information about support services/treatments/new technology for your child?

What family members are the most helpful?

What friends are the most helpful?

Any organizations? Support groups? Websites that have helped?

Tell me about your relationship with the school

Are you satisfied with the school? Why or why not?

Are there programs/technology that you would like/would have liked used in the school?

Who in your immediate family is most likely to know of current services/technology?

Who in your social network?

How easy is it to ask for things for your child?

Do you feel that you need to fight for anything? Can you explain why or why not?

Do you feel that you are an advocate for your child?

Tell me about your current advocacy efforts?

Who supports/have supported you in your advocacy efforts?

Do you feel NAME's teacher is an advocate for him/her?

Would you ask anyone for support in advocating for your child? Who?

Tell me about your involvement in your children's school. (iep meetings, field trips, class parties, visits)

-How were you encouraged to become involved

-What would encourage you to become more involved

-Do you see barriers for other parents to become involved

- how would you encourage their participation

Does your involvement in school differ from your spouse?

-Do you wish that they were more/less involved

-How would you change that (if you thought you could)

How are your children involved in NAME's classroom?

Are you familiar with the State Family Network?

-tell me about your experiences with this group

What modes of communication are best for support: phone, text, in person, email, facebook, etc.

Transition Questions

How has this been to discuss your experiences? Do you think you could have spoken about your experiences with your family members, teachers, and/or case managers? Do you have any additional comments or questions for me?

Interview Questions for Siblings

Introductory comments

Welcome and thank you for taking the time to participate in this study. As you are now aware, the purpose of this study is to gain a better understanding of how families help their child with special needs. I will be asking you some questions that may not be easy to answer. I encourage you to answer to the best of your ability. There are no wrong answers. If at any point you do not want to answer a question or do not feel like continuing, we can stop the interview. During our conversation, you can state your answers, draw, or write down words to answer. What method do you feel most comfortable with?

Statement of Confidentiality: We will be recording this session in effort to accurately record your answer. However, your identity will remain anonymous and only the researchers will have access to this recording. This discussion is confidential and any information will only be used for research purposes. A pseudonym (a fake name) will be used.

Opening question

At this time, could you please tell me how old you are and describe your family to me.

General Question

Do you think you help your brother or sister NAME?

How do you help your sibling?

Have you thought of any games, technology, programs in school for your brother/sister?

Did your family listen to these suggestions? Did teachers listen to your suggestions?
Do you have any other suggestions for helping?

Guided domain question

Tell me about your friends

Do they play with your sibling?

Tell me about when you all play together.

Do you play with your sibling's friends?

Do your friends understand your sibling?

Do you have friends that understand more than others?

-Why do you think that is?

Do you have any friends that have a sibling with a disability?

-Is it easy to talk to them about your sibling?

Have you ever helped your parents, your sibling's teacher, or your friends understand your sibling?

Did you ever make any suggestions for playing or learning? Games, technology, programs at school?

Did the adults listen to these suggestions?

-How did it work out?

Do you have any suggestions now to help your sibling in school or playing with friends?

Do you help your sibling out in school

- Do you feel comfortable with your sibling's teacher?

- Do you visit their class- what do you do there?
- Do you know their classmates are you friends with them
- Do you play with your sibling at recess
- Do your parents encourage you to go?
- Do your friends go to the classroom? Do they encourage you to go?
- If they do not attend the same school- do you wish they did? Would you visit them during lunch or recess? Would you discuss strategies for helping with their teacher

Was there ever a time that you had to stand up for your sibling?

Tell me about it.

Would your friends help you?

Would your family help you?

Transition Questions

How has this been to discuss your experiences? Do you think you could have spoken about your experiences with your parents, friends, or teachers? Do you have any additional comments or anything you would like me to know?

Do you have advice for someone else who has a sibling with a disability?

Interview Questions for Siblings- *Drawings*

Introductory comments

Welcome and thank you for taking the time to participate in this study. As you are now aware, the purpose of this study is to gain a better understanding of how families help their child with special needs. I will be asking you some questions that may not be easy to answer. I encourage you to answer to the best of your ability. There are no wrong answers. If at any point you do not want to answer a question or do not feel like continuing, we can stop the interview. During our conversation, you can state your answers, draw, or write down words. What method do you feel most comfortable with?

Statement of Confidentiality: We will be recording this session in effort to accurately record your answer. However, your identity will remain anonymous and only the researchers will have access to this recording. This discussion is confidential and any information will only be used for research purposes. A pseudonym (a fake name) will be used.

Opening question

At this time, could you please tell me how old you are.

Can you draw me a picture of you and your family?

Can you please explain the picture to me?

General Question

Can you draw a picture of you and your sibling.

What things do you like to do together?

Do you think you help your brother or sister NAME?

How do you help your sibling?

Have you thought of any games, technology, programs in school for your brother/sister?

Did your family listen to these suggestions? Did teachers listen to your suggestions?

Do you have any other suggestions for helping?

Guided domain question

Can you draw me a picture of your friends?

Tell me about them.

Do they play with your sibling?

Tell me about when you all play together.

Do you play with your sibling's friends?

Do your friends understand your sibling?

Do you have friends that understand more than others?

-Why do you think that is?

Do you have any friends that have a sibling with a disability?

-Is it easy to talk to them about your sibling?

Have you ever helped your parents, your sibling's teacher, or your friends understand your sibling?

Did you ever make any suggestions for playing or learning? Games, technology, programs at school?

Did the adults listen to these suggestions?

-How did it work out?

Do you have any suggestions now to help your sibling in school or playing with friends?

Can you draw a picture of your sibling in school?

Do you help your sibling out in school

- Do you visit their class- what do you do there?
- Do you know their classmates are you friends with them
- Do you play with them at recess
- If they do not attend the same school- do you wish they did? Would you visit them during lunch or recess? Would you discuss strategies for helping with their teacher

Was there ever a time that you had to stand up for your sibling?

Tell me about it.

Transition Questions

How has this been to discuss your experiences? Do you think you could have spoken about your experiences with your parents, friends, or teachers? Do you have any additional comments or anything you would like me to know?

Do you have advice for someone else who has a sibling with a disability?

Interview Questions for Teachers

Introductory comments

Welcome and thank you for taking the time to participate in this study. As you are now aware, the purpose of this study is to gain a better understanding of how families access, advocate for, and involve themselves in special education opportunities. I will be asking you some questions that may not be easy to answer. I encourage you to answer to the best of your ability. There are no wrong answers. If at any point you become distressed, we can stop the interview.

Statement of Confidentiality: We will be recording this session in effort to maintain the integrity of your dialogue. However, your identity will remain anonymous and only the researchers will have access to this recording. This discussion is confidential and any information will be solely used for research purposes.

Opening question

At this time, could you please state your occupation, what you do in your professional role, and how long you have held this position.

General Question

Can you tell me about your relationship with the NAME family?

Do you feel that your role as an educator is to support families?

Why or why not?

Can you describe how you would support families?

Guided domain question

Has the NAME family asked for any specific program/therapy/technology to enhance the educational outcomes of their child?

Was the school able to provide this to them?

Have you discussed other options?

Would you if you were aware of any?

How involved is the NAME family in the NAME's education

Can you describe their involvement?

Do parents come to parties? Field trips? Assist for school projects?

Do their siblings come down to the classroom?

Can you describe what they do/how they interact with their sibling?

Do they bring their friends?

Do you encourage involvement?

Why/Why not?

How could you encourage parents to become more involved?

Would you consider them advocates for their child?

In what ways

Do you feel that you have encouraged this advocacy?

In what ways?

Do you consider yourself an advocate for NAME?

Can you explain your advocacy efforts?

Would you like to be involved more/less?

What would help in advocacy for NAME?

Transition Questions

How has this been to discuss your experiences? Do you think you could have spoken about your experiences with other faculty members or administrators? Do you have any additional comments? Suggestions for other teachers?

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Education

PhD Childhood Studies, September 2009 - Present

Rutgers University, Camden

Expected date of completion: October, 2015

M.A. Special Education, January 2006

San Francisco State University, San Francisco, CA

Thesis: The Role of Behavior in Special Education Placement: Are Males and African Americans Over-Identified Due to a Misunderstanding of Culture?

B.A. International Business, January 2000

Immaculata University, Immaculata, PA

Concentration: French

Research Interests

The daily lives of families with children with complex medical, behavioral, and cognitive needs

Recreational opportunities for people with diverse abilities

The historical development of programs for children with disabilities

Awards

Chris Larsen Academic Scholarship

ETS Recognition of Excellence

Rutgers University Fellowship

CALI Award in Writing & Research

French National Honor Society

Dean's List, Immaculata University

Travel & Languages

Extensive travel in Europe, Peru and Costa Rica:

- 10 month teaching position in La Molina, Peru
- 1 month study abroad program in Dijon, France

Intermediate knowledge of Spanish and French

Teaching Experience

Assistant Professor of Special Education **August 2013-Present**
Castleton State College, VT

- Instruct undergraduate and graduate special education courses
- Co-teach Education courses
- Responsible for student teacher supervision
- Assisted in Education Department program re-design

Special Education Teacher **July 2006-June 2013**
Barneгат, NJ

- Educated students ages 3 to 6 years old with autism in a self-contained classroom
- Provided In Class Support to First Grade teachers for students with exceptional needs
- Collaborated with BCBA to implement Positive Behavioral Support Programs in self-contained classrooms in the district's 3 elementary schools

Graduate Assistant **Sept. 2009-August 2011**
Rutgers University, Camden, NJ

- Assisted Dr. Daniel Cook, Director of Childhood Studies, in research and teaching Childhood Studies 101
- Provided guidance to students in writing papers and studying for exams
- Graded papers and exams

Learning Resource Teacher **Sept. 2005-June 2006**
Pleasantech Academy Charter, Pleasantville, NJ

- Individualized instruction for Sixth Graders with various academic needs while coordinating with General Education teachers to provide individualized modifications

Student Teacher: Resource Room **Feb. 2005-May 2005**
Wagner Ranch Elementary, Orinda, CA

- Delivered "pull-out" and "push-in" services in conjunction with Resource Specialist for second through fifth graders. Responsible for weekly lesson plans, IEP meeting attendance, and providing daily in class support for students

Instructional Assistant **Sept. 2003-June 2005**
Orinda Union School District, Orinda, CA

- Assisted in special and general education classrooms to enhance the inclusion programs of kindergarten, sixth, seventh, and eighth grade students

General Education Teacher **Feb. 2000-Dec. 2000**
Colegio San Pedro, La Molina, Peru

- Collaborated with Peruvian teachers and families to provide English language classes to 4th, 6th and 7th grade students
- Integrated English classes into Science and Social Studies courses for 4th graders

Professional Service

Presentations, Leadership, and Grant Writing

Council for Exceptional Children, Teacher Education Division, November 2015
Learning from and Learning with ARC Self Advocates

Council for Exceptional Children, Teacher Education Division, November 2015
Small Special Education Program Caucus Technology Symposium
Group Presentation: *Digital Immigrants Training the Natives: Professors Keeping Up with Technological Change and Innovation*

Rutgers University, Guest Lecturer for Daniel Cook, October 8, 2015
Childhood Studies Senior Seminar

Castleton University Soundings Event, February, 2015
Disability and the Tao of Pooh

Council for Exceptional Children Teacher Education Division, November 2014
Kaleidoscope Presentation:
Partnering with Families: Understanding the Role of Social Networks in the World of Exceptionality

Rutgers University Multiple Childhoods Conference, May 2011
Session Chair: Peace, Justice, and Violence through Children's Eyes

Penn State Graduate Student Women Studies Conference, April 2010
Presentation: "Walt Whitman's Construction of Motherhood"

Rutgers University Graduate Student Conference, April 2010
Moderator: Historical Representations of Childhood Panel

ABA Aide Training

- After school workshop for paraprofessionals that provided an overview, history, and examples for implementation of the principles of ABA in the classroom

Accommodations for Students with Learning Disabilities

- Presentation on lesson accommodations to meet the learning needs of 6th through 8th grade students

Power School and Power Grade Committee

- Trained teachers in the implementation of Power School and Power Grade

Pleasantech Academy Grant Writing Committee

- Awarded a grant from Hitachi Global for \$10,000.00 to enhance school's technology

Outreach

Fitness Fuel and fun

- Coordinated a Collaborative fitness program for people with diverse abilities among ARC-Rutland Area, a local fitness studio, and Castleton University students
- Provided social and physical activities for community members

After school Social Skills Club and Lunch Bunch

- Founded and volunteered for an after school play group and a lunch time social skills group for students with autism and their peers general education

Social Justice

- Co-founder of Rutgers University Graduate Student Organization Service Committee
- Church committee involved tutoring in a homeless shelter, lobbying for education reform, and raising money to build a well in Niger, Africa

Building Women

- Character building organization devoted to aiding young girls become independent, successful, and compassionate young women